

# UNIVERSITY OF BRIGHTON

## External Evaluation of the Alzheimer's Society Live Well with Dementia programme

Review and Reflections, March 2017

### 1) Background

The University of Brighton have collaborated with the Alzheimer's Society for a number of years. The external evaluation of the *Live Well with dementia programme* (formerly known as the Self Care Programme for People with Dementia) builds on previous work carried out by the University evaluation team. This included *the External Evaluation of the Alzheimer's Society Carer Information and Support Programme* (CrISP) (Barnes et al 2013). The external evaluation of the *Live Well with dementia programme*, commenced on 1<sup>st</sup> December 2013 and concluded on 31<sup>st</sup> March 2017. The evaluation was carried out by a team of staff from the School of Applied Social Science (SASS) under contracts agreed with the Alzheimer's Society.

*'The Live Well with dementia programme aims to help people with early stage dementia develop the understanding, skills and practical tools to empower and support them to take an active role in the management of their health and well-being. It is based on self-management principles'* (Alzheimer's Society 2016).

The programme built on content provided by Self-Management UK and was reworked through a process of 'co-design' with people with dementia and Alzheimer's Society staff involved in developing and delivering the programme.

This document is intended to be a reflective account of the evaluation and of processes involved in each phase, as well as the collaborative work in between phases. It covers data gathered on co-design and delivery of the programme. Delivery was evaluated in three stages: Hastings (pilot), Salisbury (Pathfinder 1) and Chippenham (Pathfinder 2). The purpose of this is to supplement previous reports (see Appendices 5 & 6), not duplicate them, incorporating, where relevant, summary details of key conclusions from these.

### 2) Aims of the evaluation

The external evaluation ran alongside programme development and delivery. It comprised two main parts: evaluation of the co-design process and evaluation of programme delivery. The data collected at each stage was presented to the Alzheimer's Society with the aim of enabling the Society to consider our findings and recommendations alongside those from their internal evaluation and to amend the programme where appropriate.

### 3) Evaluation design

The evaluation sought to influence the development of the programme and therefore adopted an approach based on the principles of action research. Action research is an appropriate methodology which encourages both the development of knowledge and its practical application. The evaluation incorporated feedback from participants, facilitators, carers (where appropriate) and from the research team itself. This was fed back to Alzheimer's Society staff who subsequently revised and

reworked the programme. The ongoing relationship, at all stages, between the University evaluation team and Alzheimer's Society staff was crucial to the successful development of the programme.

### **3.1) Evaluation of the co-design process**

In evaluating the co-design process the evaluation team set out to answer the following questions:

1. What has been the experience of people with dementia and staff working with them in the co-design of the *Live Well with dementia programme*?
2. What has facilitated the process and what barriers have there been?

The original methodology designed for this part of the evaluation was as follows:

- Observation of co-design consultation meetings in both pre pilot and post pilot phases (numbers and locations to be determined)
- Interviews with some of the participants involved in the co-design process both people with dementia and Alzheimer's Society staff
- Feedback from the observation and interviews to be fed back during the consultation stages in short summary feedback points to the Alzheimer's Society on what is working and where there is room for improvement.

Full observation of the pre-pilot co-design consultation meetings was not possible due to the timing of the meetings in relation to ethics approval by the University of Brighton, contract negotiations for the evaluation and the location of the first two groups. Without ethics approval, data could not be collected. However, the third consultation meeting was observed by a member of the evaluation team providing useful familiarisation with the nature and content of the programme.

Once ethics approval was received, interviews were held with the two co-design partners who ran the pre-pilot groups and with the Alzheimer's Society Co-ordinator of the consultation group that was observed.

### **3.2) Evaluation of programme delivery**

The evaluation of the programme delivery addressed the following questions;

1. To what extent is the Live Well with Dementia Programme successful in providing knowledge, skills and practical tools in ways that can support people with dementia to be more actively involved in their own self care?
2. To what extent does the timeliness of the Live Well with Dementia Programme to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?
3. Are there ways in which the delivery content and/or style could be improved or made more appropriate?

The original methodology designed for this part of the evaluation was as follows;

- Observation of all workshop sessions (7)
- Post-delivery interviews with 3-4 participants with dementia
- Post-delivery paired interviews with 2 of the same people with dementia with their carer.

- Interviews with facilitators (2)

This methodology was successfully used in Hastings (pilot) and Salisbury (Pathfinder 1). Methods for Pathfinder 2 in Chippenham were moderately modified after discussion with the Alzheimer's Society and facilitators to better fit the revised programme (see Appendix 6).

The University of Brighton ethics approval complied with the ethical research requirements of the Alzheimer's Society. Throughout the external evaluation process, a fully informed, ongoing and detailed consent process, sensitive to the needs of people with dementia, was implemented and worked well in practice. Local Alzheimer's Society Dementia Support staff were available to offer support to participants following interviews but this was not needed.

All interviews were recorded and transcribed and all observation sessions were manually recorded.

#### **4) The evaluation process**

Without duplicating detailed information given in previous reports (see Appendices 2, 4, 5 & 6) we will summarize and reflect upon the main points which arose and which were fed back to the Alzheimer's Society, noting how the processes that happened in between each stage of delivery, particularly how the collaboration between the University team and the Society, led to significant changes.

##### **4.1) Pilot phase Hastings**

The *Live Well with dementia* programme piloted in Hastings, East Sussex, had been designed by the Alzheimer's Society in collaboration with Self Management UK, an organization that had previously designed programmes for people with mental health or other health problems but not dementia. It formed part of a package of provision run by the East Sussex Memory Support Service (ESMSS) designed to support people with dementia. One, which ran in the autumn of 2013, was activity based and did not focus on either memory or self-management techniques and tools. Six out of eight of the pilot participants knew each other from this. Facilitators talked about the differences and similarities between the different types of provision and how they were structured and delivered.

##### **4.1.1) Pilot delivery - reflection**

The pilot ran for seven weeks. The group met each week for two and a half hours in the afternoon in a unit in the grounds of the Conquest Hospital in Hastings. The location was not specifically designed for people with dementia and the room used was quite small, having no tables and lacking facilities for power point. The facilitators had to rely on a whiteboard, laboriously writing up selected elements of the content and noting comments from participants. Participants sat in a circle in large armchairs with no tables to put their paperwork on. It was difficult for them to get up and move around, even in the tea break. The pilot was often interrupted by noise from neighbouring rooms. The facilitators brought some supplies for drinks and snacks and made the drinks for a short tea break in an adjoining room. The unit was not connected to the main hospital in which there was a well-stocked, accessible café near the entrance. It felt isolated, somewhat marginalized. At the end of every session, carers arrived to meet their relatives, negotiating a number of doors and corridors en route.

We observed that without a car it would have been difficult to reach this unit and as most of the participants did not drive they were dependent upon carers for transport.

#### **4.1.2 Pilot assessment/suitability of participants**

From the observation and interview findings it appeared that there was one group of participants who had been able to benefit directly from the pilot. A second group had some memory of the process but little of the detailed content. For a third group it was not clear that the programme had much impact other than in the benefits of being part of a group and enjoying the social process. All the participants valued being in contact with others with the same condition and most had a sense of feeling supported in the group and by the facilitators. This was reflected in the post-programme interviews (see Appendix 2).

We were unable to interview everyone who attended the pilot but did interview 2 from group one, 2 from group two and 1 from group three. Of the joint interviews with carers, 1 was from group one and 1 from group two. Informal feedback was also given to the interviewer in conversation with a carer on the issue of follow up and from one participant by phone. The major issue for participants, not unexpectedly, was memory, so group one had memory both of content and process, group two had memory of the process but little of the content and the third group had very little memory of either process or content but could remember enjoying being part of the 'club' as one person put it. As an example, when interviewed, he could not remember anything about the programme other than that he enjoyed it and there was no evidence that he had followed up any of the paperwork. In two cases carers wanted to support the follow up and use of the programme but were unable to find out what the person had actually done each week. Even though people took notes in some cases it appeared that this note taking was perhaps an automatic and habitual response based on previous attendance of various courses or programmes or from their earlier working lives.

#### **4.1.3 Pilot content**

This was the area that caused us most concern during the pilot observation and it is where some of the most significant changes took place between the pilot and Pathfinders 1 and 2. Looking back, we noted the following:

- Amount – too much (confirmed through interviews with participants, facilitators and observation).
- Suitability for people with dementia - there was no real discussion of their current lived experience of dementia, symptoms, how it affected them and issues of acceptance. We had wondered whether this would be part of a self-management programme for people with other conditions. Participants talked most confidently and knowledgeably about their own experience so would it have been more effective to work with people's own examples and then broaden out to the concept into a more general discussion?
- Superficiality of complex concepts – it was not always clear what the context was or how the different elements of a concept fitted together.
- Developmental nature of the programme – there was no repetition of certain exercises like problem solving each week which might have enabled participants to recall a process.
- There was no specific information given about dementia. A number of questions were asked by participants implying that this would have been useful to them. We knew from discussion with people with dementia and carers that developing a better understanding of the symptoms and experience of dementia was highly valued by both.

Each session covered at least three main topics which usually included a psychological issue, a practical issue and some form of relaxation. Each session also involved an action planning process in which participants were invited to think about and record activities that they hoped to do in the

following week (such as tidying the garden, doing some cooking). Sometimes this part of the programme was neglected due to lack of time.

There seemed to be far too much content requiring participants (and facilitators) to make rapid shifts in the way that they received the information and gave no time for processing of important psychological issues, let alone absorption of new knowledge.

We considered that fewer topics in each session might have helped the processing, development and understanding of issues.

We observed that the content of the pilot was largely generic and we were unclear what content had been specifically designed for people with dementia. We observed participants engaged more with the sessions relating to practicalities where they could talk about their direct experience, e.g. distractions/eating well, rather than with more abstract ones. Some sessions seemed more difficult for participants to make sense of and we wondered whether attempts to simplify the language had actually made issues less easy to explain or understand in some cases. We observed that the way the delivery of content was structured was not 'dementia friendly'. The amount to be covered in each session meant that discussion resulting from participants' raising of personal issues/experiences was often curtailed in order for the session content to be 'got through' in the allocated time.

This was an intelligent motivated group of eight participants, six of whom had worked together with at least one of the same facilitators in a previous eight week Cognitive Stimulation Group. In general the group thought highly of the facilitators, and were compliant and respectful to them and were extremely grateful for the sessions. There were times when the level of the language and materials could have been too simplistic for them and others where the concepts were clearly already understood. However, the scripted nature of the content made it impossible for the facilitators to respond to the group's needs (as they clearly wanted to do) and made for a rushed and somewhat bland presentation. An opportunity was therefore missed for participants to use the resources of a peer group and for the facilitators to use their skills in encouraging interaction among participants. It was very far from the 'person-centred' programme that we had envisaged arising from a co-designed process. We felt very tired as the afternoon progressed and noted that many participants seemed to 'switch off' – this was not helped by them sitting in arm chairs in a circle and having no table to rest their papers or notebooks on.

#### **4.1.4 Pilot paperwork**

The pilot required reference to a lot of paperwork which the participants did not always find easy to find or to follow. Much time was spent in searching for and attempting to organize handouts. We felt more creativity was required, such as using 3-D models to illustrate certain concepts (a suggestion followed up in Pathfinders 1 and 2). Although the paperwork might have proved useful for reference after the pilot – and for sharing with carers – we felt that it hindered, rather than helped, the participants to digest the content.

#### **4.1.5 Pilot facilitators**

As we have noted, this pilot was heavily scripted resulting in little room for facilitators to develop their own language, to input their own knowledge or to make best use of their existing skills and understanding of working with people with dementia. Whilst they worked together very well, taking turns at delivering content and writing on the white board, there was little opportunity to pause, reflect and above all to take note of participants' reactions, body language and relationship with others in the group.

#### **4.1.6 Pilot feedback process**

The internal feedback process of each session was through a coloured card system in which different cards representing different responses were held up by participants following questions from the facilitators at the end of the group session. This system enabled limited feedback on the programme delivery and seemed very confusing. Although most participants held up a yellow card (representing satisfaction) it was not clear whether the process had been fully understood as it was wordy in explanation and required sorting and identifying coloured cards with different responses on them. This can be challenging for people with dementia whose perceptual abilities are sometimes diminished, causing distress. The participants seemed generally very positive but we observed that they also wanted to be very supportive of the facilitators. We recommended that it would be worth considering if the feedback questions could be clearer and the card system simplified or replaced – preferably by ongoing feedback throughout the session.

#### **4.1.7 Our points for consideration following this pilot phase**

Our main concern was the heavily scripted nature of the pilot, resulting in little room for the facilitators to call on their own expertise. There was hardly any room for ‘free’ discussion by the participants about their own situations and for them to hear from others in the group about how they were managing their dementia. At times it was quite painful to observe how participants were struggling to share information, and how the facilitators were keen to encourage this, only for the demands of the script to lead to rapid termination of someone’s story.

We felt that only half the group was at the ‘right’ level to gain benefit from the programme. We felt it would be useful for a pre-programme assessment to consider not just time since diagnosis and type of dementia but the particular symptoms/manifestations of dementia for the individuals combined with their level of self-awareness of how those manifestations impact on them and what they felt would help them.

The content of the pilot programme did not seem designed for people with dementia. Participants engaged most confidently with sessions where they could talk about their direct experiences rather than with more abstract topics. There was no specific information given about dementia, about the implications of receiving the diagnosis and the emotional impact that this has, and from the questions asked in the sessions we felt that participants would have found this useful. There was little opportunity for issues of acceptance and lifestyle changes to be shared and discussed which we felt might also have benefited this group.

Both participants and facilitators considered the sessions to be too long and the running of the group ‘too static’. The time pressure prevented facilitators from working flexibly and to enable breaks to happen when needed.

We were confused about what had happened to the feedback from the earlier co-design process we had observed, as the scripted nature of the delivery gave no room for the participants, nor the facilitators, to make any meaningful input into the programme.

#### **4.1.8 Post-Pilot co-design**

Following completion of the pilot delivery and our evaluation in the form of a fairly critical report (Appendix 2), the Alzheimer’s Society delayed the first post-pilot delivery (Pathfinder 1) whilst the content was revised. Following this revision, there was a second phase of consultation with service

user groups between January and March 2015 which was observed by the evaluators where possible and followed up with interviews with all the facilitators of the consultation meetings, including in those areas not observed. Some consultations took place with existing User Reference Groups and those who attended the pilot groups enjoyed coming back together with other participants. Feedback from observations and interviews indicated that a 'conversational style' of delivery as opposed to the formal scripted delivery of the pilot worked well; and that the chance to give feedback in the 'here and now' would be a significant improvement on the end-of-session process, used in the pilot, which made participants negatively aware of their limitations of memory and writing skills.

The details of the post-pilot co-design have been reported separately in the User Involvement in re-design summary of April 2015, included as Appendix 4. However in summary the evaluators concluded that:

- The conversational style used in the post-pilot consultation enabled a greater level of engagement amongst participants, hence was more suitable for people with dementia.
- Issues of accessibility, particularly concerning hearing and sight loss, should be taken into account in the design and delivery of the new programme.
- People with dementia were keen to have more information and knowledge about dementia and how they might deal with the challenges.
- Being aware of the services people had already been offered (such as memory support) would be useful.
- Careful thought needed to be given to the involvement of carers within the new programme.
- People with dementia were keen to be involved in developing their understanding of dementia and of improving the situation for others. Being asked their opinion made them feel valued. They welcomed the opportunity to be involved in programme development.
- There was a desire to be more active in deciding how to live their lives with dementia.

## **4.2 Preparation for evaluation of Pathfinder 1**

A great deal of consultation, discussion, reflection and re-designing took place between the end of the pilot phase and the beginning of Pathfinder 1. The development task was challenging and complex and needed to take time, which meant that we began our next evaluation phase later than anticipated, in September 2015. During the interval period our team took the opportunity to read current literature on and identify research into the concepts of self-management and living well for people with dementia. We compared some of this literature with that concerning people with other long-term conditions (Appendix 3).

### **4.2.1 Pathfinder 1 Salisbury**

Pathfinder 1 was delivered in a meeting room within the Alzheimer's Society premises in Salisbury. The evaluation team were initially somewhat daunted by the need to travel from Brighton to Salisbury each week, to arrive in Salisbury by the start time of 10.00 am. However, we were delighted to find that the premises were in central Salisbury, a short walk from the station. The office and its meeting rooms were easily accessible, immediately 'dementia friendly' and very welcoming. Participants sat around a table, giving an 'adult education' feel to the process. There



was easy access to a range of leaflets and importantly access to a laptop and projector which made for a more professional feel (than in the pilot where people were struggling to see a flip chart and shuffling papers on their knees). A member of staff was on hand to serve drinks and provided tea, coffee and biscuits in the break which helped the facilitators to take a break themselves and remain focussed on the group. This was a major difference from the pilot where one of us had remarked that the programme felt like 'a marginalised group, with marginalised staff, in a marginalised building'. This had nothing to do with the facilitators but with the unsuitable premises and facilities. It led us to note that the environment for this programme is extremely important and even though Salisbury facilities were, we considered, 'gold standard' and may not be able to be replicated, it was essential to be aware of how important the welcoming, comfortable and professional environment and the support for facilitators was to the success of the sessions.

Familiarity, safety and security are crucial to the well-being of people with dementia whose world can seem very confusing and indeed unsafe. Moreover, several of the participants were able to reach the Salisbury centre independently and as they got to know each other, those who could still drive offered lifts to others who had been obliged to stop driving or were reliant on public transport. We noted that, in rural areas, getting to and from the programme can be challenging and this should be taken into account in start and finish times of the sessions. Enquiries about some participants' regular late attendance highlighted that they could not use their bus passes until a certain time and that therefore a half-hour later start would have been helpful. These were important issues in ensuring that participants would not feel rushed and embarrassed because of arriving late.

The following issues arising from the new Pathfinder 1 still needed to be addressed. Firstly, it was still very content heavy and too much for the seven sessions. Participants needed information on dementia earlier on and the 'marketplace' and carer's sessions would have been better at the end of the programme. This was based on our observation that this very different input, attended by carers and visitors, interrupted the flow of the peer group experience and caused the dynamic to shift in an unhelpful way. Secondly, more time was needed within each session to enable the facilitators to respond more flexibly to participants' issues as they arose. Sessions would have benefitted from a longer check-in time to enable orientation and catch up to take place, and more pauses during sessions would have been beneficial both physically and emotionally for participants. Thirdly, the variety and delivery of materials between the pilot and the Pathfinder were greatly improved and use of 3D props was good and should be continued. However, a booklet entitled *Useful Things* was not effective as a key tool and could be reconsidered or discontinued.

Major considerations - these are fully discussed in Appendix 5 but in summary we felt the following were essential to note:

- **Ability to benefit:** this is a key issue as participants have to have capacity to manage and benefit from the programme. This might be less about how long they have had a dementia diagnosis and more about their 'awareness of self', their understanding of the impact of their dementia and their ability to function in, and benefit from a group process. This observation has implications for the pre-programme assessment process which was not part of our evaluation. The group process was much helped by having two 'catalysts' among the participants, a male and a female who had the capacity to engage others in reflection on their thoughts and feelings about having dementia and about the impact it was having on



their lives, including relationships. They acted as 'role models' for more reticent members of the group.

- **Venue:** The benefits of the venue for Pathfinder 1 have been outlined above and we recommend they should be replicated as far as possible when selecting venues for future delivery of the programme. A fully supported learning environment adds gravitas and dignity to the whole process.
- **Peer Support:** Noted by everyone as a main positive resource on the programme. Knowing that you are not alone with your situation and can be helped by, and help others.
- **Carers' role:** How best to involve carers, when and how. Participants were clear that they wanted the programme to be for them – i.e. not attended by carers, but obviously carers have an essential role and need to be aware of what to expect and not to be alarmed by behavioural changes that may result from the programme (such as wanting to be more 'independent' and challenging).
- **Giving and receiving feedback:** Further consideration needed on how participants can be involved in co-design as the programme continues to develop. A form of continuous feedback and adaptation during programme delivery itself seems to be a fruitful way of ensuring relevant participant input, drawing on their experiences in the 'here and now'.
- **Training in group work:** The two facilitators in Pathfinder 1 had extensive experience of working with people with dementia. They knew each other well and in our opinion had strong skills in group work. Co-facilitating any group does present specific challenges and needs much discussion and feedback between the two facilitators to decide on and carry out their agreed roles. We were impressed by the sensitivity shown to each other and to the participants, and the ability to intervene or hold back when required. The facilitators were 'tuned in' to the individuals and to the group process. However, there were still occasions when they became caught up in the need to deliver certain content and the sessions ran over. This leads us to reinforce our recommendation that all facilitators of this programme need training in group work/group dynamics, given that the peer group experience is something that all concerned have identified as extremely important and helpful.

#### 4.2.2 Post-Pathfinder 1 collaboration

We presented our report on Pathfinder 1 to the Alzheimer's Society in April 2016 and had a meeting with members of the project team at the Society's Headquarters in London at the end of May 2016. We were pleased that our recommendations had resonated with those from the Society's internal feedback and been found useful. We were invited to take part in a further evaluation of a third iteration of the Live Well programme (Pathfinder 2) aimed to begin in September 2016 which would incorporate all the points arising from both internal and external evaluations. Due to unforeseen circumstances in the Society, the start of the evaluation of Pathfinder 2 was delayed. Although we had thought that delivery would be in Salisbury, we were given the options of observing in either Bradford or Chippenham. Both these locations required extensive travel but we opted for Chippenham, North Wiltshire, as having observed in Salisbury we were interested to note the similarities and differences within the same county. It was also more practical in terms of travel. One of the facilitators was one who had delivered Pathfinder 1, the other was new to facilitating the *Live Well with dementia* programme.

The Chippenham Pathfinder 2 did not begin until 4<sup>th</sup> November, running up to 16<sup>th</sup> December. As a result of the difficulty in travelling, we negotiated for overnight stays on several Thursday evenings. In addition, Southern region was beset by rail strikes making it very hard to guarantee being on time

if travelling on the programme day (Friday). Practical concerns required creative adaptation of our methodology and, in discussion with the Alzheimer's Society, we changed some elements to be more appropriate to this stage of the evaluation.

In a change to previous methodology, we interviewed the facilitators before the programme began in order to understand if and how the recommendations from Pathfinder 1 had been incorporated; to ask about the assessment process of participants for the programme; to ask about their training; to ask about the venue; support (volunteers); adaptation of content and to hear any other observations that they had prior to the start of the programme.

This proved to be a most useful exercise especially as one facilitator was new to the Live Well programme although was an experienced dementia advisor and was used to delivering other training. He had had two days of bespoke training from senior Society project team members prior to starting his new role. The other facilitator had been co-facilitator on Pathfinder 1, hence was able to tell us a great deal about the changes that had been agreed.

### **4.3 Pathfinder 2 Chippenham**

The venue for Pathfinder 2 was the Methodist Church Hall in Chippenham. We found this to be a warm and welcoming venue, thanks to the commitment of the facilitators who had replicated, as far as they could, the 'ideal' venue at Salisbury. The redundant paperwork had disappeared to be replaced by innovative 3D models made by the facilitators, illustrating certain important points in the content. Two volunteers had been appointed to assist throughout the period of the programme. They welcomed participants, making drinks and helping them to settle. They were also able to chat to carers at the beginning and end of sessions. The process and delivery of the sessions is fully covered in Appendix 6 but our main concern at the beginning was that all participants were men in their 80 and 90s. One woman came to two sessions but withdrew as a result of hearing difficulties or perhaps from feeling out of place as the only woman; another man came to one group but did not continue due to health problems although he brought an important issue to the session: 'how do I know I have dementia?' This was a theme underlying the conversations between the core group members, four men who had struggled to accept the condition as anything but a feature of 'old age' and were reluctant to acknowledge its full impact on their lives. We observed strong and supportive relationships developing among these four men from their mutual interest in music, singing and memories of the Second World War.

Unfortunately, one session had to be cancelled due to illness of participants and we did not attend one session (on 'feelings') because we were both ill. The cancellation pushed the sessions on towards Christmas, meaning that the scheduled 'Market Place' session was postponed until January and subsequently cancelled. The facilitators managed this outcome by incorporating some of the elements of the Market Place into the last session on 16<sup>th</sup> December. We had agreed to do a 'group feedback session' (focus group) after this last session, feeling it to be more appropriate to a peer-group oriented programme than individual interviews and, after further discussion with participants and facilitators, they settled on 'fish and chips and chat' as an appropriate way to involve participants in giving feedback. The facilitators withdrew after the lunch, leaving us with two men who spoke positively and with much appreciation about their experience on the programme. A third

man, who did not want lunch, spoke to us while waiting for his carer to pick him up, expressing similar sentiments. The remaining participant, who had missed the session due to attending a funeral, had been the most active in the group and agreed to a telephone conversation with one of us – which worked out very well as he remembered many aspects of the programme and, like the others, had found it helpful.

Our evaluation of Pathfinder 2 confirmed our earlier recommendations and reinforced several of them (see Appendix 6). To summarize, we felt it essential to take into account the following issues in future programmes:

- Building in a three month recruitment phase, having a pool of possible candidates, design a trial group activity as sometimes people who are able to participate on a one-to-one basis find group work hard (and vice versa), actively engaging with carers to ensure they understand the nature of the programme, and to respond to their queries.
- Having low level contact with carers throughout the programme for mutual support and to avoid participants leaving the group because of carer anxiety.
- Provide additional training for facilitators on group facilitation skills (including an element of therapeutic group facilitation)
- Consider a budget - for transport and appropriate venues; to look into services such as community transport where people cannot access public transport.
- Provide for an allowance of 7 hours for facilitators to debrief and plan to enable tailoring of content to the particular needs of the participants.
- Consider timing of delivery – avoid winter / Christmas if at all possible as travel and illness tend to be worse at that time. Check to see if people using public transport can use their bus pass to get to the sessions on time.

#### **4.3.1 Post Pathfinder 2**

We delivered our report on the evaluation of Pathfinder 2 (Appendix 6) and agreed to present some of our observations on the whole period of the Live Well programme at an event organised by the Alzheimer's Society in London on 16<sup>th</sup> March 2017 for the project team and other staff from the Society, plus facilitators and participants. While considering our presentation, it occurred to us that we had plenty of anecdotal evidence arising from feedback from all three locations, particularly from the interviews we had conducted with participants and facilitators, but we did not have much information concerning the impact of this programme from other parts of the UK. We discussed this with the Alzheimer's Society project team and, in keeping with our action research, collaborative model of programme development, they invited facilitators from other regions to send their observations to ourselves, copied to the Alzheimer's Society. The response was very heartening so we were able to incorporate this into our presentation at the London event (See Appendix 7 for some examples).

#### **5. Final reflections**

It was important, at the event on 16<sup>th</sup> March, to be able to share our experiences of the evaluation process from start to finish and to hear how others had responded to the recommendations and to subsequent changes from both internal and external evaluations; and to hear how it had impacted on the lives of all concerned. The programme, as it stands, has changed from having a rigidly structured and scripted delivery, being far too content heavy and missing out on important peer group possibilities, to becoming a much more flexible, person-centred, group-based intervention that is sensitive to the needs of people with dementia, which takes into consideration the need for careful assessment and recruitment of participants and which requires specific training in group facilitation. We all agreed that the pilot had indeed been a useful starting point on the *Live Well with dementia* programme, and that the extensive involvement and commitment of all concerned in its development and, importantly, the openness of the Alzheimer's Society project team in making changes, has produced a potentially valuable service to offer to commissioners. In particular, we considered that general practitioners who rarely have options other than memory clinics to which to refer their patients newly diagnosed with dementia, may wish to be informed of the existence of the *Live Well with dementia programme*. Thus it is to be hoped that the Alzheimer's Society will receive the resources necessary to be able to roll out this collaborative initiative across the UK.

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**Reference:**

Barnes,M., Henwood,F., Smith,N. & Waller,D. 2013. *External Evaluation of the Alzheimer's Society Carer Information and Support Programme (CRISP)*. University of Brighton, UK.

## Appendices:

1. Self-care, self-management and dementia literature review. October 2013
2. External Evaluation of the Alzheimer's Society *Live Well with Dementia programme* - Interim Report. June 2014
3. Self-management and dementia – updated literature review. January 2015
4. External Evaluation of the Alzheimer's Society Live Well with dementia (LWwD) Programme - user involvement in redesign summary. April 2015
5. External Evaluation of the Alzheimer's Society *Live Well with dementia programme* - final report. April 2016
6. External Evaluation of the Alzheimer's Society *Live Well with dementia programme* – Pathfinder two – Chippenham. February 2017
7. Example post-delivery feedback from *Live Well with dementia programme* facilitators. University of Brighton presentation, March 2017.



## Self care, self-management and dementia - a literature review

In the last two years the Alzheimer's Society has been successfully delivering the Carers Information and Support Programme (CrISP), a group based intervention for carers of people with dementia, across England. In development is a partner programme for people with early stage dementia and this literature review forms part of that development process. The review focuses on group interventions with people in early stage dementia, taking a broad definition of self-management, from information sharing approaches to more active behavioural change interventions and covering those delivered by both lay people and professionals. It is international in scope covering research conducted in the last 20 years, English language papers only, and includes a summary of the current United Kingdom national policy position. In addition the review considers relevant literature on self-management in comparable long-term conditions.

### Key issues from the review;

- There is a significant amount of literature available on self-management of chronic long term conditions but much less that directly relates to people with early stage dementia.
- Studies included on work with people with dementia indicate that programmes are generally not lay, or peer, led although people with dementia are involved in design and delivery in some cases.
- Facilitators come from a wide range of expertise and professional background. Most studies indicate that group work with people with dementia will have two tutors and relatively small groups of participants.
- Whilst there is no indication that content of generic programmes is not relevant to people with dementia, cognitive challenges require adaptations to content and delivery methods.
- The literature recognises that to work with people with dementia necessitates working within the framework of their broader support, including family, carers, health providers and community networks.

### Background

'Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition' (Barlow 2002).

The seminal text underlying most of the thinking and writing on self-management of chronic long term conditions is *Unending Work and Care* (Corbin and Strauss 1988) which presents and develops a framework for understanding the central issue of how chronic illness gets managed at home. This framework developed the understanding of the 'work' that goes into the management of a long term condition and defines three kinds of 'work'. Managing the illness (symptom control, managing crises and limitations of activity), the work of everyday life (occupational, relational and domestic work) and biographical work (defining and maintaining an identity)(p10). A further type of work is identified as 'articulation' work (p11) which covers the organisation and coordination of the various types of work. 'Articulation' work includes identifying the work to be done, arranging for it to be done, allocation of resources and assuming and delegating responsibility for the work.

The Stanford Patient Education Research Centre in California, USA has been developing and evaluating self-management programmes for people with chronic conditions for twenty-five years and their Chronic Disease Self-Management Program (CDSMP) (Lorig et al 1999) has been exported to many countries around the world and forms the basis of the Expert Patient Programme in England. The five core self-management skills are defined as problem-solving, decision making, resource utilisation, forming of a patient/health care partnership and taking action. The key characteristic that distinguishes self-management from more traditional health promotion and patient education is how participants are encouraged to tailor self-management skills and knowledge to their own situation and needs (Lorig and Holman 2003). The concept of self-efficacy which refers to an individual's belief in their capabilities to organise and carry out a course of action to attain a goal (Bandura 1977) is a key component of most self-management models. Teaching processes for self-management programmes are recommended to include efficacy enhancement, performance mastery, modelling, interpretation of symptoms and social persuasion (Lorig & Holman 2003).

There is a broad body of evidence developing and evaluating the use and relevance of self-management programmes to a broad range of conditions from asthma, arthritis and diabetes through to neurological conditions including generic and disease specific programmes.

### Current UK national policy on self care and self-management and dementia

#### *Self care and self-management*

First highlighted in the *NHS Plan* in 2000 as one of the key building blocks for a patient centred health service, self care was developed further in the *NHS Improvement Plan* in 2004 and the *White Paper - Supporting People with Long Term Conditions* in 2005. Within the new strategic model set out in these documents level 1 - Self care concerned the majority of people living with long term conditions and



advocated developing their skills and knowledge to manage their condition in a way that enabled them to participate fully in society. Within the context of the development of condition specific education, the provision of more information for patients and more advice and support about medications, self-management programmes were to be delivered by the Expert Patient Programme (EPP). Primary Care Trusts (PCTs) and local authorities were encouraged to work in partnership with voluntary and community sectors to develop joint training programmes to support the care of people with long term conditions. By 2005 self-management was seen as one aspect of the broader health policy direction of 'self care' (DOH 2005 a&b).

### *Expert Patient Programme*

The Expert Patient Programme (EPP), the main delivery vehicle for self-management in England, was first brought forward in the 1999 White Paper *'Our Healthier Nation - Saving Lives'* (DOH 1999). Based on the CDSMP model developed in the USA the programme was piloted from 2001-2004 (DOH 2001). A commitment to increase the capacity of the EPP came in the White Paper *Our health, our care, our say* (DOH 2006 p112) and in April 2007 The Expert Patient Programme Community Interest Company (EPP CIC) was launched with a purpose to *'establish the principle of individual self-management and self care as a recognised public health measure, deliverable in a cost effective and sustained way'* (EPP CIC 2013).

### *Dementia*

The National Audit Office (NAO) report *Improving services and support for people with dementia* (NAO 2007) acknowledged that *'dementia has suffered historically from poor awareness and understanding, combined with stigmas attached to both mental illness and old age'*. Whilst dementia was given some coverage in the National Service Frameworks on Mental Health (1999), Older People (2001) and Long-term Conditions (2005) the NAO considered that it was not receiving a high enough policy priority. Recommending that their report be seen alongside the *Dementia UK* report (AS 2007) on the prevalence and costs of dementia the NAO made specific recommendations on improving diagnosis and early intervention, management of services and support in the community and the gearing up of a whole system response to the challenges.

With the publication of *Living well with dementia: A National Dementia Strategy* (DOH 2009) government policy in England set out to transform dementia services aiming to achieve better awareness, early diagnosis and high quality treatment for people with dementia at whatever stage of the illness they were. Key to this strategy and the following *Prime Minister's Challenge on Dementia* (DOH 2012) was the desire to improve the quality of life and care for people with dementia. Early diagnosis was seen as key to being able to offer medication advice, information and psychosocial support to people with dementia and their carers. Creating more awareness and support in society as a whole was seen as key to helping remove the stigma of dementia that had historically kept those living with it, and their carers, hidden and often unsupported. As the number of people receiving an early diagnosis of dementia has increased so the need to respond to the information and support

needs of this group, many of whom are still living in the community, has become more urgent. National reports and research on how well people are living with dementia (AS 2012, 2013) and their views of what quality of life means to them (AS/MHF 2010) have raised key issues about the nature of support that could enhance the lives of people with dementia and their carers.

### *Policy direction in the rest of the UK*

There are national strategy documents available for Scotland (The Scottish Government 2010), Wales (Welsh Assembly Government 2011) and Northern Ireland (Northern Ireland Executive 2011). Information on the development of policy on dementia is more substantial for Scotland than for either Wales or Northern Ireland which may relate to the structures, responsibilities and financial powers of the respective governmental bodies and to previous health and social care policy and services.

The importance of early diagnosis and early intervention is common to all the strategies but Scottish government policy focuses very particularly on post diagnostic support as one of the two key areas for change in their first strategy (The Scottish Government 2010). This focus is enhanced in the second national strategy (The Scottish Government 2013) in a national commitment on post diagnostic support for all people with dementia from 1.4.2013. The content of this commitment is based on Alzheimer Scotland's 5 Pillar Model of post diagnostic support covering understanding the illness and managing symptoms, planning for future care, peer support, supporting community connections and planning for future decision making. A model of the five pillar support can be found at [http://www.alzscot.org/campaigning/national\\_dementia\\_strategy](http://www.alzscot.org/campaigning/national_dementia_strategy) website accessed 14.10.2013.

Scottish government policy on dementia is being developed in a strong partnership with Alzheimer Scotland and the Allied Health Professions in Scotland using what is now the 8 Pillars Model of Community Support (Alzheimer Scotland 2012).

It is also notable that Scotland has a Charter of Rights for People with Dementia and their Carers in Scotland (Scottish Government 2009). Its five principles of Participation, Accountability, Non-discrimination and equality, Empowerment and Legality underpin the development of strategic and service development for people with dementia.

## **The Literature Review**

### **Methodology**

#### *Search methods*

- The following electronic databases were searched; International Bibliography of the Social Sciences (IBSS), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Web of Science (WOS), Allied and Complementary Medicine (AMED), Science Direct, Cochrane Library, SAGE Journals Online and Wiley Online Library. Academic journals including Dementia, Journal of Aging Studies, British Journal of Nursing and Nursing Times were also searched electronically. The Journal of Dementia Care was manually searched.

- Internet searches through Google Scholar were carried out alongside the more detailed database searches, enabling the location of some of the international studies and acting as a check mechanism to ensure coverage on the main searches.
- Specialist sources of research were searched including the Social Care Institute for Excellence (SCIE), the National Institute for Health and Clinical Excellence (NIHCE), and relevant work from The Mental Health Foundation, The Kings Fund and The Health Foundation was considered. The work of academics from the Universities of Stirling, Bradford, Sheffield, Northumbria, Worcester, Bournemouth, Manchester and Bangor in the UK was also reviewed as was the work of key academics from the USA and Canada.
- Department of Health publications and Scottish, Welsh and Northern Irish policy reports were searched to provide detail on the current United Kingdom policy position.

### *Search parameters*

- There were two main initial searches. The first covered “self care” “self-management” and “dementia” or “Alzheimer’s” and the second “self-management” and “long term conditions”. Other searches looked at group interventions with people with early stage dementia, information for people with early stage dementia and self-management of long term neurological conditions. The initial search of academic literature produced some sixty one items of which fifty-five were published academic articles (a few Randomised Control Trial Protocols were included within this number), three were books or book chapters and three were research reports. In addition the searches produced policy and organisational reports.

### *Scope*

- The review was international in scope covering research conducted in the years 1993 - 2013 and English Language papers only. The majority of the International references retrieved in this search are from the USA and Canada.

### *Clarification of language*

- “Self care” and “self-management” as terms are used differently both in the literature of different countries and in the understanding of the issue. In the UK for example both medical and care literatures use the term “self care” when describing processes of personal care for people with dementia in care or hospital. “Self-management” as a term is used in the UK when referring to specific group education programmes for people with long term conditions whilst “self care” is the broader policy term for the overall government drive towards helping people to manage their health better. In the USA and Canada “self-management” as a term clearly refers to developments based on the Chronic Disease Self-Management Program (CDSMP) model developed by Kate Lorig & colleagues at Stanford in the 1990s. Within this review the term “self-management” is therefore understood to be about group programmes/interventions and “self care” is understood within the broader policy context.

- The literature also uses different ways to describe subjects and participants. American literature in particular will refer to carers generally as “care-givers” and a number of studies refer to “patients”. The reviewer has not changed that language where it occurs unless there is a need for clarification but will more generally refer throughout to “people with dementia” and “carers”.

### *Exclusions*

- No literature is included on individual interventions.
- There are related bodies of work which offer perspectives that could be useful to those developing self-management programmes for people with dementia including the use of technology as a self management support mechanism and the use of creativity. The review does not cover these areas.

### *Time and resource limitations*

- All university databases have limits on the level of subscription to academic materials and not all journals (particularly those published in the USA) were available to the reviewer. Some articles were accessed through the British Library or directly from researchers, however limits of time and resources may affect the content of the review.

### *General*

- The body of work on self-management, both as a concept and specific to certain long term conditions is substantial although the work specific to self-management group interventions for people with early stage dementia is limited.
- There is related and useful work on group interventions (particularly in the USA and Canada) in early stage dementia which, whilst not specifically described as self-management, is included here.
- Work on the broader spectrum of early intervention support for people with dementia, including memory rehabilitation and psychotherapeutic interventions is not covered here although occasional reference is made where relevant.
- Some other studies which came up as part of the first search but are not included here cover self-management for people with dementia within the broader context of the role of health and social care professions, other networks and society as a whole.

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- **Self-management and dementia**

Ten studies were selected under this heading. There are five articles, two Randomised Control Trials (RCTs) and three reports. All consider the development of specific self-management interventions and provide conceptualisations of what self-management programmes for people with dementia could look like.

### *Qualitative studies*

Two studies cover the work led by Gail Mountain from Sheffield University, UK.

***Self-management for people with early dementia (Mountain 2006).*** The study explores concepts of self-management within the context of chronic disease management both in the UK (Expert Patient Programme) and in work undertaken in the USA (Lorig et al). The article draws attention to the possible reasons why dementia was, at that time, excluded from the development of self-management models highlighting limited early diagnosis, availability of a sufficient range of support services, limited attention given to the day to day lived experience of dementia, the neglect of the individual needs of the person with dementia and the impact of the disease on both the individual and the perceptions of others.

The author considers how that perspective is changing and scopes the evidence for self-management of dementia. Looking at early disclosure and support with the consequences, the need to focus on the needs of the person with dementia and develop specific interventions to promote self-management, Mountain also considers the evidence for professional education, lay and patient education and a whole systems approach towards treatment and care. The review *'supports the view that neglect of the potential of self-management can be attributed to the gap that exists between the commonly held interpretations of self-management and the prevailing understandings of the abilities of people with early dementia, on the part of both professionals and the general population.'*

***What should be in a self-management programme for people with early dementia? (Mountain & Craig 2012).*** The study reports on a two stage research project. In the first stage of the project researchers undertook a series of individual and dyad interviews with a small group of people with dementia and their carers to explore post diagnosis experience and views on maintenance of quality of life with dementia. In both stages the research gave options for people with dementia and their carers to be interviewed separately and for the group as a whole to work in smaller and separate groups. The data gathered led to the development of a number of potential topics for a draft self-management programme which was then tested with a separate group of people with dementia and their carers. Highlighting the findings of the first stage from the perspective of the people with dementia it was clear that they were looking for more information and many felt that there was an information bias towards carers. There was general agreement that *'despite potential conflicts'*, separate groups for people with dementia and carers were the best forms of delivery. *'People with dementia will want to get to know others and talk on their own terms. They will have to try and rebuild their self confidence and not be looking over their shoulder at their carer. They may talk confidently among their peers and share worries but not repeat them with the carer present in a group in case they upset and distress their loved one' (participant with dementia.)*

The second stage was a six week programme of group consultation. Delivery of the sessions mirrored that of the Lifestyle Matters programme on which the authors have previously reported (Mountain et al 2008 & Mountain & Craig 2011) and followed the work of Florence Clark on Lifestyle Redesign in the USA (Clark et al 1998). The delivery style involved facilitators (the second author, accompanied by an occupational therapy student and a volunteer from the Alzheimer's Society) guiding the group to select topics of most relevance from a menu and then assisting participants to explore issues using a mixture of techniques and methods to enhance

interaction (Allen 2001). The sessions were highly participative and each time the group met there was space for orientation, support and reflection. Facilitators delivered short information giving sessions after which group work explored the issues and coping strategies.

The final list of proposed topics for inclusion in a self-management programme were understanding dementia, rethinking dementia, living with dementia, relationships, keeping mentally well, experiencing wellbeing, dementia and daily living, keeping physically well, building and developing skills, keeping connected, maintaining a sense of self, and planning for the future. All of these topics were broken down into more detailed dimensions.

The numbers involved in this study were small 10, (5 people with dementia and 5 carers) in the first stage and 15, (7 people with dementia and 8 carers) in the second stage. However the recruitment of two separate groups for the two stages, through voluntary rather than statutory services, and the participatory and developmental methods used achieved a high level of detail and feedback from participants. The findings provide detail on both content and delivery of a draft programme as well as strong perceptions from both people with dementia and carers of the benefits of interventions for each group separately. Participants considered the menu led form of delivery to be highly desirable and valued the creation of a positive group atmosphere. The research also offers some solutions to the challenges of working with people with dementia around retention of information and suggested mediums to assist with this.

The researchers were clear that as a first stage in a process, further questions about content and delivery would need to be explored with a larger base. Key points for consideration were identified as the need for skilled facilitation suggesting the value of professional involvement and ensuring that methods of working were identified '*so that the voice of the person with dementia is heard and their needs balanced with those of their carers in ways that do not compromise the caring relationship*'.

Three studies cover the work led by Faith Martin at Coventry University, UK

***Perceived barriers to self-management for people with dementia in the early stages (Martin, Turner, Wallace, Choudhry & Bradbury 2012).*** The study is a qualitative interview and group study exploring barriers to self-management amongst people with dementia and those involved in caring for them either personally or professionally.

The group of 19 participants, who were interviewed individually or in groups, included people with dementia (7), family members (2), Alzheimer's Society representatives (2) and health care professionals (8) including clinical psychologists, community psychiatric nurses, General Practitioners and psychiatrists. The method (logic modelling) used a problem statement 'People living with dementia are not generally encouraged to take an active role in managing their care' to explore levels of reasons asking 'why does the problem occur' and using simple probes until no further answers were forthcoming. Six themes emerged covering the lived

experience of dementia, impact of diagnosis, role of carer, family and friends, impact of health care professionals, organisation of services and societal views.

The article provides a broad view of the barriers to self-management from those experienced by people with dementia themselves through to those seen by professionals and from the impact of societal attitudes. The article considers approaches that might be more relevant to people with dementia and concludes *'Interventions for people with dementia may require adaptations to reduce cognitive load, to be tailored to individual's strengths and emphasise meaningful and pleasurable activity.'*

The researchers recognised the limitations of the study acknowledging that the 'problem statement' did not specify type of dementia, age of onset or stage of dementia and that comments were inherently subjective. The findings did however reflect the barriers seen by people with dementia themselves (AS & MHF 2008).

***Conceptualisation of self-management intervention for people with early stage dementia (Martin, Turner, Wallace & Bradbury 2013).*** The study conceptualises self-management for people with dementia as covering five targets which are considered as part of an intervention. These are support to seek information about dementia: greater support to maintain an active life: issues around relationships with family/friends/carers: education/sharing of practical memory tips and techniques and support with psychological wellbeing, including low self-efficacy and perceived low self-worth. These targets are mapped onto the model of self-management of chronic disease put forward by Corbin and Strauss (1988).

A focused literature review considers the evidence for the inclusion of each of these areas in the conceptualisation of the intervention. This is an extensive literature review which provides a significant amount of evidence from other studies for the validity of the approach. From the evidence considered an intervention manual has been developed and the proposed content of sessions is shared in the article and is available on request from the authors. The team have also considered appropriate evaluation tools and developed an evaluation framework.

The conceptualisation of self-management developed here emphasises maintaining activities and relationships and working with the strengths of people with dementia rather than the more usual focus of illness management.

The researchers acknowledge that the initial focussing exercise was with a relatively small sample and therefore there is a need for more extensive work to ensure that the targets outlined in the conceptualisation are more widely endorsed. In addition they are open about the areas of the intervention where there is limited research evidence particularly the components around relationships with family/friends and carers. They also propose further work is needed to consider the levels of cognitive functioning required to engage in the elements they propose and how self-management may alter as the disease progresses.



***Qualitative evaluation of a self-management intervention for people in the early stage of dementia (Martin, Turner, Wallace, Stanley, Jesuthasan & Bradbury 2013).*** The study covers the pilot delivery of the self-management intervention developed through the earlier work and reports on an end of programme focus group and interviews to explore perceptions of the intervention. It covers process evaluation under the Medical Research Council guidelines for development of complex interventions.

Eight participants, considered to be in the earlier stages of dementia but able to cope with the programme requirements, were recruited through the Alzheimer's Society but only six completed the six, two and a half hour sessions. The intervention was delivered by an experienced 'lay' self-management tutor and a clinical psychologist specialised in older adults' mental health. A person with dementia was involved in the delivery as a 'course champion' and the whole facilitation team attended two half day training events in preparation. The evaluation is largely positive and considers both the experience of participants and the detailed content and delivery issues involved. The team considered that the intervention aims were largely met although the areas of access to information and communication with family required some changes. Other changes were proposed to make some activities less complex (goal setting) and simplifying and shortening the amount and style of the information delivery.

The accepted limitations to the evaluation concerned limited knowledge of participants' cognitive abilities and levels of impairment as clinical assessments were not made and the need to consider how to optimise involvement of family members and carers.

### *Randomised Control Trials (RCTs)*

***Psychosocial group intervention to enhance self-management skills of people with dementia and their caregivers: study protocol for a randomized control trial Laakkonen et al (2012).*** The study is a 'proof of concept study' based in Finland looking to recruit 160 people with early stage dementia and their spouses through memory clinics and psychiatric services in Helsinki. Patients and their spouses will have separate sessions over 8 weeks and subjects to be covered are similar to those in the English interventions. Searching on the International Clinical Trials Registry Platform indicates that this trial is not yet recruiting but no reasons are given.

***Managing, living, remembering (Quinn et al 2013).*** The study is the second phase of the SMART study being undertaken by the Research in Ageing and Cognitive Health (REACH) centre at the University of Bangor and funded by the National Institute for Social Care and Health Research (NISCHR) in Wales. The RCT is registered with current controlled trials and the protocol will be submitted this autumn.

A pilot single-site single-blind randomised control trial the study hopes to recruit 42 participants and caregiver pairs. The intervention of eight, 90-minute weekly sessions will be led by two members of the clinical team. Seven people with

dementia will attend each group and their caregivers will be invited to attend the first and final sessions. Caregivers will also be able to join the group at the end of each session to hear an overview of what theme has been covered. A group manual will cover the content of each session and allow space for additional notes and comments. The group is based on a self-management approach and draws on Social Cognitive Theory and self-regulation models. A flexible approach will be used and the sessions will each cover a particular theme within which participants will be able to focus on aspects that are meaningful to group members. After an orientation session themes will include: practical memory strategies, managing and coping with difficult emotions, managing relationships, planning ahead, how to find and access additional help and staying well.

Based on the findings from Phase One of the SMART study which involved designing an intervention on self-management with people with dementia and family caregivers, the group will be facilitated in an informal manner and time will be included for more social activities. Facilitation techniques will include discussion, collaborative problem-solving and goal-setting as well as creating situations where participants can experience mastery. Findings from Phase One are currently being written up with an aim for submission for publication before the end of 2013.

### Reports

***Give and Take Study: Information Use and Self-management by People with Dementia (Clarke et al 2008-2011)***. The information currently available is in the form of a research poster although academic publications are in development. The 30 month study which ran in Northumberland was funded through the National Institute for Health Research (NIHR), Research for Patient Benefit Programme (RfPB). Strand 1 collected and looked at narratives of people with dementia and carers or family members considering mechanisms for assimilating and disseminating knowledge in the early stages of dementia and the impact and use of information. Strand 2 was a personal development/self-management pilot programme drawing on the data gathered. The 10 week programme ran with small groups (8-10) of people with dementia diagnosed in the year previous to the intervention. Topics covered expectations and fears, meaning and independence, beliefs and attitudes, models of disability, being in control, internal and external barriers to independence and positive images of independence.

***Self-Management of Dementia (Wiersma et al 2011)*** This is a summary report from a consortium of academics led by the Centre for Education and Research on Aging and Health (CERAH) at Lakehead University, Ontario, Canada. The study explored meanings of self-management from the perspectives of people with dementia, partners in care and health service providers. Data was gathered through an open-ended online questionnaire (ninety responses) and forty interviews, of which seventeen were with people with dementia either as individuals or in small groups and fourteen were with health service providers. The report is interesting in that it reports how health service providers typically discussed the philosophies, approaches and environment of self-management whilst the people with dementia discussed the actualisation of self-management in the day to day. The report

highlights the fact that despite both chronic diseases and dementia getting worse over time, in terms of self-management the role of the person with dementia will change more over time and this makes programmes for people with dementia more complex and more difficult to create and manage.

The research team at CERAH were awarded an operating grant from the Canadian Institute of Health Research (CIHR) in 2012 to develop their work further in partnership with health service providers and people with dementia and their carers. <http://dementiaselfmanagement.wordpress.com/developing-a-self-management-program-for-dementia/> website accessed 14.10.13.

***Chronic Disease Self-management Programs: Relevance for Persons with Dementia - Executive Summary (Silverstein & Gottlieb 2011).*** The study set out to explore the extent to which people with Alzheimer's Disease were served in CDSMP workshops. A survey was sent to 2000 master trainers of CDSMP programs and the 253 responses covered trainers from across the USA, the District of Columbia and five other countries. Overwhelmingly respondents thought CDSMP could be helpful particularly to individuals with early stage dementia and over 80% of those trainers who respond reported having one or more individuals with suspected dementia in their workshops. Feedback indicated that all topics were potentially helpful but that some adjustments needed to be made to ensure they were not overly challenging to people with memory problems. Action planning was seen as particularly helpful because of the use of short-term achievable goals. The built-in repetition and consistent weekly routine of the programme was also seen as appropriate as was the use of a buddy system for between session reminders. Respondents commented that the presence of carers could make people with dementia feel safer although in some instances it was more problematic if the carer spoke for the person.

Currently these CDSMPs did not exclude people with dementia and most supported integrating individuals with dementia into mainstream classes. Additional insights suggested how CDSMPs could be customised for people with dementia and specific recommendations included focussing on memory loss content and memory management strategies, using additional materials (including visual aids), slowing the pace, simplifying information and reducing homework.

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### Group interventions – early stage dementia

The studies included in this section illuminate the processes that are relevant to developing appropriate group interventions for people with early stage dementia particularly recruitment, assessment, content development, peer group interaction, supporting primary relationships for people with dementia and the role, skills and varied backgrounds of facilitators.

Four studies from the USA and one from Canada describe support group interventions for people with early stage dementia. Whilst none of the studies use the term self-management they describe structured programmes run over 4-8 weeks that have both an educational and a support element to them and cover a number of the topics described in self-management programmes. Within these studies carers have

involvement in the groups at different levels and there is only one where the group was solely for people with dementia.

The work of Robyn Yale (1995) is cited by many studies on support group work and the model she developed of closed groups run over an eight week period combining education, emotional support and practical help is used by many.

### *Group intervention studies*

***Supportive Seminar groups: An Intervention for Early Stage Dementia Patients (Snyder, Quayhagen, Shepherd & Bower 1995).*** The study based in California, USA developed the format for a “Supportive Seminar Group” which was structured as eight weekly sessions of one and a half hours duration. After a joint introductory session people with dementia and their carers met separately for the first hour of each session and came together for the final half hour. Groups were small, 8-10 participants in total (4-5 pairs), and facilitated by a social worker and nurse team each of whom took one group. Topics covered included coping with memory problems, daily living, self-esteem, social and family relationships, legal and financial concerns and health maintenance.

The project was part of a larger study evaluating four non-pharmacological interventions and participants were required to meet the inclusion criteria for the bigger study. As a general measure the authors suggest that a score of 20 or above on the Mini-Mental State Examination (MMSE) or a score of 100 or above on the Dementia Rating Scale can be useful measures for group inclusion criteria.

Evaluative statements made by participants with dementia were content-analysed for recurring themes. There were four positive themes of purposefulness, gratification, belonging and surviving and three negative themes of helplessness, devaluation and unpredictability. Examination of the evaluative comments indicated that the positive comments were focused on the intervention process and/or group interaction and the negative comments addressed either the disease or social and environmental focuses outside the scope of the intervention. In conclusion the authors discuss the more cathartic nature of the separate group sessions and the more reflective nature of the united group. The study advocates the feasibility and value of the supportive seminar group as an intervention with early stage dementia patients.

***Early stage dementia group: An innovative model of support for individuals in the early stages of dementia (Goldsilver & Gruneir 2001).*** The study describes an intervention developed by a community based support agency, Circle of Care, in collaboration with a community based rehabilitation agency COTA (Comprehensive Rehabilitation and Mental Health Services) both based in Toronto, Canada. In their introduction the authors quote Yale (Yale 1995) noting that support groups for people recently diagnosed with dementia have the *‘potential to facilitate emotional adjustment to coping with and planning for the disease as it progresses’*. The intervention ran in a closed format over eight weeks each session lasting one and a quarter hours and during a late morning time slot. The sessions had a structured format and were facilitated by a social worker and an occupational therapist who suggested topics on the basis of interest and educational value. Topics included the

brain and behaviour, energy conservation, reminiscence, coping with loss and strategies to improve memory. Recruitment was through a broad base of community professionals and voluntary dementia organisations. All potential participants were interviewed and a MMSE was undertaken to determine the participants' capability of attending a discussion group and their interest in a support group.

Carers were not involved in the groups but were encouraged to contact the facilitators with any concerns or queries. At the conclusion of the group sessions an evening meeting took place with the carers to provide information, education and support. Group members were aware of this meeting and were reassured of group confidentiality.

The group were encouraged to participate actively and the study reflects on how relationships, leadership and support worked and developed within the group. Accepting that forgetfulness is a group norm amongst people with early stage dementia the study reports on how members of the group '*gave each other permission to forget, and sometimes shared with humour, jokes and anecdotes relating to poor memory.*'

The evaluation of the group was largely positive giving ideas, helping people relax and helping them think things out more clearly. Not all participants found it helpful to be with others with the same condition and some found the technical information too much. The study makes the point well that people with early stage dementia are capable and functional individuals who can and do express their feelings in a group setting and should be offered a place to '*express their concerns, fears and emotions in a safe, supportive, non-judgemental environment*'. They also stress that group process issues are unique with people with dementia and that facilitators '*must have a flexible range of group skills and be ready for the unexpected*'.

***Evaluation of an Education and Support Program for Early-stage Alzheimer's Disease (Scott Roberts & Silverio 2009).*** The study evaluated the "Taking Control of Alzheimer's Disease" programme in Massachusetts, USA. An existing education and support intervention, part of the Early Stage Program of the Alzheimer's Association, the programme ran over four two hour sessions with a three month follow up. Sessions were attended by people with dementia and their carers and included large group instruction and breakout sessions where people with dementia and carers met separately. Groups were typically 6-10 people with dementia each with a carer and were led by a trained facilitator with experience in dementia care from the Alzheimer's Association, with occasional guest speakers. Sessions focussed on education about cognitive disorders, treatments, memory enhancement, changing roles and relationships and joint planning. Participants' diagnostic status was confirmed and assessments were done at baseline, after the programme and 3 months after completion. The study reports a key benefit of the group involvement for the people with dementia being an '*experience of being understood and accepted by others coping with a similar condition*'. Noted improvements overall were an increase in joint planning and an increase in proactive behaviour changes. Improvements were not significant on measures of coping self-efficacy, adjustment to illness or knowledge of Alzheimer's Disease. The group had high education levels

which researchers felt might have influenced both initial level of knowledge about dementia and the engagement in joint planning activity.

***Memory Club: A Group Intervention for People with Early-Stage Dementia and Their Care Partners (Zarit, Femia, Warson, Rice-Oeschger & Kakos 2004).*** The study describes the Memory Club, a structured and time-limited, psycho-educational intervention for people with dementia and their 'care-partner' in California, USA. The programme ran bi-weekly over 10 sessions with express goals of increasing the information that people with dementia and their care-partners have and to empower and strengthen them as a partnership in their planning and outreaching for broader support. The structure of each session allowed the participants with dementia and their care-partners to meet both separately and together as groups. Recruitment was enhanced through strong relationships with geriatric services providers and through in-person interviews with participants and cognitive assessment of those with dementia. Sessions were facilitated by a social worker and a neuropsychologist.

***A support group for people in the early stages of dementia of the Alzheimer type (LaBarge & Tranj 1995)*** The study looked at the process and outcomes of a support group for people with early stage dementia in Washington, USA and suggests that essential elements to the success of a support group are selection screening, linking memory exercises to education, aiding failed communication, accommodating individual needs and extensive knowledge and counselling skills (full article not available).

### *Other studies*

Finally in this section some studies are included that consider processes within support groups including generational and gender differences.

***Processes and experiences of mutual support in professionally-led support groups for people with early stage dementia (Mason, Clare & Pistrang 2005).*** This qualitative study offers useful feedback on the processes of group support interventions for people with early stage dementia. The study generated group observational and individual interview data from two support groups for people with early stage dementia. The study ran over three months with two groups which were part of local day hospital services and facilitated by an assistant and consultant psychologist. Practical implications suggested by the authors relate to the benefit in ensuring as far as possible that the levels of cognitive and behavioural functioning within the group are homogenous and that cognitive difficulties may mean that members require a longer time to establish a sense of familiarity and trust. They also noted that individuals will have preferences for different ways of talking about the difficulties and experiences that arise from their diagnosis, some of which may be from a generational tendency of dealing with personal problems through other means than sharing them with others. The authors raised questions about facilitation of groups for people with early stage dementia and the need for further exploration of different degrees and styles of professional and member-led facilitation.

There is little written about support groups just for men or just for women with early stage dementia. Recognising that there are higher numbers of women with dementia



and that women comprise a high percentage of the health and social care workforce Manthorpe and Moniz–Cook (2009) consider the development of support groups for men with early dementia in Hull. Pearce, Clare & Pistrang (2002) in an interview study also explore the appraisal and coping processes of men with early stage dementia and offer a framework for understanding how men cope with their illness.

Whilst not covered here there are useful reviews that cover the broader field of individual and group psychological interventions Kasl-Godley and Gatz (2000) and Scott and Clare (2003); of cognitive training and cognitive rehabilitation Clare (2003) and of group psychotherapeutic interventions Cheston (1998) and Cheston et al (2003).

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### Self-management of relevant and comparable long term conditions

There is a substantial body of work on self-management in chronic long-term conditions like arthritis, diabetes and asthma but a much more limited amount on conditions that could be considered as being comparable to dementia. The review was able to identify and access a few articles that look at self-management programmes for people with neurological conditions including stroke, multiple sclerosis (MS), Parkinson's Disease and acquired brain injury. Many of the findings from these studies reinforce findings from other self-management studies including the importance of being with peers, skilled and knowledgeable facilitators and the provision of disease specific information. The reviewer has therefore only highlighted specific findings/comments that add something relevant to the development of self-management with people with dementia.

***Self-management after stroke: time for some more questions? (Jones, Riazi & Norris 2012).*** The authors discuss research and debate the issues of self-management for individuals after stroke. They consider the importance of being aware of the psychological consequences of stroke and the potential for individuals to '*experience a change in identity which is long lasting*'. They also recommend that a focus on behaviour change should not fail to acknowledge the role of social networks and peer support for embedding self-management strategies into everyday life.

***Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury (Hirsche, Williams, Jones & Manns 2010).*** The study reports on the experiences of people with stroke, multiple sclerosis and spinal cord injury attending the CDSM Programme in the Alberta region of Canada. The findings highlight the importance of the timeliness of programmes to individuals' situations and readiness to engage, the usefulness of core work on goal setting and coping and managing techniques, flexibility of sessions and the importance for people with neurological conditions of lay peer involvement in session delivery.

***Self-management for people with long-term neurological conditions (Chaplin, Hazan & Wilson 2012).*** The study reports on the Hertfordshire Neurological Service self-management programme which works with people with Parkinson's and MS.



The programme uses Personal Health Plans (DoH 2011), works in modular form, including a module with carers, and is delivered by a multidisciplinary team. The authors highlight components of the programme including increasing knowledge of cognitive changes, problem-solving through cognitive challenges and practising strategies through homework that appear to contribute to enabling participants to use cognitive management strategies effectively.

***Process evaluation of a self-management cognitive program for persons with multiple sclerosis (Shevil & Finlayson 2009).*** The study describes a programme for people with MS focusing on the ability to manage cognitive changes accompanying the disease. This study again highlights the importance of developing knowledge of cognitive challenges and through a combination of demonstration and practice enabling participants to transfer strategies into their everyday lives and routines.

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### The role of lay and peer tutors in self-management

Lay facilitation by those with chronic conditions themselves is a central tenet of the CDSMP programme model developed by Lorig and in programmes developed from that model including the EPP in the UK. The use of lay and often voluntary facilitators enables these programmes to have a large spread and to be delivered in a cost effective way.

***Self-management approaches for people with chronic conditions: a review (Barlow et al 2002).*** The study looked at 145 studies of which 82 were from the USA, 13 from the UK, 10 from Australia and 40 from other countries. The review noted a range of tutors delivering self-management interventions, the majority of whom were health professionals with the exception of those based on Lorig's model.

***Self-management education programmes by lay leaders for people with chronic conditions (Foster et al 2009).*** The Cochrane Review looked at self-management education programmes delivered by lay leaders for people with chronic conditions. Seventeen studies were included in the review of which 10 were from North America, 4 from the UK, and 1 each from Australia, China and the Netherlands. In their discussion the authors comment that from the limited evidence available lay-led interventions are as effective as professionally-led ones as there was no significant difference in effect shown between lay-led self-management interventions and either usual care or professionally led education interventions.

***Self-Management Education: History, Definition, Outcomes and Mechanisms (Lorig & Holman 2003 p4).*** The authors found from several studies of self-management programmes that '*peers, when well trained and given a detailed protocol, teach at least as well as health professionals*' and perhaps more importantly '*can act as models for each other*'.

None of the studies cited above covered self-management interventions for people with dementia and writing in their review on psychological interventions for people with dementia **Scott & Clare (2003)** suggest that '*it seems it is generally agreed*

*that support groups should be professionally facilitated in view of the difficult and painful emotional issues that are likely to arise’.*

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### Summary

The review is structured around three main bodies of work; research and thinking on self-management group interventions for people with early stage dementia; group interventions for people with early stage dementia and self-management interventions for people with long term conditions where there are comparable and relevant issues. The evidence gathered for the review indicates that whilst there is a significant amount of research available on self-management of chronic conditions there is much less that directly relates to people with early stage dementia. It is clear from what research there is and the very recent nature of some of the publications that this is a very current and developing area of research and interest.

There are some key areas that emerge;

### *Facilitation*

None of the studies included on work with people with dementia are lay or peer led although some of the studies include peer tutors or ‘champions’ (Martin et al 2013). The tutors/facilitators of the studies covered came from a vast range of expertise and professional backgrounds including psychologists, occupational therapists, social workers and other health professionals and most studies had at least two tutors involved with relatively small groups of participants.

### *Different perspectives that inform the research*

In the studies on self-management with people with dementia it is useful to consider the different theoretical and practice backgrounds of Occupational Therapy (Mountain) and Psychology (Martin & Turner and Quinn) which produce some differences in the design and facilitation of the programmes being developed and piloted.

### *Content, delivery techniques and style*

The broader literature on self-management indicates common ground on the content of generic self-management programmes and there is no indication that any of the studies covered here see that this content is not relevant to people with dementia. However there is consideration that programmes whose content is balanced more towards ‘everyday and biography work’ rather than ‘illness management’ work (Corbin & Strauss 1988) may be more appropriate to people with dementia. Both the evidence on work with people with dementia and people with long term neurological conditions highlights the need for programmes to be designed with a clear understanding of cognitive challenges. Using modelling and opportunities for self mastery is seen as important as is the use of mechanisms to aid and trigger retention using short blocks of input, repetition, memory triggers and support materials both written and audio.

## Pre-course assessment

It is noticeable in the studies from the USA and Canada that pre assessment is done before people with dementia join programmes.

## The role of carers

The role of carers is considered in a number of the included studies and there are examples that cover a spectrum of involvement. There is recognition that to work with people with dementia necessitates working within the framework of their broader support which covers carers and family members, their health providers and their broader networks of support.

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### External Evaluation of the Alzheimer's Society Live Well with Dementia programme - Interim Report

#### 1. Background

The external evaluation of the Live Well with Dementia programme commissioned from the University of Brighton commenced on 1<sup>st</sup> December 2013 and will run until 31<sup>st</sup> March 2016. The evaluation is being carried out by a team of staff from the School of Applied Social Science under the contract agreed with the Alzheimer's Society.

This document provides an interim report of the evaluation as agreed in the contract timetable. It covers data gathered on co-design of the programme and from the pilot delivery stage of the programme in East Sussex.

#### 2. The evaluation – aims and methodology

##### Aims

The evaluation aims to explore the extent to which the Live Well with Dementia Programme (LWWDP) is successful in providing the knowledge, skills and practical tools that can support people to live well with dementia based on the principles and desired outcomes of self care. Participants' views of the content and style of delivery of the programme will be explored as will the timeliness of the course to their individual situations. The evaluation will also identify facilitators and barriers to co-design with people with dementia.

##### Methodology

The evaluation is running alongside the programme development and delivery. It comprises two main parts: evaluation of the co-design process and evaluation of the programme delivery.

##### *Evaluation of the co-design process*

In evaluating the co-design process the evaluation team set out to answer the following questions;

3. What has been the experience of people with dementia and staff working with them in the co-design of the Live Well with Dementia Programme?
4. What has facilitated the process and what barriers have there been?

The original methodology designed for this part of the evaluation was as follows:

- Observation of co-design consultation meetings in both pre pilot and post pilot phases (numbers and locations yet to be determined).
- Interviews with some of the participants involved in the co-design process both people with dementia and Alzheimer's Society staff (numbers and locations yet to be determined)
- Feedback from the observation and interviews will be fed back during the consultation stages in short summary feedback points to the Alzheimer's Society on what is working and where there is room for improvement.

The pre-pilot co-design element of the LWWDP involved 3 consultation meetings with people with dementia, facilitated by the co-design partners from Self Management UK (SMUK) and the Alzheimer's Society (AS). The first two meetings were focus groups brought together specifically to



look at programme content the third was a consultation session with an existing Alzheimer's Society User Reference Group.

The original plan for the evaluation had been to observe these co-design consultation meetings, interview those who participated (both people with dementia, co-design partners and Alzheimer's Society staff) and then, on the basis of an analysis of these data, provide a short feedback summary to the AS on what appeared to work more or less well and where there was room for further improvement, *in terms of the process of co-design itself*.

In the event, full observation of the co-design consultation meetings was not possible as the locations of two of the three meetings were unsuitable (too distant) and the meetings were held before the research contract was signed and before ethics approval for the research had been secured. The team were able to observe the third consultation meeting but, without ethics approval, these observations could not form part of the formal evaluation process. Rather, this observation served to familiarise the evaluation team with the nature and content of the programme being proposed.

Once ethics approval was secured, interviews were held with the two co-design partners and with the AS co-ordinator of the User Reference Group that was observed. Our evaluation of the process of co-design is therefore, necessarily, limited to data collected in these interviews. We were unable to interview any people with dementia who took part in these sessions for the reasons mentioned earlier; a combination of geography and the length of time after the meetings before ethics approval was granted.

### ***Evaluation of programme delivery***

The evaluation of the programme delivery has been designed in two stages and this report covers only the pilot phase. In both phases the evaluation is seeking to answer the following questions;

1. To what extent is the Live Well with Dementia Programme successful in providing knowledge, skills and practical tools in ways that can support people with dementia to be more actively involved in their own self care?
2. To what extent does the timeliness of the Live Well with Dementia Programme to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?
3. Are there ways in which the delivery content and/or style could be improved or made more appropriate?

The original methodology designed for this part of the evaluation was as follows;

At one pilot site-

- Observation of all workshop sessions (likely to be 6-8).
- Post course interviews with 3-4 participants with dementia
- Post course paired interviews with 2 of the same people with dementia with their carer.
- Interviews with facilitators (2)

This methodology was successfully carried out. The evaluation team attended and observed all seven sessions of the East Sussex Pilot in Hastings between 13<sup>th</sup> March and 24<sup>th</sup> April 2014. This observation was followed up with individual interviews with participants of the pilot, two interviews

with two of these individuals with their carers and two interviews with facilitators. We were unable to interview one of the main facilitators due to her absence from work with illness during the interview time frame. All interviews were completed by 23<sup>rd</sup> May.

The evaluation is covered by University of Brighton ethics approvals and complies with ethical research requirements of the Alzheimer's Society. A fully informed and detailed consent process was designed for the evaluation which worked well in practice. Facilitators of the pilot were able to seek participant consent on behalf of the evaluation team during their pre course assessment process and ongoing process consent was then carried out at each observation session. Individual consents were carried out with those participants who were interviewed and additionally with them and their carers for the joint interviews. Consent was secured at the start of the pilot from the facilitators for both the observation and the follow up interviews. Local Alzheimer's Society Dementia Support Staff were available to the evaluation team for participant follow up after interviews but none was needed.

All interviews were recorded and transcribed and all observation sessions were manually recorded in detail.

The evaluation team has already submitted a key points document on 13<sup>th</sup> May 2014 based on the observation sessions alone. This report is based on the contents of that document with additional findings based on the interviews undertaken.

### 3. Findings

#### Co-design element

The aim of the consultation meetings had been to explore the relevance, for people with dementia, of the content and delivery of a standard generic self management programme and to suggest ways in which it might need to be adapted to better suit their needs and existing resources. Some 'taster' sessions were offered as part of the consultation meetings so that such assessment could be more easily made.

The co-design partner from SMUK, was clear that, apart from hearing someone with dementia speak at a conference, she had never had 'any dealings with people with dementia specifically'. It was however after hearing this person speak about how others assumed her diagnosis made her incapable of doing anything that she became convinced that a self management programme for people with dementia could work well because it would 'take into account and highlight their ability as opposed to their disability'. SMUK then approached the AS about exploring the possibilities of 'tailoring' their generic self management programme for people with early stage dementia. A 'peer support' group was consulted and agreed that such a model would be interesting and relevant for people with dementia.

SMUK amended the self management materials before testing them on people with dementia in the consultation/co-design meetings by simplifying the language, 'stripping down' and 'adding appropriateness'. The tutor manuals were also modified.

The AS co-design partner was clear that the consultation meetings could only be considered co-design in a very limited sense as there was little time and space for people with dementia to make original suggestions for either the content or the delivery of the programme. He confirmed that the AS was not looking to design something from scratch but rather 'to start from an evidence base' and the existing SMUK programme was deemed to be an appropriate starting point in this regard. SMUK

were also clear that the purpose of the co-design sessions was to ‘test some of the material to see if it actually worked’. So, rather than being asked a series of open questions about what a self management programme for people with dementia might look like, participants were asked to evaluate the suitability, for people with dementia, of an already largely defined self-management programme. The AS co-design partner made it very clear in the interview that they were ‘adapting a programme, not designing one’, however there did appear to be some ambivalence here as he later reflected:

I’d still want to think more about those kinds of things we talked about. Are we inviting people to adapt something or inviting them to tell us more about what they would like to see? And we could have done more of that certainly and I’d like to have done more of that at an early stage than we did.

In terms of the process of consultation in these meetings, the AS co-design partner reflected that expertise in working with people with dementia was very important to the successful facilitation of discussions and commented on how he had needed to support the self management expert ‘to make it more accessible to people with dementia’.

According to the AS co-design partner, in terms of changes made as a result of these consultation meetings, most of these involved ‘simplification’- of language used (more ‘everyday language’) and of tasks. They also planned to ‘shift the focus away from the facilitators’ and put more emphasis on ‘discussion within the groups’ so that lessons emerged from within these discussions. SMUK confirmed that the consultation/co-design sessions had enabled them to appreciate the importance of facilitation that can actually help with ‘linking in to people’s stories’:

...I think what worked was actually relating to the stories they told, picking up on the strands that were coming through, what the importance was to them...

SMUK also described having learnt about the need for ‘flexibility’ and ‘listening and taking on board what’s happening within the group’. Further describing gaining insight into the importance of carers and how, in the second meeting, they actively sought carers input on a ‘pacing sheet’ that had been developed and how useful this might be in supporting the people with dementia.

Overall, the process of change and adaptation that followed the consultations/co-design might be thought of as one of ‘negotiation’ between the AS with dementia expertise and the SMUK with self management expertise.

The AS co-design partner described it in this way:

...there’s almost a negotiation about the process of changing the content and, if you like, SMUK starts from the position of having a programme they are confident in and which they know works with a group of people and then we (AS) bring that group of people, that group of people, to enter in our own expertise too and say ‘these are the things I think we need to see change’, and, at the same time, SMUK, if you like has to protect the integrity of the programme that they have got confidence in.

The AS co-design partner described how they had originally assumed that SMUK would ‘do the self management part’ and the AS would ‘do the dementia part’ and that ‘this is where the negotiation sits’. He described the negotiation about language as an example of how difficult that sometimes was to achieve where, for example, the self management expert ‘understands it inside out, it’s quite

natural for them to talk in those terms and therefore perhaps it's a little more difficult for them to see the reasons for us wanting to make some of those changes'.

The AS co-design partner was reflective about the pace of change, too, saying that what they had learnt from those early consultations would be reflected 'ultimately' in the programme as its delivered: 'if not immediately in the first five (pilot) sites but certainly as it develops over the few years'.

In summary, in terms of our evaluation questions in relation to co-design at pre-pilot stage:

1. What has been the experience of people with dementia and staff working with them in the co-design of the Live Well with Dementia Programme?
2. What has facilitated the process and what have the barriers been?

We conclude:

- the co-design process was limited to a testing and informal 'evaluation' of a pre-existing self management programme that had been partially adapted by SMUK for use with people with dementia
- within this framework, there was little opportunity for people with dementia to really get involved and come up with their own ideas about self management - either about how they might currently self manage or what they might like to see in a self management programme for people with dementia (both of which might have led to the development of a rather different type of programme)
- much of the re-design or 'adaptation' that took place following these meetings necessarily involved negotiation between two different types of expertise - of self management and of dementia (and working with people with dementia)
- the involvement of the AS dementia expert in co-facilitating these sessions was crucial in enabling a better understanding of the needs and existing resources of people with dementia and how these might be better used in the proposed LWWD programme
- some of the insights gained through this process of negotiation – such as the tension between delivering a pre-set (albeit adapted) self management programme and listening to and responding to the needs and experiences of people with dementia as they emerge in the group - continue into the delivery stage, as we discuss below.

### **Pilot delivery**

The findings detailed below reflect both the session observations and the interviews with participants, participants and carers and facilitators. The points detailed in the initial key points document are assimilated and developed.

### ***Context to pilot***

The Live Well with Dementia Programme (LWWD) being piloted in East Sussex was delivered as part of the East Sussex Memory Support Service (ESMSS). This service is commissioned by East Sussex County Council and run by the Alzheimer's Society (AS) and Sussex Partnership Trust (SPT). It provides a variety of group interventions for people with a recent diagnosis of dementia aimed at supporting them to enjoy an enhanced quality of life and in remaining independent. Referrals are

generally made through the Memory Assessment Service and the group interventions include cognitive stimulation, memory management and reminiscence therapies<sup>1</sup>.

Six out of the eight participants of the LWWDP pilot group had attended a Cognitive Stimulation Group (CSG) in the autumn of 2013 as part of the ESMSS with the same facilitators. The CSG was activity based (predominantly creative) rather than concentrating on memory or self management techniques and tools. The evaluation team understood from interviews with facilitators that Memory Management Groups (MMGs), previously developed and run by SPT in the Newhaven area, were also included in the ESMSS offer and these groups looked much more at practical ways to help manage memory issues. Facilitators talked about the differences and similarities between the MMGs and the LWWDP and how they were structured and delivered with the LWWDP being the more formal. Feedback on what some participants had thought of the LWWDP in comparison with the CSG was given in interviews

This pilot was not delivered in isolation but as part of a broader delivery package. Three quarters of those attending the LWWDP had already spent eight weeks in a course together and with the same facilitators. From the observation there was evidence of an existing strong group dynamic and a familiarity that was mentioned by most of those interviewed as being key to their experience of the LWWDP. The group appeared very compliant and did not wish to be seen as critical of the facilitators who they valued highly from their previous experience. From observation we felt that this compliance together with an existing group dynamic in terms of confidence and familiarity with each other influenced how this group experienced and commented on the programme. This was born out in interviews where the view of the facilitators of how well some sessions had gone was different to what the participants felt.

### ***Assessment/suitability***

The pre course assessment process carried out by the facilitators with all participants included a baseline questionnaire covering their current capacity to live well with dementia and a short eight point statement to agree if they felt the LWWDP was right for them. In addition participants signed a standard consent form for receiving an Alzheimer's Society Service.

The second question of the external evaluation was to consider to what extent does the timeliness of the Live Well with Dementia Programme to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?

There were probably only four people (two of whom we only have observation evidence for – Frank and Peter) who were at the right level to benefit from the programme in the way that it was originally conceived. This would suggest that the assessment process is very important in terms of being able to monitor the suitability and impact of the programme. The evaluation team did not have detailed information about participant diagnosis – either type of dementia, how long since diagnosis or how their dementia affected them - other than the information that came from observation and interview. Not everyone knew what their diagnosis was and probably only those four mentioned above were able to articulate with clarity how their dementia affected them. For example Christine's current manifestation was more about spacial difficulty than memory and what was important for her was understanding and finding practical ways to deal with this and the changes she needed to make jointly with her very supportive and aware husband. Terry was very aware that for him the issue was about memory and the lack of confidence and problems with

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<sup>1</sup> East Sussex Memory Support Service Service Specification September 2013

communication that resulted. He sought help with these issues during the programme and actively tried out different ways to assist himself and his wife in dealing with his memory problems.

From the observation and interview findings it appeared that there was one group of participants who had been able to take things away from the programme and make use of them (Christine, Terry, Peter, Frank). A second group had some memory of the process of the programme but little of the detailed content (Andrew, Joyce). In a third group it was not clear that the programme had much impact other than in the benefits of being part of a group and enjoying the social process (George, Robert). All the participants valued the social contact and being in contact with others with the same condition and most had a sense of feeling supported in the group and by the facilitators. We were unable to interview everyone who attended but did interview 2 from group one, 2 from group two and 1 from group three. Of the joint interviews with carers 1 was from group one and 1 from group two. Informal feedback was also given to the interviewer in conversation with George's carer on the issue of follow up and from Peter by phone.

The major issue, not unexpectedly, was levels of memory, so group one had memory both of content and process, group two had memory of the process but little of the content and group three had very little memory of either process or content but could remember enjoying being part of the group and with others in same situation (the 'club' as George called it). As an example George, when interviewed, could remember very little about the programme other than that he enjoyed it 'I loved all the people, we got on so well together, you know' and there was no evidence that he had followed up any of the paperwork.

In the case of both Andrew and George there were carers who would have wanted to support the follow up and use of the programme but were unable to find out much from the person with dementia about what they had actually covered each week.

One of the participants from group one, Terry, voiced the impact for him of the difference in levels of participation in the group;

there was probably two or three that never contributed to the whole session in my opinion and I felt that a little bit because I was feeding and getting some good information and feedback from some of the other folk that were on the course..... I always felt that I quite often did a lot of the leading to start off with and things like that, being a joke some of the times because that's the way I do it but I just felt there was a few of them that threw us and we tried our hardest to present stuff which helped the other people but the ones that continued, just slept and slept nice and quietly they said they loved it but they just come there and just listen. There's nothing wrong in that but I felt that a little bit sided that I would have liked all of them to be like the six, I'd like the other four to be equal and just say "I tried that and it was bloody useless" or something like that, but they just say "oh we don't have the time to do that" but they've been asleep, that's why they didn't grasp what they...

Andrew also noticed;

Some were quieter, and but some of them perhaps are a longer way down the thing

The evidence gathered in the pilot indicates that it is likely that the programme had most impact on those in group one. In order for it to be targeted at those who could most benefit from it we feel it would be useful for the pre course assessment to consider not just time since diagnosis and type of dementia but its particular symptoms/manifestation for the individuals combined with their level of self awareness of how those manifestations impact on them and what they feel would help them.

### **Content**

Each session covered at least three main topics usually including a psychological issue, a practical issue and some form of relaxation plus the action planning process. From observation this did seem to be too much content and we considered that fewer topics in each session would have helped the development and understanding of the content. Facilitators worked hard to get through everything each week but in most sessions the action planning session and the evaluation at the end had to be curtailed to fit into the available time.

There was a lot to cover in the time and feedback that we were getting was that it was, that two and a half hours was a long time as well, so I felt there was a lot to cover and it was crammed into, you know, well, yeah, it took a long time.....sometimes I wondered at the end of the session how much they would have remembered from all the things that we covered (facilitator)

On further reflection the facilitator considered perhaps 60% of the content would have been a reasonable amount to cover in the time 'it was just too many different things in one'

From observation it was apparent that less content would have given more time for each issue to be developed and for facilitators to be able to judge better how the participants were engaging with and understanding the material. In particular where people raised personal issues/experiences that broadened into a discussion this often had to be curtailed in order for the session content to be got through in the time. There was a disconnect here between participants' need to share experiences and the facilitators' need to deliver a set of tools to help (self) manage a particular issue e.g. dealing with a health professional. Not having the space in the timing for the participants to explore issues as they came to them we consider led to the programme being more limited in its appropriateness for people with dementia.

Yeah, and thinking about the client group quite often people, they have to say what they want to say there and then, otherwise it's gone, so it might be that we were sort of, we were cutting people off, or saying 'we'll come back to that', it's, then it's gone and there's, you know, even if you did, you know, I don't think we always remember to come back to the things that we said we would come back to ourselves, but you know, even if we had given them that time I think perhaps the moment might have passed (facilitator)

There were also comments from participants in interviews about the amount and the sense of sometimes feeling rushed particularly in the last two sessions;

and it seemed as if they had to rush it to get all the sections of it in and to help us record it and absorb it. I thought that wasn't their fault, I think it was just there's so many sessions they had to complete inside that distance I suppose...(Terry)

There was no specific information given about dementia. A number of questions were asked by participants in the sessions which facilitators responded to where they could. From our evaluation of the CrISP programme we know how important this knowledge was to helping carers develop their understanding of dementia. Whilst everyone is different the questions implied that some knowledge and the opportunity to exchange the day to day lived experience of symptoms and problems would have been useful to these participants.

Terry in particular was concerned to know what he could expect for the future.



Yeah. I've been trying to fight, how long is it going to be for me to alter and change? ..... I keep looking for opportunities or someone to say this or someone to say that, or even to grade what sort I am even. And if someone tells me something very important it's quite often sometimes that's what I forget so I have to really watch my memory and I'm getting now to writing things down but that's it, I think my biggest fear I'm concerned about how I'm going forward.....I'd be highly delighted if I could stay at the standard I'm at now.

One of the facilitators also reflected that some of the practical memory management strategies from the MMGs might have been usefully included as part of the LWWDP.

perhaps that's something that could be added that would be quite useful.....because you know, with the group sort of managing the same condition there's usually different ideas that people can sort of pick up from each other as well as anything we're suggesting (facilitator)

There was little time for issues of acceptance or life style change to be shared or discussed. For example one participant had to stop driving during the course of the programme and found how he had been dealt with difficult to accept and raised it often. A broader issue here of loss of freedom was something that could have been discussed with more time as it was also relevant to others in the group. Feedback at the end of the sessions indicated that people would have liked more time to share experience 'I think hearing other people talking helped because then perhaps I would think, "well yes I feel like that"'(Christine). One facilitator also felt that more time was needed for participants to discuss 'what's important to them'.

We observed that the content of the programme was largely generic and it was unclear what content had been specifically designed for people with dementia. Participants talked most confidently and knowledgeably about their own experience and engaged more with the sessions relating to practicalities e.g. distractions/eating well rather than with sessions like the one on beliefs. We observed that some content made more sense than other and participants were more able to engage when they could relate concepts to their own experience. There was a superficiality as to how some of the complex concepts were presented and on occasions it felt that bits and pieces were put together without it always being clear what the context was or how they fitted together. In the sessions that seemed more difficult for participants to make sense of we wondered whether the stripping down/simplification of language had made issues less easy to explain or understand.

The programme was designed to develop certain tools through repetition of exercises like problem solving and action planning. The action planning process became familiar and could be recalled at interview as it was repeated every week but other techniques like the problem solving exercise, which was not used every week, were not recalled at interview. The questions process that carried through most of the sessions did not always work. Comments from facilitators indicated that they felt that the process they were asked to use did not always feel right to them and the language was repetitive and sometimes unclear. The facilitators were concerned that therefore they were not explaining things well and on observation there were clearly sessions where there was little response and a lot of prompting from the facilitators before participants understood what was being asked for. The communication session in particular was difficult for participants to understand what was being asked and they responded with practical examples when the session seemed to be looking more at the emotional impact of communication. Facilitators reported it had worked well when they role played it on training but 'it didn't seem to strike a chord with our group when we did it' they went on to say 'definitely with some of the questions we felt that they just, even when we

asked them we kind of felt as we were asking them 'I'm not sure people are going to be able to answer this' and then they couldn't and maybe we gave examples to help..'

From the participants' perspectives the practical sessions worked best. Action planning was remembered by all of those interviewed but not all had found it useful. Joyce felt it helped her get back in the garden 'yes it was useful because I got myself back out into sweeping the garden and doing bits and pieces around the garden' and Terry had found it a useful way to feedback to his wife about the programme 'and she learned bits about it, like you know we had to send something in we did each week and then give feedback'. Terry used the action planning process very effectively and felt it helped him and his wife to communicate,

I had a shed repair job.....my wife was over the moon to think that I'd been to the stores and got prices and have they got the right felt and that and did we need it, and then we worked out we needed a bit more and just repair and we needed a....Did the whole shed. But she was really, really pleased with me taking that product forward and recording it and talking about it when I got to the other people (Terry)

Christine, however, although she participated each week in the action planning process, in interview said that she had found it 'a bit silly' as she and her husband tended to do things according to the weather and all in all she reported she had found it 'a bit demeaning'. Andrew's wife Sarah also thought the action plans were not so helpful 'between us we didn't know what we were supposed to do' Sarah also 'wasn't quite sure whether I was getting all the information from Andrew about it, whether he had been told more but wasn't remembering'. Both Christine and her husband Gary and Andrew and Sarah had their own strong organisation systems. We felt it would have been useful for facilitators to find out more from the group about how they were currently organising their lives with family and carers so that the programme could be tailored to what would be most useful to them.

The sessions that related to practical life style issues like keeping active, healthy eating and relaxation engaged the participants more. In these areas they either had more to contribute from what they were already doing or in the case of meditation and relaxation they enjoyed the process. Some of the techniques like pacing, for example, stayed with people more when they related them to physical activity. 'I start on a job and I want to keep going until I've finished but perhaps now I think, "well, I can do that later" or I'll stop and have a cup of coffee or something' (Christine).

We did not feel that the Staying Well Plan developed in the final session worked well for participants. We were concerned that this was both too complex and unclear in terms of how it was presented in the manual and there was not enough time to explore it properly. It was also more difficult for participants to consider due to it being of a more *long term* nature. We think it would be useful to consider whether this *end of course* type action planning familiar to many training courses could be presented in a more relevant and useful way for people with dementia and their families and carers otherwise we believe its use would be limited.

### ***Practical aspects of how sessions ran***

The participants arrived promptly at 1.30pm and the group generally got underway at 1.45pm running to 4.00pm with a 15 minute break around 3.00pm. From interviews participants reported that this was quite a long time particularly in comparison with the CSG. Andrew's carer Sarah commented 'I got the impression from Andrew that he felt that it was a long time from half past one till four wasn't it, two and a half hours was a long time and you were far happier on the first course

that you did which was only for an hour and a half wasn't it?' . Christine said that she would certainly not have wanted it to be any longer.

What participants commented on more than the length of the sessions was the lack of any moving around within the sessions and the impact of that. In comparison with the CSG Christine described this group as 'very static' and others who were interviewed commented similarly about the amount of different things and activities they did as part of the CSG group. By habit people generally sat next to the same people and in a similar part of the room. The manual suggested working in smaller groups for the action planning and other sessions but this was not followed with this group except in the first session. There were issues in terms of use of additional space on a couple of occasions which limited the choice the facilitators had to break the group up however we would suggest that the time pressure to complete everything was also a major factor in restricting how the facilitators were able to work.

From observation it was clear that there were times when the energy and concentration in the group was very low and breaking up the format of the larger group would have helped with this. A very good energiser was done in one session that really helped and this technique should have been used more. The group did not appear to need a long mid-session break but they could also have been encouraged at that point to move around. Looking at ways in which the programme could provide more opportunities for participants to move around would we think be most useful in helping with energy and concentration levels. The programme contained a number of sessions on issues like relaxation and meditation and the timing of these in relation to breaks and what sessions were programmed to follow them should be carefully considered to give participants the best chance to engage and participate. A number of the participants did seem on occasions to doze or not to speak for quite long periods of time and this was commented on by others.

### ***Use of the group as a resource***

The programme was heavily scripted and there was little room for any *free* discussion by the participants of their own situations or for them to hear from others in the group. Joyce described the sessions as 'a little formal and it might have been good to have a bit more discussion between people' she also commented that this formality meant there was no 'exchange of, um, I couldn't tell you the circumstances of any other person in the group'.

The need to fit a lot into the sessions did mean that often when people raised and wanted to discuss personal issues there was not time and facilitators accepted that they sometimes got deferred and then forgotten (see above). The way that digressions away from the subject were handled within the sessions was sensitively done by the facilitators but the need always to move on meant that opportunities for the participants to speak about their own situations were limited. In the final session when reviewing what people had wanted out of the programme the facilitators acknowledged that there had not been as much time for this kind of sharing as they would have liked.

The suggestions at various points in the manual to work in smaller groups (particularly the action planning), as mentioned earlier, were not taken up except in the first session. As a result there were very limited opportunities for participants to talk other than in the big group. We feel opportunities were missed here to enable the participants to share with and support each other and to work with the resources in the group itself in ways that could develop their peer skills/support/learning.

This was an intelligent and educated group of individuals. Amongst those we observed and

interviewed we found teachers, business people, social workers and service managers and to all of these people the processes of courses were familiar. 'Oh yes, especially the flip chart!' (Christine). There were times when the level of the language and materials could have been too simplistic for them and others where the concepts were clearly already understood i.e. distractions. In general the group were compliant and very respectful of the facilitators but in interviews a number of them compared this programme with the CSG which they had found much more exciting and enlivening. Carers also made this comparison.

I don't think you enjoyed it, you didn't enjoy the session, whereas on the first course you enjoyed it and you looked forward to going next week, it was 'oh I'm going tomorrow and I'm going to the course and you know, we're gonna do this and we may be doing that' because it was more interactive (Sarah when discussing if Andrew had been bored by the course)

### **Paperwork**

The programme contained a lot of paperwork which from our observations the participants did not always find easy to find or to follow. Throughout the programme facilitators had to help some participants to locate the right paperwork. We questioned whether it was the amount or the presentation as most of the paperwork was in the form of A4 pages or booklets.

Christine felt there was 'an awful lot of paperwork' and her husband Gary warned of 'a danger of information overload'.

'Well I think there's been so much information, and bear in mind Christine's done you know, the previous..course, and we're new to this game, and we've had, I've had to set-up about four different files with all the information we get from all the different parties, that there is, in a way there's a danger of information overload and I don't know if this is a relevant point...'

Joyce and Terry both felt the paperwork was useful as did Peter but it was only clear in Terry's case that he had looked at it since the end of the programme. Sarah knew Andrew hadn't looked at it 'that's all the paperwork and it hasn't been opened since he came home from the session, the last session'.

Sally (one of the facilitators) had also felt the paperwork was causing problems

We found the Useful Things booklet to be really confusing to people within the session because we'd want to highlight to people like 'this is on page whatever' but then there was so much scrabbling around with different bits of paper and then people would be looking for their action plans and getting confused.....I suggested (to programme co-ordinators) that perhaps there's just one booklet perhaps, or that they're completely different colours, or just something to make it really obvious what you're talking about

The visual aids: seesaw and self management triangle, did not always seem to be useful or to be linked in well with the subject under discussion at the time. In interview it was clear that the facilitators had also felt this and here Sally comments again;

sometimes I struggled myself to sort of link it to whatever it was we were doing, so then I didn't feel that I was putting it across very well because you know, I think part, this is maybe the one area where the manual, to me, fell down a little bit because in sometimes it really

did explain how it linked, you know, whatever the topic was, how that linked in with the triangle at each area, and then at other times it just said 'explain how this fits in with the triangle', and I was thinking 'actually I don't really know how it fits in with the triangle.

Christine's husband Gary had a useful suggestion to make as he talked about a set of DVD's he had used at work for health and safety training and the conversation he and Christine had had about different ways of getting information;

...we were saying wouldn't it be nice instead of all these reams of paper that we've got if the funding was available to have a DVD that would, it would have to hold your attention of course, but you could both sit down, the carer and the person suffering from dementia could both sit down and watch it....if it was done in a very professional way you know there might be some really good bullet points that you might think, might stick in your brain more than wading through this amount of paperwork that we've suddenly got.

Many of the group actively took notes. In some cases it appeared that this note taking was perhaps an automatic and habitual response based on previous attendance at courses or from work processes people had done earlier in their lives as was seen in the interview with Joyce.

Interviewer: I noticed you used to take notes quite a lot

Joyce: Yes

I: Was that to help you remember?

J: Yes. And I, well I am quite forgetful now but I've always been a little bit forgetful and also, you know...

I: Yes you've always taken notes and...

J: When I've gone to lectures and taken notes and things like that or taken histories from patients and things.

I: So that's a kind of familiar thing for you isn't it?

J: Yes, yes....I've looked at bits and pieces (of paperwork) yes, and also keep referring to my book and I also got a lot of stuff off the internet about Alzheimer's.

but feedback from one carer challenged the usefulness of this process,

they were quite muddled and scribbled and I got the impression that the notes were then going over what you, the written leaflets that we already had and I didn't know whether Andrew was supposed to take notes or whether he chose to write certain things down when he wanted to and I couldn't work that out. (Sarah)

Our observations and feedback from interviews led us to question whether a paper based course is the right way for people with dementia? We suggest it may be useful to consider different information storage and dissemination methods as paperwork cannot be shared in the same way as audio or visual resources. As Gary put it 'come on you know, it's 2014, all this stacks and stacks and stacks of paper, there should be perhaps a more professional way of doing it, it would be more effective, that's the main thing, in getting the message across and teaching people' We also note that within the Literature Review there were examples where audio and visual resources had been found effective for people with conditions like Multiple Sclerosis and Acquired Brain Injury where memory and concentration were factors.

### ***Use of the facilitators as a resource***

## Appendix 2

As mentioned earlier the programme was heavily scripted and we observed that this meant there was little room for the facilitators to develop their own language, to input their own knowledge or to make best use of their existing skills and understanding of working with people with dementia, which were significant.

Whilst facilitators acknowledged the usefulness of the manual they also commented on times when they felt restricted by how they were asked to use it or the language it provided them with. Whilst the manual encouraged them to paraphrase on occasions they also felt that it was difficult within the time frame to become familiar enough with the detailed text to be able to do this. They also felt that on occasions the language of the manual lacked clarity and that sometimes questions seemed to be repetitive.

To Sally the way they were asked to do the questions process felt unfamiliar and she commented on how having to be the one just writing things on the flip chart but not commenting was hard for her.

I found it really hard because I think my natural instinct is, was to look at the group and sort of give eye contact or nod or whatever, but actually as soon as you did that then people were more likely to talk to you.....I had to almost put my back to people to stop that temptation

Sally also commented how the mindfulness exercise stood out for her as being too wordy and where her own experience could have been better used.

I've talked about mindfulness before and I think I've, in my own words I've put it across simpler or more clearly than was in the script.....there's about three or four different paragraphs saying things in slightly different ways and I think I could have just said it more succinctly and got it across, cos I'm not sure people, you know, they really got it

The facilitators had excellent skills in relating to the participants, they were attentive, supportive and humorous doing their best to make the materials work for the participants. The participants were very aware of how hard they were working and clearly liked and respected them. They regularly expressed gratitude and gave them positive personal feedback. Whilst we made it clear that we were not observing or judging the facilitators either in the sessions or the interviews all participants spoke of how good they were and did not wish to appear critical of them at all. Two of the participants spoke particularly of speaking up in the group more than what might have been usual for them to avoid difficulties for the facilitators 'I didn't want to feel I was going over the top but then I didn't want Jenny not to have anything to write up'(Christine)

One area of concern expressed by one facilitator was about whether/how to challenge either what participants were saying or their understanding. The example given was of action plans where the facilitators could clearly see that what the person had written down the previous week to do was not what they said they had done.

I wasn't sure about sort of challenging it, or just not challenging, but sort of saying 'oh I seem to recall it was, you said you did the hoovering', but I didn't really know whether to do that or not or whether that would make him feel, you know, I didn't want to make him feel embarrassed or anything like that

In observation we did not know that the facilitator had noticed this and it raised for us a question about how best to check and confirm understanding during the programme in general. Given the points made elsewhere about note taking it would not be safe for example to assume note taking

implied understanding of the issue. Clearly having fewer issues to cover in sessions would allow time for facilitators to check what is being taken in and whether participants are able to use the materials of the programme in the way intended.

### **Carers**

Carers gave feedback on a number of issues and the feedback on paperwork is included in that section. A number of carers commented on not knowing what had happened in sessions and therefore not being able to support in taking issues forward. Sarah for example felt

it would be better for partners, for carers to be on the course with the person and to understand what they were being told, because if it's a matter of managing their life better then some of them may not be at a stage where they're able to do that or to be able to impart that information to somebody else

In his individual interview Andrew had also said he would have preferred a course that included his wife as he considered her so central to his care.

Two carers were specifically part of joint interviews but the evaluation team did speak to a number of other carers during the process of arranging interviews and they were keen to talk. Feedback from the interviews and these informal conversations illustrated the potential value in bringing carers on board for at least part of the programme and also in the assessment process. Understanding more about people's current lifestyle, living circumstances and practices before and during the programme would be useful in making it as relevant as possible. Carers were able to give feedback on how the dementia manifested itself in individuals which was useful for the evaluation team to reflect on and helpful in understanding participants and their behaviour better. In helping to take forward and apply learning carers are clearly a pivotal part of the broader relational network of support so necessary for people with dementia to live well. We feel the issue of carer involvement should be explored as without their involvement much of the potential ongoing benefit of a programme like this is likely to be lost.

### **Feedback processes**

The internal feedback process at the end of each session enabled limited feedback on the programme delivery. The coloured card system seemed very confusing and although participants often used the yellow card it was not at all clear whether the process had been fully understood as it was wordy in explanation and at times even confused the facilitators. The group were generally very positive but we observed that they also wanted to be very supportive of the facilitators. In our opinion we feel the feedback process should be reconsidered as we felt the questions could have been expressed more clearly and the card system simplified. The open questions brought more useful feedback.

We feel consideration also needs to be given to finding a better way of checking out what is really working for people on this programme as they were observed as tending to be compliant but had criticisms to make in interviews. Facilitators had also reported on sessions that they felt participants had liked where this was not the feedback given in interviews. It is perhaps unsurprising that anyone with early stage dementia is likely to be grateful to be offered the kind of support and attention that a programme like this offers and therefore wish to be positive about it. At the end of one session that had seemed quite difficult one of the facilitators specifically told the participants that they (facilitators) would not take any negative feedback personally as it would help in developing the



course. This did seem to give participants permission to be more critical and some useful feedback was gained as a result.

We noted that for one participant his feedback most weeks was to do with his problems with hearing. In conversation after the programme he raised that issue again with the evaluation team and said that he would have liked to have been given more support perhaps with a hearing loop. We would suggest that in considering a better way of checking out what is really working for people on this programme that issues of hearing loss and other disabilities should be carefully considered to provide the best possible access and experience for participants.

In summary, in terms of our evaluation questions in relation to pilot delivery

1. To what extent is the Live Well with Dementia Programme successful in providing knowledge, skills and practical tools in ways that can support people with dementia to be more actively involved in their own self care?
2. To what extent does the timeliness of the Live Well with Dementia Programme to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?
3. Are there ways in which the delivery content and/or style could be improved or made more appropriate?

We summarise our main points for consideration as follows;

- The pilot was not delivered in isolation but as part of a broader package of group activities under the ESMSS. An existing familiarity and group dynamic was evident between most of the participants and the facilitators from a previous group experience. We feel that this existing familiarity is likely to have influenced how this group experienced and commented on the programme.
- From observation and interview we would suggest that only about half of the group were at the 'right' level to be able to take away any ongoing benefit from the programme as it was conceived. In order for the programme to be targeted at those who could most benefit from it we feel it would be useful for the pre course assessment to consider not just time since diagnosis and type of dementia but the particular symptoms/manifestation of dementia for the individuals combined with their level of self awareness of how those manifestations impact on them and what they feel would help them.
- The programme was heavily scripted and as a result there was little room for the facilitators to develop their own language, to input their own knowledge or to make best use of their existing skills and understanding of working with people with dementia and for any 'free' discussion by the participants of their own situations and for them to hear from others in the group about their situations and symptoms.
- The content of the programme was largely generic and it was unclear if any of it had been specifically designed for people with dementia. Participants engaged most confidently with sessions relating to practicalities and where they could talk about their direct experience e.g. distractions/eating well rather than with sessions like the one on beliefs. Some sessions seemed more difficult for participants to make sense of and in some cases we wondered

whether the stripping down/simplification of language had made issues less easy to explain or understand.

- There was no specific information given about dementia and the questions asked in the sessions indicated that participants would have found this useful. There was little opportunity for issues of acceptance and lifestyle change to be shared and discussed which we consider might also have benefited this group.
- The content of each session and of the programme as a whole was too much in our view and fewer topics in each session would have helped the development and understanding of issues. The amount to be covered in each session also meant that where participants raised personal issues/experiences that broadened into a discussion this often had to be curtailed in order for the session content to be got through in the time. Less content would have allowed the facilitators the space to judge better how participants were understanding and engaging with the materials and given the capacity to properly explore participants own concerns and experiences and to use the very considerable resources in this group. We believe this would have made the programme more appropriate for people with dementia.
- Both participants and facilitators considered the sessions to be long and the running of the group to be too 'static'. We believe both these factors impacted negatively on the energy and concentration levels in the group and on the development of peer group skills/support/learning. We would strongly suggest that sessions incorporate different ways of working and include regular movement breaks and energisers to give participants the best possible chance to engage and benefit. We recognise that the time pressure to complete everything was a major factor in restricting how flexibly the facilitators were able to work with the group.
- The programme contained a lot of paperwork which we observed participants did not always find it easy to find or to follow. There was also significant feedback in interviews on this issue from participants, carers and facilitators. Looking at this feedback we would encourage the consideration of whether a paper based course is the right thing for people with dementia or if different information storage and dissemination methods would be more appropriate for this client group.
- We observed and heard from participants in interviews the benefit for them of being able to be in sessions just with other people with dementia who share their experiences and concerns. However we would suggest that to have any lasting benefit the involvement of carers in some way in the programme is essential if there is to be follow up to the tools and techniques that this programme offers.
- The internal feedback process enabled limited feedback on the programme delivery but the the 'coloured card' system seemed confusing and it was not clear whether the process had been fully understood as it was wordy in explanation. In our opinion it would be worth considering if the feedback questions could be clearer and the card system simplified.
- Participants were largely compliant in the group sessions but more critical in interviews and there were also differences in how well facilitators had felt sessions had gone and how participants had experienced them. We feel it would be helpful to explore additional ways of checking out what was really working for people on the programme rather than relying just on an end of session evaluation.

## Appendix 2

- We found it difficult to see the pilot sessions we observed as part of the co-design process as the scripted nature of the delivery gave no room for the programme to be designed with the participants or for there to be realistic input into the design.

**Research Team** - Flis Henwood, Naomi Smith, Diane Waller, June 2014



## Self-management and dementia – updated literature review

The original self care, self-management and dementia literature review, completed in October 2013, informed the development of the Alzheimer's Society Live Well with Dementia Pilot Programme delivered in 2014.

This update focuses on research on self-management and dementia and reviews both new research and the development of studies included in the original review. It includes a short appendix reviewing research on mindfulness with people with dementia.

As it develops rather than duplicates the original review it

### Key issues from the update;

- There is a noticeable development in the body of robust research evidence since the original review.
- Both academics and practitioners involved in developing the work come from different theoretical and practice backgrounds and there is variation in how interventions are being developed.
- There is increasing commonality in the desire to develop programmes that place people with dementia at the centre of content and delivery design.
- Studies included continue to be professionally rather than lay or peer led.
- The update indicates that content is now based around issues of concern to people with dementia and there is more flexibility in delivery to allow space for other issues to arise.
- Pre-course assessment using a number of assessment scales is usual.
- The role of carers is considered in more detail in these studies with design of programmes recognising the need for both joint and separate spaces for people with dementia and their carers.

### Introduction

The original self care, self-management and dementia literature review, completed in October 2013, informed the development of the Live Well with Dementia Pilot Programme which was successfully delivered in five sites across the UK in the spring of 2014. Following the internal and external evaluation processes for the pilot the Alzheimer's Society is currently redesigning the programme for second stage delivery early in 2015. As part of that redesign process the Alzheimer's Society requested an update of the original literature review.

The original literature review was a substantive review focusing on group interventions with people in early-stage dementia, taking a broad definition of self-management, from information sharing approaches to more active behavioural change interventions and covering those delivered by both lay people and professionals. It was international in scope covering research conducted in the last 20 years, English language papers only, and included a summary of the current United Kingdom national policy position. In addition the review considered relevant literature on self-management in comparable long-term conditions.

Following the learning from the pilot this update focuses specifically on self-management group interventions with people in early-stage dementia and reviews both new research and the development of studies included in the original review. In addition, as requested by the Alzheimer's Society, it includes a short appendix reviewing research on mindfulness with people with dementia. This update should be considered in conjunction with the original review.

### Self-Management

The definition of self-management used in the original review and repeated here is from Barlow *'Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition'* (Barlow 2002 p178).

The original review gave some detail as to the background to self-management definition and development which is repeated here for reference. The seminal text underlying most of the thinking and writing on self-management of chronic long term conditions is *Unending Work and Care (Corbin and Strauss 1988)* which presents and develops a framework for understanding the central issue of how chronic illness gets managed at home. This framework developed the understanding of the 'work' that goes into the management of a long term condition and defines three kinds of 'work'. Managing the illness (symptom control, managing crises and limitations of activity), the work of everyday life (occupational, relational and domestic work) and biographical work (defining and maintaining an identity) (p10). A further type of work is identified as 'articulation' work (p11) which covers the organisation and coordination of the various types of work. 'Articulation' work includes identifying the work to be done, arranging for it to be done, allocation of resources and assuming and delegating responsibility for the work.

The Stanford Patient Education Research Centre in California, USA, has developed and evaluated self-management programmes for people with chronic conditions over twenty-five years and their Chronic Disease Self-Management Program (CDSMP) (Lorig et al 1999) has been exported to many countries around the world and forms the basis of the Expert Patient Programme in England. The five core self-management skills are defined as problem-solving, decision making, resource utilisation, forming of a patient/health care partnership

and taking action. The key characteristic that distinguishes self-management from more traditional health promotion and patient education is how participants are encouraged to tailor self-management skills and knowledge to their own situation and needs (Lorig and Holman 2003). The concept of self-efficacy, which refers to an individual's belief in their capabilities to organise and carry out a course of action to attain a goal (Bandura 1977), is a key component of most self-management models. Teaching processes for self-management programmes are recommended to include efficacy enhancement, performance mastery, modelling, interpretation of symptoms and social persuasion (Lorig & Holman 2003).

There is an existing body of evidence developing and evaluating the use and relevance of self-management programmes to a broad range of conditions from asthma, arthritis and diabetes through to neurological conditions and including generic and disease-specific programmes.

The evidence on the use of self-management initiatives with people with dementia is much more recent. Those detailed in the original review have taken place predominantly in the last five years. They situate dementia as a chronic long term condition thus developing the idea that there is potential for it to be actively managed with and by individuals, particularly in the early stages, providing appropriate support is available.

Current research focuses on the effectiveness of self-management programmes for people with early-stage dementia, considering how the principles and techniques inherent in self-management can be used or adapted in a way that is appropriate and useful to those living with the disease and those who care for them. These adaptations look, in particular, at how the agency of people in early-stage dementia can be supported, how their capacity to learn and adapt can be encouraged, how they can support each other as peers and how their relational and community networks can support them in being actively involved in their own decision making and care.

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### Methodology

#### *Search methods*

- Some of the original electronic data base searches have been repeated including International Bibliography of the Social Sciences (IBSS), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Allied and Complementary Medicine (AMED) and the Cochrane Library. Academic journals including Dementia and the Journal of Aging Studies have also been searched electronically and the Journal of Dementia Care has been manually searched.
- Internet searches through Google Scholar have been carried out alongside the more detailed database searches, enabling the location of some of the international studies and acting as a check mechanism to ensure coverage on the main searches.
- Specialist sources of research including The Mental Health Foundation, Kings Fund and the Health Foundation have been reviewed. The work of academics from the Universities of Sheffield, Coventry, Northumbria, Stirling, Bournemouth and Bangor has been updated as well as work from Finnish, Canadian and USA academics.



### *Search parameters*

- The main search term used for this update was (“self-management” and “dementia” or “Alzheimer’s”). Other searches have again looked at (“group interventions” and “people with early-stage dementia”), and separately at (“mindfulness” and “people with dementia”).

### *Scope*

- The original review was international in scope covering research conducted in the years 1993 - 2013 and English Language papers only. This revision has covered the period 2013 - 2014. The International references retrieved in this search are from Finland, Canada and the USA.

### *Exclusions*

- No literature is included on interventions with individuals.
- Work on the broader spectrum of cognitive early intervention support for people with dementia, including cognitive rehabilitation <http://great.bangor.ac.uk/about.php> (website accessed 6.1.2015) and psychotherapeutic interventions is not covered here although the developing work in these areas does have relevance to the capacity of people with dementia for relearning and adaptation.
- There are a number of large scale, long running studies recently funded through the ESRC and the NIHR around the subject of living well with dementia. The studies are not specific to self-management and are therefore not included here. They are however useful to be aware of in the context of developing work with people in early-stage dementia. Two of those studies are referenced here for information.

The PRIDE (Promoting Independence in Dementia) study led by Martin Orrell from UCL will be considering and evaluating an effective social intervention to support independence and quality of life for people with early-stage dementia and their carers. <http://www.ucl.ac.uk/psychiatry/pride> (website accessed 6.1.2015)

The IDEAL study led by Linda Clare at Bangor aims to identify what helps people to live well, or makes it difficult to live well in the context of having dementia or caring for a person with dementia. <http://www.idealproject.org.uk/> (website accessed 6.1.2015).

### *Time and resource limitations*

- All university databases have limits on the level of subscription to academic materials and not all journals (particularly those published in the USA) were available to the reviewer. Some information and updates were accessed directly from researchers, however limits of time and resources may affect the content of the review.

### General

- Detailed studies on mindfulness with people with dementia are limited but the area is clearly of developing interest.

### Layout of the update

The update is written in two sections with an appendix. The first section updates the key academic studies on self-management group interventions with people with dementia detailed in the original review and includes additional studies and publications. The second section covers group work with people with dementia not specifically referred to as self-management interventions. The studies in this section of the original review still stand as relevant and whilst they are not repeated here some of the issues covered are summarised for reference. In addition this section also covers recent publications on resilience and peer support. There is an appendix covering research on mindfulness and dementia.

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## Section One

### Self-management and dementia

At the time of writing the original review this section considered 10 studies. There were five articles, two Randomised Controlled Trials (RCTs) registered but without published protocols and three reports. All considered the development of specific self-management interventions and provided conceptualisations of what self-management programmes for people with dementia could look like.

This section follows the same format, updating those studies and discussing new research identified in the updated search. The detail of the original studies is not included again but they are summarised or referenced as appropriate.

### Qualitative studies

The original review included two studies led by Gail Mountain from Sheffield University, UK. These studies continue to feature highly in any searches on the subject. They are summarised as follows;

***Self-management for people with early dementia (Mountain 2006)*** explored concepts of self-management within the context of chronic disease management both in the UK (Expert Patient Programme) and in work undertaken in the USA (Lorig et al).

***What should be in a self-management programme for people with early dementia? (Mountain & Craig 2012)*** reported on a two stage research project developing and testing a draft self-management programme for people with dementia and their carers. Delivery of the sessions mirrored that of the Lifestyle Matters programme on which the authors have previously reported (Mountain et al 2008 & Mountain & Craig 2011).

The Lifestyle Matters Programme is funded under the Lifelong Health and Wellbeing programme led by the Medical Research Council on behalf of five UK Research Councils and is running for four years from 2011. Lifestyle Matters is an occupational therapy based intervention for people aged 65 or older living in the community, the main purpose of which is to develop and maintain wellbeing through taking part in meaningful activities and occupations as part of everyday life. The study protocol for a Randomised Controlled Trial of the Lifestyle Matters intervention was published in 2013 (Sprang et al 2013). The study, which is being conducted by the Universities of Sheffield and Bangor, has been recruited to and is currently running. The success of the intervention is considered to be '*based on positioning the older person as the expert, thereby facilitating improved confidence, and associated positive behaviours*'. The intervention encourages participants to '*undertake personal goal setting and be active in their own personal development*' (Sprang et al 2013 p2).

In the original review some more detail is given on the delivery style of the Lifestyle Matters programme which was mirrored in Mountain and Craig's 2012 study looking at what should be in a self-management programme for people with early-stage dementia. As part of the Lifestyle Matters programme, the authors are also looking at whether the programme can be adapted for people with dementia. A pilot study, *Journeying through Dementia* which is based on the work of the 2012 study, has been completed and is currently being written up with a view to developing a full Randomised Controlled Trial.

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The original review included three studies led by Faith Martin from Coventry University, UK. These studies continue to feature highly in any searches on the subject. They are summarised as follows;

***Perceived barriers to self-management for people with dementia in the early stages (Martin, Turner, Wallace, Choudhry & Bradbury 2012)*** explored barriers to self-management amongst people with dementia and those involved in caring for them either personally or professionally.

***Conceptualisation of self-management intervention for people with early stage dementia (Martin, Turner, Wallace & Bradbury 2013)*** conceptualised self-management for people with dementia as covering five targets; support to seek information about dementia: greater support to maintain an active life: issues around relationships with family/friends/carers: education/sharing of practical memory tips and techniques and support with psychological wellbeing, including low self-efficacy and perceived low self-worth.

***Qualitative evaluation of a self-management intervention for people in the early stage of dementia (Martin, Turner, Wallace, Stanley, Jesuthasan & Bradbury 2013)*** covered the pilot delivery of the self-management intervention developed through the earlier work.

The ongoing development of the work on self-management for people in early-stage dementia is currently evident in the HOPE (Help to Overcome Problems Effectively) programme <https://hopeprogramme.coventry.ac.uk/> developed by the research team at Coventry that aims to provide self-management skills and support through

programmes developed for a range of people living with long term conditions including cancer, dementia, MS, HIV/AIDS, mental health problems and to the parents of children living with ADHD/ASD.

The dementia self-management course has been developed with the Birmingham Memory Assessment and Advisory Service and offers an interactive, group-based, self-management support course for people with early-stage dementia and their carers. Courses run for six weeks, 2.5 hours per session for groups of between 8-12 participants. An online course is also offered for 6 weeks with a slightly shorter session and a smaller group of people with the use of Skype as the mechanism to meet with others. Access to a support site containing videos is available. A separate carers' course is also available.

The courses cover the following issues; goal setting and action planning, looking for solutions to problems and coping strategies, stress management (e.g. relaxation), memory tips and strategies, Life Story work, emotional management, identifying your strengths, becoming more positive, grateful and appreciating life more, healthy lifestyles (e.g. eating more healthily and physical activity), prioritising the important things in life, communication skills.

All HOPE courses work with key behaviour change techniques like goal setting and action planning, are designed around group therapeutic factors such as instillation of hope, universality, group cohesion, altruism and learning from each other and addressing key mental health concepts of hope, personal responsibility, self advocacy, education and support. Courses are tailored to meet participants' needs based on the use of systematic intervention development processes which in the case of people with dementia is the work referred to in the original review.

No further academic articles have been published specific to the development of the dementia programme at the time of writing.

### *Randomised Controlled Trials (RCTs)*

Two RCTs were included in the original review and there has been progress on both.

The first ***Psychosocial group intervention to enhance self-management skills of people with dementia and their caregivers: study protocol for a randomized controlled trial (Laakkonen et al (2012))*** was a 'proof of concept study' based in Finland looking to recruit 160 people with early-stage dementia and their spouses through memory clinics and psychiatric services in Helsinki. Patients and their spouses were to attend separate sessions over 8 weeks and subjects to be covered were similar to those in the English interventions.

At the time of the original review it did not appear that this RCT was recruiting. However the publication of a study protocol (Laakkonen et al 2012) and the following article indicates that it was, in fact, active and has now reported.

***Self-management group for people with dementia and their spousal caregivers. A randomized controlled trial. Baseline findings and feasibility (Laakkonen et al 2013)***

The article reports on the RCT mentioned above which recruited 136 people with dementia and their carers, who were randomised half to the self-management intervention and half to control groups. 67 couples participated in the self-management groups which ran for four hours weekly for 8 weeks. People with dementia and their carers met in separate but concurrent groups with 10 participants in each group. Sessions were discursive and the content varied according to participants preferences. Prior visits to participants had helped establish topic preferences. The groups aimed to enhance participants' self efficacy, problem solving skills and peer support. 72% were at a mild stage of dementia. The groups worked on the basis of a psychosocial group rehabilitation model and on self-management supporting principles based on constructive learning theory and a reflective learning model building self-management skills little by little during the intervention. Different kinds of active learning methods were used including working in pairs and brainstorming sessions and the tutors, who were trained professionals, had received group facilitation training and were tutored throughout. Group intervention was goal orientated and took advantage of group dynamics and peer support.

Findings indicated that participants were very committed with a 93% participation rate and no drop out. The intervention was tailored to the wishes and proposals of participants providing knowledge (about dementia, active lifestyle, nutrition and exercise) and skills (problem-solving and control of everyday life, goal setting). The atmosphere in the groups was positive and hopeful and there were high levels of satisfaction. Participants in all groups requested information about dementia and expert staff were brought in to provide this. The study sought to promote a patient-centred approach and participants' active agency and by giving space for participant's initiatives in the content the authors felt this was achieved.

This is one of few studies working with people with dementia and their caregivers separately but concurrently and they noted how willing all participants were to meet and be with their peers, this particularly applying to the people with dementia. The authors acknowledge that their model has similar elements to that developed by Mountain and Craig and was based on a theoretical model shown to be effective in empowering lonely older people. The control group received usual care and the article reports predominantly on the findings of the intervention.

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The second RCT included in the original review was registered but there was no protocol submitted at that stage. It was part of the SMART study being undertaken by the Research in Ageing and Cognitive Health (REACH) centre at the University of Bangor and funded by the National Institute for Social Care and Health Research (NISCHR) in Wales.

The SMART study has two phases. In the first phase the authors triangulated evidence from a systematic review and qualitative analysis of interviews with people with dementia and caregivers to inform the development of a protocol for a self-management group intervention. The second phase is the RCT of that intervention, the protocol for which has now been published under the title ***Self-management in early-stage dementia: a pilot randomised controlled trial of the efficacy and***

***cost-effectiveness of a self-management group intervention (the SMART Study) (Quinn et al 2014)***

The study is currently underway and was due to complete in December 2014. It is a pilot single-site single-blind randomised controlled trial following the intervention as outlined in the original review. 42 participants and caregiver pairs were recruited. The intervention of eight, 90-minute weekly sessions was led by two members of the clinical team. Seven people with dementia will attend each group and their caregivers will be invited to attend the first and final sessions. Caregivers will also be able to join the group at the end of each session to hear an overview of what theme has been covered. A group manual will cover the content of each session and allow space for additional notes and comments. The group is based on a self-management approach and draws on Social Cognitive Theory and self-regulation models. A flexible approach will be used and the sessions will each cover a particular theme within which participants will be able to focus on aspects that are meaningful to group members. After an orientation session themes will include: practical memory strategies, managing and coping with difficult emotions, managing relationships, planning ahead, how to find and access additional help and staying well.

Participants will be assessed at 3 and 6 months post randomisation and the primary objective is to evaluate the effectiveness of the self-management intervention in improving self-efficacy in people with dementia.

In the background section of the protocol the authors consider the current work on self-management in the field and comment that there have been limited studies that specifically put forward the views of people with dementia and their carers separately to health professionals in a way that would help to formulate a dementia-specific approach to self-management which could then be evaluated for feasibility, acceptability and clinical efficacy. This is what they hope to address with this pilot study which would lead to a full RCT of the intervention.

[Publications from the study](#)

Two publications have been developed from the first phase of the study since the original literature review was written. The first, a Cochrane Review, ***Self-management group interventions for people with MCI or dementia: A systematic review (Quinn)*** is pending publication but is not available yet.

The other is available. The article ***Help Yourself: Perspectives on Self-Management from People with Dementia and Their Caregivers (Toms et al 2014)*** is based on separate individual interviews with 13 people with early-stage dementia and 11 of their carers and presents their views on self-management and its usefulness. The findings indicate that self-management techniques are already in use by many couples although they may describe that process as ‘*coping*’ or ‘*doing things for yourself*’. The contribution the article makes to the debate is by considering how the views of people with dementia and their carers differ. For example, it highlights the point that carers focused more on the difficulties the person with dementia experienced whereas people with dementia focussed more on the impact of stigma and the importance of maintaining independence. Carers tended to see the burden of the ‘work’ to manage the condition falling to them whereas the people with



dementia themselves were more inclined to want to try and do more and to keep engaged and active.

Participants with dementia considered that keeping their minds working, keeping busy, adopting a positive and stoic attitude and humour all assisted them to self-manage and it was clear that they were actively looking for support to manage the early-stage symptoms of memory and language difficulties. People with dementia were also positive about the opportunity to be with a peer group, to learn from them and to be able to contribute and share in a way that enabled reciprocal relationships to develop.

The authors stress the importance of recognising that self-management for people with dementia happens within a relational context and those caring relationships change and come under pressure with a dementia diagnosis. They suggest therefore that interventions need to provide time to sensitively reflect on the impact of changes to relationships and explore how people with dementia can *'retain their valued identity and independence in the context of relational changes, in which the person with dementia is construed as having a somewhat diminished contribution to make'*. Integrating self-management groups into a system of ongoing support is also seen as important.

Whilst the article is based on a relatively small number of interviews, it provides useful insights into the potential benefits and challenges of self-management interventions by considering the differences in how people with dementia and their carers may see the process of managing their lives together. The authors conclude that the development of interventions designed to help people with dementia develop their self-management skills could enhance the techniques they currently use and these findings inform the Phase Two RCT discussed above.

### Reports

This section of the original review contained three reports.

The first was the ***Give and Take Study: Information Use and Self-management by People with Dementia (Clarke et al 2008-2011)*** a 30 month study which ran in Northumberland funded through the National Institute for Health Research (NIHR), Research for Patient Benefit Programme (RfPB). The study included a 10 week programme with small groups (8-10) of people with dementia diagnosed in the year previous to the intervention. There are no further reports or publications from this study.

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The second ***Self-Management of Dementia (Wiersma et al 2011)*** was a summary report from a consortium of academics led by the Centre for Education and Research on Aging and Health (CERAH) at Lakehead University, Ontario, Canada which explored meanings of self-management from the perspectives of people with dementia, partners in care and health service providers. With data gathered through an open-ended online questionnaire and interviews, the report was interesting in reporting the differences in how health service providers and people with dementia discussed self-management.

The research team at CERAH were awarded an operating grant from the Canadian Institute of Health Research (CIHR) in 2012 to develop their work further in partnership with health service providers and people with dementia and their carers and this work is now underway.

***Developing a self-management program for dementia: integrating research, care practices and client experiences (Wiersma 2012 ongoing)***

<http://cerah.lakeheadu.ca/uploads/docs/CIHR%20Announcement%20-%20EW.pdf>

website accessed 6.1.2015

Building on the previous work of this team, this study is developing a self-management programme for people living with dementia but at the same time examining the process for involving people with dementia and other knowledge providers in the development process. The study is using a Participatory Action Research (PAR) approach to look at how researchers and knowledge users (particularly people living with dementia) work together in the development, how the needs and voices of people with dementia are heard, respected and incorporated into a collaborative planning process, the barriers and facilitators to the process, the best structures for delivery of a programme and the experience of all the knowledge users in the PAR process. This study is different to both the British and Finnish studies in that it involves health service providers in the development process alongside people with dementia and carers.

The third report ***Chronic Disease Self-management Programs: Relevance for Persons with Dementia - Executive Summary (Silverstein & Gottlieb 2011)*** still stands as a useful study of the extent to which people with Alzheimer's Disease were served in CDSMP workshops. The survey of master trainers of CDSMP programs covered trainers from across the USA, the District of Columbia and five other countries. The report is useful in seeing how trainers considered issues of integration of people with dementia into mainstream courses and the kinds of adaptations that would be needed. No updating of this work was identified through repeat searches and, as the current direction of self-management development for people with dementia in the UK is towards dementia specific provision, no further comments are offered here.

### *Additional articles*

***Supporting self-management in early dementia: a contribution towards 'living well'? (Cheffey et al 2013)***

In this article the authors consider whether the Wellness Recovery Action Plan (WRAP) (Slade 2009) could be adapted for use to support self-management with people with dementia. The WRAP model, which has been in use for many years in mental health work, grew as a group learning experience although it can be used with individuals. Whilst it has not been targeted at people with dementia, the authors suggest it as a viable candidate for developing an illness-specific approach to self-management in dementia.

Whilst much of the current development of self-management for people with dementia is based on the key components suggested by the work of Lorig (Lorig et al 1999), this article considers the potential use of an established mental health



recovery model whilst acknowledging that there would need to be adaptation for people with dementia. The article references work by Daley et al in 2013 seeking to evaluate whether a conceptual framework of recovery developed for working-age adults holds value for older people with mental health problems, including those with dementia.

Whilst this article does not report on an empirical study, it does develop the debate about interventions for people with early-stage dementia and is indicative of the interest in discovering and evaluating 'self-management' as a relevant tool both for group and individual work with people with dementia.

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### Section two

#### Group work with people in early-stage dementia

In the original review this section covered five studies from the USA and Canada which described support group interventions with people in early-stage dementia. These studies illuminated the processes relevant to developing appropriate group interventions for people with early-stage dementia particularly recruitment, assessment, content development, peer group interaction, supporting primary relationships for people with dementia and the role, skills and varied backgrounds of facilitators.

Whilst none of the studies used the term self-management, they described structured programmes run over 4-8 weeks that had both an educational and a support element to them and covered a number of the topics described in self-management programmes. Within these studies carers had involvement in the groups at different levels and there was only one where the group was solely for people with dementia. None of the courses were lay led and all were facilitated by a range of health practitioners. All included a detailed pre-course assessment predominantly using the Mini Mental State Examination (MMSE).

These studies are looked at in detail in the original review and still figure highly in searches. The issues they bring up are still relevant to the development process for the Live Well Programme.

In particular;

- the need for a *'safe, supportive and non-judgemental environment'* (Goldsilver & Gruneir 2001) for people with dementia to be able to discuss the issues that affect them
- the potential for such groups to *'facilitate emotional adjustment to coping with and planning for the disease as it progresses'* (Yale 1995)
- the best ways to include and involve carers whilst protecting time for people with dementia to meet on their own
- the value of the peer group experience
- the use of experienced health and social care professionals to facilitate sessions
- recognition that group process issues are unique with people with dementia and that facilitators need to *'have a flexible range of group skills and be ready for the unexpected'* (Goldsilver & Gruneir 2001)

- the use of assessment criteria for inclusion in the group to ensure that participants have similar levels of capability and interest.

Given that the usefulness of these studies still stands, it seemed relevant for this update to consider two more recent articles that make particular reference to the importance of peer relationships and communication in group working with people with early-stage dementia.

As an introduction it is worth making reference to the work of Robyn Yale who pioneered the development of support groups for people in early-stage dementia from 1995 onwards. The model she developed - of closed groups run over an eight week period combining education, emotional support and practical help - continues to be used as the basis for many interventions. In an article from 1999 on her work she writes that *'the cohesiveness and camaraderie that develop as people with Alzheimer's reach out to and support one another is truly profound and moving and incorporates sensitivity, humour and tolerance. The research showed that, according to the individuals and their families, benefits of the group included becoming more open emotionally, feeling less alone, and enhancing understanding of one's own behaviour'*.(Yale 1999 p59)

### ***Resilience in early-stage dementia – lessons learned from early-stage Alzheimer education and support groups (Matchar & Gwyther 2014)***

This article describes a support group programme run in 2012/13 for people with early-stage dementia in North Carolina, USA. The model used was a structured, closed group which ran weekly for 8 weeks for 3 hours each time. Each session started with an update and sharing time, with people with dementia, carers and facilitators all contributing. In the second half of the session, people with dementia and their carers met separately in breakout groups. Two facilitators worked with the group of people with dementia and the article reports on how, within these breakout groups, people with dementia *'spoke candidly and demonstrated remarkable insights, tremendous depths of emotion, support for each other and resounding resilience'* (p173). At the end of the support group several ongoing programmes were offered for early-stage *'graduates'* to attend.

The article uses a definition of resilience as a *'dynamic process encompassing positive adaptation within the context of significant adversity'* (Luthar et al 2000) and considers that individuals within the groups demonstrated resilience by *'rebounding in their "new normal"'* (p170) focusing (with support from family and friends) less on what was lost than on what they could still do. The article suggests how important it is to people with dementia to still be able to contribute to others and how they appreciate the understanding that comes from being with *'others in the same boat'*. The authors conclude that people with early-stage dementia can *'not only make new friends but they also develop a strong sense of community and connection with those who share the experience'* (p174). They consider that the development and maintenance of this *'community'* is positive in sustaining and fostering resilience.

### ***Supporting the friendships of people with dementia (Ward et al 2012)***

This article looks at the literature on friendship and puts forward two case studies, one individual and one group, to explore the friendships that develop between people with early-stage dementia and the benefits that they can bring beyond the family network. They give attention to what they describe as 'facilitated friendships' and discuss their role in supporting collective agency on the part of people with dementia.

The reason for including this article is the insight it gives into the nature of friendships between people with dementia that develop from meeting in facilitated situations. These friendships can often take the place of previous social relationships some of which may prove hard to sustain after diagnosis. The case study of the group reports on how participants repeatedly expressed the importance of the shared experience and being able to discuss concerns openly '*without being ashamed*' (p296) in a way they could not always do with existing friends. The authors discuss the need for social acceptance that is common to all people and how a diagnosis of dementia can create social isolation. Connecting quickly after diagnosis with others in a similar situation is significant to the person with dementia's ongoing well-being.

The authors discuss the nature of facilitation that aims to support people with dementia in a different way within a group setting and is not about leading or directing but more about supporting and encouraging their connection to each other. They describe the role of peer support groups as '*the creation of a space that might not otherwise exist in the lives of those who attend, both a physical space and a space for collaborative meaning-making about dementia, away from the imposition of medicalised definition of the condition characterised by an emphasis on deficit*' (p299).

The final part of this section in the original review referenced some studies that considered processes within support groups. These studies are not repeated here but in particular the work by **Mason, Clare & Pistrang (2005)** noting the importance to the group functioning of ensuring as far as possible that the levels of cognitive and behavioural functioning are homogenous and being aware that individuals will have preferences for different ways of talking about the difficulties and experiences and the work by **Manthorpe and Moniz-Cook (2009)** and **Pearce, Clare & Pistrang (2002)** in considering gender differences both in group working and in how individuals deal with diagnosis are still relevant in the development of group interventions for people with early-stage dementia.

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### **Summary**

The pilot Live Well programme was based on and adapted from the Expert Patient standard self-management course. Whilst there was positive feedback particularly about the facilitators and the content, the detailed evaluation indicated that the programme was limited in effectiveness on a number of counts. It was considered that the content was too much and too complex, that sessions were too static, that the peer group was not well developed and that the course was too paper based. In

particular, there was insufficient time and space given to the participants themselves and the issues they wished to discuss. There were also concerns that limited pre-course assessment meant that some participants did not appear to benefit other than from the social engagement aspect of the programme. The absence of carers from participation limited the scope for follow up or development of issues and their insights into the particular problems of the person they cared for would have been useful.

The original review was structured around three main bodies of work: research and thinking on self-management group interventions for people with early-stage dementia; group interventions for people with early-stage dementia and self-management interventions for people with long term conditions where there are comparable and relevant issues. The evidence gathered for the original review indicated that whilst there was a significant amount of research available on self-management of chronic conditions there was much less that directly related to people with early-stage dementia. This update indicates that this still remains a current and developing area of research and interest and that the work outlined in the original review is progressing with new and additional funding and insights.

There were some key areas that emerged from the original review which are included and updated as follows;

### *The developing body of research*

There is a noticeable development in the body of robust research evidence on self-management and early-stage dementia since the original review in 2013. One full RCT (Laakkonen et al 2013) has been completed and another (Quinn et al 2014) is in progress. The *Journeying with Dementia* pilot (Mountain and Craig 2013) has recently been completed with a view to developing a full RCT and the HOPE programme is delivering self-management courses including an online course for people with dementia. In addition a Cochrane systematic review (Quinn) is pending publication.

### *Different perspectives that inform the research*

It continues to be the case that the academics and practitioners involved in developing the work and research on self-management and dementia come from different theoretical and practice backgrounds including occupational therapy, psychology and psychiatry. This does produce some differences in how programmes are developed and run and how they are linked, in the case of Lifestyle Matters (Mountain and Craig) and the HOPE programme (Martin & Turner), into wider programmes.

There is variation in how interventions are being developed with Laakkonen et al looking at separate but concurrent provision for people with dementia and their carers and Wiersma et al looking at using a PAR process for development with all knowledge partners including people with dementia, carers and health professionals. There is, however, an increasing commonality in the desire to develop programmes which place the person with dementia at the centre of the content and delivery design.

### *Facilitation*

It continues to be the case that none of the studies included are lay or peer led and only the HOPE programme specifically uses peer facilitators as co-deliverers. Tutors/facilitators come from a broad range of expertise and professional backgrounds including psychologists, occupational therapists, social workers, other health professionals and staff from Alzheimer's organisations. Groups are usually facilitated by at least two people and as well as their individual professional expertise it is clear that facilitators are also being trained in group work and in some cases are tutored within the process for support (Laakkonen et al 2013).

### *Content design*

A number of the completed studies stress the importance of designing content around the issues that are important to people with dementia and of having flexibility in delivery to allow other aspects or issues to arise. In the Finnish study (Laakkonen et al), prior visits to participants were undertaken to help establish preferences. This study also reported on clear requests for information about dementia which was provided through bringing in expert staff. The SMART study RCT (Quinn et al 2014) has sessions that have one theme each and a flexible approach that will allow participants to focus on aspects that are important to them.

### *Pre-course assessment*

It was noticeable in the group intervention studies from the USA and Canada reported in the original review that pre-assessment was uniformly undertaken before people with dementia joined programmes. Detailed pre-assessment is clearly a key part of the RCTs both completed and underway.

### *The role of carers*

In the development of a number of the studies, the role of carers is considered in more detail and there are a number of models for their involvement in the self-management interventions. There is general acceptance that to work with people with dementia necessitates working within the framework of their broader personal support network which covers carers and other family members but also friends and the wider community. There is increasing recognition of the value to people with dementia, and carers, of meeting separately and in allowing the articulation of concerns in a way that does not feel disloyal to their partnership. The process of self-management is seen as a joint process for people with dementia and their carers but, as Toms et al point out, the experiences and perspectives are different.

### *The group as a resource*

An issue increasingly addressed in all the new studies is understanding the resource that a group of people with early-stage dementia can be for each other and how they value the opportunity to meet with and form bonds with others in the same situation. The group process enables them to be honest about the challenges they face knowing that others will not judge, but understand and support them.

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### Appendix - Mindfulness and people with dementia

#### Introduction

##### *Background*

The practice of mindfulness is rooted in the contemplative traditions of Buddhist Meditation but is now becoming widely used as a therapeutic technique within western medicine. This cross over is largely credited to the work of Jon Kabat-Zinn, from the University of Massachusetts Medical Centre in the USA who, in 1979, developed Mindfulness Based Stress Reduction (MBSR) for dealing with chronic pain (Kabat-Zinn 1990).

Use of mindfulness within a health context has been pioneered in the UK by Mark Williams, Emeritus Professor of Clinical Psychiatry at Oxford University and co-founder of the Oxford Mindfulness Centre, established in 2008. With colleagues from Cambridge and Toronto Mark Williams developed Mindfulness Based Cognitive Therapy (MBCT) for depression (Segal, Williams & Teasdale 2013). MBCT is now recommended by NICE (NICE 2009) for adults with three or more recurrent episodes of depression.

The MBSR standard eight-week course is now widely available throughout the UK and there is an increasing body of evidence that indicates the effectiveness of mindfulness training and practice in helping people deal with stress, pain, anxiety and depression. There is a limited body of study on the use of mindfulness with people with dementia but an indication of a developing interest in considering the possible benefits for this group.

There is evidence that indicates the suitability and benefits of mindfulness practice to older people particularly impact on dealing with recurrent depression (Smith 2004, 2007). Smith discusses the potential to adapt mindfulness training to therapeutic work with people with dementia but considers that the standard MBSR and MBCT programmes would need adaptation to be accessible to them (Smith 2006).

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##### *Search methodology*

A simple search was carried out for this appendix on Google and Google Scholar using the search term “people with dementia and mindfulness”. Five studies of interest were highlighted by the search all of which covered group work. Three of the studies were with people with dementia living in the community and two with people with dementia living in care homes.

##### *Clarification of language*

The literature uses different ways to describe subjects and participants. American and Canadian literature in particular will refer to carers generally as “caregivers” and a number of studies refer to “patients”. The reviewer has not changed that language where it occurs unless there is a need for clarification. The UK studies will more generally refer throughout to “people with dementia” and “carers”.

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### Key studies

#### ***Mindfulness meditation: can it make a difference (Litherland and Robertson 2014) and Mindfulness and Dementia: Report of a pilot study (Leader et al 2013)***

The article (Litherland and Robertson 2014) reports on a pilot study undertaken in 2013 (Leader et al 2013), which set out to test the proposal that mindfulness meditation training has the potential to improve quality of life for people with dementia. The study had two research questions – firstly whether it was possible to teach mindfulness to people with dementia and secondly whether they derive any improvement to their quality of life from it. In developing the project the researchers considered, amongst other things, the possibility that mindfulness could help deal with the distress of the illness and, by helping people focus on the current moment, reduce confusion. It was also considered that the technique could be useful to carers.

The project was delivered in three locations and worked with 12 people with dementia and 8 carers. The course offered a standard version of the eight-week MBSR course. Sessions lasted 2.5 hours and there was an expectation that people would spend some time practicing between sessions. The course was delivered by qualified practitioners of mindfulness meditation. The evaluation included a self-completion quality of life survey tool (Warwick Edinburgh Mental Well-Being Scale), session observation, exit interviews at the end of the course and a three month follow up.

The study reported an increase in well-being following the course for all participants although increases were small. Qualitative data was strongly positive about the capacity of some people with dementia to learn mindfulness and to derive benefit from it. The benefits noted included reduction in anxiety, help with pain control, help with coping with dementia and with regulating emotions. An improved sense of self, improved cognitive functioning, restoration of previous functioning abilities, an improved sense of awareness and appreciation and improved interpersonal relationships. Outcomes for carers were overwhelmingly positive.

The authors acknowledge the limitations of the size of the study and of the open recruitment process. The study indicated that the course was most successful and useful for those in early-stage dementia and feedback was clear that content could be usefully revised in conjunction with people with dementia to make it more accessible to them.

The article reports that further funding has recently been agreed to develop a new approach to mindfulness specifically for people with dementia. Work began in 2014 and the new course will target people in early-stage dementia with materials re-written in collaboration with people with dementia.

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### ***Benefits of Mindfulness Training for Patients with Progressive Cognitive Decline and Their Caregivers (Paller et al 2014)***

This study led by Ken Paller from Northwestern University, Illinois, USA describes a programme of mindfulness training tailored to be applicable to the needs and abilities of both patients with early-stage cognitive difficulties and their caregivers. The programme worked with a meaning of mindfulness as *'maintaining awareness to events of the present moment with acceptance'* (p2). The study considers the impact of an eight-week course on a sample of 37 people (17 people with dementia and 20 of their caregivers). The course, 8 weekly sessions of 90 minutes each, was delivered to four separate groups of between 7-12 participants, with people with dementia and their caregivers attending together.

The design of the sessions was specifically orientated towards the needs of people with memory loss – pace of instruction was slow, physical exertion requirements minimal and the leader was constantly attentive to participants' levels of understanding. The content included a progression of mindfulness practices like attending to breathing, attending to bodily sensations, attending to movement and attending to thoughts with acceptance. Generally the intervention resembled that of a typical MBSR programme but there were elements also drawn from behaviour therapy and acceptance and commitment therapy.

Participants completed a battery of assessment in the early stage and after the course the main focus of which was to look at depression and quality of life. The authors give extensive detail of the results of the various assessment tools concluding that a mindfulness intervention of this sort could be run effectively with mixed groups of people with dementia and their carers and provided an additional way to cope. Results indicated improvements in well-being and mood and the researchers considered these findings provided sufficient groundwork to justify a randomised controlled trial. The researchers argue from their findings that people in early-stage dementia can learn the skills for mindfulness practice particularly if supported by caregivers learning the same skills from the same intervention.

Other findings also noted were improvements to anxiety levels, sleep quality, caregiver distress and cognition although they did not consider the findings were as robust as those for depression and quality of life. One limitation acknowledged was in not being able to say how long lasting any improvements were. However despite some outstanding questions the study indicated success in producing an intervention that could be tailored for people with dementia and their caregivers and which they found valuable.

In their introduction the authors acknowledge studies looking at the possibility of reduction in caregiver stress of mindfulness practice and this clearly comes out in the feedback in this study.

### ***Mindfulness research program: designed to enhance wellbeing in people living with dementia and their spouses (Bedard 2013)***

This study, a pilot Randomised Controlled Trial (RCT) for which there is an entry on the Clinical Trials site of the US National Institute of Health, is not yet open for participant recruitment. The study is led by Michel Bedard from Lakehead University, Ontario, Canada who is affiliated to CERAH where work by Elaine Wiersma and colleagues on self management and dementia is ongoing.

The objective of the proposed study is to investigate the efficacy of MBCT to alleviate depression symptoms, increase attention abilities and improve quality of life in individuals with dementia and their caregivers. The study is choosing to use the MBCT model which has proven success in treating various populations with depression. They recognise that along with forgetfulness and concentration difficulties depression can be a factor for both individuals with dementia and their primary caregivers and that for people with dementia depression symptoms can particularly occur early on as they still have insight into their disease.

The study, a single blind RCT offers the intervention as an eight week, weekly session of two hours with a control group undergoing an 8 week non-intervention before being crossed over to the intervention. The investigators predict that the MBCT intervention will alleviate depression symptoms and increase quality of life and they also expect individuals to experience improvements in attention and memory abilities. The study is for people with dementia and their caregivers together.

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### ***Mindfulness practice with the frail elderly and their caregivers (McBee 2003)***

In this article from 2003 Lucia McBee discusses her work in developing MBSR groups within nursing homes. Her initial work in long-term care and dementia units is described in an article from 1997 on the Wellness Group (Lantz et al 1997) and she has gone on to develop extensive practice and writing on working with mindfulness and elders. McBee trained as a geriatric social worker and became a qualified mindfulness practitioner quite early on having trained at the centre for Mindfulness in Medicine (University of Massachusetts Medical School). In this article she reports on the capacity of mindfulness to benefit the practitioner-patient relationship and to bring '*solace, support, pain reduction and even diminished agitation*' (p257) to frail elderly people with or without dementia.

Writing predominantly from a practitioner perspective McBee notes '*the complex conditions of the elderly are often bio-psycho-social, affecting the mind, body and emotions. Cognitive loss can confound a traditional therapeutic relationship*' (p258). Over a long period of practice McBee evidences the positive effects of mindfulness for residents of care homes with moderate to severe dementia, for caregivers and for care staff. She advocates mindfulness practice as a way of finding inner strengths and resources for older adults who are constantly reminded of their losses and disabilities.

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### ***Mindfulness – based group for people with dementia in Care Homes : a feasibility pilot study (Spector)***

There is notification of this pilot study from a researcher at University College, London but as yet no clinical trial details could be found. This study also plans to look at the use of MSBR for people with mild to moderate dementia in care homes developing an intervention based on the Wellness Group model (Lantz et al 1997).

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#### **Summary**

Of the five studies detailed here only three have actually completed with two being, notified but not yet active, RCTs.

Four of the studies have worked or are planning to work with interventions similar to or based on the Mindfulness Based Stress Reduction (MBSR) model developed by Kabat-Zinn. The RCT led by Michel Bedard, not yet recruiting, aims to work with the Mindfulness Based Cognitive Therapy model developed by Williams (Oxford Mindfulness Centre)

The completed studies all indicate benefits for people with dementia although acknowledging that the standard programmes do need some adaptation to be accessible.

Where information was available it was clear that programmes were delivered by qualified mindfulness practitioners.

The body of evidence for mindfulness group work specifically with people with dementia is currently limited and the evidence there is considers interventions based on proven existing models. The reviewer was unable to find specific research relevant to using mindfulness training techniques within broader programmes with people with dementia.

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# External Evaluation of the Alzheimer's Society Live Well with Dementia (LWwD) Programme - user involvement in redesign summary

## 1. Background

This summary document is based on data gathered during the user involvement in redesign consultation period between January and March 2015. It forms the second stage of evaluation of the co-design process (renamed user involvement in redesign in this stage) and covers key feedback points.

## 2. Methodology

The same methodology for evaluating the consultation used in the pre-pilot stage was repeated. It comprised the observation of two sites with follow up interviews with facilitators. In addition facilitators of the areas not observed were interviewed by phone and copies of their reports of consultation events were received.

Follow up interviews with people with dementia who were participants in the consultation meetings were not considered appropriate in East Sussex as the individuals who attended had already been interviewed in depth as part of the pilot evaluation. In the remaining area where observation took place one interview was conducted.

### Geographic areas covered and facilitation

The consultation sessions were planned to take place in four areas (East Sussex, Worthing, Monmouthshire and Worcestershire) and with two different groupings of people with dementia. Two groups were participants of the LWwD pilots and two were Service User Involvement Groups. At the time of writing the consultation in Worcestershire was still pending but the facilitator was interviewed on the basis of her ongoing contact and discussion with the group of participants who attended the original pilot. One of the Service User Involvement Groups was of Younger People With Dementia. This definition, as used by the Alzheimer's Society, denotes people who are under 65 at the time of diagnosis. This group at the time of the consultation was aged between 50-70 although the majority were in their 70s.

The groups were in all cases facilitated by Alzheimer's Society staff involved either in evaluation, user involvement or who had been facilitators of LWwD pilot sites.

### Purpose and content

- There was a shared understanding amongst all those who facilitated that the purpose of the consultation was to gather views of people with dementia about the LWwD programme to further inform the redevelopment of the materials. The meetings with previous participants on the programme had been particularly aimed at getting feedback on whether the change in emphasis of the revised programme would make it more appropriate for them and work better.



- Three key themes were explored across all the consultations; information; peer support and involvement of carers. As part of the exploration of these themes other issues arose which are also included.

### 3. Feedback from participants on key themes

The points in this section are taken from the notes of meetings supplied by facilitators and the observation reports of the research team and cover the substantive feedback given by participants on the key consultation themes.

#### ***Information about dementia***

- In all the consultations participants were extremely positive about having more information about the causes of dementia and a better understanding of the disease and how it affected them. One group thought it would be useful to have a medical person to explain it to them and others were keen to have a better understanding of the particular symptoms they had. Others felt that having more information at diagnosis could help to deal with the shock of *'thinking it was all over'* when in fact they were now doing more than they had before. There was an interest in hearing about new research on dementia and having some help to know what to trust in the media. As part of this some would welcome the opportunity to check out what they could do to help themselves and what to avoid.
- Those involved in one of the Service User Reference Groups felt they had a right to know more about their condition as the ones most affected by it and also felt that if they knew more they could help to raise awareness of early symptoms in the community. In another area participants were involved in a new project developing the skills of future medical practitioners.

#### ***Local information***

- The two groups observed talked particularly about the value of staying active and connected and the programme sessions were considered a good way to find out what was going on in the local area and how to access it. One participant described it as *'once you're in it leads to something else'*. There were clearly differences in what people could access depending on geographic area and whether what was available met what they were looking for. For example one participant in particular was looking for more intellectual stimulation than he was finding at a lunch club where people rarely talked. Others were very clear about the value of things they and their carers could enjoy together, like Supper Clubs, as well as things they could do on their own around their interests or hobbies, like the Men's Sheds Projects.
- A local contacts list was considered useful by one group and one of the pilot facilitators recalled not feeling they had known enough local information when they ran the pilot. The facilitator recognised that this was really important and that local information also needed to reflect different interests and levels of engagement.



### **Peer support**

- The value of having a space where they could be together with others with dementia was seen as significant by all participants. This space gave them the opportunity to share experiences (often difficult) and to *'learn from other people like myself'*. It was about being with *'people being in the same situation as you'* and space without carers was considered to be *'essential'* as *'you can say things here and acknowledge what is not normal'*.
- As illustration in both of the two observed consultations individuals shared very difficult experiences in their own situations covering: the difficulty of families in accepting their diagnosis *'they go into denial and say but you look fine'*; how hard it was to be a carer for a spouse as well as having dementia themselves; having to disagree with family members who wanted them to give up things they had always done and how to deal with the changing roles within relationships after diagnosis particularly around issues of safety like driving and cooking.
- One of the Service User Reference Groups felt that the great benefit to them of being involved in the group was about peer support, unencumbered by the presence of carers, and a renewed sense of purpose.
- Whilst all considered it was hugely beneficial meeting others with a similar diagnosis some were aware that it was also distressing in the long term to see people deteriorate.

### **Involvement of carers in the programme**

- There were different perspectives on the involvement of carers in the programme. Those who were previous participants of LWwD pilots were clear that they would essentially not want carers present but were more inclined to value their involvement in some way particularly as a way of helping them recall and follow up on what they learnt. Suggestions were made of paperwork as an alternative aid to memory and about whether carers could be there for a final section of each session. There was also a suggestion that carers could meet separately and share information, particularly about local activities, or provide support to each other.
- Those who were part of Service User Reference Groups were largely adamant about not wanting carers present and some felt very strongly about the importance of having a space without carers. In the observed Service User Reference Group people were very unsure about carers' involvement although some did allow that it might be useful for carers to find out about techniques to help them. From the observation it seemed that the group were responding from the perspective of how they felt about the Service User Reference Group and they were clear about not wanting their carers to be part of that.

### **Paperwork**

- One of the groups of previous LWwD participants talked particularly about paperwork. They felt there had been too much paperwork in the pilot and said the

group '*kept getting lost in paperwork*'. They thought the idea of a wall chart might be useful but one participant was definitely not in favour of the action plan making a point about how difficult it was for someone with dementia to plan for the future. She wanted to be able to respond to each day. This participant also thought the diary idea was patronising and there was a suggestion from a support facilitator that it might confuse people who used diaries as home planners

### ***Practical tips***

- All the groups were positive about the inclusion of practical tips in any programme and would look for these both from facilitators and each other. All of the groups illustrated this point by giving examples of things they did or had heard about including: using clocks to help orientation around time; wearing an information bracelet; keeping a diary to record events not just for reminders and in some areas taking up services from post offices and libraries who issued cards to people with dementia to help them access better service, or in the case of libraries not have to pay fines for books.
- In one of the Service User Reference Groups there was a lot of interest in the use of technology as a memory aid and the GPS tracking facilities.
- One participant also thought the programme could be a good place to find out about techniques like word association to deal with the very real problems he had with finding and remembering words.

### ***Course delivery***

- Feedback was given about the need to have a variety of resources to suit varying learning styles. Clear fonts and the setting out of writing was important to one and for another a hearing loop would have been useful.
- One group felt the sessions in the pilot were too similar and too static and they thought it would be good to move around more.
- One Service User Reference Group suggested it would be useful in the final session to have a visit from one or two people living with dementia as that could '*inform and uplift*' the participants at the end of the course. Some of this group were very enthusiastic and volunteered themselves. An '*expert by experience*' was the facilitator's shorthand phrase for what she understood the group to mean.

## **4. Feedback from facilitators on the process of consulting with people with dementia**

The points in this section are taken from the interviews conducted with the facilitators of the consultation sessions. They cover the substantive feedback given by facilitators on their experience of and learning from the consultation process.

### ***Did the sessions run as expected?***

- The sessions varied in size from 3 to 8 people with dementia and in most cases one or two other Alzheimer's Society staff known to the group. Overall facilitators felt the sessions were about the right length in each situation although they varied

from 45 minutes to an hour and a half. Facilitators felt that as they were looking at only a few key issues they were able to get good feedback and they commented about discussions having been meaningful and participants being very willing to discuss and share. Most participants afterwards said they had enjoyed sessions and appeared pleased to have been consulted.

- There were acknowledged differences in consulting between the Service User Reference Groups and the previous LWwD participant groups as in some cases the main facilitator was a guest speaker and in others was working directly with the group. The presence of support facilitators with knowledge of the individuals was at times helpful in prompting responses and ensuring people were encouraged to take part.

### ***How well were you able to engage people in the process of redesign?***

- Overall the main facilitators all felt they were able to engage people well in the process. Both of the Service User Reference Groups were used to being asked for opinions and with one of these groups the facilitator felt they were very used to this kind of meeting and had prepared for it to some extent. She also commented that the group contained people who had been more used to giving and receiving feedback in work environments.
- Challenges included making sure everyone's opinions and suggestions were heard and given equal validity and one facilitator in particular was aware that sometimes she needed to rephrase the questions to reaffirm what she was hearing and to ensure she was not putting her own slant on answers.
- A key issue raised here by the main facilitators was about how when you ask people with dementia about something '*abstract*' that they tend to want to become '*concrete*'. So for example asking them about the idea of sharing experiences leads them to actually sharing experiences which happened in both the observed groups. It was also the case that in the observed Service User Reference Group the group were very much focused on the experience they had in that group and their answers for example about the presence of carers would seem to have been based in that concrete experience.
- Reflecting on this point one of facilitators discussed her experience of asking people with dementia these kind of '*abstract*' questions in a consultative way. In these situations she recognised that there is often a blurring of thinking between what they are doing now and the notion of a '*potential*' group. Her sense was that to some extent it doesn't matter if they are saying things that appear to move between their experience of the group they are in and the idea of a potential group what is important is to encourage people to think beyond where they are now but allow that some don't or can't. She suggested that you therefore look for their responses around issues but also take account of the position they may be answering from.
- Facilitators acknowledged that the traditional consultation techniques of making people feel at ease and encouraging them to speak all apply to people with dementia but that they would expect some to find it easier than others. People will wander away from the subject and in bringing them back it is especially important not to make them feel bad about themselves or in any way to make them feel they have not understood or got something wrong. '*Need to be flexible to ensure you don't add in any way to negative feelings people with dementia may have of their own understanding of what is being discussed*'

- The smaller size (no more than 8) of the groups was important as *'You need to engage with them and that takes time and flexibility – the quality of the interaction can be damaged if you are not taking enough time or giving enough flexibility'*
- The presence of support facilitators was seen as positive and those support facilitators were aware that they provided a 'friendly face' and a previous connection which helped people feel at ease. It was acknowledged on both sides by the main and support facilitators in two of the sites that more conversation before the session might have been useful in clarifying expectations and roles.

### **To what extent did people understand that they were attending a consultation?**

- The understanding that this was a consultation exercise was considered high. One group fully understood the process and in another the support facilitator commented *'the way they talked about what they would like from the new programme made me think that they understood.'* In the third group the understanding was considered more mixed both in the group and at different points during the session.

### **What did you learn about delivering this kind of consultation?**

- One facilitator spoke about the fact that *'questions may need re-phrasing'* and the understanding of answers might need careful confirmation to avoid *'putting words in mouths'*. This was not about how the question was written as much as the fact that people will go off somewhere else with the question and you might need to put it in a different way to confirm what you are hearing. Another facilitator commented *'even when you do clarify sometimes the person with dementia can then go somewhere else with their response'*.
- One of the support facilitators, also a facilitator of a LWwD pilot, commented that *'you have to expect people to want to talk about their current situations and allow some time for this'* whilst also keeping on track. They considered it was useful *'not be too ambitious in the number of questions you ask'* and they felt the consultation had been just right in the amount of questions asked. One of the main facilitators commented that although it was useful to prompt at times the key issue was *'about enabling people with dementia to have the space to think and assemble what they want to say'*.
- One of the main facilitators commented from their experience in consultation work that you can never make assumptions with people with dementia as you cannot rely on how much recollection they have and you cannot assume their ability to engage with abstract concepts. *'You can never be 100% certain that you and they have the same understanding'*.

### **Was there anything you would do differently?**

- Feedback from the main facilitators indicated how different the consultation was, or could have been, between the Service User Reference Groups and the previous LWwD participant groups. Facilitators were aware in particular that people with dementia involved in the Service User Reference Groups were more familiar with being asked for their opinions and more confident in their responses. This was illustrated in two ways. Firstly one group had a good understanding of

what self-management was about for them and fully understood the difference between their Service User Reference Group and the proposed programme. Secondly both groups had a confidence about their desire and ability to be consulted with and to respond without reference to carers or supporters that was not as evident in the previous LWwD participant groups. The facilitators commented that understanding and ability to respond to the consultation could therefore vary depending on people's starting point. One facilitator also commented on how the experience of being part of a Service User Reference Group seemed to '*give people a taste*' for being consulted and developed their confidence.

- There were some comments from facilitators about whether they could/should have explained the programme more. This redesign process had been designed specifically to look at the key themes of information, peer support and the inclusion of carers and overall they felt they got some really useful feedback on all those issues with the approach they took.
- Facilitators didn't think it mattered if they knew people previously or not. '*It is swings and roundabouts if you know people better you may make assumptions whereas if you have never met them before you tend not to be able to*'

### ***Was there any particular feedback from the participants about the session?***

- Overall feedback indicated that people with dementia had enjoyed the consultation sessions. The group who most understood the nature of self management felt it was both positive and uplifting to hear about the programme. Despite the length of time since the pilots some previous LWwD participants were still very engaged, remembered the pilot and were positive about being asked for their views.

### ***Comments on the consultation process***

- It was noted that one of the previous LWwD participants (who had been observed on that pilot) engaged much more in this consultation session. This particular individual had hearing problems and in his feedback on the pilot had said he had been disappointed not to have been able to participate more because of this and felt he had needed more support. The consultation group was small and the facilitator was therefore able to look at him more and be aware when he was not registering what was being said. The additional problems that many people with dementia can have with sight and hearing are well known and the issue of accessibility particularly around communication issues does need to be taken into account in the design and delivery of the new programme.
- It was also clear from the observation that there is a difference between understanding information and knowledge and remembering it. People with dementia in all the groups were keen to have more information and knowledge about dementia and about how they might deal with the challenges. Some were also looking for more intellectual stimulation not just activity.
- It was noted how different the style of consultation was to the first stage which was more about trialling materials using very concrete examples. The level of feedback on the key issues that came forward in this group of sessions suggests that this style of consultation may have been easier for the people with dementia

to understand and participate in. Particularly in the smaller observed group the consultation had a more '*conversational*' feel to it which was clearly enjoyed by those present and which they found easy to be involved in.

- It was noted across all the observations and interviews with facilitators that there are geographical differences in memory support services offered after diagnosis. Being aware of what people have already been offered would be useful in the pre-course assessment stage.
- It was noted that the discussions on carers' involvement prompted some strong feedback. In all the discussions a key factor that surfaced was about how difficult it is for people with dementia to deal with losing roles and identities within relationships with carers and other family members. There appeared to be gender differences in how participants saw these changes, how challenged they were by them and how they spoke (or joked) about them. In the light of these issues careful and detailed thought should be given to the overall purpose, timing and nature of carers involvement in the redeveloped programme and how this is negotiated on both sides.
- Across the observations and in discussion with facilitators there was clear evidence of the desire of people with dementia to be involved in developing understanding on dementia and improving the situation for other people in the same situation. Being involved in Service User Reference Groups, working in projects with medical students, having the knowledge themselves to raise awareness in the community all seemed to give people a purpose and were making them feel valued.
- Feedback also indicated that there was great value to people with dementia of being asked their opinion. The one interview that was undertaken with a member of one of the Service User Reference Groups indicated that whilst he could not remember the detail of the meeting he did value being asked for an opinion. Although he could not remember he had also been observed giving thoughtful and useful feedback on the issues discussed during the consultation session.
- What self-management might mean to the people who took part in the consultation clearly varied but what was common to all those who took part was an evident desire to be more active in deciding how to live their lives with dementia. Two facilitators observed that for some people with dementia the experience of being part of Service User Reference Groups had '*developed their capacity to do*'. They both noted that they had also seen this increase in confidence in participants at the end of the LWwD pilots and felt that giving people with dementia an opportunity to realise what they could do on their own and a space where they could be really honest gave them a sense of '*validation*' of who they are and what they are capable of.

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# External Evaluation of the Alzheimer's Society *Live Well with dementia programme* - final report

## Section One: Background and methodology

### 1. Introduction

The external evaluation of the Alzheimer's Society *Live Well with dementia programme*, commissioned from the University of Brighton, commenced on 1<sup>st</sup> December 2013 and concluded on 31<sup>st</sup> March 2016. The evaluation was carried out by a team of staff from the School of Applied Social Science under the contract agreed with the Alzheimer's Society.

This document provides a final report of the evaluation as agreed in the contract timetable. It covers data gathered on the co-design of the programme and on the programme delivery both in pilot and pathfinder stages. The report does not duplicate the content of the *Interim Report* of June 2014 or the *User Involvement in re-design summary* of April 2015 but incorporates, where relevant, summary detail of the key conclusions from those reports. The summary feedback points from the Salisbury pathfinder site observation of January 2016 are incorporated and developed in this final report. Both the original and amended evaluation timetables are attached as Appendix 1.

### 2. Background

The Alzheimer's Society *Live Well with dementia programme* (formerly known as the Self Care Programme for People with Dementia) follows the successful development and implementation of the Alzheimer's Society *Carer Information and Support Programme* (CrISP). *'The Live Well with dementia programme aims to help people with early stage dementia develop the understanding, skills and practical tools to empower and support them to take an active role in the management of their health and well-being. It is based on self-management principles'* (Alzheimer's Society 2016). The programme built on content provided by Self-Management UK which, after the pilot phase, was reworked through a process of 'co-design' with people with dementia and with Alzheimer's Society staff who were involved in developing and delivering the programme.

*The External Evaluation of the Alzheimer's Society Carers Information and Support Programme (CrISP)* (Barnes et al 2013) and *Self care, self-management and dementia – a literature review* (Smith 2013) were both carried out by the evaluation team from the University of Brighton. The literature review informed the development of the *Live Well with dementia programme*.

### 3. Aims

The evaluation aimed to explore the extent to which the *Live Well with dementia programme* was successful in providing the knowledge, skills and practical tools that can support people to live well with dementia based on the principles and desired outcomes of self care. Participants' (people with dementia who attended the programmes) views of the content, style of delivery and impact of the programme were explored as well as the

timeliness of the course to their individual situations. The evaluation also sought to identify facilitators and barriers to co-design with people with dementia and provide new knowledge that could assist with the development of the programme.

### **4. Evaluation design**

The evaluation sought to influence the development of the programme and therefore adopted an approach based on the principles of action research. Action research is an appropriate methodological approach to encourage both the development of knowledge and its practical implementation (Corbett et al, 2007). Action research is also considered an appropriate methodology to use with people with dementia (Pipon-Young et al 2012). Principles of action research were therefore incorporated within this evaluation.

The evaluation was therefore designed to be iterative and formative, running alongside the programme development and delivery, feeding back into the development of the programme as it progressed. It comprised two main parts: evaluation of the co-design process and evaluation of the programme delivery and followed these two processes as they took place chronologically.

#### ***Evaluation of the co-design process***

In evaluating the co-design process the evaluation set out to answer the following questions;

5. What has been the experience of people with dementia and staff working with them in the co-design of the Live Well with Dementia Programme?
6. What has facilitated the process and what barriers have there been?

The original methodology designed for this part of the evaluation was as follows:

- Observation of co-design consultation meetings in both pre pilot and post pilot phases
- Interviews with some of the participants involved in the co-design process - both people with dementia and Alzheimer's Society staff
- Summary feedback from the observation and interviews to the Alzheimer's Society on what is working and where there is room for improvement.

#### ***Evaluation of programme delivery***

The evaluation of the programme delivery was designed in two phases to match the programme design – the pilot phase and the first delivery phase. In both phases the evaluation set out to answer the following questions;

1. To what extent is the Live Well with Dementia Programme successful in providing knowledge, skills and practical tools in ways that can support people with dementia to be more actively involved in their own self care?



2. To what extent does the timeliness of the Live Well with Dementia Programme to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?

3. Are there ways in which the delivery content and/or style could be improved or made more appropriate?

The original methodology designed for this part of the evaluation was as follows;

At one pilot site-

- Observation of all workshop sessions
- Post-course interviews with 3-4 participants with dementia
- Post-course paired interviews with 2 of the same people with dementia with their carer.
- Interviews with 2 facilitators

At 2-3 sites in first delivery phase –

- Observation of all sessions.
- Post-course interviews with 6-8 participants with dementia over all sites
- Post-course paired interviews with 4 of the same people with dementia with their carer over all sites.
- Interviews with 6-8 course facilitators over all sites.

### 5. Data collection

Data were collected using the following methods - observational notes of consultation/co-design meetings and programme sessions and recorded interviews with people with dementia, carers, facilitators and Alzheimer's Society staff involved in the development of the programme and the user involvement.

Observation of programme sessions focussed on how the content of the workshops was delivered and how information, knowledge, and support were generated and shared amongst participants. Attention was given to the interactions between participants as well as between facilitators and participants. Attention was also paid to how interactions changed over time and with different participants, with the aim of identifying particularly effective ways of communicating knowledge and information and supporting the development of skills and practical tools with people with dementia. All observation sessions were manually recorded in detail.

Participant interviews took place as soon as possible after completion of the programme and adopted a narrative approach. Questions focused on participants' understanding of how their dementia currently affected them and any prior information, support and care experiences. They were also asked about how they had applied any of the knowledge, skills and practical tools acquired during the programme in their everyday lives and the extent to

which they felt they could be more active in their own self-care as a result of participation in this programme. Participants were also asked about the experience of peer learning and support and whether they had been able to share experiences of the programme with other people involved in their lives. Participants were asked what had been most useful to them and if and how the structure, content and delivery of the sessions helped them.

For those who were willing, paired interviews (people with dementia and their carers) were undertaken with a subset of participants. These interviews considered the extent to which the participants have been able to share the experience of the programme with their carer and whether this had resulted in any changes to their lives and shared arrangements for living with the dementia.

Interviews with facilitators and other Alzheimer's Society staff took place as soon as possible after their involvement, either in consultation meetings or in delivering the programme.

These interviews were in person or by telephone where distance was involved.

With consent, all interviews were audio recorded and fully transcribed.

### **6. Data analysis**

In line with the Action Research methodology used in this evaluation, the reflections of the evaluators on the process of consultation (that constituted the co-design element of the programme) were fed back to the Alzheimer's Society through summary feedback points at various stages as detailed in Appendix 1.

A thematic analysis of all observational and interview data was undertaken and this formed the basis of the interim and final reports. Here, data from observations of both consultation/co-design and programme delivery stages, and from participant, participant-carer and facilitator interviews, were analysed to identify key themes that help to explain where and how people with dementia have been able to input successfully to the course design and to benefit from participating in the course in terms of enhanced opportunities for, and practices of, self-care.

### **7. Ethical approval process**

The evaluation was approved by the University of Brighton's Faculty of Health and Social Science Research Ethics and Governance Committee and complied with ethical research requirements of the Alzheimer's Society. A fully informed and detailed consent process was designed for the evaluation which worked well in practice. Participant consent was sought in advance of observation sessions and ongoing process consent was carried out at the start of each observation session. Individual consents were agreed with those participants who were interviewed and additionally with them and their carers for the joint interviews. Consent was secured from facilitators for both the observation and the follow up interviews. Local Alzheimer's Society Dementia Support Staff were available to the evaluation team for participant follow up after interviews but none was needed. An explanatory note to the consent process is attached as Appendix 2.

### **8. Amendments to the timetable and overall structure of the evaluation and additional relevant work**

In any longitudinal evaluation, particularly one following a developing programme, some changes to timetables and content will be necessary to accommodate changes to the development plans of the programme being evaluated. Such has been the case with this evaluation and, in formal agreement between the two parties, certain aspects of the evaluation have been reduced and additional pieces of work added. The changes to the evaluation timetable can be seen clearly in Appendix 1 and the details of how those changes impacted on the evaluation are given in the relevant sections of the report.

### **Section Two: Findings**

#### **1. Introduction**

The original proposal for the co-design aspect of the programme development had been for a two phase process of co-design consultation, pre- and post-pilot, and the evaluation methodology was designed around that proposal. Co-design actually continued throughout delivery as feedback from participants was used to adjust and reshape process and content. We will therefore report on three stages of co-design – pre-pilot, post-pilot and delivery.

The original proposal for the delivery aspect of the programme had been a three phase process of pilot, first phase delivery and second phase delivery and the evaluation methodology was designed around that proposal. The pilot delivery went ahead as agreed and the evaluation tracked it. Following the pilot, the Alzheimer's Society took a period of time to review the programme with the result that the next phase of delivery did not start as planned in September 2014 but was delayed until the summer of 2015. The evaluators observed only one pathfinder site due to the pathfinders in accessible geographical locations running concurrently. This was begun in September 2015 and completed in December 2015. Summary feedback points from the pathfinder observation were provided to the Alzheimer's Society on 31<sup>st</sup> January 2016.

The findings that follow are presented chronologically, focusing on design, delivery and further design of the programme as it occurred over the course of the programme development and evaluation. Reflections on the processes of co-design and delivery are dealt with separately in the conclusions (Section Three).

#### **2. Pre-pilot co-design**

The evaluation team were unable to gather data from the first co-design consultation meetings due to two factors – the distant location of the meetings and the timing of the meetings, which occurred before the research contract was signed and ethics approval given. Some data were collected via discussion with the facilitators of the co-design consultation meetings after ethics approval was given. The *Interim Report (2014)* covered the detail of the pre-pilot co-design phase evaluation and feedback. In summary, the evaluators concluded that:

- the co-design process was limited to a testing and informal 'evaluation' of a pre-existing self-management programme that had been partially adapted by Self Management UK for use with people with dementia.
- there was little opportunity for people with dementia to really get involved and come up with their own ideas about self-management - either about how they might currently self-manage or what they might like to see in a self-management programme for people with dementia.
- much of the re-design or 'adaptation' that took place following the consultation meetings necessarily involved a negotiation between people with two different types of expertise – self-management and dementia.
- there would be a tension between delivering a pre-set (albeit adapted) self-management programme and listening to, and responding to, the needs and experiences of people with dementia in the pilot phase.

### 3. Pilot delivery

The evaluation of the pilot delivery was the subject of the Interim Report in June 2014 (included as Appendix 3. In summary the evaluators noted that:

- The pilot was not delivered in isolation but as part of a broader package of group activities under the East Sussex Memory Support Service. There was existing familiarity from previous group experiences between the facilitators and some of the group which is likely to have influenced how the programme was experienced and commented on.
- Only about half of the group were at the 'right' level to be able to take away any ongoing benefit from the programme as it was conceived and it was felt that a more detailed pre-course assessment would be useful.
- The programme was heavily scripted and there was little room for the facilitators to use their own language, knowledge or existing skills and understanding of working with people with dementia. There was little room for any 'free' discussion by the participants of their own situations.
- The content of the programme was largely generic rather than having been specifically designed for people with dementia. Participants engaged most confidently with practicalities and direct experience and some sessions seemed more difficult for participants to understand.
- There was no specific information given about dementia and little opportunity for issues of acceptance and lifestyle change to be shared and discussed. Feedback indicated that participants would have found both useful.
- The content of each session and of the programme as a whole was too much and fewer topics in each session would have helped the development and understanding of issues. Personal issues/experiences raised by participants often had to be curtailed in order for the session content to be got through in the allocated time.
- Both participants and facilitators considered the sessions to be long and the running of the group to be too 'static'. Incorporating different ways of working and including regular movement breaks would have been beneficial to participants.
- Feedback indicated that participants and carers found the amount of paperwork too much and consideration should be given to whether the programme should be less

paper based and if different information storage and dissemination methods would be more appropriate for this client group.

- Participants valued highly the chance to talk with other people with dementia. However, it was clear that the programme needed to include the involvement of carers in some way to be able to follow up tools and techniques that the programme offered.
- The internal feedback process using a 'coloured card' system was confusing and not clearly understood.
- Participants were largely compliant in the group sessions but more critical in interviews. There were also differences in how well facilitators felt sessions had gone and how participants had experienced them. Additional ways of checking out what was really working for people during the programme would have been helpful.

We found it difficult to see the pilot sessions we observed as part of the co-design process as the scripted nature of the delivery gave no room for the programme to be designed with the participants or for there to be realistic input into the design. The end of session feedback system was confusing and the evaluation team felt consideration needed to be given to finding a better way to assess what was working/or not for the participants.

#### 4. Post-pilot co-design

Following completion of the pilot delivery and the evaluation of the pilot stage, the Alzheimer's Society delayed the first phase delivery whilst the programme was revised. Following this revision, there was a second phase of consultation between January and March 2015 which was observed by the evaluators where possible and followed up with interviews with all facilitators of the consultation meetings including in those areas not observed.

The detail of the post-pilot co-design has been reported separately in the *User Involvement in re-design Summary* of April 2015 included as Appendix 4. In summary, the evaluators concluded that:

- The '*conversational*' style used in the post-pilot consultation, was very different to that used in the pre-pilot stage, which had focused on trialling existing materials. The conversational style in the post-pilot stage enabled a greater level of engagement amongst participants, suggesting that this style of consultation was more suitable for people with dementia.
- The issue of accessibility, particularly around additional communication needs like hearing and sight loss, should be taken into account in the design and delivery of the new programme.
- People with dementia in all the groups were keen to have more information and knowledge about dementia and about how they might deal with the challenges. Some were also looking for more intellectual stimulation than perhaps they got in other groups.
- It was noted that there are geographical differences in memory support services offered after diagnosis and that being aware of what people had already been offered would be useful in the pre-course assessment stage.

- There was strong feedback on the issue of carers' involvement in any programme. Feedback confirmed how difficult it is for people with dementia to deal with losing roles and identities within relationships with carers and other family members. Careful and detailed thought should be given to the overall purpose, timing and nature of carers' involvement in the redeveloped programme and how this is negotiated on both sides.
- People with dementia were keen to be involved in developing their understanding of dementia and improving the situation for other people in the same situation. Feedback also indicated that being asked their opinion made them feel valued.
- What self-management might mean to the people who took part in the consultation clearly varied but what was common to all those who took part was an evident desire to be more active in deciding how to live their lives with dementia.

### **5. Pathfinder delivery**

The Salisbury pathfinder ran for seven weeks between September and October 2015 and was held at the Alzheimer's Society offices in central Salisbury. The research team observed all seven sessions and then carried out follow up interviews with participants (5), with participants and their carers together(2) and with facilitators (2) in the few weeks following. All data collection was completed by the middle of November 2015.

For ease of comparison, headings used in the discussion of findings below replicate, to a large extent, those used in the *Interim Report* of June 2014

#### ***The programme participants***

On the first session, there were eight participants in the group. Two of these withdrew in the second week – one due to ill health and one deciding it was not the right time for them to do the programme. A new person joined in week two. This group of seven then went through the whole programme and were joined in session five by an additional member who had been away for the first few weeks. The main group of seven comprised four men and three women and this group were aged between 68 and 83. They were highly motivated and the level of the programme was much more appropriate to them than was the case with the pilot programme. They were intelligent, articulate and well-educated people with a wide variety of work and life experience and skills who were keen to learn. The member who joined later was a woman and was part of a friendship group with two of the women in the existing group. All the men lived with their spouses and all the women lived alone but with family (daughters) close by and some carer support.

#### ***Assessment and suitability***

Pre-course assessment was undertaken by the Live Well programme facilitators prior to the start of the programme. Despite the individual differences in time since diagnosis, the 'awareness of self' and ability to understand the detail of how their dementia affected and limited them was significantly high in this group, making it very different to that observed in the pilot group, where only half of the group were really at the right level for the programme on offer. They were able to understand the concepts put forward in the

programme with some support and explanation and were able to articulate the practical aspects of living with dementia. They were polite and disciplined, relating well to the facilitators, being respectful of them and each other. They expressed high levels of gratitude for the opportunity to be part of the programme and understood the developmental nature of the programme they were involved in. The one exception here was the woman who joined the group late. She was further on in the progression of her dementia and had a more limited level of 'awareness of self' particularly as it related to being part of a group. For this reason and the fact that she joined the group so late she was not included in the interviews.

All the participants understood that they had dementia and most knew their diagnosis. The majority of the group had Alzheimer's disease, one had a mixed dementia and one Lewy Body. All were taking medication for their dementia. The length of time since diagnosis varied from three months to 10 years. Andrew (3 months) described himself as being '*on the outskirts*' whilst Peter (10 years) had already taken part in four drug trials. The group were very aware of their particular manifestations and could describe them well. Most recognised the difficulty they had with memory, concentration, attention, processing, word finding and for some extreme tiredness. At least two suffered with hallucinations.

There were some shared manifestations in the group. Five main issues were identified;

- a) The 'slowing down effect'. This was variously described as general tiredness, a slowing down of thought processes or not being able to start or complete things as quickly as they used to:

*'I can't do things so quickly as I used to, where I think I could, ooh, do that in a day or something like that, it might be two or three days because I completely have to stop and rethink what I'm gonna do'* (George).

*'Things I used to be able to do – I don't know how to start now – and if I do start it doesn't work out well – so frustrating!'* (Peter)

- b) Short term memory loss. This was evident and bringing thoughts to mind and processing them to words took more time. *'I find my memory is very slow now, I can probably recall something, it might take minutes'* (George). Rosemary said it was like *'thinking something can't get it up to your brain'*. Some of the group were not able to easily hold information and would repeat questions although they were often aware that they had asked the questions before but had forgotten the answer. This inability to recall had led some to give up favourite hobbies like card playing or visits to the theatre.

- c) Loss of organisational ability:

*'as a mother I was incredibly organised and, you know always on the ball but that's sort of rather gone out of the window'* (Ellen).

*'I used to be very sharp having been in the army' (Peter)*

- d) Difficulties with attention and concentration. This caused many of them to *'rush around, do this and do that'* (Andrew). Andrew also reflected:

*'I suppose it must be concentration, but you're not thinking quickly ahead, as one should do'.*

He explained how if you missed the start of what someone said which would *'click you into action'* you would not necessarily pick up what was being said and would have to ask for it to be repeated.

Others also spoke of not being able to focus on or follow television programmes or to read a book in the way they used to.

- e) Word-finding. This caused problems and speaking and finding words in conversation was something that they were not now able to do as *'smoothly as I used to be able to'* (Peter). A number of the group found they could not spell as well anymore.

There were many reflections across the sessions about how these limitations made them feel from being *'very cross'* (Ellen) to feeling like *'a clot'* (Rosemary). Robert confessed it made him feel *'like sitting in a corner and keeping quiet'* and Peter described a feeling of *'not being totally with it'*

Rosemary described her stage as where *'every now and then a little bit of who you were is taken away from you'* and how this took away her confidence. Peter agreed with this and felt this made him *'stop doing things – you either can't remember or you don't want to attempt it'*.

Everyone seemed to have been able to benefit in some way from the programme although, because of the memory problems, some clearly remembered the process more than the detail. In interview, many said it had been *'useful'* or *'helpful'* to them although not all could give clear examples of the detail of sessions:

*'The trouble is it makes perfect sense sitting here, now when I go home, it doesn't you know.....I have difficulty remembering the totality of it, but the gist of it, I do get'* (Peter).

In interviews, some were able to remember detail when prompted, particularly for some of the more memorable visual aids or images. Sheila (Peter's wife) described how things came back to him over a period of days after the session:

*'When Peter comes out immediately, he doesn't know what's happened...."Everybody's really nice but I don't know"....and then gradually he'll say*



*“Oh, I remember so and so happening” ....during the week it will come out, and then he really looks forward to coming to the next one’*

### **Physical space and environment**

The physical space and support were both significantly different to that available in the pilot programme. This pathfinder programme took place within an existing Alzheimer’s Society office where the facilities were appropriate and where additional resources were easily available for the facilitators to access. The venue was familiar to all the participants, geographically central to the town and easily accessible by a variety of forms of transport.

The layout of the room was also significantly different from the pilot. The group sat and worked around a large oval table, big enough for them to sit at comfortably and put their papers down, but not too big that they could not talk and hear across the table. In sessions where the numbers were reduced, the facilitators reduced the size of the table. The table also provided a focus for tea and refreshments of various kinds which were made available and for information and as Kate, one of the facilitators, explained:

*‘Because you’ve got something to lean on, it feels as though I’m coming to do something serious, rather than if we were sat around on sofas we would be more a peer support group’*

The space created felt more like a supportive learning environment with plenty of wall space to put up flip charts and display models being used in the sessions. There was room to move around and the observers were able to be at sufficient distance not to interfere with group interactions.

The ready access to the resources in the office meant that it was easy for facilitators to lay their hands on leaflets and memory aids for use in demonstrations. This enabled facilitators to respond, in the moment, to what a person with dementia was asking for. For example a clock with days of the week as well as time was easily available to hand round during an early discussion on daily and weekly planning challenges. The group appreciated the way that the facilitators could quickly lay their hands on information and equipment and it really helped to answer questions as they came along. We particularly noted how having the support of an additional member of staff to make tea and coffee was also significant in helping the facilitators keep focused on what was happening with the group.

There were a couple of occasions where noises off in the surrounding offices were a little distracting and once the lawns were being mowed which was quite noisy. The facilitators worked successfully around these distractions.

### **Content**

The 7 sessions covered: living well with dementia and what is self-management; balancing life and health and being active; communication with people; handling difficult feelings and being positive; understanding dementia and remembering together (with

carers/supporters); support, managing tiredness and pacing, and staying well and adapting to change.

There were a number of significant issues here - too much content, transitions between content, appropriateness of concepts, lack of content on dementia and other issues, time pressures and opportunities for participants to talk about their own situations.

### *Too much content*

The overall amount of content was still too much and the sessions were intensive, requiring significant periods of concentration. This had implications for participants and facilitators. George commented *'it's quite hard this course'* and in a later session joked *'it wears you brain out coming here!'*. Each session had two main sections of content- one before and one after the break, and the content in each section was quite substantial. Again George described the impact well:

*'My thoughts were it was quite difficult, you didn't get enough time to think, it was too rushed, been better I think with shorter sessions and probably more of them, probably more weeks because after our break I found I was...Not losing consciousness, losing....what do you call that word? Not interest so much as (prompted word concentration) yeah I was losing that more often'*

Participants did comment on how *'interested'* they were in the course and how *'stimulated'* by the discussions. For example, when asked about the amount of content, Andrew acknowledged *'Well to get us there you've got to have something'*.

Facilitators commented on the amount of content with both assessing that possibly 50% of the overall content would have been enough for the seven sessions.

*'the amount of content I felt that probably you could do fourteen sessions.....each session we were given had the potential to be divided into two and it would be a reinforcement and follow-on from the previous week'* (Kate).

### *Transitions between content*

In some sessions, the link between the two sections of content did not always make sense to the group and participants found the transition difficult. As a result, the content of the second part of each session often did not work so well or was not understood as intended.

The subject of session 3 was communication, and while the first half worked exceptionally well, the second did not. The first half included the much-remembered 'head' image. Participants were very engaged with giving thoughts and ideas about communication problems and then being given the 'head' image gave them a way of understanding why things might be so difficult for them and what might help them in the future. The second half of the session was about communication with professionals and, whilst the content was still about 'communication', it was very differently focussed from the first half and the group

seemed to find the transition difficult. Liz, one of the facilitators, explained how it felt to her:

*'It didn't flow for me at all, and we tried to talk about professionals, and talking to professionals, and that was the traffic lights and the road, that just didn't go.....It should have been two sessions....coming back after the break to talk about talking to professionals, it kind of just went "pouf", and nobody, it wasn't just one or two, it was nobody was on board with that, so I felt that one was difficult'.*

As a result, the group did not engage well with the traffic light image or with the process of developing thoughts on what would help or hinder them in those relationships and there was a fair amount of displacement activity. During the break, one participant shared what the group found a particularly shocking experience with professionals and others also voiced negative examples and this may have affected how the group approached the second half.

The first part of session 4 was about dealing with difficult feelings but the second part was about unhelpful attitudes and then positive and negative self-talk. Liz, again, found this transition was difficult for participants:

*'So you're asking them to dig deep, and then you ask them to forget about it, and I find that quite hard, because obviously for people to talk about their feelings and emotions anyway and then to, "we're talking about feelings and now we're going to talk about something else"' .*

### *Appropriateness of concepts*

While the programme needed to include sufficient content to cover the key concepts of self-management, some of the concepts used seemed less appropriate to the group and did not make as much sense as others. In some cases, the concept seemed overly complex and others just not how the group seemed to understand an issue. Some of this may have been down to the language and imagery used and in some sessions there was insufficient time for people with dementia to understand and process the dense nature of some of the content. The 'head' image that participants had responded to so well really explained why the complexity of the content was sometimes difficult for them to process in the time allocated:

*'you know, people need time to process they need time to respond and at times it felt that to deliver the content it wasn't really giving the people with dementia that time just to soak in the information or the content of the conversation...'(Kate).*

Session 6, which was on support, managing tiredness and pace setting was a good example. Again, a content-heavy session participants did not find either part easy for different reasons. The first part of the session on support using the 'balloon' image was difficult and the facilitator had to work extremely hard to help the participants work through their responses on the different layers of support:

*'I found it difficult to get them to understand the whole concept of the balloon. I liked the balloon as a concept itself, but maybe because I can understand what the balloon*

*represents....., that they are in the basket and all their supporters are in the basket. It's, you're asking them to do a lot using their imagination and trying to put themselves in a position they probably just can't do.....and imagine the wind is blowing here....so we're asking them to do a lot of, imagine about a lot of stuff, that I think some of them really, really, struggled' (Liz)*

The evaluators observed participants finding this image as too complex, with some suggesting different answers to what might have been expected and simply not understanding some parts of the diagram.

In the second half of the session, 'pace setting' seemed to be an example of a concept they understood but didn't necessarily express in the same way as presented in the programme. They were well able to talk about this issue when the facilitator helped with rephrasing.

In session 2, while the subject was balancing life and health with dementia, the discussion focused around the emotional topic of loss of identity. These issues needed exploring and it was not clear whether they were too much to be dealt with in the timeframe of this particular session or whether they actually needed an opportunity to be explored separately.

### *Lack of practical content on dementia and other issues*

In the re-writing of the programme following the pilot, attempts had been made to reduce the content but our observations suggest that more work is needed to ensure there is reduction in the right areas and that essential aspects are not missing. As with the pilot, there was, in the pathfinder, a lack of practical content on dementia. It was clear from their contributions that participants wanted to discuss issues like symptoms, drug treatments, diet and disease trajectory and the facilitators responded very well with explanation and information about these issues when they were raised. One participant would have welcomed more information up front:

*'what I needed the first week was to be straight in, the nail on the head, saying "This is it"' (Robert)*

and facilitators agreed with this

*'I would have started the first session off with an introduction to dementia. I would have done the 'brain tour' as part of that and looked at perhaps the first part of the bookcase (visual image) to help people understand what happens to factual memory' (Kate).*

During his interview, Andrew said that he had wondered whether *'it was worthwhile progressing to talk about what dementia does to us in due course'*. One of the facilitators agreed, saying that she *'felt more and more convicted about that as time went by'* (Kate). She recounted a situation where Andrew had spontaneously started to discuss the progression of the disease and the need to plan for the future. Andrew had said *'Well, let's think about people who've got cancer, they're in pain, I'm not in pain'*. This conversation had

struck the facilitator as a very straightforward comment that had reduced some of the anxiety in the group:

*'it was a very difficult conversation really, not prompted by me, just spontaneous, it is so valuable for people with dementia to talk freely about their fears and concerns with one another and support each other with those feelings and concerns'* (Kate)

Some information on dementia was given in session five which was attended by carers and both they and the people with dementia found this useful. However, some of this information would have been useful to the participants earlier in the programme. Our observations indicated that not only could this group of people with dementia take on board the enormity of their situation, they also had the capacity to help each other to deal with it and would have benefitted from more practical information to support them in this.

Participants also expressed an interest in more information on research and about food and supplements than was being provided by the programme:

*'Well I thought the course was going to be more about how we treat ourselves, like what are the best things to eat, what are the best things to do to keep fit and all that but we didn't have any mention of that'* (George)

Facilitators also felt some of these things were missing:

*'I would like to have done a session about nutrition and eating well....because I feel, we're talking about looking after yourself, but we're not talking about nutrition'* (Liz).

Some participants were currently in, or had taken part in, drug or supplement trials and were keen to share information with each other and hear more about these kinds of opportunities to help themselves. They were concerned that they were hearing lots of things through the press but were not sure what was the most useful.

### *Time pressures*

There was a lot of time pressure on the facilitators to cover everything in the session schedules. This was managed well most of the time but our observations suggest that this was sometimes at the expense of the group being able to understand and assimilate the content as well as they might have done, had more time been available. Time pressure also affected the amount the participants were able to contribute:

*'I found by the time I felt like joining in, it had moved on and my point was left in the highways and byways'* (Robert).

*'sometimes the moment's passed can't think what you want to say'* (Molly)

The 'check in and recap' time was generally about 20 minutes each session. This did not seem to be enough time for facilitators to undertake full reviews, reminding participants

what had been covered in the previous week's session before moving on to the new materials and there would have been value in allowing a longer period of time for this:

*'it allows people to process, have any recall and then share...there were some opportunities but felt that people wanted to do a bit more but I'd have to move on....I didn't really give people a chance to chat about it' (Kate).*

More time at the start of sessions for this process of review or catch up would also have helped when people were late or when they had missed the previous session.

The time pressure was particularly evident when there was a difficult or emotional discussion and the facilitators had to decide to allow the session to run over. There was an example of this in session 2 where the recap time ran over significantly due to the contributions the participants were making. We observed that allowing the run over resulted in a much better experience for the participants and gave them an opportunity to share an important discussion about the things they felt they were being forced to give up like driving and other personal interests or hobbies. We noted how little time there was within the schedule for a pause or break to be taken after an emotional or intense discussion and this would sometimes result in the group losing concentration and exhibiting displacement activity.

*Opportunities for participants to talk about their own situations.*

There was more opportunity in the pathfinder programme than in the pilot for participants to talk about their own practical ways of living with dementia and, unsurprisingly, they always found these sessions easier than the more conceptual sessions. However, we observed that there were 'missed' opportunities for the group to discuss, in the detail they might have wanted, some very important concepts that came up for them. These included choice, self-determination, anger, loss of independence and gender differences.

A good illustration of many of these concepts was the discussion about giving up driving which was, or was going to be, a major issue for most of the group. This subject brought up issues of loss of choice, loss of independence, loss of access and contact and resulting anger and upset.

Andrew worried how he would know when he reached the 'break point' because 'my driving, to my way of thinking, has not changed at all'. He went on to recognise the impact:

*'it's so important in life, isn't it? You worry because you've lost contact and the ability to get everywhere and do things..... you start falling on, becoming dependent'.*

For one participant it was a very recent decision:

*'Very, very recent, just a couple of weeks ago and I'm still crying about it because I've never had an accident or, it was my life, you know...Absolutely adored driving, yes I'm constantly miserable about it' (Ellen)*

Another said that she did not 'lose' her licence but her daughter '*took it away*' and she '*had no idea why*' (Molly). It became clear during the conversation that Molly had had an accident and whilst she did say later that she accepted the decision, what remained for her was '*not having a choice*'.

The scheduling of the programme and the time constraints the facilitators were under meant that it was not always possible to stop and discuss an issue without time running out for another part of the session:

*'It would have been lovely to have allowed them to have more time to explore some of the things that were coming to their mind, or they felt challenged about'* (Kate).

One of the overriding issues for the programme still remains how to balance the tasks of giving information and encouraging different ways of approaching or looking at things and of supporting a group process, particularly when dealing with the emotional impact of lifestyle change and acceptance. To do both successfully and in balance requires flexibility within the schedule of the programme and skill and confidence in the facilitators to open up such discussions. Within this pathfinder, facilitators had the skills and confidence to manage this and, with more time and flexibility, could have opened up these discussions more.

### ***Practical aspects of how sessions ran***

Despite the suggestion, within the manual, to work in small groups, the group mostly worked together as a group of seven/eight. The time constraints made it difficult for the facilitators to break the group down and bring it back together, although on the one occasion they did this, it worked well. As with any group, the participants on this programme tended to sit in the same place each time, further inhibiting the closer relationships that smaller group working might have enabled. However, the skill of the lead facilitator in working with the group meant that a strong group feel was maintained and they were encouraged,, and found it comfortable, to talk to those beside them and across the table. There was no evidence from interviews that people would have preferred to work more in smaller groups and it was clear that different and varied interactions took place between participants across the course of the programme.

The group understood the ground rules and group agreement although the issue of confidentiality concerned one participant who asked about it a few times. It was not completely clear but this participant's concern may have been more about sharing details of his personal and family life with the group than sharing participants' details outside of the group. This did not seem to be an issue for others who clearly understood the nature of the group agreement and felt very safe within it.

Response to the length of the session varied. Some said they found it ok although they were aware that others might find it too long. In one of the later sessions on tiredness, Andrew wondered if two and a half hours was too long and if there was too much content '*are we at the point where we have had enough*'. Peter seemed to think the length of session was fine although in discussion with his carer he owned to being a '*doer*' and that the amount of

sitting whilst not 'onerous' was unusual for him. Some of the others in the group had more of an issue with tiredness and also with cramp and George in particular would have liked more and shorter sessions

*'I think you might have got a bit more from it because if you go through too much you just don't remember it'*

In observation we noted a level of tiredness, discomfort and lack of concentration on occasions that indicated a shorter session or at least more breaks to move around would have been helpful physically, and might have added to the energy and concentration within the group. The facilitators were also aware of levels of tiredness:

*'we have to remember that dementia is not just about memory it's about attentional ability – if I have nerve cell damage I have to concentrate that much harder than you.....I'm going to feel fatigue quicker.....I personally felt bad about that, because there was nothing I could do to change that in what we'd committed to achieve' (Kate).*

Participants were not specifically asked about the timing of sessions. Most seemed positive about it being in the morning as they then went on to lunch with family or friends. George felt it was particularly good for those who got a bit tired later in the day:

*'The other thing was I was pleased it was in the mornings and not in the afternoon, I think that is very important, you're much more lively in the mornings'.*

People liked the regularity and continuity because it was 'something you can look forward to' (Andrew).

The men were always on time but the women regularly arrived late. In the case of Rosemary and Molly, who came together, there seemed to be an issue with how early they could use their bus passes which made a 10.00am start too early for them. Ellen always arrived late and in one session arrived nearly at the end, to her mortification. It was noticeable that everyone arrived on time for session five when carers accompanied them and most of them arrived on time for the final session. It prompted us to wonder whether the session might have been better starting a bit later and whether some people might benefit from a reminder call to help them with timing.

As a result of late arrivals, the sessions nearly always started late, while waiting for people to arrive, and always ran over time as a result. Most of the group did not mind this but for Robert it was an annoyance and he felt the 'timing was too loose'. He explained:

*'it didn't seem to matter as long as somebody came, it didn't matter if they came in at ten or a quarter past ten or wander in when they like'.*



This did not seem to be an issue for any of the other participants but there was a certain amount of joking about 'being late for school' that could have masked this feeling in others. As with the pilot, there was pressure to keep to a schedule. This resulted in there being insufficient time both for the more informal discussions at the start of each session- that '*bit of a chat*' (George) which reminded the group of each other again and for the 'pauses' within sessions. These 'pauses' seemed to be particularly important in allowing people to move around and take time to assimilate what they had been doing. Scheduled breaks were often late and sometimes rushed. The lateness of breaks sometimes related to amount of content being covered and where breaks were indicated in the manual, with facilitators deciding that to finish a particular topic before a break was likely to be less difficult for participants than trying to come back to it after a break:

*'What didn't work well is the breaks they put in didn't flow with the content because it would be carrying over content from before and then slipping into new content.... it would be easier for people to understand if you do one set of content, have a break and then start on something new'* (Kate).

The relaxation exercises were very popular and the group elected to include them at the beginning and end of all sessions, to good effect. These moments provided an important 'pause' in which participants could simply be together and clear their minds before starting or leaving the session and they appeared to allow participants to increase their focus on being part of a group. The lowering of lights during the relaxation exercises was also effective in creating an 'environmental pause'. Music was introduced while people were arriving for session five and in the break and was included in the following sessions to good effect after participants said they thought it helped their concentration.

### **Paperwork and presentation aids**

The use of computers, flip charts, models and visual aids for presentation was significantly improved from the pilot and made the Pathfinder programme feel much more up to date, professional and prepared. Andrew was '*impressed with the way, the presentation of it all, it was very well done*'. Using a broad variety of methods was also valuable and different participants liked different things. Liz reflected on this:

*'we all learn in different ways .....I think as long as you give them a choice of different things you are targeting most people'*.

The use of a large screen with clear power point slides to support the manual enabled a strong focus and created a professional learning atmosphere to which this group of participants responded well. The use of computers also enabled one participant to bring in photos on a memory stick to illustrate what they had done during the previous week and for video links to be used in a couple of sessions. The size of the visual images on the screen, and being able to change them, was also commented on positively by those who had some sight deterioration. It was also possible to use the screen for reminders like the 'otter' image which immediately helped everyone to get in the mood for the relaxation exercise. The technology resources were high quality and much more easily available in this venue than they might have been in others.

The use of flipcharts was extensive and effective. All significant sheets were put up around the room so people could be reminded of them. Liz confessed to being worried whether people would want flipcharts but found that they proved useful:

*'so they like to see someone write it so they can read it over, whilst you're talking about it they can see you write it and I think it helps them when it is still there, that they can just read it over'.*

In observation we noticed this was particularly true of the 'head' image which Liz labelled as she explained it.

The use of models (props) and physical demonstrations by the facilitators was excellent and participants responded well to them. The use of the 3D model of the self-management triangle was a significant improvement on the 2D model used in the pilot as it enabled physical demonstration of the concepts being put across:

*'and they can touch it and they can fold it, and they could actually look at it and pick it up, and it meant more to them than a picture of, you know, a flipchart on the wall'(Liz).*

Session 2, which was about balancing life and health with dementia introduced the 'scales' diagram which replaced the 'sea saw' image used in the pilot. Participants found it easier to understand the issue of balance through physical demonstration rather than a diagram. In a later session, the facilitators used a physical set of scales to try and replace the diagram but this prop was more complex and not as successful as the 3D triangle. The facilitators used physical demonstration to good effect and there was an element of theatrical role play in how they demonstrated things like the 'I' and 'You' statements that provoked a good response and understanding from the group. One of the best-remembered visual images of the programme was the 'head'. It illustrated how much longer it takes for a person with dementia to hear, understand, process and respond to information or input and it appeared to make absolute sense to the participants.

We were aware that, in some sessions, the use of two or three different diagrams seemed to become confusing to participants, particularly if they were then asked to add feedback on coloured post-its. The participants talked about their issues with focus and concentration, suggesting that, on occasions, there was simply too much, and too varied, paperwork put in front of participants, confusing and overloading them. We would suggest some review and simplification of presentation aids would better benefit people with dementia.

The facilitators raised the issue of lack of continuity of the PowerPoint slides:

*'With the PowerPoint that we had originally there was, just felt like a complete lack of continuity, or even brand, so that's why I changed that, so every week it looked the same, the beginning looked the same and the end looked the same and we had that, the sea otter, the sea otter meant relaxation' (Kate).*

They also had concerns about the disjointedness of some of the text of the sessions:

*'one minute she's talking about a triangle, then she's talking about scales, then it's back to the triangle, and I'm not surprised they felt a bit confused, it should have been just one thing' (Liz).*

The local knowledge resources were excellent and leaflets and information were given out in each session. This was significantly different to the pilot where the local resources were under developed but as mentioned earlier the pathfinder was helped by being in a well-resourced local office.

Not so positively received was the 'Useful Things Booklet' which did not seem to be laid out in a way that related well to the ordering of the programme and which was not well used:

*'the way the book was laid out, it wasn't particular to any particular week was it..... and almost we want to write more things than that (the action plan), almost précis what we did in the course because you don't remember it' (George).*

*'It doesn't have an index, it doesn't have a glossary, it doesn't even say how it's connected to the sessions.....I think there is a point in having supporting material but it has to concur and be in line with the programme to underpin and people go away and say "oh well that was session 1 and this is what I've done" and maybe share it with somebody' (Kate).*

Liz suggested an alternative:

*'we should give them a little folder or a little A4 clip folder. Or something like that, and at every session they got little handouts of what we'd discussed, so a picture of a scale and maybe little handouts of what was discussed.....they could physically put that in their folder and take it away and bring it back with them'.*

Completion and use of the 'activity plan' section of the booklet did not seem to feature as highly as it did in the pilot.

Following the pilot, significant attention had been given to revising the manual, particularly in terms of improving the language. However, the programme still felt too scripted at times and the facilitators often had to rephrase content to help understanding. Part of the difficulty was that the language was still very much that of 'generic' self-management programmes. This is the language of health 'management', not necessarily the most appropriate language to use with people with dementia.

*'I think we could use a better word than self-management....I don't think I would look at myself and think "Oh I'm somebody with dementia and I'm self-managing"' (Kate).*

The sessions which participants seemed to engage with most readily were those where the language was their own, enabling them to talk about their feelings and the challenges of living with dementia. Liz suggested it would have been simpler to have replaced the notion

of 'self-management' with 'live well' as the latter seemed more positive and made more sense to participants:

*'Can we change the word self-management to Living Well? Because you can have a Living Well triangle, you can have Living Well scales everything is Living Well but they're talking about self-management, so it's not, it doesn't flow well'* (Liz).

### **Use of the group as a resource**

The role and value of the 'peer group' experience was significantly different to that in the pilot programme. The group was encouraged to work together and share their experiences. They valued this aspect of the programme highly and acted as a resource for each other, in terms of both information and ideas right from the beginning.

The group acted as a resource for its members in a number of different ways – as a source of comfort and support, an enabler of honesty and openness and as a source of ideas.

- a) The abiding memory for all was how 'comfortable' they felt in the group and how much they enjoyed working together and with the facilitators.

*'it was so comforting, really comforting that you aren't alone in the world, there are people with the same problem and that to me I found incredibly comforting.....You felt very at home with them because, you know, we're all in the same boat really'*(Ellen).

*'Well I suppose it was that, you know, you were seeing people who had a similar problem and it gave you a feeling of comfort to a degree'* (Peter).

Andrew spoke about the strong sense of a bond:

*'you go into a room and you know you've all got the same illness, you immediately bond, I think'.*

Ellen spoke about encouragement:

*'I loved the fact that everybody was cheering each other on, it was marvellous, you know, we aren't alone, we can go back and sort of think about it when we go back home and think "wow", you know'.*

George found he felt more confident to speak about his dementia particularly when he found others had similar problems:

*'Yeah, especially with the other people there talking because they seemed to have the same problem, that was nice to know and I think it's given me more confidence to say that I've got dementia'.*

There were one or two members of the group who were particularly able to engage with, and offer support to, others within the group. Rosemary was described by one of

the facilitators: *'she kind of made sure everybody was comfortable and talked to people'* (Liz). This was appreciated by everyone in the group and Robert, who confessed to feeling uncomfortable in 'groups', recognised it was *'good to have somebody like her here'*.

Kate had particularly noticed the impact on participants of validation from others:

*'the standout stuff for me is how important the participants felt about being able to keep, have conversation with one another and share experience with one another, and from sharing experience it validated another member of the group or made them feel more confident and "oh well then, this must be normal, this is normal"'*.

- b) There was a level of openness and honesty that we had not seen in the pilot. Andrew spoke about how you could talk differently to people who were not family or existing friends:

*'If you were with your husband and then you go and see some friends, you'll want to say one thing, but you know, if you were talking to the other lady you'd probably say something different'*.

and Robert commented on how unthreatening it was despite not knowing anyone:

*'Never met anyone before and I didn't feel threatened by anybody there either'*.

Rosemary liked the fact that they could be honest about the subject of dementia:

*'in other clubs (dementia clubs) no one talks about what's wrong'*

A number of the participants spoke about how it was possible to *'talk about it differently'* in the group or that it was *'easier in the group'* to talk and one of the concluding feedback comments from Rosemary was that she thought they as a group had *'opened up more'* and suggested this was because *'you feel much freer – you don't want to upset family.'*

Ellen was particularly surprised by the honesty of the men in the group and how able they were to talk about their feelings:

*'I thought they wouldn't want to (be open in the group) and I think that helped them enormously too'*.

- c) The group proved to be a source of both ideas and tips. Andrew and George spoke about how talking to people in a similar situation prompted memory and thoughts:

*'You're in a group of likewise people, you know, and they are saying things and it triggers something in my mind'* (Andrew).

*'Yeah, find out how people get on what they've been doing and when they sort of start telling you, you think, oh yeah, you said that and that, it brings some things back, yeah (George).*

*'Well yeah, yeah, they're coming up with tips and things.... brilliant, yeah, that's a good idea' (George).*

They shared how they currently helped themselves by writing things down as they thought of them or making day lists:

*'I can think about it first thing in the morning and I quite often get in bed and think about it and if I'm quick enough I write it down' (George).*

George also used photos to record a process like building a shed so he could remember the stages. Rosemary wrote all her personal details down before she made important phone calls and others, like George, had someone with them who could take over if necessary:

*'she will always be there to step in if it goes wrong' (George).*

The group were all very well mannered and good at the ground rules. Some spoke more than others, especially where everyone was interested in what they had to say, no one meandered and they did not seem to have to control or manage each other. There was a strong sense of mutual respect between the group members and, even though some participants described very difficult aspects of their lives and experiences, the other group members were unfailingly attentive and supportive.

There was a great deal of humour in the group with many jokes being told. The ones that raised most laughs were those where the nature of dementia and the challenges were at the centre of the joke. A couple of people within the group were particularly good at self-deprecating humour, describing what would have been embarrassing situations, even to people without dementia, in a way that brought everyone together. There was a sense of camaraderie and fun and, whilst many in the group spoke of word-finding difficulties, quick quips or sparky funny observations were common.

The loss of friends and friendship groups was very significant for this group. Many of them spoke about this and the language they used was negative. Participants spoke of how friends would *'drop'* or *'shun'* them. Ellen talked about her experience at a regular club which made her *'feel so alone'*:

*'I mean there are still people that I know very well at the (name) club and this sort of thing and, you know, you feel that they're holding back rather, not sort of friendly like they used to be before all this happened'*

Andrew spoke about how he would duck out of meetings with friends now saying *'I have lost faith in myself in some respects'*. Andrew was a bridge player and knew he was not as

good as he was so felt he was letting his partner down. He had not told anyone yet about his dementia but sometimes felt his friends there would *'have a go at me'*.

George spoke about an experience with a school friend:

*'Yes it happened to a couple of friends and (name) for instance I've known her since I was at school, we were at school together and she very distanced herself but she's come back around now'*.

He understood why: *'I think it's more difficult for them because it's just sprung on them'*.

Rosemary understood both sides and commented that, as dementia doesn't *'show'*, she felt *'people don't know how to act'*. Even though she understood, she also said that her view about friends who *'drop you'* was *'sod em!'* She went on to say to the group *'I think of people like us (motions to the group) as my friends'*.

The formation of bonds of friendship and support was evident in the group and there is a real opportunity to encourage and support this as part of future programmes. Andrew felt that the experience of *'sharing has helped me get ideas'* and Rosemary spoke about how when you have dementia it's like *'another world you go into'*. It was clear that, in this other world, they valued the people who shared their experience and who they viewed as their friends. As Rosemary commented:

*'it feels like we have been coming here for years – something I look forward to coming to'*.

Session 6 was a more unfocused and difficult session for the group. Two participants in particular, for different reasons, needed more focussed attention from the facilitators. Participants seemed to need time to re orientate themselves back to being a group without their chosen supporters present. The facilitators were also aware of this:

*'We did wonder if having the 'marketplace' (session 5) in the middle made session 6 less effective because they'd had their carers/supporters with them...whether that had a knock-on effect on their ability to stay focused because it had been a much more informal session' (Kate).*

The group up to this point had operated very well together, and with the facilitators, and that strong dynamic was fractured a little in this session. Both facilitators were aware of the challenges for them in this session, recognising that on occasions it had been difficult to balance attention given to individuals with attention given to the group. Whilst session 5 gave participants an insight into their companions' broader lives and people had enjoyed meeting each other's families and friends, our sense was that this session would have been more appropriately placed as the concluding session of the course as the impact it had on the group was unsettling.

### *Use of the facilitators as a resource*

Despite changes since the pilot, the pathfinder programme still felt too scripted and this led to some problems for the facilitators. It was clear that there were times when they would have preferred to have been able to use their own ways of presenting and talking about issues to better fit the needs of the group. There were occasions where they did need to go 'off script' in order to respond to what was coming up in the group and their actions in these situations seemed appropriate as they managed to bring the group back to the content of the session as soon as they could. There were parts of the script where free discussion by participants was encouraged but other times when participants wanted to talk freely in ways that did not always fit with the timetable. This resulted in facilitators having to take decisions on the spot about whether to let sessions run over time or to truncate content.

The facilitators had particular skills, awareness and knowledge:

- a) Their facilitation skills were excellent, prioritising contribution and engagement from participants. They noticed who wanted to contribute and encouraged everyone to take part.

*'Remembering not to say too much...sitting back and allowing people to speak and not butting in....not wanting to cut in too quickly to move on to the next bit'* (Kate).

Only one participant commented negatively on being encouraged to speak saying *'she was putting a certain amount of pressure on and I felt it'* (Robert). The more common sentiment was expressed by Andrew:

*'I felt it got us talking together and we were not afraid to talk about ourselves which some people might be reticent'* (Andrew).

- b) They showed skill in handling situations where participants expressed individual upset or difficulty and in facilitating other members of the group to offer support and encouragement, thus solidifying the group dynamic. The level of honesty with which participants spoke meant that some very difficult personal situations were shared early on in the sessions. The facilitators supported this in a calm and encouraging way and were not overtly surprised or in any way reactive, other than supportively, to anything anyone said.
- c) Their style of delivery was appreciated:

*'marvellous, yes, I mean I, you know, it probably sounds silly but I just think the whole thing was just brilliant'*(Ellen).

*'I found it nice that it was very chatty, the course was very chatty and I think that was very nice'* (George).



- d) They had a good sense of when it was appropriate to share personal information about themselves or to use their own situation as an example and participants responded very positively to what they saw as a mutual level of trust.
- e) The two facilitators worked well together, having complementary skills and a keen shared interest in finding the best way to present the content of the course to the participants. They both had an interest in props and had lots of ideas, recognising the need to find ways to engage the parts of the brain that were still active. One had a particular flare for physical demonstration of how dementia could affect people which made her presentations very engaging. Both were very knowledgeable about dementia and the local services available.
- f) Kate, in particular, had a level of detailed knowledge of how dementia affected the brain, and the processes of diagnosis and medication that provided answers to some quite technical questions from participants. Detailed answers were often backed up with information leaflets. George found this particularly helpful:

*'I thought (she) was very understanding of my condition and probably everyone else's condition as well. She understood it exactly and I thought that was very good' .*

- g) There was evidence that the facilitators had an excellent shared planning and reflection process which resulted in them being well prepared for each session.

The knowledge of these facilitators enabled them to have a particular influence on the experience of the course for the participants, making it a better experience than it might have been if their experience and understanding of dementia and the people they were dealing with had been more limited.

### ***Involvement of carers***

Session 5 was a very different kind of session and participants were encouraged to invite their chosen supporters to attend. Four of the men invited their wives, two of the women, their daughters, and one of the women invited her closest friend. The room was laid out very differently with two big tables and the basis of the session was information giving and shared learning about services available and issues to be considered. The session was enjoyed and considered valuable and a significant amount of information was imparted and questions answered. There were a number of presentations and opportunities to talk and interact for everyone. The presentation on how dementia affected the brain was particularly appreciated by carers:

*'I think the main things from the carers' day, I thought it was a fantastic explanation, visual explanation which is incredibly helpful' (Deborah – Ellen's daughter).*

The presentation by a local solicitor on Wills and Lasting Power of Attorney caught everyone's attention and at least four participants and their carers took up the offer by the solicitor for a review and update of their existing documents:

*'the biggest thing we've probably acted on is through (solicitor name), we've had a consultation with her (Deborah).*

*'I thought we were all done and dusted because we did our wills in 2003, she's said the power of attorney we had wasn't wonderful....we found her very helpful' (Sheila).*

Two participants took part in joint interviews with their carers and a couple of issues came up relevant to the role and impact of carers in the programme. Both carers talked about how the person they cared for could not tell them much detail about the course:

*'I don't know a lot, the relaxing and things, which people talk a lot and which don't – he's more or less forgotten when he comes out, it's just the odd thing'....I keep trying to get him to have a sheet of paper and write the day and what he wants to do during the day, which is on one of your sheets isn't it?' (Sheila).*

*'I don't think you've (Ellen) really talked to me about what you've done on each session I don't really know. I met (facilitator name) and she showed me a few flipcharts so she gave me a rough idea of what's happened in each session' (Deborah).*

Carers were very aware of the emotional impact of the course:

*'The impact's been really positive, I mean I think you're happy, you've been on cloud nine every Wednesday..... and so excited about coming and from about week two saying "I don't want it to end"' (Deborah).*

*'He really looks forward to coming to the next one' (Sheila).*

Being referred to the Live Well programme had, for both partnerships, been their introduction to the Alzheimer's Society and their local services and they were extremely positive about how this had '*opened huge doors*' that they didn't know about:

*'for both of us individually and together I think because there's home support and then obviously the programme, the singing for the brain has come about and I hope to make the carers' meetings as well, so I think, you know, it's multifaceted, it's been brilliant' (Deborah).*

Deborah went on to say that this had resulted in them being more proactive about putting measures in place at home for Ellen '*like home support....seeing it as a tool to stay independent longer*'.

Sheila also talked about coming to the Alzheimer's office during and since the programme:

*'...and the thing that we both feel is how friendly and nice everybody is here. You don't feel inhibited about coming, you know that if you've got a problem, you could come and say, you know "Can I see somebody?" Or.....everybody is very open and helpful, and that's good, to feel that you've got somewhere to come isn't it?'*

### **Overall impact – two stories**

There were two participants who, in interviews, were able to explain the overall impact they felt the programme had for them.

#### Ellen's story - acceptance and positivity

Ellen was in her early 70s and had been living with dementia for a year or so. She still lived alone and independently with her beloved dogs and she walked with them every day. She was still driving, which she loved, but this was something she had to give up during the time she was on the course and she had found this very difficult. She spoke sometimes about problems in her marriage which she had now left and she had come to the course at a time when she was feeling very low. She understood the nature of the course although her memory was poor and she particularly enjoyed the group experience. Ellen was unfailingly polite and grateful throughout the course but was sometimes tearful and upset by her dementia diagnosis and the limitations it was putting on her now. She was supported by her children and in particular her daughter Deborah who attended session five and also did a joint interview with Ellen.

In her interview, Ellen talked about her early life and how she had been confident and very independent. She had found her diagnosis difficult to accept but the course had helped:

*'I was absolutely devastated when I got the, you know, what was going on and I'm sort of getting used to it now and feeling I've got to accept it, you know' .*

She also found the course had made her feel better and more like her old self:

*'it's made me much, much, stronger.....I think I'm more determined now'.*

When asked whether there had been too much 'brain' work on the course, Ellen was actually very positive *'no it helped my brain actually, it really did'*. She found it had been good to use her brain and she had started reading again. She thought the course had helped her to realise that she could still use her brain and said *'Yes I need the confidence and I think it's coming back'*.

In their joint interview, her daughter Deborah commented about the increased positivity she saw in her mother and how important she felt the shared group experience had been in that:

*'probably the main change is positivity with mum – and part of that (acceptance) I think has been meeting other people and realising how many people are affected'.*

By the end of the course Ellen and her daughter had engaged with a number of local services from the Alzheimer's Society and Ellen had made the transition to finding other ways to travel as she could no longer drive. She was continuing to see a couple of the participants through going to the 'Singing for the Brain' group and was enjoying these new-found friendships. Deborah was about to have a baby and Ellen was to be a grandmother for the first time which she was delighted about and looking forward to.

She summed up her experience of the course

*'I think I was blown away by everything, the fact that, you know, something was being done now'.*

### George's story - talking about and adapting to living with dementia

George was a retired engineer in his late 60s who had been living with dementia for a number of years. He lived with his wife who was his close supporter and was very involved with family, particularly his grandchildren. He had been on a number of drug and supplement trials and was keen to gain and share knowledge about dementia. He confessed to being '*a bit of a loner*' and said he had worked all his life in a job where he worked alone. This had made him very self-sufficient and he was keen to try and work out how to deal with the problems he had. He shared ideas and enjoyed hearing suggestions from others. One of his personal concerns had been about talking to people about his dementia as he was finding words more difficult and was concerned about how they reacted to him:

*'they sort of want to keep away and be very careful'.*

George said the course made him feel more confident and in particular '*It's given me more confidence to talk to adults, I can talk to kids alright*'

In talking to people he also felt he could be more honest now:

*'Yeah to say more of what I think than being very guarded about what you say and try not to let it show you have got difficulty with saying things'.*

He recognised that part of this was about confidence but also about acceptance and understanding himself:

*'Yeah I've got confidence no, **less** concern....just accepting that that is how I am now'.*

*'I understand my limitations better, I don't expect so much'.*

One thing George said he had really learnt on the course was '*... (everything) takes a lot longer and other people took a lot longer as well*'. He found this interesting as he was a photographer and he used photos as a memory aid for jobs that he wanted to do. He also took pictures regularly on holidays and of things he saw in the garden. He had noticed that he took better pictures now he has dementia and had wondered if this was about it 'taking longer':

*'I take better pictures with a camera I think, a lot of people commented on that (when he brought them in)...I don't know whether I take more time over it because I'm slower or something like that, it might be because I take more time'.*

### **Co-design and feedback process – pathfinder**

The pathfinder approach to co-design was different to that of the pilot in that it was explained to participants from the outset that they were involved in a programme that was still being developed. The participants were referred to as 'pathfinders' and were encouraged to give continuous feedback. However, it was still difficult for them to have any real input into the design, content or practical running of programme sessions that were still largely scripted and tightly timed. Despite this, they did help shape the more social aspects of the programme- for example, by bringing in photos and food to share and in agreeing to do the relaxation exercises at the beginning and end of each session once they had been introduced.

Some pathfinder participants, fully understood that they were being asked to look at the programme not just as a participants but in terms of 'co-designers', assisting with its further development and some welcomed this opportunity that made them feel they were helping others like themselves:

*'so the idea that I agreed to come here was, okay, I would learn something, but it might help other people' (Andrew).*

There was one participant who admitted to some confusion about whether the programme included an assessment of the facilitators and even whether presence of evaluators meant they as participants were being 'tested':

*'I didn't know whether it was true that it wasn't an assessment of those people because it still did, still felt as if we were there as guinea pigs' (Robert).*

The combination of the formal evaluation process and regular reminders to participants about being 'pathfinders' may have created the potential for this confusion but, overall, most participants understood and welcomed the opportunity to give feedback. One participant, who had been actively involved in helping develop other services, fully understood his role but admitted that he was much more *'interested in what I could get out of it'* (George). Our observations suggest that this was likely to have been the main focus for others in the group, too.

Significant improvements had been made to the internal evaluation process since the pilot but its form still remained largely the same- an end-of-session, written feedback. Participants appeared to find it difficult to complete the feedback forms:

*'We saw very quickly not to put people under pressure to write because it highlighted the loss and limited ability from a place where they had full function of their fine*

*motor skills and now they don't.....we didn't feel this was correct because you would be ending a session with people going away not feeling positive about themselves because they tried to write and they hadn't been able to spell or put down on paper what it is they wanted to say' (Kate).*

*'When you asked them to do the feedback form, they just got so distraught and upset about it because we were actually making them try and recall something they couldn't recall which was only an hour, two hours ago, and put it on paper' (Liz).*

*'Not (realistic) for people with dementia, because you're actually asking them one, to recall what they've just experienced and the emotions they experienced as well, and then to find those thoughts, to write them down, and to, yes, and writing, if they're embarrassed that their spelling is not what it used to be.....that's just going to make them anxious and not make them want to do that' (Liz).*

In the evaluation of the pilot, the evaluators, had recommended that additional ways of checking out what was working for participants, other than just the end of session form, were tried. At the start of the 'delivery' stage, we were concerned that there still didn't seem to be any opportunity to get feedback from participants in the 'here and now'. However, the facilitators picked up on this issue and, in session 4, suggested to the group that they would seek verbal feedback after each activity. The participants readily agreed with this because, as George said, '*it's so fresh*' and they clearly felt more comfortable after that and gave regular feedback. This adaptation also provided a useful short 'pause' after each activity where participants could reflect and assimilate what they'd learnt before moving on.

Facilitators actively sought to learn from each session regarding what was and wasn't working. They had a structured debrief and planning session each week in which they worked hard to adapt both the script and its delivery within the overall constraints of the programme. This continuous adaptation, as with the revised participant feedback process, can be understood as a form of 'co-design in delivery' that involves and benefits both participants and facilitators.

The facilitators had reflected a great deal on the programme and had thoughts about the overall design, and its impact:

*'we're drumming stuff into them that may, is, may not be relevant to the individual person, and is far too in depth and far too, too much. It's just too much, we could see, they couldn't recall it, could they? They couldn't even, when I did the recap in session seven, they were all like "Woah", even I, at the end, was like, "Woah, that is bizarre what we've done in seven weeks" (Liz).*

*'I think that was the key for all of them, the coming together, seemed to be more than the programme. The programme was like the cherry on top, but the coming together was more important' (Liz).*

*'I'm not saying that the content isn't appropriate, I just think it needs a rethink, is that the right focus, there's so many subjects you could be introducing....is there an opportunity on that first session to be an introduction session....where we can look at different subjects and ask the group to choose....we could have maybe ten subjects and ask the group 'what is it particularly that you want to get out of this course' (Kate).*

Both facilitators were also concerned about where people with dementia could move on to for support after the course:

*'if we did run this group, like we run CrISP, when I finish CrISP, people can then migrate, you know, nice transition into carer support group and there are other services, people with dementia don't have something to neatly migrate into which is their own, which is their safe place to be who they are, and I think that's a duty of care, you know, that we should be offering something' (Kate).*

*'I think when it comes to carers, it's different, because a carer can self-manage...these people are quite vulnerable and have been given an opportunity to come together and bond, we've actually said to them "Well that's the end of that, bye, bye!" And I felt quite bad about that, that we weren't offering them, and actually, "From this you can move into our monthly support group"....we're going to have to offer them something at the end, because it's not going to work otherwise' (Liz).*

### Section three - Conclusions

In this conclusion, we reflect on the two elements of the evaluation (co-design and delivery) separately, while noting, as discussed above, that design continues throughout delivery, through a process of continuous adaptation within the overall limits of the programme.

#### Co-design

The evaluation set out to answer two questions about co-design:

1. What has been the experience of people with dementia and staff working with them in the co-design of the *Live Well with dementia* programme?
  - Overall people with dementia welcomed the opportunity to be involved in consultation/co-design sessions leading to programme development. They were keen to be involved in anything that would help others as well as themselves and increase understanding of dementia and how it affected them.
  - In most circumstances, people understood the nature of the involvement they were being asked for, particularly in the pathfinder. It was noted that the pre-pilot focus groups which trialled a session did result in some of those who attended thinking that they were attending a course and being disappointed that there were no further sessions.

- It was more difficult for people with dementia to consider the 'abstract' idea of a 'potential' course and easier for them to respond about issues from their own experience.
- The Alzheimer's Society staff and partners working with them in the consultation meetings were aware of how it might be difficult for people to engage with 'abstract' concepts and how they might need to help them to think beyond their individual situation. They were also aware that they should never make assumptions about how much recollection was possible for people with dementia and how they might need to interpret what might be relevant and important to people from the examples they were giving of their own lives.
- They were aware of the need to give people with dementia time to respond to issues and therefore to ask a small number of questions. They recognised that they might also need to 're-phrase' as they went along, to help understanding.
- Techniques to put people at ease and being able to give enough time and flexibility to any consultation sessions were seen as essential as was the need to avoid people leaving feeling in any way bad about themselves or that they had got anything wrong.
- The facilitators of the pathfinder found that using a process of reflection and pre-session planning enabled them to adapt the programme week by week within the overall constraints they had been given.

### 2. What has facilitated the process and what barriers have there been?

- It was clear that familiarity helped people with dementia. Some consultations took place with existing User Reference Groups and for those who attended the pilot groups coming back together with some of the other participants was something they welcomed and enjoyed.
- Different kinds of groups were consulted with, focus groups of people with dementia interested in a course, User Reference Groups, pilot attendees (post course) and pathfinder attendees (during the course). Feedback from observation and interviews indicated that a 'conversational' style and setting worked well with people with dementia enabling them to feel listened to and understood. Smaller groups and the presence of familiar faces like facilitators also seemed to be appreciated.
- For the pathfinder group, being able to give feedback in the 'here and now' was a significant improvement on the end-of-session feedback process which facilitators observed they found difficult and which made them 'negatively' aware of their limitations of memory and writing skills.
- The facilitators of the pathfinder found the tight scripting of the programme meant that it was only possible to make limited changes to the delivery.

### **Programme delivery**

In both of the pilot and pathfinder programme delivery phases, the evaluation set out to answer three questions about delivery:

1. To what extent is the *Live Well with dementia programme* successful in providing knowledge, skills and practical tools in ways that can support people with dementia to



be more actively involved in their own self care?

- The programme was successful to some extent in providing knowledge, although it was the process of the programme rather than the detailed written content which was more successful in this. For example, knowledge on dementia was provided to people with dementia and carers together during session 5 but it was the questions and contributions from participants during the course and the answers and information supplied to them by each other and the facilitators that was equally significant in knowledge generation for them.
  - There was evidence that some skills were enhanced by the programme, particularly in the areas of daily planning processes, pacing, managing health, social interactions and relationships. What was more significant was the understanding they developed individually and together of how dementia was impacting on their lives and how they could come to terms with it and adapt their lives to feel more in control.
  - Again, many practical skills were shared and exchanged between participants, with input from facilitators and it was these skills and ideas, more than the practical tools such as 'action planning' contained within the formal content of the programme that stayed with them.
2. To what extent does the timeliness of the *Live Well with dementia* programme to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?
- The timeliness of the programme to individual participant's situations is less to do with length of time since diagnosis than about the level of 'awareness of self' of participants and how this shapes how far they are able to participate in the programme. In this way, the programme was at the right level for all but one of the pathfinder group and only for about half of the pilot group. This was evidenced in the pathfinder by their ability to understand and articulate the impact that their dementia had on them, their ability to engage with and understand the concepts of the programme (with some support) and, most importantly, their ability to participate within a group setting where they needed to be able to listen to and respond to others in a similar situation.
3. Are there ways in which the delivery content and/or style could be improved or made more appropriate?
- The programme is still very content heavy and the evidence from the evaluation indicates that it is too much for the seven sessions. The content is too complex in certain areas and not all of the concepts used are useful or meaningful to people with dementia or expressed in the most appropriate language for them. Some topics included in the Pilot which people with dementia would have found useful -like nutrition- have been omitted from the Pathfinder. The ordering of the programme also needs rethinking. Participants would benefit from having information on dementia earlier and the 'marketplace' and carers' session may work better at the end.
  - More space is needed within each session to allow the facilitators to respond, more flexibly, to participants' issues as they arise. Sessions would benefit from a longer check-

in time to enable orientation and catch up to take place and more 'pauses' during sessions would be beneficial both physically and emotionally for participants.

- Significant improvements were made to presentation methods and materials between the pilot and pathfinder stages of delivery and the variety of methods used in the latter is to be welcomed and should continue. The *Useful Things Booklet* needs reconsideration as a key tool of the programme as it was not effective or well used in either the pilot or the pathfinder.
- The physical environment of the pathfinder and the access to resources provided a much more effective 'learning space' than the pilot which helped the focus and concentration of the groups.

### Section Four – Recommendations

It was evident by changes and improvements made between the pilot and pathfinder stages that those involved in the development and delivery were taking and using feedback delivered through the external evaluation (both co-design and delivery) as well as through their internal feedback processes and this is to be welcomed. The development task was challenging and complex and, from the evaluation team's findings, the significant and effective changes that were made delivered a much more effective version of the programme at pathfinder than at pilot stage.

The areas that we consider would benefit from more consideration are as follows;

- **Ability to benefit.** A key issue for participants is that they have capacity to manage and benefit from the programme. This may be less about for how long they have had a dementia diagnosis and more about their 'awareness of self', their understanding of the impact of their dementia and their ability to function in, and benefit from, a group process. This observation has implications for the pre-course assessment process which was not part of our evaluation.
- **Venue.** The key elements of what made the pathfinder venue and environment such an effective 'learning space' included the accessibility, size and layout of the room, the access to and good use of appropriate technology and resources, room for the ongoing display of materials generated in the sessions and the presence of additional support staff. These should be replicated as far as possible when selecting venues for future programme delivery.
- **Content and programme length.** Reduce the amount of content or increase the length of the programme to enable people with dementia to benefit more fully from participation.
- **Key concepts.** Further consideration needs to be given to identifying and including only the most important concepts that support the Live Well approach.
- **Additional topics.** Consideration should be given to whether there are additional topics that people with dementia might wish to see included. Participants asked for more information about dementia and we would recommend that this is provided to them earlier in the programme and not just during the joint session with carers. Other content that people with dementia found useful in the pilot was omitted from the pathfinder and it would be beneficial to consider reinstating topics such as nutrition.

- **Language and terminology.** The programme would also benefit from further consideration of the 'language' and terminology used and whether it is the most appropriate for people with dementia.
- **Pace and timing.** More space for reflection and recap is required within the delivery schedules, both to allow facilitators the time to respond to issues arising from participants and for participants to have the time they need to process and consider what they are learning and discussing.
- **Scheduling.** The evaluators observed a morning and an afternoon programme and overall considered the morning a better time of day for the participants.
- **Visual content.** We recommend the development of more 3D props and other ways of visually or physically demonstrating key issues.
- **Peer support.** Participants are a resource for themselves when they come together in a group. Future development of the programme should consider how this aspect of the programme can be more explicitly developed and supported.
- **Carers' role.** Further consideration is required concerning when and how to involve carers in the *Live Well with dementia programme*, carefully balancing the support this can offer people with dementia against the disruption to group dynamics it can cause. Consideration should also be given to how best carers can support their loved ones with recording and reflecting on what they are learning, with attention being paid to what might work better than the existing 'Useful Things' Booklet.
- **Continuous feedback and adaptation.** Further consideration should be given to how participants can be involved in co-design as the programme continues to develop. A form of continuous feedback and adaptation during programme delivery itself seems to be a very fruitful way of ensuring relevant participant input, drawing on their experiences in the 'here and now'. These reflections, reactions and insights can be captured and built on both during and after the course, depending on their precise focus. People with dementia are less likely to be able to engage fully in more formal consultations about future programmes or in written feedback at the end of programmes they've participated in but these options should not be ruled out altogether, where they might be appropriate.

**Research Team** – Flis Henwood, Naomi Smith, Diane Waller, April 2016

### UNIVERSITY OF BRIGHTON

### External Evaluation of the Alzheimer's Society *Live Well with dementia programme* – pathfinder two - Chippenham

#### Section one: Background and methodology

##### 1. Introduction

The LIVE WELL WITH DEMENTIA PROGRAMME has been in development since 2013. The evaluation by the University of Brighton ran alongside that development looking at the process of co-design of the programme and at programme delivery in Hastings (pilot) and Salisbury (pathfinder 1). The pathfinder 1 evaluation concluded at the end of March 2016. A report, *External Evaluation of the Alzheimer's Society Live Well with dementia programme – final report*, was submitted in April, 2016. Since then, the programme has evolved further involving adaptations based upon findings from both the external evaluation and the internal evaluation undertaken by the Alzheimer's Society.

The University was invited to evaluate a further iteration of delivery of the *Live Well with dementia programme* (referred to as pathfinder 2). This took place in Chippenham, North Wiltshire, between November 2016 and January 2017.

This short report details findings from this stage of the work referencing, where relevant, summary detail of the key conclusions from the previous report. Background information and discussion of these findings within the broader evaluation 'story' will be given in the conclusive report, covering all aspects of the Live Well with Dementia programme of work (March 2017).

##### 2. Background:

Initial agreement to the extension of the evaluation assumed a new version of the programme (hereto referred to as the 'course') would run between September and November 2016 in Chippenham. In the event, the course started in early November, concluding mid-December. Ill health of participants resulted in one week's session being cancelled (week 4). In order to avoid extending the course beyond the Christmas period, which would have caused a disconnect with the majority of the course, facilitators adapted content by cancelling the final session, the 'market place'.

Unfortunately the evaluation coincided with a period of industrial action on Southern Trains which resulted in evaluators being unable to observe week 6 (session 5).

Pattern of attendance:

Week 1 -5 participants

Week 2 -6 participants

Week 3 - 4 participants

Week 4 - CANCELLED

Week 5 - 2 participants

Week 6 - 4 participants (*no observation*)

Week 7 – 3 participants

### 3. Aims

In-keeping with the action research approach, this extension sought to explore how the changes that had been implemented following the evaluation of Pathfinder 1 had been implemented. The evaluation aimed to explore the extent to which the *Live Well with dementia programme* was successful in providing the knowledge, skills and practical tools that can support people to live well with dementia, based on the principles and desired outcomes of self-care. Participants' (people with dementia who attended the course) views of the content, style of delivery and impact of the programme were explored as well as the timeliness of the course to their individual situations.

### 4. Evaluation design

As with the evaluation of Pathfinder 1, we set out to answer the following questions;

1. To what extent is the *Live Well with dementia programme* successful in providing knowledge, skills and practical tools in ways that can support people with dementia to be more actively involved in their own self care?
2. To what extent does the timeliness of the *Live Well with dementia programme* to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?
3. Are there ways in which the delivery content and/or style could be improved or made more appropriate?

In recognition of the fact that this evaluation centred on capturing the impact of changes to delivery made following the previous recommendations, data collection methods were slightly adapted from those of Pathfinder 1, in agreement with the Alzheimer's Society. An adaptation made to this iteration of the course was that the 'market place' session was moved to the end of the course (ie moving from week 5 to week 7). On the basis of the information- giving nature of this session and the involvement of carers which was a departure from the style of other sessions, it was decided, in discussion with the Alzheimer's Society and facilitators, that it need not be observed. Other changes reflected the recommendation that there be a greater emphasis in the evaluation on the group work element of the course and on the way that facilitators were delivering this.

Therefore revised methods agreed were:

- Pre-course joint interview with both facilitators
- Observation of six sessions (omitting the final 'marketplace' session)
- Emphasis on observing the group work element of the course
- Post-course focus group with course participants

- Individual post course interviews with both facilitators

### 5. Data collection

Data were collected using the following methods – written observational notes of programme sessions, notes from a focus group with people with dementia and recorded pre and post course face- to- face interviews with both facilitators.

Observation of programme sessions focussed on how the content of the workshops was delivered and how information, knowledge, and support were generated and shared amongst participants. Attention was given to the interactions between participants as well as between facilitators and participants. Attention was also paid to how interactions changed over time and with different participants, with the aim of identifying particularly effective ways of communicating knowledge and information and supporting the development of skills and practical tools with people with dementia.

Previous evaluation of pathfinder 1 highlighted the benefits and challenges related to working in a group. In-keeping with this a group discussion rather than individual interviews was held with course participants. Facilitators agreed that this could take place at the end of session 6 over lunch. Questions focused on:

- participants' understanding of how their dementia currently affected them
- how they had applied any of the knowledge, skills and practical tools acquired during the course in their everyday lives
- the extent to which they felt they could be more active in their own self-care as a result of participation in the course
- about the experience of peer learning and support
- whether they had been able to share experiences of the programme with other people involved in their lives
- what had been most useful to them and if and how the structure, content and delivery of the sessions helped

With consent, all interviews were audio recorded and transcribed.

### 6. Data analysis

A thematic analysis of all observational and interview data was undertaken forming the basis of interim feedback (delivered mid-January 2017) and this report.

### 7. Ethical approval process

The evaluation was approved by the University of Brighton's Faculty of Health and Social Science Research Ethics and Governance Committee and complied with ethical research requirements of the Alzheimer's Society. A fully informed and detailed consent process was designed for the evaluation which worked well in practice. Participant consent was sought in advance of observation sessions and ongoing process consent was carried out at the start of each observation session. Individual consents were agreed with those participants who

took part in the focus group. Consent was secured from facilitators for both the observation and interviews.

### **Section two: Findings**

#### **6. Introduction**

The Chippenham pathfinder 2 was preceded by pathfinder 1 which ran for seven weeks between September and October 2015 and was held at the Alzheimer's Society offices in central Salisbury.

#### **7. Pathfinder delivery**

Pathfinder 2 ran between November and December 2016 and was held in a Methodist Church hall in Chippenham. The research team observed five of the six sessions delivered. Data collection was completed by mid-January 2017, following post course interviews with facilitators that month.

For ease of comparison, headings used in the discussion of findings below replicate, to a large extent, those used in the April 2016 report on the pathfinder 1 evaluation.

##### ***The programme participants***

Eight participants were selected and expected on week one. Five attended. The same five plus one other attended in week 2. In week 3 four attended which formed the group from then on. They were all men, ranging in age from 82 - 90. The length of time since diagnosis ranged from 2 to 6 years. They had all retired from professional occupations including engineering and accountancy. Music and sport were common interests. The facilitators were mindful of the different gender balance with this group compared to the pilot in Hastings and pathfinder 1 in Salisbury and that a male dominated group may be quieter (ie less willing to share feelings as had been the experience in the mixed groups). One of the two expected female participants attended the first two sessions, then withdrew from the course. She presented as lacking confidence and clearly struggled with hearing. She mentioned that she found it hard to speak in a group although was comfortable on a one- to- one basis.

Another male participant attended once in week 2. Whilst indicating to facilitators that he found the course interesting and potentially useful to him, physical health issues prevented him from attending further sessions.

Two other participants were unable to attend due to physical health needs.

##### ***Assessment and suitability***

The uncertainty and late decision to run a course in Chippenham had a major impact on assessment and recruitment. As time was limited, there was a balance to be struck

between recruiting enough participants to render the course viable and accepting only those who met the rigorous assessment of suitability. As Fiona, one of the facilitators, commented *“it was kind of weighing up what do we do?”*. Being in the early stages of dementia was recognised as a key criteria for recruitment to ensure participants could fully engage with the content and utilise it in the future, as Mike (facilitator) put it:

*‘the type of person I feel benefits from it is somebody who is clearly indicating that I know there’s something wrong with me, I know I’ve got a diagnosis but nobody’s really wanting to talk about it .. and every activity I go to we don’t talk about dementia ... that type of mind set, that curiosity gets an awful lot out of this programme’.*

Of the eight people selected for this course, it was felt that three met the criteria robustly. However, whilst the others recruited may not have met all of the criteria so strongly, recruiters felt that as a group they could move forward together and all benefit from the course. In the event it was unfortunate that three of those who best met the criteria, particularly in terms of being in the early stages of dementia, were unable to attend the course.

Prospective participants were identified via the dementia support team and an Independent Living Worker, allowing those who live alone to be identified and included. In most cases, people were interviewed face-to-face in their own homes, with one being interviewed over the telephone.

The experience of a rather rushed recruitment period reinforced facilitators’ belief that a three month recruitment window is necessary. Ideally a pool of around 20 people could be worked with to assess suitability allowing those who would most benefit to be identified and recruited. This time span would allow for repeated contact and assessment which would ideally include a social event allowing assessment of people in a group situation. In addition, facilitators note the need for continuity and the avoidance of a long gap between last contact and the beginning of the course.

### ***Physical space and environment***

The pre- course interview with facilitators highlighted their passion that participants should feel safe and welcomed. The venue for the course was a church hall. They noted the challenges this presented in comparison to the ideal circumstances in Salisbury, where one of the facilitators, Fiona, had co-led pathfinder 1, but demonstrated real commitment to addressing these. Screens were used to good effect, reducing a large space to a more intimate one that could be replicated each week. Continuity was assured by presenting flip charts from previous sessions in the same place on the screens each week to give the message *‘this place is yours’*. Participants quickly got into a routine of getting a drink and sitting in the same place each session, indicating their familiarity with the environment. For the first time, two volunteers attended throughout the course. They added greatly to creating a welcoming and warm environment, working hard to ensure all participants received attention and support from arrival to departure. They also acted as scribes, freeing the facilitators to concentrate fully on delivery.



It was recognised that those participants who live alone and who don't drive face a challenge in getting to a venue. Facilitators involved voluntary services and colleagues to address this. Fiona said:

*'Because .. we have more and more people who do live on their own that aren't necessarily needing help and support from a carer, just can't physically manage to drive a car anymore, but it's us making sure that they are able to come and participate'.*

### **Content**

The seven sessions were as follows:

- week 1, Living well with dementia (triangle and overview of what dementia is)
- week 2, dementia umbrella and 'bookcase' facts/feelings
- week 3, Health (triangle and introduction of scales)
- week 4, cancelled
- week 5 – feelings ( DVD about receiving diagnosis, relaxation exercise)
- week 6, support and communication (hot air balloon aid, picture of head, relaxation exercise)
- week 7, future support and planning

The content had been significantly reduced from the first iteration (the pilot) in Hastings and again after the Salisbury pathfinder 1 course, taking into account feedback from participants, facilitators and evaluators. However, in Chippenham, pathfinder 2, the facilitators had the opportunity to modify, add or leave out elements of the content, according to the needs or expressed wishes of the participants as the group progressed. Such adaptations require a commitment of time for planning sessions and debriefing afterwards:

*'I worked it out ... you need your delivery time and then you need your prep time, works out to be about seven hours' worth of time' (Mike, facilitator)*

Describing materials for the course as a 'tool-kit', facilitators valued the flexibility built into this iteration of the programme. They commented that it allowed greater consideration of what participants want out of it and how content could be delivered in a way that responds to the groups' needs: As Fiona said:

*'so having that power to be able to control what we were delivering because we knew our people and we knew what worked for them, worked really, really well.'*

James, a participant, commented that the facilitators were concise and easy to follow whilst another, Roger, commented that *'the pace is critical, I had no problem with the pace'* and that he valued that:

*'everybody was prepared to listen with nobody talking over people and being able to make suggestions, hear others' suggestions and have discussions ... 'Mike' (facilitator) would start the ball rolling with a question and we would answer individually'.*

As in pathfinder 1, visual aids proved very useful in demonstrating concepts. Participants clearly found them helpful and referred to them when engaging on topics. Alongside use of the 3D triangle and bookcase, the facilitators had worked hard to further adapt existing tools, such as the scales – building in movement – and to create new ones such as the hot air balloon for demonstrating support. Such tools encouraged people to work together as a group, at times helping to ‘lighten’ discussion of serious issues and encouraging participation from all members. As Brian, a participant noted *‘it would have been easy to do something where people would fall asleep!’*

Generally the sessions worked well, taking a particular topic and using it as a thread throughout. However, there were times when discretion could have been used to adapt delivery to ensure topics were introduced at an appropriate point in the session. For example, much of session 1 was taken up with introductions of both the course and each other. This was entirely appropriate and necessary. However, this resulted in the key topic (the umbrella image and information about dementia) being introduced at a late stage which did not allow participants to explore their understanding of the disease or their experience of it. This felt like a missed opportunity as the participants were clearly engaged and had begun responding and contributing. Given that receiving a diagnosis of dementia, even though it may have been anticipated, is deeply distressing, it may be received with a mixture of relief (knowing what is wrong) followed by denial (how do I know I really have it...?). In fact Stuart, a participant who attended only one session, spent much of the time questioning his diagnosis and repeatedly asking the facilitators how ‘they’ knew he had it. We feel that this topic should be introduced earlier in the session when the participants have an opportunity to discuss, express thoughts and feelings about the diagnosis and what dementia means to them, and be supported if they express strong feelings, such as anger and despair and even denial. This follows good group work guidance where topics likely to arouse strong and upsetting feelings are not normally addressed towards the end of the session when participants have to move back into the ‘everyday world’.

With regard to other sessions, both facilitators noted that the session covering support and communication should have been split into two sessions. They felt that both topics would have benefited from being explored in greater depth, with participants being encouraged to think about their own circumstances and relating discussion to these.

Another aspect of increased flexibility valued by the facilitators related to hand-outs. They gave these much thought, really questioning how they could best ensure the handout triggered memory of the topics covered. They were easy to follow and clear, capturing the key messages from the sessions covered. Participants welcomed them and found them easy to engage with. Fiona said:

*‘So we were quite picky and choosy out of the handouts that were on offer, what we handed out and how our handouts looked’.*

***Practical aspects of how sessions ran***

The sessions were well planned and the environment was consistent, warm and welcoming. Volunteers added greatly to the experience ensuring all participants received close attention whilst also stepping back appropriately to encourage participants to engage with each other.

There was one session that stood out to both researchers and facilitators as being less successful than the others. It was the second week and a new participant, Stuart, attended which changed the dynamic of the group. One issue was that Stuart was keen to cover content that had already been covered by the others in session one. He was a forceful character and asked many questions about dementia and the others in the group were very quiet. In an effort to welcome him into the group, a one-to-one conversation developed between him and one of the facilitators who was attempting to respond to his questions. The content of his questions was indeed relevant to the concerns of the others – left over from the end of the first week's topic concerning the diagnosis of dementia and what it meant. Understandably the facilitator wanted to respond to him, as he was new to the group but, in retrospect, the points he raised were relevant to the group and could have been shared, used as a stimulus for engaging others in this important and somewhat painful issue.

Feedback was sought throughout sessions and at the end. The tendency to use closed questions such as '*was that useful?*' '*did that make sense?*' invited limited responses of '*yes*' or '*no*'. The use of more open questions, such as '*what did you enjoy about that?*' Or '*in what ways was that exercise useful?*' would have given the opportunity for deeper responses. As it was, responses were positive with a few suggestions offered by participants such as writing larger on the flip chart.

### ***Use of the group as a resource***

The four core participants related well to each other. A key aspect of their communication was discussing health issues (not necessarily dementia related) and sharing experiences. On occasion, the facilitators skilfully encouraged participation on various topics by asking each member of the group in turn to contribute. This was effective in encouraging exchanges between members, often based upon the sharing of advice or tips on how they deal with issues. An example of this was James's use of a daily journal as an aide memoire. Often, discussions started during the session would continue over the break.

### ***Facilitator training and delivery***

One of the facilitators, Fiona, was experienced in delivering the programme. The second, Mike, was a very experienced Alzheimer's Society trainer but was new to delivering this programme. Mike was aware that that the *Live Well with dementia programme* was substantially different to others delivered by the Society and was in development. Both facilitators undertook two full days of training, which they recognised as a major investment in the programme by the Alzheimer's Society. Mike in particular welcomed the opportunity for training as he acknowledged his lack of experience of delivering a programme aimed solely at people with dementia rather than to carers or mixed groups.

The training focussed on familiarisation with the content of the course, adaptations that had been made since pathfinder 1 and methods of delivery. Fiona, who had delivered the course previously, was gratified to observe that changes to the content reflected facilitators' input to the programme:

*'I thought it was really good so I feel very positive about this because I see all the changes that have been implemented and I see it is a work in progress but we're close, it's so much better than it was'.*

In addition to the training, facilitators commented that they felt very well supported and that trainers continued to be accessible if needed.

The welcomed refinements to the programme and subsequent reduction in content opened up opportunities for reflection on modes of delivery and skill development. The facilitators were very aware that encouraging greater interaction among participants was a recommendation resulting from the evaluation of pathfinder 1 and were working towards this. However, our observations of pathfinder 2 at the Chippenham site suggest that there continued to be missed opportunities for encouraging participant contributions particularly in relation to picking up on what had been said and building on it with the group. Facilitating this kind of group is a highly skilled process, often operating at the boundary between a learning group and a therapeutic group. If the Alzheimer's Society wish to progress the therapeutic element, some training in group dynamics for facilitators might support them in their work as well as enabling participants to feel more secure.

Facilitators' noted the need for such training: Fiona said:

*'the facilitator would have more confidence ... it doesn't matter what the content is that you're delivering but you need to be a person who can keep the group together and keep them going in the right direction'*

Mike commented: *'there is potential for a lot to go wrong, so you actually do need somebody who people can connect with real quickly, feel safe with'*

Notwithstanding training issues, the attitude and approach of facilitators is key, as noted by Roger, one of the participants who talked positively about them in terms of 'personality'. The committed and respectful attitude of the facilitators stood out. They emphasised the importance of ensuring participants felt 'safe' and 'welcomed' and Fiona commented on feeling privileged when participants shared their feelings and experience, demonstrating an understanding of the participant perspective:

*'it's always a privilege when people are happy to share their experiences with you, and I always feel very privileged that they are happy to do that in a group setting that they've probably never been in a group setting before, let alone shared anything personal with anybody'.*

Participant feedback demonstrated that they valued the facilitators' approach, noting that they felt listened to and comfortable asking questions.

### ***Involvement of carers***

*'what we don't realise is that for a lot of people who have got the diagnosis they get deskilled through love and sometimes it's a lot easier to just roll over and go 'yeah, alright' and go with the flow. And do you know the people this course impacted, which we didn't see coming, was actually the carers ... couldn't see it coming because we're so focused on person with dementia' (Mike, facilitator)*

Experience from this course indicates there would be benefit from greater involvement of carers of participants at the recruitment stage. This would increase their understanding of the programme's aims, content and mode of delivery and invite consideration of potential impact. Facilitators recounted two examples. In the first, the wife of Norman, a participant, fed back to the facilitators that she'd observed changes in her husband's behaviour following early sessions and was finding this challenging, questioning whether he should continue to attend. The facilitators were able to explain that he was experiencing something new, perhaps something he didn't realise he could do. The carer seemed to increase her understanding and agreed to encourage and support her husband to attend. He attended every session of the course:

*'I do think it may need to be at interview stage, that this is identified to carers that this can happen and that it can affect the person and their behaviour ... because obviously it's changing their routine, it's giving them a lot of things to think about, we're asking them to dig deep, talk about their feelings, talk about their emotions, talk about their diagnosis, so with that in mind I do think maybe at interview process that carers need to be aware of this' (Fiona, facilitator)*

The second interaction was with the husband of a participant who left the course after attending two sessions. He cited how he was struggling with his wife's different behaviour at home and, in the opinion of one facilitator, Mike, encouraged her to withdraw from the course:

*'if the carer had more understanding about the possibilities of what might happen, and if this does happen maybe this is why it's happening and can we work through that because this could just be a little blip, as opposed to pulling out.'*

Facilitators note the destabilising effect that people leaving has on the group. One suggestion for enabling greater contact was to ask dementia support workers to liaise with the carers regularly throughout the duration of the course, opening up opportunities to identify issues and to work through them with the support workers if necessary.

A longer period for recruitment would help facilitate carers briefing on the nature of the *Live Well with dementia programme* and a clarification of what all parties might expect from the experience.

### ***Overall impact***

The high level of attendance of the 'core' group is an indication of participants' engagement with the course. Disappointment was expressed by participants following the cancellation of a session or not being able to attend due to other commitments. The participants were active within the sessions with body language indicating engagement and enjoyment by smiling, laughing, leaning in to hear properly, nodding in agreement, reading hand-outs etc.

As with previous courses, participants cited mixing with other people and belonging to a group as enjoyable and beneficial:

*'it was valuable, nice meeting people with the same condition'* (Roger)

Mike, facilitator, observed that the participant who seemed at times to 'disassociate' kept coming:

*'He was enjoying the peer support group. He was enjoying the fact of just being in the room, being part of something. I think that whole exercise woke something up in him'*

### **Co-design and feedback process – pathfinder 2**

The Chippenham pathfinder 2 course was the third iteration of the programme evaluated by the team from the University of Brighton. It was made clear to participants at recruitment, and also in the first session, that their feedback was highly valued and would contribute to the further development of the programme. Feedback was sought after each substantive element of the course. The participants did not offer detail but indicated they found the content accessible, interesting and relevant.

The impact of the co-design and 'pathfinder' approach has led to significant adaptations of the content of the programme. Fiona, the facilitator who has been involved in earlier courses, notes:

*'it is quite nice that you can see that we have added to the programme and that they're actually using the things we've suggested, and that the programme is going into something that we can actually see now working ... because we were doing a lot of tweaking, especially in the first one, the second one was still quite a lot of tweaking but not as much and we're finding we're not tweaking as much now, still a little bit here and there but not as much.'*

Moving on from a previous focus on the evolving content of the course, the key issues that pathfinder 2 in Chippenham highlighted were recruitment and facilitator training, discussed above.

## **Section three - Conclusions**

The evaluation set out to answer three questions about delivery:

4. To what extent is the *Live Well with dementia programme* successful in providing knowledge, skills and practical tools in ways that can support people with dementia to be more actively involved in their own self care?

The greater flexibility of this course confirmed that dementia affects individuals in different ways and that by tailoring the course to the participants' needs there may be many different outcomes and ways in which participants become or continue to be involved in their own self-care. The fact that the facilitators were able to adapt content and pace and to be mindful of the group process showed that this course has the potential to be helpful both to those who have achieved a measure of 'success' in living well with dementia as well as to those who are yet to find ways to manage their lives 'after dementia'.

5. To what extent does the timeliness of the *Live Well with dementia programme* to the individual situations of the participants (i.e. length of time since diagnosis/onset) impact on their overall experience and their ability to benefit/or not from participation?

Findings from this Pathfinder demonstrate the importance of adequate time to allow robust recruitment. Within the short time-span available for recruitment, a total of eight participants were invited to join. They varied in terms of stage of dementia and unfortunately, of the three candidates considered the most likely to benefit from the course, one attended only once and two not at all due to other medical conditions. One other candidate attended the first two sessions only. The four core members of the group were all men in their late eighties and nineties. Observations and feedback from these participants indicated that there were high levels of engagement with the content and the facilitators. All agreed that they greatly valued meeting other people in a similar situation to themselves, '*realising there are other people who face similar problems*' (James). Roger particularly welcomed the chance to have questions answered, express his opinions and hear those of others and to gain insights to what he could expect from the future. James described the group as providing a '*support system*' and expressed disappointment following the cancellation of a session as the course was part of his structure. The majority of these participants cited the chance to share experiences and offer others support as being important. This links to the attitudes held about dementia. There was a level of acceptance which manifested itself in one as resignation and a coping strategy of '*you've just got to get on with it*' (Brian) and in another as '*there's nothing can be done about it ... I don't spend all my time thinking about having dementia*' (James).

Participants paid attention to the hand-outs distributed throughout the course and brought their folders to each session. When asked about their usefulness, they commented that it was good to have them there if they needed them.

6. Are there ways in which the delivery content and/or style could be improved or made more appropriate?

We welcomed the increased flexibility of the programme in which participants had plenty of time to bring in their own thoughts, feelings and contributions about their experiences without feeling time pressure. The facilitators adapted the content being aware of the

importance of giving time and space. With a smaller group this was perhaps easier but overall we feel flexibility is a most important element. We thought the increased use of props, including 3D ones, to be excellent and was much appreciated by the participants. Using power point was also important, lending a professional air to the proceedings. In order to increase facilitators' confidence and skills, further training related to group facilitation and group dynamics would be beneficial. Facilitation of this programme, which includes some elements of a therapeutic group, requires particular skills which would enable the facilitators and participants to feel secure.

### Section four – Recommendations

It was evident that changes and improvements had been made between the pathfinder 1 course delivered in Salisbury and Chippenham pathfinder 2, with those involved in development and delivery taking and using feedback from the external evaluation as well as through their internal feedback processes. This is to be welcomed. The Evaluator team found significant and effective changes were made, building upon the adaptations already implemented at the first pathfinder (Salisbury).

The areas that we consider would benefit from more consideration are as follows;

#### Pre-delivery:

- An adequate amount of time and resource for recruitment, ideally three months. This would facilitate identification of a pool of possible candidates, a trial group activity and time to engage actively with carers.
- Additional training for facilitators on group facilitation skills (including an element of therapeutic group facilitation)
- Bearing in mind the rural locations in which many participants live, allocation of budget to cover transport where needed (and therefore equity of access) and for securing appropriate venues.
- Appropriate timing of courses – avoid winter / Christmas periods as increased likelihood of health issues impacting on attendance.

#### Delivery:

- An allowance of hours for facilitators to debrief and plan which enables tailoring of content to particular needs of the cohort.
- Introduce challenging material (such as receiving a diagnosis of dementia) near the beginning of a session to allow sufficient time for discussion and expression of thoughts and feelings.



## Appendix 6

- Bear in mind that some participants may have visual and hearing problems and make provision for them. For example, ensure that when writing on the flip chart it can be seen by everyone in the group; likewise ensure that everyone can hear facilitators and fellow participants.
- Use of dementia support workers to stay in contact with carers throughout the course in order to offer support in understanding and coping with potential changes to their relationships with the person with dementia and thereby help avoid participants leaving the group.

We would like to thank all the participants in pathfinder 2, the facilitators and volunteers, and the Alzheimer's Society for their cooperation and support in enabling us to conduct this evaluation in a comfortable and friendly environment.

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28<sup>th</sup> February 2017

### Example feedback from Alzheimer's Society *Live Well with dementia* course facilitators (March 2017)

#### Hull feedback:

- Participants wanted something that was 'just for them'
- Programme gave them 'new found confidence'
- Group continue to meet each Tuesday
- The essence of the thinking behind the group – Living Well with dementia - has always stayed
- With memory cafe's volunteer, the group now vote on afternoons out and plan to venture out of Hull .....

#### Brighton Feedback:

*"Coming to the group has given me confidence to talk about my diagnosis and I feel like I'm part of a club and not on my own ... I went to Waitrose the other day for a coffee .. and I joined a gentleman sitting on his own and sat down to talk. Another man sat down to join us, we sat there for hours just chatting, I never would have done this before."*

*"I am no longer frightened by Alzheimer's disease and I have learnt to see a 'bad day' as simply that, a bad day".*

*"it was such a positive experience being around other people with dementia that I wanted to continue this by going to the Hop 50+, I have learnt that having dementia isn't the end of the world like I thought it was when I was first diagnosed"*

#### Chorley feedback:

*"one participant became aware of the right time to request support from adult care services and said the programme gave him the confidence to do this .. he has been confident to call his GP to discuss his health needs and has requested support from the Alzheimer's society to help him to explain his care needs/preferences during assessment. The participant said he feels like he is keeping control, something he was very worried about prior to attending the programme."*

*"2 participants regularly attend café and have said they would never have considered this without having been on the programme"*