

## What should be in a self-management programme for people with early dementia?

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**Objectives:** First, to use participative research methods to obtain views from people with dementia and carers about their experiences and the interventions that they consider can assist in facilitating independence and quality of life post diagnosis. Second, to use these views to identify priority topics for a potential self-management programme. Third, to explore the relevance of the identified topics with a consultation group of people with dementia and their carers, thus informing the creation of a draft self-management programme.

**Method:** A series of individual and dyad interviews were conducted with people with dementia and family carers to explore their experiences post diagnosis and obtain views of how quality life can be maintained while living with dementia. A further group of people with dementia and carers then met over six successive weeks to explore and provide feedback on the topic areas generated out of the initial interviews and add to the content.

**Results:** Data generated from the individual interviews identified a number of themes for a potential self-management group which were then validated through consultation. Optimum modes of delivery of a self-management programme were also indicated.

**Conclusions:** A draft programme has been constructed building upon the framework of identified priorities. The process and outputs from the consultation also indicated the significant ramifications of such a programme for services.

**Keywords:** dementia; participation; consultation; self-management

### Introduction

This article describes a series of interactions with people with early stage dementia and carers which informed the priority topics for a programme of self-management interventions and how this might be delivered in practice. As well as determining the framework for such a programme, the process also uncovered significant insights regarding the real concerns that living with dementia creates and how this impacts upon quality of life, both for the person with the condition and their family carers.

### Background

Dementia is one of large number of long term conditions. The UK Department of Health (DoH) estimates that almost one-third of the population has a long-term health condition, accounting for 80% of all primary care visits (DoH, 2008). Similar patterns are reported globally with incidence rising (Nolte & McKee, 2008). Therefore, identifying solutions to the challenge of ever increasing service demand in the face of finite resources is a pressing goal for health policy and for economies.

Self-management, where the individual with a long-term condition is encouraged to learn to manage their health and identify solutions to meet their specific needs is being promoted as an attractive, workable solution which can enable people to retain

independence and quality of life and as such is a significant policy driver (Singh, 2008). This has led to the promulgation of both generic and condition specific programmes, the majority of which are modelled upon the Chronic Disease Self-Management Programme where groups of people are trained by a lay person, who usually has personal experience of living with the same long-term condition (DoH, 2005; Lorig & Holman, 2003). However the term 'self-management' is subject to an ever increasing range of policy and practice interpretations; for example, Kendall, Ehrlich, Sunderland, Muenchberger, and Rushton (2010) identify three alternative contextually related understandings; the first is where self-management is concerned with resource allocation and rationing, the second is where self-management is orchestrated through professionals and a third where it is wholly located in the experiences, needs and aspirations of the person with a long-term condition. There is growing awareness that the Chronic Disease Self-Management Programme may not meet the needs arising from all long-term conditions and particularly those of people with specific complex problems (Kendall et al., 2010). As consequence programmes which contain other interventions and include alternative modes of delivery are also promoted as being self-managing and apart from education (which is the acknowledged cornerstone of self-management), there is continued debate about optimum programme content. For example, Weingarten et al. (2002) identify

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a combination of education, feedback and reminders for both patients and health care providers and financial incentives for those individuals who achieve treatment related goals, whereas Chodosh et al. (2005) propose personalisation, delivery of interventions in a group setting, provision of individualised feedback, a psychological component and medical involvement.

Despite the policy push underlying the promulgation of self-management programmes for long-term conditions, it is only recently that there has been interest in how the construct can be applied to people with dementia. This change has been prompted by a number of significant policy led initiatives for example, DoH (2009) and National Institute for Clinical Excellence (NICE, 2006).

Self-management of dementia requires the individual to understand the illness and use strategies to cope with their symptoms, so that independence can be retained for as long as possible. It draws on the potential that a person has to retain skills and abilities and, as a consequence, maintain activity and relationships with others, including with their communities. Taking steps to ensure continued physical and mental wellbeing are also integral to successful self-management (Mountain, 2006).

There is a growing body of evidence to demonstrate that individuals can be supported to maintain their skills for longer and build resilience (Clare & Woods, 2004; Graff, Vernooij-Dassen, Thijssen, et al., 2006; Graff, Vernooij-Dassen, Zajec, et al., 2006; Moniz-Cook & Manthorpe, 2008; Vernooij-Dassen & Moniz-Cook, 2005; Vernooij-Dassen & Olde Rikkert, 2004). Evidence also demonstrates that hobbies and interests are compromised early on in the disease process (Muò et al., 2005) and there are interesting questions regarding whether self-management strategies might ameliorate this.

Meeting the needs of people with dementia through the Chronic Disease Self-Management Programme (or UK derivative; the Expert Patient Programme; DoH, 2001) would be limiting due to the prescriptive delivery style and lack of personalisation within the programme which the original authors rationalise as enabling participants to take forward their own learning (Lorig & Holman, 2003) but would not be helpful for people with dementia. The format of an existing, provenly effective occupation based health promoting programme for community living older people (Clark et al., 1997; Craig & Mountain, 2007) was identified as potentially providing an appropriate alternative framework. This involves facilitators guiding the group to select topics of most relevance to them from a menu of possibilities, with the menu being derived from the needs of the population for whom the programme is intended. Participants are engaged over a number of sessions through a mix of didactic teaching, peer sharing and active experimentation with individual sessions also being woven into the programme (Craig & Mountain, 2007; Mountain et al., 2008). In common with the Chronic Disease Self-Management

Programme, this Lifestyle programme is located in social cognitive theory with the aim of increasing self-efficacy in those who participate (Bandura, 1997). The project described in this article sought to examine whether this programme format is appropriate for people with dementia and their carers. A number of associated issues also warranted examination including how to manage situations where people are not able to be independent participants including a consideration of appropriate levels of carer involvement.

### Project aims

The aim of this project was to work collaboratively with people with dementia to obtain insights that would inform potential intervention topics for inclusion in a self-management programme. By necessity, this included exploring how to most appropriately ascertain and represent the views of those who volunteered to participate, taking into account the possible existence of communication difficulties that can be a consequence of the dementing illness. A further goal was to begin to identify what might be the optimum modes of delivery of such a programme.

For the purpose of this study, we use the term 'carers' mainly in the context of spousal caring but in some instances, the term also refers to a son, daughter or close friend identified as being in a caring role by the person they were caring for.

### Methods

Prior to study recruitment, university ethical approval was obtained. Given the desire to work with people with dementia and their carers on their own terms to create a framework for a self-management programme with them, participatory research was considered to be the optimum methodology. This locates power with the individuals who participate, enabling them to set the agenda and own the results. It requires researchers to respect participants and the knowledge that they bring to the process (Cornwall & Jewkes, 1995). The benefits of this approach are described thus;

One way to help a person with Alzheimer's disease construct a worthy, valued, social persona is to engage the said person as a collaborator in research efforts... that we may find some pathways not only toward providing people with another means by which to construct worthy, valued, social identities but also toward the unearthing of new knowledge and perspectives about the nature of Alzheimer's disease. (Sabat, 2003, p. 10)

### The first phase of consultation

The first phase involved speaking to a range of people with dementia and their carers about their experiences of living with the illness and the interventions that they consider to be important and helpful soon after diagnosis.

In accord with the spirit of participatory research, recruitment was not pursued through statutory services. This also avoided professional gate keeping which can involve third party decisions regarding whether a person with dementia is capable of contributing (Gilliard et al., 2005). It entailed collecting only minimal demographic details from participants.

Local and national voluntary networks were approached in person by the second author. These included members of the Scottish Dementia Working Group and the Alzheimer's Society. The aims of the study were explained and they were asked to approach people with early stage dementia that they came into contact with to invite them to participate. We did not aim for a representative sample of participants as the goal was to inform an initial framework for self-management which will be both populated and extended over time. The only inclusion criteria was that the person with dementia had to be in the early stages of the condition, and therefore able to volunteer themselves independently, and their nominated carers also had to be willing to participate. The goal was to recruit a maximum of 12 participants. Ten individuals (five people with dementia and five carers) volunteered.

The participants with dementia were given a choice of whether they wished to be interviewed with their carers or separately to them. This resulted in three of the five resulting interviews with people with dementia taking place with carers, and four individual interviews; two with people with dementia and two with carers. Arrangements for interview were agreed informally; for example, the person with dementia might say;

Do you mind if my wife stays? or

I don't like to be out on my own.

It was not possible to ascertain whether these requests were as a result of loss of confidence or at the request of the carer.

A topic guide for interview was developed out of the evidence base combined with researcher knowledge of dementia and self-management (Mountain, 2006). It was devised to explore the experiences that people could recall post diagnosis and included the following themes: diagnosis, facing and managing challenges, experiences of support, quality of life including participation in leisure and recreation, and information and interventions that would have been helpful following disclosure. The same topic guide was used with people with dementia and with the carers who participated. All interviews were conducted in familiar environments at a setting requested by the person being interviewed. In the case of joint interviews, the preferences of the person with dementia were prioritised. Four of the interviews subsequently took place in public venues which included cafeterias, and a local college. One person initially chose to communicate *via* e-mail and this was followed by an interview at their house. Permission was sought to take notes throughout each

interview rather than audio recording which would have limited venue choice and information sharing. All interviews were conducted by the second author.

It quickly became evident during the first interview that the capacity that a person with dementia might have to remember the questions they were being asked, maintain attention on the question and articulate their response could easily be compromised. The work of Allen (2001) was used to inform techniques to stimulate communication and interaction. A series of cards containing questions from the topic guide were devised to provide a focus and give prompts. Interviewer notes were also shared with the participant throughout to give the person a visual reminder and a further prompt. This combination of strategies worked well.

### *Analysis of data from the first stage of consultation*

Interviews from the first phase of consultation were analysed using framework analysis (Ritchie & Spencer, 1994). This enabled the development of a matrix of themes and related sub-topics from the data as well as identification of the links across themes, different participants and venues.

### *Findings*

#### *Diagnosis and the experience of subsequent interventions*

The timeliness of diagnosis and the availability of appropriate services following diagnosis were key factors in determining how well individuals coped with receiving the news and managing the consequences in the following weeks and months. In total, six of the 10 interviewees (both people with dementia and carers) spoke of living with the symptoms of dementia for months or years before the diagnosis was confirmed. For one person with dementia, the lack of explanation for changes in their behaviour had almost led to the breakdown of their marriage and other close family relationships.

One of the most consistently reiterated issues was the availability and appropriateness of support offered following confirmation of diagnosis. Three of the five carers (who were all spousal carers) recounted experiencing agonising delays between obtaining the diagnosis and receiving offers of support and/or referral to other services. One person with dementia described feeling as though they were on a 'threshold'; aware that there might be support and information but not knowing how or where to look. The sense of urgency created out of awareness of the impact of deteriorating memory combined with fear of further decline was graphically described by two people with dementia, who were both offered services following diagnosis at locations, a significant distance away from their homes in new and unfamiliar environments. They both described how this led to additional stress and emphasised their eroding independence as they had

also been advised not to drive, and therefore required assistance to access the service.

#### *Information provided to people with dementia*

The majority of people with dementia considered that information provided following diagnosis was aimed predominantly at their carers. They described how this had increased feelings of powerlessness and helplessness. At a time when they needed support as individuals in their own right, the majority of assistance was aimed at family members. There was also an articulated perception that carers might be privy to significant information that the people with the diagnosis were not allowed to hear. Two people with dementia described feeling guilty that their partner had to accept added responsibility because of them. Two others had a very different perception, expressing the view that the service focus upon carers served to reinforce a shift of power in their relationships.

One person stated;

He is in complete control and is loving it.

Another person said of her husband,

He chooses exactly what I wear and where I go. I am like a little doll.

It was impossible to determine through this project whether these statements were as a result of long-standing unsatisfactory relationships or had been created out of the stress of living with dementia.

#### *Carer perceptions of available support*

The carers, we spoke with, described the strengths and limitations of various groups and interventions that they had been invited to participate in. While there was overall agreement that discussion and support are helpful in the initial stages following confirmation of diagnosis, the majority of those interviewed felt that many of the groups they attended were 'just about talking in circles' and that a more proactive approach was required where different 'strategies and things to try' were offered.

In the words of one person;

We've had enough sitting and talking – we want action.

#### *Managing dementia alongside other conditions*

Dementia was one of a number of long-term conditions that people with the diagnosis were living with. Examples of co-morbidities included arthritis, high blood pressure, heart disease, cancer, sensory impairment and depression. A lack of help with managing combinations of symptoms and treatments was described. As one person described;

It is hard enough getting dressed never mind putting one of these [pointing to splint on hand] on here.

#### *Managing unexpected symptoms*

Areas of concern were raised which tend not to be acknowledged. One symptom that participants described that they had not been prepared for was addictive behaviour such as increased cravings for cigarettes, alcohol or chocolate.

Another area was sex and sexuality which remains a taboo subject for many older people. This was raised by two people with dementia and by one of the carers. They described being aware of changing relationships but were fearful of the consequences of discussing intimacy. One person with dementia described how, when in a situation of particular stress they had momentarily mistaken a friend's child for their partner. Another person, (a carer) said that a paid carer had told him that engaging in a sexual relationship with his wife of 40 years was tantamount to abuse. In the absence of appropriate outlets for discussion and support, these events had caused stress and anxiety.

#### *Maintaining meaningful roles*

Maintaining a role outside the family which did not involve 'dementia' emerged as being an area of significant need. Two people (both of whom had been diagnosed with dementia for a significant period of time) were clear that the key to feeling well and retaining self-esteem was maintaining a regular volunteering role with external organisations. One person sorted clothes for a charity and the other assisted with an allotment society. One of them said;

It's the one time that people treat you like a person, it gives you distance you know.

#### *Interventions and modes of delivery to meet needs*

All those interviewed considered that following diagnosis, interventions that might be easily accessed at a time and place convenient to the person, preferably within the locality or at the GP surgery. There was also general agreement from those with dementia that, despite potential conflicts, separate groups for people with dementia and for carers are the best forms of delivery. These views are illustrated through the following quotes.

I think, and it is a personal thought, not an official one, is that carers and people with dementia should have their own distinct groups.

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 confidentially 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.

So you see the dilemma. Free speech, honest dialogue and thoughts can be constrained through no fault of anyone. Each wanting to protect the other. Do you without dementia speak differently when your partner is in the room? Yes!! Well we are no different.

### Using the interview data to identify priorities for a self-management programme

A number of potential topics for a self-management programme were readily identifiable out of the interview data. These included communication, relationships, understanding the condition and its different manifestations, keeping a sense of self, managing memory, maintaining wellbeing through meaningful activity and keeping connected. The topic list created out of the interviews was enhanced with some elements from the existing Lifestyle Matters programme (Craig & Mountain, 2007); for example, the impact of co-morbidities raised during the interviews was included within a topic of maintaining physical health. This led to 12 topics being identified for the draft programme, each containing a number of elements.

### The second phase of consultation

The second phase of consultation involved a group of people with dementia and their carers. A local branch of the Alzheimer's Society was contacted to seek permission to involve their membership in a consultation. Members were approached in writing by the Alzheimer's Society on behalf of the researchers to invite them to take part in a series of group meetings where they would be involved in providing feedback on the ideas which had emerged through the initial interviews.

Fourteen people agreed to participate (seven people with dementia and eight carers). However, one person was subsequently accompanied by both parents, leading to a group of 15. With the exception of one person, all participants with dementia had received a diagnosis at least six months previously and some individuals had lived with the diagnosis for over two years. Some members knew each other previously and others knew no one.

Table 1 provides a summary of participants.

### Methods used for the consultation

A six-week programme of group consultation commenced January 2009 to further explore what might

assist people post diagnosis, enhance the list of elements and topics identified through the interviews and also consider how a programme of interventions might be delivered. The format for delivery mirrored that of the Lifestyle programme (Clark et al., 1997; Craig & Mountain, 2007). As previously described, this involves facilitators guiding the group to select topics of most relevance to them from a menu and then assisting participants to explore the issues they provoke using a mixture of techniques. As before, methods used to enhance interaction with people with dementia were employed (Allen, 2001).

Participants decided that the group should meet during the early evening (when it was easier for family members to transport them). Weekly groups were facilitated by the second author in partnership with a final year occupational therapy student and a volunteer from the Alzheimer's society, both of whom were fully briefed. Each session was approximately two hours long including several breaks. Despite poor weather and potential difficulties with accessing the venue (a local church hall), all 15 people attended for the full six weeks.

Whole group discussions were encouraged but plenty of opportunities were also provided for small groups involving a mix of people with dementia and carers as well as separate groups of people with dementia and carers.

During the first session, participants were invited to identify their priorities. Word cards with the themes identified out of the interviews (including prompts) were used to facilitate discussion, with individuals being invited to add their ideas in small self-selected groups. For example, to expand on the theme of information; 'I'd like to understand more about...' To explore retaining interests; 'I'm interested in...' Other cards explored themes such as 'friendships', 'practical ideas about coping with dementia', 'communication' and 'relationships'. Facilitators aimed to promote participation in a safe environment. By the end of the first session, a consensus of topics for the subsequent group sessions had been reached as well as the order that they would be explored in. These were: (1) communication which included understanding dementia, (2) rethinking dementia, (3) living with dementia (with a particular focus on strategies to manage memory), (4) relationships, (5) keeping mentally well, (6) experiencing wellbeing and (7) keeping physically well. The final session also included a discussion of 'what next.' Discussions were recorded on flip-chart paper, providing a visual account which was revisited on a weekly basis.

To promote continued engagement with the process from week to week, a programme for each successive week was posted to participants.

Thereafter, at the commencement of each session, group members were greeted with time for coffee and for discussion. This provided a space for orientation and support and offered the participants opportunities to share the challenges they had faced during the

Table 1. Consultation group participants.

Person with dementia	Gender of person with dementia	Participating carers
Participant one	Female	Son and sometimes daughter in law
Participant two	Male	Wife
Participant three	Male	Wife
Participant four	Female	Both parents
Participant five (diagnosed only the week before)	Male	Wife
Participant six	Female	Husband
Participant seven	Male	Wife

preceding week. They were also encouraged to reflect on the previous session, share any ideas they had put into action and the outcomes. Following this, the facilitators and all participants (people with dementia and carers) were asked to share the challenges that the topic for the current session provoked and the information that they might find helpful to enable improved coping. The facilitators then delivered a short didactic information giving session in response. Participants then moved to smaller groups of three or four as directed by the facilitator (which might involve separating users and carers or mixed groups) to further explore the issues concerned with the topic and to share coping strategies. A range of mechanisms were introduced over time to stimulate participation including use of short narratives, objects and images. One example involved participants being invited to bring an object or picture with them to describe a favourite hobby or pastime. The facilitators worked with the groups and then used the time at the end of the session to collate the subsequent ideas and responses.

All discussions were recorded on flip-charts to provide a visual record of progress. Both facilitators also maintained their own reflective diaries of the process. These were stored securely.

Time constraints meant that it was not possible to explore all the topics within the draft programme.

#### ***Using the consultation group findings to further inform the contents of the draft self-management programme***

The final list of intervention topics within the draft self-management programme and the elements they might include is given in Table 2.

No new topics were identified to add to the draft programme with the experiences recounted by group members mirroring the underlying issues and needs described by those who had been interviewed. However, the range and depth of elements within each were expanded.

The overall consensus was that services following diagnosis are very patchy. Only four people (two people with dementia and two carers) said that they had been pleased with the speed and quality of input and information they had received. Others had waited for weeks and in some cases, months and had been given very little information. Reiterated concerns also included the impact of dementia upon family relationships with the majority of people with dementia considering that information provided following diagnosis is aimed predominantly at carers. Even though the carers were less convinced by this, a number spoke of the need for time away from their partner and the potential benefits of being able to ask highly sensitive questions without fear of causing distress for the person they were caring for. Two people spoke of wanting to 'check out' whether they were doing the right thing and considered this to be more difficult with their partner present.

Managing physical illness alongside dementia and the lack of responsiveness of service providers in this respect engendered discussion, as it had for those who were interviewed. Once again, there was also conversation about taking on smaller, additional roles which might be within the family such as looking after pets and the importance of keeping contact with a world 'outside dementia'.

#### ***Testing out methods of delivery***

A menu led form of delivery was tested, whereby participants are offered simple choices from a number of pre-selected themes and where interventions are tailored to the expressed needs of the group or of individuals. Participants considered this to be a highly desirable form of delivery. They also spoke of the need to establish a positive group atmosphere and instill hope. Comments such as the following were common:

Give the person with dementia some hope to cling onto. Show them that dementia makes you change your life but you can still be happy and productive.

Table 2. Topics within the draft self-management programme.

Topic	Dimensions
Understanding dementia Rethinking dementia	Full and timely information about the condition and what to expect Dementia as part of a process of change, health, wellbeing and activity, enabling environments
Living with dementia Relationships	Making the most of routines, memory maintenance, strategies to manage memory loss Building and maintaining friendships, husbands, wives and partners, rediscovering relationships
Keeping mentally well Experiencing wellbeing Dementia and daily living Keeping physically well	Recognising and overcoming depression, managing anger, managing anxiety Volunteering, hobbies, leisure Using everyday technology, managing finances, home and community safety Eating and nutrition, sensory impairment, developing healthy bladder and bowel habits, managing medication, sleep, managing fatigue Managing other physical conditions
Building and developing skills Keeping connected	Grading activity, problem solving strategies, learning new skills Maintaining community connectedness, accessing outside opportunities, transport and driving
Maintaining a sense of self Planning for the future	Dressing and identity, self-esteem, spirituality, keeping faith

Solutions to the challenges of working with people with dementia were posed by the group; for example, putting bite sized pieces of information on video, disk or audiotape; so, it is readily accessible to those who have difficulties with reading, processing and recalling information. When discussing the difficulty of sharing information with individuals who may still be at a point of denial one person with dementia suggested the use of stories and short narratives so that group members could relate to the content at a level they are comfortable with.

### **Facilitator reflections**

The experiences of the facilitators recorded in reflective diaries highlighted the complexity of the relationships between the person with dementia and their carer. Facilitators found that they had to be highly sensitive to the prevailing mood and abilities of all participants and ensure that dependences were not created. It was also important to manage a balance between not raising expectations or minimising difficulties while at the same time offering hope and not limiting potential as a result of personal preconceptions.

In addition to having to manage anticipated behaviours such as lack of concentration and poor recall, the impact of concrete thinking upon the group process was noted. Participants wanted clear structure and the use of objects rather than abstract discussion to assist with recall. Facilitators also had to use practical strategies as necessary.

### **Discussion**

This project represents the first stage in the development of a self-management programme for people with dementia. Future work will involve adding to and refining contents of the programme and continuing to explore modes and methods of delivery. Future questions include who is best placed to deliver this programme. Experiences described through the consultation highlighted a need for skilled facilitation, suggesting the value of professional involvement and the potential need for training for delivery in practice but this warrants further interrogation.

Whether the identified topics can be adequately customised to meet the heterogeneity of needs of people with early dementia and their family carers also needs further investigation. The level of detail that individuals were able to provide regarding the nature and extent of prevailing needs a self-management programme that might address as well as the potential complexities of delivery (including the practicalities) was unexpected. Nevertheless, the limited numbers of those involved in this first project is insufficient to finalise programme content or be confident about the delivery methods.

Identifying methods of working with families and carers so that the voice of person with dementia is

heard and their needs are balanced with those of their carers in ways that do not compromise the caring relationship is of particular importance. Given that up to 80% of dementia care is provided in the home by family members (Walker, 1995), it is important to appropriately involve carers in the development of self-managing skills alongside the person they care for. This has been less extensively addressed in existing self-management programmes but it is of particular significance for dementia given the frequent extent of carer involvement. A diagnosis of dementia can serve to deepen the gulf between person and their partner and is an area that it is already recognised as requiring further exploration (Quinn et al., 2009).

For service providers, improved timeliness of diagnosis leads to questions regarding when active interventions should be introduced following disclosure, particularly given the impact that stress can have upon symptom exacerbation. Timeliness of diagnosis, the varied symptoms experienced by people with dementia as well as well as the frequent existence of co-morbidities mean that the tailoring of any programme to meet individual needs is essential. The menu based nature of the self-management programme developed through this project with its individual as well as group components should address the need for personalisation but it does require testing in practice.

From a methodological perspective, evaluating the efficacy of the final programme will be demanding. At this point, we have some anecdotal evidence of positive ways in which the ideas and techniques have impacted on individuals but careful consideration needs to be given to how rigorous evaluation might be conducted. This is particularly important given the vulnerability of those who are involved. Thus, there are significant future challenges for researchers in developing and evaluating a self-management programme for people with dementia.

### **Conclusions**

Introducing self-management for people with dementia has far reaching implications for services and for society. It involves moving beyond a medical construct of treatment and care to one that adopts a holistic view of the person and their needs (Gilliard et al., 2005). A draft self-management programme has been produced in partnership with people with dementia and their carers who identified the content and contributed ideas regarding modes of delivery. This programme requires further exploration followed by robust testing.

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