



**An occupational approach
to supported
self-management**

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2017

Journeying through dementia



Dementia is a long term neurological condition impacting on the lives of over 850,000 people who have been diagnosed with the condition in the United Kingdom.

The condition is progressive and at present there is no cure. However there are a growing number of accounts by people living with a diagnosis of dementia describing how it is possible to live well with the condition (Weaks, Wilkinson, Houston and McKillop 2012, Bryden 1998, 2005, 2015, Scottish Dementia Working Group 2003) . Many of these focus on the importance of developing strategies to enable continued engagement in meaningful activities and life roles.

These qualitative accounts, the on-going policy focus on early diagnosis and the recognition of the value of psychosocial interventions have led to a realization that people with early stage dementia can be enabled to draw on their retained skills and develop strategies to cope with their symptoms so that independence can be retained for as long as possible. The potential of an approach to support self-management, particularly in the early stages of the condition is the focus of this current study of which you are a part.

Journeying through Dementia is an intervention that has been developed in partnership with people with dementia. The intervention focuses on ways of enabling individuals to continue to engage in activities that they find meaningful as their condition progresses.

The original research that underpins the work was undertaken in 2010 (Craig and Mountain). During this research people with dementia were clear that they wanted to continue to be active, wanted to engage in groups that did not just talk about the diagnosis but offered practical advice and support of how to continue to live well with the condition.

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Acknowledgements:

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Journeying through dementia

We don't just
want to sit and talk, we
want action!

I want people to understand that dementia
isn't an end, it's a new beginning where you
do things differently. While some things change
forever there is a lot you can still do.

We don't want to be seen as suffering from
dementia, this is a term we really do not like.
We are living with it and getting on with it with
laughter and love and that makes a difference.
We are being heard and our opinions valued.

(Agnes Houston, Chair Scottish
Dementia Working Group)

Following the initial study a series of pilot projects were undertaken whereby the content of the intervention was refined in response to feedback from people with dementia and their families.

The intervention is delivered through a combination of group-work and individual sessions and this manual describes potential content of these sessions. The manual is aimed at facilitators of the programme. A separate training course details the research underpinning the development of the programme, the background and context to its development and the theoretical framework in which it sits. The training also explores more of the practicalities of delivery.

About the programme



Introduction

This manual forms the basis of a self-management programme for people with dementia and their supporters. This component is aimed at group facilitators and provides you with the necessary information and tools to run sessions.

The programme aims to enable participants to:

- Recognise the importance of activity and its relationship to health and wellbeing
- Develop strategies to enable on-going engagement in activities individuals with dementia value and which contribute to health and wellbeing
- Identify a number of techniques that can be used to compensate for some of the ways in which dementia impacts on everyday life and functioning
- Identify possible resources (internal and external) and support mechanisms that individuals can draw on including assistive devices and technology
- Have the opportunity to openly share and discuss feelings about living with dementia in a supportive atmosphere
- Build confidence, self-esteem and self-efficacy
- Experience well-being

How the manual is structured and themes within the programme

The manual comprises of 9 over-arching themes with descriptions of sessions that relate to this theme. The focus throughout is on inviting participants to revisit existing patterns and lifestyles in the context of dementia and to develop strategies for continued engagement in meaningful activities.

The overarching themes and sessions that relate to these are as follows:



About the programme

Themes and sessions

Understanding dementia

This theme includes sessions that welcome participants to the group, explores what dementia is and offers ways of thinking about the condition that go beyond a purely medical understanding of it (the psycho-social model of dementia, dementia as change). Time within these initial meetings is spent helping individuals to reflect on their journey to date, facilitate the development of supportive relationships between group members and to provide space where individuals can ask questions.

- ▲ **Welcome and introduction** p 16
- **Ways of thinking about dementia** p 19
- ★ **Dementia as change** p 22

Living with dementia

The theme living with dementia concentrates on practical strategies individuals can use to optimise their functioning. This element includes sessions that look at ways of creating enabling environments to help individuals cope with some of the perceptual and sensory problems that dementia can cause as well as how to make the most of routines. Memory and memory maintenance and communication are topics that are specifically addressed within this theme.

- ▲ **Health, wellbeing and activity** p 25
- **Making the most of routines** p 29
- ★ **Enabling environments** p 32
- **Enhancing communication** p 36
- ◆ **Memory-maintenance** p 39

Relationships

The importance of relationships is recognised and addressed. Sessions explore how to build and maintain friendships and ways of managing conflict.

- ▲ **Building and maintaining friendships** p 43
- **Managing conflict** p 46



About the programme

Themes and sessions



Keeping physically well

Keeping physically well is an integral part of living well with dementia. Sessions included within this theme are broad and cover a number of areas including: eating and nutrition, sensory challenges, managing medication and identifying infection. In offering such a broad range of ideas it is envisaged that the facilitator will have at their fingertips material that can be customised and adapted to meet the needs of their particular group members.

- ▲ **Keeping physically well** p 49
 - Coping with sensory challenges
 - Managing medication
 - Identifying infection
- **Keeping physically active** p 53
- ★ **Diet and dementia** p 55

Keeping mentally well

A diagnosis of dementia can frequently result in a whole gamut of emotions. This theme therefore includes ideas for sessions to help participants recognise and discover techniques to cope with anxiety and experience wellbeing. The importance of sleep is included as a possible session.

- ▲ **Experiencing emotional wellbeing** p 58
- **Sleep** p 61

Dementia and daily living

Sessions here address a number of highly practical issues facing people with dementia. These include: dining as an activity, safety in the home and community and ways of managing finances.

- ▲ **Dining as an activity** p 64
- **Safety in the home and community** p 67
- ★ **Managing finances** p 71



About the programme

Themes and sessions



Building and developing skills

Building and developing skills includes sessions that look at how participants can keep physically and mentally active and at how they can be supported to learn new things including getting to grips with new technologies such as computers and mobile telephones. Holidays and leisure are included within this theme as they are seen as opportunities to build confidence and engage in new experiences.

- ▲ **Hobbies and leisure** p 74
- **Learning something new** p 77
- ★ **Mastering computers and mobile telephones** p 81
- **Taking time out: holidays and short breaks** p 84

Keeping connected

Maintaining community connectedness is integral to the wellbeing of people with dementia. Ideas for sessions within this theme look at ways that participants can access outside opportunities, factors that need to be taken into consideration in relation to driving and also ways to make the most of transport.

- ▲ **Maintaining community connectedness** p 87
- **Transport** p 91

Planning for the future

The programme ends with possible sessions that offer participants a way to look towards and plan for the future. These include: tapping into future support in health and social care and ways to celebrate the end of the group in order to look forward to new beginnings

- ▲ **Tapping into future support: health and social care** p 94
- **Moving forward: celebration and endings** p 96



- Group Recording Sheet** p 100
- Individual Recording Sheet** p 101

Inside this manual



As you look through the content of the manual you will see that a short description of the topic begins each session. This is followed by:

- Quotes of what people with dementia have said about the topic
- The aims of the session
- A brief outline of the types of things you might wish to include in terms of information giving when describing the session to participants
- Introductory activities
- Group discussion topics
- Group activity ideas
- Some sessions include ideas for further activities

People with dementia have shared the importance of beginning and ending rituals as a way of helping to understand the rhythm of the group and to support orientation. For example in some of the pilot sessions tea and coffee was made available as people arrived and this offered a way for participants to settle into the group atmosphere before beginning the session. In another of the early pilots facilitators and participants used a camera to take photographs during sessions and these were embedded into a PowerPoint that was played at the beginning of the following week's session to create a visual record and a prompt for memory. In other sessions people have simply started the session by welcoming each person by name. This is something that you will need to think about. It is also important to think of ways to provide the group with a sense of ownership. For instance, group members deciding what their group might be called.

Using the themes

The key to the success of this programme is that it offers a customised approach to meet the needs of group-members. Themes should be seen as a 'menu of possibilities', which can be chosen according to the length of the intervention programme being offered, and its relevance to the participants. The first session suggests ways that group members can be supported to select what some of these themes should be and this might form an element of each group so that as one session end the group think about what the next session might be.

There may also be activities that are not included which you may wish to use and develop. All the activities are intended as starting points; they should then be tailored to meet the needs of the participants, as opposed to the activities dictating to the group.



Inside this manual Structuring your group



Each session is divided into a series of components:

- **An element that seeks to provide information and to answer questions that group members may have**
- **An element that focuses around discussion where participants can share their experiences, issues that have been raised and to gain support from group members, drawing on themselves and each other as a resource**
- **An aspect that provides group members with the opportunity to engage in group problem solving, to develop skills and put these into practice**

The group is very much intended to act as its own resource and individuals are positioned as experts about living with dementia. Sharing strategies offers an opportunity for people facing similar challenges to learn from each other and recognizes the collective skills and expertise of group members.

Dementia is complex. This programme must cater to individual needs and the large choice of ideas for group discussion reflects the diverse populations and needs of people with dementia. Skill is required by the facilitators to select, develop and adapt the different options to meet the needs of the specific participants. It is not the intention that all the activities described should be used in a session. Feedback from people with dementia has highlighted the importance of not being overwhelmed by too much information. Although the themes are presented in a particular order groups may wish to spend several meetings working with a particular theme. The recommended length of sessions is two hours.

Ingredients of the intervention



Group work

Group work enables participants to explore themes and concepts. Through a process of peer exchange and guidance, participants have the opportunity to reflect on the range of activities that they take part in and begin to understand how these might affect their health and well-being. The group provides participants with the space, time and opportunity to share their experiences. Issues can be raised and conflicts re-enacted.

Active experimentation can also take place here. The advantages of using groupwork are well documented. Yalom (1975) emphasized the value of groups in imparting information, instilling hope and developing self-awareness through group cohesion. Shulman (1988) described the group as being 'a laboratory for learning' where ideas can be generated, solutions to problems formulated and self-knowledge and change promoted.

Within the pilot programme participants commented that the group was particularly important to them because it provided:

- **A way to reduce the sense of isolation people were experiencing**
- **A place where people could talk openly about the challenges they faced**
- **A sense of validation by the person's peer group, where views were listened to, common themes identified and where isolation was broken down**
- **A place where new skills could be rehearsed in a supportive atmosphere Social support and friendship**
- **The generation of knowledge and ideas, mainly through listening to each other and engaging in a process of group problem-solving. (On occasion this extended to participants offering each other practical support.)**
- **Modelling where other group members acted as role models**

The group facilitator must be careful to establish a delicate balance between ensuring the safety of the group, imparting information, guiding the discussion so that everyone's voice is heard and making sure that the locus of control lies within the group where members can contribute their own expertise. The facilitator should therefore act as a guide whilst also encouraging participants to use not only their own resourcefulness but also appreciate the resources of others within the group. The techniques of reflection and gentle questioning can be useful in promoting the growing insight and self-awareness that is at the heart of change within the programme.



Ingredients of the intervention



Individual sessions

It would be simplistic to assume that group-work alone is sufficient to meet the complex individual needs of older people. The group cannot address all of the needs and concerns of individual members so it is recommended that a series of individual sessions be offered. These aim to:

- **Provide participants with the opportunity to voice their worries, fears and concerns in the privacy of their home environment and help them to develop strategies to move beyond these**
- **Explore and address issues of particular pertinence to the individual that have arisen or been identified during the group sessions**
- **Offer clarification of issues in order to deepen and extend their understanding of their needs and what they are able to do to bring about positive change**
- **Help the person to identify and to pursue their individual goals**
- **Ensure that the skills, knowledge and techniques shared within the group are generalized to daily life**

Individual sessions usually take place within the person's own home at a time that is mutually convenient. They should last between one and one-and-a-half hours, although timing is flexible. It is essential that the facilitator makes a link between the general themes explored within the group and the specific issues raised by the person.

Examples of individual sessions include:

- **Help a person to identify one challenge they currently face in relation to memory and try some of the strategies that have been discussed. The individual session could look at ways of providing group members with a concrete plan and a way of monitoring their progress.**
- **Exploring potential resources in the person's local community**
- **Identifying a valued activity the person enjoys which they are struggling to undertake and look at ways of adapting this**

The individual sessions are about helping the person to facilitate change. The locus of control should always remain with the person with dementia. Family dynamics and the way that many organisations offer support to people with dementia can mean that individuals are frequently forced to adopt a passive or dependent role. Individual sessions should give the person the opportunity to step outside their usual position and enter into a relationship of mutual regard and trust.



Ingredients of the intervention



Putting ideas into practice: group outings

An important element of the intervention is putting things/ideas/techniques discussed in sessions into practice. Some of this will occur as part of the group experience and will be the focus of the individual sessions. However it is also important to include group visits and outings within the programme. The aim of the outings are to provide opportunities for participants to test out ideas, rehearse skills, step outside comfort zones and transform the discussion that has occurred within group sessions into a lived experience. Examples of outings could include a visit to a local leisure centre/library/community venue to explore the range of opportunities available for the development of new interests or hobbies.

Role of family members/care supporters and partners

Family members and friends supporting a person in their journey through dementia have an integral role to play. Organizations and groups that support the needs of individuals in a caring role offer a vital service in terms of offering space, practical help and emotional help that not only meet the needs of family members but also of the person with dementia. However, in our research people with dementia spoke of the importance of also having distinct groups created for and attended by people living with the diagnosis. The following quote reflects many of the views expressed by people we interviewed:

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.

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.

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.



Ingredients of the intervention

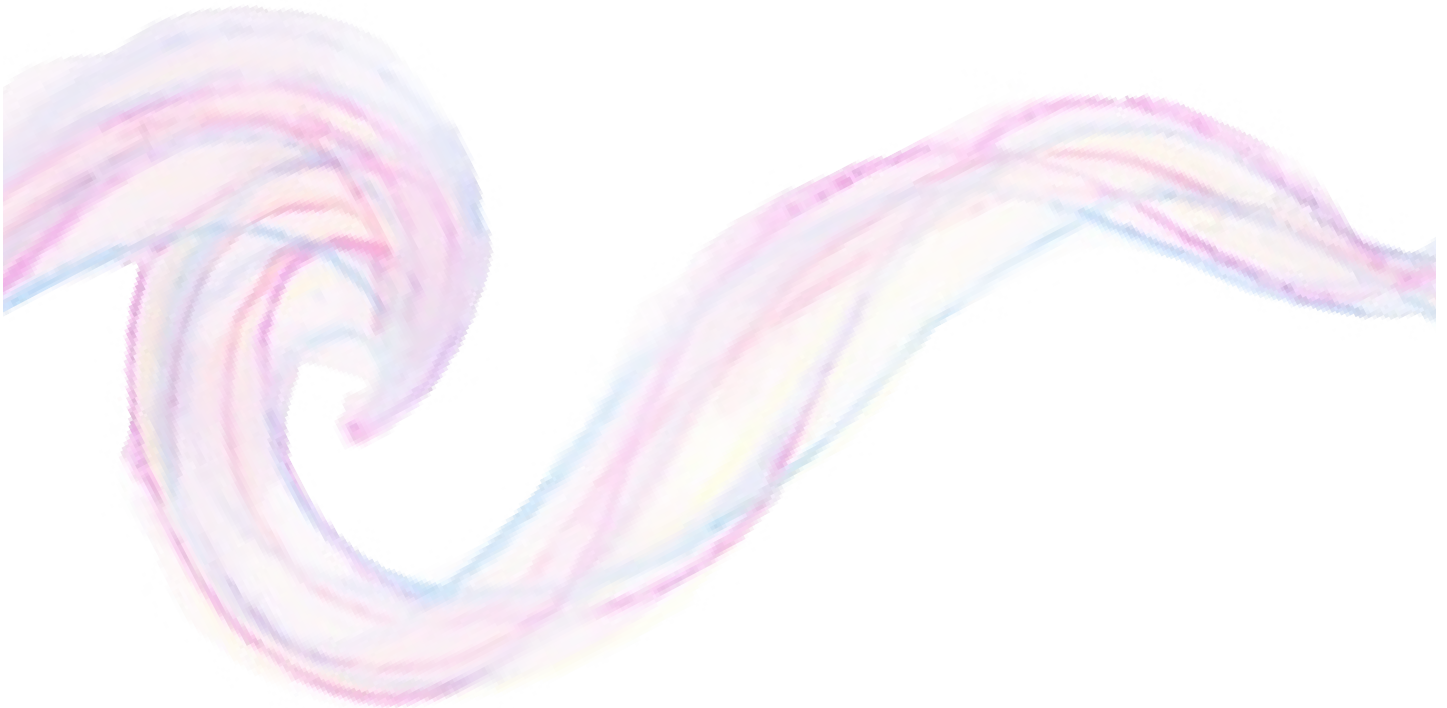


People participating in our research felt that having information they could share with family and friends was important in terms of involvement. Inviting supporters to the first, a middle and final session was suggested by people with dementia as one way that supporters could be involved. Journeying through Dementia does just this, inviting supporters to the first session, a middle session and an end session. People with dementia attending the programme also have a journal containing information and a place where they can make or record useful tips and ideas discussed during sessions. Individual sessions are also an excellent place to explore opportunities for shared activities.



What to expect

The challenge of effective working during individual sessions should not be underestimated. The person with dementia may face huge daily challenges and be living in a difficult situation where there are no obvious solutions. However, the programme is aimed to support the person in tapping into their existing strengths and locating resources that they can draw on in their on-going journey through dementia.



Features of the programme



We have consulted extensively with people with dementia in terms of the content of the programme and also how it should be delivered. People with dementia have made the following suggestions:

Sessions should be enjoyable. Living with dementia is difficult at times and the last thing that you want is to go to a meeting that is dull and depressing. It's nice to have fun even if the subject is very serious.

Noise can be very distracting and it can be difficult to follow lots of conversations when they are all happening at once. It's helpful to talk in small groups and if everyone is speaking to the whole meeting people should take it in turns so that others can listen.

There isn't a need to rush. People with dementia need time to digest information. Keep the pace steady so that information is easy to follow. One person we consulted suggested that group members could hold up a small card or coloured scarf if they hadn't understood something that had been said.

It can be helpful to make written notes on a flip chart as the meeting progresses. This can act as a visual prompt so that people with poor short-term memory can follow the information. Facilitators can then type this information up and give it to group members as a reminder of the content of sessions.

Individuals 'who are new to the field, especially people with dementia, do not have a great attention span.' Include lots of short activities and make sure that the meeting doesn't go on longer than an hour without a break.

Include food, coffee, tea, cake, biscuits. The best conversations happen when people are feeling relaxed and a social activity will give group members the opportunity to talk about what has happened in the group and to build friendships.

Don't put people on the spot. Offer people the opportunity to speak but don't put individuals under pressure. Remember that for some people it is a huge achievement just to be there.



Features of the programme



Keeping a record of group and individual sessions

It is valuable for facilitators to maintain a record of both group and individual sessions. Keeping regular records enables facilitators to:

- reflect upon the group process
- monitor the progress that individual participants are making towards achieving personal goals
- note any practical considerations that need to be taken into account with future groups and, most importantly,
- identify possible issues for further exploration within individual sessions.

When viewed collectively these notes provide a concrete record of the journeys that the group members have made. They are also a useful means by which to evaluate the overall programme. Examples of proformas to record both group and individual sessions developed specifically for the programme are included in the appendices.

Records should be completed immediately after each group meeting to ensure that observations are as accurate and as detailed as possible. Where there are two facilitators it can be helpful to separately note any observations or impressions before sharing ideas. In this way a fuller picture is developed, offering more than one perspective.



Reflecting upon the progress of the programme

In addition to documenting the group and individual sessions it is also important for group facilitators to spend time reflecting on the progress of the programme and what they can personally learn from this. Reflection is encouraged throughout the programme to enable participants to develop greater insight. It can ultimately act as a catalyst for change and development.

In a similar way, the facilitators should also take time to reflect upon what is happening in the group and their responses to this. It is also important for the facilitator to consider their own role and how this relates to that of the co-facilitator. This reflection on the part of all involved can provide illumination, insight and act as a mechanism for change.



Final thoughts/reflections

Everyone's journey through dementia will be different and this is determined by a host of factors. Whilst the programme does not change the diagnosis it offers participants a series of practical tools and techniques that can be used to help individuals to navigate and cope with living with a diagnosis and a way to continue to engage in activities that bring meaning and pleasure to life.

Understanding Dementia Welcome and Introduction



This session offers participants the opportunity to meet each other and to find out what the programme is about. There will be some exchange of information as you provide an overview of the sessions but its focus should be on creating a relaxed atmosphere where group members can feel at ease with each other. There will be time for individuals to identify particular topics they want to look at in more detail, exercising choice and decision making skills and to have space to talk about their hopes and expectations in relation to what the group might be. This will be revisited throughout the programme and will form the basis of your future planning.

It is important to remember that people will be at very different points in terms of their dementia journey and even though the programme is aimed at individuals who have recently been diagnosed with dementia, many will have been coping with dementia on their own for some time. Do not underestimate the amount of confidence that it has taken for some people to even reach this point and to recognise and talk openly about what a diagnosis of dementia means. Some participants in the group may struggle to do this and your role is to gently support individuals to engage and share at their own pace and above all to create a safe space where such discussions can unfold.

What people with dementia have said:

"Once you've met one person with dementia, you've met one person with dementia"

"I'm not saying dementia's not serious. But I'm going to say that it's a license in a way, a license to be free, to be me. I think when I got the diagnosis I got permission to be more relaxed into this person and accept her" (Agnes Houston)

"There is hope after a diagnosis of dementia. It is possible to live positively."
(Christine Bryden)

The aim is to enable participants to:

- Meet each other and to meet the facilitators
- Gain an overview of the programme
- Identify what they hope to achieve from the programme
- Identify possible topics for discussion



Welcome and Introduction

Session Agenda



Welcome: (individuals and their supporters are welcomed with tea/coffee/biscuits)



Information giving: introduction to Journeying through Dementia.

Introduction by group leaders and outline of the session recorded on flipchart (as a memory aid and point of reference). Sharing of the overall aims of the programme and about the approach we are taking (recorded on flipchart as a memory aid and point of reference). Written and visual materials (Resource 1.1 can be used as a starting point if PowerPoint is available, if not you may decide to create a hand-out or prepare a flip chart) will support this and the different elements that make up Journeying through dementia.

The key message about the programme is – everyone's journey through dementia will be different and this is determined by a host of factors. Whilst this programme does not change the diagnosis it offers participants a series of practical tools and techniques that can be used to help them to continue to engage in activities they enjoy and to navigate and cope with living with a diagnosis.

This is shared with the whole group including individuals with dementia and their supporters. There is the opportunity at this point for questions and a short break for coffee.

The group then divides – people who have accompanied individuals with dementia go to another room where one facilitator is on hand to answer any questions, people living with dementia engage in the planned session outlined below.

Introductory activities

Group participants select an image or an object from a number provided by the facilitators (Resource 1.2). They choose a partner and talk about why they have chosen this. These are then shared in a wider group context, again helping to provide a way to remember who people are within the group.

Group discussion topics:

- *What made you decide to come to this group?*
- *What do you hope to gain from this group?*
- *What will make this a good place to be?*



Welcome and Introduction

Session Agenda



Suggestions of ways to support group members (if required)

Participants work in small groups. Each group is provided with a series of word and image cards (Resource 1.3). Working together they identify what they hope the group will offer. Blank cards are also provided for group members to record their own thoughts.

The group comes back together and has a general discussion of what individuals identified as hoping to gain from the sessions. The facilitator on a sheet of flipchart paper records these. You could include at this point a general discussion of what will make the group a good place to be and things that will help or hinder this (for example, following a similar structure, reducing noise levels, providing written material as memory prompt, feeling that what is discussed is discussed in confidence). These are again recorded on the flipchart and form the basis of ground rules for the group. These are produced as written prompts for discussion.

Examples include:
meeting new people
sharing worries
learning new things
asking questions
confidence
enjoyment
discussion
practical ideas
space to talk

Activity: Designing the programme

Journeying through dementia is a menu-led approach that can be customised to meet the needs of individual groups. This part of the session invites participants to select possible topics from a menu of themes. You may decide to use this as part of the following weeks session or to adapt this to offer simple choices/the basis of discussion of the following weeks theme. Use the cards (Resource 1.4) to talk about the types of topics the programme could include. You will need to gain a balance of providing enough information without overwhelming group members. As a group agree on the focus of next week's session. End with a discussion of possible names for the group.

Finally.....

Family members/supporters who have accompanied the person re-join the group and everyone comes together. Thank people individually. Provide time for any questions or concerns to be shared. **Sharing of cake/coffee and closing ritual.**

Follow up: your role

- As a follow up to the session send a card to each of the group to thank each person for attending and remind them of the next session. (Resource 1.5)
- Use the template (Resource 1.6) to type up the information from the group and send this with the thank you card and reminder
- Possible link to next session: thinking about a name for the group

Understanding Dementia

Ways of thinking about dementia

This session considers some of the different ways of thinking about dementia. There is the opportunity for group members to ask questions about dementia but rather than seeing dementia purely from a medical model perspective the group is also invited to think about different ways of seeing dementia in terms of dementia as a disability and dementia as change. The session is all about providing participants with the space to ask questions, to get to grips with understanding what dementia is and what a diagnosis of dementia means. Many group members will have been in shock when they learned of the diagnosis and will not have had the opportunity to find out or absorb key information. Individuals may share experiences and through this begin to realise that they are not on their own. Use the group activity to begin to gently challenge some of the negative stereotypes surrounding dementia.

"People get to hear the word dementia and it is all lumped together and they think you are finished. You are not finished at all... you reinvent yourself... we are living with dementia and getting on with it with laughter and love and that makes a difference."
Agnes Houston

I have the life of Riley; it really is good. I know I have a deteriorating illness and it won't last but I could have died ten years ago if I had been given a diagnosis of terminal cancer, I'm happy with my life, if I could go back and change my diagnosis, no, I wouldn't, I am quite happy living with my diagnosis.
(James McKillop)

The aim is to enable participants to:

- Gain greater understanding of the different types and causes of dementia and its impact on day to day life
- Recognise that dementia affects people differently
- Begin to understand that it is possible to develop strategies to help reduce the impact that dementia has on different aspects of their life
- Challenge some of the negative stereotypes and help participants think about dementia in a different way (other than a medical model)



Ways of thinking about dementia

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

Series of quotes about what people living with dementia have said about their experience on word-cards (Resource 1.7). Participants select a card at random and the participant or the facilitator reads this; the person and the group then respond to the quote that forms the basis of discussion.

Information sharing

Talk about different ways of thinking about dementia: dementia as a neurological condition, dementia as a disability and dementia as change. Include reference to Kitwood's model of dementia (Dementia = neurological impairment + health + physical fitness + biography + personality + social psychology). Remind the group of the importance of personality in coping with dementia and the importance of maintaining a sense of self.

So often the press paints a very negative picture of living with dementia. However people diagnosed with the condition have gone on to do extraordinary things. Share with group a series of 'personas' (Resource 1.8) or use the video of the 'through our eyes' as the basis of the following discussion:



Discussion questions

- *What did you know/had you heard about dementia/memory problems before receiving your diagnosis? How did you hear about dementia? Was this information helpful?*
- *What is your response to the information you have just heard? How might thinking about dementia in a different way change how you feel, how you behave and what you do?*
- *If you think of dementia as change, how have you coped with change in the past? How could this experience help you now?*
- *How does your personality impact on your ability to cope with memory problems/dementia?*
- *If you have questions about dementia where do you go for help? Are there any particular sources of help that have been particularly helpful/unhelpful?*
- *Have you found it easy to talk about your experiences with friends and family? If it is difficult to talk to friends and family are there other places/support mechanisms you can draw on?*





Ways of thinking about dementia

Session Agenda



Tea/coffee break

Possible activities

- Fact or fiction activity: using the card sort activity (Resource 1.9) group members identifies things they think are true about dementia and things that are untrue. The group then works together to develop an information sheet for families and friends based around this. Share an example - for instance the 'by us, for us guide'.
- Group develop a series of questions that the facilitators answer.
- Use James McKillop's poem: Differently the Same (Resource 1.10) to consider some of the challenges of describing what living with dementia means. The group shares ways of sharing their diagnosis and talking about dementia as a disability and as change.
- Thinking back to their own story and taking what they have learned about dementia, participants use the hand-out (Resource 1.11) shaped like a footprint) to record each step of their journey so far and to talk about their future and what they would like to happen
- Create a resource list of helpful information

Finally...

Recap over the session. Final key message: Having a diagnosis of dementia is beginning of a journey. Everyone's journey will be different. Whilst some of the obstacles might be similar the way you approach and cope with these will be different.

End with coffee and cake/coffee and food/closing ritual.

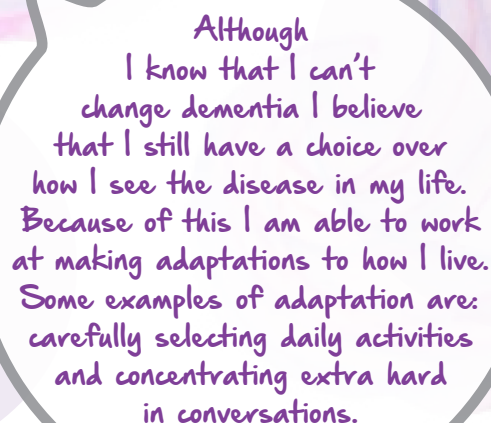


Understanding Dementia Dementia as change



The group has explored some of the emotions they have been experiencing in relation to the diagnosis of dementia and what this means on a personal level. The programme now moves to look at ways of coping with the changes that are associated with the condition. This session focuses on ways of managing transition. It helps group members to reflect on how they have previously overcome challenging times in their lives. Consideration is then given to some of the strengths and resources they can draw on during the present time as they move forward.

What people with dementia have said:



Although
I know that I can't
change dementia I believe
that I still have a choice over
how I see the disease in my life.
Because of this I am able to work
at making adaptations to how I live.
Some examples of adaptation are:
carefully selecting daily activities
and concentrating extra hard
in conversations.

The aim is to enable participants to:

- Re-frame their experiences
- To help individuals to recognise their strengths and the resources they can draw on



Dementia as change

Session Agenda



Welcome and Introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

Thinking about change: invite participants to identify times in their life when they have experienced positive life changes (e.g. marriage/births/leaving home/a job/a holiday/moving house etc.)

Talk: dementia and coping with change

Talk about dementia in the context of managing change and the constant re-adjustments individuals may need to make as dementia progresses. Talk about the importance of resilience but also emphasise the wealth of personal reserves each person is able to draw on. Consider different kinds of change people have been through.

Discussion

- *Are you someone who finds any change, whether good or bad difficult or do you find that you easily adjust to things?*
- *Can you think of any changes you have already been through (it might be helpful to include a list of prompts: (illness, marriage, divorce, bereavement, retirement, grandchildren etc.)*
- *What resources have you drawn on in the past to help you to get through these times (financial, friends, family, services, spiritual etc.)*
- *What personal resources/characteristics do you think you could draw on to help you to meet some of the changes you face following a diagnosis of dementia*
- *Can you think of a time when coping with a difficult situation led to you to change for the better?*
- *How does change lead to the development of new roles and new activities?*



Dementia as change

Session Agenda continued



Group activities

Participants choose one of the following word cards to describe how they think this characteristic might help someone to cope with dementia (Resource 1.12) (e.g. Sense of humour, stubbornness, strong spirit, insight, focus, single-mindedness, refusal to give up, problem solver, self-esteem, positive self-image, flexibility, self-confidence, assurance, single-minded, focused, faith, self-efficacy, organised, positive thinking).

Use the template (Resource 1.14) to create a managing change shield. In the first segment draw or write down your personal strengths, in the second segment draw or write down what some of the challenges will be, in the third segment draw or write down sources of help or support you will be able to draw on and in the final square draw or write down a motto that will help you to get through.

Endings:

Recap over the session. Final key message: Change is very much part of life. Being given a diagnosis of dementia is a potentially a devastating change but it is nonetheless a change, like many other changes we have experienced in the past. However by recognising and drawing on how we have coped with change in the past we can draw on a strong personal resource.



End with coffee and cake/coffee and food and closing ritual



Living with dementia Health, wellbeing and activity

To be occupied means to be involved in the process of life in a way that is personally significant and which draws on a person's abilities and powers'
(Dementia Reconsidered: Kitwood)

Journeying through dementia is underpinned by the premise that there is a relationship between the activities we participate in and health and wellbeing. The aim of the program is to promote continued engagement in meaningful activity through equipping individuals with the knowledge, skills and understanding of ways to continue to do the things they enjoy for as long as possible.

This is a key session. Group members are invited to identify activities they find meaningful, to consider how these impact on wellbeing and to share and explore ways/strategies to support ongoing engagement.

What people with dementia have said:

There is great potential for re-learning problem solving involving a greater number of simpler steps.

Let's keep up with friends, books, films, church, whatever gave us these memories. But let's also create new ones. Days out, travel, gardening, sport, reading, shared time ... as long as we want to do these things whatever we want to do. And let's remember those things too, our more immediate history and life story. Keep that camera handy.

Take us at face value as a person first and foremost, not a disease. Then help us to keep achieving to our full potential

The aim is to enable participants to:

- Understand the importance of activity
- Consider how people define themselves through the activities they take part in.
- Explore the impact that dementia has on the types of activities that individuals participate in and to look at how it is possible to adapt activities to maximise participation



Health, Wellbeing and Activity

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

Participants were asked to bring a photograph or a picture from a magazine of an activity that they enjoy or have enjoyed taking part in. Group members are asked to share these photographs and to briefly say a little about why they have chosen this particular image. Alternatively (as a back up) provide a series of images for group members to choose from. (Resource 2.1)

Invite group members to share what they gain from the activity they described. Use the word cards to act as a prompt (fun, relaxation, stimulation, friendship, mental challenge, learning something new, relationship, physical exercise, space to think, emotional-wellbeing, sense of purpose, role, social contact, sensory stimulation, confidence) (Resource 2.2)

Information sharing:

The relationship between health, wellbeing and meaningful activity

Talk about the importance of meaningful activity in enabling people to experience wellbeing. Use the World Health Organisation definition of health and talk about this in relation to health and the relation between what we do and how we feel. Talk about the benefits of meaningful activity and the consequences of not taking part (Use cards for flow diagram for reinforcement? Flow diagram: No activity, boredom, loss of interest, loss of skills, low expectations, reduced physical activity, reduced social contact). You could also include discussion of meaningful activity and its role in self-expression, communication, in building relationships, promoting physical well-being and mental and emotional well-being as well as in stimulating cognitive function.

Discussion questions

- *Have the activities you enjoyed changed over your lifetime. If so: how? Can you think of something you used to do but you no longer take part in?*
- *What do you enjoy doing? What is the relationship between activity and wellbeing? Do the activities you take part in define who you are in any way?*
- *Can you think of a way that you have changed how you have performed an activity in the past, for example, as a result of experiencing memory problems or growing older?*
- *Are there activities you would like to do but don't? What prevents you? Can you identify*



Health, Wellbeing and Activity

Session Agenda



some of the barriers?

- *Can you share ways that you have adapted activities so that you can continue participating in things you enjoy?*

Possible group activities

- Look at a series of photographs of people engaging in activities (gardening, drawing, singing, listening to music, photography, sport etc). Participants select one image that represents an activity that they enjoy or would like to take part in (Resource 2.1). Working in small groups participants discuss:
 - benefits of taking part in the activity
 - possible challenges
 - ways to overcome these
- As a group/in small group work together to problem solve ways of grading some of the activities chosen (see handout 2.2 as an example/use template: could be taken away and shared with family)
- Consider the tips for ongoing participation in meaningful activity described by people with dementia (Resource 2.4). Decide on the helpfulness or unhelpfulness of what is described. As a group develop your own ideas.
- Individuals are offered the challenge to participate in a particular activity at home during the following week. They record any challenges they face and what they did. Emphasize that if they weren't successful in completing the activity it doesn't matter - it's more helpful/useful to look at what the challenges were and to explore possible techniques they could try in the future. The importance is having time to practice. This could also be picked up/developed in the individual session.
- Create a resource based around activities that people could engage in over different periods of time (thinking about levels of concentration and fatigue) e.g. 5 minutes, fifteen minutes, thirty minutes, one hour. You could also identify possible activities and use these as the basis of a practical session offering individuals an opportunity to participate in and evaluate these.

Endings:

Recap over the session. Final key message: Meaningful activity is key to experiencing wellbeing. Dementia should not prevent you from engaging in activities that you enjoy but you will need to adapt/change how you perform activities in order to continue to maximise participation.



End with coffee and cake/coffee and food and closing ritual



Health, Wellbeing and Activity

Session Agenda



Extension activities (could form a subsequent session)

- Organise a session of 'singing for the brain': at the end look at how this activity can promote well-being and can be a useful way to exercise memory
- Organise a session of T'ai chi or circle dance: at the end look at how this activity can promote well-being
- Organise a session focusing on indoor gardening: look at how this activity can promote well-being
- Invite local library to talk about activities and resources in the local community i.e. talking books/talking newspaper

Ideas for possible outings

Use these activities as the basis of an outing to a community venue (attending a community choir/singing group, trip to a local gardening/allotment group etc.)





Living with dementia Making the most of routines

This session continues the theme of maximising skills in order to move forwards. One of the challenges people with dementia face is around the issue orientation. Poor orientation is not only a consequence of dementia but can also be the result of retirement where structures and routines once provided by employment are no longer there. This session looks at ways of re-establishing structures and routines to help individuals to manage their time, to structure the day and to reduce anxiety both for the person with dementia, their family and their carer.

What people with dementia have said:

You may have noticed that the person you care for has become increasingly unsettled by any change in their normal routine. This is not usually because they have suddenly become awkward or inflexible, rather it is likely to be because routine acts as an important back-up to memory and contributes towards helping us feel safe and secure.

By mid-day, I nosedive ...
I'm okay in the morning but I sink in the afternoon, sometimes you don't get any warning of it, the shutters just come down. Agnes would say, "This is like a fog", and it can happen any time.

The aim is to enable participants to:

- To reflect on existing routines
- Consider how having a routine may support in the structuring of time
- To examine how activities may contribute to roles and routines



Making the most of routines

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

- Group members share clock faces and talk about their favourite time of the day (Resource 2.6)

As a group talk about routines. Invite members to share examples when particular days have been associated with particular activities (For example, Monday wash day, Saturday lunch fish and chips, Sunday church, Yorkshire puddings, Friday pay-day.)

Sharing information: using routine to support orientation and reduce anxiety

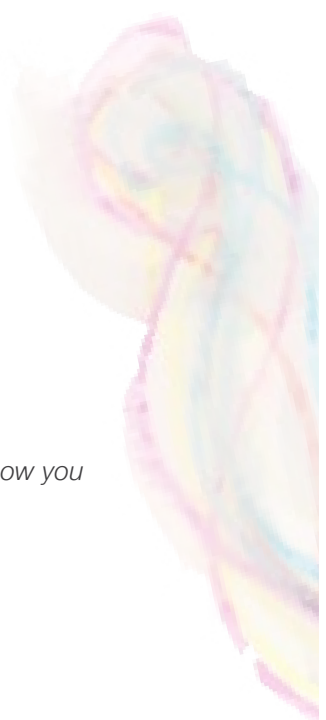
Describe how routine can play a role in maximising functioning and promoting wellbeing. Cover the following areas:

- How dementia impacts on orientation (time and place)
- Identifying when you are disorientated
- Ways to reduce disorientation



Discussion topics

- *How do you distinguish one day from another?*
- *Do you have any particular routines at present?*
- *How do certain routines give you clues about time of year or day of week?*
- *Do you have a set routine when you do particular activities or do you wait to see how you feel on a particular day?*
- *How can following a routine make you feel less stressed?*
- *How can following a routine make you feel more stressed?*





Making the most of routines

Session Agenda



Group activities

- The group explore a series of objects and talk about how they could help participants to feel orientated and support routine (for example wall charts, calendars, clocks, the dog, television, meals)
- Use resource 2.6 to look at ways of building in simple routines into your day
 - Explore routines around sleep
 - Explore routines around food and eating
 - Explore routines around taking medication
- Invite someone to speak to the group about sun-downing and orientation

Endings:

Recap over the session. Final key message: Routines can provide a structure to the day and support orientation.



End with coffee and cake/coffee and food and closing ritual





Living with dementia Enabling environments



This element of the programme focuses on the environment and looks at how design can promote as well as limit activity. The session offers participants ideas of ways to make simple changes to the physical environment in order to compensate for some of the challenges associated with dementia.

What people with dementia have said:

I can't cope with noise. Background music in supermarkets completely wipes out my brain of what I need to remember to buy.

The environment plays a major role in determining our independence. A good environment can help me to keep attached to the world by keeping my surroundings familiar and comfortable.

Whereas a person with a physical disability needs modifications to gain physical access to their environment I need modifications to help me understand my environment.

The aim is to enable participants to:

- Understand how the design of the broader physical environment can impact on the activities individuals participate in
- Consider how making simple adaptations to the environment can help to compensate for some of the perceptual challenges individuals face



Enabling environments

Session Agenda



Welcome and Introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

Use the images to stimulate discussion about pet hates and likes in terms of design - this may be in the context of places people have recently visited (confusing hospital signs, lack of signs, too many steps, long corridors, lack of stimulation, shopping centres with loud music and complex layouts) (Resource 2.7)

or

Use quotes by people with dementia as the basis of discussion (Resource 2.8)

or

At the end of the last session group members were asked to bring an image of a 'special place' – somewhere that has positive associations. Invite participants to share these images and to say a little about the place and why it is important.

Information sharing: enabling environments

Include how dementia impacts of our relationship with the environment (memory, perceptual problems, orientation and under stimulation/over-stimulation) and the importance of design in promoting wellbeing. Describe some of the features of good design for people with dementia and how the environment can compensate for some of the symptoms of dementia. Examples of assistive technology (there is the option of dedicating a further session around this)



Discussion questions

- *How has the appearance of your home changed as you have grown older (height of chairs/ beds, grab rails, bathing equipment)*
- *What is it about home that makes it home?*
- *Which environments do you feel most confident in? Do you feel more confident in your home environment than you do in other places? Why is this?*
- *Are there environments you find difficult or confusing? What makes these so? Could you do anything to change how you feel about these?*
- *What are the features of good environmental design for someone with memory problems?*
- *Can you identify technologies that you find helpful in enabling you to navigate the environment and to engage in meaningful activities?*



Enabling Environments

Session Agenda continued



Possible group activities

- Look at a series of photographs (taps, cookers, microwaves, kitchen cupboards, bath, bed, chairs, light switches, tables, mirrors, reflective surfaces). Working in small groups decide what is good about this in terms of its design and what is less good. Features may not just relate to dementia but to other conditions that participants might be living with (e.g. tap-turners for arthritis etc.) (Resource 2.9)
- Look at the handout on 'dementia friendly design' and share the following videos: <http://www.bbc.co.uk/news/health-17449048> <https://www.youtube.com/watch?v=MRcd6xzUwKs> - plan some of the practical steps participants could take to make their environment more supportive of their needs. (Resource 2.10)
- Based on the talk create a list of 'Design dos and don'ts' that can be shared with family and friends (e.g. don't constantly move things around, do label things, lighting)
- Create a plan of a house to explore what activities take place in which environments? How can the environment be adapted to maximise participation?
- Look at a range of different pieces of assistive technology and use this as an opportunity for the group to decide the strengths and limitations of this (include examples of every-day technology and technology to support leisure activities – e.g. mobile telephone with alarm for reminder)

Endings:

Recap over the session. Final key message: Small changes to the environment can help to compensate for some of the difficulties that dementia causes, help people to participate in things they enjoy and support independence.

End with coffee and cake/coffee and food and closing ritual



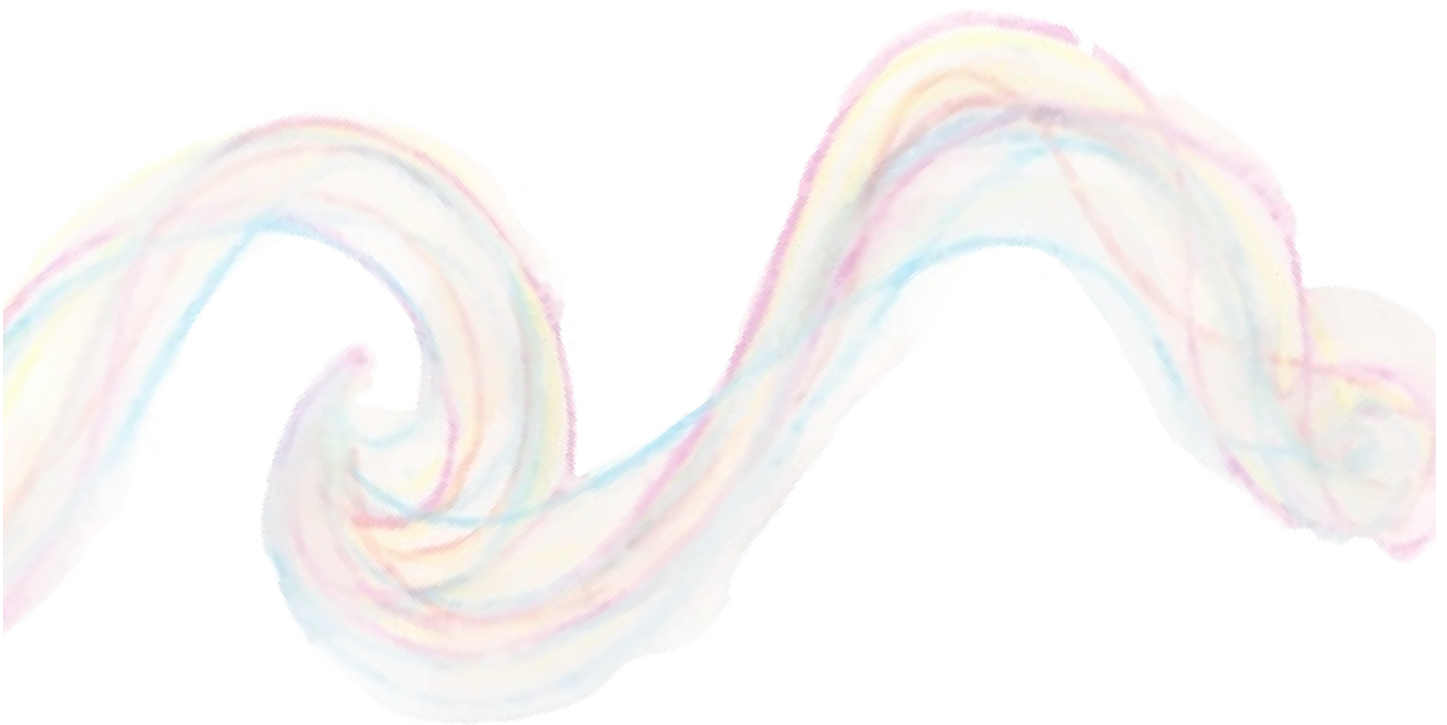
Enabling environments

Session Agenda continued



Extension activities

- Offer a session focusing specifically on different types of technology that can help people to overcome some of the challenges of dementia. Use this as an opportunity to test things out. Consider some of the specialist technologies available but also look at how everyday technology can be of value.
- Use an individual session to explore simple changes a person could make to the home environment (see examples of dementia-friendly design)
- Look at a range of apps specifically developed for people with dementia
- Use the 'dementia circles' model to invite participants to test out and share potential products: <http://www.dementiacircle.co.uk/see-the-products.html>



Living with dementia Enhancing communication



Dementia can significantly impact on a person's ability to verbally communicate. An individual may have problems following a conversation, struggle when trying to find the right word for something or say words that we don't understand. They may repeat words or phrases. This can be extremely isolating and can lead to frustration, distress and sometimes anger. It can be a factor that places stress on close relationships with family and friends.

This session explores how dementia impacts on written and verbal skills and explores a range of tools and strategies that can be used to facilitate communication considering ways of communicating that go beyond words.

What people with dementia have said:



The aim is to enable participants to:

- To explore strategies that individuals can use to promote communication
- To consider the importance of non-verbal communication and body language



Enhancing communication

Session Agenda



Welcome and Introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

Do you have any particular sayings or phrases? Or Match the saying/phrase to the celebrity (Resource 2.11) or Do you have any sayings or actions that you use to communicate with family or friends that other people wouldn't know about (for example three squeezes of a hand for I love you)

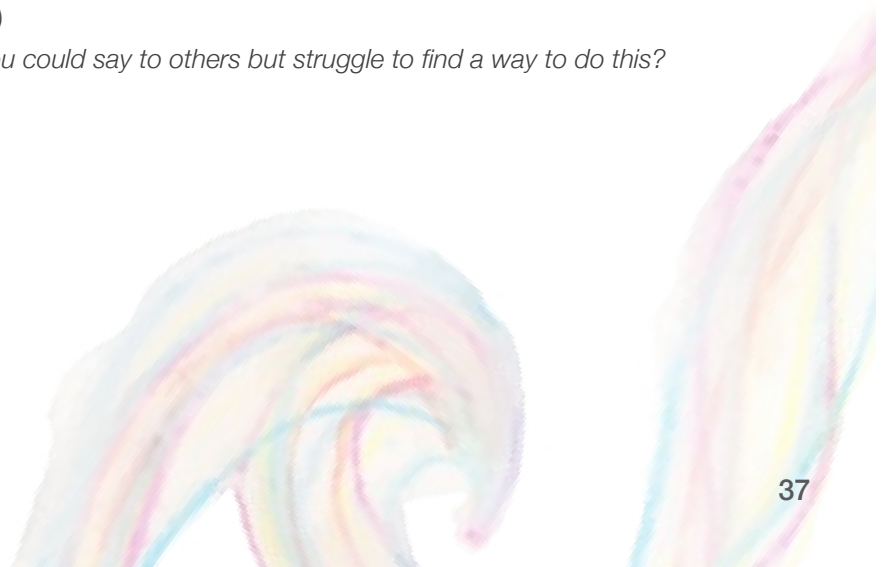
Information sharing: enhancing communication

Describe how dementia impacts on communication including some of the challenges individuals may face (including naming of objects, repetition of words and phrases). Make reference to the work of John Killick who speaks of the value of metaphor and the relationship between poetry, creativity and communication. Highlight how different activities (including more creative activities) can be used as a medium for communication.



Discussion questions

- *Do you face challenges in communicating with others? What are some of the challenges you experience?*
- *What communication strategies do you use?*
- *Are there particular situations where you find it easier/more difficult to communicate in? (For example in situations that are noisy etc.)*
- *Are there activities that help you to express how you feel? (e.g. art, poetry, music, painting, photography, sport, dance?)*
- *Are there things you wish you could say to others but struggle to find a way to do this?*





Enhancing communication Session Agenda continued



Group activity

- Group works together to create a list of what helps and what hinders communication. Turn this into a personal guide to share with friends and family.
- Use the stimulus questions from the By Us For Us Guide around enhancing communication (Resource 2.12)
- Create a list of communication strategies
- Use the session as an opportunity to explore activities that support self-expression/alternative ways of communication. For example look at poetry as a form of communication (take for example poems written by people living with dementia and read these together (Resource 2.13) or try writing around a structure i.e. these I have loved) (Resource 2.14)
- Read/share a series of poems. Invite participants to share what emotion is being communicated through the words. See if people are able to pick poems that match their feelings/emotions.

Endings

Recap over the session. Final key message: Dementia may impact on communication in a number of ways. Strategies exist that can support communication and these will need to be continually adapted as the journey through dementia progresses.

End with coffee and cake/coffee and food and closing ritual

Extension activity

Invite a speech and language therapist to talk to the group about communication strategies and technologies to support communication. Use this as an opportunity for group members to identify and ask questions.

Living with dementia Memory maintenance

Journeying through dementia focuses on helping participants to find ways to continue to engage with the activities they enjoy in the face of increasing cognitive impairment. This session looks at the relationship between activity and memory. It explores some of the tools and techniques that can support memory function and offers potential ways individuals can keep mentally active.

What people with dementia have said:

Looking after your memory means learning to think, see and feel better about yourself. It means that you can change the things you do and the way you do them ... both in these daily exercises and in everything you do.

You can help me to retrieve the memory by finding a word, a description of the event... I need you to find keys to these boxes with a word or a phrase to unlock the treasures of memory that have been locked away.

We are like the 'hummingbird syndrome where we flit from object to object. Being involved in exercises that help us with our concentration is beneficial and extremely helpful for our day-to-day living.

The aim is to enable participants to:

- Be aware of a number of different strategies to enable individuals to make the most of their memory
- Understand how memory impacts on the activities we take part in everyday life and share ideas how to overcome some of these challenges
- Have the opportunity to explore activities to support memory and memory recall



Memory maintenance Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Information giving

Relationship between activity and memory. How activities can stimulate memory and strategies for recalling important information.

Introductory activity

Invite group members to share a favourite memory? You could also pose the question: what is a memory?

or

See how many memory aids the group can name (string around finger, notes to self, lists, diaries, calendar)

or

Can anyone in the group still recall things they learned by rote when they were younger? (poems, tables, information). Share memory techniques that or mnemonics that they used (Music scales: every good boy deserves fruit, colours of the rainbow: Richard of York gained battles in vain)

Discussion

- *What strategies have you used in the past to help you to remember things?*
- *Are you someone who remembers things by looking at visual/picture cues or through listening to things/repeating things or by writing information down?*
- *Have you noticed any changes to your memory recently? How do changes in memory impact on daily activities? What is the most frustrating thing about experiencing memory problems?*
- *Are there things you think it might be ok to forget? What do you worry most about forgetting?*
- *What strategies do you use at the moment to support memory? What is helpful? What is unhelpful?*
- *Have you found any strategies surprising?*
- *What activities do you take part in to help you to keep mentally active?*

Memory maintenance

Session Agenda continued



Activity ideas

- Invite group members to look at a series of objects (diary, notebooks, post-it notes, alarm clock, family wall-planner, mobile phone, dicta-phone, digital picture frame, medication reminder). Decide ways these could be used to support memory. Invite individuals to identify what works for them, what are the qualities of the prompt that need to be there in order for it to work (e.g. familiarity, part of routine, specific to a particular type of memory difficulty, accuracy)
- Work as a group to develop a booklet of possible strategies to support memory recall. Develop a set of tasks that can be used to test these out and plan to share people's experiences of testing these out at a subsequent session.
- Create a memory board/calendar/wallet (see template: (Resource 2.15))
- Use the memory 'workout' from the By Us For Us Guide to test out different activities to support memory recall (Resource 2.16)
- Read the poem Love Songs in Age. Use this to talk about how objects can aid memory recall (Resource 2.17)
- As a group develop a list of activities that promote mental stimulation. Use a session to identify an activity the group would like to learn and try to learn something new together.
- Stress can impact on memory. Explore strategies together to look at ways of reducing stress (e.g. moving to a quieter environment)





Memory maintenance Session Agenda



Extension activity/individual session

- Look at other things that can trigger memories such as music, smell, sounds
- Group members identify one challenge they currently face in relation to memory and try some of the strategies that have been discussed. The session could look at ways of providing group members with a concrete plan and a way of monitoring their progress. Emphasise that this will take time and that where possible it is best to adapt aids the person already uses. For example if a person has always used a family calendar or a diary then encourage the person to continue to do this or to think of similar ways of supporting memory recall.

Endings

Recap over the session. Final key message: Engaging in activities to promote mental stimulation can support memory.



End with a drink and a healthy snack and a closing ritual





Relationships

Building and maintaining friendships

'Don't walk behind me: I may not lead. Don't walk in front of me: I may not follow. Just walk beside me and be my friend.' (Albert Camus)

Almost every person, during their lifetime will develop and maintain a network of social contacts, friendships and relationships. These networks help to sustain and support us. As people grow older such friendships can assume a greater importance but frequently individuals face greater challenges in maintaining these as a result of physical and sensory changes that make it more difficult to travel, use the telephone and keep in touch through letter writing and e-mail. People with dementia may face additional challenges associated with memory and communication and the stigma that having a diagnosis of dementia brings. This session provides the opportunity for participants to explore existing friendships and consider some of the strategies they might use to develop new friendships and keep in touch with existing friends.

What people with dementia have said:

My friends are still good friends. And if I am going out with a friend or one calls me, I get undepressed.

You must find a buddy you can trust, a good listener; you will need to talk

What people want is friendship, we all have different dementias and we are all in the same boat, but we could all talk about it and we could all laugh about it and that's what you need, you need something where you can have people around you with similar needs, and you can talk to them and they can talk to you and the partners can talk to each other, and it works wonders.

The aim is to enable participants to:

- Reflect on the relationships they have
- Understand the potential support that a strong social network is able to provide
- Recognize that maintaining friendships and relationships is an active process
- Consider the range of possibilities that activities can present in terms of meeting new people and developing friendships
- To reflect on the purpose that different relationships presently fulfil



Building and maintaining friendships

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

Participants think of someone they consider as a good friend and then as a group they create a list of all the things it is possible to gain from a good friendship (the link activity could have been for group members to have brought a photograph of a good friend along with them)

or

What qualities do you value in a friendship? Individuals choose from a selection of qualities associated with friendship explaining their choice (loyal, fun, intelligent, understanding, good listener, dependable, honest, kind, caring, supportive)

Information giving

Discuss the value of friendship and social support networks. Spend time talking about how friendships impact on well-being, ways they can act as a buffer and a sounding board, provide opportunities for building self-esteem, developing new interests and hobbies. Include discussion of some of the challenges of building and maintaining friendships in terms of memory, mood, communication and ways to overcome some of these difficulties. Focus on the importance of friendships as a source of support for care-partners as well as for the person with dementia.

Discussion questions

- *What do you gain from the friendships you have?*
- *What do your friends gain from your friendship?*
- *What are some of the challenges of maintaining friendships?*
- *What opportunities might dementia present in terms of developing new friendships?*
- *How can activities offer opportunities to develop friendships*





Building and maintaining friendships

Session Agenda continued



Activity ideas

- Read the poem 'differently the same' by James McKillop. What do you think James is describing? What is your response to these words? Can you identify with anything that James describes? (Resource 1.10)
- Look at different ways of keeping in touch: Internet, telephone, letter, video, photographs, audio-tape, Skype, Facebook
- Telling friends about dementia: what do you wish you could say to family and friends
- Consider your support networks. Use the handout to identify: someone you trust, someone who makes you laugh, someone you can confide in, someone who gives you practical support, someone who you turn to in a time of trouble, someone you can rely on, someone who makes you feel special, someone you love. (Resource 3.1)
- Watch the video of the 'walking group' (Innovations in dementia): use this as the basis of planning a group walk.
- Watch the following video of Agnes and Nancy talking about their friendship: <https://vimeo.com/32903503>

Endings

Recap over the session. Final key message: Maintaining and developing new friendships can offer a valued source of support, reducing social isolation, offering practical and emotional help.

End with coffee and cake/coffee and food and closing ritual

Extension activities

These all relate to providing an opportunity for an activity that can be shared with family and friends. For example, you could look at a shared picnic, at a social event the group organizes (for example a shared meal or a cinema outing or a group walk).

Relationships Managing conflict



Some degree of disagreement is an inevitable part of being close to someone. Coping with a diagnosis of dementia can often bring additional pressures of its own and the potential for disagreement or conflict increases as the person with dementia, their partner and wider family members are attempting to adjust to new roles and circumstances. This part of the programme helps individuals to predict potential danger spots and triggers and to offer group members the opportunity to begin to understand where this might originate from and strategies to how to manage these feelings.

What people with dementia have said:



The aim is to enable participants to:

- To have the space to talk about some of the difficult emotions that being given a diagnosis of dementia brings
- To explore possible strategies to manage some of these difficult emotions



Managing conflict

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

How do you deal with conflict? Are you an: Ostrich, volcano, road-runner, (Resource 3.2)

Talk: Include discussion of the following

Common causes of conflict including: different values, misunderstanding, lack of communication, control/issues of control, seeking the truth, re-writing the past. How additional conflict may arise following a diagnosis of dementia. Including the effect of change in roles, feelings of being taken for granted, lack of support, anger, grief, being misunderstood, anger directed towards the situation and the person. Ways of diffusing situations.

Discussion

- *How do you express your emotions? Are you someone who wears their heart on their sleeve or do you bottle things up?*
- *Are there emotions that are difficult to express?*
- *How can the activities you take part in help you to express difficult feelings? Are there any activities you find particularly helpful? (e.g. baking as a way of channelling energy, painting as a way to express self, exercise as a way to expend energy, listening to music to feel calm)*
- *Who can you talk to openly and honestly about your feelings?*
- *How can/do others support you?*
- *How can you support others as they work through their emotions?*



Managing conflict

Session Agenda



Activity ideas

- As a group think of a number of situations that people find emotive (causing feelings of anger, frustration etc.). Spend time trying to understand what might be happening. Then as a group decide what possible courses of action you could take.

Include the following situations:

If you feel that someone is ignoring you
If you feel rushed and not included in plans
If you feel that people are talking down to you
Being tested, quizzed or pressured for answers
Difficulty finding words
Losing things

- Discuss the By Us For Us Guide 'Tips for managing triggers' – do individuals agree with the tips given, could the group develop an alternative list?
- Use the session to explore activities that support self-expression (e.g. painting to music, an opportunity to visit the leisure centre)
- Explore community-based resources that can offer support for individuals living with dementia and their families. Individual group members could research these and as a group you could put a list together.
- Invite someone from marriage guidance to talk about simple ways to manage conflict in relationships

Endings

Recap over the session. Final key message: Dementia can place pressure on relationships with families. Finding ways to manage conflict is therefore all the more important.



End with coffee and cake/coffee and food and closing ritual

When thinking about dementia it is easy to shift the focus and to concentrate purely on cognitive functioning and neglect the importance of keeping physically healthy. However increasingly research is highlighting that physical health, mental wellbeing and cognitive functioning are integrally related to each other 'and that individuals are better able to tolerate changes experienced when diagnosed with dementia if they eat a diet rich in antioxidants, control or manage cholesterol, exercise regularly, keep mentally active and have supportive social networks' (By Us for Us Guide)

Here we begin by exploring what this relationship is and some of the potential difficulties that may arise if physical needs are not addressed. Focusing on physical health, consideration is given to some of the challenges that living with a diagnosis of dementia can bring and strategies and techniques that can be used to help to overcome these. This session links closely to diet and dementia and these themes could easily be combined.

What people with dementia have said:

How we live our lives or the lifestyle choices we make can play an important role in maintaining good health and preventing illness. When diagnosed with an illness causing dementia a healthy lifestyle also becomes important in maintaining function, coping with stress and living well with the disease.
(DASNI)

Health-wise, I get very tired, so it does cost me a wee bit in extra tiredness, but as long as I get a clear day without a meeting the next day and I can relax, but it does take it out of me in terms of strength, and again, we are getting that wee bit older. I think the benefits to myself of being invigorated by the involvement outweigh the fatigue.

The aim is to enable participants to:

- Understand the relationship between keeping physically well and keeping mentally well
- Recognise how physical health can impact on cognitive functioning
- Identify strategies to embed health promoting activities into daily routines in order to optimise physical functioning



Keeping physically well

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

What is the secret of good health? (Sayings about keeping healthy: could be a mix and match activity: an apple a day keeps the doctor away, prevention is better than cure, early to bed, early to rise keeps a man healthy, wealthy and wise, you are what you eat, your body is a temple, a moment in the mouth a lifetime on the hips, breakfast like a king, lunch like a Lord, supper like a pauper) Resource 4.1

Is there any truth in these? What traditional health remedies have you tried?

Or share following quote from person with dementia and invite participants to respond to this in the context of their own experience

How we live our lives or the lifestyle choices we make can play an important role in maintaining good health and preventing illness. When diagnosed with an illness causing dementia a healthy lifestyle also becomes important in maintaining function, coping with stress and living well with the disease. (DASNI) Resource 4.2

Information giving:

Importance of keeping physically well when living with dementia (include information about delirium)



Discussion questions

- *Based on what you have heard, what is the relationship between physical health/well-being and dementia?*
- *What activities do you currently take part in to keep yourself physically well? (Diet, exercise, particular types of activity)*
- *What are some of the challenges to keeping physically well? What stops you? Can you share some of the ways you have tried to overcome these challenges (for example in one of the pilot studies one person shared how their loss of confidence was a barrier and how he had borrowed his son's dog and now goes for a regular walk)*



Keeping physically well

Session Agenda



Example activities

There are a number of opportunities here and much will depend on the priorities of the group:

Coping with sensory challenges

Existing sensory problems can intensify some of the difficulties experienced by people with dementia (for example making it harder for people to see/recognise objects or follow conversation). Dementia can also lead to individuals experiencing increased sensory changes. The Scottish Dementia Working Party have provided a very helpful guide to what some of these sensory changes may be and ways of coping with them. If you choose to focus on coping with sensory challenges as the focus of the activity you may find the following activities useful:

- As a group explore how sensory problems (poor eye-sight and hearing) can impact on the experience of living with dementia.
- Develop strategies that can help to overcome some of the challenges e.g. always putting glasses/hearing aids in the same place, arranging regular eye checks/hearing aid tests/ identifying opportunities for further support.
- Look at a range of assistive equipment to help manage sensory changes
- Invite an optician/hearing aid specialist to speak to the group. Offer the group the opportunity to develop a list of their own questions to form the basis of the discussion.

Managing medication

Once a person receives a diagnosis of dementia it is important for the person to review with their doctor existing medication they are taking and to look at some of the side effects of the medication, particularly if they increase the risk of confusion. In some cases individuals will have been offered medicines that can potentially slow down the progression of symptoms. This session offers the opportunity to invite a pharmacist along to the session to look at the types of checks individuals might wish to undertake with their GP, to ask questions regarding medications and interactions with diet and to explore some of the equipment that and reminders that can help individuals to manage their medication.



Keeping physically well

Session Agenda



Identifying infection

Many physical conditions can lead to increased confusion or agitation. There is an opportunity to discuss the impact of physical conditions such as chest and urinary tract infections, ways to spot these early and also how to access help. If you choose to focus on identifying infection as the focus of the activity you may find the following activities useful:

- Begin by looking at what services GP surgeries can offer. Work together to create a guide of 'how to get the most out of your doctor'
- Use the list of tips developed by the Scottish Dementia Working Party of how to build confidence in accessing services as the basis of discussion and an opportunity for participants to develop their own guide. (Resource 4.3)
- Discuss how infection can impact on dementia. Share a list of 'signs and symptoms of infection'. Look at ways to minimise the risk of infection. Work together to create a guide for families and friends. (Resource 4.4)

Endings

Recap over the session. Final key message: There is a close relationship between physical, cognitive and mental health. It is essential that every step is taken to keep as physically well as possible when living with dementia as physical health can significantly impact on how it is to live with the condition.

End with coffee and cake/coffee and food and closing ritual



Keeping physically well Keeping physically active

Engaging in physical activity can positively impact on the wellbeing of people with dementia. An active lifestyle has been shown to reduce the risk of falls, to maintain independence in functional activities of daily living and can contribute towards positive mental health improving confidence and self-esteem. Active living often promotes social contacts, providing the opportunity for social interaction and reducing feelings of isolation.

Physical activity may take a number of different forms including engaging in physical exercise as part of hobbies and leisure for instance, walking and attending a gym or as part of everyday routines such as gardening and house-work.

This session offers an opportunity for group members to explore the relationship between physical activity and well-being and to try a range of activities that could increase activity levels and be meaningful to individuals.

Physical activity is not regarded as something separate and distinct, but as part of what we do on a day-to-day basis. Individuals are helped to consider ways of making small, sustainable adjustments and changes to their lifestyle so that when viewed as a whole over time they can positively affect levels of general physical health and fitness.

***Group members who have not taken part in any regular exercise for some time or those with certain health issues should consider seeking medical advice before engaging in a sustained programme of physical activity.**

The aim is to enable participants to:

- Explore the relationship between physical activity, health and wellbeing
- Recognise opportunities where physical exercise could be incorporated into daily routines
- Identify some of the barriers to taking part in physical activity and develop ways to overcome these
- Participate in a range of leisure activities which are based on physical activity

Introductory exercises

Group lists ways of keeping physically active



Keeping physically active

Session Agenda



Group discussion topics

- *How can physical activity affect health and wellbeing? (for example physical health, fitness, emotional health, ways of coping with stress, social contact, sleep)*
- *What physical activities do individuals currently engage in/enjoy?*
- *How does dementia impact on the ability to participate in physical activities?*
- *What are the barriers to keeping physically active/well?*
- *Is exercise the only way to keep physically active or are there other ways to keep fit?*
- *Apart from keeping fit what other opportunities can taking part in physical exercise provide?*

Activity ideas

- Organise a session of armchair aerobics. Talk about how group members could practise these exercises at home
- Work together to create an active community booklet containing details of physical activity groups, sports and leisure facilities, sports events, dance classes, local gyms, walking groups). The group could identify potential venues that are dementia friendly
- Invite a local walking group to talk about the opportunities that exist in the community and ways to access these. These could form a focus of an outing
- This element of the programme lends itself very well to a series of practical taster sessions that group members can participate in (e.g. an indoor gardening group, t'ai chi)
- Organise a visit to a leisure centre where group members can try a range of activities for example bowling, swimming or using the gym
- In many areas a voluntary warden scheme exists. Wardens have a detailed knowledge of the fauna and flora of the local area and frequently lead voluntary walks, which are graded according to difficulty.
- Invite group members to go ten-pin bowling. The strength of this activity is that most bowling alleys have a range of different equipment for bowling, which means that everyone can participate.
- Sometimes having a specific goal in mind can help to increase motivation by giving a person something to work towards. A sponsored walk to raise money for a local charity could provide a real impetus.

Endings

Recap over the session. Final key message: There is a close relationship between physical, cognitive and mental health. Engaging in physical activity as part of everyday routines can support well-being.

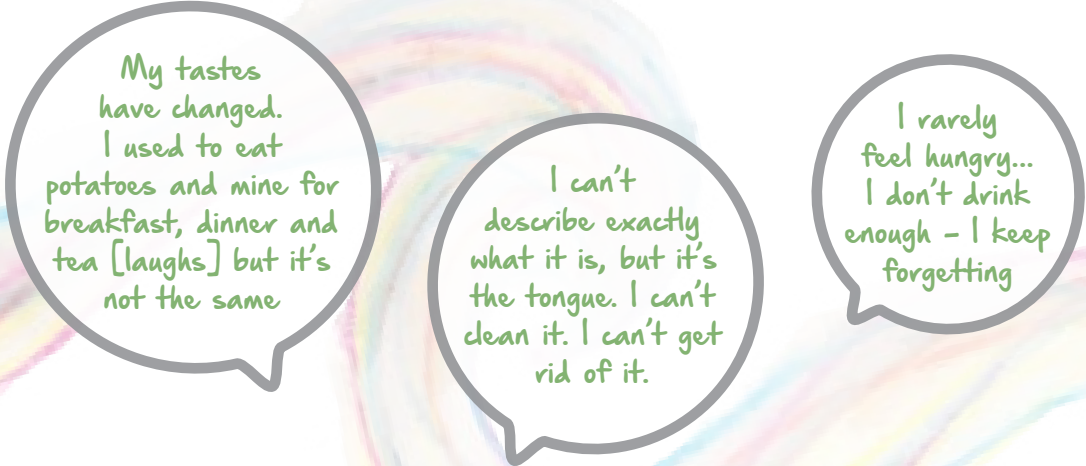
End with coffee and cake/coffee and food and closing ritual

Keeping physically well Diet and dementia



A balanced, healthy diet is key to preventing problems that can arise from missing out on important nutrients and to keeping physically, cognitively and mentally well. This is particularly true for some types of dementia (vascular dementia), where unhealthy lifestyle choices can raise blood pressure and increase the risk of cerebrovascular disease. Poor diet may be the consequence of making poor food choices, experiencing cravings (as a consequence of damage to areas of brain responsible for registering satiety and appetite control), under-nutrition as a result of using utensils to eat or prepare meals. Other difficulties can include problems in asking for food or communicating hunger, forgetting to eat or drink and olfactory dysfunction, which can reduce appetite. Diet and dementia is a theme could be included within the overall topic of keeping physically well or you may as a group decide to hold this as a session in its own right.

What people with dementia have said:



My tastes have changed. I used to eat potatoes and mine for breakfast, dinner and tea [laughs] but it's not the same

I can't describe exactly what it is, but it's the tongue. I can't clean it. I can't get rid of it.

I rarely feel hungry... I don't drink enough - I keep forgetting

The aim is to enable participants to:

- Understand the relationship between keeping physically well and keeping mentally well
- Recognise how physical health can impact on cognitive functioning
- Identify strategies to embed health promoting activities into daily routines in order to optimise physical functioning



Diet and dementia

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

What foods do you enjoy? What are your healthy and unhealthy pleasures?

Information giving

Include importance of eating and drinking healthily when living with dementia

Discussion

- *Does what you eat and drink affect what you do and how you feel?*
- *How do eating and drinking patterns change with age? Have you noticed any changes in your eating and drinking patterns since developing dementia?*
- *What are the barriers/challenges to eating a healthy diet? (For example, the difficulties in eating, problems in chewing or eating, forgetting whether or not you have eaten). Talk about strategies that can support this.*
- *Have you noticed any changes to food preferences/the taste of food or drink since developing dementia?*
- *How can maintaining a healthy diet become an activity in its own right?*
- *Do you have a dining routine? For example, eat particular foods on certain days, eat in a set place or at a set time, have a main meal at lunch time and a smaller dinner, have particular days when you eat with your family. How might having a dining routine help? (Discuss how it can support orientation)*

Activity

- Exploring healthy alternatives. The group participates in a food tasting session focusing on trying healthy alternatives to high fat foods; for example crème fraîche instead of cream, semi-skimmed milk instead of full fat. This could be developed as a 'taste test' so that participants sample different foods made with high fat and low fat alternatives and then have to guess which is which. If participants have a sweet tooth (for example craving chocolate) look at healthy foods that can act as substitutes.



Diet and dementia Session Agenda



- Quote to the group some of the ideas of ways to maintain a good described by people with dementia in the food and mealtime 'by us for us guide'. Work together to create advice sheets to share with family and friends (for example techniques that can act as prompts to remind people to eat, techniques to remind people that they have eaten)
- Invite participants to share their food likes/dislikes. Create a group cookbook that includes photographs or illustrations of favourite dishes. It might be that each of the pages is devoted to one of the participants' 'signature dish' or 'top recipe'. This could be an ongoing theme or activity, taking place over a number of weeks.
 - If individuals identify challenges in relation to eating food (physically using cutlery, recognising different foods) organise a practical session using different types of crockery/cutlery and trying different ways of eating (finger food etc)
 - Invite a person who attends the Alzheimer's Café or local luncheon club to talk about the opportunities available in the community for healthy eating socially.
 - Ask participants to spend a little time thinking about the food that they eat and the factors that their food choices are based on (predominantly taste but could pick up here whether people are having difficulties cooking or preparing food or eating)

Extension activities

- Invite a dietician to talk to the group, focus the session particularly around elements of a balanced diet and ways to maintain healthy bladder and bowel habits.
- Invite a person who attends the Alzheimer's Café or local luncheon club to talk about the opportunities available in the community for eating socially.
- Look at ways of ordering food on-line.
- Organise a session where you cook and share a meal together. Use this as a way to demonstrate techniques of remembering how to follow a recipe (e.g. wipe-able recipe cards to mark of stages once completed).

Endings

Recap over the session. Final key message: There is a close relationship between diet and physical, cognitive and mental health. Every step should be taken to eat healthily. This may mean not only looking at what you eat and drink but also at when and how you eat and drink.



End with a drink and a healthy snack and a closing ritual



Keeping mentally well Experiencing emotional well-being



When a person is diagnosed with a long term condition the initial response of shock and denial may be closely followed by feelings of low mood and depression as the person comes to terms with what is happening to them. This session offers participants the opportunity to talk about some of these feelings, how they impact on daily living and to consider a range of restorative activities, coping mechanisms and sources of support. It focuses particularly on ways of identifying and coping with anxiety, and approaches to expressing and managing difficult feelings.

What people with dementia have said:

I try to keep myself in a positive frame of mind, although at the time of diagnosis I felt as if I lost my sense of self and purpose

Be careful not to put yourself in situations where you will encounter stress and keep your emotions in check. This will help in maintaining a level existence. If you cannot avoid stress, try to keep it short term if possible and learn coping strategies to help you manage the stress in your life.

When I was given my diagnosis, it was truly more than a shock. My mental and emotional world fell apart and I slipped into a very, very dark and painful place. SDWG

The aim is to enable participants to:

- Recognise how dementia impacts on mental well-being and how anxiety and depression impact on the symptoms of dementia
- Explore a range of coping mechanisms and identify potential restorative activities and sources of support
- Practise a range of anxiety management techniques



Experiencing emotional well-being

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

What do you do to relax? Group members identify what they do to relax. You could consider what the most unusual relaxation activity is or activities that people describe as being particularly effective.

Information giving

- Untangling the relationship between anxiety and memory
- Why people with dementia might experience anxiety (feeling under scrutiny, practical issues, family dynamics, thoughts about the future)
- How anxiety impacts on memory

Questions to reflect on, to think about and to share

- *What activities enable you to experience a sense of wellbeing? These may be feelings of enjoyment, accomplishment, and increased self-esteem?*
- *Are there any activities that you find stressful? If so why? How do you cope with stress at the moment? Are there activities you can take part in that you find relaxing?*
- *What impact does your mood have on memory, energy and concentration (could focus particularly on stress)*
- *How do you express yourself when you feel stressed?*

Activities

- Reflecting on how emotions impact on functioning. Use Resource 5.1 (developed from the by us for us guide dealing with grief) to look at the physical impact of emotion and the psychological impact.
- Use examples (Resource 5.2) from the 'by us' 'for us' guide to develop a series of self affirmations (I don't need to worry about making mistakes. If I do, I'll forgive myself, it is important to allow myself time to grieve)



Experiencing emotional well-being

Session Agenda



- Use the four-picture sensory relaxation technique (Resource 5.3). Invite group members to practice this. If participants' memory recall is good introduce the five-finger relaxation technique.
- Working in small groups individuals describe particular situations they find stressful. Explore ways of making these situations less stressful.
- Explore some of the coping mechanisms that people with dementia have identified as being useful: discuss possible strengths and limitations of each. Work together to create a list of coping mechanisms that can help individuals to cope with some of the emotions they may experience
- As a group create a relaxation tape
- Explore a number of creative activities that can help to alleviate stress. For example, painting to music, mindfulness colouring books (Resource 5.4)
- Host a session of T'ai Chi or Yoga

Endings

Recap over the session. Final key message: A diagnosis of a long-term condition such as dementia brings with it a whole host of emotions. Recognising these emotions and seeking appropriate sources of help is key to living with the condition.



End with a drink and a healthy snack and a closing ritual



Keeping mentally well Sleep

Sleep is an important and very necessary part of everyday life. Insomnia and sleep disturbances significantly affect concentration levels, mood, cognition and actual and perceived coping ability. Insomnia can be both a symptom and cause of anxiety affecting health and wellbeing (Pandi Perunal et al 2002). The quality of sleep people experience will directly affect their lifestyle and tiredness and fatigue will make participation in activity during waking hours far less satisfying (Royal College of Psychiatrists 2005).

Sleep disturbance is common for people living with dementia with research suggesting that it affects approximately 50% of individuals (Sleep Health Foundation). Causes include disorientation due to the inability to separate dreams from reality when sleeping, disruptions in the sleep/wake cycle, reduced lighting and increased shadows causing people with dementia to misinterpret what they see and become confused. These problems can be compounded by factors not relating to dementia such as pain, nocturnal incontinence, and lifestyle. Indeed, low levels of activity and a sedentary lifestyle may reduce the amount of sleep a person requires which in turn can make sleep difficult to achieve.

Sleep disturbances do not only impact on the person with dementia but also on those living and caring for the person so this is an important topic to consider.

What people with dementia have said:

Our reality can become caught between dreams and daily life. Our dreams are so real it is difficult to recall what is dream and what is not

Dreams can be elusive while we toss and turn waiting for sleep. Dementia disturbs the circadian rhythm of our bodies so it feels like permanent jet lag. We cannot find the switch to turn off our brain. Warm milk, a hot bath or relaxing music may help.

The aim is to enable participants to:

- Reflect on current sleep patterns
- Understand how sleep affects day to day activities
- Consider how activity levels affect the quality and quantity of sleep a person has
- Recognize the factors that help or hinder a good nights rest
- Where necessary develop strategies to improve sleep



Sleep Session Agenda



Welcome and introduction

Introductory activities

Participants describe the perfect way to wake up in the morning (for example, to the smell of a cooked breakfast, to breakfast in bed, after having a lovely dream).

Information giving

Explain some of the factors that can cause difficulties in sleeping. Look at these factors in terms of the ageing process (pain, needing the toilet, low mood) and also in terms of some of the factors that relate to dementia (confusion between night and day, not recognizing home, difficulty in communicating physical discomfort, disorientation) If appropriate include information about sundowning.....

Group discussion questions

- *On average how many hours do you sleep each night?*
- *Have you noticed any changes to your sleep patterns?*
- *Describe your bed-time rituals and routines. Do they help or hinder a good night's sleep?*
- *How might sleep affect the day-to-day activities you are involved in?*
- *How does activity affect sleep and sleeping patterns?*
- *What prevents you from having a good night's rest?*
- *Apart from sleep, are there activities that you consider to be restorative, that make you feel relaxed and well-rested?*
- *Is there anything you would like to change about your sleeping pattern?*

Activity ideas

- Share ways of improving sleep and develop a short booklet called 'Tips to improve your sleep patterns'. This could be expressed in written or in pictorial form.
- As a group, practise a relaxation technique based on deep breathing. Group members could use the session to create their own relaxation tape. Resource 5.5



Sleep Session Agenda



- Use the hand-out 'sleep hygiene' to discuss strategies to improve sleep Resource 5.6. As a group create your own hand-out.
- As a group explore how music can enhance the quality of sleep. Consider different types of music. Invite group members to bring in examples of music that they find particularly relaxing and as a group compile a 'list of music to take to bed'

Endings

Recap over the session. Final key message: Quality of sleep impacts directly on quality of participation in activity and on wellbeing. Dementia can be a significant source of sleep-disturbance but a number of techniques exist to help overcome some of the ways that dementia impacts on sleep-patterns. End with a drink and a healthy snack and a closing ritual

Extension activities

- Look at examples of commonly available products include night-lights, intercom systems, clocks showing whether it is night or day.
- Look specifically at the environments where sleep takes place. Invite the group to develop a list of qualities or criteria that the environment must have in order to make it restful. Using this checklist encourage the group to put some of these into practice in their own homes and to give their own bedrooms a score based on how relaxing they are.
- Use individual sessions to offer practical help to make positive changes to the environment.

Dementia and daily living

Dining as an activity



Food and mealtimes are about more than just nutrition. The act of preparing and sharing a meal with others offers the opportunity to connect with others, to socialise to give and receive support and to build relationships. Mealtimes can provide a structure and a rhythm to the day and when made into a social experience can increase enjoyment of food.

For the person with dementia mealtimes offer individuals the space to continue with important roles; for example, preparing food, setting the table, making the tea or coffee, clearing away. Increasingly the evidence suggests that food choices can be influenced in the context in which meals are eaten. For people with dementia in particular there is strong evidence that dining in an informal, relaxed atmosphere increases the amount of food eaten.

This component of the programme enables the group members to explore their present eating habits and consider how preparing and sharing a meal can help to develop and strengthen social relationships and break down isolation. This need not be complex or time-consuming but could be something as simple as meeting with friends on a regular basis to have tea and biscuits, eating a packed lunch together or joining a luncheon club.

Within this session there is also the opportunity to plan, prepare, cook and share a meal. This will naturally be dependent on the resources available within the venue where the group is held. Throughout this element you will need to adopt good food hygiene and to check for any food intolerances or allergies that group members might have.

What people with dementia have said:

I just enjoy their company so much... even just to go for a coffee, so it isn't even the idea of just the food'

Would it be easier if they just did the shopping? Sure, but they know how much I still like to be able to do it and so I only go once a month like to do a large amount of shopping but I still keep my hands in that way and having [family] go with me now alleviates all of the problems of... not buying something that I should be buying and buying too much of something that I've already got at home.



Dining as an activity

Session Agenda



The aim is to enable participants to:

- Reflect on their present eating habits and dining routines
- Consider the difference between eating and dining as an activity
- Consider how dining can promote social contact and support routine
- Explore some of the challenges that dementia can present in the context of dining and look at ways to overcome these

Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activities

- Participants describe a 'memorable meal' (e.g. wedding breakfast, a birthday)
- Who would your ideal dinner date be?

Talk: Cover the following elements.

Talk: Dining and dementia. Importance of good nutrition, cues in the environment, challenges facing people with dementia in terms of eating (how memory, perceptual and motor problems impact on person's ability to use cutlery). Changes in taste that occur naturally with ageing and for people with dementia.



Group discussion topics

- *Do you have a dining routine? For example, eat particular foods on certain days, eat in a set place or at a set time, have a main meal at lunch time and a smaller dinner, have particular days when you eat with your family. How does this impact on activities during the week?*
- *How has dementia impacted on your dining routine? What strategies are you using/could you use to continue to make dining into a pleasurable activity?*
- *What opportunities do you have for sharing meals with others or for making dining into a social activity? Discussion could include the potential for eating with friends, going to luncheon clubs, joining others at a community café or sharing a faith lunch.*
- *How could you make eating a meal into a special activity?*



Dining as an activity

Session Agenda



Group activity ideas

- Design your ideal dining experience. Use the guidance in Resource 6.1 to look at ways of gaining the most from meal-times (for example think about dining rituals, the time of eating, noise, the importance of lighting).
- Devote a session to exploring favourite eating-places in the local community. Group participants are invited to identify their favourite restaurant, café or dining venue. Talk about what makes a restaurant into an enjoyable place to dine and things to consider in relation to eating out when living with dementia (e.g. how busy and distracting the restaurant is, travel, factors relating to the design of the restaurant).
- As a group think of ways to create an ambience for a romantic meal
- Dining out: concerns and solutions. As a group talk about individuals' concerns about dining out. Work as a group to develop joint solutions to overcome these concerns
- Invite a member of local luncheon club, community or Alzheimer café to talk about the opportunities available in the community for eating socially.
- As a group create a cookery book of foods to eat and enjoy (including finger food etc.)

Endings

Recap over the session. Final key message: The dining experience is about so much more than feeding the body. Finding a way to make mealtimes into a social or special occasion creates opportunities for interaction and relationship building. End with a drink and a healthy snack and a closing ritual

Further activities and opportunities for outings

- As a group plan, shop for, prepare and share a meal together. Use this to look at possible strategies that might be helpful in the future (e.g. ordering food on-line, shopping when less busy, looking at ways to pay for food etc)
- Make a local public house the venue for a session or include a pub lunch as part of an outing. Alternatively have a group picnic or barbecue. Eating outdoors can add a completely different dimension to dining and would be a good opportunity to consider further ways to make eating into a 'special occasion'.





Dementia and daily living

Safety in the home and in the community

The living environment has a significant impact upon independence. Dementia can result in a number of changes that can affect a person's ability to safely carry out activities in the home environment (for example forgetting how to use household appliances, experiencing problems with balance, loss of depth perception). Moreover, many people are not only living or learning to cope with a diagnosis of dementia but are also living with a number of additional health conditions associated with ageing. For example loss of visual acuity associated with ageing is a common risk factor for falls. If a person is living in a poorly lit environment or one beset with environmental hazards, risk is significantly increased. In addition to environmental hazards, factors such as reduced mobility, lower body weakness and increased reliance on a range of medication also greatly increase the risk of falls.

This session also recognises that fears relating to safety outdoors (including fear of crime) can severely limit perceived choices of individuals and, in turn have a negative effect on quality of life.

Journeying through dementia offers the opportunity to look at two potential areas; firstly how participants can take positive steps to keep themselves safe in the home environment.

Second the group members look at wider security concerns including ways of keeping the home safe and steps to increase personal safety when out and about in the community.

What people with dementia have said:

I have left the electric heating plates on the cooker switched on several times and am worried about causing a fire or people hurting themselves. Next week, I'm getting a new cooker, which automatically switches off when it is not being used and glows red when it's on.

It's easy to get lost ... everyone has done it. We can get turned around and get distracted or confused in a large crowd or busy traffic. Anyone can be fooled by a faulty memory or streetscapes that only seem familiar. Persons living with dementia are like everyone else but with extra challenges. Memory loss or reduced ability to solve



Safety in the home and in the community

Session Agenda



The aim is to enable participants to:

- Increase awareness of safety in the immediate and wider environment
- Develop strategies to reduce potential hazards
- Identify activities that are potentially risky
- Consider the range of equipment which can be used to increase both home security and personal safety

Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

Group members share something they have done that has been 'risky'

or

Group members choose a photograph from a selection showing different types of 'risky behaviour' (operating a gas cooker, scissors, balancing on a type rope) and either use these to talk about what is risky or put these in order with the 'most risky' first

Information giving: managing risk

Use the previous activity to highlight that we do 'risky' things on a day-to-day basis and the difference between risk and riskiness. Include how levels of risk are very individual and relate to the context, skills and also level of familiarity a person has with an activity. Consider how dementia might increase the risks associated with performing certain activities (as a result of loss of short-term memory or perceptual problems). Emphasise that there are steps individuals can take to reduce risk and increase safety.

Group discussion topics

- *Are there any activities that you do at home which are potentially unsafe?*
- *What activities help or hinder home safety?*
- *How can dementia impact on safety? (poor memory, disorientation, perceptual problems)*
- *How do you decide when a certain level of risk is reasonable?*
- *Does fear of falling ever limit the activities you take part in?*
- *Do you take any measures to reduce your risk of falling at home?*



Safety in the home and in the community

Session Agenda



Group activity ideas

- Develop a booklet of how to reduce the risk of falls and accidents in the home
- Explore a range of equipment to look at how technology may reduce risk in the home environment (for example fire alarms, kettles that switch off automatically, electronic reminders, anti-flood sink stoppers, carbon monoxide detectors, smoke alarms)
- Create a series of dos and don'ts to minimise risk aimed at family members (don't make huge changes to the home environment, do introduce new equipment in a timely manner etc.)
- Demonstrate how to move from lying to standing after a fall.
- Spot the hazard! Ask the group to identify potential safety hazards from photographs or pictures of a series of environments.

Safety around the home and community

Introductory activities

What would make the world a safer place?

Group discussion topics

- *When considering personal safety are there things that you could do when you were younger that you couldn't do now? (For example, being able to leave your door unlocked, letting children play outside, leaving the key under the back door step.) Why do you think this was so? (Bobby on the beat, more things for young people to do, more understanding society, good neighbours who lived nearby.)*
- *Are there activities that you don't take part in or only do at certain times because you are worried about your personal safety?*
- *How does dementia impact on your confidence when you are out and about in the community?*
- *Are there practical steps you take to increase your confidence/how safe you feel when you are out and about?*
- *How do you protect yourself against scams? (For example, offers that are 'too good to be true').*



Safety in the home and in the community

Session Agenda



Group activity ideas

- Talk about ways of spotting a scam. Bring in newspapers and see if you can spot any adverts that might be suspicious!
- Invite a crime prevention officer to advise the group about ways to protect themselves and their homes. Participants can generate a series of questions prior to this. If it is not possible for an outside speaker to come, arrange for the group to see a video about crime prevention.
- Talk about the telephone preference service now available, which screens out cold callers and advertising.
- Ask a fire prevention officer to talk to the group about how to reduce the risk of fire at home and what to do in case of a fire.
- Look at a range of equipment available to help people feel safer in the community. For example 'secret purses', personal alarms and information bracelets for individuals who have conditions such as diabetes.
- Look at ways to reduce disorientation and some of the equipment that can support with this (for example GPS in mobile phones, devices to help locate where people are). Work together to develop a list of strategies to increase confidence when out and about in the community (walking similar routes, joining walking group)

Endings

Recap over the session. Final key message: Dementia can impact on confidence. However, there are a number of simple steps you can take and a number of resources you can draw on to help increase safety in the home and community.

End with coffee and cake/coffee and food and closing ritual

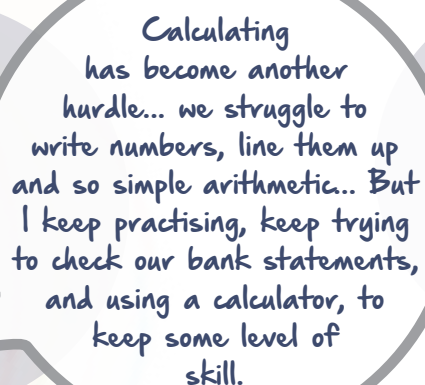


Dementia and daily living Managing finances



The programme recognises that finances can be a source of anxiety and tension for many people with dementia and their care partners. Coping with any change in financial circumstances can be challenging. However these may be compounded if a care partner is trying to assume control over monies and budgeting or if expensive specialist equipment is required, particularly if group members are living on a retirement pension. Sessions can be tailored to meet a range of needs but the focus is on how to help people with dementia make their own decisions in terms of who will look after their financial needs in the future when they arrive at a point when they can no longer manage these.

What people with dementia have said:

A large, light grey speech bubble with a dark grey outline, containing handwritten text. It is surrounded by several other smaller, faint speech bubbles of the same color. A colorful, wavy line in shades of pink, yellow, and blue flows from the bottom left towards the speech bubble.

Calculating
has become another
hurdle... we struggle to
write numbers, line them up
and so simple arithmetic.. But
I keep practising, keep trying
to check our bank statements,
and using a calculator, to
keep some level of
skill.

The aim is to enable participants to:

- Understand the relationship between finances and activity
- Explore some of the ways that dementia impacts on an individual's ability to manage finances and develop strategies to enable group members to take control of finances
- Look at the range of financial benefits individuals may be entitled to



Managing finances Session Agenda



Welcome and introductory activities

Can people remember what was in their first pay packet and what they spent this money on?

Talk: managing finances

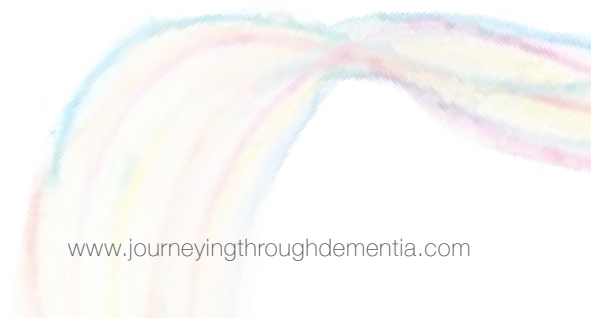
Include the following points: how dementia can specifically impact on a person's ability to manage finances independently (make reference to memory and dyscalculia). Consider some of the changes that families may need to make in how they manage financial affairs and some of the hidden financial costs of living with a diagnosis of dementia (in terms of equipment, adaptations etc). Look at some of the financial benefits offered by the state to offset some of these costs. Make reference to direct payments and to some of the legal steps a person with dementia may wish to take in terms of protecting their rights.

Discussion

- *Are there things that you enjoy that don't cost very much?*
- *What are the main challenges of managing money in today's society?*
- *How do memory problems impact on the ability to manage finances? (e.g. remembering pin numbers, coping with bills, recognizing the monetary value of particular coins or bank notes)*
Are there techniques/tips that can help with this?
- *How can managing finances provide an opportunity to maintain or develop new skills?*
- *If you had a question about finances, to whom would you go?*

Group activities

- Use the coping with finance hand-out (resource 6.2) to explore potential challenges in managing money and potential sources of support to help with this.
- Invite a person from the Office of Fair Trading to talk about ways participants can protect themselves against financial abuse





Managing finances Session Agenda



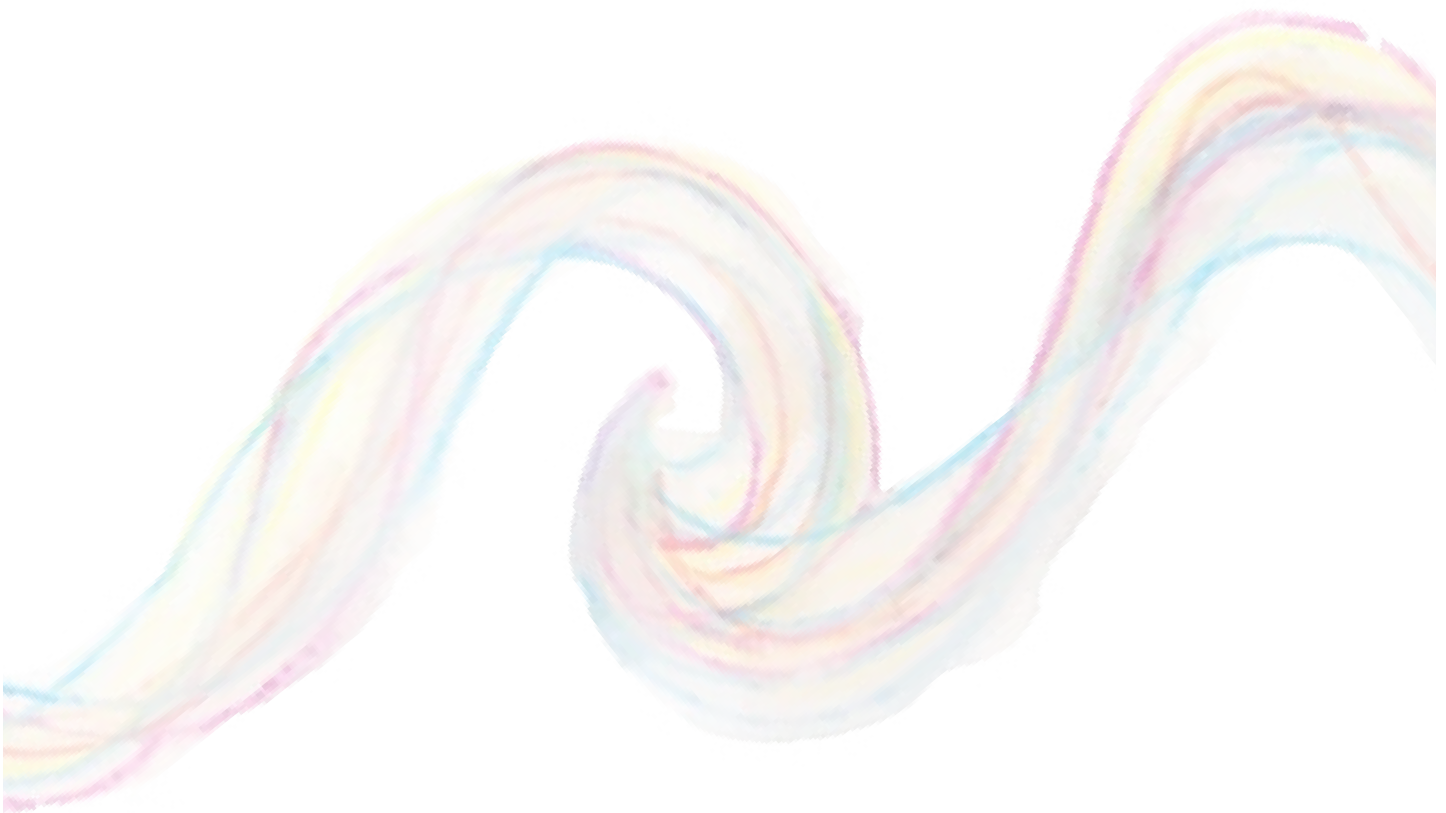
- Develop a list of 'top tips' for managing money – think about ways that can help in day to day transactions (for example having the correct change in your purse/wallet to pay for a specific item, setting up direct debits and standing orders)
- Look at the range of benefits individuals and their families may be entitled to
- Thinking about the future: invite a solicitor to talk about managing personal affairs and enduring power of attorney.

Endings

Recap over the session. Final key message: Finances can be a source of concern. However by accessing the range of support available it is possible to find ways to manage your money.



End with coffee and cake/coffee and food and closing ritual



Building and developing skills Hobbies and leisure



Interests and pastimes include meaningful activities stimulated by skills, interests and aspirations. These are not directly essential for the maintenance of independence, but are essential if quality of life and a sense of personhood is to be maintained (Csikszentmihalyi, 1993). Dementia may impact on a person's ability to engage in interests and past-times. However individuals living with dementia have spoken of the value of continued involvement through adaptation to how and where the activity is performed. This session very much focuses on the grading of activity.

What people with dementia have said:

Our experiences during leisure mean something important to each of us. Leisure allows us to continue to express who we are and what we value about ourselves by using our unique skills and abilities gained over our lifetimes.

The background of this section features a soft, watercolor-style rainbow with yellow, orange, and pink hues. A grey speech bubble with a white border contains the text, which is written in a casual, handwritten-style font.

The aim is to enable participants to:

- Reflect on hobbies and pastimes understanding how dementia has impacted on the individual's ability to engage in these
- Connect with past interests
- Understand the barriers which prevent a person from engaging and maintaining hobbies and pastimes and explore ways of overcoming these
- Develop strategies to help to re-engage with these where appropriate and to explore the range of equipment which exists that might enable a person to do so



Hobbies and leisure Session Agenda



Information sharing

Discuss the value of continued engagement in hobbies and past-times.

Introductory activity

What is the most unusual hobby a group member has engaged in?

Group discussion topics

- *What are the benefits of engaging in hobbies and past-times?*
- *Are there particular hobbies that individuals enjoy and still engage in?*
- *What are the challenges of continuing to engage in hobbies? How does dementia impact on a person's ability to continue to take part in valued activities?*
- *What strategies have people found helpful in enabling continued engagement in hobbies and leisure interests?*
- *What are the benefits and drawbacks of focusing on developing new interests and hobbies rather than trying to master existing/previous hobbies?*

Group activity ideas

- Invite the group to consider a pastime that they currently enjoy. Ask them to list all of the benefits that they gain from taking part in this activity.
- Group members are asked to think of an activity that they have previously enjoyed or presently enjoy but find difficult. Working as a group consider ways of simplifying the activity. This might be the time it takes, the number of stages, materials that are used, equipment that could facilitate the process, doing the activity in a different way, or with others. Look at ways of compensating for some of the challenges that dementia brings (memory, ways of sequencing, number of steps required).



Hobbies and leisure Session Agenda



- Ask group members to consider an activity that they enjoy doing but which they no longer participate in. Invite them to think about what prevents them from taking part in this and what they would require to resume the activity. In recognition that many older people enjoy gardening, use a practical session to create an indoor garden or to pot up a series of tubs or hanging baskets. Invite a local gardening or allotment group to speak about the opportunities for engaging in this activity in the community.
- Explore the range of equipment available to help older people to continue hobbies or interests. This could be combined with a visit to a craft outlet.

Endings

Recap over the session. Final key message: Hobbies and leisure interests can promote well-being and support a sense of personhood. There are ways to adapt activities to enable continued engagement.



End with coffee and cake/coffee and food and closing ritual



Building and developing skills Learning something new

Within this element of the programme participants look at ways of keeping mentally active and explore how the process of learning something new can affect their health and well-being. People often make the assumption that having a diagnosis of dementia means that it is impossible to learn new things. Increasingly we know from accounts written by people living with the condition that this is untrue. Dementia can cause people to lose confidence and as a result the idea of taking the risk to try something new may feel difficult and scary, especially if there is the possibility that it may result in some kind of failure. Also it may take longer to learn new things and memory problems may mean that a different or new approach to learning needs to be used. However people with dementia have described how they have learned how to use a computer from scratch or mastered the art of the digital camera and as a result of this have been able to access incredible opportunities. If such skills can be learned early enough there is a good possibility that they may offer increased stimulation and that such skills can be generalized into everyday functioning.

What people with dementia have said:

Being told I had dementia led to a door re-opening after a difficult time in my life: new challenges, new friendships. I wanted to raise awareness about dementia and show that people with dementia can re-learn forgotten skills as well as learn new ones.

The most exciting possibility is that a person challenged by dementia might actually for a period of years become more intelligent in verbal and non-verbal problem solving given that normal problem solving strategies are quite inefficient. It is possible that a person who is forced to slow down and simplify may develop new creative and intuitive strengths which are not only valuable in themselves but can be adapted for problem solving.

The aim is to enable participants to:

- Reflect on the skills and abilities individuals possess
- Identify skills, knowledge or new learning they would like to develop or acquire
- Understand what the barriers are that prevent individuals from accessing such opportunities and to consider ways to overcome these



Learning something new

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activities

Participants describe a time when they learned something new: you could frame this around: What is the most unusual thing you have ever learned to do? What is the most difficult thing you learned? What is your earliest memory of learning something? What learning has given you the greatest sense of accomplishment?

As facilitator record examples of things people have learned and start to draw out from the conversation how group members learn (through doing, by watching others, through practice)

Information giving

Include information about how mastering new things relates to self-esteem and relationships, factors that can impact on learning and conditions that facilitate the process (non-judgmental, time, structure, clear goals, mirroring an activity, building things into routine). Discuss the advantage of learning something completely new as opposed to revisiting existing skills.

Discussion questions

- *What are the advantages and drawbacks of learning new things rather than trying to master an activity that you already know?*
- *What do you think you could gain through learning a new activity?*
- *How might dementia stop you from learning new things? How could you overcome these challenges?*
- *What resources are available if you wanted to learn something new?*
- *What skills/talents do people in the group have that they could share?*
- *What activities do you share with friends and family?*

Learning something new

Session Agenda



Group activities

- Share inspirational case studies/personas/descriptions of what people with dementia have gained through new learning. Consider the resources that have enabled this to happen. Identify similar opportunities in the local community.
- As a group learn a new activity together (e.g. making a hand-made book, using an ipad, preparing a particular dish, photography etc.)
- Invite group members to think of an activity they would like to learn. This might be something they would like to do together (a particular dance, a craft) or it might be a skill that they would like to master on their own (photography, a new recipe, changing a plug). Talk about resources they could use to help them do this. Using an individual session to revisit people's progress.
- Skills sharing: invite group to demonstrate/share an activity they enjoy
- Create a list of dementia friendly community-organisations where people can access and learn new things (e.g. local history society, local sports centre, galleries and museums, local colleges)
- Invite a speaker to talk about opportunities for volunteering in the community

Endings

Recap over the session. Final key message: Maintaining and developing new friendships can offer a valued source of support, reducing social isolation, offering practical and emotional help.



End with coffee and cake/coffee and food and closing ritual





Learning something new

Session Agenda



Extension activity

- Organise a visit from or to a local college or arrange for the group to attend a taster session. Many colleges are happy to organise these and they often provide community outreach opportunities. Explore ways to access these.
- Focus a session around learning new technology. Again a number of colleges or libraries offer sessions in the community using lap-tops – link this with the session on building and maintaining friendships (e.g. looking at the Internet and e-mail or social media). You could dedicate an entire follow up session (see outline of learning something new: mastering computers and mobile telephones)
- Visit the local library to look at what is available in the community
- Look at opportunities in the community that could form the basis of shared activities for the person and their family. Use the following as inspiration: <http://www.moma.org/learn/disabilities/dementia>
- Use an individual session as the focus of an activity of learning something new with a family member. Explore things individuals could share together.



Building and developing skills Mastering computers and mobile telephones



Over the last ten years technological advances have moved apace to the point that mobile telephones, digital cameras, DVDs have become part of everyday life. During this time there has been a growing recognition that technology can help people living with dementia to compensate for some of the difficulties that the condition brings. For instance, individuals have spoken of the number of opportunities that being able to use the Internet and e-mail have provided in terms of communication and in performing simple practical timesaving tasks such as ordering shopping and on-line banking. This session enables participants to explore the potential of a range of technologies and offers individuals the opportunity to master skills in using the computer and digital media. This element of the programme builds on the session 'learning something new'.

What people with dementia have said:

The computer is great assistive technology. Often, I couldn't find my mouse cursor on the screen. But Windows lets me make it bigger and add a tail, so it's easy to find. I use the Outlook Calendar to keep track of all my appointments, setting one reminder a full day in advance and another just a few hours before.

I work on E-mail a lot. For those of us with memory problems, that thread of replies... the Re: Re: Re:... becomes our memory. We can scroll up to the start to remember where we've been and what other people have said.

It was wonderful to get e-mails regularly from friends in the USA and in Canada who also had a diagnosis of dementia and yet like me were still able to communicate.

The aim is to enable participants to:

- Recognise how digital technology can offer a source of stimulation and support memory
- To explore approaches to learning new things
- Build confidence in learning something new



Mastering computers and mobile telephones

Session Agenda



Introductory activities

Invite group members to share memories of 'new technology': for example first television, first radio. Use this as an opportunity to talk about it felt, worries that people had about getting to grips with this technology.

Talk

Include discussion in terms of how being able to use a computer can be a great benefit for a person with dementia and their care partner. Talk about computer and memory, ways of using the Internet to keep in touch with others and reduce social isolation, how the Internet can help in terms of finding information. Look at potential resources to help people use the computer.

Potential discussion questions

- *What might be some of the benefits of being able to use a computer?*
- *How could a computer act as an aid to memory?*
- *What strategies and resources have people used/could people use to learn the computer? (Grandchildren, free classes etc.)*

Group activity

- The group activity provides the opportunity for a practical session or a series of practical sessions that look at ways to learn how to use a computer. Use this as an opportunity to explore community resources either accessing a local college or library.
- Group members should be given simple step-by-step diagrams and instructions to follow. It is important not to overload individuals with information. Keep tasks simple and focused. Ideas for sessions could include:
 - Sending an e-mail
 - Looking at a web page (Alzheimer's Society, Scottish Dementia Working Group, DASNI)
 - Finding information using the Internet (use the Internet information hunt)
 - Using a group discussion board (the DASNI) site is good for this
 - Sending a text message



Mastering computers and mobile telephones

Session Agenda



- If group members already have skills look at ways of using the computer for:
 - Digital scrapbooking
 - Powerpoint as a tool for building your family tree
 - Look at the number of apps for people with dementia

Endings

Recap over the session. Final key message: Over the last ten years technological advances have moved apace to the point that mobile telephones, digital cameras, DVDs have become part of everyday life. During this time there has been a growing recognition that technology can help people living with dementia to compensate for some of the difficulties that the condition brings.



End with coffee and cake/coffee and food and closing ritual

Building and developing skills

Taking time out: holidays and short breaks



This part of the programme recognises the importance of building in planned breaks both for the person with dementia and their supporter/family/friends. It looks at the range of opportunities that are available in this country and abroad and considers the advantages and drawbacks of the person with dementia and their care partner taking separate or joint holidays in terms of their present circumstances and possible future circumstances as dementia progresses. Group members take a joint problem solving approach to look at strategies to overcome some of the barriers that dementia poses in terms of taking holidays. The group is provided with information regarding the range of organisations that offer specific breaks and support for people with dementia and their carers.

What people with dementia have said about holidays?

Being away from a familiar environment and routine can feel challenging but I like to push myself and it is good to get away together sometimes.

Travelling alone can be difficult even for people with early stage dementia, who may be worried about getting lost in unfamiliar places, or coping if there is a problem such as a cancelled train or plane. However, many people with dementia do travel alone successfully.

The aim is to enable participants to:

- Recognise the possible challenges and the value of having regular breaks and holidays away from the home environment, particularly with regard to family relationships
- Identify some of the resources available for people with dementia and their families



Taking time out: holidays and short breaks

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activities

Individual members share the most 'exotic' place they have ever travelled to. Mark this on a map

or

Group members describe their ideal holiday: what would be the 'ingredients' of a good holiday? (relaxation, sun, alone, with family, outdoors, a beach, hills)

Talk

Include the following elements: the importance of taking a regular break, some of the challenges and the potential benefits of holidays, charities and organisations that can offer support with holidays for older people and people with dementia.



Discussion

- *Have you noticed any changes in the type of holidays you take and the destinations you go to over the last few years?*
- *What factors impact on your choice of holiday? (for example: cost, transport, time of year, mobility)*
- *What do you gain from going on holiday? (Relaxation, romance, relationship, time for you, physical fitness, thinking time, new friends, new hobbies) What is the minimum amount of time you need to go away for in order to experience a benefit?*
- *What opportunities do holidays provide in terms of developing new interests/hobbies/activities and building new friendships?*
- *How does/will dementia impact on your choice of holiday and holiday destination?*
- *What concerns do you have about going on holiday? (worry about being in a different place, worries about leaving the house, pets, what happens if something goes wrong, concerns about travel, loss of confidence, negotiating problems)*
- *What resources are available if you would like to go on holiday? (family members, friends, accommodation etc.)*



Taking time out: holidays and short breaks

Session Agenda



Group activities

- To be alone or not to be alone: As a group explore the advantages and drawbacks of holidaying alone
- Work as a group to create an advice sheet for people with dementia who want to travel abroad. Use the Alzheimer Scotland advice sheet (including checklist) on holidays as the basis of discussion (resource 7.1)
- Watch the following video of dementia adventure
- and use this as the basis of discussion regarding the strengths and limitations of holidays organised specifically for people living with dementia and their families
- As a group create a leaflet to provide information about the range of organisations available that can offer support with holidays. The following may provide a useful starting point:
 - Tourism for all UK: info@tourismforall.org.uk - offers advice and information
 - Dementia Adventure: <http://www.dementiaadventure.co.uk/holidays> a registered charity committed to helping people living with dementia to get outdoors, connect with nature and their community
 - Holidays for all: www.holidaysforall.org.uk A consortium of accessible holiday providers offering holidays in the UK and abroad
 - Can Be Done Holidays holidays@canbedone.co.uk

Endings

Recap over the session. Final key message: Dementia can place pressure on relationships with families. Finding ways to go on holiday or to take a short break can provide stimulation and offer space for families to spend quality time together.



End with coffee and cake/coffee and food and closing ritual

Dementia will ultimately impact on a person's ability to drive safely and ultimately this will necessitate the person using other methods of transport. Effective transport systems are essential for minimizing social isolation and for fostering engagement of people with dementia with their community. Previous studies have linked difficulties in accessing public transport with barriers to taking part in activities in the local community, meeting with friends, going on holiday and seeing family.

It is therefore important that the programme addresses this issue, explaining barriers to accessing transport and how individuals might overcome these if they so choose. Challenges can exist on a number of levels and may not simply relate to issues arising as a consequence of dementia. Mobility, for instance may be an issue, or have difficulties in reading and understanding a timetable or simply may never have used public transport before and as a consequence lack confidence. In the Lifestyle Matters study undertaken by Craig and Mountain (2004) participants cited problems travelling to the group as being the single largest obstacle in attendance.

What people with dementia have said:

It is a bitter blow losing your license and you have no idea just how crippling it is until it happens to you. Your mobility is turned upside down. Your freedom to get up and go at a moment's notice is gone. You lose your independence.

At this stage the GPS solves my problems. When I can no longer drive I will use buses and I can ask the bus driver if I can't understand the bus stop signs.

I use the same roads most of the time and only go from place A to place B.



Transport Session Agenda



The aim is to enable participants to:

- To consider how dementia impacts on driving
- To understand the relationship between activity and transport
- Understand what potential opportunities could be made available if individuals are able to access different modes of travel
- Identify barriers which prevent this from happening
- Consider ways to overcome these barriers
- Provide opportunities to try out different forms of transport within the safety of the group
- Recognize that travel can be a leisure activity

Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activities

Ask group members to list all the different types of transport they have used recently or invite the group to describe the most unusual mode of transport participants have used (this is a good way to draw on their experience)

Information giving

How dementia impacts on choice of transport and importance of finding different types of transport in order to access meaningful activity

Discussion questions

- *How has dementia impacted on your transport choices?*
- *How does the availability of transport affect what you do on a day-to-day basis?*
- *Are there activities you no longer do because transport is a problem? For example not going to church because of Sunday bus timetables.*
- *What are the challenges of travelling by public transport (buses, trains) when living with dementia?*
- *What are the strengths and limitations of different types of transport in and around the area?*
- *How can travel be a form of activity or a leisure pursuit?*



Transport Session Agenda



Activities

- Share the video: <https://www.youtube.com/watch?v=eIUdbwt9C9> and use this as the basis of developing a guide to transport for people living with dementia.
- Discuss the strengths and limitations of a range of transport choices in the locality
- Plan a journey together, considering the stages involved, possible barriers and ways to overcome these
- Invite participants to identify creative problem solving techniques when overcoming barriers to using public transport (for example noting key landmarks on a journey, carrying just the right amount of money for the bus/train fare)
- During a computer session use the Internet to check train times, the availability of trains and any discounts that might be available. Look at how the computer and Google-maps might enable individuals to 'virtually' rehearse their journey.
- Work with the group to explore possible things to do if they become lost.

Endings

Recap over the session. Final key message: Being able to navigate public transport can potentially be a key link to accessing valued activities in the community. A range of resources exists to support individuals in managing transport.

End with a drink and a healthy snack and a closing ritual



Transport Session Agenda



Extension activities

- Invite someone with responsibility for community transport to speak to the group. Use this as an opportunity for participants to ask questions. Examine potential transport passes that can alert drivers to the fact the person may need more time or support to access the vehicle
- If you are using community transport services invite one of the participants to take responsibility for booking transport
- The theme of transportation provides the opportunity to explore the range of transport options available in the local community. Depending on the needs of the group you could begin by arranging a visit that is relatively local and, as time progresses, consider ways of negotiating longer journeys.
- Within individual sessions use a graded approach to using public transport. If a person experiences difficulty or anxiety when travelling on a bus arrange to travel with them for the whole journey during the first session and then gradually withdraw this support over the weeks so that you meet them after one bus stop, two bus stops and then at the terminus.
- Invite a person from the DVLA to talk about driving and dementia



Keeping connected

Maintaining community connectedness

Community connectedness is the product of fostering the engagement of older people in their community. This part of the programme invites group members to consider how the community can provide a source of support and also how it might offer opportunities for people with dementia and their families to develop new roles and interests by accessing local groups and resources or through volunteering.

What people with dementia have said:

Make sure we retain social networks. It is very hard for us to be who we once were so let us be who we are now...Include us in activities of community organisations

Being socially active is fun, it keeps you active, provides mental stimulation, maintains language skills, connects you with people with similar interests and provides companionship and a sense of accomplishment.

The aim is to enable participants to:

- Identify the range of community organizations that exist in the locality and to build understanding of what these offer
- To consider how to access relevant organisations, identifying potential barriers and ways to overcome these.



Maintaining community connectedness

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

Introductory activity

See how many community resources the group can name that they currently access or may like to access in the future

or

Look at a map of the local community: identify key resources that individuals currently use or resources that could support participants in their on going journey with dementia

Information giving

What community resources can offer.



Discussion questions

- *What do you understand by the term community? What communities are you already part of? (faith, community, geographical community)*
- *What community groups/organisations have you come into contact with in the past? (participants are invited to share experiences of these)*
- *Do you think that people in general are aware of dementia or is it still very much a hidden condition? What steps do you think the community could take to make it more dementia friendly?*
- *What do you already know about organisations that specifically support the needs of people living with dementia?*
- *What would prevent you from making contact and using services offered by the voluntary sector? What factors would support you?*
- *How might you play an active role in contributing to some of these services? What do you feel you have to offer the voluntary sector?*
- *How can community and voluntary sector organisations help to support you in developing new roles and new activities?*
- *What are the strengths and limitations of being part of a group that is specifically aimed at people with dementia and their carers?*



Maintaining community connectedness

Session Agenda



Group activity

As a group compile a small booklet of community based organisations that could offer services that you could either contribute to or that might provide you with support. Don't confine this list to organisations that specifically focus on the needs of people with dementia: for example talking books, the Blind Society and Age UK and have a number of services you could tap into. Alternatively as a group list services participants would like to access, for example: holidays, sitting services, help with the garden etc. and research possible organisations that offer these. Invite individuals attending the Alzheimer's Society to talk about the services they offer and the great benefits that people can experience through attending sessions in the community. Invite a range of voluntary organisations to hold an 'information fair' and open this up to the wider community as a way of celebrating the range of local community facilities.

Endings

Recap over the session. Final key message: Many voluntary sector organisations exist. Taking time to understand what they offer and ways to access these many open up future opportunities both to receive support but also for developing new roles as a volunteer.



End with coffee and cake/coffee and food and closing ritual

Extension activities

- Arrange for a talk from a community organization about the volunteer opportunities available.
- Organise a group visit to a local volunteer project
- Look out for opportunities where the community comes together (e.g. festivals, celebrations, summer and Christmas fayres). Look at ways you can contribute to these to raise awareness of dementia in the community.
- Arrange for a visit to a dementia cafe
- Talk about the Dementia Advocacy and support Network International (DASNI) which is a group specifically for people with dementia. This is an internet based support group. You could hold a session at a local college or place which has access to the web and dedicate a session to explore the web-site.
- Watch the following video and use this as the basis for discussion: <https://www.youtube.com/watch?v=mdqucRPRQTo>



Planning for the future: Tapping into future support: health and social care



This session needs to be handled with great sensitivity. If person can be part of the decision making process then this is certainly the preferred approach as joint decisions can be made and discussed openly in a warm and supportive atmosphere. However if at any point you feel that group members are not ready for such a discussion then you may wish to consider ways of adapting this and possibly offering it as one of the separate sessions.

Welcome and introduction

Introductory activity

Using resource 9.1 group members complete the phrases :

- When I think about the future I look forward to....
- When I think about the future I worry about...

Collect these slips of paper and place them in a hat. Draw each one out in turn and talk about each as a group. These will form the main focus of the discussion.

Discussion

- *What have been your experiences of receiving outside help and support? Are there things you wouldn't want support with?*
- *What will help you to feel in control of future decisions?*
- *Have you spoken about what you would like to happen in the future and have you written this down somewhere. What happens if your thoughts around this change in the future?*

Group activity

- Use resource 9.2 to explore your current needs and your perceived future needs
- Wish lists..... in an ideal world what support would you find useful. Compare this to what might be available.
- As a group decide when particular services might be helpful. Use the word cards of resource 9.3 as a starting point:



Tapping into future support: health and social care

Session Agenda



- equipment and adaptations
 - meals on wheels
 - home care
 - respite care
 - day care
 - care in a care home
- Match the health professional to their role using resource 9.4
 - It is important to use this part of the programme to look at some of the practicalities that individuals may meet in the future. It would be a good opportunity to invite a number of outside speakers. Provide group members with plenty of advance warning so they can prepare questions relating to any concerns they have. For example you could:
 - Invite a person from social services to talk about the community care assessment. Include information about what the assessment is and how to gain a referral. Use this as an opportunity to discuss direct payments. This may require a separate session.
 - Arrange for a talk on the legal aspects of care including enduring power of attorney and the Mental Capacity Act.

Endings

Recap over the session. Final key message: Thinking about the future is difficult for everyone. However by considering what is important now can help to put things in place and make decisions in the future less stressful.



End with coffee and cake/coffee and food and closing ritual

Planning for the future: Moving forward: celebration and endings



The programme represents a journey, a bridge at a point of huge transition. However, its aim is not to create a culture of dependency. The final sessions provide participants with the opportunity to celebrate their achievements, the relationships they have formed and consider the key learning they will take from the group as they continue forwards. The final session includes participants' supporters/care partners.

This programme will for many have occurred at a key time in the person's life. The prospect of it coming to an end will therefore be extremely emotional. Indeed, over time the group will have provided members with a safe environment for the discussion of personal issues. This may have led to the challenging of deeply held ideas about who they are and what having dementia means. It could have been a place where they received social support and possibly developed new skills. It is therefore inevitable that many individuals will view the ending of the group with a range of emotions.

As James McKillop states;

Perhaps encourage them to meet up outside the planned meetings, to go for a coffee or explore the countryside, go to the theatre/pictures of local museums. Train them to depend and rely on themselves more and more. While it would be good to go on seeing them ad infinitum remember there is another body of people waiting in the wings to start their course. And when they finish, more will be waiting and so on.

The final sessions aim to support each person in negotiating and managing this time of transition. You will need to consider how you will prepare group members for the ending of the programme and to look towards sources of support on which they can draw in the future.

You will have been preparing the group for this final session for some time. People will need space to talk about how it feels to come to the end of the programme and time to allow individuals to celebrate and reflect on their achievements. It can be useful to dedicate time in the sessions over the final weeks to allow the group to decide how they would like to spend their final meetings and how to involve family in this. This is important as it gives the group a sense of ownership and control over the process. It also provides an excellent model if the group members decide that they wish to continue to meet independently without input from group leaders. This final session includes family members or supporters.

The aim is to enable participants to:

- Reflect on their achievements
- To identify what they have learned through taking part in the programme
- To provide individuals with the space to say goodbye to each other and to move forward to the next phase of their journey with dementia.



Moving forward: celebration and endings

Session Agenda



Welcome and introduction

Recap over the last week using visual map as reference. Introduce this week's session.

What people with dementia have said:

Any dangers? Yes. People will form relationships with themselves and with the facilitators. You love someone who gives their best to help you. It can be a wrench stopping the group...

Introductory activity

Individuals share one memorable moment/one thing they have appreciated about being part of the group or individuals look through photographs taken over the duration of the group

Information giving ... together

Recap over the original aims of the group and then a walk through session by session with participants sharing things they remember/things they have found helpful/unhelpful. Use the handouts that group members have been sent to offer a possible structure.

Discussion questions

- *What would you tell someone who is thinking about coming to a group like this?*
- *What do you think you have learned over the last 12 weeks?*
- *How do you think you can keep putting into practice what you have learned?*



Moving forward: celebration and endings

Session Agenda



Possible activities

- The group explores ways of maintaining relationships and think about how to keep in touch: through letter writing, e-mail or the telephone. Participants could create a telephone tree to help this process.
- Reflect on 'golden, moments': precious memories or famous quotes spoken by participants
- Exchange names, telephone numbers and addresses
- Present each participant with a certificate or a transitional object such as a plant, a reminder of the importance of growth and of being continually nurtured. Such objects can be powerful symbols of transition.

End with a shared meal with participants and their families and supporters.





Thank you for reading.
For more information please visit
www.journeyingthroughdementia.com

Journeying through dementia Group Recording Sheet



Date	Time	Venue
Facilitators		
Group Participants		
Session Outline and resources required		
Description of session		
Theme of next session – resources required		
Key Learning Points/Reflections		



Journeying through dementia

Individual recording sheet

Date	Time	Venue
Name of participant		Name of facilitator
Identified aim/goal of session		
Description of session		
Date/time of next session – resources required		
Key learning points/reflections		

This manual is a development of an earlier publication: *Journeying through Dementia*:
Claire Craig and Gail Mountain. The publication was designed by Helen Fisher.



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Journeying through dementia: an occupational approach to supported self management

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