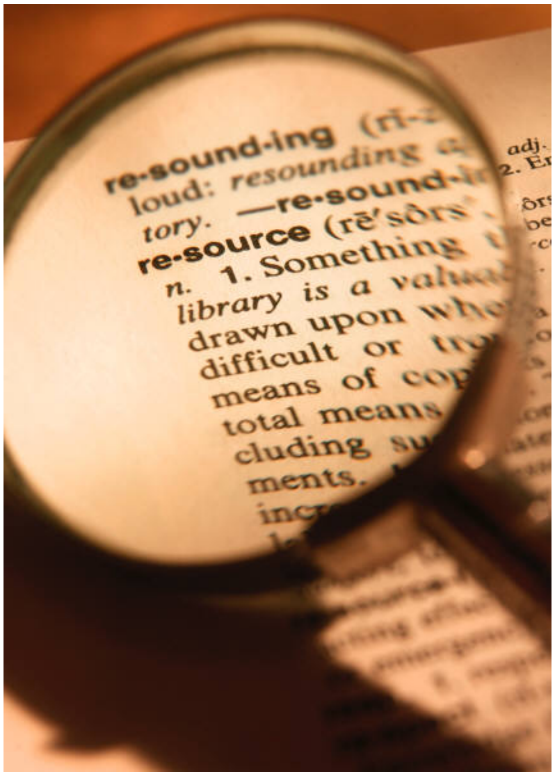
Care Services Improvement Partnership CSIP

National Older People's Mental Health Programme.

Strengthening the Involvement of People with Dementia

Supplementary Resource



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Campaign and support groups

PROP (People Relying on People Group), Doncaster

PROP is a group of young people with dementia and their carers/partners who are actively involved in service development.

The group has existed for many years, meeting weekly as a whole group and also separately for people with dementia. They are a close knit, supportive group who are seen as 'Change Agents', speaking at, and attending conferences and training events; being involved in staff recruitment and development; research and information.

Further information: caroline.kendrew@dsh.nhs.uk

Huddersfield - Living Positively with Dementia Project

Huddersfield branch of the Alzheimer's Society provides support groups for carers of people with dementia as well as weekly group meetings for people in the early stages of dementia. The group has developed the confidence to welcome visitors, generally from statutory services who sit with the group, listen, ask questions and learn from group members. Group members, whilst not active campiagners, are very keen to have their voices heard.

For further information, contact:

Jean Dutton, karen@alzheimers-hudds.org.uk

Scottish Dementia Working Group (SDWG)

This group, based in Glasgow, consists of younger people with dementia who are campaigning for improved services. They were actively involved in **recruitment and selection** of their full-time Involvement Officer

For further information contact SDWG national co-ordinator Philip Bryers at pbryers@alzscot.org

You can join a list for email updates from SDWG by visiting http://www.alzscot.org/pages/sdwg.htm

Additional resources are listed in further reading section

Focus groups

The issues Bruce & Bamford raised are:

familiarity - in order to make the groups distinctive yet avoid generating anxiety were:

- holding the focus groups in a familiar setting
- meeting participants informally beforehand
- inviting a member of staff to the initial meetings
- using ritual to frame the questions

context - the importance of enabling people with dementia to say what they want by thinking about confidentiality, triggers and interactions with others

background information on participants - this can help in

- managing the group process;
- asking appropriate questions and avoiding others;
- enabling more accurate answers 4. domination by one or two individuals -
- can be helped by having background information.
- Stimulus materials can be used to refocus the group discussion.
- use of techniques e.g. holding up a hand, using gestures may help to manage such situations

parallel conversations

- can happen in any size group
- it's more difficult to wait for people to respond in a group setting, so you may choose to allow particular parallel conversations to happen
- you may instigate parallel conversations to allow people to voice their opinions
- having a shell or scarf or equivalent to allow comment
- the facilitator may 'hold' a comment for a person with dementia until it can be said

idealized accounts -

people in a public situation may decide to show a particular 'persona' or want to be seen in a particular way and thus will act and speak accordingly. Through interpretation, it can offer some insight into that person's coping abilities and strategies. Thought needs to go into whether these are challenged in this situation or accepting them as they are offered.

storytelling

people enjoy telling stories about themselves and can be interpreted in different ways:

- communicating something about the situation, perhaps in metaphor

- fulfilling another purpose e.g. bonding or catharsis Cheston & bender (1999) identified 3 functions of storytelling:
- to create an identity for oneself
- to create a sense of interdependency
- to explore and make sense of current experiences

interpreting data - by reflecting on the group later you can identify themes

- caution is needed in interpretation though. You may not be able to check them out with people later as they may no longer recall them

Advisory networks

'Including people with dementia:advisory networks and user panels' by Lynne Corner, University of Newcastle. chap 5 in 'The Perspectives of People with Dementia: Research Methods & Motivations' (2002) ed Heather Wilkinson, pub Jessica Kingsley

Summary of chapter -

- people with dementia and their carers can be meaningfully involved as participants on advisory or user panels
- researchers need to be flexible and responsive in the methods and techniques selected to involve people with dementia
- people with dementia can make a significant contribution to the research

The user panel described in this chapter explored how and when members would like to be involved; identifying and prioritising topics for investigation; designing adn evaluating the content and form of available outcome measures.

For further information, contact: Quality Research in Dementia Advisory Network
http://www.qrd.ion.ucl.ac.uk

Read further information on a focus group established at The Grange Day Unit at:

www.olderpeoplesmentalhealth.csip.org.uk/ add url

User panels (See further reading)

Working with black and minority ethnic groups

Consultation events *NE Leeds - Raising awareness within Caribbean and African communities*

Video 'Remember Me' (produced by Alzheimer's Society for African & Caribbean communities) shown to church and women's groups with discussion about issues raised. Initiative has led to the formation of a local support group.

For further information, contact:

Penny Redwood, Project Manager, NE Leeds DSC, penny.redwood@leeds.gov.uk

'Let's move on:Black and minority ethnic older people's views on research findings' , Joseph Rowntree Foundation, May 2004. Whilst not specifically about dementia, the report outlines outcomes of research with older people from ethnic minority groups. http://www.jrf.org.uk

Video 'Sahara Lo' (produced by the Alzheimer's Society for South Asian communities). Contact the Alzheimer's Society London regional office. Telephone 020 7620 3020

Email: rol@alzheimers.org.uk

Cross cultural dementia network - ethnic communities, awareness raising groups. The Cross Cultural Dementia Network collates details of organisations that work with ethnic communities, rural populations, refugees and people of different sexual orinetation. The network aims to encourage and facilitate sharing resources and best practice betweeen organisations that are working towards reaching out to those underservced populations.

For list of groups that are part of this network, click on
http://www.alz.co.uk/adi/crosscultural/crossculturaleth.html

Enabling effective involvement

Dick and Cunningham (2000) identified that in order to be involved people need the following**:**

Have the information needed in order to be involved

- understanding that there are choices in order to be involved
- knowing about rights and opportunities to be involved
- being kept informed about these rights and opportunities
- information given in the right mode of communication and in accessible ways
- information given at the time and in the way that is most likely to support good communication and understanding
- information given by someone who is known and trusted
- choices and options which are relevant, of value and have meaning

Know what the choices and options are

- understanding what the choices and options are
- having a reasonable range of choices and options
- choices and options which are accessible
- direct experience of choices and options may be essential, simply being told is often not enough
- sometimes decisions can only be made through direct experience at the time - opportunity to do this
- support and encouragement to extend choices through trying new experiences
- carers' commitment to extending choices
- access to individual and/or collective advocacy

Feel free to express wishes

- feeling safe and sufficiently at ease (e.g. the right environment, the right people, the right relationships)
- communicating with people who are known and trusted
- having the supports that are needed
- understanding and being understood
- not being constrained by fear of reprimand, retribution, rebuke
- not being constrained by dismissal of views and wishes
- not being constrained by fear that necessary care and supports will be withdrawn

Be listened to and understood and having views respected and heard

- people taking the time it need to listen

- listeners who understand what is expressed and meant
- in some situations, listeners who are familiar with individual preferences, likes and dislikes
- respect for views expressed even if they conflict with listeners' own views

- listeners who don't re-interpret, hear selectively or make assumptions without checking these out
- recognition that preferences, views and choices may change
- access to individual and/or collective advocacy

Be able to influence what happens and make decisions that matter

- involvement making a difference that matters
- experiencing this difference
- action following involvement within a timescale that is meaningful
- clarity about what can and can't be influenced, about the boundaries of decision making
- clarity about other people who also will be involved in specific decisions
- access to individual and/or collective advocacy

Consulting through conversation

A project undertaken in Edinburgh to inform service planners and providers about the needs of people with dementia, by asking for their views. A small group of people who have regular contact with people with dementia asked individuals, in the course of conversation, the broad question 'What are the things which are important to you in life?'. They then recorded these responses which were later collated into a report which in turn informed the dementia chapter of the Community Care Plan for Edinburgh.

For further information, contact Liz Taylor, Dementia Care Co-ordinator, liz.taylor@lpct.scot.nhs.uk

Using Advocacy

Advocacy is about speaking out about people's views, wishes and rights.'
'..it's not my job to decide what is best for that person, it's to stand by that person..' (a dementia advocate in Cantley et al, 2003)
Advocates can be involved for different lengths of time, depending on the situation. In working with people with dementia, they tend to need time to develop a relationship, for communication and to build up a picture of what the person wants to say. Advocates need to find ways of keeping the person with dementia as actively involved as possible and will have to be flexible in their approach.

There are several models of advocacy available to utilise: self advocacy, peer advocacy, volunteer (citizen) advocacy
independent professional or paid advocacy, professional advocacy. Cantley (2003)

Finding an advocacy service

There is no-one stop shop for advocacy but the following web sites have links to advocacy projects:

You can use an on-line search facility of all advocacy services including dementia advocacy at:
http://www.advocacyacrosslondon.org.uk

http://www.advocacymapping.org.uk/index.php

The Older People's Advocacy Alliance have published a published a directory of advocacy services for older people

http://www.opaal.org

The Independent Mental Capacity Advocate (IMCA) service

The Mental Capacity Act 2005 created.the IMCA service Its purpose is to help particularly vulnerable people who lack capacity who are facing important decisions made by the NHS and local authorities (LAs). The Department for Constitutional Affairs and the Department of Health are working together to bring the Mental Capacity Act into force in April 2007. The Act will apply to England and Wales for adults aged 16 and over. There is information on the Department of Health's website on the IMCA pilot sites and IMCA implementation process:

http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/IMCA/fs/en

Mind in Brighton and Hove run an advocacy service (Dementia Advocacy Service) for people with dementia who are over 65years old. They also run an inpatients forum.

Contact: Karen Gerty/ Shirley Gray: 01273 720 371

A code of practice for Advocates publisher. Action for Advocacy, May 2006
www.actionforadvocacy.org.uk
info@actionforadvocacy.org.uk

Quality Standards for Advocacy Schemes pub. Action for Advocacy

Using the Braford Dementia Group well being tool

NE Leeds DSC

Involving service users in both the development of their own care planning and the development of the day centre

- Bradford Dementia Group Well-being profile. This tool was used to good effect in involving both the service users and staff in recognising and better understanding people's experience of the day centre. The profiling tool provides a structure for looking for signs of both well and ill-being through careful listening and observation www.bradford.ac.uk/acad/health/dementia

For further information, contact Penny Redwood, Project Manager, DSC, penny.redwood@leeds.gov.uk

Using Dementia Care Mapping

Dementia Care Mapping (DCM) is a set of observational tools that have been used in formal care settings such as hospital wards, care homes and day care facilities in the UK since 1991. DCM is both a tool and a process. The tool is the observations over a number of hours of people with dementia living in formal care settings. The process, is the use of DCM as a driver for the development of person-centred care practice including, careful preparation of staff and management teams, feedback of the results of the map, action-planning by the staff team on the basis of this feedback, the monitoring of progress over time and then the cycle of re-mapping commences'
'In brief, during a DCM evaluation, an observer (Mapper) tracks five people with dementia (Participants) continuously over a representative time period (E.g. 6 hours in a waking day)'
Brooker & Surr 2005

Strategic Lead for DCM at Bradford Dementia Group: Dawn Brooker d.j.brooker@bradford.ac.uk

Telephone interviewing

Telephone interviews can be a method of overcoming some of the difficulties of engaging with people with dementia who are not attached to local services, who live remotely, or prefer the privacy/anonymity of using the telephone. Telephone interviews can allow survey or questionnaire based responses to be explored in more detail.

LINK: Heather Wilkinson, chap11, 'The Perspectives of People with Dementia'

However, telephone interviews can be difficult, with a large proportion of non-verbal communication being inaccessible.

See Communicating with people with dementia: meeting the telephone challenge (link to a handout I did for a training workshop for helpline staff

See "What I would like to happen if I phone the helpline" by James Mckillop (another handout which we will need to get permission to use -shouldn't be a problem)

Observations

Observation is a widely used method of gaining information and evidence of practice. Spending a period of time observing interactions, practice etc., can produce valuable information that otherwise might not have been noticed.

For instance carrying out an 'observation' that enables the 'observer' to take notice of what is happening in terms of the senses (smells, sounds, sights, feel) during a specific timeframe (e.g. half an hour) can raise awareness of practices. You may choose to also undertake the same exercise involving service users. Service user comments or responses may be tape-recorded and played back for validation or clarification.

In NE Leeds DSC such exercises were carried out in both an in-patient unit and residential homes to good effect.

For further information, please contact penny.redwood@leeds.gov.uk

Involving people living in Care Homes

Leeds NE Dementia Services Collaborative Project: Undertake a Quality Audit with the residents

Aims:

- to incorporate the views of residents into the development plan of the home
- to create an ethos of quality audit into everyday staff working

Quality Audit

- This project took place in a couple of local authority specialist homes in Leeds for people with a dementia. The aims were to
- incorporate the views of residents into the development plan for the home

- create an ethos of quality audit into everyday staff working practice. The residents comprise people with a diagnosis of dementia who require 24 hour care at different levels and who have a range of communication difficulties.
  Their views were sought in the following ways:
- on an individual basis whilst undertaking other activities such as personal care or sitting and chatting

- during monthly residents meetings

- observations by managers of particular locations in the home and residents responses to what was happening. The views of relatives, professional and staff were also sought to complement the residents views.

- The DH have published National Minimum Standards, of which Std 33 is entitled 'Quality Assurance'. The required outcome is that 'the home is run in the best interests of service users'. Therefore it is an obligation to seek the views of residents on the services that they receive.
    - Care Homes for Older People: National Minimum Standards. Std 33

    - The process was evaluated through interviews with staff by the Project Manager of the 'Involving People with dementia Project' and the local Project Manager. The staff were given the chance to reflect on how the process had been for both themselves and the residents.
      * *Outcomes - process:*

Different approaches are needed for each resident. Everyone expresses themselves individually and thus their preferences need to be taken into account. Staff who know the residents will know how to communicate with them and thus will use these skills and understanding in this exercise. Consultation does not have to be approached in any different way to normal communication.

Staff were required to use their skills in verbal and non-verbal communication

It was possible for staff to undertake the consultation during their normal work and activity programmes, thus not necessitating a separate allocation of time. Having said that, communicating with people with dementia can take time and energy and did require a commitment on the part of staff to see the consultation through. This was particularly true as it was the first time that they had been asked to undertake such task and were anxious about it. Sitting and chatting should be a normal part of life in the homes anyway.

Outcomes - for residents

Residents enjoyed being for asked their opinions and their views were sought successfully individual improvements could be made and incorporated into monthly care planning reviews

The observations improved the quality of life in the homes as they were incorporated into the home development plan

Outcomes for staff

Having overcome initial anxieties, some staff were able to enjoy the exercise.

Some staff who initially were sceptical about the point of the exercise came to review their opinions on realizing that residents' views could be gained

The most resistance lay in the need to complete questionnaires for each resident. This added to the need for recording which some staff found stressful and difficult.

The evaluation process gave staff an opportunity to reflect on the process, their practice and the benefits for the residents. Thus it contributed to their personal and professional development and is an important part of the development of the consultation process

Through the evaluation, staff were able to reappraise their skill levels and competencies and recognize, in some cases that they were more skilled than they gave themselves credit for.

National Minimum Standards - Quality Assurance
Outcome: The home is run in the best interests of service users
Standard 33
in particular:
33.1 Effective quality assurance and quality monitoring systems, based on seeking the views of service users, are in place to measure success in meeting the aims, objectives and statement of purpose of the home
33.2 There is an annual development plan for the home, based on systematic cycle of planning - action-review, reflecting aims and outcomes for service users.
33.6 Feedback is continuously sought from service users about services provided through e.g. anonymous user satisfaction questionnaires and individual and group discussion, as well as evidence form records and life plans; and this informs all planning and reviews.

Patient Stories

Piloted with people in a dementia assessment unit in Leeds

The method involves two staff members who have been trained in the methodology, interviewing a service user using a non-directive but semi-structured interview approach either individually or in a group. The staff have particular issues in mind that they would like to hear views on. The service user stories are taped in order that the two members of staff can better reflect on issues raised by the service user(s). These are then 'mind-mapped' to future clarify these issues. The service user(s) is/are given control through choices they make as to location, timing, participation, ending and interviewer and should be given feedback after the interview.

Preparation for listening to the story

- full day training in the use of the methodology
- identifying people who would be willing and able to be interviewed in this way
- engaging with them and gaining their consent to undertake the process including the recording and then usage of their information to improve service delivery
- clarifying the service user preferences and ensuring that they are acted upon
- getting hold of a suitable recording instrument (e.g. mini disk, small tape recorder). Ensure that it's of reasonable sound quality!

The interview

- check consent is still in place
- endure that person with a dementia understands and is willing to undertake interview
- be prepared to end interview whenever the person with a dementia wants

After the interview

- listen to, and discuss the recording, preferably straight after the story has been told or within 48 hours
- decide how these issues should be taken forward e.g. in service development plan. How can these changes be implemented? Who need to be involved and sanction them? Is there any reason why they can't be implemented immediately?

- feedback to the person or people with dementia who gave their stories

For further information about this pilot, please contact: Nicky Needham, Leeds Mental Health Trust
nicky.needham@leedsmh.nhs.uk

Using 'Talking Mats'

'Talking Mats' is a low tech visual communication framework using picture symbols to help people with communication difficulties to understand and respond more effectively.

It is designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way of effectively express their opinions. Talking Mats can help people arrive at a decisions by providing a structure where information is presented in small chunks supported by symbols. It gives people time and space to think about information, work out what it means and say what they feel in a visual way that can be easily recorded.

Stirling University are currently undertaking research into the effectiveness of using this system with people with a dementia

For more information: http://www.speechmag.com/archives/joanmurphy2.html

Contact Joan Murphy, University of Stirling joan.murphy@stir.ac.uk

Video observations

Use of video to include the experiences of people with a dementia in research (but obviously could be used in other involvement activity). Useful tool in examining non-verbal communication in different settings.

Cook (2002)

Developing Dementia Cafes

DeCaf, Alwoodley, Leeds

Prior to developing our cafe we wanted to test out whether local people with dementia and their carers would like to have such a cafe. We sent out questionnaires via agencies, both statutory and voluntary to everyone we collectively knew to ask their opinions.

DeCaf initial questionnaire
The response was overwhelmingly positive so we went ahead and developed it.
The cafe is run as far as is possible according to the wishes of the customers. A basic premise of the cafe is that our customers should be as involved in different aspects of it as possible. We gain their views (both people with dementia and their carers) by:

- asking their opinions about the different aspects of the cafe. This happens mostly during conversations around the tea table
- observing individual reactions to what happens at the cafe
- people feel able to tell us as we have created an atmosphere in which they know that they will be listened to

Evaluation
After a year's opening, we wanted to check out how we were doing. We employed an independent person to undertake the evaluation.
It was important to gain the view of everyone who was willing to give one and to this end we employed a combination of:

- questionnaires to each customer. Separate questionnaires were sent to each person to ensure that both the person with dementia and their carer could give their view with an opportunity for support at either the cafe or in their own home.
- 1:1 semi-structured interviews at the cafe which enabled people who were more cognitively impaired to contribute. Props were also used.
- separate questionnaire for staff LINK to DeCaf evaluation questionnaires

Initial consultation as to whether such a cafe was viable consisted of a questionnaire to all people with dementia and their carers and partners that were known to local services. As a result of the resounding 'yes', plus ideas, a multi-agency group went ahead with the planning and execution.

Customers are now involved in both the running and planning of the cafes which open fortnightly in a local community centre.

Cafes are being developed across the city in different localities and for different ethnic communities

For further information, contact:

Penny Redwood, Leeds Social Services, penny.redwood@leeds.gov.uk

Al's Cafe

Birmingham Working Age Dementia Service is a multi-disciplinary mental health service involving people with dementia and their carers in this cafe plus a carers group. Both people with dementia and carers have been involved in service development, through a stakeholder event, lobbying and developing a Support Worker role.

For further information, contact:

Jo Scarle, Occupational Therapist, jo.scarle@bsmht.nhs.uk

Domiciliary Care

'Involving people with dementia in their home care' Project undertaken in Gateshead.

Power point presentation: Contact Paul Gertig paulgertig@gateshead.gov.uk

Quotes from the home helps who took part:

"I've learnt more about myself going in"

"Before we were doing a job, no-one was taking any notice, but now we are getting acknowledgement for doing it"

One of the Home Helps acknowledged that the three weekly meetings have helped her in "gaining more confidence".

At the beginning I didn't think what you suggested would help. I thought it was a waste of time and then it clicked"

"You've opened our eyes to a lot of stuff. I've been on courses but this has opened my eyes to Alzheimer's"

"It's done us all good. I wasn't one to speak up before. I did speak up and asked questions at another course recently. It's improved my confidence"

"There have been bits from every session that we've took back to our clients. I use it with other clients without dementia"

"I feel the stakes are higher. I now feel we are being given importance. I am pleased this is happening especially for [person's name] as people are listening."

Heiser (2002)

User Panels

User panels are a way in which service users can discuss issues of importance to them, and be consulted on plans, proposals or decisions, usually at an early stage. When they work effectively they can be a useful sounding board, a place for dialogue between service users and decision makers, and can focus on issues from the perspective of the service user.

Discussion & Web based fora

Websites can open up new worlds for people, providing opportunities to communicate and connect with others. They can also be a place to overcome social exclusion and isolatio, reducing boundaries of time and place where people can retain their anonymity if preferred. Websites run *by* people with dementia highlight issues that they identify as important providing a place for support, information exchange, campaigning and self advocacy.

http://www.dasninternational.org/ advocacy and support network - an international web based forum for people with dementia. Hosts regular on-line chat sessions

www.alzheimersforum.org a UK based website for and by people with dementia.

Computer based activity can present accessibility issues for people with dementia. Nada Savitch is conducting research on the design of accessible websites for people with dementia. Contact her at nada@innovationsindementia.org.uk

http://www.icchp.org/upload/upload/1_B_Accessible%20websites%20for%20people%20with%20dementia:%20a%20preliminary%20investigation%20into%20information%20architecture_Nada%20Savitch.rtf

Developing local fora for people with dementia in Wales

Pilot project being run by the Alzheimer's Society with funding from the Welsh Assembly (Age Alliance Wales).

Will develop a framework for user-led forums for people with dementia.

For further information contact Rachida Haout, Alzheimer's Society rhaout@alzheimers.org.uk

Public speaking

Listening to people with dementia talk about their experiences can be a very successful way of raising awareness. It presents a perspective that is often ignored and it can challenge people's misconceptions.

See Alzheimer's Society branch guidance "Supporting people with dementia to speak in public"

Hear people with dementia talking about their experiences:

Radio 4's "You and Yours" programme dedicated a month of programming to dementia. Listen to a person with dementia and his wife talk about the impact of dementia on their lives
http://www.bbc.co.uk/radio4/youandyours/items/03/2006_31_wed.shtml

People with dementia have spoken on behalf of the Alzheimer's Society at local, national and international conferences and events, and to a wide variety of audiences. These guidelines describe the practical aspects to consider when supporting people to speak in public. They apply whether you are organizing an event yourself or are supporting a person with dementia to speak at an event organised by others.

'I think people should hear as much as they can, from the inside out. It gives them a glimpse of how it is for us' (person with dementia) Type of event
There is an increasing demand for people with dementia to speak at public events, such as dementia-related conferences. Although the motives of organisers usually include increasing understanding of dementia, it is important to ensure that their needs do not override the needs of people with dementia. Token involvement should be avoided at all costs.
You may already organise or attend events whose main aim is to promote greater understanding of dementia. You could consider adapting all or part of such events to enable people with dementia to play a direct role in raising awareness.
Identifying a speaker
Many people are not keen to do public speaking. However, you may know a person with dementia who has experience of public speaking (perhaps through work) or who would like to accept a new challenge, with the right level of support. People may also approach you with the aim of raising public awareness about their life with dementia.
You may have an obvious choice of speaker for an event. If you are trying to find someone, however, consider the following:

Distance to the event

Involvement by a local speaker is preferable and often more relevant to the audience. Some people may be prepared to travel - however, the impact on their health and well-being must be considered.

One speaker or several?

Standing in front of an audience (no matter how big or small) can be overwhelming at the best of times. It might be less intimidating for a speaker if they could share the effort with another speaker or speakers. **Audience size**

Consider the size of the audience carefully. An audience of 150 health and social care professionals may have a very different effect on the speaker than an audience of three Society staff members. Being filmed for a TV report or video will be different again. **Time of day**
Programmes are often planned before speakers are identified. Many people, however, have periods

when they feel 'at their best' and this should be taken into consideration. You may need to be flexible.

Starting points

It is important to plan the event well in advance. It may take a person with dementia longer to prepare for a speaking engagement and they may need more support.

Ensure that the organisers are aware of all relevant issues and are prepared to adapt their event accordingly.

Keep in touch with the person with dementia in the lead-up to the event. Ongoing and informal contact can be supportive, as concerns can be allayed and any issues dealt with as they arise.

A nominated person should be responsible for liaising between the organisers and the person with dementia in the planning stages. They should ensure that the person with dementia remains informed and central to the planning process.

Defining content

Public speaking by people with dementia is still relatively rare. Consequently, organisers are often non-prescriptive about the content of the talk and want to focus on personal experiences. A blank slate can be difficult to work with; it might be helpful if you can help the person with dementia to choose a few experiences or issues to highlight. It may be useful to link the presentation to the rest of the programme. For example, at a conference on the quality of care, a person with dementia could talk about the importance of the support they receive from their local branch.

By identifying the purpose of the talk and considering its content, you can help to avoid the person with dementia being added to the programme as a token gesture.

Confirmation of details

The speaker's role should be confirmed as early as possible. Encourage the event organisers to be as specific as possible about what they want and ask them to confirm the details of the event in writing. This will be a useful reference when checking details and plans later.

Conditions

Some people may agree to speak only on certain conditions. For example, they may want to leave the event straight after their talk or they may want to use a pseudonym.

Contingency plans

Think about situations in which things may not go according to plan. Discuss these with the person with dementia and the organiser. Event organisers should be prepared to accept changes right up to the last minute.

Involving other people

It may be helpful to involve friends or family of the person with dementia. They may help you to ensure that you take the person's needs into account adequately and they can also be a great source of support. Their presence at the event can also be very helpful.

Presentation practicalities

Discuss how the person would like his or her presentation to run. Consider the following:

Does the person prefer to read out a prepared presentation or be interviewed?

Would the person be happy to answer questions if they are submitted beforehand?

If there is somebody with the person to provide support, should they sit by the person's side or in the front row of the audience?

Discuss how the person might feel about different scenarios - for example, being approached at coffee break by a member of the audience, or talking about very personal issues to a large audience of unfamiliar people.

Expenses

No one should be left out of pocket as a result of his or her involvement. The usual expenses procedures should apply but consider extending budgets to include: taxis; support costs, such as travel for a family member or friend; and accommodation costs, if necessary.

Sometimes, fees are paid to speakers at bigger events. Check whether this is the case and ensure that the fee is passed on to the speaker.

Checklist

Draw up a checklist of 'things to do' based on issues that have come up during the planning process. Here are some ideas:

Before the event

Ensure that practicalities, such as timing, venue and audience size, have been confirmed.

If you are organising transport and/or accommodation, confirm details and arrange for payments to be made from the expenses budget.

If possible and desirable, arrange for the person to visit the venue so that they can familiarise themselves.

A 'trial run' can be a great help. It can also highlight any difficulties that may arise.

On the day

Ensure that everyone is confident about their role and knows what is expected of them, including the organisers.

Be prepared to cancel the event on the day if, for example, the person is not well or is unwilling to participate. Rely on your contingency plans.

Check that all the equipment is working, and that the environment is appropriate - for example, check the temperature.

If possible, enlist an extra person to support you and to provide back up.

After the event

Ensure that there is time and support available to enable your speaker to give feedback.

Thank the person with dementia. This may seem obvious but can easily be forgotten in the aftermath of an event.

Send a card or flowers/gift, or encourage the event organisers to do something similar.Keep in touch with the speaker and inform them of any issues that arise from their talk. Think about other opportunities for the person to get involved, if they are keen to do so.

Remember

Speaking on behalf of or with the Alzheimer's Society is an enormous task for a person with dementia and takes a lot of hard work. This work should be acknowledged through the provision of adequate time and appropriate support throughout the whole process.

The experience should be as positive and enjoyable as possible for all concerned. You can never account for all eventualities, but ensuring that the person with dementia is at the centre of the planning process and pre-empting any potential problems should help the event to run smoothly.

Finally, don't forget your own support needs. Ensure that you have someone to talk to and share ideas with, both before and after the event.

Support and advice

ALZHEIMER'S SOCIETY BRANCH GUIDANCE - JUNE 2003

Involving people with learning disabilities who have a dementia

People with learning disabilities may experience a higher risk of dementia because of premature ageing. Also, people with Down's syndrome have an increased genetic risk of developing dementia.

Heather Wilkinson at the Centre for Research on Families and Relationships has carried out research studies around learning disablity and dementia, with colleagues in the UK and USA.

See research briefing on getting service users views, best practice in learning disability and dementia

http://www.crfr.ac.uk/Reports/rb28.pdf

"A place at the table? Involving people with learning difficulties in purchasing and commissioning services" (1999) Simons, K. Available for purchase from BILD publications
http://www.bild.org.uk/03books_finance.htm#01APlaceAtTheTable

People with a learning disability: their concerns about dementia, Heather Wilkinson, Diana Kerr & Catherine Rae, Journal of Dementia Care vol 11(1), pp27-29

Memory Service Evaluation Project

How can an NHS Mental Health Trust engage with service users and carers to inform the development of memory services, what can we learn from the experience to inform further development of user involvement in dementia service monitoring and planning and does user involvement in planning lead to services being more person centred?

"The Project Intervention described was the work of the Memory Service Evaluation Project. It supported the evaluation of memory services across the Trust area and will particularly seek ways of maximising the involvement of service users in the evaluation work and in wider consultation around the development of memory services. It was a participatory action research project (Waterman et. al. 2001) engaging service users' carers and staff in reflecting on the outputs of the project work to develop best practise in supporting user involvement activity in this area of work."

Nick Dent, East Kent Memory Services

Full Document available including newsletters at: www.olderpeoplesmentalhealth.csip.org.uk/ add full url

Lotus Group Project

LOTUS stands for ‘listening openly to users of service’

“The North East Wales NHS Trust covers Wrexham Borough and the County of Flintshire. The mental health directorate was keen to involve service users in the development of older persons’ services and replicate the success of service user engagement in adult services. Following an initial meeting of key staff we agreed basic principles for the group and decided that the group would be both service user and carer focussed. In order to gain interest we put together an advertising campaign to find volunteers. We gave out leaflets via the Community Mental Health teams for older people and also targeted GP surgeries. Leaflets were distributed in all the nursing/residential homes in the area and to the voluntary sector including Age Concern and Alzheimer’s society. The inpatient unit targeted patients and carers, as did the day hospital and memory service. “

Julie Roberts Clinical Service Manager older person service
Mike Roberts Team Manager, Community Mental Health Team

Read the full document at:
www.olderpeoplesmentalhealth.csip.org.uk/ add full url

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Brooker D and Surr C (2005) Dementia Care Mapping: Principles and practice, Bradford Dementia Group http://www.bradford.ac.uk/acad/health/dementia

Developing Dementia Cafes, Redwood, P. Journal of Dementia Care vol 13(4), 2005pp 20-22

Cantley C ed (2003) Hear What I say. Dementia North

'*People with dementia reveal their views of homecare'* - Sue Heiser, Dementia Development Team, Kensington & Chelsea, article in Journal of Dementia Care, Jan/Feb 2002 pp.22-24

'Don't leave me hanging on the telephone: interviews with people with dementia using the telephone' Ann Mason & Heather Wilkinson, University of Stirling. Chap 11 in 'The Perspective of People with Dementia: Research methods and Motivations' (2002), ed Heather Wilkinson, pub. Jessica Kingsley.

Dick S and Cunningham S (2000) Nothing about me, without me. The Consultation and Involvement Trust Scotland Tel: 0131 667 2497

Further reading

Focus Groups

Alzheimer Society groups

'How to include people with dementia in the activities of Alzheimer Associations' pub Alzheimer's Disease International http://www.alz.co.uk/adi/publications.html ; >factsheets

People of different sexual orientation

for list of organisations that are part of the Cross Cultural Dementia Network (part fo Alzheimer's Disease International) click on http://www.alz.co.uk/adi/crossculturallg.html

Rural populations

click on http://www.alz.co.uk/adi/crosscultural/crossculturalrural.html

'Influencing public policy' , Alzheimer's Disease International, Jan 2000, includes basic campaigning steps. Click on http://www.alz.co.uk.adi/publications.html and scroll down publications page.

Making service user involvement work:supporting service user networking and knowledge Joseph Rowntree Foundation http://www.jrf.org.uk/knowledge/findings/socialcare/1966.asp

Bamford C and Bruce E(2002) Successes and challenges in using focus groups with older people with dementia, chap 9 in Wilkinson H ed, The Perspectives of People with Dementia

User panels

Insert example by Rachel Norman/ Dementia Voice - user panels to consult people with dementia on health and social service planning delivery

- LINK: Quality Research in Dementia Advisory Network
- http://www.qrd.alzheimers.org.uk/QRD_advisory_network.htm

Link: article by Rachel Canning who has vascular dementia about her experience of being a member of the consumer advisory network of QRD

http://www.qrd.alzheimers.org.uk/Newsletters/QRDNewsletter_July2005.pdf

'Including people with dementia: Advisory networks and user panels',Lynne Corner in 'The Persectives of People with Dementia: research methods and Motivations' (2002) ed. Heather Wilkinson. pub Jessica Kingsley.

Campaign and support groups
Memory Lane Group

This is an example of how a consultation event can develop into a regular campaigning group. Three consultation events were initially held over three months for local people with dementia and their carers in West Leeds. At the second meeting, separate sessions were held for carers and people with dementia to talk about their needs and gaps in services. The group has now evolved into a very supportive social group, starting with lunch and then moving onto business. They are linked into the Leeds Older People's Reference Group and the group is now built into the governance structure of Older People's Mental Health Services in Leeds.

Contact: jenny.thornton@leedsmh.nhs.uk

'Working with people with dementia and their families' Pilot groups in Leeds to gain the views of Memory Service users with dementia and thier carers.

Powerpoint presentation ~ Contact: Jenny Thornton, Project Manager
jenny.thornton@leedsmh.nhs.uk

Moor Allerton Care Centre, *Leeds*

The Care Centre incorporates Extra Care Housing for older people and for people with dementia. It also includes a Resource Centre with a Day Centre for people with dementia. We wanted to involve people who might use the Resource Centre in determining how it should develop. To this end we called a couple of consultation events at the centre, inviting both people with dementia and their carers along.What worked

both people with dementia and their carers had some good ideas about what they'd like, which were feasible

having prompts to aid discussion as well as aids for comfort or interest e.g. dolls

nice refreshments

What didn't work so well:inviting professionals along at the same time

Other thoughts:it was unrealistic to think of separating some people with dementia from their partners or carers in an unknown situation

clarity about the purpose of a meeting may still need further clarity on the day as people may be seeking other information or their own agendas

For further information, please contact

Sarah Fox, Centre Manager sarah.fox@mha.org.uk

Penny Redwood, Leeds Social Services penny.redwood@leeds.gov.uk

Participation in regulation

Bridging the Gap -

Participation in regulation adds value to the information gathered by regulators and helps inform the process, as below:

- regulators provide information to existing users on the availability and quality of services and on the registration status of people in the social care workforce
- People who use services, sometimes with support from their carers or advocates, use this information to make informed decisions about their social care, including the appropriate level of risk
- People who use services contribute to the information that regulators gather and make available to other users. This increases the quality of information and helps incentivise providers to improve the quality of care provided
- Better information is therefore available to potential recipients of social care to improve their awareness and understanding of what services are available to them and the choices they have

Download from; http://www.brc.gov.uk/publications/bridgegap.asp

Can regulation stimulate innovation?. Download from: http://www.brc.gov.uk/work_programme/innovation/index.asp

Therapeutic approaches

In day care

Link to *Melcombe Day Hospital* for people with dementia in Weymouth. Staff here use music, drama and comedy as a way of helping to stimulate memories and aid communication. Weekly themes are used such as a circus, a pirate ship and a Victorian music hall. The effects that this therapeutic approach has on people who use the service has been an inspiration to staff, turning what was, in effect, a weekly "sitting service" with low staff morale into an award winnng, person centred environment.

presentation can be downloaded at http://www.commhosp.org/presentations/Drama%20as%20a%20Powerful%20Clinical%20Tool.pdf

Contact: Lesley Benham, team leader at lesley.benham@northdorset-pct.nhs.uk

The Park Lodge day centre is run by the West Kent branch of the Alzheimer's Society. There is a community approach to the running of the day centre, with activites and events decided by service users. The day session opens with a community meeting, a pivotal part of the day where members of the group acknowledge each other and discuss events affecting the group. People with dementia are supported to chair these community meetings and record decisions that are taken. As well as being a place for participating in a wide range of activities (e.g. art, computers, hockey and football, local walks) there is much discussion within the community from current affairs to more profound issues around memory loss and its effects. On one occasion, whilst discussing the availability of drugs for dementia, the community decided it was an issue for their local MP to respond to. Rather than representatives from the group attending the MPs next surgery, they decided there was strength in numbers and invited the MP to one of their community meetings. The MP accepted the invitation, responded to questions, and took their comments away.

2002 event for people with dementia at the Cafe Royal in London, organised by the Living with Dementia programme at the Alzheimer's Society. See pdf

In March 2006 the first UK convention for and by people with dementia was held in Newcastle. It was a collaborative event organised between Dementia North, the Scottish Dementia Working Group and the Living with Dementia team. Click here to read the press release http://www.alzscot.org/pages/media/ukconvention.htm Contact Philip Bryers for further information pbryers@alzscot.org

Wilcock PM, Brown GCS, Carver J and Machin S (2003) Using Patient Stories to Inspire Quality Improvement within the NHS Modernisation Agency Programmes. *Journal of Clinical Nursing* 12 pp 422-430

Dewing J and Pritchard E (2004) Including the older person with a dementia in practice development. *Practice Development in Nursing* McCormack B, Manley K and Garbett R eds. Oxford: Blackwell

RCN (1999) RCN Clinical Leadership Toolkit 6.1-6.22

Morris S and Smith J (1998) Understanding mind maps in a week How to do a mind map http://jcu.edu.au/studying/services/studyskills/mindmap/howto.html

Kate Allan: Communication and consultation Joseph Rowntree Foundation http://www.jrf.org.uk/bookshop/details.asp?pubID=366

www.dementianorth.org.uk/dninvolve_people_with_dementia_pro.htm

Care Homes for Older People: National Minimum Standards. Standard 33: The home is run in the best interests of the residents. www.dh.org.uk/assetRoot/04/05/40/07/04054007.pdf

Merevale House. A care home for younger and older people with dementia in North Warwickshire. The home promotes freedom, choice and empowerment, and belongs to people with dementia themselves - "it is their home". Residents meetings are held weekly, many have been involved in the interview and selection of new care staff and each is encouraged and supported to pursue their own interests.
Share, newsletter of the Alzheimer's Society
http://www.alzheimers.org.uk/News_and_campaigns/Newsletters/PDF/Share0610_october2006.pdf

Kate Allan carried out extensive research in care settings (particularly residential and nursing homes) about the best methods with which to consult people with dementia

Read a summary of her findings at http://www.jrf.org.uk/knowledge/findings/socialcare/541.asp

Involving people with dementia in research

'Make it easy on yourself: Advice to researchers from someone with dementia on being interviewed'. James McKillop and Heather Wilkinson, Dementia vol3(2). 2004

Useful tips when interviewing people with dementia

For examples of research methods that aim to engage with people with dementia see

D. Reid, T. Ryan, P. Enderby (2001) What does it mean to listen to people with dementia? Disability and Society vol 16 (3) pp. 377-392

Pearce, A, Clare, L, Pistrang, N (2002) Managing sense of self: coping with the early stages of Alzheimer's disease. Dementia vol 1 (2) pp.173-192

Freeman. E, Clare.L , Savitch. N, Royan. L, Litherland. R, Lindsay, M (2005). Improving website accessibility for people with early stage dementia: a premilinary investigation. Ageing and Mental Health, vol 9, pp 442-448

http://www.projects.ex.ac.uk/folk.us/findex.htm

user focused monitoring http://www.scmh.org.uk/80256FBD004F6342/vWeb/wpKHAL6H9FWP