

Care Services Improvement Partnership **CSIP**

National Older People's Mental Health Programme



Strengthening the Involvement of People with Dementia

A Resource for Implementation

DH INFORMATION READER BOX

Policy HR / Workforce Management Planning / Clinical	Estates Commissioning IM & T Finance Social Care / Partnership Working
Document Purpose	Best Practice Guidance
ROCR Ref:	Gateway Ref: 9062
Title	Strengthening the Involvement of People with Dementia
Author	CSIP Older Peoples Mental Health programme
Publication Date	November 2007
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT PEC Chairs, NHS Trust Board Chairs, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads, Third sector organisations
Circulation List	Voluntary Organisations/NDPBs
Description	This toolkit contains advice and examples of positive practice which can facilitate the active and meaningful involvement of people who have dementia in the planning, delivery and evaluation of health, social care and other support services.
Cross Ref	Everybody's Business: A Service Development Guide (DH 2005)
Superseded Docs	N/A
Action Required	N/A
Timing	N/A
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Foreword

In August this year, I announced the development of a new National Dementia Strategy and Implementation Plan. Work on the Strategy is now well underway and this resource implementation toolkit marks an important milestone as it is the first document produced as part of this work.

Dementia is increasingly becoming an issue that will affect us all, especially as we face the demographic challenges of an aging population. It is my intention that the Strategy will bring about a culture change in health and social care and tackle the stigma typically associated with dementia.

Services need to begin gearing up for the Strategy and its implementation. They should start thinking about how to shape themselves so they are better able to tackle the challenge of dementia and meet the needs of people with this devastating illness. There are small steps that all services can take now. One of these steps is to strengthen the involvement of people with dementia in the planning and delivery of their care. It is important that they are involved in all discussions and decisions concerning their care, from diagnosis to end of life.

The nature of dementia means that it is not always easy to communicate with people who have it. This has led to the widely held assumption that people with dementia are not capable of expressing their views or making decisions. However, people with dementia want to be heard. With sufficient care and support, they can identify and communicate their individual needs and preferences. It is important, therefore, that all individuals working with people who have dementia have the skills and knowledge to communicate effectively.

There are some excellent examples up and down the country where dedicated health and social care staff have built up innovative methods of communication and are actively involving people with dementia in the planning and delivery of their care. I want to build on this good practice and ensure that active engagement and involvement is a reality everywhere. This toolkit is designed to equip the workforce with the necessary skills. It aims to support practitioners and commissioners to positively involve and engage with people who have dementia. It also aims to support people with dementia and their carers by making them aware of how their own involvement can be improved.

The toolkit builds on and strengthens the section on *Involving service users and their carers* in *Everybody's Business*. Most importantly, people with dementia and their carers have been involved in its development. Therefore, it provides a true reflection of the skills and techniques people with dementia believe are important for engagement and involvement. It also demonstrates the valuable contribution that people with dementia can make.

I hope *Strengthening the Involvement of People with Dementia: A Resource for Implementation* will help everyone who is involved in delivering dementia care as well as people who have dementia themselves. Through this toolkit and the ongoing work to develop and deliver the Strategy, I am confident that we can improve services and support for all people with dementia.

A handwritten signature in black ink, appearing to read 'Ivan Lewis'.

Ivan Lewis MP
Parliamentary Under Secretary for Care Services



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Introduction

By 2025 it is estimated that over one million people in England will have dementia (Alzheimer's Society 2007). It is fair to say that many practitioners may find the prospect of meaningful user engagement for people with dementia a considerable challenge – what is clear though, is that it is not impossible. There are many models of involvement and a whole range of approaches that can be used. Staff find that continually utilising the various techniques available for involvement develops skills in communication as well as enhancing a positive sense of achievement and learning.

This toolkit augments the section 'Involving services users and their carers' in 'Everybody's Business – a service development guide' (DH 2005). It sets out best practice and draws on the information and experience of a wide range of people, most importantly, those living with dementia. Our aim is to ensure that the mental health needs of older people are met in a person centred manner. In order to do this we need to challenge our own and others' assumption that people with dementia are not capable of expressing their views. It is the person with dementia who is the real expert.

Fundamentally, it is about care and support for people that ensures they can live a life that has meaning and purpose, identifying their individual wants, needs and preferences, ensuring dignity, respect and remembering that the individuality of human needs does not diminish with the passage of time or with diagnosis.

1. Purpose and Background



"To help our voices to be heard we would like to ask you to step back, take a breath and pause from everyday life, give time and think about what you are saying. Listen to us. Hear us. We are here!"

(Alzheimer's Society 2002)

Purpose

Involvement and engagement is not new and the general principles apply to everyone, whatever a person's diagnosis. There are many political drivers around citizenship and partnership and it has been a duty since 2001¹. In short, there is a plethora of information and yet we still know that people with a diagnosis of dementia are not being properly involved in decisions about their care and service. This toolkit has been developed to help commissioners and practitioners positively involve, engage and connect with people with dementia. It will also help inform those with dementia and their carers about the various models, tools, techniques and resources which can be used to improve involvement.

Designed in two parts, this first document provides information, references and identifies further reading. It is a valuable point of reference in its own right explaining some of the why and how around involvement and begins to address organisational issues. The second document is complementary, building on the 'how to', it is a rich resource providing a variety of tools, techniques and practice examples. This is already on the CSIP's Older People's Mental Health website www.olderpeoplesmentalhealth.csip.org.uk; However, neither practice nor research stand still. Therefore these documents are the foundation of a web based facility holding more in depth knowledge, web links and practical resources. We encourage everyone to share their ideas to ensure involvement becomes commonplace to ongoing care and support and urge you to add your projects, experiences, hints and tips for others to share. In this way, the toolkit will become a 'living and developing' guide for all to use.

¹ Section 11 of the Health and Social Care Act 2001 (now S242 of the consolidated NHS Act 2006) places a duty on NHS trusts, Primary Care Trusts and Strategic Health Authorities - to make arrangements to involve and consult patients and the public in service planning and operation, and in the development of proposals for changes. This duty is supported by the document 'Strengthening Accountability – Involving Patients and the Public'

It is designed to:

- Illustrate why it is important to involve people with dementia
- Help you think through what might best suit your specific objective for involvement
- Provide tools and a list of various resources to facilitate involving people in service development and planning
- Suggest practical ideas about how to connect with people with dementia, wherever they are in services
- Enable you to make contact with others involved in similar work
- Provide you with examples of good practice

If you have practice examples or tips to share please link to the toolkit resource web page on CSIP's Older Peoples Mental Health website www.olderpeoplesmentalhealth.csip.org.uk or email Tony.Jameson-Allen@csip.org.uk

Language and Terminology

There are variations across different settings and disciplines in the language conventionally used and people may be more comfortable with some terms rather than others. Whilst we recognise this might not work for everyone, for the purposes of the toolkit the term 'people with dementia' is predominantly used to denote service users, clients, patients or people who have lived with, or are living with, dementia. The term 'carer' is used to denote those who play an important role in supporting people with dementia. This can include people with dementia for they too care about their fellow 'sufferers'; sons, daughters, wives, husbands, friends - indeed all those identified as care partners.

Background

This toolkit arose from the 'Involve People with Dementia Project' (IPWDP) based at the Dementia North Centre.² Funded by the Department of Health from 2002 until 2005 the project utilised work from four case study sites in the Dementia Services Collaborative (DSC) which is a large multi agency service improvement programme working across the North East Yorkshire and Humber. The IPWDP combined a review of literature and good practices nationally with more detailed work from the case studies to produce the 'Listen to Us' report which is a recommended companion publication (Cantley et al 2005). Our intention is to build on this experience and produce a repository of practice examples. We are grateful to the DSC pilot project leads Penny Redwood and Jenny Thornton from Leeds, Jean Hamilton from Sunderland and Paul Gertig from Gateshead for their help in producing this toolkit and to people with dementia, their carers and colleagues throughout the country who have shared their knowledge.

² Dementia North: A Dementia Development Centre and partnership between The Dementia North Trust – registered charity No 1075528 and Northumbria University

Key Messages

For people with dementia

As a person using a service you have a right to be involved:

- You have a personal perspective about dementia that no-one else can provide
- Involvement can increase confidence and self esteem
- It can provide a role and occupation and contribute to a better quality of life
- You can provide positive examples of living with dementia encouraging others to get involved
- You will contribute to removing the stigma associated with dementia as with mental health in general

For commissioners

Involving people who use a service is a policy requirement:

- It can evidence where services are no longer required and how new services should be shaped optimising the value of available resources
- Feedback through involvement gathers data for audit and evaluation purposes and feeds into performance assessment frameworks
- It ensures fair access to public services and benefits
- It ensures equality of treatment and protection
- Involvement improves standards and responsiveness
- Involvement generates new ideas

For practitioners

People who are involved, whether practitioners or those receiving services, feel empowered:

- Information gathered and acted upon ensures the most relevant services are provided.
- It meets the personal and social needs of people using services
- It can assist people with dementia and practitioners to develop their potential
- It illustrates respect for individuals and their communities
- It promotes dignity, individuality, rights, responsibilities, identity and personal preferences
- Involvement promotes trust in services and may guard against abuse

People want to have their say and be involved.

Below are a number of quotes from the 'Living with dementia'³ programme providing more insight into why we need to focus on this area.

"Listen us. Hear us. We are here"

"I'm still me. My memory may not be as good as it as, but it doesn't stop me from being me".

"Support is the key to me leading as normal a life as possible. People knowing and treating me as the person I still am. Giving me room to live."

"You need to focus on the ability and the contribution that we can make rather than what we can no longer do."

"Being encouraged to do as much as possible keeps me going. It stops me feel unwanted and builds my confidence"

"Don't just tell me what to do. Help me to make choices".

"Challenge the stigma!"

"Be more positive!"

"You must listen to us much more - please!"

"We are the real experts"

"We need support and care just as all others do and our carers are of enormous importance and we value them greatly. But we also need empowerment and independence"

"We are all fragile human beings, fragile egos in some respect. Very few people are so secure in themselves and their self-esteem that they can do without others, but we are all people with certain strengths and certain limitations" (Stein G)

The area of involvement of people with dementia is still relatively new and continues to evolve with more and more people stepping forward to have their voices heard. As our understanding of dementia grows we are more able to appreciate the effect and understand how we can adjust our approach accordingly, supporting those with dementia to communicate what they consider to be important to them.

³ People with dementia are becoming increasingly involved in the work of the Alzheimer's Society. Through a national programme called 'Living with dementia', people with dementia have been sharing their views and raising awareness at a local and national level. Alzheimer's Society 2000 - 2006

2. Involvement and the benefits



"Talking to someone who really understands makes me realise I am not alone"

(Alzheimer's Society 2000-2006)

In the past it was thought that people with dementia were unable to express views about what they wanted from their service or needed for themselves. Very often we relied on relatives or those caring for them to explain what was wanted. We now recognise that not only has our increased understanding of dementia meant we can develop skills which help us communicate better but we have growing evidence that the needs of carers, their perception of what people with dementia want and what the service should provide do not always run in tandem with the thoughts and wishes of those for whom they are caring.

Due to the nature of dementia, communication often becomes increasingly difficult and people with dementia can feel progressively isolated from society. There are huge benefits to be gained from networking and discussing issues with other people who have dementia. Participants in the DASNI - Dementia Advocacy and Support Network International - worldwide internet community for people with dementia regularly discuss how involvement has contributed to an improvement in their quality of life. Their motto is: 'A worldwide organisation by and for people diagnosed with dementia, working together to improve our quality of life'
<http://dasninternational.org>

Elaine Smith, who was diagnosed with vascular dementia in 2003 says "Memory loss makes each day a challenge, but I have realized that if I don't give up, I will always conquer, I will always be able to fight". She credits her attendance at a national Canadian event for and by people with dementia, the first ever 'Changing Melody' forum shortly after her diagnosis, with providing the motivation she needed to fight back against the disease.

Christine Bryden, who was first diagnosed with dementia in 1995 says in her book 'Dancing with Dementia' :

'I operate in a different way to you, and need a different type of interaction, which is slower and more meaningful. People want to be busy, to talk fast, to ask for responses, but I can't cope with that' (Bryden 2005)

Christine Bryden was the first to give a plenary presentation on behalf of people with dementia at the ADI (Alzheimer's Disease International Conference in Christchurch, New Zealand – 2001).

Peter Ashley, who was diagnosed in 2000 with early stage DLB (Dementia with Lewy Bodies) was the second to give a plenary presentation at the ADI Conference in Barcelona 2002. He used the phrase 'Living with Dementia' by stating at the end of each of his presentations 'I'm living with Dementia, not dying from Dementia'

The Office of the Deputy Prime Minister in their report **"Making Life Better for Older People"** notes that increased participation and engagement results in:

- better physical and mental health
- reduced spending on intensive health services
- enhanced quality of life
- increased contribution to society

However, there is a difference between traditional consultation and involving someone. The difference is in who has the control. When a person is 'consulted' then service providers control the agenda but when a person is 'involved' then they can have control over the agenda. Most people are not satisfied merely to be consulted and we often end up without a choice.

There are some underpinning values which need to be clearly understood in order to involve people with dementia in a meaningful way.

Underpinning Values

- Everyone has the same human value and varied need as anyone else irrespective of their degree of disability or dependence
- Every person with dementia is an individual
- Everyone has the right to forms of support which do not exploit family and friends

The Social Model of Disability and its relevance to dementia

The social model of disability was originally conceived by the disability movement as a tool for gaining insight into their situation and to recognise how they were oppressed:

It is society which disables people. It is attitudes, actions, assumptions - social, cultural and physical structures which disable by erecting barriers and imposing restrictions and options. Disability is not inherent. (Oliver M 2004)

Thus, for people with dementia, when we assume that they cannot give their views or speak in public or even have views, then we are acting in a disabling way which denies them not only opportunities, but also restricts the rights to self determination. Using this model enables us to afford people the individual attention and respect they rightly deserve and that is accorded to all service users in contemporary policies. The social model of disability has implications for the way in which services are organised and participation is conceived. It also enables us to confront the ways

in which we discriminate against people with dementia and marginalise them (e.g. service user involvement failing to include people with dementia). Dementia is an impairment and it is society and services which cause it to be a disability.

The social model of disability broadens our thinking away from dementia as an illness or condition to a person who lives not only with cognitive impairment but also a range of social restrictions and barriers. It enables us thus to conceptualise someone with a diagnosis in a much more holistic manner, appreciating better the difficulties that can be faced, from an individual's perspective.

Services are set up as a 'medical' model where we look to 'fix' people and if we cannot – we give up. However, if we involve people, discover their wants and needs then we are more likely to obtain a better outcome for all. 'The social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment - whether physical, sensory or intellectual' (Oliver M 2004)

It is important to be clear about why you want someone to participate...

In order to ensure effective and 'real' involvement it is important for all parties to have a clear sense of what the participation is to achieve. Areas where involvement can make a difference include:

- Developing services which are more sensitive to the needs of users by working with service commissioners
- Identifying gaps in services for strategic and locality planning purposes
- Assessing quality of service and the development of good practice
- Evaluating a specific service
- Developing new services
- Empowering people using a service both in respect of control over services they receive (including a potential role in management) and their own lives more generally (Dick and Cunningham in Cantley ed 2001)

Five Core Components to ensure effective involvement

Research with older people suggests the following 5 ingredients as examples of what needs to be present for effective involvement to be taking place.

1. Having the information needed in order to be involved
2. Knowing what the options are
3. Feeling free to express views and wishes
4. Being listened to and understood and having views respected and heard
5. Being able to influence what happens and make decisions that matter

('Nothing about me, without me' Dick and Cunningham 2000)

Culturally competent care

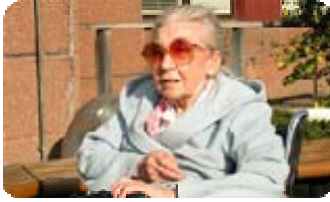
Dementia affects people from any community or background - it does not discriminate. People have basic needs irrespective of culture and it is therefore important to recognise that the basic needs for attachment, comfort, identity, inclusion and occupation need to be met, but in a culturally sensitive manner. Working in a person-centred way should ensure that we are culturally sensitive (Mortimer J 2002).

Factors to consider when involving people in service planning

Preparation and consensus on the process are key to successful involvement. It can take some time but it is important to have given and received all the information necessary and gained agreement on the 'ground rules'.

- Be clear about the aims and scope of participation before starting the process
- Identify and engage any existing local or regional user initiatives
- Clearly communicate the aims and scope to potential participants from the outset in appropriate, accessible ways
- Before participation begins ensure there is political will and organisational commitment to change and sufficient resources to actively address the service user priorities
- Ensure that service user participation is responsive to the perspectives, priorities, needs and aims of local service users. These may not match traditional service categories or managerial service priorities
- Be aware of the power relations between service users and be professional throughout the process
- Consider ways to prevent or creatively manage any conflict together with the participants and remain aware of the need to share information and decision-making power
- Value the knowledge and expertise of people who use services and ensure that this can be communicated in ways that they are comfortable with
- Work towards creating diverse, flexible, continuous participation strategies that are integral to the decision-making structures of an organisation. These should be appropriate to and planned with service users so be prepared to rethink those structures to accommodate new ways of working and communicating
- Make sure that adequate time and resources are available to support effective, inclusive participation
- Plan a framework to monitor and evaluate the impact of participation with the involved service users, as well as the experience of the process itself
- During the process, plan with participants how feedback will be communicated to them and how to respond further if required
- Address any issues of representation with service users
- Think creatively and consult on efficient ways to involve people who may otherwise be marginalised from the process
- Ensure that all staff involved (including front-line workers) understand the principles and practice of service user participation and are empowered by organisational structures, processes and management strategies to make it a success (Social Care Institute for Excellence 2004)

3. The Experience of Dementia



"Even if I forget my facts, I can remember the feelings"

(Alzheimer's Society 2000-2006)

Having some sense of what it must be like to live with significant memory loss is crucial to being able to understand what people with a diagnosis of dementia face in their daily lives, both alone and when with other people. However, it is not only about understanding from a professional or carer point of view that is important; it is also knowing something of the feelings that are engendered as, whilst there is some commonality, these will be unique for each person. We must also recognise that memory loss is but one component that contributes to the difficulties faced by people with dementia. Many physical activities can be impaired which are just or even more debilitating – walking, tremor, speech impairment, reading, writing, etc. to name but a few and all of these without necessarily reducing the intellectual competence of the individual concerned.

Some people have begun to speak publicly about their experiences. These narratives provide a powerful insight into what it feels like to live with dementia. However, people often refer to having "a small window of opportunity" in which to speak out, whilst other people do not want to or are not able to. It is essential that other techniques are used which do not just rely on a person's motivation to share or record their story, if **real** engagement is to occur and a true person-centered approach is taken. The following pages provide some insight into the value of involvement for those living with dementia. They express some of the thoughts and feelings they have about their diagnosis and how important it is for them to be involved and valued.

Alzheimer's Disease International provides links to worldwide Alzheimer's organisations and signposts the ones that have special pages for people with dementia <http://www.alz.co.uk/havedementia/>

The experience of dementia

People with dementia are just that - people! They have the same wants, needs and ability to feel and experience as much as anyone else. The following pages illustrate how some people living with a diagnosis of dementia feel. Each person is an individual, with personal experiences and views. The best way to find out what people want and need is to **really** connect with them. It may be challenging for both parties but it can be equally rewarding for both.

It is the social, interpersonal and emotional aspects of life, along with physical health that matter most to people with dementia.

Personal testimonies:

The following are quotes from people who participated in the Alzheimer's Society's 'Living with Dementia' programme 2000-2006

About dementia:

"I forget to hear what I am saying".

"I find myself asking questions which I know have already been answered but which I haven't registered

"I begin to think I can manage something. Then all of a sudden it goes"

About memory:

"When I try to remember something it goes further away from me"

"One of the difficulties is that I cannot remember I am going to forget things"

"My memory still has hiccups"

About feelings:

"It's as though I can't think. It's a mild panic"

"Even if I forget my facts, I can remember the feelings"

"I feel bad about having to answer lots of questions that I should know and I can't always remember".

About support:

"Talking to someone who really understands makes me realise I am not alone"

"I like meeting others like myself"

"I get upset if I do something silly. I need reassurance that I'm not that bad"

"I need support not pity"

'One size doesn't fit all'

Culturally Competent Care

People's backgrounds and beliefs are fundamental to who they are and how they understand and react to the world. The following are some important issues for people to consider when communicating and involving people and their carers who originate from different ethnic groups:

1. language
2. religious belief and observance
3. cultural practices (including food and personal care practice)
4. social care support
5. coping mechanisms

(Iliffe & Manthorpe 2004)

In order to address the above it is important to:

1. Take responsibility for your own need to learn about diverse cultures, so you can deliver good care.
2. Consult with people from different cultures in the community about how they can be included: invite them to visit, visit them and build links
3. Learn the best ways to communicate for each person's culture and think about how best to build the relationships with them.
4. Make sure you know how to access the materials and services you need to make full inclusion a reality - leaflets, interpreters etc
5. Talk to the person with dementia about what their identity means to them and find ways to support it.
6. Be creative about how to occupy someone with dementia from another culture.
7. Carry out an equality impact assessment to ensure the needs of all people with dementia are met, taking into account factors such as age, disability, gender, race, religion or belief, and sexual orientation.

4. Communication Matters



'Dementia is a disability, in that it makes communication harder but not impossible. It is only the behaviour of others, in not listening hard enough or well enough, that changes this disability into a handicap'

(Cantley et al, 2005)

The basis of engagement is communication – for any of us.

'We all need to communicate with other people. Communicating our needs, wishes and feelings is vital - not only to improve our quality of life, but also to preserve our sense of identity'.

'We tend to think of communication as talking, but in fact it consists of much more than that. As much as 90% of our communication takes place through non-verbal communication such as gestures, facial expressions and touch.

- non-verbal communication is particularly important for a person with dementia who is losing their language skills
- when a person with dementia behaves in ways that cause problems for their carer, they may be trying to communicate something

(Alzheimer's Society 2005)

What skills are required to communicate with people with dementia?

The skills required are the same as those needed for communication with anyone. Verbal communication with people with dementia may become more difficult as dementia progresses but remember you still have many other ways in which to give and receive messages. Malcolm Goldsmith refers to the need to "keep our minds open", to "provide extra energy" and to "accept the possibilities of communication" in order to understand the language of dementia (Goldsmith M 1996).

Good communication skills are therefore essential in hearing the voices of people with dementia and most people have the skills or at least some of them. It may be that the prospect is daunting and this leads to a lack in confidence in ability. It is, however, likely that people are more skilled than they think. Staff interviewed at one of the 'Involvement' pilot sites in the North showed a high level of skill, but a low recognition of those skills until this was pointed out to them. Some of this is practice but most of it is rewarding and don't forget, you can always ask the person you were communicating with how they felt it went. Feedback is useful for both parties.

Communication issues

How we do this in practice is, to some extent, culturally determined but there are common mechanisms in our brains which have responsibility for particular functions. The process of communication requires the ability to:

1. receive information
2. retain it
3. interpret it
4. formulate it
5. encode it
6. express the idea

In order to do this, several systems are involved:

1. cognition
2. sensory
3. neurosensory
4. neurophysiological
5. neuromotor

In other words, there's plenty of room for mistakes and mis-messages in any communication!

Common communication difficulties in dementia:

The ability to use words, to construct sentences and to understand and respond to speech will change as a person's condition changes. Understanding more about the different barriers to communication can help identify techniques for overcoming those barriers or compensating for losses.

Aphasia: impairment of language where the communication centres of the brain are affected. It is usually used to describe a speech impairment, but also covers other language problems including reading (dyslexia), writing (dysgraphia) and handling numbers (dyscalcula).

UK Connect is an organisation that does a lot of work with people with aphasia, using tools to develop communication and regain confidence

<http://www.ukconnect.org/communication.aspx>

Dysarthria: difficulty in speaking, where resulting speech is unclear, perhaps as the result of a stroke. Often the rate of speech becomes slower as well.

Be careful not to single out dementia as being the primary barrier to communication. It is important to look at the whole person and consider that the difficulty might be due to a physical illness or perhaps a visual or hearing impairment. There may be distractions within the environment and there could well be cultural differences which cause misunderstandings or lead to misconceptions.

What skills are required to communicate?

10 tips to improve communication.

Always believe that communication is possible

Try to focus on the non-verbal signs as well as verbal

Avoid making assumptions: check things out with the person

Make your communication a two-way process that engages the person

Avoid the use of jargon or complicated explanations. Keep your conversation as simple as possible without being patronising or sounding childish

Try to avoid questions which have 'why' in them. The reasoning involved in giving an answer may be too difficult. This in turn could make them annoyed or upset.

Be a good listener. Give the person your full attention and resist the temptation to finish their sentences or talk at them.

Talk at a slower pace so that the person has an opportunity to grasp what is being said

Maintain a calm and unhurried approach

Above all, don't be afraid to try or say 'I don't understand'.

Always talk to the person with dementia and never try communicating through a third party eg wife, husband. Bear in mind that the view of a relative or friend, no matter how caring, can be subjective rather than objective.

Many further examples of different ways of communicating, tools, techniques and practice examples can be found in the companion **Involvement Resource Toolkit**. This includes examples of a project undertaken by Kate Allan whilst at Stirling Dementia Development Centre (DSDC) and published by Joseph Rowntree Foundation. *Communication and Consultation: exploring ways for staff to consult people with dementia about services* (Allan 2001). The study explored how care staff in residential settings can encourage people with dementia to express their views of services. Approaches included the use of pictures to stimulate conversation, the use of 'third person' approaches. Using various activities to explore communication and learning about how people communicate their needs and views in non-verbal ways

<http://www.jrf.org.uk/knowledge/findings/socialcare/541.asp>

download entire report: <http://www.jrf.org.uk/bookshop/details.asp?pubID=366>

Some of the communication tools include 'Talking Mats'. This is a visual framework that uses picture symbols to help people with a communication difficulty understand and respond more effectively. For further information, contact Joan Murphy, University of Stirling joan.murphy@stir.ac.uk

5. The Process



"Don't just tell me what to do. Help me to make choices".

Alzheimer's Society 2000- 2006

Whilst involving people with dementia requires thought into the individual mode of communication, everyone has the same rights as anyone else to be included and be heard wherever they live or wherever they come from. Thus time and consideration need to be given to any inclusion work to ensure that it is not tokenistic or inappropriate.

It is worth thinking about existing and long term relationships and how these might be affected by any interventions you might make e.g. where relatives may object or have radically different views; your continuing professional relationships.

Involvement, consultation and participation

It is important to be clear that there are distinctions between these approaches so that you can consider the relative merits and inclusiveness.

Involvement is a process and not a one-off event. 'The concept of involvement as a process is particularly important where people have not been accustomed to making decisions, where life experiences, including experiences of care, have discouraged involvement and, worst of all, where opportunities for involvement have simply been absent. The process of involvement is a cumulative one where the experience of influencing a decision in one area may lead to greater self-determination in others and new opportunities to express opinions may lead to greater confidence to do so in other situations.' (Dick & Cunningham, 2000)

Consultation (e.g. focus groups, questionnaires) tends to be a 'one-off' event which lacks the commitment of real and meaningful continued involvement in the process of decision-making. In order to really engage and involve people with dementia a commitment to greater involvement needs to be explicit and planned.

Participation implies greater collaboration and involvement on an equal footing where those using the service and staff are treated alike. We need to recognise the power imbalances between staff and service users and ensure they are taken into account. We also need to recognise the expertise that people with a dementia bring which staff may not have. The reciprocal nature of sharing experiences and being listened to with a view to decision-making together provides real involvement and empowerment for the person.

Partnership v consultation

Looking for partnership rather than one off consultations is likely to be more enabling for people with memory loss as it can help in building trust. Bear in mind too that more than one interview is going to be necessary to gather the information that would be useful to you. However, the key point is to assess each situation individually and consult accordingly. Always allow the person with dementia to set the pace and 'go with the flow', make it a 'safe' environment both physically and psychologically and don't be afraid to be creative and imaginative!

What helps involvement?

People with dementia involved in the Alzheimer's Society Living with Dementia programme identified the following things that helped them to get involved:

- being respected and listened to
- a welcoming attitude from staff and carers
- being given encouragement
- a clear and prompt response to issues raised
- early diagnosis
- individual's acknowledgement of the diagnosis
- varied opportunities to get involved or have a say
- opportunities to take part without it involving 'consultation'

What hinders involvement?

People from the Alzheimer's Society Living with Dementia programme said that these barriers made involvement more difficult:

- fear that I will not be taken seriously
- lack of time for people to listen and make relationships
- lack of money
- poor access to transport
- lack of diagnosis
- negative attitudes about the abilities or rights of people with dementia
- being asked about issues that are not relevant
- lack of feedback about what has happened as a result of being involved
- lack of personal identification with issues of 'dementia' or 'Alzheimer's'

Important issues regarding involvement and consultation

- It is possible to consult people with dementia about their views of services
- It is possible for staff to undertake service user consultation work
- There are many different possible approaches to communication and consultation
- Approaches to communication and consultation must be developed on an individual basis
- Giving the person with dementia maximum control over opportunities for communication and, subsequently, consultation seems to be the best strategy
- Devising and trying out approaches to communication and consultation requires considerable amounts of time and energy
- Communication and consultation should not be seen as a special activity which is set apart from other work
- Organizational features of services do not always support efforts to undertake work of this nature
- Investing effort in developing communication and so consultation can be highly rewarding for staff
- Staff need to be helped to recognise the complexity of the task they face and the sophistication of their own skills
- Staff need to be supported in tolerating vagueness and confusion
- There are dangers in adopting pre-planned approaches
- Progressing from general to specific approaches is a rational way to approach the task
- There is a need to recognise the importance of apparently small details of communication
- Staff need to be open-minded about approaches which seem unsuccessful
- Documentation and reflection are important parts of the process
- Particular approaches to communication may function as confidence-boosters for staff
- Many people with dementia express needs and preferences in non-verbal ways
- The issue of consent applies to practice as well as research
- Communication and consultation can be personally very demanding

Allan, K. Communication and consultation: Exploring ways for staff to involve people with dementia in developing services. Joseph Rowntree Foundation. The Policy Press. Bristol 2001 Download: <http://www.jrf.org.uk/bookshop/eBooks/186134810X.pdf>

Effective involvement and advocacy

Where people with a dementia are unused to speaking up for themselves, in groups or with unfamiliar people and issues, or where there are barriers to communication or involvement, advocates may be appropriately involved. Advocates can be a key to involvement for some people and allow people who otherwise are likely to go unheard to have their chance to be involved. Advocates can be people with dementia themselves who have an ability to fulfil this role.

We must always recognise the enormous support and dedication given by the caring community and people with dementia are the first to recognise the great burden placed on their shoulders; counselling is as much a need and right for carers as it is for people with dementia. All of that said the role of the carer is just that and not to assume the identity of their charge, the individuality of the person being cared for must prevail for as long as capacity exists (we must have "carers not keepers" P J Ashley - 2003)

Different Approaches

A range of approaches can be used to involve people with dementia in service development and planning. The appropriateness and effectiveness of particular approaches will be determined by several factors such as:

- individual strengths, abilities and needs of people to be involved
- time/location/settings etc
- individual circumstances e.g. background, personality, current situation, relationships & interests
- aims and purposes of the involvement
- staff skills

Examples of involvement activity

For detailed information, resources, tools, techniques and practice examples see the **Supplementary Resource Toolkit** at:
www.olderpeoplesmentalhealth.csip.org.uk

6. Organisational Issues



Managers can't just decide on a policy and implement it like any other. It is a hearts and minds thing and needs a culture change, so there needs to be a lead from the top, lots of training for staff and lots of independent support and training for the service users.

Manager, SCIE Practice Guide 2006

Involving service users in planning, developing, commissioning and providing services has become a mainstream activity. But hearing the views of people with dementia has not yet become so mainstream. Many current policies, reports and legislation support and require the consultation of service users and carers, but how do we make sure that not only are voices heard but also acted upon? If we are committed to hearing what people with dementia have to say and if we are really listening to what people are saying, then we have a responsibility to do something with this information. Ensuring it is happening however is more challenging. Most organisations have Service User Involvement Strategies to fulfil the statutory duty of involvement. However, many strategies fail to address the specific needs of involving people with a dementia.

Huge strides have been made in establishing service user involvement in working age adult mental health services, learning disability services and physical disability services. Whether these strategies are age discriminatory or not, the reality is people with dementia are generally notable by their absence in involvement activities. Involving service users, particularly from a marginalised group such as people with dementia, in service delivery and planning requires a culture change at all levels if their voices are to be taken seriously.

Managers need to ensure that people receive guidance on ethical and governance requirements prior to beginning any involvement initiative. We need to ensure service users understand the nature of the process, consent is received, anonymity assured and people feel free to express their views without fear or risk of any adverse response from those who provide the service. We also need to be prepared to deal with any instances of abuse or unacceptable practice that comes to light in course of involvement work (Cantley et al, 2005)

Taking a strategic approach by making links between organisational priorities, central government policy, locally defined priorities and the priorities of people with dementia can be important in gaining management agreement for engagement work.

Practice Development

Professional training can develop confidence and skills in involvement and long term investment in professional development is essential to developing and maintaining culture change. 'The work entailed in involving people with dementia can be immensely rewarding for staff but also complex, challenging and emotionally draining. Experience has shown that can be difficult to sustain staff motivation and

momentum when involving people with dementia, particularly if staff have to struggle with other conflicting demands on their time' (Cantley et al, 2005)

Management Matters

- Provide strong leadership in promoting involvement for people with dementia
- Demonstrate the organisation's value commitment to involving people with dementia
- Promote an organisational culture that challenges negative assumptions about the lack of ability of people with dementia to be involved in service development
- Assess how the organisation is currently operating in relation to involving people with dementia
- Ensure that there are arrangements to involve relatives of people with dementia in their own right
- Ensure appropriate training and development activities are available for people with dementia who want to develop their confidence and skills in involvement work
- Harness the expertise that exists amongst staff in dementia care
- Support staff who are prepared to question long held practices, attitudes and beliefs
- Provide staff with training and development opportunities to enhance their skills and confidence in this work
- Ensure that ethical guidance is available to staff
- Give staff dedicated time and the other resources needed to develop this work
- Ensure good leadership from specialist, expert dementia involvement worker(s)
- Encourage staff to try new ways of working in a context of ongoing learning through reflection and review
- Ensure that the views shared by people with dementia during different involvement activities are collated to ensure maximum impact
- Ensure staff and middle managers undertaking involvement work understand the strategic planning and financial cycles into which user views must feed
- Ensure that there are clear arrangements for staff and managers to convey service user feedback on inter-agency matters
- Ensure that issues raised by people with dementia are taken seriously and that the people involved receive feedback about follow-up actions

Dementia North (2005), Listen to us: involving people with dementia in planning and developing services - guide produced as part of Department of Health funded development project 'Involving people with dementia' in 4 case study sites in NE England

<http://www.neyh.csip.org.uk/silo/files/listen-to-us.pdf>

Bringing about successful changes in an organisation

'There are two things needed for an organisation to succeed in participation. One is the determination to make it work. You must really want this to happen; you must really want to hear the views of service users and take them on board. It has to become part of the aims of the organisation. The other thing is the willingness to...[change]. You can't simply carry on working in the time-honoured ways of organisations'. (Chief Executive, voluntary organisation. SCIE Practice Guide 2006)

Change is difficult, can be perceived as threatening and people generally opt for the status quo. Empowering service users to have a significant voice in how we run services requires a new mindset if we are to be true to our word.

You may want to consider what helps make change strategies work and why they often fail.

Growing demands for cost-effectiveness and evidence-based practice have led to the development of targets and measures to inform how effective services are.

Unfortunately, these outcomes or impacts of care do not necessarily reflect outcome measures for people with dementia. As people with dementia can and have provided information about their desired outcomes, the imperative to take these into account if we wish for truly effective services should prevail.

Ethical issues in 'involvement'

Ethical Issues

Depending on the nature of your 'involvement work', you may have to seek approval from your local Ethics Committee. However, there is variation in local practices and it is generally not required if you are not undertaking research. Capacity is situation-dependent. It is important not to assume that because someone cannot consent in one situation that they may not be able to do so in another.

In person-centered care, a primary concern is to nurture personhood. This requires us to focus on relationships in order to connect with that person. It also involves us in seeking understanding which recognises individual experience, which in turn, values and respects an individual. Thus, in ascertaining the best way to address the issue of consent with someone who has a dementia, we need to be person-centered in our approach and creative with our communication.

Consent processes must include face-to-face encounters with the person with dementia in order to seek permission or consent. The aim is to ensure that people have made a positive choice to be involved rather than the assuming that it is OK. Finding a way that gives a person the best chance to understand is key.

It is generally accepted good practice to inform carers or relatives about intended involvement of the person with a dementia. Not only can they give useful or significant information about how best to go about seeking consent, but they may also be able to assist in the process.

Key Areas:

- Confidentiality
- Consent is 'informed consent' – make sure people understand the nature of what they are engaging in
- People feel confident enough to express their views without fear of adverse response e.g. loss of service
- There is protection for vulnerable people
- People have the right to choose whether to be involved or not, and to change their mind at any time (and to feel safe to do so)
- The data collected is secure
- Clarity is provided beforehand about how you will deal with sensitive issues that may arise
- Only data that is required is collected
- There is the ability and process in place to deal with any instances of abuse or unacceptable practice that comes to light during the course of the 'involvement work'

Conclusion

Developing person centred services remains an operational and policy imperative - consultation and involvement with people who have dementia is key to ensuring the right kind of services for the estimated 700,000 people, of all ages who are living with dementia.

The message is simple - people with dementia need be involved. They are key stakeholders, best placed to afford a view on how services can help and support them. As we progress and diagnose people with early stage dementia this possibility will become more of a reality; those with such an early diagnosis are able to express what it is like to have such a condition and it is imperative that their voices be placed high on the agenda. This means more than simply asking people with dementia what they want from their service, it is as much about connecting with people, valuing them as individuals and ensuring this informs the support we offer.

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Acknowledgements

Editorial Board:

Peter Ashley

Veronica Brown

Tony Jameson-Allen

Alison Laver

Tricia Nicoll

Penny Redwood

Sally Rogers

Nadine Schofield

Debbie Smith

We would like to thank the following people who also contributed to the development of this toolkit:

Paul Gertig

Jean Hamilton

Rachael Litherland

Jenny Thornton

Members of the Northern Everybody's Business Managed Learning Network

CSIP's Older People's Mental Health Team