Finding out what a dementia friendly community means to people with dementia and carers

Making Hampshire a dementia-friendly county

Toolkit for engaging people with dementia and carers

April 2012
Dementia-Friendly Hampshire

Finding out what a “dementia-friendly community” means to people with dementia.

This is a guide for people working with people with dementia and their carers.

In particular it is for those who want to support people with dementia and their carers to have a say in building a more dementia-friendly Hampshire.

Inside you will find notes to support you in finding out what is important to people with dementia about their communities, and what can be done to make them better places in which to live well with dementia.

You will find guidelines for discussing the issues with people with dementia face to face, as well as a questionnaire for people who might prefer, and are able to work alone.

You will also find a description of “walking the patch” – a way of finding out what it is really like for people with dementia out and about in their communities.

We have included findings from previous consultation work with people with dementia, to help you think about the various ways in which people with dementia in other areas are interacting with their communities, and the barriers they face.

This guide is aimed squarely at finding out what people think about their communities - it is not intended to be a comprehensive and exhaustive guide to consulting with people with dementia, so we have included links and suggestions for further reading.

It gives us a somewhere to start in developing dementia friendly communities. If people with dementia tell us they all want to use the café in the garden centre – then we start there.
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Why talk to people with dementia and carers?

The idea of making our communities better places to live for people with dementia is something which engages the enthusiasm and interest of all sorts of people. Traders, leisure companies, transport providers, planners, service providers, health and social care organisations, charities are all potentially affected, all have a role to play in forming a vision about what a dementia-friendly community should look like.

The most important stakeholders in this process of course are people with dementia, and those who care for and support them.

“Nothing about us without us” is a slogan which carries great resonance for disability rights campaigners – and is one which is increasingly being articulated by people with dementia as well. The voices of people with dementia and their carers should be at the start and the heart of the process of creating dementia-friendly communities.

Dementia-friendly communities need to be responsive to what people want, but perhaps more importantly, people with dementia should have the right to have a sense of ownership, investment, responsibility and of connectedness to their own communities.

Why is it important for this work?

- People with dementia have a right to a say in decisions that affect their lives.
- Involving people with dementia sends an important message about the values inherent in the notion of dementia-friendly communities.
- It engenders a sense of ownership and investment.
- On a practical level it gives us a somewhere to start in developing dementia friendly communities. If people with dementia tell us they all want to use the café in the garden centre – then we start there.

Further reading:

The South West Dementia Partnership has produced a guide to engagement with people with dementia called “what works” - you can download a copy free of charge here: http://www.southwestdementiapartnership.org.uk/2011/10/what-works-resource-pack/

The Care Services Improvement Partnership has produced “Strengthening the involvement of people with dementia” toolkit – which you can download here: http://www.dhcarenetworks.org.uk/_library/Resources/Dementia/CSIPComment/strengthening-the-involvement-of-people-with-dementia.pdf/
Things to bear in mind before you start:

- For some people the concept of dementia-friendly communities might be a difficult one to grasp. So make sure that YOU understand what this is all about so that you can in turn make it clear to participants. In doing so, make use of accessible language – the introductory paragraphs in the paper questionnaire (appendix) are examples of the kind of language you might use in getting the idea across.

- Find out whether there are any existing consultation processes or initiatives you might access.

- Are there conflicting needs between carers and people with dementia that you need to take into account (see below) – which might influence how you carry out the work.

- Make sure that you have enough time, and staff or volunteers available to make this an enjoyable experience in which people feel they have the time and support to have their say in the way that best suits them.

- Make sure you tell participants what will happen next, and how they can stay involved, if they want to.

What are we trying to find out – and why?

At this stage of the process – we are interested in:

- The ways in which people with dementia engage in their communities.
- What helps, and hinders this process.
- What people have stopped doing since their diagnosis and why.
- What new things people might like to be doing.
- What can be done to help.

Once we have identified the issues – we can begin to think about how we might begin to address them.
How can we go about finding out what people’s issues are?

There are a number of ways you can go about talking to people with dementia and their carers, and these include:

- By talking to people 1-1
- By talking to people in a group setting.
- By asking people if they would like to fill out a questionnaire, either on-line, or on paper.

And

- By “walking the patch” with people with dementia – to get a feel for how they really experience getting out and about in their communities.

These are not mutually exclusive; some people might want to get involved in group work, as well as having a 1-1. You might also want to offer a 1-1 conversation with people who seemed to have more to say during a group conversation.

There are lots of other ways to support people to express their views

People respond to different approaches at different times in different ways. The communication needs of individuals, the person’s background and interests, and their relationships with staff needed to be taken into account before identifying the most appropriate approach.

Talking to people 1-1.

Some people find it a lot easier to talk on a 1-1 basis.

People with more advanced dementia will often have more particular needs with relation to communication, and may find group working more challenging, and may be sidelined by more vocal group members.

By working on a 1-1 basis we can provide a more person-centred approach that is more likely to meet their particular needs, and more likely to give us the information we need to move forwards.

Effective communication is the key to

Further reading

The SCIE Open Dementia E-learning course has an excellent module on effective communication – you will find it here
successful 1-1 discussions.

Don’t forget that people with dementia have good days and bad days – if you are working regularly with someone, and they are having a bad day – you can always come back to the conversation another day.

**Group discussions**

Some people may feel pressurized by 1-1 interviews and may worry about the impact of what they say. Group discussions can overcome this by generating a group rather than individual response. Hearing the views of others can also help people articulate their own thoughts.

Many people with dementia will be happy to work in a group – especially if it is an established group where people know and feel comfortable with each other.

You can use the questions and structure of the paper questionnaire, which you will find as appendix 2 – as the basis for your group discussion.

Don’t feel too restrained by the questions or structure – you should think of these as guidelines for a conversation.

Here’s what people with dementia have said about running an affective meeting:

- Distribute easy to understand agendas before meetings. This gives us a chance to prepare and write down our thoughts.
- Meetings should be short, with only one or two agenda points. We get tired and find it difficult to concentrate after a while.
- It helps if you give us some ideas but sometimes we will want to talk about things that are important to us.
- Slow down the pace of discussion to give people time to say what they want to say. Don’t talk too much!
- It helps to take turns so that everyone can have their say, even if this is not in words.
- Refreshments are essential. They help us to relax and make our journey worthwhile.
- Send us an easy to understand record of the meeting as soon as possible.

*Tip:*

You may find that conversation veers away from the topic in hand – that’s OK – and you will often find that you get some good results by allowing the conversation to take its course – it’s more important that people feel relaxed and that their input is valued.
Carers and people with dementia.
You will be aware that people with dementia and their carers often have different, and sometimes conflicting needs and points of view, and that this can influence the methods you use to seek their views.

Where people need space to articulate their own perspective – you might consider running 2 different sessions.

- One to consider the views of people with dementia.
- One to consider carers views.

People should feel free to go to either or both sessions, but you need to be clear about the issues under discussion. This can help if people with dementia or their carer feel anxious about being separated.

This will not guarantee there won’t be any muddying of the waters between carers issues and those of people with dementia – but it can certainly help to keep things as clear as possible.

Tools for 1-1 work and group discussions
You can use the questions and structure of the paper questionnaire, which you will find as appendix 2 – as the basis for your conversations with people with dementia and carers.

Don’t feel too restrained by the questions or structure – you should think of these as guidelines for a conversation.

You might also consider bringing along some pictures of commonly-used areas within the community – the shops, library, parks, bus or train stops, leisure centres and so on – these can be useful as:

- prompts for discussion, especially if people are struggling with direct questions.
- reminders of the topic in hand – to help people to stay focused.
- as props – some people feel more confident when they have a physical object they can handle and refer to.

Further reading
Innovations in Dementia (CIC) in partnership with Alzheimer’s Society and Bristol and South Gloucester LINKS has produced an evaluation of a series of consultation events with people with dementia and carers – it describes a range of strategies and recommendations for creating dementia-friendly meetings. Copies available on request from steve@innovationsindementia.org.uk
Questionnaires

Some people prefer to work alone, and are able to fill out a questionnaire.

Appendix 2 is a paper copy of a questionnaire we have prepared to help people to have their say on what a dementia friendly community means to them.

If you know of people that would like to fill out the questionnaire – print out a copy, adding your contact details on the last page.

We have used this structure as the basis for an on-line questionnaire – many people with dementia and carers are happy and able to use online resources.

Websites like www.surveymonkey.com provide an easy-to-use vehicle for online questionnaires.
Walking the Patch

This can be a very effective way of finding out more about how people with dementia experience their local environment.

Arranging to go with them to visit these places can give us some really valuable insights into how they experience their environment.

It can also help us to identify ways in which we can support local facilities to become more dementia-friendly.

Who should go?

It is tempting to assume that this activity is only suitable for people in the early stages of dementia.

Certainly, people in the early stages may need less support, and may be more active in their communities.

However it would be wrong to assume that people with more advanced dementia cannot enjoy the process and have nothing to offer.

Much will depend on the activity you choose, the person’s particular needs and preferences, and the level of support you have available to you. See “safety” and “consent” below for more information.

It is best to do this on a 1-1 basis, as you will need to be giving your full attention to the person, and to their experience. If you have more than one person with dementia, you will need the same number of people to accompany them.

If carers want to come with you, that can be a big help, but bear in mind that the focus is very much of the person with dementia and their experience.

Where to go?

You may have already identified places in the community where people with dementia go, or have said they would like to go.

In the past we have accompanied people with dementia to supermarkets, restaurants, pubs, gymnasiuims, railway stations, and leisure facilities.

If you have not identified specific venues, then a leisurely walk in a high street or park can be useful, not just to get a feel for how people find their way around, but can also serve to prompt people to particular places they might like to explore.
It can be really helpful to have a specific goal in mind. Like:

- Buying a specific item in a shop
- Finding out the time of a particular bus or train, either at a train or bus station or by phone or online (we can walk the patch metaphorically as well as literally)

Remember:

- Knowing the location of toilets can be a big help, for all concerned.
- Think about how the person will travel to and from the walk.

**When to go?**

You might want to think about going during less busy periods. This will reduce the stress on the person with dementia, and make it easier for you to focus on what they are telling you and experiencing.

**The process**

You should explain clearly to the person with dementia what this process is all about.

Depending upon the person you may need to remind them that you are just trying to find out what it is like for them to be out and about.

Try and keep it as informal as you can, and as enjoyable as possible for all concerned.

Try and keep the whole exercise within 45 minutes.

You should persuade the person to explain how they are making decisions as they navigate their way around. Get them to talk about what it is like for them.

Pay particular attention at key decision points, and use prompting questions where necessary like:

- What are you looking at?
- “How did you choose between this way and that way?”
- Can you see that notice?
- “What do you think it means?”
Don't expect the person to explain every decision - you can learn a lot from observation…..so as well as listening to what they tell you – try and be as observant as you can. Make a mental note of how well they are navigating the environment, what use they are making of formal and informal aids to navigation, and the nature of any interactions with those they encounter.

It's OK to reflect back what the person is telling you, or what you observe:

  - “did you find X difficult?”
  - “it looked to me like you were struggling with XX”
  - “you found XXX useful didn’t you?”

Remember:

- you may need to reassure the person and point them in the right direction or assist with an activity (such as finding money) –

- It should be an enjoyable experience – but be careful that the person doesn’t get distressed.

**After the walk**

It can be helpful to have a conversation about the walk. Questions you might find helpful include:

- Did they enjoy it?
- What did they enjoy most /least?
- What was helpful / unhelpful?
- What can be done to make it better?

From what the person has told you, and from your observations, it is possible that you might have some ideas together about how improvements can be made.

**Walking the patch -Issues to bear in mind**

**Safety**

- You should be conscious of the safety and support needs of people with dementia whilst you are out and about. Talk to them and their carers about safety issues, and whether the person needs any particular support whilst out and about,

- As a service provider –you should apply your usual health and safety, and risk assessment procedures.
**Consent**

- You should make sure that the person is able to consent. You should consider getting written consent if you are likely to use their words in any reporting that you do.

- Agree with the person how you are going to record what they say, i.e. by writing it down, sound recording, photos, video recording, asking someone else to take notes. If the person is not happy with these, then you will have to make mental notes, and write it down as soon as you can after the walk.

A copy of Innovations in Dementia’s ethical code of practice for involving people with dementia is included as appendix 3
Approaching providers with what people tell you.

This is all about working towards a more dementia-friendly community, so it is important that we do something with what we learn.

Depending upon what you learn – you may have information about:

- Places in the community where people with dementia go.
- Places they would like to go.
- Things that help people to connect with their communities.
- Things that are a barrier to their communities.
- Things that people would like to do.
- Things that people have stopped doing, and why.
- What might help people to stay connected, reconnect or make new connections.

Some of these things might be very general in nature, like for example, a lack of green spaces in urban areas…..

…..or it might be something very specific – like a particularly helpful shopkeeper, or a piece of poor or non-existent signage.

The first question might be:

“**If things are to move forwards then who needs to know?**”

So, if there are issues around outdoor areas and townscape, then the planning department would be a good place to start.

For very specific issues – like signage in a building – then the manager is probably the best person to start with.

If there are issues that retail premises share in common – then the town or shopping centre manager, or traders association would be another option.

If there is a local Dementia Action Alliance, then this can be another very effective way of raising issues, especially those of a more general nature.
The next question might be:

“What is the best approach to take?”

Your approach will depend upon the relationships that you have built up with providers of services and facilities.

In some instances an informal approach will work well, and in others, especially larger providers, it can pay to begin the approach in writing or by email.

You should introduce yourself, and let the provider know about your work in making Hampshire a more dementia-friendly county.

Make sure you have the briefing note for businesses “Why do we need to be dementia-friendly” at hand, and ready to give to providers.

This will explain why they need to think about becoming more dementia friendly.

You can go on to explain that you been talking to people with memory problems and their carers about their experiences – and that you feel that there is something that they should know about how they can make their service better.

This will help them to understand what their specific issues are so far as people with dementia and carers are concerned.

In our experience, what people have to say about their communities and the places within them are rarely wholly negative. There are frequently positive comments to be made, very often about the attitude of staff that can outweigh, or at least sweeten potentially negative comments in other areas.

If there are positive things to say, then start there. Then you can move on to pointing out the areas where they might use some help.

This is where you can use some of the improvement tools to show providers how they can make changes for the better:

- “Checklists for dementia-friendly environments” gives some basic guidance on things to consider in making indoor environments easier for people with dementia. It also provides links to more detailed audit tools if needed.

- “Dementia awareness raising options for staff” describes a range of options for raising awareness of dementia among staff.

- “Help-pack” for customer facing staff” – is a basic awareness guide designed especially for customer-facing staff. It gives a very brief introduction to dementia, but focuses mainly on how to support customers who may be having problems.
Appendix 1

Summary of findings

Dementia Capable Communities - The views of people with dementia and their supporters

February 2011

The full report can be found at:


Executive Summary

People told us about the things which make the difference in a dementia-capable community:

- The physical environment
- Local facilities
- Support services
- Social networks
- Local groups

People told us that they kept in touch with their local communities:

- Through local groups
- Through the use of local facilities
- Through Walking
- Through the use of support services

People told us they had stopped doing some things in their community because:
Their dementia had progressed and they were worried about their ability to cope
They were concerned that people didn’t understand or know about dementia

People told us that they would like to be able to:

- Pursue hobbies and interests
- Simply “go out” more
- Make more use of local facilities
- Help others in their community by volunteering

People told us that 1-1 informal support was the key to helping them do these things.

People told us that communities could become more dementia-capable by:

- Increasing its awareness of dementia
- Support local groups for people with dementia and carers
- Provide more information, and more accessible information about local services and facilities
- Think about how local mainstream services and facilities can be made more accessible for people with dementia.

…and they told us that in order to do this:

- Communities need knowledgeable input, not least from people with dementia
- There needs to be continued media attention and public awareness campaigns
- Dementia needs to be “normalised”
- Communities need more funding for supporting people with dementia
- Communities should make better use of existing resources
- Organisations should work together more effectively
Appendix 2

Paper version of sample questionnaire
Is your community “dementia-friendly”?

What is a “dementia-friendly community”?

People with memory problems have told us that for them, a “dementia friendly community” is one which supports them to:

• carry on doing the same things they have always done - like going to the shops, getting on a bus, playing golf, or just sitting in a park.

• find their way around and feel safe

• keep in touch with people and feel that they belong in their community.

What can help to make a community “dementia-friendly”?

Memory problems of course can make these things more difficult – but things can be made easier if we live in a community which is easy to find our way around and in which people are helpful and supportive.

For example – people have told us that things that help include:

• People who understand about memory problems – this can be people in shops, bus drivers, friends and family or anyone you come into contact with.

• Clear signposting, so people know where they are going and where things are.

• Clearly-written information on things like bus timetables or leaflets about services.

• Being able to spend time with other people in a similar situation

• Having someone to go with.
Why are we asking these questions?

We want to find out what people with memory problems do in your area, what facilities they use, and what helps or hinders them.

We want to find out more about what makes places easier to live for people with memory problems.

It would be a big help to us if you could let us know what you think by answering the questions in the BLUE BOXES below.

About you.

Tick the box that most applies to you:

I am a person with dementia or memory problems

I am the carer or friend of a person with dementia or memory problems – and am filling in this form on their behalf

I work with people with dementia or memory problems – and am filling in this form on their behalf

None of the above

I live in __________________________________________

We don’t need to know your full address – just which part of town, or which village you live in.
When you are out in your local area – what sort of things do you do?

What helps you to do these things?

What makes it more difficult for you to do these things?
Are there things that you used to do, but have stopped doing?

If so, why have you stopped doing them?

What might help you to start doing them again?
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
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<tbody>
<tr>
<td>Are there new things that you would like to be able to do in your community?</td>
<td></td>
</tr>
<tr>
<td>If so, what do you feel is stopping you?</td>
<td></td>
</tr>
<tr>
<td>What might help you to start doing them?</td>
<td></td>
</tr>
</tbody>
</table>
Finally – what do you think could be done to make your community more dementia-friendly?

If you would like someone to contact you about what you have said, or want to find out more about dementia-friendly communities, please write down your contact details here:

Once you have finished this form – please hand it to:

Or send it to:

If you would like to talk to someone about this form – please call

Thank you for your help.
Innovations in Dementia Ethical code of practice

Involvement of people with dementia in projects, consultations, evaluation and research

Background

People with dementia are routinely involved in the work of Innovations in Dementia. This might be as co-researchers on a project, being consulted by a commissioning or policy body, or giving their views as a beneficiary of a project.

Innovations in Dementia is committed to ensuring as wide a range as possible of people with dementia are given opportunities to participate, and have their voices heard. We pride ourselves on our engagement work with people with more advanced dementia, including people living in care homes, who are seldom heard.

We work with a steering group of people with dementia called ThinkTank who review the work of the organisation, and help to direct it strategically.
Respecting the rights of people with dementia

Our collaboration with people with dementia is built on a rights based approach that promotes and supports people to have their voices heard, including those with advanced dementia. However, we want to ensure that the dignity, rights, safety and well being of people we work with, are respected at all times.

We are committed to providing accessible information about our work to people with dementia, to ensure they are as fully involved as possible in decisions about their engagement with us.

Informed consent

Informed consent should be acquired from all people with dementia (and others) who are involved in the work of Innovations in Dementia.

This includes:

- Providing enough information about a piece of work and its anticipated outcomes, to assist people in making a considered decision about participation
- Explaining how information and data will be stored and used
- Helping people to consider the advantages and disadvantages of being involved
- Making people fully aware that they do not have to get involved in a project
- Reminding people at regular intervals about their role in the project and that they can withdraw from a project
- Helping people to think about the implications of how the information will be used, for example whether identification may be possible
People with dementia may need extra help to give informed consent. We use various methods to help people to understand and decide whether to be involved in our work. This includes:

- Using visual props and cues to help people to make a decision. These include objects, Talking Mats, written information.
- Providing accessible written information to back up a consent discussion

**Ongoing consent**

We believe that consent in an ongoing process. We provide routine reminders, verbal and/or written, that prompt people to reconsider and reflect on their involvement

**Involving supporters**

We acknowledge that people with dementia may need support to give consent and to understand the consequences of their decisions.

For this reason, we may involve a family member, support worker from a partner organisation or other support in the consent process, where appropriate.

**Involvement in setting agendas**

Innovations in Dementia has a steering group of people with dementia that we call *ThinkTank*. This group of volunteers helps to influence the type of work that we undertake and also take part in all our projects. This group of ‘specialists’ contribute their personal experience of living with dementia as well
as their knowledge and skills to external projects. Individuals within this group are supported to identify and use their skills both within Innovations in Dementia and with partner organisations.

We also work with groups of people with dementia in support groups, day centres and care homes in partnership with care providers in the statutory, voluntary and private sectors.

ThinkTank help us to review our policies and procedures regularly in the way that we work with people with dementia.

**Confidentiality**

Innovations in Dementia recognises that people with dementia are often assumed to lack capacity and are therefore denied their rights to confidentiality. We always start from a position of assuming that people with dementia have capacity and can make informed decisions and give consent around their roles within Innovations in Dementia.

All data is confidential and is only used in the way that an identified project intends. People with dementia are made aware of the project limits at the outset of a piece of work, and are reminded routinely throughout the life of a project.

We give people various options for example complete anonymity, use of first name only etc.

All data collected during a piece of work must be stored securely in a locked drawer or password protected.
Where information is to be publicised, people are assured of anonymity or their agreement is given for personal details to be included.

Consent forms are always completed for films and photographs. People with dementia are asked to provide a witness to their signature. This is often a family member.

**Health and safety**

At Innovations in Dementia, we start from the position that the person with dementia has the capacity to understand risk and to be supported to make their own decisions about risk taking and risk management. However, we acknowledge that this can also be variable – from situation to situation, from person to person and in different time frames. We will support the rights of people with dementia to take risks whilst ensuring that appropriate risk assessments are carried out.

The safety of people with dementia is given priority at all times. Individual and group risk assessments are carried out on every piece of work. Health and safety regulations are strictly observed.

Innovations in Dementia holds professional indemnity and public liability insurances.
**Staffing**

Innovations in Dementia is run by three co-directors, Nada Savitch, Rachael Litherland and Steve Milton, who also carry out work in the organisation.

All directors are CRB checked and approved.

Where associates and volunteers of Innovations in Dementia have contact with people with dementia and others, appropriate checks take place.

**Finance**

All the work of Innovations in Dementia is funded or commissioned as a special project or programme. Costs of the projects are included in project templates and budgets and staff are paid from individual project budgets. Where people with dementia are involved as project consultants, payments are made to them, for example in return for views and expertise.