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Dementia Capable Communities

The views of people with dementia and their supporters

Executive summary and recommendations

February 2011

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

Comment and recommendations

Which aspects of a community make it a good place for people to live?

The physical environment

Our ability to maintain links to our community is closely linked to our ability to get around. Mobility and orientation for people with dementia can be severely hampered by the physical environment.

Good design and attention to orientation can make a significant difference to a person with dementia's ability to navigate their surroundings.

Guidance is available on environmental design, and there is potential for people with dementia to develop a role in advising and assessing access issues at a local level.

Recommendation – That we build on the potential for people with dementia in advising on access issues.

Service providers have obligations to consider the needs of disabled people in the way in which they provide services. Similarly, building regulation also requires the needs of disabled people to be considered in matters of building and design.

Recommendation – Service providers should be made aware that many people with dementia are considered “disabled” under The Equality Act 2010

Recommendation – People with dementia and their supporters should be made aware of their potential rights under the Equality Act 2010, and supported to press for their rights if necessary.

Local facilities - especially shops and public transport

Most people with dementia said that it was the attitude of staff that made the biggest difference.

Many concerns were expressed about a lack of understanding of dementia, and many people said that this was stopping them from using local facilities.

Others reported very positive experiences of using local facilities, again usually linked to the attitude of staff.

People with dementia had three recommendations:

- “Staff should be made more aware of the needs of people with dementia”
“Education education education!!!”
- Services and facilities could have someone responsible for making sure that everyone is included and able to participate.
- A village champion for dementia

Recommendation – That we support and encourage the development of a role for people with dementia in raising awareness and training of staff.

Support services

Some had struggled to access or obtain support services

For others it is the lack of more informal 1-1 support that was lacking, perhaps from a volunteer “buddy” or befriending scheme. Most said that this kind of support would enable them to continue to maintain their links and be active and visible within their communities.

Recommendation - That we consider the potential for further development of “buddy” schemes to support people with dementia in the community.

Social networks

Many people with dementia and carers report that family and friends “drift away”.

Long established social networks can break down quite quickly and people with dementia and carers can find themselves having to negotiate a new set of relationships.

Some supporters expressed concern that people might be wary of helping because they fear that things will escalate, and they will get “roped in”.

A fear of escalation is one of the rationales for “circles of support” currently operating for people with other disabilities. The circle might include neighbours, friends, milkman, shopkeeper, who volunteer to support the person but in a specific and limited way.

Recommendation - That consideration be given to the applicability of “circles of support” to people with dementia.

Local groups

Many of the people with dementia who gave us their views are members of EDUCATE, or of a local group, like Singing for the Brain or a memory café.

So while it is not surprising that there is a lot of support and praise for local groups, there is no denying the impact that they have had on the people with dementia who gave us their views.

The phrases “safe haven” and “place of safety” were used frequently by both people with dementia and their supporters.

Others described the groups as a focus around which they could venture further into the community around them.

Others mentioned the feeling of mutual support and empowerment, as well as the ability to educate others about dementia.

It is clear that for many people with dementia and their supporters, local groups provide a very important anchor to their communities. However, while support groups for carers are common, groups for people with dementia are still the exception rather than the rule.

Recommendation - The continued support and development of local support groups for both people with dementia and carers must be prioritised.

Barriers

With very few exceptions people with dementia said that they had stopped doing things in their community because of their dementia, and because they were wary of the attitude and reaction of others.

The responses would suggest that thinking around a social model of dementia has had little impact on those who responded. (a social model of dementia being one in

which consideration is given to the effects of the physical and psycho-social environment as well as any individual impairment)

A social model of dementia has much to offer both in terms of campaigns to reduce stigma and raise awareness, and much needs to be done to enable people with dementia and their supporters to access the alternative perspective they provide.

Recommendation = Organisations responsible for providing support and information to people with dementia and their supporters should ensure that the information they provide is informed by a social as well as a medical model of dementia.

Recommendation - Public awareness campaigns should reflect a rights-based approach to dementia.

The most common response to the question “what can a community do to make itself more accessible?” was - “to increase and improve awareness of dementia”

Recommendation - That we maintain and support awareness campaigns nationally and locally.

Recommendation - That we consider how can we support and encourage the development of a role for people with dementia in raising awareness of dementia.

Information

Many people with dementia said they found it hard to understand information produced for the general public, and that this presented a barrier to engagement with their communities.

Recommendation - That guidance is produced to enable service providers to produce information that is accessible people with dementia.

Recommendation - That the applicability of the Equality Act 2010 to people with dementia be investigated.

About the people with dementia who responded

This is not a representative sample!

People with more advanced dementia are unlikely to have been heavily represented, if at all, in the responses we received.

It is likely that most of the people with dementia that responded were in the earlier stages of dementia – and their comments must be understood in that light.

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People with more advanced dementia are often excluded from consultations and research. However, with the right support and encouragement, people with more advanced dementia are able to have a say in the decisions which affect their lives.

Recommendation - That future consultations consider the need to allow the voice of a wider range of people with dementia, including those with more advanced dementia.