

Executive summary

About this report

This report describes the findings of the Listening well project, a piece of stakeholder consultation work designed to ensure the authentic involvement of people with dementia in the development of the dementia strategy for Northern Ireland. Listening well was a two-strand process, which consisted of seven one-to-one interviews with people with a dementia diagnosis, and a group listening event held in March 2009. The group event involved two focus groups with a further seven people who had been diagnosed with dementia, together with ten carers. Further information about the methodology of this project can be found on pages 7 to 11.

The report also sets the findings of Listening well in the context of the development of strategic approaches to improve the lives of people with dementia throughout the UK, the Republic of Ireland and the rest of Europe.

Findings

Finding out about having dementia

- People received a diagnosis via a number of routes, including referral by their GP to a specialist assessment, eg from an NHS consultant, private medical assessments and referrals as a result of a hospital admission. For those who could remember, this process ranged from a week to a few months.
- People wanted to be given their diagnosis with clarity and without delay. They wanted doctors and other professionals to take sufficient time and to be sensitive about the language they used in providing the diagnosis.
- Receiving a diagnosis could be extremely disturbing, but it was recognised that early diagnosis offered significant advantages, enabling future plans to be made while the person with dementia had the mental capacity to be fully involved.
- People with dementia and their families wanted explanations of what the diagnosis meant and what the future held, and they wanted family and friends to deal sensitively with the emotions that it generated.
- Health professionals need education in recognising dementia and in communicating the diagnosis.

Personal feelings about getting a diagnosis

- People reported feelings of shock and a sense of being left ‘in limbo’ after diagnosis. Doctors and other health professionals need to be aware of and respond to these feelings appropriately by providing support, or perhaps by referring people on to some form of counselling.
- Some people could cope well with getting a diagnosis of dementia, providing they had enough time and information to think through what it meant to them.
- In some cases, people’s negative experience of getting a diagnosis was made worse by a lack of communication between doctors and healthcare professionals.
- The emotional impact of getting a diagnosis was particularly mentioned by carers.

After diagnosis: treatments, information, care and support

- Once a diagnosis had been made, experience was varied, both in terms of access to prescribed medication and to information, care and support for people with dementia, their carers and their family.
- Access to medication for the person with dementia, and access to information, care and support for the person with dementia and their family/carers were seen as very important.
- Support from family and friends, and from organisations like Alzheimer’s Society, were seen to be important.
- More signposting to sources of information, support and advocacy is needed.

Coping personally with dementia

- In spite of fears and anxieties, many people identified a range of practical and psychosocial mechanisms for coping with dementia.
- Carers often undertook a range of responsibilities, and needed support and training to help them.
- It appeared that more resources and training were directed to the later stages of dementia, with inadequate support being available to enable people to stay in their own homes for as long as possible.

Living with dementia in the future

- People with dementia and their families/carers need to be offered information and support to plan for the future.
- There is a role for independent advocacy, information and support for people with dementia and their families/carers, at the time of diagnosis and on a regular basis afterwards.

Media presentation and public awareness of dementia

- There was a lot of interest in how dementia was presented to, and understood by, people who did not have direct experience of living with dementia. Inaccurate and stereotypical presentations of dementia, and a failure to talk openly about it, were matters of concern.
- There is a need to increase public awareness and challenge the stigma associated with dementia.
- Although there were some serious concerns about how the media portrays dementia, there was also general agreement that the media has an important role to play in raising awareness and breaking down stigma.

Recommendations

The following recommendations arose from this research:

Raising awareness of dementia

- 1 Training which provides health and social care workers with an understanding of dementia and how it affects a person and the skills they need to support that person's well-being is essential. It should be offered to both generic and specialist health and social care staff in order to raise their awareness of the prevalence of dementia and the various ways in which the symptoms of dementia may become apparent.
- 2 Organisations working in the field of dementia in Northern Ireland, including the Department of Health, Social Services and Public Safety (DHSSPS), should consider how they might encourage and support people with a dementia diagnosis (and their families and carers) to speak more publicly about their lives in order to dispel myths and taboos about dementia and reduce the social exclusion that people with dementia may experience.
- 3 Organisations working in the field of dementia in Northern Ireland should consider how they can work with national and local media in order to encourage balanced media representations of dementia.

Improving the experience of receiving a diagnosis of dementia

- 4 Health and social care trusts in Northern Ireland must ensure that facilities are in place to enable early assessment and early diagnosis of dementia.

- 5 Health and social care professionals and staff at all levels must undertake training, appropriate to their roles, on how to communicate a diagnosis of dementia and how to support people with dementia and their families and carers immediately after diagnosis.
- 6 The DHSSPS should provide funding for the production of information packs for people who are newly diagnosed with dementia and for their families and carers. This initial information should signpost people to sources of support and further information. It should be prepared in consultation with health and social care staff, staff and volunteers in voluntary organisations and with people with dementia and their carers.
- 7 The person who makes the diagnosis should ensure that information about the diagnosis is shared with other health and social care professionals who are involved in the person's care, in line with professional guidelines on confidentiality and consent.
- 8 All those involved in the process of making a diagnosis should ensure that the needs of the person with dementia and their family/carers are taken into account.

Improving access to information, support and advocacy after diagnosis

- 9 Every person diagnosed with dementia should be allocated a key worker, whose responsibilities should include facilitating access to appropriate independent information, support and advocacy, both for the person with dementia and for their family/carers.
- 10 Health and social care trusts in Northern Ireland should ensure that there is a more comprehensive and consistent system in place for providing sound and sufficient practical advice, information and support (including peer support) for people with dementia and their families/carers. This system should include advocacy and/or signposting services, which have an important role to play in supporting people to access information and communicate their views. It should also enable people with dementia to make their own decisions while they are able to do so.
- 11 Health and social care trusts in Northern Ireland should ensure that adequate advice and support is available to people at all stages of their experience of dementia, paying particular attention to the wishes of many people to remain in their own homes for as long as possible.
- 12 The DHSSPS should ensure that prescribing policies, and the information about prescribing that is provided to people with a dementia diagnosis, are consistent and transparent.

- 13 Independent information, support and advocacy should be offered to people with dementia and their families/carers as soon as they have a diagnosis. It should not be assumed that people know enough about the kinds of support that might be available to enable them to seek out appropriate help.
- 14 Training and support should be made available to family/unpaid carers of people with dementia.

Further research

- 15 The DHSSPS should commission research to further investigate people's positive and negative experiences of being assessed and diagnosed.
- 16 Organisations working with people with a dementia diagnosis in Northern Ireland, including the DHSSPS, should work together to conduct research with seldom heard groups, such as people with learning disabilities and minority ethnic communities, in order to gain a fuller understanding of their perspectives and needs in relation to dementia.