

Listening well

People with dementia informing development
of health and social care policy

November 2009

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Most of all, the researchers would like to thank all the research participants for giving their time, experiences and views so openly and honestly. We sincerely hope that this report helps to make a positive difference in their lives, and the lives of others living with dementia, by helping to shape a dementia strategy for Northern Ireland.

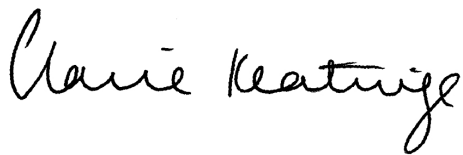
Preface

The Department of Health, Social Services and Public Safety is leading the development of a dementia strategy for Northern Ireland. Focusing largely on the recommendations of the Bamford Review report, Living fuller lives, it is expected that the strategy will be launched in 2010.

There are over 16,000 people living with dementia in Northern Ireland at present and this number is expected to rise to over 47,000 by 2051. Listening well brings the experience and views of some of those people to the very heart of policy-making, and these must be seen to influence the services, treatment and support that will be prioritised in the dementia strategy for Northern Ireland.

Listening well describes the reality of living with dementia. The voice of people with dementia, when listened to, can have a powerful effect and I hope that it will go some way to convincing the Northern Ireland Executive of the need for dementia to be recognised as a significant health and social care priority.

I would like to thank all the people with dementia and carers, whose generosity made Listening well possible.

A handwritten signature in black ink, reading 'Claire Keatinge'. The script is fluid and cursive, with the first name 'Claire' written in a larger, more prominent hand than the surname 'Keatinge'.

Claire Keatinge
Director, Northern Ireland
Alzheimer's Society

Foreword by Baroness Blood

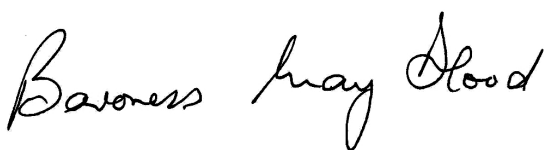
We probably all know someone with dementia; it could be a person who is close to us, whose condition has progressed over a number of years, or perhaps we have heard someone well-known talk about their own experience through broadcast or print media. Some of you will have dementia yourselves. Being more aware of dementia adds to our understanding but it can also change our attitudes and behaviour, and these have an important part to play in transforming the experience of people with dementia and those who care for them.

In recent years the subject of dementia has been more prominent in the media and in TV and radio drama. People with dementia are increasingly speaking publicly about their experience and the subject often crops up in our ordinary conversations, or those we overhear in local cafés or while waiting for a bus. Despite the fact that it is more talked about now than it ever was, I have no doubt that we could all do with knowing more about the condition and understanding how it affects people with a diagnosis and those close to them.

Who better to tell us about how it feels to have dementia and the challenges it presents, than those with first-hand experience; people with dementia themselves and those who care for them. Of course, a diagnosis of dementia has a profound effect on a person, but people living with dementia still want to enjoy life, to meet up with friends and family and to do things that make them feel good. In that, we are no different from each other.

Alzheimer's Society undertook the Listening well project to make sure that people with dementia are actively involved in the development of the dementia strategy for Northern Ireland. Through this project, some of the people who stand to be most affected by the strategy have had the opportunity to state their views in their own words.

It has been said that listening is an art and this Listening well report paints a picture that policy-makers and legislators would do well to study closely.

A handwritten signature in black ink that reads "Baroness May Blood". The script is cursive and fluid, with the first letters of each word being capitalized and prominent.

Baroness Blood

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.

Introduction

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 and to inform the development of the dementia strategy for Northern Ireland. The Department of Health, Social Services and Public Safety (DHSSPS) is responsible for the delivery of the strategy, which is currently in development.

Listening well was a two-strand process, which consisted of seven one-to-one interviews with people with a dementia diagnosis, and a 'listening event' that involved two focus groups. The focus groups, which were held on 12 March 2009, involved a further seven people who had been diagnosed with dementia, together with ten carers. Although Listening well was a small study, its findings resonate with other reports and with recent research carried out by Alzheimer's Society with people with dementia, published in *Dementia: Out of the shadows* (Alzheimer's Society, 2008).

This report also sets the findings of Listening well in the context of plans to develop a strategic approach to improving the lives of people with dementia throughout the UK, the Republic of Ireland and the rest of Europe.

The work was led by Alzheimer's Society in Northern Ireland and carried out in partnership with staff from the Mental Health Foundation – the UK's largest mental health research and development charity. All the interviews and the listening event took place in Northern Ireland and all the participants live in Northern Ireland. Further details of how this project was carried out can be found in the Methodology section.

1 Context

A major report to Alzheimer's Society, Dementia UK (Alzheimer's Society, 2007a), estimated that across the United Kingdom, 1.1 per cent of the population has dementia – a total of almost 700,000.¹ This is expected to increase to 940,110 by 2021 and to 1,735,087 by 2051 – an increase of 38 per cent over the next 15 years and of 154 per cent over the next 45 years.

All the UK governments have committed to developing strategies for improving the lives of people with dementia and their families and carers. These are all at different stages of development and implementation. In this section, further contextual information is given about the prevalence of dementia and the development of a dementia strategy in Northern Ireland. Further brief information is provided in Appendix A about prevalence and the development of dementia strategies in England, Scotland, Wales, the Republic of Ireland and the rest of Europe.

Prevalence of dementia in Northern Ireland

A Northern Ireland supplement to the Dementia UK report (Alzheimer's Society, 2007b) estimated that there were 15,850 people with dementia in Northern Ireland – a figure that is projected to increase to over 20,500 by 2017 and to over 47,000 by 2051. This represents a percentage increase of 30 per cent and 200 per cent respectively.

In Northern Ireland, it is estimated that 396 people have young onset dementia (onset before the age of 65 years), although this figure may well be an under-estimate and true figures may be up to three times higher for a number of reasons. Late onset dementia is much more common. The number of people with dementia increases with age up to the age band 80-84, and then declines in older age bands; 68 per cent of people with dementia are aged 80 and over and 17 per cent are aged 90 or over.

Approximately two women for every man are affected by late onset dementia, reflecting the fact that women, on average, live longer than men.

¹ The estimate in Dementia UK is 683,597, but Alzheimer's Society uses the figure of 700,000 in public messages. Therefore, the actual figures given for each country in this report do not add up to exactly 700,000.

It is estimated that 53 per cent of people with late onset dementia live in the community in private households and 47 per cent live in care homes. The proportion living in care homes rises with age. Mapping local levels of social care support in Northern Ireland was difficult for the authors of the Dementia UK report as there was no local data available on service provision specific to older people with mental health problems. However, when looking at figures for the provision of residential and nursing care, home care and day care services to *all* older people in England, Scotland, Wales and Northern Ireland, marked variations were found in the levels of provision and expenditure across all services and in each country. Significantly higher proportions of older people were supported in institutions in Scotland and Northern Ireland than in England and Wales. The proportion of people over the age of 65 in receipt of day care services was lower in Northern Ireland (1.1 per cent) than in England, Scotland and Wales (1.7 per cent, 1.3 per cent and 1.6 per cent respectively) (Alzheimer's Society, 2007b).

The development of a dementia strategy in Northern Ireland

In Northern Ireland there has been a great deal of interest in recent years in mental health and learning disabilities, much of it centred around the Bamford Review of Mental Health and Learning Disability, which was commissioned by the Department of Health, Social Services and Public Safety (DHSSPS, 2007a) in 2002. Bamford produced a number of interlinked reviews under one overarching title, encompassing policy, services and legislation. *Living fuller lives*, (DHSSPS, 2007b) is the part that covers dementia and the mental health issues of older people. The recommendations of the Bamford Review are far-reaching and cover a broad range of mental health issues for older people. Amongst these recommendations are several which are particularly important for people with dementia. For example:

- Dementia and mental health issues in older age should be included in all training programmes for health and social care staff (including those working in the independent sector). This should be undertaken on an inter-agency and multi-disciplinary basis where possible. Training and education programmes for carers should also be provided.
- Independent, specialist advocacy services should be available for older people with mental health issues. These should be commissioned on a regular basis to ensure equity of access and service delivery to agreed standards.
- Health and social care professional education and training at undergraduate and postgraduate level should include more training in the area of dementia and functional mental illness. This education should include experience of dealing with these conditions in the community.

- Primary care staff should receive more training in the early detection of dementia and functional mental illness and recognise the benefits of doing this.
- Systems which are sensitive to the particular needs of carers should be in place within GP surgeries, eg flexible access.
- Dementia care should be considered as a Locally Enhanced Service within the General Medical Service (GMS) contract with GPs.
- Older people with dementia should have access to similar crisis/home treatment teams as younger people with mental health problems or those with physical illness.
- Respite care provision should be a clear and identifiable part of any commissioning or service planning process.
- There should be adequate induction, supervision and ongoing training for staff, particularly in the management of dementia and mental health needs.
- Commissioners should seek proposals on how a palliative care approach for people with advanced dementia can be rolled out to all care settings.
- Anyone with a diagnosis of dementia should have a key worker for the duration of their illness.
- Pre- and post-diagnostic support should be available for people with dementia and their carers.
- Services for younger people with dementia should be located within either the mental health programme or older people's programme of care. There must be a clear policy in place and a dedicated lead for the planning and delivery of services for young people with dementia. Services must also be appropriately funded given the complex needs of this group.
- There should be adequate financial support for young people with dementia and their carers to enable them to meet the extra costs of caring.
- People with a learning disability should have access to good quality dementia care.

The Dementia UK report Northern Ireland supplement (Alzheimer's Society, 2007b) makes recommendations which cover some similar ground.

- 1 Make dementia a health and social care priority for Northern Ireland.
- 2 Increase funding for dementia research.
- 3 Improve dementia care skills.
- 4 Develop community support.
- 5 Guarantee carer support packages.
- 6 Hold a Northern Ireland Assembly-backed debate on who pays for care.

- 7 Develop comprehensive dementia care models.
- 8 Ensure equitable access to health and social care services for people with dementia across Northern Ireland.
- 9 Ensure access for people with dementia to all clinically effective interventions and treatments on the NHS.

All of this detailed work about dementia will be invaluable in the development of a dementia strategy for Northern Ireland, which is currently underway.

2 Methodology

The work on which this report is based was the Listening well project, which consisted of seven one-to-one interviews and a listening event comprising two focus groups.

The interviews

In February 2009 seven interviews were carried out across Northern Ireland. These interviews were arranged through referrals from Alzheimer's Society outreach services and members of the Northern Ireland Dementia Forum. People with dementia were invited to take part. Information about the project was communicated to all participants verbally and then followed up in writing in advance of the interviews. The interviews were carried out by researchers from the Mental Health Foundation, using digital voice recorders. Interview transcripts were documented and analysed.

Interviews lasted about 45 minutes and were conducted according to an interview schedule with nine key questions, as well as follow up questions for the interviewer to use as prompts if necessary (see Appendix B). The questions were drafted in consultation with Alzheimer's Society in Northern Ireland and aimed to elicit information reflecting some of the key issues that came out of the Bamford Review (DHSSPS, 2007b). As issues of public awareness and media presentations of dementia were important themes in the findings for Dementia: Out of the shadows (Alzheimer's Society, 2008), a question was also included on this topic. The interviews also aimed to elicit information about people's coping mechanisms, particularly in relation to their sense of self and sense of well-being – described as their 'psychosocial well-being'.

Interviews were carried out across Northern Ireland. They took place in people's homes, which were mainly private houses but included some care home settings. The only people present at the interviews, bar one, were the interviewer and the person with dementia. This had been negotiated and agreed in advance with both the person with dementia, family carers and care staff (where involved). Staff from Alzheimer's Society provided support to family carers, where appropriate, while the interview was taking place.

The focus groups

The listening event was held in Belfast on 12 March 2009 and involved two focus groups. It was arranged by Alzheimer's Society in Northern Ireland. People with a dementia diagnosis in contact with locally based services provided through Alzheimer's Society were invited to take part. Referrals also came through members of the Northern Ireland Dementia Forum. A total of 17 people participated in the listening event (excluding researchers and staff), seven of whom had a diagnosis of dementia. Information about the project and how the focus groups would be conducted was sent to participants in advance.

Each focus group was facilitated by a researcher from the Mental Health Foundation supported by a note taker. A member of staff from Alzheimer's Society was present in each group to provide support to participants if necessary. The focus groups were recorded using digital recorders, and the researchers from the Mental Health Foundation analysed the focus group transcripts and wrote up the findings.

The focus groups lasted 1 hour and 15 minutes and were conducted using a topic guide, in the form of nine main questions, as well as follow up questions for the facilitator to use as prompts if necessary (see Appendix C). The topics were drafted in consultation with Alzheimer's Society in Northern Ireland, using some similar questions to those used in the interviews, as well as questions that explored in more depth themes that had emerged from the interviews. These included questions to explore further what the process of being diagnosed was like, and how people found out about what help was available when they were diagnosed and after the diagnosis.

Each focus group included people with dementia and carers. During the planning process for the event, the idea of holding separate groups for people with dementia and carers was considered. However it was decided that this might have generated anxiety and concern among potential participants or might have inhibited some from getting involved at all. Nor would it have been ethical or practical to only inform participants that they were being split into separate groups on the day of the event itself. Before and during the focus groups the researchers emphasised that the main aim was to get the views of people with dementia and therefore it would be their voice that would be prioritised over the voice of carers. All the carers who attended agreed to this and the honesty and enthusiasm of people with dementia to participate in the groups indicated that the presence of carers did not significantly inhibit them from speaking. It should also be noted that three carers participated without the person for whom they cared being present.

Ethical issues

Ethical issues were carefully managed during this work, honouring human rights, confidentiality, legislation requirements and local policies on research with vulnerable people. Informed consent was actively negotiated with participants over a period of days or weeks and participants were asked to complete a consent form.

Participants were supported sensitively and appropriately when difficult emotions arose, and were later given appropriate information on accessing help locally if it was needed.

Participants were free to withdraw at any time from the interviews and focus groups. None of the participants withdrew their consent or withdrew from the interviews or focus groups.

Methodological limitations

It should be noted that there are some limitations to the conclusions that can be drawn from the interviews and the focus groups.

The number of people participating in both strands of the project was small and therefore it cannot be inferred that these views are necessarily representative of the views of other people with dementia in Northern Ireland, or their carers. However, the views expressed do represent valid and important experiences for those who reported them and a number of common themes and issues emerged. Several of these echo other qualitative research carried out with people with dementia. As a 'snapshot' therefore, the findings are of significance.

As participants in both interviews and focus groups were self-selecting, it was not a random sample of people with dementia and their carers. However, in terms of gender, geographical spread, and living circumstances, the range was broad. There was a reasonable age range, including one person with dementia who was 46 years old, although the group did not include anyone over the age of 76.

The fact that participants were self-selecting also suggests that they were more likely to be people with dementia who were comfortable discussing their experience of dementia and diagnosis. It also meant that the sample tended to be weighted towards people who had less severe symptoms of dementia and were not, therefore, in the later stages of dementia. This is understandable given the cognitive and physical symptoms experienced by people with more advanced dementia, and is indicative of one of the fundamental challenges of undertaking research with

people with dementia. However, it suggests caution in inferring that the key themes identified from the interviews and focus groups also reflect the experience of people in later stages of dementia, particularly in respect of institutional care settings and end of life care.

The gender balance of people in the focus groups was somewhat skewed because there were five men with dementia but only two women. In some ways this may appear to be surprising, as for several reasons women are more likely to have dementia than men. There is fairly good evidence to show that there is a greater resistance on the part of men to acknowledge health problems or seek help for them. However one reason for the greater incidence of dementia among women is that they have greater life expectancies than men, which means that many women may develop dementia after the death of their partner or spouse. This may mean they have less close support available from carers and are therefore less able or willing to participate in research of this nature. More speculatively, given the high number of female carers who accompanied the men taking part in the research, it might also have been the case that the carers played an active role in encouraging and supporting people to participate.

Carrying out research with people with dementia is also challenging because of the impact that dementia may have on their ability to participate fully in the interview process or in group discussions. People's ability to understand questions, recall events, and clearly articulate answers can be affected by dementia. In focus groups, some people may also find it difficult to participate in discussion, particularly with people they have not met before.

The interviewers and facilitators were very mindful of these challenges. In preparing and carrying out the work they used the experience gained from undertaking the research for Dementia: Out of the shadows, as well as advice from Alzheimer's Society, to ensure that people could participate as fully as possible. Furthermore, the presence of carers did assist at times in helping to clarify or give more detail about what the person with dementia was saying.

Because of time constraints and other challenges associated with including seldom heard groups (eg people from minority ethnic communities and people with learning disabilities) the participants in the interviews and focus groups did not include anyone from these groups. This clearly indicates a need for work to be undertaken with a particular focus on these groups, to ensure that they are consulted in developing the dementia strategy and to ensure that, as far as possible, their views and experiences are included in it.

Several participants made very positive comments about the support received from Alzheimer's Society in Northern Ireland, but it should be borne in mind that Alzheimer's Society in Northern Ireland organised the event and many of the participants had used services provided by Alzheimer's Society, so this may have resulted in some possible bias in the Society's direction.

3 Findings from the Listening well project

This section describes the key findings from the research. Priority is given to reporting the views of people with dementia.

The findings are in four main sections:

- Finding out about having dementia
- Personal feelings about getting a diagnosis
- After diagnosis: treatments, information, care and support
- Coping personally with dementia.

Finding out about having dementia

The process of getting a diagnosis

Receiving a dementia diagnosis was clearly a major, life-changing event for both the person getting a diagnosis and their family, potentially having a huge impact on practical matters and on the psychosocial well-being of both the person with the diagnosis and their family/carers.

Generally, people wanted the diagnosis to be made and communicated clearly and without delay. They also wanted doctors and other professionals to be mindful of the language they used and to take sufficient time in communicating the diagnosis. Explaining what the diagnosis meant and what the future held, and dealing sensitively with the emotions that it generated, also came out as being very important for both the person getting a diagnosis and their family.

There is evidence of considerable variation in people's experience of getting a diagnosis and of the route through which it was reached. Some were referred by GPs for a specialist assessment, eg from an NHS consultant, some were diagnosed through private medical assessments, and others got referrals as a result of a hospital admission. For those individuals who could remember, the process of getting a diagnosis ranged from a week to a few months.

Although similar themes about the process of receiving a diagnosis emerged, there were some differences of emphasis in the findings from the one-to-one interviews with people with dementia and those from the focus groups.

In the focus groups, when the topic of getting a diagnosis was discussed, about half of the participants were generally quite positive about the experience, while others were generally more negative. Amongst those who were more negative, concerns revolved around it being a long, drawn out, uncertain and, at times, distressing process. Several people reported that it took over a year and two people said they had still not been told their diagnosis, although in one case the person had had four years of tests and had been put on the drug Exelon. One of the people who had not received a diagnosis said:

‘Give me a final diagnosis, something that I can latch on to because I just feel lost.’

In the interviews, none of the people with dementia described major frustrations with the actual process of being assessed and diagnosed. This could, perhaps, be taken to indicate that they had experienced relatively good practice in assessment and diagnosis. However, if that is so, it runs counter to evidence elsewhere, such as in *Dementia: Out of the shadows* (Alzheimer’s Society, 2008), where for many people the process of being assessed was overly protracted and frustrating (though this was often reported by the carer rather than the person with dementia). It is important to be cautious in drawing too many conclusions from people’s recollections of receiving a dementia diagnosis because it clearly proved difficult for some to recall fully what had happened. Nevertheless, the fact that several said they could remember how they felt would appear to indicate some ability to remember, and their recollections are therefore of considerable value.

Some people described being left ‘in limbo’ while waiting for the diagnosis, or being told in a way and in circumstances that were insensitive and less than helpful.

‘You are told you have Alzheimer’s and then you are just left on your own and from that day to now you are coping with it all the time and you have nobody to turn to...medically you have nobody to turn to.’

‘I was in a hospital bed and a doctor came up, drew the curtains, and told me I had dementia...I don’t understand why I am in hospital.’

The experience of being diagnosed and what happened next was not always so negative, as one participant indicated:

‘After I was diagnosed I must say the consultants were excellent, they left no stone unturned.’

Carers generally reflected the views and experiences of people with a dementia diagnosis, although their reporting of the diagnostic process tended to be slightly more positive. Nevertheless, concerns were expressed by carers about the length of time it took to get a diagnosis, confusion about what the actual diagnosis was, as well as the prognosis, and as one person indicated, general concern about the process and its emotional impact:

‘I think the process of being diagnosed is very uncertain and I think that the method of diagnosis here in Northern Ireland is far from ideal... never mind all of the feelings that that process actually brings to you, the fear, the uncertainty, the anxiety.’

Carers also reported that doctors often did not have enough time to give to the person with dementia, or did not take into account the need to be very clear when communicating with a person with dementia. Seeing different doctors and other professionals was confusing, as was the number of assessments that took place.

Educating health professionals about making a dementia diagnosis

Dementia: Out of the shadows (Alzheimer’s Society, 2008) noted that dementia is greatly under-diagnosed; it is estimated that only a third of people with any form of dementia actually get a formal diagnosis. It gave several examples where symptoms or health concerns described by the individual and/or their carer were dismissed by GPs. In some cases GPs did not take symptoms seriously, or told people that they were just a natural sign of ageing. Conversely, in some cases, a diagnosis was not made where younger people were showing symptoms because it was believed that dementia is an illness only associated with old age. There was evidence of doctors appearing to be reluctant to diagnose a condition where it is difficult to do so with absolute certainty. In some cases, it appeared that GPs did not have the necessary skills to identify the symptoms in order to make a referral to a specialist for a full assessment and possible diagnosis – a finding that is confirmed elsewhere (Alzheimer’s Society, 2008).

In line with these findings, focus group participants felt that GPs needed more education about dementia:

‘The GPs need to have some sort of master class and bring it to the fore a wee bit, explain you know a wee bit about this illness.’

‘My doctor said you are too young to have dementia.’

Concern was also expressed about professionals not knowing enough about the different types of dementia, particularly for younger people with Korsakoff's syndrome.

The benefits of early diagnosis

In addition to reducing the anxieties and frustrations associated with a lengthy period prior to receiving a diagnosis, several interviewees and focus group participants thought that early diagnosis was very important. It helped to ensure good care, treatment, information and support, and enabled people to plan ahead, for example in financial matters. As one carer explained:

'You need to be doing it now, the stage when you are early diagnosis and you can still get consent, we left it too late.'

This accords with views expressed in *Dementia: Out of the shadows* (Alzheimer's Society, 2008) which noted similar practical benefits associated with early diagnosis and also noted that it could potentially enable people with dementia to get access to medication sooner than would otherwise be the case.

Personal feelings about getting a diagnosis

The feelings of people with dementia

As this report has already shown, the feeling of shock and the sense of being left 'in limbo' were important themes that emerged. Doctors and other professionals need to be aware of and respond to these feelings appropriately by providing support, or perhaps by referring people on to sources of independent information, support and advocacy.

Some people showed they could cope well with getting a diagnosis providing they had enough time and information to think through what it meant to them. The fact that some people reported quite positive experiences showed that giving a diagnosis could be done well.

Four people reported negative feelings when they were informed of their diagnosis, including feeling depressed and upset. One participant commented:

'I felt awful, I felt like I was thrown out of a community.'

Despite these feelings one participant said they were glad that they knew, and another talked about the importance of accepting the diagnosis as a way of coping with it.

People's negative experiences of getting a diagnosis were exacerbated in some cases by a lack of communication between doctors and health care professionals – one person in the focus group reported that their GP still did not know the diagnosis.

Carers' views on the impact of the diagnosis

The emotional aspects of getting a diagnosis were particularly mentioned by carers, one of whom said:

'Getting a diagnosis is like a hammer hitting you.'

Carers also emphasised the effect of language and the impact of words associated with dementia:

'We knew she was having problems with dementia but when the doctor said it was Alzheimer's, it was horrible.'

Nevertheless, carers recognised the importance of getting a diagnosis and there was some positive reporting of the diagnostic process, which both the carer and the person with dementia shared:

'I think getting a diagnosis is important, it's a bit like a bad diagnosis is better than the uncertainty of none.'

As found by some people with dementia, there were reports from carers of perfunctory communication from doctors, for example:

“Right ok you have got Alzheimer's, right bye, there's your diagnosis.”

It was all the more difficult when carers had to explain the diagnosis to the person themselves:

'How we put it across to Mummy we don't know if that's right, we don't know if we are getting the right concept of what they are telling us.'

After diagnosis: treatments, information, care and support

Once a diagnosis had been made, experience was variable, both in terms of access to prescribed medication and to information, support and advocacy. Several people reported receiving no support, care or information from the doctor after being given the diagnosis. By contrast, there were also some very positive accounts of help received from professionals. This included a very comprehensive package of advice and support that was provided following diagnosis, giving information about healthcare professionals, financial advice and practical domestic advice.

Interviews indicated that both medication and information were considered to be important, as was support for the person with dementia and their family. It is important to be cautious about drawing too many conclusions from interviewees' recollections, but those who had been prescribed medication and/or given information about dementia expressed satisfaction with how they had been treated, in contrast to feelings expressed by those who had not been prescribed medication.

Medications prescribed for dementia

People with dementia, in both interviews and focus groups, indicated what appeared to be inconsistencies in the prescribing of medication for dementia, in relation to who got medication and who didn't. Those who were on prescribed medications for dementia (usually Aricept) reported it to be helpful, although it may be that beneficial effects were more apparent to carers than to the people with dementia. The beneficial effects of medication to treat symptoms of Alzheimer's disease were described in the following terms:

'When she went on Aricept the quality of her life was definitely in her case increased by the use of this drug.'

'[Reminyl] is great, it is brilliant. I don't feel any different from what I was, since I've been told it you know, it's just the family noticed it.'

Information and advice

It is not easy to obtain a clear picture of what professional support or help was available to people with dementia and their families/carers. In interviews, virtually no other professional support or help was mentioned, apart from medication. Nor was support from voluntary sector organisations mentioned, although Alzheimer's Society had been providing support through locally based services to a number of

the participants. Focus group discussions did note the significant support offered by Alzheimer's Society. Alzheimer's Society and support groups were felt to be very helpful and useful sources of information for both people with dementia and their carers. However, several people mentioned that they had to find the information about such groups themselves, some using the internet.

In light of the reported lack of information and support in some instances, and the difficulties encountered by people with dementia and their families in gaining a full picture of what kinds of help and support may be available, some people thought that advocacy could play an important role in supporting people with dementia and their families to get information about treatments, care and services to which they are entitled.

Several people indicated that they did not want or need any support, although a couple of those people did also mention regular appointments at a memory clinic and a nurse coming to visit them every so often.

Support is also very important for people who live in care homes. The two participants who were living in care homes generally expressed satisfaction with where they lived, feeling comfortable, safe, and not feeling lonely. However, neither identified any particular help they received from the staff working in the home in respect of their dementia. Describing the staff, one said:

'It's just a job. They do their job and they are very, very nice girls...but there is nobody I think really trained to help you with dementia.'

Some people with dementia would have liked more information and two said that they had not received any information. As one person explained:

“‘You have dementia and sorry about that’. That was really it...no more information at all about it.’

In the focus group discussions, several people reported receiving little or no information from doctors or other health care professionals, and being left in a state of 'limbo' – an expression that was used more than once.

One person who was interviewed felt it was particularly important to know what impact the dementia would have on his life expectancy:

'So that's all I asked of the doctors, who have details, "How long do you think I am going to last?" Nobody could say.'

Group discussions indicated that practical advice and support was considered to be very important and much-needed. For most people there was a lack of practical advice, information and support for people with dementia and carers in the period after diagnosis, while the person generally still retained mental capacity. This reinforced the case for early diagnosis, which could provide an opportunity to address issues which can become more complicated, time consuming and distressing if left until after the person loses the mental capacity to deal with them. As one person pointed out with reference to the legal processes around the power of attorney:

‘You have got to get a neurologist to say that you are *compos mentis* at the time you made this decision.’

Overall, the interviews and the focus groups indicate that there are significant inconsistencies in provision of appropriate information and support for people with dementia and carers across Northern Ireland. Examples of good practice were reported alongside reports of inadequate or poorly-timed access to information, support and advocacy.

Support from family and friends

Although professional advice and support was apparently patchy (or perceived to be so), families, organisations like Alzheimer’s Society and other groups were clearly very important as sources of advice, information and support. But again, there needs to be better and more consistent signposting to ensure people find out about possible sources of help. Family members – including partners, children and siblings – and friends were mentioned by nearly all participants as being very important sources of support. One person said:

‘I would get lots of calls each day, people, friends...would call up now that didn’t [before].’

Another person said:

‘I have such support from [partner] that I don’t know how I would manage to live if she weren’t around. I would be getting lost... repeating myself over and over...forgetting.’

However, this support was not always straightforward and people with dementia sometimes showed considerable insight into how their family saw the situation:

‘I do get the impression that my wife doesn’t understand, she is always shouting at me and because I don’t remember things she says, “I told you, I told you that this morning” – that’s not helpful...she shouts and argues and fights with me and it is something that I put up with and have to put up with, it is most annoying.’

‘I am getting good support from my family...the biggest problem I have is repeat, repeat, repeat...really annoying for people you know’.

All the participants in the focus group mentioned the importance of families being supportive and helpful, even when the symptoms of the dementia may make this difficult. This support included being able to talk on behalf of the person with dementia, if necessary, when being seen by professionals.

Coping personally with dementia

Coming to terms with dementia – the perspective of the person with dementia

As might be expected, several people with dementia had struggled to come to terms with having dementia and being able to cope with it. They described a range of feelings they had experienced since being diagnosed. These included anxiety, worry about what will happen to their family as they become more unwell, frustration, fear and uncertainty of about what the future may hold. At times in the focus groups, these feelings caused participants to be quite upset:

‘I get panicky, I get frightened.’

‘I am just sitting living in limbo and I don’t know what way things are going to go...if it’s going to get worse...I have felt it and my family I think feel it, things are getting very difficult, the memory loss is getting more severe, I tried to hide it, I tried to keep it to myself...I am protecting myself you know...I am frightened.’

Yet despite the situation looking very bleak at times, people also showed resilience and coping mechanisms:

‘When you do face it, you sit back there and think I have been through that, its time to move on and enjoy life you know.’

Another person spoke of dementia being:

‘Just another little hurdle to overcome.’

Coming to terms with dementia – issues for the families and carers of people with dementia

The views and perspectives of people with dementia and of their carers are understandably sometimes quite different. Carers were frequently under a lot of strain and some were particularly vocal about how dementia in the person they cared for impacted on their own lives.

Carers had much to say on the support that they needed in order to come to terms with their situation and they described how they had to find out about what help was available by themselves, for example by searching the internet for information. There was relatively little evidence of an adequate level of support being offered unsolicited.

Comments from carers were fairly general but the emphasis tended to be on a lack of practical support and information, as well as respite breaks:

‘Any help we got we had to go and seek it ourselves...then when we did get involved with people it was helpful yes, but as I say we had to go looking for it.’

‘There is virtually nothing in the system for people who have been diagnosed or in a good place with their dementia or with the people who are trying to support them to stay in the community.’

Carers often had to take on the responsibility for making practical arrangements, such as sorting out financial matters and undertaking financial planning. This was sometimes made more difficult when having to deal with the bureaucracy of some banks and other financial institutions. It was also difficult when it had been left too late and the person with dementia no longer had the mental capacity to consent to conferring a power of attorney to enable someone else to manage their affairs.

Those who cared for people with dementia often showed insight into what they needed – and what they had and had not been offered:

‘I think part of the problem that a diagnosis is essentially a medical one and as you say you are kind of left to get on with it...and it is dependent on your own life skills or, you know, what you have learnt over the years.’

‘It’s the help that we need and the training that we should be getting - how to handle, how to do it, how to accept because you know, at some stage [my] other half will not be my wife.’

‘It’s a learning process for us still and you know my mother is able to walk around the house and do things like that, so she is still young and I think those issues, the financial issues, the care package, regardless about the family, you still need more help. A family can’t do it all, it really is hard.’

It was suggested that appropriate, dementia-specific training and support for carers could alleviate a lot of the strain inherent in their situation. Also, carers agreed that there was a need for a co-ordinated care package. The level of involvement and the number of people involved was clearly variable. One carer reported that the person they cared for had not been seen by a doctor for four years after the diagnosis. On the other hand, there were also indications, in some instances, of too many people being involved, and of care being delivered in an unco-ordinated way. One person asked:

‘Can you not have one care worker who can look after that person and assess everything at each stage? There are so many people calling to the house and all that is very confusing. Who are you coming into my house, it gets very invasive you know.’

Another person suggested an approach they believed would be beneficial both to people with dementia and to their carers:

‘With the diagnosis should come a package or something that says, you know, this is what you have got and this is what is available, this is what you’ll need. Everything like from medical through to personal care, through to money, through to financial.’

Many family carers understandably want to support a family member with dementia in their own home for as long as possible, delaying or removing the need for institutional care. However it seemed that the majority of resources and training were directed towards care facilities for people in the later stages of dementia. There was very little for the person with dementia (or their carers) while the person remained in the community, to enable them to live in their own homes for as long as possible. Clearly, people need the resources and support to be able to do this. However, for some people, the information they were given focused on the lack of support available until the person’s dementia was more advanced. One person said that a professional told them:

“‘The transition between being diagnosed and having to go into a home sucks, for want of a better word, there is nothing there to assist.’”

The level and the nature of support that is required is a very individual matter as some people will need more support than others, and assumptions should not be made without involving those who are living with dementia. People stated that it was sometimes assumed that families can cope, without ensuring that this was the case. For one carer who had been a nurse, the assumption was that she could deal with it, despite having a physical disability herself:

‘The [carers’ support group] just say, “You know all about it and there is nothing else we can tell you”, and they don’t give me any help at all.’

The level of support that was available was not always seen as adequate. One carer was receiving direct payments for social care but commented:

‘The package I can get from the system is totally inadequate and I find it increasingly difficult, as the situation is getting worse, to get help.’

Where support was provided to carers it was greatly appreciated; several carers spoke highly of Alzheimer’s Society, domiciliary care, and where health and social care services had laid on information and advice sessions for people with dementia and their carers:

‘The Alzheimer’s Society was very good for going to those meetings and just like this, listening to other people and then you kind of know what’s ahead of you, that kind of prepares you.’

One final point that should be noted is about the concept of actually being a ‘carer’. Although many people are comfortable with being described as a carer, and indeed, there has been a lengthy process of getting recognition for the concept of caring and the contribution of carers, one carer questioned the language used because they did not feel that it properly represented the situation they and their partner were in:

‘I am not even sure that I like the term ‘carer’ because in some way it denotes an unequal relationship, whereas what we are about is trying to create something together.’

The role of early diagnosis in helping people to cope

As highlighted earlier in this report, getting a diagnosis, particularly at an early stage, can be helpful in getting access to appropriate treatment and support. In addition, there were indications that being diagnosed also helped people to get on with their lives and maintain their independence. This helped:

‘Not to let it get you down because you can deal with it.’

Specifically, having a diagnosis could enable people with dementia (and their families) to identify their own practical and psychological coping strategies, or to be given advice and suggestions. Such advice and suggestions may be very simple, but people may require the input of services to help identify what is useful for them.

Practical ways of coping

People with dementia used a whole range of activities and strategies to retain cognitive and other faculties and/or to provide mental exercises and well-being. Practical activities included:

- using a computer
- doing newspaper ‘codewords’
- use of memory notes and reminders
- gardening
- reading and watching TV
- pilates
- walking
- prayer
- photography.

Similar findings were evident in *Dementia: Out of the shadows* (Alzheimer’s Society, 2008), where a range of activities that helped people to deal with dementia and maintain a quality of life were noted. Some of these involved physical exercise, such as bicycle rides, bowls or dog-walking, some were activities to exercise the mind, such as Sudoku or jigsaw puzzles, and some were mainly for relaxation or distraction, including listening to music. People also reported ways that they had found to help them remember things, for example, by writing things down. When and how these were used seemed very dependent upon the individual and their circumstances. It seems likely that the experience of people with dementia and their families and carers could provide a valuable resource of ‘tools’ that can be used to support other people with dementia and their carers.

Psychological ways of coping

Generally, psychosocial well-being, together with quality of life, can be influenced and potentially improved by helping the person with the dementia (and advising their carers) to identify quite simple, and usually cost-neutral psychological and practical coping strategies. Several of these were identified by people who took part in interviews and focus groups. In order to help people identify what is best for them, the provision of independent information, advocacy and signposting to services is likely to be necessary.

Some people who were interviewed described psychological coping strategies that involved coming to terms and consciously accepting the diagnosis. For one person this involved seeing some benefits in having to give up work as it meant no longer having the stress of commuting. Another participant described coming to terms with the diagnosis in the following terms:

‘I was quite content, I had a fair idea what dementia was so I was quite content to let it go. I would get through it alright, I hope.’

Another person said:

‘I thought, “Well, I will just have to accept it,” and that was that.’

Similar findings were reported in *Dementia: Out of the shadows* (Alzheimer’s Society, 2008), where people seemed to agree that an attitude of acceptance was important. This included accepting what the diagnosis meant, what it might mean in the future, and also what was being lost from the past.

Carers echoed many of the concerns held by people with dementia. It was noticeable however that, in some ways, carers experienced more difficulties in coping with the situation. Many were very worried about looking after their loved one because of the person getting confused, lost, and losing insight into their condition, together with worries about what the future might hold:

‘My problem now is that I am the resource and I ain’t supported and I ain’t gonna last.’

The support of family and friends was described by many people – those with dementia and their carers – as being enormously important, both emotionally and practically. Knowing other people with a dementia diagnosis and getting peer support from them was also very helpful for several participants. For a couple of people, giving support to others with a diagnosis was also important.

The Listening well focus groups echoed the findings of *Dementia: Out of the shadows* (Alzheimer's Society, 2008) in valuing support from Alzheimer's Society and support groups. Alzheimer's Society received considerable praise from focus group participants for providing good information and preparing carers, although one carer thought it should be more widely publicised. Comments included:

'You are just listening to other experiences and that is the best support you can get.'

'I could not fault them now they really were good.'

One carer gave the example of the Alzheimer's Society suggestion that they should put together a family album for their mother:

'They [Alzheimer's Society] told us to do that which was very good and in our respect at the stage at what we are at now its marvellous, so it was good learning, very, very helpful...we didn't know what to do and they helped us with that as well.'

Discussions in the focus group emphasised that in order to cope well psychologically, it was important not to feel alone. Interestingly, participation in the focus group itself was seen as very helpful in this respect:

'The most helpful thing I have had is being here this morning, honestly, I can see where I might be going and I can see where I hope I am not going...everybody is speaking so truthfully and openly about things.'

Living with dementia in the future

People in the focus groups were asked if there was anything they would like now or in the future that might help them, and if they had made any plans for the future. Comments on these issues were also made in the individual interviews.

What people would like

Making choices or formulating a view on needs or preferences is very much dependent upon having some sense of available options. This is particularly so in the case of a person with dementia. One person observed that people do not know what they do not know – in other words, they may be ill-equipped to express a desire for something that they do not know is potentially available.

‘It’s a question that I really can’t answer because I don’t know if there is anything else available or what else I could get that would help me. I would certainly be willing to try anything that is going to help me.’

The provision of information, support and opportunities to make choices and plans is essential, and this is an important role for both statutory and voluntary sector organisations, working with people with dementia and their families. Again, this suggests a potentially important role for information, support and advocacy, both at the time of diagnosis and on a regular basis after diagnosis.

Planning for the future

Most people who were interviewed did not want to think too much about the future; most had not made concrete plans and were comfortable with this. Although most people had not planned for the future in detail, there was considerable discussion on what the future held for them. One person had looked into how long they had to live but had found this upsetting, and they said they had even momentarily thought of taking their own life:

‘You’ve got five to ten years, 15 years of your life so you had to plan, what’s my family going to do...you have to think of it, you don’t want to be a hinder (sic) to your family...But then you get on with life and then you say right that’s ok because they could have told you, “Six weeks to live you have cancer”, you know. I have a life ahead of me, you know.’

Other participants shared this fear but also were finding ways of coping with it:

‘It is frightening and sometimes you do get scared and you think, “oh my goodness what’s ahead?” The only way you can deal with this is just take every day at a time and do the best you can.’

Several carers talked about the importance of planning ahead, particularly in terms of financial matters, such as making wills and obtaining power of attorney. Two carers spoke of their regret that they had not been able to do more at an earlier stage of the dementia, when their relative had sufficient mental capacity to plan ahead.

‘We are having to look to the future of what the problems could be and try and iron them out now.’

Several carers talked about the issue of residential care for people with more advanced dementia and there was a consensus that providing the support to people to stay in their own homes was the preferred option. However, both of the participants who lived in care homes considered the obvious advantages of living independently, but on balance indicated that they preferred their current situation.

Media presentation and public awareness of dementia

There was a lot of interest in how dementia was presented and understood by people who did not have direct experience of living with dementia. Inaccurate and stigmatised presentations of dementia, or a failure to talk openly about it, were all matters of concern.

Being open about dementia

One person had chosen to be very open about their diagnosis with people they knew:

‘I felt it was important that they realised that somebody with Alzheimer’s, properly treated, at an early stage, could remain considerably near normal if the NHS, as it has done in Northern Ireland, is providing the pill [Aricept] for free.’

Also, as indicated in *Dementia: Out of the shadows* (Alzheimer’s Society, 2008), telling friends and family about a dementia diagnosis could be an important part of the adjustment process for people with dementia. However, that report also showed that for several people, disclosure of their diagnosis resulted in the loss of friends and being stigmatised or avoided, or even not believed, all of which were unhelpful and upsetting.

Increasing public awareness and tackling stigma

Participants expressed a general view that dementia is not well understood by the wider public, and the public do not always understand what life is like for people with dementia and their families. As one person remarked:

‘They [the public] don’t understand that the Alzheimer’s sufferers have to work things out in their head for the answer and that takes time and

they don't have that time, they don't give you that time so therefore... they throw their arms up and then that puts you on a downer. You just say, "God, is that how they think of me", and you just go down on a downer and that has happened to me a few times but it is just ignorance on the people's behalf, they don't understand. They don't know what it's like to have Alzheimer's and to me that's an awful pity because you wouldn't get hurt as much if people did understand.'

Carers related examples of stigma and prejudice. One carer talked about going on a holiday with their spouse and the reaction of other people when they found out their spouse had dementia:

'They looked at it as if the person was mentally ill and anything to do with anything mental is all taboo.'

Media coverage of dementia

There were some serious concerns about how the media portrayed dementia, alongside more positive reports. There was also general agreement that media coverage is important to inform people about dementia and give the issue more publicity. One participant said:

'I think the word "Alzheimer's" should be used more often to get people educated.'

Raising public awareness through the media and through people's own personal stories was felt to be helpful in terms of public understanding of dementia, and in dispelling myths and challenging ignorance and prejudice. Overall, this may be a slightly more optimistic conclusion than was reached in *Dementia: Out of the shadows* (Alzheimer's Society, 2008), which concluded that the stigma of dementia was very pervasive and that media representations of dementia often did not help. That publication also noted that media coverage often focused on new 'cures' for dementia, raising people's expectations and hopes. However, media stories tended to oversell the possibility of new cures, and expectations were often not met.

4 Conclusions and key recommendations

The findings in this report are derived from a small study, but show significant parallels with other studies and with the views of people with dementia and their families in other parts of the UK and Europe. The recommendations which follow may also be familiar, as many of the issues and possible solutions have been recognised before. However from the points of view of those directly or indirectly affected by dementia, there is great concern about why some of the possible measures have not been put in place. For that reason, the list of recommendations that follows includes some which have been made in other reports, but where further action is still urgently required. The development in Northern Ireland of a dementia strategy presents a unique opportunity to act on the findings and recommendations from this report and, in so doing, to transform the experience of people currently living with dementia and of those who will develop dementia in the future.

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 to 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 services 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.

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Appendix A

The development of dementia strategies in England, Scotland, Wales, the Republic of Ireland and the rest of Europe

England

The prevalence of dementia in England

Of the 700,000 people with dementia in the UK, it is estimated that 574,717 live in England (Alzheimer's Society, 2007a). There is considerable variance in the prevalence across England, with prevalence being higher in rural and coastal local authorities, and lower in urban and metropolitan authorities.

The development of a dementia strategy in England

The Department of Health in England published the National Dementia Strategy in February 2009. The key objectives of the strategy are as follows:

- Objective 1: Improving public and professional awareness and understanding of dementia.
- Objective 2: Good-quality early diagnosis and intervention for all.
- Objective 3: Good-quality information for those with diagnosed dementia and their carers.
- Objective 4: Enabling easy access to care, support and advice following diagnosis.
- Objective 5: Development of structured peer support and learning networks.
- Objective 6: Improved community personal support services.
- Objective 7: Implementing the Carers' Strategy.
- Objective 8: Improved quality of care for people with dementia in general hospitals.
- Objective 9: Improved intermediate care for people with dementia.
- Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.

- Objective 11: Living well with dementia in care homes.
- Objective 12: Improved end of life care for people with dementia.
- Objective 13: An informed and effective workforce for people with dementia.
- Objective 14: A joint commissioning strategy for dementia.
- Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.
- Objective 16: A clear picture of research evidence and needs.
- Objective 17: Effective national and regional support for implementation of the Strategy.

Scotland

The prevalence of dementia in Scotland

According to Alzheimer Scotland, in 2007 there were 58,000 people in Scotland with dementia. The figure estimated in Dementia UK is 56,106. During the life of the next Scottish parliament, the number of people with dementia will grow by almost 4,500, and in less than 25 years' time there will be 102,000 people with dementia in Scotland (Alzheimer's Society, 2007a). To put this another way, Alzheimer Scotland claims that today one in 90 Scots have dementia and by 2031 this will have risen to one in 50.

The development of a dementia strategy in Scotland

Scotland does not currently have a national dementia strategy, although in June 2009 it was announced that a wide ranging consultation was about to take place, in order to help shape a strategy that would be in place by the end of the year. It is likely that this will build on Alzheimer Scotland's Dementia Manifesto, which in 2007 set out costed proposals for the next Scottish parliament on seven priority areas, which were:

- making dementia a national priority
- early diagnosis and support
- better dementia training
- making dementia drug treatments available on the NHS
- free personal care
- raising public awareness
- research funding.

Wales

The prevalence of dementia in Wales

Of the 700,000 people with dementia in the UK, it is estimated that 36,924 live in Wales. By 2021 it is predicted that the number of people with dementia in Wales will have increased by 31 per cent, and in some parts of Wales the number of people with dementia is forecast to increase by 44 per cent (Alzheimer's Society, 2007a).

The development of a dementia plan for Wales

Wales is developing a dementia plan, which was put out for consultation in June 2009 (Welsh Assembly Government, 2009). It seeks to come up with evidence-based actions 'to enable individuals and communities to develop progressive and innovative ways to help people overcome the difficulties and challenges that dementia brings to individuals and families'. It sets out four levels of action:

- Level one: strengthening individuals
- Level two: strengthening communities
- Level three: improving infrastructure and access to services for all
- Level four: making structural changes to economic, cultural and environmental conditions.

The draft dementia plan for Wales is possibly more explicit about the broader social context within which health and social care services are delivered than the dementia strategy in England, but essentially it identifies a similar range of needs and action points.

The Republic of Ireland

The prevalence of dementia in the Republic of Ireland

The Alzheimer Society of Ireland estimates in its Dementia Manifesto 2007-2009 that there are 38,000 people with dementia in Ireland, rising to 70,115 in 2026 and 103,998 in 2036 (Alzheimer Society of Ireland, 2007).

The development of a dementia strategy for the Republic of Ireland

There is currently no explicit dementia strategy for the Republic of Ireland, although discussions have been taking place for some time on what is needed. The Alzheimer

Society of Ireland is campaigning for the government of the Republic of Ireland to recognise and designate dementia as a national health priority. It sees one of the key ways to achieve this as being the full and accelerated implementation of An action plan for dementia (APD), which was a report from the National Council on Ageing and Older People (O'Shea, E and O'Reilly, S, 1999).

The APD sought to address some of the failures of policy in the field of dementia care identified at that time. It set a strategic direction for dementia care designed to strengthen the capacity of the health and social care system to meet the needs of people with dementia and their families and carers. The APD was based on six core principles:

- person-centred models of care which respect the preferences and rights of the person with dementia
- comprehensive provision
- bias towards home care solutions
- care requirements to determine funding
- needs-based provision
- evidence-based practice linked to national quality and outcome targets.

The APD made 33 recommendations for change at a total cost of approximately £45 million in 1999 prices. Translated to euros and adjusted for inflation, this equates to a current investment of €73 million (O'Shea E, 2007). The government's 2001 Health strategy quality and fairness: A health system for you (Department of Health and Children, 2001) accepted the general thrust of the APD and committed to its implementation, but over a seven-year period. It is in this context that the Alzheimer Society of Ireland's Dementia manifesto 2007-2009 calls for a greater level of investment, ie €35 million per annum for the next three years. It claims that this would enable investment in enhanced and flexible community based services, early diagnosis, intervention, awareness and education and medical and social research.

The rest of Europe

The prevalence of dementia in Europe

While it is beyond the scope of this report to set out the situation across the whole of Europe, it is worth noting that in 2006 it was estimated that 7.3 million Europeans (across the 27 member states) between the ages of 30 and 99 years of age had some form of dementia (Commission of the European Communities, 2009).

The development of dementia strategies in Europe

The development of dementia strategies is uneven across Europe. In addition to the National Dementia Strategy for England (Department of Health, 2009), which is mentioned above, several other European countries have adopted, or are in the process of adopting national plans (European Commission – Public Health Information, 2009). For example:

- France – in February 2008, France adopted the French national plan on dementia 2008-2012, with a funding of €1.6 billion over five years for 44 measures.
- Norway – Norway has adopted the Dementia plan 2015 with five main strategies for meeting future care challenges.
- Germany – early diagnosis of neurodegenerative diseases, including Alzheimer's disease, was defined in 2008 as one of the six priority areas of the German Federal Ministry of Education and Research.

In addition, on 22 July 2009, the European Commission adopted proposals to tackle Alzheimer's disease (European Commission press releases, 2009). The objective of this European initiative is to tackle the main problems posed by Alzheimer's disease and dementias in four key areas:

- acting early to diagnose dementia and to reduce the risk of dementia in the first place
- improving research co-ordination between EU countries
- sharing of best practice
- providing a forum to reflect on rights, autonomy and dignity of patients.

Appendix B

Listening well interview topic guide

- 1 Could you start off by telling me what age are you?
- 2 Could you tell me what kind of dementia you have?
Interview prompt:
 - Suggest names of different types of dementia (eg Alzheimer's, vascular) if they are not sure.
- 3 When were you diagnosed with dementia?
- 4 Can you tell me how you found out that you had dementia?
Interview prompts:
 - How long did this take, including getting a diagnosis?
 - How did this make you feel?
- 5 Can you tell me what information and help you got?
Interview prompts:
 - Was this easy to get?
 - Was this useful?
 - Were there other things you would have liked?
- 6 And what help and treatment do you get now?
Interview prompts:
 - Have these been easy to get?
 - Have these been useful?
 - Who helped, eg family, friends, professionals?
 - Are there other things you would have liked or want for the future, eg advocacy?
 - What helps you the most?
- 7 What would you say has changed for you having dementia?
Interview prompts:
 - What changes in your life have you made?
 - Have you made any plans for the future?
- 8 Have you seen people with dementia on the TV, or in newspapers and magazines?
Interview prompt:
 - How did it make you feel?
- 9 Is there anything I haven't asked you about that you want to tell me?

Appendix C

Listening well focus group topic guide

- 1 Could you tell me what kind of dementia you have?
- 2 How long have you been diagnosed with a dementia?
- 3 Have you been prescribed any medication for your dementia?
Prompt:
 - What's the name of the medication?
- 4 What was the process of being diagnosed like?
Prompt:
 - What were the positive and negatives?
- 5 What was the most useful help or information you got after you had been diagnosed?
Prompts:
 - Was this easy to get?
 - How did you get to know about what help was available?
 - Who has helped you the most, eg family, friends, professionals?
 - What was the least helpful?
 - What could be improved?
- 6 What other support or help do you need now and for the future?
Prompt:
 - Where would you go to get it or find out?
- 7 What would you say has changed for you, having dementia?
Prompts:
 - What changes in your life have you made?
 - What plans have you made for the future?
- 8 Do you think that people in general have a good understanding of dementia?
Prompts:
 - Has the media helped with this?
 - How could people get a better understanding?
- 9 Is there anything else that I haven't asked about that you would like to tell me?

