

Alzheimer's Society response: Northern Ireland Dementia Strategy

Executive summary

Dementia stands to be an exemplar of cost effective care and support that enhances quality of life whilst delivering value for money. Early intervention and effective community support has great potential to improve quality of life and deliver cost efficiencies.^{i ii iii} These are key concerns in the current financial climate. The strategy is an excellent opportunity to improve quality of life and achieve value for money.

Services underpin a person's right to the highest attainable standard of health. The strategy must be clear on how it will achieve this. Our response contains examples of services that enhance quality of life for people with dementia and carers in Northern Ireland and deliver value for money, including peer support, effective information and low-level community support.

The strategy needs a stronger focus on the actual experience of people with a diagnosis and their families with a clear description of the challenges faced in terms of poor outcomes. The Society has worked to put people with dementia and carers at the heart of our strategy consultation response. This evidence is throughout our response and we would be happy to help with any future consultation work.

Improving hospital care for people with dementia must be a key target of the strategy. The NHS could make savings of at least £80 million a year by reducing length of stay by a week, for the top four reasons for admission to hospital for people with dementia. This indicates potential savings of hundreds of millions of pounds across all reasons for admission.^{iv}

The strategy needs clear regional leadership to drive work forward and to have clear accountability for the work. The strategy should put in place local leaders with explicit responsibility for dementia care development in acute trusts, care homes and community teams.

The need for NHS funded clinically effective drugs for treatment of Alzheimer's disease to be consistently prescribed is very important to many people we consulted. The Society wholeheartedly applauds the Minister's inclination not to endorse NICE regarding these drugs and will be welcomed by all those who currently benefit and who might do so in the future.

1. Introduction.

Alzheimer's Society welcomes this opportunity to respond to the draft dementia strategy 'Improving Dementia Services in Northern Ireland', to present some key issues emerging from our discussion with people with dementia, carers and others with an interest in the condition, and to make some recommendations on how the strategy might be strengthened. As well as commenting in general terms we will highlight what we believe to be key points. These relate to awareness raising, need for early diagnosis, access to care and support and independent advocacy, quality of care, leadership and workforce issues as well as the economic case for investment in dementia care and support now.

Alzheimer's Society has been adamant from the outset that people with dementia must be involved in the development of the strategy and the Society facilitated a research project with the Mental Health Foundation to secure their views, in the spring of 2009. This research was funded by DHSSPS. Listening Well^Y documents the experience of a range of people living with dementia across Northern Ireland and the impact of dementia on their lives and the lives of those close to them.

2. Alzheimer's Society

Alzheimer's Society is the leading care and research charity for people with all forms of dementia, their families and carers. Alzheimer's Society in Northern Ireland provides information, support and signposting, through services including carer support groups; carer information programmes; information/support visits; advocacy; activity/befriending groups; domiciliary care and a dementia helpline.

Alzheimer's Society campaigns for improved health and social care and greater public awareness and understanding of all aspects of dementia.

3. Dementia in Northern Ireland.

Dementia is a complex, degenerative medical condition, which presents those with a diagnosis with gradual and profound impairment in memory, thinking and communication, as well as skills needed to do everyday tasks. Information, care and support, at as early a stage as possible, can allow people with dementia to live well as their condition progresses, and to make decisions and to plan ahead. Though health and social care needs in the

early stages may be relatively few these are subject to change and increase significantly. A person may live for several years with dementia and be in the late stages for a protracted time, so these needs will become complex and health and social care response must be tailored to need and be dementia specific.

Dementia stands to be an exemplar of cost effective care and support that enhances quality of life whilst delivering value for money. A strong body of research shows that early intervention, effective community support and reducing the need for institutional care all have great potential to improve quality of life and deliver cost efficiencies. These are key concerns in the current financial climate. The majority of the costs of dementia care come from institutional care, such as residential care and hospital care. Research shows that providing early support to a person with dementia can reduce or prevent the need for more costly institutional care.^{vi vii viii} Providing care and support that enables people to remain in their communities also promotes better quality of life.

A compelling case can be made for cost effectiveness of providing information, care and support at an early stage, to reduce need for longer term or hospital care. Investment in low level, appropriate care in a person's home can improve the experience of living with dementia as well as cutting expenditure. Key recommendations have the capacity to deliver both better care and support for people living with dementia as well as better value for money.

While information about prevalence of dementia and projections for the future are important from a policy and planning perspective, people living with dementia now, their families and carers must be right at the core of the strategy and throughout it, if it is to achieve its objectives of providing services, support and information that people with dementia and carers say they need.

For this reason Alzheimer's Society has undertaken to consult with service users and Society members who have experience of dementia, to establish how well health and social care provision meets their needs and if it supports people with dementia to live well and independently. It is a little disconcerting that three sections elapse in the draft before it focuses on the particular perspective of people actually living with dementia.

Dementia UK Northern Ireland supplement^{ix} estimates there to be at least 16,000 people living with dementia in Northern Ireland; 62% have Alzheimer's disease; the most common form of dementia. The report also highlights the fact that Northern Ireland has the highest percentage of people over 65 supported in residential or nursing care homes; 4% compared to 2.5% in England and 2.8% in Wales. There is also significantly less uptake/availability of home and day care. It could well be that inadequacy of home and day care in Northern Ireland is compelling people to resort to long- term care earlier than they might have chosen otherwise.

4. General Comments.

Alzheimer's Society believes a well thought-through dementia strategy, which has an adequately resourced implementation plan, has the capacity to transform the lives of people living with dementia now and in the future. It could also encourage cultural change through awareness raising and provision of information on dementia to the general public. It need not have huge funding implications, particularly in the currently constrained economic climate, but it must make more efficient use of available funding and have realistic costs attached to identified priorities.

Considerable sums are already spent on dementia care, but it is of variable quality and isn't generally providing the best outcomes for people with dementia and their families. The Society's consultation response suggests services the Strategy can deliver that will enhance quality of life for people with dementia and their carers and provide value for money. These services include peer support such as dementia cafes and effective information for people with dementia and carers, with post diagnosis support of this nature being a key target.

The strategy offers an excellent opportunity to improve early intervention in dementia. The evidence is clear that early intervention in dementia has economic value and significant cost savings, with a report by Professor Sube Banerjee that demonstrates an estimated value and potential savings of £950 million over 10 years.^x The strategy can deliver early intervention through improving diagnosis rates, providing low-level support in people's own homes and providing a package of post-diagnosis support such as peer support and quality information. Investing in low level, appropriate care in a person's home and in their community improves the experience of living with dementia, supports independent living will pay dividends for people living with dementia and ultimately the public purse.

Our consultation responses suggest that focus on quality of care and outcomes for people living with dementia might be improved by setting agreed minimum standards in regulated services. Dementia is a really clear example of where spending on low level care can significantly reduce need for more intensive or long-term residential and nursing care and deliver both quality of life for people living with dementia, savings public expenditure in the long run.

Alzheimer's recognises and appreciates that the draft strategy touches on many key issues for people living with dementia, from diagnosis to end of life. The final strategy needs to be strengthened with greater detail about the current situation for people with dementia and carers in Northern Ireland and recognition that this must be addressed. A strategy needs to be a detailed, systematic plan of action designed to achieve specific outcomes for people with dementia and their families, as well as health and social care workers and society in general. The Society's response provides suggestions of actions that will enhance the final strategy, such as strengthening the key

worker proposal, providing low-level support in the community and ensuring people with dementia and carers have access to comprehensive information.

The strategy needs a clear description of the challenges faced and the poor outcomes in dementia currently experienced. There must be a stronger focus on the actual experience of people with a diagnosis and their families and the consultation process must address this. The Society has worked to put people with dementia and carers at the heart of our strategy consultation response. We spoke with 85 people who use Society services and received 101 responses to our membership questionnaire. This research gained a clear picture of present experiences and what people would like to see in the future. This evidence is throughout our response and will hope it helps to provide the Department with a clear picture of present experience. We would be happy to help with any future consultation work. A stronger focus on this will enhance the terms of reference at appendix 4 which state the strategy will seek to ‘highlight current service provision, its capacity and future demand, recognising the importance of engagement with service users and carers as part of the process’.

There are some particular things we would expect to see in the draft and Alzheimer’s Society takes the view that evidence of the experience of people with dementia and carers is critical. We wholeheartedly support the development of mental capacity legislation in Northern Ireland and are confident it will enable people to be involved in their care and support. Involvement of people with dementia in discussions about care and support, service provision and decisions about their welfare including advance planning will sometimes benefit from support from independent advocates. Trusts must inform people with dementia of the availability of independent advocacy so that people are not inadvertently excluded from such provision because they have not been informed of its existence.

People with dementia and those close to them know better than anyone what having dementia or being close to someone who has, feels like and what supports them to live well with dementia and what detracts from their capacity to do so. People living with dementia are also acutely aware of the impact on care of a skilled health and social care workforce, which is led with conviction, from the top. Identified local leaders with explicit responsibility for dementia care development in acute trusts, care homes and community teams will provide the momentum and motivation needed to make this a reality.

Encouraging early diagnosis and intervention are central to initiating a course, which will produce the best possible outcome for people living with dementia, as the condition develops.

A strategy aiming to transform the lives of people with dementia, needs to address every aspect of the experience of having dementia for that person and those close to them and at each stage, as their condition progresses. The Society suggests a clearly defined care pathway to help make this a reality. People living with dementia know what matters to them, what care and support is needed and how well they are served by health and social care

in their own homes, in respite, in hospital and in long term care when independent living is no longer possible. At all stages as their condition develops, people with dementia are members of this community with the same rights as everyone else.

The message from people with dementia is clear: for many people, following diagnosis there is no support or advice. The strategy must be specific about recommendations like the key worker role and what form it might take, appropriate treatments and therapies and how they might be provided to those who could benefit from using them.

Services underpin a person's right to the highest attainable standard of health. Values and principles are envisaged as underpinning all services but will be contingent on workforce knowledge and skill, dementia awareness and a strong culture of quality care.

5. Comment on Strategic Aims.

For ease of reference and clarity, this response will follow the path as it is described by people with dementia and carers and those close to them, with reference to specific section in the draft document, where appropriate. In advance of that Alzheimer's Society would like to comment briefly on the draft Strategy's stated aims.

Alzheimer's Society welcomes and supports the stated aims of the draft Strategy as outlined; to raise public and professional awareness of dementia, to provide information and support to reduce risk of developing dementia in the population in general and to provide care and support to people living with dementia from early diagnosis and continuously as the condition develops.

Specific direction on what is going to change in services to meet current and growing need, as well as to improve services, which are known to be of poor quality, inadequate or completely absent is needed. The Society's response to this consultation identifies key service developments that will ensure all people with dementia live well whilst delivering value for money, for example early intervention, peer support and robust information services for people with dementia and carers.

The Society was very pleased with the Strategy's aim to develop quality care and support for people with dementia, by involving them and their carers in design of services and developing and communicating information about services so people can make informed decisions. The Society is very much in agreement. Here again, independent advocacy can play a big part in supporting authentic involvement of those living with dementia.

Alzheimer's Society supports the aim of developing combined mental health and capacity legislation, which is already underway. Well-crafted legislation will support and empower people living with dementia to make decisions

about their own care throughout their illness and in advance, in the event that they lose capacity as their condition advances.

6. Consulting service users and Society members

In order to establish how well people are currently served and how service provision might be improved to allow people with dementia to live well, Alzheimer's Society set up a range of opportunities for people with dementia, carers and Society members to express their views on what needed to change to ensure people living with dementia have the care and support they need. Clearly the input of all concerned has helped shape this response and the views of those with whom we consulted will be evident in anonymous quotes throughout.

We asked approximately 85 people who use Alzheimer's Society services about health and social care and support they receive currently, how well it meets their needs, what improvements they would make to sustain the best possible quality of life and about quality of care for people with dementia living in their own homes, in care homes, or when a person with dementia is in hospital.

We received 101 responses to our members' questionnaire. The questionnaire covered respondents' experience of services and support for people living with dementia, what types of support they would like to see in the strategy, their views on adequacy and quality of care, skills of health and social care workforce, early diagnosis and importance of involving people with dementia in decision making. It also sought views on how best to address need for dementia research.

Members tell us:

- 13% of respondents receive high quality care always, so it can be done but 41% said it was sometimes or always of poor quality.
- 70% stated that health and social care workers had some skills and knowledge to provide care and support to people with dementia but not enough.
- 90% of respondents said people with dementia don't get enough help and support and 88% that carers don't get enough.
- There was universal agreement that people with dementia are often not listened to or included in decisions being made about their health and welfare. 54% of respondents expressed support for provision of independent advocates for people with dementia.
- 53% of respondents felt that the outlined strategic approach to dementia research was insufficiently focussed given its importance in finding cause and cure for the condition and improving quality of care for people with dementia.

Alzheimer's Society knows from speaking to people with dementia and carers that they routinely struggle to get a diagnosis, to find relevant services and support, to establish how health and social care personnel relate to each other and to secure good quality of care when living in their own homes or when in hospital. The picture can become more dismal still when a person with dementia needs to move into a care home as and if deterioration in their general health and developing dementia demands it.

7. Awareness raising and early diagnosis.

Alzheimer's Society welcomes the strategic focus on awareness raising, but suggests that effecting cultural change will require an additional target to those at 6.1, particularly if one of its objects is to reduce stigma and promote inclusion.

A general awareness and risk reduction campaign needs to happen at an early stage of implementation of the strategy, so as to power change in public understanding, to counter misinformation and to promote early diagnosis and intervention. Provision in the action plan has no target dates for health promotion element and lacklustre or skewed deadlines on awareness raising, involving several public bodies. These diverse but related issues need to be coordinated.

Targets for provision of dementia information pack for GPs and information on local services are scheduled to complete by March 2011 but plan to address stigma, raise awareness and promote early intervention will not be produced till December of the same year.

It is widely acknowledged that early diagnosis and intervention are important in supporting a person with dementia to live well. What has been termed the 'fear factor' can deter people from seeking GP help in the first place and this is a huge obstacle, which requires concerted public awareness raising and intervention as well as professional skill and knowledge on part of medical practitioners. Early diagnosis is key to supporting early intervention in dementia, which promises greater cost effectiveness in dementia, a vital concern in the current financial climate, as discussed throughout our response. Public awareness is a crucial to supporting early diagnosis and intervention in dementia and should be prioritised.

Section 6 entitled 'Raising Awareness of Dementia' tasks the Public Health Agency with drawing up and leading on a plan to address stigma; raise public awareness about what can be done to prevent and delay dementia and raise awareness of benefits of seeking medical help early. Target date for agreeing the plan is December 2011 with implementation presumably commencing sometime in 2012.

Given the importance of changing attitudes and behaviour in relation to dementia to produce a positive dynamic, encourage cultural change and

promote early diagnosis and intervention, the time line needs to support rather than undermine impact of other actions which depend on enhanced public understanding and availability of services. For this reason Alzheimer's Society suggests target dates attached to action points 8, 11 and 12, should coincide at the earlier date of March 2011.

Service users tell us:

“ We need information and campaigns to educate the public about dementia, that it's not just part of old age and that help is out there.”

“Dementia is talked about a lot more now, there seem to be more people living with it. Information leaflets in clinics and TV programmes about it help to increase understanding of the subject.”

“It needs easier access to memory clinics, more information in GP surgeries and libraries and people willing to speak about their experience of having dementia or caring for a member of their family with it.”

8. Experience of diagnosis and beyond.

Alzheimer's Society recommends that strategy must plot a clear, flexible, reliable and consistent course, from initial consultation to diagnosis and beyond.

Early diagnosis and intervention are important to people with dementia and their families, because of the nature of the condition. Enhancing quality of life and utilising time, are of the essence. The prospect of gradual and irreversible impairment of skills and consequent fluctuation or loss of capacity to make decisions, is a major issue for people living with dementia and those close to them. Early diagnosis and intervention in dementia also promise greater cost effectiveness, a key concern in the current economic situation.

Unfortunately the process of diagnosis is often experienced as lengthy, problematic and unnecessarily stressful for people with dementia and those close to them. Though people with dementia have varied experience of diagnosis, some key issues emerge about significant gaps in some GPs' knowledge of symptoms of dementia and understanding of how it affects a person. People go to their GPs because they know something is wrong, but they can be discouraged and dismissed by GPs who fail to recognise symptoms or the need for referral or who may even be inclined not to pursue a referral because of conviction that 'nothing can be done'.

The combination of lack of professional expertise or confidence on the subject of dementia has serious implications, if it delays a diagnosis. Diagnosis is the first step in securing information, treatment and care, which supports people living with dementia to live well and independently. There are serious and irrevocable consequences for anyone who is deprived of this opportunity.

Timing and pace of consultation with GPs is also an issue; people report long gaps between initial diagnosis and follow up appointments and obtaining follow up information about dementia. People with dementia and carers need to know how dementia affects a person, how it can impair skills and why. For example a person may experience changes in their field of vision, or apparent optical illusions relating to patterns and colours on floor surfaces. Having an explanation helps to demystify things, which may be causing concern and undermining a person's confidence. Poorly explained and paced consultations can be dispiriting for people with dementia and the feeling that the person is being rushed through to accommodate GP's tight schedule doesn't help matters.

It is obvious that people in the early stage of dementia and carers may have little sense of how the condition will progress and what care and support they might need in time, so the onus is on health and social care providers to ensure continuity and follow up subsequent to diagnosis. The proposal of the key worker, as discussed below, would be very effective at providing this continuity.

The Society recommends that memory services use the Royal College of Psychiatrists memory accreditation scheme as the standard for memory services.

Service users tell us:

"It's hard to be snappy (when attending GP post diagnosis) "

"Earlier diagnosis and prompt provision of medicine would make a big difference. I had to learn on the job. The first doctors I encountered were unhelpful and I had to flounder for years before I got the situation sorted out."

" Strategy needs to change attitudes to dementia and stop doctors saying "I forget things too"

9. Key Worker.

Alzheimer's Society is pleased to see recommendations from Listening Well and Living Fuller Lives reports documented in Section 4. We recommend that the final strategy develops the role of Key worker further, with an attached action point.

The message from people with dementia and carers is clear – a key worker at the point of diagnosis would make a huge difference to quality of life. Through the Listening Well report people with dementia called for increased public and professional awareness of dementia, improved diagnosis, availability and access to timely information about dementia and services, amongst other things. It particularly called for a 'key worker' to be allocated to every person

with a diagnosis of dementia. In our discussions with people with dementia and carers for this consultation, having a designated and available source of dementia specific support from the point of diagnosis, with whom people can build up some kind of familiarity and sense of connection, is the ideal. People are often unsure where to go next or how to secure services or if they are available to them where they live. Having a key worker would make a huge difference. Positive feedback on the key worker idea affirms need for a 'constant'; a person or service with expertise in dementia and knowledge about services, as well as having someone on hand in case of emergency.

The key worker role is broadly defined as a designated person who supports the person with dementia and their carer from point of diagnosis on. The key worker can press for consistency and transparency in provision of services and prescribing practice and facilitate peer support and access to training and support for carers and family. The final strategy should be clear that the key worker is available from the point of diagnosis.

Concerns about the cost of the key worker proposal are understandable. However, the cost effectiveness of key workers can be enhanced through work to improve dementia diagnosis - people are not likely to require intensive support if reached earlier in their condition. Key worker provision need not be hugely expensive and may even be already in existence in some form, but it needs to be available to everyone from the point of diagnosis. Providing a key worker would greatly enhance quality of life for people with dementia and carers and greatly strengthen much-needed post diagnosis support.

Service users tell us:

"This is a good idea. Although care workers do their best many are not sufficiently qualified to deal with specific needs."

"Someone who keeps in regular communication would be good. In the early stages I didn't know where to go or to whom, for help, support care and advice."

"There must be someone who knows what is available and how to speed up provision of services and what forms to fill in."

"I now know a lot about dementia because I have lived with it; I've read books. I'd love to have had someone who knows as much as I do, earlier on."

10. Investing in support for people living with dementia at home

The evidence is clear that early intervention in dementia has economic value and significant cost savings. A report by Professor Sube Banerjee demonstrates an estimated value and potential savings of £950 million over

10 years through providing early intervention in dementia.^{xi} Carer support and counselling at diagnosis can reduce costly care home placement by 28%.^{xii} From the outset people need clear diagnosis with effective post-diagnosis support, ongoing information as their condition develops and a connection with key health and social care personnel with expertise in dementia, to whom they can refer at every stage of their illness. This provision will inform, support and enable people with dementia and carers to secure services they need to live well with dementia. The strategy is an excellent opportunity to ensure this is in place.

Alzheimer's Society believes that low level care and support has the added benefit of supporting the work of a family carer and the ability of carer to sustain caring role over a period of time. It can also avert crises and reduce as far as possible the need for hospital admission and resort to living in long term care.

Investing in supporting people to live well at home, which is most often the preferred option, could offset the cost of moving into a care home by deferring or dispensing entirely with the need for it with significant consequent savings to both individual and public purse.

The need to live well and independently from the point of diagnosis as dementia progresses is a key requirement for people with dementia and their families. It is largely contingent upon the actual availability and quality of information, care and support from health and social care providers and these must be addressed in the strategy.

Those we consulted on the strategy report considerable variation in the quality and particulars of service provision they receive in their own homes. From our survey 88% of respondents were getting some but not enough help and support. The general consensus was that there is a need for more, and more flexible provision in every type of service. People need more information about dementia and what services are available and accessible to them, they need more informed and skilled care workers and less restricted time allocation and activity. They also need access to 24 hour care, including night care to sustain capacity to live well and independently. They also want consistency in prescribing available and clinically effective drug treatments on NHS.

The need for NHS funded clinically effective drugs for treatment of Alzheimer's disease to be consistently prescribed to those who benefit from them, is a point of considerable importance to many of those we consulted. Alzheimer's Society campaigned for continued availability of Alzheimer's drugs to people in the early stage of dementia. Not only do these drugs benefit people with dementia by enhancing their ability to function and extending the period when impairment of skills is at its least intrusive, but they can effect a considerable benefit to family carers and be instrumental in sustaining independent living for longer. Given that the drugs in question cost a modest 1% of the total drugs bill, the Minister's inclination not to endorse NICE in this instance, makes strategic sense, will be welcomed by all those

who currently benefit from the drugs and who might do so in the future, and Alzheimer's Society applauds it wholeheartedly.

Alzheimer's Society also broadly welcomes the Strategy's holistic model for supporting people with dementia outlined in Section 5. It places a person with dementia at the centre of a community, which is aware and understanding and connected with families and carers who are supported to access services, which are 'seamless'. Provision of health and social care services, which promote and sustain independence, is declared to be a prime consideration of the strategy.

The commitment that Health and Social Care Board and Public Health Agency will draw up standards to inform local commissioning for dementia care should certainly contribute to improving quality of care in all settings but with a target date of June 2011, will not be manifest at a sufficiently early stage of the implementation of the strategy. Perhaps pulling this forward, so that it has realistic possibility of informing commissioning process sooner might provide early gains.

The case for provision of independent advocacy in supporting people with dementia to be fully informed and involved in decisions made about their treatment, care and welfare, is well made in the draft strategy but is not associated with any action. There must be a commitment to provision of independent advocacy at this point. Advocacy not only supports people with dementia to assert their rights to make decisions relating to their own lives but can nurture and develop best practice in dementia care. It can't reasonably be treated as an optional extra, when taking a human rights- based approach.

From Alzheimer's Society consultation with service users and Society members it is apparent that there is a huge diversity in provision of care packages and lack of transparency or rationale with regard to criteria required to secure particular services. Funding shortfalls seem to be the default response for failure to provide for assessed need and this will undermine fundamentally commitment to provide a care plan for everyone with a diagnosis of dementia in line with NISAT (single assessment tool). Availability and quality of home care services are subject to funding gaps, waiting lists and significant regional disparity, with inevitable negative impact on the health and wellbeing of people living with dementia in their own homes and those caring for them.

In broad terms continuity and skill of care work personnel is a recurring theme. Consistent, quality care and support in the home, with appropriate respite care can avert crises for people with dementia but they are aspirations which are widely under achieved. Good domiciliary, daycare and respite care do not dispense with need for emergency care or out of hours support but it is what happens habitually and can be relied upon, that has most positive impact for people living with dementia. The needs of a person with dementia and their family cannot satisfactorily be met during office hours; dementia is a complex condition, which presents different challenges as it develops, so it requires a considerable degree of flexibility in services to accommodate it.

The issue of night care emerges as a key thing for many people. It is necessary where a person with dementia has broken sleep pattern and requires attention at intervals through the night. Carers report sleep deprivation as a result of inadequate or irregular sleep and its impact on the quality of support they can offer during the day, with obvious negative implications for long term caring capacity. Issues like this can compel people to resort to care homes, when living at home is the preferred option for both the person with dementia and their carer.

Equally important is the need for provision of flexible and timely respite. Respite which doesn't suit specific need or is inadequate or poorly timed can disrupt routine to little or no advantage. It can even effect a decline in a person's general health and accelerate progress of dementia. People with dementia could certainly benefit from home visits from optometrists, podiatrists and hairdressers. While these services are provided by some day centres, they are not provided by all, for no apparent reason.

It is naturally difficult for people in the early stages of dementia and their carers to envisage how dementia will develop and what care and support they might need in time, but health and social care providers will have some insight into this and they need to anticipate it. Not having access to services you need to live well and to sustain independence can and do leave people very stressed as a result of enduring unnecessary additional pressures. Having to 'fight' for care and support is a common experience for carers.

Dementia is a serious, degenerative and complex medical condition, which presents those with a diagnosis and their families with significant challenges in their everyday life. It is quite outrageous that it sometimes seems to those living with it, to be treated as a private misfortune.

People with dementia have a right to health and social care and support they need to live well, just as those living with other complex medical conditions do.

Peer support and opportunities to meet other people with dementia and carers are highly beneficial and very important. Social and emotional needs must also be addressed to ensure people live well. People can experience significant social isolation as the stigma surrounding dementia means people are excluded from their previous social activities and support networks. People with dementia and carers want to know that they are not alone and to get practical advice from others who are in the same situation. The Alzheimer's Society, in common with many other voluntary organisations, runs support groups and cafes. These provide an informal environment in which people can discuss those issues that matter most to them and seek advice and support from others. These forms of support are particularly cost effective as they can allow health and social care professionals to access significant numbers of people in one place at one time. The Strategy should address the provision of peer support for both people with dementia and carers, which boosts quality of life in a cost-effective way.

Simple things like provision of assistive technology for people with dementia, is often difficult to secure as compared with mobility aids for elderly people without dementia. A recurring source of stress to people living with dementia is unskilled, time and activity- restricted home care workers who are subject to regular change.

Service users tell us:

“It’s not good enough to encourage early diagnosis, we need to invest in services that bring benefits to people living with dementia at the same time.”

“Constant change of personnel and variation in level of support is a big problem.”

“A sitting service for a few hours at a time; a person who can prepare a snack, play a game or just chat is great.”

“Care varies from one care worker to another; it’s mostly good but more hours are needed.”

“A special telephone number for weekends and holidays would be great, We’d appreciate regular, helpful contact from someone with experience of dementia.”

“My mum attended a day centre, I knew she was in good hands, with people who understood the condition. She enjoyed it so much I would see her arrive home with a beaming smile. She needed company and a stimulating environment.”

“ I really enjoy time spent out and about with the extra care worker.”

“carers need time out as much as possible; it’s 24/7 and it can wear you down.”

“ we need more hands on support, respite and financial support.”

11. Information.

Provision of comprehensive information about dementia and about services available to those who need them, in a range of formats and through a range of media, will go a long way, in a very cost effective way, towards achieving one of the key aims of the strategy. The strategy should prioritise the provision of information about dementia and dementia services for people with dementia and their families. The Society has undertaken research with people with dementia and carers about the most effective forms of information provision for their needs and we would be happy to share this with DHSSSP.

Reducing risk of developing dementia requires the population to be well informed, to be aware of the impact of lifestyle choices and to recognise signs early.

Information can also support people living with dementia in a potentially far-reaching way. 'Information at all stages' was a common call from Society's consultation with service users. Lack of appropriate information was a recurring source of frustration and needless additional stress.

Information is a key part of effective post-diagnosis support. A diagnosis of dementia is difficult information to take in; it needs to be communicated well, at an appropriate pace and the person with dementia and carer need immediate and ongoing follow up. Though they may not require services at that point, they will do as dementia progresses and ready access to relevant information about what services are available and how they can be accessed is crucial. This continuity can help mitigate isolation and shock described by many. It is also a crucial lever to providing choice, independence and control, which are major determinants of quality of life. Provision of information is a relatively inexpensive form of support and represents great value for money in terms of the quality of life it provides. Key features of effective information for people with dementia and carers include:

- A core set of information, provided free of charge to each person with dementia and their carer at the time of diagnosis.
- Separate publications for the person with dementia and for carers – carers and people with dementia have different needs for information.
- The provision of information to each person with dementia and carer at the time of diagnosis should be a mandatory part of the care pathway

Members and service users said:

“ Public information sessions in town halls and medical centres.”

“More information sessions for people living with dementia and distributing leaflets door to door to educate everyone, would be really good”

“ Leaflets in clinics, libraries and public places making the case for early diagnosis.”

“Lots more people with experience of dementia to talk publicly about it, particularly high profile people like Terry Pratchett and John Suchet.

“Documentaries and advertisements on TV and radio reach so many people.”

12. Dementia and Diversity.

Dementia is prevalent across social, economic, gender, race and sexual orientation and people live with dementia in a wide range of personal relationships, geographic environments and settings. The Strategy must pay attention to the detail or particulars of people's lives in order to achieve its aims.

Several consultation participants stressed the need for special attention to be paid to people living alone or with no evident, close relations or family support at time of diagnosis and subsequently. It must establish and address the needs of people living with little or no support, in rural settings or those who might be susceptible to isolation or exclusion as a result of language barriers, minority ethnic origin or prevailing social prejudice.

In the case of people living alone, follow up must be initiated by GPs to ensure their condition doesn't deteriorate as a result of isolation or lack of care, support and treatment. Equally, the strategy needs to focus on the particular needs of people with dementia who have a learning disability or who come from minority ethnic backgrounds or who are lesbian, gay, bisexual and transgender.

The experience of younger people with dementia is a source of considerable concern, because the traditional association of dementia with older people has clearly determined the nature of services and support available. As a result people with early onset dementia and their families find themselves experiencing added stress because of lack of appropriate care and support.

The situation facing younger people with dementia at diagnosis is aggravated by the assumption that dementia is a condition of old age and services provided are more appropriate to that age group and life stage. Younger people with dementia may be coping with work or may have had to given up work because of their condition. They may also have significant family responsibilities, a young partner and children and considerable financial pressures.

Section 7 states that a regional tertiary service will be set up to which people with atypical forms of dementia may be referred from local memory services. It is not clear if this service will address particular needs of younger people with dementia, but if so it needs to be made clear as this group has very specific and distinct needs to those facing older people with dementia.

Day care services are in the main not geared towards the interests of younger people. The provision of peer support and of stimulating leisure activities are key to sustaining social skills and good quality of life for younger people with dementia and for supporting their families.

The social and emotional needs of people with dementia are often overlooked or downplayed, but there is the need to sustain social interaction and activity for the person with dementia and carer, particularly for younger people. People of all ages want to pursue social and leisure activities they enjoy. A person who likes to go swimming might be restricted in pursuing their interest because of single sex changing facilities in swimming pools.

Befriending schemes can perform a really valuable role in giving a person with dementia an opportunity to engage in pleasurable social and leisure activities in the company of people who understand dementia and how it affects a person. Equally, activity clubs and dementia café -style services give people

a chance to do ordinary, pleasurable things in their leisure time, in the company of people with experience of dementia, and who understand how impairment can affect a person's ability to function.

Service users tell us:

"There's nothing appropriate to the needs of younger people with dementia"

"care in day centres is not right for younger people with dementia. It's not stimulating enough and sometimes not respectful."

" I get respite but as the condition has progressed I find nowhere really available for a person with a learning disability and dementia."

"Safe, reliable transport is an issue in rural areas, as it can let you get to daytime activities outside home. These can help maintain skills and provide enjoyable social events."

"getting a care home that's near enough to visit using public transport is a big problem."

"Sheltered accommodation needs to provide an additional bed so someone can stay overnight with a person with dementia."

13. People with Dementia in Hospital wards.

Alzheimer's Society calls for nursing staff to be trained at the outset (pre registration) and supported in the acute care environment, to care for people with dementia. In this way they can play a leading role in establishing and sustaining good practice and in implementing care plans envisaged by the strategy. The combination of improving care and reducing lengthy stays in acute wards for people with dementia can effect a real, strategic health gain and makes economic sense.

People with dementia, aged over 65, currently occupy one quarter of all hospital beds at any one time. Counting the Cost; Caring for People with Dementia on Hospital Wards^{xiii} found an unacceptable variation in the quality of care provided to those with dementia, in hospital across England, Wales and Northern Ireland. This not only has negative consequences for the person with dementia and their carers but seriously inflates the cost to the NHS at the time and subsequently.

People with dementia spend longer than their counterparts without dementia, who are being treated for the same condition, and their general health and their dementia deteriorate between admission and discharge. This decline can be instrumental in propelling the person with dementia into long term care on discharge. One in three people with dementia do not return to their own home subsequent to being treated in hospital, but are admitted to a care home.

The main thrust of Counting the Cost is clear; improved care on hospital wards can produce major savings for the NHS, which can in turn fund appropriate training in the health and social care workforce and free up funds to provide effective care in the community. The NHS could make savings of at least £80 million a year by reducing length of stay by a week, for the top four reasons for admission to hospital for people with dementia. This indicates potential savings of hundreds of millions of pounds across all reasons for admission.^{xiv} This is an investment, which has far reaching effects for people with dementia and for the quality of care as well as the potential for great cost effectiveness.

Critically, 80% of nursing staff who reported working with people with dementia in hospital wards said they didn't feel they were sufficiently well trained to care for people with dementia. Some had no training in dementia at all. Quality of care for people with dementia in all settings is largely determined by dementia specific workforce skill and a culture of care, which supports those in caring roles to apply their skills.

Alzheimer's Society welcomes the strategy commitment to providing an acute care pack to enhance knowledge and skills on the care of people with dementia in acute wards and to ensuring individual care plans are drawn up for each person with dementia, when they are admitted to hospital. More needs to happen to ensure people with dementia get better care when in hospital and to halt the accelerated decline in their health, which too often occurs. The Society would like to see further commitments in the Strategy to improve the quality of hospital care for people with dementia and deliver efficiency savings, including:

- Work to reduce the number of people with dementia being cared for in hospitals by improving the access of people with dementia to intermediate care and work to shift funds and reconfigure services to provide alternative services in the community.
- Place a requirement that hospitals identify a senior clinician to take the lead for quality improvement in dementia and for defining the care pathway.
- Require hospitals to reduce the use of antipsychotic drugs to treat people with dementia on a general ward.
- Involve people with dementia, carers, family and friends in the care of people with dementia to improve person-centred care.

Service users tell us:

“In hospital it’s a nightmare; no support or understanding whatsoever.”

“there is a tendency to relegate people with dementia to a lower priority once a diagnosis of dementia is made. It’s an illness and should be treated as such, with as much care and attention as heart disease or stroke.”

“ I stayed in hospital to explain to medics he couldn't answer their questions because of his dementia. Lack of communications between health and social care staff was appalling.”

14. Care homes

Alzheimer's Society supports the draft Strategy in its conviction that improving care in care homes is a particularly pressing issue for Northern Ireland and we are pleased to see it included. We would however add or expand on some key points as follows:

- There is great benefit for carers, residents and care homes alike when homes support residents to be fully involved in the care of the person with dementia. We suggest this is added to the standards for commissioning.
- We support actions to reduce inappropriate antipsychotic medication use and to improve medication processes in homes. This is very important and we would like to see a regular review of progress and tight timelines for action.
- We welcome moves to enhance staff training, as staff are a major determinant in the quality of care in care homes. Home from Home report^{xv} found that training needs to be embedded in a supportive atmosphere the allows good practice to flourish – it is important that homes encourage ongoing training and don't treat it as a 'one-off' event.
- The standards for commissioning should also incorporate provision of activity and occupation for people with dementia, for example as well as life history work, homes should also assess what activities residents enjoy and are able to partake in, and provide these.

Service users tell us:

“The chief carer where my sister (with dementia) lives is very sympathetic and caring but she hasn't the staff or time to oversee everything. So much time is taken up with completing forms and staff need more training.”

“Good care has been fostered by very vigilant social worker and extremely helpful residential home.”

“Regarding respite in care homes, only once have we got good care. All others were disgracefully substandard in basic care.”

15. Dementia and the end of life

People with dementia at the end of their lives have very specific needs. The impairment in capacity and difficulties with communication brought about by dementia make decisions about care and treatment more challenging. Pain and other symptoms can go unrecognized and untreated. People with dementia can be in the terminal stage of their illness for several years and

they are frequently subjected to inappropriate medical interventions at the end of their lives.^{xvi}

Dementia is a terminal condition - 60,000 deaths a year, across the UK, are directly attributable to dementia^{xvii}. The need to deliver quality palliative and end of life care to people with dementia will only become more pressing. One in three people over 65 will end their lives with dementia.^{xviii}

The Society welcomed the End of Life and Palliative Care Strategy; it is important that the Dementia Strategy backs it up to ensure quality end of life care.

We are pleased that trusts will be required to develop palliative and end of life care services for people with dementia as part of the End of Life Strategy. These services must include / deliver:

- Communication and involving families and advanced care planning are essential components to excellent end of life care for people with dementia.
- Pain is under-recognised and under-treated in people with dementia.^{xix} – services must include the development of protocols for assessing and identifying untreated pain in all care settings.
- Support for carers
- The end of life care and treatment wishes of people with dementia can be easily overlooked. To ensure people's wishes are honoured, carers should be closely involved in end of life care and staff must understand how to ascertain a person's wishes, for example reading non-verbal communication signs.
- Must extend across care settings – for example, many people with dementia enter the end of life phase in care homes.
- Support to enable people with dementia to die at home where this accords with their wishes.

16. Workforce.

Dementia is a complex, degenerative condition, which has a profound affect on a person's mental, physical and psychological state and consequent impact on those close to them. The way each person experiences dementia and the rate of their decline will depend on the type of dementia, the resilience of the person and the support available to them. Understanding how dementia can affect a person and having the appropriate skills helps support that person to live well and to function to the best possible extent.

Working with people with dementia is a specialised skill and staff must be equipped to deliver person-centred care to respond to the needs of people with dementia so as to ensure a high quality service for that person. At every stage of a person's experience of dementia the quality of their care is largely dependent on the skills and expertise of those giving care and support. The competency and quality of the dementia workforce underpins the success of the Strategy as a whole. The value placed on caring for people with dementia

is poorly reflected in every setting and tackling workforce skills is a key to rectifying this.

Shortcomings in the training and continued professional development of GPs has been identified as a source of significant stress and dissatisfaction and the strategy commits to work with DSDC to address this. Alzheimer's Society commends this approach but it must go further in order to reach all those who deliver care and support to people living with dementia and in all settings.

Workforce and domiciliary care

Service users experience of securing domiciliary care indicates huge variation in provision, type and quality of care and support available. There has to be commitment and clarity on RQIA role in registering and monitoring domiciliary care, not just agencies providing care, and dementia respite. There is also a need for a pool of care workers, registered with Trusts, trained and competent to ensure adequate standards of care to people receiving care and support in their own homes. There must also be a requirement for care workers secured through direct payments to be Access NI checked.

Workforce and hospital care

As documented in Counting the Cost report, nursing staff across Northern Ireland, Wales and England want more access to specialist advice and help when caring for people with dementia. A staggering 80% of nurses who are working with people with dementia on hospital wards do not feel they had sufficient training. Some had no training in dementia at all.

The negative repercussions of this training deficit are reflected in the universal 'horror' expressed by service users who had experience of members of their family enduring undignified, humiliating and distressing experiences while in hospital. Social care tasks like helping with eating, drinking and toilet routines as well as engagement in quiet, gently paced conversation at intervals throughout the day, have the capacity to sustain the highest attainable standards of health and dignity in a person with dementia, while they are in hospital. Lack of dementia-specific skills and understanding of the condition, together with inadequate staffing levels, which make personal attention impossible, aggravate the disorientating effects of an already unfamiliar environment.

Alzheimer's Society is pleased that strategy commits to developing an acute care pack to support staff caring for people with dementia in hospital and production of an individual care plan outlining specific dementia related support. However, the absence of an appropriately skilled staff or a source of clear leadership on dementia may undermine the desired effect of making good care a reality for all patients with dementia. We strongly recommend that hospitals have a dementia care lead to champion and embed good workforce practices, such as regular training.

Workforce in care and nursing homes

Standards of care in care and nursing homes need to be assured. DHSSPS establishes dementia standards in care and there is an 'expectation' that staff will have skills they need to perform their work, but there is no requirement in nursing and homes for dementia specific training. The Department can ensure workforce development through providing strong leadership to drive the agenda forward, working with curricula bodies, royal colleges, commissioners and providers and through the regulation system.

Service users tell us:

“ A carer needs to be on the spot, fighting for the patient.”

“some care workers are good but some aren't and they come from the same agency.”.

“more training in dementia care for all health and social care staff is needed.”

17. Leadership

Leadership is an important issue because the best dementia care is provided in environments where there is strong leadership in place. The strategy must recognise the need for good leadership across all areas of care. The strategy should put in place local leaders with explicit responsibility for dementia care development in acute trusts, care homes and community teams. This would combat the historic problem that no one person has had responsibility in many areas. Nominated leaders within service providers and organisations set the right tone, provide guidance and give a clear message that improving dementia services is a priority. We would like to see the final strategy recommend organisations and care settings appoint dementia leads to provide all staff with solid leadership. The implementation of training must be supported through effective management. Good leadership sets the tone and culture of care and ensures that staff are supervised and monitored.

It is essential that the strategy has clear regional leadership to drive work forward and to have clear accountability for the work. Alzheimer's Society is pleased to see the draft action plan appoints clear leads for each workstream. Local and regional leadership is also vital to offer help and advice, coordinate implementation, and facilitate discussions between commissioners and people living with dementia and the final strategy must emphasise this clearly.

18. Implementation and monitoring:

The Society is pleased with plans to establish a jointly-led group to oversee implementation of the strategy. It is vital that progress is monitored on an annual basis with a benchmarking activity to establish the current situation.

Monitoring should result in an annual report that shows where progress is happening and where it needs to happen. Action must be taken in response

to the report and the strategy must give direction around this, for example, publicizing progress in each area.

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- ^{iv} Counting the Cost; Caring for People with Dementia on Hospital Wards; Report researched and written by Louise Lakey, Senior Policy Officer, Alzheimer's Society; 2009
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- ^{xv} Home from Home; Research and writing Samantha Sharp, Senior Policy Officer, Alzheimer's Society; 2007
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