

# Executive summary

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## 1 Summary

**There are now 800,000 people with dementia in the UK and there are estimated to be 670,000 family and friends acting as primary carers.** The current financial cost of dementia is £23 billion a year to the NHS, local authorities and families and the cost will grow to £27 billion by 2018. Yet this significant spend is often not being deployed effectively and is not delivering good outcomes for people with dementia and carers.

**Given the numbers of people with dementia and the rising costs, it is vital that we understand how well people are living with the condition.** This must be based on the outcomes that are important to them, to help chart progress and the opportunity for action.

**Dementia 2012, the first in a series of annual reports, describes how well people are living with dementia in 2012 in England, Wales and Northern Ireland.** Living well is assessed by exploring the seven outcomes that people with dementia and carers have told us are important to them as described in the Dementia Action Alliance National Dementia Declaration for England. These outcomes take into account public services that must form part of the approach, but also wider issues such as family and community.

**It is acknowledged that there is work being undertaken to improve quality of life for people with dementia and their carers, and much has been achieved.** Three years on from publication of the National Dementia Strategy for England, and following plans in Wales and Northern Ireland, much is being done within health and social care to improve support and services for people with dementia and their carers. In addition, a range of organisations have committed to acting on dementia, including members of the Dementia Action Alliance.

**However, Dementia 2012 shows that at the current time people are still not living well with the condition.** For many people with dementia and their carers, quality of life remains extremely varied. Not only do people face potential battles for a diagnosis and support from the health and social care system, but everyday things we all take for granted – having control over daily life, spending time with friends and family, socialising and enjoying hobbies – are made difficult by a lack of understanding of dementia in our communities.

**Alzheimer's Society believes that dementia must be recognised as a challenge for society.** Given the breadth of the quality of life issues that must be addressed to ensure that people live well with the condition, and the size of the dementia challenge, good quality of life for people with dementia and their carers cannot be achieved in isolation or by a few. We must work in partnership to improve quality of life, focusing on all outcomes that are important to people living with dementia, including developing dementia friendly communities. This partnership must have people with dementia and carers at the heart and must include a range of partners from business, the public sector, civic and voluntary organisations, as well as the government, NHS and local authorities.

**We must see a major shift in societal awareness and understanding about dementia, and a move towards the development of dementia friendly communities.** While recognising the difficulty and urgency of the challenge, the potential for progress if we work together is huge.

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## 2 Methodology

Dementia 2012 presents new evidence from people with dementia in the early stages of the condition and living in their own homes. A survey was distributed to people with dementia via Alzheimer's Society dementia support workers and dementia advisers in England, Wales and Northern Ireland.

The report also draws on existing research and current work. For example a range of public policy documents, research literature, learning from good practice and existing indicators.

YouGov also completed a poll of the UK adults for Alzheimer's Society in December 2011. 2,070 individuals were asked about both their own quality of life and their perceptions of how well people are able to live with dementia.

## 3 Key findings

Key findings of the report are based on an Alzheimer's Society survey completed by people living with dementia and a YouGov poll of the general public.

### 3.1 How well are people living with dementia?

People are not living well with dementia. Dementia 2012 found that:

- 17% of people with dementia responding to the survey said that they are not living well with dementia at all, 55% said they are living quite well with dementia and only 22% said that they are living very well with dementia.
- In addition, a YouGov poll of 2,070 members of the general public found that respondents perceive people with dementia to have either a fairly bad quality of life in the UK (39%) or a very bad quality of life in the UK (19%). Only 1% thought that people with dementia have a very good quality of life, while 6% thought they had a fairly good quality of life.

Issues that contribute to how well people are living with dementia are explored in the report by focusing on the outcomes important to people with dementia and carers, as described in the Dementia Action Alliance National Dementia Declaration. Key findings are as described below.

### 3.2 Choice and control over decisions

The National Dementia Declaration identifies having personal choice and control or influence over decisions as a key outcome for people with dementia. This section in the full report explores how much control people living with dementia feel they have over their day to day lives, experiences of getting a diagnosis, financial issues, opportunities to plan for the future and end of life care. Key findings from the survey of people with dementia include:

- 14% of respondents felt that they were not able to make choices about their day to day life and 37% of respondents felt that they were only sometimes able to make these choices.
  - For someone with dementia one of the foundation stones for being able to make choices is receiving a timely diagnosis. However, the survey for this report found that many respondents struggled to receive a diagnosis:
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- One third (31%) of people with dementia said that they struggled to get a diagnosis. (It is important to note that respondents to the survey are in touch with Alzheimer's Society and therefore more likely to have received a diagnosis and to be receiving support.)
- 68% of respondents had a gap of longer than a year between noticing their symptoms and getting a diagnosis. 8% of respondents had to wait five years or over for a diagnosis.
- Other data shows that only 43% of people with dementia have been formally identified in the UK.
- In addition, the YouGov public poll found that 30% of the general public thought they would struggle to get a diagnosis if they had dementia.

### 3.3 Services that are designed around individual need

The National Dementia Declaration identifies having services and support that meet their individual needs as a key outcome for people with dementia. This section of the report explores issues such as whether services are designed around need, individuals feel supported by their GP, people are able to access a range of good quality services, people living with dementia feel that their care is delivered by well trained professionals and their carers are supported in their role. Key findings from the survey of people with dementia include:

- 34% of people with dementia responding to the survey said that the support services that they receive only sometimes (25%) or do not (9%) help them to live as independently as they need to.
  - Respondents want services that are better designed around their needs. 44% of respondents said that professionals either only sometimes (28%) or do not (16%) involve them in decisions about their care and support. In addition, 46% of respondents said either that they only sometimes (25%) or never (21%) have a choice over the support services they receive.
  - 47% of respondents felt that their carer is only sometimes (30%) or is not (17%) getting the support that they need to carry out their caring role.
  - 83% of respondents said that research into improving care for people now was important; 83% said that research into the cause was important and 87% said that research into the cure was important. 82% of respondents also felt that there should be more funding for dementia research.
  - The YouGov public poll asked people how good or bad access to services was for people with dementia. Nearly half (48%) of respondents said it was bad, while only 9% rated access to services as good.
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### 3.4 Support and knowledge to help people live well with dementia

The National Dementia Declaration identified that people need the right support and knowledge to help them live their lives. This section of the report particularly focuses on the social networks that people living with dementia have and the importance of peer support. It also looks into their information needs now and in the future. Key findings from the survey of people with dementia include:

- When asked if they lost friends after their diagnosis of dementia 12% of respondents said yes, most of them, 28% said yes, some of them, and 47% said no. 4% of respondents reported that they haven't told their friends.
  - 49% of people with dementia responding to the survey said that they sometimes have opportunities to meet and talk to other people with dementia and 18% reported that they never have opportunities (67% in total).
  - When asked if they ever felt lonely, 61% of people with dementia reported that they felt lonely always (6%) or some of the time (55%). When asked if they ever felt anxious or depressed, 77% also reported that they felt anxious or depressed always (9%) or some of the time (68%).
  - 48% of respondents reported that they felt like a burden to their family and 19% of people felt that they were a burden to friends.
  - In addition, 40% of respondents to the YouGov poll of the general public felt that having dementia would mean they would be lonely and 57% felt that having dementia would mean that they would feel anxious.
  - 32% of surveyed respondents reported that they were receiving some but not enough information about their condition and 6% reported that they had not received any information. 27% of respondents also reported that they had received some but not enough information to plan for the future and 19% said that they had not received enough.
  - 75% of respondents thought that it was either very or quite important to hear about research into dementia and 64% indicated that being asked to take part in dementia research was important for them.
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### 3.5 Living in an enabling and supportive community

The National Dementia Declaration identified two outcomes that are strongly related to how people live in the community. This section of the report has a particular focus on exploring the evidence from people with dementia and carers on whether they feel part of their community, the work that is already being undertaken to make communities dementia friendly and what needs to happen next. Key findings include:

- 22% of respondents to the survey of people with dementia said that they did not feel part of their community and 38% said that they felt part of their community only sometimes.
  - 61% of respondents think that their community doesn't understand at all (25%) or has only a little understanding (36%) of how to help them live well. 71% would like their community to understand how to help them live well a lot (57%) or a little (14%) and 67% think that this understanding would make their life a lot (45%) or a little (22%) better.
  - In addition, the YouGov poll of the general public asked whether they felt people with dementia were included in their community. 60% rated the inclusion of people with dementia in their community as bad (38% as fairly bad and 23% as very bad).
  - The poll also asked the public if society is geared up to deal with people who have dementia. Only 5% said that this was true and 75% said that this was false (while 20% did not know).
  - There are possible negative outcomes for people with dementia if they are not supported to live well within their community. For example, some survey respondents feel that they are a burden to health and social care professionals (10%) and people in the wider community – neighbours (8%); people working in banks/post offices/shops (9%) and the police (4%).
  - Respondents also reported that they perceived that they very often do not have a voice in their community. Only 12% of survey respondents said that they always have a voice, 31% only sometimes and 41% never.
  - The top five solutions that people with dementia report could be done in their community to make it easier for them to live life the way they want are:
    - Better understanding of dementia and less social stigma attached (25%). People with dementia would like the following to have more of an understanding of dementia: family (54%), friends (58%), neighbours (51%), health and social care professionals 58%), people working in banks, post offices and shops (62%), the police (54%).
    - More public awareness of the condition (17%).
    - More local activities and opportunities to socialise (13%).
    - More tolerance and patience from others (7%).
    - More community spirit (7%).
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## 4 Recommendations

Recommendations for action are outlined in detail at the end of each section of the report. For easy reference, in the Executive summary the recommendations have been grouped into five key areas where action is required if the dementia challenge is to be met. These are topline recommendations only and further details on the action required are at the end of each section.

### 1 Improve awareness and understanding

- Rates of diagnosis must be increased to two-thirds by 2015 and three-quarters by 2017.
- A major shift in public awareness and understanding of dementia is required to reduce stigma and encourage people to visit their GP with problems about their memory. This should combine large-scale public campaigns with targeted work to increase understanding of dementia among a range of individuals and organisations, such as the police, banks and retail outlets.
- All health and social care staff should have access to dementia care training that is consistent with their role and responsibilities and access to expert advice. In particular, key stakeholders such as Royal Colleges, university deaneries, local education and training boards, and workforce advisory groups must prioritise action on dementia.
- The Mental Capacity Act 2005 must be comprehensively implemented. Analysis of the emerging evidence on how the Act is being applied, and further evidence on this, is vital.

### 2 Improve health and social care systems

- The government should put forward plans to implement the recommendations from the Dilnot Commission on Funding of Care and Support (2011).
  - It must also be recognised that implementing the Dilnot recommendations will not go far enough to reform the social care system. Extra funding is needed to ensure that people with dementia and carers can access better quality as well as more care. We must consider as a society where this money can come from.
  - Resources should be shifted from inappropriate acute and residential care for people with dementia into the community setting. This would help ensure that the right support is available for people with dementia and carers such as early intervention and prevention services, and respite care services. Commissioners in Wales, England and Northern Ireland should also prioritise the integration of health and social services in dementia.
  - It must be ensured that people with dementia and carers are fully involved in the personal budgets agenda.
  - The inappropriate prescription of antipsychotic drugs should be reduced.
  - People with dementia should be provided with good quality end of life care that meets their needs.
  - Robust data across health and social care to support delivery on dementia is required.
  - Dementia clinical networks should be created by the NHS Commissioning Board to ensure effective use of clinical expertise to improve services for people with dementia and carers.
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### **3 Ensure that people living with dementia have appropriate information and support**

- Every person diagnosed with dementia and their carers must be able to access peer support (such as Dementia Cafés) that is delivered in the most appropriate way for them.
- Local authorities should have responsibility for ensuring that there is independent provision of information about local services across the spectrum of the statutory, voluntary and independent sectors. This information should be presented in a format which is accessible to people with dementia and carers.
- Organisations providing written information should consider how they could enhance these services by providing follow-up assistance for people with dementia, supporting them to understand and act on information.
- Local authorities should ensure that people with dementia have access to a named contact throughout their life with dementia.

### **4 Ensure that people with dementia are recognised as active citizens with the potential to live well in the community**

- Work must be undertaken to understand what makes a dementia friendly community and how communities can best support people with dementia and carers to live well.
- Communities must be enabled to understand how to help people with dementia and carers live well within the community. Support should be provided to community agencies, for example, shops, businesses, the public sector and churches, as they contribute to developing dementia friendly communities.
- People with dementia and carers must be at the heart of the dementia friendly communities work. They should be key partners, speaking out about their experiences of living well with dementia and the solutions they would like to see.
- There should be particular work to apply the thinking and practice of dementia friendly communities to health and social care services to ensure that social networks are maintained and developed.

### **5 Research**

- The government should signal commitment to dementia research by significantly increasing its investment: a target of £100 million would be appropriate and ambitious.
  - Information about research, and opportunities to participate in research, should be considered as part of the overall package of information to individuals.
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## 5 What is Alzheimer's Society doing to meet the dementia challenge?

Alzheimer's Society will be working with a range of partners and organisations to meet the dementia challenge. In particular the Society will:

- Continue to work with the Dementia Action Alliance and fulfil the outcomes committed to in the Society's action plan.
  - Lead work in the area of dementia friendly communities, as committed to in the Society's Dementia Action Alliance action plan and the Society's five year strategy, Delivering on dementia (2012–2017). The strategy includes a key ambition to work with people affected by dementia, partners from business, the public sector and civic organisations, to define and develop dementia friendly communities.
  - Continue to increase awareness and understanding of dementia, for example through campaigning to improve early diagnosis and the Worried About Your Memory? project.
  - Provide a range of information services, resources and training for health and care professionals who work with people with dementia.
  - Provide local information and services across England, Wales and Northern Ireland to people affected by dementia in their communities.
  - Continue to provide a unique research programme funding research into the cause, cure, care and prevention of dementia to improve treatment for people today and to search for a cure for tomorrow.
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