

# Living well with dementia: A National Dementia Strategy

## Accessible Summary



# National Dementia Strategy

## Accessible Summary

This booklet is an accessible version of the full-length **National Dementia Strategy's executive summary**. It tells you about most of the points in the full-length **Strategy** but in less detail.

### What the words mean

When we say **we** in this booklet, we mean the **Department of Health**.

When we say **services**, we mean **health and social care services** in England for **people with dementia** and family or friends who look after someone with dementia.

When we say **carer**, we mean **family carer**.

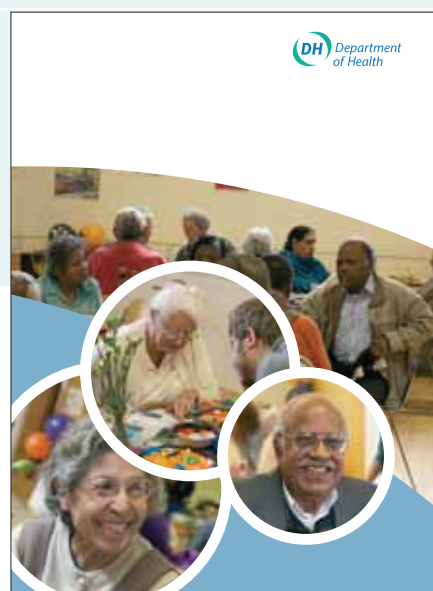
When we say **Strategy**, we mean the **National Dementia Strategy**.

When we say **commissioning**, we mean planning and paying for services.

### Words in bold type

There is a list of the **meanings** of some of the words in this booklet on pages 4 and 5. These words are in **bold** type.

Some other words are also in **bold** but are not in the list on pages 4 and 5. These words are to help you see quickly what the **information** on each page is about.



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## Useful words

This list tells you the meanings of some of the words in this booklet. The words in this list are in **bold** type in the booklet.

|                            |  |
|----------------------------|--|
| <b>Alzheimer's disease</b> | The most common illness that causes dementia   |
| <b>consultation</b>        | When the Government asks people what they think about its plans for the future   |
| <b>dementia adviser</b>    | A person who advises people with dementia and their carers where to go for help  |
| <b>diagnosis</b>           | Deciding what is wrong with a person's health  |
| <b>executive summary</b>   | The summary of the <b>National Dementia Strategy</b> which appears at the beginning of the full-length <b>Strategy</b> |
| <b>ethnic group</b>        | People with a similar heritage, often people who come, or whose ancestors came originally, from another country        |
| <b>family carers</b>       | Friends or relations who look after people with dementia   |
| <b>general hospitals</b>   | Hospitals that provide a range of services, rather than specialising in one sort of disease                            |

|                                   |   |
|-----------------------------------|---|
| <b>intermediate care</b>          | Help for people who are not quite ill enough to be in hospital, but not quite well enough to manage on their own at home          |
| <b>National Dementia Strategy</b> | The Government's 5-year plan for improving health and social care services in England for everyone with dementia and their carers |
| <b>objectives</b>                 | What we want the <b>Strategy</b> to achieve   |
| <b>outcomes</b>                   | What the <b>Strategy</b> will mean for people with dementia and their carers  |
| <b>social care</b>                | When someone is cared for in the community  |
| <b>specialist assessment</b>      | Used in this booklet to mean a health check done by a dementia specialist   |
| <b>stigma</b>                     | The idea that something (in this case dementia) is shameful   |
| <b>Strategy</b>                   | The <b>National Dementia Strategy</b>   |
| <b>telecare</b>                   | Special equipment that helps people receive care from far away, for example by telephone  |

## What is this booklet about?

This booklet is a shorter version of the full-length **National Dementia Strategy executive summary**.

It is about the Government's plans for **improving health and social care services** in England for everyone with dementia and their carers.

**The booklet tells you about:**

- what dementia is
- why we need to improve services for people with dementia and their carers
- the **17** things we want to happen over the next 5 years (our **objectives**)
- what the **Strategy** will mean for people with dementia and their carers (the **outcomes**).



## What is dementia?



Dementia is an illness caused when parts of someone's brain stop working properly. We do not fully understand the causes yet.

There is no cure for dementia, which gets more common with age. Once a person has dementia they will get worse over time until the end of their life. However, people who have dementia can often have good quality of life for a number of years.

### **People with dementia have problems with:**

- thinking clearly
- remembering things
- communicating
- doing day-to-day things like cooking or getting dressed.

## People with dementia may also have problems like:

- being depressed
- mood swings and aggression
- wandering or getting lost.

There are several different types of dementia. The best known is called **Alzheimer's disease**. Some people use 'Alzheimer's disease' to mean all the different types of dementia.

If dementia is **diagnosed** early enough, there are lots of things that can be done to help people **overcome the problems** and to improve their **quality of life**.





## What is the effect of dementia?



Dementia is very common. There are about **700,000** people with dementia in the UK. Dementia has a big effect on our society.

Most people with dementia are **over 65 years old**, but there are at least 15,000 people under 65 who have the illness.

Dementia can **affect anyone** whatever their gender, **ethnic group** or class. People with learning disabilities are at particular risk.

The number of people with dementia in minority ethnic groups is about 15,000 but this figure will rise as populations get older.

Dementia makes the lives of people who have it, and the lives of their families and carers, very difficult.

**Family carers** are often old and frail themselves. The **strain of caring** for someone with dementia can cause physical or mental illness in the carer.

Dementia is becoming **more common** and the **cost** of looking after people with dementia is going up.

| Year                           | 2008        | 2038             |
|--------------------------------|-------------|------------------|
| People with dementia in the UK | 700,000     | 1.4 million      |
| Estimated cost                 | £17 billion | Over £50 billion |

If we **spend money now** to improve the quality of life for people with dementia and their carers we will save money in the future as well as make things better for everyone concerned.

The Government has identified dementia as a national priority.



# About the Strategy



We want to develop services for people with dementia and their carers that are fit for the 21st century. We want services that meet the needs of everyone, regardless of their age, **ethnic group** or social status.

The **Strategy** is our 5-year plan to help us do this.

The Strategy is for:

|                      |        |                                      |                             |
|----------------------|--------|--------------------------------------|-----------------------------|
| People with dementia | Carers | Health and social care professionals | Anyone affected by dementia |
|----------------------|--------|--------------------------------------|-----------------------------|

Before writing the Strategy, we talked to many people and organisations.

We also had a **consultation**.

**During the consultation:**

- we ran about 50 events where over 4,000 people came to talk about our ideas
- over 600 people replied to our ideas in the consultation document.

When people had told us what they thought, we used what they told us to help us write the **Strategy**.

The Strategy has **3 key steps** to improve the quality of life for people with dementia and their carers:

|   |   |  |
|---|---|--|
| 1. Ensure <b>better knowledge</b> about dementia and remove the <b>stigma</b> | 2. Ensure <b>early diagnosis</b> , support and treatment for people with dementia and their family and carers | 3. <b>Develop services</b> to meet changing needs better |
|---|---|--|



# 1. Ensure better knowledge

There is a lot of **ignorance** about dementia. This ignorance is not only among the public, but also among the people who provide services.

Many people do not realise that there are **ways of supporting and treating people with dementia**. In fact, if there is a **diagnosis** early enough, a lot can be done to help with the symptoms and to help people to cope.

**We want to:**

Help everyone to **understand** dementia better

Get rid of the **stigma** attached to dementia

One of the **key messages** in the **Strategy** is the need for better education and training for professionals.



## 2. Ensure early diagnosis

At the moment, we think that only about a **third of people** with dementia ever have a proper **diagnosis**.

When people see specialist services, it is often too late in their illness. This means that the illness will have got worse and the chance of improving their quality of life is less.

**So it is very important to:**

|                                |   |  |
|--------------------------------|---|--|
| Have an <b>early diagnosis</b> | Give people the <b>information</b> they need as early as possible | <b>Start</b> support and <b>treatment</b> as early as possible |
|--------------------------------|---|--|

Some people argue that it is better not to tell someone if they have dementia. But our **consultation** told us that most people believe they should have the right to be told.





### 3. Develop services

We need to develop a **range of services** that fully meet the changing needs of people with dementia and their carers in the future.

People who replied to our **consultation** generally agreed on what these services should be.

**We will be testing these out, but they are likely to include things like:**

|  |   |  |
|--|---|--|
| GPs working side by side with mental health services | GPs knowing how to spot the first signs of dementia | Having one person who is responsible for dementia services in a hospital |
|--|---|--|

Making sure people with dementia get information and support as soon as possible

Giving everyone with dementia their own personal **dementia adviser** to help them

Helping people with dementia to stay in their own homes for longer

The success of the **Strategy** will depend on service providers **working together** to make sure they provide properly co-ordinated services to people with dementia and their carers.

We also need to make sure people get good-quality services **wherever they live**.

The full-length Strategy gives more information about the **type of services** we think need to be developed.





## Objectives and outcomes

We want a system where people affected by dementia:

- know where to go for help
- know what services they can expect
- seek help early for problems with memory
- are encouraged to seek help early
- get high-quality care and an equal quality of care, wherever they live
- are involved in decisions about their care.

The **Strategy** lists **17 key objectives** that we want to achieve and what this will mean for people with dementia and their carers.



| <b>Objectives</b><br>What we want the Strategy to achieve   | <b>Outcomes</b><br>What the Strategy will mean for people with dementia and their carers   |
|---|--|
| 1. Raise awareness of dementia and encourage people to seek help  | <p>The public and professionals will be more aware of dementia and will understand dementia better.</p> <p>This will:</p> <ul style="list-style-type: none"> <li>• help remove the <b>stigma</b> of dementia</li> <li>• help people <b>understand the benefits</b> of early <b>diagnosis</b> and care</li> <li>• encourage the prevention of dementia</li> <li>• <b>reduce other people’s fear and misunderstanding</b> of people with dementia.</li> </ul>  |
| 2. Good-quality, <b>early diagnosis</b> , support and treatment for people with dementia and their carers, explained in a sensitive way | <p>All people with dementia will have access to care that gives them:</p> <ul style="list-style-type: none"> <li>• an early, high-quality <b>specialist assessment</b></li> <li>• an <b>accurate diagnosis</b> which is explained in a sensitive way to the person with dementia and their carers</li> <li>• <b>treatment</b>, care and support as needed after the <b>diagnosis</b>.</li> </ul> <p>Local services must be able to see all new cases of people who may have dementia in their area promptly.</p> |

| <b>Objectives</b><br>What we want the Strategy to achieve                       | <b>Outcomes</b><br>What the Strategy will mean for people with dementia and their carers  |
|---|---|
| 3. Good-quality <b>information</b> for people with dementia and their carers    | People with dementia and their carers will be given good-quality <b>information</b> about dementia and services: <ul style="list-style-type: none"> <li>• at <b>diagnosis</b></li> <li>• during their care.</li> </ul>  |
| 4. <b>Easy access</b> to care, support and advice after <b>diagnosis</b>        | People with dementia and their carers will be able to see a <b>dementia adviser</b> who will help them throughout their care to find the right: <ul style="list-style-type: none"> <li>• information</li> <li>• care</li> <li>• support</li> <li>• advice.</li> </ul> |
| 5. Develop structured <b>peer support</b> and learning networks                 | People with dementia and their carers will be able to: <ul style="list-style-type: none"> <li>• get <b>support</b> from local people with experience of dementia</li> <li>• take an <b>active role</b> in developing local services.</li> </ul>                       |
| 6. Improve community <b>personal support services</b> for people living at home | There will be a range of <b>flexible services</b> to support people with dementia living at home and their carers.<br><br>Services will consider the <b>needs and wishes</b> of people with dementia and their carers.  |

| <b>Objectives</b><br>What we want the Strategy to achieve  | <b>Outcomes</b><br>What the Strategy will mean for people with dementia and their carers   |
|--|--|
| 7. Implement the <b>New Deal for Carers</b>  | Carers will: <ul style="list-style-type: none"> <li>• have an <b>assessment</b> of their needs</li> <li>• get better <b>support</b></li> <li>• be able to have good-quality <b>short breaks</b> from caring.</li> </ul>  |
| 8. Improve the <b>quality of care</b> for people with dementia in <b>general hospitals</b>   | This way people with dementia will get better care in hospital: <ul style="list-style-type: none"> <li>• it will be clear <b>who is responsible</b> for dementia in <b>general hospitals</b> and what their responsibilities are</li> <li>• they will work closely with specialist older people's <b>mental health teams</b>.</li> </ul> |
| 9. Improve <b>intermediate care</b> for people with dementia   | There will be more <b>care</b> for people with dementia who need help to stay at home.   |
| 10. Consider how <b>housing support, housing-related services, technology</b> and <b>telecare</b> can help support people with dementia and their carers | Services will: <ul style="list-style-type: none"> <li>• <b>consider the needs</b> of people with dementia and their carers when planning housing and housing services</li> <li>• try to help people to <b>live in their own homes</b> for longer.</li> </ul>   |

| <b>Objectives</b><br>What we want the Strategy to achieve                     | <b>Outcomes</b><br>What the Strategy will mean for people with dementia and their carers  |
|---|---|
| 11. Improve the quality of care for people with dementia in <b>care homes</b> | Services will work to ensure: <ul style="list-style-type: none"> <li>• <b>better care</b> for people with dementia in care homes</li> <li>• <b>clear responsibility</b> for dementia in care homes</li> <li>• a <b>clear description</b> of how people will be cared for</li> <li>• visits from specialist <b>mental health teams</b></li> <li>• <b>better checking</b> of care homes.</li> </ul> |
| 12. Improve <b>end of life care</b> for people with dementia                  | People with dementia and their carers will be <b>involved in planning</b> end of life care.<br><br>Services will consider people with dementia when planning local end of life services.  |
| 13. An informed and <b>effective workforce</b> for people with dementia       | All health and <b>social care</b> staff who work with people with dementia will: <ul style="list-style-type: none"> <li>• have the <b>right skills</b> to give the best care</li> <li>• get the right <b>training</b></li> <li>• get <b>support</b> to keep learning more about dementia.</li> </ul>  |

| <b>Objectives</b><br>What we want the Strategy to achieve   | <b>Outcomes</b><br>What the Strategy will mean for people with dementia and their carers  |
|---|---|
| 14. A <b>joint commissioning</b> strategy for dementia  | Health and <b>social care</b> services will work together to develop systems to: <ul style="list-style-type: none"> <li>• <b>identify the needs</b> of people with dementia and their carers</li> <li>• best meet these needs.</li> </ul> There is guidance in the <b>Strategy</b> to help services to do this. |
| 15. Improve <b>assessment and regulation</b> of health and care services and of how systems are working               | There will be <b>better checks</b> on care homes and other services to make sure people with dementia get the best possible care.   |
| 16. Provide a clear picture of <b>research</b> about the causes and possible future treatments of dementia            | People will be able to get information from <b>research about dementia</b> .<br>We will do lots of things to identify gaps in the research information and do more research to fill the gaps.   |
| 17. Effective national and regional support for local services to help them develop and carry out the <b>Strategy</b> | The Government will give advice and support to local services to help them carry out the <b>Strategy</b> .<br>There will be more good-quality information to help develop better services for people with dementia.   |

We know that different areas will improve services at different speeds. So we know that not all areas will be able to carry out the whole **Strategy** within five years. But we will expect local services to meet the Strategy **objectives** as far as possible within this period.

## How to find out more

To find out more about the **National Dementia Strategy** you can:

Visit [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia)

To get more copies of this accessible summary booklet, or a copy of the full-length National Dementia Strategy, you can:

Visit [www.orderline.dh.gov.uk](http://www.orderline.dh.gov.uk)

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Remember to say whether you want the full-length Strategy (order number 291591a) or the accessible summary booklet (order number 291591b) when you order the booklets.



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