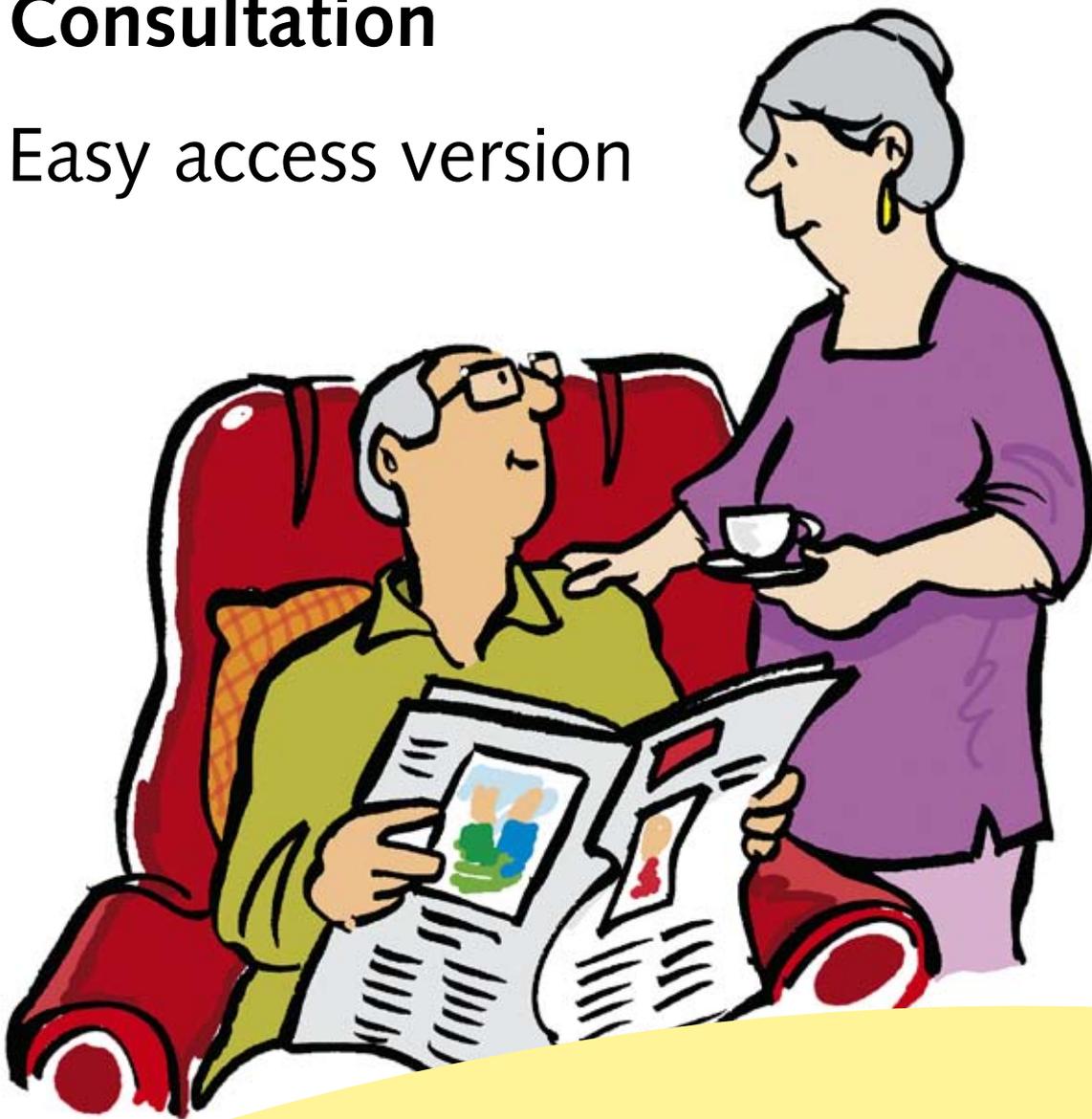
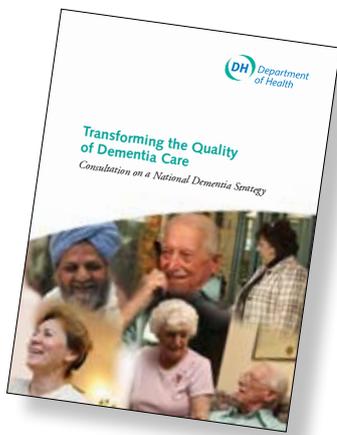


National Dementia Strategy Consultation

Easy access version



Easy read



Easy access version

This booklet is a shorter version of the full-length **Transforming the Quality of Dementia Care – Consultation on a National Dementia Strategy**.

It tells you about most of the points in the full-length booklet 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 **care and support services** in England for people with **dementia** and their **family carers**.

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

Words in bold type

There is a list of the **meanings** of some of the words in this booklet on page 2. These words are in **bold** type.

Some other words are also in **bold**, but are not in the list on page 2. These words are to help you see quickly what the **information** on each page is about.

Support

You might like to have someone to **support** you when you look at this booklet.

Contents

Useful words	2
What is this booklet about?	4
What is dementia?	6
What is the impact of dementia?	8
What do we mean by dementia services?	10
Problems we need to solve	11
The National Dementia Strategy	15
The consultation	19
The 15 recommendations	21
The questions we would like you to answer	25
How to answer our questions	27
Comments or complaints	29
What will happen next?	30
How to find out more	31

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.

acute care	Medical treatment, usually in a hospital, for patients who are ill or recovering from an injury
Alzheimer's disease	The most common illness that causes dementia
Alzheimer's Society	A charity for people with dementia and their carers
care and support services	Used in this booklet to mean services for people with dementia and their carers
carers	Used in this booklet to mean family carers
commissioners	People responsible for planning and paying for health services
consultation	When the Government asks people what they think about its plans for the future
dementia	An illness caused when parts of a person's brain stop working properly and where the problems caused, such as poor memory, get worse over time
dementia care adviser	A person who could advise people with dementia and their carers where to go for help
diagnosis	Deciding what is wrong with a person's health
discrimination	Treating someone unfairly because of their illness, disability, race, religion, gender or age
draft strategy	The consultation booklet
family carers	Friends or relations who look after a person with dementia
final strategy	The strategy we will publish at the end of this consultation
general hospitals	Hospitals that provide a range of services, rather than specialise in one sort of disease
intermediate care	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



interventions	Things that can be done to make a person's illness less of a problem
memory service	Somewhere people can go to get a diagnosis of dementia and which can provide help on living with dementia
mental health	How a person feels in their mind
minority ethnic	People who come, or whose ancestors came originally, from another country
primary care	The care that someone gets when they first need help with a health problem. This help is usually from their GP
psychiatry	The branch of medicine which looks after a person's mental health
residential care	When someone lives and is cared for in a care home
social care	When someone is cared for in the community
specialist assessment	Used in this booklet to mean a health check done by a dementia specialist
stigma	The idea that something (in this case, dementia) is shameful
Strategic health authorities (SHAs)	Organisations responsible for regional healthcare
strategy	The National Dementia Strategy
third sector	The collective name for organisations like charities, local groups and voluntary organisations

What is this booklet about?

This booklet is a shorter version of the full-length **Transforming the Quality of Dementia Care – Consultation on a National Dementia Strategy**.

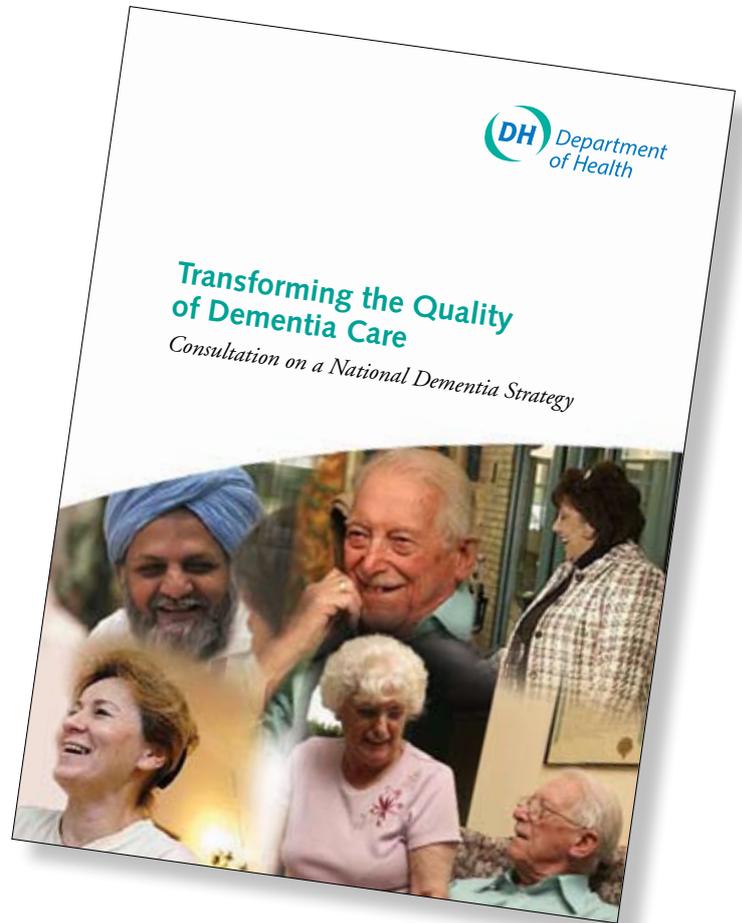
It is about a government plan for improving **care and support services** in England for people with **dementia** and for their carers. The plan will be called **The National Dementia Strategy**.

The **strategy** will be a **5-year plan** for improving services for people with **dementia** and their **carers**.

The booklet tells you about:

- what **dementia** is (see page 6)
- the problems that we have with services for people with **dementia** at the moment
- the plans we are making to help solve the problems (the **strategy**)
- how to tell us what you think about our plans.

This booklet is part of a **consultation** on our plans.



Consultation

A **consultation** is when the Government asks people what they think about its plans for the future.

This **consultation** is about making care and support better for **people with dementia**.

The **consultation** lasts from 19 June until 11 September 2008. So please tell us what you think before **11 September 2008**.

We tell you how to do this on page 27.



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** it will get worse until they die. However, people who have **dementia** often live for 7 to 12 years after the illness has been diagnosed and can 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 ways that the effects of the illness can be handled and reduced.



What is the impact of dementia?

Dementia is very common. There are about **700,000 people** with **dementia** in the UK. **Dementia** has a big impact 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 everyone** whatever their gender, ethnicity 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 also cause physical or mental illness in the **carer**.



Estimated costs to the UK

Dementia is becoming more common.

It is estimated that the cost of dementia care is more than for cancer, heart disease and stroke put together. And **costs are rising**.

Year	2008	2038
People with dementia	700,000	1.4 million
Estimated cost	£17 billion	Over £50 billion

If we **invest now** to improve the quality of life for people with **dementia** and their **carers** we will save money in the future on:

- the cost of **hospital care** for people with **dementia**
- the cost of **residential care** homes.

The Government has identified dementia as a national priority.



What do we mean by dementia services?

There are lots of **different services** which people with **dementia** may need. They include:

- **primary health care**, such as GPs
- **specialist services** from professionals with experience in managing people with **dementia** and in **mental health** (for example, old-age psychiatry)
- care provided in **general hospitals** (for example, specialist services for old people and people with brain problems)
- **social care** provided by **local authorities** and the **third sector**.



We have used examples of existing high-quality **dementia** care services to help us plan our **strategy**.

Problems we need to solve

Although there are lots of examples of good services for people with **dementia**, these good services are not available in many places.

Lack of understanding

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 treating dementia**. In fact, if **dementia** is diagnosed early enough, a lot can be done to help with the symptoms of the illness and how people cope.



We need to change services so that people get a good **diagnosis of dementia** and get **treatment early**.

Lack of diagnosis

At the moment, only half of people with **dementia** have a **diagnosis** to tell them officially that they have **dementia** or have any contact with **specialist services** during their illness.

When they do have contact with specialist services, it is often late on in their illness. This means that the illness will have got worse and the chance of improving their quality of life is less.

If **dementia** is not **diagnosed**, the person with **dementia** and their **family carers** do not have the chance to:

- **make choices** for themselves
- **plan** for their futures
- **get help, support and treatment** (this includes social and counselling treatments as well as drugs).

We need to help people **recognise** the first signs of **dementia** and do something about it quickly.



Differences in quality map of UK

We know that we don't do enough to diagnose and treat people with **dementia** in the UK.

There are also big differences in the amount and quality of **diagnosis** and treatments in **different parts of the country**.

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



Lack of choice

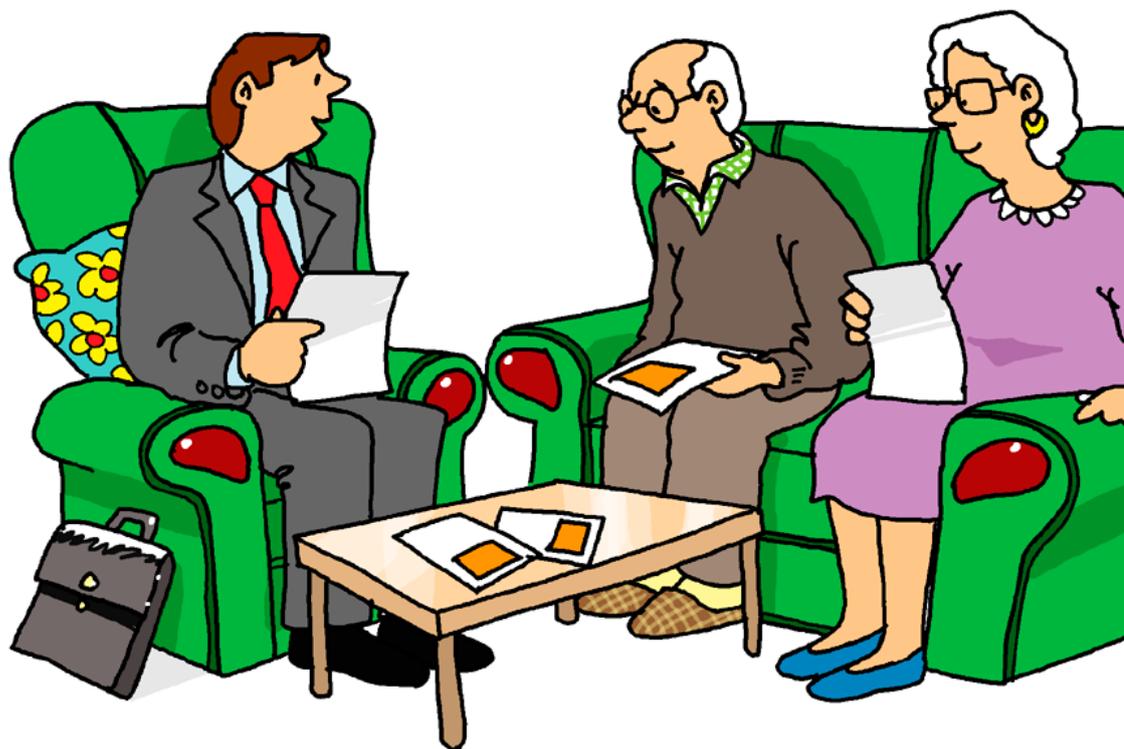
People with **dementia** have the same **human rights** as other people.

We need to **involve people** in making the choices that will allow them to plan ahead and to care for themselves.

They, their families and carers have the right to expect services that give them **dignity** and treat them with **respect**.

Most people with **dementia** want to **live in their own homes** for as long as possible. If that is no longer possible, they want care homes with well-trained staff, offering **good-quality care**.

At the moment, many people do not have the chance to make these sorts of choices and decisions about their own lives and futures.



The National Dementia Strategy

The final **National Dementia Strategy** will be our 5-year plan for improving services for people with **dementia** and their **carers**.

This **consultation** booklet is a **draft** for the **final strategy**. We have based the ideas in the **draft strategy** on a report by a large group of people interested in **dementia**, including people with **dementia**, their **carers** and professionals.

You can find the full report on the **Alzheimer's Society** website at www.alzheimers.org.uk.

We have already had **feedback** on the existing **dementia** services from lots of different sources. It is clear from the feedback that most people agree on the sorts of things we should do to improve services.



What will the strategy do?

The **strategy** will have **3 main aims**. Since August 2007, we have been working on a 1-year project to look at how we can:

1. **improve awareness** of **dementia** among both the public and health and **social care** professionals
2. make sure that **diagnosis** is made as early as possible to allow for early **intervention**
3. deliver **high-quality care and support** for people with **dementia** and their **carers**.



Who is the strategy for?

The **strategy** will be a guide to help local services improve their **dementia** services.

The strategy will:

- **provide a guide** for people with **dementia** and their families about what they can expect from high-quality health and **social care**
- **give advice** and help on how to plan, develop and monitor services to:

Strategic health authorities (SHAs)

Local authorities

Hospitals

Primary care trusts (PCTs)



What kind of services do we want?

We want the **strategy** to help deliver services for all people with dementia and their families which:

- are based on the **needs and choices** of people with **dementia** and their families
- provide services that meet **recognised quality standards**
- meet with other **government recommendations** about healthcare
- support people to access a range of services from the NHS, **social care** and charities
- ensure that people from all backgrounds and communities can get access to high-quality services
- help local health and **social care** services to **respond to local needs**.

This **strategy** is designed to meet the needs of **everyone** with **dementia**, no matter of what type, age, ethnic origin or social status they are.



The consultation

This **consultation** is part of a 1-year project to decide what we should say in the final **National Dementia Strategy**.

It is one of the most important stages in deciding on the **final strategy**.

The **draft strategy** gives a list of 15 **recommendations** for things we could do that we think will improve the quality of life and the quality of care for people with **dementia** and their **family carers**.



We want to hear **what you think** about the 15 recommendations.

Who do we want to hear from?

We want to hear from:

- people with **dementia**
- families and carers of people with **dementia**
- health and **social care** professionals
- the general public.



What should you think about?

You can comment on as few or as many of our **recommendations** as you like.

When you tell us what you think about the recommendations, you may like to think about these questions:

How practical are they?

What are the main priorities?

Will they be affordable?

How effective will they be?

We tell you how to tell us what you think on page 27.



The 15 recommendations

This list shows our 15 **recommendations** and the **outcomes** we want to achieve.

We have used the same words for the titles of the recommendations as in the longer booklet. This will help you when you respond to the **consultation**.



Improved awareness

Recommendation 1

Increased public and professional awareness of dementia

Outcome: The public and professionals will be more aware of **dementia** and will understand **dementia** better. This will:

- help remove the **stigma** of **dementia**
- help people **understand the benefits** of early **diagnosis** and care
- encourage the **prevention** of **dementia**
- **reduce discrimination** against people with **dementia**.

Recommendation 2

An informed and effective workforce for people with dementia

Outcome: All health and **social care** staff involved in the care of people who may have **dementia** will have the skills to give the best quality care.

We will achieve this through:

- good basic training
- ongoing professional and vocational development in **dementia**.

Early diagnosis and intervention

Recommendation 3

Good-quality early diagnosis and intervention for all

Outcome: All people with **dementia** will have access to care that gives them:

- a quick and high-quality **specialist assessment**
- an **accurate diagnosis** which is explained sensitively to the person with **dementia** and their **carers**
- **immediate treatment**, care and support after the diagnosis.

The system must be able to deal with everyone who may have **dementia**.

Recommendation 4

Good-quality information for those with dementia and their carers

Outcome: People with **dementia** and their **carers** will get the **information** they need about:

- **dementia**
- the services available after diagnosis
- the services available throughout their care.

Recommendation 5

Enabling continuity of support and advice

Outcome: People with **dementia** and **their** carers will get **support and advice** throughout the illness.

Improved quality of care
<p>Recommendation 6 Improved quality of care in general hospitals</p> <p>Outcome: People with dementia will get better care in general hospitals.</p>
<p>Recommendation 7 Improve home care for people with dementia</p> <p>Outcome: People with dementia and their carers will get home care services that better meet their needs.</p>
<p>Recommendation 8 Improve short breaks for people with dementia and their family carers</p> <p>Outcome: People with dementia and their family carers will get short break services that better meet their needs.</p>
<p>Recommendation 9 A joint commissioning strategy for dementia</p> <p>Outcome: Commissioning and planning systems will be set up to decide what services people with dementia and their carers need and how best to meet these needs.</p>
<p>Recommendation 10 Intermediate care for people with dementia</p> <p>Outcome: People with dementia will get intermediate care which is accessible to them and meets their needs.</p>
<p>Recommendation 11 Improved dementia care in care homes</p> <p>Outcome: People with dementia will get better care in care homes.</p>

Recommendation 12

Improved registration and inspection of care homes

Outcome: There will be a better system for **checking care homes** to make sure that they give good-quality care to people with **dementia**.

Delivering the strategy

Recommendation 13

Clear information on the delivery of the strategy

Outcome: People will be able to get **good-quality information** about how **dementia** services are improving because of our strategy.

Recommendation 14

A clear picture of research evidence and needs

Outcome: People will be able to get information from **research about dementia**. We will be able to identify gaps in the research information and do more research to fill the gaps.

Recommendation 15

Effective support of implementation

Outcome: Local services will be able to get advice and **support from the Government** to help them carry out the strategy.



The questions we would like you to answer

There are 12 questions we would like people who respond to this **consultation** to help us answer:

1. Are these the **right recommendations** and outcomes?
2. Is there anything that we have **missed out** which would help us carry out the **National Dementia Strategy**?
3. What are your **priorities**? What do you think we should **do first**?
4. What should be the **timetable** to carry out the strategy?
5. Is there anything you or your organisation could do to **help us** carry out these recommendations?
6. Have we suggested the right **ways to achieve our recommendations**?
7. Do you agree that a **specialist should be responsible** for the **diagnosis of dementia**?



8. How often should people be referred to a **memory service**? Should people be able to refer themselves, or should they go to a GP first?

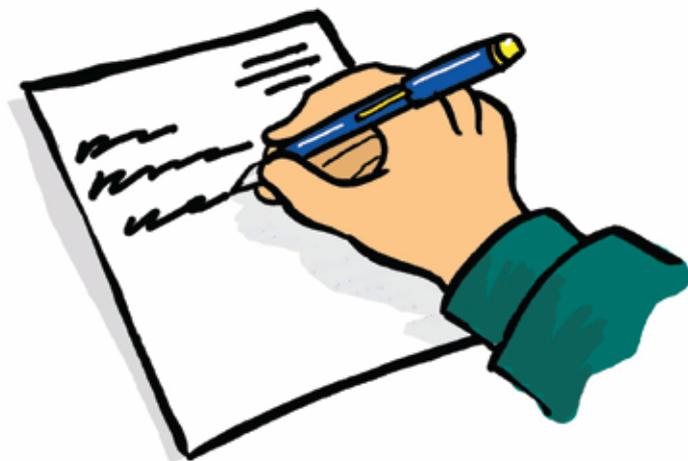
9. How would the **dementia care adviser** be able to ensure continuity of care?

10. What more could be done in **acute care, home care and care homes**?

11. What should we do to give people with **dementia** and their families more control over their own care? This would include more control over how money is spent on their care.

Somewhere people can go to get a **diagnosis** of **dementia** and which can provide help on living with **dementia**.

12. Does this **draft strategy** meet the needs of people from minority groups such as **ethnic minorities** or people with learning disabilities?



How to answer our questions

To answer these questions, you need a response form.

To get a copy of the form you can:

Download it at: www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm

Write to us at: David Corcoran
The Dementia Team
Department of Health
8E13 Quarry House
Quarry Hill
Leeds LS2 7UE

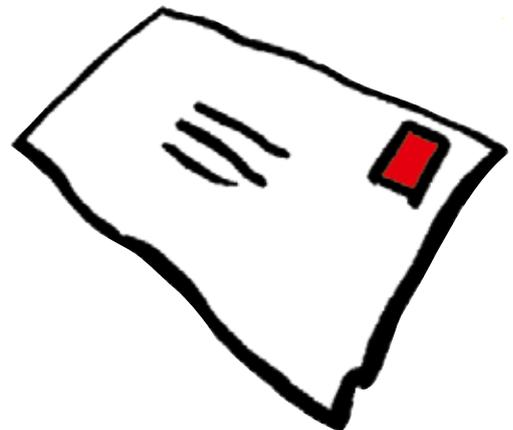


We also have an **easy read version** of the form if you would like one.

Send your completed form

By **email** to: dementiastrategy@dh.gsi.gov.uk

By **post** to: David Corcoran
The Dementia Team
Department of Health
8E13 Quarry House
Quarry Hill
Leeds LS2 7UE



Please tell us

When you send us your form, please say if you are:

- responding as an individual, or
- giving the views of an organisation.

If it is an organisation, please say who the organisation represents and how the views of members were collected.

Freedom of information

The Freedom of Information Act says that public organisations **must share information** if people ask for it.

If you do not want the information that you give us to be available to other people, **please explain why** you would like us to keep it **confidential** when you send us your form.

We will try to **respect your wishes**, but **we cannot promise** to keep your information confidential in all circumstances.

We will **not** usually share your personal details with other organisations.

This **consultation** began on **19 June 2008**.

It will end on **11 September 2008**.

Please let us have your comments on our recommendations before **11 September 2008**.

Comments or complaints

If you have a **comment or complaint** about this **consultation**:

Write to: **Consultation Co-ordinator**
Department of Health
Skipton House
80 London Road
London SE1 6LH

Or email: mb-dh-consultationscoordinator@dh.gsi.gov.uk

(Please do **not** send your response to the **consultation** to either of these addresses.)



What will happen next?

When we have had everyone's responses, we will **publish a summary** of what people have said. We will also publish a list of the **next steps** we will take.

To get a copy of the summary and next steps you can:

Download it at: www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/index.htm

Or to get a paper copy: tbc

???

We will publish the summary and next steps by **xx 2008**.



How to find out more

To get more copies of this easy access booklet, or a copy of the full-length consultation **Transforming the Quality of Dementia Care – Consultation on a National Dementia Strategy** – you can:

Download it at: www.dh.gov.uk/dementia

Email: dementia.strategy@dh.gsi.gov.uk

Telephone: 0113 254 6888

(Please see the back cover for the reference number and further details.)

To get more copies of this easy access booklet, or a copy of the full-length consultation – **Transforming the Quality of Dementia Care – Consultation on a National Dementia Strategy** – you can: pdfs of front covers of both documents

Visit: www.orderline.dh.gov.uk

Or write to: **DH Publications Orderline**
PO Box 777
London SE1 6XH
Email dh@prolog.uk.com
Telephone: 08701 555 455
Fax: 01623 724 524



Remember to say whether you want the **full-length consultation** or the **easy access** version when you order the booklets.

© Crown copyright 2008
?????? ?p k June 08 (???)
Produced by COI and the
Department of Health

www.dh.gov.uk/publications