

# Improving Dementia Services in Northern Ireland

## A Regional Strategy



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# Introduction

This is an accessible version of the full length document *Improving Dementia Services in Northern Ireland – A Regional Strategy*.

The booklet will tell you about the main points in the full length strategy but in less detail.

The strategy aims to:

- ✓ help everyone understand dementia better and say how people with dementia can be helped to live full lives
- ✓ raise public awareness of steps they can take that may cut down on the risk of developing dementia
- ✓ share information about dementia so people with dementia can make the choices that work best for them
- ✓ listen to what people with dementia say they want services to be like
- ✓ support family carers and encourage all staff to work together to develop good quality services for people with dementia



# Helpful words



<b>acute care</b>	Medical treatment, usually in a hospital, for patients who are ill or recovering from an injury
<b>Alzheimer's disease</b>	The most common type of dementia
<b>assistive technology</b>	Any product or service designed to enable independence for disabled or older people
<b>care and support services</b>	Services for people with dementia and their carers
<b>carers</b>	Family carers and friends
<b>consultation</b>	When the government asks people what they think about its plans for the future
<b>dementia</b>	An illness when parts of a person's brain stop working properly
<b>diagnosis</b>	Deciding what is wrong with a person's health
<b>draft strategy</b>	Consultation booklet
<b>final strategy</b>	The document we will publish at the end of this consultation
<b>general hospitals</b>	Hospitals that provide a range of services, rather than specialise in one sort of healthcare need
<b>informal care</b>	Care and support given by family carers
<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>memory service</b>	Somewhere people can go to get a diagnosis of dementia and information about living with dementia
<b>mental health</b>	How a person feels in their mind
<b>minority ethnic group</b>	People who come from, or whose ancestors came originally from, another country or culture
<b>primary care</b>	Care that someone gets when they first need help with a health problem. This is usually from their GP
<b>psychiatry</b>	The branch of medicine looking after a person's mental health
<b>residential care</b>	When someone lives and is cared for in a care home
<b>respite care</b>	Short-term, temporary relief to those who are caring for family members
<b>social care</b>	Practical and emotional support for people to enable them to live as full a life as possible
<b>specialist assessment</b>	A health check carried out by a dementia specialist
<b>stigma</b>	The idea that something (in this case, dementia) is shameful and should be hidden
<b>strategy</b>	A plan for how to get things done – in this case a way of improving dementia services
<b>supported housing</b>	Housing and services to help people continue living independently



# About the strategy



The number of people in Northern Ireland with dementia is getting bigger and we want to develop services for people with dementia and their carers in the best way.

The strategy sets out how this can be done.

## The strategy is for:

- ✓ people with dementia
- ✓ families and carers
- ✓ health and social care staff
- ✓ anyone affected by dementia



## And is about:

- ✓ the public and professionals having better understanding of dementia
- ✓ getting support and information as soon as possible – we call this early diagnosis
- ✓ getting the right type of support and service
- ✓ making sure you have the services you need from well trained staff
- ✓ making changes to the law
- ✓ continuing to research the causes and cures for dementia

# Why dementia is an important condition

Dementia is a condition which affects parts of the brain. People with dementia tend to have problems with:

- ☑ thinking clearly
- ☑ remembering things
- ☑ talking about things with other people
- ☑ doing day to day things like getting dressed, driving or cooking

Dementia is more likely to happen in old age and there is no cure, however people who have dementia can have a good quality of life.

**People with dementia may also have problems like:**

- ☑ depression
- ☑ mood swings and aggression
- ☑ getting lost

There are different types of dementia but most people will have heard of Alzheimer's disease. Over half of the people diagnosed with dementia have Alzheimer's disease.

If dementia is diagnosed early, the problems of the illness can be talked about and managed better.



# The impact of dementia



Dementia is very common among people aged 65 and over. The number of people with dementia is growing. This is because there are more people living longer and developing the condition. In Northern Ireland there are 19,000 people living with dementia. Most people with dementia are over 65 years of age but it is thought there are between 400 and 1,000 people under the age of 65 with this condition. Adults with a learning disability are also at risk of getting dementia.

Dementia can make the lives of people who have it and the lives of their families very difficult. We need to make sure people get the right services.

The costs of dementia care are large, both to people with dementia and their carers and to health and social care services. As the number of people with dementia increases the cost of caring for people will rise.

Year	2009/10	2029/30
Cost	£230m	£460m

At the moment there is no cure for dementia and we know some things increase the risk of getting different types of dementia, like getting older, if you're male or female, if it runs in your family or if you have a learning disability. Other reasons thought to increase the risk of getting dementia are:

- smoking
- alcohol
- overeating
- high blood pressure



We think there are some things that can be done to protect against developing dementia like:

- ✓ staying active – doing physical exercise
- ✓ eating a healthy diet
- ✓ keeping your brain active by doing things like crosswords, playing board games and reading
- ✓ socialising and maintaining friendships and interests



## Understanding dementia

Not everyone understands what dementia is or what this means for the person and their family. We want people to understand dementia better. This means not only the public but health and social care staff and people who provide services.

### Better knowledge:

- ✓ we want people to know about dementia so they can get the right help as soon as possible. If there is an **early diagnosis**, a lot can be done to improve someone's quality of life through giving the correct information and support
- ✓ there is **stigma** attached to dementia. Better knowledge and a greater understanding of the disease by the public and professionals will help to reduce this
- ✓ health and social care staff and people who provide services need more **education, training and information** on dementia and dementia care



# Early diagnosis and information



To get the right help and support for a person a diagnosis of dementia is needed. An early diagnosis means that you can get information and support from **specialist services** and you can improve your quality of life. Of the 19,000 people in Northern Ireland with dementia, only about half have had a proper diagnosis.

## Having an early diagnosis means that:

- you can start getting treatment and support to improve your quality of life
- you can say what help and support you want
- you and your family or carer can plan for the future



# Supporting people with dementia

There are different services and types of support people with dementia may need to improve their daily life. These services should be available to everyone.

## These services are:

- ☑ primary healthcare such as GPs and professional staff who work together
- ☑ specialist services from staff who are experienced in providing dementia care in:
  - » memory clinics
  - » mental health staff
  - » residential care
  - » nursing home care
  - » care in your own home
  - » respite and intermediate care
  - » housing support. This could be assistive technology to help you stay in your own home or housing suitable for people with dementia
  - » care you receive in general hospitals

The strategy asks service providers in Northern Ireland to work together to make sure people with dementia and their carers have choice and have good quality services.



## Supporting carers



Caring for someone with dementia can be difficult and lonely. The strategy wants to make sure carers:

- ☑ understand what the diagnosis means to both the person and the family
- ☑ know who to go to when help is needed
- ☑ get the right information and practical support to help them carry on giving care

This will be achieved by carers being asked by staff what their needs are, and by then giving carers the right information and practical support.



# Recommendations of the strategy

The strategy makes a number of recommendations for the future. The recommendations are linked to six statements called **values and principles** of the strategy and have been developed by a range of people like service providers, professionals and people with dementia and their families.



The values and principles of the strategy are:

- ✓ **dignity and respect** – people with dementia have the right to be understood and listened to
- ✓ **autonomy** – people with dementia and their carers will be asked their opinion of services and what they need
- ✓ **justice and equality** – people with dementia whatever their gender, ethnicity or class have the right to good quality services wherever they live
- ✓ **safe, effective person-centred care** – people with dementia will be consulted about the help they want. Services and treatments will improve the lives of people with dementia and their carers
- ✓ **care for carers** – carers are important and need good information and practical support to be able to continue
- ✓ **skills for staff** – people who provide care or services to people with dementia will be trained

# Recommendations



## 01. Increased public and professional awareness of dementia

- ✓ help remove the stigma of dementia
- ✓ increase public awareness of dementia and how important it is to get help early
- ✓ work in partnership with the public, voluntary and private providers to raise awareness of dementia

## 02. An informed and effective workforce for people with dementia

all health and social care staff who provide care and support for people with dementia will have good basic training and ongoing developmental training in dementia

## 03. Good quality early diagnosis and interventions

all people with dementia will have access to care that gives specialist assessment, accurate diagnosis and appropriate treatment, care and support after diagnosis

## 04. Good quality information for those with dementia and their carers

people with dementia and their carers will get the information they need about dementia and dementia services when they need it

## 05. Good quality information for everyone on the action they may take to prevent or delay the onset of dementia

the public will be informed of helpful measures that can be taken to promote a healthy lifestyle



**06. Enabling continuity of advice and support**  
people with dementia and their carers will get advice and support throughout their illness

**07. Improved quality of care and services for people with dementia and their carers in respect of:**

- general hospitals
- care homes
- short stay/respice care services
- intermediate care services
- assisted/supported housing
- palliative (end of life) care services
- services for younger people with dementia
- services for adults with a learning disability and dementia

**08. Clear information on the delivery of the strategy**  
people with dementia and their carers will get good quality information about how dementia services are being delivered and if they are improving because of the strategy

**09. Introduce new mental health legislation**  
people with dementia and their carers will benefit from new legislation, which will respect a person's right to make decisions and act on those decisions. If a person is unable to make decisions, the legislation will provide for substitute decision-making

**10. Continue to contribute to research on dementia**  
Research into dementia needs to continue. People from Northern Ireland should contribute both locally and internationally to research





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