

Healthcare  
Improvement  
Scotland

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# Assessment, diagnosis, care and support for people with dementia and their carers

## Part 1 of 2

A booklet for people with dementia, friends, family  
members and unpaid carers



## Thank you



We would like to thank all the people with dementia and unpaid carers who contributed to both the guideline and this booklet.

Thanks also to the voluntary sector organisations who took part in this work.

## Who is this booklet for?



This information is for:

- adults who have been **diagnosed** with dementia including people with **young onset dementia**

**Diagnosed** means a doctor has decided what your illness or health condition is.

When a person under the age of 65 develops dementia it is called **young onset dementia**.



- adults who may be going through **assessment** for dementia

An **assessment** is how doctors and healthcare staff make a decision about your treatment.



- family members, friends, unpaid carers and care partners who are caring now, or could be caring in the future for a person who has been diagnosed with dementia

Your carer may not think of themselves as a carer.



Your carer may see themselves as your wife, husband, son or daughter.

An unpaid carer or care partner is anyone who supports a friend, family member, or neighbour because of their old age, physical or mental illness, disability or an addiction.



More information and advice that may be useful to you at different stages of your dementia journey can be found in Part 2 of this document on pages 14 to 20.

## What is this booklet about?



The booklet will cover:

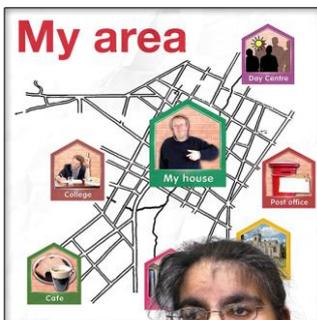
- assessment for dementia
- diagnosis
- support after diagnosis



The booklet will **not** cover:

- childhood dementia because this is extremely rare
- treatment

Guidance is in the [National Institute for Health and Care Excellence \(NICE\) dementia guideline](#)



Each health board is responsible for meeting the needs of their own area.

This may mean that what is available to you in one area may differ to someone living in a different health board area.

## What is dementia?



Dementia is a brain condition that can affect:

- thinking and how quickly your brain works
- how you remember things
- language
- understanding
- emotions



It affects different parts of the brain over time.

It can affect people physically and change the way the brain deals with senses like sight and taste.



There are over 100 different types of dementia.

There are around 90 thousand people living with dementia in Scotland.



For more information on dementia and the different types:

- look at [Alzheimer Scotland's website](#)
- or call the 24 hour Freephone Dementia Helpline on 0808 808 3000



Policies in Scotland that give details about the treatment and support that people living with dementia and unpaid carers are entitled to include:

- [The charter of rights for people with dementia and their carers in Scotland](#)
- [The Scottish Government's National Dementia Strategy](#)

## How is dementia diagnosed?



Getting a dementia diagnosis can take a long time and can be:

- difficult to understand
- upsetting
- overwhelming



You will have an initial assessment carried out by your GP or other healthcare staff.

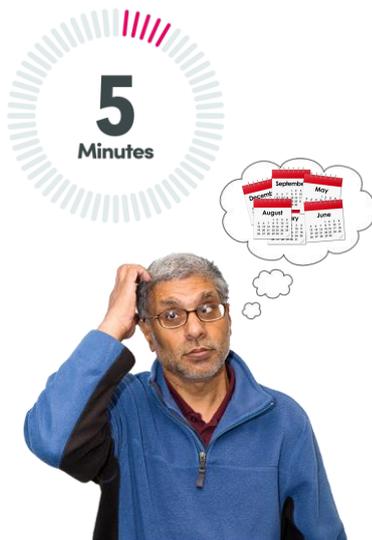
A family member can come to the appointment to support you.



A diagnosis is usually based on several tests and assessments that could include:

- **mental ability tests** – checking how you learn, understand and remember things
- blood tests
- brain scans

## Mental ability tests that may be part of dementia assessment



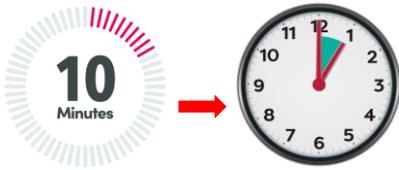
### Rapid Direct Tests

These will take less than 5 minutes to do.

You might be asked a set of memory questions.

You might also be asked to:

- draw certain shapes on paper
- count backwards
- say the months of the year backwards



## Extended Direct Tests

These will take between 10 minutes and 1 hour to do.

You might be asked to remember several words and be asked to repeat those words in 5 minutes.

You might be asked to watch the assessor and copy their movements.



## Questionnaires

These can be done in your own time and can be done on your own or with family or friends close to you.



## Remote Cognitive Assessment

This is assessment over the phone.

It involves a lot of testing to see what you remember, as well as several general questions.



The assessment should not just be based on mental ability tests.

Family members should be asked about your health and **wellbeing** - if you feel comfortable, healthy and happy

## Will I need to see a specialist?



A specialist may consider scanning your brain.

Some people will need one or more scans and others will not need a scan at all.

Scans help healthcare staff to



This then helps healthcare staff to:

- find out what type of dementia you have
- understand how your condition will progress
- know what treatments may help

## The types of scans



- **CT scan**

X-rays taken from different angles to produce images of your brain and show changes in brain structure.

- **PET scan**
- **SPECT scan**



These scans use a radioactive liquid that is injected into your arm or hand.

**Radioactive** means it gives off energy and the scan checks this to see how well blood flows through your brain.



- **MRI scan**

Makes detailed images of your brain to check if there are changes to brain structures.



A small number of people may get a **lumbar puncture**.

This is when fluid is taken from around your spine.

## How can technology be used for support and monitoring?



After you have had a diagnosis of dementia it is important for health and social care staff to be able to **monitor** and support you.

**Monitor** means to check your body and wellbeing to keep track of any changes or issues.



You might want face-to-face contact with healthcare staff:

- to help staff notice and discuss physical changes in you
- because you or your carer cannot use a smart phone or computer





You might want contact like phone calls or video calls that may:

- let you get quicker support
- help you or your carer to feel reassured and connected to healthcare staff

It is important that you and your carer discuss what kind of monitoring is best for you.

## Who will be involved in a dementia diagnosis?



GP Surgery



Hospital



Although different staff may be involved, a diagnosis will be given by a trained specialist in dementia.

You may get your diagnosis from:

- your GP
- specialist experts in dementia in a hospital
- or by care teams made up of people with different specialist knowledge



Your carer should be able to attend and be included in any discussions.

If you or your carer need more time to fully understand the diagnosis, healthcare staff should be understanding.



For some people, a dementia diagnosis can be a relief or explain a change in behaviour.

There is no right or wrong way to react to your diagnosis.

## How will a diagnosis be discussed?



Healthcare staff should:

- give you information before, during and after your diagnosis
- tell you and your carer about your diagnosis in a clear and sensitive way
- understand any communication needs you have and make you feel comfortable to ask any questions
- offer advice and information about wellbeing





It is important to remember that:

- everyone experiences dementia differently
- focusing on the things you can still do and enjoy will help you to stay positive
- with the right help and support most people can live well with dementia

Healthcare staff should discuss with you:



- if known:
  - the type of dementia you have
  - **symptoms** - these are the signs of your dementia
  - how your condition may change in the future



- dealing with **stigma** and how this can affect your life

**Stigma** is when a person or group is treated unfairly because people do not understand the difficulties they face.



- where to get free courses about dementia
- where to get help if you need support with everyday tasks – this is called social care support



- where to get more information about:

- dementia and support
- benefits and carers rights
- **peer support** - when people use their own experiences to help each other
- support for mental health
- **power of attorney** – when you give someone the legal power to make decisions for you when you cannot make decisions for yourself
- **advocacy** – a way to make sure your voice is heard



- the importance of completing the [Herbert Protocol form](#) which has information to help the police if you go missing



## What support can I expect after diagnosis?



This is called **post diagnostic support**.

The Scottish Government has guaranteed at least 1 year of post diagnostic support for everyone diagnosed with dementia.

It should:

- be the type of support that is right for you and your carers
- look at all your health needs
- be **culturally appropriate** - from someone who knows your culture and background
- look at how to deal with stigma
- have different services working well together
- tell you about other support services (see pages 14 to 20) of Part 2 of this document)
- give information in an accessible way which is repeated over time





Living well with dementia means staying healthy, both physically and mentally.

It is important to:

- eat healthy food
- do things that keep your brain active, like puzzles



You can get more information online on the [Brain Health Scotland](#) website.

### It's OK to ask



When you go to your healthcare appointments we encourage you to ask 4 questions that will help you and your healthcare staff make decisions together.



This will make sure that the care is right for you.

1. What are the benefits of my treatment?
2. What are the risks of my treatment?
3. What other treatments can I try?
4. What if I do nothing?



Find out more online about [It's OK to ask](#) and [realistic medicine](#).



These things should be discussed with you and your carer:

- how to understand dementia and how to live with memory loss
- how to live safely at home and look after yourself
- support with communication
- future care plans (see page 19) including **do-not-resuscitate (DNR)** conversations



If you have a **DNR** document it means healthcare staff will not try to bring you back to life if your heart stops beating.

- making plans for the future including looking after yourself and your money

This includes the need for power of attorney and **guardianship**.



If a doctor has said that you cannot make decision in some or all areas, someone else called a **guardian** will get the power to make decisions for you.

A court must decide who should be your guardian.



- the importance of a Carer Support Plan which should include emergency contact phone numbers



- the 4 options for [self-directed support](#) and how to get it



- support when moving from one care setting to another

- where to get information about:

- your human rights
- free personal care
- financial support
- employment issues



- how to get advocacy



What you want to happen in the future should be discussed with you and your carers at the start of your dementia journey.

Your wishes should be recorded in an future care plan.

## What is a future care plan and how do I make one?

A future care plan explains how you want to be cared for in the future.



Healthcare staff should start and support discussions about future care planning as early as possible in your dementia journey.



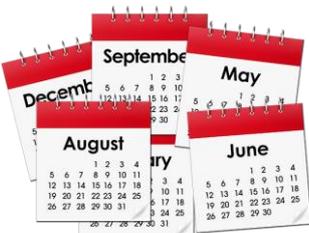
Healthcare staff involved in your planning should be trained in:

- dementia and dementia care
- how to talk to people with dementia to check their health needs

A discussion about a future care plan should:



- explain what it is and why it is important, in a way you understand



- happen more than once and change as your needs change



- happen at home or another place that is quiet and private



- think about what your carers and family need

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