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Embargoed  
until 00:01 on Thursday  
16 November 2023

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

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



Embargoed  
until 00:01 on Thursday  
16 November 2023



PLAIN  
LANGUAGE  
COMMISSION  
CLEAR  
ENGLISH  
STANDARD

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## Acknowledgements

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 third sector organisations who contributed to this work.

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# Who is this booklet for?

This information is for people who:

- have been diagnosed with dementia
- may be going through assessment for dementia
- are 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.

**It applies to adults living with dementia, including those with young onset dementia.**

Your carer may not think of themselves as a carer and 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 old age, physical or mental illness, disability or an addiction.

‘ Nobody chooses to be a carer. I did it not as an obligation, but because of the love I had for my mum. It was the most natural thing to do and was an absolute honour too.

(Carer of person with dementia)

Details of further information and advice that may be useful to you at different stages of your dementia journey can be found on page 32.



# What is this booklet about?

**This booklet shares recommendations from a clinical guideline about dementia produced by the Scottish Intercollegiate Guidelines Network (SIGN).**

The clinical guideline is based on what we know from current medical research. It also gives advice based on the opinion of healthcare professionals who are trained on how best to manage your care.

If you would like to see the guideline, please visit [www.sign.ac.uk](http://www.sign.ac.uk)

On page 40 you can find out how we produce guidelines.

The booklet will cover:	The booklet does not cover:
<ul style="list-style-type: none"><li>• Assessment for dementia</li><li>• Diagnosis</li><li>• Support after diagnosis</li></ul> 	<ul style="list-style-type: none"><li>• Childhood dementia, because this is very rare</li><li>• Treatment, because the guideline development group agree with the guidance on treatment provided in the <a href="#">National Institute for Health and Care Excellence (NICE) dementia guideline (NICE) (2018), Dementia: assessment, management and support for people living with dementia and their carers</a></li></ul> 

The guideline encourages all health and social care professionals to adopt person-centred care and see people living with dementia and unpaid carers as individuals in their own right.

It is important to be aware that each health board is responsible for meeting the needs of its own area. This may mean that what's available to you in one area may differ from what's available to someone living in a different health board area. **Recommendations may depend on what's available in each health board.**

## What is this booklet about? continued

There are two different types of recommendations in this booklet.



**Recommendation  
based on the research evidence**



**Recommendation  
based on clinical experience**

# What is dementia?

**Dementia is a brain condition that can affect memory, thinking, mental agility, language, understanding and emotions.**

Dementia affects different parts of the brain over time. It can affect people physically and change the way the brain processes senses such as sight and taste. There are over 100 types of dementia. The most common are Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies, and frontotemporal dementia.

In Scotland, it is estimated that there are around 90,000 people living with dementia. However, many people are living with dementia but are undiagnosed. When dementia occurs in someone under 65 it is often referred to as young onset dementia.

## Information

For more information on dementia and the different types, please see [Alzheimer Scotland's website](#).

24-hour Freephone Dementia Helpline: 0808 808 3000

## Information

There are a number of policies in Scotland that outline the treatment and support that people living with dementia and unpaid carers are entitled to.

These include:

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


# How is dementia identified and diagnosed?

It is important to be aware that each health board is responsible for meeting the needs of its own area. This may mean that what's available to you in one area may differ from what's available to someone living in a different health board area. **Recommendations may depend on what's available in each health board.**





Identifying the signs of dementia and having a formal diagnosis of dementia can be confusing, upsetting, overwhelming and take a long time. An initial assessment will be made by your GP or other healthcare professional. A family member is welcome to attend the appointment to provide reassurance and support.

How you are assessed will depend on your personal circumstances. It is important that you receive the right approach for your own circumstances.

A diagnosis is usually based on several tests and assessments. These could include mental ability tests, blood tests and brain scans. The table below shows the type of mental ability tests that may be part of your assessment.

Mental ability tests that may be part of dementia assessment	
Mental ability test	What happens
<b>Rapid direct tests</b> 	These will take less than 5 minutes to complete. In these tests, you might be asked a set of memory questions. You might also be asked to: <ul style="list-style-type: none"><li>• draw certain shapes on paper</li><li>• count backwards, or</li><li>• say the months of the year backwards.</li></ul>

## How is dementia identified and diagnosed? continued

Mental ability tests that may be part of dementia assessment	
Mental ability test	What happens
<b>Extended direct tests</b> 	These will take between 10 and 60 minutes to complete. In these tests, you might be asked to remember several words and be asked to repeat them in 5 minutes. You might also be asked to watch the assessor and copy their movements.
<b>Self-completion questionnaire</b> 	You can complete this in your own time.
<b>Informant questionnaire</b> 	This is completed with you or with family or friends close to you.
<b>Remote cognitive assessment</b> 	This method is for over-the-phone assessment. It can be similar to rapid or extended direct testing. It involves a lot of memory testing, as well as several general questions.

### Recommendation based on clinical experience

The assessment should not only rely on mental ability tests. Family members should be asked about your health and wellbeing.



## How is dementia identified and diagnosed? continued

### Will I need to see a specialist?

#### Recommendation based on clinical experience

After your initial assessment, you may be referred to a specialist for further tests.

Not everyone will need to see a specialist, particularly if the tests and assessments show that dementia is a likely diagnosis.

If you do see a specialist, they 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 professionals to find out what type of dementia you have and can help rule out other brain conditions. Finding the type of dementia can help healthcare professionals understand how your condition will progress and what treatments may help.

Scanning options will vary in different health board areas but could include the scans listed in the table below.

Scanning options	
Scan	How it can help
<b>Computerised tomography (CT)</b>	Involves combining a series of X-rays taken from different angles to produce images of your brain. This shows changes in brain structure that can give more information about the type of dementia.

## How is dementia identified and diagnosed? continued

Scanning options	
Scan	How it can help
<b>Positron emission tomography (PET)</b>	Detects an injected substance that has a low level of radioactivity. PET scans can be used to assess brain activity or to detect specific abnormal proteins. These scans can give information that might support a diagnosis of which disease is causing your dementia.
<b>Magnetic resonance imaging (MRI)</b>	Uses a strong magnet and radio waves to produce detailed images of your brain. MRI scans are used to see if there are changes in brain structures, which can help diagnose some types of dementia.
<b>Single-photon emission computerised tomography (SPECT)</b>	Involves injecting a slightly radioactive substance attached to a dye. SPECT imaging can be used to study the flow of blood throughout the brain. This allows doctors to get information about specific types of dementia and decide on the right course of treatment.

## How is dementia identified and diagnosed? continued

In a small number of people, healthcare professionals will take samples of spinal fluid, using a lumbar puncture, to help make a diagnosis of Alzheimer's disease.

### Recommendation based on clinical experience

A lumbar puncture may be used to take a sample of the fluid around your spinal cord and brain. Levels of certain proteins in this fluid can indicate if your brain is affected by Alzheimer's disease.

## How can technology be used during and after assessments for support and monitoring?

After you have had a diagnosis of dementia, it is important for health and social care providers to be able to monitor and support you. As well as in-person visits, some monitoring might be done using remote technology, for example video calls.

### Recommendation based on the research evidence

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

As a person living with dementia, you might prefer to have face-to-face contact with healthcare professionals, instead of by video call or telephone.

Face-to-face contact with healthcare professionals may help them notice and discuss physical changes in you.

## How is dementia identified and diagnosed? continued



### Recommendation based on the research evidence

It may be more difficult to choose remote technology as your main tool for monitoring support if you don't feel you or your carer have sufficient skills or training to use it.

Technology such as smart phones or computers for making video calls can also be costly. You will not be required to own these technologies. Face-to-face monitoring and support will be available to you if you prefer.

Remote technology often provides quicker access to support. More regular monitoring using technology might allow you or your carer to feel reassured and connected to healthcare professionals.

If you feel that your needs are not being met while using remote technology, you or your carer should discuss this with healthcare professionals. It is important to let them know that you would prefer a different form of contact.

## Who will be involved in a dementia diagnosis?



### Recommendation based on the research evidence

Every person's diagnosis is different, which means the people who are involved in your diagnosis will depend on your individual circumstances. For example, you may receive your diagnosis through your GP, specialist experts in dementia in a hospital or from a care team made up of people with different specialisms.

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

Your carer should be able to attend and be included in any discussions. Healthcare professionals should acknowledge the importance of their role and expertise.

## How is dementia identified and diagnosed? continued

### When will a diagnosis of dementia be discussed?

Each person who receives a dementia diagnosis will process the information differently. It may take time for you and your carer to fully understand the impact of a diagnosis.



#### Recommendation based on the research evidence

It can be helpful for healthcare professionals to discuss your diagnosis early on, so that you can access support and services. The discussion will be tailored to you. If you or your carer need more time to process the diagnosis, healthcare professionals should be understanding about this.



#### Recommendation based on clinical experience

For some people, a dementia diagnosis can be a relief or explain a change in behaviour. You might not feel that way, and that's okay. Other people may have been admitted into hospital for a different medical issue and been given a diagnosis unexpectedly. How you react to your diagnosis is completely individual; there is no right or wrong response. Healthcare professionals should work with what is best for you, as an individual.



At diagnosis I thought my life was over, I had no future. Now my life is certainly different, but not over – I have a future.

(Person with dementia)

## How is dementia identified and diagnosed? continued

### How will a diagnosis be discussed?



#### Recommendation based on the research evidence

Where possible, support should be available to you and your carer before a diagnosis is given. It can help you to process the information more clearly, and ask any questions you or your carer might have about dementia. You should have access to information before, during and after your diagnosis.

The healthcare professional should tell you and your carer about your diagnosis in a clear, sensitive and empathetic way. They should understand any communication needs you have and make sure you feel you can ask questions.

Your diagnosis may feel overwhelming, but healthcare professionals will discuss with you that a positive and hopeful quality of life is still possible. Your healthcare professionals will be able to offer advice and information about wellbeing, and how to maintain your sense of self after diagnosis.



#### Information

It's important to remember that:

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

## How is dementia identified and diagnosed? continued



### Information

Healthcare professionals should discuss the following with you:

- If known, the type of dementia you have, the symptoms and how your condition may progress.
- Tackling stigma and how it can negatively affect your life.
- Where you can get more information about dementia and the support available, including peer support. This includes information about support for mental health (see page 32).
- Where you can get free educational courses to learn more about dementia.
- Where you can get information about benefits and carers' rights.
- Where you can get help if you need support with day-to-day tasks (social care).
- Where you can get information about power of attorney and advocacy.
- The importance of completing the [Herbert Protocol form](#), which will contain information to help the police if you go missing.

# What support can I expect after diagnosis?

It is important to be aware that each health board is responsible for meeting the needs of its own area. This may mean that what's available to you in one area may differ from what's available to someone living in a different health board area. **Recommendations may depend on what's available in each health board.**

A diagnosis of dementia can be difficult for you and those around you. However, support is available for you after a diagnosis. The Scottish Government has guaranteed at least one year of post-diagnostic support for everyone diagnosed with dementia.



## Recommendation based on the research evidence

Post-diagnostic support should:

- be flexible, sensitive and tailored to your individual needs
- meet the needs of both you and your carers
- be welcoming and accessible for you and your carers
- provide support that is culturally appropriate
- address the potential barriers caused by stigma about dementia
- be linked up between different services
- signpost you and your carers to services provided by charities (see page 32)
- provide information in an accessible way, which is repeated over time
- take into account all your health needs, not just those related to your dementia
- consider your carers' need for social, emotional and educational support.



## What support can I expect after diagnosis? continued



### Information

The key to living well with dementia is staying healthy, both physically and mentally. A good diet, exercise and brain stimulation are crucial in maintaining good health and wellbeing. You can find out more information from [Brain Health Scotland](#).



I may have dementia but I'm still the same me. (Person with dementia)

### It's OK to Ask

When you go to your healthcare appointment(s), we encourage you to ask four key questions that will help you and your healthcare professionals make decisions together. This will make sure the care is right for you.

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

Learn more about [“It's OK to ask”](#)

Learn more about [realistic medicine](#)

## What support can I expect after diagnosis? continued



### Recommendation based on the research evidence

You can expect care that supports both you and your unpaid carer:

- to help you continue living at home
- to plan your care
- to understand dementia
- with advice on self-care
- with emotional needs
- with clear information about how to access support if things change
- to help you stay safe, including driving and in the kitchen
- with communication
- living with memory loss
- through access to health professionals
- to think about and plan for the future.



I have recently completed my year of post diagnostic support. I have found this very useful. My support worker has helped me get an alarm system and Keysafe installed in my flat, and has helped me consider how best to approach discussions about future care with my family. She was friendly helpful and considerate in assisting me in coming to terms with my brain disease. (Person with dementia)

## What support can I expect after diagnosis? continued



### Information

The following information should be discussed with you and your carer:

- Managing your symptoms.
- The importance of you and your carer taking part in anticipatory care planning discussions, including do-not-resuscitate discussions.
- The importance of making plans for your financial and personal welfare, including the need for power of attorney and guardianship.
- The importance of a Carer Support Plan (which should include phone numbers of people to contact to help manage a crisis).
- The availability of the four options for [self-directed support](#) and how this can be accessed.
- Access to respite care and rehabilitation.
- Support when moving from one care setting to another, including hospital and care home.
- How to access independent advocacy (see page 33).
- Where you can find information on your human rights, including access to free personal care.
- Where to receive financial support.
- Employment issues.

## What support can I expect after diagnosis? continued

### Recommendation based on clinical experience

People with more advanced dementia may struggle to take part in discussions to plan their care needs. Future wishes should be discussed with you and your carers at an earlier point in your dementia journey. Your wishes should be recorded in an 'anticipatory care plan'.

### What is an anticipatory care plan and how do I create one?

Anticipatory care plans are records of the wishes about future care made by people with dementia and their carers. Healthcare professionals should initiate and support discussions about anticipatory care planning. Having an anticipatory care plan is important because dementia is progressive and can cause death. It may become harder to make decisions or communicate your wishes as your condition progresses.

### Recommendation based on the research evidence

Healthcare professionals involved in your anticipatory care planning should be:

- aware of the importance of anticipatory care planning
- equipped with specialist knowledge of dementia and dementia care
- suitably trained in discussions on assessing people with dementia health needs
- aware of education and toolkits available to support anticipatory care planning.

## What support can I expect after diagnosis? continued



### Recommendation based on the research evidence

Discussions about anticipatory care planning should:

- take place as early as possible
- take place at appropriate times in your dementia journey. This could be when you are diagnosed or if you change where you are living
- include information about what anticipatory care planning is, why it's important and what the benefits can be
- ensure you understand that anticipatory care planning can help others make sure your wishes are carried out and support you to have a 'good death'
- be tailored to your needs
- consider the needs of your carers and other family
- take place over a series of conversations
- update your plan over time in response to your changing needs
- happen at your home or another place that is quiet, free from distractions and ensures confidentiality.

# How might I feel after a dementia diagnosis?

**Getting a dementia diagnosis can be difficult to cope with and accept, for both you and those close to you.**

It is common to feel nothing or numbness at first. It is also common to feel relief if you have been concerned for some time and just want a diagnosis to confirm what is wrong with you. Feelings of loss and grief are common.

## **What is meant by grief?**

Grief is a universal experience that affects us all at some point in our lives. It is most commonly associated with our feeling of loss following the death of a loved one.

If you are living with dementia, you may experience different types of grieving at different stages of your journey. Your carer may also have feelings of loss and grief.

There are types of grieving that you and your carer may find yourselves experiencing. These are:

- anticipatory grief (see page 21)
- bereavement (see page 23).

More information for carers about complicated grief can be found on page 30.

## How might I feel after a dementia diagnosis? continued

### How do I know if the feelings I am having are anticipatory grief?

Anticipatory grief happens before death, while a person is still living.

#### Information based on the research evidence

You may not think you are grieving after diagnosis and instead:

- think you are just angry and sad at the same time. If you have had to give up work, you may be grieving for the loss of status and purpose in life
- feel your future has been taken away against your wishes and there is nothing you can do. You may be grieving for the plans you may have made for your future, which you may not see fulfilled
- you may be scared of leaving your partner alone or not seeing your children/grandchildren or being present at family occasions like birthdays and weddings
- you may be worrying about how your dementia may progress and who will care for you.



The first time my husband asked who I was and why I was in his house it was at 3am. I was shocked, upset, confused and scared all at the same time. I tried to reassure him, but I didn't know what to do or say, and I just wanted to cry.  
(Carer of person with dementia)

## How might I feel after a dementia diagnosis? continued

Your carer may also be feeling anticipatory grief because they are:

- feeling scared about the future on their own
- thinking about plans for retirement that may now not happen
- sad that you may never see your children's life events or grandchildren
- constantly thinking about what may or may not lie ahead, and whether they will be able to cope
- feeling guilty because they don't want to be a carer.



Loss of communication was the worst thing. You're living together, but you're totally alone. (Carer of person with dementia)

### Information based on the research evidence



These feelings and emotions are all normal but can be overwhelming and may arise at any point from receiving a diagnosis of dementia until a person's final weeks of life. Anticipatory grief may be heightened during important life events such as birthdays, weddings and funerals. It can also happen when there is a significant move to a care environment for the person living with dementia, like a hospital admission or move to long-term care. Your carer may also experience anticipatory grief at this time, as they contemplate a future without you at home with them.



## How might I feel after a dementia diagnosis? continued

‘ I tried so hard to make the most of each day, but I couldn’t stop worrying about the future, and it just seemed to take over my thoughts all the time. (Carer of person with dementia)

### What is it like to experience grief when you have dementia?

Experiencing a bereavement such as the loss of a family member or friend when you have dementia may be hard to process.

#### Information based on the research evidence

Because you may not be able to remember information, you may repeatedly re-experience grief, confusion and distress.

You may need support from healthcare professionals if you have a bereavement to help you process the loss and to manage any distress, agitation and confusion that comes with it.

Having to repeat information may be difficult and stressful for your carers, but seeing you in distress can also be difficult to cope with. It is often difficult for carers to know how best to tell you about a bereavement. They will want to cause you as little distress as possible.

#### Recommendation based on clinical experience

Support for people with dementia who face grief should be given by professionals with appropriate training ([as defined by the Promoting Excellence Framework in Dementia](#)).

# What support is available to manage distress?

It is important to be aware that each health board is responsible for meeting the needs of its own area. This may mean that what's available to you in one area may differ from what's available to someone living in a different health board area. **Recommendations may depend on what's available in each health board.**

Sometimes dementia can cause you to become distressed. Behaviour that may come with feeling distress may include:

- aggression (eg hitting, pushing or swearing)
- agitation (eg restlessness, pacing up and down or fidgeting)
- sleep problems (eg being awake during the night and/or oversleeping during the day).

## Information

Distress is an unpleasant feeling that upsets your wellbeing. When you are distressed you can feel overwhelmed and unable to carry on in your usual way. It is normal for people to experience distress from time to time. Distress can have various causes, for example a recent argument, thinking about something upsetting, feeling unwell or in pain. How each person experiences and manages distress is unique and individual to them.

## Why might you experience distress?

There are a basic human needs that every person shares. These include:

- feeling safe to experience love and belonging
- taking part in enjoyable/meaningful activities
- feeling comfortable and free from pain.

## What support is available to manage distress? continued

When these needs are not met, this can cause distress. When you have dementia, you may find it difficult to recognise or express these needs and this can add to your distress.

### What should happen if I am distressed?

You and your carer should be offered a detailed assessment. This assessment will gather information about you, including your:

- physical and mental health
- life story
- social circumstances
- day-to-day abilities
- spiritual/religious beliefs (if you have them).



#### Recommendation based on the research evidence

This assessment should try to identify what is causing your distress. This may be done by identifying possible unmet needs you may have.

Interventions to help reduce your distress should be individually tailored for you.

Interventions may include activities that take into account your interests, preferences and past experiences.

This type of assessment should be carried out in care homes as well as in other settings. Within care homes, staff should receive suitable training and ongoing support to help them to understand the distress shown by people with dementia.

## What support is available to manage distress? continued

### How should sleep problems be treated?



#### Recommendation based on the research evidence

To try to improve your sleep, it's a good idea to combine different things, such as:

- giving you and your carer(s) information about healthy habits and changes to your surroundings that may improve your sleep
- increasing the amount of time you have outside in daylight
- physical exercise and individualised social activities.

### What support should be offered to my carers when I am experiencing distress?



#### Recommendation based on the research evidence

Your carers may be offered education and training to help them understand and manage your distress.

This education and training should be individualised to their situation.

It may include:

- problem-solving strategies
- stress management and coping strategies
- communication skills
- learning about possible underlying causes of distress and how to identify them
- talking about their own thoughts and responses
- crisis management.

## What support is available to manage distress? continued

### Using the Mental Health Act to support care

#### Information

Sometimes healthcare professionals might want proof that you are capable of making decisions otherwise they might have to take them for you under the Mental Health Act. They will also discuss loss of capacity with you and your carer and whether it's time to activate a power of attorney.

In some cases, people can become severely distressed and may become a risk to their own safety or that of their carers. If this happens, you may need to be sectioned under the Mental Health (Care and Treatment) (Scotland) Act 2003. This Act covers situations when someone can be taken to a psychiatric hospital against their will. If this happens, and there is no alternative, your healthcare professional should discuss this with you and your carer beforehand.

‘ Admitting my husband to hospital when I reached a crisis point and having him sectioned for 6 months was devastating for me. I still can't forgive myself that he felt imprisoned for doing nothing wrong, and I felt helpless to change it.  
(Carer of person with dementia)

# What do I need to know about dementia, end-of-life care and dying?

**It is important to understand that dementia is a progressive condition.**

This means it will continue to get worse over time, although the way it progresses is different for everyone. It is important that you, your carers and family understand that palliative care is not end-of-life care, but goes on from diagnosis to the end of your life. Palliative care focuses on making your quality of life as good as possible by relieving discomfort or distress. Dementia can cause death and many people with dementia will need end-of-life care. Having an anticipatory care plan can help you have 'a good death' with your wishes taken into account. It also helps your carer and family feel they have made sure your wishes have been carried out, which can help reduce guilt and prolonged grief.

**What do healthcare professionals need to know so they can support me?**



## Recommendation based on the research evidence

Your healthcare professionals should:

- be aware that the way 'end of life' is usually defined may not apply to people with dementia and make sure they don't misunderstand your needs as a result
- focus on your individual needs and not define end of life by stages of dementia (for example, early, mid and late )
- make sure you, your family and carers get information so you understand that dementia is progressive, that it can cause death and that end-of-life care may be needed at any time
- be aware that palliative care continues from diagnosis to end of life.

## What do I need to know about dementia, end-of-life care and dying? continued

### Information

You, your family and carers should be given information about the progressive course of dementia. Dementia can be a cause of death and a palliative approach to care is appropriate at all stages.

## What support can I expect when moving from one place to another, such as transferring from home to hospital, respite care, rehabilitation, care home or other setting?

### Recommendation based on the research evidence

Before and during a transition, healthcare professionals should provide care and support that is tailored to your specific needs. This care should focus on quality of life and consider all your physical, emotional and spiritual needs. Healthcare professionals should work with you and your carer to develop a plan to address unmet needs identified before any move between care settings.

### Information

If a move to long-term care can be anticipated in advance, healthcare professionals should have early discussions with you and your carers. At these discussions, you can plan for expected needs and wishes.

# Information for carers about grief

How will I know if I am experiencing complicated grief?

## Information

Bereavement grief when the person with dementia dies is normal. It is the same grief experienced by anyone losing a loved one.

## Recommendation based on the research evidence

Other feelings may include sadness, anger, guilt and numbness. If these feelings don't lessen with time and if your feelings of grief are affecting your ability to resume your own life and move forward, this is known as complicated or prolonged grief.

“ People keep telling me he's in a better place and at peace now, but I'm not. When will I stop feeling guilty and be able to get on with my life again?

(Carer of person with dementia)



## Information for carers about grief continued



### Information

The feelings below are very common and completely normal.

- You may feel guilty about your caring journey and ask yourself if you could have done more for your loved one.
- You may repeatedly question yourself about decisions you made and how and why you made them.
- You may feel you didn't do enough and "can't move on with your life".

## What can help manage feelings of grief?



### Recommendation based on clinical experience

Healthcare professionals should be aware that carers of people with dementia may experience complicated grief, and should consider offering you referral for psychological therapy, as appropriate.

# Where can I find out more information?

The organisations we have listed below may be able to answer any questions you have and offer support.

SIGN accepts no responsibility for the information they give.

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## National organisations



### The Alliance

[www.alliance-scotland.org.uk](http://www.alliance-scotland.org.uk)

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations.

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### Care Information Scotland

[www.careinfoscotland.scot](http://www.careinfoscotland.scot)

Tel: 0800 011 3200

Care Information Scotland provides information about care services, including options for self-directed support. It offers information on support for carers, including how to access respite care.

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### Citizens Advice Scotland

[www.cas.org.uk](http://www.cas.org.uk)

Tel: 0800 028 1456

The Citizens Advice Bureau can give free, confidential, impartial and independent advice and information on a wide range of subjects, including benefits, debt and money advice, consumer issues, work-related problems and housing.

## Where can I find out more information? continued

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### National organisations continued

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#### Department for Work and Pensions (DWP)

[www.gov.uk](http://www.gov.uk)

The DWP provides information about benefits and claim forms.

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#### NHS 24

[www.nhs24.scot](http://www.nhs24.scot)

Freephone 111

NHS 24 is an online and out-of-hours phone service providing access to health advice and information 24 hours a day, 365 days a year.

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#### NHS Inform

[www.nhsinform.scot](http://www.nhsinform.scot)

Tel: 0800 22 44 88

Scotland's national health information service provides people with information on medical conditions, self-help advice and a directory of local support groups.

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#### Scottish Independent Advocacy Alliance

[www.siaa.org.uk](http://www.siaa.org.uk)

Promotes, supports and advocates the principles and practice of independent advocacy. Offers details of where to access independent advocacy in each area of Scotland.

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#### Self Directed Support Scotland

[www.sdsscotland.org.uk](http://www.sdsscotland.org.uk)

Self Directed Support Scotland provides information, advice and support to access care.

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## Where can I find out more information? continued

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### National organisations continued

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#### Social Security Scotland

[www.socialsecurity.gov.scot](http://www.socialsecurity.gov.scot)

Social Security Scotland provides information on benefits and how to access them.

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### Resources for people with dementia and their carers

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#### About Dementia

This is an Age Scotland forum working with people living with dementia and unpaid carers to bring about changes to policy and practice in Scotland.

<https://www.ageuk.org.uk/scotland/what-we-do/dementia/about-dementia/>

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#### Age Scotland

Information and advice for people with dementia and their carers.

[www.ageuk.org.uk/scotland/information-advice/dementia/](http://www.ageuk.org.uk/scotland/information-advice/dementia/)

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#### Alzheimer Scotland

Alzheimer Scotland has a dedicated helpline.

Helpline number: 0808 9808 3000

Resources for people living with dementia

[www.alzscot.org/living-with-dementia](http://www.alzscot.org/living-with-dementia)

[www.alzscot.org/ahpresources](http://www.alzscot.org/ahpresources)

Webinars

[www.alzscot.org/ahpinnovation](http://www.alzscot.org/ahpinnovation)

## Where can I find out more information? continued

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### Resources for people with dementia and their carers continued

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#### Alzheimer Scotland

Charter of rights for people with dementia and their carers in Scotland.

[www.alzscot.org/sites/default/files/images/0000/2678/Charter\\_of\\_Rights.pdf](http://www.alzscot.org/sites/default/files/images/0000/2678/Charter_of_Rights.pdf)

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#### Alzheimer's Society

Information and support for people affected by dementia.

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

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#### British Deaf Association

Dementia-specific resources for people who are deaf and living with dementia.

<https://bda.org.uk/dementia>

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#### Connecting people, connecting support

Resources and activities online for people with dementia, their family members and supporters.

<https://dementiatogether.online>

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#### Chartered Institute of Housing

Scottish housing and dementia framework to help organisations support people to live well with dementia.

[www.cih.org/policy/scottish-housing-and-dementia-framework](http://www.cih.org/policy/scottish-housing-and-dementia-framework)

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#### Dementia UK

Resources for people with dementia and their carers.

[www.dementiauk.org/get-support](http://www.dementiauk.org/get-support)

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## Where can I find out more information? continued

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### Resources for people with dementia and their carers continued

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#### Dementia Carers Count

Offers a range of free services that give family carers the opportunity to understand more about dementia and to connect with others in a similar situation. They offer practical advice on the reality and challenges of being a carer.

[www.dementiacarerscount.org.uk](http://www.dementiacarerscount.org.uk)

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#### NHS Inform

Dementia: information and support resources.

[www.nhsinform.scot/illnesses-and-conditions/brain-nerve-and-spinal-cord/dementia](http://www.nhsinform.scot/illnesses-and-conditions/brain-nerve-and-spinal-cord/dementia)

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#### NHS Inform

Anticipatory care planning information.

[www.nhsinform.scot/care-support-and-rights/decisions-about-care/](http://www.nhsinform.scot/care-support-and-rights/decisions-about-care/)

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#### NHS Near me

Near Me is a video consulting service that enables people to attend appointments from home or wherever is convenient.

[www.nearme.scot](http://www.nearme.scot)

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#### Sight Scotland

Guidance about sight loss and dementia.

<https://sightscotland.org.uk/articles/information-and-advice/dementia-and-sight-loss-guide>

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## Where can I find out more information? continued

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### Resources for people with dementia and their carers continued

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#### The Scottish Dementia Working Group (SDWG)

A national, member-led campaigning and awareness-raising group for people living with dementia in Scotland.

[www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group/contact-sdwg](http://www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group/contact-sdwg)

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#### Young Dementia UK

Information and support for younger people with dementia and their families.

[www.youngdementiaukhomes.org](http://www.youngdementiaukhomes.org)

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#### Alzheimer's Society

School teaching resources to make it easy to teach and learn about dementia.

[School teaching resources | Alzheimer's Society \(alzheimers.org.uk\)](http://www.alzheimers.org.uk/school-teaching-resources)

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### Resources for carers

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#### Age Scotland

Dementia carers' rights training.

[www.ageuk.org.uk/scotland/what-we-do/dementia/age-scotlands-dementia-training-project/training-for-unpaid-carers-of-people-with-dementia](http://www.ageuk.org.uk/scotland/what-we-do/dementia/age-scotlands-dementia-training-project/training-for-unpaid-carers-of-people-with-dementia)

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#### Alzheimer Scotland

Resources for carers.

[www.alzscot.org/living-with-dementia/caring-for-someone-with-dementia/resources-for-carers](http://www.alzscot.org/living-with-dementia/caring-for-someone-with-dementia/resources-for-carers)

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## Where can I find out more information? continued

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### Resources for carers continued

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#### Carers Trust

Works to transform the lives of unpaid carers through collaboration, influence, evidence and innovation.

<https://carers.org/help-and-info/introduction>

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#### National Dementia Carers Action Network (NDCAN)

A national, member-led campaigning and awareness-raising group for current and former carers of people with dementia in Scotland.

[www.alzscot.org/our-work/campaigning-for-change/have-your-say/national-dementia-carers-action-network](http://www.alzscot.org/our-work/campaigning-for-change/have-your-say/national-dementia-carers-action-network)

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#### NHS Education for Scotland

Caring for a Person Living with FTD: a supportive series of resources for carers.

<https://www.nes.scot.nhs.uk/nes-current/caring-for-a-person-living-with-ftd-a-supportive-series-of-resources-for-carers>

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#### Tide

Tide is a body that works to connect, enable and mobilise carers and former carers of people with dementia to use their experience to influence change.

<https://www.tide.uk.net/resources/>

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#### Tide

Advice on living with grief and bereavement.

[www.tide.uk.net/what-we-do/living-grief-and-bereavement/](http://www.tide.uk.net/what-we-do/living-grief-and-bereavement/)

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## Where can I find out more information? continued

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### Resources for carers continued

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#### Tide

Moving Forward Toolkit

A guide for families and relatives involved in or supporting someone to move into a care home.

[www.tide.uk.net/projects/moving-forward](http://www.tide.uk.net/projects/moving-forward)

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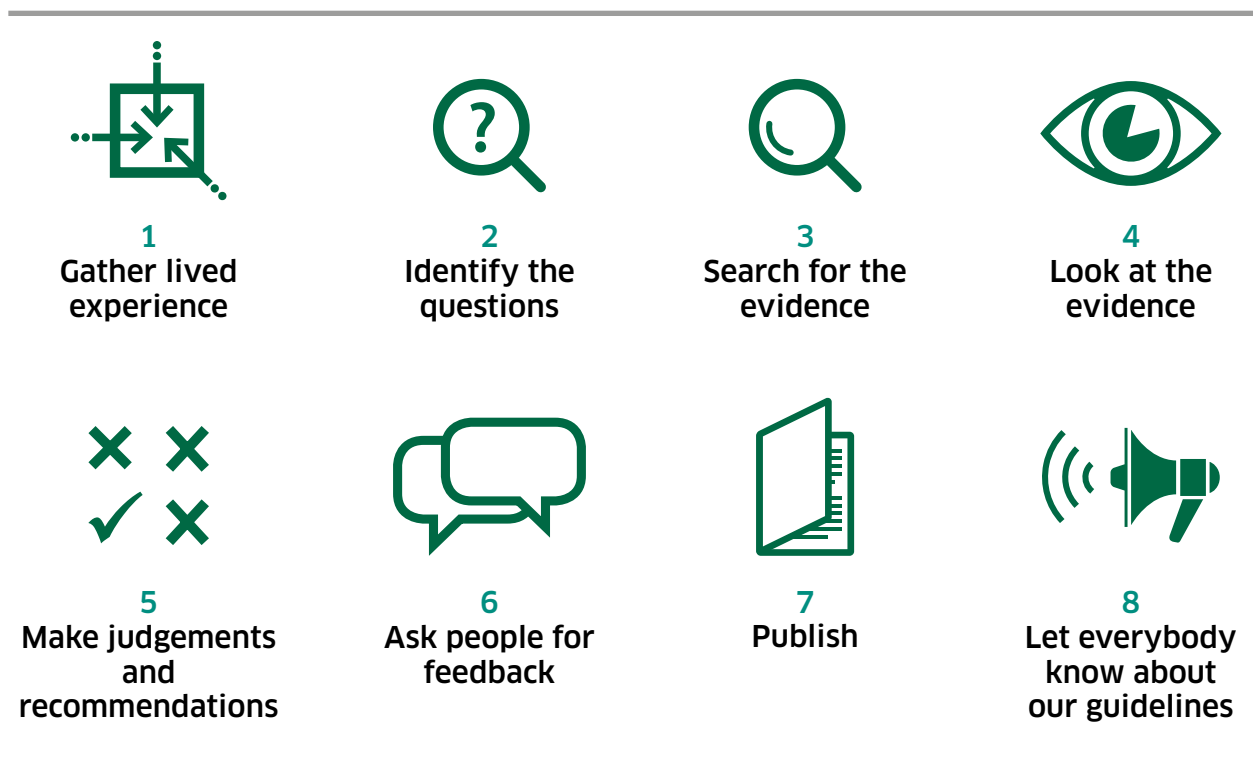
#### Scottish Dementia Research Consortium

A membership organisation including researchers, healthcare professionals, people living with dementia and anyone else with an interest in research.

<https://www.sdrc.scot>

# How are SIGN guidelines produced?

Our guidelines are based on the most up-to-date scientific evidence. We read research papers to find evidence for the best way to diagnose, treat and care for patients. If we cannot find this out from the research evidence, we ask healthcare professionals to use their clinical experience and judgment to suggest treatments.



You can read more about us by visiting [www.sign.ac.uk](http://www.sign.ac.uk) or you can phone 0131 623 4720 and ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.

The Scottish Intercollegiate Guidelines Network (SIGN) writes guidelines which give advice for healthcare professionals, patients and carers about the best treatments that are available. We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

We are happy to consider requests for other languages or formats. Please phone 0131 623 4720 or email [sign@sign.ac.uk](mailto:sign@sign.ac.uk)

## Cover images

It's important to note that these images are posed by models and may not accurately reflect the experiences of those living with the condition. It's also important to note that these models do not have dementia themselves.





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