



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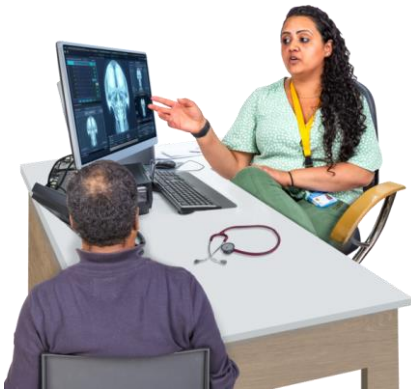
Assessment, diagnosis, care and support for people with dementia and their carers

Part 2 of 2

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



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
- relief if you have been worried and want to know what is wrong with you
- loss
- grief

What is grief?



Grief is the feeling of loss after the death of a loved one.

If you are living with dementia you may experience different types of grieving at different times.

Your carer may also have feelings of loss and grief.

There are 3 types of grieving:

- anticipatory (see page 3)
- bereavement (see page 5)
- information for carers about complicated grief can be found on page 11



How do I know if I am feeling anticipatory grief ?



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

You may not think you are grieving after your 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 plans have been taken away and there is nothing you can do



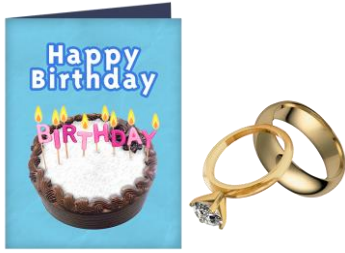
- feel scared of leaving your partner alone



- feel sad you may not see your children or grandchildren or be at family occasions like graduations and weddings



- feel worried about how your dementia may progress and who will care for you



Anticipatory grief may feel stronger:

- during important life events like birthdays, weddings, and funerals
- when the person with dementia moves to a different care environment like hospital or long term care

Your carer can also feel anticipatory grief at this time as they think about a future without you at home with them.

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



Experiencing a bereavement like the loss of a family member or friend may be difficult to deal with.

Because you may not be able to remember the information, you may keep experiencing the grief, confusion and distress.



You may need support from healthcare staff after bereavement.



It is often difficult for carers to know how best to approach telling you about a bereavement.

They will want to support you and cause you as little distress as possible.



Support for people with dementia experiencing grief should be delivered by staff with the right training as detailed online in the [Promoting Excellence Framework in Dementia](#).

What support is available to manage distress?



Distress is an unpleasant feeling that can make you feel:

- upset
- overwhelmed
- unable to do everyday things

It can be caused by things like:

- a recent argument
- thinking about something upsetting
- feeling unwell or in pain



Distress can make people:



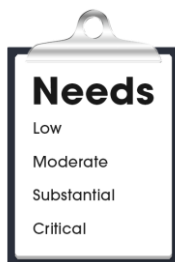
- feel angry– this can make them hit, push or swear
- feel restless, pace up and down, or fidget
- have sleep problems like being awake in the night or sleeping a lot in the day



It is normal to experience distress from time to time.

Everyone copes with distress in their own way.

What should happen if I am distressed?



You and your carer should be offered an assessment to get information about your:

- physical and mental health
- **life story** - the story of your life from birth to the present
- **social circumstances** – things that have shaped your life, like where you lived, your education and healthcare
- day to day abilities
- spiritual or religious beliefs if you have them



This assessment should try to find out why you are distressed and if there is anything you need.

Ways to help you may include activities that you like or have enjoyed in the past.



This type of assessment can be done in any care setting.

Care home staff should get training and support to help them understand distress shown by people with dementia.

How should sleep problems be treated?



- healthcare staff should give you and your carers information about what may improve your sleep



- get more time outside in daylight
- try to get more physical exercise and do social activities that you enjoy

What support should be offered to my carers when I feel distressed?



Your carers may be offered education and training to help them to understand and cope with distress including:

- ways to solve problems and cope with stress
- communication skills
- ways to find out what is causing the distress
- how to cope with distress and when things are very difficult or dangerous



Using the Mental Health Act to support care



If you cannot make decisions for yourself this is called a **loss of capacity**.

Healthcare staff might have to make the decision for you using a law called the Mental Health Act.



They will talk with you and your carer about:

- loss of capacity – not being able to make decisions for yourself
- the need to use your Power of Attorney



Some people can become very distressed and may become a risk to themselves or their carers.

If this happens a person may need to be sectioned under the Mental Health (Care and Treatment) (Scotland) Act 2003.



This law means someone can be taken to a psychiatric hospital against their will.

If this happens, and there is nothing else that could be done, your healthcare staff should discuss this with you and your carer before admission.

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



Dementia will 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 the same as end of life care.

Palliative care happens from diagnosis to end of life.



Palliative care works to make your quality of life as good as possible by making your discomfort or distress better.

Many people with dementia will need end of life care.



Having a future care plan can help you to have 'a good death' with your wishes listened to.

It also helps your carers and family feel they have made sure your wishes have been carried out.

What should healthcare staff do to support me?

Your healthcare staff should:

- focus on what you need
- know that palliative care happens from diagnosis to end of life
- give you, your family and carers information about how dementia gets worse and that end of life care may be needed at any time



What support can I expect when moving from one care setting to another, like from home to hospital?



Healthcare staff should:

- provide care and support that is right for you, before and when you move

This care should look at your quality of life and what you need including physical, emotional and spiritual needs.



- work with you and your carer to make a plan to deal with any of your needs that are not being met, before any move to a new care setting
- have early discussions with you and your carers before you move to long term care so you can plan for what you need and want.

Information for carers about grief

How will I know if I am experiencing complicated grief?

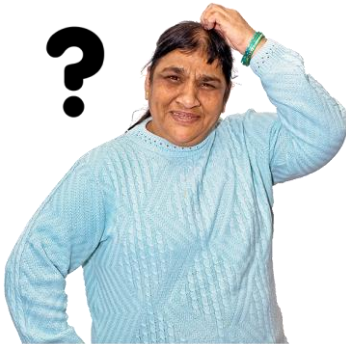


Bereavement grief when the person with dementia dies is normal, and is the same grief experienced by anyone losing a loved one.



You may feel:

- sad, angry, guilty or not feel anything
- guilty about your caring journey and asking yourself if you could have done more for your loved one
- questioning yourself about decisions you made and why you made them
- you did not do enough and cannot move on with your life



These feelings are completely normal.



Complicated or prolonged grief is when these feelings:

- do not get easier with time
- are stopping you from getting on with your life

What can help manage feelings of grief?



You may find talking about your feelings of grief with other family members, friends or support groups helpful.



If this does not help, you should talk to your GP or other healthcare staff.



Healthcare staff should refer you for psychological therapy if you are experiencing complicated grief.

Where can I find out more?



The organisations we have listed on pages 14 to 20 may be able to answer any questions you have and offer support.

SIGN accepts no responsibility for the information they give.

National organisations

The Alliance (the Health and Social Care Alliance Scotland)

Brings together a range of health and social care organisations

www.alliance-scotland.org.uk/



Care Information Scotland

Tel: 0800 011 3200

www.careinfoscotland.scot

Information about care services, self-directed support, support for carers, including how to get respite care.

Citizens Advice Scotland

Tel: 0800 028 1456

www.cas.org.uk

Free advice and information on subjects including benefits, debt and money advice, work-related problems and housing.



Department for Work and Pensions (DWP)

<https://www.gov.uk/government/organisations/department-for-work-pensions>

The DWP provides information about benefits and claims forms.

NHS 24

Freephone 111

www.nhs24.scot

NHS 24 gives health advice and information 24 hours a day, 365 days a year.



NHS Inform

Tel: 0800 22 44 88

www.nhsinform.scot

Gives information on medical conditions, self-help advice and a directory of local support groups.

Scottish Independent Advocacy Alliance

www.siaa.org.uk

Gives details of how to get advocacy in each area of Scotland



Self Directed Support Scotland

www.sdsscotland.org.uk

Gives information, advice and support to access care

Social Security Scotland

www.socialsecurity.gov.scot

Information on benefits and how to access them.

Resources for people with dementia and their carers

About Dementia

Age Scotland forum working with people living with dementia and unpaid carers to change policy and practice in Scotland.

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



Age Scotland

Information and advice for people with dementia and their carers

www.ageuk.org.uk/scotland/information-advice/dementia/

Alzheimer Scotland

Helpline: 0808 9808 3000

Resources:

www.alzscot.org/living-with-dementia

www.alzscot.org/ahpresources

Webinars

www.alzscot.org/ahpinnovation

[Charter of rights](#) for people with dementia and their carers in Scotland



Alzheimer's Society

Information and support for people affected by dementia

www.alzheimers.org.uk/



British Deaf Association

Dementia-specific resources

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

Connecting people, connecting support

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

<https://dementiatogether.online>



Chartered Institute of Housing

Scottish housing and dementia framework

www.cih.org/policy/scottish-housing-and-dementia-framework

Dementia UK

Resources for people with dementia and their carers

www.dementiauk.org/get-support/

Dementia Carers Count

Free services that support family carers to understand more about dementia and to connect with others in a similar situation.

www.dementiacarerscount.org.uk



NHS Inform – www.nhsinform.scot

[Dementia information and support resources](http://www.nhsinform.scot)

Future care planning information

<https://www.nhsinform.scot/care-support-and-rights/decisions-about-care/future-care-planning/>

Instructions on how to use Near me and

www.nearme.scot

Sight Scotland

Dementia and sight loss guide

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



The Scottish Dementia Working Group (SDWG)

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

alzscot.org



Young Dementia Network

Supportive accommodation for people with young onset dementia

www.youngdementiaukhomes.org/

Alzheimer's Society

[School teaching resources](#) to make it easy to teach and learn about dementia.

Resources for carers

Age Scotland

Dementia carers' rights training

Ageuk.org.uk/scotland

Alzheimer Scotland

Resources for carers

Alzscot.org



Carers Trust

Help and information for carers

Carers.org

National Dementia Carers Action Network (NDCAN)

A group for current and former carers of people with dementia in Scotland

Alzscot.org

NHS Education for Scotland

Resources for people caring for a person living with Frontotemporal Dementia

Nes.scot.nhs.uk



Tide (Together In Dementia Everyday)

Resources and information for carers

Tide.uk.net

[Living grief and bereavement](#)

[Moving Forward](#) - A guide for families and relatives involved in or supporting someone to move into a care home



Scottish Dementia Research Consortium

For researchers, healthcare staff and people living with dementia

www.sdrc.scot/



You can read more about SIGN online at:
www.sign.ac.uk

Phone 0131 623 4720 to ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.



If you would like this information in another language or format please:

- phone 0131 623 4720
- or email: sign@sign.ac.uk