

Contents

Introduction	3
What is dementia?	7
Keeping well and connected	10
Home	22
Health	28
Independence	40
Getting around	46
Work	53
Money	61
Support	71
Future plans	78
Appendix 1: Types of dementia	87
Appendix 2: Care and support glossary	94
Appendix 3: Dementia campaigns and research	100

In this resource you will see references to Health and Social Care Partnerships. These partnerships were created in April 2016 and are the organisations formed as part of the integration of services provided by Health Boards and councils in Scotland. They are responsible for the planning, funding and delivery of a range of community health services and social work/social care services.



Introduction

If your GP or specialist has told you that you have dementia, then this is the booklet for you. You may also find this helpful if you are a family member or a friend of a person who has been told they have dementia. There is a DVD included at the back of this publication which you might find helpful to watch before reading this booklet.

Dementia is the general term for a range of brain disorders that can affect all aspects of memory, thinking and behaviour. This booklet is for people with any type of dementia. More information about the different types of dementia can be found in **Appendix 1** on p. 87.

You may be feeling a range of emotions. Shock, disbelief and even relief are all natural responses to a diagnosis of dementia. Getting a definite diagnosis can make it easier to get support and advice. You can start making decisions, find ways to manage some of the symptoms and discover how to live well with a diagnosis.

Since 2013, the Scottish Government has committed to ensuring that those diagnosed with dementia are offered a minimum of one year of post-diagnostic support from a named dementia link worker. Scotland's National Dementia Strategy 2017–20 recognises that many people are diagnosed later in life, and already have significant care needs. The strategy sets out a commitment to work towards offering post-diagnostic support to those people as part of their existing care support but with an emphasis on a more coordinated approach. Those who are diagnosed earlier in the illness and who have little or no need for formal health or social care support will continue to be offered post-diagnostic support from a named dementia link worker. This represents a change in approach but this will be developed throughout the period of this strategy. Ask your doctor or contact Alzheimer Scotland for more information (also see the **Support** section on p. 71).

You will most likely want to know where you go from here, what others in this situation have found helpful and what support is out there.

You might be reading this because you suspect you may have dementia. At this stage, it could be useful to read **Worried about your memory?**, a booklet from NHS Health Scotland that gives practical advice and information for anyone concerned about their memory. www.healthscotland.com/documents/3250.aspx

If you or someone you know has been diagnosed with dementia under the age of 65, NHS Health Scotland and Alzheimer Scotland have produced the booklet and DVD, **Younger people with dementia: living well with your diagnosis**. It is based on the experiences of people with younger-onset dementia and their carers, to provide practical steps about how to live well after a diagnosis. To access this resource, visit:

www.healthscotland.com/documents/30274.aspx

The DVD for this resource is also available at:

www.healthscotland.com/topics/stages/healthy-ageing/dementia/living-well-with-dementia.aspx (BSL version)

You can also ask for a copy of the DVD and either of these booklets from Alzheimer Scotland's 24-hour Freephone Dementia Helpline on **0808 808 3000**.

About this publication

This publication has been written in discussion with people who have a diagnosis of dementia and their families or carers. It includes information that they felt was helpful or would have been helpful to them at and around the time of their diagnosis. The quotes in speech bubbles are all from people who have a diagnosis of dementia or from carers.

This publication tries to answer some of the questions you may have about a diagnosis of dementia. Each section looks at a different area of your life and suggests ways to adapt to any changes you may face.

Web links to helpful information are included within this booklet. If you can't access this information on the web, contact Alzheimer Scotland's Freephone 24-hour Dementia Helpline on **0808 808 3000** and they may be able to provide the information in another format.

Introduction: **at a glance**

- This publication is for people with dementia, particularly those who have been recently or newly diagnosed.
- It includes information that people with dementia and their families found helpful around the time of diagnosis.
- There is an accompanying DVD, *Living well with dementia*, at the back of this publication.
- There is life after a diagnosis of dementia – it just might mean you have to make adjustments.
- You are not alone – there are many people who can, and will, help you according to your individual and cultural needs.

What is dementia?

There are over 100 causes of dementia (most of which are very rare) and it is possible to have more than one type of dementia at the same time. Different types of dementia can have different symptoms but what they all have in common is that your brain cannot work as well as it should. Around 93,000 people in Scotland have dementia, so you are not alone.

Everything we do is controlled by our brain. It analyses and makes sense of what we see and hear. It helps us to do things like think, move, speak and write. It contains all of our memories.

When someone has dementia, it is because some of the brain cells are damaged and dying. This affects how we are able to remember, think and act, and why it is more difficult to manage everyday activities.

Remember, these changes can be gradual. Although it may become difficult to continue with some of your usual activities, you may rediscover other things to enjoy – for example, painting, walking, sorting out your family photographs or listening to music.

Alzheimer's disease is the most common form of dementia overall, but there are rarer types of dementia.

Appendix 1 on p. 87 outlines the most common types of dementia and the possible symptoms and treatment.

People can live for many years with dementia. This will vary from person to person, and will depend on many things, like the type of dementia you have and whether or not you have other health conditions.

Every person with dementia will experience it differently. People who know you may notice your symptoms more than you do yourself.

At the moment there is no cure for dementia but a lot can be done to help cope with the various symptoms and enable you to live well with a diagnosis of dementia.

Is dementia inherited?

This is a complex question. Most forms of dementia are not inherited, although genetics can play a part. If you have a family history of dementia and would like further information you should discuss this with your GP or consultant.

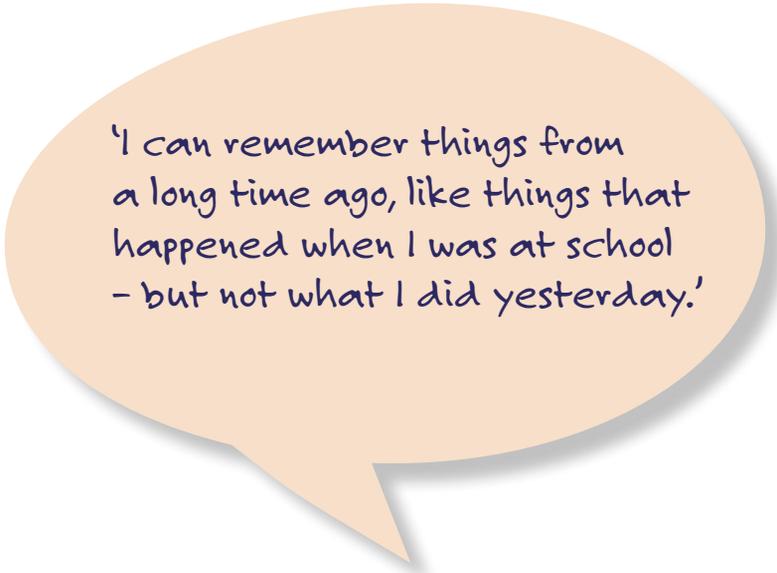


Further information

Alzheimer Scotland information sheet, Genetics and dementia. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

What is dementia? at a glance

- There are various forms of dementia and many symptoms.
- Damage to the brain caused by dementia makes everyday activities more difficult.
- Every person with dementia experiences it differently.



'I can remember things from a long time ago, like things that happened when I was at school - but not what I did yesterday.'

Keeping well and connected

Getting support

You may want to talk to someone about how you feel. Perhaps you can talk to your partner, a close relative, a religious or spiritual leader or someone else with dementia. Or you may choose to talk to a health and social care worker, for example, your dementia link worker, your community psychiatric nurse, doctor, social worker or someone from the local Alzheimer Scotland service.

Try to start talking openly about dementia. Your family, friends, neighbours or colleagues may not know what's important to you and how you can help each other until you talk about it. You can also discuss the possible impact of the most likely symptoms.

Appendix 1 on p. 87 outlines the common effects of different types of dementia.

Some people or communities can find it difficult to speak about a diagnosis of dementia, as it is sometimes viewed with fear or misunderstanding. It is important to share experiences and to raise awareness of dementia and what helps to live well with a diagnosis.

Since 2013, the Scottish Government has committed to ensuring that those diagnosed with dementia are offered a minimum of one year of post-diagnostic support from a named dementia link worker. Scotland's National Dementia Strategy 2017–20 recognises that many people are diagnosed later in life, and already have significant care needs. The strategy sets out a commitment to work towards offering post-diagnostic support to those people as part of their existing care support but with an emphasis on a more coordinated approach. Those who are diagnosed earlier in the illness and who have little or no need for formal health or social care support will continue to be offered post-diagnostic support from a named dementia link worker. This represents a change in approach but this will be developed throughout the period of this strategy.

Understanding dementia

Many people don't understand enough about dementia. They may have ideas about what people with dementia are like, and what they can and can't do. When someone hears you have dementia, they may make assumptions about you.

If you think this is happening, talk to the person and explain how your illness actually affects you – and how they can help you.

And try not to make this kind of assumption about yourself. Just because you have dementia, it doesn't mean you can't keep doing the things you want to do. Ask for help if you need it, and try to make the most of living with dementia.

'I'd always rather know what's likely to happen – that way at least I can make plans.'



Family and friends

Dementia may affect people in your life in different ways. You may have a partner or family member supporting you, who has responsibilities and commitments or may still be working.

Receiving a diagnosis can be an emotional time for everyone close to you and it is important to know that there is support available for anyone who requires it. There may be local services offering counselling that you, your family and friends would find helpful at the time of diagnosis and later on. Your doctor may be able to refer you to get this sort of support.

Children

You may have children or grandchildren who live with you or are in your close family. Even if you have not spoken to them about it, they may have noticed changes in you caused by dementia.

It will reassure children if you can involve them in family decisions – however young they are – and explain what's happening as much as possible.

It may take time to sink in and children will respond in different ways.

Try to answer their questions honestly. Even if your answer is 'I don't know', it is better than saying nothing.



Further information

NHS Health Scotland booklet, Steps to deal with stress.
www.healthscotland.com/documents/5828.aspx

Counselling and Psychotherapy in Scotland (COSCA) provides information on counselling and psychotherapy services near you. www.cosca.org.uk

The British Association for Counselling and Psychotherapy can also direct you to qualified experts in your area.
www.bacp.co.uk

Tips on talking about dementia to family and friends, especially to children:

- Keep it simple, use everyday words and avoid jargon.
- If something isn't understood then try to explain it using different words rather than simply repeating it.
- Don't make light of their fears, especially if they've noticed changes in you and have come to their own conclusions.
- Don't make promises you can't keep.
- Reassure them that it's not their fault and it hasn't been caused by anything they have done.
- Make it clear that it's OK to ask you questions and to tell you how they feel.
- Let them know how they can help, in real terms, like reminding you to take your house keys and phone when you go out.
- Talk about the things you can still do together.
- Don't be afraid to use humour when you're talking about dementia. It can ease tension and reassure someone that laughter is still part of your life and the relationship between you.



Further information

Alzheimer Scotland Dementia Helpcard

Go to www.alzscot.org or call the Dementia Helpline for more information on **0808 808 3000**.

NHS Health Scotland booklet. Understanding dementia: A guide for young carers.

www.healthscotland.com/documents/3884.aspx

The Mental Health Foundation guide, The milk's in the oven, suggests ways to talk to children about dementia.

www.mentalhealth.org.uk/publications/milks-oven

Your partner

It is important to talk about the impact of dementia on your lives and the decisions and choices you can make together. You and your partner need time for yourselves and to see your own friends.

Dementia may have an emotional and physical impact on the sexual feelings, desires and needs of both you and your partner. It may be helpful to talk things over with your partner. If you feel you need to, speak to a professional, such as a counsellor, who may be able to help.



Further information

Alzheimer Scotland information sheet, Sexuality and dementia. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Relationships Scotland can provide relationship counselling, sex therapy and support. www.relationships-scotland.org.uk

'My wife and I had split up because of how I behaved, but when I was diagnosed with Alzheimer's my daughter told her. We're now back together, and she's realised that I'm not a bad guy, it's the illness.'

On your own?

You may not currently have a partner or close family, but you may have a circle of people around you, including friends, neighbours and work colleagues, who will be able to support you following your diagnosis.

You may be an active member of your faith organisation, sports clubs or special interest societies linked to your hobbies, or you might be involved in support groups because of personal circumstances.

It's important to stay in touch with people. News of your diagnosis may reassure people who have noticed changes in your behaviour towards them.

It may be difficult to talk about what changes your diagnosis may mean for your relationships with people, especially at first, and to ask for help, but you still share a history and things in common.

If it feels uncomfortable to talk about your symptoms, it can be easier to focus on what practical support would help you carry on doing things together, like the offer of a lift if you no longer drive.



Further information

Alzheimer Scotland booklet, *Friendship and dementia*.
Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

'I volunteer with children. I love working with them - it's lots of fun and they don't notice that I have dementia. They love it when I lose at games!'

Keeping active

Being socially active has considerable benefits for your physical, emotional and mental health, as well as your general wellbeing. A diagnosis of dementia may also prompt you to do things you've always wanted to, or visit favourite places.

Things may take more planning and require some help and support. You may find you don't want to go out as much, or prefer quieter places.

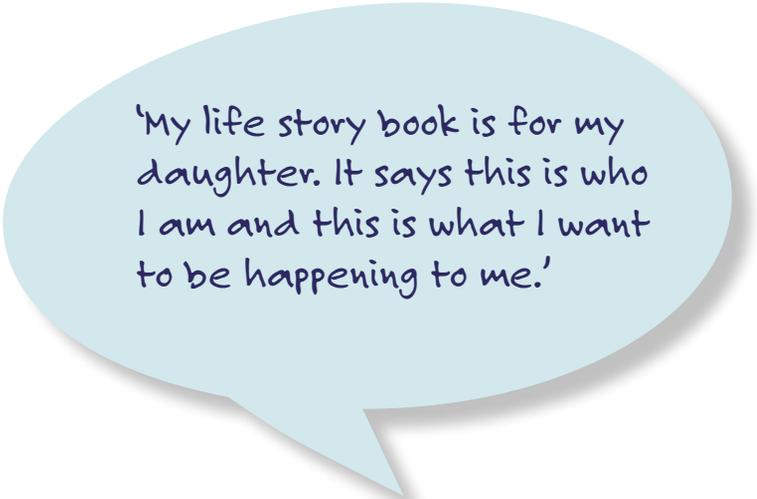
Focus on what you like doing and don't worry about making mistakes. Humour can sometimes be a good way of managing situations.

Being active regularly with others will keep you physically fit and socially active. Some change may be helpful, like going swimming when the pool is quieter.

Recording your life story

You could make a personal record of your experiences. Creating a 'life story' is an enjoyable activity you can do with family and friends to share your memories. This could be an opportunity to talk about your likes and dislikes.

Your life story collection could include personal photos and videos, favourite objects, music, poetry, films, and even smells (like soap or perfume) or textures (such as sofa materials) – anything that is special to you and triggers certain memories and emotions.



'My life story book is for my daughter. It says this is who I am and this is what I want to be happening to me.'

Holidays and outings

When planning holidays or trips, you will need to tell travel and medical insurance companies about your diagnosis and may require a doctor's letter. Some insurance cover makes specific provision for dementia.

Make the most of what you're entitled to. You may get concessionary rates or free entry to lots of places, including sports venues, cinemas, theatres, museums and galleries, as well as National Trust for Scotland and Historic Scotland sites. And there are 'benefits' other people can share. If they take you to a football match, for instance, their ticket may cost less as your 'carer' – and you might get better seats. You may have to show that you qualify for discounts, perhaps by providing evidence of a qualifying benefit.

A diagnosis of dementia may also entitle you to discounts for some travel, and offers of extra help when flying or using trains and coaches. There's more information in **Getting around** on p. 46.



Further information

Alzheimer Scotland information sheet, Travel and holidays. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

There are companies that specialise in holidays for people with dementia, such as Dementia Adventure and Mind for You. Call **01245 237548** or visit: www.dementiaadventure.co.uk, mindforyou.co.uk or www.tourismforall.org.uk

'My tip is to be positive, and challenge yourself. That's what I do. And speak to other people with dementia – join a group like I did.'

New connections

A diagnosis of dementia doesn't stop you forming new relationships, including friendships, with other people with dementia.

You may have other things in common and also find it a great relief to talk freely with someone who shares similar experiences of dementia. Your partner or family members might also benefit from meeting with other carers in a similar situation.

You may also make new friends through online communities. You could create your own web forum or blog to get in touch with other people with dementia. This may be particularly helpful if you live in a remote or rural area where it is difficult to meet up in person.

Be aware that people in online communities may have different symptoms from you, be at a later stage or live in another country. Don't assume that you'll have the same experiences, good or bad. If you're online, consult someone you trust to ensure you stay safe. Never give your personal information out to someone online.

Getting involved as a volunteer or charity fundraiser can also expand your social circle. It can maintain your skills and put your experience to good use too.



Further information

The Scottish Dementia Working Group (SDWG) is the independent voice of people with dementia within Alzheimer Scotland. Members keep in touch through local groups, events and newsletters. www.sdwg.org.uk or call **0141 410 1171**

Talking Point is an **Alzheimer's Society** online forum for people with dementia and their carers across the UK. forum.alzheimers.org.uk

The National Dementia Carers Action Network (NDCAN) is a national campaigning group. Members have personal experience of caring for a person with dementia. www.alzscot.org/ndcan

Keeping well and connected: at a glance

- Relationships may change after your diagnosis – you're still the same person but you might need more help and support.
- Try to talk about dementia openly and involve children in family decisions. Explain what would help you and what support you would like from your family and friends.
- You can still have fun with family and friends, and enjoy activities together.
- Creating a 'life story' is a good way to share and record precious memories.
- It's important to stay connected to a range of people and keep active in your community.
- You may develop new friendships, including with other people with dementia.
- It's OK to tell people that you have difficulty communicating or with your memory.



Home

Living well with dementia includes feeling safe and independent in your own home.

Owning or renting your home

Get financial advice early on about the cost of staying in your home. Solicitors who specialise in helping people with conditions like dementia can advise on property ownership and rental agreements.

Check the small print of mortgage protection insurance or other cover relating to your home. A diagnosis of dementia may mean you can make a claim.

If you rent property, you already have certain legal rights as a tenant when dealing with landlords and letting agents, and additional protection because of your diagnosis.

These extra rights include having 'reasonable adjustments' made, like painting doors a darker colour so they are more visible. You can contact your local **Citizens Advice Bureau, Shelter Scotland** or your local authority for advice about this.

Adapting your home

Simple changes to your home can make it easier to manage.

Depending on your circumstances, your Health and Social Care Partnership may have a duty to provide you with aids and adaptations. Some will even provide you with a free fire safety check and install smoke alarms for you. You can ask for an occupational therapy assessment to determine what help you might be entitled to.

You may have already done things like fitting smoke alarms, bath rails and non-slip mats, and security systems like door chains and spyholes.

An occupational therapist, who can be contacted through your local Health and Social Care Partnership, community mental health team or link worker, can advise on what would be most helpful, based on your needs, wishes and general circumstances. Health and Social Care Partnerships will sometimes pay for alterations and equipment.



Further information

Alzheimer Scotland and **Law Society of Scotland** can provide details of suitable solicitors and law centres near you. Go to www.alzscot.org, call the Dementia Helpline on **0808 808 3000** or visit www.lawscot.org.uk

Shelter Scotland can advise on your rights if you rent your home. Call **0808 800 4444** or visit scotland.shelter.org.uk

The **Citizens Advice Bureau** can advise on your rights if you rent your home, as well as answer questions you have about other benefits or help you may be entitled to. www.citizensadvice.org.uk/scotland

The **Legal Services Agency** mental health legal representation projects (Strathclyde, and Edinburgh and the Lothians) support people with dementia and their families. www.lsa.org.uk

Layout and alterations

What alterations to the design and layout of your home will help you most will depend on your needs. Simple things can help you and make your home safer for everyone. For example:

- A downstairs bedroom and bathroom, a wet room, or a ramp instead of steps outside, can help with mobility and balance problems.
- Clear pictorial signs on doors to the kitchen or toilet may help you find your way around the house.
- Strongly contrasting plain colours for things like door frames and walls, or walls and carpets, may be helpful.
- Reduce clutter on surfaces and leave only essential items on worktops.
- Repair loose banister rails and ragged carpet edges and remove rugs so there's less risk of slips and trips.
- Rearrange furniture and fit electric night lights so you don't bump into things at night.
- Install extra lights and stronger bulbs for good, even lighting, especially on steps and stairs.



Further information

Care and Repair Scotland offers advice and assistance to disabled people or people aged over 60 who are homeowners, tenants who rent from private landlords or crofters.

www.careandrepairsotland.co.uk

Aids and equipment

Tools and equipment to help you do something are often referred to as 'assistive technology'. This can include simple tools, like prompting devices that play messages at pre-set times and handheld locators to find misplaced items. Things you might use anyway, like large-dial clocks or talking books, can help if dementia affects your sight.

'Telecare' refers to equipment and services to keep you safe but independent and can be particularly helpful if you live on your own. Telecare equipment can sense risks like smoke or gas and will know if you fall. It will automatically contact someone to come to your assistance. This may be accessed through your Health and Social Care Partnership. There may be a charge for this service.

There are also 'environmental control systems' that operate domestic appliances and things like lighting by remote control, as well as 'activity monitoring systems' that monitor movement around your home through sensors.

Decisions about changes to your home should involve everyone who lives there to get the right balance between living your life as you choose and keeping safe.

You may not need technology to help you, particularly at first, but each person is different. For example, do you need a device to switch off the cooker if you forget, or is it just as effective to put a clear reminder nearby? Do what you need to encourage you to carry on doing the things you like.

Changing accommodation

A diagnosis of dementia may prompt you to think about your current living situation, taking into account how changes may affect you in the future. Some people find moving into different accommodation at an early stage in the dementia journey allows them to live independently for longer with support available if they need it.

Accommodation is available with built-in assistive technology, such as monitoring systems and alarms.

Are you homeless?

A diagnosis of dementia makes it especially important that you have secure accommodation and support. Homelessness covers staying with friends, or in a hostel, bed and breakfast or property in poor condition. Under new legislation, individuals have the right to a permanent home.

Talk to your local social work department, especially if you are worried about maintaining your tenancy or paying your rent.



Further information

Information on funding for housing adaptations.
www.gov.uk/disabled-facilities-grants

Shelter Scotland provides information on disabled people's housing rights. Call their free advice line on **0808 800 4444**.
scotland.shelter.org.uk/get_advice/advice_topics/renting_rights/disabled_peoples_rights_in_rented_accommodation

Home: at a glance

- It is a good idea to talk about housing needs and plans for the future.
- Alterations to your home can make life easier and safer for everyone.
- There may be funding available for home improvement.
- There are lots of different types of aids and equipment you may find helpful.
- You might consider making changes to where you live or may think about moving.

'My wife uses a whiteboard and writes instructions for the day - like what to wear - and puts up Post-it notes to remind me to lock the door or how to use the microwave.'

Health

It is important to look after your health following a diagnosis of dementia. Your usual health checks (such as blood pressure, cholesterol, eye tests and dental check-ups) can help you keep fit and well, and better able to cope with symptoms of dementia.

As someone with a diagnosis of dementia you should try to schedule a general health review at least every 15 months with your GP or practice nurse. If you experience any changes to your symptoms, or develop any new symptoms, you must tell your GP or practice nurse as soon as you can.

You may also be within the age range for health screening (such as breast screening, bowel screening, prostate screening or abdominal aortic aneurysm screening), so it is important for you to continue to take part in tests and attend appointments. Ask your doctor for more details of screening programmes.

Many older people with dementia, particularly those with diabetes, may experience problems with their feet. Ask your doctor about referring you to a podiatrist for help with your feet.

Other conditions and disabilities

If you have other conditions and disabilities, consider the impact dementia and possible symptoms may have on how you manage them. Your doctor and other health professionals can help.

Speak to your doctor if you have any particular health concerns, like hearing loss or worsening eyesight. An eye health check is recommended annually over 60. Specialist support, like low-vision clinics, can help you to overcome problems caused by sight loss.

Check if drugs prescribed for dementia will affect other medication and if side effects might have a particular impact on your condition or disability.

Visiting hospital

If you do go into hospital for treatment or for an operation, it is important to let staff know as much as possible about your needs, likes and dislikes. Some people write these things down in an Advance Statement (see p. 83). You may be asked to complete a document called 'Getting to know me', which many hospitals in Scotland are using.

Some hospitals use a (voluntary) scheme, called The Butterfly Scheme, which uses a butterfly symbol to let people know, discreetly, that you have dementia and to be aware.

Some drugs for dementia affect anaesthetics. Make sure that you or someone you trust tells the doctors about your medication, so that they can take this into account when planning your care.

'A couple of weeks ago I cooked my wallet - you either get depressed or get on with it. You have to learn to laugh.'

'I have peaks and troughs, I'm much better in the morning. Later in the day I have less energy, and bad reactions.'

Wellbeing

Wellbeing means feeling good about yourself as an individual. Keep enjoying the things that give meaning to your life. You may find counselling and therapy helpful, especially as you and your family come to terms with the diagnosis. Your doctor should be able to refer you.

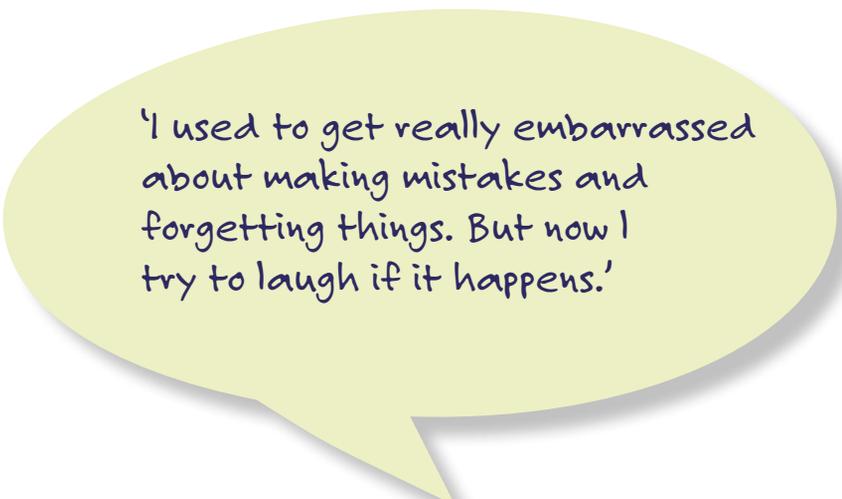
After you have come to terms with your diagnosis, you may find that living with dementia changes your emotional reactions.

Try to work out what triggers a difficult reaction and make plans for how to cope with it in the future. For example, if crowds make you anxious, can you take someone with you? There are useful suggestions in the **Tips for coping** section on p. 34.

You may find that you get more tired than you used to. Having dementia can mean it takes more effort and concentration to do things. When you are tired it's harder to concentrate and you're less likely to remember things and more likely to be confused.

Don't push yourself too hard, listen to your body if it's telling you to rest, and ensure you are getting enough sleep. Get the balance right though – giving up your favourite activities may leave you feeling low.

Spiritual faith is important for some people, whether through religious involvement, a sense of spirituality from spending time with friends and family, enjoying nature or meditation.



'I used to get really embarrassed about making mistakes and forgetting things. But now I try to laugh if it happens.'

Stress, depression and anxiety

A diagnosis of dementia can cause a variety of emotions for you, and for your family and friends. Remember, these are all natural reactions, but it is important to recognise if these emotions are getting too much for you or your family members.

We all get down from time to time, but depression is different as it is an illness.

If you are concerned that you or one of your family or friends are depressed or anxious – perhaps they're quieter, or crying more than usual – it is important that you speak to your doctor about how this can be treated. There are many treatments available for depression and anxiety, including medical treatments and talking therapies.

It is also important to recognise if you are becoming stressed. Speak to your doctor as there are lots of things you can do to reduce stress. Your doctor may be able to refer you to a clinical psychologist.



Further information

NHS Health Scotland booklet, *Steps to deal with stress*.
www.healthscotland.com/documents/5828.aspx

Breathing Space is a free, confidential service. It provides a safe and supportive space in times of difficulty by listening and offering advice and information.

Visit www.breathingspace.scot or call **0800 83 85 87**.

A British Sign Language interpretation service can be accessed through the website.

NHS Living Life is a telephone service based on cognitive behavioural therapy (CBT). It provides help for people experiencing low mood, mild to moderate depression, symptoms of anxiety or a combination. Call **0800 328 9655** (Mon to Thur: 10 am to 9 pm; Fri 10 am to 6 pm) or visit www.nhs24.scot/our-services/living-life

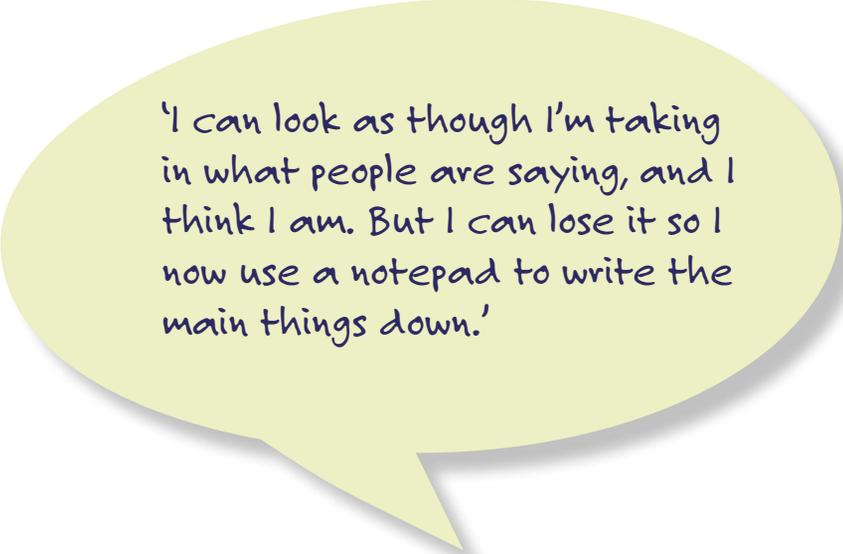
Samaritans can be called free at any time, from any phone, on 116 123, whatever you're going through. www.samaritans.org/how-we-can-help-you/contact-us

Helping your memory

There are many positive steps that you can take to help yourself cope. Remember, changes are not going to happen suddenly. You will have time to adjust your lifestyle and to find help when you need it. Ask your dementia link worker, community psychiatric nurse and other people with dementia about how better to cope.

These are some of the tips people with dementia recommend:

- Write things down. Make lists of what you need to do or keep a diary and get into the habit of checking it regularly. Make notes of where things are.
- Put a reminder board on the wall to help you remember things.
- Decide on a place to keep important things like money, keys and glasses. Put them in the same place every time so that you can track them down.
- Ask your family and friends to phone you to remind you about the things you need to do.
- If you like gadgets, a mobile phone or personal organiser can act as a diary, plus you can set reminder alarms, for example, to take a pill or go to an appointment.



'I can look as though I'm taking in what people are saying, and I think I am. But I can lose it so I now use a notepad to write the main things down.'



Tips for coping

- Write things down.
- Don't be afraid of asking for help, and accepting help from people you know and trust.
- Keep important things in one place.
- Ask your family or friends to phone you to remind you about things you need to do.
- Electronic gadgets such as mobile phones suit some people and can help you cope.
- Be patient with yourself.
- Concentrate on the things you can do.
- Make a routine for yourself.
- Know your good times of day.
- Use the Helpcard from the back of this booklet to show people to explain that you have dementia and might need a bit of help.
- Ask other people to help you work out what risks you should or shouldn't take.
- When you are buying expensive or significant items, consider asking people you trust to come with you.

'Because my memory was bad I used to buy extra things - huge packs of toilet rolls, a cupboard full of them. Now I always write a shopping list.'

Physical activity

Physical activity can help delay or reduce some mobility problems associated with dementia by improving your balance and muscle tone, and can reduce the risk of trips and falls. It can also help you to sleep better.

Starting an exercise regime in the early stages of dementia will make it easier to maintain. It is a good idea to ask your doctor before starting a new form of physical activity and build it up slowly. You should aim to do 30 minutes of activity on at least five days of the week, which can be achieved throughout the day rather than all at once. Older adults should also undertake physical activity to improve muscle strength, balance and coordination at least two days a week. Avoid sitting for long periods of time – if possible, get up and move around at regular intervals.

Your local leisure services department should be able to tell you about activities near where you live. The Dementia Helpline **0808 808 3000** can tell you if there is a dementia advisor in your area.

You may enjoy gardening as a way to stay active. If you do, remember to store compost in a cool place and open carefully in a well-ventilated area, ideally outdoors. Gardeners should wash their hands immediately after handling compost, as research has found disease-causing strains of Legionella bacteria in potting soil on sale in Britain.



Further information

The national **Paths for All** project runs organised walks throughout Scotland. Check if there's one in your area at www.pathsforall.org.uk/find_a_health_walk

Visit the **NHS inform** website for information on the health benefits of exercise and ideas on how to keep active. www.nhsinform.scot/healthy-living/keeping-active

Diet

A healthy diet is especially important when you have dementia. It reduces the risk of coronary heart disease, some cancers, diabetes and strokes (which can make a difference if you have vascular dementia).

Planning and preparing meals may maintain your interest in food and keep you mentally active. You may find it helpful to have support from friends or family to cook and prepare meals, especially if you are experiencing loss of interest in cooking and having some difficulty in remembering to eat. It can also be more enjoyable cooking with or for friends and family if you live on your own.



Further information

Mental health charity **Mind** has advice on eating to improve your mental wellbeing. www.mind.org.uk

'I go swimming several times a week and I feel much better for it, and not just physically. There's a real feel-good factor.'

Drinking and smoking

Having a diagnosis does not mean that you can't enjoy an alcoholic drink, as long as you are sensible about it and don't have a condition that is affected by alcohol, such as Korsakoff's syndrome. However, it is very important that you check with your doctor first, as some medication can have a negative reaction when mixed with alcohol.

To keep health risks from alcohol to a low level it is safest not to drink more than 14 units a week on a regular basis.

If you regularly drink as much as 14 units per week, it is best to spread your drinking evenly over three or more days.

beta.gov.scot/news/new-alcohol-guidelines

Smoking damages your health generally and adds to the risk of stroke, putting you at higher risk if you smoke when you have vascular dementia. There is plenty of support available to help you quit.



Further information

Alzheimer Scotland infosheet, Healthy living with dementia. Go to **www.alzscot.org** or call the Dementia Helpline on **0808 808 3000**.

For more information about how many units are in a drink, see Making a change, **www.healthscotland.scot/publications/alcohol-brief-intervention-resources**

For further information and advice about alcohol and health, call the **Drinkline** helpline on **0300 123 1110**. **www.gov.scot/Topics/Health/Services/Alcohol/safer-drinking**

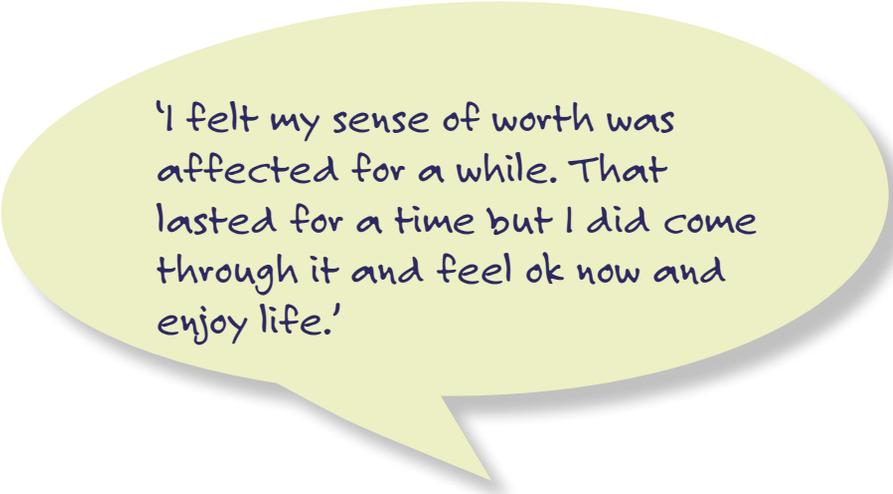
Alcohol Focus Scotland offers advice on drinking and health. **www.alcohol-focus-scotland.org.uk/alcohol-information/alcohol-and-health.aspx**

For further advice on how to stop smoking call **Quit Your way Scotland** on **0800 84 84 84** or visit **www.quityourway.scot**

All NHS Health Boards offer specialist stop smoking services, or you can get support and free nicotine-replacement therapy (NRT) from your local pharmacy.

Health: at a glance

- Specialist support groups can help you find ways to live well with dementia and an existing condition or disability.
- Keep doing the things that give meaning to your life to improve your wellbeing.
- Don't push yourself too hard.
- Carry on with regular health checks like visits to the dentist, optician and podiatrist.
- A healthy diet reduces the risk of poor nutrition that can make symptoms worse.
- Physical activity that you enjoy is good for your brain and your body.
- Concentrate on the things you can do.
- Make a routine for yourself.
- Know your good times of day.



'I felt my sense of worth was affected for a while. That lasted for a time but I did come through it and feel ok now and enjoy life.'



Independence

You may have a lot of commitments and responsibilities, and you'll want to continue to make your own decisions as much as possible. Living well with dementia includes staying as mentally, physically and emotionally independent as you can and want to, for as long as possible.

Let family and friends know where you would appreciate their involvement and support.

Your rights

People with dementia and those who care for them have the same human and legal rights as every other citizen. It is important that this is recognised and respected.

There is a wide range of legal provision designed to provide rights and protection in Scotland.

Scotland has introduced a Charter of Rights for people with dementia and their carers. The charter is not law but it explains your existing rights as set out in human rights law and other legal provisions.

www.alzscot.org/charter_of_rights

There are also Standards of Care for Dementia in Scotland. The standards are based on the Charter of Rights and say that you have the right to:

- a timely diagnosis
- be regarded as a unique individual and to be treated with dignity and respect
- a range of treatments, care and support
- be as independent as possible and be included in your community
- have carers who are well supported and educated about dementia
- end-of-life care that respects your wishes.

The standards apply to everyone with a diagnosis of dementia in Scotland, regardless of where they live, their age, the support they receive or the severity of the illness. The standards apply wherever the service is being provided – whether it is in your own home and community, or in a care home or hospital.



Further information

Alzheimer Scotland's booklet, *Standards of Care for Dementia in Scotland*, provides a guide to what you should expect when the standards are met.

www.alzscot.org/standards

Alzheimer Scotland explains what the Charter of Rights for People with Dementia and their Carers in Scotland covers.

www.alzscot.org/charter_of_rights

Care Information Scotland outlines your rights as someone who needs care.

www.careinfoscotland.scot/topics/your-rights

Mental Welfare Commission for Scotland can advise on your legal rights under mental health and adult incapacity law. Call the advice line on **0800 389 6809**.

www.mwcscot.org.uk

Being involved

You and your family should be involved in decisions about your care and be given as much choice as possible.

Any services you receive should meet your individual and cultural needs and should encourage you to use your abilities to the full.

Advocacy

You can get help from an 'advocate' to make sure your views are heard and to guide you through complicated health, financial and social service systems.

Advocacy can be particularly useful if you lack a support network of friends and family, or if you face additional barriers to communication, such as speech or hearing difficulties, or if your first language is not English.



Further information

The **Scottish Independent Advocacy Alliance** (SIAA) can provide information on independent advocacy, which empowers people who need a stronger voice by enabling them to express their own needs and make their own decisions. www.siaa.org.uk

Mental health charity **Mind** offers advice on different sorts of advocacy. www.mind.org.uk/information-support/guides-to-support-and-services/advocacy

Managing risk

Everyday life carries risks you probably manage without consciously thinking about.

You, and your family and friends, may find it helpful to talk about some of the risks dementia may bring. You might want to do things you've always enjoyed or try new things. So it's important that you say what you want to do, what risks might be involved and how best to manage them. For example, you might enjoy walking in the town. Think about what you would need so that you can still do this safely.

Simple ideas can set everyone's mind at rest, like always carrying identification plus your mobile phone. You could also use a Helpcard – a wallet-sized card that you can show to people to explain that you have dementia and might need a bit of help. There is a Helpcard provided at the back of this booklet or you can go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000** for a free supply that you can put in your wallet, each handbag you use and coat pockets.

You and your family may find it reassuring for others in your community – such as shopkeepers, local police officers and neighbours – to be aware of the situation. You can address any worries they may have and focus on symptoms in which they can provide particular help.

Keeping safe

Because dementia can affect your judgement, some people may try to take advantage of you. Say no to 'cold callers' – people who try to sell you something that you haven't asked for, either door to door or by post, phone or email. Don't buy anything significant without first discussing the deal with someone you trust.

You can reduce the number of phone calls you receive from people who try to sell you things by registering free with the **Telephone Preference Service** on **0345 070 0707** or by visiting **www.tpsonline.org.uk**

To reduce unwanted mail, register free with the **Mailing Preference Service** on **0207 291 3310** or go to **www.mpsonline.org.uk**

Ask your computer manufacturer or internet supplier to install a good spam filter on your computer to cut down on unsolicited emails.

And remember, if an offer sounds too good to be true, it probably is.



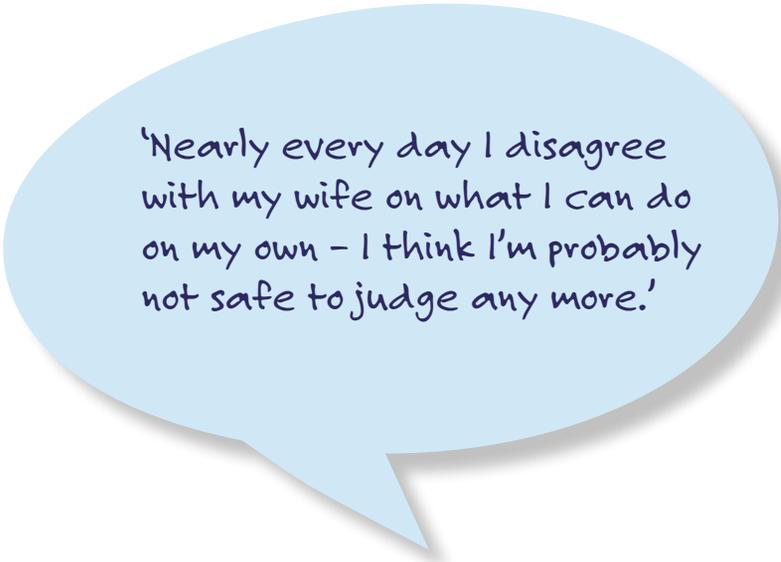
Further information

Alzheimer Scotland information sheet, Stress and distress. Go to **www.alzscot.org** or call the Dementia Helpline on **0808 808 3000**.

Alzheimer Scotland information sheet, Travel and holidays. Go to **www.alzscot.org** or call the Dementia Helpline on **0808 808 3000**.

Independence: at a glance

- You have certain legal and human rights following a diagnosis of dementia.
- Get involved in decisions about care and choices available.
- Involve your family in helping you maintain your independence.
- Decide together what's a priority and what's an 'acceptable risk'.



'Nearly every day I disagree with my wife on what I can do on my own - I think I'm probably not safe to judge any more.'

Getting around

How you get around is an important part of living well with dementia and staying independent.

Driving

A diagnosis of dementia doesn't automatically mean you can no longer drive, but dementia can make your reactions slower and affect your judgement. If you want to keep driving, you need to know you are safe and feel confident behind the wheel. You may prefer to stop driving if you find it stressful or worrying.

You should ask your doctor if medication for dementia has any impact on your driving.

The law

If you hold a current driving licence you must inform the Driver and Vehicle Licensing Agency (DVLA) when you are diagnosed with dementia. You must also surrender your driving licence to the DVLA if your doctor advises you not to drive for a period of three months or longer. If you do not tell the DVLA, your doctor has a duty to do so on your behalf.

You must also tell your insurance company, or your insurance may not be valid. Driving without valid insurance is a criminal offence.

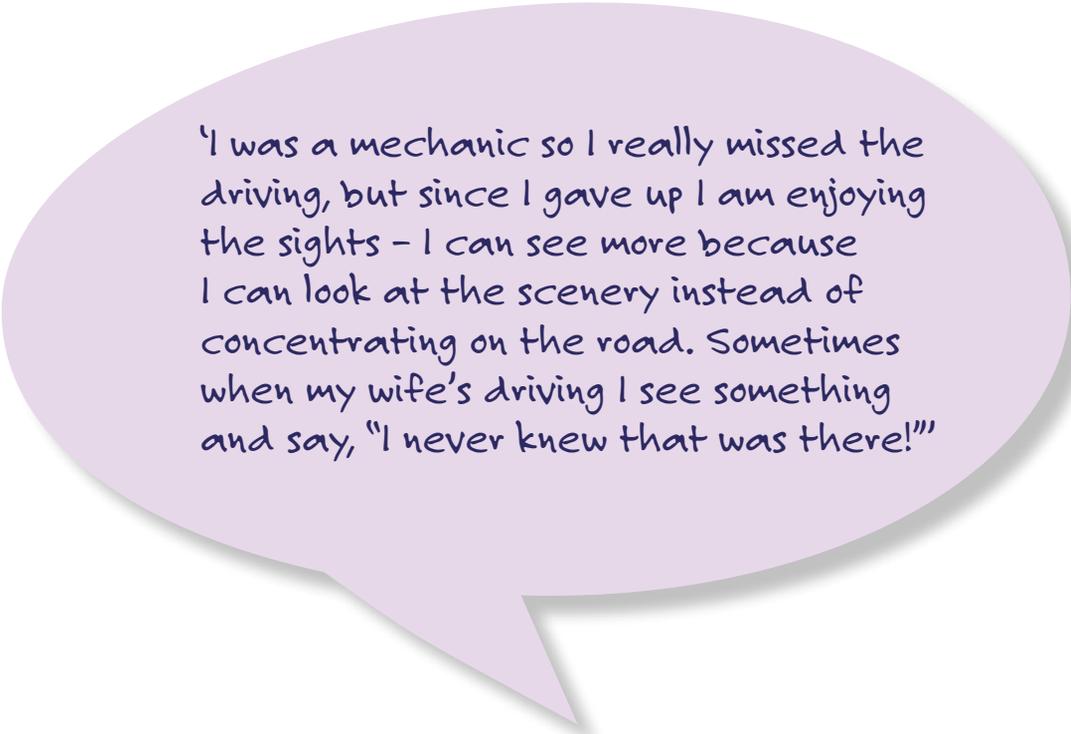
If you want to carry on driving, tell the DVLA. They will send you medical forms to complete and will seek your permission to get a report from your doctor.

The DVLA may want you to have a driving assessment. If so, they will refer you to your nearest assessment centre at no cost to you. This can take several months to arrange. An assessment looks at the impact dementia may have on your driving performance and safety. It makes allowances for typical bad habits that drivers develop. Alternatively, the DVLA may opt to arrange a driving appraisal for you via the Driving Standards Agency.

If the DVLA decides it's safe for you to drive, they will issue you with a new driving licence, usually for a year at a time – you will be reviewed annually. If the DVLA decides it's unsafe for you to continue driving, you must return your licence. You can appeal, but you must do this quickly (within 21 days). You may have to stop driving at some point, so try to make arrangements for getting someone to drive you, or to arrange other transport. If you are aged 70 or over you are required to renew your driving licence as long as you have not been prevented from driving for any reason.

Driving safely

If you keep driving, be sensible. You will be safer on routes you know well. Don't drive when you are tired and stay away from busy and fast roads. Driving at night or in wet conditions can also be more difficult.



'I was a mechanic so I really missed the driving, but since I gave up I am enjoying the sights – I can see more because I can look at the scenery instead of concentrating on the road. Sometimes when my wife's driving I see something and say, "I never knew that was there!"'

Other ways of getting around

A diagnosis of dementia gives you certain rights that can help you find alternative ways of getting around. For instance, your hospital may provide patient or volunteer transport to take you to and from appointments. Some services and discounts may not be available until you are claiming disability benefits.

Public transport

The National Entitlement Card allows people 60 or over and people with disabilities to travel by bus for free and travel by train at a reduced price in Scotland, and offers concessions on ferry journeys if you live in the Western Isles, Orkney or Shetland.

If you find travelling with someone makes things easier, they may also be able to travel free under the same scheme.

Community transport may be available in areas with limited public transport. Contact your local social work department about schemes like Dial-a-Ride or door-to-door transport. Local supermarkets may run special buses for shoppers, so getting familiar with bus timetables may help.



Further information

Contact the **DVLA** at Drivers' Medical Enquiries, DVLA, Swansea SA99 1TU. Call **0300 790 6806** or visit www.gov.uk/driving-medical-conditions

The **Scottish Driving Assessment Service** offers assessments throughout Scotland. Assessments are free under the NHS, but you need a referral letter from a doctor before an appointment can be arranged. Call **0131 537 9192**.

You may be eligible for a 'blue badge' from your local authority to park for free in disabled parking bays and on-street spaces if your mobility is limited. There may be a fee for this.

www.gov.uk/blue-badge-scheme-information-council

To find out how to apply for a National Entitlement Card from **Transport Scotland** visit www.entitlementcard.org.uk/how-get-your-nec



Train travel

You can ask for help to use ScotRail services.

www.scotrail.co.uk/form/assisted-travel

You may also be eligible for a Disabled Person's Railcard to get a discount on train fares across the UK.

www.disabledpersons-railcard.co.uk

Information on travelling by train.

www.gov.uk/transport-disabled

Taxis

Setting up your own account with a local taxi company can cost you less in the long run and save any worries about handling money. It helps to choose a company you already trust and like.

Managing your own account and ordering taxis in advance can also help you keep your independence.

Cycling and walking

Walking and cycling keep you healthy, allow you to get around independently, and can provide you with mental stimulation as well as exercise. Dementia may slow your reactions and affect your judgement as a road user or pedestrian.

Try to cycle off road, away from busy traffic, when possible. You will be safer on quieter routes you know well and in good weather conditions. Make sure your bike is well maintained. High-visibility clothing is sensible, whether you're cycling or walking, and a helmet is recommended if you're on a bike (whether you have dementia or not).



Further information

Royal National Institute of Blind People (RNIB) can advise on mobility aids if dementia affects your vision.

www.rnib.org.uk/eye-health-sight-loss-other-medical-conditions/dementia-and-sight-loss

Air travel

Airlines and airports are legally required to make 'all reasonable efforts' to provide assistance if you have a disability or medical condition.

You can request specific help when you book, either online or through a travel agent. This might include help with registration at check-in and to move through the airport.



Further information

Advice on air travel. www.gov.uk/transport-disabled/planes

Alzheimer Scotland information sheet Travel and holidays. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

The **Scottish Dementia Working Group (SDWG)** leaflet, Travelling with dementia. Go to www.sdwg.org.uk/wp-content/uploads/2008/05/Travelling-with-Dementia.pdf

Getting around: **at a glance**

- You may still be able to drive but you need to know you are safe on the road.
- You must tell the DVLA and your insurance company about your diagnosis.
- Make the most of discounts on public transport.
- Cycling and walking keep you independent and provide healthy exercise too.
- Request help from airlines, airports, and train and bus companies to make travel easier.



'I became aware I had problems with my driving - once I looked at the speedometer and I was doing 120 mph! I realised I wasn't safe.'

Work

If you are working, a diagnosis of dementia might not mean you have to stop. However, it will depend on how the dementia affects you and what your job involves. Consult your union rep (if you have one) as they can give you advice on continuing to work with your diagnosis and your employer's legal duties to you as an employee with a disability.

If you can, carry on for as long as you and your employer are happy and feel able to do so. You may find it helps you to cope with dementia to maintain a routine, keep involved, use your work skills and enjoy the company of colleagues.

Telling people at work

Speak to your employer as soon as you feel ready.

If the organisation you work for has its own occupational health service, you may be offered specialist support and advice.

There may be safety issues if you operate dangerous machinery, carry out life-critical procedures or drive in your job. If you're unsure, check your contract and speak to your line manager.



Further information

Signpost your employer to the Business Disability Forum.
businessdisabilityforum.org.uk

Know your rights

You have more rights once you've told your employer about your diagnosis.

Dementia counts as a disability under the Equality Act 2010, giving you legal protection from discrimination, unfair dismissal or being encouraged into early retirement.

By law your employer must:

- make 'reasonable adjustments' to help you stay in work
- assess what risks you face because of health issues
- put adequate control measures in place.

Check the terms and conditions of your employment and company policies on equality and diversity, and disability.

The situation is more complicated if you've already been dismissed or resigned because of undiagnosed dementia. It might be difficult, but not impossible, to have your situation reconsidered.



Further information

Call the **Healthy Working Lives Adviceline** on **0800 019 2211** for free and confidential advice on any matter concerning health and wellbeing in the workplace.
www.healthyworkinglives.scot

Government information on disability rights at work.
www.gov.uk/rights-disabled-person/employment

Get employment advice

You can also get independent advice on staying in work, and on benefits while you're employed, from:

- your union
- the Trades Union Congress (TUC)
- the Advisory, Conciliation and Arbitration Service (Acas)
- the disability employment advisor at your local Jobcentre
- the Citizens Advice Bureau
- Alzheimer Scotland.

The Access to Work scheme offers practical support, including funding to cover extra costs to help you stay in work.



Further information

Find out if you are eligible for Access to Work.

www.gov.uk/access-to-work

A disability employment advisor can help you assess your strengths, abilities and skills.

www.gov.uk/looking-for-work-if-disabled

Make adjustments

Be realistic about what you can and cannot do, what is likely to cause you problems and ways round this. If your employer has an in-house occupational health specialist, they should discuss adjustments with you.

For instance, it may be possible to:

- rearrange your workload, giving you tasks separately instead of all at once
- change your hours or work schedule, giving you time to rest when you need to
- find you a quieter place to work, reducing noise and distraction
- alter your way of working, like simplifying your routine
- reduce your responsibilities, perhaps by delegating more
- provide technology to help you – you may already use online reminders to keep track of meetings and deadlines
- offer you individual support – perhaps a mentor or ‘buddy’ you can call on.

You might want to explain to colleagues why your symptoms have made these adjustments necessary and where you may need extra help. You may want to ask your partner or a friend to help you.

If reducing your hours, dropping a grade or changing jobs seems the best option, you’ll need to think about the financial implications of a lower income and the possible impact on your pension or future benefits.



Further information

The **Disability Rights UK** guide, *Doing careers differently*, explains your right to changes that will help you stay in work. www.disabilityrightsuk.org/how-we-can-help/publications/doing-life-differently-series/doing-careers-differently

Deciding to leave

You may find that your job becomes too much, even with a supportive employer.

Don't feel you have failed somehow, just because you have an illness that makes certain work difficult. You could find a different or part-time job, or take up voluntary work or study.

Aim to leave on a good note. Take time to make your decision, and talk it through with your employer as well as your family.

Your union can help negotiate terms for early retirement on the grounds of ill health. Your employer may agree to enhance your pension rights, and claiming National Insurance credits can protect your right to a state pension.

You may find there is a benevolent fund for people in your area of work to help avoid financial hardship.

It is also a good idea to get advice about what welfare benefits, or other financial support, you will be entitled to after you leave work. This will help you make an informed decision and plan ahead better.

See the **Money** section on p. 61 for more information on pensions, insurance and benefits once you leave work.



Further information

Benefits and employment advice for you and your carer and advice on taking time off work because of ill health.

www.citizensadvice.org.uk/scotland/benefits/sick-or-disabled-people-and-carers

Working as a professional

If you have to be licensed or accredited by a professional body to do your job (as a lawyer, dentist or estate agent, for instance) you may need to speak to the relevant organisation about your diagnosis and what impact it may have on your professional status.

Do you work for yourself?

If you are self-employed or own your business, it is up to you how long you continue working or whether or not you change the way you work.

Your diagnosis might impact on your business partners and senior staff in your company. It might also affect clients if you are self-employed and tied to a contract or long-term agreement. If you tell them about your dementia they may be able to offer support and help you make adjustments. You may be able to reduce your hours, or delegate or sub-contract some work. If you work for yourself or your partner, it is important to make adjustments so that you can continue working for as long as you feel able to.

Check any income protection and critical illness insurance policies and ask the provider if dementia is covered. If you have an accountant, legal or other business advisor, they may also be able to help.

You should consider putting a power of attorney in place so family members or other people involved in the business can take financial and legal decisions on your behalf if you're unable to do so (see **Future plans** on p. 78).

Carers' rights at work

Carers have employment rights too. A partner or family member, or someone else who lives with you and provides care, can request flexible working hours under the Work and Families Act 2006.

Any employee has the legal right to take a reasonable amount of time off work to deal with an emergency involving someone dependent on them. Under the Equality Act a carer should not be refused a job or treated differently because of their caring responsibilities.

Your carer's employer may be willing to negotiate other changes that would help you both. They may already have policies in place to support carers, over and above their legal requirements.

Staying in work is probably important to your carer, for financial reasons and their own self-esteem and wellbeing.



Further information

Find out more about carer rights to flexible working.
carers.org/article/flexible-working

Work: at a glance

- Priority: tell your boss – then they have a legal duty to try to help you.
- Dementia may not mean you have to stop working.
- Adjustments to your job can help you manage.
- Negotiate terms for early retirement if you decide to leave.
- Check insurance policies.
- Carers have employment rights too.

Money

A diagnosis of dementia is likely to affect your income and financial commitments. Knowing where you stand financially will help you and your family get on with your lives and plan ahead.

Long-term arrangements, like a power of attorney, mean someone you trust can help with future financial decisions. This is explained in the **Future plans** section on p. 78.

Your mortgage or rent might be your biggest financial outgoing. There is information on owning and renting property in the **Home** section on p. 22.

Joint accounts

It is worth checking what accounts or financial agreements you hold jointly with your partner or a family member and what the small print says about incapacity due to illness.

You may want to separate your own and your partner's accounts, and arrange power of attorney so that your partner can manage your accounts if necessary.

Dementia can sometimes change the way people handle money, like starting to spend compulsively or gamble, which can make them more vulnerable to internet and other scams. It is possible to have limits set on bank accounts to manage withdrawals.



Further information

The **Money Advice Service** is free and independent.
www.moneyadviceservice.org.uk/en

Managing household bills and spending

Sorting out your day-to-day finances makes it easier to work out what you're entitled to.

It might be easier to get all your income paid straight into your bank account, including benefits, pensions, sick pay and wages. You could also switch regular bills to direct debits or standing orders.

Online banking makes it easier to track spending. You can ask your bank or building society to monitor your current account for erratic or unusual spending behaviour.

Involving other people

If you feel you need help coping with money, you can allow a named individual to manage your bank account by setting up a continuing power of attorney (see **Future plans** on p. 78). They can make withdrawals and arrange other transactions (like paying bills) on your behalf.

You may want some support to:

- go through important documents
- fill in forms
- communicate with officials like your bank manager or insurance provider
- ask questions and clarify your options
- keep a record of what is agreed.

See **Support at appointments** on p. 75 for more information.



Further information

Get advice on involving someone else in managing your money.
www.moneyadvice.org.uk/en/articles/planning-ahead-for-when-you-cant-manage-your-money



Credit and debts

People of working age are more likely to have ongoing financial commitments, such as a mortgage, credit card, personal loans, or other forms of credit.

If you are worried about debt, you should get money advice as soon as possible. Don't ignore letters: speak to any lender, explain the circumstances and get advice. You don't need to pay for good money advice; your Health and Social Care Partnership or the Citizens Advice Bureau can provide this free of charge.

Insurance

Check the small print of any insurance policies you have, including mortgage and loan protection insurance, life and personal accident cover. Do they mention dementia? Do you need to inform the insurance company of your diagnosis?



Further information

National Debtline (Scotland) can help with money worries **0808 808 4000**.

www.nationaldebtline.org

Pensions

If you've stopped work, or plan to, check your position regarding your pension.

State pensions

State pension age is the date you can begin receiving your state retirement pension. The state pension age is changing. From April 2017 state pension age for a woman is 63 and 9 months, and will gradually increase between now and November 2018 when it will be 65 for both men and women. It will then increase to 66 by October 2020 and 67 by April 2028. If you leave work before you reach state pension age you may be able to protect your state pension by getting National Insurance contribution credits. Credits are for people who are in certain circumstances – for example, people who are ill or unemployed and claiming certain benefits. People who are caring for someone else for 20 hours or more each week can also receive credits.

Occupational and personal pensions

If you have a company pension plan (occupational pension) or a personal pension plan, leaving work early will affect the amount of money you will receive. But many pension plans will allow you to take your pension early, or at least a lump sum, if you retire because of dementia. Check with your pension provider or talk to an independent financial advisor.



Further information

Advice on claiming your state pension.

www.gov.uk/browse/working/state-pension

Claiming benefits

You, or a person who cares for you, may be entitled to financial help from the benefits system, including some if you are still working.

The benefit and tax credit system is complex and can be daunting for anyone. Significant changes are being made to the benefits and tax credits system over the next few years because of changes in benefits legislation. It is always a good idea to get help from a benefits advisor who can tell you what benefits you are entitled to and help you with any forms. Benefits advice can be made available in other languages, or you could ask for an interpreter.

Most local authorities also provide benefits and welfare rights advice. You should check how to access this with your social worker or link worker. The Citizens Advice Bureau can also help you claim benefits. Contact telephone numbers are listed in the telephone directory or visit Citizens Advice Scotland's website www.cas.org.uk. You can also contact Citizens Advice Direct on their helpline on **0808 800 9060**.

The Disability and Carers Service, part of the Department for Work and Pensions (DWP), offers support to people claiming benefits related to disability (including dementia) and their carers. Visit www.gov.uk/browse/benefits/disability

It's always worth seeking advice – even if you think you are not entitled. Try the government's online benefit calculator to get an idea of what you're entitled to.
www.gov.uk/benefits-calculators

For you

Attendance Allowance

This is a social security benefit for people aged 65 or over who are physically or mentally disabled and need help with personal care or require supervision to remain safe. If you are aged under 65 then you will need to claim **Personal Independence Payment** instead.

Employment and Support Allowance

This is a benefit for people unable to work due to illness or disability and not entitled to Statutory Sick Pay, Income Support or Jobseeker's Allowance. You can also claim when Statutory Sick Pay ends.

Visit www.gov.uk/employment-support-allowance to find out about Employment and Support Allowance or call **0800 055 6688** (textphone **0800 023 4888**) to make a claim.

Statutory Sick Pay

If you're still employed but off work because of dementia, you're entitled to a maximum of 28 weeks' Statutory Sick Pay. Some employers, like the civil service, have their own occupational sick pay scheme that provides more than the statutory rate or for a longer period. You should check your contract of employment or ask your employer about this.

Find out more about Statutory Sick Pay at www.gov.uk/statutory-sick-pay or to make a claim call **03000 560 630**

Universal Credit

Universal Credit was introduced to replace Income Support, Income-based Jobseeker's Allowance, Income-related Employment and Support Allowance, Tax Credits and Housing Benefit. Since 2014, people who get the old benefits are gradually being moved across to the new system. www.gov.uk/universal-credit

The Scottish Welfare Fund

The Scottish Welfare Fund is run by local authorities and is split into two parts:

- Crisis Grants to provide a safety net in an emergency when there is an immediate threat to health and safety.
- Community Care Grants to enable independent living or continued independent living, preventing the need for institutional care.

The scheme does not include loans.

Help with council tax

Anyone who has a low income may be entitled to help with council tax. If you have a diagnosis of dementia and receive a benefit, such as Attendance Allowance, Disability Living Allowance, Personal Independence Payment or Employment and Support Allowance, you could be entitled to help with your council tax.

If you live alone you could be entitled to a council tax exemption. If other people live in the house you could be entitled to a council tax discount. Find out more about help with council tax from your Health and Social Care Partnership or contact your local Citizens Advice Bureau.

For carers

Carers may also be eligible for financial support.

Carer's Allowance

A carer 16 or over who looks after you for at least 35 hours a week may be able to receive Carer's Allowance, possibly Income Support, and National Insurance credits, provided they're not studying for more than 21 hours per week. In some circumstances, Carer's Allowance can affect the benefits you receive so it is always a good idea to seek advice before the claim is made.

If your partner is still working, a friend or family member who provides you with care or support for at least 35 hours per week can claim Carer's Allowance.

Carer's Credit

If your carer is looking after you for 20 hours a week or more they can apply for Carer's Credit to protect their state pension.



Further information

Find your nearest carers' centre to get advice on entitlements.

[carers.org/our-work-locally](https://www.carers.org/our-work-locally)

For information on Carer's Allowance visit

www.gov.uk/carers-allowance

Money: at a glance

- Priority: putting a power of attorney in place early on can give you peace of mind about future financial decisions (see **Future plans** on p. 78).
- Get financial advice so you know where you stand and can plan ahead.
- You can get someone you trust to help manage day-to-day money.
- Check the small print on policies, pensions and agreements.
- There are benefits you can claim while you're still working.
- Your carer may be eligible for help too.

Support

Your right to support after diagnosis

Since 2013, the Scottish Government has committed to ensuring that those diagnosed with dementia are offered a minimum of one year of post-diagnostic support from a named dementia link worker. Scotland's National Dementia Strategy 2017–20 recognises that many people are diagnosed later in life, and already have significant care needs. The strategy sets out a commitment to work towards offering post-diagnostic support to those people as part of their existing care support but with an emphasis on a more coordinated approach. Those who are diagnosed earlier in the illness and who have little or no need for formal health or social care support will continue to be offered post-diagnostic support from a named dementia link worker. This represents a change in approach but this will be developed throughout the period of this strategy. This person's role is to help you:

- understand your type of dementia, come to terms with your diagnosis and manage any symptoms
- stay connected to community and social networks
- get support from other people with dementia, their families and carers
- plan for your future care and support, to make sure it's shaped around your preferences
- put in place arrangements for future decision-making, such as power of attorney or Advance Statements.

At the end of the year, you should have developed a personal plan for your future, based on your wishes, goals and expectations, which will help other people to support you in the future.

The commitment started in April 2013 and services are now working to implement the commitment locally. Ask your doctor or contact the Dementia Helpline on **0808 808 3000**.



Support services from your local Health and Social Care Partnership

Depending on the level of your needs you may be eligible for services from your local Health and Social Care Partnership. If you are assessed as needing social care and support or 'community care services', you should expect to have some choice over how you receive that support.

If you want, you can ask the social worker or care manager to organise this for you. They will arrange for services to be provided by the Health and Social Care Partnership or by an agency. But you can also direct your own support using a system known as Self-directed Support. By choosing how you receive your own support you can live as independently as possible for as long as possible because you personally take charge of the care you receive.

Self-directed Support

Self-directed Support is about people making informed choices about their support and having as much control over it as they want. It's also about offering people flexibility so they can use their support in the ways, and at the times, that suit them best.

Health and Social Care Partnerships must offer four options to everyone they are going to provide support to. The four options are:

1. The Health and Social Care Partnership gives you funds to organise and pay for the support of your choice. This is called a Direct Payment.
2. The Health and Social Care Partnership or a service provider handles the money but you decide what it is used for.
3. You allow the Health and Social Care Partnership to arrange your support.
4. Any combination of options 1, 2 or 3.

See the **Alzheimer Scotland** leaflet Self-directed Support and dementia. Go to **www.alzscot.org** or call the Dementia Helpline on **0808 808 3000**.



Help for carers

Your family should be involved in all discussions and decisions about care and other services so you get help that suits you all.

Carers are entitled to an assessment of their needs. Adult carers are assessed using the Adult Carer Support Plan and young carers using the Young Carers Statement. Carer groups and carer training may be available in your area. Contact the Dementia Helpline on **0808 808 3000** or ask your link worker if you have one for information about carer training and support.

Support at appointments

You may feel that you would like some support when you go to appointments, as they can be very overwhelming. You can ask a carer or a family member to attend with you, but you can also ask for professional support at these appointments, such as an advocacy worker.

If English is not your first language, or if you are deaf or hearing impaired, you may find it useful to arrange to have an interpreter present at appointments. The interpreter will translate the conversation for you. It is important to make contact with local minority ethnic or deaf community support groups within your area, who may be able to refer you to suitable support.



Further information

Carers' centres all over Scotland provide training and support. www.careinfoscotland.scot/topics/support-for-carers/carers-centres

Carers Scotland offers a voice for carers as well as practical help and advice on coping. www.carersuk.org/scotland

Carers Trust offers information, online training and a discussion forum. carers.org/article/dementia

Royal National Institute of Blind People (RNIB) offers advice on dementia and sight loss. www.rnib.org.uk/eye-health-sight-loss-other-medical-conditions/dementia-and-sight-loss

NHS Health Scotland Living well with dementia DVD at the back of this publication has a British Sign Language translation.

NHS Health Scotland booklet and DVD, Coping with dementia. www.healthscotland.com/topics/stages/healthy-ageing/dementia-resources.aspx

Scottish Council on Deafness. www.scod.org.uk
Telephone **0141 248 2474**, textphone **0141 248 2477** or
text **07925 417338**.

Action on Hearing Loss. www.actiononhearingloss.org.uk
Telephone **0808 808 0123**, textphone **0808 808 9000**,
text **07800 000 360**.

Deafblind Scotland. dbscotland.org.uk
Telephone **0141 777 6111**, email
info@dbscotland.org.uk

Support: **at a glance**

- The Scottish Government has guaranteed that everyone diagnosed from 1 April 2013 will get individual support from a named and trained person – a dementia link worker – for at least a year after diagnosis.
- Health and Social Care Partnerships are the main route to getting support.
- Assessments help you to find out what support might suit you.
- Involve your family or carer in discussions and decisions.
- Carers can benefit from an assessment too.
- You are not alone – share experiences with other people with dementia.

Future plans

The nature of dementia means that things are inevitably going to change – how quickly, and how much, is hard to predict.

But there are things you can do now to put you and your family and friends in a better position to deal with whatever happens. Planning ahead puts you in control and makes sure your personal wishes are known and clearly understood.

You may already have given this some thought, especially at key points in your life not connected with dementia, like having children, getting married or a family crisis.

It may involve difficult and emotional discussions, but it can give you and the people close to you peace of mind to know that you have agreed on important issues.

It is important to make your views and wishes known. Talk to your carer, family, friends and others, like your doctor, at an early stage about what you want to happen in the future, in case they have to make decisions on your behalf. Ideally, write down your views and wishes so they are on record.

Future legal and financial decisions

Everybody, not just people with dementia, should plan ahead for the possibility that they will no longer be able to make decisions themselves about their care or property, or say what they would like to happen when they die. Planning ahead can put your mind at rest. There are three documents that can be prepared – a power of attorney, a will and an Advance Directive – sometimes called a living will. For those with a diagnosis of dementia, an Advance Statement can also be completed.

Solicitors can prepare all of these documents to ensure they are filled in correctly. It isn't a lengthy process, usually only a couple of visits to the solicitor is enough. Legal aid can often be obtained if you feel you can't afford the legal fees and it is a quick process to see if you qualify. Not all solicitors provide legal aid, but you can check with the Scottish Legal Aid Board www.slabb.org.uk for solicitors in your area who do.

Power of attorney

You may wish to legally appoint your partner, a friend or family member as an 'attorney' to make health, welfare and financial decisions on your behalf if at some point you cannot make them yourself. This is known as granting 'power of attorney'.

Age Scotland has produced a guide on power of attorney in Scotland. This can be found at www.ageuk.org.uk/scotland
You can also visit www.publicguardian-scotland.gov.uk/power-of-attorney

Granting power of attorney is a good way of making sure your views, choices and decisions are respected in the future.

People often do this anyway, because no one knows what the future holds and it is reassuring to know someone you trust will be acting with your best interests in mind. Your partner may want to set one up too.

Without power of attorney, your family may be unable to make significant decisions on your behalf, or manage your financial affairs for you. There are ways of doing this but they involve possibly lengthy and costly court proceedings.

There are two main types of power of attorney: 'welfare power of attorney' and 'continuing power of attorney'. A welfare power of attorney covers your health and personal affairs, such as where you live and what care and treatment you receive. This type can only be used once you have been assessed as lacking mental capacity. A continuing power of attorney covers your finances, including property and bank accounts. This type may be used as soon as it's registered. Many powers of attorney are joint, giving both continuing and welfare powers to a named person or persons in the same document, although you can appoint different people for each if you prefer.

It's also a good idea to appoint at least two people as attorneys so that you have at least one attorney in place should something happen to the other. This is called a 'substitute' attorney. You can also appoint two or more people to be joint attorneys.

If you are on your own, or don't have family members or friends willing and able to act as attorney, you can appoint a solicitor to be your continuing power of attorney. Solicitors will not normally accept appointment as welfare power of attorney.

The completed documentation needs to be signed by:

- the people you've chosen as attorneys
- you, and witnessed by someone other than anyone you are granting power of attorney to
- a doctor or a solicitor, stating that in his or her opinion, you understand what you are doing and are not acting under duress. Usually they will charge for this.

You then pay a fee to register your power of attorney with the Office of the Public Guardian. Until it is registered it cannot be used. This can take up to 10 weeks. There is an accelerated procedure for registration if emergency action is needed. It is also possible to complete the paperwork online which can help speed up the process.



Further information

The Office of the Public Guardian offers advice on power of attorney, including an indication of costs.

www.publicguardian-scotland.gov.uk/power-of-attorney

Making a will

A will makes clear what you want to happen with your money and property after you die.

You may have already written a will. It is good to regularly check that it still reflects what you want to happen after your death. Making a will is good practice for everyone.

Power of attorney can be drawn up at the same time as a will and can usually be included in the cost. It may work out cheaper to do both at the same time, but do ask for a cost estimate first. The executor of your will could be the same person you appoint as attorney.

You can draw up your own will but it's safer to involve a solicitor or qualified will writer to avoid errors or omissions that could cause problems. They will also make sure your will is kept secure.

Other legal safeguards

There may be other things you need to look at for your future peace of mind and to protect the people you care about.

This might include sorting out legal ownership of property or other possessions if you and your partner are not married or in a civil partnership, or you are not divorced from a previous partner. There may be custody or immigration issues that you want to settle.

Future care and treatment

Taking action now means important decisions are not left until things reach crisis point and relieves the burden of responsibility on your family and friends.

Written instructions provide the best possible guide for professionals faced with difficult decisions about what treatment or care to give you.

Advance Directive

In Scotland, adults with legal capacity can influence their own medical treatment and even refuse to accept treatment. However, a problem can arise if someone loses the ability to communicate.

An Advance Directive is a written witnessed statement of your wishes as to what treatment you might wish or not wish to have in the last stages of your life. Typically many people say in their Advance Directive that they would not want certain treatments that would only serve to prolong life somewhat when death is inevitable. Usually people say they would wish the continuation of all pain-relieving treatment but not to receive artificial feeding or resuscitation. Close relatives are often faced with having to make 'end-of-life' treatment decisions with doctors and the existence of an Advance Directive is a huge help to them in making such decisions.

Most Advance Directives are witnessed by solicitors, and it is certainly wise to discuss your directive with your doctor. It is also very important to advise your welfare attorney of the existence of a directive – which is normally placed with your medical records.

Advance Statement

An Advance Statement is a similar statement of someone's wishes – but it serves a different purpose. An Advance Statement does not deal with treatments when death is imminent. Instead, Advance Statements contemplate a period of future illness (from which you may recover) where you may not be able to communicate your wishes to others. Doctors are bound to follow what is in an Advance Statement unless there are clinical reasons for not doing this. Any departure by a doctor from an Advance Statement may be challenged. An Advance Statement again is a witnessed document which is normally placed with medical records.

An Advance Statement ensures your personal preferences about care, support and medical treatment are followed wherever possible. This is a chance to clarify what is really important to you.

Once you've written your Advance Statement, it needs to be kept where the right people can refer to it easily. For instance, your GP should have a copy.

Your statement might include things like:

- I would want to stay in my own home as long as possible.
- I would want to keep to a strict vegetarian diet.
- I would want to carry on going for walks.
- I would want to involve my same-sex partner and daughter in my decisions.
- I would not want my father visiting me and being involved in my decisions.

It's not a guarantee that your wishes will be followed, just that they will be taken into account. If they're not followed, the doctor or other professional involved in your care or treatment must explain why to you and your family.

Review your Advance Statement regularly to make sure it reflects changing circumstances.

Care options

Many people with dementia remain in their own homes, but you may want to consider alternatives for the future.

Plan ahead and discuss your options with the support of an expert like your community psychiatric nurse or social worker. They will be able to tell you what is available in your area.

This is an opportunity for you and your family to voice your opinions and wishes, and avoid any misunderstandings or ill feeling at a later date.

There are care homes available which can provide care for people with dementia.



Further information

Alzheimer Scotland information sheet, Making decisions about future treatment. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

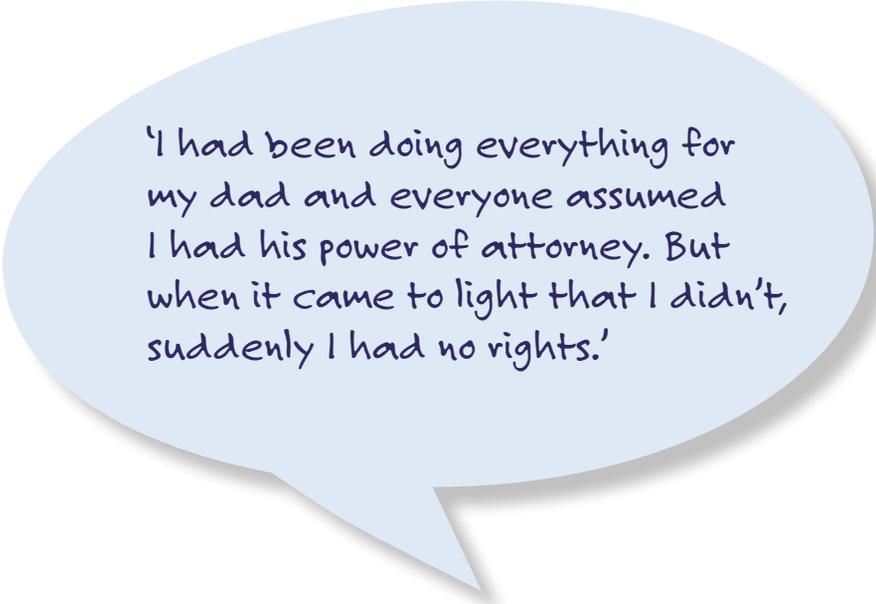
The **Good Life, Good Death, Good Grief** website has information on planning future care. www.goodlifedeathgrief.org.uk

The **Care Inspectorate** offers information on choosing and using care services. www.careinspectorate.com



Future plans: **at a glance**

- Planning ahead puts you in control and makes your wishes known.
- Power of attorney can set your mind at rest – someone you trust will be acting with your best interests at heart.
- If you already have a will, this is a good time to review it.
- Advance Directives and Advance Statements can also clarify what is important to you.
- Talking about care homes now means important decisions won't be made in a hurry.



'I had been doing everything for my dad and everyone assumed I had his power of attorney. But when it came to light that I didn't, suddenly I had no rights.'

Appendix 1:

Types of dementia

There are many types of dementia, some of which you may have heard of, such as Alzheimer's disease. Some kinds, such as frontotemporal dementia (FTD), are more common in younger rather than older people.

Following a diagnosis, you may want to know what to expect in detail. This section gives a brief outline of the various types of dementia, likely symptoms and the possible impact on everyday life.

It directs you, where possible, to more information. However, for some forms of dementia, easily accessible information can be more difficult to find.

You should also bear in mind that symptoms vary from person to person and from day to day. You may prefer to cope with any changes as they happen rather than trying to predict the specific impact of your diagnosis.

It is possible for someone to have more than one type of dementia at the same time.

My diagnosis:

There are many very rare conditions that can cause dementia. There are also conditions that can accompany dementia, such as Parkinson's disease and Huntington's disease. If you are diagnosed with a rare form of dementia, organisations like Alzheimer Scotland may be able to signpost you to specific support groups.



Further information

Alzheimer Scotland information sheets on rarer forms of dementia. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Alzheimer's disease

This is the best known and most common form of dementia generally. Alzheimer's disease comes on gradually and usually progresses slowly over several years. It can cause particular problems with memory and thinking.

Learning new information can become harder – it may be difficult to remember recent events, appointments or phone messages.

Forgetting the names of people or places and struggling to understand or communicate with others are common symptoms. It can become difficult to find the right words to describe familiar objects and to make decisions.



Further information

Alzheimer Scotland information sheet, Alzheimer's disease. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Frontotemporal dementia (FTD)

FTD is caused by damage to brain cells in the frontal and temporal lobes of the brain. It is sometimes referred to as Pick's disease, although this term is used less often today.

There are two main forms of FTD. One causes changes in a person's behaviour to begin with, and the other affects language and communication. FTD is a complex condition and, like other forms of dementia, it is difficult to predict the exact course of the illness in any individual.

People with FTD can lose insight into their condition and can be easily distracted. A person may find it difficult to plan and organise things and may also develop compulsive routines.



Further information

Alzheimer Scotland information sheet, Behaviour variant frontotemporal dementia (FTD). Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Vascular dementia

There are various forms of vascular dementia, in which the blood supply to the brain becomes blocked and starves brain cells of oxygen, causing small strokes [sometimes referred to as 'mini strokes' or transient ischaemic attacks (TIAs)] that affect different parts of the body.

Strokes on the left side of the brain affect the right arm and leg, memory and speech. Strokes on the right side affect the left arm and leg.

Strokes on either side can make it harder to recognise familiar objects and manage complex tasks. They may also cause mood swings and personality changes.

This form of dementia progresses in steps, and it is very difficult to predict how it will affect someone, and when.

Sudden changes, as strokes occur, may be quite mild and last for only a few hours or days, especially in the early stages, and then stabilise.



Further information

Alzheimer Scotland information sheet, Vascular dementia. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Dementia with Lewy bodies

This is caused by clumps of protein – known as Lewy bodies – that build up inside nerve cells in the brain that control thinking and movement. Some people with Parkinson’s disease develop dementia, so symptoms can be very similar.

Dementia with Lewy bodies can be difficult to diagnose because the symptoms fluctuate and don’t necessarily suggest a form of dementia.

Memory can become patchy, although short-term memory may be unaffected to begin with. Drowsiness and lethargy are common symptoms. It might become difficult to solve problems, form organised sentences and make plans.



Further information

Alzheimer Scotland information sheet, Dementia with Lewy bodies. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Parkinson’s UK factsheet, Dementia with Lewy bodies
www.parkinsons.org.uk/information-and-support/dementia

Korsakoff's syndrome and alcohol-related dementia

Korsakoff's syndrome is caused by lack of thiamine (vitamin B1), which affects the brain and nervous system. People who drink excessive amounts of alcohol are often thiamine deficient. This is not strictly a form of dementia but has similar symptoms, especially memory loss, personality changes and difficulty learning new skills. It does not progress once the person stops drinking – indeed it may initially improve.



Further information

Alzheimer Scotland information sheet, Korsakoff's syndrome. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Treatment for dementia

There is no cure for dementia, but various treatments, including drugs, can help manage symptoms. They may not be suitable for everyone, but knowing what is available may help you discuss appropriate treatments with your doctor. Always consult your doctor before starting any treatment, including herbal and other alternative remedies, as they can have serious side effects.

General treatments

It's important that the person you care for has a healthy, balanced diet and gets some exercise. The longer they stay fit and healthy, the better their quality of life will be.

Widely available treatments, not just for dementia, may help with certain symptoms and general mental and physical health:

- Physiotherapy can help with problems with flexibility and walking.
- A dietitian can give you advice on healthy eating, and help if you find your eating habits change because of dementia.

- Speech and language therapy can be helpful with problems with speaking clearly, communicating or swallowing.
- Occupational therapy helps maintain skills and abilities.
- Music and aromatherapy may reduce anxiety and improve low moods.
- There are drugs for depression, and to relieve restlessness and problems sleeping.

There is a range of ‘talking’ and other psychological therapies that can help with different aspects of dementia, including stress and anxiety. Some of these may also help your carer and family.

Specific treatments

A doctor and psychiatric consultant can advise on what drugs might be suitable for you, taking into account what form of dementia you have and other factors, including possible side effects.

Alzheimer’s disease

The drugs most commonly used to treat mild to moderate Alzheimer’s disease are donepezil (Aricept®), rivastigmine (Exelon®) and galantamine (Reminyl™). Memantine (Ebixa®) is available for people in the mid to later stages of Alzheimer’s disease.

Vascular dementia

Aspirin is widely used to reduce the risk of further brain damage, including reducing the risk of strokes. There are also drugs available to control high blood pressure, to help prevent strokes and to treat diabetes and high cholesterol levels.

Drugs used for dementia symptoms

These can be used to treat restlessness, aggression and some of the other psychiatric symptoms which can appear in people with dementia. They include drugs for anxiety and depression, drugs to help sleeping difficulties and antipsychotic drugs, but because of their potential side effects they should only be used if other options fail. The dose should be as low as possible for as short a time as necessary and carefully monitored. This is particularly relevant with antipsychotic drugs.

Antipsychotic drugs should not normally be given to people with dementia with Lewy bodies. You should check with your doctor as they can cause a very severe reaction if taken incorrectly.

Dealing with specific symptoms

Other sections of this publication look at how to cope with the impact of various symptoms in certain situations and settings, like making your home safer.

You can get specific advice about changes in behaviour. There is rarely a right or wrong way – just what works for you and the people who care for you.



Further information

Alzheimer Scotland information sheet, Stress and distress. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Appendix 2:

Care and support glossary

A diagnosis of dementia will bring you into contact with various health and care professionals and services. This is a rough guide to what they can provide. Care and support in your area may not include all of them, or be particularly designed for younger people. Alzheimer Scotland is a good place to start finding out what help is available locally.

People who can provide treatment, support or advice

Clinical psychologist

This is a health professional specially trained in diagnosing and assessing dementia and other mental health problems, who can provide a range of psychological treatments to help with symptoms and your overall wellbeing.

Community psychiatric nurse (CPN)

This is a qualified mental health nurse, part of a team working with the consultant psychiatrist, who will help you and your family cope with your diagnosis and everyday living.

Dementia advisor

Dementia advisors provide information and advice to help the person and his or her carer and family find the dementia support they need, connect them to local groups and services, and help local communities to be more dementia friendly.

Dementia link worker or post-diagnostic support worker

This is a named and trained person who works with a person with dementia, their partner and family for at least a year following diagnosis. They help people understand and come to terms with their diagnosis, maintain their existing connections in the community and put them in touch with other people in the same situation. They help people plan for their future care and future decision-making. This person may also be called a post-diagnostic link worker or memory clinic link worker.

Dentist

Dentists are qualified to treat the diseases and conditions that affect the teeth and gums. Some dentists will do home visits. Talk to your dentist about this or ask your local Health Board about the Community Dental Service.

Dietitian

It is particularly important to eat well and not become dehydrated when you have dementia. A dietitian can give you advice on healthy eating, and help if you find your eating habits change because of dementia, or symptoms mean you struggle to swallow.

Doctors and nurses at your local practice

They should be able to advise on treatment and put you in touch with other medical services, and other sorts of care and support locally.

Health visitor and community district nurse

These nurses can visit you at home if you have any general health problems.

Occupational therapist

The occupational therapist (OT) is expert at helping people to continue doing as much as they can in their daily lives, for example with social and practical activities. He or she can recommend the right equipment to help, from bath and toilet equipment to memory equipment. You might be able to borrow equipment to try it out. The OT can also advise carers on how to support someone living with dementia to maintain skills, routines and roles. You can find an OT through the Health and Social Care Partnership, your GP, your local Alzheimer Scotland support organisation or through the community mental health team.

Physiotherapist

People in the moderate to late stages of dementia often have difficulties with walking and some experience falls, or don't feel able to access the activities they used to take part in. Physiotherapists can give advice around exercise to improve strength and balance, provide walking aids and/or advice to assist walking, and provide advice around the prevention of falls. They can also advise carers on the safe way of helping someone to move. Referrals to a physiotherapist are made through the community mental health team or by a GP.

Podiatrist

Podiatrists (chiropodists) usually work in clinics, but can make home visits. NHS podiatry services are available free of charge for people who have a foot problem or have a medical need for podiatry treatment. Personal footcare, such as toenail cutting, is not provided by NHS podiatry services.

Psychiatrist

A psychiatrist is a qualified doctor specialising in mental health. Their particular area of interest may be dementia generally, old age or younger people with dementia. It is usually, but not always, a psychiatrist who makes and gives a diagnosis of dementia. They can prescribe drugs as well as advising on other forms of treatment, like counselling and different types of therapy.

Social worker

Social workers can help to assess your needs, in consultation with you and your family. They can advise you on how to have your support provided, for example, through direct payments (see **Support** p. 71). They are employed by the Health and Social Care Partnership.

Speech and language therapist

A speech and language therapist can provide support and advice on how to maximise communication, both verbal and non-verbal. They can also assess and give advice if there are problems with eating, drinking and swallowing. GP, mental health services and Health Boards have details of local adult speech and language therapy services.



Types of service or support

Day centres or day opportunities

Day centres are generally more suited to people in the later stages of dementia who need more support as they have the staff to offer structured activities. They may also be open in the evenings and at weekends.

Dementia cafes and drop-in centres

These bring together people with dementia and their carers to mix socially, share experiences and get advice and information in a cafe-like community setting (sometimes an actual cafe).

Home care

Regular, short visits to your home by a care worker can be particularly helpful in the later stages of dementia with things like getting washed and dressed.

Home support

Home support helps you continue to do things that are important to you, and not just in your home. It might include supporting you to go shopping or visit friends, or simply providing you with company.

Respite care

This can give both you and your carer a break, or provide you with some support if your carer is away. Respite care can mean someone comes to stay in your home or you can stay temporarily in a care home.

Self-directed Support

Self-directed Support is about people making informed choices about their support and having as much control over it as they want.

The Health and Social Care Partnership must offer the four options to everyone they are going to provide support to (see p. 73).

Voluntary services

Local charities and community groups often run schemes that offer the chance to socialise and get involved in activities.



Further information

Care Information Scotland explains what services are available, including in your area.

www.careinfoscotland.scot

Care Information Scotland has specific advice on care services for people with dementia. www.careinfoscotland.scot/topics/care-at-home/dementia-services

The Self-directed Support in Scotland website explains how people can manage their own care and support.

www.selfdirectedsupportscotland.org.uk

Alzheimer Scotland leaflets Self-directed Support and dementia. Go to www.alzscot.org or call the Dementia Helpline on **0808 808 3000**.

Appendix 3: Dementia campaigns and research

The **Scottish Dementia Working Group** is a national campaigning group, run by people with dementia. They are the independent voice of people with dementia within Alzheimer Scotland. The working group campaigns to improve services for people with dementia and to improve attitudes towards people with dementia.
www.sdwg.org.uk

The **National Dementia Carers Action Network (NDCAN)** is a national campaigning group that aims to represent and raise awareness of the particular challenges encountered by carers of people with dementia. Members have personal experience of caring for a person with dementia.
www.alzscot.org/ndcan

The **Dementia and Neurodegenerative Research Network** is funded by the Chief Scientist Office to promote a culture of clinical research in dementia and neurodegenerative diseases across Scotland and improve recruitment to high-quality studies from both urban and rural areas to advance understanding and develop new treatments.
www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease

Innovations in Dementia is a community interest company based in England that involves people with dementia in developing new treatments and approaches to dementia care.
www.innovationsindementia.org.uk

The **Alzheimer Scotland Dementia Research Centre**, at the University of Edinburgh, was created to provide a high-quality environment for dementia research and to house a brain tissue bank.
www.alzscotdrc.ed.ac.uk

Join Dementia Research is a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies.
www.joindementiaresearch.nihr.ac.uk