

younger people with dementia

Living well with
your diagnosis

the scottish
dementia
working group

run by people with dementia



Alzheimer Scotland
Action on Dementia

We are happy to consider requests for other languages or formats. Please contact 0131 536 5500 or email nhs.healthscotland-alternativeformats@nhs.net

This publication uses the term 'carer' when talking about someone, usually your partner, family member or friend, who supports you to live well with dementia on a daily basis. Not everyone likes this term to describe what they do, but it is often used officially – when claiming benefits or seeking support, for instance.

For the purposes of this guide, based on how most benefits, and NHS and Social Work services are currently provided, 'younger' means under the age of 65.

Call Alzheimer Scotland's Freephone 24-hour Dementia Helpline on **0808 808 3000** or **email helpline@alzscot.org** for information and support. Some mobile networks charge for this number, so check with your provider.

We would like to thank all of the people with younger onset dementia and their family carers, as well as all of the organisations that have assisted in the production of this resource. With special thanks to the Glasgow Younger Person's Service at Alzheimer Scotland and the Scottish Dementia Working Group.

Published by NHS Health Scotland

Woodburn House
Canaan Lane
Edinburgh EH10 4SG

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ISBN: 978-1-84485-572-8

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NHS Health Scotland is a WHO Collaborating Centre for Health Promotion and Public Health Development.

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There is a great deal of information in this booklet. It has been designed and informed by people with a diagnosis of younger onset dementia (dementia diagnosed under the age of 65) and their carers. They have suggested that you may want to dip in and out of this information, rather than reading it all at once. There are helpful tips and signposts to more advice throughout this booklet.



Introduction

Dementia is the general term for a range of brain disorders which can affect all aspects of memory, thinking and behaviour.

It's not just older people who develop dementia. You may be reading this because you or someone you know have been diagnosed with dementia at a much younger age.

You may be feeling a range of emotions. Shock, disbelief and even relief can all be 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.

Everyone in Scotland diagnosed from 1 April 2013 is now entitled to a minimum of a year's worth of support after diagnosis. Ask your doctor or contact Alzheimer Scotland for more information.

'Getting early intervention, getting an early diagnosis is the best way.'

Person with dementia

'There was just doubt and fear about what was going to happen.'

Person with dementia

'It was a relief to get the diagnosis and know what was wrong and how get help.' Person with dementia

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

You can also ask for a copy 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 and their families. It includes information that they felt was helpful or would have been helpful to them at and around the time of their diagnosis. It is specifically written for younger people with dementia and their families.

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

'Now I'm in a better place for dealing with it ... dementia is not that bad, nasty thing that it was, because I know how to handle it.' Person with dementia

Introduction: at a glance

- This publication is for younger people with dementia – those who are under 65.
- It includes information that people with dementia and their families found helpful around the time of diagnosis. Accompanying video clips are available online at www.alzscot.org and there is a DVD in the back of this booklet.
- 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.

'Before I used to be frightened about the future – now I just take every day as it comes. It's not the end of the world – there's life after dementia.'

Person with dementia

What is dementia?

There are over 100 forms of dementia (most are very rare) and it is possible to have more than one type of dementia at the same time. Different forms of dementia can have different symptoms but what they all have in common is that your brain cannot work as well as it should.

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.

There is a general lack of understanding about dementia affecting younger adults. Dementia is strongly associated with old age but there are around 15,000 people in the UK under the age of 65 who have dementia, with just over 3,000 in Scotland.

Alzheimer's disease is the most common form of dementia overall, but it is more likely that younger people will have other, rarer types of dementia.

Appendix 1 on page 82 outlines the most common types of dementia found in younger people, 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 you have other health conditions.



Further information

Alzheimer Scotland factsheet, *What is dementia?*

Go to www.alzscot.org/information_and_resources and search for 'what is dementia'.

Every person with dementia will experience it differently. People who know you may notice your symptoms more than you do yourself. The rarer forms, which are more common in younger people, include frontotemporal dementia, which can be very complex and difficult to diagnose.

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. This is more common in younger onset dementia. 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 factsheet, *Genetics and dementia*.
www.alzscot.org/downloads/genetics.pdf

'It's not taboo any longer,
you can say right out
you've got dementia -
you can get help.'

Person with dementia

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.

'It's important to accept who you are. I can't remember what it was like before my diagnosis. This is who I am now ... quick to laugh, quick to cry.'

Person with dementia

Keeping well and connected

Family and friends

Dementia may affect people in your life in different ways. You may have young children or teenagers, parents who need care and support themselves, a partner with responsibilities and commitments, and a wide circle of friends.

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.

Try to start talking openly about dementia. Your family and friends 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 page 82 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.

'Family' means what you want it to mean. It can include close friends and former, as well as current, partners.



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



Children

You may have children who live with you, or are still dependent on you if they have left home. Even if you have not spoken to them about it, they will probably 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. How you answer will also depend on each child.

‘My family – I come from a big family. They’re all very good. They understand things and make all sorts of allowances for us. If we go for a meal or go to a party in someone’s house and the party’s in full swing – we’ll leave. They understand we’re leaving and why we’re leaving.’ Carer

‘I’ve still got my mum so I’m still able to do things with her, do activities with her, say “I love you mum” and give her a hug.’ Young carer

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 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

NHS Health Scotland. *Understanding dementia: A guide for young people.*

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.

You can ask for a copy of either of these guides from Alzheimer Scotland's Freephone 24-hour Dementia Helpline on **0808 808 3000** or by emailing helpline@alzscot.org

Children may find **Carers Trust** online communities and local support groups for young carers helpful.

www.youngcarers.net/i_care_for_someone_who

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 and if you feel you need to, speak to a professional.



Further information

Alzheimer Scotland factsheet, *Sexuality and dementia*.

www.alzscot.org/pages/info/sexuality.htm

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

'The most wonderful counsellor came out to our house and talked to us. The counsellor just normalised the situation for us and invited us to a therapeutic group - it was amazing.' Carer

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 religious organisation, sports clubs or special interest societies linked to your hobbies, or be involved in support groups due to 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, or how you can still be involved in certain activities if some aspects become difficult.



Further information

Alzheimer Scotland booklet, *I'll get by with a little help from my friends.*

www.alzscot.org/pages/info/friends.htm

'I still go my walks with my dog, look after my cat, see my friends. I think it's important that I do as much as possible for myself for as long as possible, for my self-esteem, and probably my pride and me.'

Person with dementia



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 and less busy 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.

'Some of his friends to this day have been absolute diamonds, they understand the situation and they're great. They are absolutely wonderful.' Carer

'There is a great tendency to feel a bit isolated and make yourself isolated. You've really got to push hard and make sure that you live a kind of normal life ... seeing friends and so on'

Person with dementia

Recording your life story

You could make a personal record of your experiences. Creating a 'life story' is a fun 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 materials) – anything that is special to you and triggers certain memories and emotions.

'A social worker came in to see her and sat with her asking questions about her life when I wasn't there. She developed a life story book and it ended up being a history of my wife's life, along with all her likes and dislikes. I learned things about my wife that I hadn't known about before. It was fantastic.'

Carer

Holidays and outings

When planning holidays or trips, you will need to tell travel and medical insurance companies about your diagnosis and you 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 page 42.



Further information

Alzheimer Scotland booklet, *Travel and holidays*.

Go to www.alzscot.org/information_and_resources and search for 'travel'.

There are companies that specialise in holidays for people with dementia, such as Dementia Adventure.

'Holidays just take a little bit more organising.' Carer

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 for younger people with dementia and carers. You could create your own web forum or blog to get in touch with people of your age 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.

But 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. And if you're online, take care to keep your personal information secure.

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** 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

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

The **Dementia Advocacy and Support Network** is an international online forum. www.dasninternational.org

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.
- 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 younger people with dementia.

'We also link in with the support group that we have - we meet up with their partners and themselves once a month, as well, for the supper club, which is really good because it's something we'd all do normally.' Carer

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. There may be changes you may want to make, for example, adding your partner to the deeds of your property. 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 local authority may have a duty to provide you with aids and adaptations. 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, that you can access through your local social work department, can advise on what would be most helpful, based on your needs, wishes and general circumstances. Local authorities will sometimes pay for alterations and equipment.



Further information

Alzheimer Scotland and **Law Society Scotland** can provide details of suitable solicitors and law centres near you. Go to www.alzscot.org/information_and_resources and search for 'solicitors'.

www.lawscot.org.uk

Shelter Scotland can advise on your rights if you rent your home. Call **0808 800 4444**

The **Citizen's 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.adviceguide.org.uk/scotland

The **Legal Services Agency** mental health legal representation projects (Strathclyde, and Edinburgh & 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.

- 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 only leave 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 property owners and people over 60.

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, automatically contacting someone to come to your assistance. This may be accessed through your local social work department. 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 paste a clear reminder nearby, which will encourage you to carry on doing things like cooking for yourself?



'I use my mobile phone reminders all the time. It really helps.'

Person with dementia

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 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.



Further information

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

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 and your diagnosis may make your housing needs a priority.

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



Further information

Shelter Scotland provides information on disabled people's housing rights. Call their free advice line on **0808 800 4444**.
www.shelter.org.uk/disabledrights



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.

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 have a review of your condition, at least every 15 months, by your GP or practice nurse.

You may also be within the age range for health screening (such as breast screening or cervical screening) so it is important for you to continue to attend these and get help to attend if you need it.

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. Dementia can affect visual processing so it's harder to perceive depth and contrast, for instance. An eye health check is recommended every two years under the age of 60 and annually over 60. Specialist support, like low vision clinics, can help overcome problems due to sight loss.

Staying connected with other people who share and understand your condition or disability can provide practical and emotional support.

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

Wellbeing

Improving your overall wellbeing will make you more physically and emotionally resilient and better able to deal with dementia.

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.

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

On a more practical level, don't push yourself too hard and listen to your body if it's telling you to rest. Get the balance right though – giving up your favourite activities may leave you feeling low.



Further information

Alzheimer Scotland factsheet *Dementia and deafness: What you need to know*

www.alzscot.org/pages/info/deafness.htm

Deaf Connections and **Alzheimer Scotland** have developed a British Sign Language DVD to help deaf people with dementia.

www.deafconnections.co.uk

Royal National Institute for the Blind (RNIB) offers advice on dementia and sight loss.

www.rnib.org.uk/dementia

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 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 important too 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. They provide a safe and supportive space in times of difficulty by listening and offering advice and information. A British Sign Language service can be accessed through the website.

Call **0800 83 85 87**

www.breathingspacescotland.co.uk

NHS Living Life is a new telephone service based on cognitive behavioural therapy (CBT). They provide help for people suffering from low mood, mild to moderate depression, symptoms of anxiety or a combination of both.

Call **0800 328 9655** (Monday to Friday 1 pm to 9 pm)

Physical activity

Keeping physically active is good for your body and your brain. It can improve your mood too, especially continuing to do the sorts of exercise you enjoy and that provide you with a social life as well, like dancing, going to the gym or playing football or golf. You may just need a bit more support.

Physical activity can help delay or reduce some mobility problems associated with dementia by improving your balance and strengthening muscle tone. 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 up slowly. You should aim to do 30 minutes of activity each day, which can be achieved throughout the day rather than all at once.

Your local authority leisure services department should be able to tell you about activities near where you live.



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 **Active Scotland** website for a list of all local activities, sports clubs and green spaces by postcode. www.activescotland.org.uk



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.



Further information

Mental health charity **Mind** has advice on eating to improve your mental wellbeing.

www.mind.org.uk

'I have a tupperware box with his sandwiches and the fruit bowl sits beside it, with a post-it that says 'Lunchbox' on it. It's working really well, and I know that he's eating a balanced lunch.'

Carer

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 reduce the risk of damage to your health, UK Government guidelines recommend that men should not regularly drink more than three to four units of alcohol a day and no more than 21 units a week, and women should not regularly drink more than two to three units a day, and no more than 14 units a week. The guidelines also suggest having at least two days a week without alcohol.

Smoking damages your health generally and adds to the risk of stroke, which put you at higher risk if you smoke when you have vascular dementia. If you can, try to give up – there is plenty of support to help you quit.



Further information

Alzheimer Scotland factsheet, *Healthy living with dementia*. Go to www.alzscot.org/information_and_resources and search for 'healthy living with dementia'.

For more information about how many units are in a drink. www.healthscotland.com/documents/5843.aspx

For further information and advice about alcohol and health, call the **Drink Smarter** helpline on **0800 7 314 314**. www.drinksmaarter.org

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

For further advice on how to stop smoking call **Smokeline** on **0800 84 84 84** or visit www.canstopsmoking.com

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.

'I really like to go out cycling, it's a good activity. It's good for relations and meeting people. It's good to do, I enjoy it.'

Person with dementia

Independence

Even if you have family, work and financial commitments and responsibilities, you will most likely be free to make your own decisions.

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.

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 are a wide range of legal provisions which are 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.dementiarights.org/charter-of-rights

'I used to be really, really independent and I wouldn't ask anybody for anything whatsoever. And I do find now that I do ask. I struggle, you know, with things, but I will ask if I need the help now.'

Person with dementia

There are also new 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 diagnosis
- be regarded as a unique individual and to be treated with dignity and respect
- access a range of treatments, care and supports
- be as independent as possible and to 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 *Standards of Care for Dementia in Scotland*. A guide for people with dementia and their carers explains what your rights are and the quality of care, support and treatment you should receive to stay well, safe and listened to.
www.alzscot.org/campaigning/national_dementia_strategy

Alzheimer Scotland explains what the Charter of Rights for People with Dementia and their Carers in Scotland covers.
www.dementiarights.org/charter-of-rights

Care Information Scotland outlines your rights as someone who needs care.
www.careinfoscotland.co.uk/myrights

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

Being involved

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

Any services you receive should meet your individual and cultural needs, even if they are not specifically designed for younger people, and should encourage you to use your abilities to the full.

Advocacy

You can get help from an 'advocate' to make sure you and your family's 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/help/rights_and_legislation/mind_guide_to_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 whether dementia means there is more significant risk in any areas of your life and what you want to do about it. For instance, is there an increased risk when you go walking alone? You might not get lost because you know the local roads well and have no problem with finding your way. But dementia could make you less aware of road safety.

Simple solutions can set everyone's mind at rest, like always carrying identification plus your mobile phone. You could also use a Helpcard – a wallet-size card that you can show to people to explain that you have dementia and might need a bit of help. Call the Dementia Helpline on **0808 808 3000** for a free supply of Helpcards 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 where they can provide particular help.



Further information

Alzheimer Scotland factsheet, *When people with dementia walk*.

Go to www.alzscot.org/information_and_resources and search for 'walking'.

Alzheimer Scotland advice on holidays and travelling alone if you have dementia.

Go to www.alzscot.org/information_and_resources and search for 'travel'.

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'.
- Consider using the dementia Helpcard in the back of this booklet.

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 whether 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 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 yourself. 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 and make arrangements for getting someone to drive you, or to arrange other transport.

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.



Further information

Contact the **DVLA** at Drivers Medical Group, DVLA, Swansea SA99 1TU. Telephone **0300 790 6806**.

www.gov.uk/dvla-medical-enquiries

The **Scottish Driving Assessment Service** offers assessments at a number of places throughout Scotland. Assessments are free under the NHS, but a referral letter from a doctor is required 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.directscot.org/article/DSContent_42

'I missed driving at first, but it's had a positive effect on my life. I now walk and enjoy seeing my neighbourhood and being more involved.' Person with dementia

Other ways of getting around

A diagnosis of dementia gives you certain rights that can help if you have to 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 over 60 and people with disabilities to travel by bus for free 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 authority 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

To find out how to apply for a National Entitlement Card from **Transport Scotland** telephone **0141 272 7100**.

Train travel

You can ask for help to use ScotRail services.

www.scotrail.co.uk/content/disability-and-inclusion

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. But dementia may slow your reactions and affect your judgement as a road user or pedestrian.

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 for the Blind (RNIB) can advise on mobility aids if dementia affects your vision.

www.rnib.org.uk/mobilityproducts

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 booklet, Travel and holidays.

Go to www.alzscot.org/information_and_resources and search for 'travel'.



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 and trains.
- Cycling and walking keep you independent and provide healthy exercise too.
- Request help from airlines and airports to make air travel easier.

'He wasn't comfortable driving so he decided to surrender his driving licence. That way it wasn't being taken away from him.' Carer

Work

Many younger people with dementia say their first symptoms appeared at work, like forgetting appointments or how to do familiar jobs.

But a diagnosis of dementia might not have to mean you have to stop working. It will depend on how the dementia affects you and what your job involves.

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.

In a few jobs – for instance, if you're in the armed forces, or work on a plane or ship – you are legally obliged to tell your employer if you have dementia. 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.



Further information

Signpost your employer to the Business Disability Forum.
www.efd.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 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 due to 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.

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 adviser 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 adviser can help you assess your strengths, abilities and skills.

www.gov.uk/looking-for-work-if-youre-disabled/looking-for-a-job

'I found it really difficult to manage at work.'

Person with dementia

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 group **Radar** guide, *Doing work differently*, explains your right to changes that will help you stay in work. Go to www.radar.org.uk and enter ‘doing work differently’ into the search box.

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 benefits, or other financial benefits, 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 page 56 for more information on pensions, insurance and benefits once you leave work.



Further information

Benefits and employment advice for you and your carer.
www.adviceguide.org.uk/benefits_sick_or_disabled_people_and_carers_s.htm

Advice on taking time off work because of ill health.
www.adviceguide.org.uk/scotland/off_work_because_of_sickness.htm

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 you change the way you work.

Your diagnosis may have an impact on your business partners and senior staff in your company and on 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 feel able to 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 adviser, 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 page 73).

'She and I, together, had come to the conclusion that she shouldn't work anymore. It was time to stop.' Carer

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 and 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.

www.carers.org/help-directory/right-flexible-working

'My colleagues and my manager were very supportive. They realised that sometimes I have to take time off to go to an appointment as I have to go with him. So that's fine.' Carer

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 page 73.

Your mortgage or rent is probably your biggest financial outgoing. There is information on owning and renting property in the **Home** section on page 21.



Further information

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

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 you 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 behave with money, like starting to spend compulsively or gamble, or make them more vulnerable to internet and other scams. It is possible to have limits set on bank accounts to manage withdrawals.

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, sick pay and wages from part-time work, and 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 page 73). 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.



Further information

Get advice on involving someone else in managing your money.
www.moneyadvice.service.org.uk/planningahead

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. They may also still have dependent children or young people who are financially dependent on them. Younger people with dementia may have less income coming in and may have difficulty keeping up repayments on credit agreements or meeting other financial commitments.

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 local authority or the Citizen's Advice Bureau can provide this free of charge.



Further information

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

www.nationaldebtline.co.uk/scotland

'I never have a lot of money in my purse, I just take out every day, in the house, what I need and put it in my purse.' Person with dementia

Pensions

If you've stopped work, or plan to, check the 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 between 61 and 68, depending on your date of birth and your gender. 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.



Further information

Advice on claiming your state pension.

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

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 adviser.

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?

Claiming benefits

You, or a person who cares for you, may be entitled to financial help from the benefits system, including some while 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 new welfare legislation. It is always a good idea to get help from a benefits adviser 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 local authority. 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

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. Call **08457 123456** (textphone **0845 604 5312**) or visit www.gov.uk/browse/benefits/disability

You can appoint someone as a joint account holder or 'permanent agent' to collect your benefits from the Post Office for you. Ask for an application form at any Post Office.

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-adviser

For you

Employment and support allowance (ESA)

This is a benefit for people unable to work due to illness or disability and not entitled to statutory sick pay, income support or jobseekers allowance. You can also claim when statutory sick pay ends.

Find out about ESA at www.gov.uk/employment-support-allowance or call **0800 055 6688** (textphone **0800 023 4888**) to make a claim.

Personal independence payments

Personal independence payments (PIP) will replace Disability Living Allowance (DLA). Over time all DLA claims will be transferred to PIP. If you already get DLA, you will eventually get a letter and follow-up phone call asking you to apply for PIP. You should seek advice to help you with this process.

Personal independence payment is paid according to your daily living and mobility needs, and can be claimed online.

Find out about personal independence payment at www.gov.uk/pip or to make a claim call **0800 917 2222** (textphone **0800 917 7777**). For advice or information about existing claims, call **0845 850 3322** (textphone **0845 601 6677**).

Statutory sick pay (SSP)

If you're still employed but off work because of dementia, you're entitled to a maximum of 28 weeks SSP. 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 at the DWP website or ask a benefits advisor.
www.dwp.gov.uk

Universal Credit

During the course of 2013, the government is introducing a new benefit called Universal Credit which will replace income support, jobseeker's allowance, tax credits and housing benefit. From 2014 to 2017, people who get the old benefits will be 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.

'I didn't know there was such a thing as a carer's allowance or anything. I didn't realise that there's structured things in place for carers and I'm aware now that carers can have a little bit of time, respite.' Carer

For carers

Carers may also be eligible for financial support.

Carer's Allowance

A carer over 16 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. 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' centres to get advice on entitlements.
www.carers.org/what-carers-centre-0

For information on carer entitlements, contact the Carer's Allowance unit on **0845 608 4321** (textphone **0845 604 5312**).

www.gov.uk/browse/benefits/disability

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 page 73).
- 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.

'Benefits are so confusing, so it was really good to speak to someone who knew what they were talking about, to help me fill in the forms.'

Person with dementia

Support

Services designed specifically to meet all the needs of younger people with dementia and their carers are still few and far between, but they are slowly growing.

Your right to support after diagnosis

The Scottish Government has set out a commitment that everyone diagnosed with dementia from 1 April 2013 will get individual support from a named and trained person – a link worker – for at least a year after diagnosis. 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 powers 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 Alzheimer Scotland for more information.

Support services

The local council social work department is the main route to getting support services in your own home or through services near where you live.

It's worth contacting the social work department as soon as possible, either directly, or through your GP or local voluntary organisations, even if you don't feel you need any help just yet.

A social worker can carry out an assessment and discuss any particular questions you may have. With your consent, they may talk to other people involved in your care. They can then advise on what local support might suit you and your family best. They may also be able to help you access welfare benefits and other financial support.

You can also get help from Alzheimer Scotland, which provides services all over Scotland, including support groups, carer education, welfare rights advice and one-to-one support.

People newly diagnosed will be allocated a link worker and they will help you navigate through the range of services available.



Further information

The 24-hour **Alzheimer Scotland** Dementia Helpline can answer questions about services. Call **0808 808 3000** or email **helpline@alzscot.org**

Alzheimer Scotland factsheet, *Community care and assessments*.

'I've seen an occupational therapist, she was really nice. She came out to see if I needed any help with things in my house or anything. And I saw a social worker. He was helpful as well.'

Person with dementia



Directing your own support

New legislation means you must be offered the option of having greater choice and control over how your support needs are met. This is called self-directed support and allows you to decide how the funding you are allocated for care and support is used. This includes the option of taking all or part of the funding as a direct payment. You must use the funds to meet your care needs but many people have been quite creative about how they do this. For example, some people have used the money for computer software or equipment to keep connected with others, or to pay for support to help them go away on holiday with their family rather than having respite in a care home.



Further information

The **Self-Directed Support** in Scotland website explains the ways you can choose to receive care funding.

www.selfdirectedsupportscotland.org.uk

Services for younger people

Specific services for younger people with dementia are not available everywhere. Check with your local social work department if there are any in your area.

Although local dementia services and activities may not be designed for people your age, or are not geared towards the symptoms of rarer forms of dementia, you may still find them useful. Other support may be available if you have an additional condition linked to your dementia, such as a brain injury or Parkinson's disease.

Services vary in what sort of support they offer. Some might involve very structured activities while others are more about socialising.

You may find community-based services such as day opportunities, home support or counselling groups are the most common type of local support specifically for people your age.

Appendix 3 on page 95 outlines various types of service.

People newly diagnosed will be allocated a link worker and they will help you navigate through the range of services available.

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 can request an assessment of their own needs. Carer groups and carer training may be available in your area. Even if these are for carers generally, or focus on caring for older people with dementia, they may still offer helpful support from people in similar situations and address common concerns like legal and financial issues.

'They're generally around the topic of dementia with some social activities thrown in, such as a walk or a social get-together for a party event or something like that.'

Person with dementia

'I go to a group for people who are carers of people who have early onset dementia. It's an absolute lifeline as a carer. And it's given me the opportunity to find out what my next stages are. What are my next steps? What's going to happen next? How do they deal with that?' Carer

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 help you understand what is being said and help you to ask any questions you may have. 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

Alzheimer Scotland carer training.
www.alzscot.org/pages/carers/index.htm

Alzheimer Scotland guide for carers, *Looking after yourself*.
www.alzscot.org/pages/info/lookingafter.htm

Carers centres all over Scotland provide training and support.
www.careinfoscotland.co.uk/carerscentres

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.
www.carers.org/help-directory/alzheimers-and-dementia

'It was really helpful to have a bi-lingual support worker who could explain things to us.' Carer

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 link worker – for at least a year after diagnosis.
- Local authority social work departments are the main route to getting support.
- Assessments help you to find out what support might suit you.
- Services designed for older people with dementia may still be helpful.
- 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.

'I knew that I could take advice from others who had been there before. It was an enormous relief to know that this is something we knew we had to learn to live with. Instead of just ... flying in the dark.' Carer

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.

There is a lot you can do - it just takes a bit more planning.' Person with dementia

Future legal and financial decisions

Everybody, not just people with a diagnosis of 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 which 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, although they don't need to, and it isn't a lengthy process, usually only a couple of visits to the solicitors 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.slab.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'.

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. 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' 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. 'Continuing power of attorney' covers your finances, including property and bank accounts. This type may be used as soon as it's registered. Most 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.



Further information

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

www.publicguardian-scotland.gov.uk/whatwedo/power_of_attorney.asp



WIG Newsletter

Community Connections Series



Making a will

A will makes clear what you want to happen with your money and goods 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. The executor of your will could be the same person you appoint as attorney.

You can draw up your own will but it may be safer to involve a solicitor or qualified will writer to avoid any errors or omissions that could cause problems in future. 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.

'I've also got a will. I think it was really important to plan those type of events or those type of documents, have them in place - so that has been done. We do talk about the future.'

Person with dementia

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 which 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.



Further information

Alzheimer Scotland factsheet, *Making decisions about future treatment*.

The **Good Life, Good Death, Good Grief** website has information on planning future care.

www.goodlifedeathgrief.org.uk/content/advance_care_planning

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 is more and more 'long-stay' or residential care available that is designed especially for people with dementia. Not much is aimed at younger people, but a good care home should provide activities and support that suit your individual needs.



Further information

Alzheimer Scotland booklet, *A positive choice – choosing long-stay care for a person with dementia*.

Go to www.alzscot.org/information_and_resources and search for 'positive choice'.

Alzheimer Scotland guide for carers when someone moves into long-stay care, *Letting go without giving up*.
www.alzscot.org/pages/info/lettinggo.htm

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

www.scswis.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 long-stay care now means important decisions won't be made in a hurry.

'They explained power of attorney and we had that set up immediately. So, that's health and welfare. That was the first thing we did.' Carer

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 more commonly found in younger people, 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 occur 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.

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's Society factsheet, *Rarer forms of dementia*.
www.alzheimers.org.uk/rarercauses

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 factsheet, *Alzheimer's disease*.
Go to www.alzscot.org/information_and_resources
and search for 'Alzheimer's disease'.

Frontotemporal dementia (FTD)

This form of dementia tends to affect people in their 40s and 50s. It is believed to be the second or third most common form of dementia in younger people.

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

There is a lack of easy-to-read information about FTD, although this is slowly changing.

Frontotemporal Dementia Support Group
www.ftdsg.org

The Association for Frontotemporal Degeneration (US)
has some useful resources, including advice on talking to children about FTD.

www.theaftd.org/support-resources

Alzheimer's Society factsheet, *What is frontotemporal dementia?* www.alzheimers.org.uk/frontotemporal

Vascular dementia

There are various forms of vascular dementia, where 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 ischemic 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. More extreme symptoms can include hallucinations (seeing or hearing things that aren't real) and delusions (developing false ideas).

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.

One kind of vascular dementia is called cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL). CADASIL is a relatively rare condition in which multiple small strokes progressively damage blood vessels in the brain and other parts of the body. People commonly develop CADASIL between their 30s and 50s. As CADASIL is an inherited condition you may wish to speak to a genetics counsellor for information and advice. Discuss this with your GP or other medical professional.



Further information

Alzheimer Scotland factsheet, *Vascular dementia*

Go to www.alzscot.org/information_and_resources and search for 'vascular dementia'.

Information on CADASIL www.cadasil.sgul.ac.uk

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 from day to day and don’t necessarily suggest some 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.

Other common symptoms are feeling confused and experiencing visual hallucinations – seeing colours, shapes, animals, people, or objects that aren’t there. Occasionally hallucinations are auditory – hearing music or voices – or involve taste, smell and touch.

To someone with dementia, these hallucinations can seem puzzling, rather than upsetting or frightening. They may also experience delusions – false ideas about another person or situation.

Physical effects can include muscles feeling weak, stiff or rigid, which can make it hard to start moving and to move quickly. As a result, someone with this form of dementia may become clumsier and have problems walking and keeping their balance.

There may be changes in voice and facial expression. Some people experience double vision and difficulty judging distances. Others find their sleep patterns change, falling asleep easily during the day but staying awake at night, talking in their sleep or acting out dreams.



Further information

Alzheimer Scotland factsheet, *Dementia with Lewy bodies*.
www.alzscot.org/downloads/lewybody.pdf

Parkinson’s UK factsheet, *Dementia with Lewy bodies*
www.parkinsons.org.uk/parkinsonsdementiaandlewybodies

Alcohol-related dementia or Alcohol Related Brain Damage (ARBD)

Alcohol-related dementia is a form of dementia caused by prolonged use of alcohol. There is also a particular brain disorder associated with heavy drinking called Korsakoff's syndrome, caused by lack of vitamin B1. 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 factsheet, *Alcohol-related brain damage*.
www.alzscot.org/assets/0000/0166/alcohol.pdf

Posterior cortical atrophy

Posterior cortical atrophy (PCA) is a rare degenerative condition normally caused by Alzheimer's disease. The first symptoms tend to occur when people are in their mid-50s, but are often subtle and can take time to diagnose.

In the early stages the main problems are with vision, such as difficulty recognising faces and objects in pictures, literacy and numeracy. As the disease progresses, people also develop the typical symptoms of Alzheimer's disease, such as memory loss and confusion.



Further information

The **PCA** support group, run through the National Hospital for Neurology and Neurosurgery, offers the opportunity for contact with other people who have had a diagnosis of Posterior Cortical Atrophy. It holds several meetings a year and circulates a newsletter to members between meetings.
www.ucl.ac.uk/drc/pcasupport

The **RNIB** website offers advice on dementia-related sight loss.
www.rnib.org.uk/dementia

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

A healthy lifestyle, with plenty of fresh vegetables and fruit and daily exercise, is important. As well as aiming to do 30 minutes of activity a day, you should try to reduce the amount of time you spend sitting or being inactive as this will help to improve your overall health.

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.
- 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 are a range of 'talking' and other psychological therapies that can help with different aspects of dementia, including stress and anxiety and difficulties with memory and problem solving, confusion, language and behaviour. Some of these may also help your carer and family.

Specific treatments

Your doctor and psychiatric consultant can advise you 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 Alzheimer's disease are donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl). Another drug called memantine (Ebixa) is also available for people in the mid to later stages of Alzheimer disease.

Vascular dementia

Aspirin and warfarin are widely used to prevent blood clots and reduce the risk of further strokes. There are also drugs available to control high blood pressure, diabetes and high cholesterol levels.

Anti-psychotic drugs

These can be used to treat restlessness, aggression and psychiatric symptoms which can appear in people with dementia. But because of their potential side-effects, they should only really be used if other options fail, at as low a dose as possible, for as short a time as necessary, and carefully monitored.

Anti-psychotic 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 factsheet, *Behaviour that challenges – Understanding and coping*.

www.alzscot.org/downloads/behaviour.pdf

NHS Health Scotland booklets and their associated DVDs.
Facing dementia (for older people with a diagnosis of dementia)

www.healthscotland.com/documents/15.aspx and

Coping with dementia (for carers)

www.healthscotland.com/documents/1469.aspx

These are available from Alzheimers Scotland's 24-hour Dementia Helpline on

0808 808 3000.

Appendix 2: Caring for someone with a learning disability and dementia

This appendix – as well as the rest of the publication – may be helpful if you care for someone with a learning disability who develops dementia.

People with a learning disability are at greater risk of developing dementia than the general population, and of doing so at a younger age. One in 10 people with a learning disability is likely to develop dementia before they are 65. The risk is even higher among people with Down's syndrome.

How to tell if someone with a learning disability has dementia

Knowing what type of dementia the person you care for has can help you understand how it might affect them.

Alzheimer's disease is the most common form of dementia among people with a learning disability, but there are other types, and it's possible to have more than one form of dementia at the same time. Dementia may progress quicker in people with Down's syndrome.

There is no 'test' for dementia in people with a learning disability, but hopefully any changes will be picked up quickly during their normal, regular health checks.

You might notice some common early signs of dementia in the person you care for. They may:

- lose daily living skills
- struggle with kerbs, stairs or steps
- no longer enjoy activities or hobbies
- talk less because it's difficult to find the right words
- get confused more often
- become less sociable.

If you're worried about the person you care for, rule out other things first, especially if they can be treated quickly. Changes in the person you care for may be due to an infection, underactive thyroid, deteriorating eyesight, depression or pain, which can have similar symptoms to dementia.

Talking about dementia

If the person you care for is diagnosed with dementia, think about how to share the information with them in a way they can easily understand. It might be easier to talk about what changes they can expect in everyday life. It is important they understand what is happening so they can be properly involved in any plans for the future, including what care they may need.

Other carers and family members should try to use the same words to describe dementia and the possible effects. There are easy-read leaflets and other materials that may help.

You will probably want to talk to anyone the person you care for is close to, or lives or works with, so these people understand why their friend may behave differently in future and so they don't worry it's because of something they have done.

Things to consider

You may find a lot of the information in this publication helpful. It applies to younger people with dementia in general, but there are some specific things you may want to think about.

Living arrangements

The person you care for will need increasing support as dementia progresses. It may become more difficult for them to live independently, whether on their own or with a partner or family member, in a shared tenancy or group home.

But they should continue to live in the same place, supported by familiar and consistent care and routines, for as long as possible. This will help them to retain everyday skills.

Where the person lives can be adapted along 'dementia friendly' principles (see **Home** on page 21) and to meet their personal requirements. Someone with Down's syndrome may not be very tall, so make sure signs (on toilet doors, for instance) and reminder notes are at the right level for them to see easily.

If the person you care for does need to move to more suitable accommodation, it is probably better that this is part of a learning disability service rather than general dementia care.

Care and support

People with dementia increasingly rely on their long-term memories. Creating a 'life story' can be a helpful and fun way to share and record personal experiences, likes and dislikes. This could be in the form of a photo album or memory box, for example, and provide a link to their background and events or people from their past.

Non-verbal cues and body language will probably become even more important in communicating with the person you care for. It may be hard to know how dementia is affecting them. For instance, they may struggle to explain if they have problems seeing clearly; dementia can cause sight loss, but they may just have the wrong glasses on.



Further information

What is dementia? **Down's Syndrome Scotland** easy-read booklet for adults with a learning disability (£4.50).
www.dsscotland.org.uk/resources/shop/whatisdementia

You can buy a range of booklets on dementia from **Down's Syndrome Scotland**, including advice for GPs and the person's brothers and sisters.
www.dsscotland.org.uk/resources

There are resources available on dementia and learning disability specialist Karen Watchman's website, and a discussion forum for staff and carers to share ideas.
www.learningdisabilityanddementia.org

The **Easyhealth** website has information on dementia and learning disability (from various organisations) to help both paid and family carers and people with a learning disability.
[www.easyhealth.org.uk/listing/dementia-\(leaflets\)](http://www.easyhealth.org.uk/listing/dementia-(leaflets))

Alzheimer's Society factsheet, Learning disability and dementia.
www.alzheimers.org.uk/learningdifficulties

Appendix 3: 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 these 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 reporting to the consultant psychiatrist, who will help you and your family cope with your diagnosis and everyday living.

Dementia Advisor and Outreach Worker

Dementia Advisors or Outreach Workers (employed by Alzheimer Scotland) provide information and advice to help you, your partner and family find the dementia support you need, connect you to local groups and services, and help your local community to be more dementia friendly.

Dementia Link Worker

A named and trained person who will work with you, your partner and family for at least a year following your diagnosis. They will help you understand and come to terms with your diagnosis, maintain your existing connections in the community and put you in touch with other people in your situation. He/she will help you plan for your future care and future decision making. This person may also be called a Post-diagnostic Link Worker or Memory Clinic Link Worker.

Dietician

It is particularly important to eat well and not become dehydrated when you have dementia. A dietician 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 district community nurse

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

Occupational therapist

An occupational therapist will suggest things to make your life easier and safer, including using equipment and finding new ways to carry out everyday tasks.

Physiotherapist

Physiotherapy can help if dementia causes problems with your general mobility.

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. 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 you have your support provided, for example, through direct payments (see support). They are employed by the local authority.

Speech and language therapist

Your GP can refer you to a speech and language therapist to help with any communication problems.

Types of service or support

Day centres or day opportunities

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

Dementia cafés 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 café-like community setting (sometimes an actual café).

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.

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.

Respite care

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

Self-directed support

There are different ways care from your local council is offered and funded. Self-directed support gives you more control over how care and support is provided and new legislation means all councils must offer various options, including payments direct to you.

The term 'personal assistant' is often used to describe a person you employ using direct payments to help you remain independent and do the things you enjoy. For instance, they may accompany you to social and sporting events as well as helping with everyday tasks like shopping.

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 is aimed at older people but explains what services are available, including in your area.
www.careinfoscotland.co.uk/getstarted

Care Information Scotland has specific advice on care services for people with dementia.
www.careinfoscotland.co.uk/dementia

The **Self-Directed Support in Scotland** website explains ways you can manage your own care and support.

Alzheimer Scotland has produced a booklet, *Taking charge – a short guide to self-directed support for people with dementia and their carers*. Copies are available via the 24-hour Dementia Helpline on **0808 808 3000**
Go to www.alzscot.org/information_and_resources and search for 'self-directed support'

Appendix 4: 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 Scottish Dementia Clinical Research Network hosts a research register of people who are interested in taking part in current or future research studies into the causes and impact of dementia.

www.sdcrn.org.uk

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/index.htm

This booklet is for you if your doctor has told you that you have younger onset dementia (dementia diagnosed under the age of 65). Your doctor may have told you that you have a particular kind of dementia, such as Alzheimer's disease, vascular dementia, frontotemporal dementia or dementia with Lewy bodies. The information in this booklet, however, is for people with any type of dementia.

It has been written in discussion with people who have had a diagnosis under the age of 65 and their families, and it includes information that they felt was helpful or would have been helpful at and around the time of diagnosis.

The quotations in speech bubbles are all from people who, like you, have younger onset dementia.

This booklet may help to guide you following your diagnosis.

Sections include:

- What is dementia?
- Keeping well and connected
- Home
- Health
- Independence
- Getting around
- Work
- Money
- Support
- Future plans

Appendices include:

- Caring for someone with a learning disability and dementia



www.healthscotland.com



Alzheimer Scotland
Action on Dementia

Dementia **24**
Helpline **HOUR**

Freephone **0808 808 3000**
Email: helpline@alzscot.org

A rectangular box containing the Alzheimer Scotland logo, the text 'Alzheimer Scotland Action on Dementia', the 'Dementia Helpline 24 HOUR' logo, and contact information: 'Freephone 0808 808 3000' and 'Email: helpline@alzscot.org'.