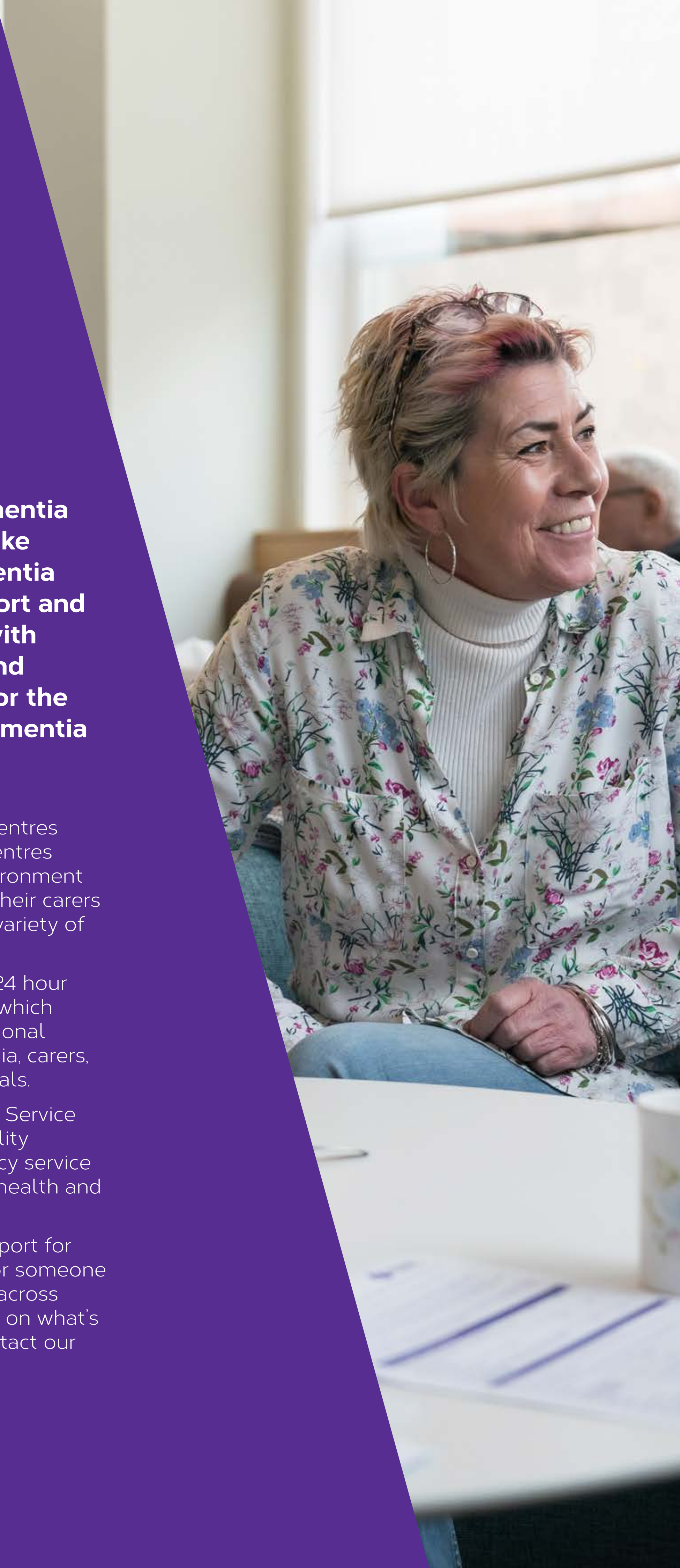
Alzheimer Scotland
Action on Dementia

Younger people with dementia

Living well with your diagnosis



Alzheimer Scotland is Scotland's national dementia charity. Our aim is to make sure nobody faces dementia alone. We provide support and information to people with dementia, their carers and families, we campaign for the rights of people with dementia and fund vital dementia research.

We have Dementia Resource Centres right across Scotland. These Centres provide a safe and friendly environment for people with dementia and their carers to visit and take part in a wide variety of activity groups.

We are also very proud of our 24 hour Freephone Dementia Helpline which provides information and emotional support to people with dementia, carers, families, friends and professionals.

Our National Dementia Advisor Service provides a responsive, high quality information, advice and advocacy service relating to all aspects of brain health and dementia.

We also have a network of support for people living with and caring for someone with dementia in communities across Scotland. For more information on what's going on in your local area, contact our Helpline on **0808 808 3000.**

What's inside

Hello and welcome

For the purposes of this booklet, 'younger' means under the age of 65.

We hope this becomes a valuable resource for you or anyone you know who has just been diagnosed with a younger onset dementia. We have a range of further information and a wider range of materials available through our website, **www.alzscot.org**

It is important that you give yourself the time and space to process all the information which relates to your diagnosis. On the following pages, you'll find important and practical information to help you feel more confident, reassured, and prepared.

24 hour Freephone Dementia Helpline

Our 24 hour Freephone Dementia Helpline provides information, signposting and emotional support to people with dementia, their families, friends and professionals. Call **0808 808 3000** or email **helpline@alzscot.org**

National Dementia Advisor Service

Our National Dementia Advisor Service provides a responsive, high quality information, advice and advocacy service relating to all aspects of brain health and dementia. The service is available from 9am - 5pm, Monday to Friday, and can help with a wide range of issues such as accessing health and social care support, help with complaints, power of attorney, guardianship, and money and legal matters. You can call the service on **0300 373 5774** (charged at a local call rate), or email **NDAS@alzscot.org**

What is dementia?

There are over 100 causes of dementia (most of which are very rare) and it is possible to have more than one kind at the same time. Different types of dementia can have different symptoms but what they all have in common is that they cause changes in the brain that affect how it functions. It is estimated that around 90,000 people in Scotland have dementia with around 3000 of those having a young or younger onset dementia.

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, taste, smell, speak and write. It contains our memories and determines how we see ourselves in the world.

When someone has dementia, it is because some of the brain cells are damaged and dying. This affects how we remember, think and act, and is why it becomes more difficult to manage everyday activities. These changes can be gradual and every person with dementia will experience it differently. Although it may become difficult to continue with some of the usual activities, it can be possible to rediscover other things to enjoy – for example painting, walking, or listening to music.

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

People can live well for many years with dementia. This will vary from person to person and will depend on many things, like the type of dementia and whether they have other health conditions. Every person with dementia will experience it differently. At the moment there is no cure for dementia, but a lot can be done to help cope with the various symptoms.

> "I'd like to let people know that I'm so much more than just a person with dementia."
>
> – Scottish Dementia Working Group member with younger onset dementia

You can find more in-depth information about the different types of dementia here:

www.alzscot.org/our-work/dementia-support/information-sheets

www.raredementiasupport.org

> "Dementia does not define someone. People with dementia can learn new things, continue with work and hobbies, and live a full and enjoyable life."

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.

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 any symptoms you may have.

More information can be found at:

Counselling and Psychotherapy in Scotland (COSCA) provides information about services near you at **www.cosca.org.uk**

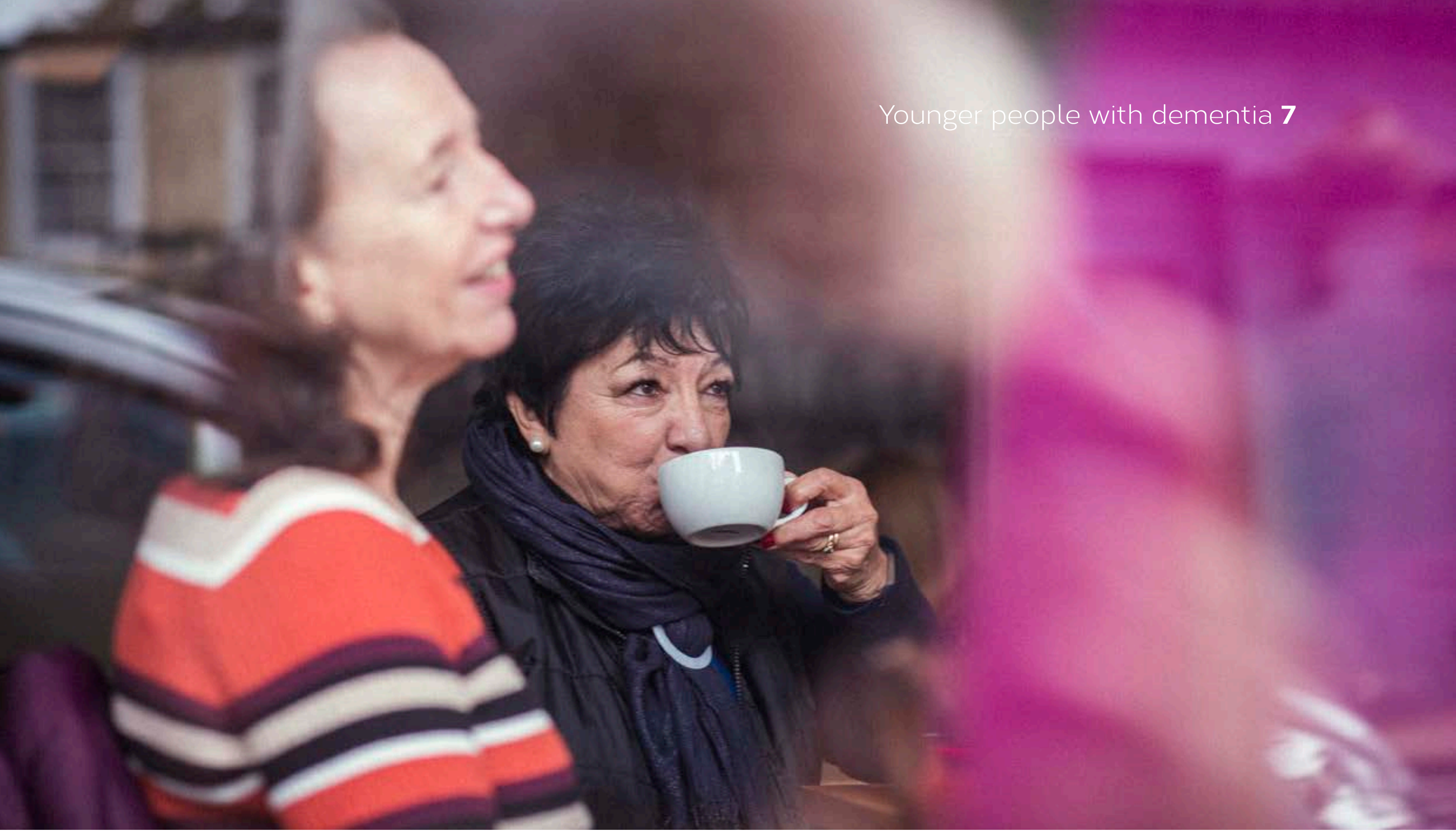
The British Association for Counselling and Psychotherapy can also direct you to qualified experts in your area at **www.bacp.co.uk**

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

- keep it simple – use everyday words and avoid jargon
- if something isn't understood then try to explain it using different words
- try to understand how they feel – especially if they've noticed changes in you and have come to their own conclusions
- don't make promises you can't keep
- 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.

Several useful books have been written to help younger children understand dementia and what they can do to help. Examples include 'My Grandma has dementia' by Alex Winstanley, 'Grandma, It's Me!' by Y.Y Chan, and 'Remembering for both of us' by Charlotte Wood.

Children may also find Carers Trust online communities and local support groups for young carers helpful: **https://carers.org** or **www.careinfoscotland.scot/topics/young-carers-and-young-adult-carers/**



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 and if you feel you need more support, speak to a professional such as a counsellor.

Access our factsheet, Sexuality and dementia at **www.alzscot.org/pages/info/sexuality.htm** or contact **www.relationships-scotland.org.uk** for further advice.

If you live alone

If you do not have a partner or close family, 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 a religious organisation, sports club or special interest society linked to your hobbies. It's important to stay in touch with friends and associates at any clubs that you are part of. News of your diagnosis may reassure people who might have noticed changes in you.

You might find it difficult to talk about your diagnosis with friends at first. This is understandable. Try to remember that you still share a history and have things in common, things that connect you and form the basis of your relationship. None of those things will ever change so it is important not to distance yourself from people just because you have received a diagnosis of dementia.

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

Keeping active

Your brain thrives on company and benefits greatly from the stimulation of interaction with others. If you continue to learn and challenge yourself mentally, you can help to maintain your brain's function.

Being socially active has considerable benefits for your physical and mental health, as well as your general wellbeing. It can make managing your condition much easier and, in some cases, can help slow its progression.

A diagnosis of dementia may motivate you to do things you've always wanted to do or prompt you to revisit favourite places. It may take more planning to arrange these things and require a bit more help than you're used to. Try not to let that put you off though, it's important that you continue to do all the things you enjoy.

Sometimes, you may find you don't want to go out as much or that you prefer quieter places. That's fine too, there's no right or wrong way to approach your situation. Do what makes you feel most comfortable. Focus on what you like doing and don't worry about making mistakes. Also, try to remember that laughter is always good medicine and humour can often be a good way to lighten the mood and help you feel more able to cope.

Regular exercise is also something that can help with your physical and mental health. You might consider joining a local walking group or decide to go swimming more regularly, perhaps at times when the pool is quieter. These types of activities will not only help you stay physically fit, but they will also provide opportunities to socialise and stay connected.

Recording your life story

You could make a personal record of your life experiences. Creating a 'life story' can be an enjoyable activity you can do with family and friends to share your memories. This could also be an opportunity to talk about your likes and dislikes. Your life story collection could include personal photos and videos, favourite objects, music, poetry, films, and even smells (like soap or perfume) or textures (such as sofa materials). Include anything that is special to you and triggers certain memories and emotions. These could be labelled so that other people are able to talk with you about your life.

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 has 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.

More information can be found here: **www.thistleassistance.com**
www.alzscot.org/travelandholidays

New connections

A diagnosis of dementia shouldn't stop you forming new relationships including friendships with other people with the condition. You may find this helpful - you could have many other things in common, aside from dementia and it could bring great relief to talk freely with someone who has shared experiences. Your partner or family members might also benefit from meeting with other carers in a similar situation.

You may also find new friends through online communities. This could be particularly helpful if you live in a remote or rural area where it is more difficult to meet up in person. Participating with online groups can be valuable – they can offer a source of information and advice, provide practical support, and encourage you to be more socially active, as well as being a source of relaxation, entertainment and a way to pursue interests.

There are some things to bear in mind, though. Be aware that people in online communities may have different symptoms, be at a later stage of their condition or even live in another country. Try not to assume that you'll have the same experiences, either good or bad. If you do get involved with online communities, tell someone you trust to ensure you stay safe. Never give your personal information out to someone online.

The Scottish Dementia Working Group is a campaigning and awareness raising group for people with dementia living in Scotland. Find out more at **www.alzscot.org/sdwg**

Talking Point is an Alzheimer's Society online forum for people with dementia and their carers across the UK, **http://forum.alzheimers.org.uk** and The Dementia Advocacy and Support Network is an international online forum, **https://dementiaallianceinternational.org** where you'll find helpful information about staying connected.

Home

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

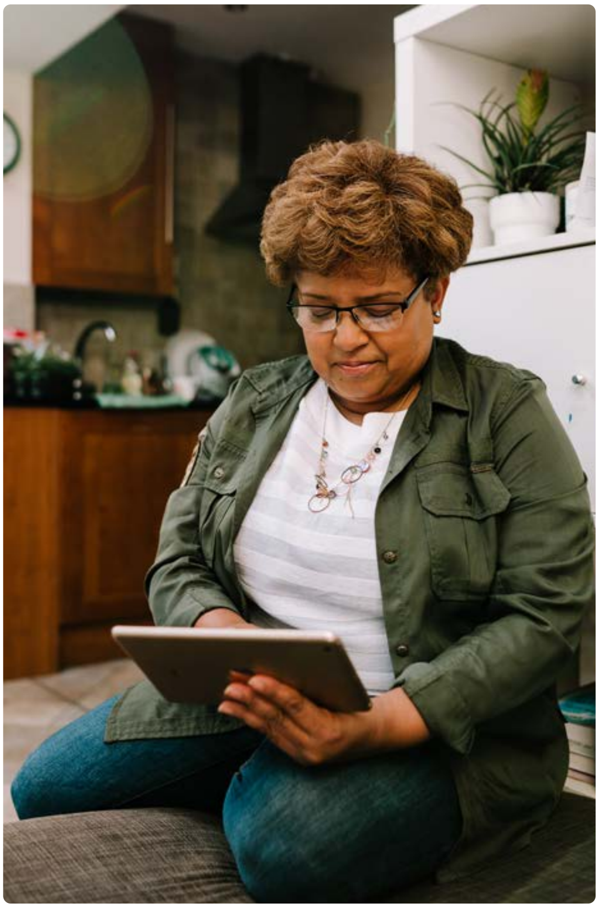
Owning or renting your home

Get financial advice early about the cost of staying in your home. There may be changes you want to make, for example, making sure the title deeds are in order and how you want them to be. 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.

Contact your local Citizens Advice Bureau, Shelter Scotland or your local authority for advice about this.

www.cas.org.uk

https://scotland.shelter.org.uk



Adapting your home

Depending on your circumstances, your Health and Social Care Partnership 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. An occupational therapist, who you can access through your Health and Social Care Partnership, can advise on what would be most helpful, based on your needs, wishes and general circumstances. Health and Social Care Partnerships will sometimes pay for alterations and equipment.

For advice on your rights if you rent your home, Shelter Scotland can help on **0808 800 4444.** The Citizen's Advice Bureau can also help at **www.adviceguide.org.uk/scotland** or you can call them on **0800 028 1456.** The Legal Services Agency mental health representation projects can also support people with dementia and their families, find out more at **www.lsa.org.uk**

Layout and alterations

Any alterations to the design and layout of your home 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
- less clutter on surfaces with only essential items left on worktops
- secure bannister rails, with ragged carpet edges and rugs removed so there's less risk of slips and trips
- electric night lights, with furniture arranged so you don't bump into things at night
- extra lights installed, with stronger bulbs for good, even lighting, especially on steps and stairs

Care and Repair Scotland offers advice and assistance to disabled property owners and people over 60. **www.careandrepairscotland.co.uk**

Aids and equipment

Tools and equipment that help you carry out tasks 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. Decisions about changes to your home should involve everyone who lives there to get the right balance between living your life as you choose and keeping safe. You may not need technology to help you, particularly at first, but each person is different. For example, do you need a device to switch off the cooker if you forget, or is it just as effective to put a clear reminder nearby?

Changing accommodation

A diagnosis of dementia may prompt you to think about your current living situation, considering 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 about housing adaptations can befound at **www.gov.uk/disabled-facilities-grants**

If you are homeless

A diagnosis of dementia makes it especially important that you have secure accommodation and support. Homelessness covers staying with friends, or in a hostel, bed and breakfast or property in poor condition. Under new legislation, individuals have the right to a permanent home. Talk to your local housing department, especially if you are worried about maintaining your tenancy or paying your rent.

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, cervical screening or a prostate exam) so it is important for you to continue to take part in tests and attend appointments.

Other conditions

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 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 for those 60 or over. Specialist support, like low-vision clinics, can help overcome problems due to sight loss. Check whether drugs prescribed for dementia will affect other medication and if side effects might have a particular impact on your condition or disability.

Visit our website for more information about dementia and sight loss at **www.alzscot.org/dementia-and-sight-loss,** and the Royal National Institute for the Blind (RNIB) offers advice on dementia and sight loss which can be found at **www.rnib.org.uk/dementia**

Access the Alzheimer Scotland factsheet on dementia and deafness: What you need to know at **www.alzscot.org/dementia-and-deafness**

Deaf Connections and Alzheimer Scotland have also developed a British Sign Language DVD to help, find it at **www.deafconnexions.org.uk**

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 and 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 very important for some people, whether through religious involvement, a sense of spirituality from spending time with loved ones, enjoying nature or meditation. Don't push yourself too hard, listen to your body if it's telling you to rest, and ensure you are getting enough sleep. Get the balance right though – giving up your favourite activities may leave you feeling low.

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

Specific support with depression can be found here:

www.nhs.uk/nhs-services/mental-health-services

www.samh.org.uk or call **0344 800 0550**

www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/depression-dementia

https://breathingspace.scot or call **0800 83 85 87**

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 on at least five days of the week, which can be achieved throughout the day rather than all at once.

Our Dementia Advisors can help with advice about activities in your local area, **www.alzscot.org/dementiaadvisors.** And why not visit the Active Scotland website for a list of all local activities, sports clubs and green spaces by postcode, **www.activescotland.com**

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).

Making good food choices can help ensure that your brain gets the nutrients it needs. Your diet is also vital for maintaining a healthy weight and avoiding conditions such as high blood pressure and diabetes, which can affect brain health. Research shows that following a Mediterranean-style diet has great benefits for your brain. Rich in olive oil, it includes lots of vegetables, fruit, fish, beans, and wholegrains. It also avoids too much meat and sweet, sugary foods.

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

Mental health charity Mind has advice on eating to improve your mental wellbeing at **www.mind.org.uk/information-support/tips-for-everyday-living/food-and-mental-health**

Drinking and smoking

Having a dementia diagnosis does not mean that you can't enjoy an alcoholic drink, if you choose to do so and don't have a condition that is affected by alcohol, such as Korsakoff's syndrome. You don't need to avoid it completely but exceeding recommended weekly limits can affect your brain and increase your risk. However, it is very important that you check with your doctor first, as some medication can have a negative reaction when mixed with alcohol. It is safest not to drink more than 14 units a week on a regular basis. If you regularly drink as much as this, it is best to spread your drinking evenly over three or more days.

Smoking damages your health generally and adds to the risk of stroke, putting you at higher risk if you smoke when you have vascular dementia. It causes damage to the blood vessels that supply the brain, interrupting the supply of vital oxygen and nutrients. Stopping smoking, at any stage of life is hugely beneficial and can halt the development of many different health problems.

There is plenty of support available to help you quit.

www.nhs.uk/live-well/

www.brainhealth.scot/understanding-brain-health

www.drinksmarter.org

www.alcohol-focus-scotland.org.uk

Independence

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

Your rights

You, and anyone who may help care for you, continue to have the same human and legal rights as every other citizen. It is important that this is recognised and respected. There is a wide range of legal provision designed to provide rights and protection in Scotland. For example, the Adults with Incapacity (Scotland) Act 2000, as well as the Charter of Rights for people with dementia and their carers. It's not a legal document, but it explains your existing rights as set out in human rights law and other provisions.
www.alzscot.org/charter_of_rights

There are also Standards of Care for Dementia in Scotland. These standards say that you have the right to:

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

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

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.

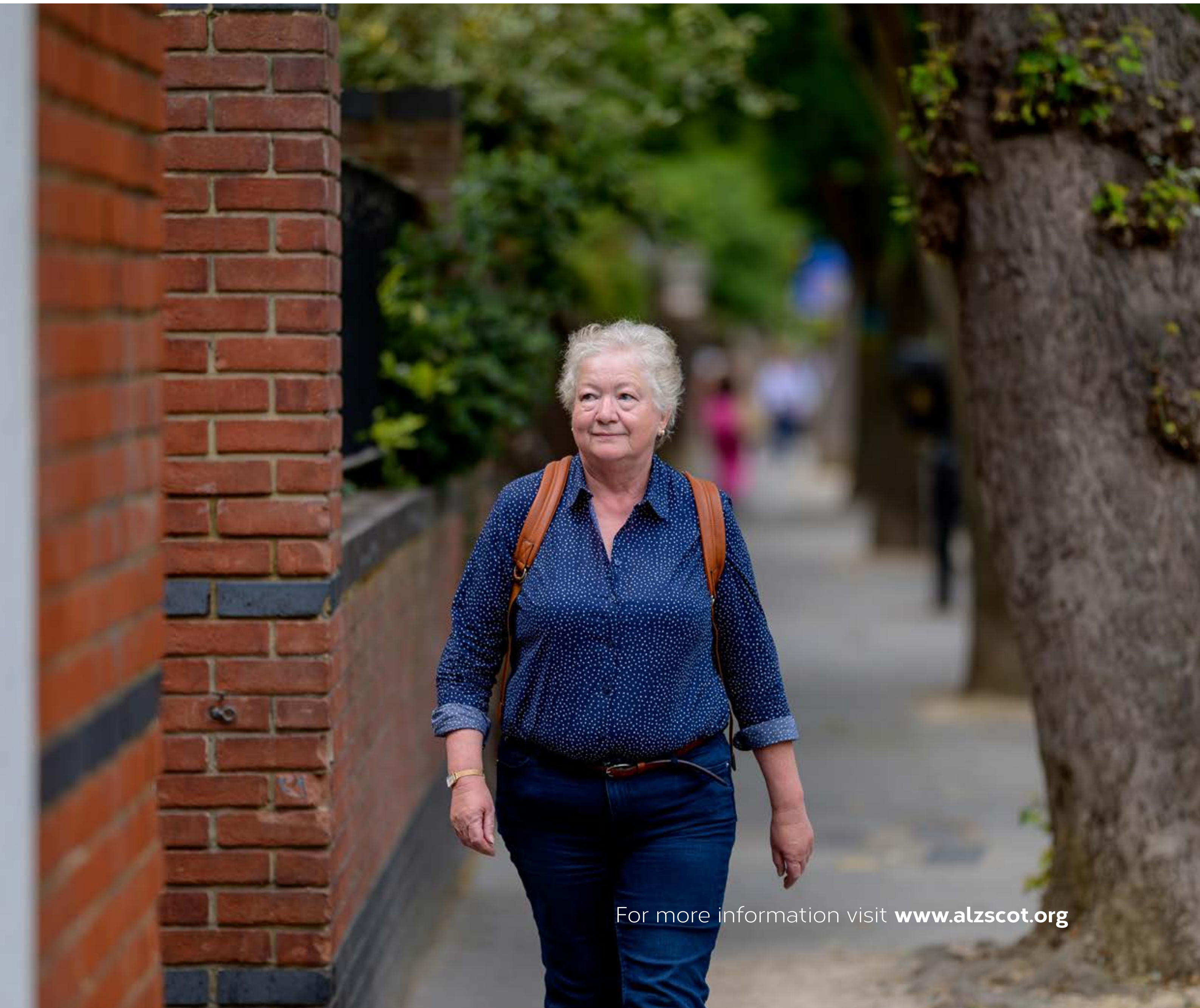
Advocacy

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 English is not your first language.

Find out more about advocacy services from the Scottish Independent Advocacy Alliance at **www.siaa.org.uk** or call **0131 510 9410**, and the mental health charity, Mind, at **www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/types-of-advocacy/**

Managing risk

Everyday life carries risks you probably manage without consciously thinking about. You, along with your family and friends, may find it helpful to talk about some of the risks dementia may bring. You probably want to do things you've always enjoyed, or you might want to try new things. So, it's important that you say what you want to do, what risks might be involved and how best to manage them. For example, you might enjoy walking in the town. Simple ideas can set everyone's mind at rest, like always carrying identification plus your mobile phone, if you have one. You could also use a help card – a wallet-sized card that you can show to people to explain that you have dementia and might need a bit of help. You can call the Dementia Helpline on **0808 808 3000** for a free supply of help cards that you can put in your wallet, each handbag you use and coat pockets. The ADAM (About Dementia And Me) website can help with suggestions for technology that could support you when out and about. **www.meetadam.co.uk**



Getting around safely

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 hold a current driving licence, you must inform the Driver and Vehicle Licensing Agency (DVLA) when you are diagnosed with dementia. If you do not tell the DVLA your doctor has a duty to do so on your behalf. You must also tell your insurance company, or your insurance may not be valid.

Driving without valid insurance is a criminal offence. If you want to carry on driving, tell the DVLA. They will send you 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 to plan for getting someone to drive you, or to arrange other transport.

For more information, contact the DVLA on **0300 790 6802** or at **www.gov.uk/dvla-medical-enquiries.** The Scottish Driving Assessment Service also offers assessments at their Centre in Edinburgh. These are free under the NHS, but a referral letter from a doctor is required. Call **0131 537 9192** for more information. You may also be eligible for a 'blue badge' if your mobility is limited. Find out more at **www.mygov.scot/apply-blue-badge**

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.

Concessionary travel

If you are over 60 or have a disability, you could be eligible for free bus travel. This can be accessed via the National Entitlement Card. If you are eligible, this also allows for free travel for carers or companions. You can learn more about the National Entitlement Card here: **www.transport.gov.scot/concessionary-travel/60plus-or-disabled-free-bus-travel**

Information about the application process in your local area can be found by visiting: **www.transport.gov.scot/concessionary-travel/how-to-apply-for-or-renew-your-national-entitlement-card/**

Cycling and walking

Walking and cycling can keep you healthy, allow you to get around independently and 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. Try to cycle off road, away from busy traffic, where possible. You will be safer on quieter routes that 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).

Public transport

Community transport may be available in areas with limited public transport. Contact your Health and Social Care Partnership about schemes like like Dial-a-Ride, MyBus or door-to-door transport. Local supermarkets may run special buses for shoppers, so getting familiar with bus timetables may help.

www.firstbus.co.uk/bus-accessibility

www.scotrail.co.uk/plan-your-journey/accessible-travel

www.thistleassistance.com

Taxis

In some areas of Scotland, you can set up your own account with a local taxi company. This 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.

www.careinfoscotland.scot/topics/care-at-home/transport/taxi-card/

Air travel

Airlines and airports are legally required to make 'all reasonable efforts' to help 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. Get more advice on air travel at:

www.alzscot.org/supported-travel-assisted-boarding

www.gov.uk/transport-disabled/planes

Work

Many younger people with dementia say their first symptoms appeared at work, like forgetting appointments or how to do familiar jobs. A diagnosis of dementia may not mean you have to stop working. It will depend on how the dementia affects you and what your job involves.

Consult your union rep (if you have one) as they can give you advice on continuing to work with your diagnosis. 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.

More information about working with dementia can be found here:
www.gov.uk/access-to-work

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 an aeroplane 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 unsure, check your contract and speak to your line manager. You can signpost your employer to the Business Disability Forum at **www.efd.org.uk** for more advice.

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 because of undiagnosed dementia. It might be difficult, but not impossible, to have your situation reconsidered.

For more information, you can call the Healthy Working Lives Adviceline on **0800 019 2211.** Government advice on disability rights at work can also be found at **www.gov.uk/rights-disabled-person/employment**

Get employment advice

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

From:

- your union
- the Trades Union Congress (TUC)
- the Advisory, Conciliation and Arbitration Service (ACAS)
- the disability employment advisor at your local Jobcentre
- the Citizens Advice Bureau
- Alzheimer Scotland's National Dementia Advisor Service

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 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
- 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.

The Access to Work scheme offers practical support, including funding to cover extra costs to help you stay in work. More information can be found at **www.gov.uk/access-to-work**

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 can find benefits and employment advice for you and your carer at **www.adviceguide.org.uk/benefits_sick_or_disabled_people_and_carers_s.htm**

Advice on taking time off work because of ill health can be found at **www.citizensadvice.org.uk/work/time-off-work/time-off-work-overview/**

Working as a professional

If you must 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.

If you work for yourself

If you work for yourself or own your own business, it is important to make adjustments so that you can continue working for as long as you feel able to. If you tell business partners and staff about your condition, they may be able to offer support and help you make any necessary adjustments. You may be able to delegate or sub-contract some work. Check any income protection and critical illness insurance policies and ask the provider if dementia is covered. If you have an accountant, legal or other business advisor, they may also be able to help. You should consider putting a power of attorney in place so family members or other people involved in the business can take financial and legal decisions on your behalf if you're unable to do so.

Carers' rights at work

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

Any employee has the legal right to take a reasonable amount of time off work to deal with an emergency involving someone dependent on them. Under the Equality Act a carer should not be refused a job or treated differently because of their caring responsibilities. Your carer's employer may be willing to negotiate other changes that would help you both. They may already have policies in place to support carers, over and above their legal requirements. Staying in work is probably important to your carer, for financial reasons and their own self-esteem and wellbeing.

Find out more at **www.carersuk.org/help-and-advice/work-and-career/your-rights-in-work/**

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.

The Money Advice Service offers free and independent advice at **www.moneyhelper.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. In some instances, you may want to separate your own and your partner's accounts and arrange power of attorney so that your partner can manage your accounts. Dementia can sometimes change the way people handle money, like starting to spend compulsively. There is also the risk of becoming 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 will make it easier to work out what you're entitled to. It might be easier to get all your income paid straight into your bank account, including benefits, pensions, sick pay and wages. You could also switch regular bills to direct debits or standing orders. Online banking makes it easier to track spending. You can ask your bank or building society to monitor your current account for erratic or unusual spending behaviour.

Involving other people

If you feel you need help coping with money, you can allow a named individual to manage your bank account by setting up a continuing, or financial, power of attorney. 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

Credit and debts

If you are still of working age, you are more likely to have ongoing financial commitments, such as a mortgage, credit card, personal loans, or other forms of credit. You may have young dependent children or older children who are financially dependent on you. It may also mean you have less income and 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. You don't need to pay for good money advice; your local authority, Health and Social Care Partnership or the Citizens Advice Bureau can provide this free of charge.

The National Debtline (Scotland) can also help with money worries on **0808 808 4000** or at **www.nationaldebtline.co.uk/scotland**

Pensions

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

State pensions

State pension age is the date you can begin receiving your state retirement pension. If you leave work before you reach state pension age, you may be able to protect it 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.

For advice on claiming your state pension, see **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. Many pension plans will allow you to take your pension early, or at least a lump sum, if you retire because of dementia. Check with your pension provider or talk to an independent financial advisor.

Insurance

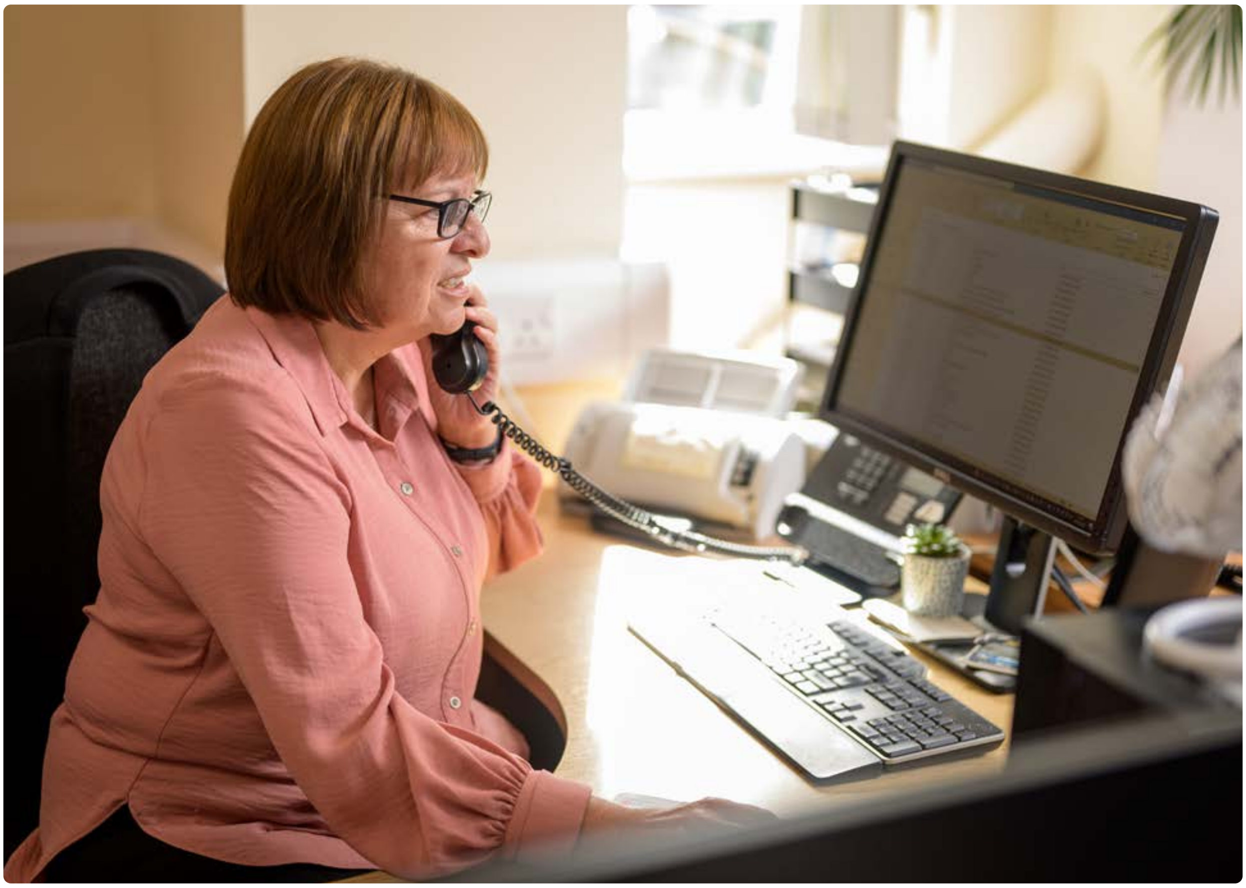
Check the small print of any insurance policies you have, including mortgage and loan protection insurance, and life and personal accident cover. Do they mention dementia? Do you need to inform the insurance company of your diagnosis?

Claiming benefits

You, or a person you care for, may be entitled to financial help from the benefits system. The social security system is complex and can be daunting. It is always a good idea to get help from a benefits advisor who can tell you what you are entitled to claim and help you to apply for the right benefits. Local authorities provide benefits and welfare rights advice and you can also seek help and advice from your local Citizens' Advice Bureau. Contact details for local services are available from Citizens Advice Scotland website, **www.cas.org.uk** or call **0800 028 1456.**

Social Security Scotland offers support to people claiming benefits related to disability (including dementia) and their carers. Visit **www.socialsecurity.gov.scot/benefits**

Remember, it's always worth seeking advice – even if you think you are not entitled.



For you:

Statutory Sick Pay

If you're still employed but off work due to dementia, you're entitled to a maximum of 28 weeks of Statutory Sick Pay (SSP) paid by your employer. Some employers have their own occupational sick pay scheme that pays 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 **www.gov.uk/statutory-sick-pay**

Universal Credit

Universal Credit is a payment to help with your living costs. You may be able to claim Universal Credit if you're on a low income or if you cannot work.

Find out more and make a claim at **www.gov.uk/universal-credit**

Employment and Support Allowance

If you have worked as an employee or have been self-employed, and your entitlement to Statutory Sick Pay has ended, you might be able to claim New Style Employment and Support Allowance (ESA). You can apply if you have a disability or health condition that affects how much you can work and have paid enough National Insurance contributions in the last 2 -3 years.

Find out more and make a claim at **www.gov.uk/employment-support-allowance**

Adult Disability Payment

Adult Disability Payment is extra money to help if you have a long-term condition like dementia that affects your everyday life. The amount you get depends on how your condition affects your ability to do everyday activities and get around. You can claim this benefit if you are working or not, and your income and savings do not affect your entitlement.

Find out more and make a claim at **www.mygov.scot/adult-disability-payment**

The Scottish Welfare Fund

The Scottish Welfare Fund is run by local authorities and provides two sources of support to people on low incomes:

- Crisis Grants to provide a safety net in the event of an unexpected emergency; and,
- Community Care Grants to help you or someone you care for to start to live, or to carry on living, a settled life in the community.

The scheme does not include loans.

Find out more at **www.mygov.scot/scottish-welfare-fund**

For carers:

Carer Support Payment

A carer aged 16 or over who looks after you for 35 hours a week may be able to claim Carer Support Payment depending on their individual circumstances. In some circumstances, a claim for Carer Support Payment can affect the amount of benefits you receive so you should always seek advice before someone makes a claim for looking after you.

Find out more and make a claim at **www.mygov.scot/carer-support-payment**

Carer Allowance Supplement

Carers in Scotland who claim Carer Support Payment, or who have an existing claim for Carer's Allowance, may be eligible to receive an extra payment of Carer Allowance Supplement twice a year. These payments are made automatically if you receive one of these benefits on the qualifying date each year.

Find out more at **www.mygov.scot/carers-allowance-supplement**

Carer's Credit

If your carer is looking after you for more than 20 hours per week, they can apply for Carer's Credit to help with gaps in their National Insurance record. This will protect their future state pension entitlement.

Find out more at **www.gov.uk/carers-credit**

Support

Your right to support after diagnosis

Anyone living in Scotland who receives a diagnosis of dementia is entitled to a minimum of one year post diagnostic support from a named Post Diagnostic Support Link Worker.

This person's role is to help you:

- understand more about your type of dementia, 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 (if you feel it would be helpful)
- 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. This will help other people to support you as time goes on.

Follow this link for more in-depth information to help you make the most of your post diagnostic support: **www.alzscot.org/pds**

Accessing post diagnostic support

If you are newly diagnosed with dementia, you may be referred directly for post diagnostic support by the professional who gave you your diagnosis or by a member of the team where you received your diagnosis. If this hasn't happened, then it is your right to contact them to ask why. Alternatively, ask a health and social care professional (such as your GP, Community Mental Health Nurse or health and social care professional) to refer you. If it is considered that services other than post diagnostic are more appropriate for you then you will be advised of this.

Alzheimer Scotland Dementia Advisors

As well as Post Diagnostic Support Link Workers, we have a network of Dementia Advisors right across Scotland. They are here to offer you and your family or carer more general advice and support, along with linking in with local businesses and communities. Any advice and support they provide is confidential.

Our Dementia Advisors also run a range of therapeutic groups, as well as carer support and education activities both within and out with our Dementia Resource Centres.

Your local Dementia Advisor can:

- provide general information and advice
- help you find the specific dementia support that you need
- connect you to local groups and services
- help your local community be more dementia friendly
- help you influence the policies and services that affect you

Find out more about what our Dementia Advisors do here:
www.alzscot.org/dementiaadvisors

Support services

Your local Health and Social Care Partnership is the main route to getting support services in your own home or through services near where you live. It's worth contacting the Health and Social Care Partnership, 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 or care manager can carry out an assessment and discuss any 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.

The 24 hour Freephone Alzheimer Scotland Dementia helpline can answer any questions on **0808 808 3000** or email **helpline@alzscot.org**

Alzheimer Scotland's National Dementia Advisor Service

For more complex issues and for anyone who doesn't have a local Dementia Advisor, our National Dementia Advisor Service provides a responsive, high quality information, advice and advocacy service relating to all aspects of brain health and dementia. The service is available from 9am - 5pm, Monday to Friday, and can help with a wide range of issues such as accessing health and social care support, help with complaints, power of attorney, guardianship, and money and legal matters. You can call the service on **0300 373 5774** (charged at a local call rate), or email **NDAS@alzscot.org**

Alzheimer Scotland Brain Health and Dementia Resource Centres

Our Centres are evolving. With the importance of brain health underpinning so much of what we do, we are gradually transforming our Centres to reflect that work – they will become known as Brain Health and Dementia Resource Centres. No matter the sign above the door, all our centres offer friendly, accessible environments for everyone to enjoy. Whether you want to pop in for some information, advice or support, our friendly staff and volunteers will be able to help you.

Each Centre is also a base for our wide range of local groups and therapeutic activities such as music sessions, arts and crafts and football reminiscence. Our newly refurbished centres follow the principles of dementia friendly design and reflect a feel of the local feel area, creating a sense of homeliness and familiarity which we know is important in helping you feel at ease. Visit **www.alzscot.org/drc.**

Free personal care

Anyone in Scotland who requires help at home with personal care can access this for free. Personal care includes, for example, help with dressing, eating, washing, going to the toilet, simple treatments (such as eye drops), staying safe and support (such as reminders).

Self-directed Support

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

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

These options are:

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

Help for carers

Your family should be involved in all discussions and decisions about care and other services, so that you get help that suits you all. Carers are entitled to an assessment of their needs. Adult carers are assessed using the Adult Carer Support Plan and young carers using the Young Carers Statement. Carer groups and carer training may be available in your area. 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. Ask your link worker or contact our 24 hour Freephone Dementia Helpline on **0808 808 3000.**

More information on Self-directed Support can be found at **www.selfdirectedsupportscotland.org.uk**

Support at appointments

You may feel that you would like some support when you go to appointments, as they can be overwhelming. You can ask a carer or a family member to attend with you, but you can also ask for professional support at these appointments, such as an advocacy worker. If English is not your first language, or if you are deaf or hearing impaired, you may find it useful to arrange to have an interpreter present at appointments. The interpreter will translate the conversation for you.

The Carers Trust offers information, online training and a discussion forum at **https://carers.org/help-for-carers/chat-to-carers-online**

Future plans

The nature of dementia means that things are inevitably going to change – how quickly, and how much, is hard to predict. Planning 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. Talk to your carer, family, friends, and others, like your doctor or Post Diagnostic Support Link Worker, at an early stage about what you want to happen in the future, in case they must make decisions on your behalf. Ideally, write down your views and wishes so they are on record.

Future legal and financial decisions

Everybody, not just people with dementia, should plan 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. 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. You can use a solicitor to prepare these documents. Although you don't have to use a solicitor, it might be advisable to avoid mistakes. Normally, 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.

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. Without power of attorney, your family may be unable to make significant decisions on your behalf or manage your financial affairs for you. There are 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, with your agreement. Many powers of attorney are joint, giving both continuing and welfare powers to a named person or persons in the same document, although you can appoint different people for each if you prefer.

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. Your doctor will usually charge for this.

It must be registered with the Office of the Public Guardian. Until it is registered, it can't be used. Find out more at: **www.publicguardian-scotland.gov.uk**

Making a will

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

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

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

You can draw up your own, 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 consider, including sorting out legal ownership of property or other possessions if you and your partner are not married or in a civil partnership, or you are not divorced from a previous partner. There may be custody or immigration issues that you want to settle.

Future care and treatment

Acting 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

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.

Many people say in their Advance Directive that they would not want certain treatments which would only serve to prolong life 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 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.

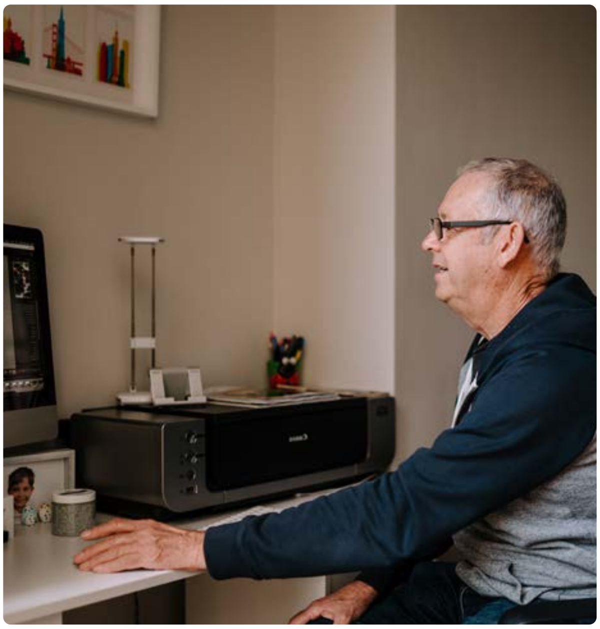
Advance Statement

An Advance Statement is a similar statement of someone's wishes – but it serves a different purpose. 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 deviation by a doctor from an Advance Statement may be challenged. An Advance Statement is a witnessed document which is normally placed with medical records.

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 considered. 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.

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

Contact us

We hope you have found this guide useful but if you have any questions or need further advice, you can:

Visit our website at **www.alzscot.org**

Call our 24 hour Freephone Dementia Helpline on **0808 808 3000** or email **helpline@alzscot.org**

Or for general enquiries email us at **info@alzscot.org**

Find us on social **@alzscot**

24 HOUR
Dementia
Helpline

Alzheimer Scotland
Action on Dementia

Freephone 0808 808 3000
Email helpline@alzscot.org

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