



**Alzheimer
Scotland**
Action on Dementia

Dementia: After diagnosis

A resource for those recently
diagnosed, their carers and families





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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**.



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Hello and welcome

We hope that this booklet becomes a valuable resource for you or anyone you know who has just been diagnosed with dementia. You can also find further information and a wider range of support material on our website, www.alzscot.org.

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



Our 24 hour Freephone Dementia Helpline provides information, signposting and emotional support to people with the illness, their families, friends and professionals.

Call **0808 808 3000** or email helpline@alzscot.org

What is dementia?

Dementia is a condition associated with the progressive loss of the powers of the brain. There are many different causes of dementia and many different types, but the most common is Alzheimer's disease.

Other types include vascular dementia, Lewy body dementia, frontotemporal dementias (including Pick's disease) and alcohol-related dementias such as Korsakoff's syndrome. It is also possible to have more than one type of dementia, for example Alzheimer's disease and vascular dementia. What all these diseases have in common is that they damage and kill brain cells, so that the brain cannot work as well as it should. In Scotland, it is estimated that over 90,000 people have dementia. It is most common in older people but can affect people in their 40s, 50s or even younger. It is estimated that around 3000 people in Scotland are affected by younger onset dementia.

The causes of dementia

We do not yet know exactly what causes dementia. Alzheimer's disease damages individual brain cells one by one, so the brain can't work as well as it used to. A protein called amyloid builds up in deposits, called plaques, and tiny filaments in the brain cell form tangles. Dementia research is trying to find out why these changes happen and what can be done to stop them.

Some rare kinds of Alzheimer's disease affecting people under 65 can be inherited. Faulty genes may cause the build-up of the amyloid protein. Recent research seems to show that there may also be a genetic factor in other cases of Alzheimer's disease. However, this does not mean that someone whose parent had Alzheimer's will automatically develop the disease.

With vascular dementias, there are problems with the blood supply to brain cells. For example, some people have tiny strokes (or infarcts) which damage small areas of the brain.

In frontotemporal dementias, the parts of the brain responsible for decision making, control of behaviour and emotion and language are affected. It is not fully known how this happens but there seems to be an abnormal growth of some types of proteins in the brain cells. In around 30-50% of cases of frontotemporal dementia, the person may have a family history.

Dementia with Lewy bodies is caused by small, round clumps of protein that build up inside nerve cells in the brain. The protein clumps damage the way brain cells work and communicate with each other. The nerve cells affected by Lewy bodies control thinking and movement.

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

www.alzscot.org/infosheets

www.raredementiasupport.org

The symptoms of dementia

Every person who receives a diagnosis of dementia is different. How your condition impacts you depends on which areas of your brain have been affected.

Though one of the most common and recognisable symptoms of dementia is memory loss, that in itself doesn't mean you have the condition. We can all forget things from time to time and as we get older, our memories do naturally deteriorate. But when you have dementia, memory loss and forgetfulness can affect you day-to-day. At times, you may forget the names of family members as well as strangers. Or you may forget that you've eaten lunch or that you've already told a story - so you repeat it without realising. Some days, you might remember past events much more easily than recent ones. Or you may lose your sense of time or place.

Memory loss, though common, is not the only symptom of dementia - the condition can be characterised by a range of other things. For example, at times it might be tricky to find the right words to use or you could find it harder than normal to concentrate. If you begin to lose interest in your usual activities or feel anxious or tense, try not to worry. These are all symptoms of the condition you're learning to live with and there are things you can do to help alleviate them.

Whatever you're going through, you're not alone. There's help available, and this guide provides links to a range of support and services.

Coping with behavioural changes

You might not notice many, if any, changes in your behaviour immediately. This may gradually change over time which can be difficult to deal with and there could be times when you feel a little bit out of control. Although it isn't possible to stop these changes completely, there are useful steps you can take to minimise their impact on your life. For example, it can help to work out if something triggers a certain reaction. Consider things like:

- do some behaviours happen at a certain time of day?
- do you find your environment too noisy or stressful?

It might be useful to keep a diary for a couple of weeks so that you can try to build a picture. If you'd rather not do it yourself, you could ask a family member or someone who lives with you to do this for you, noting down any time they notice a change in you.

If there is a sudden change in your mood or behaviour, it may be caused by something other than dementia. If you're in pain or any kind of discomfort, it's always worth contacting your GP to ask for an assessment. That way, they can rule out or treat any underlying cause like an infection. Some conditions can impact those with dementia much more commonly. For example, delirium is a serious but treatable condition that can start suddenly if you're unwell. That's why getting help from your doctor whenever you feel unwell is so important. More information about accessing GP services can be found here:

www.nhs.uk/nhs-services/gps/

Keeping an active social life, doing regular exercise and continuing with the activities you have always enjoyed are good ways of minimising changes that are out of character. Listening to your favourite music, watching your favourite film or doing some gardening can all help you feel more at ease, relaxed and confident. You could try a new activity like dance, tai chi, swimming or join a walking group to help you stay active and sociable, as well as help you manage mood or behaviour changes.



As time goes on, you might like to think about other therapies that are available, such as music therapy or even taking some time out for a massage. Animal-assisted therapy can also have great benefits if you're feeling a bit down or are struggling with your feelings. There's lots of information available about the benefits of interaction with animals, particularly dogs, to help people with dementia feel calmer and happier. If you'd like to learn more about this kind of assistance, here are some useful links:

<https://dementiadog.org>

www.verywellhealth.com/how-does-pet-therapy-benefit-people-with-dementia-98677

Digital devices like tablets and smartphones can also be very useful. From online games, puzzles and dedicated dementia apps to YouTube and FaceTime, they can provide a way to help you stay in touch with others, stimulate your brain and enjoy a range of activities.

There's also a wide range of technologies available to help make life simpler at home. If you would like to find out more about these, take a look at the following link. There's lots of information about what options are available:

www.alzscot.org/adam

Getting support

When you receive a dementia diagnosis it's normal to experience a range of emotions. It's important that you take some time to process the news and remember – you're not facing this alone.

Adjusting to your diagnosis will help you find your 'new normal'. Your life doesn't have to revolve around the condition, it's important that you keep doing the things you enjoy. Do what makes you happy, whether that's seeing friends or family, walking, painting, reading. This will bring you comfort and could open a new network of friends. Dementia is the beginning of a new chapter – but it doesn't have to be a bad chapter.

Post diagnostic support

Every person with a diagnosis of dementia in Scotland is entitled to one year of post diagnostic support. This is delivered by a named person who will work alongside you and those close to you. This support will be provided by a Post Diagnostic Support Link Worker, a Community Mental Health Nurse or a Health and Social Care Worker. Whatever their job title, they will be there to provide stability while you adjust to your diagnosis.

The range of support provided will:

- help you to understand your illness and manage your symptoms
- support you to stay connected to your community
- help you to meet others who are coping with the same sort of challenges as you are
- help you to plan for your future decision-making
- support you to think about your future care by helping you develop a personal plan that captures what matters most to you.

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 support are more appropriate for you then you will be advised of this.



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

Alzheimer Scotland Dementia Advisors

As well as Post Diagnostic Support Link Workers, Alzheimer Scotland has a network of Dementia Advisors based across Scotland. They can offer you, your family or carer advice and support, along with linking in with local businesses and communities. Any advice and support they provide is confidential.

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

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

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

Health and Social Care Workers

Now that you have received a diagnosis of dementia, it is likely that you will meet a range of health and social care professionals at different times throughout the various stages of the condition. These professionals are trained to provide important support and can help you continue to live well. You will probably meet in a range of places, from local clinics to the hospital. Some will be NHS medical specialists such as doctors or nurses and they will work alongside Allied Health Professionals, such as occupational therapists.

Others who may help you are social care professionals, such as social workers, arranged through your local council. Or you might see other staff from a private business, or a voluntary organisation.



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 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 activities such as music sessions, arts and crafts and football reminiscence.

Our Centres follow the principles of dementia friendly design and reflect a feel of the local area, creating a sense of homeliness and familiarity which we know is important in helping you feel at ease.

Find out more about our Centres and our work on brain health here:

www.alzscot.org/drc

www.brainhealth.scot



Maintaining social connections

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

Being socially active has considerable benefits for your physical, emotional 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 do these things and require a bit more help than you're used to – but try not to let that put you off. 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, they will also provide opportunities to socialise and stay connected. Exercise is also known to improve memory and reasoning skills so it's a great pastime to build into your routine.

A diagnosis of dementia shouldn't stop you forming new relationships and

friendships with other people with the condition. Picking up new skills and hobbies can help stimulate your brain, too. Be creative. You could try learning a new language or even a musical instrument. Try a new activity in a group, or with a friend. This will help to keep you motivated while getting that added social benefit.

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 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 to you, 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.

Getting involved as a volunteer or charity fundraiser can also expand your social circle. This can help maintain your skills and give you an opportunity to put your experience to good use, too.

Keeping well

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 stay fit and well, and better able to cope with symptoms of dementia.

If you've had a diagnosis of dementia, you should try to schedule a general health review at least every 15 months with your GP or practice nurse.

If you experience any changes to your symptoms, or develop any new symptoms, you must tell your GP or practice nurse as soon as you can. You may also be within the age range for health screening (such as breast screening, bowel screening, prostate screening or abdominal aortic aneurysm screening), so it is important for you to continue to take part in tests and attend appointments. Ask your doctor for more details of screening programmes.

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

Other conditions and disabilities

If you have any other conditions or disabilities, consider the impact dementia and possible symptoms may have on how you manage them. Your GP and other health professionals can help. Speak to your GP if you have any health concerns, like hearing loss or worsening eyesight. Check if drugs prescribed for dementia will affect other medication and if side effects might have a particular impact on your condition or disability.

Vision

An annual eye health check is recommended if you are aged over 60 and specialist support, like low-vision clinics, can help you to overcome problems caused by sight loss. If you notice a deterioration in your eyesight, it is important that you speak to your GP or optician because other symptoms of dementia, like confusion or disorientation, can feel worse if you aren't able to clearly see visual clues such as friendly faces or street signs. If you feel like it's becoming a bit of a struggle to navigate safely when you're out and about, or even in your own home, ask your GP for further advice.

Hearing

It is important that you have regular hearing checks so that any changes can be quickly identified. Hearing loss could make it more difficult for you to communicate with others which you could soon begin to find frustrating. If you do notice that your hearing is beginning to deteriorate, you should contact your GP in the first instance. They will be able to refer you for a hearing check if necessary.

Some audiology departments have specialists who are trained in dementia care. They will often use specialist diagnostic tests which take your condition into account.



Visiting hospital

If you go into hospital for treatment or for an operation, it is important to let staff know as much as possible about your needs, likes and dislikes. Some people write these things down in an Advance Statement. You may be asked to complete a form called 'Getting to know me', which many hospitals in Scotland use. Some hospitals use a (voluntary) scheme, called The Butterfly Scheme, which uses a butterfly symbol to let people know, discreetly, that you have dementia and to be aware.

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

Wellbeing

Wellbeing means feeling good about yourself. 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 your diagnosis. If you feel this may be beneficial, your GP may be able to refer you for specialist support. Some medical conditions can have a knock-on

effect on your brain's wellbeing. Among them are those that affect blood supply, including diabetes, high blood pressure and atrial fibrillation. Conditions that might leave you feeling socially isolated, such as hearing loss and depression, can have an impact too – as can a history of head injury.

After your diagnosis, you may also find that living with dementia changes your emotional reactions. Try to work out what triggers a difficult reaction and make plans for how to cope with it in the future. You might also find that you get more tired than you used to. Having dementia can mean it takes more effort and concentration to do things. When you are tired it's harder to concentrate and you're less likely to remember things and more likely to be confused. Don't push yourself too hard, listen to your body if it's telling you to rest, and ensure you are getting enough sleep. Get the balance right though – giving up your favourite activities may leave you feeling low.

Monitor your overall health with regular check-ups with your GP. This will help you pick up on any concerns early. Follow medical advice closely and take any medications as prescribed.



Stress, depression and anxiety

A diagnosis of dementia can cause a variety of emotions for you, and for your family and friends. Remember, this is completely natural; but it is important to recognise if these emotions are getting too much for you or your family members to manage. We can all feel down from time to time, but this is not the same as depression. Depression is a condition that can last for a prolonged period and cause feelings that dominate your life. If you feel sad, hopeless or have lost interest in things you used to enjoy, you should seek help.

If you are concerned that one of your family or friends is depressed or anxious – perhaps they're quieter or crying more than usual – it is important that you speak to your GP about how this can be treated.

There are many treatments available for depression and anxiety, including medical treatments/medications and talking therapies.

It is also important to recognise if you are becoming stressed. Long term stress can harm your brain and make it harder to keep on top of other things that are important to keep it healthy. Make time for yourself and the things that help you to switch off and relax.

Try to take steps to protect your sleep. Your brain cleanses itself while you sleep, flushing out waste products that build-up during the day. Aim for between 7-9 hours of good quality sleep every night. Not getting enough sleep can affect your memory and your ability to think clearly in the short and long term.

Speak to your GP as there are lots of things you can do to reduce stress and depression. Specific support with depression can be found here:

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

www.samh.org.uk

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



There are lots of different things that influence the health of our brain. Some factors are beyond our control but there are many things we can do to make positive changes in our lives. Below are some examples of steps you can take to improve your general health as well as your brain health.

Physical activity

Physical activity can help delay or reduce some mobility problems associated with dementia by improving your balance and muscle tone and can reduce the risk of trips and falls.

Being physically active is one of the best things you can do to boost brain health. Regular exercise helps maintain a good blood supply to the brain, improves mental wellbeing and promotes good quality sleep. There are lots of ways you can become more active. Whatever works for you, aim to complete at least two to three hours of moderate intensity exercise every week. This could be broken down to around 30 minutes activity on at least five days of the week – maybe scattered throughout the day rather than all at once.

Starting an exercise regime in the early stages of dementia will make it easier to maintain. It is a good idea to ask your GP before starting a new form of physical activity and build it up slowly. Older adults should also undertake physical activity to improve muscle strength, balance and coordination at least two days a week. Avoid sitting for long periods of time – if possible, get up and move around at regular intervals. Your local leisure services department should be able to tell you about activities near where you live. Our Dementia Advisors can also help with advice about activities in your local area.

Our Dementia Advisors can help you find out more about the support available in your area. For more information, visit www.alzscot.org/dementiaadvisors

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, 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.

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 if you are sensible about it 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 risks to your health. However, it is very important that you check with your doctor first, as some medication can have a negative reaction when mixed with alcohol. To keep alcohol-related health risks to a minimum, it is safest not to drink more than 14 units a week on a regular basis. If you regularly drink as much as 14 units per week, it is best to spread your drinking evenly over three or more days.

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

Your home

Simple changes to your home can make it easier to manage. Depending on your situation, your local Health and Social Care Partnership may have a duty to provide you with aids and adaptations. An occupational therapist, who can be contacted through your local Health and Social Care Partnership, Community Mental Health Team or Post Diagnostic Support Link Worker, can advise on what would be most helpful, based on your needs, wishes and general circumstances.

Layout and alterations

The most beneficial adaptations 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.

For example:

- a downstairs bedroom and bathroom, a wet room, or a ramp instead of steps outside, can help with mobility and balance problems
- clear pictorial signs on doors to the kitchen or toilet may help you find your way around the house
- strongly contrasting plain colours for areas 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 lighting installed, with stronger bulbs for good, even lighting, especially on steps and stairs



Alzheimer Scotland's Allied Health Professionals can also help. Visit www.alzscot.org/ahpresources for more information.

Money issues

Managing money can become more difficult when you have dementia. This can be even trickier if you have a sudden drop in your income. It might feel daunting but try not to worry too much, there are lots of ways to make it easier for you to cope. For example, you could set up direct debits or standing orders to make sure important bills are paid.

There is always help available. You might not know if you're able to claim certain benefits to help financially so it is worthwhile finding out if you are eligible. Our Post Diagnostic Support Link Workers and Dementia Advisors will be able to offer further information about benefit entitlement.

A diagnosis of dementia might be a good prompt to sort out your financial affairs. You may reach a stage in your condition when you are no longer able to make some important decisions. When this happens, someone you trust – often a family member or carer – can make these decisions on your behalf, if you have granted them power of attorney. Setting up a financial power of attorney is a good idea. This is a legal document that allows someone to make decisions on your behalf if you become unable to do so, and to support you to manage your finances.

Having a power of attorney can provide peace of mind as it offers reassurance that you have the support of someone you trust if you are unable to make decisions yourself. Your attorney will have the information they need to make those decisions with confidence.

If you don't set up a power of attorney and you become unable to make decisions for yourself, the person who acts on your behalf may not be who you would have chosen. Unless legally documented as power of attorney, your next of kin, family or other people close to you do not have the legal right to make decisions for you.

It's better to do this as early as possible so that you are fully involved in the process, with ownership over how you would like your affairs to be managed and who you choose to support you in the future. It will also offer reassurance that you have made your wishes and preferences clear.

Having these arrangements in place will help you and your family get on with your lives and plan ahead with confidence.

More detailed information about power of attorney can be found here:
www.alzscot.org/powerofattorney

Involving other people

A person to whom you grant power of attorney can work with you as well as acting independently, with your permission while you are able, to 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 such as your bank manager or insurance provider
- ask questions and clarify your options
- keep a record of what is agreed

A welfare power of attorney, usually set up at the same time, allows you to choose a person to be involved in decisions about your health and welfare if you are no longer able.





Managing household bills and spending

Sorting out your day-to-day finances makes it clearer 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 also ask your bank or building society to monitor your current account for erratic or unusual spending patterns.

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?

Pensions

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

Claiming benefits

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

Most local authorities provide benefits and welfare rights advice. You should check how to access this with your social worker or Link Worker.

The Citizens Advice Bureau can also help you claim benefits, visit Citizen's Advice Scotland website for more information at www.cas.org.uk

You can also contact Citizen's Advice Scotland directly using their helpline on **0800 028 1456**

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

Visit www.gov.uk/browse/benefits/disability

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 want to keep driving, you need to know you are safe and feel confident behind the wheel. You may prefer to stop driving if you find it stressful or worrying. You should ask your doctor if medication for dementia has any impact on your driving. If you hold a current driving licence, you must inform the Driver and Vehicle Licensing Agency (DVLA) when you are diagnosed with dementia. You must also surrender your driving licence to the DVLA if your doctor advises you not to drive for a period of three months or longer. If you do not tell the DVLA, your doctor has a duty to do so on your behalf. You must also tell your insurance company, or your insurance may not be valid. Driving without valid insurance is a criminal offence. If you want to carry on driving, tell the DVLA. They will send you medical forms to complete and will seek your permission to get a report from your doctor. The DVLA may want you to have a driving assessment. If so, they will refer you to your nearest assessment centre at no cost to you.

Other ways of getting around

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

Public transport

The National Entitlement Card allows people aged 60 or over and people with disabilities to travel by bus for free and travel by train at a reduced price in Scotland, and offers concessions on ferry journeys if you live in the Western Isles, Orkney or Shetland. If you find travelling with someone makes things easier, they may also be able to travel for free under the same scheme. Community transport may be available in areas with limited public transport. Contact your local social work department for advice. Local supermarkets may also 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

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 maintain your independence.

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

Cycling and walking

Cycling and walking keeps you healthy, allows you to get around independently, and can provide you with mental stimulation as well as exercise. Dementia may slow your reactions and affect your judgement as a road user or pedestrian. Try to cycle off road, away from busy traffic, when possible. You will be safer on quieter routes you know well and in good weather conditions. Make sure your bike is well maintained. High visibility clothing is sensible, whether you're cycling or walking, and a helmet is recommended if you're on a bike (whether you have dementia or not).

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.

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



Helping your memory

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

These are some of the tips people with dementia recommend to help with your memory:

- make lists of what you need to do or keep a diary, get into the habit of checking it regularly and make notes of where things are
- put a reminder board on the wall to help you remember things
- decide on a place to keep important things like money, keys and glasses – put them in the same place every time so that you can track them down
- ask your family and friends to phone you to remind you about the things you need to do
- if you like gadgets, a mobile phone, tablet or Alexa can act as a diary, plus you can set reminder alarms, for example, to take a pill or go to an appointment

Tips for coping with dementia

- write things down
- don't be afraid of asking for help and accepting help from people you know and trust
- keep important things in one place
- ask your family or friends to phone you to remind you about things you need to do
- technology such as mobile phones, tablets and Alexa can help you cope
- be patient with yourself
- concentrate on the things you can do
- make a routine for yourself
- know your good times of day
- our help card can be shown to people, to explain that you have dementia – you can order one through our 24 hour Freephone Dementia Helpline **0808 808 3000**
- ask other people to help you work out what risks you should or shouldn't take
- when you are buying expensive or significant items, consider asking people you trust to come with you

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](https://www.instagram.com/alzscot)

