

Caring for someone with early stage dementia



Who we are

Age Scotland is the national charity for older people. We work to improve the lives of everyone over the age of 50 so that they can love later life.

Our vision is a Scotland where everyone can love later life.

Our mission is to inspire, involve and empower older people in Scotland, and influence others, so that people can make the most of later life.

Our three strategic aims are to:



Help older people to be as well as they can be



Promote a positive view of ageing and later life



Tackle loneliness and isolation

How we can help

We know that growing older doesn't come with a manual. Later life can bring changes and opportunities to your life and you may need to know about rights, organisations and services which are unfamiliar to you.

That's why we provide free information and advice to help you on a range of topics including benefits and entitlements, social care, legal issues such as Power of Attorney, housing and much more. All of our guides are available to download for free from our website, or you can contact our helpline team to have copies posted to you for free.

The Age Scotland **helpline** is a free, confidential phone service for older people, their carers and families in Scotland looking for information and advice.

Later life can bring times when you just need someone to talk to. Our **friendship line** is part of our wider helpline and older people can call us for a chat. We're here to listen, provide friendship and offer support.

For information, advice and friendship



Call us free on: 0800 12 44 222
(Monday – Friday, 9am - 5pm)



Visit [agescotland.org.uk](https://www.agescotland.org.uk)
to find out more.



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Caring for someone with early stage dementia

Are you a carer?

Many carers do not see themselves as carers but see themselves just doing what anyone would do to support friends or family. If you look after your partner, relative or friend who needs help because they are ill or have a disability, then you are a carer. It doesn't matter whether you live with the person you care for, or for how long you help them.

This guide is for someone who is caring for a person living with early stage dementia. You might be a friend, family member, partner or relative. You may give support for a few hours a week, or for 24 hours a day, every day. You could be helping the person living with dementia to develop a routine, for taking medicines and locking doors and windows at night. Being a carer is not always easy, and sometimes you will need support too.

This guide discusses what services are available to support you, and provides information about practical things you might want to think about. Everyone experiences dementia differently, but having support in place can help you both live well for as long as possible.

What to expect

Different types of dementia affect people in different ways:

- **Alzheimer's disease** usually starts in the part of the brain vital for forming memories and for understanding what things mean. Damage to this part of the brain means someone might struggle to find the right word in a conversation, forget people's names or unnecessarily repeat words and phrases. Symptoms usually progress gradually over time.
- **Vascular dementia** is caused by a reduced blood supply to the brain due to conditions such as high blood pressure, stroke or irregular heart rhythms. In the early stage it can appear similar to Alzheimer's disease, but symptoms can suddenly get worse.
- **Frontotemporal dementia** is caused by damage to the front areas of the brain. Changes to the person's character might be the most noticeable symptoms. They may be less motivated, less kind, less polite, or they may behave impulsively.
- **Dementia with Lewy Bodies** is related to Parkinson's disease and people living with it can have many of the same physical symptoms, such as slower movement and tremors. In the early stage it is common for people to experience sudden changes in alertness, hallucinations and delusions.
- **Posterior Cortical Atrophy** is a rare form of Alzheimer's disease which causes damage to the brain cells at the back of the brain (posterior). This part of the brain is vital for judging space and distance, and for making sense of what we see. Damage in this area of the brain can make people clumsier, and they can increasingly struggle with things such as parking a car or getting dressed. Activities such as reading and using a computer can be more difficult for them. They might fail to spot things right under their nose, or tell coins and notes apart when handling money.

The person you care for may behave in a way that you find difficult to understand. If their behaviour is challenging or difficult to manage you should speak to your GP and contact your social work department for a care needs assessment.

Where do we get support?

There are a range of people and organisations that can help you.

Who's who?

As a carer for someone living with dementia you will probably find yourself coming into contact with a lot of different professionals and services for the first time. The information below explains why they might be involved in providing support, including the Post diagnostic support that everyone newly diagnosed is entitled to and a care needs assessment from your local council.

Community Psychiatric Nurses are mental health nurses who visit people in their homes. They provide practical advice and support for people living with dementia. They can also administer medication and keep an eye on any side effects.

Dementia Advisors are a local point of contact for people living with dementia, their families and carers. They can help you keep active in the community and put you in touch with sources of support.

Dementia Link Workers provide one to one support for people living with dementia, their families and carers. They provide information and advice and can help you plan for the future.

Dietitians can assess, diagnose and treat diet and nutrition difficulties. They give information and advice on food choices.

District Nurses visit people in their homes and provide help on a range of health issues including wound care and supporting people to manage problems with continence.

GPs look after people's general physical and mental health needs and can make referrals for specialist support.

Occupational Therapists help people to live independently and do as much as they can in their daily lives. They can give advice on changes to the home environment that can make life easier and equipment that can help with daily activities. This might include equipment to help with memory.

Physiotherapists can help if you have difficulties walking or have fallen. They provide advice on exercises to improve strength and balance, and equipment to help with walking and moving around.

Podiatrists help to treat foot conditions and problems. They give advice on how to look after feet and what types of shoes to wear.

Social Workers assess the care and support needs of people who have physical and mental health difficulties or disabilities and the support needs of carers.

Speech and Language Therapists support people who have difficulty with communication. They also help people with eating, drinking and swallowing difficulties.

Post diagnostic support

People who are diagnosed with dementia in Scotland should receive at least a year's post diagnostic support. This is often provided by an Alzheimer Scotland Dementia Link Worker or Dementia Advisor. They are interested in what matters to the person diagnosed. This may include help to understand dementia and manage the symptoms, assistance with practical things like claiming benefits, sorting out legal matters or discussing different care options for the future. They can also put you in touch with local services, and opportunities to do things you would enjoy. For more information about post diagnostic support contact Alzheimer Scotland.



Alzheimer Scotland

0808 808 3000

www.alzscot.org

Care needs assessment for the person you care for

The person you care for, or yourself, can ask your council's social work department to assess their care and support needs. A social worker, occupational therapist or other health professional will arrange to visit and talk with you both about the help you think you need.

The support may include help with tasks like washing and dressing, eating and drinking, taking medication, getting around the home or making sure they are safe.

Your council is likely to have a waiting list for an assessment. If the need is urgent because there is a risk of harm, make sure the social work department knows that you need urgent help.

The social worker will consider if they would benefit from support at home and in a community setting such as a lunch club or day centre. Any care that is classed as Personal Care will be free, but there may be charges for other types of support.

You should have some choice about how the care is provided. Under the rules for Self-Directed Support care may be arranged and provided by the council or health board, or you and the person you care for may be able to arrange some or all of the care yourselves.

The care needs assessment will take into account the care you provide, so you must be honest about what you can and cannot do.

Self Directed Support Scotland can advise you about the options for how care is provided and put you in touch with local support. Call them on **0131 475 2623** or see their website **www.sdsscotland.org.uk**.

Age Scotland's guides **Care and support at home: assessment and funding** and **Care and support at home: practical help** explain about free personal care, how the assessment is carried out and the types of equipment and support that are available.

Adult Carer Support Plan

Since 1st April 2018 carers in Scotland have rights because of the **Carers (Scotland) Act 2016** and the **Carers' Charter**. These are rights to help from your council or, in some areas of Scotland, your health board.

You have the right to help with your caring role and also support to help you to look after your own health and wellbeing.

The council or health board must also make sure there is a local information and advice service for carers and provide information about any short breaks available to local carers.

If the council agrees that you are a carer they should offer you an Adult Carer Support Plan and work with you to try to ensure that this meets your needs. They may already know that you are a carer, or you may need to ask them for an assessment.

The Adult Carer Support Plan must include:

- your personal circumstances and nature of your caring role
- how much care you are able and willing to provide
- information about the personal outcomes that matter to you, so you can be a carer and also look after your own health, wellbeing and interests
- the support available locally
- the support you qualify for according to the council's local rules.

Some of the questions you may be asked may seem quite personal and difficult to answer: you will need to explain what care you provide, what support you have and what support would help you.

You could prepare for the assessment by thinking about:

- any care you find difficult for health or personal reasons
- whether you have time to look after yourself – eating, sleeping, looking after your own health, seeing friends and doing things you enjoy
- how caring fits in with your work and family
- any issues that may affect your ability to continue caring.

If you qualify for help under local rules, your council or health board should provide support. They may provide you with support or services or work out a budget you can use to arrange and pay for support for yourself. The support you receive could include help to claim benefits, training, leisure activities or support with housework and gardening.

You do not have to pay for any carer's support you receive from the council or health board under your Adult Carer Support Plan. If you receive other services, such as support with your own care needs, you may need to pay for this, or you may qualify for Free Personal and Nursing Care.

For information about local rules about who qualifies for help or contact details for your local carers centre, call the **Age Scotland** helpline on **0800 12 44 222**.

Emergency planning

Your Adult Carer Support Plan should look at what happens in an emergency if you are unable to provide care so everyone knows what to expect and what help the person you care for would need. For more information see the **Coalition of Carers** website **www.carersnet.org** or contact your local carers centre.

Hospital discharge

If the person you care for is going to be discharged from hospital, you should be involved in planning for the return home or move to a care home. You may need to know whether they will need more care, or how best to manage new medication. You may need to ask for more support for yourself.

It is best to talk to the hospital as early as possible to make sure you are clear about the discharge plan and the support available to you both. For more information see the **Coalition of Carers** website www.carersnet.org, contact your local carers centre or centre or see our **Hospital Discharge** guide.

Change in care needs

If your needs or those of the person you care for change, you should get the assessments updated. Contact the social work department and ask for a reassessment.

For more information see Age Scotland's guide **Care and support at home: assessment and funding**.

Care Information Scotland provides information on care services for older people in Scotland, their carers and families.



Care Information Scotland

0800 011 3200

www.careinfoscotland.scot



Care for yourself

Caring for someone close to you is an important role, but at times it can be physically and emotionally challenging. The person living with dementia will need a carer long term and this might feel overwhelming. It can be easy to overlook your own needs but you need to look after yourself too.

Talk to others

It is useful to talk things through with your friends and family and explain how caring is affecting you. You will probably find if you are open and honest about things that people are more likely to help out. They might have questions about dementia and how to behave around the person you care for. Remind them that the person living with dementia is still the same person they were before being diagnosed. Give them advice about communicating, for example, the person may find it easier being asked questions that only need a 'yes' or 'no' answer.

Carer's groups are a good way to have a chat and share experiences with others. No matter what you are going through there is probably someone who has been through the same thing and understands how you feel. Alzheimer Scotland runs groups across Scotland for people caring for someone with dementia.



Alzheimer Scotland
0808 808 3000
www.alzscot.org

Many people find online groups are a useful way to talk with other carers. You could have a look at the forum on the **Carers UK** website: **www.carersuk.org/forum**.

Support from health services

It is important to look after your physical and mental health. If you are finding things difficult or feeling stressed, anxious, tired or depressed you should speak to your GP. Let them know you are a carer and tell them how you are feeling. Nobody can manage everything on their own so don't be afraid to ask for help. Your GP will take time to listen and discuss support and treatment options with you.

Counselling

Counselling also gives you the opportunity to talk with someone. A counsellor will listen to you without judging you or your situation. Your GP or local Carer's centre may be able to give you information about counselling services and may refer you for free support. You can also contact the British Association for Counselling and Psychotherapy who can help you find qualified counsellors in your area. There may be a charge for their services.



British Association for Counselling and Psychotherapy

01455 883300

www.bacp.co.uk

Taking time out

It is important to take regular breaks from caring and make time for yourself. Having a break does not mean you are letting down the person you care for. It is time you need to have a rest, catch up with friends and family, attend appointments and do things that are important to you. Check if respite breaks are included in the care needs assessment of the person you care for or the support you are entitled to as a carer. Respite care can include:

- someone to care for the person living with dementia so you can go out.
- the person you care for attending a group, activity or day centre.
- the person you care for having a temporary stay in residential care.

Shared Care Scotland offers information and advice to carers about respite services.



Shared Care Scotland

01383 622462

www.sharedcarescotland.org.uk



Supporting the person living with dementia

Dementia affects everyone differently and no two people will have symptoms that develop in exactly the same way. Strategies that work for some, may not work for others.

Ideas for communication

Not everyone living with early stage dementia will find communicating difficult, but some people find it harder to communicate as their dementia progresses. They may find it difficult to understand people they do not know or others might struggle to understand them. They could have trouble finding the right word or repeat words and phrases. As their carer, you are probably best placed to support the person but you may need to learn new ways to understand and communicate with them.

You could:

- avoid distractions: it can be difficult to hold a conversation if there is background noise such a TV or radio
- try alternative ways of explaining things: a map may be the best way to show someone where to find the right bus stop
- choose a private setting to discuss a personal or difficult subject
- use non-verbal communication: eye contact, smiling and gestures give context to your words
- listen with our eyes: watch their body language to help you understand language and emotion
- speak clearly, calmly and slowly and avoid jargon and complicated language
- use short questions that only need a “yes” or “no” answer and use different words if that helps to clarify the answer
- use pictures, diagrams and lists
- help with written communication if they find reading and writing difficult
- resist the temptation to answer for the person if they are taking a while to respond.

Adapting your home

Most people with dementia want to stay in their own home for as long as possible, but memory difficulties and confusion may lead them to forget where things are kept and how things work. There are small changes that you can make to the design and layout of the home to support the person you care for.

Increased lighting levels can be helpful to people living with dementia. As you age, changes to your eyes can affect how much light you need to see properly. Many people with dementia have difficulties with their ability to see different colours and shapes; good lighting can help with this.



Daylight alerts people to the time of day so keep curtains and blinds open in during the day. This might reduce symptoms such as confusion or sleep disturbances. You can buy clocks that let you know the day, date and time and whether it is day or night.

A floor which contrasts with the colour of the walls reduces the risk of falling as it will stand out against the walls and furniture. Patterned flooring may be confusing as it can be difficult for people to identify if it is a design or a hazard, such as a hole. Highly polished, shiny flooring may appear to be wet, and can reflect light which can be confusing and may increase the risk of slipping.

Stairs and steps should be well lit and clearly marked to reduce the risk of falls. Electric cables and small items of furniture or bags increase the risk of falls too. Rugs can also be a hazard, especially on uncarpeted floors, and for some people living with dementia small rugs may look like a puddle or hole which needs to be avoided.

For more information see the Age Scotland publication **A Carers guide to creating a dementia friendly home**.

Organising the kitchen

Signs or pictures on the front of kitchen or bathroom cupboards show where things are stored. Glass fronted cupboards or open shelving units can also help.

If they enjoy cooking but find it hard to follow recipes, adapt recipes to be similar but simpler, and use a kitchen timer to reduce the risk of burnt food.

If you are worried about safe use of the oven, look at safety devices which turn off cookers or gas supplies if they are left on for too long. If you think safety devices would help, ask your council's social work department for help.

Disability Information Scotland provides information about living with long-term conditions.



Disability Information Scotland

0300 323 9961

www.disabilityscot.org.uk

Care and Repair services offer advice and assistance to older people and disabled homeowners to repair, improve or adapt their homes so they can live safely and comfortably.



Care and Repair

0141 221 9879

www.careandrepairsotland.co.uk

Checklists and reminders

Short checklists can help to remind people living with dementia of everyday tasks which may help them stay independent. For example, instructions on how to make a cup of tea, what to unplug at night, or what to take with them when they leave the house. They might find using a daily diary or to-do list helpful, especially if they are worried about missing appointment or managing medicines.

Getting into a routine

Having a routine and sticking to it can help to reassure the person living with dementia and make it easier for them to keep track of what they need to do each day. They could get up at a regular time and have a list of what they need to do, such as taking medication or preparing meals. Simple gadgets might help with this, such as a pill box with different compartments for different days and times, or a clock that shows the date and day of the week.

Technology

Technology can be a useful support for some people who are living with dementia. Some equipment and support is designed specifically to help with the symptoms of dementia, but other equipment, such as a phone with a simple keyboard, could be useful too. Get advice from Alzheimer Scotland or Disability Information Scotland before you buy any equipment and check with your local social work department as equipment may be available free as part of a care needs assessment.

Assistive technology can help people with daily tasks that they are starting to find more difficult. These include item locators to help find lost keys and recorded reminders to lock the door at night.

Telecare support to stay safe at home can include personal alarms and gas, smoke and flood detectors. These will alert a callcentre or a family member if there is a problem.

There are many types of digital technology that can help people to record their life story, memories and important dates. They can also record personal information such as their hobbies and likes and dislikes, which can be useful if they need to tell a professional what is important to them.

The Disabled Living Foundation provides information and advice on equipment and technology for daily living.



Disabled Living Foundation

0300 999 0004

www.dlf.org.uk

Shopping

Some people living with dementia find shopping difficult because of noise, crowds or problems reading labels or handling money. Many supermarkets now have staff who understand about dementia: they offer relaxed lanes where you won't be hurried and you can take your time to pack your bags at your own pace.

If you are supporting them to do their own shopping, choose quieter times, or make arrangements with a local shop where staff understand about dementia.

If they can no longer manage to go shopping, you could support them to shop online so they can still make their own choices.

Travel

Sometimes people living with dementia feel anxious about travelling or find it confusing and stressful but you can make travel easier if you plan carefully and talk to them about what might help. People may feel worried or anxious about continence when it comes to long journeys, speak to your GP or see our **Bladder and Bowel problems** guide for information about the help available.

Travelling by car: if you are together in the car, keep in mind that they may feel anxious and talk to them about what works best for them. They might find it less stressful to sit in the back of the car. Placing a coloured blanket on the seat makes it easier to see where the seat begins and helps if they have difficulties with balance.

Travelling by train: you can book “assisted travel” in advance so staff will expect you and provide assistance such as help with luggage or changing trains.

Travelling by plane: book assisted travel well in advance and allow plenty of time to arrive and check in.

Travelling by bus: drivers are experienced at supporting passengers and can let you know when you’re at the right stop if you are going to somewhere unfamiliar. There may be a local Dial-a-Bus scheme in the area which can pick you up at home and take you to places such as shopping centres.

Travelling on foot: make it a habit for the person you care for to always have money, your contact details, a charged mobile phone and the number of a trusted taxi firm.



For more travelling tips contact **Alzheimer Scotland.**
0808 808 3000
www.alzscot.org

Help cards

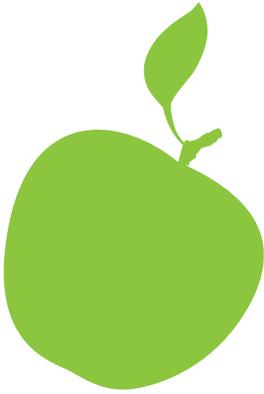
Help cards are really useful if someone living with dementia has difficulties as they let others know about the dementia and what they need help with. The card will be recognised by people such as bus drivers, shop workers and police, and there is space on the card for your contact details. You can get a card from Alzheimer Scotland



Alzheimer Scotland

0808 808 3000

www.alzscot.org



Keeping you both well

Diet

Eating a varied, balanced diet is one of the best ways to look after yourself. Having a healthy diet involves eating lots of fruit and vegetables, starchy foods such as bread and pasta and moderate amounts of meat and fish. Try to eat fewer foods that are high in saturated fat such as processed meats, butter and cheese. Instead eat foods containing unsaturated fat such as oily fish, nuts and seeds. Eating sugary snacks like chocolates and fizzy drinks can mean your diet is too high in sugar so try to only eat these very occasionally. When you are caring for someone, having a healthy diet might be easier said than done. Your routine is probably busy and demanding, with little time to make healthy meals. Just do what you can.

Take a look at Age Scotland's guide **Eat Well** for ideas about healthy eating.

Older people need to stay hydrated, and not having enough to drink can make dementia symptoms worse. Water is a great choice, but anything is better than nothing. Fruit juice, soup and tea all help.

If forgetting to drink is a problem, using a clear glass with a coloured liquid such as diluting juice can help to remind them to drink. Try and keep drinks in their line of sight.

Some people living with dementia lose interest in food or experience a change in their eating and drinking habits. It might be difficult for them to remember to eat and drink or concentrate on finishing a meal. You can support the person you care for to enjoy meal times and get the best out of their diet if you eat meals together; they can copy you if they forget to eat or are confused about how to use cutlery.

Using plain but brightly coloured plates can help them to see pale coloured foods on their plate. It might be useful if you give them gentle reminders to eat and drink throughout the day.

Background noise, such as televisions and radios can be distracting when eating, but some people living with dementia find playing soft music can help them relax and concentrate on their meal.

Their likes and dislikes may change or their appetite might be smaller than it used to be. Encourage them to explore different types of foods and find things that they enjoy. If they prefer sweet foods try and choose healthier options like fruit or sweet vegetables, such as carrots and sweetcorn. If they do not have much of an appetite they could try eating smaller portions and regular snacks through the day. Meals with strong flavours or different colours might help them to feel hungrier.

If the person you care for is having difficulties with eating and drinking, encourage them to speak to their GP. They may be referred for specialist support from a speech and language therapist.

Being active

Regular physical activity is not only good for health, but it can help to get rid of stress and improve wellbeing. Combining being a carer and finding the time to be active can be a challenge.

Picking an activity you enjoy is important as you will be more likely to stick to it. You could try swimming, playing football or even a brisk walk. Simple changes to your routine can make a big difference: you could get off the bus a couple of stops early or stand up whilst talking on the phone.

If the person you care for is able to be active, it can help them to feel positive and to concentrate. If they are concerned about meeting and remembering new people or following instructions, see if there are local activities that have taken steps to include people with dementia. There are dementia friendly choirs, sports and walking groups that understand how to include people with dementia.

If the person you care for needs your support, find something you can enjoy together that encourages them to use their skills and interests.



Paths for All

Walking is a great activity for everyone.

Paths for All is a charity that promotes the benefits of being physically active through walking. It supports a network of community health walks throughout Scotland: free group walks which are led by trained volunteers and are accessible to everyone. They want to ensure that everyone living with dementia and their families, friends and carers can take part in walking. Dementia friendly walking groups understand the needs of people living with dementia and they support they may need.



Paths for All

01786 641 851

www.pathsforall.org.uk

If you would like information on activities in your local area phone the **Age Scotland Helpline** on **0800 12 44 222**.

For more information on being active speak to your GP practice which can give you information and advice or see our guide to **Health and wellbeing in later life**.

Staying warm

Over the winter it is important you and the person living with dementia keep warm at home. Being cold for any length of time can put you at risk of colds, flu and hypothermia. Try to make sure that rooms both of you are in during the day are kept warm to at least 23°C. Keep bedroom windows closed at night so you do not breathe in cold air as this can increase the risk of chest infections. Layer your clothing to maintain body heat and try not to sit down for long periods of time. Get up, move around and have hot meals and drinks.

There are benefits, grants and schemes which may help make your home more energy efficient and improve your heating. Being energy efficient can help you save money on fuel bills. Home Energy Scotland give information and advice on how you can save money and energy and make your home warmer.



Home Energy Scotland

0808 808 2282

www.energysavingtrust.org.uk/scotland/home-energy-scotland

Smoking

It is common knowledge that smoking is bad for your health. If the person you care for smokes and has memory difficulties, it could increase the risk of a fire. There is plenty of support available if you want to stop smoking. A good place to start is by speaking to your GP or call NHS Inform on **0800 224488**.

If the person you care for does continue smoking try to make it as safe as possible. For example, encourage them to use disposable lighters instead of matches. The Scottish Fire and Rescue Service can make sure their home is as safe as it can be. You can contact them for a free home safety visit.



Scottish Fire and Rescue Service

0800 0731 999

www.firescotland.gov.uk

Alcohol

Many of us enjoy an alcoholic drink now and then, and alcohol can be an important part of socialising and celebrating. However, regularly drinking more than the recommended daily limits of alcohol increases the risk of developing conditions such as cancer, heart disease and stroke. Drinking alcohol can make some dementia symptoms worse: it can increase confusion and affect memory so the person you care for should try to limit the amount of alcohol they drink. Certain medicines do not mix well with alcohol: if you need advice about this speak to your GP or pharmacist. Changing can be difficult, especially for people who have been drinking heavily for a long period of time. If you want to stop drinking or cut down you could get in touch with Drink Wise, Age Well. They help people make healthier choices about drinking as they age. They provide information on alcohol unit guidelines, tips for cutting down and how to get help if you need it.



Drink Wise, Age Well
www.drinkwiseagewell.org.uk

Practical things to think about

The period after a diagnosis is a good time for the person you care for to think about legal, financial, health and care matters for the future. Making decisions for the future while they still have the mental capacity to do so can help them to feel in control, and you can feel reassured that you know their views and wishes for the future.

Power of Attorney

As a carer, family member, friend, relative or partner you do not have the automatic right to make decisions on behalf of the person you care for. You could encourage them to set up a Power of Attorney while they have the mental capacity to do so. A Power of Attorney is a legal document which they can use to give someone else the power to make decisions on their behalf if they become unable to do so, and to support them to make decisions. The person you care for might want you to be their Power of Attorney; this is a big responsibility, so take time to consider if it is the right decision for you.

It is best to have Power of Attorney drawn up by a solicitor. Without a Power of Attorney in place, in most cases someone would have to go to court to gain the authority to act on another person's behalf if they had lost mental capacity. This can be a very expensive and stressful process.

See Age Scotland's publication **A Guide to Power of Attorney in Scotland** for more information or contact the office of the **Public Guardian in Scotland**. See their website www.publicguardian-scotland.gov.uk or call **01324 678398**.

Wills

If the person you care for makes a will, this allows them to decide what happens to their money and possessions when they die. It is possible to write a will without a solicitor, however, it is best to have it checked over as small mistakes can mean that the will is not valid. Wills can be changed at any time, as long as the person still has the mental capacity to do so and the changes are made properly – you should check this with a solicitor too.

See Age Scotland's publication **Making your Will** for more information.

Advance Directives

An Advance Directive is a document which allows someone to make decisions about their future medical care. It is a way of making sure that medical staff, friends and family know what treatment they do not want, should they lack the capacity to make the decision in the future.

See Age Scotland's guide **Planning for your future healthcare** for more information.

Driving

Many people living with dementia are able to continue driving for a while, however they must fulfil certain legal requirements, including telling the Driver and Vehicle Licensing Agency (DVLA) and their insurance company about their diagnosis. If a person living with dementia has not disclosed their diagnosis to the DVLA and are then involved in an accident, they can be prosecuted.

For more information see the Life Changes Trust publication **Driving and dementia -my experiences.**



Life Changes Trust

0141 212 9600

www.lifechangestrust.org.uk

You can also take a look at our **Older Driver's guide.**

Bus passes and carer's discounts

In Scotland, people over the age of 60 are entitled to a bus pass called a National Entitlement Card which permits free travel on buses and coaches. People living with dementia under the age of 60 may also be entitled. If the person living with dementia needs you to help them when travelling by bus they can get a 'companion logo' on their National Entitlement Card which will allow you to travel with them for free.

Many local services will offer a discount for carers. This can help people living with dementia access leisure centres, cinemas, museums etc. either by offering a cheaper price or a free carer place. Contact local services and ask if they offer discounts.

You can find information about bus passes at **www.transport.gov.scot** or call the **Age Scotland Helpline** on **0800 12 44 222** for information and advice.

Learn new skills

In the early stages of dementia, it is likely that the person you care for will be able to remain independent, but in later stages they will probably become unable to do things they could before.

If you care for your partner, you may have to take on new responsibilities that will change your roles in the home. You should plan for this as early as possible, if you need to learn new skills and take over responsibilities such as cooking or online banking. Be open about the changes you need to make to avoid misunderstandings.

Care homes

If the needs of the person you care for become too much for you to manage even with the support of carers, you will have to think about a care home. You should contact your council's social work department and ask for a reassessment of your needs as a carer and also the care needs of the person you care for. Everyone experiences dementia differently, and some people might never need to move to a care home. The decision to move to a care home can be very difficult, but you should not feel that you have let the person you care for down. Continuing to stay at home might be unsafe for them and a care home may be the only option for them to get the support they need.

Age Scotland has a range of publications about care homes which explain how care home funding works and how to choose a good care home. To find out more phone the **Age Scotland Helpline** on **0800 12 44 222**.

Money Matters

Dealing with money

The person you are caring for might find managing money day to day increasingly difficult. They may find it hard to count change or recognise different notes and coins.

They could set up a direct debit to make sure regular bills such as gas, electric, TV licence and Council Tax are paid without them having to remember to do this. You may need to support them to check their bills to make sure the right amount is paid.

Some people living with dementia use contactless bank cards as an easy way to pay for amounts up to £45. You will sometimes need to use your PIN number with the card so make sure they would manage if they needed to enter the number. It is still important they check their bank account, on a paper statement or online.

A chip and sign card can be useful for people who find it difficult to remember a pin code. A signature on a receipt is checked against the one on the credit or debit card.

If you care for your partner, it may be that they dealt with money matters for the household. You might feel overwhelmed having to handle the finances for the first time. Try and organise important documents such as bank statements, wills and insurance policies and put them in a safe place. You may need to arrange a Power of Attorney or transfer accounts such as gas or electricity into your own name. If you want to be more confident managing money call the **Age Scotland Helpline** for information and advice on **0800 12 44 222** and see Age Scotland's publication **Money matters**.

Benefits and social security for carers

The benefits and social security system can provide financial support for carers. You might be eligible for Carer's Allowance.

To claim Carer's Allowance you must care for a person who gets Attendance Allowance, Disability Living Allowance care component (at the middle or highest rate) or Personal Independence Payment (daily living component). These are benefits for people who need help looking after themselves due to a health condition or disability. Most people living with dementia are likely to become entitled at some point after their diagnosis.

Carer's Allowance overlaps with State Pension and a claim can mean the person you care for receives less in income-related benefits, such as Pension Credit. See our guides to **Carer's Allowance** and **Pension Credit** for more information.



For details and information about entitlements and a benefits check call the **Age Scotland Helpline** on **0800 12 44 222**.

For information about benefits for the person you care for see our guide **Benefits for people living with dementia**.

Discrimination and dementia

Unfortunately some carers and people living with dementia find that others treat them unfairly because of the condition. You and the person you care for should not experience discrimination. The 'Charter of rights for people with dementia and their carers in Scotland' sets out the rights of people with dementia and carers. This includes being able to participate, to feel included and to be treated with dignity and respect. You can get a copy from the Health and Social Care Alliance Scotland (The ALLIANCE).



The ALLIANCE
0141 404 0231
www.alliance-scotland.org.uk

If you believe you or the person you care for have been treated unfairly or discriminated against, call the **Age Scotland Helpline** on **0800 12 44 222**.

Advocacy

Sometimes carers and people living with dementia find it difficult to have their views and wishes heard. This can be really worrying, especially if you are having to communicate with a lot of different services and professionals, such as health and social work during a care needs assessment. An advocate can stand up for you and support you to express your views on issues that are important to you. They can help to make sure that your views are taken into account when decisions are being made about your lives. The Scottish Independent Advocacy Alliance can help you find advocates in your area.



Scottish Independent Advocacy Alliance
0131 524 1975
www.siaa.org.uk

Campaigning

Age Scotland is proud to host **About Dementia: Shaping Our Worlds Together** – Scotland’s forum for improving lives. Funded for five years by Life Changes Trust, we work with people affected by dementia across Scotland to shape the policy and practice that affects them in everyday life. Launched in 2019, we have been finding out what needs to change for people living with dementia and those who care for them, and what we can do together to make these changes happen. The project covers many areas of life, including transport, housing, human rights, and prevention of dementia.



About Dementia
0333 323 2400 / aboutdementia@agescotland.org.uk
www.ageuk.org.uk/scotland/what-we-do/dementia/about-dementia/

Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) are a national campaigning and awareness raising group. They exist to make the voices of carers heard and raise awareness of the issues impacting carers. The group is open to anyone who has experience caring for a person living with dementia.



National Dementia Carers Action Network
0141 410 0100 or **0141 410 1171**
www.alzscot.org/ndcan

Together in Dementia Everyday (TIDE) is a national involvement network for carers and former carers of people with dementia. TIDE gives carers a voice and raises awareness of their needs and rights.



TIDE
0141 353 5607
www.tide.uk.net

Dementia Carer Voices is a project which engages with professionals and students to promote a fuller understanding of the carer journey and provides a platform where carers can express their views and experiences of caring for a person living with dementia.



Dementia Carer Voices
0141 404 0233
www.alliance-scotland.org.uk

Employment

If you are employed and also a carer, you might need to think about requesting flexible working. Having some flexibility could help you better manage the demands of being a carer as the person's dementia progresses. You can request:

- a change to the hours you work
- a change to the times when you are required to work
- to work from home

Contact your local Citizens Advice Bureau for advice about informal and formal requests for flexible working or see their website **www.citizensadvice.org.uk/scotland/work/rights-at-work/flexible-working/flexible-working-what-is-it**.



Citizens Advice Bureau

You can call Scotland's Citizens Advice Helpline on **0800 028 1456** for advice or for details of your local bureau or see their website **www.citizensadvice.org.uk/scotland/about-us/get-advice-s/**



Equality and Human Rights Commission

provides information on workers' rights.
0808 800 0082
www.equalityhumanrights.com

You can call the **Age Scotland Helpline** on **0800 12 44 222**.

Useful contacts



Age Scotland

Age Scotland provides information for people through our publications and online. The Age Scotland Helpline provides information, friendship and advice to older people, their relatives and carers.

Age Scotland Helpline: **0800 12 44 222**
www.agescotland.org.uk

About Dementia

Age Scotland is proud to host About Dementia: Shaping Our Worlds Together – Scotland’s forum for improving lives. Funded for five years by Life Changes Trust, we work with people affected by dementia across Scotland to shape the policy and practice that affects them in everyday life. Launched in 2019, we have been finding out what needs to change for people living with dementia and those who care for them, and what we can do together to make these changes happen. The project covers many areas of life, including transport, housing, human rights, and prevention of dementia.

Tel: **0333 323 2400** / **aboutdementia@agescotland.org.uk**
www.ageuk.org.uk/scotland/what-we-do/dementia/about-dementia/

Alzheimer Scotland

Alzheimer Scotland campaigns for the rights of people with dementia and their families and provides services and support.

Tel: **0808 808 3000**
www.alzscot.org

Care Information Scotland

Care Information Scotland provides information on care services for older people in Scotland, their carers and families.

Tel: **0800 011 3200**
www.careinfoscotland.scot

Carers Scotland

Carers Scotland provide information and advice to carers on a range of issues including benefits, care and support services.

Tel: **0808 808 7777**
www.carersuk.org/scotland

Citizens Advice Bureau

You can call Scotland's Citizens Advice Helpline for advice, or for details of your local bureau or see their website.

Tel: **0800 028 1456**

www.citizensadvice.org.uk

Disabled Living Foundation

The Disabled Living Foundation provides information and advice on equipment and technology for daily living.

Tel: **0300 999 0004**

www.dlf.org.uk

Disability Information Scotland

Disability Information Scotland provides information, support and advice to people living with long-term conditions and their families.

Tel: **0300 323 9961**

www.disabilityscot.org.uk

Life Changes Trust

The Life Changes Trust is a charity committed to working with people living with dementia and those who care for them.

Tel: **0141 212 9600**

www.lifechangestrust.org.uk

Shared Care Scotland

Shared Care Scotland offers information and advice to carers about respite services.

Tel: **01383 622462**

www.sharedcarescotland.org.uk

How you can help

Our vision is a Scotland where everyone can love later life.

All the information and advice we provide is free and completely impartial and in helping people access their rights and entitlements, it can be life changing.

We are an ageing population and more people than ever are coming to us for support. You can help us be there for those that need us most.



Make a donation

No matter how small or large, donations make a massive difference and help us continue our important work.

- ▶ Call **03330 15 14 60**
- ▶ Visit **age.scot/donate**
- ▶ Text **LATERLIFE** to **70085** to donate £5.*



Fundraise

Whether it is having a bake sale, running a marathon or knitting small hats for the Big Knit, there are so many ways to raise vital funds to support our work. To find out more, call **0333 323 2400** or visit **age.scot/fundraise**.



Leave us a gift in your Will

By choosing to leave us a gift in your Will, you can help Age Scotland to continue being there for vulnerable older people in the years to come. To find out more, call **0333 323 2400** or visit **age.scot/legacy**.

* Texts cost £5 plus one standard rate message

Let's keep in touch



Sign up to our newsletter

Our regular newsletters by email contain details of our campaigns, services and how you can support our work.

Sign up today by visiting [**age.scot/roundup**](https://age.scot/roundup)



Follow us on social media

Our social media channels are a great way to keep up to date with our work and issues that affect older people.



[**/agescotland**](https://www.facebook.com/agescotland)



[**@AgeScotland**](https://twitter.com/AgeScotland)



[**@age_scotland**](https://www.instagram.com/age_scotland)



[**/AgeScotland**](https://www.linkedin.com/company/AgeScotland)

Age Scotland is the national charity for older people. We work to improve the lives of everyone over the age of 50 so that they can love later life.

Our vision is a Scotland where everyone can love later life.

Contact us:

Head office

0333 323 2400

Age Scotland helpline

0800 12 44 222

Email

info@agescotland.org.uk

Visit our website

www.agescotland.org.uk

Follow us on social media:



/agescotland



@AgeScotland



@age_scotland



/AgeScotland



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