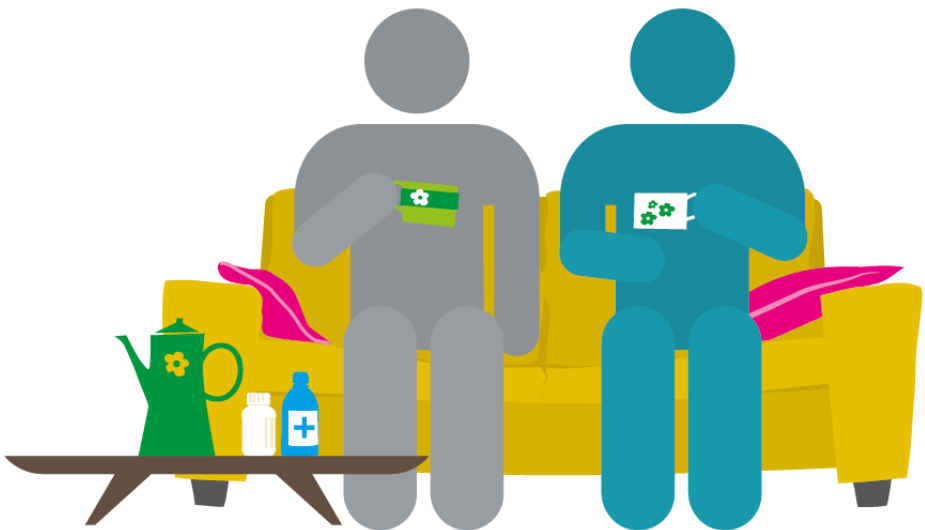


Caring for someone with early stage dementia



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 and promote their rights and interests.

Our vision is a Scotland which is the best place in the world to grow older.

Our mission is to inspire, involve and empower older people in Scotland, and influence others, so that people enjoy better later lives.

We have three strategic aims:



We help older people to be as well as they can be



We promote a positive view of ageing and later life



We 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.

Our **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.



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.

We are grateful to the Life Changes Trust and the National Lottery for funding the first edition of this guide.

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Please note that the inclusion of named agencies, websites, companies, products, services or publications in this information guide does not constitute a recommendation or endorsement by Age Scotland or any of its subsidiary companies or charities.

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Introduction

Are you a carer?

Many people look after someone else but do not see themselves as carers; they feel they are just doing what anyone would do to support friends or family. If you support 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, how often you help them, or how long you spend providing the help. You may give support for a few hours a week, half an hour every day, or for 24 hours a day, every day. Whatever support you provide, being a carer is not always easy, and sometimes you will need support too.

This guide is for anyone caring for a person living with early stage dementia. It explains what services are available to support you, and provides information about practical things you might want to think about. Everyone experiences caring and dementia differently, but having support in place can help you both live well for as long as possible.



Age Scotland runs free workshops covering topics including carers' rights and understanding dementia. Call the **Age Scotland helpline on 0800 12 44 222 for more information.**

What to expect

Dementia can lead to a range of symptoms. These vary depending on the cause of dementia and the individual. You may find the person you care for behaves in ways you find difficult to understand. For example, they may come across as being stubborn when they are struggling to understand the world around them.

Their symptoms may also change from one day to the next, or even within the same day. They may be more able to manage tasks at certain times of day than others. It can be helpful to be aware of this when planning outings or daily routines.

In the early stages of dementia, the person you care for may not behave very differently at all. However, if their behaviour becomes challenging or difficult to manage, do not feel you have to cope alone. Speak to your GP and contact your social work department for a care needs assessment.

Types of dementia

There are many causes of dementia. These have different sets of symptoms and progress in different ways. Details of some of the more common causes of dementia are listed below. However, everyone experiences dementia differently, and two people with the same diagnosis can experience the same condition differently.

- **Alzheimer's disease** is the most common cause of dementia. Two specific proteins build up in brain cells and these cells become damaged. This damage usually starts in the part of the brain vital for forming memories and for understanding what things mean. Someone might struggle to find the right word in a conversation, forget people's names or unnecessarily repeat words and phrases. Symptoms usually progress steadily and 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 dementia caused by Alzheimer's disease, but with vascular dementia, symptoms can get suddenly worse.
- **Frontotemporal dementia** is caused by damage to the front and side areas of the brain. These areas are important for behaviour and language. Changes to the person's character might be the most noticeable symptoms. They may come across as being less motivated, less kind, less polite, or they may behave impulsively.
- **Dementia with Lewy Bodies** is related to Parkinson's disease and can cause many of the same physical symptoms, such as slower movement and tremors. In the early stages it is common for people to experience hallucinations, delusions and sudden changes in alertness.
- **Posterior Cortical Atrophy** is a rare form of Alzheimer's disease. It causes damage to cells at the back of the brain vital for judging space and distance, and for making sense of what we see. It can cause people to become clumsier and to struggle with things like reading or using a computer. People may become unable to see objects that are right in front of them or to tell coins and notes apart when handling money.

Where to 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 different type of support each service can offer is explained below.

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 look out for any side effects.

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

Dementia Link Workers offer one-to-one support for people living with dementia, their families and carers. They can provide information and advice and 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 practical help with 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. They can prescribe medications and make referrals for specialist support.

Occupational Therapists support people to live independently and to continue doing activities that are important to them. They can give advice on changes to the home environment and equipment that can help with daily life. This might include memory aids.

Physiotherapists can help people who have difficulties walking or are at risk of falls. They prescribe exercises to improve strength and balance, and equipment to help with walking and moving.

Podiatrists treat problems and conditions affecting the feet. They advise 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 who have difficulties with eating, drinking and swallowing.

Post diagnostic support

People diagnosed with dementia in Scotland should receive at least 12 months of support on the things most important to them following their diagnosis. For example, they may want help with understanding dementia, managing their health and wellbeing, or planning for their future. Starting in April 2024, people diagnosed with dementia have a choice of how and when to receive this support. The options available will depend on where they live. It may be offered by Alzheimer Scotland, an NHS professional, through peer support, or at a Meeting Centre. See page 27 for more information about Meeting Centres. They can ask their doctor for a referral for post diagnostic support or contact Alzheimer Scotland for more information.



Alzheimer Scotland

0808 808 3000

www.alzscot.org

Care needs assessments

You or the person you care for can ask for their care needs to be assessed by the Council's social work department. A social worker, occupational therapist or other health professional will arrange to visit and talk with you both about your situation. It is important to be honest about the care and support you currently provide and what you can and cannot continue to do.

There is likely to be a waiting list for an assessment. However, let the social work department know if you feel there is a risk either to your safety or the safety of the person you care for.

The assessment will consider what kind of support the person you care for might benefit from. This may include support at home with tasks like washing and dressing, eating and drinking, taking medication, getting around the home or making sure they are safe. It may also include support in the community, such as a lunch club or day centre.

Any personal or nursing care will be free, but there may be charges for other types of support. Under the rules for Self-Directed Support, you and the person you care for can choose how care is arranged. You may want it to be arranged and provided by the Council or health board, or you can choose to arrange some or all of the care yourselves.



Self Directed Support Scotland can advise you about the options for how care is provided and put you in touch with local support. 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 and nursing care, how the assessment is carried out, and the types of equipment and support available.

Adult Carer Support Plan

Since 1st April 2018, carers in Scotland have had rights set out in the **Carers (Scotland) Act 2016** and the **Carers' Charter**. These include a right to have help from their Council or health board with:

- their caring role
- looking after their own health and wellbeing while caring.

The Council or health board must also make sure there is a local advice service for carers. As part of this, they must provide information about any short breaks available to local carers.

If you are considered a carer, they should provide you with an Adult Carer Support Plan and work with you to try to ensure this meets your needs. You can request an Adult Carer Support Plan if this has not already been offered.

The Adult Carer Support Plan must include:

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

You will be asked some questions that may seem quite personal and difficult to answer. You will need to explain what care you can and cannot provide, what support you already have and what additional support would help you.

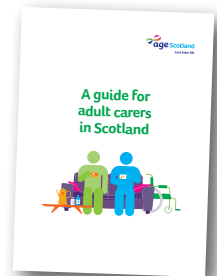
You could prepare by thinking about:

- 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 support under your local criteria, the rules of Self-Directed Support allow you to choose how it is arranged; it can be arranged for you, or you can arrange some or all of it yourself. **Self Directed Support Scotland** can provide advice and put you in touch with local services if needed. See their website www.sdsscotland.org.uk or call **0131 475 2623**.

You do not have to pay for any support you receive 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 yourself.

For information about who qualifies for help, or contact details for your local carers centre, call the **Age Scotland helpline** on **0800 12 44 222** or see our **Adult Carer's guide**.



Emergency planning

Your Adult Carer Support Plan should include what would happen in an emergency if you were unable to provide care. It ensures someone would be available to step in, who would know how to support the person you care for.

For more information see the **Coalition of Carers** website www.carersnet.org/carersrights or contact your local carers centre.

Changes in care needs

You should ask the social work department for an updated care needs assessment and Adult Carer Support Plan any time there are changes to your needs or those of the person you care for.

There are different ways you can get support at home as needs change. For more information see Age Scotland's guides **Care and Support at Home: Assessment and Funding** and **Care and Support at Home: Practical Help**.

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



Care Information Scotland
0800 011 3200
www.careinfoscotland.scot



Hospital discharge

The hospital should involve you in the discharge planning of the person you care for, whether they are returning home or moving into a care home. Their care needs assessment should be updated during the discharge process. You should both be told what has changed and if any equipment or adaptations will be needed.

Talk to the hospital as early as possible to make sure you are clear what will happen and what support is available. You may need to ask for your Adult Carer Support Plan to be updated.

See the Coalition of Carers website **www.carersnet.org/carersrights** or our **Hospital Discharge** guide for more information, or contact your local carers centre.

Call the **Age Scotland helpline** on **0800 12 44 222** for help finding information or to order a copy of the guide.



Caring for yourself

Caring for someone close to you is an important role, which at times can be physically and emotionally challenging. The person living with dementia will need care for the rest of their life, and this might feel overwhelming. It can be easy to overlook your own needs, but it is vital you look after yourself too.

i Age Scotland runs free **workshops** for people caring for someone with dementia. Call the **Age Scotland helpline** on **0800 12 44 222** for more information.

Talk to others

You may find it useful to talk with those closest to you about how caring is affecting you. It can be hard for others to understand what you are going through unless they have experienced caring for someone with dementia themselves. You may need to explain the challenges and how they could help. This could be by taking on tasks not related to your caring role, to free up more of your time.

Your friends and family may 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. They may appreciate some advice on communicating with someone living with dementia. See page 15 of this guide for some suggestions.

Carer's groups provide an opportunity for you to speak to other people in your situation. No matter what you are going through there is likely to be someone who has been through the same thing and understands how you feel.



Alzheimer Scotland runs groups across Scotland for people caring for someone living with dementia.
0808 808 3000
www.alzscot.org



Together in Dementia Everyday (TIDE) runs virtual coffee mornings and focus groups for carers of people living with dementia.
www.tide.uk.net



Alzheimer's Society hosts an online forum accessible worldwide, for people living with dementia, their carers and families.
<https://forum.alzheimers.org.uk>



Carers Trust is a charity that supports a network of local carer groups across locations in the UK. Contact Carers Trust to find carer groups in your area.
0300 772 9600
www.carers.org



Carers UK has a directory of local carer support services, including carer groups. Search support where you live at **www.carersuk.org** or call their helpline. Carers UK also hosts **Carers Connect**, an online forum accessible to Carers UK members (free to join).

0808 808 7777

www.carersuk.org / www.carersuk.org/forum



You can also call the **Age Scotland helpline** on **0800 12 44 222** for help finding a carer's group near you.

Support from health services

It is important to look after your physical and mental health. Speak to your GP if you are finding things difficult or if you are feeling stressed, anxious, tired or depressed. Community Link Workers in some areas, Dementia Link Workers and Dementia Advisors can also provide advice, support and information for carers.

Counselling

Counselling gives you the opportunity to talk with someone removed from your situation, who will listen to you without judgement. Your GP or local carers centre can advise you about counselling services and may refer you for free support. The British Association for Counselling and Psychotherapy can also help you find qualified counsellors in your area and provide details of how much they charge.



**British Association for
Counselling and Psychotherapy**

01455 88 33 00

www.bacp.co.uk/search/therapists

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 recharge. It can help you stay well enough to continue your caring role. It should include time to 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 support plan of the person you care for or your Adult Carer Support Plan. Respite care can include:

- someone to care for the person you care for so you can go out
- a place at a group, activity or day centre for the person you care for
- a temporary stay in residential care for the person you care for.

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



Shared Care Scotland

01383 622462

www.sharedcarescotland.org.uk



Age Scotland offers a free **Community Connecting**

Service to help you find groups and activities you might enjoy in your local area. Call the helpline on

0800 12 44 222 for more information.



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 dementia will experience difficulty communicating, but some people find it harder to communicate as their dementia progresses. They may find it hard to understand what people are saying, or others might struggle to understand them. They could have trouble finding the right word, or repeat words and phrases. Even if you have known the person a long time, 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 as a TV or radio
- choose a private setting if you need to discuss a personal or difficult subject
- use non-verbal communication: eye contact, smiling and gestures give context to your words
- listen with your eyes: watch their body language to help you understand their language and emotions
- speak clearly, calmly and slowly and avoid jargon and complicated language
- use short questions that only need a “yes” or “no” answer
- give them plenty of time to respond: they may need extra time to process what has been said
- resist the temptation to answer for the person if they are taking a while to respond
- try alternative ways of explaining things: pictures, diagrams or lists can sometimes help
- offer help with reading and writing if you notice they are finding this difficult



Further resources and support about dementia and communication are available on the **Alzheimer Scotland** website www.alzscot.org or by calling **0808 808 3000**.

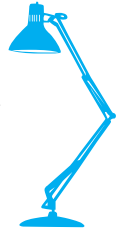


Age Scotland runs free **dementia awareness workshops** that include information about communication. Visit www.age.scot/dementia or call the Age Scotland helpline on **0800 12 44 222** for details.

Adapting the 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.

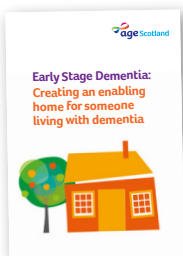
Increased lighting levels can be helpful to people living with dementia. As you age, changes to your eyes can affect how much light you need to see properly. Many people with dementia have difficulties with their ability to see different colours and shapes; good lighting can help with this.



Daylight is important for body rhythms and for knowing the time of day, so keep curtains and blinds open during the daytime. This might reduce confusion or sleep disturbances. You can buy clocks that tell you the day, date and time and whether it is day or night.

Having furniture, floors and walls in contrasting colours can reduce the risk of falls. This is because items stand out from one other and are easier to identify. Designs on flooring may be seen as a spillage or an uneven surface. Highly polished, shiny flooring may look wet, and can reflect light. This can be confusing and may increase the risk of slipping. Small rugs or mats may look like a puddle or hole in the ground.

Stairs and steps should be well lit and clearly marked, with a handrail on at least one side. Keep floors clear of clutter and electric cables. Rugs can be a tripping hazard, especially on uncarpeted floors.



For more information see the Age Scotland publication **Early Stage Dementia: Creating an enabling home for someone living with dementia.**

Organising the kitchen

It can be helpful to have signs or pictures on the front of cupboards to show where things are stored. This can help the person to carry out tasks independently for longer. Glass fronted cupboards or open shelving units can also help.

Simplifying any recipes they enjoy making may enable the person you care for to continue cooking for themselves for longer. You could also try replacing a complicated oven timer with a simple wind-up timer.

If you are worried about safe use of the oven, look at safety devices that turn off cookers or gas supplies if they are left on for too long. The Council's social work department can help with this.



SGN can fit free locking cooker valves that allow you to turn off the gas supply with a key if needed.

0800 912 1700 / www.sgn.co.uk/LCV



Living Made Easy provides information on equipment that can help make activities of daily living easier.

www.livingmadeeasy.org.uk



Care and Repair offers advice and assistance to older people and disabled homeowners looking to repair, improve or adapt their homes so they can live safely and comfortably. **www.careandrepairsotland.co.uk** or call the **Age Scotland helpline** on **0800 12 44 222** for help finding your local number.

Checklists and reminders

Short checklists for everyday tasks may help someone living with dementia to stay independent for longer. 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 appointments, or need help managing medicines. Simple gadgets can also help, such as a pill box with compartments for different times of day and days of the week.

The importance of routine

Having a routine and sticking to it can be reassuring for the person living with dementia. It can also 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.

Technology

Technology can be a useful support for some people living with dementia. Some equipment and technology is designed specifically to support people with symptoms of dementia. Other devices and equipment, such as a phone with a simple keypad, can be useful too.

Equipment recommended by a care needs assessment may be provided free. Get advice about the suitability of any equipment you would like to buy for yourself. You could ask Disability Information Scotland, Alzheimer Scotland or an occupational therapist.



Disability Information Scotland
0300 323 9961 / www.disabilityscot.org.uk

Alzheimer Scotland
0808 808 3000 / www.alzscot.org

Telecare can support people living in their own homes to stay safe. Devices can include personal alarms and gas, smoke and flood detectors. These will alert a callcentre or a family member if there is a problem.

Assistive technology can help people with daily tasks they are starting to find more difficult. Examples include item locators to help find lost keys, and devices that can store and play back reminder messages at set times, e.g. a reminder to lock the door at night.

Some people use technology to record their life story, memories and important dates. They may also record personal information, such as their hobbies and likes and dislikes, and use this to let professionals know what is important to them.

ADAM provides information about useful technology that can help make daily living easier and more enjoyable for people living with a long-term condition, such as dementia. It has been developed by the Digital Team at Alzheimer Scotland.



ADAM

0808 808 3000 (Alzheimer Scotland helpline)

www.meetadam.co.uk

Living Made Easy provides information on equipment and technology for daily living.



Living Made Easy

www.livingmadeeasy.org.uk

Shopping

Some people living with dementia find shopping difficult because of noise, crowds or problems reading labels or handling money.

If you are supporting the person you care for to do their own shopping, it can help to choose quieter times, or make arrangements with a local shop where staff understand about dementia.

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

Travel

Some people living with dementia may feel anxious about travelling or find it confusing and stressful.

Travel can be made easier by planning carefully and talking to the person you support about what might help. For example, they may feel worried about continence on long journeys. If this is the case, speak to your GP or see our **Bladder and bowel problems** guide for information about the help available.



Travelling by car: if the person you support is anxious on car journeys, 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 can make it easier to see where the seat begins, which may help if they have difficulties with vision and perception.

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

Travelling by plane: book assisted travel well in advance via the airline or tour operator, and allow plenty of time to arrive and check in.

Travelling by bus: drivers are experienced at supporting passengers. You or the person you support can ask to be reminded when the bus reaches the right stop. There may be a local Dial-a-Bus scheme in the area that can pick people up at home and take them to places such as shopping centres.

Travelling on foot: if the person you care for likes to go for walks, make sure they always take 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

People who need assistance can carry cards explaining the help they need. These can be shown to travel operators, shop workers and police.



The **Alzheimer Scotland** free **Helpcard** explains that the carrier has dementia, what help they might need, and provides space for emergency contact details.
0808 808 3000
www.alzscot.org



Thistle Assistance provides a free **card and app** to communicate travel needs due to a condition or disability. These are recognised by many public transport operators across Scotland.
0131 524 5153
www.thistleassistance.com

The Herbert Protocol

The Herbert Protocol is an information-gathering tool to help police in their search for a person living with dementia who has gone missing. It is a nationally recognised scheme supported and endorsed by Police Scotland.

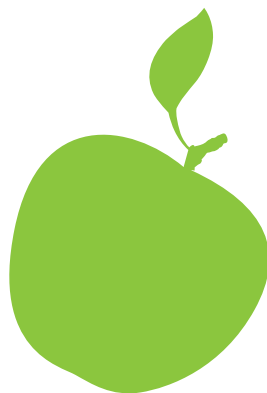
Carers of a person living with dementia are encouraged to complete the Herbert Protocol form when the person with dementia is diagnosed, and to update it regularly. In the event the person goes missing the form is given to police so they can begin their search without unnecessary delay.

The form covers questions a police officer would need to ask if a person with dementia were reported missing. It asks for a list of places the person knows well, any health issues or known risks, and details to help identify the person and get them to safety.



Search **Herbert Protocol** at **www.scotland.police.uk** or call the **Age Scotland helpline** on **0800 12 44 222** for help accessing the Herbert Protocol form.

Keeping you both well



Diet

Eating a varied, balanced diet is one of the best ways to look after yourself. This might be easier said than done when you are caring for someone, but doing what you can will help you to stay well and feel more energised.

A healthy diet includes 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 lots of sugary snacks like chocolates and fizzy drinks can make your diet too high in sugar, so try to only eat these very occasionally.

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



Hydration

Staying hydrated is important for our overall health. Water is a healthy choice, but tea, coffee, diluted fruit juice and even soup all help. As a carer, you may find you are always on the go. Keeping a water bottle with you may help you to stay hydrated.

People with dementia and older people may not feel thirsty when they need to drink. On top of this, not drinking enough can make dementia symptoms worse.

Age Scotland's guide **Hydration matters** explains more about why drinking enough is important.



Supporting eating and drinking

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 to concentrate on finishing a meal. Eating meals together can help with this. The person you care for is more likely to eat if you are eating too, and can copy you if they become confused about how to use cutlery.

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

The likes and dislikes of the person you care for may change, and they may start to dislike some textures. Encourage them to explore different types of foods and find things they enjoy. If they prefer sweet foods, try to choose healthier options like fruit or sweet vegetables, such as carrots and sweetcorn.

Some people have a smaller appetite than before. Eating little and often can encourage some people to eat more overall. Meals with strong flavours or different colours might also be more tempting than plain foods.

If remembering to drink is a problem, try to give them gentle reminders when you are around. Brightly coloured cups can also help remind people to drink. Try handing drinks directly to them and keep drinks that are placed on a table in their line of sight.

Encourage the person you support to speak to their GP if you are concerned about changes in their eating habits. They may be referred for specialist support with nutrition, chewing or swallowing.

Being active

Regular physical activity can help to ease stress and improve wellbeing, as well as being good for overall health. Making time to be active while caring for someone may not feel like a priority, but it could help you stay well enough to care for the person you support.

It is important to find something you enjoy as you will be more likely to stick to it. Doing an activity with a friend or in a group can also help. You could try swimming, playing football or joining a fitness class. Many classes are held online which can be easier around caring responsibilities.

Small changes to your routine can also make a big difference. You could get off the bus a couple of stops early, stay standing while talking on the phone, or try going for a walk with a friend instead of meeting for coffee.

If the person you support can keep active, this may help them to feel more positive, and is good for concentration.



Paths for All

Walking is a great activity for people of all ages and fitness levels.

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 people of all abilities. They want to ensure that everyone living with dementia and their families, friends and carers can take part in walking. They offer dementia friendly walking groups with volunteers who understand the needs of people living with dementia and the support they may need.



Paths for All
01786 641 851
www.pathsforall.org.uk

Social connection

Connecting with others is important for overall wellbeing, both for you and for the person you care for. Your Adult Carer Support Plan should include support that allows you time to connect with others if this is important to you.

Many people living with dementia find it helpful to connect with others in a similar situation. **Meeting Centres** provide a social space where people living with dementia and their loved ones can take part in activities they enjoy. Every Meeting Centre is different as activities are based on the interests of its members.



For more information about **Meeting Centres**, call the **Age Scotland helpline** on **0800 12 44 222**, or search Meeting Centres at **www.agescotland.org.uk**.

You could also search for local activities that are dementia friendly. There are choirs, sports clubs and walking groups that have taken steps to understand and include people living with dementia. A Dementia Advisor can let you know about groups in your area, or you can call the **Age Scotland helpline** on **0800 12 44 222**.

For more information on being active speak to your GP or see our guide to **Health and wellbeing in later life**.

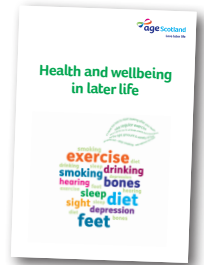
Staying warm

Over the winter it is important that you and the person you care for keep warm at home. Being cold for any length of time can put people at risk of colds, flu and hypothermia. It can also increase the risk of heart attacks and strokes in older people. Try to make sure the rooms you use 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 to avoid sitting down for long periods of time. Get up, move around and have hot meals and drinks.

There are benefits, grants and schemes for making homes more energy efficient that may help you save money on fuel bills.



Call the **Age Scotland** helpline on **0800 12 44 222** and ask to speak to our expert Energy Adviser.



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 they want to stop smoking. A good place to start is by speaking to their GP or calling **Quit Your Way** on **0800 84 84 84**.

If the person you care for does continue to smoke, try to make it as safe for them 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 Fire Safety Visit.



Scottish Fire and Rescue Service

0800 0731 999 or text **FIRE** to **80800**

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 can increase the risk of developing conditions such as cancer, heart disease and stroke.

Alcohol can also worsen some symptoms of dementia, such as confusion and memory loss. If this affects the person you care for, it may be best they limit the amount of alcohol they drink.

Certain medicines do not mix well with alcohol and drinking can cause medicines to be less effective. You should speak to your GP or pharmacist if you need advice about this.

Cutting down on alcohol can be difficult, especially for people who have been drinking heavily for a long period of time. Get medical advice if this is the case as it may be best to cut down gradually.



With You provides free and confidential support to help people reach their goals around drinking. Find a service near you by visiting www.wearewithyou.org.uk or call the **Age Scotland helpline** on **0800 12 44 222** for help finding the right number.



Alcoholics Anonymous provides free self-help groups across Scotland. Its 12-step programme involves getting sober with the help of regular support groups. You can call them on **0800 9177 650** or use their web chat at www.alcoholics-anonymous.org.uk.

The Age Scotland guide **Health and Wellbeing in Later Life** provides more information about recommended alcohol intake. Call the **Age Scotland helpline** on **0800 12 44 222** to order a copy.





Practical considerations

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. It can also help you feel reassured that you know their views and wishes for the future.

Power of Attorney

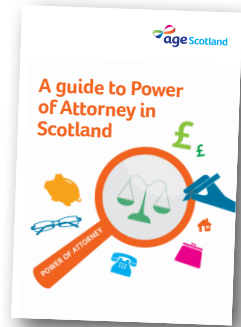
As a carer, family member, friend, relative or partner, you do not have the automatic right to make decisions on behalf of the person you care for. They may want to think about giving you this right. They can do this by setting up a Power of Attorney while they have the mental capacity to do so.

A Power of Attorney is a legal document that gives permission for a specific person or people to make decisions on someone else's behalf if they become unable to do so for themselves. It can also allow a specific person to help manage another person's finances even while the person could still do this. Becoming someone's Attorney is a big responsibility, so take time to consider if it is the right decision for you.

It is a good idea to have a Power of Attorney drawn up by a solicitor to make sure there are no mistakes. Without a valid Power of Attorney in place, in most cases someone would have to go to court to be allowed to act on another person's behalf if that person lost mental capacity. This can be a very expensive process and may take some time.

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**.

Call **01324 678 300** and select **option 1** or visit **www.publicguardian-scotland.gov.uk**.



Wills

The person you care for may want to make a Will if they do not have one already. Writing a Will allows them to decide what happens to their money and belongings when they die. It is best to have a Will either written or checked over by a solicitor as small mistakes can make the Will invalid. Wills can be changed at any time, as long as the person still has the mental capacity to understand and make this decision. Changes should also be checked with a solicitor.

Age Scotland offers a free Will-writing service in partnership with Solicitors for Older People. Other solicitors may also offer discounted or free services. See Age Scotland's publication **Making your Will** for more information or call the **Age Scotland helpline** on **0800 12 44 222**.



Advance Directives

An Advance Directive is a document that allows someone to make decisions about their future medical care. It is a way of making sure that medical staff, friends and family know their wishes about receiving certain treatments or care in case 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 by law tell 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 is involved in an accident, they can be prosecuted.

For more information see our **Older Drivers' guide**.



Insurance

Most insurance policies will not be valid if the policyholder does not declare that they, or anyone else covered by the insurance, have a diagnosis of dementia. Examples of people to tell may include life, car, travel, or house insurance providers.

Bus passes and discounts

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

Many local services also offer a discount or free entry for carers, such as leisure centres, cinemas, museums and other local attractions.



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.

New responsibilities

In the early stages of dementia, it is likely that the person you care for will be able to remain independent. However, 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 could change your roles in the home. You should plan for this as early as possible, as you may need to learn new skills and take over tasks such as cooking or online banking. It is usually best to be open with the person you care for about the changes you need to make, to avoid misunderstandings.

Care homes

Everyone experiences dementia differently, and some people living with dementia might never need to move into a care home. However, there may come a time when the person you care for needs more help than you can give them, even with additional support. At this point, you should contact your Council's social work department and ask for a reassessment, both of your needs and theirs.

Deciding if someone should move into a care home can be difficult. However, keep in mind that a care home may be the best option for them to stay safe and 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 and order copies of these publications, call the **Age Scotland helpline** on **0800 12 44 222**.



Money matters

Dealing with money

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

Setting up direct debits can help to make sure regular bills such as gas, electric, TV licence and Council Tax get paid on time. You may need to support them to do this, with their consent. It can also be a good idea for you to help them check their bills and bank statements regularly.

Some people living with dementia use contactless bank cards as an easy way to pay for amounts up to £100 but a PIN is still sometimes required. If remembering a PIN is a problem, they could apply for a chip and sign card instead. They will be asked to sign the receipt and their signature will be checked against the one on the card.

If you care for your partner and you are having to handle the household finances for the first time, you may be feeling overwhelmed. If you would like help to feel more confident managing money, call the **Age Scotland helpline** for information and advice on **0800 12 44 222** and see Age Scotland's **Lifebook** and **Money Matters** guides.



Benefits and social security for carers

Carer's Allowance is being replaced by a new Scottish benefit called Carer Support Payment. A pilot scheme opened for applications in the Dundee City, Perth and Kinross and Western Isles areas in November 2023, and applications will be open to all areas of Scotland from spring 2024. Existing Carer's Allowance claimants will be transferred to Carer Support Payment over the next two years.

To be eligible, you must spend at least 35 hours per week caring for a person who gets a health or disability benefit due to needing support caring for themselves. This could be Attendance Allowance, the care component of Disability Living Allowance, or the daily living component of either Personal Independence Payment or Adult Disability Payment. Your weekly income must also be below a certain amount after tax and some expenses.

Both the current and the new benefit for carers overlap with some other benefits, including State Pension. This means you cannot claim the full amount of the carer's benefit and State Pension at the same time. Claiming the carer's benefit can also reduce the amount that the person you care for can claim in income-related benefits, such as Pension Credit. A benefit check can help you identify which benefits to claim to maximise your income.



Call the **Age Scotland helpline** on **0800 12 44 222** to ask for a benefit check or for more information about the carer's benefit in Scotland.

Knowing your rights

Discrimination and dementia

Unfortunately, some people living with dementia and their carers 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 your rights, including the right to be able to participate in community life and in making decisions that affect you, and to be treated with dignity and respect. You can get a copy of the Charter 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

As a carer, you may find you are speaking to services and professionals you are unfamiliar with. It can sometimes be difficult to know how to ask for what you need if systems and processes are new to you.

An advocate can stand up for you and support you to express your views on issues that are important to you. They can also 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 to find advocates in your area.



Scottish Independent Advocacy Alliance

0131 510 9410

www.siaa.org.uk

Campaigning

Certain organisations work to support the rights of people with dementia and their carers and families. You can contact them to ask for support in getting policy changed or to get involved in campaigning.

Age Scotland is proud to host **About Dementia** – Scotland’s forum for improving lives for people affected by dementia. We work alongside people with lived experience of dementia to shape the policy and practice that matters to them. Through regular group meetings, we connect with our members to hear their views.



About Dementia

0333 323 2400

age.scot/aboutdementia

Age Scotland also coordinates the **Dementia Friendly Communities (DFC) Network**. The DFC Network unites people and communities in Scotland that are committed to helping people living with dementia to feel included and enabled.

Membership is informal and is not limited to those who are part of a dementia friendly community. Anyone interested in supporting dementia friendly communities in Scotland is welcome to join.



Visit **www.age.scot/dfcn** for more information or contact Age Scotland’s Community Development Officer Colm McBriarty at **colm.mcbriarty@agescotland.org.uk** or by calling **0333 323 2400**.

Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) is a national campaigning and awareness raising group. It aims 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 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
07719 957 879
www.tide.uk.net

Employment

The Carer's Leave Act was passed on 24th May 2023 and will come into effect in 2024. It will give rights to unpaid carers who are in employment. This will include the right to take one week's unpaid leave per year to cover caring commitments.

If you are an unpaid carer in employment, you may also want to think about requesting flexible working if you do not already have this. This could help you better manage your caring commitments in the long term. You could request:

- a change to the hours you work
- a change to the times when you are required to work
- to work from home, more frequently or as standard



Citizens Advice Bureau

Citizens Advice Scotland can provide information about formal and informal requests for flexible working. Call the Scottish Citizens Advice Helpline on **0800 028 1456** for advice or to get the number for your local bureau, or visit **www.cas.org.uk**.



Equality Advisory and Support Service (EASS)

provides advice on discrimination and workers rights. **0808 800 0082**
www.equalityadvisoryservice.com

You can also call the **Age Scotland helpline** on **0800 12 44 222** for information and advice.

Useful contacts



Age Scotland helpline 0800 12 44 222

The Age Scotland helpline provides information, friendship and advice to older people, their relatives and carers.

If you need an interpreter call **0800 12 44 222** and simply state the language you need e.g. Polish or Urdu. Stay on the line for a few minutes and the Age Scotland helpline will do the rest.

You can call us on **0800 12 44 222** for a copy of our publications list or download copies of our publications from our website at **www.agescotland.org.uk**.

Age Scotland's dementia training team offers free online courses on dementia, including Carer's Rights. Visit **www.age.scot/dementia** or call the **Age Scotland helpline** on **0800 12 44 222** for more information

About Dementia

Age Scotland is proud to host About Dementia – Scotland's forum for improving lives for people affected by dementia. We work alongside people with lived experience of dementia to shape the policy and practice that matters to them. Through regular group meetings, we connect with our members to hear their views.

Tel: **0333 323 2400** / **age.scot/aboutdementia**

Alzheimer Scotland

Provides services and support for people with dementia and their families and campaigns for their rights through the National Dementia Carers Action Network. The Alzheimer Scotland Digital Team has also developed ADAM, an online tool providing information about useful technology that can help make daily living easier.

Tel: **0808 808 3000**

www.alzscot.org / www.meetadam.co.uk

Care Information Scotland

Provides information on care services in Scotland.

Tel: **0800 011 3200**

www.careinfoscotland.scot

Carers Scotland

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

Tel: **0808 808 7777**

www.carersuk.org/scotland

Carers Trust

A charity supporting a network of local carer organisations, helping them to deliver local services. Contact Carers Trust to find your local carer organisation.

Tel: **0300 772 7701**

www.carers.org

Citizens Advice Bureau

Offers general advice on employment, housing, debt, benefits and consumer issues.

Tel: **0800 028 1456**

www.cas.org.uk

Living Made Easy

Information on gadgets, devices and equipment to help people live independently.

www.livingmadeeasy.org.uk

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

Shared Care Scotland

Offers information and advice to carers about respite services.

Tel: **01383 622462**

www.sharedcarescotland.org.uk

Dementia Carers Count

Offers support and resources for carers of people living with dementia, including live online courses and a forum.

Tel: **0800 652 1102**

www.dementiacarers.org.uk

How you can help

Our vision is a Scotland which is the best place in the world to grow older.

All the information we provide is free and impartial. It helps older people access their rights and entitlements and can be life changing.

We are also a lifeline for older people who are feeling lonely and isolated. You can help us to support older people who need us most.

Together, we can make a difference.



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 **AGESCOTGIVE** to **70085** to donate £5*
- Complete the **donation form** and return by Freepost



Fundraise

Whether it's having a bake sale or running a marathon, 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 us to continue being there for 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

Please donate today



Complete the form and return to RSBS-KEHC-GBBC, Age Scotland, Edinburgh, EH9 1PR

Your details

Title:	Forename:	Surname:
Address:		
	City:	
Postcode:	Date of birth:	

By providing us with your telephone number and email address you are consenting to us contacting you via phone, text and email.

Email:	
Home tel:	Mobile tel:

I WOULD LIKE TO DONATE

£75 £50 £25 Other (£)

I wish to pay by (please tick):

MasterCard Visa CAF

CharityCard Cheque (payable to Age Scotland)

Signature

Name on Card

Card No.

Expiry date Security code

Date

I prefer not to receive a thank you acknowledgement for this donation

I would like information about leaving a gift in my Will

I WOULD LIKE TO MAKE MY DONATION WORTH 25% MORE

I want Age Scotland** and its partner charities to treat all donations I have made for the four years prior to this year, and all donations I make from the date of this declaration until I notify you otherwise, as Gift Aid donations.

giftaid it

I am a UK tax payer and understand that if I pay less income tax and/or capital gains tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Yes, I want Age Scotland** to claim Gift Aid on my donations

I do not wish you to claim Gift Aid on my donations

Date

Keeping in touch

We will stay in contact by post unless you ask us not to. We will never sell your data and we promise to keep your details safe and secure. You can change your mind at any time by emailing us on contact@agescotland.org.uk or calling us on 0333 323 2400.

You can read Age Scotland's privacy policy at [age.scot/privacypolicy](https://www.agescot.org.uk/agescot/privacypolicy).

**Age Scotland, part of the Age Network, is an independent charity dedicated to improving the later lives of everyone on the ageing journey, within a charitable company limited by guarantee and registered in Scotland.
Registration Number: 153343. Charity Number: SC010100. Registered Office: Causewayside House, 160 Causewayside, Edinburgh EH9 1PR.

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 which is the best place in the world to grow older.

.....

Let's keep in touch

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



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 at [agescot/roundup](https://www.agescotland.org.uk/agescot/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.



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