



Caring for someone with early stage dementia





Being Dementia Aware

This information guide has been prepared by Age Scotland and contains general advice only, it should not be relied on as a basis for any decision or action and cannot be used as a substitute for professional advice.

Neither Age Scotland nor any of its subsidiary companies or charities accepts any liability arising from its use and it is the reader's sole responsibility to ensure any information is up to date and accurate.

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.

Contents

Caring for someone with early stage dementia	p2	Keeping well	p23
What to expect	p3	Diet	p23
Where do I get support as a Carer?	p5	Being active	p25
Who's who?	p5	Staying warm	p26
Post diagnostic support	p7	Smoking and alcohol	p27
Care needs assessment	p8	Practical things to think about	p29
Care for yourself	p11	Power or Attorney	p29
Talk to others	p12	Wills	p30
Support from health services	p13	Advance Directives	p30
Counselling	p13	Driving	p31
Taking time out	p14	Bus passes and Carer's discounts	p31
Supporting the person living with dementia	p15	Learn new skills	p32
Ideas for communication	p15	Care homes	p32
In your home	p16	Money Matters	p33
Organising the kitchen	p17	Dealing with money	p33
Checklist and reminders	p18	Benefits and social security System	p34
Getting into a routine	p18	Your Rights and dementia	p35
Technology	p29	Legislation and caring	p36
Shopping		Advocacy	p36
Travel		Campaigning	p36
Help cards		Employment	p38
		Useful contacts	p39

Caring for someone with early stage dementia

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. Your caring role might include helping the person develop a routine, reminders to take medication, explaining letters or making sure doors and windows are locked at night. Being a carer is not always easy, and sometimes those providing support need support too. You may be wondering what to expect as the condition progresses, how best you can support them now and where to turn to for help. This guide discusses what services are available to support you, and provides information about important things to sort out and 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.

Age Scotland's Early Stage Dementia Project raises awareness of the early stage of dementia and the signs and symptoms of the condition. We do this through training, campaigning and our information and advice resources. We want more people who are worried they may have dementia to seek a diagnosis sooner. Early diagnosis is crucial and can help prolong the quality of life of people with dementia.

What to expect

It is useful to know what might be expected with the kind of dementia the person you are caring for has.

- **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. However, symptoms can get worse very suddenly
- **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 have less control.
- **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 may behave in a way that you find puzzling or difficult to understand. Remember it is part of the condition. If the person's behaviour is challenging or difficult to manage you should speak to your GP and contact your Social Work department for a care needs assessment (see section 'Care needs assessment' for more information).

Where do I get support as a Carer?

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

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. This can feel overwhelming and it might be difficult to understand who does what. The 'who's who' guide below explains who you are likely to come into contact with and what for. You can use this as a quick and easy reference if you are feeling unsure about what someone does and why they might be involved in supporting the person you care for.

Community Psychiatric Nurse – 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 – 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 (see section 'Post diagnostic support' for more information).

Dementia Link Worker – 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 (see section 'Post diagnostic support' for more information).

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

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

GP – a GP looks after people’s general physical and mental health needs and can make referrals for specialist support if you need it.

Occupational Therapist - 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 (see section ‘Care needs assessment’ for more information).

Physiotherapist - a Physiotherapist can help if you have difficulties walking or have had falls. They provide advice on exercises that can improve strength and balance, and equipment to help with walking and moving around.

Podiatrist - a Podiatrist helps to treat foot conditions and problems. They give advice on how to look after feet and what types of shoes to wear.

Social Worker – Social Workers assess and support people who have physical and mental health difficulties or disabilities and carers (see section ‘Care needs assessment’ for more information’).

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

Post diagnostic support

In recent years a lot of work has been done to make sure people living with dementia and carers have access to support. In many areas it will be from an Alzheimer Scotland Dementia Link Worker or an Alzheimer Scotland Dementia Advisor. In other areas they might be known as something different. They are interested in what matters to you and will focus on what you feel you need support with. This may include help to understand dementia and manage the symptoms, assistance with practical things like claiming benefits, sorting out legal matters or discussing the different care options for the future. You might want information about local groups for people living with dementia and carers, or ways you can continue doing activities you enjoy. You can feel reassured that if you or the person you care for have any questions, concerns or worries that there is someone you can contact who understands your situation. For more information about post diagnostic support contact Alzheimer Scotland.



Alzheimer Scotland

Freephone Dementia 24 hr helpline: **0808 808 3000**

www.alzscot.org

Care needs assessment

You and the person you care for have the right to request an assessment of your needs through your Council's social work department. A Social Worker, Occupational Therapist or other health professional will arrange to visit and talk with you both about what you think you need help with.

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

This might include

Support for the person you care for:

As time goes on it is likely the person living with dementia will start to find tasks like washing and dressing, eating and drinking, taking medication or getting around the home more difficult. This is known as personal care. They will probably need more supervision to keep themselves safe. The Council will consider if the person would benefit from support in their home or community. This might include care at home, a place in a day centre or making adaptations to the home. If they are 65 or over and need help with personal care they will get it for free. Nursing care is free at any age. For other help, each council has discretion about which services it will charge for, and what it will charge.

Support for you as a carer:

The support you need to continue your caring role, looking after your own health and wellbeing and balancing other parts of your life such as employment and socialising. It is important to be open and honest about how being a carer affects you so they have a good understanding of your situation. Be realistic and think of things you cannot do or have trouble with. The assessment is not a test to see how good you are at caring. It is about getting the right help and support that you need to make life easier. After the assessment the Council will consider if you would benefit from support. This may include getting support from a carers centre, information and advice about coping with the caring role or funded support such as respite care.

In general, if you or the person living with dementia have been assessed as needing care and support you should be offered choice and control over how your care is provided. You might want to take control of the budget for your support and spend it in a way that suits you better. This is your right under Scotland's 'Self-Directed Support Act. The person you care for might be able to exercise this choice even if they can no longer manage their finances. Payments can be paid to someone who has the authority to act on their behalf (see section 'Power of Attorney' for more information).

If you disagree with the Council's assessment, you can ask for another discussion of your needs. If you are unhappy with how the assessment was carried out you have the right to complain. You should use the Social Work department's complaints procedure. If you need information and advice phone the **Age Scotland Helpline** on **0800 12 44 222**.

If the needs of you or the person you care for change you should get the assessment 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 (open 7 days: 8am-10pm)

www.careinfoscotland.co.uk



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 when you are caring for someone else. But looking after yourself and taking a break when you need it can help you better cope with your role. Here are some suggestions for looking after your health and well-being.

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. Let them know that the person living with dementia is still the same person they were before being diagnosed. It is useful if the both of you let people know what works best. 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 meet with other carers. You can 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 Freephone Dementia Helpline:
0808 808 3000 (24 hour helpline)
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 **Carer's UK** website: **www.carersuk.org/forum** or the **Carer's Trust** website: **space.carers.org**.

If you cannot find a local carer's group and would be interested in setting one up contact Carers Scotland.



Carers Scotland
0808 808 7777
www.carersuk.org/scotland

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 should 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 Counsellors in your area. There may be a charge for their services. Before you agree to meet a Counsellor, make sure he or she is registered on the British Association for Counselling and Psychotherapy register. This is to make sure they are qualified to provide support.



British Association for Counselling and Psychotherapy
01455 883300 (Monday to Friday: 9am-5pm)
www.bacp.co.uk

Taking time out

It is important to take a break regularly 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 take part in activities and groups. You should speak to your Council's social work department as this may be included as part of the care needs assessment. They might arrange services that can help. Respite care is the term used for services that give you a break from caring. 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. Here are some ideas for supporting the person you care for that you may find useful.

Ideas for communication

Not everyone living with early stage dementia will find communicating difficult. But as their condition progresses it is likely their ability to communicate will be affected. 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. Here are a few suggestions to keep in mind that might make things easier.

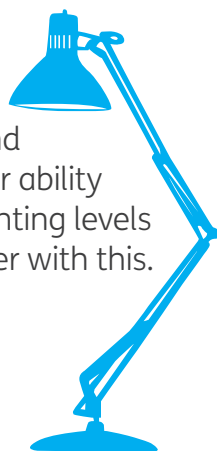
- Avoid distractions. It can be difficult to hold a conversation if there are background noises such a TV or radio.
- Try alternative methods. For example, if you're describing something complicated, such as where a bus stop is, try sketching a simple map.
- Choose the right setting. If you are discussing a personal or difficult subject, then think about where it takes place. Is the setting private?
- Non-verbal communication. Make eye contact, smile, nod and make sure that your face and hands are visible as they can help to give context to your words.

- Speak clearly, calmly and slowly. If you are talking about complicated subjects, try and keep language easy to understand.
- Keep questions simple. Try to use short, open questions that only need a 'yes' or 'no' answer. If you need to clarify something, think of a different way of asking rather than using the same words.
- Pictures, diagrams or written bullet points might help the person make sense of content.
- Reading and writing. Some people living with dementia find reading and writing difficult. You might need to explain letters to the person or help them fill out forms.
- Be patient and considerate. Resist the temptation to answer for the person if they are taking a while to respond.

In your home

For many people living with dementia staying in their own home for as long as possible is very important. Memory difficulties and confusion may lead them to forget where they are, 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.

Increasing lighting levels can be helpful to people living with dementia. As we age, changes to our eyes can affect how much light we need to see properly and many people with dementia have difficulties with their ability to see different colours and shapes. Increasing the lighting levels at home could help the person you care for cope better with this.



Daylight is useful as it can alert people to the time of day. This might reduce symptoms such as confusion or sleep disturbances. Keep curtains and blinds open during the day to help the person you care for understand what time of day it is.

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.

Most falls happen on stairs and steps, so these areas should be clearly lit and marked. Electric cables such as extension leads, and small items of furniture such as foot stools can all be easy to trip over. 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 stepped around.

For more information on making the home dementia friendly see the Age UK publication *At home with dementia*.

Organising the kitchen

Signs or pictures on the front of kitchen cupboards might remind the person you care for where things are stored. Glass fronted cupboards or open shelving units can also help with this.

If they enjoy cooking but find it hard to follow recipes, try and adapt the recipes to make it easier. For example, if a recipe with lots of steps or ingredients is too difficult to manage, try to find a shorter one. If they find it difficult to remember when they put something in the oven, using a kitchen timer to remind them to check on it can help.

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 provide information, support and advice to people living with long-term conditions and their families.



Disability Information Scotland

0300 323 9961

www.disabilityscot.org.uk

Care and Repair 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 do in the shower, 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 medications.



Getting into a routine

Having a routine can help to reassure the person and make it easier for them to keep track of the tasks they need to complete each day. Encourage them to get up at a similar time every morning and make a schedule of tasks they need to do. For example, taking medication or preparing meals. Once they have a schedule they should try and stick to it as often as possible. Making use of simple gadgets might help with this. For example, a pill box with different compartments for different days and times, or a clock that shows the date and day of the week.

Technology

Some people with dementia find technology can support them to live well. There are many different types of technology available which vary in price. Some may be provided for free by the Council. You should contact you Council's social work department and ask for a needs assessment for the person you care for.

There are different types of technology:

Assistive technology can help people with daily tasks that they are starting to find more difficult. For example, item locators that can help to find commonly misplaced items, such as keys. Reminder aids can be programmed to play a message at a certain time, such as reminding someone to lock the door at night.

Telecare supports people to remain safe in their home. For example a personal alarm which allows someone to call for help if they have fallen or are unwell. Gas, smoke and flood detectors automatically alert staff at a response centre or a family member if there is a problem. Some gas detectors can switch off the gas supply when they detect a problem.

Whilst not for everyone, some people find **digital technology** useful. MindMate is an app you can download on to a tablet. The person can document their life story so they can remember special times and important events, such as a wedding or holidays. MindMate can be shared with friends, family and professionals. This helps people to understand more about them and their experiences. They can also store personal information, such as their favourite food, hobbies, music and likes and dislikes. This is really useful if the person has memory difficulties and has an appointment with a professional or needs to visit a hospital. It lets others know what is important to them.

MindMate website: www.mindmate-app.com

If the person you care for does not use digital technology, they could get an Age Scotland Lifebook. A Lifebook is a booklet where they can write important and useful information about themselves. To order one call **Age Scotland Enterprises** on **0800 456 1137** (Edinburgh) or **0800 500 3159** (Glasgow).

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



Disabled Living Foundation

0300 999 0004 (Tuesday to Thursday: 10am-4pm)

www.dlf.org.uk

Shopping

Some people living with dementia find shopping difficult. Shops can be crowded and noisy which they might find overwhelming. The person may struggle to find the items they want or to read and understand the labels.

Offer to go with them if they are finding shopping difficult. Having someone there to give them a hand will make things easier. If they are shopping by themselves they can ask a member of staff for assistance.

If crowds are a problem try not to go shopping when it will be busy, for example, early evenings during the week or at weekends. You could ask the local shop if they can keep items aside for someone else to pick up later. If they feel the shops are too busy they could order their shopping online. Most supermarkets offer an online shopping and delivery service.

Travel

Sometimes people living with dementia feel anxious about travelling or find it confusing and stressful. Here are some tips for making journeys easier.

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

Most train companies have assisted travel which involves a member of staff supporting the disabled traveller to complete their journey and give them the help they need. Assistance should be booked before travel so the right arrangements can be put in place, and staff can give the best service possible.

When travelling by plane plan ahead and allow plenty of time to arrive and check in. You can also request assisted travel in airports, but make sure at least 48 hours' notice is given.

On buses if they feel worried that they might forget where to get off, they can ask the driver to remind them. You might want to contact your local Council to see if there is a Dial-a-Bus scheme in the area. These buses will pick up the person living with dementia from their home and take them to local places, such as a shopping centre. This is a useful option if the person you care for finds travelling by ordinary buses too difficult.

If they are out and about by themselves it can be helpful if they carry extra money, your contact details and the name and contact details of a trusted taxi firm in case they get lost or feel unsure how to get home.

For more travelling tips contact **Alzheimer Scotland**.

Help cards

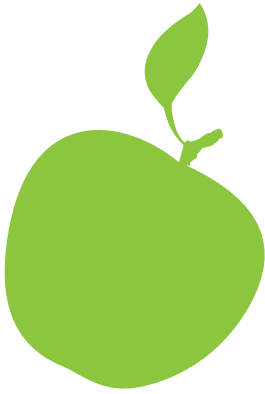
Help cards can be carried by people living with dementia when they are out and about. These are really useful if they run into difficulties as they let others know they have dementia and what they need help with. They can show the card to staff and officials, such as bus drivers, shop workers, etc. so they can support them. There is also space to record the details of someone who can be contacted in an emergency. If the person you care for is interested in getting a help card you should contact Alzheimer Scotland.



Alzheimer Scotland

Freephone Dementia Helpline: **0808 808 3000**

www.alzscot.org



Keeping well

Diet

Eating a varied, balanced diet is one of the best ways to contribute to good health. The healthier you are, the easier it might be to cope with the challenges of being a carer. Having a healthy diet involves eating lots of fruits 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, seeds and avocados. 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. However, 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 tips on eating healthy and ideas for quick and nutritious snacks.

It is important the person living with dementia has a healthy diet as well. Making sure they have plenty of fluids is also vital. Some people living with dementia find not having enough to drink can make their symptoms worse. Water is a great choice, but anything is better than nothing. Fruit juice, soup, smoothies and tea all help.

However, 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 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. Similarly, using plain but brightly coloured plates to serve meals 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. But 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. Adults who are generally fit and well should aim to be active for 30 minutes a day. Just fit in what you can manage: even 10 minutes a day can help. Simple changes to your routine can make a big difference. For example, get off the bus a couple of stops early or stand up whilst talking on the phone.

It is important the person you care for is active too. Being active might help them to feel more positive and concentrate on what they can still do. However, some people living with dementia find it difficult to get involved in physical activities. They might feel worried about getting lost in unfamiliar places. They may need help to understand instructions or recognise other people at a group or activity.

If the person needs support the two of you could do activities together. Chances are you know you them best and understand what they need help with. Do activities that encourage them to use the skills and interests they have.

Walking is a great activity for people of all ages and fitness levels. It is simple, free and you don't need any equipment. You could join a dementia friendly walking group.

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 what they might need support with.



Paths for All
01259 218888
www.pathsforall.org.uk

Extend is a charity that provides exercise classes for older people and anyone with a disability. There may be a charge for classes.



Extend
01582 832760
www.extend.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 see **www.nhs.uk/livewell/fitness** or speak to your GP practice which can give you information and advice.

Staying warm

Over the winter it is important you and the person living with dementia keep warm in the home. As we get older it takes longer for our bodies to warm up. Being cold for any length of time can put us at risk of colds, flu and more serious health conditions such as hypothermia. Try to make sure that rooms both of you are in during the day are kept warm to at least 18°C (65°F). 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 (Mon to Fri: 8am-8pm & Sat: 9am-5pm)

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

Smoking

It is common knowledge that smoking is bad for our 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 talk to Smokeline. Smokeline is Scotland's national stop smoking helpline. They can give information and advice about how to stop smoking and can work with you to come up with a plan that's right for you and takes into account the effects of living with dementia.



Smokeline

0800 84 84 84 (open 7 days: 8am-10pm)

www.canstopsmoking.com

If the person you care 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 can seriously harm your health. It increases the risk of developing conditions such as cancer, heart disease and stroke. Some people living with dementia also find drinking alcohol can make their symptoms worse. For example, they may feel more confused or find their memory is more affected. The person you care for should try to limit the amount of alcohol they have. Certain medications do not mix well with alcohol. If you are unsure about the effects of alcohol on medication ask your GP or pharmacist. Changing your drinking habits, or supporting the person you care for to change theirs, 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

Drink Smarter is run by the Scottish Government and provides information and advice about alcohol issues, how to cut back and general advice about health, well-being and relationships.



Drink Smarter
Telephone: **0800 7314 314**
www.drinksmarter.org

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 the person with dementia to feel in control, and you can feel reassured that their views and wishes are being followed.

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's 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 visit the website for

The Office of the Public Guardian (Scotland):

www.publicguardian-scotland.gov.uk

Wills

You should talk to the person you care for about making a will. It is important that everyone, whatever their age thinks about arranging a will. A will 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 advisable 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 *Advance Directives* factsheet 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 the Age UK publication *In the driving seat*.

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 provides entitlement to free travel. People living with dementia under the age of 60 are also 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 for free if you are travelling with them.

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. Alternatively phone 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 the person you care for will be able to remain independent. However, as time goes on 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. It is a good opportunity to prepare for this whilst your partner is in the early stages of the condition. For example, if your partner has always done the cooking, get involved with them and learn how to cook too. Learning the tasks your partner does can help you be more prepared to take on extra responsibilities when the time comes. Be open and talk about the changes to avoid misunderstandings.

Care homes

If the needs of the person you care for become too much for you to manage, you will have to think about long term options, such as a care home. You should contact your Council's social work department and ask for a reassessment of both your needs. Remember that everyone experiences dementia differently, and some people might not get to a stage where they 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 the person and a care home may be the best option for them to get the support they need.

Age Scotland has a range of publications on 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. Instead of handling money or typing in a pin code you just swipe your card over the card reader to pay. This is an easier way of paying for things, as long as the person understands that they have paid. You can only do this for amounts of up to £30 at one time. If the person you care for uses a contactless bank card 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 person can use their signature to pay for things by signing a receipt that is checked against the one on their debit or credit 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 system

The benefits and social security system provide financial support. 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.

Claiming Carer's Allowance can mean the person you care for gets less in income-related benefits, such as Pension Credit. You should get advice about this before making a claim.

Did you know? Each year billions of pounds of benefits go unclaimed. It is important you get all the money you should be and it could make a real difference.

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

For more information see Age Scotland's publications *Benefits maze* and *Benefits for people living with dementia*.

Your rights and dementia

Unfortunately some carers and people living with dementia find that others treat them unfairly because of the condition. But you and the person you care for should not be discriminated against. You might want to have a look at the 'Charter of rights for people with dementia and their carer's in Scotland.' It sets out the rights people with dementia and carers have at every stage of the condition. 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, you may want to seek advice. Call the **Age Scotland Helpline** on **0800 12 44 222**.

Legislation and caring

The Carer's (Scotland) Act 2016 is a new piece of legislation that will come into effect on April 1st 2018. The act aims to increase the rights of carers including a support plan for every carer. Carers are to be involved in the development of carer's services and each Council must provide an information and advice service for carers.

More information from the Scottish Government's Carers Policy Branch.

Carers Policy Branch

The Scottish Government, St Andrews House
Regent Road, Edinburgh EH1 3DG

Email: **carerspolicy@gov.scot**

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 the person 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

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

The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia.



DEEP
01392 420076
www.dementivoices.org.uk

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
0151 237 2669
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

The Scottish Dementia Working Group is a campaigning group run by people living with dementia. The group campaigns to improve services for people with dementia and attitudes towards them. It is open to anyone who is living with a diagnosis of dementia in Scotland.



The Scottish Dementia Working Group
0141 418 3936
www.sdwg.org.uk

Employment

If you are employed and being a carer at the same time, you might need to think about requesting flexible working. Every employee has the right to request this if they have worked for their employer for 26 weeks, and can make one request every 12 months. However, under the Equality Act 2010 employees caring for someone who has dementia have the right to request flexible working from their first day in post, and as many times as they need to each year. 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

You should make a request in writing to your employer. Explain what effect you think the proposed change would have for them and how it might be dealt with. Once your employer has received it, they must meet you within 28 days. They must then write to you within 14 days of the date of the meeting stating if they agree to your request and the reasons behind the decision. If your employer has refused your request, you have the right to appeal against the decision. Contact your local Citizens Advice Bureau for advice.



Citizens Advice Bureau
0808 800 9060
www.cas.org.uk/bureaux

The Equality Commission provides information on workers' rights.



The Equality Commission
0808 800 0082
www.equalityhumanrights.com

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

Useful contacts



Age Scotland

Age Scotland is the largest charity in Scotland dedicated to enabling everyone to make the most of later life. We provide 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

Alzheimer Scotland

Alzheimer Scotland is the leading dementia organisation in Scotland. It campaigns for the rights of people with dementia and their families and provide an extensive range of innovative and personalised support services.

Freephone 24 Hour Dementia Helpline: **0808 808 3000**
www.alzscot.org

British Association for Counselling and Psychotherapy

The British Association for Counselling and Psychotherapy is a professional body representing counselling and psychotherapy

Tel: **01455 883300**
www.bacp.co.uk

Care and Repair

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

Telephone: **0141 221 9879**
www.careandrepairsotland.co.uk

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.careinfosotland.co.uk

Carers Policy Branch

For more information on the Carer's (Scotland) Act 2016 contact the Scottish Government's Carers Policy Branch.

The Scottish Government
St Andrews House
Regent Road
Edinburgh EH1 3DG

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**
Email: **carerspolicy@gov.scot**
www.carersuk.org/scotland

Citizens Advice Bureau

The Citizens Advice Bureau Provides face to face information and advice on a range of issues.

Tel: **0808 800 9060**
www.cas.org.uk/bureaux

DEEP

The Dementia Engagement & Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia.

Tel: **01392 420076**
www.dementiavoices.org.uk

Disabled Living Foundation

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

Tel: **0300 999 0004**

www.dlf.org.uk

Disability Information Scotland

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

Tel: **0300 323 9961**

www.disabilityscot.org.uk

Drink Smarter

Drink Smarter is run by the Scottish Government and provides information and advice about alcohol issues, how to cut back and general advice about health, well-being and relationships.

Tel: **0800 7314 314**

www.drinksmaarter.org

Drink Wise, Age Well

Drink Wise, Age Well 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.

www.drinkwiseagewell.org.uk

Extend

Extend is a charity that provides exercise classes for older people and anyone of any age with a disability.

Tel: **01582 832760**

www.extend.org.uk

Home Energy Scotland

Home Energy Scotland give information and advice on how you can save money and energy and make your home warmer.

Tel: **0808 808 2282**

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

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

MindMate

A digital technology app for people living with dementia.

www.mindmate-app.com

National Dementia Carers Action Network

Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) are a national campaigning and awareness raising group.

Tel: **0141 410 0100** or **0141 410 1171**

www.alzscot.org/ndcan

Paths for All

Paths for All is a charity who aim to significantly increase the number of people who choose to walk in Scotland and raise awareness about the benefits.

Tel: **01259 218888**

www.pathsforall.org.uk

Scottish Dementia Working Group

The Scottish Dementia Working Group is a campaigning group run by people living with dementia. It is open to anyone who is living with a diagnosis of dementia in Scotland.

Tel: **0141 418 3936**

www.sdwg.org.uk

Scottish Fire and Rescue Service

The Scottish Fire and rescue Service can make sure your home is as safe as it can be. You can contact them for a free home safety visit.

Tel: **0800 0731 999**

www.firescotland.gov.uk

Scottish Independent Advocacy Alliance

The Scottish Independent Advocacy Alliance can help you find advocates in your area.

Tel: **0131 524 1975**

www.siaa.org.uk

Shared Care Scotland

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

Tel: **01383 622462**

www.sharedcarescotland.org.uk

Smokeline

Smokeline is Scotland's national stop smoking helpline.

Tel: **0800 84 84 84**

www.canstopsmoking.com

The ALLIANCE

The ALLIANCE is the national third sector intermediary for a range of health and social care organisations.

Tel: **0141 404 0231**

www.alliance-scotland.org.uk

The Equality Commission

The Equality Commission provides information on the rights of workers.

Tel: **0808 800 0082**

www.equalityhumanrights.com

TIDE

TIDE enables carers to have a powerful collective voice and raises awareness of their needs and rights.

Tel: **0151 237 2669**

www.tide.uk.net

Age Scotland's Early Stage Dementia Project is funded by the Life Changes Trust to support the charity in raising awareness of early stage dementia and promoting the impact healthy active ageing can have on reducing the risk of dementia.

www.agescotland.org.uk/earlystagedementia



LOTTERY FUNDED

This work is supported with funding from the Life Changes Trust. The Trust is funded by the Big Lottery



0333 323 2400
info@agescotland.org.uk
www.agescotland.org.uk

Age Scotland helpline
0800 12 44 222

Age Scotland Enterprises
0800 456 1137 (Edinburgh)
0800 500 3159 (Glasgow)



www.facebook.com/agescotland



www.twitter.com/agescotland



www.youtube.com/agescotland

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.