

# Living well with early stage dementia



## Being Dementia Aware

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# Living well with early stage dementia

This guide is for someone living with early stage dementia. It explains 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. Family members, friends and carers of people living with dementia may also find the information useful. Everyone experiences dementia differently, but having support in place can help you live well for as long as possible.

Age Scotland's future planning wants 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.

## Where do I get support?

As a person living with dementia there is a range of information, support and advice that is available to you. There are a number of people and organisations that can help.

### Who's who?

After a dementia diagnosis 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.

**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, put you in touch with other people living with dementia and provide information and advice (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 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, people with 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 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 might include help to understand dementia and manage the symptoms, assistance with practical things like claiming benefits, sorting out legal matters or discussing different care options for the future. You may want information about local groups for people living with dementia or ways you can continue doing activities you enjoy. You can feel reassured that if you 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 Helpline:  
**0808 808 3000** (24 hour helpline)  
[www.alzscot.org](http://www.alzscot.org)

## Care needs assessment

At some point most people living with dementia will need support to live comfortably and safely in their own home and community. As time goes on it is likely you will start to find tasks like washing and dressing, eating and drinking, taking medication or moving around the home more difficult. This is known as personal care. You will probably need more supervision to keep yourself safe. For example, remembering to lock doors and windows at night or switching the oven off after cooking. If you think you need care and support you 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 visit and talk with you about what you think you need help with. The Council will consider if you would benefit from support. This might include care at home, a place in a day centre or making adaptations to the home. If you are 65 or over and need help with personal care you 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.

If you have a carer they also have the right to request an assessment of their needs.

In general, if you 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.' You might be able to exercise that choice even if you can no longer manage your finances. Payments can be paid to someone who has the authority to act on your 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 your needs or circumstances 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](http://www.careinfoscotland.co.uk)**

## **Talk to others**

It can be useful to talk things through with your friends and family and explain how dementia is affecting you. You might be worried that if you tell them about your diagnosis they will treat you differently. But usually people find if they are open and honest about things, family and friends are more likely to give support. It is helpful to let people know what works best for you. For example, if you find it easier being asked questions that only need a 'yes' or 'no' answer.

Dementia groups are a good way to meet other people living with dementia. 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 for people living with dementia.



### **Alzheimer Scotland**

Freephone Dementia Helpline: **0808 808 3000**

**[www.alzscot.org](http://www.alzscot.org)**

## Support from health services

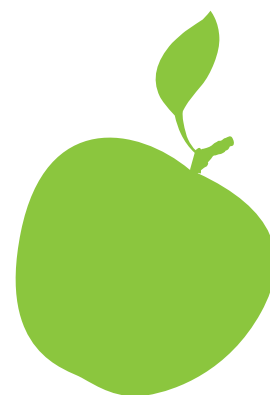
It is important to look after your physical and mental health. If you are finding things difficult or feeling stressed, anxious, tired or depressed you should speak to your GP. Let them know how dementia is affecting you and tell them how you are feeling. There is a lot of support out there so don't be afraid to ask for help. Your GP should take time to listen and discuss support 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](http://www.bacp.co.uk)**



## Looking after yourself

### 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 dementia. 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. Making sure you have plenty of fluids is also really important. 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.

Adopting a healthy diet can be easier said than done. Some people living with dementia lose interest in food or experience a change in their eating and drinking habits. It might be difficult to remember to eat and drink or concentrate on finishing a meal. Here are some suggestions to help you enjoy meal times and get the best out of your diet.

If forgetting to drink is a problem, using a clear glass with a coloured liquid such as diluting juice can help to remind you. Try and keep drinks in your line of sight. Similarly, using plain but brightly coloured plates to serve meals might help you to see pale coloured foods on your plate. When you are with family members, friends or a carer it may be useful if they can give you reminders to eat and drink.



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.

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



Take a look at Age Scotland's guide *Eat Well* for tips on eating healthy and ideas for quick and nutritious snacks. You can also speak to your GP for information and advice.

## Being active

Regular physical activity is not only good for health, but it can help to get rid of stress and improve well-being. Being active might help you to feel more positive and concentrate on what you can still do.

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 have no limiting health conditions and are generally fit 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. If you do not feel like going out you could try some activities in the home. For example, do stretches, march on the spot or try an exercise video.

Some people living with dementia find it difficult to get involved in physical activities. You might feel worried about getting lost in unfamiliar places. You may need help to understand instructions or recognise other people at a group or activity.

If you need some support you could ask friends and family if they can do activities with you. Chances are they know you best and understand what you need help with. Doing activities with others is also a good way to socialise and stay motivated.

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](http://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](http://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](http://www.nhs.uk/livewell/fitness)** or speak to your GP practice which can give you information and advice.

For more information and advice check out our ***Healthy Living & Dementia*** guide.

## Keeping warm

Over the winter it is important to keep warm in your 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 you are in during the day are kept warm to at least 18°C (65°F). Keep your bedroom window 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](http://www.energysavingtrust.org.uk/scotland/home-energy-scotland)**



## Smoking

It is common knowledge that smoking is bad for our health. Heavy smokers may also have a higher risk of developing all forms of dementia when compared to non smokers. If you have memory difficulties it could also 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 talking 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](http://www.canstopsmoking.com)**

If you do continue smoking try to make it as safe as possible. For example, use disposable lighters instead of matches.

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.



### **The Scottish Fire and rescue Service**

**0800 0731 999**

**[www.firescotland.gov.uk](http://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, you may feel more confused or find your memory is more affected. You might need to limit the amount of alcohol you 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 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](http://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](http://www.drinksmarter.org)**

## Community connecting

Taking part in community activities is a great way to get out and about, build social networks and meet new people. Age Scotland's community development officers support around 900 member groups across Scotland which provide a range of services supporting older people, from Men's sheds, to lunch clubs and befriending services.

**Alzheimer Scotland** offers a wide range of welcoming community activities, such as singing groups, football memories groups, walking groups, cinema groups and much more.

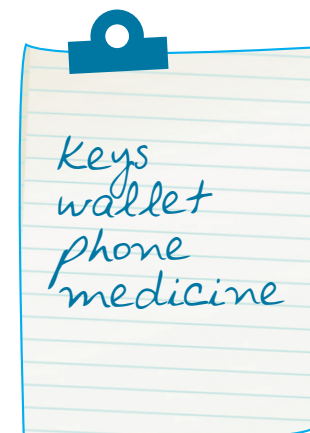
Call the **Age Scotland helpline** on **0800 12 44 222** for information and advice and to find out about opportunities in your local area.

## Useful hints and tips

Dementia affects everyone differently and no two people will have symptoms that develop in exactly the same way. Ideas that work for some, may not work for others. You will figure out what works best for you, however here are some ideas that you may find useful.

### Checklists and reminders

Short checklists might help to remind you of everyday tasks. For example, instructions on how to make a cup of tea, what to do in the shower, or what to take with you when you leave the house. If there are things you need to do regularly like locking the doors or switching the oven off, write a reminder note and put it in a place where you will see it. You might find using a daily diary or to-do list helpful, especially if you are worried about missing appointments or medications.



### Getting into a routine

Having a routine can help to reassure you and make it easier to keep track of the tasks you need to complete each day. Try and get up at a similar time every morning and make a schedule of tasks you need to do. For example, taking medication or preparing meals. Once you have made a schedule try and stick to it as often as possible. Making use of simple gadgets can 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.


## Organising the kitchen

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

If you 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 you find it difficult to remember when you put something in the oven, using a kitchen timer to remind you 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.

## In your home



**Increasing lighting levels** can be helpful to some people living with dementia. As we age, changes to our eyes can affect how much light we need and some people living with dementia have difficulties with their ability to see different colours and shapes. Increasing the lighting levels in the home could help you 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 you understand what time of day it is.



**A floor which contrasts with the colour of the walls** reduces the risk of you falling as it will stand out against the walls and furniture. Flooring which is patterned may be confusing as it can be difficult for some people living with dementia 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. 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'

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](http://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.careandrepairscotland.co.uk](http://www.careandrepairscotland.co.uk)**

## Technology

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

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 can help to find commonly misplaced items, such as keys. Reminder aids can play messages 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 living with dementia find **digital technology** useful. MindMate is an app you can download on to a tablet. You can document your life story so you 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 you and your experiences. You can also store personal information, such as your favourite food, hobbies, music and likes and dislikes. This is really useful if you have memory difficulties and have an appointment with a professional or need to visit a hospital. It lets others know what is important to you.

**MindMate** website: [www.mindmate-app.com](http://www.mindmate-app.com)

If digital technology is not for you, you could get an Age Scotland Lifebook. A Lifebook is a booklet where you can write important and useful information about yourself. 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.



**The Disabled Living Foundation**

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

[www.dlf.org.uk](http://www.dlf.org.uk)

## Shopping

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

Talk with family members, friends or a carer and let them know you are finding shopping difficult. You could ask someone to go shopping with you to give you a hand. If there are times when you are shopping by yourself, you 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 staff at your local shop if they can keep items aside for someone to pick up later. If you feel the shops are too busy you could order your shopping online. Most supermarkets offer an online shopping and delivery service. If you feel unsure or have not done it before ask a family member, friend or carer if they can give you a hand.

## Travel

Sometimes people living with dementia feel anxious or confused about travelling. Here are some tips for making journeys easier.

Most train companies have assisted travel which involves a member of staff supporting a disabled traveller. 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 give yourself plenty of time to arrive and check in. You can also request assisted travel in airports, but make sure you give at least 48 hours' notice.

On buses if you worry you might forget where to get off ask the driver to remind you. Contact your local Council to see if there is a Dial-a-Bus scheme in your area. These buses pick you up from home and take you to local places, such as a shopping centre. This is a good option if you find travelling by ordinary buses too difficult.

It is helpful to carry extra money and the contact details of a trusted taxi firm in case you get lost or feel unsure how to get home.

For more travelling tips contact [Alzheimer Scotland](#).

## Help cards

Help cards are really useful if you run into difficulties as they let others know you have dementia and what you need help with. You can show the card to staff and officials, such as bus drivers, shop workers, etc. so they can support you. There is also space to record the details of someone who can be contacted in an emergency.

If you are interested in getting a help card you should contact Alzheimer Scotland.



**Alzheimer Scotland**

Freephone Dementia Helpline: **0808 808 3000**

**[www.alzscot.org](http://www.alzscot.org)**



## Communication

Not everyone living with early stage dementia will find communicating difficult. But as your condition progresses your ability to communicate is likely to be affected. You will probably need to learn new ways to communicate and it is important to keep family members and friends up to date about what works best for you. Here are a few suggestions to make communication easier.

- Avoid distractions. It can be difficult to hold a conversation if there are background noises such as a TV or radio.
- Try alternative methods. For example, if someone is describing something complicated to you, such as where a bus stop is, suggest they 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. If you find it difficult to hear and understand what someone has said, non-verbal communication, such as eye contact, smiling and nodding can help to give context to words. Let others know that this is important.
- Speak clearly, calmly and slowly. If someone is talking to you about complicated subjects, it can be helpful if they try and keep language easy to understand.
- Keep questions simple. You might find it easier if others ask you short questions that only need a 'yes' or 'no' answer.
- Pictures, diagrams or written bullet points might help you make sense of content.
- Reading and writing. If you find reading and writing difficult you might need others to explain letters to you or help you fill out forms.



## ***Practical things to think about***

The period after a diagnosis can be a good time to think about legal, financial and healthcare matters for the future. Making decisions for the future while you still have capacity can help you feel reassured that your views and wishes are being followed. Capacity is the ability to make decisions for ourselves. For more information see Age Scotland's publication *A guide to mental capacity in Scotland*.



## Power of Attorney

Family members, friends, carers and relatives do not have the automatic right to make decisions on your behalf. A Power of Attorney is a legal document which you can use to give someone else the power to make decisions on your behalf if you become unable to do so yourself, and to support you to make decisions.

There are three types of Power of Attorney in Scotland.

- **General Power of Attorney** is usually created for a set amount of time or for a specific issue.
- **Continuing Power of Attorney** allows someone to appoint a specific person to look after their property and financial affairs and could include the powers to manage bank accounts, claim benefits or pay bills.
- **Welfare Power of Attorney** allows someone to appoint a specific person to make decisions about their health and welfare.

It is advisable to have power of attorney drawn up by a solicitor. Without a Power of Attorney in place, in most cases a person would have to go to court to gain the authority to act on your behalf if you did lose 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](http://www.publicguardian-scotland.gov.uk)**

## Wills

It is important that everyone, whatever their age thinks about arranging a will. A will allows you to decide what happens to your money and possessions after death and can give you peace of mind. 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 you to set out decisions about your future medical care. An Advance Directive is a way of making sure that medical staff and family know what treatment you do not want. They can then follow your wishes should there come a time when you cannot make decisions for yourself.

See Age Scotland's *Advance Directives* factsheet for more information.

## 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.



## Driving

Many people living with dementia are able to continue driving for a while, however you must fulfil certain legal requirements. This includes telling the Driver and Vehicle Licensing Agency (DVLA) about your diagnosis. If a person living with dementia has not disclosed their diagnosis to the DVLA and are subsequently 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](http://www.lifechangestrust.org.uk)**

You can also take a look at the Age UK publication *In the driving seat*. Call the **Age Scotland Helpline** on **0800 12 44 222**.

If you do have to stop driving it can be very difficult to accept. But it does not mean you will lose your independence. Have a look into public transport options and try and plan how you will get to places you need to. If you have limited public transport, you could get in touch with the Community Transport Association. They can give you information and advice about alternative transport options in your area.



**Community Transport Association**

Advice Service: **0345 130 6195** (Mon - Fri: 10am-4pm)

**[www.ctauk.org](http://www.ctauk.org)**

Traveline Scotland provide timetables and journey planner for all bus, rail, coach, air and ferry services in Scotland.



**Traveline Scotland**

**0871 200 22 33** (open 24 hours)

**[www.travelinescotland.com](http://www.travelinescotland.com)**

## 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 to these.

If you need help when travelling by bus you can get a 'companion logo' on your National Entitlement Card which will allow a carer, friend or family member to travel for free if they are travelling with you.

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, who is eligible for them and how to apply at **[www.transport.gov.scot](http://www.transport.gov.scot)**.

Alternatively phone the **Age Scotland Helpline** for information and advice **0800 12 44 222**.

## Care homes

For many people living with dementia staying in their own home for as long as possible is very important. However, you will need to think about long term options, such as care homes. The decision to move to a care home can be very difficult. But for some people, continuing to stay at home might be unsafe, and a care home may be the best option for them to get the support they need. If you are not managing at home, you should contact your Council's social work department and ask for reassessment of your needs.

Age Scotland has a range of useful publications on care homes. This includes 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**.

## Life Story Book

For many people living with dementia, a Life Story Book can be used to preserve memories. This could include the name of your favourite school teacher, favourite holiday; to names of family and friends. Life Story Books can be used as a useful tool to share stories and reminisce over photos. Books come in many different styles and are entirely personal to you.

For more information visit Alzheimer Society at **[www.alzheimers.org.uk/download/downloads/id/1434/remembering\\_together\\_making\\_a\\_life\\_history\\_book.pdf](http://www.alzheimers.org.uk/download/downloads/id/1434/remembering_together_making_a_life_history_book.pdf)**

# Money Matters

## Dealing with money

You might find managing money day to day increasingly difficult. Some people living with dementia find it hard to count change or recognise different notes and coins.

You may wish to set up a direct debit to make sure regular bills such as gas, electric, TV licence and Council Tax are paid without you having to remember to do this. It is important to still check your bills to make sure the right amount is paid.

Contactless bank cards are an easier way of paying for things. Instead of handling money or typing in a pin code you just swipe your card over the card reader to pay. You can only do this for amounts of up to £30 at one time. If you use a contactless bank card it is still important you check your bank account, on a paper statement or online.

A chip and sign card can also be useful for people who find it difficult to remember a pin code. You can use your signature to pay for things by signing a receipt that is checked against the one on your debit or credit card.

Try and organise important documents such as bank statements, wills and insurance policies and put them in a safe place.

If you want to be more confident managing money call the Age Scotland Helpline for information and advice and see Age Scotland's publication *Money Matters*.

## Benefits and social security system

There are a range of benefits out there that you might be eligible for that could provide financial support. Attendance Allowance and Personal Independence Payment 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.

Pension Credit gives you extra money if you are on low income and have reached State Pension age.

Carers Allowance is a benefit for people who spend at least 35 hours a week caring for someone who has a disability. The person they care for must be getting a specific benefit because of their disability, which in some cases has to be paid at a certain rate.

**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. The extra money might help with the additional costs of living with dementia, such as travel and care costs.

For detailed 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 for people living with dementia* and *Benefits maze*.

## Your rights and dementia

Unfortunately some people living with dementia find that others treat them unfairly because of the condition. You should not be discriminated against because you are living with dementia. 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 their 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 of the charter of rights by contacting the Health and Social Care Alliance Scotland (The ALLIANCE).



**The ALLIANCE**

**0141 404 0231**

**[www.alliance-scotland.org.uk](http://www.alliance-scotland.org.uk)**

If you think you have been discriminated against or treated unfairly, you may want to seek advice. Phone the **Age Scotland Helpline** on **0800 12 44 222**.

# Employment and dementia

There are more people being diagnosed with dementia while they are still in employment. Some people are reluctant to tell their employer about their dementia diagnosis. In general, employees are not obliged to tell their employer, unless it is in their contract of employment. The exception is if you are in the armed forces, or work on a plane or a ship, in which case the law requires you to. However, in order to work well and get the support you need you should consider being open with your employer about your diagnosis. This is important as there may be safety issues involved, for example if you work on a building site or operate machinery. Employers have a duty to help an employee with dementia overcome disadvantage in the workplace. This might include noise reduction, a better lit environment and time off for check-ups and appointments. What's 'reasonable' will depend on the size and resources of the organisation and how effective the adjustments will be. For information and advice you should contact your local Citizens Advice Bureau.



**Citizens Advice Bureau**  
**0808 800 9060**  
**[www.cas.org.uk/bureaux](http://www.cas.org.uk/bureaux)**

The Equality Commission provides information on workers' rights.



**The Equality Commission**  
**0808 800 0082**  
**[www.equalityhumanrights.com](http://www.equalityhumanrights.com)**

For more information see Age Scotland's publication *Dementia and the workplace: a guide for employers in Scotland*.

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

# Advocacy

Sometimes people living with dementia find it difficult to have their views and wishes heard, particularly if they are living alone or do not have a lot of friends and family around. This can be really worrying, especially if you are having to communicate with many different services and professionals, such as health and social work during a care needs assessment. An advocate can stand up for you and support you to express your views on issues that are important to you. They can help to make sure that your views are taken into account when decisions are being made about your life. The Scottish Independent Advocacy Alliance can help you find advocates in your area.



**Scottish Independent Advocacy Alliance**  
**0131 524 1975**  
**[www.siaa.org.uk](http://www.siaa.org.uk)**

# Campaigning

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](http://www.sdwg.org.uk)**

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.dementiavoices.org.uk](http://www.dementiavoices.org.uk)**

# How you can help others

Volunteering can make a positive difference to people and communities. It's also a good way to make new friends, build a sense of achievement and have fun. Volunteer Scotland provide information and advice about volunteering and can help you to find volunteering opportunities. If you do volunteer it is important to be open about your dementia diagnosis so you can be best supported in your role.



**Volunteer Scotland**

**01786 479 593**

**[www.volunteerscotland.net](http://www.volunteerscotland.net)**

Each Council area has its own volunteer centre which can help you find local opportunities.

There are also many researchers who are interested in working with people living with dementia. They want to understand more about the condition, look at treatment options and improve services. If you are interested in volunteering for dementia research or want to know more contact Join Dementia Research. You can do this by phoning the **Alzheimer Scotland dementia helpline** on **0808 808 3000** or visit the web page **[www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)**.

## *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](http://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 provides 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.careandrepairscotland.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.careinfoscotland.co.uk**

## 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**

## Community Transport Association

The Community Transport Association provides information and advice about community transport options in your area.

Advice Service: **0345 130 6195**  
**www.ctauk.org**

## 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](http://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](http://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](http://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](http://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](http://www.energysavingtrust.org.uk/scotland/home-energy-scotland)**

## Join Dementia research

If you are interested in volunteering for dementia research or want to know more, contact Join Dementia research.

You can do this by phoning the Alzheimer Scotland dementia helpline on **0808 808 3000** or visit:

**[www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)**

## Life Changes Trust

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

Tel: **0141 212 9600**

**[www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk)**

## MindMate

A digital technology app for people living with dementia.

**[www.mindmate-app.com](http://www.mindmate-app.com)**

## 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](http://www.pathsforall.org.uk)**

## Scottish Dementia Working Group

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.

Tel: **0141 418 3936**

**[www.sdwg.org.uk](http://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](http://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](http://www.siaa.org.uk)**

## Smokeline

Smokeline is Scotland's national stop smoking helpline.

Tel: **0800 84 84 84**

**[www.canstopsmoking.com](http://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](http://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](http://www.equalityhumanrights.com)**

## Traveline Scotland

Traveline Scotland provide timetables and journey planner for all bus, rail, coach, air and ferry services in Scotland.

Tel: **0871 200 22 33** (open 24 hours)

**[www.travelinescotland.com](http://www.travelinescotland.com)**

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](http://www.agescotland.org.uk/earlystagedementia)**



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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](http://www.facebook.com/agescotland)



[www.twitter.com/agescotland](http://www.twitter.com/agescotland)



[www.youtube.com/agescotland](http://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.