

KNOWLEDGE IS POWER

Scotland

Handy hints that might help
make life a little easier after
a diagnosis of dementia

**“Dementia is life changing, but it’s not life ending.
Take advantage of every opportunity offered to you.
You must learn to ask for help, because nobody should
be going through this on their own”.**



This booklet was written by people living with dementia, for people living with dementia. It is based on the original booklet created by our friends in Wales – with DEEP appreciation and recognition of their wisdom. It includes information and advice that we hope you may also find useful in Scotland.

This booklet has been funded by
Life Changes Trust



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Some advice from us to you...

Do things that make you feel empowered - focus on what you can do.

It's okay to feel down. It helps to talk to someone else going through the same thing.

Use strategies to help you adjust. Things like using new technology can help with reminders. I use Alexa; she reminds me about everything.

See if you can get involved in helping others who have a diagnosis or who want to learn more about dementia, by going to talk to people about your experiences of living with dementia.



Keep smiling, live for the day, and don't give up!

If you feel tired or have a 'down day', take care of yourself and have a rest.

Join a group or class that suits you. There are lots out there.

Connect with other people who are living with dementia: Peer support is invaluable.



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The UK Network
of Dementia Voices



Groups in the DEEP Network in Scotland -STAND, Scottish Dementia Alumni, The Beacon Club and Dementia Voices East Dunbartonshire, have all joined together to produce this practical resource for you.

Contents

Benefits and allowances	Page 1
Travel and Mobility Car	Page 3
Public Transport	Page 4
Access assistance	Page 6
Schemes and Campaigns	Page 9
Technology	Page 11
Legal considerations	Page 13
Support you may come across	Page 15
Useful phone numbers	Page 17
Useful websites, peer support, and involvement opportunities	Page 18
Recommended reading	Page 20
Notes	Page 23

Benefits and allowances

PIP (Personal Independence Payment) for under 65s

This is a government provided allowance for disability (not means tested). It has 2 components, and both have 2 rates (basic and enhanced):

- 1) help for day to day living needs, and
 - 2) for mobility support/needs.
- It can be a gateway to accessing other types of support.
 - Citizens Advice Bureau can help you complete the form.
 - Apply to the Department for Work and Pensions to see if you qualify.



<https://www.gov.uk/pip>



0800 917 2222

NB In 2022 this is being changed to Adult Disability Payment.

Attendance Allowance for over 65s

You might qualify for an Attendance Allowance (from the Government). This helps with extra costs if you need someone to help look after you (check if you're eligible). This is awarded to the person who has received a diagnosis of dementia.



<https://www.gov.uk/attendance-allowance>



0800 731 0122

NB In 2022 this is being changed to Pension Age Disability Payment.

Care needs assessment



If you think you, or someone you know, needs help to cope day-to-day, the first step is to get a needs assessment.

Apply to the social services department of your local council (for free), and they can recommend services to help you with things like equipment, home adaptations, practical help from a paid carer, access to day centres and clubs.

Carers Allowance: payable to carer if the carer is working; conditions apply.

Council Tax Rebate: 25% off UK wide; conditions apply. Check with your local Council. This can be claimed under the (unfortunate) heading of Severe Mental Impairment. Further useful information can be found here

 <https://www.moneysavingexpert.com/reclaim/severe-mental-impairment-dementia-council-tax-rebate/#benefits>

Employment Support Allowance: UK wide long term sickness payment. Either contribution based or income based. Contact  www.cas.org.uk or  **0800 0232581** for assistance with this.

Self-Directed Support (SDS) is about giving you more choice and control over the care and support you receive to enable you to live as independently as possible. Anyone who is assessed as eligible to receive social care support can request that their support is provided through one of the four SDS options.

The national organisation for SDS is SDSS link below:

 <https://www.sdsscotland.org.uk/>

Travel and Mobility Car

A blue badge for car parking

A blue badge is for people with a disability (including dementia), to place on the car dashboard to give parking concessions. This is available for a payment of £20.

- The blue badge is for the person, not the vehicle.
- There are other schemes available (e.g. exemption from most road tolls in UK).
- Apply through your local council or here:



<https://www.gov.uk/apply-blue-badge>

Mobility Vehicle through Personal Independence Payment (PIP)

A car can be supplied on lease if you use mobility PIP (on enhanced rate, if you choose to use it this way). No tax to pay, insurance, service and tyres are also covered within the scheme.

- This only applies for three years. If the person who has the diagnosis is no longer using the car it would have to be given back.

It is worth reading Driving and Dementia when considering the pros and cons of driving.



<https://www.lifechangestrust.org.uk/publications/driving-and-dementia-my-experiences-james-mckillop>

Public Transport

The Thistle Assistance Card

The Thistle Assistance Card is designed to fit in your purse or wallet along with your credit and loyalty cards. As it's purely an information card, Thistle Assistance is free to everyone and comes with stickers to allow you to personalise how you use it. Symbol stickers indicate your type of disability or impairment, while short message stickers provide read-at-a-glance information for transport staff about the help you require.

An information leaflet outlines how to get the most from your card. And if your circumstances or requirements change, simply request or acquire a new card to reflect your current or changing needs.



www.thistleassistance.com/get-the-card/

Bus Travel

Local bus companies may offer 'journey assistance cards' you can show to a staff member; such as "count my change for me". Please check with your local bus companies e.g., Stagecoach.

Bus passes

Disability bus pass & disability bus pass plus (this means you can travel with a companion for free). Apply for your bus pass through your local authority.

Trains

- Network Rail can offer assistance at stations if you book it in advance (advisable).
- Some Stations have a 'Calm Corner' waiting room to get away from the crowds and noise in the station (check particular stations, ask when booking your ticket).

Disability rail card

This allows you, and 1 person accompanying you, 1/3 off rail travel throughout the UK. Sign up for their newsletter and receive offers and discounts to other places. This is a chargeable card, but you can use vouchers such as Tesco to pay.



<https://www.disabledpersons-railcard.co.uk>



0345 605 0525

You may be able to get free train travel in Scotland if you have a visual impairment due to dementia.

Always check ahead of travelling about assistance available at airports, train stations, on buses, and so on.



Access assistance

‘Just Can’t Wait’ toilet card

This is a card to use in a shop or café when you just can’t wait to use the toilet.

- The cards are available from the Bladder and Bowel Community



<https://www.bladderandbowel.org/help-information/just-cant-wait-card/>



0800 031 5406

Key to access disabled toilets

The RADAR Key Scheme: Available from public libraries, Disability Scotland, or Disability UK and online at Amazon.

- You have to pay a small amount for the key (about £4.00), but then it is yours to keep.

Changing Places



www.changing-places.org

have a register of accessible toilets with changing facilities

They also campaign contact



PamisChangingPlaces@dundee.ac.uk to find out more.

Wheelchair access

- You may be eligible for a wheelchair/walker from your local council. Apply to the social services department.
- Red Cross also have a wheelchair hire scheme



www.redcross.uk



0300 456 1914

CEA (Cinema exhibitors association) card

A card which enables carers to accompany the cardholder for free entry into certain cinemas. This has a nominal charge for the administration.



<https://www.ceacard.co.uk>



01244 526 016

Relaxed cinema screenings and theatre performances

Some cinemas and theatres offer relaxed screenings and performances (lights left on, breaks, quieter music, and no adverts before the film). Enquire and encourage at your local cinema or theatre.

The Sunflower Lanyard, wrist band or badge

This is a lanyard that is increasingly being used to let people know you may have a disability (a need) that can't be seen.

It is recognised in most supermarkets, airports, buses and trains.

- You can get assistance at airports, for you and your group.
- Pick one up in a participating shop, airport, station or venue at the desk or till. The lanyards are free, and you don't need to provide proof of your disability.

Lanyards are also available for a small charge from



www.hiddendisabilitiesstore.com

“The Sunflower lanyard really works and doesn't highlight you as vulnerable, just highlights you might need help! I use it all the time and it costs nothing but is worth everything.”

Supermarket 'quiet hours'

Many supermarkets are starting to have a 'quiet hour' when they turn the music off and staff are especially aware to help shoppers.

- Check with your local supermarket. If they don't have one, enquire if they might be willing to start one.



Schemes and Campaigns

Carers' Emergency Card

This is a card the carer can carry in case anything happens to the carer, to inform that there is a person being cared for who may be alone at home (available from local carers organisation or local council).

Message in a bottle scheme

The Lions Charity run a free 'message in a bottle' (it is a small white plastic pot) scheme to store important information. This includes contacts, diagnosis and medication. It is often stored in the fridge as a recognised place to look! There is also a sticker which is put by the front door usually to make people (Emergency services for example) aware that you have one. Ask your GP practice or local pharmacy for a message in a bottle.

The Herbert Protocol

The Herbert Protocol is a national scheme that encourages family and friends to put together useful information, which can then be used in the event of a vulnerable person going missing. Or you can download the form from this address:



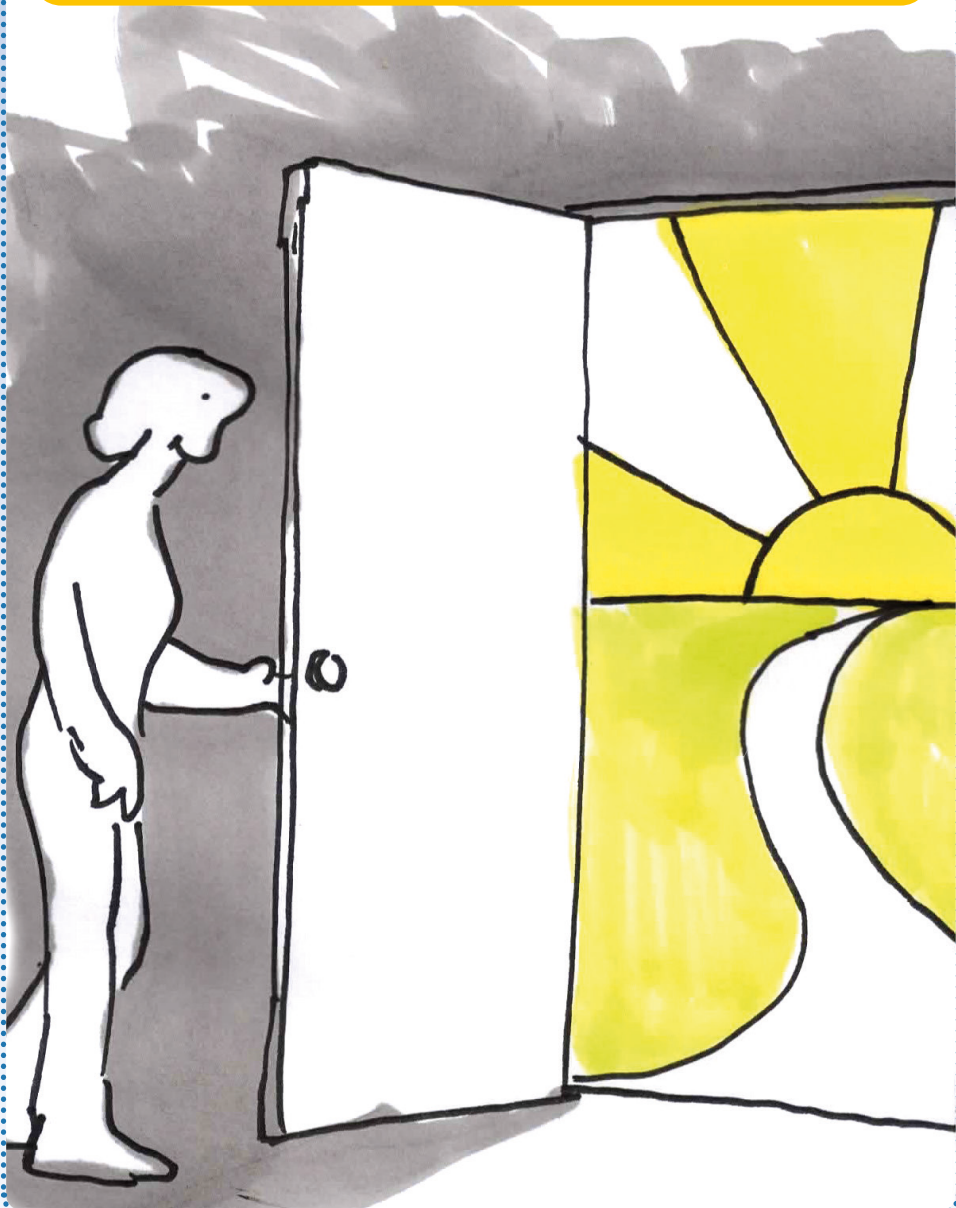
<https://www.scotland.police.uk/spa-media/dtrezvca/herbert-protocol-edinburgh-form.doc>

- Contact your local police force online or by phone to obtain the form, fill it in, and keep it safe at home. This can easily and quickly be shared should someone go missing.

Medical ID bracelet or necklace

You can buy medical identification jewellery to help show what your needs are if anything happens to you.

Make the most of the services and supports that are available to you. Knowing what is out there really can help you - knowledge is power!



Technology

- Alzheimer Scotland have an online digital information point that helps you find the technology you need. It's called Meet Adam.

 <https://meetadam.co.uk>

- Many people find gadgets like Amazon Alexa incredibly useful for reminders, news, and connecting with others. If you own an iPad or another kind of tablet device, you may find that will meet your needs rather than an expensive gadget marketed at people living with dementia.

Telecare devices

This is a personal alarm, which you wear as a pendant or bracelet, that lets you call for help if you need it.

- Contact your local council's adult social services department and ask for a free care needs assessment for the person who has the diagnosis. Depending on your needs, you may have a telecare service provided.
- Speak to your GP or an occupational therapist. They may recommend a telecare system as part of a continuing health or care package, but there's often a charge for telecare services.



Mobile phone Apps with GPS tracking systems

If you have a 'smart phone', you can get free phone Apps with GPS tracking systems, to keep safe. Purple Alert is a free app designed by people living with dementia and carers, Alzheimer Scotland staff, Police Scotland, Social Work, Dementia Friends Scotland, Health and Social Care Partnerships. and Telecare Services. A community minded app for people with dementia if they are missing.

 <https://www.alzscot.org/purplealert>

Track a Phone - you may find there are ways for somebody else to track your phone. These apps will vary depending on the model of your phone.

Keep going, keep up as much independence and activity as you can.



Legal considerations

Lasting Power of Attorney (LPA)

This is a legal document that lets you appoint one or more people to help you make decisions or to make decisions on your behalf if you cannot make your own decisions.

- This gives you more control over what happens to you.
- There are two types - Property & Financial affairs, and Health & Welfare.
- You may find help or guidance from the Office of the Public Guardian and: Age Scotland or Alzheimer Scotland
- Information also available here:



www.publicguardian-scotland.gov.uk



Advanced care directives and Anticipatory Care Planning (ACP)

Advance care directives tell the doctors about specific kinds of treatment that you would or would not want no matter how sick you are. An Advance Care Plan is how the doctors should manage your care.

This is a legal document where you specify what actions should be taken for your health if you are no longer able to make decisions for yourself.

- You may find help or guidance from Age Scotland or Alzheimer Scotland and here:



<https://compassionindying.org.uk/making-decisions-and-planning-your-care/scotland/>

ACP is a person-centred, proactive approach to help people to consider what is important to them and plan for their future. Everyone can benefit from having an ACP. The ‘thinking ahead’ philosophy about ‘What Matters to Me’ is appropriate at any age or stage of life.



<https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/>

Support you may come across

Ask at your GP practice as there may be other health services which may be able to be offered at home such as podiatry, dentists, and opticians.

Psychologist / Community Psychiatric Nurse (CPN)/Young Onset (under 65s) Dementia Nurse

Offer advice on assessments, carer stress, working around dementia and coming to terms with it.

Social worker

They can help you with needs assessments, helping you to find useful resources and services (e.g. respite).

Dementia Link/Support workers

Ask your GP if there are any dementia support workers in your area. Sometimes they are called different things depending on who employs them.

Occupational therapist (OT)

They will help you live life to its fullest by adapting the environment and focusing on what you can do to maximise your safety, quality of life and your engagement in activities.

Speech and Language Therapist

Can help with communication and difficulties with swallowing.

Audiologist

Can help with hearing difficulties and issues often experienced like hyperacusis.

Physiotherapist

Can work with you and your carers to promote physical activity and maintain your mobility and independence for as long as possible.

Dementia Advisors

Dementia Advisors are in most areas of Scotland and are employed by Alzheimer's Scotland. Please contact Alzheimer Scotland to find out what is available in your area and how they can help you to be involved in your community.



Independent Advocacy

Independent Advocacy will help you get the information you need to make good choices and give you the help you need to express yourself clearly.

Independent Advocacy can help you with:

Adult Support and Protection Act.

Adults With Incapacity Act.

Mental Health Act.

Power of Attorney.

Welfare Benefits Assessments.

In Scotland everyone who has dementia is entitled to this free service under People who are covered by the Mental health (Care and Treatment) (Scotland) Act meaning they have a legal right to independent advocacy.

 www.mygov.scot/advocacy/


You can find your nearest advocacy worker here

 <https://www.siaa.org.uk/find-advocate/>


Useful phone numbers

- 24-hour Freephone Dementia Helpline | Alzheimer Scotland

 helpline@alzscot.org

 **0808 808 3000**

- Dementia UK – to speak to a dementia specialist nurse (Admiral Nurses)

 **0800 888 6678**

Useful websites, peer support, and involvement opportunities

- Life Changes Trust.

 www.lifechangestrust.org.uk

- Dementia Together – A space where people with dementia, families, and supporters can come together to explore ways of living well with dementia.

 <https://dementiatogether.online/>


- UK DEEP Network (Dementia Engagement and Empowerment Project).

 www.dementiavoices.org.uk

- Tips shared by people living with dementia for people living with dementia

 www.dementiatip-share.org.uk

- Alzheimer Scotland and Scottish Dementia Working Group.

 www.alzscot.org


- Age Scotland.

 <https://www.ageuk.org.uk/scotland/>

- Carers Trust Scotland.

 www.carers.org

- Dementia Carers Count.

 www.dementiacarers.co.uk


- TIDE – together in dementia everyday – a UK wide network for carers.

 <https://www.tide.uk.net/our-work-in-scotland/>


- Join Dementia Research.

 www.joindementiaresearch.nihr.ac.uk

- ndcan (National Dementia Carers Action Network).

 www.alzscot.org

- Rare Dementia Support.

 www.raredementiasupport.org


- Young Dementia Network.

 www.youngdementiauk.org

- Lewy Body Society.

 www.lewybody.org


- Dementia Diaries.

 www.dementiadiaries.org

- Walking and outdoor.

 www.pathsforall.org.uk

- Sporting Memories Network.

 www.sportingmemoriesnetwork.com

- Playlist for Life.


 <https://www.playlistforlife.org.uk/>



Recommended reading:

All downloadable at

 <https://www.lifechangestrust.org.uk/our-dementia-programme>

- **Sensory booklet** (Agnes Houston)
 - **Talking Sense** (Agnes Houston)
 - **Self-Management** (Alumni)
 - **Dementia & GP Services** (Alumni)
 - **Driving and Dementia** (James McKillop)
 - **Recipe for Life** (STAND)
 - **Work after a diagnosis of dementia** (Martin Robertson)
 - **Scottish Dementia Plans** – Also available in easy read and audio versions
-  <https://www.gov.scot/publications/dementia-covid-19-national-action-plan-continue-support-recovery-people-dementia-carers/pages/0/>



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The Scottish Knowledge is Power version has been adapted by the following Scottish DEEP groups:

The Beacon Club, Dementia Voices East Dunbartonshire, Sottish Dementia Alumni and STAND in Fife.

Based on the original Knowledge is Power booklet created in Wales by: Caban Bangor University Educators, DEEP United Dwyfor & Meirionnydd, and Fuse & Muse, Swansea. For more advice on how to develop the Knowledge is Power booklet or to access other resources created in partnership with Bangor University please visit this page:



<http://dcdc.bangor.ac.uk/products-created.php.en>

For more information about these groups and so much more please visit:



**[www.dementiavoices.org.uk/
deep-groups](http://www.dementiavoices.org.uk/deep-groups)**

Please note that the Scottish version of Knowledge is Power has been put together during the time of COVID 19 2020/2021. The information contained in this booklet therefore may differ in a post COVID-19 Scotland.

Please let us know what you think – send your email to **Niblock@myid.org.uk**

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