

CARER DIRECTORY

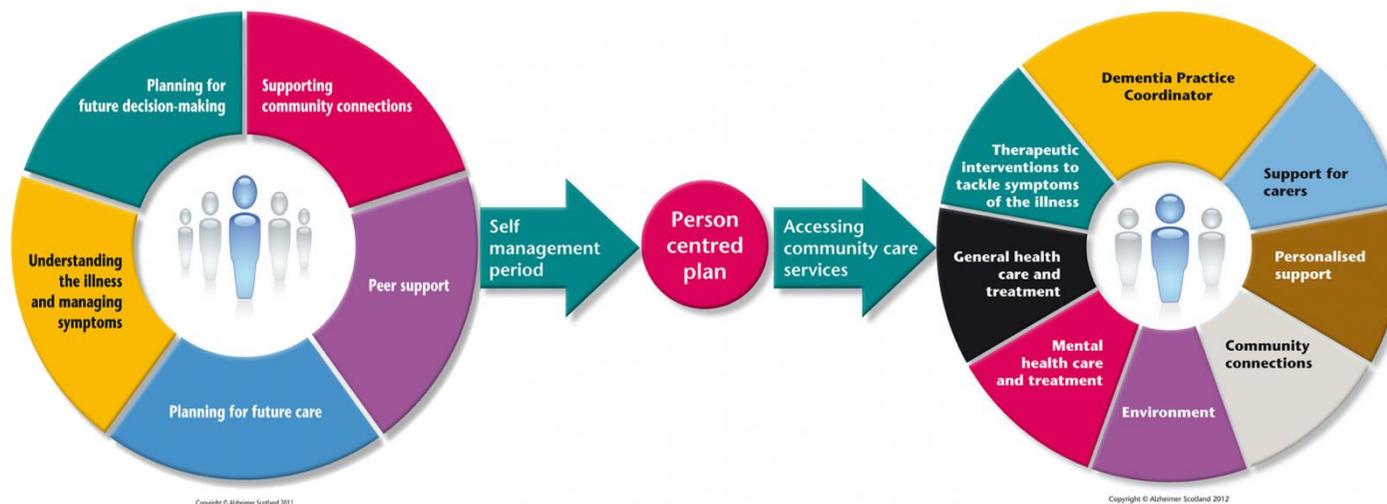
2023

This booklet is designed to help families support people to live well with a diagnosis of dementia. In addition to the information provided during the course, we hope that it can be used as a valuable resource to help families understand the diagnosis, access support and navigate services.

The PDS Group course is presented by Alzheimer Scotland Forth Valley in partnership with the Falkirk and Clackmannanshire Carers Centre



Introduction to the Role of a Link Worker



In the first session, we outline the role of a **Link Worker and Alzheimer Scotland** and the Carers Centre **support services** and what the respective organisations can offer families caring for loved ones with a diagnosis of dementia. We also provide you with **Laura’s List** - a short checklist of benefits and entitlements and ‘must-haves’ to get in place to ensure optimal financial and legal support for you and your loved ones.

The above diagram is an illustration of the role of a Link Worker working within Alzheimer Scotland’s Five and Eight Pillar models. As you can see, our role is wide and varied. Each of the pillars represents how people living with dementia (PLWD) are best supported.

The Carers Centre provides information and support for carers of all ages, seeking to ensure they are recognised, valued and supported. Empowering carers to care with confidence while acknowledging the need for them to have a life outside of their caring role.

Understanding a dementia diagnosis is a learning curve for all. Everyone living with a diagnosis is unique: the support you receive should therefore be bespoke and tailored to meet your needs. One of the objectives of the course is to help you feel less isolated in your carer role and enable you to feel more confident about accessing timely support. **To help you identify the questions that you need to ask and to identify the people and local agencies who can help you.**

In this booklet, we incorporate some of the topics discussed during the six sessions into the 5-pillar model and hopefully, provide you with a comprehensive guide to accessing advice, support and guidance to assist you in your caring role.

Here is a chart that will help you to cross-reference this directory with the information in your handouts and session materials:

| ALZHEIMER SCOTLAND FIVE PILLARS | PDS GROUP SESSIONS & HANDOUTS |
|--|--|
| Understanding the illness & managing symptoms | What Do You Need to Know? (1) & Debunking Dementia (2) |
| Community Connections | Debunking Dementia (2) & What Next? (6) |
| Peer Support | Who Cares for the Carer? (3) & What Next? (6) |
| Planning for future decision-making | What Do You Need to Know? (1) |
| Planning for future care | Local services & how to access them; Self Directed Support (4) & The Hospital (5) |

Post Diagnostic Support: Alzheimer Scotland & Carers Centre Groups

Forth Valley

Alzheimer Scotland & Carers Centre initiative

- 8 week programme
- 6 week programme online

“Dementia does not define me”

“It’s been hard work but we’ve also had fun”

People living with dementia

- Debunking dementia
- Independence: managing symptoms & coping strategies
- Communication: hints & tips
- How to stay connected
- Staying active & eating well
- Safeguarding preferences
- Peer : peer support

Carers

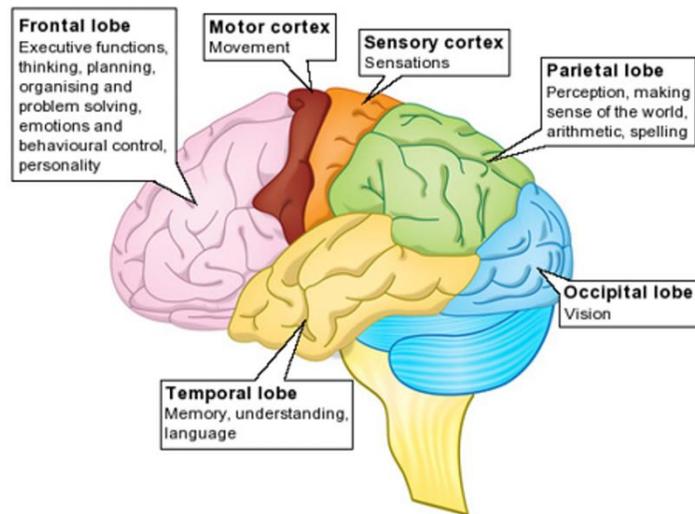
- Introduction to the Carers Centre
- Carers Card & Carers' Rights
- Benefits check
- Legal matters: PoA & driving
- Support: in the home, in the community and in hospital
- Peer : peer support

PILLAR ONE: Understanding Dementia and Managing Symptoms

Definition: to help to understand the illness, practical support, advice and signposting to enable you to identify possible strategies to support your loved one.

In 'Debunking Dementia' (2) Occupational Therapist Ruth Gardener, spoke about the various types of dementia, how these impact different areas of the brain, resulting in different challenges for the person living with dementia and for those supporting them. In the materials for this session, there is an information sheet about brain function; about medications and about why it is important to understand the diagnosis.

Brain Function



Making sure nobody faces dementia alone.

The following websites offer information about the various types of dementia and provide updates on developments regarding dementia and dementia research:

- Alzheimer Scotland website
<https://www.alzscot.org> and <https://www.alzscot.org/alzscotapp>
- Wendy Mitchell lives with a diagnosis and advises others regarding hints and tips to live well with a diagnosis.
<https://dementiatip-share.org.uk/>
- Alzheimer's Society
- <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms>
- <https://www.alzheimers.org.uk/news>
- The BBC frequently reports on this topic within their health pages. Although you can't search through their 'Health' site easily you can use their search engine for news reports and programmes about dementia.
<https://www.bbc.co.uk/news/health>
- **Brain Health** - Alzheimer Scotland understands the importance in brain health and research. We hope to inspire and empower individuals to look after their brain to reduce the risk of diseases which can lead to dementia.

'What is my risk and what can I do about it?' Currently pharmacological interventions can only address symptoms but not the disease itself. 'What can we do...?' is the question that Brain Health seeks to answer to reduce the incidence in dementia and to slow down disease progression in those already diagnosed.

Nothing can be done (yet) about genetics or life changing events which trigger dementia, and which often remains undiagnosed during a long and largely asymptomatic period. But the great news is, that our lifestyle can and does make a difference.

In 2020, a report was commissioned to look at modifiable risk factors. The report identified twelve key factors which if addressed or redressed, could eliminate 40% of all dementias.

Exercise, diet, social interactions, learning new skills, stopping smoking and reducing alcohol intake, avoiding stress and rest are core to brain health and mental well-being. These ideas are not new – but now we have the proof that they have major impact.

Brain Health has an ambitious programme beginning with children’s education; encouraging us all to make a ‘brain health plan’ through pledging change and developing new brain health hubs as a portal to NHS services.

If you want to know more, go to:

<https://www.futurelearn.com/.../understanding-dementia...> for a 4-week online course for adults on brain health
<https://www.alzscot.org/brain-health-scotland>
<https://www.brainhealth.scot/> and <https://www.brainhealth.scot/sport>
<https://www.joindementiaresearch.nihr.ac.uk/>

MANAGING SYMPTOMS – understanding the illness and how to manage some of the associated symptoms

Debunking Dementia also addresses some of the symptoms and challenges that dementia poses for the person with the diagnosis and for families and carers. Information sheets on caring and living with dementia are available here: <https://www.alzscot.org/our-work/dementia-support/information-sheets> and <https://www.alzscot.org/ahpresources>

Sundowning, personal care and communication are frequently identified as flashpoints for families. Here are a few pointers and ideas which might help:

➤ **KISS: THE GOLDEN RULE**

- **Keep It Simple Stupid!** Short sentences, clear phrases, familiar words, simple routines, simplified wardrobes and clothes selection. Less frustration = fewer battles.
- **Keep it calm:** try to stay calm if you can. You are their anchor, the person who makes the world safe and secure. If you are angry, the world is a much more frightening place. The person living with dementia cannot change: we are the ones who have to adapt. If this is

difficult for you, consider Mindfulness as an real exercise to help develop a more positive mindset. It's much more than sandals and white socks. Try: <https://www.facebook.com/tenforzenscotland/> and <https://www.tenforzen.co.uk/>

- **Will teams-manship work?** Perhaps acknowledge tha this is hard for you too. "I'm sorry, I'm finding this hard, David". That makes you a team not the "manager". And perhaps they will also want to help you as they did before. Acknowledge their feelings, even if you don't quite get what's going on. That's team play too.
- **Humour, boosting self-esteem in an authentic way works wonders** – even if some days it's through gritted teeth. Stick at it.
- **Try not to take over, even with the best of intentions.** People with dementia do better, the more they make (supported) decisions for themselves. Their past history, all the things that they've done, eclipses the diagnosis. It's a trite thing to say and sometimes it's hard to remember – but it can help you to look at those old photos too.
- **WHAT'S GOING ON? Changes in behaviour:** behaviour can change for many reasons and while there are medications which can help with some behavioral changes, it is not always the answer. Looking at a change in behavior as a form of communication might help to identify **triggers**. And learning distraction/ de-escalating techniques might help you to manage these changes.
- **Delirium** is a common, serious but usually treatable condition that starts suddenly in someone who is unwell, often as a result of an infection, commonly a urinary tract infection (UTI). Read about the symptoms of delirium and how it can be managed. People with dementia can be at greater risk. For more information on signs and symptoms - <https://www.alzheimers.org.uk/get-support/daily-living/delirium>
- **Triggers:** we talk a lot about triggers as that's often where a lot of the frustration and agitation comes from. Things to consider:
 - **Environment:** hot/cold, dark/light/ noisy/quiet? Strange/familiar? Cluttered or clear easy spaces and clear delineation? e.g. vision/spatial confusion can make dark floors look like a hole. Is that the reason, that Ann doesn't want to go into the bathroom?
 - **Cold:** distress or anxiety can make people cold. You need to be Goldilocks and see if you can find out what is 'just right'.

- **Noisy:** can sound very noisy when you have dementia and your hearing is OK. In restaurants or cafes, can you book ahead a request a quiet area so that your day out isn't spoiled?
 - **Photos/tablets:** is the sight of something in the room triggering a repetitive/obsessive questioning behaviour? Without causing distress, could the object be placed somewhere less visible or put away?
 - **Pain:** is there unresolved pain? Scrunched up face, clammy hands...
 - **Needing the bathroom:** establish a routine of regular visits to the bathroom to avoid discomfort, embarrassment. Make it a team thing. "I'll need to use the loo before we set off. How about you?"
 - **Feeling insecure:** new routine, visitors, odd phone call?
 - **Sundowning:** agitation as the natural light fades. Can you distract?
- **SUNDOWNING:** it certainly manifests itself in greater frustration, wandering, tiredness, snippy, obsessive rootling about for something, and that 'I want to go home'. And although it occurs usually at the end of the day – it can happen at other times too.

Sudden escalation in agitation? It might be sundowning, or maybe not. Check for infections. Even hypertension can lead to a sudden rise in this type of behaviour. **If in doubt, always seek medical advice.**

Regular sundowning, consider:

- **Pulling curtains** before the natural light fades outside, but putting on house lights reasonably brightly
- **Avoid shadows and reflections** on windows or mirrors – they can cause confusion, seeing people
- **Plan a gentle activity or routine** – afternoon tea with a piece of cake and a sit down and chat. Nothing too tiring. A puzzle together.
- **Can white noise help?** Music – classical is possibly better (unless they're a real fan on The BeeGees or?); birdsong; spa type music – Spotify on your phone or Alexa might be a good assist. **'White noise'** is a tried and tested therapeutic intervention to aid sleep and to calm agitation. See
- <https://www.earjobs.com.au/blogs/news/the-therapeutic-benefits-of-white-noise> This is an Australian site but you can easily find white noise machines in the UK.
- **Doll and pet therapy** has also been used as a means to bring pleasure and to soothe without infantilising the person with dementia. See <https://www.dementiauk.org/get-support/complementary-approaches/doll-therapy/>
- **Stroking the dog/cat.** No need to explain – the dog loves you anyway

<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/sundowning>

- **COMMUNICATION:** language, the ability to understanding, to articulate, is often one of the first skills to be impaired by dementia. People with dementia experience:

| COMMUNICATION: what's happening? | Tip |
|---|---|
| Difficulty remembering thoughts, opt for repetition or formulaic conversation | Routine really does help. Can Alexa help with music, medication prompt, calling friends? Does singing help |
| Word finding | People with dementia often lose 1 word in 4. If your wife/father/husband is looking confused, just check that what you have said is what they heard. And a hug is communication too. Words are only a small part. |
| Loss of confidence – do you tell friends or not? | The decision to tell friends is entirely up to your loved one and you. In most instances, telling family and friends and asking them to ‘re-introduce’ themselves – if necessary – helps everyone including those friends who are awkward, might want to help but don’t know how. |
| Tiredness/frustration/being snippy | <p>A day out, a meeting with friends – that brain is overheating and might need a quiet day to follow. Pace the days and enjoy the moment.</p> <p>Mental exercises – word search, jig saws, crosswords, Sudoku all should be done for fun not because it’s ‘good for you’! Quizzes on TV, looking at old photos, rummaging through the button box, handling fisherman’s reels – that’s fine too.</p> <p>Silence can be companionable too</p> |

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| <p>Loss of vision/hearing</p> | <p>People with dementia can get ‘tunnel’ vision. Perhaps John isn’t picking up the tablets because he can’t see them. Put them directly in front.</p> <p>It is essential to ensure your loved one has regular eye/hearing tests.</p> <p>The Sensory Centre based in Camelon, Falkirk can be accessed by people with a visual or hearing impairment. They can provide quality services, advice, and information for PLwD who have additional sensory impairments.</p> <p>http://www.forthvalleysensorycentre.org/</p> |
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- **PERSONAL CARE:** it’s not unusual for personal care to become a bit of a battleground. And it’s a tricky one because everyone feels more vulnerable without clothes. Encourage your loved one to do as much for themselves as they can. Light touch/supervision/prompt/kindly reminder is the way to go rather than attempting a full on sheep dip!

| PERSONAL CARE: what’s happening? | Tip |
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| <p>Dressing/undressing</p> | <p>Try to do a Marie Kondo gradually on the wardrobe paying attention to likes/dislikes in terms of clothes (formal/casual, colours, feel, is this person usually too hot or do they feel the cold?)</p> <p>If navy trousers work well, get two pairs of the same.</p> <p>Hand in hand dressing for coats & jackets and hand in hand for jumpers. Hands and arms first, over the head second if you’re helping..</p> <p>Make life easy – looks at M & S trousers for women – pull ups without zips and buttons but which look classic.</p> <p>Same for men. There are trousers which look classic but which are pull ups. Cords, chinos</p> |

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| | <p>etc. from websites like www.chums.co.uk</p> <p>Make shoes easy too – abandon laces if these are becoming tricky but keep the classic look.</p> <p>Offer a choice but limit the options: ‘would you like the red sweater or the blue one?’</p> <p>Lay night clothes on the bed, hotel style – does that make them look more appealing? Is there a contrast with the bed?</p> <p>If someone really will not change from nightdress to day clothes, can you put on something warm and go for a drive in the car with some sandwiches perhaps to change the mood? Does it matter if they are in the car and warm and comfortable if they’re not wearing the right clothes? Avoid battle lines if they’re unimportant.</p> |
| <p>Changing dirty clothes</p> | <p>Put clothes out the night before and remove the clothes that need washing</p> <p>Good news is that we sweat less as we age</p> <p>Dropped food on the front. Show Jane where it is on you – remember the tunnel vision – then point to her and encourage her to remove it herself</p> |
| <p>Washing – dislike of water, insistence that it’s already been done</p> | <p>Is it the right time? Is the room too hot/cold? Can you ensure privacy by using a draped towel/Velcro bathing/changing towel?</p> <p>Can you call it something else? The special day; a pamper day; the spruce up day; Fresh Friday?</p> <p>Mirrors in bathrooms– do they think there is a stranger is in the room?</p> <p>People with dementia often find water frightening. If someone really will not bathe can you try with their permission to a) wash their hands b) wash their feet? Something which makes them feel comfortable and warm and which they enjoy. Do it together.</p> <p>What colour is the floor? Dark floors can look like holes. Space perception has changed.</p> <p>Are they steady on their feet? Do they need a mat in the bath/shower? A rail on the side?</p> <p>If it’s a wash at the sink – that’s OK. Make sure flannel, soap etc are easy to find. Is the soap dispenser easy to use or is an old-fashioned bar of soap better?</p> |

Magiplugs ensure that the bowl does not overflow.



Magiplugs ensure that the bowl does not overflow.

Shampoo Cap
Dry | Shampoo
Cap No Rinse...
£5.99

If washing hair is an issue, consider ‘No Rinse Shampoo Caps’. Good if someone is feeling a little off colour, can’t get to the hairdresser etc.

Top Toes – NHS trained volunteers offer a toenail cutting service in Forth Valley. Contact Top Toes Team on 07596375674 or email maureen.hill@nhs.net

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| <p>Toileting: accidents happen because the brain doesn’t translate the impulse of needing to go to the bathroom. Or legs don’t work fast enough.</p> | <p>Prompt before leaving the house or before/after lunch. But use yourself as an example. ‘I think I’d better just visit the loo before we go out. How about you?’</p> <p>Radar keys for out and about https://www.falkirk.gov.uk/services/roads-parking-transport/streets-parking/public-toilets.aspx</p> <p>Use disabled loos if you need to help pull up those clothes.</p> |
| <p>Incontinence</p> | <p>Continance for light urinary issues https://www.ageukincontinence.co.uk/incontinence-shop/washable-incontinence-products/washable-incontinence-pants.html</p> <p>No need to go to those itchy pads and pants if the accidents are few and far between.</p> <p>Continance wear is on prescription in the UK – phone your District/Community Nurse for a referral to the Continance Service. (Pads only though. If you want greater absorbency pants you will need to purchase privately)</p> <p>For products like Kylie sheets to protect mattresses, try sites like www.completecareshop.co.uk; capatexcare.co.uk. Shop around for best price.</p> |

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| | <p>Just Can't Wait Cards are available from https://www.ageukincontinence.co.uk/toilet-card and https://www.bbuk.org.uk/just-cant-wait-cards/</p> |
| <p>Time – everything takes so long!</p> | <p>Yes. It does, doesn't it?</p> <p>If you would like to understand how your loved one thinks and feels and would like to be supported take a look at Dementia Sensory Challenges and the hints and tips in your packs. All written by people living with dementia. And remember that your insight is probably better than any expert.</p> <p>Some excellent videos by OT Teepa Snow on all these topics.</p> <p>https://www.youtube.com/user/teepasnow</p> |

- **EXERCISE is excellent for mental well-being.** The pandemic has presented carers and those living with a diagnosis with various challenges and none more so than finding meaningful activity to help keep the brain active.

Keeping physically active outdoors is very beneficial when living with dementia but it is not always feasible in the winter.

To ensure that individuals remain as stimulated as possible indoors, there is a wide range of activities that are do-able at home. Consider nature tables, planting seeds, crafting a twiddle-muff or cushion, making memory boxes (past careers, sport, family history, local interest), encouraging grandchildren to “interview” and make a home video of memories; jigsaws; magic painting books, cookery. Revisit favourite films and TV programmes with catchlines...

If your loved one has a particular interest, hobby, or skill, please reach out to your Link Worker who can provide you with a list of online resources. Here’s a small selection of what’s available:

- **Free colouring websites** – online colouring activities
<https://www.thecolor.com/>

- **BBC RemARC** – using reminiscence as a distraction tool might help to stimulate good memories, aid conversation, and de-escalate tension.
<https://remarc.bbcrewind.co.uk/>
- **Armchair gallery** – this armchair gallery app is a dementia friendly resource; it allows you to see objects and paintings from English Galleries and Country Houses. <https://apps.apple.com/gb/app/armchair-gallery/id1324486946>
- **Life story** – a good way to aid reminiscence, capture important events and record life stories etc.
<https://www.dementiauk.org/get-support/living-with-dementia/creating-a-life-story/>
- **RVS** crafts, dancing and hobbies: <https://www.facebook.com/VirtualVillageHall>
- **Music** is often very important and meaningful for people living with dementia. Not just music of their era, but music which has proved to be the soundtrack to their lives: <https://www.playlistforlife.org.uk/> Music can soothe agitation; can help to relive happy moments; can support fluency through song; can be the lullaby for sleep.
- **DEMENTIA AND DIET:** food preferences often change in dementia to reflect the change in sense of taste There are many things to combat changes of this nature and there is a wealth of information to support you to adapt and change to meet the needs of your loved one. Your Link Worker can offer additional support in this area.
<https://www.alzheimers.org.uk/get-support/daily-living/changes-eating-habits-food-preference>

There are many companies which also offer **home delivery meal services of nutritious well-balanced meals**. These might be useful for carers living apart from their loved ones – or might form part of your back up plan, in the event of the carer themselves becoming unwell.

- **The Parsley Box:** Parsley Box meals don't need to be kept in the freezer or fridge and therefore they can be left out to encourage a PLwD to cook and eat independently. <https://www.parsleybox.com/>
- **Wiltshire Farm foods:** over 300 meals to choose from delivered straight to your door.
<https://www.wiltshirefarmfoods.com/>

- **Blueberry Hill:** a local based team of chefs in Stirling offering a weekly meal delivery service. <https://www.blueberryhillmeals.co.uk/> Blueberry Hill meal drivers will unpack and put away and try to keep the same driver each week.
- **Jelly Drops:** as long as the swallow function is working well, if your loved one has a sweet tooth but doesn't drink as much as you like, you might try boosting fluid intake with Jelly Drops, made from over 95% water. <https://www.jellydrops.com/>
- **Meal Makers:** matching home cooks to people who would like home made meals. By subscription but the annual fee is very modest. <http://mealmakers.org.uk>
- **WANDERING:** if the person you care for either wanders, or sometimes misses the right turn, you might want to investigate **GPS devices** like Buddi Trackers or phones such as those by **Doro** with easy emergency call features. **Remember to set the ICE function (In Case of Emergency) on your loved one's phone.** You can research Buddi Trackers and easy to use mobile phones here: <https://www.alzscot.org/adam> or try <https://www.techsilver.co.uk/> It is also worth asking whether Social Services or MECS can help.

NB. Please remember that while you think that a Buddi Tracker is ideal, your loved one might not wish to carry or use a tracker and by law, their right to decide must be respected unless they are legally incapax in all aspects. A more persuasive way to discuss the issue might be to assure them that while you support their independence, you can't help worrying. Explain your concerns and how they would help to put your mind at rest if they would agree to use a tracker.

- Some carers find it helpful to complete a form like **The Herbert Protocol** which contains information that will help to speed up police enquiries in the event of someone going missing. See <https://www.scotland.police.uk/your-community/forth-valley> bottom of the page for the local form to complete. <https://www.scotland.police.uk/what-s-happening/missing-persons/the-herbert-protocol/>
- Downloadable App: **Purple Alert** - www.purplealert.org.uk . This app can help locate a loved one with a diagnosis who has gone missing. Please see the website for additional information and user guidance.
- **Blue Badge scheme:** if the person you care for, is inclined to wander or struggles with processing the manoeuvres required to get in and out of a car when the door is only a quarter open, you might find a Blue Badge helpful. It will enable you and your loved one to continue to access the local community safely. <https://www.falkirk.gov.uk/services/roads-parking-transport/streets-parking/blue-badge-scheme.aspx>

The form you require is green in colour and entitled **Risk in Traffic Eligibility**. You will need to meet the desired criteria but assistance to complete the form is available from your allocated Link Worker or from the local Alzheimer Scotland Dementia Advisor if the period of post-diagnostic support has ended. **If impaired mobility is an issue, you should complete the normal Blue Badge form as usual.**

- **SUPPORT, ADVICE AND GUIDANCE** is available by telephone, online, and via video calls with Link Workers, Dementia Advisors (Alzheimer Scotland) and Care Support Workers (**Carers Centre**). At **Alzheimer Scotland**, we have access to other **Allied Help Professionals (AHP)** such as Occupational Therapists, Speech & Language professionals who might be able to offer initial advice. Other charities (Heart & Stroke, Parkinsons, Diabetic Society, MECCOP, SSAFA and Age UK) are also helpful.
- **Living Well Falkirk** is a local website to help residents live well, physically and mentally. There are online assessment tools and access to professional advice if required. <https://livingwellfalkirk.lifecurve.uk/>
- **24-hour Alzheimer Scotland Dementia helpline 0808 808 3000**
- **Talking Point** is an excellent online resource for carers. Carers register anonymously to participate in an online forum for practical advice from carers on anything and everything. There are also Factsheets to inform carers about different aspects of dementia. <https://forum.alzheimers.org.uk/>
- Downloadable App: **Cognicare**, a digital companion to support you on the go. https://play.google.com/store/apps/details?id=com.cognihealth.cognicare&hl=en_GB&gl=US
- **MECCOP** supports minority and ethnic carers of Indian, Pakistani, Bangladeshi, Chinese, (Hong Kong and mainland China), Nepalese, African, African-Caribbean or Arabic origin. MECCOP acts “on behalf of its service users in securing access to a variety of supports and services to undertake or sustain a caring role”. MECCOP operates in Edinburgh and the Lothians but endeavours to provide advice to all ethnic and minority carers. Tel. 0131 467 2994

Talking to others who are experiencing similar circumstances can help you feel less isolated.(See also section on **Peer Support**)

- Age UK <https://www.ageuk.org.uk/scotland/>

- Finding it difficult to **get your point of view across**? Tide has a toolbox for carers to assist in conversations with professionals such as Social Services, hospitals and care providers. <https://www.tide.uk.net/tide-in-scotland/>
- Assistance to buy specialist equipment as a one off is sometimes available from **charities for retired professionals**. For the Armed Services, try <https://www.ssafa.org.uk/forth-valley>
- **ASSISTIVE TELECARE** is another important area which can either help to promote safe independence for the person living with dementia or provide carers with peace of mind. **Products range from trackers to timed light switches, interactive units such as Alexa, My Home Helper, cooker isolator switches, pressure mats, perimeter alarms and so on.**

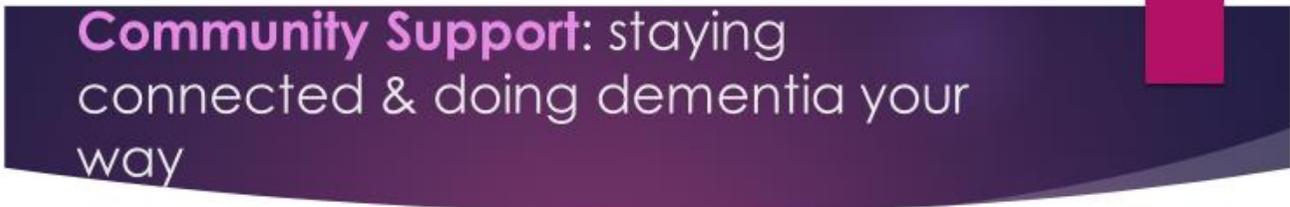
As discussed during the course or at the Re-Connector session, choosing the right piece of technology is the key. Please speak to your Link Worker who can offer you advice support and possibly the opportunity to try a product before you buy. You can also search for a product by using **ADAM (About Digital And Me)** by going to: <https://www.alzscot.org/adam> where you can search by product type or by situation or issue.

- **Dementia Circle** finds, tests and shares products and digital solutions in order to help families live well with dementia. <https://www.alzscot.org/living-with-dementia/staying-independent>
- Stirling University is home to the **Iris Murdoch Centre and its department of Dementia Design and Development (DSDC)**, found at Innovation Park in the grounds of Stirling University. DSDC has an internationally recognized dementia-specific design suite and gardens. The Centre showcases up to the minute design ideas to create a dementia friendly environment. Post Covid, please call prior to visiting but if you are unable to visit in person, you have the option of accessing the **virtual design suite online**. T. 01786 467740. <https://dementia.stir.ac.uk/>
- The **Local Authority/Social Services** can help carers and PLwD to access different pieces of technology as well as the more traditional community alarm system typically used for falls e.g. Mobile Emergency Centre's (MECS pendant) This type of support is only available via a telecare referral; talk to your Link Worker or call the local Social Work office on T. 01324 506070.

- **Just Checking** is an activity monitoring system that helps people with dementia live in their own homes by showing family and professionals their day-to-day capabilities — or where support is needed, this can be privately purchased or accessed through referral to MECS <https://justchecking.co.uk/>
- **SAFETY:** your Link Worker can refer you for a free **Fire Safety Check** to ensure that all fire safety precautions are addressed. Or you arrange a visit yourself by calling T. 0800 0731 99. There is new legislation regarding the fitting of smoke, heat and gas alarms which came into force early in 2022, for more information about what this entails and how support can be accessed please contact your Link Worker.
<https://www.firescotland.gov.uk/your-safety/online-hfsv-checker.aspx>
- **Scams & fraud protection:** a dementia diagnosis can affect many areas of an individual’s life. PLWD can be more vulnerable to scams and unscrupulous callers. **Trading Standards** together with Police Scotland have taken a pro-active approach and offer practical support to reduce the risk of being scammed. See <https://www.tsscot.co.uk/news/scam-share/> **Truecall devices** can reduce scam/cold calls by over 90% and can be fitted by your local Trading Standards Team (devices are limited to a 1st come 1st served basis). Ask your Link Worker for a referral.
- **Report all scams to Advice Direct Scotland on 0808 164 6000.** If you have been the victim of fraud, report it to Police Scotland on 101 or 999 in an emergency. If you receive a suspicious text message you can forward it to 7726. The free-of-charge ‘7726’ service enables your provider to investigate and take action if malicious content is found. If you receive a suspicious email, forward it to report@phishing.gov.uk. You can use the National Cyber Security Centre's scam website reporting service to send links from websites which you think are trying to scam the public.
- In addition to the Truecall device, the **CIFAS “Protective Registration”** scheme costs £25 for two years. CIFAS place a flag alongside their name and personal details in their secure National Fraud Database. Companies and organisations who are signed up as members of the database will see the individual is at risk and take extra steps to protect them, preventing fraudsters from using their details to apply for products and services.
<https://www.cifas.org.uk/pr>

PILLAR TWO: Community Connections

Definition: support to stay in touch with your community (e.g. family, friends, associates) and to make new connections



Community Support: staying
connected & doing dementia your
way

- ▶ **Community – it's the way that you define it**
- ▶ Family & friends
- ▶ Lunch & supper groups: The Snowdrop Café, the Friendship Club, The Almond Tree
- ▶ Outdoors: Men's Shed, Hen's Shed, Braveheart walks
- ▶ Relaxed performances: McRoberts & Festival Theatre Edinburgh
- ▶ Dancing, art & crafts, choirs, musical groups, A Day at the Movies (Thornhill Court), Tea Parties (Festival); Resonate (Alloa); Third Age
- ▶ Church lunch group – St Andrews Bo'ness
- ▶ Holidays: Dementia Adventure; Bikes on the Beach; Cycling without Age Scotland

- ▶ **'Dementia-friendly' is relaxing – but it's the welcome that counts!**

What is community? Community is the people and groups where each of us feels at home, with people whom we trust and whose company we enjoy or whose interests we share. Most of us have a community which is a mix of family and friends, interest groups (e.g. the choir, a painting club, a golf club, the local gym); professional colleagues and for some, church or another spiritual 'club' club.

Over a lifetime, your 'community' shifts and changes – people move away, you play golf less because walking becomes more difficult. You're busy looking after your grandchildren. Sometimes people lose their community or their community shrinks so much that it becomes socially isolating. Carers can become isolated too. **If you have a diagnosis of dementia but you remain socially active, there is a very good chance that the progression of the disease will decelerate – as long as you are doing what you want to do.**

If your community (however you define it) is intact and you feel happy and fulfilled, we don't want you to change anything. **But if you or your loved one have become dislocated and need a fresh start, Alzheimer Scotland Link Workers and Dementia Advisors are here to listen to your wish list. We will try to suggest ideas, open a few doors and find local ways to help support you to re-engage. The choice is yours.**

More and more services are being made available for people with dementia and for their carers. However, finding the support that will best meet your needs is seldom easy. And there might be other considerations. Perhaps you feel shy and would rather have someone to go with you. Or you might worry about how to find your way there and back.

Some services are run by the Social Work department, some by the Health Board, some by voluntary organisations and some by private companies. Some are designed to support dementia, others are simply a good place to be. At Alzheimer Scotland, we can't do everything for you and nor should we, but perhaps we can figure it out together.

➤ **COMMUNITY CONNECTIONS: Online**

Since March 2020, Alzheimer Scotland has developed many online groups for people with dementia and their carers to enjoy.

Online might not be for you but the good thing is that it doesn't matter where you live. Want to try baking with others? Try Cherie Raby's monthly 'Round the Kitchen Table' with friends in Lothian. There is an online Men's Group for carers all over Scotland and even an art group run by an artist in Tayside!

Falkirk online groups are:

- **Friday Feeling Group** – every Friday 2-3pm,
 - **Juke Box Days** – every Tuesday & Thursday 11am & 2pm, Thursday is a repeat of Tuesday **Please ask for more information if you are interested.**
 - **Online Café** – online the first Friday of the month.
 - **Get on the ‘What’s On’ list for your area:** we provide a list of activities which can keep you abreast of everything that’s on offer in your local area. If you are interested in receiving an updated list, please email our Dementia Advisor dpaterson@Alzscot.org. If you can shop online, you probably have the skills to attend our groups!
 - **Check out our national Facebook page.** You don’t need to join Facebook to see what is going on: <https://www.facebook.com/AlzheimerScotland/>
 - **Unfamiliar with online but feel that you’re missing out? AbilityNet** offer free IT support at home. Volunteers are PVG checked (Protection of Vulnerable Groups) who can offer advice and support to stay connected or help resolve technical issues when they arise. A referral for this service can be actioned by your Link Worker <https://abilitynet.org.uk/>
- **COMMUNITY CONNECTIONS: At Home**
Support from home can be accessed via many routes. A selection of options is detailed below.
- **Care Support Worker:** a Care Support Worker or Companion Support Worker is a bit like a Man Friday, offering support in many areas, encouraging individuals to live well with their diagnosis and helping them to remain as independent as possible while providing some valuable respite for carers. They will and can assist with meal making and personal care but their role is focused on enabling individuals to enjoy a good quality of life. Care Support Workers who are well matched end up feeling like a really good friend.

The services of a Care Support Worker can be accessed via a Local Authority Community Care Assessment or purchased privately using Attendance Allowance to fund the cost. You can either request support directly from Social Services (t. 01324 506070) or ask your Link Worker for a referral.

(NB. It's easy to confuse **Care Support Workers** (supporting people with dementia) with **Carer Support Workers** (Carers Centre, supporting carers).

- **Strathcarron Hospice** supports people within their own homes via its **Strathcarron Hospice Compassionate Communities project**. **Connecting People** can match your loved one to a befriender with similar interests who will arrange a scheduled telephone call or write a letter. If you would like more information on this initiative, please contact your Link Worker.
- **SSAFA** – the Armed Forces charity have local representatives who can harness support for retired veterans. The charity provides a helping hand with local volunteers, practical advice, financial support and in case of need, equipment which is not funded by the NHS or Social Services. SSAFA's Falkirk, Stirling and Clackmannanshire branch has recently established a befriending initiative for veterans with dementia. See <https://www.ssafa.org.uk/get-help/supporting-older-veterans> To enquire about a befriender, please contact your Link Worker or Dementia Advisor.

➤ **CONNECTIONS: Community Groups**

Below is a small sample of the type of groups that are facilitated by Alzheimer Scotland Forth Valley. The local Dementia Cafés hosted by Alzheimer Scotland offer you chance to chat with a Link Worker and the opportunity to talk to others living with dementia, their friends and family.

CENTRAL FALKIRK

Dementia Café: Central Perk Café, Graham's Road. Every Thursday from 10.00 am -12.00 noon

Musical Memories*, St Francis Xavier's Church, Hope St, Falkirk 1st Monday of the month, 11.00am-12.30 noon.

The Woodlanders: a great annual favourite and an AlzScot group from spring-summer, hosted by the rangers. Camp-fire cooking, walks, bird-box making, windchimes, kazoos, a chance to dip into ranger knowledge about the local wildlife.

STENHOUSEMUIR

Garden Club*, 35 Johnstone Avenue, Monday & Thursday from 10.00am -12.00 noon

CAMELON

The Brain Gym*, a 10-week programme that promotes well-being and self-management. Wednesday 1-3 pm

BO'NESS

Dementia Café: Richmond Park Hotel Every Wednesday from: 10.00 am – 12.00 noon.

* Book a place or by referral only

STIRLING & CLACKMANNANSHIRE

Resource Centre & Brain Health Hub

Dementia Café: Every Tuesday 10.30am-12pm

Activity Tuesday *: Every Tuesday 1.30pm – 3pm

Carers Cuppa: Every Thursday 10.30am-12pm

Musical Minds*: 1st Thursday of the month 1.30pm-3pm

The Brain Gym*, is a 10-week programme that promotes well-being and self-management for people with dementia, 10.30am-12pm

Celebrating Sports* 3rd Thursday of the month 1.30pm-3pm.

Community

Kings Park Walking Group: Every Wednesday 2pm-3.30pm

Café at the Birds and Bees, Easter Cornton Road: Every Wednesday except the last week of the month, from 10.30am – 12

Lunch at the Birds and Bees: The last Wednesday of the month at 12 noon.

Online Group Activities

Friday Feeling Group: Every Friday 2pm-3pm

Juke Box Days: Every Tuesday & Thursday 11am-2pm

Stirling Golf Club Initiative – following the success of trial session last year, Stirling Golf Club is now committed to supporting golfers and budding golfers! with a diagnosis. People living with dementia will be offered a golf session with an Academy Leader and the carers will be offered a resilience and well-being session. Speak with your Link Worker or Dementia Advisor Donna Paterson for further details.

➤ **OTHER: Places & Spaces**

There are many groups, cafes and places in and around Falkirk, Stirling and Clackmannanshire which are not specifically for dementia but which are dementia friendly. (If you had a wooden leg, would you only visit bars for people with wooden legs?)

Here are a few examples:

- **Talbot House (Grangemouth):** morning tea & coffee, lunches for £5.50 on Tuesday & Thursday from 9.30 am – 1.00 pm. Contact: jayne17872@hotmail.com
- **Men's Shed:** for wood-workers, recyclers, boys-toys, banter. Hens are welcome too! <https://dennybonnybridge.wixsite.com/mensshed/contact>
- **The Almond Tree:** Christian Caring Coffee Shop in the centre of Falkirk. Contact almondtree@struthers-church.org T. 01324 626000
- **Braveheart Walks:** Various throughout Forth Valley for all abilities. <https://braveheart.uk.net/walking/walking-timetables/>
- **Cycling without Age Scotland:** <https://cyclingwithoutage.scot/> for free hire of trishaws with a volunteer pilot or pilot your own!
- **Tuesday Club (Bo'ness):** thetuesdayclub@standonline.org.uk for people with dementia and their families
- **CarronKith** host a **Movie Matinee** at Thornhill Court every month on Saturdays with an ice-cream interval! Contact carronkith@outlook.com for details.
- The **Festival Theatre** in Edinburgh and the **MacRoberts** in Stirling hold many events which are “dementia-friendly” – easy signage, raised lighting, freedom to move in and out of auditoria. The Festival Theatre also hosts tea dances and impromptu musical play-alongs. In Falkirk,

Please also remember that if you and/or the person you care for has a particular and life-long interest, you don't need to seek out dementia-friendly places to visit or to join. You don't need to live in a silo just because you have a diagnosis! If you're out of ideas and wish to try something, check out: <https://u3asites.org.uk/scotland/home> or <https://www.aliss.org/>

- Did you know that you can hire **adult wheelchairs to access beaches** for free? <http://www.beachwheelchairs.org/> Free wheelchairs are for hire at North Berwick, Portobello (Edinburgh) and St Andrews. <https://hamishfoundation.co.uk/beach-wheelchairs/> Both are charities and there aren't many chairs available so you need to book early – but no need to forego gritty sandwiches or that 99 cone any more!

- People living with dementia can often feel that **holidays and travel** are a thing of the past. Well, perhaps they are just now! But once normal life resumes, Dementia Adventure specialises in creating small group holidays for people living with dementia, their partners, family, friends or carer <http://www.dementiaadventure.co.uk/holidays>
- If you are caring for someone with dementia who **has mobility issues** and you would like to find somewhere to stay that addresses physical needs, check out: <https://www.euansguide.com/> Euan's Guide is akin to TripAdvisor for People with physical disabilities.

➤ **COMMUNITY CONNECTIONS: Access**

Access to the community can be more problematic when living with a diagnosis. Consider whether the following might help:

- **Blue Badge scheme: the Blue Badge scheme** might enable you and your loved one to continue to access the local community safely. The form you require is green in colour and entitled **Risk in Traffic Eligibility**. **If mobility is impaired more by physical issues**, the ordinary Blue Badge might be more appropriate and is valid for a longer period. There are eligibility criteria but assistance to complete the form is available from CAB or from your allocated Link Worker.
- **CEA CARD: visiting the cinema can be a positive experience for everyone** and can bring families together. In recognition of the support people might need when planning a visit to the cinema the **CEA card** entitles the supported person to be accompanied by a carer free of charge. <https://www.ceacard.co.uk/>
- **Need the loo?** Accessing the community when you are experiencing continence issues can be a challenge. The **'Just Can't Wait'** card can offer a PLwD the benefit of a discreet and clearly communicated request to use toilets which are not available to the general public. (e.g. in retail shops) <https://www.bladderandbowel.org/help-information/just-cant-wait-card/>
- **RADAR keys to access disabled public toilets are free from Community Hubs** if you meet qualifying criteria i.e. have a disability and provable low income/associated benefit. Otherwise, keys are available to buy online or from Boots the Chemist on the High Street and in the Central Retail Park (Falkirk)
- **Lost your driving licence but still want to get around independently? Think about a Taxi Card:** in Falkirk and Clackmannanshire, people with dementia can request a Taxicard regardless of whether they hold a bus pass or whether they can physically catch a bus.

During the pandemic, the Falkirk Transport Department kindly agreed to extend the scheme to include those who have a diagnosis of dementia after discussions with Alzheimer Scotland. Please ask your Link Worker or Dementia Advisor to apply on your behalf. Clackmannanshire residents can hold a bus pass and a taxi card providing they receive Attendance Allowance.

Taxicard journeys are booked in advance and save £2 off every journey which begins and ends in your Local Authority area.



PILLAR THREE - Peer Support

Definition: a safe environment to enable you to meet with your peers to gather info, hints, tips and support.

- **PEER SUPPORT & OUR CAFÉS: we have two versions. Online and Community Cafes.**

The Café is a very relaxed get-together for carers and individuals living with a diagnosis.

- **Monthly Cafe (Online): you are free to drop in at any time** but to ensure you are provided with log in details, please contact your allocated Link Worker or our Dementia Advisor dpaterson@Alzscot.org

The Café Falkirk meets the first Friday of every month on Microsoft Teams.

We rarely talk about dementia but it's all about peer support: the Café helps to build relationships and friendship in an easy, informal setting. We talk about films, music, places that we'd like to go, famous people we've met, tattoos that we'd choose (if we were brave enough!); we've hosted a wide range of guests from Andy Scott of Kelpies fame; to Janice Forsyth BBC Radio 4; Simon the Staffa, a famous taxidermist and we've held three mindfulness and relaxation sessions led by Teresa Johnston (<https://www.facebook.com/SunriseHolistic/>) and Martin Stepek (<https://www.facebook.com/tenforzenscotland/>)

On the practical side, we invite partners who work with us so that you know how to tap into their support too. Guests have included the local Dementia Nurse Consultant on support in care homes and hospitals; Community Officers for Fire Safety on safety home checks and the new fire regulations and Trading Standards (Scams); Brian Health Scotland; Action on Rights; SP Priority Services (support during power cuts, access to best tariffs); how to use assistive technology to better support you.

STIRLING & CLACKMANNANSHIRE:

Dementia Café: Dementia Resource Centre 2-4 Mill Street. Drop in, every Tuesday 10.30am – 12pm

Falkirk:

Dementia Café: Central Perk Café, Graham's Road. Thursday from 10.00 am -12.00 noon.

Dementia Café: Richmond Park Hotel From: 10.30 – 12.30 noon.

Here's what one of founder members says:

*Until the Café, I had no outlet and no one who truly understood just how difficult things were. I walked into the Café a stranger and left with more friends than I could imagine, friendships that have endured through the years.
We left feeling we had somewhere safe to go.*

➤ **PEER SUPPORT: Other Alzscot groups**

Consider also the Scottish Dementia Working Group activists led by people with a diagnosis <https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group>

Alzheimer Scotland hosts a once a month online Men's Group specifically aimed at supporting male carers who might be looking after their wives or mothers and struggling with the challenges that this brings. A Link Worker opens and ends the meetings but discussions remain private among the men who attend. Contact: Jeni Sinclair JeniSinclair@Alzscot.org; Ellen Donnelly edonnelly@Alzscot.org

➤ **PEER SUPPORT: The Carers Centres**

- **Who Cares for the Carer? Carers need support too, which is why the Post Diagnostic Support programme online sets aside one whole session (3) to look at carer support.** No-one understands a carer better than another carer.

The Falkirk & Clackmannanshire Carers Centre: The Carers centre is now opening up to host some Care with Confidence sessions again.

It is using a blended approach of face to face sessions, or if desired you can attend these sessions via Zoom. For up to date details, check the 'What's on' page on their website <https://centralcarers.org/whats-on/> Contact catherinebrunton@centralcarers.co.uk for details or centre@centralcarers.co.uk . If you live in Stirling, your local Carers Centre is: <https://www.stirlingcarers.co.uk/>

- **Carers have rights:** it's important to know your rights because many professionals have only a rough idea of carers' rights or are aware that carers are considered to be Equal Partners in Care. <http://www.knowledge.scot.nhs.uk/media/6525401/core%20principles.pdf>
- **The Carers (Scotland) Act**, which was passed on 1 April 2018, stated that all carers must be offered an **Adult Care Support Plan (ACSP)/ Young Carer Statement** documenting the impact that caring has on their lives. Any impact which is deemed “**substantial**” or “**critical**” must be considered by Social Services and addressed appropriately. Carer Support Workers will assist with completion of ACSPs, often a prerequisite to getting Social Service support.

Alzheimer Scotland can provide a card which lists all Carers' Rights for easy reference. Ask your Link Worker.

- **Registration with the Carers Centre gets you a Carers Card:** <http://centralcarers.org/carers-involvement/forth-valley-carers-card/> During the pandemic, the card proved invaluable with regard to accessing protected shopping times; being identified as a carer at GP surgeries for flu/C-19 vaccination slots; and perhaps it can help with hospital visiting as per John's Campaign <https://johnscampaign.org.uk/>.
- In cinemas, Historic Environment Scotland sites and elsewhere, carers often go free on presentation of the Carers' card or AlzScot card.

The Carers Centre strapline is: **Involve, Inform, Support**. The Centre facilitates carers' **involvement** in public policy discussions through its quarterly fora and participation on Integrated Joint Boards (IJBs); it **informs** via its **Care with Confidence** series (regular topics include Power of Attorney; delirium, depression and dementia; sleep routines; chair yoga; scams etc); and it **supports** carers in all their care commitments by referring and signposting to other support agencies in Social Services and the third sector.

There is no obligation to join anything but it's well worth getting in touch. The Falkirk & Clackmannanshire Carers Centre is a pro-active agency with a range of activities and services for carers, most of which are free.

Carers need time out: if you haven't had a break for a while, or want to start a new hobby to offset the stress of your caring commitment, ask about **Creative Break** funding at your local Carers Centre. Via the Centre, you can apply for up to £ 400 in funding that is just for you, to enable you to safeguard your own mental and physical wellbeing, either by taking a break or by developing or starting a new relaxation pastime.

- **If you struggle to get out of the house because of your caring commitment, you might prefer online support.** **Talking Point** is an excellent online resource for carers and for people with dementia. Talking Point is about practical tips from those who live with dementia everyday. Carers register anonymously to participate in an online forum for practical advice from carers on anything and everything. There are also Factsheets to inform carers and people with dementia about different aspects of dementia.
<http://forum.alzheimers.org.uk/>
- **Tide:** tide (Together in Dementia Everyday) is a new charity in Scotland, founded in 2017 with money from Life Changes Trust. Tide seeks to empower carers of people living with dementia to speak about their lives and their needs, in the hope of building a fairer, more equitable life for carers whose life chances are often compromised by their commitment to care. Tide supports a human rights based approach whereby carers have the right to the same life opportunities as their (non-caring) peers. To find out more
<http://tide.uk.net/our-work-in-scotland>
- **Carron Kith:** Carron Kith is the new name for a local community group which was set up in 2016 as a self-help or 'Peer Support' Group. It is aimed at people in the Carron Valley Area (including Denny, Larbert, Falkirk and Grangemouth) who feel they would benefit from the company of others.

The Group promotes the benefits of Kith –a group of friends, acquaintances or neighbours, who like spending time together and have common experiences, interests and shared concerns. Contact: Lesley Aitkenhead – 07787 435059 or Nicola Allison - 07950 659158 or Email : Carronkith@outlook.com

- **Want to have your say in influencing dementia strategy?** The government is working on the 4th iteration of Scotland’s Dementia Strategy and needs direct input from carers and from people with dementia.

The Cross Party Group on Dementia at Holyrood is attended by representatives from Alzheimer Scotland, tide, Age UK but always welcomes the voice of “lived experience”.

Contact Chris Kelly PA/Senior Administrator, Alzheimer Scotland Tel. 0141 410 1172 for an invite stating your contact with your Link Worker.

PILLAR FOUR: Planning and Decision-Making

Definition: Advice and support to make sure you and your loved one are prepared for the future

Make sure that you are aware of all benefits and entitlements for the person whom you support and for you. At the end of this directory, you will find **Laura's List** – an easy reference tool to check that you have all the essentials in place. Talk to your **Link Worker** or your **Care Support Worker** who can refer you to a qualified Benefits Advisor.

- **POWER OF ATTORNEY/GUARDIANSHIP: it's not the same as a will. It's important to what Power of Attorney can do for you, how it can protect your wishes and preferences; and the responsibilities that are held by those whom you appoint as your Attorney.** There are **financial powers** and there are **welfare powers**. And these can only be granted when someone has full capacity. Post Diagnostic Support includes a discussion about Power of Attorney if this is something that you haven't yet done or considered or you wish to know more.

The Carers Centre often holds information sessions on Power of Attorney or you can book a special session which is given by **Solicitors for Older People Scotland (SOPS)**. More information can be accessed via www.solicitorsforolderpeoplescotland.co.uk

- Additional information regarding P.O.A is available from the **Office of Public Guardian** www.gov.uk/government/organisations/office-of-the-public-guardian

Alzheimer Scotland is currently in discussion with **SOPS** to consider particular implications of Powers of Attorney. How do you protect your house? What does deprivation of liberty mean? Who decides? Watch this space...

- **ADVICE ON BENEFITS:** Personal Independence Payment (PIP), Disability Living Allowance (DLA), Attendance Allowance, Carers' Allowance, Pension Credit, Council Tax rebates – it's confusing isn't it? Your Link Worker or your Carer Support Worker (Carers Centre) can explain about entitlement eligibility and refer you to a Benefits Advisor at the Carers Centre. Or contact Lyn McKay directly on: lyn@centralcarers.co.uk

- **REGULAR HEALTH CHECKS AND REVIEWS ARE IMPORTANT:** hearing, sight, teeth/dentures, medication reviews – try to ensure that these are checked regularly. In dementia, it can make a difference.
- **KNOW YOUR CARERS' RIGHTS:** rights to weekly respite, rights to short breaks, rights to live your own life, rights to work, rights to life balance. The right to be consulted about hospital discharge arrangements. Every adult who is a carer must be offered an **Adult Care Support Plan** (See Pillar 3: Peer Support & Carers Centres)
- **DO YOU HAVE A 'WHAT IF..? PLAN?:** the importance of planning for the What ifs....? has been highlighted by the pandemic. "What if my daughter can't visit, who will do the shopping/laundry/feed the dog?" It's always good to plan for an emergency. See https://www.enable.org.uk/wp-content/uploads/2017/07/ENABLE_Emergency-Planning-Workbook_17.12.15_Proof.pdf
- **FIRE SAFETY:** have you ever left a pan on the stove to answer a phone call? If your husband's mobility has declined, how will you help him out of the house in the event of a fire? A **Fire Safety check** is free and can be arranged to ensure that all fire safety precautions are addressed. That might include cooker sensor alarms, cooker isolator switches, a fire escape plan or just security on doors and windows or advice about the new legislation regarding the fitting of smoke, heat and gas alarms (in force early 2022). For a referral to the local Community Fire Safety Officer, please contact your Link Worker or call T. 0800 0731 99.
- **DEMENTIA FRIENDLY HOME:** making small changes within the home can make a big difference to people with dementia. Changes to sight are discussed in **Debunking Dementia/Management of Symptoms** section. Information to help you choose specific adaptations to make life easier and ideas which are easy and low cost to implement may be found here: <https://www.nhs.uk/conditions/dementia/home-environment/> and <https://www.ageuk.org.uk/globalassets/age-scotland/documents/ia---factsheets/dementia/dem-11-dementia-enabling-home-may-21.pdf>

Familiar is good in dementia. But these publications enable you to see your home or your loved one's home in a different way, identifying possible trip hazards, or dark areas which look like black holes or empty spaces; or areas which need to be automatically lit to ensure safe walking at night.

- **ASSISTIVE TELECARE/TECHNOLOGY:** consider whether a switch to an easier mobile with an emergency call button (eg. Doro phone); an easier remote for the TV; a GPS Buddi Tracker; a Tile key finder might be a good investment for later on. See <https://meetadam.co.uk/catalogue> and Pillar One. Would requesting a MEC community alarm provide reassurance in the event of falls? <https://www.falkirk.gov.uk/services/social-care/care-at-home/mecs.aspx>
- **HOSPITAL SUPPORT:** given the current pandemic and confusion around visiting rights and treatments, it's important to know how to access additional support at hospital and what can be done to prepare for a hospital stay.
- **GETTING TO KNOW ME:** this document can help care and support staff get to know you or your loved one quickly in order to tailor their care better. It is not an extensive document and can be completed within a short time frame. <https://www.alzscot.org/our-work/dementia-support/information-sheets/getting-to-know-me#:~:text=It%20asks%20for%20brief%20information,they%20like%20to%20do%20for>
or [https://www.eddn.org.uk/wp-content/uploads/2017/09/Getting to know me form - editable.pdf](https://www.eddn.org.uk/wp-content/uploads/2017/09/Getting_to_know_me_form_-_editable.pdf)
- **BUTTERFLY SCHEME:** Make sure that you have registered with the **Butterfly Scheme** whereby a discreet butterfly symbol is placed above the bed of a patient to indicate they might need a little extra support or prompt with eating, drinking, medication etc. It is likely that the Community Psychiatric Nurse will have done that for you at your first meeting but it's useful to check.



- **HOSPITAL WHITE BOARDS:** use these boards to write short notes to staff about those details of care which make a difference. Don't write anything private – but “No coffee please” or “John takes one sugar in tea”
- **EIO CARDS:** carry details pertinent to the card carrier if they are unable to answer questions posted by medical and emergency staff. PDS Group participants, please see information packs (5) & <https://eiocard.com/> . Referrals available from your Link Worker or Dementia Advisor.
- **Carer Liaison Officer Katie Baker** (Carers Centre) will advise families on navigating the processes and systems of the hospital, including visiting rights and discharge procedures. Katie can be contacted on Mob: 07545502405.
- **ISSUES ON THE WARD? STRUGGLING TO VISIT/SPEAK TO STAFF?:** if you cannot resolve these directly with the Charge Nurse, your Link Worker can request additional support from **Dementia Nurse Consultant Shona Mackie and her team**, who support families whose loved one is in hospital. Please talk to your Link Worker.
- **PASTORAL AND CHAPLAINCY SUPPORT** is available in Forth Valley Royal. Call 01324 566000 for details. Email: fv.spiritualcare@nhs.scot

PILLAR FIVE: Planning for Future Care

Definition: Planning ahead, making decisions in a timely manner. Having meaningful discussions with your loved one can help ensure that their wishes are known and acted upon

A question that is often asked of Link Workers, is: ‘Who is responsible for care once I/your loved one has been discharged from the Community Mental Health Service?’

Unlike diabetes, or cardiac issues, there are no regular check ups scheduled for people living with dementia. So the person who is ‘in charge’ is you. If you have a medical concern, call your GP. If you need day:day support, get in touch with Social Services. Being the one in charge is both a good thing (you get to decide); and a bad thing (you can’t always help when you need it most). And that’s why, it’s good for both the person with dementia and their families to plan.

Plan for the short term (what might I need, six months – a year ahead?) and plan for the long term. What are your care preferences in the later stages of the illness? Most people want to stay at home – and that’s fine. But you need to plan ahead and have those important discussions with your family.

Due to the progressive nature of dementia, it’s likely that a person’s capacity will reduce over time. However, **the ability to make informed choices and decisions is time and decision specific.** Someone might not be able to evaluate road risk but be perfectly capable of choosing what they wish to watch on television or which activities they enjoy.

A good understanding of your loved one’s needs and wishes is essential to ensure that they are supported to make decisions about their care and day to day life for as long as possible. If care preferences are well known and documented (even informally), it might help to avoid conflict among family members or attorneys later on.

- **ACCESSING SERVICES AND ARRANGING A COMMUNITY CARE ASSESSMENT:** at some point, you might require the support of the local Social Work department to recruit paid care support. You will need a Community Care Assessment or Single Shared Assessment which can either be submitted to Social Services by your Link Worker after discussions with the person with dementia and/or you, their carer.

Or you can request help via your GP, or ask for an assessment directly. In Falkirk T. 01324 506070. (See also **Flow Chart** entitled '**Help!**' at the end of the Directory)

- Social Workers do their best, but their caseloads are high. **It is really helpful if you can record what is happening in a daily diary to identify patterns and needs; and prepare for meetings and assessments beforehand by listing the key areas in which you need support.** Something like a bullet list on one side of A4.
- **It might be that grab rails in the bathroom would help;** or a higher toilet seat or that you need **someone to come and assist with personal care,** medication prompt or meal preparation. Perhaps social isolation is the issue and **day care support** at a specialised day centre might help. There are several options available in Forth Valley, each of which is slightly different, each of which has different eligibility criteria. A Community Care Assessment or Single Shared Assessment via any of the above, is the route to go. The emphasis is always on prompting and supporting the skills that remain; rather than 'taking over'. Sometimes we all need a little help from time to time and carers and families might struggle to do it all. Accepting a helping hand from professionals can boost independence and ensure that you remain at home safely.
- **A first package of care is usually very 'light touch'. i.e. a medication prompt, assistance with showering or bathing once a week.** The idea is to introduce increases in care support slowly and at a pace which is acceptable and least intrusive. It is rarely perfect at the outset. Hopefully, the agency providing the care will want to work with you, to provide the service that suits you. Compliment them on what they do well but don't be afraid to point out the things that would make it better. Be prepared to top up what is available using Attendance Allowance.
- **SELF DIRECTED SUPPORT (SDS):** is a means to arrange formal support and care which might offer you more choice as to times, the agency or Personal Assistant and the type of support that you need. It can cover all your support inputs or co-exist with other supports.

Ask your Link Worker, Carer Support Worker or contact **SDS Forth Valley** for a better understanding of how SDS works and its implications. Can you be employed by the person you care for as a formal carer? Not if you are their Power of Attorney. SDS Forth Valley provides free aid and assistance to help you to understand and manage your individual budget and guidance to help you build a service to meet the agreed health and social care outcomes. <https://sdsforthvalley.org/>

- The **HEALTH AND SOCIAL CARE PARTNERSHIP** has created a new website which allows people to access information, advice and support for health and well-being, including taking a self-assessment test, which may help you find the solution for you and your loved ones needs. <https://livingwellfalkirk.lifecurve.uk/>

- **WHERE TO START? Your Link Worker can support you if planning for the future is something that you would like to do and can do.** Prompting conversations about the future is a sensitive issue so understanding the correct format for your loved one is key.

Here are a few examples of where you might start:

- **Life Story** – a good way to capture important events, stories etc. <https://www.dementiauk.org/for-professionals/free-resources/life-story-work>
- **Planning for What if....?** (Also Pillar Four) It's always good to plan for an emergency. See https://www.enable.org.uk/wp-content/uploads/2017/07/ENABLE_Emergency-Planning-Workbook_17.12.15_Proof.pdf
- **Anticipatory Care Plan:** this is a more extensive document which might need input from your health care professionals or support from your Link Worker. Some of the questions contained within the document can be difficult (e.g. Do Not Resuscitate and Do Not Attempt Resuscitation Orders) and must be approached sensitively. <https://www.nhsinform.scot/campaigns/anticipatory-care-planning>
- **PLANNING IS TOO UPSETTING:** sometimes, there is never a right time. And there is no point distressing loved ones, just because 'it's on the list'. You/the Power of Attorney are the experts, the best people to know whether planning is helpful and whether there is a right time. If that is the case, accept that you are doing your best by being there, and by supporting your loved one in many different ways.

Accessing advice and support from your Link Worker or the wider dementia community might also help you understand their position and give you the strength needed to continue in your caring role.

- **I CAN'T CARRY ON: knowing when you cannot continue to care because it is not safe for you or not safe for the person you care for, is one of the most painful decisions that carers face.** Choosing a good care home and understanding the financial assessment process

can be daunting. Age Scotland has excellent publications regarding the process. It also has a small checklist booklet giving tips on what to look out for when you visit prospective homes. See also <https://careinfoscotland.scot/topics/care-homes/paying-care-home-fees>

- **CHANGING YOUR CARING ROLE: the caring doesn't stop when the person you love moves to a care home.** It might give you the chance to be less of a carer and more of a wife, a husband, a daughter or son if someone else takes on the practical management of care.

Alzheimer Scotland has a guide for carers called '**Letting Go Without Giving Up**' which you might find helpful. See www.alzscot.org/information_and_resources and search for '**Letting Go**'

- **STAYING AT HOME:** most people living with dementia wish to stay in their own homes for as long as possible. Unless there are difficult medical complications, **caring for someone at home right to the end is perfectly possible** as long as you have good support and access to the right equipment (eg. hospital bed, riser etc) should that be necessary.
- **Make an appointment with your GP and/or Community Nurses** to understand whether this is feasible, what it might entail for you as a family and who else might be able to offer support. (eg. Community Services from the local hospice)

And finally.....

RESEARCH & PARTICIPATION IN TRIALS, CONFERENCES: volunteering, speaking up and speaking out

Introduction: “How can I get involved in research about dementia?”

Research into dementia is accelerating and expanding rapidly. It’s an exciting field, and there is now a real buzz nationally and internationally. It’s not for everyone and not everyone is suitable for every trial. However, some of you might want to get involved in research or find out more, but just don’t know where to start.

So here’s how.

The Neuroprogressive and Dementia Network (NDN) is funded by the Chief Scientist Office to promote a culture of clinical research in dementia across Scotland and improve recruitment to high-quality studies from both urban and rural areas.

The Network has grown from four centres in Grampian, Greater Glasgow & Clyde, Lothian and Tayside to now cover the whole of mainland Scotland.

NDN is driven to engage, involve and support people with lived experience of neuro-progressive conditions such as dementia, and to offer the opportunity to participate in research.

There are a number of ways you can take part.

See: <https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/get-involved>

- **Contact Join Dementia Research** and sign up online either for yourself or on behalf of your loved one at www.joindementiaresearch.nihr or call the Alzheimer Scotland helpline **Tel. 0808 808 3000**, who will help you to sign up over the phone.

- **Contact the NDN through their friendly administrator Neil Wright** at Tay.NDNTayside@nhs.scot or by phone 01382 423086 ext. 55996 and fill in our '**Permission to Contact**' form. NDN will then get in touch locally if there are any studies for which you might be suitable. There is a screening process to ensure the best outcome for the trial and for each volunteer.
- **Would you like to be a 'Partner in Research'?** You can become engaged whether you are a person with dementia, a carer or someone with an interest in the disease.

You can help shape future research, give comments on leaflets or academic papers, even talk at a conference or help man a stand.

Please follow the link to find out more information about being part of 'Partners in Research' <https://youtu.be/aNACIbDrjZc> or additionally contact Tay.ppipartners@nhs.scot or phone Neil Wright on 01382 423086 ext 55996.

- **Would you want to donate your brain tissue after death?** This helps researchers understand dementia at a cellular level. You can do this by phoning the Alzheimer Scotland number on 0808 808 3000 or contact us at Tay.NDNTayside@nhs.scot.
- **Do you have a loved one in a care home, a contact within or work in a care home?** The researchers at ENRICH (Enabling Research in Care Homes) would love to hear from the care home to tell them how they can become involved in research. Contact Tay.enrichscotland@nhs.scot.



The Boy, The Fox, The Mole and The Horse

Laura's Checklist of Essentials

Laura's Checklist is a short summary of things that you might need to know if you have just been diagnosed with dementia. You might not need them now: you might never need them. Everyone is different. But knowledge is power!

Use the boxes to the left of the items to check things off as you complete them.

MONEY ESSENTIALS — KNOW YOUR ENTITLEMENTS!

- ATTENDANCE ALLOWANCE:** If you don't already receive PIP or DLA, you have a diagnosis and need some support, and you're over 65. ask about Attendance Allowance. (DLW /Carers' Centre/Citizens Advice Bureau)
- CARERS' ALLOWANCE:** if you receive PIP or DLA or Attendance Allowance and someone helps to support you, they might be entitled to Carers' Allowance. Check at the Carers' Centre T. 01324 611510
- COUNCIL TAX REBATE:** if you have a diagnosis of dementia, and you live alone or with one other person and you receive a benefit, you will be entitled to either 100% or 25% rebate on Council Tax.
- PENSION CREDIT:** if your income is low, you might be entitled to Pension Credit.
- ENERGY TARIFF:** you can register for Priority Services in case of a power cut; and for tariff checks to ensure that you have the best rate. T. 0330 1010 167

LEGAL ESSENTIALS — STAY IN CONTROL

- POWER OF ATTORNEY** ensures that your wishes are respected in financial and welfare matters all your life. It is different from a will but like a will should be completed long before you need it. Legal aid is more available than you think.

- GUARDIANSHIP** if you don't have Power of Attorney—(but it's much more expensive)
- DVLA:** everyone who has a diagnosis of dementia must inform the DVLA if they are still driving. You might be able to carry on driving for a while under an annual licence. If you continue to drive and don't tell DVLA, you could face a £ 1000 fine.
- ADVANCE PLANNING BOOKLET:** take time to write down the people and things that are most important to you so that you have a formal record
- WILL:** if you haven't already done so, wills can be done at the same time as Power of Attorney. You cannot make a will if you lack capacity and an Attorney cannot make a will for you. Don't leave money to the state unintentionally.

GETTING OUT AND ABOUT

- BUS PASS:** free for 60s+ - and you might be entitled to a free companion pass
- TAXICARD:** now available to people who have a diagnosis of dementia with a referral from Alzheimer Scotland. Have you recently given up driving? This might be helpful to keep you connected to the groups that you enjoy.
- BUDDI TRACKER:** for those who enjoy getting about on their own but take the wrong turn occasionally.
- DORO Secure Phones:** phone with GPS locator and Alert Button

COMMUNITY CONNECTIONS & PEER SUPPORT

- HOW DO I FIND OUT WHAT'S ON?** Take a look at www.alzscot.org. Or download the Alzheimer Scotland app.
- COMMUNITY CONNECTIONS:** Family, friends, theatre, golf, walking, lunch clubs—it's good to stay active. Can we put you in touch

with a group that you might enjoy?

PEER:PEER SUPPORT: Alzheimer Scotland Falkirk hosts two weekly cafes in Falkirk and Bo'ness. It also offers a guided weekly walking group, a 'Try Something New' group and Brain Gym. Some are online; some are in the community. Ask your Link Worker or Dementia Advisor. Our groups are lively, friendly and inclusive!

AT HOME

DESIGN: look at your home with fresh eyes. Do you need to adjust the lighting? Check that there are no trailing wires, rugs or trip hazards? Visual perceptions can change with dementia. Do you need something to hold onto in the bathroom e.g. grab rails? Magiplug to prevent accidental flooding? ADAM (About Digital and Me) <https://www.alzscot.org/adam>

WHITEBOARDS: are useful reminders to keep everyone on track with appointments.

DIET: tastes can change with dementia. If you find that you prefer more sweet things, explore new taste sensations with fruit, honey, yoghurt. Drink as much water and dilutant juice as you like. Hydration helps concentration!

SUPPORT AT HOME

HOME CARE/SELF DIRECTED SUPPORT (SDS): if you need a little more support at home, your Link Worker can help with a referral to Social Services or care agencies

YOUR DIRECTORY: Useful Contacts & Addresses

Think of yourself as the conductor of an orchestra. There are many musicians in an orchestra and not all are playing all the time. But you do need to know who does what and how to find them when you need them.



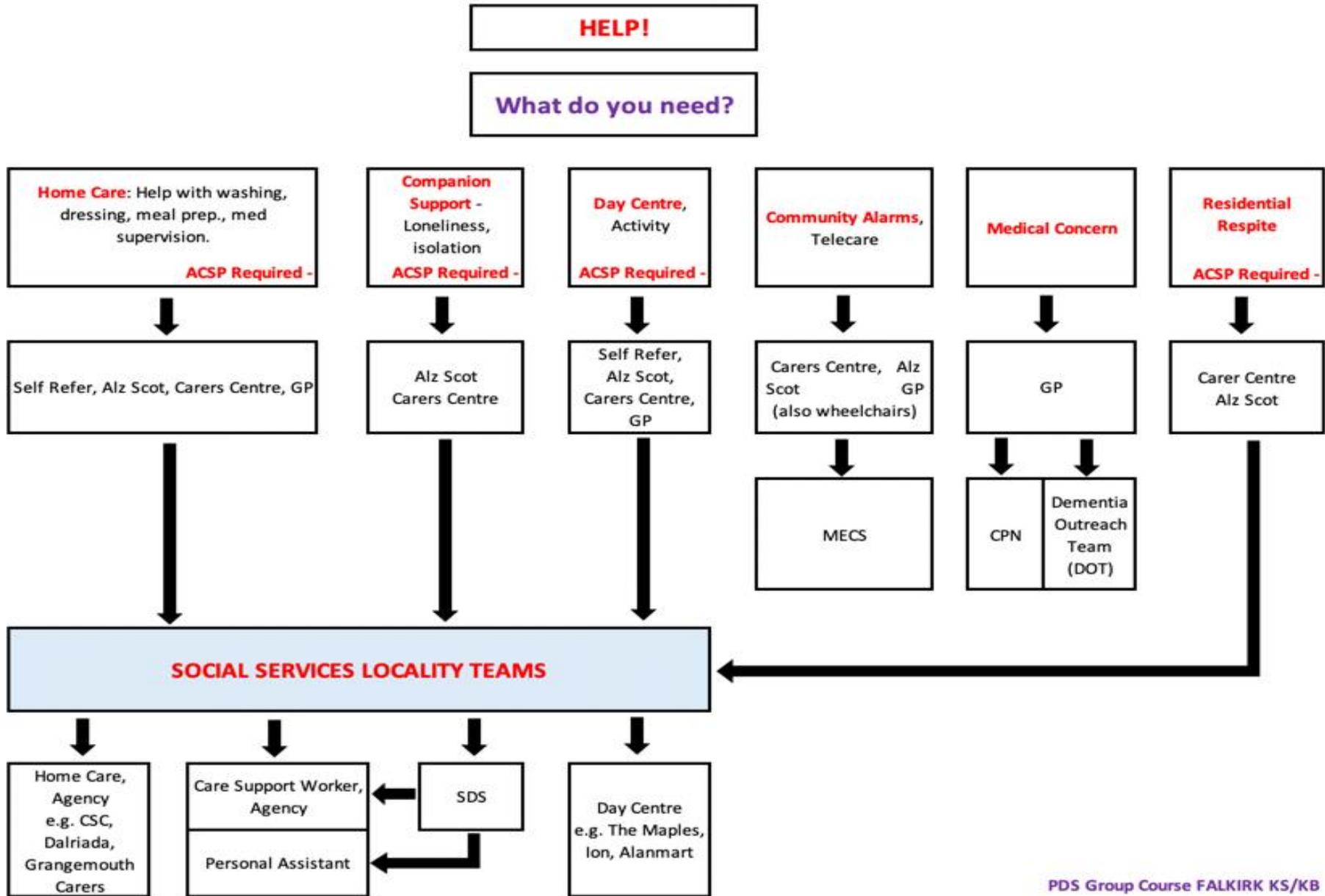
Every carer will find it helpful to compile their own directory of names and addresses that are key in building in up their own network of support.

| NAME | CONTACT | FOR |
|--|---|---|
| <u>GP</u> | | |
| <p><u>NHS Inform</u> For all conditions and general health information</p> <p>Covid 19: symptoms, information, what to do</p> | <p>https://www.nhsinform.scot/illnesses-and-conditions/brain-nerve-and-spinal-cord/dementia</p> <p>https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/coronavirus-covid-19-general-advice</p> | <p>General information about dementia</p> <p>Information about Covid-19</p> |
| <u>Dentist</u> | | |
| <u>Pharmacist</u> | | |
| <u>Taxi company</u> | | |
| <u>Care Agency</u> | | |
| <u>Companionship support</u> | | |
| <p><u>Social Work Department</u> Duty Worker</p> <p>Emergency Duty Team (out of hours and weekends)</p> | <p>01324 506070 (Falkirk)</p> <p>01259 727010 (Clackmannanshire)</p> <p>01786 404040 (Stirling)</p> <p>01786 470500</p> | <p>For: Home care support, companionship support, referral to Day Centres, Self Directed Support assessment, care home transition, at home equipment such as grab rails</p> |
| <p><u>Alzheimer Scotland (Falkirk HQ)</u> Local & national dementia news</p> <p>Donna Paterson (Dementia Advisor)</p> | <p>01324 559480</p> <p>https://www.facebook.com/alzscotFalkirk/</p> <p>01786 831171 / 07733 302772</p> | <p>For: Post Diagnostic Support (PDS); advice re living with dementia; access to community/activity groups online and local post Covid; referral to Day Care post Covid; activity packs for people living with dementia;</p> |

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|--|---|---|
| <p>National 24 Hour Helpline (free)</p> | <p>0808 808 3000</p> | <p>Blue Badge, EIO card, fire safety check & SP Energy referrals, Council Tax rebate SMI etc;</p> |
| <p><u>Carers Centre, Falkirk & Clackmannanshire</u></p> <p>Local news and support for carers Carers Centre Falkirk HQ</p> <p>Catherine Brunton, Training Co-ordinator PDS Group Co-host</p> <p>Lyn MacKay, Benefits Advisor, CAB</p> <p>Katie Baker, Hospital Liaison worker</p> | <p>https://www.facebook.com/fccentralcarers</p> <p>01324 611510</p> <p>M: 07857 671347</p> <p>Catherinebrunton@centralcarers.co.uk</p> <p>Lyn@centralcarers.co.uk</p> <p>Katiebaker@centralcarers.co.uk</p> | <p>For: Adult Care Support Plans (ACSP) Young Carers' Statement Care Support Groups, 1:1 care support & care with Confidence Training sessions Carers' Card ID (concessions) Creative Break funding, advice on Carers Rights</p> <p>Assistance with benefits and entitlement applications</p> <p>Support re discharge, complaints FVRH & other local</p> |
| <p><u>Department of Works and Pensions</u></p> | <p>0800 731 0122</p> | <p>For: advice on Attendance Allowance, Carers Allowance</p> |
| <p><u>Community Mental Health Team for Older Adults</u> Falkirk Community Hospital</p> <p><u>Dementia Outreach Team</u> (Referral via GP)</p> | <p>01324 673808</p> | <p>For: Referral to CPNs (Community Psychiatric Nurses) regarding concerns about decline in cognition or wellbeing and request for assessment of presentation.</p> <p>For: sudden changes in baseline behaviour not explained by urinary infections, general infections or delirium</p> |
| <p><u>MECS</u></p> <p>(Mobile Emergency Care Service)</p> | <p>01324 506520</p> | <p>For: Falls and safety alarms if required, referral via AlzScot, Carers Centre, Social Services, Occupational Therapists</p> |

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| <p>Office of the Public Guardian Hadrian House, Callendar Business Park, FK1 1XR</p> | <p>01324 678300</p> | <p>For: advice and support relating to role of Attorney</p> |
| <p><u>Advocacy</u> 1 The Bungalows, Larbert FK5 4SZ</p> | <p>01324 557070</p> | <p>For: An independent Advocacy service, protecting your rights and getting your voice heard</p> |
| <p><u>Home Energy Scotland</u></p> | <p>https://www.homeenergyscotland.org/</p> | <p>For: A one stop shop for energy advice, grants for new boiler schemes. Please speak to your Link Worker for referral</p> |
| <p><u>Alzheimer Scotland Counselling Service</u></p> | | <p>For: 6 counselling sessions with trained counsellors to support people with dementia or carers. Please speak with your Link Worker to discuss the referral process. Counselling, if appropriate, provides additional support and can relate to any issue. An entirely confidential service.</p> |
| <p><u>Exercise, balance classes and so much more..</u></p> | <p>https://www.falkirkcommunitytrust.org/whats-on/strength-and-balance/</p> | <p>For: always good to look around and see what's available locally. This is a good place to check out exercise classes, arts and drama.</p> |
| <p><u>Seated exercises, NHS approved, demonstrated by young Heather Bryson</u></p> | <p>https://www.youtube.com/channel/UCUKFEBgehYIY6qo7qvS-Wyg</p> | <p>For: a series of chair exercises which can be done in the comfort of your own home. NHS approved and led by cheery 8-year old!</p> |
| <p><u>Brain Health Scotland</u></p> | <p>https://alzscot.orcha.co.uk/about</p> | <p>For: a health app library</p> |
| <p><u>Dial a Journey</u></p> | <p>http://www.dial-a-journey.org/</p> | <p>For: a door:door service for those who are unable to use conventional transport or if you have relinquished your licence. Includes hospital transfers. Scheme is free to join.</p> |

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PDS Group Course FALKIRK KS/KB



Resilience is core to living well with dementia – the ability to have confidence that one bad day is just one bad day, and that tomorrow, is full of promise.

It takes enormous personal courage to remain positive even when your world appears to become more closed and less familiar. And it goes without saying that carers need resilience in spades.

Somehow we're often programmed to remember negative things.

Learning resilience is perhaps a way to go beyond survival to be able to practise joy – and happiness is the best decelerator for dementia that there is.