



RENFREWSHIRE CARERS CENTRE
A Lifeline for Carers in Renfrewshire



Dementia Information Booklet for Carers

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Introduction from the Carers Centre Manager

Welcome to the Renfrewshire Carers Centre Dementia Booklet.

Renfrewshire Carers Centre is a one stop shop for unpaid Carers, established by Carers for Carers. We can assist you with all aspects of your caring role and support you through your caring journey. Our staff are caring, experienced and knowledgeable, as well as being Dementia Friends. Many of our staff are Carers or have been Carers previously. We are passionate about supporting Carers and want to ensure Carers are well informed, involved, supported and empowered.

Caring for someone with Dementia can be a demanding, intense, and at times, a stressful journey, but it is also filled with meaningful and rewarding moments. Many Carers speak about both the joys and the hardships of looking after a loved one with Dementia. While they often grieve the inevitable losses that come with the illness, they also develop a deep appreciation for the person and the shared activities, memories, and social connections they can still enjoy together.

The challenges Carers face evolve at different stages of the illness. Adapting to the diagnosis and dealing with the changes can be very stressful. However, being well prepared and understanding the type of care that may be required can assist in your caring journey. It can also be helpful to have a supportive network of family and friends who understand how to support you.

Seeking help and figuring out what works best for you and your loved one can be difficult, however there are many resources available to make life easier for both of you. Our information pack offers guidance on the various types of support you can access.

Please get in touch if we can assist you in any way,
Best wishes,
Diane



What is Dementia?

Knowing more about Dementia can help you better support a person with the condition. It can help you come to accept their diagnosis and changes they may go through.

Dementia is a group of symptoms. It's caused by different diseases that damage the brain. The symptoms get worse over time and include:

- memory loss
- confusion and needing help with daily tasks
- problems with language and understanding
- changes in behaviour

Dementia isn't a natural part of getting older. The diseases affect the brain in different ways, resulting in different types of Dementia. The most common types of Dementia are:

- Alzheimer's disease
- Vascular Dementia
- Dementia with Lewy bodies (DLB)
- Frontotemporal Dementia (FTD)
- Mixed Dementia

In Scotland, an estimated 90,000 people have Dementia. Dementia can affect a person at any age but it's more common in people over the age of 65.

Health and Social Care Services

It is important that the person has had a proper diagnosis. If not, speak to your doctor. Tell them about any changes in the person's condition. You can also ask for a referral to a specialist and about other services which may be appropriate for you such as:

- Community mental health or community psychiatric nurses give practical help and advice on mental health.
- District or community nurses can provide some nursing care at home.
- Occupational therapists can give advice and support on the activities of daily living.
- Physiotherapists can help improve the person's mobility, independence and reduce their risk of falls.

Day hospitals provide medical assessment, rehabilitation, and occupational therapy. The person with Dementia has a right to an assessment from their local social care service, to work out what their needs are and what services would help, for example this may include arranging respite care. There is no charge for an assessment but there may be charges, or a contribution required for some services. As a Carer, you also have the right to an assessment of your needs (Adult Carer Support Plan or Young Carer Statement), and to be offered support from various services, many of which are free of charge.

NHS Inform | Scottish health information you can trust:

<https://www.nhsinform.scot/>

Renfrewshire Health and Social Care Partnership Adult Services Response Team | Request an assessment of the person you care for:

<https://www.renfrewshire.hscp.scot/article/5040/Adult-Social-Care>

Renfrewshire Carers Centre | Request an Adult Carer Support Plan or Young Carer Statement:

<https://renfrewshirecarers.org.uk/contact/>

Adult Services Referral Team (ASeRT)

If you think that you or the person you care for needs care and support, you can contact ASeRT, the referral service for Renfrewshire HSCP. A referral will be made from ASeRT to your local adult services social work duty team to allow for a screening process to take place. This will determine whether you or the person you care for meets the eligibility criteria for a formal assessment of your needs.

Examples of the services you may be able to access following assessment include: care at home, occupational therapy, rehab and enablement, sensory impairment services, and telecare.

- They know that asking for care or referring someone you think would benefit from care isn't always easy, especially if you're unsure of the types of care available or necessary.
- Their team are experienced as the first point of contact for care referrals and will make sure your unique situation is handled confidentially. They will work with you to get as much helpful information as they can (such as medical conditions, GP contact details, and personal circumstances), answering any questions you have.
- You can make a care referral online, by email, over the phone, or by post. Anyone can make a referral including family members, hospital nurses, social workers, neighbours, and a person can also refer themselves.

- They will then pass your referral on to the appropriate care service to ensure that the right care is given at the right time.
- They will respond to care referrals within 1 working day and make sure it is passed to the relevant care service swiftly.

Contact ASeRT on 0300 300 1380 or adultservicesreferral.sw@renfrewshire.gov.uk

Caring for Someone with Dementia

Dementia doesn't just affect the person with the illness - it affects the people most involved in their day-to-day care and support. Whether you are a partner, spouse, son, daughter, grandchild, or friend, your role as a Carer brings challenges and changes in your relationship. You don't have to do it alone - there is help and support for you, as well as the person you care for.

You may not think of yourself as a Carer, particularly if the person with Dementia is a partner, parent, or close friend. But both you and the person with Dementia will need support to cope with the symptoms and changes in behaviour. It's a good idea to:

- make sure you're registered as a Carer with your GP
- ask for an Adult Carer Support Plan or Young Carer Statement
- check if you're eligible for benefits for Carers
- find out about support such as information, training and support groups that could help you

Sharing your experiences with other Carers can be a great support as they understand what you're going through. You can also share tips and advice. Taking regular breaks can help you to look after yourself and better support you in caring for someone with Dementia. Family and friends may be able to provide short breaks for you to have time "just for you".

Support for Carers in Renfrewshire: <https://renfrewshirecarers.org.uk/adult-services/>

Find a GP practice:

<https://www.nhsinform.scot/scotlands-service-directory/gp-practices>

Renfrewshire Citizens Advice Bureau | Information about benefits and money advice:

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

Advice Works, Renfrewshire Council Website | Where to get money and benefits advice:

<https://www.renfrewshire.gov.uk/article/2103/Where-to-get-money-and-benefits-advice>

Rethink Dementia - Scottish Government Campaign

A government-backed campaign is urging people in Scotland to shift the narrative around dementia to help people diagnosed with the condition stay socially active and connected. The campaign challenging people to 'Rethink Dementia' has been launched by the Scottish Government in partnership with Scotland's local council body COSLA: <https://www.cosla.gov.uk/>

In Scotland, Dementia currently effects an estimated 90,000 people, 3,000 of whom are under the age of 65. When a friend or relative is diagnosed with dementia, it's natural not to know what to do. But, helping someone stay connected and socially active can help them stay well for longer. It's time to rethink dementia:

<https://www.nhsinform.scot/campaigns/rethink-dementia/>

Your Rights as a Carer

The Carers (Scotland) Act 2016 outlines some new and important rights which aim to increase support for both adult and young Carers to enable you to continue to care, if they wish to do so, in better health and to have a life alongside caring. Some of the key rights contained within the act include:

- Adult Carers have the right to an Adult Carer Support Plan
- Young Carers have the right to a Young Carer Statement
- Carers have the right to support to meet any 'eligible needs'
- Carers have the right to be involved in Carer services
- Carers have the right to be involved in hospital discharges of the person they care for.

The Carers' Charter summaries the key provisions within the Act:

<https://www.gov.scot/publications/carers-charter/>

Adult Carer Support Plan and Young Carer Statement

If you care for someone, you can have an assessment to see what might help make your life easier. This is called an Adult Carers Support Plan (ACSP) if you are aged 18 or over and a Young Carer Statement (YCS) for people under 18. An ACSP/YCS might recommend things like:

- someone to take over caring so you can take a break
- training on safer handling of your cared for
- putting you in touch with local support groups so you have people to talk to

An ACSP/YCS is free, and Carers have a right to one. Find out more about Renfrewshire Carers Centre's Adult Carers Support Plans and Young Carers Statements and how to get one:

<https://renfrewshirecarers.org.uk/adult-carers-support-plans/>

Advocacy

The Renfrewshire Carers Centre Advocacy Service

The Carers Centre provides 1:1 Advocacy to Carers who are experiencing issues as a direct result of their caring role.

The service aims to ensure that your views are heard and provide accurate information to allow you to make informed choices about your caring role and issues affecting you.

How can Advocacy help?

Advocacy may be of help when you are experiencing difficulties with the following:

- Social work, health, and other support services
- Hospital discharge planning
- Transition from home into long term care
- Attendance at meetings/reviews
- Housing

You First Advocacy

You First is an independent advocacy service for adults within Renfrewshire who are receiving health and social care services.

Advocacy is about empowering people standing up for and supporting their rights and wishes, taking their side and ensuring that they are being listened to as they engage with services.

You can contact You First on: 0141 849 1229

Scottish Independent Advocacy Alliance

There are independent advocacy organisations across Scotland helping people to have their voices heard in decisions which affect their lives. Independent advocates work in a variety of settings including the community, education, care homes, prisons and hospital settings.

Find your nearest independent advocacy organisation:

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

The Renfrewshire Citizens Advice Bureau - in Carers Centre

In partnership with Renfrewshire Citizens Advice Bureau, a CAB adviser is in our Carers Centre weekly. The following services will be available:

- Benefits check/income maximisation
- Completion of benefit applications (inc. PIP)
- Attendance Allowance etc
- Energy advice including grants
- General consumer advice
- Housing advice
- Complaints

If you would like to book an appointment, please get in touch with us by phone or email.

Post Diagnostic Support

NHS Dementia Post Diagnostic Support Service

Every person with a new diagnosis of Dementia in Scotland is entitled to a minimum of one year of Post Diagnostic Support (PDS) from a named person who will work alongside the person and those close to them.

The 5 Pillars Model provides a framework for people living with Dementia, their families and Carers with the tools, connections, resources and plans to allow them to live as well as possible with Dementia and prepare for the future.

Contact the service team on: 01592 643355, Ext 27288

Alzheimer Scotland Dementia Link Worker

Your local Dementia Link Worker can provide five key pillars of post-diagnostic support, flexible to suit your needs:

<https://www.alzscot.org/our-work/campaigning-for-change/current-campaigns/5-pillar-model-of-post-diagnostic-support>

This includes:

- Help to understand the illness and manage your symptoms.
- Support to keep up your community connections and make new ones.
- Peer support - the chance to meet other people with Dementia and their partners and families.
- Help to plan for future decision-making help to plan for your future support.

Living well with Dementia

Dementia can affect all aspects of a person's life, as well as those around them. With the right care, information, and support when you need it, many people can, and do, live well with Dementia for several years. If you need help, don't be afraid to ask for it - from family and friends, professionals such as doctors, nurses, and social workers, and charities like Alzheimer Scotland.

Helping someone with everyday tasks

In the early stages of Dementia, many people can enjoy life in the same way as before their diagnosis. But as symptoms get worse, the person may feel anxious, stressed, and scared at not being able to remember things, follow conversations or concentrate. It's important to support the person to maintain skills, abilities, and an active social life. This can also help how they feel about themselves.

Let the person help with everyday tasks, such as:

- shopping
- laying the table
- gardening
- taking the dog for a walk

Memory aids used around the home can help the person remember where things are. For example, you could put labels and signs on cupboards, drawers, and doors.

Alzheimer's Society | Find out more about how to make your home Dementia friendly:

<https://www.alzheimers.org.uk/get-support/publications-factsheets/making-your-home-Dementia-friendly>

As Dementia affects the way a person communicates, you'll probably find you have to change the way you talk to and listen to the person you care for.

Alzheimer's Society | Read more about communicating with someone with Dementia:

<https://www.alzheimers.org.uk/about-Dementia/symptoms-and-diagnosis/symptoms/communicating-and-Dementia>

Help with eating and drinking

Eating a healthy, well-balanced diet is an important part of a healthy lifestyle for everyone. People with Dementia may not drink enough because they don't realise they're thirsty. This can lead to increased confusion and make the symptoms of Dementia worse. A person with Dementia may struggle to recognise the food and drink in front of them. They may also be unsure how to begin eating.

Alzheimer's Society | Find out more information on eating and drinking from Eating and Drinking:

<https://www.alzheimers.org.uk/get-support/daily-living/eating-drinking>

Help with incontinence and using the toilet

People with Dementia may often experience problems with going to the toilet. Both urinary incontinence and bowel incontinence can be difficult to deal with. It can also be very upsetting for the person you care for and for you.

Although it may be hard, it's important to be understanding about toilet problems. Try to retain a sense of humour, if appropriate, and remember it's not the person's fault. If you're still having problems with incontinence, ask your GP to refer the person to a continence adviser, who can advise on things like waterproof bedding or incontinence pads.

Alzheimer's Society | Find out more information on toilet problems:

<https://www.alzheimers.org.uk/get-support/daily-living/toilet-problems-continence>

Help with washing and bathing

Some people with Dementia can become anxious about personal hygiene and may need help with washing. Washing is a personal, private activity, so try to be sensitive and respect the person's dignity, however, be prepared to stay with the person if they don't want you to leave them alone.

Alzheimer's Society | Find out more information on washing and bathing:

<https://www.alzheimers.org.uk/get-support/daily-living/washing-dressing>

Sleep problems

Dementia can affect people's sleep patterns and cause problems with a person's "body clock". People with Dementia may get up repeatedly during the night and be disorientated when they do so. They may try to get dressed as they're not aware it's night-time. If sleep problems continue, talk to your GP or community nurse for advice.

Alzheimer's Society | Find out more about sleep problems and treatments:

<https://www.alzheimers.org.uk/about-Dementia/symptoms-and-diagnosis/sleep-problems-treatments-Dementia>

Planning for the Future

It's important to plan ahead as a Carer and some of the key things you need to think about are:

- Emergency Care Planning
- Future Care Planning
- Legal matters
- When your caring role comes to an end
- Bereavement

Emergency Care Planning

An Emergency Plan will detail the immediate care needs of the person who's cared for. This includes support needs, daily routine, risks and the contact details of family members and/or friends.

As a Carer, you will be issued with a Carers Emergency Card, which will identify you as a Carer. Should an emergency occur, the Carers Emergency Card will alert services that a plan is in place and health, social care and other support services can be arranged, as necessary.

Renfrewshire Carers Centre | Complete a Carers Emergency Plan:

<https://renfrewshirecarers.org.uk/emergency-care-plan/>

Future Care Planning

This is a record of the person's wishes, developed over time with those close to them and the practitioners who provide their care. It provides them with reassurance that their care preferences are known and will be considered if their condition deteriorates.

NHSGGC | Planning for Care:

<https://www.nhsggc.scot/your-health/planning-for-care/>

Legal Matters

Power of Attorney

You can use powers of attorney to appoint someone you trust to look after your financial affairs (continuing power of attorney) and/or your personal welfare (welfare power of attorney). Having a power of attorney in place doesn't mean you can no longer make decisions for yourself. If your attorney is making decisions on your behalf your wishes must always be considered.

Renfrewshire Health and Social Care Partnership | Power of Attorney:

<https://www.renfrewshire.hscp.scot/PoA>

MSM Solicitors - in our Carers Centre

If you are looking for legal advice, we have a Legal Surgery in our Carers Centre which is held monthly. This will include information about:

- Wills
- Powers of Attorney
- Advance Directives
- Guardianship
- Trusts

Jonathan McNamara from MSM Solicitors and Estate Agents, in partnership with Solicitors for Older People Scotland, delivers this service.

Jonathan can meet you for an initial appointment in the Centre and then, if required, we can book a further appointment for you at home, in the Centre, or at MSM Solicitors' office – whichever is most convenient.

Please get in touch with us to organise an initial appointment.

If you'd like to see what they do, you can click here:

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

Making a will

The absence of a will can cause extra worry, expense, and delay after someone dies. Wills are best prepared by solicitors. Ask the solicitor how much it will cost before you start. Before you see the solicitor, think about what property you have and how it is going to be divided and make some notes. This helps give clear instructions to the solicitor. Choose an executor (a person to manage your estate when you die). Your solicitor may want your doctor to certify that you are still mentally capable enough to make or change your will. Your doctor may charge for carrying out this service.

Citizens Advice | Wills:

<https://www.citizensadvice.org.uk/scotland/family/death-and-wills/wills-s/>

Property

Many people worry about being forced to sell their house if they have to go into a care home. The local authority will not count the value of your house if your spouse or partner still lives there or if a relative aged over 60 or a dependent child under 16 lives there. You should take advice if you are thinking of giving away your house or other property.

Care Information Scotland | Paying care home fees:

<https://www.careinfoscotland.scot/topics/care-homes/paying-care-home-fees/>

When your caring role comes to an end

You can continue to receive support from Renfrewshire Carers Centre for up to twelve months, after your caring role has ended. During this time the Centre can support you to access other community groups or you can become a volunteer with the Centre.

Bereavement

Dealing with the loss of someone you looked after can be particularly difficult. Bereavement support could help you come to terms with it.

Renfrewshire Bereavement Network:

<https://www.renfrewshire.gov.uk/renfbn>

Local Support

Renfrewshire Carers Centre

Alzheimer's Carers Support Group

First Thursday of every month

Check Renfrewshire Carers Centre's 'What's On' Calendar here:

<https://renfrewshirecarers.org.uk/whats-on/>

Renfrewshire Carers Centre Training - Examples of Sessions

Caring for someone with Dementia

Dementia affects the brain, making it harder to remember things or think as clearly as before. It's an umbrella term for over 100 different types of illnesses and disease symptoms. Symptoms of Dementia may include memory loss and difficulties with day-to-day tasks, language and problem-solving.

Topics that are covered:

- Types of Dementia
- How does Dementia affect people?
- Treatments and medications

Dementia - Communication

Communication can be stressful and frustrating at times for people with memory problems.

In this session we discuss:

- How we communicate
- The order in which we learn communication
- Conversation skills and behaviours that are challenging

Dementia Meaningful Activities

We all need purpose in life and the activities we take part in supply some of that purpose. It gives us routine and structure to our life. Everyone wants to feel needed, valued and that we contribute. *In this session:*

- Why do we need activities?
- What activities do for us
- How to encourage involvement
- What are the long-term benefits?
- How to look after yourself

Responding to distress in Dementia

This session will help you:

- Understand what is happening to the person you care for
- Understand that when a person is expressing stress and distress, they can be communicating unmet needs
- Identify the common types, causes and triggers for distressed behaviour
- With how to respond when a person with Dementia is expressing stress and distress (strategies)
- Have knowledge of interventions to alleviate distress
- Recognize the importance of gaining access to professional support

Alzheimer Scotland - Renfrewshire

Supporting people with Dementia, their Carers, families, relatives, and friends at any stage of the illness. The following support is on offer:

- Information and advice
- Day care
- Community activities for people with Dementia and Carers
- Peer support groups

Alzheimer Scotland | Renfrewshire Office:

<https://www.alzscot.org/living-with-Dementia/getting-support/find-support-near-you/renfrewshire-office>

Alzheimer Scotland's 24 hour Freephone Dementia Helpline provides information, signposting and emotional support to people with the illness, their families, friends and professionals.

Contact them on: 0808 808 3000

St Mirren FC Charitable Foundation - Football Memories

Football Memories is a programme run by St Mirren FC Charitable Foundation in partnership with Alzheimer Scotland.

It's open to men and women of all ages at various cognitive stages of Dementia. It's a fantastic way to make new friends and spend time in a safe environment with people going through the same experience and who also share a passion for sport.

Carers are welcome to join and participants are supported by trained, experienced members of staff. This group runs regularly at the SMiSA Stadium and you can check out their info using the link below.

SMFC Charitable Foundation | Football Memories:

<https://smfcfoundation.co.uk/Our%20Programmes/football-memories/>

OneRen - Sporting Memories

Sporting Memories uses memories of sport and physical activity to tackle loneliness, depression, and Dementia. At Sporting Memories, they ensure everyone finds fun, friendship and increased wellbeing with lots of quizzes, games, and fun activities. This project has made such a positive impact to the people of Renfrewshire, helping to reduce loneliness and isolation and they are very proud and excited to be part of the journey.

Sporting Memories Renfrewshire:

<https://www.oneren.org/wellbeing/active-wellbeing/sporting-memories/>

Johnstone & Villages Dementia Friendly Group - Still Here

Still here is a Dementia friendly group for those living with the condition and their Carers. They provide support and entertainment, outings, and events. This group meets regularly and you can find out more info via their Facebook community group.

Johnstone Dementia Friendly Community Group | Facebook:

<https://www.facebook.com/johnstoneDementia>

Links

We have written this information booklet using our own services as well as services across Renfrewshire who support people with Dementia and their Carers. We have provided links where appropriate but want to add them all in one handy place, as well as a few extra resources you may like to check out.

Renfrewshire Carers Centre: <https://renfrewshirecarers.org.uk/>

NHS Inform: <https://www.nhsinform.scot/>

Renfrewshire Health and Social Care Partnership:
<https://www.renfrewshire.hscp.scot/>

Renfrewshire Health and Social Care Partnership | Dementia: https://www.renfrewshire.hscp.scot/media/6019/About-Dementia/pdf/About_Dementia.pdf

Renfrewshire Citizens Advice Bureau | Free, impartial and confidential advice:
<https://www.renfrewshirecab.org.uk/>

Alzheimer Scotland | We are Scotland's Dementia charity: <https://www.alzscot.org/>

Alzheimer's Society: <https://www.alzheimers.org.uk/>

NHS Greater Glasgow and Clyde: <https://www.nhsggc.scot/>

NHS Dementia: <https://www.nhsggc.scot/your-health/heads-up-mental-health-support/mental-health-conditions/Dementia/>

Renfrewshire Council | Money and Benefits Advice:
<https://www.renfrewshire.gov.uk/article/2103/Where-to-get-money-and-benefits-advice>

Citizens Advice Scotland | Carers Help and Support:
<https://www.citizensadvice.org.uk/scotland/family/help-for-adults-in-the-community-s/carers-help-and-support-s/>

Care Information Scotland: <https://www.careinfoscotland.scot>

St Mirren FC Charitable Foundation: <https://smfcfoundation.co.uk/>

Convention of Scottish Local Authorities | The Representative Voice of Local Government in Scotland <https://www.cosla.gov.uk/>

OneRen: <https://www.oneren.org/>

Age Concern Scotland | Working for Older People in Scotland
<https://www.ageconcernscotland.org.uk/>

Your Notes





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enquiries@renfrewshirecarers.org.uk
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Renfrewshire Carers Centre is a Scottish Registered Charity
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