

KNOWLEDGE IS POWER

— FOR CARERS IN WALES —

**A guide for carers of people
living with dementia**



This booklet was written by carers of people living with dementia, for carers of people living with dementia. It includes information and advice that we hope you may find useful.

Knowledge is Power

Knowledge is Power for Carers is about caring for people living with dementia, and has been co-created by carers at the Dementia Services Development Centre (DSDC) Wales, Bangor University.

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Other Booklets in this Series

Knowledge is Power Wales: Handy hints that might help make life a little easier after a diagnosis of dementia.

Knowledge is Power 2: Handy and helpful tips for day-to-day life with dementia.

You can view them online at:

<https://www.bangor.ac.uk/dsdc/resources-to-support-people-living-with-dementia-and-carers>

Adaptions for England & Scotland

Adaptations for people in England and Scotland are also available and can be accessed through Dementia Voices:

www.dementiavoices.org.uk/deep-resources/knowledge-is-power

“ Try to make the most of the services and supports that are available to you. Knowing what is out there really can help you – knowledge is power! ”

Introduction

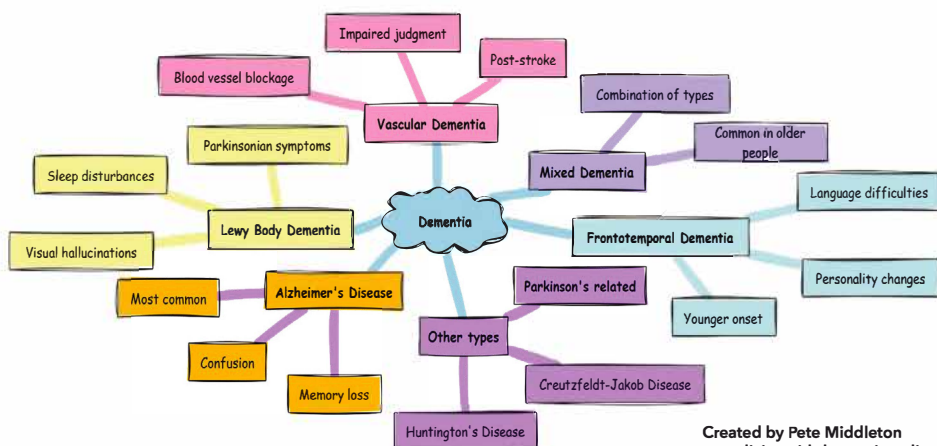
We have found that the most valuable knowledge is what is passed between carers, and we want to share some of this with you. Caring for someone living with dementia can be challenging and overwhelming; but finding the right support can make life easier for you both.

This booklet is designed to provide you with essential information and tips to help you navigate the complexities of caring for someone living with dementia, acknowledging that every experience is unique and there is no "one size fits all" solution.



Understanding Dementia

There are many types of dementia and symptoms can differ. The image below provides a general overview of some of the characteristics commonly associated with different types of dementia (but these can vary).



Created by Pete Middleton
www.livingwithdementia.online

It helps to find out as much as you can about your type of dementia. These websites provide information about types of dementia, support available, and other guides for carers:

www.dementiauk.org/information-and-support

www.alzheimers.org.uk/about-dementia

www.raredementiasupport.org/what-is-rare-dementia

isupportdementiacarers.co.uk

What you can do as soon as you get a diagnosis

Find out what support is available and accept what is offered



This could be through your GP or memory clinic. Ask if you have one point of contact that can help you. Also, contact social services through your local authority and find out what they can do for you. You can access them without a diagnosis too.

Don't leave it too late to find out what support is available – bring in help as early as possible, that's when it will have the most impact.

Set up your own personal network. This means finding out who can help you at different times, and knowing who you can turn to in a crisis. This might include, for example, social services, community psychiatric nurse (CPN), GP, etc – whoever you've got in your circle that can offer to help.



Try not to reject input from services because you feel like you can deal with everything when it is needed, as 'down the line' all the vital help can be difficult and stressful to navigate.



Support from your General Practitioner (GP)



Inform your GP that you are a carer for a person living with dementia. Ask whether they have a carers' registry

Some offer a confidentiality waiver, allowing the carer to speak on behalf of the person living with dementia.

Legal matters



(more in the 'legal and money matters' section)

- ✓ Lasting Power of Attorney (LPA) & writing a will – do this as soon as possible.
- ✓ As a carer, you have a legal right to an assessment of your needs (as does the person you care for).

Peer support from other carers



Joining a group can be scary, but it's worth it. Ask around and find out if your local area has a group of any kind, so that you can be in touch with other carers.

Some groups do separate sessions for carers and people living with dementia so both can get a break from each other.

Talking with and listening to other people in the same situation may provide more advice than anywhere else.

Start a WhatsApp group with other carers. Support, friendship, and advice can be instant, and so valuable.

“

Try different groups and you might find one that suits you. They won't all be your cup of tea.”

”

Support from family and friends



Talking to family and friends after the diagnosis is a good idea. Telling them can be difficult, but knowledge is power!

You cannot expect everyone to react in the same way, and that's OK. Utilise your friends and family and the type of support they might offer - embrace help and support that is offered.

Help your friends and family to help you by talking to them about what they can do. You need to show them how to help you.

“

It can be very hard making time for yourself, but it is true that you can't pour from an empty cup. My friends would come for a coffee at my grandmas to make it easier to still socialise.

”



Which organisations can support you?

Dementia helplines

Wales Dementia Helpline:
0808 808 2235

Dementia UK Helpline:
0800 888 6678

Alzheimer's Society Support Line:
0333 150 3456

Organisations that offer support

These organisations are available nationally, but please also look for organisations in your area. When researching services, sometimes use 'carer' as a keyword rather than dementia.

Age Cymru:

Give information and advice on benefits, health, money, housing, or care.

www.ageuk.org.uk/cymru **0300 303 44 98**

Alzheimer's Society:

For information, advice, and support.

www.alzheimers.org.uk **0333 150 3456**

Carers Trust Wales:

Work to improve support, services, and recognition for anyone who is caring for someone.

www.carers.org **0300 772 9702**

Carers Wales:

Provides advice and information to carers.

www.carersuk.org/wales **029 2081 1370**

Citizen's advice:

Offer advice on benefits and grants, legal and financial matters, rights, work, housing and more.

www.carersuk.org/wales **0800 702 2020**

Cruse Pre-bereavement Support:

Trained volunteers can help people living with dementia and carers to deal with feelings of loss and grief.

www.cruse.org.uk **080 8808 1677**

Dementia Carers Count:

National charity offering in-depth practical and emotional support to friends and family.

www.dementiacarers.org.uk 0800 652 1102

Dementia UK:

Provide support and advice for the whole family, and opportunity to speak to Admiral Nurses.

www.dementiauk.org 0800 888 6678

NHS dementia information service:

Guides you through the time after a dementia diagnosis via a series of emails.

https://bit.ly/dementia_info_NHS

Rare Dementia Support (RDS):

RDS empower, guide, and inform people living with a rare dementia and those who support them.

www.raredementiasupport.org 020 3318 0243

Together in Dementia Everyday (TIDE):

RDS empower, guide, and inform people living with a rare dementia and those who support them.

www.tide.uk.net carers@tide.org.uk

Young onset dementia network:

An online influencing community working collaboratively to improve lives.

www.youngdementianetwork



“

Try not to feel guilty when asking for help.
Nobody is superhuman.”

”

Health and Social Care Professionals – Who they

General Practitioner (GP)

Your first point of contact for health matters and referrals to other services.

Audiologists

Diagnose and treat balance or ear problems.

Clinical Psychiatrists

Diagnose and treat patients with mental health conditions.

Clinical Psychologists

Usually work at mental health trusts, offering counselling, therapy and advice. Among the treatments they offer may be psychotherapy, cognitive behavioural therapy, acceptance and commitment therapy, and relaxation techniques.

Community Pharmacists

Supply prescriptions and over the counter medicines at local pharmacies. They offer advice on medicines, symptoms, and general health matters.

Community Psychiatric Nurses (CPNs)

Are nurses trained in mental health. They see clients in their own homes, outpatient departments, or GP surgeries. They can discuss problems with you and give practical advice and support.

Continence Nurses/Advisors

Specialise in supporting people who have bladder and bowel problems, offering support, assessments, treatment and advice regarding continence.

Dietitians

Work closely with speech and language therapists to advise on diet, help maintain a healthy weight and offer advice on food consistency where swallowing may be difficult.

District Nurses (DN)

Provide support mainly in the patient's own home. They identify health care needs and discuss care plans. They work closely with GPs and palliative care teams.

Geriatricians

Are doctors that focus on the care and well-being of the older adults. They also offer advice on symptom management, access to community services and advanced planning.

Multi-Disciplinary Team (MDT)

Is a term used to describe health and social care professionals working together to provide care or support (this could include any/all of those listed here).

are and how they can help you

Neurologists

Are medical doctors who specialise in diagnosing and treating diseases of the brain, spinal cord, and nerves.

Occupational Therapist (OT)

help people continue daily routines with as much independence as possible. They can offer advice on reducing risk of falls, fatigue management, moving, handling and equipment, and adapting your home.

Orthoptists and Ophthalmologists

Diagnose and treat eye movement disorders and visual impairments.

Palliative Care Team

Includes doctors, nurses, social workers, dietitians, and anyone else involved in a person's care. They can offer support for symptom management and planning for the end stages of illness.

Podiatrists

Take care of people's feet to help them remain mobile, prevent falls and promote independence.

Physiotherapists (Physio)

Work to promote physical activity and maintain mobility and independence for as long as possible, as well as reducing the risk of falling. They can give carers advice on the safest way to carry out daily activities.

Social Workers

Enable access to appropriate care and support for you and the person you are caring for. They also offer advice on needs assessments, respite and residential care (they will often be your 'go to' person for further advice and support).

Speech and Language Therapists (SLT or SALT)

Can help with speech, language, communication, and swallowing difficulties.



Legal and money matters

Carer entitlements



You may be entitled to Carer's Allowance, Carer's Credit (protecting gaps in your National Insurance record), or other financial support. The following can help you:

Turn2us: Provide advice and support on financial matters, and help you find out what you are entitled to.

www.turn2us.org.uk

Citizen's advice: Offer advice on benefits and grants, legal and financial matters, rights, work, housing and more.

www.citizensadvice.org.uk/wales

0800 702 2020

Pensions



Depending on the scheme you might be able to take your pension early and/or withdraw a lump sum.

You can fill in an 'Expression of Wishes' form that tells your pension provider who should receive your pension should you pass away before retirement.

Becoming an appointee



You can become an appointee for the person you care for, while they have mental capacity. This allows you to manage only money matters and/or receive benefits for them. This is different from an LPA (see below). Contact the Department of Work and Pensions (DWP), or visit:

www.gov.uk/become-appointee-for-someone-claiming-benefits

Make a will



A will lets a person decide what happens to their money, property and possessions after their death, and ensures their wishes will be carried out. Without a will, things will be legally and financially challenging for those left behind. The will can also describe funeral wishes.

Advanced care directives ('living will'/'advance decision')



This is a legal document where you specify what actions should be taken for your health if you are no longer able to make decisions for yourself. This is a good time to discuss wants and hopes for end-of-life care, including conversations around treatment options and funeral plans.

“

At the beginning, you need to have the very difficult conversations. It's a must.

”

Lasting Power of attorney (LPA)



This is a legal document that allows decisions to be made on someone's behalf. It should be drawn up as soon as possible, while a person has capacity. There are two types - 1) health and welfare, 2) property and financial affairs. This is important and can be done for both you and the person you care for. You can do this online or via a solicitor (there is a fee, but reduced if in receipt of certain benefits).

www.gov.uk/power-of-attorney

If no LPAs are in place, you are at risk of decisions being made without you. In this case you would need to apply to the court of protection for deputyship if the person has lost capacity.

www.gov.uk/become-deputy

If you are a working carer, you have legal rights



Telling your employer is important. Ask about the company carer policy and have conversations about flexible working and how they can support you. To find out more about your rights at work:

www.carersuk.org/help-and-advice/work-and-career

“

Make sure that things get sorted early - I didn't but wished I had

”

Legal and money matters

Carer's needs assessment



If you provide unpaid care and support for someone living with dementia, you are legally entitled to have an assessment of the support you need to help you in your caring role and to support your personal well-being.

This assessment should consider: the extent you are able and willing to provide care; your wishes or need to work and participate in education, training, or leisure activities that are important to you; emergency care planning; your eligibility for Carer's Allowance. Contact your local authority or a carers charity.

PIP (Personal Independence Payment)



This is a government provided allowance for people under state pension age and is not means tested. You can apply for PIP for the person who you care for. It has two components, and both have two rates, basic and enhanced: 1) help for day-to-day living needs, and 2) for mobility support/needs. Citizens advice and social workers can help. It can be a gateway to accessing other types of support.

Apply to the Department for Work and Pensions:

www.gov.uk/PIP

0800 917 2222

NHS Continuing Healthcare (NHS CHC)



This is a package of care that is arranged and funded by the NHS for individuals who are not in hospital, but who have complex, ongoing healthcare needs. Specific eligibility criteria must be met to qualify.

NHS CHC can be provided in your own home, or a care home and covers the cost of your assessed health and personal care needs, and if you live in a care home your accommodation and board costs too.

Speak to your GP/District Nurse/Social Worker for further details. Age UK provide more information about NHS CHC:

<https://bit.ly/Continuinghealthcare>

Direct Payments



If you have been assessed as needing social services support, you may be offered, or can request, a Direct Payment instead of receiving the support arranged by your local council. Direct Payments can offer more flexibility and choice over how your well-being is supported. They can be used to employ a personal assistant or carer, enable access to activities which may support your confidence, independence, health, or pay for respite.

Find out more about how Direct Payments can be used here:

https://bit.ly/Wales_direct_payments

Apply to your local council's social services department:

www.gov.uk/apply-needs-assessment-social-services.

Other support you might be entitled to



Funding and services differ by local authority, please make sure you're looking at advice for your area.

Council tax discount:

www.gov.uk/apply-for-council-tax-discount

Winter fuel discount:

www.gov.uk/winter-fuel-payment

Help with water rates:

www.dwrcymru.com/en/support-with-bills ☎ 0800 0520145

House adaptation grants:

www.gov.uk/disabled-facilities-grants

If you want to find out more, visit: www.turn2us.org.uk

“

It can feel uncomfortable if you've never claimed anything before. You're not getting anything that you're not entitled to. It's an entitlement, not a hand-out.”

”

Day-to-day living

Travel



A Blue Badge for car parking: A Blue Badge is for people with a disability, including dementia, to place on the car dashboard to give parking concessions. The Blue Badge is linked to the person living with dementia, not the vehicle. It is free to apply in Wales. Apply through your local council or here:

www.gov.uk/apply-blue-badge

- ✓ **Vehicle tax:** You may be entitled to a reduction/exemption. To find out more: www.gov.uk/vehicle-exempt-from-vehicle-tax
- ✓ **Motability cars:** These can be obtained by the carer on behalf of the person living with dementia
To find out more: www.motability.co.uk
If you have concerns about the person you care for driving, the DVLA can offer advice.
- ✓ **Public transport:** You may be able to get a companion card for bus and rail travel. Contact your local council who will assess whether you meet the criteria and process your application.
To find out more: <https://portal.tfw.wales/en/disabled>

Carer's cards and discounts



Carers receive discounts at various places when visiting with the person they care for. Please ask the places that you plan to visit. A Carer's Card, or carer's allowance letter can be used as proof.

Carers Card UK:
www.carerscarduk.co.uk

Discounts for carers:
discountsforcarers.com

CarerSmart:
<https://carers.org/grants-and-discounts/carersmart-discount-club>

Hynt Card for cinema and theatre:
www.hynt.co.uk/en

Personal care



Personal care can mean many things from brushing hair, shaving, toothbrushing, applying make-up, nail clipping, to incontinence care. There are some aspects of personal care that can feel difficult and embarrassing (e.g. male-female / child-parent), and it's OK to feel like this.

“

It's important for people to be as independent as possible for as long as possible. If someone is doing something and it's causing no harm, let them. Don't sweat the small stuff!”

”

Enjoying time together



It is important to enjoy time together, and for the person you care for to do things they enjoy. Suggestions of things to try:

- ✓ Try and have a goal for each day, it can be going to the shop or something small.
- ✓ Joining a group or a class of things that interest you.
- ✓ Spending time with family and friends.
- ✓ Visiting familiar and favourite places.
- ✓ Visit the cinema or theatre.
- ✓ Going for walks. Circular routes are handy.
- ✓ Gardening or spending time in nature.
- ✓ Creative activities, such as painting, craft and making things.
- ✓ Create a playlist of songs that will calm.
- ✓ Re-live memories with photos that have names and places written on them.
- ✓ Cognitive stimulation such as puzzle activities.

“

There is still humour, joy and fun to be had.

”

Day-to-day living

Remaining safe:



The Herbert Protocol: This is a national scheme that encourages family and friends to put together useful information, which can then be used in the event of a person going missing. Contact your local police force to obtain the form, fill it in and keep it safe at home. This can easily and quickly be shared should someone go missing.

Message in a bottle scheme: The Lions Charity run this free scheme to store important information (contacts, diagnosis, and medication) in the fridge and/or car, including a sticker to make someone aware the information bottle is there.

Scams: Be aware of scams. Tired carers and people living with dementia can be taken advantage of.

Alzheimer's Society scam advice: https://bit.ly/scams_advice

Equipment that can help



Smart speakers: Interactive voice assistants, or 'smart speakers', such as Alexa, Google Assistant, or Macsen (for Welsh speakers: <https://techiaith.cymru/products/macsen/>) can be particularly helpful.

Trackers: To keep the person you care for safe while out and about, GPS tracking systems are available on mobile phone Apps, watches, keyrings and more.

Personal alarms and monitoring systems (telecare): There are many options available (there may be a fee), see the NHS website for more details: https://bit.ly/NHS_alarms_telecare

Fire safety: Local fire teams give free advice and support. Motion activated lights: Can help reduce risk of falls and accidents at night.

Motion activated lights: Can help reduce risk of falls and accidents at night.

Curtain across the door: Can prevent a person leaving unnoticed.

Key safe box: Ensures someone can always get into the house.

Preparing for outings



Get a disabled toilet key (RADAR key):

shop.disabilityrightsuk.org/products/radar-key

Knowing where toilets are available can help:

www.toiletmapp.org.uk

Pack a go bag, always travel with spares (especially if incontinence can become an issue).

Plan ahead for walks and outings. Research where to park and where the toilets are. Check that the place is open. Use Google Maps Street View to look for obstacles. Consider the time of day that works for you both. And don't do too much.

Take a photo of the person you care for before you go out, then you have a photo of them in what they are wearing should they get lost.

Ensure the person has ID on them, which will help if they get lost.

Carrying a card showing that the person with you is living with dementia can help you discreetly explain this.

Don't be afraid to ask for help!



Being organised



Keep a record: Keep a physical record of all official documents. This could be a diary and/or folder. Photocopy any forms that you've sent off. Write down and store any phone numbers because you never know when you'll need them. Records that you keep can be useful to provide evidence for applications (e.g., CHC, PIP etc).

When making applications, apply as soon as possible because things can take weeks, and chase applications up if you haven't heard anything.

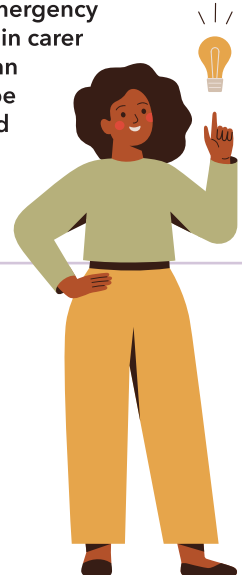
- ✓ **This is Me:** Fill in a "This is Me" form (Alzheimer's Society) and keep multiple copies. Update it regularly.

www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me

- ✓ **Information pack:** Create an information pack that includes full medical history, important information to provide during consultations, an ongoing record, and medication.

- ✓ **Contingency plans:** Make another folder/document with passwords, accounts, paperwork, insurance, emergency contacts, in case something happens to the main carer and someone else has to take over. Attaching an A4 sheet to the fridge with instructions could be helpful. Make contingency plans for if you need to go into hospital. Make a plan with social services if there is nobody else to step in.

“ As a carer, you are the co-ordinator, it has to be down to you to organise and contact people. You have to be pro-active which is harder as things progress ”



In case of hospital admission



If the person you care for is admitted to hospital, the following information may be useful in helping you feel prepared.

Preparation for a hospital admission could include contacting the hospital beforehand to ask what support they can give, and also what information you can provide that will be helpful to them.

- ✓ **Active offer:** If you speak Welsh remember to tell the hospital so that they can record and provide care in the language that is convenient for the person who needs care.

- ✓ **Keep a hospital bag:** Have a bag prepared for both of you. Include clothes, medication, information pack (as above)/This is Me, toiletries, phone/tablet and charger, and something comforting/entertaining.

- ✓ **John's Campaign:** An initiative which allows the carer to stay with the person they care for in hospital.
johnscampaign.org.uk

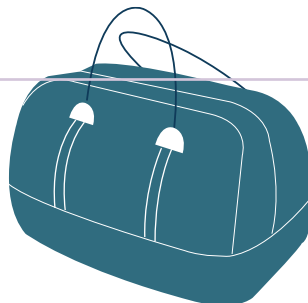
- ✓ **Dementia Nurses:** Can advocate for the person living with dementia in hospital, will assess care needs and initiate that support in the hospital.

- ✓ **The Butterfly Scheme:** A discrete indication that a person has dementia, visible to hospital staff.

butterflyscheme.org.uk

The following Alzheimer's Society guide provides more helpful advice about admission to hospital:

https://bit.ly/hospital_stay



Your mental health and well-being

Your physical, emotional, and mental well-being is important. If you don't look after yourself, you can't look after somebody else.

Short breaks and Respite



This is to support the caring relationship and promote the health and well-being of the carer and the person living with dementia. A short break is a form of service or assistance which enables the carer(s) to have sufficient and regular periods away from their caring routines or responsibilities.

Breaks from caring responsibilities may:

- ✓ Be for short or extended periods.
- ✓ Take place during the day or overnight.
- ✓ Be enjoyed together through community activities or groups and supported holidays.
- ✓ Involve replacement care, in or away from the home, allowing the carer and the person living with dementia some time to themselves.
- ✓ This could be pre-planned or in the event of an emergency.

There are many ways a break can be supported, and across Wales options will vary. Your local council may work closely with local charities and private providers who provide short breaks on their behalf, or that you can privately fund.

- ✓ Contact your local carers organisation and/or local council for advice and guidance on the options available for you.
- ✓ Short break needs, preferences, and options can be discussed during a Carer's Needs Assessment.
- ✓ It is good to have a place in mind in case something happens to the carer.
- ✓ When a person is in respite you can always call to check how they are.



Mental health and ways to help yourself



Mental health and ways to help yourself Please reach out and talk to someone. Be open to support.

- ✓ Your family and/or friends.
- ✓ A network of carers.
- ✓ Healthcare professionals such as your GP or social worker.
- ✓ Talking therapy.
- ✓ Acceptance and commitment therapy.
- ✓ Maintain your interests if possible.
- ✓ Make time for yourself.
- ✓ Relaxation techniques.
- ✓ Breathing exercises.
- ✓ Going for a walk.
- ✓ Mindfulness/yoga/meditation.
- ✓ Anything that works for you (e.g., music, puzzles).

There may come a time where you start to feel burnt out. These organisations are there to help in a crisis or when times are tough.

Samaritans:
www.samaritans.org 116 123

Mind:
www.mind.org.uk 0300 102 1234

Suicide prevention UK hotline:
0800 689 5652

NHS Wales urgent mental health support:
111 option 2



Care options



There might come a time when professional carers are needed to support you, this can be in your home, or in a care home setting. These can both be funded in many different ways, including continuing healthcare (CHC), local authority funding, self-funding, or a combination of these (see page 10 for legal and money matters).

Care at home



Apart from seeking support from family, friends and neighbours, accepting help at home can be a difficult step, but it is very important that you both get the help you need.

Types of care at home include:

- ✓ **Paid carers** who help with personal care and daily living activities – they may visit a few times a week, every day, or several times a day. This can be planned with social services as part of your carer’s assessment together with the option of using direct payments (see page 10 for legal and money matters), or by a private arrangement.
- ✓ **Live-in care**, where a paid carer stays in the person’s home to provide round-the-clock support, this can be through an agency or arranged privately:
- ✓ **A befriender or support worker** who can provide the person with companionship and take them out to groups or activities.
- ✓ **Cleaner or gardener** to help with household and garden chores. Find out more about care options near you:

www.liveincarer.org/hiring-a-live-in-carer

www.homecare.co.uk

Caring at home is not always possible in the long term. Make no promises around care homes, as there may come a time when this is the best option for everyone.



When the time came, I asked myself is she safe at home? Am I coping?



When thinking about care homes



This is a difficult and emotional time but trust yourself to know what is in everyone's best interest.

There are different types of care home (residential, care, nursing), and some are dementia-specific.

All care homes are different, make a shortlist and visit every one. Prepare by writing a list of questions. Visit more than once if possible. Get a feel for them, what you like and don't like, and whether you feel they will meet the needs of the person living with dementia.

Discuss how the home will adapt as dementia progresses.

It is always good to take someone else with you, who will notice different things and can help by taking notes and asking questions that you might not think of at the time.

If you can, look up reviews and reports online:

www.carehome.co.uk

The transition from home to care home



You can identify an appropriate care home long before you need it. Discuss with the person you care for (if appropriate), your close network, and agencies that support you.

Where available, you may wish to prepare yourself and the person living with dementia by going for respite in the care home you choose.

Create an individual care plan with the home. Discuss how involved you want to be and talk to them about your concerns. Work with the care home to prepare and ensure the transition is as smooth as possible. They will be able to guide you through the process.

- ✓ Finding, choosing and paying for a care home (Age UK):

https://bit.ly/Care_home_guide

- ✓ Choosing a care home (Alzheimer's Society):

https://bit.ly/choosing_care_home

The end of the caring journey



This is an emotional time, and you may think “What do I do now?”. The person you have been caring for has died, and with it you have lost your purpose. This may leave you feeling lost and isolated.

It can be a worrying time, with potential loss of financial support, depending on your circumstances (see www.turn2us.org.uk for financial support guidance).

Living bereavement is not the same as actual bereavement, and you might need to turn to specialist support at this time.

Your GP, clinical psychologist or local mental health team may be able to recommend tailored support for you. You can also find out which other organisations offer bereavement counselling.

Bereavement Counselling is offered by



Wales Bereavement Information and Support Service (BISS):

https://bit.ly/Wales_BISS

0800 090 2309



Cruse Bereavement Support:

www.cruse.org.uk

080 8808 1677

It can feel difficult to connect with your groups and networks afterwards, but if you belong to a carers group, they can offer invaluable and understanding support.



Practical things you need to do



Refer back to prior wishes and/or decisions regarding funeral plans. The funeral director will guide you through this difficult process.

You may qualify for a (means tested) funeral grant. Find out through the government website.

“Tell us once” – when you register a death, the registrar can inform most government agencies for you. You will be supplied with a reference number.

Get several death certificates to make the process of informing third parties more efficient.

For a step-by-step guide of what to do, please see:

www.gov.uk/when-someone-dies

After spending time caring for someone else, when they have passed away you are not going to be the same person you were before – it will take you time and you will need support to renew your sense of purpose.



Caring for someone with a rare dementia

Much of the information and advice presented in this booklet applies to carers of people living with any type of dementia. However, for people affected by rarer forms of dementia, experiences, symptoms and support needs can differ.

To find out more about rare dementias, please visit Rare Dementia Support (RDS: www.raredementiasupport.org).

Some specific advice from carers of people living with a rare dementia includes:

- ✓ Assume that most health professionals have no idea about the condition, even if they have experience of dementia care.

- ✓ Print out information about your condition from RDS and highlight what is relevant. Add anything unique to you. Use this to inform professionals who are involved with your care.

- ✓ Create an information pack that includes full medical history, a prompt sheet of most important information to provide during consultations, an ongoing record, and medication. Possibly include colourful boxes and highlight the most important bits of information.

- ✓ Try to join a specific group or forum for your condition. This can be more helpful than many professionals. Hands on experience and coping strategies are really useful. For some people talking to others in your situation is helpful.

- ✓ If possible, try to anticipate future needs and start to make enquiries as it usually takes a significant amount of time to get support.

- ✓ Be persistent when trying to access help. Do not assume it is readily available.

- ✓ Accept help when offered but make sure they are informed about the condition.

In conclusion

Caring for someone living with dementia is a journey filled with challenges and rewards. It requires patience, compassion and resilience; but it is important to remember that you are not alone.

Seek support from healthcare professionals, support groups and other carers, who not only understand, but can also empathise with your experience.

Prioritise self-care, stay calm and patient, as your well-being is paramount in providing the best care possible.

Celebrate and embrace the moments together that you hold dear, cherish the times of connection and be kind to yourself on difficult days.

The support you give is invaluable and the care and dedication you provide will make a significant difference to the person's life.

By implementing the tips and strategies in the booklet, you can improve quality of life for you and the person living with dementia, and make the caregiving experience more manageable.

“ Take it one day at a time, cherish the small moments, and never hesitate to seek support – you're not alone on this journey ”



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We would love to hear from you!

Please get in touch if you would like to:



Tell us how the booklet has helped you.



Make suggestions for amendments.



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