KNOWLEDGE 2 IS POWER

Handy and helpful tips for day-to-day life with dementia

"You don't know what you don't know"



This booklet was written by people living with dementia for people living with dementia 2024

We would like to thank Bangor University Dementia Educators (the Caban group) who contributed their knowledge and personal photographs for this booklet.

If you are living with dementia, are a carer or family member affected by dementia and would like to learn about the opportunities to share your lived experience with researchers and students at Bangor University, please contact Dr Catrin Hedd Jones, 01248 388872, c.h.jones@bangor.ac.uk

You may also like to visit our website:

http://dsdc.bangor.ac.uk/supporting-people.php.en

While we hope these tips are useful for all people living with a diagnosis of dementia, please note that this booklet has been developed by people living in Wales, therefore some information is specific to Wales.

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Cooking and eating

"We all make mistakes, don't stress about them."

Prompts to eat and drink

You can set reminders or alarms on your phone or smart device to prompt you to eat or drink (for more information on smart devices please see page 16).

It may help to put out labelled meals on your kitchen worktop as a reminder to eat.

By not washing up pots and plates until each evening you can see what you have eaten during the day.

If you keep a drinks bottle with you, then you can see you are drinking.

You can make your drink more noticeable by mixing juice or squash with water.

Making a cuppa

A transparent kettle makes it easy to see how much water is inside.

Pouring water into the kettle from a jug can be easier than taking the kettle to the sink to refill it.

A heat sensitive mug allows you to see whether the drink inside is hot or has cooled.



Preparing food

You may find it harder to 'throw food together' by eye but can still enjoy making delicious meals by following a written recipe.

Following a step-by-step picture recipe using flip cards, a memory board or photographs, can help keep you on track rather than working from memory.

Having transparent containers for different ingredients may make it easier to see what you have available.



Measure and arrange all your ingredients before starting a recipe.

If you are cooking a many-part meal you can reduce stress by cooking the vegetables in advance, then reheating them.

Making several portions provides convenient meals for later or for freezing. You can label the meals you would like to freeze so you can easily identify them.

Dementia may alter your sense of taste and smell. Seasoning to taste is easier than trying to remember whether you have seasoned.

For more information on the sensory changes that can occur with dementia please visit: https://bit.ly/SensesBook

Cooking safety

Keeping your oven gloves on the cooker handle reduces the chance of opening the cooker without them.

An induction hob has many safety features. It's the pan, not the hob surface that gets hot. If liquid or food overflows onto the hob, the induction will shut down.

Kitchen timers can be useful to keep track of many cooking processes.

Turning an electric cooker off at the plug socket ensures that the hob isn't left on.

You can also access free advice on support from your local fire safety team.

Cutlery, crockery, and storage

"Keep everything in its place, and let your family know to put items back in their place."

You may find what you need more easily if there is a picture reminder on the cupboard door, your doors are made of glass, or you remove the cupboard doors entirely.

Keep the items you use regularly in the lower shelf of kitchen cupboards.

Steak knives have serrated edges which make for a sharper blade. You may find it easier to use a steak knife to cut other types of meat.

A Knork is an extra strong fork which also functions as a knife or scoop. It may reduce the coordination demands as you can eat with one hand.

Hobbies and activities

"I tell my smart device to play 50s and 60s music."

Television and film

Subtitles with TV programmes may be helpful or may be distracting, try and see what works best for you.

You may prefer watching programmes in the language you are most comfortable with. For example, S4C is a Welsh-language channel

High quality headphones produce good quality sounds and are comfortable to wear. You can listen to music or watch the television at a volume of your choice without disturbing others.

Many cinemas offer relaxed or 'dementia friendly' screenings, where the films are easier to follow, lights are dimmed and not switched off, and sometimes refreshments are provided.



Nurturing new skills

- <u>Dementia Craftivists</u> is a welcoming online community for sharing creative skills and 'having a go', whether it's knitting, painting, or woodwork. You can learn new skills through kits, demonstrations, or tutorials.
- Dementia Diaries is a UK-wide project that brings together people's diverse experiences of living with the many different forms of dementia as a series of audio diaries. It serves as a public record and a personal archive that documents the views, reflections, and day-to-day lives of people living with dementia, with the aim of prompting dialogue and changing attitudes. To learn more please visit: https://dementiadiaries.org/



Relaxation

As your needs and preferences change, consider how the activities that help you relax can be adapted. You may want to ask family, friends, or your carer for support in finding different ways to relax.

Aim to keep one space in your house as your calm and peaceful place to go for moments of solitude or serenity.

Listening to meditations, soothing music, or calming nature sounds may help you relax or even fall asleep.

Socialising

Taking part in planned social activities gives structure and routine to your week. Many communities have social activity groups especially for people living with dementia and their family members, as well as inclusive groups such as local walking or coffee clubs.

Here are some examples of online peer-to-peer support and social groups for people living with dementia; you can drop-in on your terms when you feel like it.

- The Caban Group work closely with the academic staff and students at Bangor University to inform students and researchers about what is important to people living with dementia, their families, and carers. They also created the Knowledge is Power resources.
- Lleisiau DEMENTIA voices from Wales is an independent group giving a voice to people living with dementia and carers in Wales. You can find them on X @LleisiauW
- The 3 Nations Dementia Working Group (England, Northern Ireland, and Wales) are a friendly group of people diagnosed with dementia who want to make a difference.
- The Zoomettes is a UK wide virtual group for women living with dementia.
- Dementia UK have compiled a searchable listing of face-toface and online groups and services across the UK, that are tailored to the needs of people with young onset dementia.
- Dementia Talking Point is an online community by the Alzheimer's Society where anyone who is affected by dementia can receive valuable support.
- Dementia Alliance International provide online peer-to-peer support groups and social groups for people with dementia through Facebook and Zoom.

Enjoying the outdoors

"Fresh air is good for everyone. Just being outside, it can be as simple as sitting on your doorstep."

Some community groups offer dementia friendly exercise or activities, such as gardening, tai chi, gentle aerobics, or walking.

You do not need a garden to grow plants. You can create beautiful houseplant displays and grow herbs and some vegetables on a windowsill.

Some plants, flowers or herbs with varied scents, shapes, colours, and textures can help stimulate and engage your senses.

You can attract beautiful wildlife by planting for pollinators and leaving seeds and nuts for the birds.





"If you stick to simple tasks like hedge trimming or weeding you cannot go wrong, and the result is satisfying. It feels like you have a purpose." There are lots of gardening and outdoor aids and tools that make it easy for you to keep gardening and enjoying outdoor jobs.

A kneeling stool offers a dry, soft surface and has handles to help you get up.

Cordless electric powered tools can let you do outdoor tasks without the hassle of cables. They are often light, quiet, and efficient.

Rehoming tools you no longer use keeps your shed or garage clutter free and gives you more space.

Cut the grass at your own pace, with breaks if necessary, and feel a sense of achievement from seeing the transformation.

An allotment can be an inexpensive and rewarding way of growing your own fruit and vegetables.

You can hear Teresa's experience of tending to her allotment here: https://bit.ly/Teresa_story

A polytunnel lets you enjoy gardening all year round, even on cold, rainy, or windy days.

Raised beds provide height so they are easier to tend to.









Household chores

"We got a cordless vacuum, and it is fantastic. I don't have to worry about plugs or cables... it has simplified the process for me."

It's okay to ask for help from family, friends, or carers, to find easier ways to contribute to chores and still feel productive around the house.

If household chores start to feel too much, you may want to consider employing a cleaner to come regularly or whenever you need a helping hand. This reduces the pressure of physically demanding jobs like hoovering or cleaning hard to reach places.

Try to keep clutter to a minimum, especially in the bedroom.

Drawstring kitchen bin bags are easier to seal than trying to tie a knot in the top of a full bag.

"If there is a lot of clutter, it is almost like it clutters my mind."

Shopping

"Click and Collect is brilliant, and you can ask for help to put your shopping in the car."

Make a list

Make a list before you go shopping. A list of 'Do not need' items may help you avoid buying the same product repeatedly.

Small or familiar shops

Find a shop that suits your preferences and go to that one consistently.

A smaller supermarket may be easier to navigate, you are not faced with overwhelming choice, and staff may come to recognise you; this may make asking for help less daunting.

Some supermarkets have a designated quiet hour when no music is played, and staff don't restock shelves so there is more space to move through aisles.

The Sunflower lanyard can be worn to indicate a hidden disability. It indicates to staff in places like supermarkets, bus, and train stations that you may like extra support. Learn more about Sunflower cards and where to get one here: https://hdsunflower.com/



"I wear it all the time when I go out. People need that visible clue."

Travelling by bus or car

You may qualify for a bus pass, which saves on parking costs.

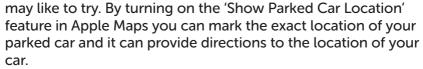
If you tell the bus driver where you want to go, they may be able to prompt you when it's the best stop to get off.

You may be eligible for a Blue Badge to park in disabled spaces. You don't need to have a car to apply for a Blue Badge. The Blue Badge is linked to the person with a disability, rather than a vehicle. You can use it with any car, this includes taxis and hire cars that you're travelling in as a passenger.

If travelling by car, try to park close to the entrance, so you can find your car easily if you get lost. It may help to take a photo of where you park.

Put something unique on your car like a picture, sticker, or air freshener.

There are plenty of 'find my car' Apps for Android and iPhones that you



A supermarket's parking time limit may be negotiable. If you make the supermarket aware that you need extra time, they may be able to add your car's number plate to a list in the system to avoid fines.



Where possible, stay connected with a shopping companion

It can be fun to make shopping a social event and go for coffee or have lunch while you are out.

If separated find somewhere to sit down and wait until your companion finds you. There are usually chairs by the checkout tills where you can wait. It can help to wear a distinctive coat or hat.

Have your home address and the phone number of your shopping companion in your bag or pocket in case you get disorientated. Take your mobile phone with you so you can ring your partner or carer.

Should an emergency or accident happen to your carer, if they carry a 'Carers Card' from Carers Wales, emergency workers and others will know that they are caring for someone.



Packing and paying for shopping

Ask for help if you would like assistance with packing your shopping.

Bagging cold items together or in a freezer bag means you don't have to rush home.

Some supermarkets have a 'slow lane' so you can pack and pay at your own pace.

You may prefer to take your own small shopping trolley with you. There are 3-in-1 shopping trolleys that act as a stable walking aid, shopping basket and a seat.

Using a supermarket's mobility scooter can help reduce fatigue during a long shopping session. If you use a mobility scooter, staff and customers are made aware you may need a helping hand.

Paying by contactless card transactions or Chip and Pin can be easier than carrying notes and coins with you. Purchases then leave a digital trail.

Prepaid cards can be used to make purchases, like a debit card. Having a preloaded card can help you stay in control of your spending. You can only spend the money you have loaded to it, so there is no risk of spending too much or overdraft charges.

You can avoid the hassle of crowds and parking by using the home delivery option. Alternatively, Click and Collect allows you to collect your shopping at your convenience. Debit or credit cards details can be saved so your payment details autofill.

Smart devices

"I have found my smart device helpful to support my independence with prompts, reminders and brain activities."

What are smart devices?

A smart device is an electronic device that is able to connect, share, and interact with you and other smart devices to improve the quality of day-to-day life and convenience in the home.

Interactive voice assistants, or 'smart speakers', such as Alexa, Google Assistant, or Macsen (https://bit.ly/macsen, for Welsh speakers) can be particularly helpful. Some of the functions include playing music and programmes; telling the date, time, weather, and news; controlling lights; and transcribing speech to text.

Some other popular smart devices are phones, tablets, smartwatches, and thermostats.



You can use your smart speaker to:

- Remind you to eat and drink.
- Remind you to take your medication(s) and order your medication(s).
- Set multiple timers while cooking and name each countdown.
- Play word games like Trivial Pursuit.
- Play your favourite music or radio station.
- Ask questions and it can provide answers, e.g., cooking temperatures, weather forecast, what is the latest news.

Using a digital photo screen, you can upload photos from a phone to play them as a slideshow, this helps with memory and is fun to watch.

Smart watches will speak the time aloud when you tap them.

What is a smart plug?

A smart plug is a device that plugs into your power socket, which you then plug another device into.

With a smart plug you can control lights, electronic devices or appliances via an app on your smartphone or tablet over Wi-Fi.



Keeping organised

"If I am going out, I like to organise my clothes and everything I need the night before, so I don't get into a panic in the morning."

Have a place for everything. Keeping things in a predictable place helps to find them. Try to find a single and logical place for everything so everyone can tidy items away properly and you know where to find them.

It is easier to keep track of clothes when they are hung or laid out in sight.

You may find it helpful to keep your phone charger plugged into the same power socket.

Reminders and notices

A noticeboard or whiteboard in the kitchen can be a good place to write or pin appointments and reminders. If you live with someone, they can write notes e.g., "out walking the dog, will be back at 1pm."

If you leave important items by the door, you are more likely to take them with you.

You can set reminders on your phone, your smart speaker, or place written notes by the door so that you don't leave without important items (e.g., mobile phone, raincoat), and so you are prompted to check that the lights are switched off and windows are closed before leaving the house.

To help you plan and manage your time, you can have two monthly-planners so you can see the current month and the following month.

A digital clock or watch may feel less 'busy' to read than an analogue face.

Calendar Apps

Using the Calendar App on a smartphone or tablet means you can see your weekly or monthly plan when you are out and about. Emailed meetings or appointments can go straight into your calendar.

Through your calendar, you can set an activity or reminder to repeat (e.g., change the bedlinen, put the bins out, feed the dog) and be reminded of birthdays or special occasions in advance.



This booklet was developed through requests for suggestions during the COVID-19 pandemic. You can read how the booklet was created here: https://bit.ly/KiP_Process

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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.
- Order copies of this booklet.

Please visit https://bit.ly/KIPCymru2 or follow the QR code to fill in a short questionnaire.

Or, contact Catrin Hedd Jones: (c.h.jones@bangor.ac.uk / 01248 388872)



