

A guide and ideas to positively support those living with dementia, developed by the Optalis Dementia Care Advisors team.

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Introduction

The Dementia Care Advisors (DCA) team is a specialist advice and information service supporting people living with dementia and their families and carers, in the Windsor and Maidenhead area. The team provide support, advice, education, information and therapy to help adults live well with dementia. This booklet explores different experiences and actions people who are living with dementia may take during their dementia journey and provides insight and ideas for those supporting them.

Two key words

There are two words to remember that will help you understand and communicate with a person with dementia, they are **SAFE** and **RESPECTED**. We all need to feel safe with the people we are with and the environment we are in, and feel that we are being respected and listened to. Even if it is hard to follow what they are saying, it will help that you are listening. This is particularly important for someone with dementia who is no longer able to rely on their brain

to give them the correct information. It can be very scary to live with dementia and no longer trust that brain. Think of the moment you lose your car in a car park where you are convinced you left it, or the moment you wake up in a hotel and are briefly disorientated until you realise where you are. That feeling of slight panic and confusion which only lasts a moment is how it feels most of the time with dementia.

Being a carer

Being a carer can feel impossible sometimes, it seems that you need to have endless patience, are endlessly tired and get no reward. In can be hard not to argue back, particularly when it feels 'personal', but there is no point in arguing as dementia will be the only winner in any argument. Try and picture a giant letter 'D' between you which gets in the way of all communication. Every person's journey is individual, one person's experience may be totally different to another, well meaning friends may give you all sorts of advice, but you know your loved one best so trust your own judgement. Carers sometimes find that they are dealing with difficult behaviours that other family members or visitors don't seem to encounter. This is because they trust you and know that you won't abandon them even if they are not on their best behaviour, and they can show you they are upset or irritable. So in a way you should take this as a compliment as it means you are the most important person to them. You are doing a great job, give yourself a pat on the back even if nobody else does. Above all, make sure you get support and help wherever and whenever you can, dementia is a difficult journey for everyone involved and almost impossible to do alone.

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Tips: coping with unusual behaviour

Try to remember that the person you are caring for is not being deliberately difficult, their sense of reality may be very different to yours but very real to them. Dementia can affect a person's ability to use logic and reason so things that may seem obvious to you might appear to be very different for the person with dementia.

- Ask yourself whether the behaviour is really a problem. If the behaviour is linked to a particular activity such as washing or dressing, ask yourself if this task really needs to be done right now or if you could leave it for a while until the person has calmed down.
- Try to put yourself in the person's situation. Imagine how they might be feeling and what they might be trying to express.
- Offer as much reassurance as you can.
- Remember that all behaviour is a means of communication. If you can establish
 what the person is trying to communicate, you will resolve the problem much
 more quickly.
- Distract the person with calming activities such as a hand massage, stroking a pet, a drive in the country or by playing their favourite music.
- Try to make sure that you have support for yourself and breaks when you need them.
- Some people find unusual behaviours, particularly a repetitive behaviour, very irritating. If you feel you can't contain your irritation, make an excuse to leave the room for a while.
- If you find the person's behaviour really difficult to deal with, ask for advice from professionals or other carers before you become too stressed. Medication may sometimes be used for these behaviours, they may be a physical cause, don't assume that it's due to the progression of the Dementia.

Remember that it is possible to be the cause of the behaviour through a lack of

understanding of what the person is trying to communicate. Try stepping away from the situation, look at the person's body language and try to understand what they might be feeling at that time. Give the person space to calm down and offer reassurance.



Activity

It is not unusual for a person with dementia to go through the motions of the activity they may previously have carried out at work. This can indicate a need to be occupied and to feel there is a purpose and structure to their life.

We all need a purpose in life and it is important to help someone feel involved in day to day life. Perhaps involve them in what you are doing or give them little tasks to do (even if you keep repeating the same task).

You could try:

- Folding laundry
- Setting the table for dinner
- Polishing shoes
- Sorting nuts and bolts
- Sorting the mail
- Preparing dinner
- Caring for house-plants



Asking the same question over and over again



A person may repeat questions for a couple of reasons. Alongside their memory loss and forgetfulness, repeating questions can be due to the person's feelings of insecurity or anxiety.

Try to be tactful and patient, and encourage them to find the answer for themselves. For example, if they keep asking the time, and you know they are able to understand the clock, suggest that they look at the clock themselves.

It may help if to move the clock to a position that is more visible, a digital clock that displays the TIME, DAY, and MONTH, this can provide clarity and reassurance. If they are no longer able to read or process information, gentle and

positive reassurance can really help someone settle. If they are asking the same question again and again, then they have forgotten or not been able to process the answer, so for them it will feel like the first time of asking. Just calmly answer the question again as if it were the first time, or find other ways to distract from the topic.

Anxiety

People with dementia may become anxious about future events such as a visitor arriving, which can lead to repeated questioning. It may help if you don't mention the event until just before it takes place.

Anxiety is common because the person with dementia is living in an insecure world, where the brain they have trusted all their life is letting them down. The past may be hard to remember, particularly the recent past, the future may be scary as things are changing all the time - so the present and living in the moment is sometimes all there is. So try to live the moments together, encourage enjoyment in the little things that happen day to day. Reassurance and a positive attitude and body language can help someone feel safe. The sentence I have used most in my career is probably, 'Don't worry, I can help you sort this out.', Most of the time with no idea what I am 'sorting out' but the reassurance seems to help.



Fidgeting

Someone with dementia may fidget constantly. As with pacing, try to distract their attention and offer reassurance. Try giving the person something to occupy their hands, this may require supervision to ensure the persons safety.

Hiding and losing things

People with dementia sometimes hide things and then forget where they are – or forget that they have hidden them at all. The wish to hide things may be due to feelings of insecurity and a desire to hold on to what little the person still has.

- However impatient you feel, try to be reassuring.
- Don't leave important documents lying around, and make sure you have a spare set of keys.
- Try and find out the person's hiding places so that you can tactfully help find 'missing' items.
- If the person hides food, check hiding places regularly, and discreetly dispose of any perishable items.

Lack of inhibition

Due to their failing memory and general confusion, the person may behave in a way that other people find embarrassing. In a few cases, this may be due to specific damage to the brain. Try to react calmly.

Some people with dementia may

undress in public, having forgotten when and where it is appropriate to remove their clothes. If this happens, take the person somewhere private, and check whether they are too hot or are uncomfortable or want to use the toilet.

Language

Language skills tend to reduce with dementia, so reading body language and tone of voice become more important. Keep eye contact, with positive and open body language and facial expression. Because language skills are reducing, you may need to keep sentences less complicated and give more simple instructions or choices.



Multiple phone calls

Some people with dementia phone their loved ones over and over again – particularly in the middle of the night. This can be very frustrating and distressing. The person with dementia may forget that they have already called, or may be insecure or anxious. You of course know that they have called many times, but for

them it feels like the first phone call, so they will be surprised if you tell them they have called already and may well deny it. If you are receiving repeated calls, it may help to get a phone with a number recognition display or an answer-phone. If you are busy working, especially as many people are working at home, it's likely that it is easier for your loved one to get in touch with you, You may feel guilty about not answering every call, but it's important to look after yourself and get some rest, you can always call back.



Night-time waking

Many people with dementia are restless at night and find it difficult to sleep. Older people often need less sleep than younger people in any case. Dementia can affect people's body clocks so that they may get up in the night, get dressed or even go outside. This can be very worrying – and exhausting – for carers.

- Make sure the person has enough exercise during the day and that they use the toilet before bed.
- Try a walk before bedtime, a warm milky drink and soothing company before they fall asleep.
- If the person wakes up, gently remind them that it is night-time.
- During the light summer months it can feel like daytime even late at night or very early in the morning, so put a clock that shows whether it is am or pm next to the bed and consider darker curtains or blackout blinds.





Pacing up and down

Pacing may indicate that the person wants to use the toilet but is unable to tell you. Try asking the person whether they need to use the toilet, or lead them towards it. If they are adamant that they want to pace, try to find somewhere they can walk safely. If a person has always been active and walked regularly, they may be feeling frustrated and want some fresh air. Help to choose comfortable clothes and shoes, offer drinks and snacks, check their feet regularly for redness, swellings or blisters, and try to persuade them to rest from time to time.

Repeatedly asking to go home

This may take place in residential care, or when the person is already at home. It can be a sign of anxiety, insecurity, fear or depression. The concept of 'home' might evoke memories of a time or place where the person felt comfortable or safe, or of a home, family and friends that no longer exist. If the person doesn't recognise their present environment as 'home', then it isn't home for them. Try to understand and acknowledge the person's feelings and reassure them that they are safe and loved.



Repetitive actions

Actions such as repeatedly packing and unpacking a bag, or rearranging the chairs in a room, may relate to a former activity such as travelling or entertaining friends. If so, this may serve as a basis for conversation. Alternatively, it could signify boredom or a need for more contact with people.

Restlessness

Some people with dementia experience general restlessness. This can be a sign of hunger, thirst, constipation or pain, or the person may be ill or suffering from the side-effects of medication. Other possibilities are boredom, anger, distress or anxiety, stress due to noisy or busy surroundings, or lack of exercise. It may also be due to changes that have taken place in the brain. If the person seems upset, try to find the reason, give them some reassurance, then try to distract them with an interesting activity, or by involving them in some form of exercise.

Repetitive phrases or movements

This can be due to noisy or stressful surroundings, or boredom. Encourage the person to do something active, such as going for a walk. It can also be a sign of discomfort, so check that the person isn't too hot or cold, hungry, thirsty or constipated. Contact the GP if there is any possibility that the person may be ill or in pain, or experiencing a side-effect of medication

Shouting and screaming

The person may continually call out for someone, shout the same word, or scream or shout over and over again.

They could be in pain or ill, experiencing difficulties with visual perception or hallucinations, or the behaviour could be due to another reason which you may need to call medical help for.

A person with dementia may feel lonely or distressed, if their short term memory is damaged they may not remember that you are in the next room and believe they are alone. They may feel anxious about their failing memory, bored, or stressed by too much noise

If the person shouts out at night, a night-light in the bedroom may be reassuring.

Consider how the room looks in the dark. Are there shadows or shapes that cannot be seen when the light is on but that could be misinterpreted and look frightening in the dark?

If they are calling for someone from their past, try talking to them about this period in their life and respond to the feelings the person is showing. Avoid harsh facts that may cause distress – if the person they are asking for has died, they may not remember this fact and will feel they are hearing it for the first time.

Sleeplessness and sundowning

Many people with dementia, especially in the middle stages, experience periods of increased confusion at dusk, with their disorientation continuing throughout the night.

Sundowning may be caused by:

- Mental and physical tiredness at the end of the day
- Reduced lighting and an increase in shadows
- Less need for sleep, common among older adults
- · Mixing up day and night.



Suspicion

Some people with dementia can become suspicious. If they have mislaid an object they may accuse someone of stealing it, or they may imagine that a friendly neighbour is plotting against them. Have you ever lost something and been convinced of where you last saw it, then find it somewhere else? That too is a feeling that someone with dementia lives with constantly. So you can see where anxiety, paranoia and fear start to creep in. Someone familiar reassuring you that everything is OK can make all the difference.



These ideas may be due to failing memory, an inability to recognise people, and the need to make sense of what is happening around them.

- If this happens, state calmly what you know to be true, if appropriate, and then reassure and distract the person.
- Try to remember that although the person's interpretation may be wrong, the way the person feels is real.
- Explain the situation to others if appropriate
- Don't automatically dismiss the person's suspicions if there is any possibility that they may be true.

Trailing and checking

Living with dementia makes many people feel extremely insecure and anxious. This can result in the person constantly following their carers or loved ones around, or calling out to check where they are. A few moments may seem like hours to a person with dementia, and they may only feel safe if other people are nearby.

This behaviour can be very difficult to cope with, but try not to speak sharply.

If you are busy, give the person something absorbing to do – perhaps distraction through a pet, task or activity, or you can hum or sing, or put the radio on.

Make sure you also find some time for yourself, ask a neighbour or friend to be with your loved one while you go for a walk or pop to the shops.

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Activities for people living with dementia

Staying active and following a gentle routine can help people living with dementia maintain their skills and mobility, and may improve sleeping patterns. We have put together a list of activity ideas over the next few pages to help you plan some fun and stimulating activities at home.

General Tips

- It's important to try to stay calm and positive around the person with dementia even if that's not how you are feeling, body language, tone of voice and a smile are often more effective than words.
- Please remember it is not about completing any task, it is often better to spend a short time on one task and move to another.
- Develop a daily routine, keep it simple. Routine is important and helps people feel more safe and secure. Perhaps you could arrange a regular time of day to connect, to help give you structure and something to look forward to.

- Consider linking an activity to a person's work life or interests – for example, someone that worked in an office may enjoy an activity that involves organising.
- Be respectful of personal beliefs and individual or cultural values.
 Ensure cultural and spiritual needs are included in daily routines and activities.
- If you have access to a computer, tablet or smart-phone, there are many good websites offering lots of resources and ideas. Music sites, games, word searches, puzzles, solitaire, reminiscence sites and great advice from charities like Alzheimer's UK.

Cooking together, if this is a safe activity to do, involve your loved one with the menu planning, you could have a theme, such as baking.

Creative time – with crafts such as knitting, painting or colouring, some of which may be hobbies never tried or long forgotten. Many people find joy rediscovering hobbies. They are a good way of distracting and relaxing people, try doing it together if there are others in the house.



Create a scrapbook - write memories down as

they occur during reminiscence or chat times, it doesn't need to be a chronological record, just a collection of memories, perhaps add some of those photos. Once it is compiled it is a lovely book to sit and look through together. Perhaps make more than one - specific books about family, job, holidays, TV shows, pets, hobbies and interest. Handwritten or typed up and printed on a computer, either is fine.

Daily living tasks can be activities like washing up, folding laundry, laying the table, dusting. These help someone feel involved and provides an activity.

Environment – Place things around the home that people can pick up and use or look at. Magazines, objects, photos, books, things that are reminiscent to their own life.

Games - card games, dominoes and board games like Scrabble are a nice way to spend time together, again don't worry if you don't complete them or follow the rules. For example just making words from the tiles of the Scrabble game can be challenging and fun without using the board.



Gardening if the environment is safe and the person is supervised, or you could plant indoor seeds in pots.

Go on a virtual 'walk' with someone using photos and chat, or via Google Street View if you have a smart phone or computer, through familiar streets past and present.

Memory or Rummage Boxes are an excellent activity to create and look through together, with a variety of multi-sensory objects that can be handled, looked at, smelt, listened to and even tasted. These can be generic or themed to a topic such as a job, hobby, decade or entertainment. (Please refer to the Creating Memory Boxes Guide later in this booklet).

Music can often be a very successful mood changer, helping to lift up or calm down the mood or take you back to a familiar memory. Try singing along or maybe get up for a bit of a dance, even dancing in your own lounge can be very uplifting. Theme a session, write a playlist together to listen to, use CDs or online resources and singalongs.



Pampering - Hand massage or manicure, some time to pamper and relax together.

Photos – these can be a great way of revisiting the past, don't worry too much about identifying who is who in the photo. For example an old family photo of a day at the beach can produce lots of conversation about what people are wearing, what they may be doing on a beach, sand, shells, sun cream, picnics, even the British weather.

Puzzles – jigsaws, crosswords, quizzes, word searches – are all a good distraction, remember it doesn't need to be completed, just have a go at solving them together.

Relaxation - Listening to recordings of birds singing, the sea etc. can be very relaxing, as can holding objects with different textures.

Stay connected - Phone the family, write them a letter, even use Apps and social media platforms that allow you to use video calling such as Skype, WhatsApp and Zoom if you are able to. Seeing someone's face as well as hearing their voice, can make you feel closer.



The Television and computer often feel 'real' so may feel like there is company in the house, particularly if you discuss what is going on. Drama and soap operas may be hard to follow and remember plots, so quizzes, music, nature shows, sport, cookery or antique shows are often more effective. Watching old movies together, or TV from the past is a nice reminiscence activity.

Notes:

Well done

We know it's hard, but some of these ideas will hopefully help you with things to do when at home. Above all, don't forget you are only human not superhuman. Do your best, ask for help when you need it, don't worry if things don't work, try something else, then something else. If things are really difficult walk away, go into another room if you need to for a few minutes. Make sure you stay safe and well.

A guide to Creating Memory Boxes

A memory or rummage box is an excellent activity to create and look through together. Using a variety of multi-sensory objects that can be handled, looked at, smelt, listened to and even tasted. These can be generic or themed to a topic such as job, hobby, decade or entertainment.

Ideas for what to include

Photos of family, weddings, holidays, jobs, houses, pets etc. (originals may get damaged)

Favourite films on DVD, pictures of old film stars, cinema or theatre stubs or programmes.

Themed quizzes or questions about a particular topic.

Old toys from your past or your children's past, even Christmas decorations and objects.

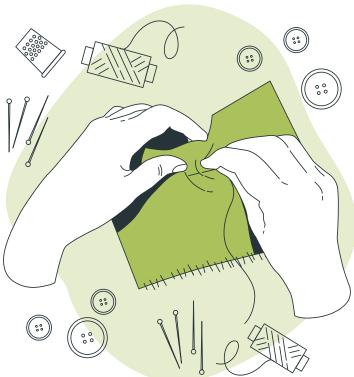
Think about jobs and careers and items that can bring back memories, e.g. tape measure, nurses watch, ruler, paint brush, pen and pad, sewing buttons and ribbons onto pieces of material.

Objects relating to hobbies:

Sports

- sports memorabilia
- · tickets & programmes
- information on sporting events
- stress ball in shape of favourite sport





Gardening

- old seed packets
- gardening magazine
- photos of gardening tools

DIY related items

- blocks of wood
- sand paper
- photos of tools

Craft related items

- wool
- material
- make up
- wooden spoons
- recipe cards

Include items related to the senses:

Things to look at:

- colourful card or paper
- pictures
- · colourful objects

Things to smell:

- perfume
- soap
- dried tea
- coffee
- mint sauce
- grass and plants

Things to listen to:

- music CDs
- sound recordings of birdsong, water,animal noises, children's laughter etc.
- · bells

Things to taste:

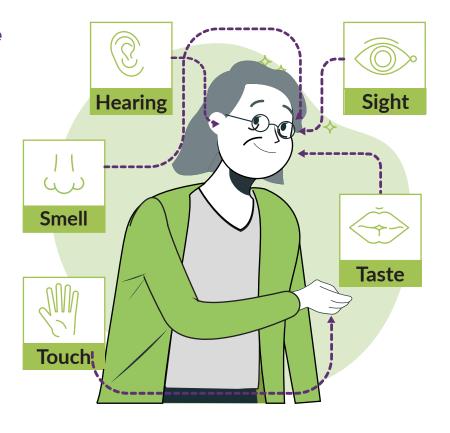
- sweets
- crisps
- drinks
- fruit
- savoury spread
- jelly

Things that are tactile to touch

- material
- fur
- sandpaper
- water

Natası

shiny treasure



Change and update

These boxes are meant to be shared and to stimulate chat and reaction. Keep changing the object and follow the person's lead, if they are bored of one thing then move onto another. Try talking about how the items makes the person feel.

Contrast two things to look at or two flavours to taste. Make sure items that are dangerous or could be eaten are removed after the activity.

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10 Minute Gentle Chair Exercises

Devised by Emma Holgate

These exercises can be done in your chair at home and will help your circulation, energy, concentration, and general wellbeing. Don't do any exercises you can't do due to a physical disability, and don't push yourself if it hurts. Try to incorporate them into your daily routine.

Count each round of six aloud to aid concentration. Do not worry if someone cannot follow an exercise, just show it visually and do not criticise. The more you do these exercises, the more likely someone will pick up the routine and stay engaged. These can be done alone, with others, or via phone or computer. Have fun.



1

Take a deep breath in slowly, hold briefly then breathe out slowly

Repeat 6 times



2

Lift **both** arms up and then down

Repeat 6 times



3

Shrug shoulders up and down

Repeat 6 times



4

Roll **right** shoulder round in a circular movement

Repeat 6 times



5

Roll **left** shoulder round in a circular movement

Repeat 6 times



6

Put your hands on your shoulders and bring your elbows together

Repeat 6 times



7

Cross your arms and hold in front of you, then gently twist to the **right**

Repeat 6 times



8

Cross your arms and hold in front of you, then gently twist to the **left**

Repeat 6 times



9

Roll your arms around each other and raise them **up high** then **down low**

Repeat 6 times



10

Raise your **right** knee up

Repeat 6 times



11

Raise your **left** knee up

Repeat 6 times



12

March with your feet to the tune of The Grand Old Duke of York



13

Put feet together then step to the **right**

Repeat 6 times



14

Put feet together then step to the **left**

Repeat 6 times



15

Stretch your **right** leg out in front of you and make a **circle** with your foot

Repeat 6 times



16

Stretch your **left** leg out in front of you and make a **circle** with your foot

Repeat 6 times



17

Point the toes of your **right** foot up, then down

Repeat 6 times



18

Point the toes of your **left** foot up, then down

Repeat 6 times



19

Stretch your right arm out in front of you and make a circle with your hand Repeat 6 times



20

Stretch your **left** arm out in front of you and make a **circle** with your hand

Repeat 6 times



21

Touch each finger with your thumb on your **right** hand

Repeat 6 times



22

Touch each finger with your thumb on your **left** hand

Repeat 6 times



23

Make a fist with your **right** hand then release

Repeat 6 times



24

Make a fist with your **left** hand then release

Repeat 6 times



25

Wave with your **right** hand

Repeat 6 times



26

Wave with your **left** hand

Repeat 6 times



27

Place one palm up and one palm down on your lap, then switch.

Repeat 6 times



28

Take a deep breath in slowly, hold briefly then breathe out slowly

Repeat 6 times



29

Finally – give yourself a round of applause, smile and congratulate yourself and anyone else that has done it with you, well done!



Dementia care advisors team

Supporting you and your family to live well with dementia at every stage of the journey

Our office is based at: Boyn Grove Community Resource Centre 11 Courthouse Road Maidenhead, SL6 6JE

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If you would like this leaflet in another format please contact us.





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