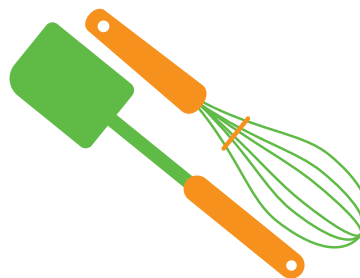
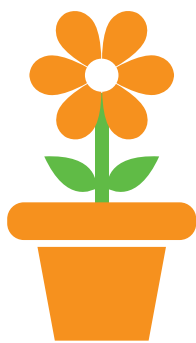


Caring for someone with dementia at home

A resource pack for carers



Introduction

Caring for someone with dementia

We are living in unprecedented times, with everyone having to adapt quickly to an uncertain and stressful change in their lives. Coping with caring for a person with dementia in this situation may well bring extra challenges and pressure.

You may not be able to use your usual coping strategies and support. You may also feel anxious about the coronavirus and what will happen if you or the person you care for becomes unwell. Some carers may feel worried, frustrated, stressed, and upset. These worries and feelings are normal and understandable because this situation is not like anything else we have experienced before.

This time is also likely to be unsettling for the person you are caring for. Their routine is likely to be disrupted and they may not be able to do the activities that maintain their well-being. They may pick up on distressing messages in the news, or the anxieties that those close to them are experiencing. They might become bored or anxious and may not understand the need for physical distancing. This might result in some changes in the person's behaviour and this could add further stress to a difficult situation.

This pack has been put together with some suggestions that might help you and the person you care for cope with this difficult time. There are some ideas about how to look after yourself, how to respond to any changes in the behaviour of the person you care for as well as information about where to seek additional practical and emotional support.

Some general ideas to keep in mind:

- Use any practical support available e.g. with shopping, obtaining medication etc. – anything that might relieve some pressure and help keep you and the person you care for safe.
- Pay attention to how you are feeling and seek support early. It might help to have regular phone contact with someone at a point in the day to check in and talk about how your day has been, rather than waiting until you are feeling stressed and overwhelmed.
- Be kind to yourself – remember that most people would find this situation really hard.
- Take one day at a time; if today has been difficult things could be better tomorrow.



Top tips for managing at this difficult time

It is important to stay up-to-date with the latest government guidance on physical distancing to help keep you and your loved one safe.

You might hear the term 'social distancing' used, which can be misleading because although you may be physically separate from your extended family and social supports, **you are not alone**. There are a range of supports available from different sources. Below are some top tips for managing physical distancing at home when caring for someone with dementia.

1. **Focus on safe hygiene.** If the person you are caring for has memory problems they may forget to wash their hands. Consider setting up a handwashing routine or having a sign in the bathroom to remind them to wash their hands for 20 seconds. You may need to demonstrate good hand washing behaviour first. Try to encourage your loved one to do the same but take a break if they appear to become stressed. When coughing/ sneezing try to use a tissue and put these in the bin straight after. Avoid touching your face.
2. **Plan for cover in caregiving.** Consider who you would want to step in if you become ill and are unable to care for your loved one. Reach out to those people you want to cover to make a plan for if they need to step in. Doing this when you are feeling well may feel hard but it is important to have a plan tailored for you should there be a problem.
3. **Explain the pandemic in a way your loved one understands.** Depending on where they are in their dementia try to put it in a way they can understand it. Don't over-explain things if they are unable to grasp it. There are some communication cards to aid these

conversations available online at www.aphasiafriendly.co/covid-19-accessible-information.html that may be helpful.

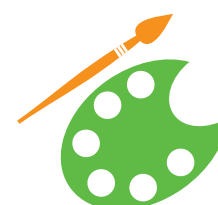
4. **Plan for the future.** Try to make sure you have everything you need at home for the foreseeable future. Organize a food delivery or ask someone else to help with this. If possible arrange for repeat prescriptions to be delivered or ask someone else to help with these.
5. **Establish a daily routine.** Routines provide structure and purpose. You and your loved one may find it reassuring to do things at the same time each day/week. There may be certain times of the day that work better for you for certain activities. Staying entertained with activities is important to keeping stimulated and retaining a sense of purpose; this will help to fight off boredom. Try to have a good mix of activities that need to be done, rest, and leisure. Perhaps set daily goals and tick these off as you go.
6. **Look after your mental and physical health.** Remember to get sufficient food and drink, to help boost your immune system and energy levels. Rest when needed and where possible. Try to stay positive; remember the physical distancing measures will come to an end!
7. **Keep connected.** Talk with family, friends and neighbours. Share how you are feeling. Consider regular phone or video calls with others. You could also stay in touch by sending each other letters and cards. Let people know if there is a problem. You may find others are feeling anxious about the situation and staying in touch helps everyone to feel better.

Activities

What we do with our day greatly affects how we think, feel, and behave. We can use activities to structure our days, providing us with a sense of routine and purpose. Below are some ideas for activities that can be done with your loved one in the home; try to focus more on doing the activity rather than the end result. You may need to help your loved one get started with an activity by demonstrating it first. "Can you help me with ... ?" can be a useful way of introducing an activity.

Consider setting up different areas around your home for different activities. You could ask others to bring you activities (e.g. games, films) that they could leave on your doorstep. If a person is occupied with an activity they are less likely to become distressed, although they will likely also need periods of rest.

- Involve your loved one in de-cluttering e.g. tidying and sorting through cupboards
- Take a walk around your garden if possible, taking time to look at and talk about what you see
- Work on your garden together or set up a station inside where seeds can be planted
- Paint, colour, draw
- Listen to your loved one's favourite music- perhaps create a playlist of their favourite songs and talk about the memories associated with these
- Make posters or cards to send to family and friends
- Play games together (these could be on the computer)
- Do puzzles or jigsaws at a table
- Watch a funny film or television programme
- Bake together- it might be that your loved one helps with part of a task (e.g. mixing the ingredients in a bowl with a spoon)
- Look through family photo albums, magazines, old postcards, books etc.
- Recite poems and proverbs from childhood and reminisce about these
- Listen to short audiobooks
- Create a rummage box filled with items that your loved one can safely pick up, feel, explore, and look through
- Telephone and video call family and friends, or spend time writing letters to them
- Sing together!



Self-care tips for carers

The current circumstances relating to coronavirus and self-isolation can be a particularly difficult time for people who have the added responsibility of caring for a loved one. Changes in routine, reductions in support and uncertainty about the future can leave people feeling vulnerable and overwhelmed. If you are a carer it is particularly important to look after yourself. It's harder to look after your loved one if you're not as well as possible.

Looking after yourself includes looking after your physical and emotional needs and staying connected with others for social support:

- **Take care of your basic needs:** Rest when you can and eat sufficient and healthy food. Drink plenty of water to help stay hydrated.
- **Engage in physical activity:** If you have access to the internet, you could visit www.royalvoluntaryservice.org.uk and search for 'exercises' for ideas of physical activities that you can do at home.
- **Stay connected to family and friends:** Arrange to speak to someone most days on the phone, through social media or over the garden fence at a safe distance. Perhaps even arrange set-times to call your nearest and dearest at a convenient time for all. If you have a mobile phone, why not download the WhatsApp application and set up group chats with your family and friends.
- Avoid using unhelpful coping strategies such as tobacco and alcohol.
- **Take regular breaks:** As people often say, caregiving is a marathon, so it's essential to pace yourself for the long haul. An effective way to pace yourself is to take regular little breaks during the day. These breaks can fit

into your schedule, allow your brain and body to rest, relieve stress and keep you focused on important tasks. For example, the next time you have a few minutes, you could give one of these a try:

- Close your eyes, slow your breathing, and count slowly to 10 and then back down to 1. Repeat.
- Drink a glass of water. Dehydration makes you tired, headachy, and cranky.
- Listen to some upbeat music.
- Watch a funny video or television programme.
- Take a short walk outside. If you can't leave your loved one alone, just step outside the door and breathe some fresh air, leaving the door open so you can still keep an eye on them.
- Get all your thoughts out on paper. Don't worry about being organized, neat, or even making sense. Just start writing things down on paper and don't stop until your brain is clear.
- Think about what you're grateful for. Maybe think or write down three every day.
- Take a nice bath
- Do puzzles, games, coloring books for adults or artwork.

It is ok if you are finding this a difficult time, and if you are struggling to do all the things you have previously managed. Many people are in the same situation, and there is no script or 'right' way to do this. What's important is keeping yourself and your loved one safe, both physically and emotionally. If you are noticing that this is becoming harder to do, use the helplines and support services at the end of this booklet to reach out for support, before reaching a crisis point.

Managing stress

During times of uncertainty and worry it is normal to find ourselves looking to the future or caught up in any number of hypothetical situations, often imagining worst case scenarios. While this is normal, it isn't particularly helpful and can lead us to feel more anxious and worried.

Try to notice when you might be doing this, and then practise the exercises below to see if you can connect to the present moment instead.

Dropping Anchor

- You can do this sitting or standing
- Plant your feet firmly on the floor
- Push them down, feel the floor beneath you, supporting you
- Notice the tension in your legs as you push your feet down
- Notice your entire body, and the feeling of gravity flowing down through your head, spine, legs, and into your feet
- Now look around and notice what you can see, hear, or smell around you
- Notice where you are, and how you are feeling

Below is a quick and easy breathing exercise to use when you might begin to feel overwhelmed, frustrated, or anxious.

It works to slow your heart rate and control your breathing to manage the physical effects of stress and anxiety.

Just be cautious if you have any lung or respiratory conditions, and be sure to listen to your body if it is telling you to stop.

Take 10 Breaths

- Take 10 slow, deep breaths
- Focus on breathing out as slowly as possible
- Notice how it feels as your lungs empty and then refill
- Notice the gentle rise and fall of your shoulders
- See if you can let your thoughts come and go as if they're just cars passing by your house
- See if you can notice both your breathing, and then your body, and then the space around you
- Notice what you can see, hear, touch, and smell in the room



More ways to manage stress

Mindfulness of Household Activities

- Pick an activity that you need to do around the home. For example, ironing, hoovering, washing dishes, anything mundane that you have to do
- Do this activity mindfully
- Engage in it fully, don't be tempted to multi-task, just do the task you've chosen to do
- Use all of your senses (sight, sound, smell, taste, and touch). For example, notice the colour and shape of the clothes you're ironing, the warmth when you're folding them, the smell of the fabric softener, the sound of the hiss of the steam, the feeling in your arm and shoulder as you move the iron
- If your mind starts to wander, that's ok, just bring it back to what you're doing
- If you begin to feel bored or frustrated, that's ok, just recognise these feelings and then bring your attention back to the task

Mindfulness of Pleasant Activities

- Pick an activity you enjoy which can be done inside, or in the garden if you have one
- For example, painting, eating a meal, listening to music, enjoying a bath, reading, gardening, colouring, the list goes on...
- Do this activity mindfully
- Engage in it fully, don't be tempted to multi-task, just do the task you've chosen to do
- Use all of your senses (sight, sound, smell, taste, and touch)
- Notice and savour each moment
- It's normal for our attention to wander, don't be tempted to give up, or tell yourself off, just notice when it happens and then bring your attention back to your task

Five Senses Mindfulness Exercise

Sit in a comfortable upright position with your feet planted flat on the ground and your hands rested on your thighs or desk. Don't breathe in any particular way. Just bring attention to each part of the breath. Now bring your awareness to each of your 5 senses. Focus on each for 10-20 seconds and try to build up to a minute.

- **Hear:** Begin to notice the sounds around you. Try not to judge them - just notice them. You might hear internal sounds, like your breathing. You might hear more distant sounds like traffic. You might begin to notice subtle sounds you did not hear before.
- **Smell:** Shift your attention to notice the smells around you. You might smell food or trees and plants if you're outside. Sometimes closing your eyes can help you notice.
- **See:** Observe your surroundings and notice the colours, shapes and textures. If you really look, you may notice things that have gone unnoticed.
- **Taste:** You can do this one even if you don't have food in your mouth. We often have tastes in our mouths that go unnoticed. You may begin to notice an aftertaste of a previous drink or meal.
- **Touch:** Notice the sensation of contact between you and your chair and clothing. Notice the pressure between your feet and the floor, or your body and the chair. Observe the temperature on your hands or feet. Take time to feel the textures that you noticed by sight a moment ago.

When you've finished, pause to notice how your body feels in this moment. Compare how you feel now with how you felt 5 minutes ago - what has changed?

For more mindfulness activities, please visit www.oxfordmindfulness.org/for-you/resources/

Progressive Muscle Relaxation exercises (PMR)

When we are anxious or stressed, our bodies often feel tense. This is because we're designed to respond to threat by either fighting, or fleeing, and our bodies respond to feelings of stress and anxiety as if they are a very real threat.

PMR helps to show our bodies that we aren't in danger by deliberately tensing, and then letting go of that tension in each part of our body - signalling to our minds that we are safe.

PMR can be helpful to do before going to bed, if you are finding it difficult to 'switch off' or relax.

Find a quiet place free from distractions. Lie on the bed or recline in a chair, loosen any tight clothing, and remove glasses. Rest your hands in your lap or on the arms of the chair. Take a few slow even breaths.

Now, focus your attention on the following areas, being careful to leave the rest of your body relaxed.

Work through the following parts of the body one by one, squeeze the muscles, hold for 15 seconds, feel the muscles getting tighter and tenser, then slowly release the tension. Notice the difference in feeling and sensation between tension and relaxation.

(Avoid any areas where you have an injury or pre-existing pain)

- **Forehead** - raise your eyebrows as high as they can go. Hold for 15 seconds then release
- **Jaw** - grit your teeth or jut out/clench your jaw. Hold for 15 seconds then release
- **Neck and shoulders** - raise your shoulders as high as you can. Hold for 15 seconds then release
- **Arms and hands** - pull your hands into fists then straighten your arms in front of you. Hold for 15 seconds then release
- **Buttocks** - tense the muscles in your buttocks. Hold for 15 seconds then release
- **Legs** - raise your legs, or squeeze the muscles in your thighs or calf. Hold for 15 seconds then release
- **Feet** - curl your toes under your feet, or point them to the ceiling. Hold for 15 seconds then release

Take a deep breath in...hold...and then breathe out, imagine you're breathing out all the tension

Enjoy the feeling of relaxation sweeping through your body. Continue to breathe slowly and evenly.



Challenging behaviour

People with dementia often struggle to communicate their needs in a way that those around them can easily understand. This can lead to some of their needs being unmet and the person becoming distressed, or the person trying to meet the need for themselves in a way that can feel challenging (for example

constantly walking due to feeling bored or needing to be physically active). Considering the following universal needs that apply to everyone might assist you in working out how to help the person you are caring for, especially if you notice a change in their behaviour:

| Need | Ideas of how to meet that need |
|---|---|
| Physical comfort and freedom from pain | <p>Ensure the person is suitably dressed for the temperature/environment they are in.</p> <p>Could they be hungry/thirsty/tired/constipated?</p> <p>Might they be disturbed by noises in their environment (e.g. from a TV)?</p> <p>Might pain relieving medication or a change in position (a short walk or stretch) help them feel more comfortable?</p> <p>It is also important to keep in mind whether the person might be physically unwell as this can lead to significant and sudden changes in behaviour – check with the person’s GP if you have concerns about this.</p> |
| Love and belonging | <p>When we feel anxious our natural tendency is to be with the people we feel safe with to seek comfort and support. The person you care for may need to stay close to you for more time than usual.</p> <p>Help the person to connect with important people in their life – friends, family members, other members of the community etc.</p> <p>Try video calling (e.g. FaceTime, WhatsApp, Zoom, Skype).</p> <p>Look through photos together to remember significant family members and events.</p> <p>Keeping items that are familiar or comforting close to the person might help, such as a favourite jumper or keepsake.</p> <p>Online church services or community events.</p> |
| Positive touch | <p>Holding hands, hugs, kisses, massage – whatever you and the person you care for feel comfortable with.</p> |
| Fun | <p>Support the person to connect with their sense of fun/humour. Are there TV programs that help them laugh, what helps them see the funny side of life?</p> |

| | |
|--|---|
| <p>Feeling safe</p> | <p>Keep distressing TV or radio programs to a minimum.</p> <p>People can sometimes misinterpret and be frightened by shadows, especially when it gets dark at night. Make sure rooms are well lit where possible.</p> <p>Listen to what the person wants to say and show that you have heard and understood how they feel by saying “I can see you’re feeling worried/frightened” etc.</p> <p>Offer the person plenty of reassurance that they are safe and that you are there to help them.</p> <p>Offer an explanation of the situation in a way that the person can understand.</p> <p>Repeat this explanation and reassurance as much as necessary.</p> <p>Try to maintain a routine to help the day feel consistent and predictable – write this down on a piece of paper or whiteboard and tick each item off once it is complete.</p> <p>Be aware of the pace the person can manage their every day activities, try to avoid a sense of rushing.</p> |
| <p>Esteem needs – feeling valued, skilled</p> | <p>Support the person in using the skills they still have.</p> <p>Can they help with practical tasks around the house?</p> <p>Are there activities they still enjoy which connect them to a previous job role and sense of meaning/purpose?</p> <p>Ensure to provide lots of positive praise and compliments on activities done.</p> |
| <p>Control over environment and possessions</p> | <p>Help the person feel in control of their surroundings as much as possible.</p> <p>Offer choices in food, clothing, activity etc.</p> <p>Keep to two or three options if the person finds too much choice overwhelming.</p> |
| <p>Occupation and exploration</p> | <p>If appropriate take a local walk.</p> <p>Try some chair exercises or other exercises in the home.</p> <p>Support the person with activities they can still manage e.g. listening to music (there are lots of concerts/performance currently available online), arts & crafts, puzzles, games, household jobs (dusting, washing/drying up), relaxation.</p> <p>Ask family and friends to send cards, photographs, voice/video messages etc. and review these with your loved one.</p> |

It is also worth keeping in mind whether there are patterns to when the person you care for becomes distressed. Are there times of day when things are more difficult? Are particular tasks (meal times, getting dressed) difficult? Try a diary to help identify patterns.

If you have noticed triggers to the person feeling distressed it might be possible to predict and prevent them. For example, people with dementia often become more unsettled in the late afternoon/early evening. Planning a relaxing activity for this time and starting it before the person becomes distressed may help. If the person you care for becomes distressed when you have to attend to another task, try

setting up an activity that might distract them (e.g. a favourite TV program).

Sometimes it can feel confusing for a person with dementia if someone tries to “correct” their viewpoint; this can lead to disagreements and the person with dementia becoming upset. Instead it might be helpful to “go along with” their viewpoint, for example if they believe they need to go and collect their children from school try not to disagree with them, instead ask them to tell you more about their children, engage in conversation with the person. This is called validation and the aim is to connect with what the person is thinking and feeling, to help them feel reassured.

Online resources

| Type | Intro / Website |
|--|---|
| Museums | Some museums are now offering virtual museum tours www.artsandculture.google.com |
| Activities | NAPA (National Activity Providers Association) have a range of ideas for activities www.jweb.org.uk/events/dancesyndrome-free-online-dance-sessions Purple Patch Arts Activities www.purplepatcharts.org/daily-activities |
| Music | Gig Buddies Coronavirus fest live music on Facebook www.facebook.com/coronavirusfest/posts/107087974260788 You can stream classical music online. Many operas are also now available to stream online too. You could search for some of these by visiting the website operavision.eu or search on YouTube.com for 'Opera on the Sofa' or 'The London Symphony Orchestra'. |
| Live Zoo Feeds | San Diego zoo www.animals.sandiegozoo.org/live-cams Edinburgh Zoo www.edinburghzoo.org.uk/webcams/penguin-cam/#penguincam |
| Exercise and Health | Live well in isolation www.nhs.uk/live-well British Heart Foundation 10 minutes living room workout www.youtube.com/watch?v=O5YX5xg8Seg&feature=youtu.be Gentle chair based exercise video www.youtube.com/watch?v=nkLjS5B64Rs&feature=youtu.be Mind Well www.mindwell-leeds.org.uk/home/information-on-coronavirus Leeds Rhino's foundation wake up shake up www.youtu.be/1dnNEQyBRok |
| Supporting older people and those living with dementia | The silver line www.thesilverline.org.uk/what-we-do/ Dementia UK information for families looking after individuals with dementia www.dementiauk.org/get-support/coronavirus-covid-19 Information for families regarding coronavirus www.alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care |
| eBooks, eAudio and EMagazines | Leeds Library www.leeds.gov.uk/leisure/libraries/ebooks-and-eaudio |

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|------------------|---|
| Theatres | Many theatre productions are now available to stream online. You could search for some of these by visiting YouTube.com and searching for 'National Theatre.' You could also visit www.willowsmusical.com |
| Online colouring | The colour www.thecolor.com Colour by numbers www.coloritbynumbers.com/online |
| Self Help | You can try some applications like Headspace, Unmind, Sleepio and Daylight. Try meditation, there are different resources like www.oxfordmindfulness.org/for-you/resources |

TV / radio resources

| Type | Programme Details |
|------------|--|
| Television | <p>HealthCheck UK Live, is a new daytime programme on BBC One which will feature Mr Motivator providing expert advice on getting people active and keeping healthy. Presented by Angela Rippon, Michelle Ackerley and Dr Dr Xand van Tulleken, it will offer health advice and companionship for people at home.</p> <p>The Green Goddess exercise segments will feature on BBC Breakfast at approximately 6.55am and 8.55am on Monday, Wednesday and Friday. These will be streamed, either live or pre-recorded, from her home. Following her TV segments, the videos will then also be shared across BBC Breakfast's social media accounts.</p> |
| Radio | <p>5 live Sports Extra and BBC Sounds are teaming up with Sport England to broadcast a series of exercise programmes designed for the older generation. '10 Today' is a collection of ten 10-minute exercise programmes designed to get older people more active in their homes. Each weekday 5 live Sports Extra will broadcast a new exercise, repeating it every 15 minutes between 0500 and 1000 for two weeks. The complete collection of all 10 exercises will also be available as podcasts on BBC Sounds from Monday morning.</p> |



Useful contacts

Medical Emergency – 999 / Less Urgent – 111 or www.111.nhs.uk

Already receiving specialist mental health services?

If you're already receiving care from Leeds and York Partnership NHS Foundation Trust, then you will have a contact for your Care Co-ordinator or another health professional in the team looking after you.

These contact details might be written in your care plan. If you cannot find this or you need urgent help accessing our services, call our **Single Point of Access** on **0300 300 1485**

Helplines for carers that offer information, advice and support

Carers Leeds

Tel: **0113 380 4300**

(Mon, Tue, Thu, Fri 9.00am-4.30pm, Wed 8.00am-6.30pm)

Dementia UK **admiral nurses** Freephone: **0800 888 6678** or email helpline@dementiauk.org.

National Careline

Freephone: **0800 0699 784**

Carers UK

Freephone: **0800 808 7777** (Mon and Tues 10am-4pm)

Carers Direct

Tel: **0300 123 1053** (Monday to Friday 9am-8pm, Saturday and Sunday 11am-4pm)

Alzheimer's Society

Tel: **0333 150 3456** (calls are charged at normal network rate) or local Leeds number on Tel: **0113 231 1727**

Emotional support

Mind can provide information on a range of topics such as different mental health problems, where to get help (including support in your own area), medication and alternative treatments and advocacy. Tel: **0113 305 5800**. (Mon to Thur 9am-5pm and Friday 9am-4pm)

Samaritans is a free and confidential 24/7 telephone service that offers the opportunity to talk about how you're feeling and explore support options. Tel: **116 123** (free) or **0113 245 6789**

Cruse Bereavement Care

Tel: **0113 234 4150** or **0844 477 9400**

Practical support

The Trussell Trust provide emergency food parcels. Tel: **01722 580 171**

Voluntary Action Leeds offer help with shopping, collecting medicines, transport to medical appointments, welfare checks and dog walking. Tel: **0113 378 1877**

Citizens Advice Bureau offer free, confidential advice about money, legal, consumer and other problems. Tel: **0300 330 11921** (Mon to Fri 9.30am to 4.30 pm). You can also chat to an advisor online at:

www.citizensadvice.org.uk/contact-us

Other advice and support

Age UK – If you need advice or information on money, care or health. Tel: **0800 678 1602**. (open 8am to 7pm, every day of the year). They also have a website www.ageuk.org.uk

Silver Line is a confidential, free helpline for older people across the UK that's open 24 hours a day, every day of the year. For information, friendship or advice tel: **0800 4 70 80 90**. They also have a website www.thesilverline.org.uk

Independent Age offers advice about care, money and health for older people. Tel: **0800 319 6789** (Mon to Fri 8.30am to 6.30pm and Sat 9am to 1pm)