

# Resource pack for care homes during the COVID-19 pandemic

Developed by Bristol Dementia Wellbeing  
Service, Devon Partnership NHS Trust

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We are here to help:



Contact your DWS Senior Dementia Practitioner directly  
Call our Access Point: 0117 904 5151 (8am-6pm Mon – Fri)  
Or email us: [dpn-tr.enquiriesBristolDementia@nhs.net](mailto:dpn-tr.enquiriesBristolDementia@nhs.net)

## Reasons for developing this resource pack

We recognise that the COVID-19 pandemic is impacting significantly on care homes and raising particular challenges for care home residents, their families and care staff. With many care homes closed to visitors, and people at home advised to stay at home, residents may lack access to the stimulation, routines and support they normally receive. This is further complicated by staff shortages placing further pressure on staff with maintaining the health and wellbeing of residents.

Understandably these challenges may lead to care home residents having fewer interactions, which can lead to boredom and anxiety. This is especially so for those needing to be isolated from others. Boredom can be a key trigger for distressed behaviours such as aggression, calling out and seeking reassurance. This resource pack is designed to firstly help all staff think about ways in which they can make a connection with residents and maintain wellbeing at this difficult time.

This resource pack brings together lots of useful guidance (produced by NHS teams across the UK) on a range of issues:

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\*To jump to a particular topic press 'Ctrl' key and click on the relevant page number.

Please note we have also created a separate resource pack focussing on supporting the wellbeing of care staff.

## Talking about COVID-19 with residents

People living with dementia are likely to have noticed that the world is currently a little different and may be asking “what is happening?”, “why can’t I go out?”, “why has X stopped visiting?”. Others with more significant cognitive difficulties may not remember everything, but may be feeling that things are different or that they have not seen a certain person in a long time. Those living with dementia are likely to be experiencing the same feelings of uncertainty, fear, anxiety, agitation and frustration, and thus it is important to ensure that we talk to and reassure people living with dementia about COVID-19.

### STEP 1: Help the Person living with dementia to feel safe & reassured

- When we feel anxious we communicate this through our body language and tone of voice
- People living with quite advanced dementia are often able to tune into our emotions and will pick up on our own anxieties about COVID-19
- Try to show your sense of humour, make jokes, smile, laugh and communicate safety and reassurance to help them feel at ease

### STEP 2: Communicate effectively

- Ensure the person has what they need to communicate well (e.g. hearing aid, glasses), make eye contact and (whenever possible) let them see your face
- Break down information into manageable simple facts
- Consider using tools to help:
  - Communication cards (<http://www.aphasiafriendly.co/covid-19-accessible-information.html>)
  - Easy read COVID-19 information sheet (<https://www.mencap.org.uk/advice-and-support/health/coronavirus-covid-19>)
- Allow time to understand and to ask questions – don’t rush this conversation
  - May need to repeat things as asking somebody to remember lots of new information

### STEP 3: Explain what the virus is

- If the person has intact verbal communication skills, the impact of COVID-19 is similar to a “nasty flu” and “is contagious”.
- People living with dementia are less likely to learn and retain unfamiliar terms such as “coronavirus”, “social distancing” and “self-isolation” so generally avoid these
- Explain that the most common symptoms are a “dry cough” and/or a “high temperature” (“fever”)
- Highlight importance of washing hands regularly (see separate detailed guidance on this).

### STEP 4: Explain why we have to keep our distance & restrict our movement

- Phrases like “contagious flu” will help the person to understand the severity
- Say that “the flu spreads when people are too close” so “we need to stay apart to stop it spreading”.
- Mention “government guidance” is for “everyone to stay at home” to “keep them safe”. You could add that “spending time in the garden or a short walk is allowed”
- It may be reassuring to add that “the government is taking this very seriously, and want to protect people”

### STEP 5: Explain why family and friends cannot visit presently

- Explain that the Government are “telling everyone to stay at home” and that “this is to keep us and our family safe, and to avoid people living becoming ill”.
- Explain that this means that, whilst family may still want to visit, “the Government cannot allow this” and repeat the phrases “the Government is taking this very seriously” and “we want to protect people living”.
- Use this conversation to start to explore alternative ways for the person living with dementia to keep in touch with their relatives and friends including; phone calls, video calling or letters.

### STEP 6: End the conversation with reassurance & answer any questions

- Smile and use positive statements like “we will get through this” and “this won’t last forever”.
- Support the person to ask follow up questions, using the ‘easy read’ and visual prompts if required.
- Repeat the information –whenever necessary – word for word - at regular intervals.

## Ideas for Activities

While it may seem surprising to focus on meaningful activities during this crisis, evidence shows that if we keep people engaged in tasks that they enjoy and offer appropriate stimulation then we are less likely to see behaviours that challenge.

- Display activities that will happen in the home on a visual activities planner (make sure activities that are not possible in the current climate are removed to avoid disappointment).
- Individual risk assessments are needed to ensure any activities are safe for people to do (taking into account their Covid-19 status and physical/cognitive/emotional difficulties).
- Build handwashing into the start and end of activities wherever possible and ensure activity items are thoroughly cleaned after use.



## Activities continued...



For further ideas see the **College of Occupational Therapists Toolkit for Care Home Staff** (for a range of helpful tips for engaging care home residents, including what to do if you have less than 5 or 15 minutes):

<https://www.rcot.co.uk/about-occupational-therapy/living-well-care-homes-2019/a-z-activities>

## Further activities to maintain wellbeing & reduce distress

- I. **‘Reminiscence’** – Useful for those distressed/preoccupied by the here and now
- II. **‘Simulated Presence Therapy’** – Useful for those feeling disconnected from family and friends

### Intervention 1 – ‘Reminiscence’

- If the person living with dementia is acutely distressed about the COVID-19 pandemic and preoccupied by events in the here-and-now, consider supporting them to reminisce about more positive life events.
- This may be done through generating a life story, looking at old photographs, looking at photographs of celebrities and familiar places, looking at ‘old’ objects and games, watching ‘old’ films and documentaries and/or listening to ‘old’ songs. NOTE – ‘old’ is generational specific, identify the period in time for which the person living with dementia has the ‘strongest’ and fondest memories.
- Some of the benefits of ‘reminiscence’ work are said to include;
  - Improved social interaction and self-esteem
  - Aids communication/gives a point of reference for dialogue
  - Provides diversion and distraction, and reduces agitation
  - Promotes concentration
  - Provides a way to affirm who the person living with dementia is and what they have accomplished in their life
  - Enables a discussion of older memories, which are more likely to be intact (“able memory”).
- However, take care, as the memories evoked may be unhappy. If you know the person living with dementia well, then you will know what topics to avoid (if your intention is to improve their current sense of wellbeing).
- You may find the reminiscence ‘prompt’ cards on the following page particularly helpful if you struggle to bring to mind potential topics to reminisce about, questions to ask and/or activities to do. We would advise you to print and cut these out, and place them in convenient locations around the person living with dementia’s home, for ease of access.

## Reminiscence Activities



### Reminiscence

#### Work

When did you leave school?  
What chores did you do as a child?  
What did you do as a job?  
What hours/days did you work?



### Reminiscence

#### Work

Can you remember work colleagues/friends?  
How did you travel to work?  
What did you spend your first pay packet on?  
Did you enjoy your job?



### Reminiscence

#### Family

What did you dad do for a living?  
What did you mum do for a living?  
Do you have any brothers or sisters?  
Do you have any children, nieces or nephews?



### Reminiscence

#### Family

Do you remember your grandparents?  
What did you spend your pocket money on as a child?  
When you were a teenager what did you do with your friends?  
Games played as a child?



### Reminiscence

#### General Subjects

Do you enjoy doing any hobbies? (Knitting, sewing, woodwork, sports?)  
Do you remember going to your first dance?  
Have you ever met a famous person?  
Have you ever gone to see a musician play live? Who is your favourite musician?



### Reminiscence

#### General Subjects

Does any smell bring back a particular memory?  
Do you play any musical instrument or ever tried?  
What is your favourite T.V programme?  
Do you like to watch any sports? (tennis, football, rugby)



### Reminiscence

#### General Subjects

What is your favourite foods?  
What foods or drinks do you dislike?  
What kind of films did you enjoy going to watch at the cinema?  
What is your favourite film?



### Reminiscence

#### General Subjects

What is the best age to be?  
Do you find that listening to music changes your mood?  
What is the one thing that would brighten up your day?  
What relaxes you? (bath, a manicure, sitting outside)?  
What is your favourite plant?



### Activities

Cleaning the windows  
Going for a walk in the garden  
Looking at a newspaper  
Looking at a magazine or book of interest  
Helping tidy/put things away  
Doing a puzzle (crosswords etc in activity cupboard)



### Activities

Doing an activity (active ties in cupboard)  
Playing skittles  
Playing catch  
Playing cards/dominos  
Looking after the dolls (doll therapy)  
Talking about the wall art  
Music CD sing-along

## **Intervention 2 - Simulated Presence Therapy**

### **Context**

Simulated Presence Therapy (SPT) was developed by Woods & Ashley (1995) as an intervention to reduce levels of anxiety, agitation and behaviours that challenge (formerly known as 'challenging behaviours') in people living with dementia.

### **What is it?**

It involves a close family member/familiar carer making an audiotape or videotape of their voice, usually reminiscing about memories that are significant and happy to the person living with dementia. This tape is then played using headphones through a smart phone, tablet device, personal stereo, CD /DVD. It should be played in a quiet room.

### **Theoretical Background**

The theory is that SPT is effective as the voice of a close relative ('adult attachment figure') can reduce separation anxiety experienced by the person living with dementia by replicating a carer's presence. An environment is created that may provide comfort through stimulation of preserved remote memories ('old' or 'long-term' memories) and the positive emotions associated with those memories.

This is particularly important when thinking about the impact of self-isolation – and associated enforced distancing from family members as a result of the COVID-19 pandemic – on someone living with dementia.

### **Evidence Base**

As with many 'non-pharmacological' interventions, SPT has been evaluated by a limited range of studies and there is little agreement between the studies about the how effective it is or for whom it is most effective.

The most recent review of the evidence was a systematic review and meta-analysis (Zettler, 2008). The review suggests that there is some evidence to support the use of SPT but that due to the small number of studies and some methodological weaknesses, the results need to be treated with caution. They conclude that the individuals most likely to benefit from SPT are:

- Those living with moderate to severe dementia who are unable to remember the content of the audiotape (i.e. they will not remember they have heard the recording before).
- Those who do not have a hearing impairment.
- Those who have retained conversational skills.
- Those who had previous secure attachment styles.
- Those who have/had a significant and high quality relationship with the person who created the audiotape.

There were wide variations between the studies in how often SPT was used with individuals. Some studies used it routinely twice per day and some only after an episode of agitation was observed by staff.

- If in isolation, ask close family members to send recordings digitally via text or email.

## Behaviours that challenge & meeting universal needs

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. Alternatively, the person might try to meet the need for themselves in a way that can feel challenging (e.g. constantly walking due to feeling bored).

To work out how best to help a resident, especially if you notice a change in their behaviour, consider the eight universal needs that we all share (see image).



It may be more difficult to meet these needs during the pandemic. Difficulties might include:

- Providing meaningful and reassuring touch due to use of PPE
- Giving opportunities for fun and enjoyment due to social distancing
- Enabling residents to be active, especially those who are shielding

For an excellent short video on this topic hold down the 'Ctrl' key on your keyboard and click on the picture to follow the link to YouTube.



Care homes across the UK have been very inventive in tackling these issues. On the next page are ideas and suggestions to help meet resident's needs and sustain their wellbeing during the pandemic.

Universal Needs	Ideas and Suggestions (see YouTube video: <a href="https://www.youtube.com/watch?v=blJjUwBhVpk&amp;feature=youtu.be">https://www.youtube.com/watch?v=blJjUwBhVpk&amp;feature=youtu.be</a> )
Physical comfort	<ul style="list-style-type: none"> <li>Consider the following:               <ul style="list-style-type: none"> <li>Is the person suitably dressed for the conditions (e.g. temperature, sun in their eyes)?</li> <li>Could they be hungry / thirsty / tired / constipated?</li> <li>Might they be disturbed by noises around them (e.g. from a TV)?</li> <li>Might pain-relieving medication or a change in position (a short walk or stretch) help?</li> <li>Could they be more active and make use of a garden (whilst maintaining social distance)?</li> </ul> </li> <li>Remain extra vigilant for signs of pain/discomfort (other health professionals are less present)</li> <li>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.</li> </ul>
A sense of belonging	<ul style="list-style-type: none"> <li>Help the person connect with important people in their life – friends, family members, other members of the community etc. through cards and letters</li> <li>If the technology is available try video-calling (e.g. FaceTime, WhatsApp, Zoom, Skype).</li> <li>Take advantage of schemes like ‘Adopt a Granny’ where volunteers make regular contact with older people (e.g. <a href="https://chdliving.co.uk/adopt-grandparent">https://chdliving.co.uk/adopt-grandparent</a>)</li> <li>Look through photos together to help them remember significant family members and events.</li> <li>Keeping familiar or comforting items close by might help, e.g. a favourite jumper or keepsake.</li> <li>Keeping in regular contact with chaplains and other religious leaders (e.g. online services)</li> </ul>
Reassurance and pleasure from meaningful touch	<ul style="list-style-type: none"> <li>No rinse shampoo and conditioner caps – residents can have their hair washed and a gentle head massage from staff allowing them to feel pampered without direct physical contact</li> <li>Using therapeutic dolls and soft toys (shown to have benefits for some but not all residents)</li> </ul>
To have fun and enjoyment	<ul style="list-style-type: none"> <li>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?</li> <li>Exercise classes, competitions, balloon ‘volley ball’ (see the ‘Ideas for Activities’ section above)</li> <li>Entertainers performing remotely or from a distance in the garden</li> </ul>
To feel safe and secure	<ul style="list-style-type: none"> <li>Keep distressing TV or radio programs to a minimum</li> <li>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.</li> <li>Reassurance and explanation (repeat as much as necessary):               <ul style="list-style-type: none"> <li>Offer plenty of reassurance that they are safe and that you are there to help them.</li> <li>Offer an explanation of the situation in a way that the person can understand.</li> </ul> </li> <li>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.</li> <li>Be aware of the pace they can manage their everyday activities, try to avoid rushing them.</li> <li>Wearing washable photos of themselves over PPE so residents can tell who they are</li> <li>Make sure rooms are well lit where possible to avoid misinterpreting shadows</li> </ul>
To feel valued and treated with dignity & respect	<ul style="list-style-type: none"> <li>Support the person in using the skills they still have:               <ul style="list-style-type: none"> <li>Can they help with practical tasks in their room?</li> <li>Are there activities they still enjoy which connect them to a previous job role and sense of meaning/purpose?</li> </ul> </li> <li>Ensure to provide lots of positive praise and compliments on activities done.</li> <li>Help residents to look their best e.g. a blow dry can help people feel good about themselves</li> </ul>
To feel in control of one’s life and possessions	<ul style="list-style-type: none"> <li>Help the person feel in control of their surroundings as much as possible. e.g. offering choices in food, clothing and activities (2-3 options if too much choice is overwhelming)</li> <li>Providing cleaning tools so residents can maintain their bedrooms to their own standards</li> <li>Staff taking extra time to introduce themselves, ask if it’s ok to enter residents’ rooms, and giving the reason for wanting to enter (to provide a sense of control over their own space)</li> </ul>
Being active or occupied	<ul style="list-style-type: none"> <li>Try some chair exercises or other indoor exercises.</li> <li>Support the person with activities they can still manage e.g. listening to music (there are lots of concerts/performances currently available online), arts &amp; crafts, puzzles, games, household jobs (dusting, washing/drying up), relaxation.</li> <li>Ask family and friends to send cards, photos, voice/video messages etc. and review together.</li> </ul>

## Supporting people who ‘walk with purpose’

### Previously referred to as ‘wandering’

There are normally many positive aspects to people living with dementia ‘walking with purpose’ (e.g. exercise, stress reduction), so it is often appropriate to provide safe walking areas, rather than deny people the opportunity to engage in this behaviour (James, 2011). Under normal circumstances, we would not attempt to treat /intervene with ‘walking with purpose’ unless: there is a risk to the person’s nutritional intake; it is causing extreme fatigue; risk of falls; or distress to the person or others. However, if the person has a suspected or confirmed case of COVID-19, the care home may receive clear medical guidance to isolate the resident to their bedroom (Gordon et al., 2020).

We know that most behaviours that challenge happen around interactions with carers when they are trying to get people to do what they do not want to do, either to stop some problematic behaviour (e.g. stop going into someone else’s room) or to start a behaviour aimed at enhancing a person’s wellbeing (e.g. start taking medication or start getting washed/dressed) (Stop Start Scenarios). If care home staff are instructed to isolate a resident and stop them ‘walking with purpose’, this intervention itself may trigger an escalation in behaviours that challenge (e.g. physical/verbal aggression).

There are many common biopsychosocial causes of walking with purpose (James, 2011). Understanding the reason or **need** that the ‘walking with purpose’ is meeting / trying to meet for the person will help us to decide what interventions might be appropriate to try to meet this need.

To help understand why the person living with dementia ‘walks with purpose’, you may find it helpful to answer the following questions:

- **Prior to COVID-19 what was their level of activity?** Have they always been a person who walks a lot or is this something new? Did they enjoy a daily walk outside? Perhaps they walked for a newspaper or walked the dog each day?
- **Do they ‘walk with purpose’ because they have ‘time shifted’ and believe they are elsewhere?** They may believe they are at work or in their childhood home. If so what did they do for a job, what were their hobbies and routines?
- **What do they do when they ‘walk with purpose’?** – Do they gather things, rub surfaces, move furniture, push/pull items or go into different rooms? Do they say anything when doing this? Are they seeking out a particular person, place, company, food or reassurance?
- **Are they usually safe ‘walking with purpose’ or is there a falls risk?**
- **Is there a time of day when they are more likely to need to be active and ‘walk with purpose’?** Is the time of day significant to them? For example, is it the time they used to go to/return from work, is it the time they would do a specific chore, e.g. walk the dog or collect the children?
- **What sort of things (or time of day) are they more likely to sit down for?**
- **Think ‘PINCHME’ (PAIN, INFECTION, CONSTIPATION, HYDRATION, MEDICATION, ENVIRONMENT)** to rule out treatable causes of symptoms.

We may not be able to eliminate the risk or stop the person ‘walking with purpose’ completely, but every effort needs to be made to meet the person’s needs in other ways while they are isolated, minimising the risk.

## Primary Preventative Strategies

- Things we do to improve the person's quality of life and reduce the likelihood of Behaviour that Challenges)

Interventions need to be chosen according to what we think the unmet need may be. The following is not an exhaustive list, but ideas could be:

### Exercise seekers:

- Playing 'football' with a large exercise ball up and down the corridor, when others are not around, or in their room if it is large enough.
- Dancing to lively music that they like.
- More use of garden areas if on the ground floor. Allow them time in the garden when others are not using it and encourage them to be active e.g. carrying a watering or sweeping.

### Being busy seekers:

- Can they have an individualised rummage box in their room that has objects that are more easily sanitised?
- Encourage them to sort their drawers and wardrobe, even if this means messing things up first so that they need to sort, fold and put the things away.

### Reassurance / company seekers:

- The BGS guidance recommends that care homes should take advantage of videoconferencing software on smartphones, tablets and portable computers as much as possible to maintain human contact for residents (Gordon et al., 2020).
- Consider Simulated Presence Therapy (SPT) if the sight or sound, on audio or video, of a loved one may provide comfort and reassurance. Having a video/audio recording may enable care home staff to play this repeatedly if videoconferencing contact is forgotten by residents with dementia.
- If the person is calm and does not walk if they have another person with them this may build a case for a period of one to one staff support.

### Environmental adaptation:

- Try to make the person's room as recognisable as their space and homely as possible. Family cannot come in to visit but may be willing to drop off some extra items to help with this. If the room is not enriched, they will seek elsewhere.
- Do they have access to individualised music (such as Playlist for Life)?
- Do they have access to a TV and programmes on that do not need too much understanding of language? Be careful of having the news on or programmes with distressing content that they may interpret as real.
- Do they have access to a DVD player and DVDs of familiar and favourite films, sports they like?

## Secondary (reactive) strategies

- Things to do when we notice a behaviour occurring or getting worse (i.e. if a resident tried to leave their room)
- People are most likely to 'walk with purpose' when they have moderate/severe dementia. At this cognitive level, the person will have little understanding of what is said to them and is unlikely to be aware of, or retain information about "coronavirus" or "COVID-19". They are unlikely to benefit from verbal explanations about the risks to themselves or others of leaving their room.
- A simple explanation such as "There is a nasty flu", "We need to stay in our rooms" may be helpful.

### If the person cannot be encouraged to remain in their room:

- Close other's bedroom doors, unless this is a risk, as they are less likely to open a closed door.
- Can a portion of the unit be given over to them so they have the space to move around?
- If you are trying to get the person to stop doing something (i.e. walking), you may have to walk with them and match their speed, then gradually change the rhythm or pattern rather than opposing them (Snow, 2012).
- Avoid telling a person to stop doing something, instead greet them with a smile and a wave, say their name and ask the person for help with something. Ensure the task/activity is meaningful to them and their interests.

### References:

Gordon, A., Burns, E., Astle, A., Barker, R., Kalsi, T., Williams, C., and Clegg, A. (2020). *Managing the COVID-19 pandemic in care homes. GOOD PRACTICE GUIDE*. [www.bgs.org.uk/COVID-19](http://www.bgs.org.uk/COVID-19).

James, I.A. (2011). *Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment*. Jessica Kingsley Publishers.

Snow, T. (2012). *Dementia Caregiver Guide; Teepa Snow's Positive Approach techniques for caregiving, Alzheimer's and other forms of dementia*. Cedar Retirement Community.

## Tolerating Personal Protective Equipment

During the COVID-19 pandemic medical, care and mental health professionals may need to wear Personal Protective Equipment (PPE) such as aprons, gloves and masks more often than before, especially when completing personal care with individuals with a confirmed COVID-19 diagnosis.

This could obviously be quite disorientating and potentially scary for a person living with dementia, especially if they have some level of cognitive impairment, and have not seen such PPE before or have not seen a professional wearing such attire. It is worth imagining how it would feel if someone came into your room first thing in the morning wearing PPE equipment.

For individuals who may already find personal care/self-care interventions difficult to tolerate, the introduction of PPE equipment is likely to exacerbate this distress. Unfortunately it will also make it more difficult for the individual with dementia to recognise carers that they are possibly familiar with, further exacerbating their distress. Additionally, if there is a lot of staff sickness within the team who usually look after the person living with dementia, 'new' members of staff may have to attend to the person living with dementia's needs, again risking further distress.

Here are some suggestions as to how you can reduce such PPE-related distress:

- Ensure all new staff or bank staff **familiarise themselves with care plans** before attempting to assist, even where time is limited.
- **Buddy up** experienced staff with less experienced staff to ensure continuity of approach, particularly for individuals living with dementia who find personal care difficult.
- **Prepare everything** you need in advance of the task you are completing to minimise the time spent in the equipment, or preparing the equipment in front of the resident.
- To support the person living with dementia to recognise you and/or understand who you are you may wish to **write your name and role on your PPE gown/clothing**.
- Before you go in to see the person living with dementia, **notice how you are feeling**. If you are anxious or scared, the person living with dementia may pick up on your body language or facial expression, and are likely to feel the same. Take a deep breath and try to remain calm, positive and reassuring when entering.
- **Knock on the person living with dementia's door and enter slowly**, greeting them using their name and introduce yourself with a smile, stating your name and your role (don't assume they know who you are).
- See how they respond and **allow them to get a good look at you** before approaching.
- **Acknowledge the mask or specific PPE equipment** you are wearing saying "Sorry I look a bit funny today, I'm wearing this to protect us both from any bugs or germs we might have".
- If you have already spoken to the person living with dementia about COVID-19, and they have retained this, **refer back to this discussion about the virus**.
- Depending on the individual, **you could make a joke about your gear**, "I look like an astronaut" or "Would you wear something like this?"
- If the person living with dementia finds it difficult to understand you with the mask on, **consider using laminated signs with basic information** e.g. 'I'm here to help'. Ensure these are appropriately sterilised as per infection control guidance.
- **Use all the skills you would usually to put the person living with dementia at ease**, talk about their family or pictures in their room/house. Hum a tune together or get some relaxing music on in the room. All of these things should help to settle the individual and ensure a sense of connectedness is maintained.

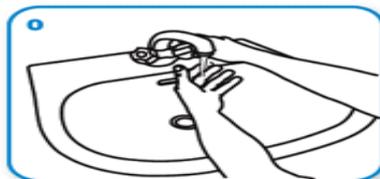
## Supporting People with hand washing

Whilst handwashing is crucial to reducing the spread of COVID-19, it is something that a person living with dementia may struggle to do. This may be due to cognitive impairment and/or sensory difficulties.

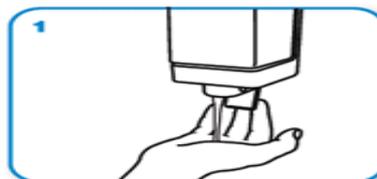
People living with dementia can experience aversion to the smells, images, sounds and the tactile sensations of hand washing. They may also have problems with balance, muscle tone or co-ordinating their hand movements, not understand the step-by-step process of hand washing, or simply lose concentration and forget what they were doing.

The following suggestions should be tailored to the specific strengths and difficulties of the person living with dementia whom you are supporting to hand wash;

- **Explain the process of hand washing using the World Health Organisation's (WHO) step-by-step hand washing guide if needed:**



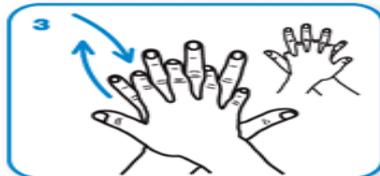
Wet hands with water



apply enough soap to cover all hand surfaces.



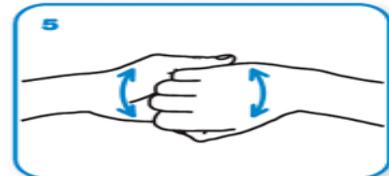
Rub hands palm to palm



right palm over left dorsum with interlaced fingers and vice versa



palm to palm with fingers interlaced



backs of fingers to opposing palms with fingers interlocked



rotational rubbing of left thumb clasped in right palm and vice versa



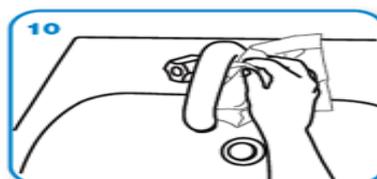
rotational rubbing, backwards and forwards with clasped fingers of right hand in left palm and vice versa.



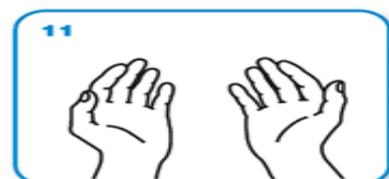
Rinse hands with water



dry thoroughly with a single use towel



use towel to turn off faucet



...and your hands are safe.

Here is the link should you wish to print:

[https://www.who.int/gpsc/clean\\_hands\\_protection/en/](https://www.who.int/gpsc/clean_hands_protection/en/)

- **Prompt hand washing** at appropriate times, either verbally, by gesture (miming turning a tap or rubbing one's hands together), or using a handwashing image or poster. If required you may need to physically help the person living with dementia to wash their hands. Remember to promptly give praise and acknowledgement each time they wash their hands.
- **Tackling sensory issues** - If you know that the person living with dementia has a preference for liquid soap or solid soap bars ensure that the correct one, and ideally the preferred/usual brand, is to hand. Also find out if they favour a particular smell, or if they prefer unscented soap. If they dislike the sensation of touching soap, consider placing the soap in a fabric pouch, so they only have to touch the suds.
- **Water Temperature.** Assessing a safe water temperature may be difficult for the person living with dementia, and they may need assistance. Some people living with dementia may find slightly warm water more tolerable than cold water.
- **Antibacterial Hand Gel** - If soap and water are really not an option or not available, then use antibacterial hand gel. You may need to demonstrate how to use this and assist. Again, you may need to investigate whether scented or unscented ones, gel or spray ones are preferred.
- **Hand Lotion** - Some people living with dementia are distracted by the tactile sensation after they have washed their hands. Investigate if this is eased by using a preferred hand lotion immediately afterwards. Repeated hand washing can also dry out the hands, so consider using hand lotion regularly after hand washing.

Supporting someone living with dementia to effectively hand wash will be particularly important if they are unable to refrain from touching their face.

In discussing the difficulty of getting someone living with dementia not to touch their face, Teepa Snow (Dementia Care Expert) states:

*"It's not going to happen, so we've got to let go of that one. The face is a highly sensitive part of the human body, the hands are highly sensitive parts of the human body, and the more that someone is anxious or nervous from losing contact with other human beings, what else are they supposed to do with their hands? Touching the face is one of the very first things babies ever do in the world, and we're saying now that we've got to get them to not do that? That's not going to happen. The idea that we can regulate behavior of someone who is [living with dementia], to not do a habitual behavior that is based on a sensory need, is illogical."*

Here is a link to the 'being patient' interview with Teepa Snow:

<https://www.beingpatient.com/covid-19-dementia-caregiver-steps/>

## End of Life & Bereavement

Conversations about death and dying can be uncomfortable. During this COVID-19 crisis, these conversations will likely become more frequent and we need to respond in helpful ways. The following section includes some ideas to support someone who may be dying, knows someone who may be dying, or is bereaved.



### Common reactions to the news of death

- Shock and numbness
- Overwhelming sadness
- Tiredness or exhaustion
- Anger
- Guilt

These feelings may not be there all of the time, and powerful feelings may appear unexpectedly and suddenly.

The residents you are supporting may not have experienced a recent bereavement; but due to the news frequently covering stories relating to death and dying, the current crisis may bring up memories of past losses. Experiences of bereavement and loss are individual; there is no right or wrong.

### Supporting people to talk about someone's death

#### Consider the environment and surroundings

If you are having a conversation about end of life or bereavement, think about how the environment can be helpful:

- Try to reduce time pressures or interruptions
- Find a quiet, private place to talk
- Consider the time of day that the interaction takes place, and whether the resident generally better able to communicate in the morning/afternoon
- Give the person your full attention – try to avoid distractions

Adapted with permission from the 'Talking to people about dying during the Pandemic' guide that was kindly shared by Oliver Bekarma, Deborah King, Joanna Marshall, Susannah Thwaites (Tees, Esk and Wear Valleys NHS Foundation Trust)

## General Advice

- It is okay to say “I don’t know what to say but I am here for you to listen and help”. Follow the lead of the person so that they feel in control of the time you are with them
- Let the person know that crying is a normal way to release feelings. It is important that people do not keep their emotions bottled up.
- Use your non-verbal communication skills (open body language, gentle smile and nod)
- Don’t force them to talk
- Try to avoid clichés e.g. ‘I understand how you feel’; ‘You’ll get over it’; ‘Time heals’ these can sound impersonal. Being genuine, concerned and empathic will convey a sense of comfort and support.
- Show them you have listened by checking out you have understood what they have said and summarising what they have told you
- Try not to worry about “saying the wrong thing”. It is better to address the situation than ignore it.
- If you can’t think of something to say, offer your support, eye contact, and ask what you can do for the grieving person
- How long a person needs to grieve is entirely individual
- Allow the individual to talk to you about other people who have died if they want to. Such news will bring up memories of other deaths.
- A series of short conversations is often easier than a long conversation.
- Talk openly and honestly if they need to about pets left behind, funerals.
- Some people need an end to the conversation and doing something practical and physical can help. Cooking, exercise, tv.

## Practical tips

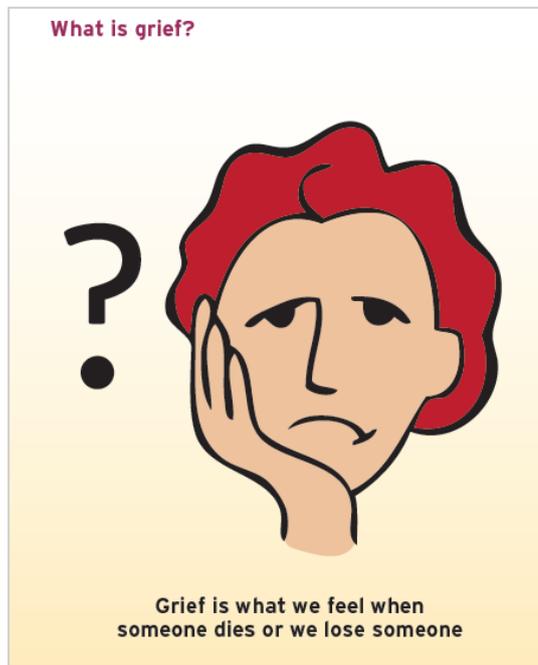
- Allow residents to talk to other people about the person who has died
- Encourage residents to eat properly and try to get enough rest (even if they can’t sleep).
- Try to set routines – this might be to re-establish old routines or set new ones
- Provide a comfortable place to relax
- Perhaps provide information for residents to seek help and support if they need it e.g. information about chaplaincy support if they are religious.
- Depending on the person’s abilities, communication cards may help to explain concepts about grief (see next page)

## Look after yourself too

- Don’t feel guilty if you’re struggling – ask for support from others
- Consider your own wellbeing – you may be struggling with your own worries too
- Stay grounded. Try to remain calm, gentle and present despite the chaos around us
- Talk to colleagues too about these issues. We are all human.

## Communication cards about grief

Depending on the person's abilities, the following images may help to facilitate conversations about grief. Please follow this link for the full *Bereavement Loss and Dementia* brochure from Cruse: <https://www.cruse.org.uk/bereavement-and-dementia>



Grief could be caused by:		A Funeral	
	Someone dying		A funeral is a gathering when someone dies
	A medical diagnosis		People come together to remember and talk about the person who has died
	A pet dying		They may sing songs and say prayers
	A relationship ending	<p>It can help to go to the funeral, but it is OK if you do not want to go.</p>	
	Not being able to reach a goal you wanted		
	Not being able to do the things you used to		



**Bereavement can affect different people in different ways.**

**It can affect:**

- Feelings
- Thoughts
- Behaviours
- Physical reactions
- Relationships

**Feelings**

**You may feel:**



Sad / upset



Angry / frustrated



Confused



Lonely

It's okay to have lots of different feelings

**Thoughts**

**You may:**



Have difficulty concentrating



Feel confused



Have difficulty making decisions



Have a loss of confidence in your abilities

**You may have thoughts such as:**



"Why me?"



"I feel lonely and scared"



"It can't be true"



"Will I always feel this way?"

### Behaviours

You may find you:



Eat more / less



Sleep more / less



Cry



Want to talk



Not want to talk

### Physical reactions

You may:



Get headaches



Feel sick



Feel pain



Get short of breath



Feel exhaustion

### Relationships

Relationships may change - a death can:



Bring family and friends together



Push family and friends apart



Make you feel alone even when you're with people

You may feel sad on special days:



Anniversaries



Holidays and festivals



Birthdays

### What helps:



Sharing your feelings with someone you are comfortable with



Give yourself time



Remember it's ok to go through a hard time

Other things that might help:



Eat properly



Try to get enough rest



Do the things you normally do

**Do things that may give you comfort, such as:**



Visiting the grave/a place that holds special memories



Making a book of sympathy cards



Making a memory book/box about the person



Finding a poem, saying or song that helps



Planting something in memory of the person



Putting together a calendar to help you plan and look forward to coming events

**Remember:**



What you decided to do is up to you



Acceptance takes time

“Grief doesn’t always disappear with time, this doesn’t mean you will always feel as bad as you do right now because life will grow around the grief”

“It’s okay for grief to be part of your life”  
(Lois Tonkin)

## Supporting residents approaching end of life

### How to start a conversation with someone about end of life

- You know that you have COVID-19 and that you are very unwell, is that something that's on your mind. Do you know what is happening?
- If you were to become more unwell, what would be important to you?

### How to tell someone that they are dying

This should **only** be done by a healthcare professional when it is clear that the end of the life is near.

- Making sure you have enough time so that the conversation won't be rushed.
- If possible, have the conversation in a place that's comfortable for the person and where you won't be interrupted.
- Ask the person if they would like anyone else to be told, given that visits are limited with COVID-19. This could be a family member, carer or friend. They can support the person and help to check that they've understood what they're being told.
- Use clear language. Avoid euphemisms such as 'going to a better place'. Using the word 'dying' where appropriate can avoid confusion.
- If someone has difficulty communicating, there are things you can do to support them. Speech and Language therapists can help.
- Check that they've understood what you've told them.
- Allow them to ask any questions. If you don't know the answer, be honest and say you don't know. You can try and find out and let them know as soon as possible.

They may wish to explore:

- What will happen when they feel more unwell or the end draws near
- Making the most of the time that they have left
- What happens to their body after they die
- Spiritual and religious practices that are important to them

## Namaste care: Spirituality in end of life care for people with dementia 'to honour the spirit within'

Namaste care is a loving approach that focusses on gentle sensory experiences that are very individual to the person. These ideas are intended to be considered alongside things that are in keeping with the person's lifelong religious or spiritual beliefs and traditions and also alongside medical aspects of care such as pain management as this is also an important aspect of Namaste.

Being with a loved one at the end of life is a basic human drive but is much more complex during the current rules about social distancing and shielding due to the COVID-19 pandemic. Whether or not families are able to be with the person staff could encourage them to consider the following so that they feel included in a special way despite possibly not being physically present with the person. We know that where and how people die lives long in the memories of those left behind.

### Touch

Touch is nurturing and a powerful human connection and communication and an important element of any Namaste intervention:

- Holding or stroking the person's hand – gloved hand is better than no hand.
- Stroking their hair.
- Applying creams or lotions in the form of a simple hand massage to provide loving touch rather than just for providing 'care'.
- Gently washing their face with a warm cloth.
- Ask the family to provide something for their loved one to cuddle- a cushion or family toy.
- Consider tucking the person in with sheets/blankets so that they feel secure (but not so tightly that they feel restrained)

### Sounds / Music

Hearing is the last sense to be affected by the dying process:

- Having a recorded message or a letter from loved ones that can be read by staff saying goodbye and talking about happy memories.
- The four simple phrases suggested by Dr. Ira Byock, are "Please forgive me," "I forgive you," "Thank you," and "I love you".
- Nature sounds; did they love the countryside, seaside, birds, animals, being beside water?
- Music that they loved and meant something to them; this could be religious in nature or just a favourite piece.
- Reading aloud a favourite book, passage, poem as well as prayers.

### Smell

Smell more than any sense is linked to memory and emotion:

- Smells that remind them of a special person or relationship; perfume / aftershave / soap that person used.
- Smell that reminds them of a favourite pastime or experience; baby powder, cut grass, flour, compost.
- Essential oil diluted in water- lemon balm is safest in a room spritz or on a tissue on the person's pillow.

### Taste

The person may not be eating in any normal sense but having favourite tastes applied on the sponges to their tongue may be possible during mouth care.

### Visual

- Soft lighting that is not too bright or harsh.
- Flowers nearby (is this appropriate in the setting)

### References / Resources

- Simard, J. and Volicer, L., 2014. *The end-of-life Namaste Care program for people with dementia*. Health Professions Press, Incorporated.
- Kendall, N., 2019. *Namaste Care for People Living with Advanced Dementia: A Practical Guide for Carers and Professionals*. Jessica Kingsley Publishers.
- Stacpoole, M., Thompsell, A. and Hockley, J., 2016. Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes. London, UK: St Christopher's.
- Byock, I., 2013. *The best care possible: A physician's quest to transform care through the end of life*. Penguin.
- <https://namastecare.com/namaste-care-individual-program/>

## Further resources

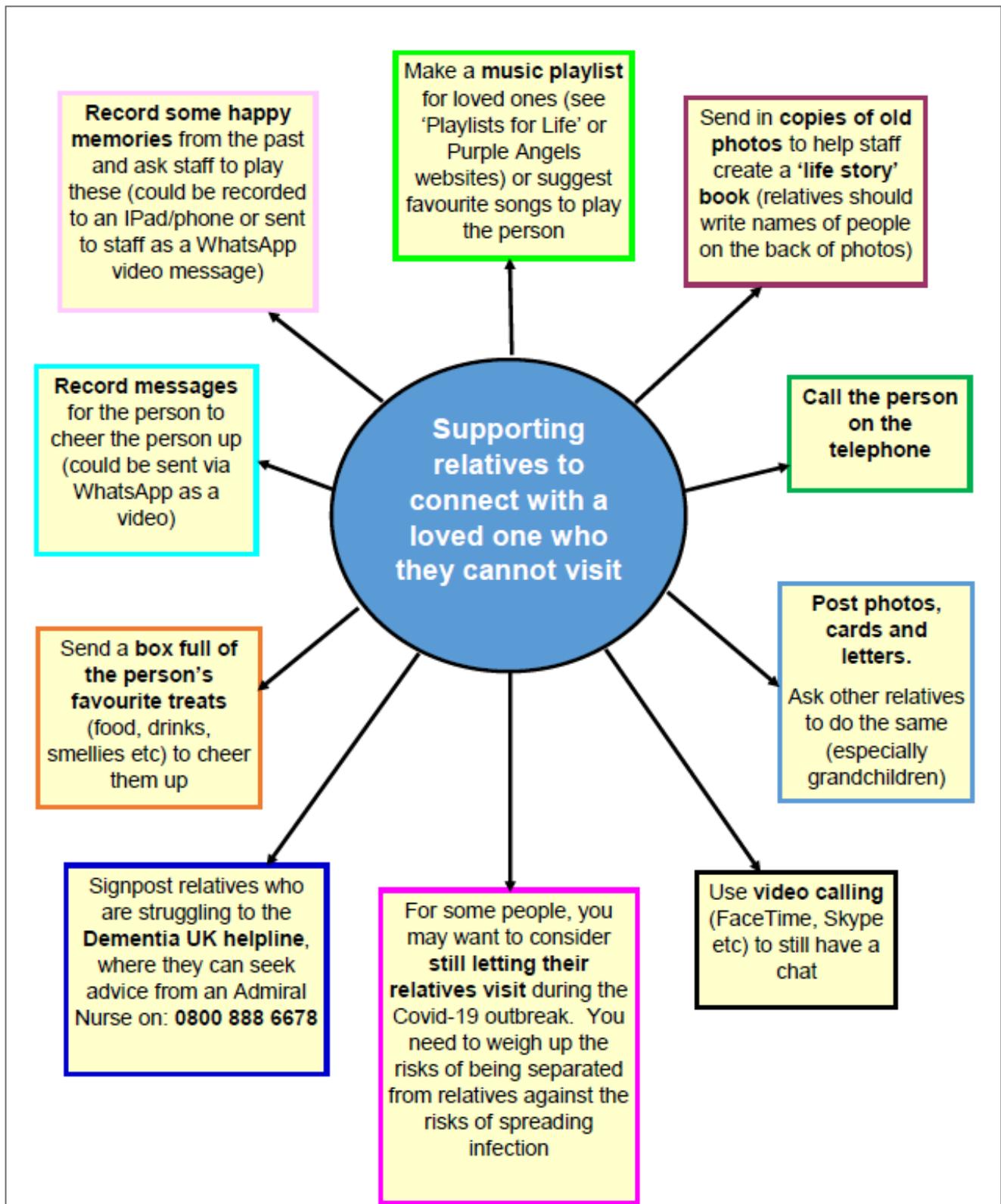
### Further advice and strategies:

- **Cruse Bereavement care:** <https://www.cruse.org.uk/get-help/coronavirus-dealing-bereavement-and-grief>
- **The Irish Hospice Foundation:** <https://hospicefoundation.ie/bereavement-2-2/covid19-care-and-inform/>

### GriefChat

- GriefChat is a safe space for grieving or bereaved people to be able to share their story, explore their feelings and be supported by a qualified bereavement counsellor. In addition to this, GriefChat can help bereaved people to consider if they need additional support and where to get this from. Using GriefChat is free of charge and is open Monday-Friday, 9am-9pm (UK time) to grieving or bereaved people. [www.griefchat.co.uk](http://www.griefchat.co.uk)

## Activities for Relatives



## Chaplaincy Support for Care Homes

In times of stress, many people find their religion helpful and comforting. However, during the current COVID-19 pandemic, religious ministers and priests will not be able to attend care homes. NHS Chaplains want to support care home staff in any way they can remotely and have produced this document, which includes prayers and non-religious readings for people who are dying. You may not share the faith of your resident, but at this time, if they request a prayer or you think it may help, it is perfectly acceptable for people who do not share the faith of those asking to pray with them.



### Christian Prayers and Readings

#### The Lord's Prayer

*This prayer is familiar to all Christians; saying it with a patient can be comforting. The patient may or may not join in if you say this. Please note that the last two lines (in italics) are not used by Roman Catholics*

Our Father, who art in heaven,  
hallowed be thy name;  
thy kingdom come;  
thy will be done;  
on earth as it is in heaven.  
Give us this day our daily bread.  
And forgive us our trespasses,  
as we forgive those who trespass against us.  
And lead us not into temptation;  
but deliver us from evil.  
*For thine is the kingdom,  
the power and the glory, for ever and ever. Amen.*

#### The Hail Mary

*This is a prayer familiar to all Roman Catholics and saying it with them may be comforting. Once again they may or may not join you in saying this.*

Hail Mary, full of grace. The Lord is with thee.  
Blessed art thou amongst women,  
and blessed is the fruit of thy womb,  
Jesus.  
Holy Mary, Mother of God,  
pray for us sinners,  
now and at the hour of our death.  
Amen.

#### Psalm 23

*This psalm is associated with difficult times as the words indicate. It can be used with any Christian or Jew. Patients who ask you for a prayer may be comforted if you simply say this.*

The Lord is my shepherd; therefore can I lack nothing.  
He makes me lie down in green pastures and leads me beside still waters.  
He shall refresh my soul and guide me in the paths of righteousness for his name's sake.  
Though I walk through the valley of the shadow of death, I will fear no evil;  
For you are with me; your rod and your staff, they comfort me.  
You spread a table before me in the presence of those who trouble me;  
You have anointed my head with oil and my cup shall be full.  
Surely goodness and loving mercy shall follow me all the days of my life,  
And I will dwell in the house of the Lord for ever.

#### Psalm 23 - Authorized (King James) Version

*This version of Psalm 23 may be more familiar for people from the Church of England.*

The LORD *is* my shepherd; I shall not want.  
He maketh me to lie down in green pastures:  
he leadeth me beside the still waters.  
He restoreth my soul:  
he leadeth me in the paths of righteousness for his name's sake.  
Yea, though I walk through the valley of the shadow of death,  
I will fear no evil: for thou *art* with me;  
thy rod and thy staff they comfort me.  
Thou preparest a table before me in the presence of mine enemies:  
thou anointest my head with oil; my cup runneth over.  
Surely goodness and mercy shall follow me all the days of my life:  
and I will dwell in the house of the LORD for ever.

## **How to support a resident when they cannot attend the funeral of a loved one**

When patients in hospital wards have been unable to attend family funerals in the past, Chaplains have sat with them and offered to say some of the words that are used in a funeral service (if it was a Christian funeral).

If you feel comfortable, care home staff could offer to do this for residents who cannot attend the funeral of a loved one.

You may wish to begin with the prayers above – The Lord’s Prayer, The Hail Mary and Psalm 23, and possibly some of the prayers that follow.

## **Key moments in a Christian funeral service**

There are key moments in a Christian funeral service. Firstly, the commendation when we simply commend the soul of the departed to God. That is followed by the committal, when the body that has carried the soul is committed either to the ground or to be cremated.

It may be helpful if somebody were to read these words quietly for the resident at the time of the funeral.

### **The Commendation**

*This is when we simply commend the soul of the departed to God.*

God our creator and redeemer,  
by your power Christ conquered death and entered into glory.  
Confident of his victory and claiming his promises,  
we entrust (name of person) to your mercy in the name of Jesus our Lord,  
who died and is alive and reigns with you,  
now and for ever. **Amen.**

### **The Committal**

*This is when the body that has carried the soul is committed either to the ground or to be cremated.*

We have entrusted our brother/sister (name of person) to God's mercy,  
and we now commit his/her body to the ground/to be cremated:  
earth to earth, ashes to ashes, dust to dust:  
in sure and certain hope of the resurrection to eternal life  
through our Lord Jesus Christ,  
who will transform our frail bodies  
that they may be conformed to his glorious body,  
who died, was buried, and rose again for us.  
To him be glory for ever. **Amen.**

## **Prayers to support people with other religious faiths**

Chaplains work with people of all faiths and none. There are further prayers to support Muslim, Sikh, Buddhist, Hindu and *Jewish people* – *please contact the Chaplaincy team if you want us to send you a copy of these.*

## **Worship and prayer streamed**

Many churches are streaming their worship and prayer in real time. It might be worth contacting local ministers and priests to see if this is happening locally.

## **Prayers for people who are dying**

*These prayers can be said with people who are dying. There are some prayers for Christians, but also some words that may bring comfort to people who are not religious*

### **For Christians**

God of mercy, look kindly on (name of person) as death comes near. Release Him/Her, and set Him/Her free by your grace to enter into the company of the saints in light.

Be with us as we watch and wait, and keep us in the assurance of your love; through Jesus Christ. **Amen**

Loving and merciful God, we entrust our brother/sister to your mercy.

You loved him/her greatly in this life; now that he/she is freed from all its cares, give him/her happiness and peace for ever. The old order has passed away; welcome him/her now into paradise where there will be no more sorrow, no more weeping or pain, but only peace and joy with Jesus, your Son, and the Holy Spirit, for ever and ever. **Amen.**

### **For people who are not religious**

Into the freedom of wind and sunshine

We let you go.

Into the dance of the stars and the planets

We let you go.

Into the arms of death that waits for us all

We let you go.

Think not that you are dying but remember that you lived.

Go gently on your voyage, beloved.

Let love call you home with the ebb tide.

May the moon light a way across the waters for you.

May the earth cradle you,

The breeze blow you swiftly

Until you reach the place where your weary vessel need labour no more,

Go gently, beloved, go.