

For families and carers

thoughts on death and dying during the Covid-19 pandemic

Introduction

Coronavirus (Covid-19) has had a major impact on how we experience and think about many aspects of our lives, including the end of our lives. Daily media broadcasting of statistics and personal stories of people who have died or are seriously ill confronts us all with our human vulnerabilities and mortality. For those who already have health issues, are in an especially vulnerable group or have a family member with dementia living at home or in a care home, this is a particularly anxious time.



The pandemic has, in many ways, rewritten the route, and rituals, we might normally expect to follow with respect to death and dying. Everyone's situation is different so there can be no standard response to help with coping during this time, but you may find some of the following information, suggestions and resources helpful.

Coronavirus and dementia

A diagnosis of dementia on its own is not thought to make someone more vulnerable to catching coronavirus but the association with older age and other life-limiting conditions does increase the risk of serious illness. Also, a person with dementia may experience difficulties in following the rules and guidance aimed at protecting us all, such as, social distancing, self-isolating, and regular hand washing, so creating a potentially greater risk of exposure to the virus.



You can find a fuller guide on coronavirus written specifically for people with dementia and carers [here](#).

Coronavirus is often portrayed in the media as a frightening experience where the person requires intensive care in hospital to be kept alive, unable to breathe on their own without the help of a ventilator. It is important to note that for many people it is a mild illness, even for many of those in vulnerable groups, and most people can be supported successfully in their home environment. The person living with dementia may of course become unwell as a result of other health problems. Should admission to hospital be necessary, regardless of the reason, some helpful advice is available [here](#).

Care and support for those who are dying

Where someone with dementia does become seriously unwell, especially those with advanced dementia and those experiencing additional health conditions, it may be that admission to hospital, with intensive care and ventilation, would not be in the person's best interest. There may be little prospect of recovery and interventions of this nature could cause unnecessary distress. Medical staff may assess the person would be better cared for within their current place of residence, in a familiar setting, with family, friends or staff who know, love and understand them. It is important to acknowledge that dementia is a life-limiting condition and that a person with a diagnosis of dementia will die with, or of, dementia.



Covid-19 and associated measures to control it have changed the way care and support of a dying person is delivered, including the involvement of family and friends. Where people may have gathered together to spend time with the dying person and be involved directly in their care, restrictions due to the virus have made much of these normal and important activities impossible. Health and Social Care staff in all settings have demonstrated exceptional levels of skill and empathy during this period and many have been a channel of connection between relatives and friends and the person who is dying as never before.

If the person with dementia is in hospital or a care home where visiting has been severely restricted, the end of a person's life is deemed to be an 'exceptional circumstance' and visits are facilitated, albeit likely to be only closest relatives for a restricted time and with associated conditions, such as the wearing of protective clothing and equipment. The guidance around visiting [care homes](#) and [hospitals](#) is changing as restrictions ease and continuously under review. Refer to the [Scottish Government](#) website for the most up to date details.



Marie Curie have some helpful information about the care a person receives at the end of their life in relation to coronavirus which you can read [here](#).

Respecting the person's wishes

The important thing is that the best, most appropriate care is given in the most suitable environment for each and every individual. Ideally the care is assessed in conjunction with the family and informed by any known wishes of the person. These wishes may or may not be written down. The person may have discussed and completed an Anticipatory Care Plan (ACP) with their relative, health professional or care home staff and a Do Not Resuscitate form (DNR) may already be in place. They may have a Welfare Power of Attorney or Guardian who has the legal right to be consulted but even if this is not the case the carer views as someone who knows the person are very important.

Recognising your feelings

Each step of the person's dementia will have brought about changes to the relationship you have with the person you care for, along with a range of accompanying emotions. This pandemic is a time of heightened feelings when you might find that your emotions may change from moment to moment, hour to hour, or day to day. This may seem overwhelming and uncontrollable. You may find yourself bursting into tears and behaving irrationally. However, distressing as this is, it is normal. Your emotional state is likely to impact on your physical health e.g. you may experience a knot in your stomach, loss of appetite, or have difficulty sleeping.



The feelings you experience may include:

- **Fear:** this emotion can be fuelled by imagining the worst-case scenario, not trusting the staff who are looking after the person you care about, or fearing how life will be when the person is no longer with you. You may also be fearing how distressed the person will be without you and how you are unable to protect them.
- **Anger:** there are many reasons why anger may take over. It is often driven by fear and can be a destructive and exhausting emotion.
- **Guilt:** it can sit on our shoulder whispering in our ear 'if only I had...', 'I should be there ...'. Feelings of guilt are part of loving someone, the current situation is not your fault. You will have demonstrated your love over and over again, and deep down the person you love and care for will know how much you care.

Things that might help:

- If possible, try not to let your imagination run ahead of you. Take each day as it comes.
- You may find it helpful to have time on your own reflecting and perhaps writing down how you are feeling.
- Try some therapeutic activities such as reading poetry, painting or taking part in some kind of meditation. The Mindfulness Association runs free, live, daily sessions which you can try [here](#).

Saying goodbye

This is a difficult time where being with someone when they are dying may be restricted. Never assume this will be the case for you, always ask if you can visit. Staff will be as accommodating as possible. It might help to think about saying goodbye as not being one specific event. For some, saying goodbye to a person with dementia may happen at different points as the illness progresses but for others this will not be the case. It is important to remember that there are many ways of connecting other than physically being with the person. Everyone will be different and some of these ideas and approaches may or may not work for you but are worth considering:

- You can talk or sing on the telephone or iPad. You can also make recordings of your voice or music you know the person enjoys.
- You can send items that you think might bring comfort.
- A photograph of the person, sent to you from care staff, might be reassuring – for example, if you can see that the person is peaceful.
- A shared reading or prayer, sitting quietly in a garden or other place special to the person (or both of you), talking to the dog/cat or simply focusing your thoughts on the person may be the right thing. Writing or reading a letter to your loved one. We all have very individual ways of saying goodbye and each is to be respected.

Tell staff your fears, they will be able to advise and support you. You will not be a nuisance!

Organising and attending the funeral

The person may not have expressed any wishes about how they wanted to die but may have left detailed instructions of the type of funeral they would like. Coronavirus may prevent honouring these instructions and leave the family feeling they have let the person down.

Changes to funeral ceremonies during the pandemic have been especially challenging as funerals are culturally a rite of passage and an important ritual. They are an opportunity to celebrate the individual's life, a chance to say goodbye and a way of offering support and love for the individuals closest to the person. After the funeral the 'wake' is an important part of healing.

How funerals are being held is changing all the time and undertakers along with spiritual and religious leaders will accommodate your wishes as best they can. Do feel you can still discuss what your plans would have been, even if they are not all possible, you and everyone involved will know you have done your very best under the circumstances and there may be some compromises that can be made whilst still adhering to the coronavirus restrictions.

Increasingly, funerals are available to watch online at the time of the service and for a few weeks after. A benefit of this is that families and friends from far and wide can be part of the service. Frail relatives who perhaps would have struggled to attend in person can now tune in from the comfort of their home to pay their respects. Ask the undertakers about this online option. Orders of service can be emailed to people beforehand so that they can more fully participate.

Gathering after the funeral is currently not permitted under the coronavirus restrictions – [see here](#) for more details: However, you could meet up with a large group of family and friends online to celebrate the person's life, arrange phone calls to each other, or commit to a get-together when restrictions ease.

The Scottish Government have also taken into account specific religions burial needs during coronavirus outlined [here](#).



Coping after the funeral

Bereavement is different for everyone. We all cope in unique ways. Your way is right for you. Life after a death and the funeral is always difficult. This is likely to be compounded with social distancing, being unable to hug, hold hands and give comfort in the usual ways. You may feel very isolated and alone. Ensure you have someone you can talk freely to, when you need to. This may be with a family member or by phoning a helpline where you can be anonymous. See links to organisations who provide a listening ear:

Alzheimer Scotland

24 hour Freephone Dementia Helpline: 0808 808 3000

Samaritans

Helpline: 116123



24 HOUR
Dementia
Helpline



**Alzheimer
Scotland**
Action on Dementia

Freephone 0808 808 3000
Email helpline@alzscot.org