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## GUIDANCE

# Death and grieving in a care home during Covid-19: The experience of care staff, residents and families

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Many people enter a care home because they are no longer able to live independently in their own home. For these people, the care home is their home.

*'There is growing international evidence that people living in care homes are particularly vulnerable to severe COVID-19 infections and that they are experiencing high rates of mortality as a result<sup>1</sup>.*

In these unprecedented times, there are understandable additional pressures, fears and challenges for residents, care staff and their family and friends.

This document should be read with *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic<sup>2</sup>* which is a guide to help people to understand their experience of grief during this strange and challenging time. The document explains some of the emotions which people may experience and also offers some advice on what might be helpful.

The circle of people who look after and support care home residents are presented with a unique set of circumstances. Care staff will have similar experiences of grief but they will also have experiences that are different. This means that the support they need may be different.

## THE EXPERIENCE OF CARE STAFF

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Residents in care homes are generally older and more frail and, because of this, death of a resident is something that is expected in a care home. This means that death is something that care staff regularly have to cope with. While care staff have considerable experience of death, it does not make each death any easier to cope with.

Care staff develop close relationships with the residents that they care for. The resident can feel like part of their family. The experience of loss and grief can be the same as when any member of the family dies. What is not normal in the Covid-19 pandemic is the number of residents that are dying in a short time. While care staff may have developed ways of coping with the death of one resident, they may find it much more difficult to cope with the death of multiple residents in close proximity.

Part of the role in supporting a resident at the end of their life is to offer comfort, relieve symptoms and preserve dignity. Care staff may be concerned that they were unable to care for the residents in the way that they would have liked to because of the restrictions on contact and the need to wear Personal Protective Equipment (PPE). How a resident dies in a care home now, during the time of Covid-19, may be different than what would normally happen. Family and friends are not permitted to visit. All of the support and care is offered by care staff. Care staff need to support the resident but also offer comfort and reassurance to their loved ones who are naturally distressed because they were unable to be there.

Care staff may be more frightened when offering care, regardless of whether the resident has tested positive for Covid-19 or not. Thinking about this fear and the need to change the way care is offered may cause feelings of guilt. This misplaced guilt can have a negative impact and add to the experience of grief. It is important to understand that fear is normal and it is essential that the way care is offered changes in order to protect care staff, the resident and others.

What can help care staff is to focus on all of the care. They should remember what they are pleased with, what they are good at and did well. Staff should be reminded that there might be times it is not exactly perfect, but this happens in the complex care work they provide.

The experience of grief is happening at the same time as care staff worry about their own health and the health of their family at home.

Normal ways of coping with the death of a resident before restricted visiting and physical distance may no longer be available. Covid-19 can evoke a range of feelings such as of powerlessness and despair. Staff shortages as colleagues become ill and the availability of PPE are an additional cause of pressure, stress and anxiety which impacts on grief. Everyone is experiencing the stress and the experience of loss but we all manage this experience differently. Some people will cry, others may be angry and others may use humour. Care staff will rely on their colleagues more than ever but at times, may also become angry or irritated by them during these circumstances.

The whole care team is very important to the residents at this vulnerable time in their lives. Remembering together all of the efforts everyone has made, all of the thought and care the team has given, is an important way of reflecting the essential role they provide. There are many suggestions of what might help in the *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic* document.

**Note to Care Staff** – Be kind to yourself and make sure you find things to do to help you to cope with how you feel. Managing your own grief and that of residents and their families is a huge burden.

## THE EXPERIENCE OF STAFF WHO DID NOT KNOW THE RESIDENTS WELL?

Even if care staff don't know someone well, their role at this stage of the residents lives has value and makes a difference. Even with all of the changes that Covid-19 brings, being present, talking, caring and thinking how best to help someone will have made a difference.

Working in many settings at this stage and possibly hearing about many deaths can feel overwhelming. A staff member may not know the rest of the care team that well, for various reasons, but they should be encouraged to reach out. Sharing feelings, fears and distress can help connect people who are in a similar position.

Care staff should look out for resources at the start of a shift. Who is there to help with the practical tasks? Who will guide you through the process and who can you speak with if your resident has died?

## THE EXPERIENCE OF RESIDENTS LIVING IN A CARE HOME DURING COVID-19

Residents have a range of strengths and weakness and so how they respond will be different. Some may be aware of the seriousness of the situation through the news, care staff and what they can see happening around them. Others may be aware that something serious is happening but not fully understand what it is. Even residents in the moderate to later stages of dementia will be affected by the changes in the day to day life of the care home. They may experience a range of emotions, sadness, anxiety, low mood, anger, frustration or numbness. This means that they will need more emotional support at a time when staff have less time and may be less available to listen because of their own worries.

Residents will notice that care staff are wearing PPE, busier, anxious or not at work. New staff that they don't know may not support them in the same way as the regular staff. All of this will increase their anxiety. When we are worried we turn to the people we love and trust for comfort and support. Residents are unable to see loved ones face-to-face because of restricted visiting and may not fully understand why they do not visit and may also be worried about them. If they don't have someone to share their worries with they may become more worried and feel very lonely.

There are also likely to be changes to normal routine. Residents may not be spending time in the lounge or the dining room with the people they normally would. They are being asked to keep a physical distance from people they normally sit close beside. This can feel very unsettling and they may not fully understand why this is happening.

Some residents may not be able to come out of their rooms because they are unwell or have tested positive for the virus and others will have died. They will be missed by some of the other residents who will ask where they are. Some residents may become more distressed as they worry about what is going to happen to them or because they don't understand what is happening.

## THE EXPERIENCE OF FAMILY AND FRIENDS

Family and friends may experience a range of different feelings following the death of a loved one living in a care home. Many of these will be similar to the experiences detailed in *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic* but others will be different.

In the same way that families of people who have died in hospital feel, they may be worried about how their loved one died. The difference is that the person died in familiar surroundings with the staff they knew well. This should give family some comfort during this very difficult time.

Some people may feel relief that the person has died, particularly if they have been frail for some time or they were at the end stages of dementia. They may then experience guilt as a consequence of this relief.

With dementia, the person and those who love and care for them experience a series of losses as the condition progresses. Some people may have grieved for the person some time ago as the person lost ability and dementia changed their relationship.

**Note to family and friends** – It is important to know that all of these feelings are normal. There is no right or wrong way to grieve. Be kind to yourself and talk to family and friends about how you are feeling.

Follow the advice in *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic*.

## HOW CAN STAFF SUPPORT RESIDENTS?

Try to maintain communication with residents, even if it feels like it's always sad news. As we know, older people are a wise and resilient group. Even if care staff feel that residents will become more distressed, they should talk to them, as they are already aware that something is happening.

For residents who have additional needs with memory and understanding the guidance *Supporting older people and people living with dementia during self-isolation*<sup>3</sup> and *Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic*<sup>4</sup> will help. Information may need to be repeated many times if residents forget and ask questions again. For some residents you may feel it is better to focus on their personal wellbeing and distraction, using a gentle statement such as 'yes there are sad things happening but we're here to help you'.

The usual focus on activity and wellbeing is really important. Routines and being connected to other people are important ways to feel safe. Try to support residents to maintain contact with family and friends by phone or video calls. Are there school children or local people who could send messages?

Remember that residents may feel apprehensive with staff wearing PPE so explain to the residents that is to protect them from the virus. Create a laminated card with your name and picture on it to help them to understand who you are.

## WHAT CAN MANAGERS DO TO SUPPORT CARE STAFF?

Managers and supervisors may not know what to say or may worry about saying the wrong thing. This situation is not like anything any of us has experienced before.

Staff may be feeling powerless, overwhelmed and feel that there is nothing they can do. It is important to remind them how important their care has been and how much they are valued.

Managers will be very busy at this time with numerous demands on their time. It is essential, however, that staff feel that they can speak to and seek support from senior colleagues.

Where possible, develop rotas to accommodate regular and more frequent breaks. This may be difficult in a climate of reduced staff and creativity may be required. Time out is essential for staff at a time when their work can be emotionally draining.

At the end of a shift offer a check-in with staff to ask how they are feeling. It can be helpful for staff to come together at their end of a shift to recognise how difficult the shift has been and to offload feelings before they go home. This can be a challenge with staff shortages but it doesn't have to be a long session, even 10 minutes would be enough. Some people may not want to do this but for others it can be helpful. Check-ins should be facilitated, if possible, by a senior member of the team who can offer support.

Consider ways that the staff can collectively remember the residents who have died and celebrate the person's life.

Services such as CRUSE or local wellbeing helplines can offer support and advice.

## SUPPORT SERVICES

CRUSE bereavement care has a range of resources and a 24-hour helpline.

<https://www.cruse.org.uk> 0808 808 1677

## REFERENCES

- <sup>1</sup> Adelina Comas-Herrera (CPEC, LSE) and Joseba Zalakain (SIIS) 12 April, 2020 Mortality associated with COVID-19 outbreaks in care homes: early international evidence. <https://ltccd.org/2020/04/12/mortality-associated-with-covid-19-outbreaks-in-care-homes-early-international-evidence/>
- <sup>2</sup> The British Psychological Society (2020). *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic*. <https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Supporting%20yourself%20and%20others.pdf>
- <sup>3</sup> The British Psychological Society (2020). *Supporting older people and people living with dementia during self-isolation*. <https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Faculties/Older%20People/Supporting%20older%20people%20and%20people%20living%20with%20dementia%20during%20self-isolation.pdf>
- <sup>4</sup> Duffy, F. & Richardson, J. (2020). *Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic*. Northern health and Social Care Trust. <http://www.northerntrust.hscni.net/clear>



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