

Death and grieving in a care home during the COVID-19 pandemic

**A guide to supporting
staff, residents and
their families**



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

This document should be read with *Grief and bereavement during the COVID-19 pandemic: supporting yourself and others*, which is a guide to help people to understand their experience of grief during this strange and challenging time.¹ It explains some of the emotions which people may experience and also offers some advice on what might be helpful.

The circle of people who love and support care home residents presents 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

Residents in care homes are generally older and more frail, and because of this, the 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 their 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. 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 have been more frightened when offering care, whether the person had tested positive for COVID-19 or not. Thinking about this fear and the need to change the way care was offered may cause feelings of guilt. This misplaced guilt can have a negative impact and add to the experience of grief. It is important that care staff understand that fear is normal and recognise that it was essential to change the way care was offered in order to protect them, the resident and others. They should be encouraged to think about the whole picture, remember what they are good at and what they did well. There might be times when this wasn't perfect, but this happens in complex care when there are many demands on staff time and they are working in challenging situations. When we do our best it is good enough.

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 everyone manages this experience differently. Some people will cry, others may be angry and others may use humour. Care staff need their colleagues more than ever but at times may also become angry or irritated by them. These reactions are normal under the circumstances and are not a sign of not coping.

The experience of staff who did not know the residents well

Some new or agency staff may feel unsupported or overwhelmed as they navigate their way around new colleagues and unfamiliar procedures. They may not yet feel part of the team so it will be important that they share concerns with managers or more experienced colleagues and make use of any support mechanisms that have been put in place for staff.

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 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 concerns 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. There are likely to be changes in behaviour as residents try to make sense of what's happening. The document *Supporting carers and care staff to understand and respond to changes in behaviour in people with dementia during the COVID-19 pandemic* may be helpful.²

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 the document *Grief and bereavement during the COVID-19 pandemic: supporting yourself and others* but others will be different.¹

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 progressively lost abilities and dementia changed their relationship.

It is important for family and friends to know that all of these feelings are normal. There is no right or wrong way to grieve. They need to be kind to themselves and talk to family and friends about how they are feeling. The advice in the document *Grief and bereavement during the COVID-19 pandemic: supporting yourself and others* may be useful.¹

How can staff support residents?

It is important for care staff to keep open channels of communication as the residents will already be aware that something is happening. Residents too need to feel involved and confident that they have the most up-to-date information. Many residents will have faced adversity or challenges throughout their life and have developed strong coping mechanisms and resilience. Their expression of distress and sadness is appropriate and they will benefit from talking to care staff and knowing that they are there to offer support and reassurance.

For residents who have additional needs with memory and understanding, the guidance *Supporting a person with dementia following a bereavement during the COVID-19 pandemic* will help.³ It explains how to tell a person with dementia that someone has died and highlights the need to repeat information to help with remembering and understanding. A structured routine will also help to increase feelings of safety and security, as will maintaining contact with family and friends through phone or video calls where possible.

Care staff should explain to residents that they have to wear PPE to protect the resident and the staff from the virus. It may be helpful for staff to create a laminated card with their name and picture on it to help the resident to understand who is providing the support.

What can managers do to support care staff?

Managers will have many additional demands at this time, and can also feel overwhelmed on occasion. Being visible, available and supportive in words and actions demonstrates strong leadership and creates a protective environment.

Ensuring clear and regular communication with staff is particularly important to ensure good team working and support. Rumours and anxiety breed in a vacuum of information, so regular communication is important even if there is nothing significant to report.

Tolerating and managing uncertainty both personally and for care staff will be beneficial and help decrease feelings of powerlessness and help care staff to appreciate the normality of their feelings.

Managers also need to be compassionate with themselves and demonstrate that we all need to look after ourselves. Part of this is enabling care staff to have down time in a shift without feeling guilty.

Where possible, managers should ensure care staff have regular breaks, access to healthy food and drinks, and rotas that allow for time to sleep and relax.

Developing buddy systems for junior or new staff can also promote collaboration and support.

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.

www.cruse.org.uk

0808 808 1677

Anyone who is in crisis and experiencing distress or despair can call the Northern Ireland crisis response helpline, Lifeline, on 0808 808 8000.

Local psychological helplines

All Psychology Helplines are open to staff from within the Trust, local GP practices, and Independent Care Providers.

All Trust helplines are available at the following times:

Monday to Friday, 9am to 9pm

Saturday and Sunday, 2pm to 6pm

Northern HSC Trust

028 9441 3644

Western HSC Trust

028 7161 1281

South Eastern HSC Trust

028 9250 1332

Belfast HSC Trust

028 9615 1888

Southern HSC Trust

028 3756 2600

References

1. Rooney N, Meekin S, Regional Bereavement Coordinators Network. Grief and bereavement during the COVID-19 pandemic: supporting yourself and others. Belfast: PHA, 2020. Available at: <https://www.publichealth.hscni.net/publications/covid-19-bereavement-resources>
2. Duffy F and Richardson J. 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, 2020. Available at www.northerntrust.hscni.net/CLEAR
3. Duffy F and Ballentine J. Supporting a person with dementia following a bereavement during the COVID-19 pandemic. Northern Health and Social Care Trust and Northern Ireland Hospice, 2020. Available at www.northerntrust.hscni.net/CLEAR



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