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GUIDANCE

Talking about death – End-of-life care guidance for the psychological workforce

'Neither the sun nor death can be looked at steadily'
(Francois de la Rochefoucauld, 1613–1680)

This quotation shows us that it has *always* been tricky to think about death never mind talk about it. This is not just a modern phenomenon. It is a taboo area. The way we communicate as staff is affected by these taboos and also by our own beliefs and experiences¹ and our personal beliefs and values can affect our clinical decisions and willingness to talk about death².

For most of us in psychology it has not been part of our work. And yet this Covid-19 crisis is forcing us to face our own fears and the fears of our colleagues, patients and carers like never before.

The Dying Matters coalition found that 68 per cent of the public reported that they are comfortable talking about death but less than 30 per cent of us have actually discussed our wishes around dying³. Only four per cent have an advance directive.

With the Hospice movement and the growth of palliative care, the idea of the 'good death' has become important in the last 50 years. The idea of a 'good death' has its origin in palliative care, where **open communication, relief of symptoms, individual dignity, respect and acceptance of death** are prominent features^{4,5,6}. We may have our own personal and professional recollections of 'good' and 'bad' deaths. Or we may not yet have encountered this at all. There is no one definition of 'a good death' – this varies depending on era, cultures and faith. Yet we know it is important and '*How people die remains in the memory of those who live on.*' (Dame Cicely Saunders – Founder of the Modern Hospice Movement)

And yet we also know that because of the nature of Covid-19 the way we might traditionally help people to have a good death will be severely challenged. People may feel that they cannot care for patients in the way that they would like due to restrictions on contact. This might lead to experiencing feelings of powerlessness and despair. Our usual coping mechanisms such as socialising with colleagues and gaining support and comfort from family and friends will not be available.

As managers and supervisors, we know it is our duty to support our teams and colleagues. However, this is difficult as we are all affected by the very same situation. We may be

managing this whilst being worried for the health of our own families, we may feel the pressure to 'fix' the situation and we may also be experiencing system pressures where we have to find quick and innovative solutions to problems that we have never experienced as a service. Never has the ability to work as a team been more important yet we may, conversely, experience anger and irritation at our colleagues. This context is important when we think about how we support each other and particularly our colleagues who are caring for patients who are dying.

HOW TO SUPPORT STAFF

Here is an offering of some guidance to help **managers and supervisors** support staff. It is not an exhaustive list and managers you will know your colleagues and how best to adapt this to suit their needs and your particular services. And many of you are already doing this.

REST

Build regular and increased rest breaks in for staff and where possible develop rotas with this embedded. This may be a challenge due to staffing shortages but it is very important that people have increased rest time due to the emotional toll of their work.

CONSIDER A CHECK-IN

It may be useful to consider introducing a check-in for staff at the end of rotas. This can be a twenty-minute space for staff to come together at their end of shifts. The purpose of this is to try to ensure that people have the space to offload difficult feelings before they go home. Some people will choose not to use this but for others this can be helpful. Check-ins should be facilitated, where possible, by a senior member of the team with experience of supporting teams.

INCREASED SPACE FOR SUPPORT

It is acknowledged that managers will be very busy at this time with numerous pulls on their time. However, it is essential that staff have access to senior colleagues during this time.

SUPPORT

Managers and supervisors may feel concerned about saying the wrong thing or not knowing how to support their colleagues in this time.

Acknowledgement of staff distress is important. As well as acknowledging staff distress, it is important to think through ways that staff can be kind to themselves and find comfort. Help colleagues think about the things that help them. Make sure that people have this time built into their day. This may include calls with their own family, taking time out off the ward etc.

Staff may be concerned that they cannot care for people who are dying in the way that they would like – help them think about alternative ways that they may be able to help them 'die well'. This may include supporting phone calls with relatives or by helping patients write letters for their loved ones. Remember to remind staff of all the ways that they are showing care to people – they may feel powerless and overwhelmed so it is important to help them think about how much they are doing and how much this is valued.

Consider ways of how the team can collectively remember patients who have died – staff will not be able to attend funerals so it is important to consider how we might develop memorials for patients such as using online platforms for example.

Be prepared for emotion – distress can be manifest in different ways, particularly at times of stress. Some people will cry, others may demonstrate anger or even humour. If a member of staff appears to be acting in a way that is uncharacteristic of them, consider whether this is a manifestation of distress and keep compassion at the centre of discussions.

GENERAL ADVICE FOR STAFF SUPPORTING END-OF-LIFE

End-of-life care is a dynamic process that is negotiated and renegotiated among patients, families and health care professionals. That is why knowing the person as well as you can and ongoing communication with them are so vital. And yet our challenge in this Covid-19 crisis is that we may not have time to get to know our patients. We need to explore how to have conversations with them, family and friends that can help us give them the most dignified death we can. This might be phone calls, Twitter, Skype other digital methods.

Patients, and particularly those with dementia, might not be able to verbalise their need for pain relief and their general needs for comfort and care; a particular feature of dementia is that an individual's communication skills deteriorate so that their ability to express their views and wishes is lost at an earlier stage than other life limiting conditions⁷. Dementia patients are unlikely to have any assessment of spiritual needs before death or documentation of any known religious beliefs⁸. People's ability to self soothe will decrease. They will be more reliant on others to recognise signs of distress and to bring comfort. E.g. music, smells etc.

WE KNOW IT IS IMPORTANT TO:

- Be sensitive to the person's feelings.
- Help the person to be remembered.
- Encourage the person to tell you what they're afraid of, even if it's hard to talk about.
- Not dismiss your own fears. They are important too.

ASK PATIENTS:

- How are you feeling?
- Is there anything you want to talk about?
- Is there one thing particularly frightening you?
- **Is there anything that helps you feel calm?**
- Check out 'How is this conversation going for you?'
- We also have to help a person have a conversation about **what is important to them**.

TOP TIPS

- **There are various ways to talk about dying – find the one that suits you and the person concerned.**
- It is important to take your cue from the other person.
- **Don't assume people don't want to talk. Often people do.**
- They may well change their minds about what they want for themselves so you need to keep on talking and listening.
- Focus on their achievements, relationships and values.
- Ask them what brings them comfort and sustenance.

SIGNPOSTING

There are times when we might be worried about our colleagues and we might feel that people require some additional or different support.

Greater Manchester Health and Social Care Partnership <https://hub.gmhsc.org.uk/mental-health/>

NHS Staff Helpline. The phone line will be open between 7am and 11pm every day and the text service will be 24/7.

0300 131 7000 or text FRONTLINE to 85258.

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

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

Take care of yourself – You won't have all the answers. Have your own support mechanism in place with colleagues to take care of yourself. There are more resources coming out each day.

Epilogue: Last word – from a person with dementia – interviewed about end-of-life 2017⁹
'It's like you said about you should talk about it making it easier, but even doctors and nurses they are still human aren't you, just because you're a doctor it doesn't make it any easier talking about what we were talking about now does it? ...So it must be hard for you all as well as it is for me, because we are all human aren't we.'

ACKNOWLEDGEMENT

This guidance has been adapted from *Supporting staff when caring for patients who are dying*, a Pennine Care NHS Foundation Trust document written by Polly Kaiser and Jayne Taylor.

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COVID-19 BEREAVEMENT WORKSTREAM CONTRIBUTORS

Prof Nichola Rooney, Consultant Clinical Psychologist; Chair DCP NI. (GROUP LEAD)

Dr Angel Chater, Chair Division of Health Psychology, University of Bedfordshire.

Dr Becci Dow, Consultant Clinical Psychologist, Vice-Chair (FPOP), Oxford Health NHS Trust.

Dr Frances Duffy, Consultant Clinical Psychologist, Northern Health and Social Care Trust, NI.

Dr Theresa Jones, Senior Research Associate, Anthrologica.

Dr Elaine Johnston, Lead ICU Clinical Psychologist, Chelsea & Westminster Hospital. BPS CDT Committee.

Polly Kaiser, Consultant Clinical Psychologist Pennine Care NHS Foundation Trust.

Prof Elaine Kasket, Registered Counselling Psychologist. Cyberpsychologist. University of Wolverhampton.

Dr Sarah Meekin, Head of Psychological Services Belfast Health & Social Care Trust.

Benna Waites, Consultant Clinical Psychologist, Wales. Co-chair DCPLeadership and Management Faculty.

Dr Elaine McWilliams Consultant Clinical Psychologist in End-of-Life Care, North Tees & Hartlepool NHS.



the british
psychological society
promoting excellence in psychology

St Andrews House,
48 Princess Road East,
Leicester LE1 7DR, UK

☎ 0116 254 9568 🌐 www.bps.org.uk ✉ info@bps.org.uk