

Talking to People about Dying during the Pandemic

During the COVID-19 pandemic we are faced with a potentially life threatening situation to some of the population with many others being unwell.

This guidance is in response to this situation and may help you as a mental health worker to navigate the topics of dying, grief and bereavement when working in inpatient or community settings.

Conversations about death and dying can be very uncomfortable. During this COVID-19 crisis, these conversations will become more frequent and we need to respond in helpful ways, when we are working with someone who may be dying, knows someone who may be dying, or is bereaved.

Why talk?

It helps anxiety and distress.

It helps people understand what is

It can sort out practical things and wishes for afterwards.

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.

People who use mental services may already have experienced adversities and have the experience and peer networks to cope with issues that the pandemic raises. For some, however, it may appear to confirm their worst fears or create more hopelessness or despair. It may prompt intrusive memories of other threats and losses. If you know the person, you may know what may be triggered for them. Be mindful that people may not react as expected.

How to start the conversation

Consider these conversation starters:

- 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

How to talk generally about someone's death.

- Avoid clichés that sound impersonal and not relevant to the person. Being genuine, concerned and empathic will convey a sense of comfort and support
- 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 service user so that they feel in control of the time you are with them
- Ask what you can do to help the person. Ask what they would like if they were to become more unwell
- Use your non-verbal communication skills (open body language, gentle smile and nod)
- Find a quiet, private place to talk
- Give the person your full attention – try to avoid distractions
- Explore cues – don’t assume you know what the person is trying to say
- Don’t force them to talk
- Show them you have listened by checking out you have understood what they have said
- Show them you have heard by summarising what they have told you
- Provide information that is honest, accurate and appropriate for the person’s level of understanding
- Try not to worry about “saying the wrong thing”. It is better to address the situation than ignore it. An apology is always possible!
- If you can’t think of something to say, offer your support, eye contact, and ask what you can do for the grieving person
- You cannot and should not stop a person feeling sad or crying– but you can support them by listening and talking

- 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 and them
- Some people need an end to the conversation and doing something practical and physical can help. Cooking, exercise, tv.
- 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.
- Talk to colleagues too about these issues. We are all human.
- Please record people's final wishes. Use the regional Deciding Right documentation and planning.
<http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-resources/>
- Finally, use the chaplaincy as a resource of support for people who use our services and also for ourselves.

The traumatic nature of an epidemic

- People may not get to see their loved ones because of isolation.
- Infection control may mean that funerals are small or cannot take place in person.
- Other people in the family or support network may also be sick or worried.
- There is little certainty and the threat is going to continue for some time.
- The media is full of scary stories and it is hard to escape from reminders.

.....These factors can make grief harder to deal with.

The interaction between home and work

One of the particularly difficult aspects of a viral epidemic, is that it affects healthcare staff as well as the people who use our services. It does this all at the same time. We may be worried about our colleagues if they are also ill.

Departments may have fewer staff to manage demand or be staffed with people we are not used to working with. We may be concerned about bringing the virus into units with vulnerable patients or scared we may take the virus home to our families, some of who may be in high risk groups. We ourselves may be deployed into roles or areas that are not in our usual skill set. Turning up for work during such time requires us to manage our fears and trust that our leaders will be making wise decisions about our safety and contamination.

Anxieties are normal during abnormal times. When everyone is under threat at the same time, it can be more stressful. The widespread nature of the problem might rally more people to collective positive action. Sometimes it can make people irritable, controlling, avoidant, needy or 'hard'. The things that affect us the most may not make sense to us.

Be aware of how you react.

Stay grounded in your motivation to do a job well.

Be forgiving of others.

Keep well informed and well connected.

Raise concerns and ideas for action.

Informally support each other emotionally.

Focus on the things you can control rather than those you can't.

Find safe people to talk through your worries.

Looking after yourself afterwards

Talking about dying and being with people who are dying can be challenging. You may also be worried about death at this time. You may have already lost people close to you in your personal and professional life.

It is perfectly normal to experience feelings of shock, denial and frustration at the prospect of someone dying.

Use the same resources and advice for yourselves that you give others.

Stay connected with others. Rest. Smile when you can.

AND BREATHE....

B – Be kind to yourself.

R – Respect your body by not overindulging alcohol, drugs, and bad food; by getting enough sleep, and by moving around at least a little every day.

E – Engage with others in big and/or small ways. We're not asking you to bloom into a social butterfly or anything. Just try not to isolate. Connect with colleagues, phone a friend, wave to your neighbors.

A – Allow your emotions to ebb and flow. Don't run from them. Expect that grief emotions will bubble up, their intensity will rise, and they will wash over you and recede.

T – Take life one minute, hour, and day at a time. The enormity of what it means to live life without your loved one is overwhelming, but remember that coping with grief is something that happens bit-by-bit and day-by-day

H – Allow yourself space and time to remember, honor, and to connect with your loved one's memory and their continued impact on the world.

E – Your critical voice has a lot of expectations about what grief *should* be like and how you *should* cope. Remember, there are very few "shoulds" when it comes to coping with grief. Everyone copes in their own way and at their own pace. So give yourself a break.

Based on <https://whatsyourgrief.com/self-compassion-in-grief/>

What to say....

Things you can say when someone is diagnosed with COVID-19

What they say	What you say
I'm scared.	This is such a tough situation. <i>I think anyone would be scared.</i> Could you share more with me?
I need some hope.	Tell me about the things you are hoping for? <i>I want to understand more.</i>
You people are incompetent!	I can see why you are not happy with things. <i>I am willing to do what is in my power to improve things for you.</i> What could I do that would help?
I want to talk to your boss.	I can see you are frustrated. <i>I will ask my boss to come by as soon as they can. Please realize that they are juggling many things right now.</i>
Do I need to say my goodbyes?	I'm hoping that's not the case. And I worry time could indeed be short. What is most pressing on your mind?

Grieving when someone you cared for has died from COVID-19

What I'm thinking	What you can do
I should have been able to save that person.	Notice: <i>am I talking to myself the way I would talk to a good friend?</i> Could I step back and just feel? Maybe it's sadness, or frustration, or just fatigue. Those feelings are normal. And these times are distinctly abnormal.
OMG I cannot believe we don't have the right equipment / how mean that person was to me / how everything I do seems like it's blowing up. This makes it very real – this could happen to my mum/partner/child. What if I am carrying the virus and take it home – this could be my family member.	Notice: <i>am I letting everything get to me?</i> Is all this analyzing really about something else? Like how sad this is, how powerless I feel, how puny our efforts look? Under these conditions, such thoughts are to be expected. But we don't have to let them suck us under. Can we notice them, and feel them, maybe share them? And then ask ourselves: <i>can I step into a less reactive, more balanced place even as I move into the next thing?</i> Notice: <i>Am I speaking as a professional or a family member?</i> Could I step back and just take a breath – and think as a professional? Maybe it's sadness, or concern, or fear. Those feelings are normal. And these times are distinctly abnormal. Make time to talk to someone.

<https://docs.google.com/document/d/1uSh0FeYdkGgHsZqem552iC0KmXlgaGKohl7SoeY2UXQ/preview#>

Links and references to source material

<https://www.cruse.org.uk/Coronavirus/death-talk>

<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/individual-needs/talking-approaching-end-life#why>