

COVID-19: Evidence-based advice for difficult conversations



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With the help of several colleagues, I've put together some evidence-based guidance. We hope this will be helpful to those of you who are likely to be having – and training people who will have - difficult conversations in the care of people with COVID-19.

The evidence comes from research on thousands of difficult conversations recorded across various health and social care settings in the UK, Australia, and the US. A version with references to the original publications can be found on the blog page of the Real Talk website.

We're not providing recommended phrases or scripts. Instead we're providing a series of evidence-based principles. We think this is the best way to help you and your colleagues to communicate flexibly according to individual circumstances. Circumstances will include phone calls, conversations when the staff member is wearing Personal Protection Equipment, and conversations with people who have varying degrees of knowledge and distress. Also included is advice to help somewhat reduce the emotional burden on the member of staff.

The advice is designed to support you to do your best. We recognise that you and your colleagues will face circumstances in which optimal practice is just not possible.

Prepare yourself and the environment as best you can

Clarify in your own mind the purpose of the conversation you are about to have. Remember that this conversation will change this person's world. Remind yourself to deliver it carefully – in a way that shows caring. Consider what you will say at end of the conversation, make sure you know what support is locally available, and when they will have their next conversation with a member of staff or other professional. Identify someone you could talk to before, and/or debrief with after.

Know that you are doing this from a place of compassion.

Prepare the environment, where possible try to find a comfortable private setting where you will not be interrupted.



Why: *this can help self-reflection as well as self-care. It is likely that we will shape our talk better if we are clear about what we are doing, and why. It pays to be aware of and deal with your own emotions beforehand if at all possible, so that when you actually have the conversation, you are focused on and sensitive to the person receiving the news. This helps you design what you say to meet the needs of this particular person, here and now.*

Finding a comfortable, private setting helps you and also shows the person that you are talking to that you are prioritising them and their needs.

Start the conversation with ‘signposting’

If possible and appropriate, start with a clear outline of what is going to follow (e.g. an update, a decision to be made, etc.). Much of what is said may well not be remembered – ideally offer to record and/or write down key points.

How to show compassion and empathy throughout

Show compassion and empathy throughout, using tone of voice, and by saying particular things that attend to emotion (theirs, and yours too). Try to speak slowly throughout, even though you may be feeling under pressure and rushed.

Compassion and empathy involves a balance - showing some understanding about another person’s emotions, but not overly claiming that you can possibly know what they are going through. Over-claiming can come over as unbelievable and insincere, or as trivializing their unique suffering. Say things that show you know this is difficult, that you are sorry, sad. Explicitly refer to the difficult emotions the person may be feeling. But do so with some tentativeness - show you do not know for certain what they are feeling, for instance ‘I guess this must be very hard...’. It is also empathic to tell the person you cannot imagine what they are going through – this shows you recognise the uniqueness of their experience.

You can also say things that convey the difficulty for both of you. And more broadly, use ‘we’, not just ‘I’.



Why: *this can reduce the emotional load on you. Saying something like ‘I know this is difficult for both of us’ recognises the likely position of the person you are talking to, but also makes it clear that it is not easy or comfortable for you either. And using ‘we’ rather than ‘I’ can help to convey that the unwell person has been managed by a team, making joint decisions. This can help you and the person you are talking to understand that you’re not individually responsible for this bad news and for this conversation.*

What does the person you are talking to know, expect, and feel?

First, find out what the person you are talking to already knows and/or expects, and how they feel about that.



Why: *this helps you work out if they already know that death is likely, it helps you to fit what you are going to say to what they know and feel. For instance, it can tell you whether they already have a lot of health knowledge – and this helps you judge whether more or less technical terms are appropriate. It can help you gauge how the person might respond emotionally. Also, speaking aloud about what's been happening sometimes helps the person recognise the poor prognosis for themselves.*

Are they with someone, can they talk to someone afterwards?

After you have found what they know, expect and feel, find out who is with them or who they could talk to afterwards. The presence or absence of support is relevant, but if asked right at the start it could easily be heard as very bad news.

Bring the person (further) towards an understanding of the situation – how things are, what has happened or is likely to happen

Describe some of the things that are wrong with the unwell person, in such a way that you are forecasting that bad news is going to come. You may for example describe the person's normal state and compare it to today.



Why: *basically, you are trying to bring someone towards recognition, rather than induce shock. On a pragmatic note, we know that doing so tends to make these conversations shorter and calmer.*

Tell them clearly what you know and / or expect to happen. Preface with wording that shows compassion, for instance, 'We are so sorry...' 'I wish this weren't the case but'.

If the person has not died yet, but is expected to do so, provide information on what the dying process will be.

Use the ‘D word’ or a ‘gentler’ term that is nevertheless unambiguous

Do not feel you absolutely must use the words ‘died’ or ‘dying’, but if you use alternative terms or phrases make sure they are not ambiguous. If possible, and if you judge the meaning of what you are both saying to be clear, try to match the terminology you use to the terminology being used by the person you are talking to.



Why: research with very experienced doctors, nurses, patients and relatives has found that they often avoid using the ‘D word’. Importantly though, the indirect terms and euphemisms they use are ones whose meaning is nevertheless very clear to everyone – ‘passed away’ is one such. Using ‘the d word’ can feel very brutal and blunt to some people. Some euphemistic, indirect phrases are highly ambiguous, some are not, ‘Passed away’ is clear in its meaning, and seems to be less shocking and distressing to some people than saying ‘Died’.

Dealing with crying

During the conversation, the person you are speaking to may start to show distress, which you might hear or see in different ways – more pauses, changes in voice quality, quietly speaking, a creaky or tremulous voice or even full on sobbing. Modify your own delivery to be softer and more lilting. Allow silence. Brief further sympathy - ‘I’m so sorry’ - may need to be repeated. Acknowledge the distress before moving on with further information delivery.

In the event of full on sobbing give the person you are speaking with time – repeated phrases such as ‘it’s ok’ and ‘take your time’ are fine. The person crying may well apologise – just reassure them it is fine: ‘please don’t worry’, ‘it’s perfectly understandable to be upset’. People receiving difficult news struggle to take it in. You may need to repeat things, keeping them as clear and simple as possible, and checking as you go on to see whether they are following or whether it is OK to carry on.



Moving towards the end of the conversation with ‘Screening’ – are there things you would like to ask, that I have not said, or explained enough?



Why: Try to avoid the phrase ‘anything else’ because in some circumstances, we know this can be heard as conveying you’re not expecting there to be anything else. Offering ‘Are there things I have not covered or explained enough?’ removes the implication that the person has not understood things, and lessens the burden on them.

Moving towards the end of the conversation with words of comfort and attention to what happens next

As you move towards the end of the conversation, if possible, try to deliver something that is of comfort and that you can say truthfully. For instance, you might say that the person was not alone when they died, died peacefully, that they were cared for as well as possible, and/or that the person you are talking to has coped very well during the conversation.

Try to take some burden off the person with whom you are talking – that is, don’t leave them wondering what happens next. Given them advice on who they can call for support. Be very clear on where they can find information. If the patient has not died yet, highlight ongoing and continued care, and that they are not being abandoned. Explain how pain or other symptoms will be controlled.



More information:

Contact the Real Talk email at realtalk@lboro.ac.uk

www.realtalktraining.co.uk

Professor Parry’s work is supported by the National Institute for Health Research (NIHR) Academy. The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

Many thanks to Becky Whittaker, Sharan Watson, and Dr Ruth England for their input.

Summary of the key principles

Prepare yourself and the environment as best you can:

- What is the key purpose of this conversation?
- If possible, find a comfortable and private place to have this conversation.
- How will you end the conversation – what advice or referral for support can you offer the person? What professional (doctor, nurse, registrar for death) do you anticipate they will speak to next?
- Support yourself – who can you talk with to debrief?

Start the conversation with ‘signposting’

Show empathy and compassion throughout. Show understanding without claiming you can possibly fully understand. This is a balance

Find out some of what the person you are talking to knows, expects, and feels

At this point and not before, find out if they are with someone, or have someone to talk to afterwards

Bring the person (further) towards an understanding of the situation – how things are, what has happened or is likely to happen

Use clear terms: either die, dying, death OR ‘gentler’ terms that are nevertheless unambiguous

If they cry, acknowledge with soft tone of voice, express sympathy: I’m sorry. If they apologise for crying, reassure them it’s OK, understandable. If you can, avoid giving further information until they’re slightly calmer

Move towards ending the conversation – ‘screening’ understanding and unanswered questions

Offer words of comfort and give information on what happens next