COURAGEOUS CONVERSATIONS

Primary Care Training Workshop

Courageous Conversations COVID-19

Learning points from scenarios 1, 2, 3 and 4

- Acknowledge difficulties of isolation and of restricted family contact.
- Acknowledge difficulties of remote consulting.
- Give patient a degree of control “is now a good time to speak?”, “Is it okay to go on?”, “Tell me if you’ve had enough for now”.
- What do they understand about what is happening to them?
- Have they thought about their future care? Are they happy to discuss this?
- Check practical issues – food and medicine supply, any help from nursing or social care staff?
- If patient is unaware of the seriousness of their condition, consider a ‘warning shot’ e.g. “I’m afraid things are not looking good”.
- Leave silence after this – wait to see if patient asks for clarification or shows understanding.
- Answer patient’s questions honestly but be clear of why they are asking and what they mean – don’t assume if you’re not sure.
- Discuss reasons for decision not to admit to hospital, use oxygen, ventilate, etc and disadvantages of hospital admission for frail, elderly patients.
- Make it clear that they will still receive care and treatment focused on comfort and relieving symptoms.
- Be willing to say, e.g. “I think your chance of recovery is small” and in response to “Am I going to die?”, be willing to say that this is quite likely, but not certain.
- Be ready to give information about the likely progress of symptoms and mode of dying.
- Consider discussion of DNACPR/Allow Natural Death documentation
- Discuss means of keeping in touch with family – phone, Skype, WhatsApp or recorded messages – it will be important for them too.
- Offer to speak to family members.
- Check understanding.
- Offer review – say when, who and how to access your team if necessary.

Useful words and phrases

Here are some words and phrases suggested by colleagues that you may find useful.

Keeping silent but attentive may be best of all.

Reflective questions, i.e. repeating a word or phrase the patient has said as a question and clarifying questions can be very useful.

- 'Can you explain what you mean by that?'
- 'Why do you ask that question? Or 'What makes you ask that question?'
- 'What did they/the hospital/the specialist tell you – what did you understand from that?'
- 'What do you think is going on?'
- 'Are you the sort of person who likes to know all the details?'
- 'It is less good/more complicated than we thought/hoped' *('warning shot'*)
- 'That must be difficult/hard for you.'/'I can imagine that this must be a very difficult time for you'
- 'I can see that is really difficult/frightening/upsetting' *(in response to verbal or non-verbal cues)*
- 'The disease has reached a point where cure is unlikely/not possible, but we will do all we can to help you achieve what is important to you.'
- 'What are the things that make life worth living for you?'
- 'What is most important to you now?'
- 'What do you think might help you now?'
- 'What would you like us to do?' 'What would be most helpful?'
- 'Are you frightened?'
- 'Are there particular things you worry about/fear?'
- 'What you told your family/friends/carers about your illness?'
- 'Can we arrange a meeting when there is more time for you to talk and one of your family can be present?'
- 'Some people at this stage of the illness are worried/concerned about the future/ what the future might hold/how things are going to progress *(but careful with 'progress' - in some cultures that means improve!*), is that the case with you?'
- 'Some people find talking about the future/getting worse very difficult.'

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In response to the 'how long?' question:

- 'Have you had any thoughts yourself …' or 'I see you have discussed your recent scan with the colleagues in the hospital. Was there any discussion about the future at the time?'
- 'For most people at this stage of the disease we'd be looking at weeks/months/years – but everyone is different, so it is hard to predict.'
- 'Do you want to know when the outlook changes?'

NB: It can be helpful to explain that average survival figures are only of limited relevance to an individual, and how even the most qualified and experienced doctor will regularly get the prognosis very wrong.

- 'I am happy to talk as much as you want today but will make time for you each time we meet to ask me anything you want to.'
- 'Would you like to bring someone with you (*spouse/family/friend – don't assume who they'd prefer*) when we meet next?'
- 'Would you like me to talk to your family/anyone else about this.'
- 'Shall we arrange to meet again?'

Phrases to avoid – they could give a signal that you don't want to have this conversation.

- 'Don't worry'
- 'You must stay positive'.
- 'There is no need to worry about that now'
- 'Let's just see how it goes'
- 'It's not that bad'
- 'I know what you are feeling/going through'

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COVID-19: Evidence-based advice for difficult conversations

Professor Ruth Parry
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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. If you would like a version with references to the original publications, please email the Real Talk team realtalk@lboro.ac.uk.

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 both helps you, and 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, but it 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 'its 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 Becky Whittaker at
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www.realtalktraining.co.uk

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 more 'gentle' 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