

Communication guide for end-of-life conversations



This guide is intended to help and support staff through difficult conversations with patients and their loved ones.

It includes guidance on particularly sensitive conversations, such as giving unwelcome diagnostic news of a life-limiting condition or telling a someone that their loved one has died. Time can sometimes be relatively short for these conversations so it is important that staff use a clear set of skills to both gather and provide information efficiently, effectively, and compassionately.

Making conversations easier

PROGRAMME AIM

To improve the care experience, clinical outcomes and enhance patient safety by supporting staff to take a skilled, sensitive and person-centred approach in all conversations with patients and their loved ones.

Calgary-Cambridge Framework

This Guide is based on the different elements of the Calgary-Cambridge Framework (see diagram overleaf), which has been adopted by the HSE as the foundation for the National Healthcare Communication Programme (see www.hse.ie/nhcprogramme).

Use of good communication skills benefits staff and patients as research shows improved experience of healthcare, reduced burn-out and reduced patient complaints.

In this Guide we highlight key skills to use for some of the many difficult conversations that staff face. It is important to note that patients who are, or may be, nearing the end of their lives are seen in many health and social care settings. Therefore, it is important that all patient-facing staff have knowledge and skills in sensitive and effective communication with people with life limiting conditions, and people who are nearing the end of their lives. Of course, they also need to be able to sensitively and effectively communicate with those who are close to the unwell patient.

A series of useful phrases

We don't intend to tell you exactly what to say instead we are highlighting certain skills and providing a series of useful phrases under the relevant sections of the Calgary-Cambridge Framework. These phrases can of course also be used during phone conversations and with family members as well as with patients. The Guide is designed to support you to do your best. It is important to bear in mind that difficult, sensitive conversations are often uncomfortable and effortful for all involved, including staff. This means that these conversations can feel difficult and uncomfortable for you, even when your communication is good, sensitive, and effective.

Providing structure

- Making organisation overt
- Attending to flow

Initiating the conversation

- Preparation
- Establishing initial rapport
- Identifying the reasons for the conversation

Gathering information

- Explore the person's problems
- Understanding the person's perspective

Physical examination

Providing information & planning

- Provide the right amount and type of information
- Aid recall and understanding
- Incorporate the person's perspective
- Shared decision-making and planning

Closing the conversation

- Forward planning
- Ensuring appropriate point of closure

Building the relationship

- Greeting and introductions
- Non-verbal behaviour
- Involve the person and share your thinking
- Demonstrate empathy

Adapted From: Silverman, J., Kurtz, S., & Draper, J. Skills for Communicating with Patients (3rd ed). Oxford: Radcliffe Publishing (2013).

SKILLS

Preparation

Prepare yourself and your environment. Remember you are doing very many consultations each day but for the patient and their loved ones this is a unique and vital conversation. If you have access to information from colleagues, notes or letters, read these carefully.

Although you will feel time is short, slow down – patients and their loved ones need time to process what you are saying. If they can do this it will save you time overall.

Establishing Rapport

Explain who you are, your role, the team – even if you have already met the patient, re-introduce yourself. Ask their names and relationship to patient. Ask how they like to be addressed. Acknowledge this is a difficult time.

Identifying the reasons for the conversation

Explain your reasons for the conversation. Find out what they know already and what they want to discuss.

Exception: if there is difficult news to give, deliver it towards the beginning of the conversation, and ensure you do this step by step – give a warning shot first, recap the ‘story’ of what has happened so far, give hints and clues that the difficult news is coming. These skills allow you to build sensitively towards giving the news. Avoid bluntly announcing the news without build up, because blunt announcements can result in severe emotional reaction on the part of the receiver, or even a very uncomfortable end to the conversation.

Signpost your goal for the meeting. Restate their concerns and summarise shared agenda.

Ask the patient/family to stop you if you use language they don’t understand.

Hearing sad news and making major decisions can often be too much for one meeting – if possible, plan another conversation for decision-making.

USEFUL PHRASES

Clarify in your own mind the purpose of the conversation you are about to have. Remember that this conversation may change this person’s world.

Hello my name is _____. I’m one of the doctors in the team who are looking after your mother.

How does your mother like to be addressed?

We wanted to meet to update you on your father’s condition. I’ve read through the notes and examined your father this morning. Before I start, can you tell me what you know already about your father’s illness and what you most want to discuss today?

Explore further with phrases such as:

What is your sense of how things are going?

So you have noticed that your father is getting weaker and struggling to breathe. That is also our main concern and we’d like to talk about how we best care for him from here on.

It’s my job to explain things clearly. If I use language that sounds confusing, please stop me so I can explain things better.

SKILLS

Providing the right amount and type of information

Once you have established what the patient and/or loved ones know and want to know more about, merge this agenda with the information you want to provide.

Key skills

Chunk and check – provide small chunks of information and allow this to sink in. If the person understands it they should respond, either by acknowledging what you have said or asking a question.

Pauses – pause after each piece of significant information. *Your father has a severe chest infection (pause) and he is very seriously ill (long pause).*

Aid recall and understanding

Avoid jargon – use easy to understand language, avoid or explain jargon.

Structure the conversation – *first I'll talk with you about the diagnosis, and then we'll talk about how we can manage it.*

Emphasise the important bits – *so the most important thing to remember is that...*
Continue to pause and not talk too much.

Watch their non-verbals – do they look like they are understanding and participating in the conversation or have they switched off?

Continue to provide empathic support – *this must be really tough.*

USEFUL PHRASES

I reviewed the healthcare record and spoke with the doctors who were caring for your wife and now I would like to hear from you directly. Just so I know where to begin, can you tell me your understanding of her condition?

What is your sense of how things are going?

ASK: Do you remember why we ordered the CT scan?

TELL: Your brother is very sick. His lungs are not working. *(Pause)*

While we continue to provide maximum support to your dad, there is the possibility that he will not recover. *(Pause)*

I wish we had a clearer answer about what is going to happen. If the treatment is working, we would expect to see some definite improvement in 2 to 3 days. *(Pause)*

ASK: I have shared a lot of information with you. Let me stop now and hear what questions you have... How are you feeling about what we have discussed?

ASK TO MOVE ON: While we hope for the best, many people also want to prepare for what might happen if the treatments don't work. Would that be helpful for you?

SKILLS

Incorporate the person's perspective

Ask what is important to the patient now.

Use non-verbal responses to show you care –

pause, make eye contact, perhaps offer tissues, if appropriate.

Acknowledge and validate how people feel, this builds connection and trust and makes emotion less overwhelming so they can participate in the conversation.

Explore emotions to better understand values and concerns.

Use open-ended questions and allow time to respond.

Allow the person/family to speak without interruption.

Reflective listening – reflect what you observe or hear with a statement. To explore their thoughts further, use “*tell me more*”.

Invite questions.

USEFUL PHRASES

When you notice emotion – G.I.V.E.*

Get it's emotion

Pause when you notice emotion. Don't answer feelings with facts. We do not need to suppress or resolve emotion. Offer connection, not information or false reassurance.

Identify the emotion

It looks like you were not expecting this news. I hear you're frustrated. I can see you really love your mum. Can I check in with you? You seem a bit quiet. Need a break?

Validate

This is a lot to hear. Yes, it is scary. It's overwhelming – everything you have been through.

Explore

Tell me more – what are you most worried about?

I'm going to summarise so we're all on the same page – please tell me if I got it right.

You mentioned that your brother is “*a fighter*”. Tell me more about that.

I gave you a lot of information. What questions do you have?

* Special thanks to Dr Laura K. Rock, Assistant Professor, Harvard Medical School for sharing her work on improving emotional interactions using the mnemonic G.I.V.E.

SKILLS

Shared decision making and planning

Use 'we' and make suggestions – *so what we think it would be best to do now would be to keep your father comfortable and provide him with good care and see how the next 24-hours go. How does that sound?*

Explore patient's views and wishes – *what do you think your dad would want at this time?*

Get to know your patient as an individual. What was life like before they became ill? What do they enjoy? Important relationships?

Instead of listing treatment options, use open questions to understand goals.

Avoid *"what do you want"* and instead, ask *"what would he think"* or *"say"*.

(The word "want" leads to conversations about interventions rather than about perspectives and values).

Understand values and goals before discussing specific treatments.

When patients or family ask for specific treatments or express their goals, find out more by asking *"tell me more about that"* or ask *"why do you feel she would make that choice?"*.

Explore and discuss likely outcome of treatments they are describing.

USEFUL PHRASES

Tell me about your mother. What kinds of things does she like to do?

Tell me about your dad's most recent really good day.

What would your father say is most important to him?

What have been your sister's biggest concerns? What kind of outcomes would be acceptable to your dad? What situations would he want to avoid?

Imagine your mother sitting in her ICU room watching everything we're doing. What would she say?

What do you think will happen if we do —?

Thank you. This is really valuable information.

SKILLS

Moving towards appropriate point of closure

Briefly summarise what was discussed.
Allow family to correct or add information.

Forward Planning

Explain what will happen next.

Agree on a time for a follow-up meeting.
Encourage family to use hospital resources (clergy, social work) and to attend to their own well being.

Emphasise support – that they are not alone.

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 this has been a conversation about a person who is nearing the end of their life, and if they have not yet died, then highlight ongoing and continued care, and that they are not being abandoned. Explain how pain or other symptoms will be controlled.

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?

So, just to review, we talked about how we will continue the medications your wife is on for now, and we will see whether there are any changes in the next day or two. If we see that things are getting better or worse before then, we will contact you right away.

This is very hard on you. You may not be thinking about yourself but you need to take care of yourself as well. Are you getting any sleep?

I am here all night and you can always reach me if you want to talk. Just ask the nurse to page me.

Avoid this language	Try this instead
We need you to make a decision. What do you want us to do?	Can you help me to understand what is most important to your mother so that we can give her the best care.
Do you want us to be aggressive? Do you want us to do everything?	We will provide your sister with the best possible care. From what you have told me about your husband, it sounds like he really did not want to go through more invasive tests and might prefer to focus on his comfort. We need to discuss whether life support machines would be what your dad would choose if he could discuss his medical situation at this point.
We should talk about withdrawing care.	Based on what's important to your wife it makes sense to stop drawing blood for lab tests. We will continue to do everything we can to make her comfortable.
We hope he will recover.	Your sister's pneumonia is better, but this last illness has made her lung condition worse and she probably won't return to the condition she was in before she was hospitalised. She can breathe without the ventilator now, but probably won't be able to live on her own anymore.

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