

Serious Illness Conversation Guide role-play cases

Actor case one

Chronic obstructive pulmonary disease (COPD) – Mr/Mrs Smith

Character's clinical problem

Mr/Mrs Joe/Josephine Smith is a 68-year-old retired salesperson with COPD and is on steroids and oxygen. She also has diabetes, chronic kidney disease and chronic hip pain. S/he has had three hospitalisations this year, each for complications of COPD, as well as two emergency department visits, once for a fall, and once for a repeat prescription of diabetes medication over the weekend. S/he was recently hospitalised again for an exacerbation of COPD, with worsening shortness of breath, increasing muscle weakness, fatigue, worsening joint pain and stiffness, and a 5kg weight loss. S/he has only recently returned home following a post-acute rehabilitation stay.

Even before this admission, Mr/Mrs Smith's functional status was declining. S/he has required increasing assistance from his/her spouse with household tasks and personal care, and has required short rehabilitation stays after each of the last three hospitalisations. S/he has missed the last three appointments with his/her GP due to cycling in and out of the hospital. Based on his/her multiple comorbidities, declining functional status and repeat hospitalisations, his/her prognosis is most likely less than two years.

Personal history

Life experience – You are fairly social, and a good salesperson. University educated but not a particularly strong student. You get easily lost in the medical details. You love the outdoors.

Values – Relationships and continuity are important to you. You appreciate being straightforward, but are not a real 'details' kind of person.

Emotion – You are scared that things are getting harder than they used to be, like shopping and sorting things around the house. You are emotional (sad and surprised) when you hear your prognosis. You are not sure you want to engage in the conversation, but you continue once the clinician reassures you it is about understanding your wishes for the future. When you get your prognosis, you find it hard to believe that time is short because you always leave hospital feeling better.

Social – You are willing to share your prognosis with your spouse but you don't want to involve your daughter. You think she is too busy with her own life, and you are very, very protective of her. If pushed, you are tentatively OK with the clinical team bringing her into the conversation. You are worried about finances as well.

Suggested responses to the guide prompts

Prompt	Suggested response
How are things going?	Things are better now. Yet again you have me feeling better after a few days in the hospital. I'm fixed up and ready to get back at it!
Set up When pushed gently	I'm feeling ok right now. I'm home again and things are feeling more normal. I don't think we need to have a big conversation. Sure. I'm open to it. No, I don't need someone else here with me, I'm comfortable talking to you about this myself.
Illness understanding If pushed	I know I have several things wrong with my body – my sugars, my lungs, my kidneys, my hip – but they keep getting me fixed up. I feel much better after being in the hospital and finishing rehabilitation. I take it day by day... I'm determined to get through this. Yes, I can see that I have been getting weaker and that I have been coming to the hospital more. But, again, you seem to get me fixed up in the hospital, and you always get me back home again.
Information preferences	Well, I guess it would be helpful for me to know everything you can tell me. But try to keep it simple... all this medical talk is hard for me.
Prognostic communication	Is that really true? I've been feeling weaker but that news is a lot to take in. I know this is important though. I've been worried about this for a while.
Priorities	I need to be here for my family, my spouse isn't young anymore. I would love to get back out and do some more tramping again even though I haven't done that for years (as a salesperson, maybe using a little humour to try to redirect or avoid the conversation). My main goal is to stay alive... I want my spouse to feel secure/supported, financially and otherwise.
Worries	Appearing weak, helpless. Becoming a burden on my family – each hospitalisation results in more work for them; it is embarrassing and hard for me. I'm supposed to be the strong one. I'm worried about having to be in hospital for a long time because each time I'm hospitalised it has been getting harder, but if that's what it takes, that's what it takes.
Getting through the tough times	I'm not a particularly religious person but my church does help. Sometimes nature is my church. My family too! We're a tight group.
Critical abilities If the clinician brings up the ventilator/ breathing machine	I want to be able to eat and speak. That's how I made my living. I'm ok with not walking much anymore, but I worry about not being able to go to the bathroom on my own. You have talked about it before. Again, you feel you need to be able to eat and speak but you are willing to endure significant discomfort for a short time if it will help long-term.

<p>Trade-offs/what you will do for more time</p>	<p>I am used to hospitals and will go if it helps when I get short of breath and if it allows me more time with my family, but each hospitalisation has been getting harder. I'm okay with tests and treatments that will allow me to live longer, and the uncertainty they entail, as long as they are not too burdensome (do not require too much recovery time or a prolonged hospitalisation) and get me feeling better. I don't enjoy rehab and if things get worse, I do not want to live in a rest home.</p>
<p>Family understanding</p>	<p>Well, my spouse knows what's going on. That these are long-term illnesses and we want them to stay long-term. I don't want to worry my daughter. When she checks in, I tell her I'm doing fine (very protective). I haven't talked with my spouse specifically about my wishes but realise that I probably should.</p>

If the clinician is less skilled, you may shut down, give less information, and your emotions may continue to escalate.

What a less skilled clinician might do:

- Not respond to your emotion – keeps talking or provides more information when you are upset.
- Keep going through the questions on the guide without responding to emotion (and perhaps ignore the fact that you don't really want to have this conversation).

If they do these things, push and ask detailed questions, such as how they will support your breathing, eg, 'Will I go to ICU?', 'Will I be on machines?', 'Will I have a breathing mask (BiPAP)?', etc. You will get more and more anxious the longer they don't respond to your anxiety, fear or sadness.

If the clinician is more skilled, you will be able to move forward in the conversation more easily, your emotions will settle down and you will be more forthcoming.

What a more skilled clinician might do:

- Acknowledge your emotion and sit with it (this helps you feel understood and less distressed).
- Gradually help you increase your prognostic awareness by pointing out that you noticed you're getting weaker.
- Not try to push for specifics (like BiPAP) if you are not ready.
- Explore relationship with daughter and suggest talking with her about your illness, and that she might already be worried.

If they do these things, allow them to move forward with the guide and the conversation.

Actor case two

Pancreatic cancer – Mr/Mrs Jones

Character's clinical problem

Mr/Mrs Steve/Sue Jones is a 55-year-old teacher with stage IV pancreatic cancer. S/he has received three months of chemotherapy so far, which s/he is continuing. His/her most recent CT scan showed some response of metastases to the chemo. He/she returned to work four weeks ago, though not with a full class load. Prognosis at this stage is likely months to a year.

Personal history

Life experience – You have worked as a teacher your entire life, and are looking forward to retirement and your first grandchild. You have one son, who is recently married. You've been happily married for 30 years.

Values – You are very close to your family. You value working hard, and teaching is your mission. You believe in positivity and overcoming adversity. But you also believe in planning, and can engage with the discussion when framed that way.

Emotion – You are not sure you want to engage in the conversation, but you proceed once the clinician reassures you. When you get your prognosis, you are not ready to believe that time is short because you feel pretty good now (the chemo is working after all), and have a positive attitude which had taken you far in life. A big part of you feels you will beat it, and a new drug is just around the corner.

Social – Your spouse is very involved, as is your one adult son.

Suggested responses to guide prompts

Prompts	Suggested response
How are things going?	Things are ok, feeling better in the last few weeks. I went back to work last week.
Set-up When pushed gently	I'm really feeling ok right now. Do we have to talk about this? Okay, I understand. Let's talk.
Illness understanding	I know I have pancreatic cancer and that it spread, so I know it's not good, but I've been feeling a bit better recently.
Information preferences	I want to know everything I can about what's going on.
Prognostic communication	I'm not like everyone else. I'm going to beat this. I deal with this by staying positive. Are you really saying I only have that long left to live? [Give resistance for 15 seconds. If the clinician tries to force his/her views on you or continues to provide information without responding to emotion, you will shut down and will resist proceeding with the conversation. If the clinician aligns with your hopes and explains the need to plan for the future, proceed with the conversation.]
Priorities	My son's wife is pregnant; I want to see my grandchild. I was planning to retire in one or two years, and my spouse and I want to travel. In the meantime, I want to spend as much time as I can with my family.
Worries	Being a burden. Having my spouse see me really sick. Being helpless. Leaving my spouse alone without things being in order. I worry about what happens if the treatment stops working.
Getting through the tough times	Supporting my family and knowing I can be there for them.
Critical abilities	I want to be able to spend time with my family. We love talking over dinner together. I want to be able to think clearly. I want to be at home. My father had a terrible experience in a rest home.
Trade-offs/what you will do for more time	I want to do whatever I can to have time to spend with my family so I can see my grandchild and spend time with my spouse, now that we'll have more time after I retire. I haven't really made any immediate plans for retirement.
Family understanding	I haven't talked with my spouse about my wishes, but now I'm wondering if I should. My son and his wife are so busy I don't want to bother them.

If the clinician is less skilled, you may shut down, give less information and your emotions may continue to escalate.

What a less skilled clinician might do:

- Does not set up conversation well, and does not clearly explain why you are having this conversation now.
- Talks a lot, but does not put you at ease – provides information, does not respond to emotion.
- Follows the questions on the guide, but is nervous and doesn't respond to emotion. (As this happens, you get more and more anxious.)
- Overemphasises the prognosis and doesn't understand your positive attitude. Tries to force his/her views on you.

If they do these things, push and ask detailed questions about the cancer and the next chemotherapy treatment (you will get more and more anxious the longer they don't respond to your anxiety, fear, or sadness).

If the clinician is more skilled, you will be able to move forward in the conversation more easily, your emotions will settle down and you will be more forthcoming.

What a more skilled clinician might do:

- Acknowledges your emotions and gives you ample time after hearing the prognosis.
- Aligns with your hopes (such as your desire to see your newborn grandchild). As a result, you feel understood and might gradually become less distressed.
- Does not try to push the conversation further than you are ready for today.

If they do these things, allow them to move forward with the guide and the conversation.