

Serious Illness Conversation Guide role-play cases

Acute hospital admission

Congested heart failure, hypertension, and chronic renal failure - Mr./Mrs. King

Character's clinical problem

Mrs./Mr. Janey/Jamie King is a 76 year-old with a history of congested heart failure (CHF), hypertension (high blood pressure), and chronic renal failure (ineffective kidneys). Over the last few years s/he has had several admissions with exacerbations of CHF requiring IV frusemide (a medication to reduce fluid in the system). A recent ECHO (a heart scan) confirmed a worsening ejection fraction (meaning the heart is getting weaker). This is consistent with the symptoms of increasing fatigue, shortness of breath and reducing appetite Janey/Jamie has reported to the community heart failure nurse specialists.

Note: Heart failure occurs when the heart muscle doesn't pump as well as it should. Common heart failure symptoms include:

- Shortness of breath on exertion
- Shortness of breath when lying (people often need to sleep with extra pillows)
- Fatigue and weakness
- A reduced ability to exercise
- A rapid or irregular heart rate
- Persistent cough with white or pink phlegm
- Increased need to urinate at night
- Swelling in your feet, legs and sometimes the abdomen
- Reduced appetite and nausea

Janey/Jamie has been resident at the local caravan park for the last five years. S/he tends to keep to her/himself, pottering in the small veggie patch at the back of the caravan and listening to her/his radio. S/he does not have any close whānau but the owner of the caravan park and several of the other long term residence keep any eye out for each other.

Hospital admission day 1: Mrs./Mr. King has a six day history of increasing cough, shortness of breath and leg swelling. S/he was admitted overnight with chest pain and new onset atrial fibrillation (fast irregular heart beat). IV Frusemide (intravenous medication via a drip to reduce fluid in your system – it does this by making you urinate a lot) and digoxin (to slow your heart rate) has commenced and symptoms are improving.

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Hospital admission day 6: Mrs./Mr. King has not improved as anticipated. S/he has developed acute on chronic renal failure and the possibility of requiring dialysis has been discussed with the patient. BNP (a blood test result measuring of heart failure) remains elevated, shortness of

breath on minimal exertion continues and s/he has increasing oxygen requirements.
Recovery is now uncertain.

Personal history

Life experience – You have lived at the local caravan park for the last 5 years. You like having your own space and tend to keep to yourself but you do appreciate the fact that the park manager and other residence keep an eye out for each other. If you have some spare veggies from your patch at the back of the caravan, you like to be able to share them with your neighbours as your way of saying thank you.

Values – Maintaining relationships has sometimes been a bit of a challenge for you and you can be wary of people asking too many questions if you don't understand the relevance. You appreciate information being delivered in a straight forward manner.

Emotion – You find the hospital environment challenging. Being at home in your caravan is your secure space and your daily routine helps you feel in control. Being surrounded by others, sharing a 4 bedded ward room and adapting to the ward routines, has been difficult for you on past admissions. It increases your anxiety and you're always very keen to get fixed up and home again as soon as possible.

Day 1 of the admission: You know your symptoms have been getting worse and yesterday's irregular heart rate and chest pain scared you. It was horrible not being able to catch your breath and the feeling of your heart racing. You did worry you might be dying. But you are starting to feel a bit better now and while you don't enjoy hospital, you realise this is the best place for you at the moment. You are confident you will recover and be home within a few days.

Day 6 of the admission: You are increasingly scared and worried about your deterioration in health. You always assumed you would get better but are now realizing you may not. You are tired, exhausted and your thoughts are turning to what will happen to your garden and your caravan if you don't. Dialysis has been discussed and, while you understand it will help your kidneys recover, the idea of being dependent of dialysis and needing to be hooked up to machines regularly is causing you to feel very anxious. It is not a way you think you want to live your life.

Social – You don't want to worry anyone and are reluctant to have staff notify the caravan park manager (listed as your first contact).

Suggested responses to the guide prompts

Prompt	Suggested response Day 1	Suggested responses Day 6
Set-up	<i>I'm feeling a lot better today so I don't think there is much to talk about is there? Unless you are here to tell me when I can go home?</i>	<i>OK. I wondered when you might be back. I know things aren't going so well.</i>
When gently pushed	<i>I guess so (tentative)..</i>	



Support	<i>No, it's just me. No one else needs to be involved.</i>	<i>I don't want to be bothering anyone.</i>
Illness Understanding	<i>I've had a bit of trouble with my heart and breathing over the last few years. They tell me it was all that smoking in my younger days, clogged up my arteries. My ankles had been a bit more swollen than usual last week but yesterday things ramped up another level. My heart started racing and I was getting chest pain. If I'm honest I thought I was having a heart attack and it might be the end. Turns out it was just a bit of a dicky rhythm. They gave me some pills and hooked me up to the drip that makes me keep going to the toilet and now I'm feeling much better.</i>	<i>I know I am getting sicker. My breathing isn't getting better and now my kidneys are packing up. They talked to me about dialysis yesterday. I've been awake half the night thinking about what that might mean for me.</i>
Information Preferences	<i>I like it pretty straight up. Just tell me how it is.</i>	<i>Just tell me what I need to know.</i>
Prognostic Communication	<i>I hope I will continue to do well too! I know my heart is dodgy and I have times when my legs are more swollen and my breathing is worse than others, but I've never really thought about what it mean in the long term. That's a lot to take in.</i>	<i>I'm finding it a bit hard to get my head round how quickly things are changing. This time last week I thought I'd be home by now, instead I realizing I mightn't get better or if I do I'll need things like dialysis. It's a lot...</i>
Priorities	<i>To get better and to get out of hospital. I find it really hard being here with all these people. I just want to get home, back to my garden. There is lots to do at this time of the year.</i>	<i>Getting out of this place. It makes me really sad to think I mightn't see my garden again.</i>
Worries	<i>I'm not good with lots of people. I like to keep myself to myself, so when I get sick like this and need to come into hospital and have others do things for me, I find it tough. When my heart went all funny yesterday, I did worry for a while that I might be dying. I'm pleased I'm not!</i>	<i>How quickly things are changing is terrifying me. And the dialysis thing. I just don't know that I could spend the rest of my life reliant on a machine and being tied to treatment. I feel panicky just contemplating it.</i>
Getting through tough times	<i>My life hasn't always been an easy one. It's usually just me muddling along the best I can. My garden is pretty important to me. I like watching things grow and having my hands in the soil each day.</i>	<i>When I get scared or overwhelmed in this place and with everything that is happening, I imagine my garden and what is sprouting this week and what might be getting ready to harvest.</i>
Critical Abilities	<i>Being able to care for myself. My caravan's not big so as long as I can potter around in there OK, I'll be happy. And still being able to tend my garden.</i>	<i>Being well enough to care for myself again. It is horrible having to rely on the nurses to help me shower and toilet. I wouldn't want to be like this long term.</i>

<p>Tradeoffs/ What you will do for more time</p>	<p><i>I don't like being in hospital. I feel so hemmed in. I'm all right being here for a few days, but I really struggle if it gets to be longer than a week.</i></p> <p><i>I could not end up in one of those rest homes. Too many people in your space all the time. The thought makes me shudder. If I end up needing to be somewhere like that, I think I'd rather not be here.</i></p>	<p><i>The doctors have said dialysis might be my only chance. But I'm just not sure that I want a life that means being hooked up to a machine 3 times a week. I think I might rather just bow out gracefully. Let nature do what it does. If I get better, fine, if I don't, then that might be fine too. Life is what it is and if this is the end of mine that is how it is.</i></p>
<p>Whānau understanding</p>	<p><i>I don't have any family. It's always just been me. Sue, the park manager keeps an eye out for me, but I don't want you bothering her unless there is something really bad happening.</i></p>	<p><i>I have been thinking that I might need to let Sue know what's going on. I'd like to be able to tell her about what I want done with my caravan and my possessions, if I don't come home.</i></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 how they will support your breathing e.g. will I go to intensive care? Will I be on machines? Will I have a breathing mask? Do I have to have dialysis? 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:

- Would 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 dialysis) if you are not ready
- Explore relationship with Sue 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.