

ACP Conversation practice session

CASE 1

- 72 year old retired barber/hairdresser
- COPD, CHF, diabetes, infected leg ulcers, obese
- Just been referred for home oxygen
- three hospitalisations this year (2 for exacerbation of COPD & 1 for CHF)
- Mobility limited to around the house
- Married and lives with spouse. Adult children do not live locally.
- **Setting:** GP practice or hospital.
 - **Note:** if hospital, patient came in for a COPD exacerbation and improved with treatment; now feeling somewhat better and able to engage in conversation.

CASE 2

76 year old retired cook.

Stage 4 lung cancer, hypertension

Currently four weeks through a six-week course of palliative chemotherapy

One recent hospital admission for dehydration secondary to post chemo nausea and vomiting

Lives alone

Domestic assistance for vacuuming 1x week

Daughter and grandchildren help out with shopping the weeks she is feeling more unwell with chemo

Setting: Home visit by district nurse or community palliative care team to assess symptom control.

CASE 1 - documentation

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Narrative

“What does seriously ill look like to me? Being too sick to say what I want and not being able to breath.

If I get that sick again? Well, I'd want you to fix me up, of course! Phone an ambulance, bring me into hospital ... I can't stay at home when I am like that. I'm too sick – I can't breathe!

The Dr said I came within an hour of dying last time I was in hospital. Just proves what I've always known – that I am a fighter and I don't give up in a hurry! That last admission they talked about CPR and Intensive Care. They said jumping on my chest would be a waste of time with all that is going on with my heart and my lungs. After they explained it to me, I agreed! Sounds like a terrible thing to go through for no benefit. It does make me even more determined to keep going with everything else though, especially if they think it was going to help and get me fixed up again. Including antibiotics and that BiPAP machine.”

Would there be a point, do you think, where you would want us to stop trying to save you, and concentrate more on keeping you comfortable?

“The only exception to this would be if my brain started to go.... I couldn't imagine not recognising my family... spending my days lying in a bed with my mouth open dribbling all day long. No thank you!

Or if I couldn't get back home ... they're not gonna put me in one of them homes – shoot me if that ever happens! Couldn't bear it, to be gaga, dribbling my food, staring at the walls...”

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Setting: Home visit by district nurse or community palliative care team to assess symptom control.

“I am going to die from this damn thing. The cancer is going to kill me but at the moment I am doing OK - I still have my independence. I am proud of my attitude. I am not going to give into it without a fight.

I'm currently having chemotherapy. This means I am travelling in and out to hospital 2-3 times a week. It is limiting my social life and the chemo leaves me feeling pretty drained. I am looking forward to the chemo finishing so I can start getting involved in activities outside the hospital. I am keen to start going to a euchre group around the corner and get back to my weekly aqua-aerobics.

If my health is going down the tubes because of progression of my cancer and there is no possibility of recovery then please keep me comfortable and let me die. I am very clear I don't want to be kept alive hooked up to machines if there is no hope. It is important to me that my kids don't see me moaning and groaning and dying in pain. I recently watched my best friend die and it was horrible to see her in so much pain. I don't want that for myself. Please give me enough pain relief to keep me comfortable.

But if I am in an accident or have some other sudden health event and doctors believe my life can be saved and/or extended with good quality of life (in other words if they can make me well enough to return home again and keep living independently) then YES I would want interventions. They're the experts and they know what my body could cope with, given it's so full of cancer.”

CASE 3

84 year old retired school teacher

Parkinson's disease; medication no longer working as well; cognitively intact

Two hospitalisations this year; one with an ICU stay due to complications from hip surgery after a fall

Worsening balance issues and several falls at home

Spouse deceased

Lives in Granny Flat on daughter's property

Two other kids live locally; multiple grandchildren

Setting: GP Practice or home visit; you know the patient very well.

Narrative

"Look ... I'm deteriorating, there's no hiding that. My daughter is having to do more and more for me, and I'm becoming a burden. She says I'm not. But I don't want her to be looking after me. Especially when I can't take myself to the toilet ... ah no ... I don't want her to have to nurse me. I would rather go into the old people's home. I don't want to go back to hospital. No point. They can't fix this ... what's the point in trying to keep this old body alive, just so I can deteriorate further? No ... that's not for me. I'd like to just go to sleep and not wake up."

Are you saying that if you become more unwell, even if there was something that could be done to improve things, to keep you going, you wouldn't want us to try?

"No! Please ... just let me go. I don't want to get to the point where I'm just stuck in bed, can't move, can't speak, lost my marbles. No ... last time I was in hospital they prodded and poked me ... tubes everywhere, no privacy, so noisy ... and so much fuss! I never want to go through that again. They wanted to give me a feeding tube, because I'm having trouble swallowing solid food now – but I told them no – it won't achieve anything, except keep this broken body going – and I don't want that."