

Topic 2 Toolkit

Caring for Australian Indigenous peoples
affected by life-limiting illness

2022

The edited versions of the Tom's Story Case Scenario videos provide a number of points to pause and reflect on the interactions, and to consider the expert comments provided.

These have been added in to the transcripts at various sections.

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Transcript Topic 2: Toolkit

Caring for Australian Indigenous peoples affected by life-limiting illnesses

Tom's story



Tom's story (part 1) 8 min 12 sec

Cec (Tom's wife): Tom, Tom the ambulance is coming to take you to hospital!

Jimmy (son): Mum, mum what happened?

Cec: He couldn't sleep, he was hot and sweaty, couldn't keep still, he got up to go to the toilet.

I heard a crash. He just fell.

Jimmy: Dad, dad you okay old mate?

Tom: Yeh! Yeh, I'm alright!

Jimmy: Okay, okay everything's fine dad. The ambulance is coming, we're all here.

[In hospital]

Sarah (Nurse): Hi Tom, what have you been up to then? Having a bit of excitement to start your day?

What happened this morning Tom?

Tom: I was on the way to the toilet and next thing I knew I was on the floor. Felt I couldn't get my breath.

Sarah: You must've both got a fright. What happened just before you fell?

Tom: Not sure, just remember being on the floor.

Sarah: That's okay Tom, we'll have a look at everything and see if we can find out what's going on.

You've been coming to the hospital for some time now, haven't you? How long's it been?

Cec: Yeh, it's been a while now hey, over a year now.

Sarah: What's your biggest worry at the moment?

Tom: I'm okay really. I've got the family coming around to help Cec, which is a good thing.

Sarah: Tom, I can see a difference in you since we saw you last and I can see that you're in pain and that you seem to be having trouble breathing. Tom I'd like to talk to you about some medications we

can use to help manage your pain and breathing. How would you feel about having a chat about that? Perhaps there's someone else you'd like to be here while we talk about these things? Or I can ask Nancy our Aboriginal liaison officer to come in? [Tom nods] Okay Tom, I'll let you rest now and I'll come back in a little while. Here's your call button, I'm just going to put it right there, if you need me just call, just press it okay. Alright, I'll be back soon.

#1 Initial Interaction

- Sarah's approach is bright and loud. She seems to be making a joke, (eg, 'a bit of excitement'. After this she shows some empathy - (eg, 'You must've both got a fright'.)
- Tone down initial greeting - try to match the family's mood / nonverbals
- Add an introduction or reminder about who she is (name, previous times she has cared for Tom and family), where she's from too - "I'm from ___ and now live out at" Consider the Clinical Yarning Framework concept of the social yarn.
- Take some time to ask about the family / home, what's been happening
- Find some common ground, "I remember last time you were here you were telling me about..."

#2 Asking, 'what's your biggest worry?'

- Good to ask an open-ended question, but she needs to spend more time listening and making sure she understands what Tom is saying
- Also need to ask if there's any other family that they would like to involve? Would he prefer to wait for the family to get here before discussing everything? Remember palliative care is family-centred and there are kinship systems to consider for many mob (not all though)
- She could try, "That's good to hear that you have the family coming around. Is there anything else that's worrying you at the moment?" and then wait (allow silence) to see what the response is.

#3 Statement about noticing a difference

- Sarah says, 'I can see that you're in pain and that you're having trouble breathing', and then goes on to talk about medications
- Sarah's tone here seems confrontational / condescending (telling rather than asking). She could try, "It looks to me like you're in pain and that you're having trouble breathing. Is that right?" and then wait / listen to the response
- Offer to wait and have this conversation with the whole family if Tom wishes
- Observing the body language of Cec and Jimmy at this point indicates that there is some concern about medication. Sarah could stop and ask about this (eg, are you worried about taking pain medication?)



Sarah: Tom's back in with us following a collapse this morning. I started admitting him, but he just wasn't comfortable talking to me about this last episode. Actually I felt really uncomfortable and I didn't really know what to say.

Nancy (Aboriginal liaison officer):
What's the biggest concern about Tom at the moment?

Sarah: He's in a lot of pain, and he's having trouble breathing. I mentioned that I'd like to try some tablets to try and help manage his symptoms but he just stopped engaging with me. I don't know why?

Nancy: Well he's probably worried about a lot of things at the moment. I think first and foremost we need to let him settle in with the family and he's also likely to be sensing something is really different this time.

Sarah: Absolutely, it's been documented that his condition has been deteriorating by his team.

They've also mentioned that his prognosis is very poor. That has also been discussed with his family.

Nancy: And I'm sure Tom and his family are really aware of that.

Nurse: Absolutely, he has definitely deteriorated since I saw him last. I'm really worried about his symptoms; they need to be managed properly.

Nancy: Yes, we do need to be mindful though that Tom may want to use a traditional healer or he may want to use some traditional medicines.

Sarah: Oh okay, I don't really know much about that so what would I need to do to arrange for that to happen.

Nancy: Importantly we need to take the cues from the family first. They may already be dealing with some traditional medicine or some healers. If not though we can always contact the local Aboriginal medical service and see if they're dealing with any traditional healers at the moment, but importantly we need to take the cues from the family first.

Sarah: Yes.

Nancy: Should we go and see him?

#4 Sarah talks to Nancy

- Sarah acknowledges to Nancy that she felt uncomfortable and didn't know what to say. She noticed that Tom stopped engaging with her when she mentioned using medication for pain/breathlessness.
- Sarah acknowledging that she felt uncomfortable and didn't know what to say is important. Nancy realises that Tom and his family probably need 'time to settle in' - they don't want to be rushed into making decisions and may actually need to talk to other family members before any decisions can be made
- Sarah has lost the connection because Tom does not feel totally safe in her care. He needs time to process this, yes, but he also needs to have the whole family come on the journey with him.
- Tom trying to relay all of this information with family would be next to impossible when he isn't sure of what is happening himself. If he is unsure, then the family starts getting fearful, emotions raise to the surface and fights start.
- This may have already happened and now Tom feels responsible for creating wedges and discord in the family and as an Elder, this would be particularly upsetting. Thus, another reason why he would withdraw.

#5 Nancy responds

- Nancy points out that Tom is likely to be worried about a lot of things and is "sensing something is really different this time". Sarah is concerned that Tom's condition has deteriorated and that he has a poor prognosis. She emphasises that his symptoms need to be "managed properly"
- Nancy points out that Tom probably has a sense that he might be starting on the end-of-life journey, although she doesn't say these words. She indicates that the priorities might be different for Tom and his family now that this is the case. Maybe she needs to be clearer with Sarah about this
- Sarah has not acknowledged that Tom is in the end-stages of his illness; she is still focused on 'managing' or 'fixing'.

#6 Taking cues from the family

- Nancy points out that they need to 'take their cues from the family'
- Nancy says this a couple of times - it indicates her approach in letting Tom and his family lead decision-making (family-centred care) about what care or management they want, not rushing them or trying to persuade them to do what is 'right'
- Nancy points out the possibility that Tom and his family might want to involve a traditional healer or traditional medicine which Sarah is not familiar with
- Again Sarah jumps to problem-solving, 'what do I need to do to arrange for that to happen' rather than giving time to let the family make their wishes known
- Many non-Indigenous clinicians feel they need to have all the answers and we don't expect them too. That's a key message for non-Indigenous healthcare staff - we do not think less of them if they can't 'solve' everything for us. If anything, if they try to, we may think less of them and disconnect
- The biggest challenge for most people is not what they say when they communicate with us, it's what they hear and understand.

Tom's Story (part 2) 6 min 10 sec

Nancy: Hey Tom, good to see you. How you doing Cec? Good to see you Jimmy. You been alright Uncle, you been up to country lately?

Tom: We was up there a month or two ago, that right Cec, yeh.

Cec: Yeh, about that.

Nancy: How's all the mob?

Tom: They're all good.

Nancy: Now Uncle, I hear that you've been talking to Sarah the nurse and she's told me that you're in a little bit of pain, and that you're breathless.

Tom: Yeh, I don't want them to put me on that morphine. Remember Cec when they gave it to Aunty Joyce. That morphine, made her real drowsy. She couldn't even speak and then she died the next day.

I'm not staying here, we can manage at home. Anyway I want to see Uncle Joe!

Jimmy: Yeh that's okay Dad, I'll talk to Uncle Joe. I'll get him to come have a yarn, okay. But let's listen to what Sarah has to say first hey.

Sarah: Tom it's understandable that your experience with Aunty Joyce would make you cautious about morphine. We would use a small amount to help manage your pain and breathing without making you drowsy. From what you're saying, it's really important for you to be awake and not drowsy, is that right?

Tom: Yep, not drowsy. I want to be awake so I can have a yarn with everybody, keep in control.

That's what this is all about isn't it?

Sarah: Let me look at this brochure with you, it's good. It tells you all about morphine and how it might help you. It helps explain the medical jargon. Let's go through it together. Fades out

Okay so Tom does that make a little more sense now about why we're wanting to use morphine to help control your pain and breathing? Why don't you have a yarn with your family? I'll have a chat with the doctors now. I'll come back and we can talk about anything that you need to.

Jimmy: Hey Sarah, I'll start tracking down Uncle Joe.

Sarah: Who's Uncle Joe?

Jimmy: Uncle Joe is an elder back in country; he's what you call our traditional healer. It's really important that he's part of all the decisions that are made.

Sarah: Does he need to come down here, or can we get him on the phone?

Jimmy: Oh, I can get him on the phone.

Sarah: Okay well I can try and set up a family meeting via teleconference. Would that be okay?

Jimmy: Yeh, no worries. Thanks Sarah.

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Sarah: Jimmy I was wondering if you'd like us to move your dad into a single room, up near the entrance of the ward. There's a big area there where your whole family can wait and probably visit your dad in larger numbers than just the usual two visitors at a time policy.

Jimmy: Sounds great, thank you.

Sarah: Okay, is there anything else that you need right now?

Jimmy: Dad knows that he's not going to make it back to country to die. I really do think he needs to share his stories with the folks back home. I think he really needs to say his final goodbyes, it's really important.

#7 Nancy and Sarah go to see Tom and his family

Nancy greets everyone and asks about Country and the mob before talking about his pain / breathing. The contrast between Nancy's approach and Sarah's first greeting is very obvious. Nancy is much quieter, more relaxed and spends time on the social connection first - a good example of a social yarn with a focus on the family

Her tone when she says, "Now Uncle..." sounds a bit condescending - like he's in trouble for not doing what he's been told. This may mean he becomes reluctant to talk with Nancy about his worries.

In a real-life situation, if Tom is senior to the health worker, there's no way that she would talk like this to an Elder.

#8 Tom talks about his worries

Sarah acknowledges Tom's reluctance and the experience behind that, and checks to make sure she understands, 'From what you're saying, it's really important for you to be awake and not drowsy, is that right?'

It is good that Sarah is demonstrating that she has been listening and checking to make sure she has understood correctly

The words she uses to explain could be simpler and more direct, (eg, 'I can understand that what happened with Aunty Joyce would make you worried about having morphine. We would just try a small amount to help with the pain, not too much so you don't get drowsy. It sounds like it's really important to you to be awake and not drowsy, is that right?')

#9 Tom talks about what's important to him

Tom agrees that he wants to be awake and in control so that he can have a yarn with everybody, saying, 'That's what this is all about isn't it?' He seems to be talking about the end-stage of life being about spending enjoyable time with loved ones and being able to yarn with them.

Sarah moves on to show Tom the brochure about Morphine. Taking the time to acknowledge that she has heard what Tom said would help to build trust and rapport, (eg, 'You're right Tom, many people want to be able to spend time with their loved ones before they pass on. I'm hoping that giving you a little bit of morphine will help you to be more comfortable and enjoy the time with your family.')

After this she can go into the brochure explaining using morphine and it might be that Tom and his family are more receptive. Sarah leaves them to discuss whether they want to start morphine. At this point, if she hasn't already, it would be good for her to ask if there's anyone else who should be included in conversations about care (eg, Uncle Joe).

#10 Jimmy talks to Sarah

Jimmy talks to Sarah about getting in touch with Uncle Joe and says that "Dad knows he's not going to make it back to Country to die..."

- o Using the family as a gauge with regard to what terminology is appropriate when talking about dying and death. Many families will not want to say 'die', but rather 'back to Country to pass'
- o Sarah has offered a larger room to allow more visitors which is good
- o Jimmy acknowledges that Tom isn't going to get back to Country and that it's important he gets to say his final goodbyes.
- o Sarah and/or Nancy could talk about what supports are available to help Tom go back to Country or offer some alternative ways to bring Country to him.