

Serious Illness Conversation Guide: Customisation of the guide for Aotearoa New Zealand

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Background

Early conversations about health consumers' values and goals have been linked to better serious illness care, including improved quality of life, fewer hospitalisations and lower anxiety.ⁱ The failure to identify and use consumer values and goals to direct care is associated with harmⁱⁱ – the harm of not having the benefit of a quality person-centric conversation and the harm of unwanted or unwarranted treatments. These conversations are infrequent, late and limited.ⁱⁱⁱ When conversations do take place they are often not documented well, which is a concern for patient safety.^{iv}

In Aotearoa New Zealand, the 20 district health boards (DHBs) agreed to fund a national clinical communication programme supported by the Health Quality & Safety Commission to increase the clinical communication capability of their workforces. The aim has been to increase quality conversations with people and reduce the occurrence of harms.

The first component of the training programme is implementation of the Serious Illness Conversation Guide. The guide was developed by US non-profit organisation Ariadne Labs^v with Atul Gawande, following the publication of his book *Being Mortal*. The guide responds to health care professionals feeling ill-equipped to have quality conversations with seriously ill people.

The guide is a list of patient-centred questions designed to help clinicians gain a more thorough understanding of their patient's life in order to inform care decisions. The questions address:

- a patient's understanding of their illness
- their preferences for information
- their personal goals
- their fears and worries, as well as their sources of strength
- the abilities they find most important to their daily life and trade-offs they are willing to make for the possibility of more time
- how much their loved ones know about their wishes.

A randomised control trial using the Serious Illness Conversation Guide has shown that more patients in the intervention group had a conversation with their clinicians than those in the control group, and the conversations happened earlier in the course of illness. The conversations were of better quality, addressing such things as prognosis, values and goals, and end-of-life care planning. Patients in the intervention group reported lower levels of anxiety and depression than patients in the control group.^{vi}

Serious Illness Conversation Guide and associated training supports clinicians to:

- identify patients who would benefit most from conversations about values, goals and preferences
- initiate conversations using best practices in serious illness communication
- document the discussions in a retrievable location so all providers can access the patient's goals.

Why customise the Serious Illness Conversation Guide for use in New Zealand?

In the process of exploring the feasibility of bringing the guide to Aotearoa New Zealand, a number of clinicians involved in the national ACP programme used the Ariadne version of the guide to support conversations with patients. They reported feeling uncomfortable using some of the words and language in the Ariadne version. It was suggested that this discomfort was partly due to a difference in clinical and consumer culture as well as a difference in the way we say things in Aotearoa New Zealand. This discomfort could have become a potential barrier to the use of the guide and a decision was made to explore this in more depth with users and, if need be, adapt the guide.

Co-design workshops

The aim of these workshops was to explore the experience of consumers and clinicians in using the Ariadne version of the guide and to use that to adapt the wording in the guide to improve the experience. It was important for us to include Māori clinicians and consumers to ensure the Māori world view was heard. Patient autonomy does not squarely align with Māori tikanga (custom), which suggests that the 'patient' is not the only decision-maker and that clinicians include the wider whānau (family) in a collective decision-making model.

Three workshops were set up in three different cities (Whangarei, Christchurch and Wellington) and took place in August 2018.

Who attended?

Twenty-four consumers including current patients and members of the public attended, along with 25 clinicians, including doctors, nurses, allied health workers and cultural advisors. Thirteen attendees identified as Māori.

Structure of the workshop

The group was asked to work in pairs to read the guide prompts/questions to each other to get a sense of how it felt to say and hear the words. The group was split into tables that worked together to categorise each prompt as follows:

1. GREEN: The prompt works well – we're happy with it as it is.
2. ORANGE: The prompt could do with some work.
3. RED: We don't respond well to this prompt. It needs a rethink.

An additional WHITE category was used by groups if they could not come to a consensus about a category for a particular prompt or if they want to add a prompt they thought was missing.

The group then worked on coming up with alternative wording for the ORANGE and RED prompts. The original pairs were then asked to read the new prompts/questions to each other to get a sense of how it felt to say and hear the new words.



Acknowledgement:

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Customised guide

| Theme that emerged | Response incorporated into the Aotearoa New Zealand version |
|---|---|
| Setting up the conversation was key to connecting and ensuring that the person was ready to talk and had ample opportunity to have whānau, family and friends attend if desired. This speaks to the Māori custom of whakawhanaungatanga (the process of establishing relationships, relating well to others). | We highlight this in the training and training resources. We softened the language used in the introduction. |
| Concern was raised about having people engage in a conversation of this nature without their whānau, family and friends being there to support them. This is very important for cultures where collective decision-making is preferred. | The training and associated material are being adapted and a prompt added to the guide to double-check whether the person wanted others with them. |
| The language used was felt to be too wordy and formal, and the groups wanted it to be simple and straight forward, and to use plain language. | We adapted the words and tone of prompts to accommodate this. |
| The tone and language were described as paternalistic, 'telling me...' | We changed the wording of the prompts to be more inclusive and to emphasise that the clinician and patient are in this together; we used 'we' instead of 'I'. |
| Caution was raised about the way the clinician ask the patient to tell them what they know (can be seen as testing the patient). | We changed the wording to accommodate this and reflect checking in and offering further information. |
| Saying the doctor was worried raised a number of objections: 'What's the doctor got to worry about, it's not him who is sick', 'Worried sounds scary/very serious', 'Difficult to hear anything else after that'. | We use 'concerned' rather than 'worried'. |
| The lack of a pause or exploration of how the person was feeling following the prognosis sharing felt rushed and unfeeling. | We added a note to allow pause and time for reflection. |
| The prompts that explore choices were initially seen as controversial and raised concern from consumers and clinicians. When asked to think of alternative wording, the groups reassessed their initial response and left these largely unchanged. | We did not remove or substantially change these prompts. We will continue to assess them as more people use the Aotearoa New Zealand version. |
| The closing of the conversation did not provide opportunity for further questions, to check in on how the patient was feeling nor an opportunity to provide resources. | The closing was adapted to accommodate this feedback. |

The first version of the Aotearoa New Zealand Serious Illness Conversation Guide is currently being used in clinical practice pilot sites. We will revisit the language in the future as part of our continuous improvement programme.

The table below shows the changes made:

| Stage | Ariadne wording | Aotearoa New Zealand wording |
|---------|--|--|
| SETUP | 'I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – is that ok?' | 'We want to make sure you have the best care possible. To do this it would be good to talk about what is happening with your health and what things are important to you. Is that OK?' |
| | | 'This is an important conversation. Would you like someone to be here with you?' |
| ASSESS | 'What is your understanding now of where you are with your illness?' | 'To make sure we are on the same page, can you tell me your understanding of what's happening with your health at the moment?' |
| | 'How much information about what is likely to be ahead with your illness would you like from me?' | 'In terms of your health, how much information about what might happen in the future would you like from me?' |
| SHARE | 'I want to share with you my understanding of where things are with your illness...' | 'This is my understanding of where things are at...' |
| | 'It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility.' | 'It can be difficult to predict what will happen with your health. I hope that you will continue to live well for a long time, but it is possible you could become unwell quickly. It is important we prepare for that possibility.' |
| | 'I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, eg. days to weeks, weeks to months, months to a year).' | 'I wish this were not the case, but I am concerned that time might be as short as... (express as a range, eg. days to weeks, weeks to months, months to a year).' |
| | 'I hope that this is not the case, but I am worried that this may be as strong as you will feel, and things are likely to get more difficult.' | 'I hope that this is not the case, but I am concerned that this may be as well as you will feel and things are likely to get worse.' |
| | | 'Allow silence, explore emotion.' |
| EXPLORE | 'What are your most important goals if your health situation worsens?' | 'What are your priorities if your health does get worse?' |
| | 'What are your biggest fears and worries about the future with your health?' | 'What worries you when you think about your health changing?' |
| | 'What gives you strength as you think about the future with your illness?' | 'What helps you through the tough times?' |
| | 'What abilities are so critical to your life that you can't imagine living without them?' | 'What abilities are so important for you, that you can't imagine living without them?' |
| CLOSE | 'If you become sicker, how much are you willing to go through for the possibility of gaining more time?' | 'If your health does get worse, how much are you willing to go through for the possibility of more time?' |
| | 'How much does your family know about your priorities and wishes?' | 'How much do your family/whānau know about what is most important to you?' |
| | 'I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what's important to you.' | 'I have heard you say... is really important to you. Keeping that in mind, I suggest that we... This will help us make sure your care focuses on what is important to you.' |
| | 'How does this plan seem to you?' | 'How does this plan seem to you?' |
| | 'I will do everything I can to help you through this.' | 'I will do all I can to help you get the best care possible.' |
| | | 'Is there anything you would like to go over again/ask/talk about?' |

ⁱ Mack J, Weeks J, Wright A, et al. 2010. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 28(7): 1203-8. URL: www.ncbi.nlm.nih.gov/pubmed/20124172; Wright A, Zhang B, Ray A, et al. 2008. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 300(14): 1665-73. URL: www.ncbi.nlm.nih.gov/pubmed/18840840; Chiachiaro J, Buddhahumaruk P, Arnold RM, et al. 2015. Prior Advance Care Planning Is Associated with Less Decisional Conflict among Surrogates for Critically Ill Patients. *Annals of the American Thoracic Society* 12(10): 1528-33. URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC4627426; Detering K, Hancock A, Reade M, et al. 2010. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 340: c1345. URL: www.bmj.com/content/340/bmj.c1345.

ⁱⁱ Wright A, Keating N, Balboni T, et al. 2010. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 28(29): 4457-64. URL: www.ncbi.nlm.nih.gov/pubmed/20837950; Teno J, Gruneir A, Schwartz Z, et al. 2007. Association between advance directives and quality of end-of-life care: a national study. *J Am Geriatr Soc* 55(2): 189-94. URL: www.ncbi.nlm.nih.gov/pubmed/17302654; Teno J, Clarridge B, Casey V, et al. 2004. Family perspectives on end-of-life care at the last place of care. *J Am Geriatr Soc* 52(2): 189-94. URL: www.ncbi.nlm.nih.gov/pubmed/14709580; Wright A, Keating N, Ayanian J, et al. 2016. Family Perspectives on Aggressive Cancer Care Near the End of Life. *JAMA* 315(3): 284-92. URL: www.ncbi.nlm.nih.gov/pubmed/26784776.

ⁱⁱⁱ Heyland D, Allan D, Rocker G, et al. 2009. Discussing prognosis with patients and their families near the end of life: impact on satisfaction with end-of-life care. *Open Med* 3(2): e101-10. URL: www.ncbi.nlm.nih.gov/pubmed/19946391; Mack J, Cronin A, Keating N, et al. 2012. Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study. *J Clin Oncol* 30(35): 4387-95. URL: www.ncbi.nlm.nih.gov/pmc/articles/PMC3675701; Wright 2008, op.cit.

^{iv} Heyland DK, Ilan R, Jiang X, et al. 2016. The prevalence of medical error related to end-of-life communication in Canadian hospitals: results of a multicentre observational study. *BMJ Qual Saf* 25: 671-9; Yung, et al. 2010. Documentation of advance care planning for community-dwelling elders. *Palliat Med* 13(7): 861-7.

^v More information: www.ariadnelabs.org

^{vi} Bernacki R, Paladino J, et al 2015. Delivering more, earlier, and better goals-of-care conversations to seriously ill oncology patients. *Journal of Clinical Oncology* 33(29) (suppl): 39; and www.ariadnelabs.org/areas-of-work/serious-illness-care/research.