**The national patient deterioration programme and shared goals of care**

**Accessible transcript**

**Visual**

**The screen appears. An image of two women standing close together, smiling at the camera, fills the top half of the screen. Overlaid text on the image reads ‘Ō tātou hiranga | What matters to us, Shared decision-making and advance care planning virtual hui, 2–3 December 2020. The bottom half of the screen is white and there is black text on the left-hand side which reads ‘The National Patient Deterioration Programme & Shared Goals of Care.’ Alex Psirides, Emma Forbes & Jan Dewar. In the top right corner is a logo which reads ‘our voice tō tātou reo, advance care planning’. Alex is shown in a video box to the right-hand side. Alex has short dark hair and is wearing glasses and a black shirt. There is a picture on the wall behind him. The video box stays throughout his presentation.**

Audio

Kia ora, my name is Alex Psirides. I've been asked to talk to you today about the national patient deterioration programme and the shared goals of care component of that. I'll be talking along with my two other colleagues from the Health Quality & Safety Commission of New Zealand, Emma Forbes and Jan Dewar, who'll be talking about the other components of the programme. I'm an intensive care consultant in Wellington Hospital, and I'm also the national lead for the deteriorating patient programme, and I'm talking to you today within that capacity.

**Visual**

**The next slide appears. On the left hand side are three rectangles. The top one is light blue and has the text ‘No-one noticed’ inside. The box below that is dark blue and has the text ‘No-one listened’ inside. The bottom box is grey and has the text ‘No-one wanted all of this’ inside. To the right of the top box is an image of a pair of binoculars, to the right of that is a green box with the text ‘National EWS & VSC’ inside. To the right of the middle box is the image of an ear with an ‘x’ beside it. To the right of that is a yellow box with the text ‘Kōrero Mai’ inside. To the right of the bottom box is the image of a person in a hospital bed, connected to a drip, and a monitor readout on the wall. To the right of that is an orange box with the text ‘Shared Goals of Care’ inside. Each of the boxes on the right is connected by a column of dots.**

Audio

So I wanted to begin by giving an overview of the national patient deterioration programme. It is an entire rapid response system that encompasses three different work streams. The programme came about because, essentially, there were patients who were deteriorating onwards, which were detected through a variety of means. There were obviously complaints that have been made to the Health Disability Commissioner. There are internal audits within hospitals that identified that many of these patients, despite them being in monitored areas on wards, were deteriorating, and sometimes the deterioration was not being picked up. So the national deteriorating patient programme essentially was formed around these three work streams. The first was to develop a national early warning score and vital signs chart that improves the detection and escalation of deteriorating patients. The second workstream was based around a common complaint to both the Health and Disability Commissioner and within DHBs, coming from patients and whānau saying that no one listened when they knew that something was going wrong, which is a patient- and whānau-enabled escalation process known as Kōrero mai, which allows patients and their advocates to speak up if they feel that they're deteriorating, things are getting worse, and that not due attention is being paid to that process. But the one I'm talking about today with regard to both the content of the survey and the most recent workstream has been brought about from the repeated observation, both in my own practice as an intensivist and within the literature from patients and whānau describing once they reached the intensive care unit that after considerable efforts have been put into saving someone's life and keeping them alive, often on artificial machines, the comment that actually, at the end of the day, they didn't want all of these things to happen. And the realisation that much of the acute care that is provided may actually not align with patients' preferences and goals. And this workstream is called the shared goals of care approach, which is what I'm just going to outline over the next few minutes, the reasons why this is included in the national deteriorating patient programme.

**Visual**

**The next slide appears. In the middle are two boxes outlined in red, slightly off set from each other. Inside is a block of text which Alex refers to. In the bottom left of the screen is image of the bust of Hippocrates, comprising of a man’s head, with a beard.**

Audio

So I want to go back in time in history to the much beloved Hippocratic oath, which essentially is the foundation of both medieval and modern medicine. It is an oath that is still taken in some medical schools that doctors on graduation are asked to repeat this. It is largely tokenistic and may have little application to modern health care. But there are parts of it that I believe have been largely forgotten. The concept of medicine in general, as discussed by Hippocrates many, many years ago, was that medicine is here to do away with the sufferings of the sick and to lessen the violence of disease. But the part that is often forgotten by treating doctors who can get involved in the melee of acute health care is that medicine must also refuse to treat those who are overmastered by their disease, and realising that in such cases, medicine is powerless. And that is really the heart of what the shared goals approach of care is, to ensuring that the care we provide is both warranted and wanted by the patients.

**Visual**

**The next slide appears. In the top left of the screen is an orange rectangle with the words ‘Critical care conveyor belt’ written inside. At the right end of the rectangle is a blue arrow pointing right. Along the bottom of the screen is the image of a conveyor belt. Images on the belt, from the left to the right, are a prostrate figure, a red arrow points right, along to an ambulance, a red arrow points right to a figure in a hospital bed, another red arrow points right to a doctor running, with a final red arrow pointing to a figure lying in a hospital bed, connected to a drip and machines, with a monitor screen on the wall. Alex talks through this.**

Audio

And there's all sorts of reasons as to why acute care medicine may actually end up providing excessive care to patients who may not want it. There's this concept of what I call the critical care conveyor belt, which I'm essentially working in the unit on the right-hand side of the screen. And there's a process by which, if you become acutely unwell in many settings, certainly in the community, then in most cases, you will have an ambulance summoned to your side, which results in a hospital admission. If, during your hospital admission, you are to, again, acutely deteriorate, in most modern hospitals and certainly almost every hospital in New Zealand, you will be attended to by a rapid response or medical emergency team who will carry you through to the intensive care unit. My point remains that all treatment essentially is provided by default as the maximum possible setting unless you opt out of this. So the physicians involved in your care are not meaning you unwell. They want to do everything for you, and the same for the nursing members of staff who will be heavily involved in your management during your time here. But the default provision of treatment is maximal. You will get everything that people think you should get unless we actually ask you whether you want it or not.

**Visual**

**The slide remains, but across the bottom of the screen, five boxes appear. The two on the left are green and have written inside them ‘ACP’. The next two are orange, written inside them is ‘SGC’. The one on the right is purple and reads ‘PC’.**

Audio

And there's a variety of means by which patients are now enabled to opt out of the system. So I want to differentiate, I suppose, between advance care plans and the shared goals of care approach and how they work differently. They are complementary. One informs the other, but they're not the same thing. If, as a patient, there are things you want to receive and things you do not want to receive, then generally that takes the form of an advance care plan. It's relatively situation-specific, but covers what your wishes and needs are should you become incapacitated and unable to tell those involved in your health care what you would like to happen. And this can obviously be an accident at any point. Your advance care plan may say that if I deteriorate acutely, I do not wish to go to a hospital, in which case, the first two stages are avoided. No one will call an ambulance – unless, of course, you're in a community setting and people aren't aware of those decisions. By the time you reach the hospital, all the treatment that should be provided to you should be in keeping with your wishes. And this is where the shared goals of care process comes in. It's shared because it is a discussion between clinicians, patients, and whānau. It is not clinicians telling patients what should happen and it's not patients telling clinicians that these are things that must happen. It is a shared process that ensures the treatment that is provided is likely to achieve the outcome that the patient wants. And this process can be carried through for episodic consideration. So for each admission, it may be different, because you may be readmitted to a hospital with a new condition for which a different shared goals of care processes is required. Unfortunately, if you are carried through to the end and end up in intensive care, and it becomes apparent you are dying despite maximal intervention, then palliative care is probably the only step that actually could make sure that your wishes are followed with the intent that if you were dying, that you're able to do so with dignity, comfort, and with your symptoms being appropriately managed.

**Visual**

**The next slide appears. Written in large purple text are the words ‘What do dying people look like?’. The word ‘dying’ is written in black.**

Audio

So why do we have this problem? Why do hospitals provide maximal treatment by default? The answer is fairly simple, which is that people don't want to get it wrong. But it's also complicated by the fact that actually it's quite hard to work out what dying patients actually look like.

**Visual**

**The next slide appears. On the left is a photograph of an intensive care ward. There is a patient in a bed, surrounded by machines and equipment. To the right of the picture is a white box. In the box, in purple, is written ‘is this patient dying?’. The word ‘dying’ is written in black.**

Audio

And it gets even harder surprisingly in intensive care units. Because it is very easy to provide a large amount of technology to people whereby we render them unconscious, we put them on life support machines, dialysis machines, an alarming array of pumps and monitors. But the more machines we have, the harder it can be to actually work out what's happening to the patient. And it's very easy to confuse dying or at least to hide dying with technology. Sometimes the only way to be sure is to continue doing what you're doing and allow the patient to tell you over time which direction they may be following. So there is the clarity that possibly was there 20, 30, 40 years ago is no longer there when assessing patients acutely.

**Visual**

**The next slide appears. In black is a depiction of a person in a hospital bed, connected to a drip.**

Audio

I have a lot of sympathies for junior colleagues who are asked to attend patients in the middle of the night. When they meet a patient who has become suddenly unwell or has had a slow deterioration during their hospital admission, they are faced essentially with this dilemma.

**Visual**

**The screen divides in two. To the left is a black square, still with the image of the hospital bed. Underneath is text which Alex refers to. To the right is a white square again with the image of the hospital bed. Underneath is text which Alex refers to.**

Audio

They have someone who they know is unwell, but what they don't know is what's going to happen if they do things or what's going to happen if they don't do things. And this differentiation between a person who is dying from an irreversible process for whom palliative care may be the most appropriate option versus someone who's sick with a reversible process who would benefit from aggressive care is extremely difficult to make. And even as someone with 10 years of being an ICU consultant, when faced with a patient who is acutely unwell, I sometimes struggle to differentiate between these two. Out of hours in any major hospital, you are essentially being looked after by more junior staff who may not have that experience. So the ability to differentiate, again, is difficult.

**Visual**

**The next slide appears. The screen is blue. Written in the middle in white is a quote with Alex refers to. To the bottom left is an illustration of a patient in a hospital bed, connected to a drip.**

Audio

So what this leads to is not only full maximal support, but also not actually conversing with patients prior to them deteriorating about what it is they would like if they were to deteriorate. This quote's from an Australian palliative care physician. I am repeatedly struck with how appropriate it is. No one likes talking about difficult things, and this includes death, and this includes not providing full treatment by default. Doctors are often - and nurses, clinicians in general, are often uncomfortable asking patients what they would like. And the default process of admitting someone to ICU for two weeks to see what happens may indeed save you one hour of difficult conversation. Patients and whānau may not want to talk about things going badly wrong, because, while you may hope for the best, the reality may be that that isn't statistically likely to happen to you. And as much a part of our process is actually enabling the conversations that allow the shared mental model of what doctors think may happen and patients fear may happen to be aired. But particularly to make sure that the care that's provided is actually aligned with the patient's goals and wishes.

**Visual**

**The next slide appears. It is titled ‘Doing ‘Everything’’. Below this is a block of text showing different methods of treatment. To the left of the title is a depiction of a medical professional with a stethoscope around their neck. To the right of the title is the depiction of a mechanical claw above a row of vials.**

Audio

It's not infrequent for intensivists to be told by patients or their whānau that they want everything done. The concept of everything is extremely difficult, because every intervention that can be provided as part of everything has a downside to it. There is very little that we do to patients at the end, certainly from an intensive care perspective, that doesn't have potential complications and harm. And there is a degree of burden and suffering that goes with every intervention that is really only morally justifiable if it aligns with what the patient actually wants at the end of this. There is a certain amount of discomfort and pain that people may put up with if they know that it is designed to get them back to the quality of life they had before. But many of the interventions – and this is a list of things we can do – may not be medically indicated, may indeed be futile, and may be not what the patient wants. Which is why the concept of doing everything is extremely difficult to define, because everything requires specific indications for treatments and often ignores the down side, the harmful side of actually what everything means for the patients and their whānau.

**Visual**

**The next slide appears. It is titled ‘Spectrum of Treatment’. Across the middle of the screen is a coloured band, fading, left to right, from red to green. Below the band, on the left is a red box with ‘DNR’ written inside it. On the right, again under the band, is a green box. Written inside it is ‘Do everything’. The words ‘Goals of Care’ appear in a box in the middle under the rectangle. This box is also shaded from red to green.**

Audio

Goals of care essentially is designed to try and bridge this gap between the old process of do not resuscitate, which is an extremely emotive term that understandably provokes fear in patients. The concept around if you need resuscitation as an inpatient in a hospital despite being treated for an acute problem, which means that if your heart actually stops as an end point of your deterioration, it is extremely unlikely resuscitation will actually be able to help you. Versus the concept at the other end of doing everything is this binary distinction that has been enforced for many years within medicine, where patients are essentially given the choice of opting out of resuscitation without explaining that the treatment they would be offered would actually be aligned around the things that they want. So the concept of goals of care is addressing this balance between not resuscitating if your heart stops versus doing everything. It's much more nuanced, it's much more subtle. And certainly even 30, 40 years ago, where the treatment options available to you were much more limited, these binary choices weren't really as relevant as they are today, where there are many, many more treatments that are likely to be successful but with themselves may include burdensome therapy that may not be indicated or may not be wanted by the patient. So goals of care in my mind sits within this spectrum of treatment between do not resuscitate and do everything.

**Visual**

**The next slide appears. The background is dark purple. The title at the top reads ‘the bad death’. Below is a list of bullet points which Alex refers to. At the end of the list, written in yellow, are the words ‘the default’. To the right of the title is a depiction of a person in a bed. Another person is sitting on the bed crying. At the foot of the bed is a person comforting a crying child, behind them is another person crying.**

Audio

By default, if we're doing everything and there is no discussion around what patients want if they're dying, then many patients within the hospital who acutely deteriorate are condemned to receive what I have relatively subjectively called a bad death. This is based on extensive literature describing what patients and their whānau actually want. If I were to die in hospital or if I were to die, these are the things and places I would like this to happen. The majority of patients will describe idyllic settings where they may be at home surrounded by their loved ones in control of the process. Almost everyone wants to be free of pain. They want to be free of distress. They want to be able to communicate with their family. And they want people around them at that time. No one essentially chooses to die acutely in a hospital surrounded by strangers immediately or during a procedure that isn't going to change their outcome in a hospital bed, surrounded by monitors and alarms, physically exposed often as part of resuscitation, which takes no account of their dignity and almost complete ignorance of their cultural and spiritual needs. But also, most importantly, many patients may have actually been unaware they were dying, because there's been no facilitated process within the space, within the treatment, to talk about the what if. The what if being we will treat you for this problem, but we need to talk about what happens if the treatment doesn't work or if you have another complication. So much of the shared goals of care process is a conversation around if we think you're dying, what would you like us to do to try and avoid the bad death, which is what most patients would not want for themselves?

**Visual**

**The next slide appears. It is titled ‘The Problem with Unwarranted or Unwanted Treatment’. To the right of the title is a profile drawing of a face. Beside that is a black circle, within the circle is a drawing of two pills and a syringe. Below the title are three bullet points which Alex talks through.**

Audio

So in a nutshell, shared goals of care is an approach to reduce unwarranted or unwanted treatment. It is a contract between patients, whānau and the clinicians responsible for treating them. And we are very much aware that the therapy that may be provided by default has the potential to cause significant suffering that may not alter the outcome. We know it contributes to moral distress for clinicians, that providing treatments that may not actually help the individual contribute towards staff burnout, nurses, doctors, and other people involved in health care. And the third reason just to reduce unwanted or unwanted treatment is that the health care dollar is limited. I can't stress enough, this is not the primary reason for the programme. But we have to accept responsibility for taxpayers' dollars within New Zealand. That the health care dollar we spend is spent efficiently to make sure that the most good can be done to the most number of people with the finite budget that we have. And if expensive treatments are provided by default but patients don't want, that is not the best use of health care expenditure, and in fact, may take treatments away from others because the money isn't available to treat those who are more likely to benefit and suffer less.

**Visual**

**The next slide appears. In the middle is a logo which reads ‘Health Quality & Safety Commission New Zealand Kupu Taurangi Hauora o Aotearoa’. The blue and green company logo comprises of three thin square blocks with white circles of differing sizes within them. Below this, in a blue rectangle, is written ‘Shared Goals of Care: part of a national programme to reduce unwanted or unwarranted treatment’.**

Audio

So in a nutshell, the shared goals of care programme is the third part of the workstream. It's the third workstream within the national programme that aims to reduce unwanted or unwarranted treatment. And I hope in the few minutes preceding that I've given you an overview as to why we felt the programme was justified and required as part of a national approach to the deteriorating patient. There is a series of principles that drives where we got to this point, and I'm going to hand over to my colleague Emma Forbes, who is now going to outline those in more detail. Thank you.

**Visual**

**The next slide appears. It is the image of two women standing close together, smiling at the camera, fills the top half of the screen. Overlaid text on the image reads ‘Ō tātou hiranga | What matters to us, Shared decision-making and advance care planning virtual hui, 2–3 December 2020. The bottom half of the screen is white and there is black text on the left-hand side which reads ‘the shared goals of care principles’ Emma Forbes. In the top right corner is a logo which reads ‘our voice tō tātou reo, advance care planning’. Emma is shown in a video box to the right-hand side. She has shoulder length blonde hair and is wearing a black top. The video box remains for her presentation.**

Audio

Tēnā koutou katoa. Ko Ruahine oku pai maunga, Ko Manawatū te awa, ko tangata Tiriti te iwi. Kei Kupu Taurangi Hauora o Aotearoa o e mahi ana. Ko Emma Forbes tāku ingoa. No reira, tēnā koutou, tēnā koutou, tēnā koutou katoa. Thank you, Alex. My name is Emma Forbes, and I'm the quality improvement advisor for the patient deterioration programme. Today I'm going to talk to you about the shared goals of care principles. I'm going to cover off how we develop these and also go through them so you get a sense of what they actually entail. And finally, I'm going to summarise with what it is we're asking hospitals to do as part of this work.

**Visual**

**The next slide appears. The title is ‘Our process to develop principles’. Below is a list of bullet points Emma talks through. In the top right corner of the screen is the Commission’s logo. The logo remains in the following slides. In the bottom right corner is the logo of the MidCentral DHB and below that is the logo of the Waitematā DHB. In the bottom left of the screen is written ‘our voice tō tātou reo, advance care planning’. This remains in the following slides.**

Audio

The process that we use to develop the principles is quite clear. We establish a multidisciplinary working group, which is made up of consumers and clinicians. And we were very keen that people who were on the working group had experience of shared goals of care discussions and training. With this working group, we went through a series of meetings and we developed some draft principles and a form for testing. We're very happy and grateful that MidCentral DHB and Waitematā DHB both offered teams to help us with this testing. And what we were testing was not only about having the shared goals of care discussions and documentations on the ward, we were actually really keen to understand

what was entailed when they were going through the preparation to align with the draft principles. The work that we are doing with these two DHBs was interrupted due to COVID, unfortunately.

**Visual**

**The screen remains but the bullet points are replaced by three different ones, which Emma talks through.**

Audio

But what that did mean is that we were able to release the test version of the form with some fact sheets to the sector as part of the COVID-19 response, and those are available on the talkingCOVID website. The hiatus with the COVID-19 period also gave us the opportunity to work with our, the Commission's Māori health outcomes team to go through how we could embed Te Tiriti o Waitangi articles into principles of shared goals of care. Now I'm just going to go through what those four articles are briefly so that actually you can see how they have been incorporated into the principles. The first one is kāwanatanga, which is about partnering and shared decision-making. Second is tino rangatiratanga, which is about recognising Māori authority. Ōritetanga, which is about equity, and wairuatanga, which is about upholding values, belief systems, and world views. So having done that work with our Māori health outcomes team, we then finalised the principles and form with the working group again, when we're able to catch up and meet with them all again. And these principles and in form have been endorsed by the patient deterioration leadership group.

**Visual**

**The next slide appears. In the centre of the screen is text which Emma refers to. In the bottom left is a drawing of five people in a circle. One is seated on the left, holding a paper, then two are standing to the right, then two more are seated. They are on a blue circle.**

Audio

So what is it about shared goals of care discussions that were really important? So these discussions need to take place before episodes of acute deterioration so that everyone can fully engage without the pressure of an evolving clinical crisis. You really want people to have the time to really explore what is important to them and to come up with actually what will happen should the person deteriorate during their current admission.

**Visual**

**The next slide appears. It is titled ‘The ten principles’. Below are three points,**

**numbered 1–3, which Emma talks through.**

Audio

So we've got 10 principles, and I'm going to go through these with you. The first one is that shared goals of care are when patients, whānau, and clinicians explore patients' values, the care and treatment options available, and agree the goals of care for the current admission if the patient deteriorates. Our second principle is that health service providers ensure that government systems, organisational culture, and structures encourage shared goals of care discussions through resourcing and by supporting patients, whānau, and clinicians to have these discussions. That's really important that the organisations themselves see this as a very high priority piece of work to be doing. Cultural safety is an essential component of shared goals of care discussions, and that really is important for those who are having these discussions.

**Visual**

**The screen remains but points 1-3 are replaced by points 4-7. Emma talks through these.**

Audio

Principle four is that patients, whānau, clinicians are supported before, during, and after shared goals of care discussions. And we know from the work that we did with MidCentral and Waitematā that this is where a lot of the effort went into in terms of figuring out actually how are people going to be supported before they have this. What's their trading? What's involved? How are they going to be role-modelling? What's the information that needs to be provided? And then after and during the conversations, what discussions, what do people need? The fifth principle is that patients have those they want to have with them, including those who have decision-making responsibilities at the discussions. And where possible, that shared goals of care discussions take place in appropriate environments to maintain patients' privacy and dignity. The seventh principle outlines that shared goals of care discussions are facilitated by the appropriate clinicians and may include other members of multidisciplinary teams involved in patients' care.

**Visual**

**The screen remains but points 4–7 are replaced by points 8–10. Emma talks through these. In the bottom right corner of the screen is a drawing of two pieces of paper, on the left labelled ‘Back’ and on the right labelled ‘Front’.**

Audio

The eighth principle is that shared goals of care discussions happen as early in the admission as possible and with the agreement of the patient. The patient, whānau, or clinician can begin the discussion. And that's where that whole- that starting premise I had about the fact that we want people to have these discussions before an emerging crisis occurs. Shared goals of care discussions result in a shared understanding through engaging with the patient and whānau, sharing the clinician's understanding, and exploring the patient's values and what is important to them. And finally, the 10th principle is that the shared goals of care discussions and decisions are documented in a clearly identifiable and accessible clinical form with information available to all clinicians caring for patients. So this could be either through a paper-based form, like what we've developed for the shared goals of care documentation, or it could be electronic, or it could be some other way that you have of documenting these discussions.

**Visual**

**The next slide appears. This is titled ‘Asking hospitals to’ and is followed by a list of bullet points which Emma talks through. From the third bullet point is a black arrow pointing to four boxes on the right, which are the four goals of care options. The top left box is blue, the other three are orange. Within each box is text which Emma talks to. Behind the four squares is a grey square rotated onto its corner.**

Audio

So what are we asking hospitals to do? Well we're asking hospitals to review their current approaches, what currently happens in the organisations. What's the current experience of patients and staff and whānau with their current approaches? And then align what currently happens with the shared goals of care principles. That may mean some changes, that may mean some ways of adjusting and adapting what is currently happening. We really would like hospitals to move towards using the four goals of care options rather than the binary. So that is about using that options are on curative and restorative, whether to attempt or not attempt CPR, and to improve quality in life or to the comfort whilst dying. Probably the key thing to remember here is that shared goals of care discussions are about exploring what matters most to patients and deciding with patients and whānau and also to make sure that all involved are supported before, during, and after discussions. I'm going to hand over now to Jan, who is going to talk through a bit more in depth about the process of having shared goals of care discussions. Thank you.

**Visual**

**The screen returns to the image of the two women. In the white box below the picture, the text is now ‘What are Shared Goals of Care discussions?’ Jan Dewar. The video box on the left shows Jan. She has short dark hair and is wearing glasses. This video box remains for her presentation.**

Audio

Well, thanks, Alex and Emma, for outlining the reason behind the shared goals of care and also the principles that we've used to develop them. I'm just going to introduce myself and then continue on talking about more detail. Ko Hananui te maunga, ko Waihopai te awa, ko Takatimu te waka, ko Murihiku te marae, ko Ngāi Tahu te iwi, ko Jan Dewar tōku ingoa. So, as I said, I'm Jan Dewar. I'm a nurse by background, and I've been working alongside Emma and Alex on the shared goals of care programme. So let's just have a bit closer look at what the shared goals of care discussions are.

**Visual**

**The next slide appears. The Commission’s logo is in the top right corner, and ‘our voice tō tātou reo, advance care planning’ is in the bottom left. These remain in the following slides. The slide is titled ‘The SGOC discussion – preparation’. Below this are two blue bands. In the top one is written ‘whakatakatu’, in the one below is written ‘preparing’. Underneath are drawings depicting the various stages of preparation, which Jan refers to. To the right is a picture of a form. The title down the left side of the form in a green rectangle is ‘Prepare’, with points that Jan talks through.**

Audio

One of the really important stages is preparing to have the discussion with the patient and the family or whānau. It is important to get yourself prepared so that you've read the notes, you know where the patient's at. It's good to talk to other team members to see if they know information about the patient, such as the nurses or the other members of the MDT. They may have things to add. Also important to make sure that the person does have capacity to have the discussion. Check if there's an advance care plan or advance health directive or an enduring power of attorney. It's just really important to know who's in the room and who needs to be there to make a decision. It's important also to seek agreement with the person to have the conversation with the people that they want to have there. You would record who is there so that in the future, if you need to come back to that, you've got that recorded.

**Visual**

**The next slide appears. It is titled ‘The SGOC discussion – discuss. Below this are two blue bands. In the top one is written ‘kōrerotia’, in the one below is written ‘talking’. Underneath are drawings depicting the various stages of the discussion, which Jan refers to. To the right is a picture of a form. The title down the left side of the form in a green rectangle is ‘Discuss’, with points that Jan talks through.**

Audio

The next part of the process, really, is to go and have the discussion. So we all recognise that sometimes these discussions are quite difficult to have. And sometimes they're not ones that you have often. So it's important just to breathe. Be yourself. Be relaxed. Take a colleague with you, if that's going to help support you and the patient. And then when you get in the room, just begin by checking the patient's understanding about their current condition and what might lie ahead. It's good to check how much information they want from you and share your understanding of their current condition as well. Next you explore their values and what is important to them. Think about their priorities, their hopes, their worries, what helps them, and also what they would be willing to go through for more time. At this point, you would summarise what you've understood from the conversation and check that they have understood the same thing. At this point, the aim is to really be on the same page and understanding where things are at.

**Visual**

**The next slide appears. It is titled ‘The SGOC discussion – recommend and close. Below this on a green bubble is written ‘review decide’. This is surrounded by various pictures of people, screens, papers, and seesaws weighing up words, and a green arrow pointing to another bubble, with ‘offer treatment’ written inside. To the right is a picture of a form. The title down the left side of the form in a green rectangle is ‘Recommend and close’, with points that Jan talks through.**

Audio

Then you would come to the point of the discussion where you are recommending a way forward. So if you explain that in plain language to whoever's in the room and work with them to reach a shared decision, and then you would document the goal. If other things come up during the discussion that other staff members might need to attend to, say the social worker or the physio or someone else on the team, you would just tick the box on the back and record that in the clinical file. If for some reason you're not able to have the discussion with the person there, you would record that as well to make sure that it's clear who the discussion was had with and document that also in the clinical file.

**Visual**

**The next slide appears. This is titled ‘Document the decision’. Underneath this is a drawing with the words ‘shared goals of care’ in the middle. Above this is a drawing of two blue bands. In the top one is written ‘tuhinga’, in the band below is written ‘documenting’. There are pictures of forms to the left, and an arrow below with the word ‘share’, in a green box across it. To the right is written ‘shared goals of care’ with text beside it, which Jan refers to.**

Audio

Documenting the decision is an important part, obviously, so that everyone knows what's going on. The shared goals of care form that the Commission has developed has the options on the front of it, so that's where you would record them and – or you might have a different recording mechanism, but it is important to get them recorded.

**Visual**

**The next slide appears. It is titled ‘Options A & B’. Below are two boxes outlined in black, with text inside which Jan refers to. The top box A has a blue rectangle along the left hand side, with ‘Attempt CPR’ written inside. The bottom box B has an orange rectangle along the left-hand side.**

Audio

The options on the form which we are hoping nationally would have the same wording. So option A is a curative and restorative goal, and that would be where you were aiming to attempt CPR. ICU referral would be appropriate for this person should they deteriorate suddenly. You would expect a MET call or a triple seven call to come if they deteriorate. Option B – the goal is still curative or restorative, but it may not be appropriate to attempt CPR, and may, in fact, do more harm than benefit. Or the person might desire not to have CPR. You would need to make a decision and tick a box there about whether referral to ICU would be appropriate or not. And triple seven calls would be appropriate, and that's what you would expect to happen if they deteriorated.

**Visual**

**The next slide appears. It is titled ‘Options C & D’. Below are two boxes outlined in black, with text inside which Jan refers to. The top box C has an orange rectangle along the left hand side, with ‘Do not attempt CPR’ written inside. The bottom box D has an orange rectangle along the left hand side.**

Audio

Option C is about improving quality of life and aims to control symptoms, enhance well-being. And it should be treatments that are easily tolerated by the patient. It wouldn't be appropriate with this goal to attempt CPR. And it's unlikely to be of benefit to refer to ICU. You would need to make a decision about whether triple seven calls are appropriate or not for option C. Option D is about comfort while dying. So treatment is aimed to reduce suffering and allow an actual death. You will have your local guidelines for end-of-life care that you would follow. But at this stage, attempting CPR, referring to ICU, or triple seven or MET calls are not appropriate.

**Visual**

**The next slide appears. It shows the form which Jan talks to.**

Audio

So putting it all together, this is what the form that the Commission have developed with the clinicians and consumers. And as I said, it's hoped that the four options would be the same across the country. The discussion side of the form runs along the same format as the Serious Illness Conversation Guide, and the Serious Illness Conversation Guide training is really helpful, or some other communications training, to be able to have this conversation in a way that is logical and flows and works for the patients and whānau.

**Visual**

**The next slide appears. This is titled ‘Sign off and passing on the information’. There is a list of bullet points on the left which Jan talks through. On the right is an image of the signing off form.**

Audio

The last part is about signing off the decision that you have made together with the patient and their whānau. Just to let you know that we've had a legal opinion and there is no requirement for the patient to sign this form. The shared goals of care document is about a discussion that you have had. So if treatment is initiated, usual consent processes would be required. Another important step is to make sure that the shared goals of care information is included in a discharge summary and shared with the next provider of care. That primary care really do appreciate hearing this information. It helps with their discussions, and it should be a reciprocal thing where advance care plans and other information comes into the hospital with the patient and the shared goals of care information goes out. So everyone is in the same loop and understands where things are at.

**Visual**

**The next slide appears. This is titled ‘Remember…’.Below are bullet points which Jan talks through. At the bottom is a box outlined in red. Inside is a block of text which Jan reads through.**

Audio

I guess the last thing to say is remember that support may be needed. So it's OK to start the conversation. Have silence. Give time. Come back to it. It may not all happen in one sitting. It's important for yourself to debrief. It's OK to talk to colleagues. It's OK to take a colleague with you to support the discussion. And the main focus of the shared goals of care decision is to move away from a binary decision about CPR versus not for CPR or do not resuscitate. We're moving really firmly in the direction of the patient, family, and whānau being included in the discussion and in the decision and having autonomy over their own health.

**Visual**

**The next slide appears. The title written vertically down the left hand side is ‘Workshop’. To the right are the pictures of the three stages of the sharing goals of care discussion which Jan went through previously.**

Audio

We have this lovely infographic, which lays out all of the steps that I've just talked about. And we really look forward to seeing you at our workshop so that we can discuss together what implementation of shared goals of care might mean in your organisation. My thanks for listening, and we will look forward to seeing you at the workshop.

**Visual**

**The video ends.**