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**Shared goals of care frequently asked questions**

# Shared goals of care approach

## What are shared goals of care?

Shared goals of care is a process of shared decision-making between the patient, whānau and clinical team to determine the overall direction during an episode of care (for example curative, restorative, focused on improving quality of life OR providing care at end of life).

## Why is the system for discussing resuscitation complex?

It is complex because treatment options are constantly evolving in our complex health care environment. A shared goals of care approach provides the opportunity to address unwanted or unwarranted treatment options within that environment.

## Does the shared goals of care approach apply for every adult admitted to hospital?

The principles that underpin shared goals of care will, in time, apply to all adult patients. In implementing the principles, organisations will be asked to identify areas of priority for implementation. Your organisation will probably undertake a phased roll-out.

## Does the shared goals of care form replace the current ‘do not attempt CPR’ form?

The shared goals of care process provides the basis for clinical treatment plans. There are many forms relating to shared goals of care, including national forms (look for ‘Shared goals of care forms’ under [Ngā whāinga tauwhiro – Shared goals of care](https://www.hqsc.govt.nz/our-work/advance-care-planning/acp-information-for-clinicians/shared-goals-of-care/) at hqsc.govt.nz)

Importantly, shared goals of care use a process of shared decision-making between the patient, whānau and clinical team to determine the overall direction during an episode of care (for example, curative, restorative, focused on improving quality of life OR providing care at end of life). Old ‘do not attempt CPR’ forms tended to provide a binary option (for or not for CPR (cardiopulmonary resuscitation), which did not allow for the complexity of modern medicine.

# Shared goals of care and advance care planning

## When a patient comes to hospital and they have an advance care plan, what do I do with it in relation to shared goals of care?

An advance care plan gives the clinical team an indication of patient wishes if they cannot voice them directly themselves. The team can then use the advance care plan to guide the patient and whānau through the next stages, setting up a kind conversation and drilling down into some important issues.

If the patient can participate directly in the discussion, the advance care plan is secondary to that.

It is important to remember that an advance care plan allows a person to share what is important to them now and in the future. A shared goals of care conversation is a targeted advance care planning discussion for that particular episode of care. If the person has capacity, they will be fully involved in the shared goals of care discussion, and their previous advance care planning and thinking will help inform their preferences. If the person is no longer able to participate in the shared goals of care discussion, their preferences in their advance care plan will provide guidance and any relevant advance directives will direct care.

## How do I deal with a previous shared goals of care form in the patient’s notes from an earlier admission?

The form is only valid for an episode of care.

A previous shared goals of care form could be used to inform and improve the quality and context of subsequent shared goals of care discussions.

An advance care plan can be used for multiple admissions.

If you have had a shared goals of care discussion with a patient, if appropriate, talk to them about advance care planning. Advise them that an advance care plan is a good way to capture discussions for the long term so clinicians have a framework for kind, focused discussions in the future.

# When and where to have the discussion

## Can the shared goals of care discussion be held and decision made/form completed before the episode of care, for example, in a pre-admission clinic?

Yes. Having the discussion before admission results in kind, calmer conversations in which patients and whānau can participate more fully.

If having the discussion before admission, make sure:

* you have sought permission to have the conversation
* patients and whānau are supported before, during and after the process
* appropriate support persons are present
* cultural needs are considered
* facilities are appropriate (facilities in outpatients are often more respectful and private than an open ward and therefore better support the discussion).

## What is the timeframe for having the discussion and agreeing the decision with the patient after they are admitted?

Discussions are best held as early as possible and within 24 hours of admission.

A discussion held before an episode of deterioration allows the patient and whānau to participate better in the process. It also allows the treating team to focus rapidly on providing appropriate care, should a patient deteriorate.

We acknowledge having conversations in the emergency department is challenging, however it often means support persons or whānau are present to engage in the discussion, unlike in the ward, such as during morning ward rounds.

# Deciding the level

## What do I do when there is a discrepancy between patient and whānau wishes or expectations and the opinion of the health care team?

Despite careful shared goals of care discussions there may be situations where a discrepancy occurs between patient and whānau wishes or expectations and the opinion of the health care team regarding the care that could be provided.

In these situations, seek advice from colleagues and from your organisation’s policy and procedures.

You will also need to review regularly, with patients and whānau, the shared goals of care discussion and decision to ensure they remain appropriate and that any change in the patient’s condition and circumstances have been considered. Some examples of where a decision should be reviewed are if:

* there was a time-limited decision to treatment
* the patient’s condition changes significantly
* the patient asks for a review of the discussion and decision
* there is a transfer of care.

You will need to escalate and discuss the situation with the senior clinician responsible for the care of the patient. If there is disagreement or any concerns that agreement can’t be reached with the patient and whānau, it is important this is clearly documented.

In general terms, clinicians do not have to provide treatments that are not clinically indicated. A patient does not have a right to resuscitation and cannot require the medical team to provide resuscitation if it is not medically indicated.

However, if time is limited, consider talking with another colleague and remember that intensive care unit (ICU) or outreach services, as well as clinicians working in older persons health, are very used to providing support for these types of situations. ICU colleagues would rather help determine appropriate care before a rapid response call rather than make a decision in an acute scenario.

## What do I do when the patient decides the treatment level of shared goals of care but the whānau disagree?

Whānau cannot legally consent for a patient or determine appropriate level of treatment. Use the Serious Illness Conversation Guide (with the permission of the patient) to find out whānau goals, priorities, fears and worries for the patient. (Search [Aotearoa Serious Illness Conversation Guide](https://www.hqsc.govt.nz/our-work/advance-care-planning/acp-information-for-clinicians/what-clinicians-can-do/serious-illness-conversations/aotearoa-serious-illness-conversation-guide/) at hqsc.govt.nz)

If the whānau claim enduring power of attorney (EPOA), it only comes in to play if the person has lost capacity and the EPOA has been activated for health. Usually it is best practice to align the EPOA with the medical team to determine the shared goals of care. An EPOA cannot compel you to give unwarranted treatment. It also cannot withhold clear lifesaving treatment that the treating medical team advises.

## Is there an example of when option B on the shared goals of care form would be appropriate?

Option B is where the goal of care is curative or restorative and the treatment aims to prolong life and enhance its quality, but where CPR would not be medically indicated. An example could be an older, well patient with some minor comorbidity with colon cancer in whom surgical resection is indicated due to the early presentation and high chance of surgical cure. Referral to ICU maybe be appropriate in this case, however, if the patient sustained a cardiopulmonary arrest, then CPR would be likely to cause harm and/or not be desired by the patient.

## Can you give me an example of when option C would be appropriate and how it is used?

Option C is where the goal of care is primarily improving quality of life and the treatment aims to control symptoms and enhance wellbeing. In this case, the treatment should be easily tolerated and ICU care is unlikely to be appropriate. However, a rapid response team may need to provide escalating ward-based care. For example, a 60-year-old person admitted with severe chronic obstructive pulmonary disease is treated with nebulisers, oral antibiotics and steroids. The patient deteriorates rapidly with the clinical picture in keeping with evolving pneumonia. The rapid response team uses the form and can easily see that BiPAP (bilevel positive airway pressure) has previously not been tolerated well by the patient but agrees that intravenous antibiotics would be indicated.

# Completing the form

## I am a junior doctor in my first two years of training (prevocational registration with New Zealand Medical Council) – can I complete the form?

The principles do not specify a level of practitioner able to complete the form, however, your organisation may have guidance on this so check the organisational policies on shared goals of care or resuscitation.

The shared goals of care principles do highlight that organisations need to support clinicians before, during and after the process. If you do not feel prepared or equipped to have shared goals of care discussions, we encourage you to seek support from a colleague.

If you feel able to have a discussion, document this in the clinical record or on the discussion side of the form. If a shared goal of care is agreed, let the senior clinician responsible for care of the patient know within 24 hours. If a shared goal of care is not agreed, escalate and discuss the situation with that senior clinician.

## As a nurse or allied health worker I often have discussions with patients and whānau about shared goals of care; where do I document these?

Document a discussion in the clinical record or on the discussion side of the form. You can also talk to the senior clinician responsible for the care of the patient at a suitable time to convey your discussion.

## The patient can’t participate in the discussion – what do I do?

* Look for any existing advance care plan, or advance directives, to guide or direct care.
* Speak to whānau about what they understand the patient’s preferences to be.
* Document and sign the shared goals of care form for the current admission with the reasons for not having the discussion. Other documentation may also need to be included in the clinical record.

## How long is the form valid for and if the patient deteriorates what do I do with the form and any revised decision?

The form is valid for the duration of that episode of care, however, we encourage the clinical team to review the form in light of any change in clinical condition and consider revising the shared goals of care.

If the decision is revised cancel the initial form with clear strike-through on both sides, and sign and date it. File the initial form in the clinical record and complete a new form with the revised shared goals of care. File this prominently in the clinical record.

## What do I do if I attend a patient who has suffered a deterioration, I view the shared goals of care form and disagree with the decision?

The shared goals of care decision-making process and documentation do not replace clinical judgement. If the patient’s condition changes or you have any deterioration concerns, review the shared goals of care in line with protocols and clinical judgement.

If the shared goals of care change, the previous form needs to be clearly crossed out and a new decision discussed, agreed and documented.

# Serious Illness Conversation Guide or other conversation frameworks

## Do I have to use the Serious Illness Conversation Guide to inform my discussion?

The Serious Illness Conversation Guide is a communication skills framework developed by Adriane Labs in the USA and adapted for use in Aotearoa. It provides a useful tool to support these discussions. (See[: Aotearoa Serious Illness Conversation Guide](https://www.hqsc.govt.nz/our-work/advance-care-planning/acp-information-for-clinicians/what-clinicians-can-do/serious-illness-conversations/aotearoa-serious-illness-conversation-guide/) at hqsc.govt.nz)

If you wish to develop your communication skills further, you may consider attending advanced communication skills training.

## I find having these discussions confronting at times; how can I get help and support?

Serious illness conversations can be confronting, and your organisation may have trainers who provide appropriate training for clinicians of all grades. You can also see the Health Quality & Safety Commission website for details on the Aotearoa guide and some online training (e-learning) modules. (Visit [advance care planning/information for clinicians](https://www.hqsc.govt.nz/our-work/advance-care-planning/acp-information-for-clinicians/).)

Most organisations also have a variety of existing processes to provide employee support, such as the Employee Assistance Programme (EAP).

## If colleagues find these discussions challenging and leave others to ‘pick up’ the discussion and decision with the patient and whānau, what should I do?

If a clinician avoids these types of discussion, it is possible they feel ill equipped and unprepared to have them. Find out locally who provides training in serious illness conversations and consider running group training together.

Consider viewing these discussions as a quality marker in morbidity and mortality sessions or peer review to raise colleagues’ awareness.

## Is it ok to use my personal cellphone to have a video call with a patient when whānau cannot attend the discussion?

Check your organisation’s local policy on using your personal device. Using telehealth to connect patients and whānau for these conversations is an important aspect of providing support during and after discussions and is a principle of shared goals of care.

Recording of conversations is subject to privacy considerations by all parties.

## What would help when having these discussions with patients and whānau in a four-bedded room?

* Acknowledge this is not the ideal environment for the discussion and offer apologies.
* Seek an alternative space for either the patient and whānau or the adjoining patients if possible during the discussion and decision time.
* Ask a nurse or colleague to join you – they may be able to deal with potential distractions like catering staff or other patients and whānau without you leaving the discussion.

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