NEW ZEALAND DEMENTIA FOUNDATION

Te Whatu Ora
Health New Zealand

SHARED GOALS OF CARE CONVERSATIONS

Three tools to help support end of life care for aged care residents living with dementia mate wareware

E TORU NGĀ TAPTAPU, THREE TOOLS. #1

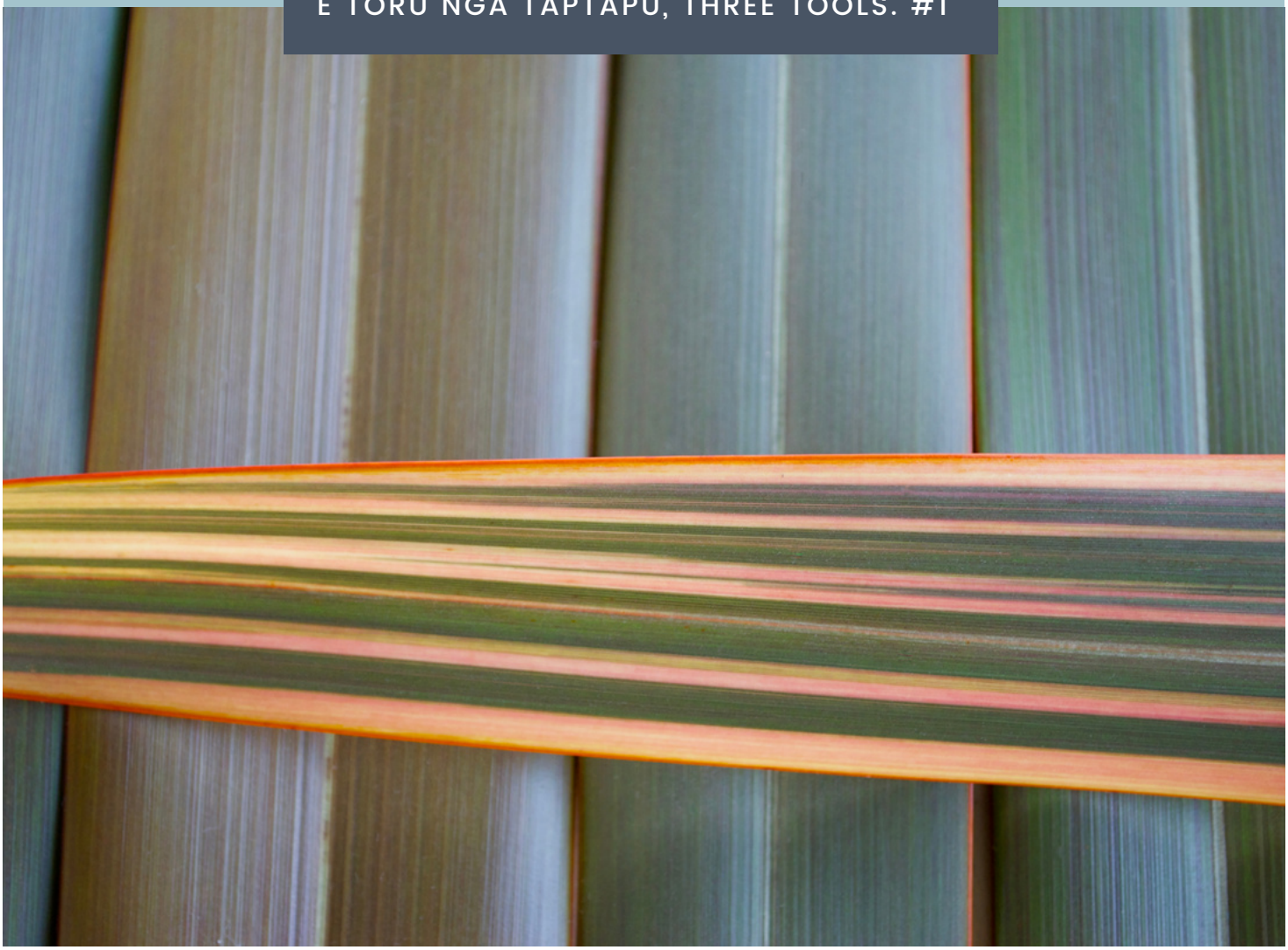
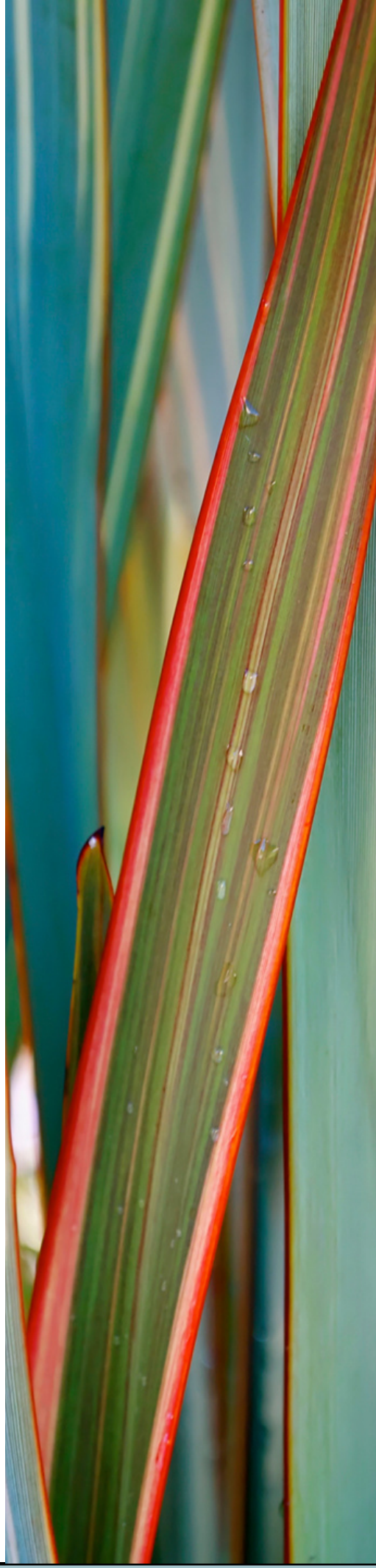


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KA MAHI TAHI MĀTOU, KIA OHOKA TE PITOMATA HAI PUANANĪ.
WE WILL WORK TOGETHER IN ORDER TO AWAKEN POTENTIAL TO FREELY TRAVEL IN ANY CHOSEN DIRECTION.





We started the Dementia End of Life Project by listening. We engaged with staff across aged residential care, Māori health, home care, health, mental health, and palliative care in surveys, focus groups, and working groups.

We heard about three key challenges for best practice end-of-life care for aged residential care residents with dementia :

- residents often enter the facility without any prior advanced care planning.
- coordination amongst services, including primary care, can sometimes be difficult
- teams sometimes lack confidence in developing and implementing individual end-of-life care plans.

The project identified three existing evidence-based tools that, when used routinely, can help address these challenges and support high-quality, person-centred end-of-life and palliative care for our residents living with dementia. In short, three tools that every aged residential care facility should know about!

In these *E toru nga tapu tapu / Three tools* booklets we introduce each of the three tools in the context of dementia and aged residential care. The tools support community teams (Gerontology, Mental Health Services Older People, Palliative Care, Primary Care etc) to be involved and work jointly. In this way, the tools and workbooks are for providers across the continuum. We also provide easy access to the tools through a webpage hub

www.nzdementia.org/3tools

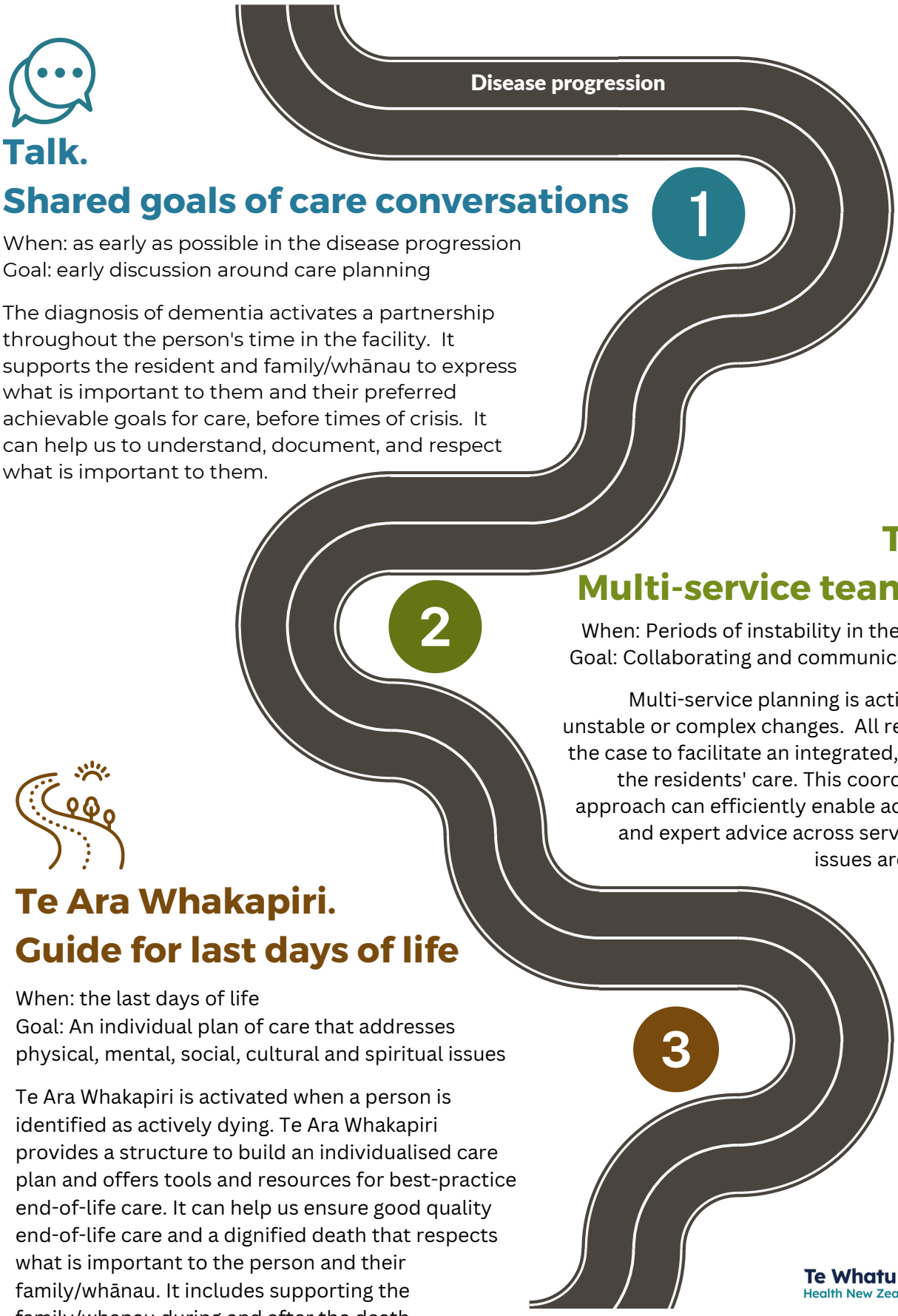
Thank you for your commitment to meeting the unique end-of-life care needs of people living with dementia. We warmly encourage you to find out more and embed any of the tools you are not already using regularly.

Jane Large

Project Leader
Dementia End of Life Project

E TORU NGA TAPUTAPU: THREE TOOLS TO SUPPORT END OF LIFE CARE FOR PEOPLE LIVING WITH DEMENTIA IN AGED RESIDENTIAL CARE

Find out more at www.nzdementia.org/3tools



Talk.

Shared goals of care conversations

When: as early as possible in the disease progression
Goal: early discussion around care planning

The diagnosis of dementia activates a partnership throughout the person's time in the facility. It supports the resident and family/whānau to express what is important to them and their preferred achievable goals for care, before times of crisis. It can help us to understand, document, and respect what is important to them.

Teamwork.

Multi-service team meetings

When: Periods of instability in the disease progression
Goal: Collaborating and communicating across services

Multi-service planning is activated in response to unstable or complex changes. All relevant teams review the case to facilitate an integrated, holistic approach to the residents' care. This coordinated collaborative approach can efficiently enable access to consultation and expert advice across services so that complex issues are considered jointly.

Te Ara Whakapiri.

Guide for last days of life

When: the last days of life
Goal: An individual plan of care that addresses physical, mental, social, cultural and spiritual issues

Te Ara Whakapiri is activated when a person is identified as actively dying. Te Ara Whakapiri provides a structure to build an individualised care plan and offers tools and resources for best-practice end-of-life care. It can help us ensure good quality end-of-life care and a dignified death that respects what is important to the person and their family/whānau. It includes supporting the family/whanau during and after the death.

Te Whatu Ora Health New Zealand

NEW ZEALAND DEMENTIA FOUNDATION

SHARED GOALS OF CARE CONVERSATIONS: WHAT ARE THEY AND WHY ARE THEY IMPORTANT?

Shared goals of care conversations are a way to help to ensure that we understand and respect our residents' priorities.



Shared goals of care conversations bring together the resident, healthcare professionals, and family / whānau, to align their goals and expectations for the resident's treatment and care [1]. They can help us strengthen our person-centred dementia care through to the end of life.

As part of person-centred dementia care, our aim is for every resident to have a care plan that "identifies what they can do and what their strengths and wishes are, as well as identifying what support they may need" [2]. This is also the approach of shared goals of care conversations. The aim is to help ensure that all residents receive appropriate and necessary care through to the end of life that reflects their values, wishes, and preferences [1].

The shared goals of care initiative for aged residential care is part of a broader programme from Te Tāhū Hauora Health Quality & Safety Commission. The approach is targeted to situations where someone in our care has a serious illness with a risk of deterioration [1]. As all our residents living with dementia fit this description, shared goals of care should be a standard tool in our care planning for residents living with dementia.

POTENTIAL BENEFITS:

- improvements in quality of life and reductions in anxiety and depression
- greater likelihood of care decisions in accordance with wishes
- medical care that prioritises wellbeing near death

POTENTIAL BENEFITS FOR FAMILY / WHĀNAU:

- feel more respected, heard, and supported
- experience less distress around making surrogate decisions
- less challenging bereavement adjustment

POTENTIAL BENEFITS FOR CARE PROVIDERS:

- enabling timely and confident decisions to be made
- improved relationship with family / whānau
- earlier integration of services

[3,4,5]

This booklet introduces shared goals of care in a dementia mate wareware context. It introduces some of the resources available from Te Tāhū Hauora Health Quality & Safety Commission that support a structured approach to having and recording shared goal of care conversations.

PRINCIPLES OF SHARED GOALS OF CARE CONVERSATIONS



Shared goals of care are when residents, whānau and clinicians, explore residents' values, the care and treatment options available and agree the goal of care for the current admission if the resident deteriorates.

Aged residential care facilities ensure that governance systems, organisational culture, and structures encourage shared goals of care discussions through resourcing and by supporting residents, whānau and clinicians, to have these discussions.

Cultural safety is an essential component of shared goals of care discussions.

Residents, whānau and clinicians are supported before, during and after shared goals of care discussions.

Residents have those they want to have with them, including those who have decision-making responsibilities.

Shared goals of care discussions take place in appropriate environments to maintain residents' privacy and dignity.

Shared goals of care discussions are facilitated by the appropriate clinician/s and may include other members of multi-disciplinary teams involved in residents' care.

Shared goals of care discussions happen soon after admission.

Shared goals of care discussions result in a shared understanding through engaging with residents and whānau, sharing clinicians' understanding and exploring residents' values and what is important to them.

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 the resident.

Adapted from
www.myacp.org.nz [6]

Te Tāhū Hauora
Health Quality & Safety Commission

Te Kāwanatanga o Aotearoa
New Zealand Government

WHEN TO HAVE SHARED GOALS OF CARE CONVERSATIONS

Ideally, shared goals of care discussions occur before the resident experiences a clinical crisis. The aim is to help timely and appropriate decision-making when crises or end of life situations do arise.

It is recommended that all residents and /or their family and whānau are offered the chance to talk about shared goals of care for this 'episode of care' within the first two to three weeks of moving into your facility [7]. This can be seen as part of getting to know the person living with dementia and helping your care facility prepare for the provision of care and appropriate supports for the person.

The shared goals of care conversation is not a one-off discussion, it is added to over time. Ideally you would revisit the shared goals of care decision with the resident and /or whānau as part of regular 6 monthly care plan reviews or where there has been a significant change [7]. This might be for example:

- change in care package or level of care
- progression in the person's dementia
- change in other health conditions
- problems with nutrition and hydration
- complex symptoms [8]
- distressed responses to a previously accepted intervention

Staff can find themselves being informally asked questions by family and friends about the prognosis, decline, and best care options of the resident living with dementia. This can be seen as another prompt to revisit the goals of care conversation in the context of change. The AFIRM framework can help staff to respond in these situations. The response will be tailored to the scope of practice of the staff member and who is asking (for example, whether it is appropriate to share health information with the person). [9]



From Stirling et al., Talking about dementia and dying

HOW SHARED GOALS OF CARE CONVERSATIONS WORK

The shared goals of care form supports the discussion with prompts and space to document the discussion on the one side; on the flip side is where the shared goals of care plan is documented — the goals that will inform the care and treatment decisions should the person deteriorate.





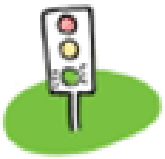
Know your own feelings about dementia and dying



Check if there is already an advance care plan directive, EPOA, or court appointed welfare guardian.



Nursing and allied health staff and care assistants can play a part in this stage of preparing for the discussion.



There needs to be agreement from the resident or surrogate decision maker to go ahead with the discussion.



Be familiar with

the serious illness coversation guide



the shared goals of care form



Review the resident's information to gain an understanding of their future health care needs.

Make sure the discussion is being held with the right people.



Check what support people would the resident like to have present. Check who the family think should be present and who is the EPOA



Consider how to support the resident to be involved in this specific task of supported decision making. If the resident is not able to engage, there is advice in the Frailty Care Guides about capacity assessment and EPoA.



Consider taking other team members. People may appreciate having the staff who spend the most time with them.

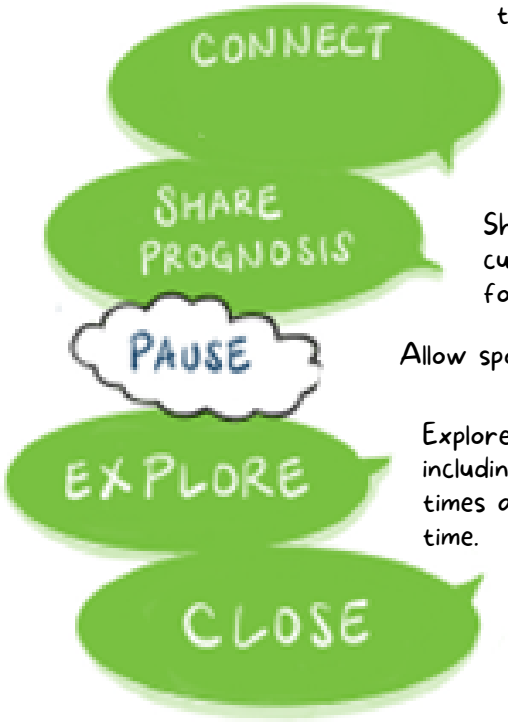


Check in about cultural needs and preferences. Be ready to work in a way that is person-centred in relation to aspects of culture that are most important to the person.



Organise to have enough time for the discussion.
Ensure a suitable meeting space with privacy and no interruptions.





Build rapport, including cultural considerations and acknowledging the difficult conversation.

Explore the resident's (and EPoA's and whānau's, as appropriate) current understanding of their condition and what may lie ahead, and find out how much information they would like to know.

Share information about the team's understanding of their current condition and what may lie ahead. Summarise and check for shared understanding.

Allow space to respond. Acknowledge emotions.

Explore the resident's values and what is important to them, including their priorities, hopes, worries, what helps in tough times and what they would be willing to go through for more time.

Explain your recommendation in plain language and then reach a shared decision with the resident, EPoA, family and whānau for the goal of care.
Check who else needs to know and ensure and reassure ongoing support.

Capture the conversation



Capture the plan



Adapted from

Te Tāhū Hauora Health Quality & Safety Commission

Te Kāwanatanga o Aotearoa New Zealand Government

[1, 9, 10]

Please insert your facility's name or logo here

Shared goals of care
Aged residential care

Family Name: _____

Given Name: _____ Gender: _____

AFFIX RESIDENT LABEL HERE

Date of Birth: _____ NHI#: _____

Prepare

Consider the resident's capacity, their privacy, support people, cultural and future health care needs.

Is the resident competent to make health-related decisions? ☐ Yes ☐ No

Do they have:

- an Advance Care Plan and/or Advance Health Directive? ☐ Yes ☐ No ☐ Unknown
- a legally appointed guardian? ☐ Yes ☐ No ☐ Unknown
- an enduring Power of Attorney (EPoA)? ☐ Yes ☐ No ☐ Activated

Full name of EPoA or legal guardian:

Seek agreement with the resident to have the discussion, with the people they want present.

Full name(s), relationship(s) and role(s) of those present: _____

If discussion not held with the resident, record reason: _____

Discuss

Ask about their understanding of their current condition and what may lie ahead.

Ask how much information they want to know.

Share your understanding of their current condition and what may lie ahead.

Explore the resident's values and what is important to them — their priorities, hopes, worries, what helps in tough times and what they would be willing to go through for more time:

Summarise and check for shared understanding.

Recommend and close

Explain your recommendation in plain language.

Reach a decision and document the goal of care overleaf.

Additional comments: _____

☐ Further information in clinical record.

Document follow-up plan in the clinical record.

Please insert your facility's name or logo here

Shared goals of care
Aged residential care

Family Name: _____

Given Name: _____ Gender: _____

AFFIX RESIDENT LABEL HERE

Date of Birth: _____ NHI#: _____

Following the discussion, select the agreed goal of care:

Attempt CPR

A The goal of care is **restorative.**

☐ Treatment aims to restore the health status to best possible.

Transfer to acute hospital if treatment cannot be provided on site.

Attempt CPR: it is clinically recommended and in accordance with the resident's known wishes.

Additional comments: _____

Do not attempt CPR

B The goal of care is **restorative.**

☐ Treatment aims to restore the health status to best possible.

Transfer to acute hospital if treatment cannot be provided on site.

Do not attempt CPR: this is likely to cause more harm than benefit or is not desired by the resident.

Additional comments (e.g. specific treatments to do): _____

C The goal of care is **on site active care.**

☐ Treatment aims to slow decline and enhance quality of life.

Do not transfer to acute hospital, unless comfort cannot be maintained or transfer is advised by GP/NP.

Do not attempt CPR: this is likely to cause more harm than benefit.

Additional comments (e.g. antibiotics, subcutaneous fluids): _____

D The goal of care is **comfort.**

☐ Treatment aims to optimise comfort rather than attempt to prolong life. When in the last hours or days of life, consider end-of-life guidelines such as *Te Ara Whakapiri.*

Do not attempt CPR or transfer to acute hospital.

Additional comments (e.g. any treatments to be/not be provided): _____

This plan has been discussed with the person. If not, record reason overleaf.

Name: _____ Date: / /

Designation: _____ Signature: _____

☐ Usual general practice team informed.

This plan is not valid unless signed and dated.

Clinically review the resident if there are concerns or a change in their condition. Any change to the goal of care requires a new plan and the earlier plan crossed out.

Include a copy of this plan with transfer information.

SHARED GOALS OF CARE—ARC FORM

SUPPORTED DECISION MAKING

Supported decision-making has been defined as: "the process whereby a person with a disability is enabled to make or communicate decisions with respect to personal or legal matters".[11]

Our legal system focuses on substitute decision-making that allows someone else to 'step in' and make decisions for a person living with dementia. While this will still be the most appropriate approach sometimes, there is now a move to supported decision- making where possible. The United Nations Convention on the Rights of People with a Disability (UNCRPD) sets out that people have the right to make decisions about their own life. They have a right to support, help, and assistance in making decisions. [11,12]

We use supported decision-making ourselves, for example when the mechanic explains the options for repairing our car, or we ask whānau for advice about a purchase. We discuss and consult but the final decision is ours. [13]

Likewise we use supported decision-making in everyday decisions in care. An example might be when a kaiāwhina / carer prepares two favourite shirts that are appropriate for the weather for a resident living with dementia to choose from, because the resident is overwhemed by picking something from their whole wardrobe on their own. This simple example shows some useful steps:

- understanding the person's previous wishes and what's important to them
- gathering information
- understanding the person's communication needs and providing easy to understand information to help them be involved in the decision
- offering, exploring, and honouring meaningful choices.[11, 12]

These same steps to supported decision-making also apply to 'big' decisions like shared goals of care, along with identifying who the person living with dementia wants to support them.



ADAPTED FROM SINCLAIR ET AL, 2018 [11]

HELPING WHĀNAU MAKE DECISIONS

Bringing people together to converse sets the intention for everyone to be on the same page. When there are robust cultural processes in place everyone can participate in an open transparent dialogue and information can be easily clarified.



Kotahitanga is a process where whānau come together as a collective and make unified decisions. When the kaumātua, whānau and their care team are aligned, they will have a powerful partnership; this alliance can ensure the care provided to kaumātua is of the highest standard.

Ensure appropriate cultural processes are in place in the first instance as this will enhance the outcomes of the hui. This may take longer but the outcomes will be more satisfactory for everyone.

Be prepared for some discussion and debate. This is a positive and respectful process that ensures everyone understands what is happening and everyone has an opportunity to be on the same page. Bringing people together makes room for the airing of past issues. Sometimes it is acceptable when voices are raised as people express themselves and express mamae (emotional pain) while working towards kotahitanga (consensus through unity).

If it seems as though things are not going very well during a hui, especially if people have conflicted views about a particular issue, make sure the kaupapa (agenda) is adhered to. It is important that everyone feels as though their point of view has been listened to and there has been an opportunity to find a middle ground or compromise.

If whānau do not understand something that is said, they may feel too vulnerable or embarrassed to ask for clarification, or they may be feeling overwhelmed or extremely stressed. Silence does not mean agreement. When either party bottles things up it can create a blockage in the relationship and can result in resentment. In some circumstances, a skilled mediator or community leader who is fluent in te reo and is experienced working with Māori communities may need to be seconded to support a whānau hui.

Every health and care professional should have effective communication with kaumātua and whānau. Ideally, effective communication (clear communication style that is easy for people to understand) and a safe space for kaumātua and whānau to ask questions will result in a better understanding of the end of life care wishes and preferences of kaumātua. This will support kaumātua and their whānau to achieve the outcomes they want and will help to reduce inequities within health services. Going the extra mile is contributing to building a supportive compassionate community.

This advice is shared byKathleen Mason (Rongowhakaata, Ngāti Porou) and Dr. Tess Moeke-Maxwell (Ngāi Tai ki Tāmaki & Ngāti Porou). You can find out more about how to support Māori whānau and to provide care to adults and kaumātua at end of life on the Te Ipu Aronui website:

https://www.teipuaronui.co.nz/

RESOURCES

Te Tāhū Hauora Health Quality & Safety Commission offers a range of resources to provide tools, training and support to implement or improve shared goals of care planning at www.myacp.org.nz

Note: if you are reading a paper copy, visit www.nzdementia.org/three tools for these links



SHARED GOALS OF CARE RESOURCES FOR AGED RESDENTIAL CARE

- Shared goals of care form
- Fact sheet for nurses and allied health workers
- Fact sheet for lead clinicians
- Demonstration video



RESOURCES TO HELP EMBED SHARED GOALS OF CARE

- Implementation guide
- Shared goals of care resources
- Serious illness guide resources
- Training
- Legal framework



SHARED DECISION MAKING

- Ministry of Social Development / Te Manatū Whakahiato Ora
- Centre for Public Representation
- A guide for people living with dementia, family members and carers



OTHER RESOURCES

- Frailty guides including capacity
- Talking about death and dying
- Advance care planning in dementia

CULTURAL RESOURCES AND ACKNOWLEDGEMENTS

REFERENCES



CULTURAL RESOURCES FOR CONVERSATIONS ABOUT END OF LIFE

- Te Ipu Aronui website: culturally informed care at the end of life
- Serious illness conversations: A reference guide for health care professionals. Chapters 3&4
- Whenua ki te whenua: A guide for families to talk about advance care planning
- He Waka Kakarauri guide to a model for engaging Māori in advance care planning conversations.

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SOUTH ISLAND ALLIANCE
best for people, best for system

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