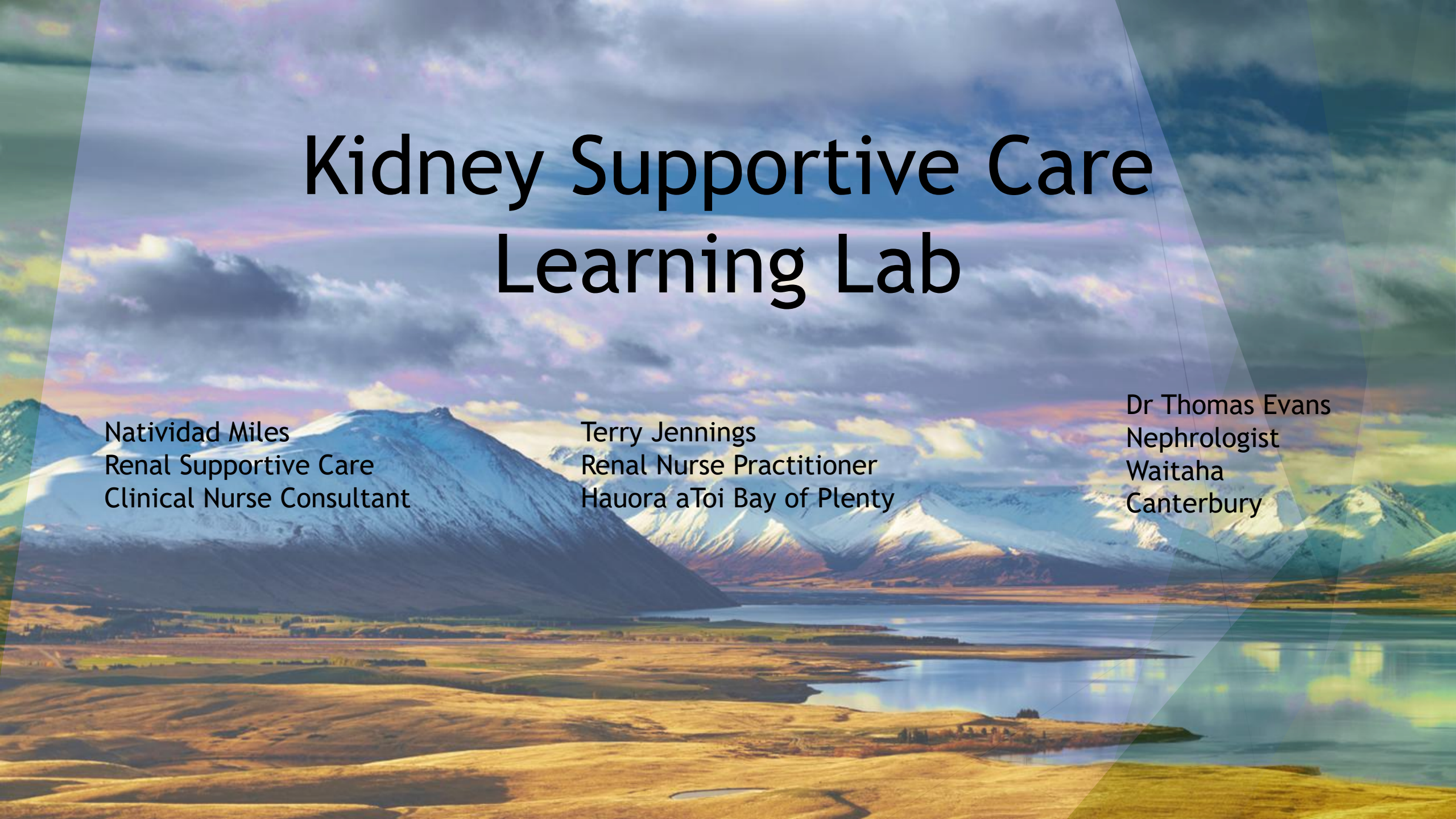


Kidney Supportive Care Learning Lab

Natividad Miles
Renal Supportive Care
Clinical Nurse Consultant

Terry Jennings
Renal Nurse Practitioner
Hauora aToi Bay of Plenty

Dr Thomas Evans
Nephrologist
Waitaha
Canterbury



- *‘E hono ana tātau ki te whenua mai i te matihe o te ora tuatahi tae noa ki te whakamutunga. E kawea ana te wairua i roto i te puku o te hau ki te okiokinga o ngā tīpuna.’*

- *‘We are connected to the land from the first breath of life to the last. Our spirit is carried within the belly of the wind to the resting place of the ancestors.’*

Kidney supportive Care

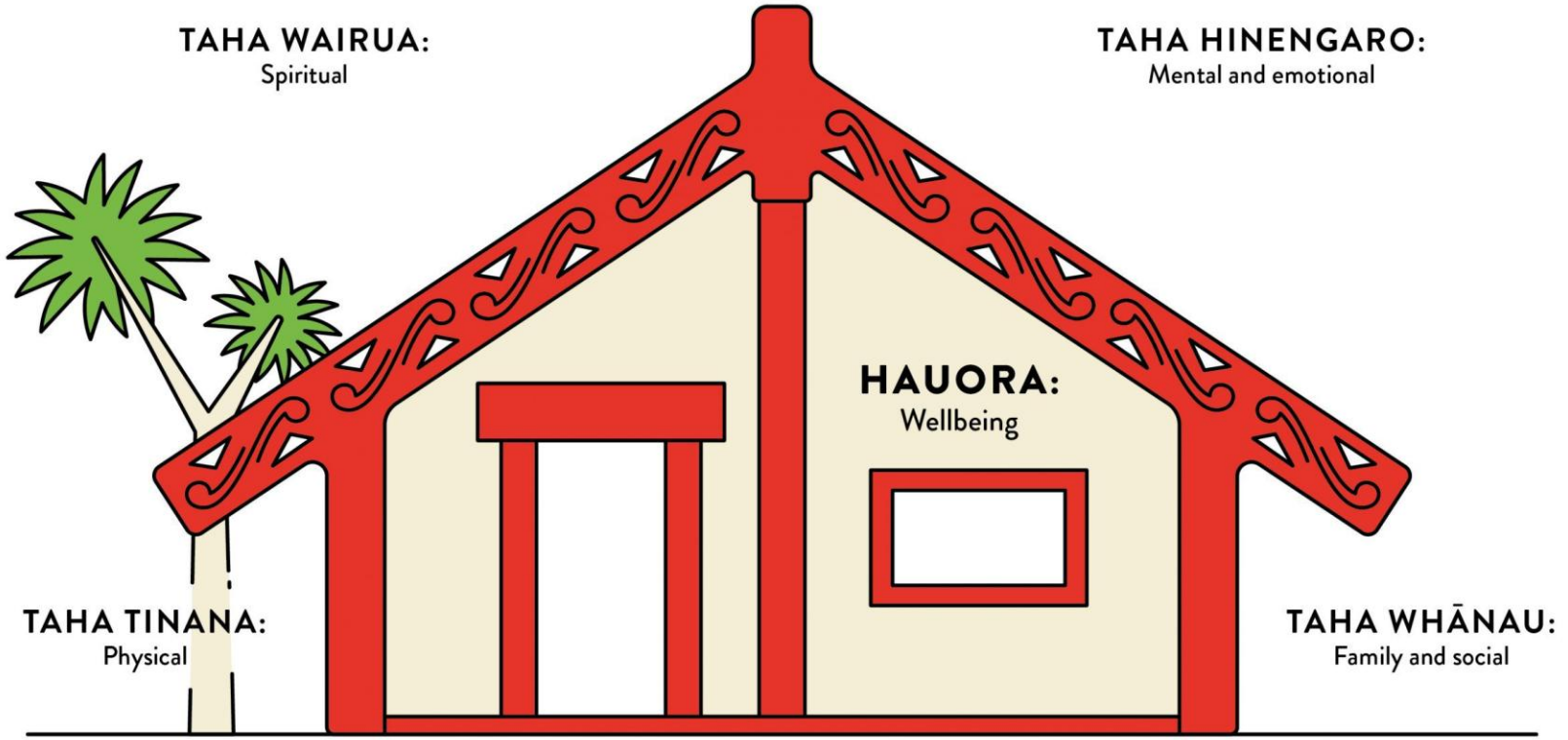
- Kidney supportive care (KSC) is an approach integrating nephrology and palliative care to improve quality of life for people with chronic kidney disease (CKD).





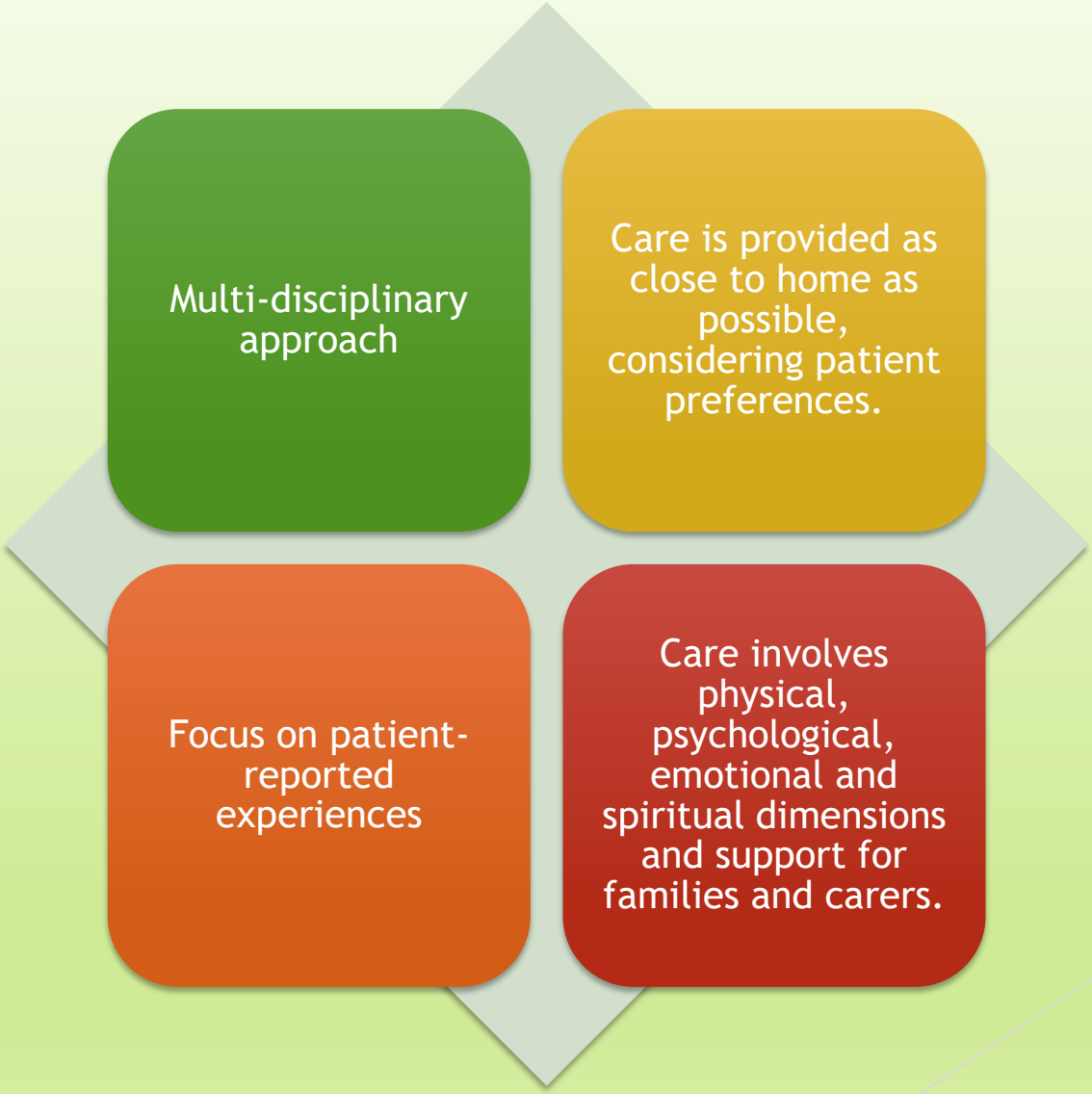


Te Whare Tapa Whā



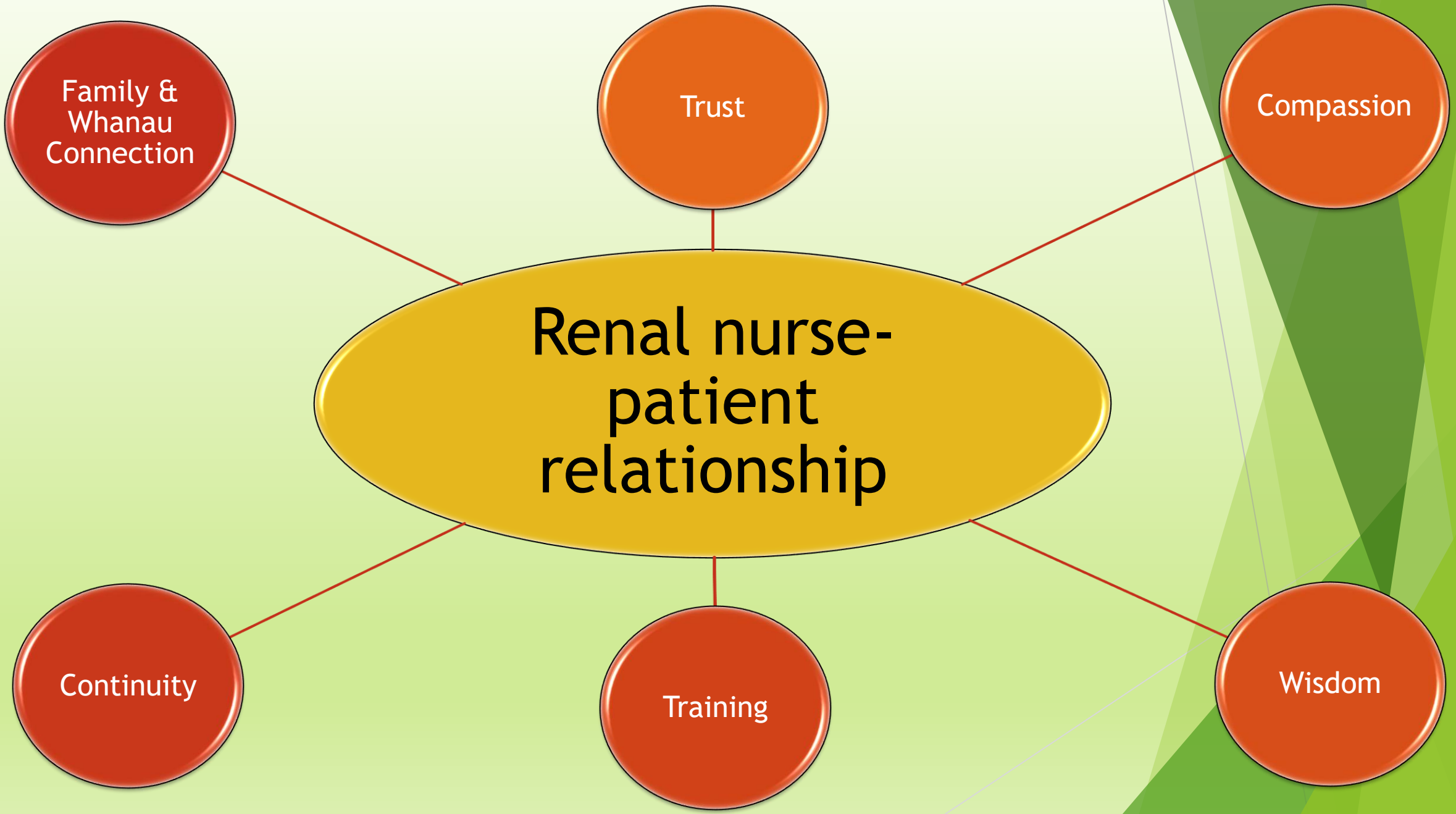
Ngā mihi to Professor Sir Mason Durie, who was instrumental in the development of the Te Whare Tapa Whā model.

Kidney supportive care



The role of nurses in Renal supportive care

Identify	Identify manageable symptoms
Recognise	Recognise early cues of change in health
Connect	Connect with family and whanau
Alleviate	Alleviate emotional distress
Conversation	Start a serious illness conversation
Guide	Offer guidance to the team on current status


Family & Whanau Connection
Trust
Compassion
Renal nurse-patient relationship
Continuity
Training
Wisdom

Learning Lab agenda

- Symptom Management with case vignette
- Recognising opportunites, video simulation
- Communication skills in difficult conversation
- Discussion on empowerment
- Wrap up and takeaways

Quick Poll (Session one)

1. What are the barriers if any in having these conversations?
2. Who usually starts difficult conversations in your unit?

More Than Treatment: Managing Symptoms in Dialysis and CKD”

Natty Miles and Terry Jennings

“Symptom management in CKD isn’t the responsibility of one role—it’s everyone’s business. When we work together, we don’t just treat disease, we improve how patients live every day.”

Key Symptoms in Dialysis/CKD Patients

Pruritus (itching) – very common, distressing, sleep-disrupting

Fatigue and low energy

Fluid overload (oedema, breathlessness)

Muscle cramps during/after dialysis

Nausea and poor appetite

Sleep disturbance

Depression and irritability

👉 Symptom burden is often more distressing than the disease itself.

Why Symptoms Occur

- Accumulation of uraemic toxins
- Fluid and electrolyte imbalance
- Inflammation
- Dialysis adequacy issues
- Dry skin and metabolic changes
- Medication side effects

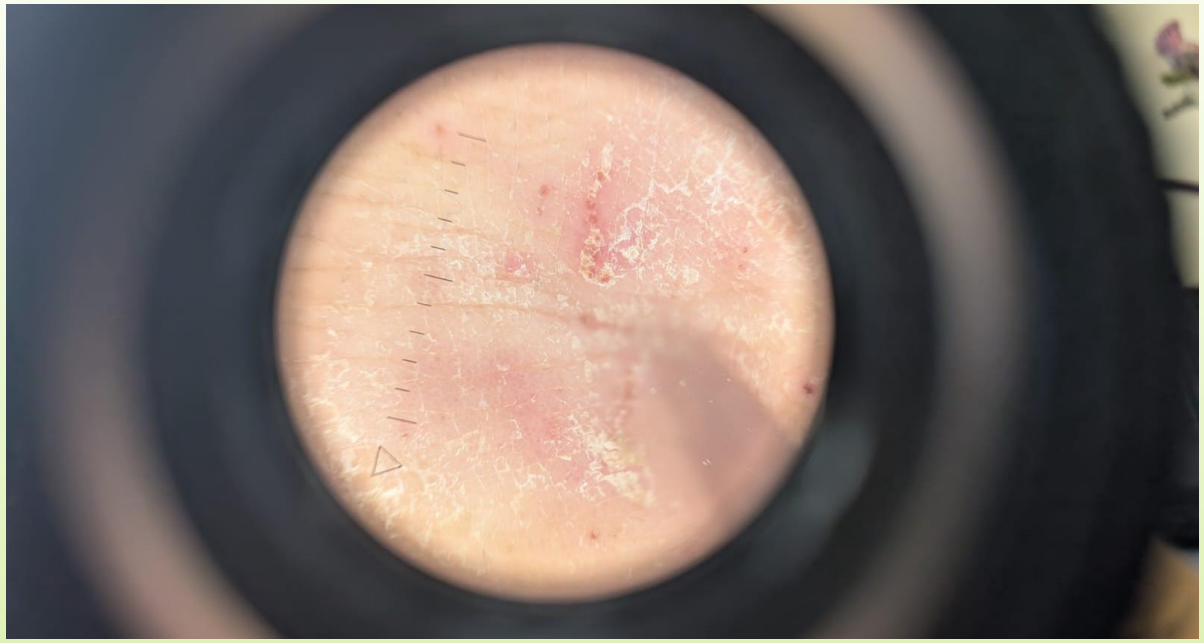
Focus Symptom – Pruritus (Itching)

Uraemic pruritus:

- Affects up to 70% of dialysis patients
- Can be **generalised or localised**
- Often worse at night or after dialysis
- Leads to:
  - Sleep deprivation
  - Anxiety and irritability
  - Skin damage from scratching

Nursing Assessment of CKD-Associated Pruritus (CKD-aP)

- ASSESS ITCH SEVERITY USING WI-NRS (0-10 Scale)
- Determine onset, duration, location, and pattern of itching.
- Identify aggravating and relieving factors
- Assess impact on sleep, mood, daily activities and quality of life.
- Inspect skin for dryness, scratch marks/excoriation, skin breakdown, signs of infection
- Observe scratching behaviour and patient distress
- **Review**
  - CKD stage and dialysis adequacy
  - Medications
  - Relevant laboratory results: urea/creatinine, calcium/phosphate, PTH, Hb





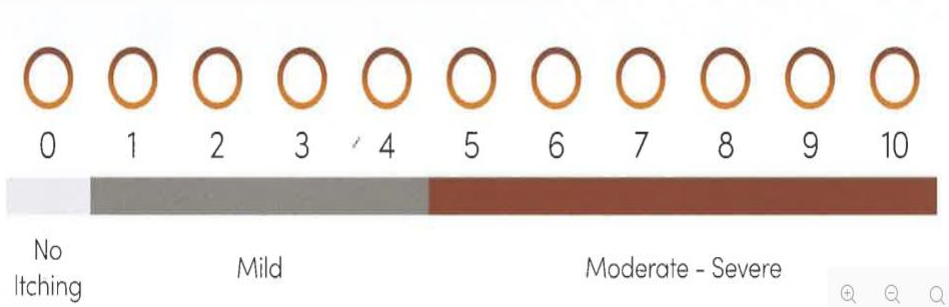

Macule
Papule
Plaque
Telangiectasia
Burrow
Vesicle
Bulla
Petechiae
Petechiae
Comedo
Papilloma
Erythema
Pustule
Wheal
Purpura
Nodule
Ecchymosis

CHRONIC KIDNEY DISEASE ITCH ASSESSMENT

Name

Worst Itch – Numeric Rating Scale

Please rate the worst itch you have felt in the previous 24 hours. Select one option:



Adapted from Phan et al, 2012 and Fishbane et al, 2019

CHRONIC KIDNEY DISEASE ITCH ASSESSMENT

Nurse: _____

Patient: _____

Exclude itch from other possible causes:

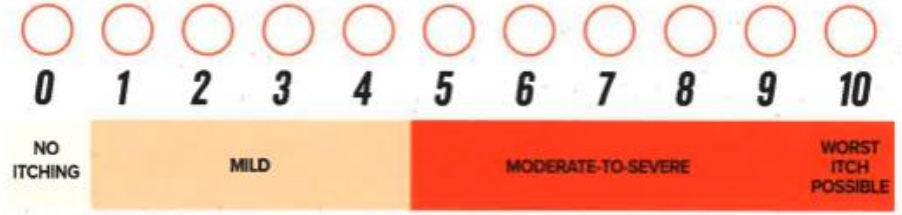
Dermatological causes	Adverse reactions	Systemic causes
Y N	Y N	Y N

Comment: _____

Worst Itch Numeric Rating Scale (WI-NRS)

(To be completed with the patient)

Rate the worst itch felt in the previous 24 hours (select one option).



Adapted from Phan *et al.* 2012 and Fishbane *et al.* 2020.[12]

Follow-up recommendations for Nephrologist to consider

- ◯ Schedule follow-up to assess suitability for CKD-aP treatment
- ◯ Refer to dermatologist
- ◯ Consider investigations/treatments for alternative causes

Abbreviation: CKD-aP, CKD-associated pruritus.

Reference: 1. Phan NQ, *et al. Acta Derm Venereol.* 2012;92(5):502–507. **2.** Fishbane S, *et al. N Engl J Med.* 2020;382(3):222–232.

IPOS-Renal Patient Version

www.pos-pal.org

Patient name : .....

Date (dd/mm/yyyy) : .....

Patient number : ..... *(for staff use)*

Q1. What have been your main problems or concerns over the past week??

1. .....

2. .....

3. .....

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	0☐	1☐	2☐	3☐	4☐
Shortness of breath	0☐	1☐	2☐	3☐	4☐
Weakness or lack of energy	0☐	1☐	2☐	3☐	4☐
Nausea (feeling like you are going to be sick)	0☐	1☐	2☐	3☐	4☐
Vomiting (being sick)	0☐	1☐	2☐	3☐	4☐
Poor appetite	0☐	1☐	2☐	3☐	4☐
Constipation	0☐	1☐	2☐	3☐	4☐
Sore or dry mouth	0☐	1☐	2☐	3☐	4☐
Drowsiness	0☐	1☐	2☐	3☐	4☐
Poor mobility	0☐	1☐	2☐	3☐	4☐
Itching	0☐	1☐	2☐	3☐	4☐
Difficulty Sleeping	0☐	1☐	2☐	3☐	4☐
Restless legs or difficulty keeping legs still	0☐	1☐	2☐	3☐	4☐
Changes in skin	0☐	1☐	2☐	3☐	4☐
Diarrhoea	0☐	1☐	2☐	3☐	4☐

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?

1._____	0☐	1☐	2☐	3☐	4☐
2._____	0☐	1☐	2☐	3☐	4☐
3._____	0☐	1☐	2☐	3☐	4☐

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worried about your illness or treatment?	0☐	1☐	2☐	3☐	4☐
Q4. Have any of your family or friends been anxious or worried about you?	0☐	1☐	2☐	3☐	4☐
Q5. Have you been feeling depressed?	0☐	1☐	2☐	3☐	4☐

	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0☐	1☐	2☐	3☐	4☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0☐	1☐	2☐	3☐	4☐
Q8. Have you had as much information as you wanted?	0☐	1☐	2☐	3☐	4☐

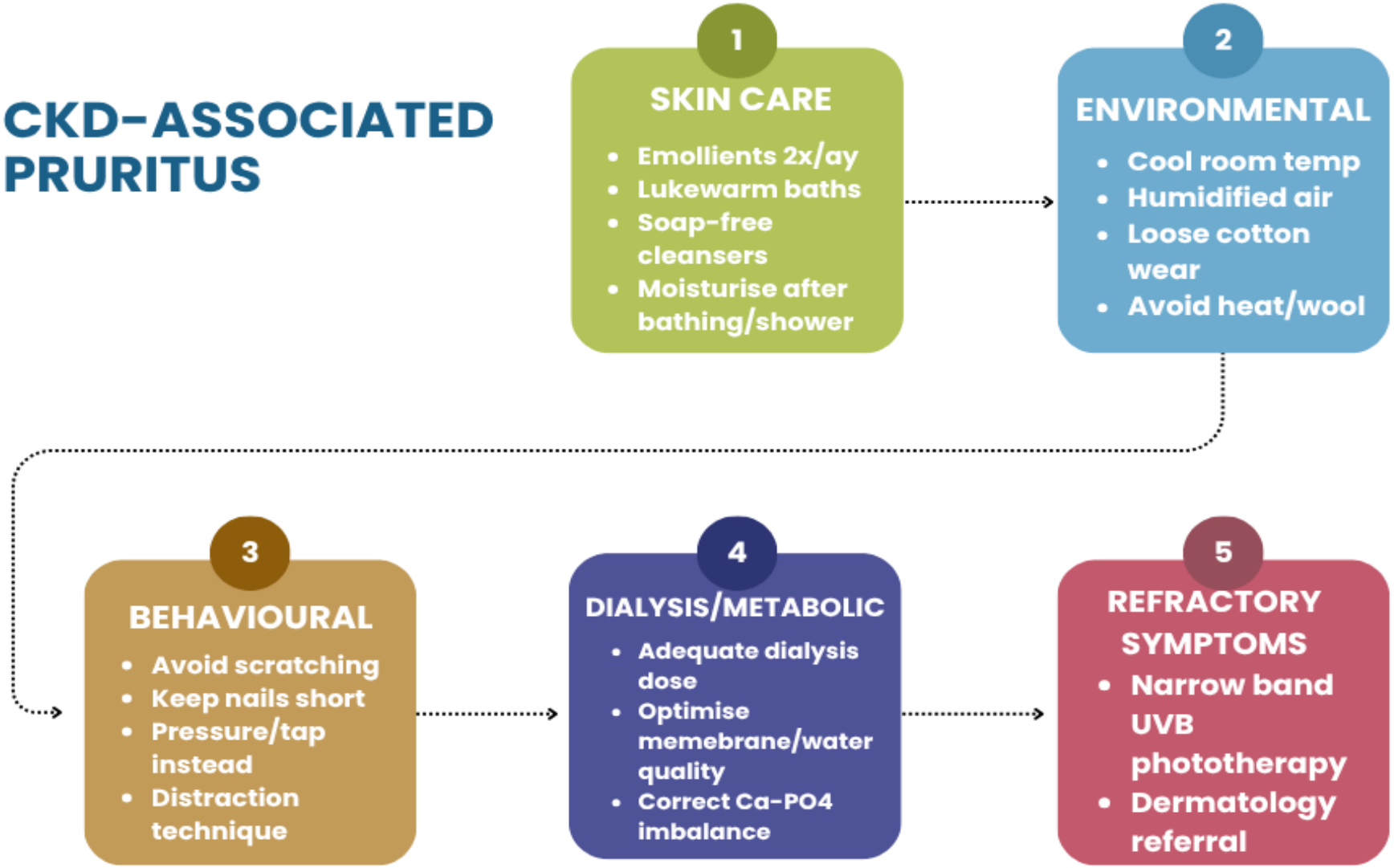
	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0☐	1☐	2☐	3☐	4☐

	None at all	Up to half a day wasted	More than half a day wasted
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests	0☐	1☐	2☐

	On my own	With help from a friend or relative	With help from a member of staff
Q11. How did you complete this questionnaire?	☐	☐	☐

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

CKD-ASSOCIATED PRURITUS



ASSESSMENT “ITCH”.

I- INTENSITY

Severity using WI-NRS or 0-10 scale

T- TIMING

Onset, duration, pattern, nocturnal symptoms

C- CHARACTERISTICS

Location type of itch, triggers/relief

H- HARM/IMPACT

Skin damage, sleep disturbance, quality of life

Clinical Scenario: “The Itch That Won’t Stop”

- Mr. Ali is a **59-year-old male** with **end-stage kidney disease (ESKD)** secondary to **type 2 diabetes and hypertension**. He has been receiving **haemodialysis three times per week for the past 10 months**.
- Over the last **3 weeks**, he reports **worsening generalised itching**, especially at night. He says:
- “I can’t sleep at all. I scratch until I bleed. It’s driving me crazy.”
- He has also **missed one dialysis session recently** due to fatigue and poor sleep.

What would you do as a primary nurse?





Communication Tools

Examples of Pharmacological treatments available (NZ)

Topicals

- Emollients- with high water content (due to dry skin)- Sorbolene/Menthol
- If no improvement try topical analgesic agent – Pramoxine- over the counter and safe

Do not use

- Topical NSAIDs (affects residual renal function) or
- capsaicin – unpleasant side effects burning.

Systemic

- Antihistamines – may only help short term – sedating
- Gabapentinoids – used for neuropathic pain
  - Gabapentin – in divided doses after HD causes sleepiness, GI upsets, dry mouth blurred vison.
  - Pregabalin 25mg-75mg – Day time drowsiness and dizziness
- Antidepressants ??
  - Sertraline 50mg OD may take up to 4 wks. to be effective.
- Evening primrose oil

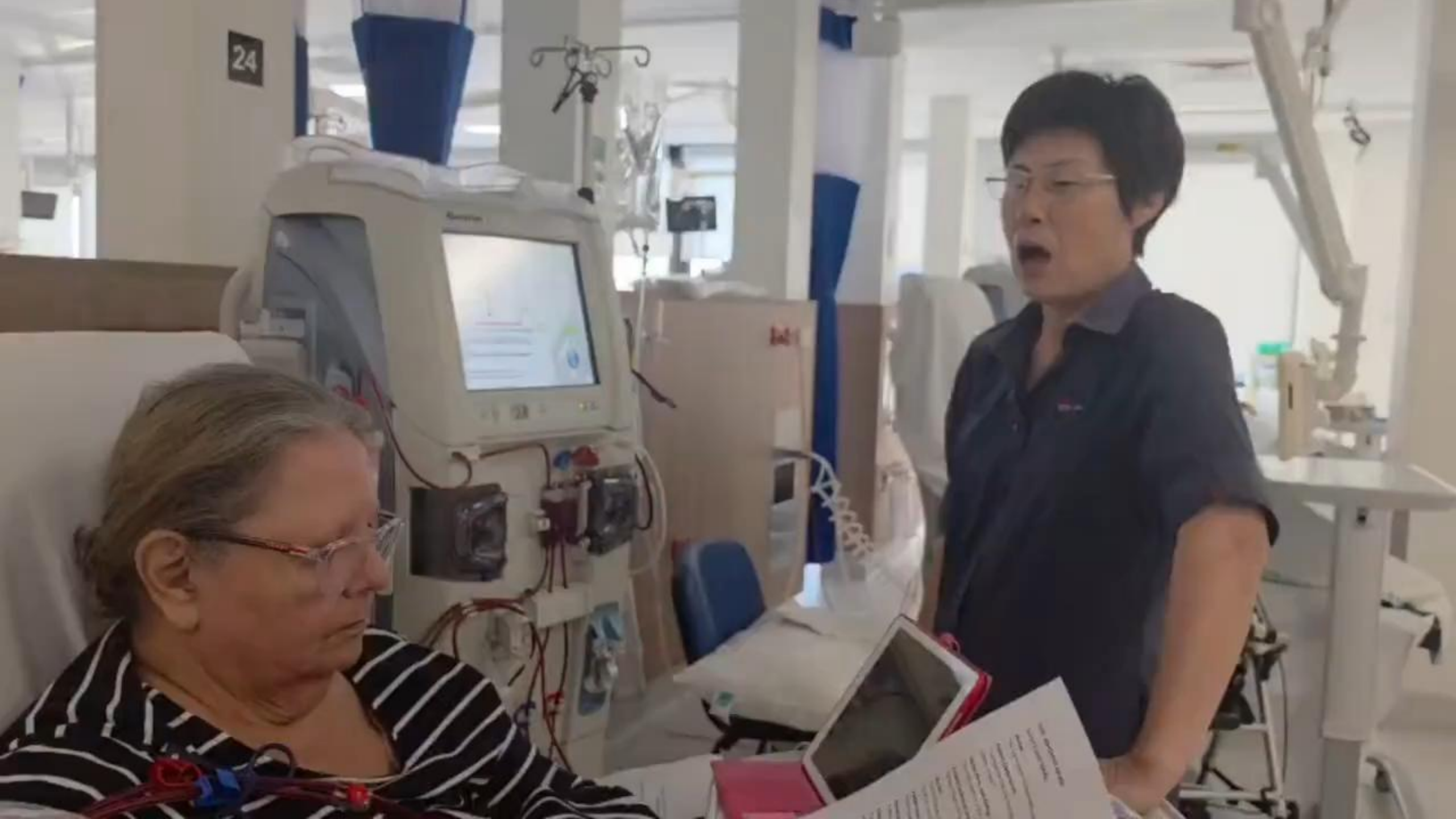
Symptom Management: Everyone's Business

- CKD symptoms are frequent, complex, and ongoing
- Nurses, doctors, and allied health all play a role
- Patients and families are active partners in care
- Early recognition + teamwork improves outcomes
- Comfort, dignity, and quality of life are shared goals

Key message:
👉 *Better symptom control happens when everyone is involved.*

Synopsis of video ;Recognising opportunities

- Nurse patient relationship after a missed dialysis session


24

Session 3 Group work / discussion

- What verbal or none verbal cues did the patient give?
- Where there any moments the patient was inviting deeper discussion
- What could ‘missing’ dialysis represent
- What would you say first?
- When would you explore further vs moving on?

Session 4 Synopsis of video

Frail patient with advanced CKD deteriorating

- Concerns about burden vs benefit of dialysis.
- Patient withdrawn and fatigued
- Daughter is opposed to stopping dialysis



Session 4 work in groups discuss (10 mins)

- What might the daughter be feeling?
- What makes this situation difficult/ challenging as the nurse?
- As the nurse why might hold you back?
- What would you say?
- What should you NOT do?
- Why do nurses hesitate to have these conversations

Nurses are:

- Trusted
- Continuously present
- Skilled in relational care

- Self empowerment:
- We can start this conversation and involve the doctor as needed
- This is within my scope to explore
- Core nursing skill!



tō tātou reo
advance care planning

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Image by Glenda Rees

What matters most to you when you think about your health changing?



My Advance Care Plan & Guide

Plan the healthcare you want in the future and for the end of your life

Name: _____

Date: _____

our voice | Advance Care Planning
tō tātou reo

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

Authors: Leigh Manson (senior programme manager, New Zealand national advance care planning programme) and Jane Goodwin (national SICG trainer and advance care planning facilitator for Canterbury District Health Board)

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 harm[ii] – 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

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?

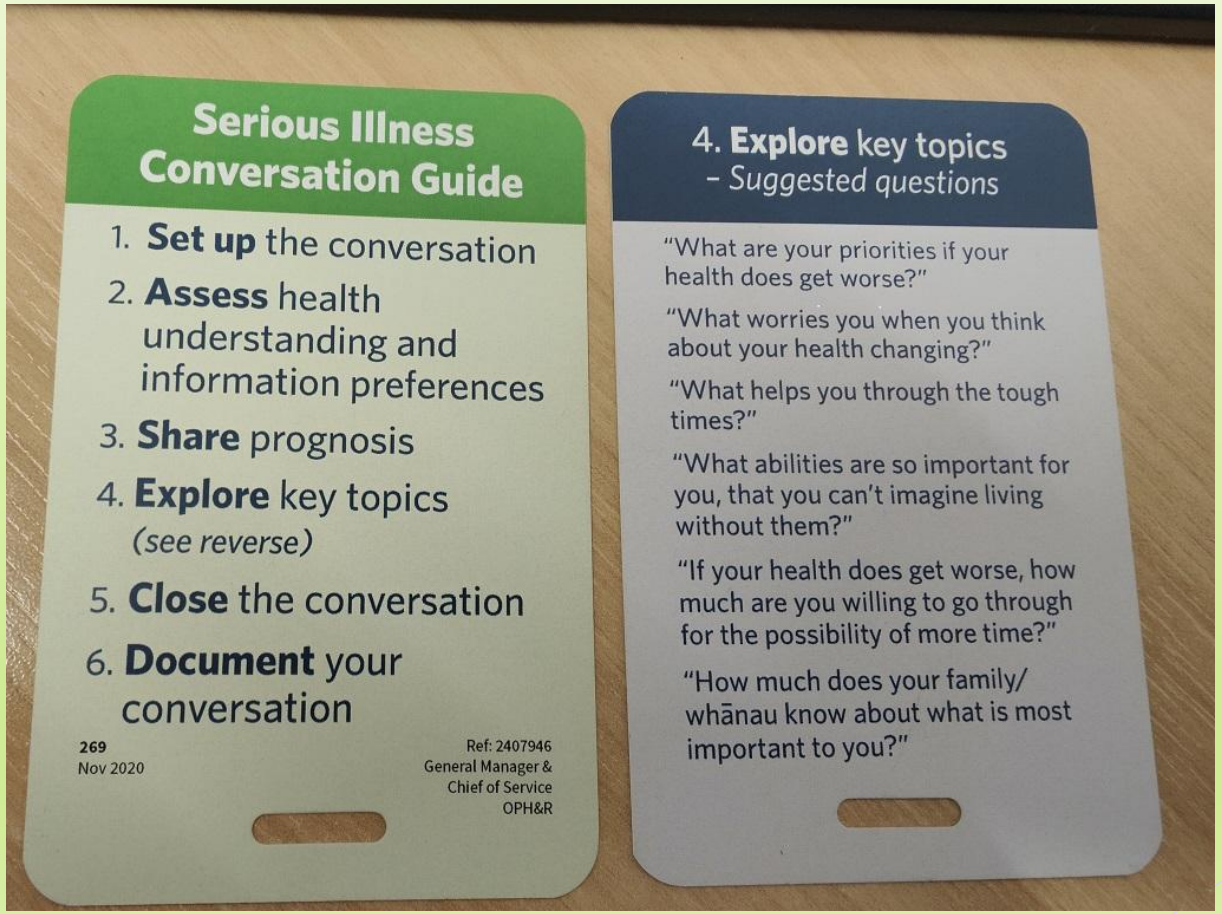
Twenty-four consumers including current patients and members of the public attended, along with 25 clinicians, including doctors, nurses, allied health workers and cultural advisors. Thirteen attendees identified as Māori.

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.

tō tātou reo advance care planning

Serious Illness Conversation Guide Aotearoa



Kidney Supportive Care



- Patient Centred Care- focus on quality of life, care closer to home
- Team Approach – blends nephrology care with palliative support
- Eases suffering- focus on patient reported experience
- Not just for end of life- supports patients at any stage
- Complements treatments – works with or without dialysis

Core focus areas

- Symptom relief
- Conservative management
- Shared decisions- matched to values and patient preferences
- Future planning
- Patient and Family support

Not all hero's wear capes!

- Acknowledge the work Nurses do – its not easy!
- Renal work -Emotionally draining (grieving process).
- Nurses vulnerable due to longevity of care provided.
- Important to include some self care - your well being
- Ensure processes in place to assist: EAP, Debriefing, Mortality meetings, Peer support





Take home message



Tools: ACP Serious illness conversation guide, IPOS RENAL - to assist with conversations

Feel empowered/ confident to take these tools back to your units- to implement as a team

KSC –

- Not just about treatments decisions
- Its about nursing!
  - Listening, recognising cues,
  - Having courage to start conversations that matter
- Its the conversations that matter.
- We are well placed to start these conversations.