

Box 1: Whakataukī.

“He kokonga whare I kitea,
He kokonga ngākau e kore e.”

The corners of a house can be seen, but not the corners of the heart.

This whakataukī (Māori proverb) reflects the idea that we are not always certain about the inner thoughts or feelings of others. This encourages us to be mindful of the ways in which we engage. This whakataukī reminds us to enact care, love and respect for others. In addition to this, it gives value to kindness and patience, for we are never sure what other people are going through. In our kindness and compassionate gestures, we can bring light to others in their times of darkness.

Box 2: The value of whanaungatanga in caring for our boy—Davina Collins.

AJ is 20 months old and has a hypoxic brain injury. Over the course of the last year, AJ has struggled with dystonia, seizures and frequent respiratory infections. Despite this he is a little boy full of mischief, smiles and an ability to laugh and enjoy time with his whānau. AJ has spent long periods of time in hospital and when at home has been supported by a team of community health professionals. Communication and whanaungatanga is integral to the care of any child and their whānau. Without this, mistakes can be made and distress caused for both AJ and us as a whānau.

It is essential we can connect and come together as a team—whānau and health professionals as one whānau around the child. We need to bring our baskets of knowledge together—the whānau of being the experts in their child and the health professionals their skills, training and experience. We must work together as a team. When big decisions need to be made, it is important we have trusting relationships with health professionals who are working with us.

“We row this waka [canoe] together as a whānau (family & health professionals). We need to be on the same waka and heading in the same direction.”

*The most important ways in which whanaungatanga can be established is through taking time to get to know AJ and us as his whānau. Get to know AJ as a little boy, beyond his illness. Get to know us as a whānau—what matters to us, our beliefs and values. We need health professionals to always respect our culture and acknowledge that just because we are Māori, we don’t all do things the same. Different iwi, different tribes have different perspectives and different ways of doing things. We would love to be cared for by more Māori clinicians. When that’s not possible, engaging with kaiaatawhai (cultural support team) and kaumātua (Māori elders) is really important to us and is a huge support in connecting with hospital staff. **We need health professionals to not be judgemental and authentically connect with us, listening to our perspective and our experiences of caring for AJ.***

We know that we won’t always have a health professional that knows AJ or us as a whānau, especially when we have to come to the emergency department in the middle of the night or weekends, but what helps in these situations is communication, hearing what we are saying and health professionals taking the time to connect with us.

Listening is the most important way you can connect. AJ’s voice needs to be heard—in day-to-day care, in decision making always.

“We are his voice—we are speaking for AJ, understand our voice for AJ.”

Figure 1: Te Whare Kāiao graphic illustrating the concept of the living whare.



Figure 2: Ārai graphic symbolising the veil between the physical and metaphysical worlds.



Figure 3: Waka and kai hoe graphic illustrating the collaborative partnership between whānau and health professionals.



Figure 4: Three baskets of knowledge graphic.



Figure 5: Tamaiti graphic illustrating the child's relationship with their environment.



Table 1: Te Whare Kaiao—considerations in providing paediatric palliative care.

Taha hinengaro	<p>Child's likes/strengths/important connections and toys</p> <p>Therapeutic support for child and siblings</p> <p>Child's understanding of what is happening—developmentally appropriate</p> <p>Child and whānau hopes, worries and fears</p> <p>Whānau support to be able to spend all their “being” with their child</p> <p>Whānau understanding of what is happening</p> <p>Te Wā Aroha (goals of care and advance care plan)</p> <p>Discuss support services and consider alignment with child and whānau beliefs</p> <p>Mana Motuhake (autonomy and independence)—support strong whānau voice</p> <p>Acknowledge feelings, emotions and uncertainty</p> <p>Listening to child and whānau!</p> <p>Whānau strengths and vulnerabilities</p>
Taha wairua	<p>Karakia (prayers, chants and incantations) and waiata (songs, singing)</p> <p>Kaumātua, chaplain or tohunga (expert [on spiritual wellbeing]) support</p> <p>Mirimiri (massage) and Rōngoa Māori</p> <p>Whānau-led care</p> <p>Appropriate physical space to meet spiritual-, cultural- and faith-based needs</p> <p>Acknowledge whānau beliefs and spiritual messages</p> <p>Acknowledge HOPE always</p> <p>Memory making—maintaining connection for future (photos, castings, dreams, wishes)</p> <p>Clothing, korowai (cloak), pounamu (greenstone)—items of significance that need to be kept with child</p> <p>Health professional support—what's helpful? What's not?</p> <p>What is important to child and whānau</p> <p>Child never left alone</p>
Taha tinana	<p>Symptom management—managing distress, multimodal—medicines and non-pharmacological measures</p> <p>Positioning</p> <p>Personal cares and hygiene</p> <p>Referrals for continuing care if transitioning to different environment, e.g., home</p> <p>Physical environment—lighting, aromatherapy, noise, favourite toys, temperature, home comforts if in hospital</p> <p>Anticipatory planning and medicines available</p> <p>Physical touch and comfort—cuddles</p> <p>Comfort assessment—whānau/clinician partnership</p> <p>Equipment to support comfort</p> <p>Developmental care—support children to reach their full potential, involving siblings</p> <p>Practical medical supplies and resources</p> <p>Nutrition and hydration—benefits and burdens—consider role of comfort feeding</p>

Table 1 (continued): Te Whare Kaiao—considerations in providing paediatric palliative care.

Taha whānau	<p>Practical whānau support (considering extended whānau) —meals, food, housing, practical supplies</p> <p>Sibling recognition and support</p> <p>Consider family dynamics</p> <p>Information—how much? When? How would they like information provided?</p> <p>Who is important to have present for a hui? Who is decision maker?</p> <p>Financial support</p> <p>Acknowledge and involve all whānau important to child</p> <p>Acknowledge tipuna</p> <p>What strengthens whānau during difficult times?</p> <p>Explore tikanga and wishes for after-death care</p> <p>24/7 plan for communication and support for whānau.</p>
Whenua	<p>Location of care</p> <p>Hospital setting—consider environment—double room, relaxed visiting policy, whānau able to stay, space for whānau to gather for kai together</p> <p>Supporting home routine to maintain connection to home</p> <p>Bringing home into the room—pillows, duvet, toys, items of significance</p> <p>Where do whānau feel most connected to?</p> <p>Transitional objects—connection to significant place</p> <p>Whakapapa (genealogical descent lines)</p> <p>Where do they want to be after death?</p> <p>Where is the whānau whenua?</p> <p>Community connections and support</p> <p>Key health professional relationships</p>