

Hearing 'the patient's voice': Exploring patient perceptions of hospice services to inform future service design

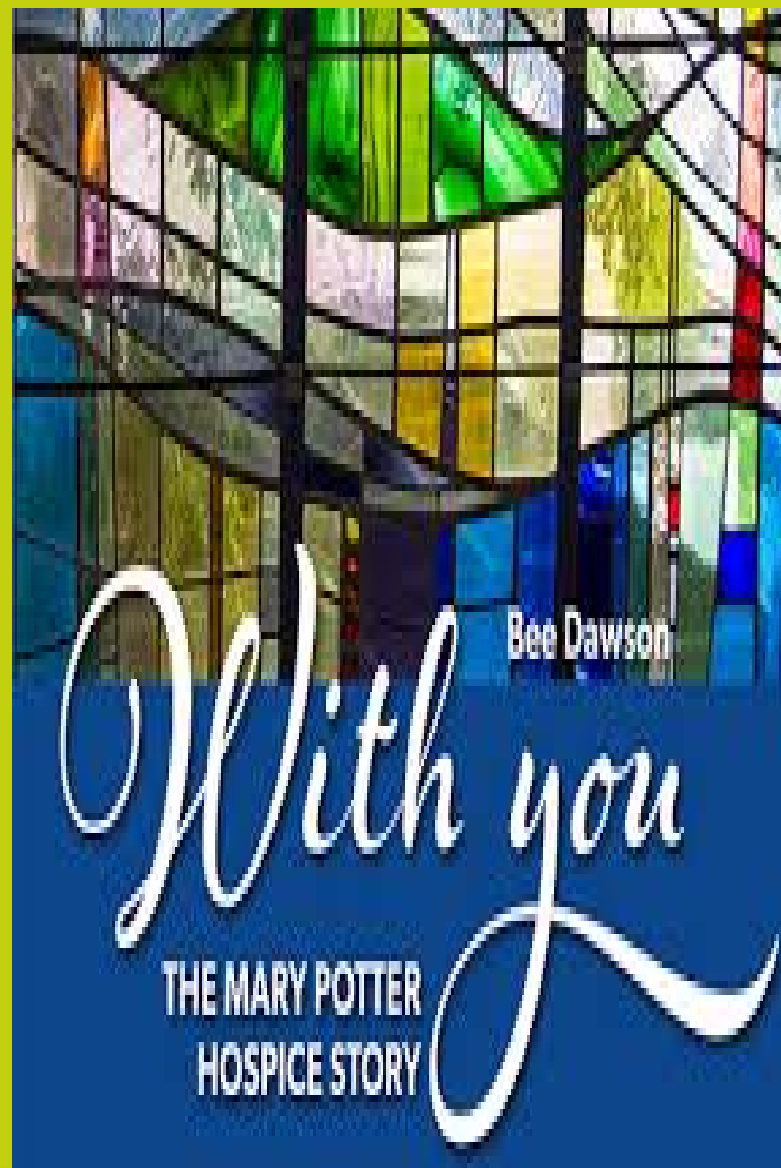
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N.B. The full research team: Teresa Read, Martin Woods, Penny Brander, Sue Buckley and Marianna Churchwood.



Greetings from Mary Potter Hospice New Zealand

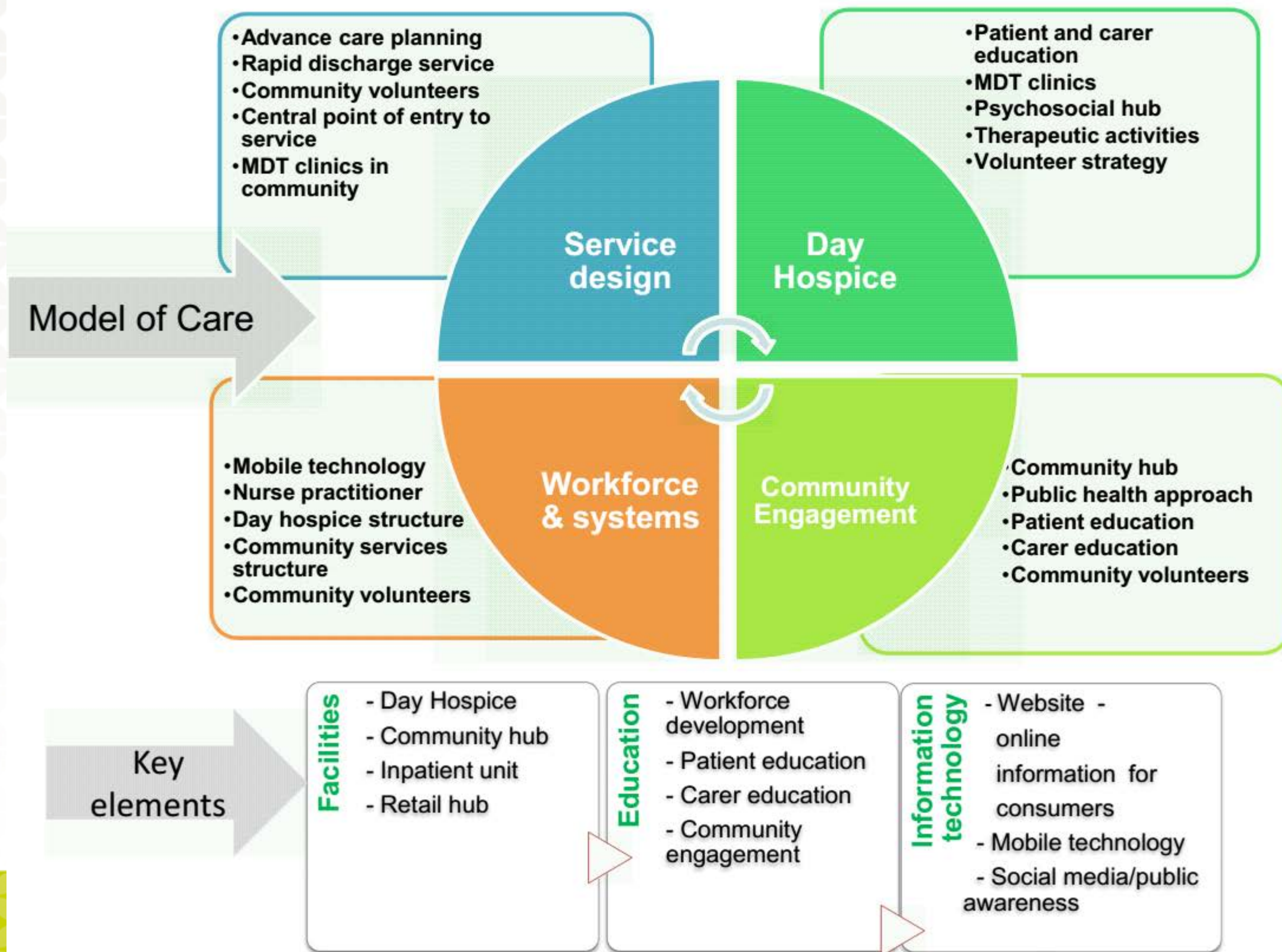


**CAPITAL & COAST
DISTRICT HEALTH BOARD**



Mary Potter provides palliative care services free of charge to our patients through an 18 bed In-Patient Unit in Newtown and three community palliative care teams based in Wellington, Kapiti and Porirua. Most of the work is in the community takes place in our patient's home. On any one day, we have 240 to 260 people in the care of our community teams. We care for 850 people a year.

Towards 2026 - Enhanced Community Service Model



Enhanced Community Service Model key projects

Allied Health
Leadership
Model

Maori
Service
Plan

Strengthening
Medical
structure

Consumer
Engagement

Practice
Sharing

Service
Model

Caseload
Management

Day Hospice

Pacific
Service
Plan



The study aimed to explore patient experience of inpatient and community services while in the care of Mary Potter Hospice...



Patients were encouraged to describe their care experiences within the domains of *staffing, environment and communication* and to identify areas where care and support could be improved (Hospice New Zealand, 2012; McIlfatrick, S. et al., 2014).

Background

The study aligned with Mary Potter Hospice's determination that:



- 'It is important that we develop support which begins with people's personal experiences and ask: "What would improve that?"'
- The study was viewed as an opportunity to validate the Mary Potter proposed future model of care and pilot a process of seeking on-going consumer feedback in the Hospice service in order to evaluate current practice (as is outlined in, for instance, MacLeod, Vella-Brincat & MacLeod, 2012) and identify areas and strategies for improvement.

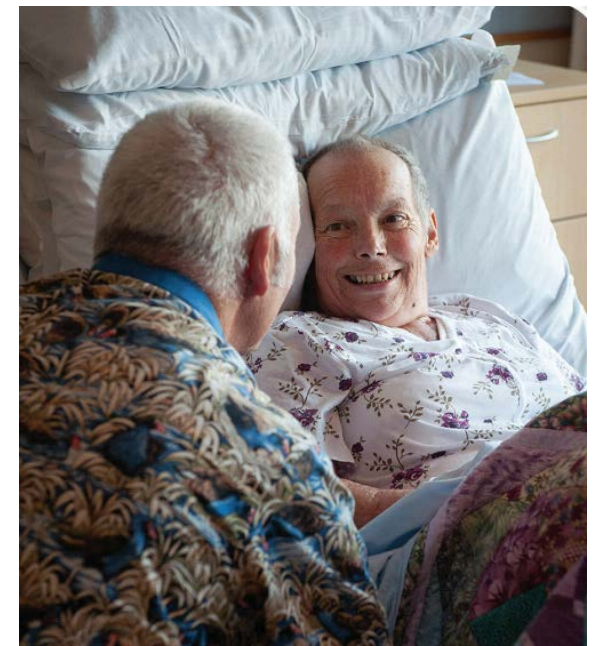
Methods



- Qualitative design incorporating in depth semi structured recorded interviews.
- Patients who were receiving or had received (within the last year) both IPU and Community based services were invited to participate.
- Analysis – Thematic analysis incorporating the standard stages of Organisation, Familiarisation, Reduction and Analysis (Guest, MacQueen & Namey, 2012).
- Coding frame and themes were developed by 2 of the researchers.

Recruitment

- A phone call was made by the Quality Manager, based at Mary Potter Hospice, who introduced the purpose of the study and ascertained the individual's interest in participating.
- A follow up letter outlining the project aims was sent to those expressing an interest together with a copy of the Participant information sheet .
- Those individuals who were still interested in proceeding were informed that the Interviewer would contact them within a week to arrange a time and place, as agreed by the participant, to meet in order to further explain the study, answer any questions, obtain written consent and conduct the interview.



Participants

Inclusion criteria

10-15 consecutive patients currently in the care of Mary Potter Hospice who have:

- received palliative care in the IPU and Community service across the greater Wellington region within the last year
- been determined by the Multidisciplinary team, not to be experiencing any significant psychological or other issues whereby participation would likely incur undue stress.

Exclusion criteria

- patients experiencing dementia, delirium and/or other related cognitive impairment disorders
- considered by the Multidisciplinary team, to potentially be within the last week of life.



Risks and benefits

As is always the case when considering a research project involving such a vulnerable population, great care was taken to avoid any possible foreseeable harm to participants.



However, it was not anticipated that participation in the project would result in any significant risks to those who take part.

Rather it was considered that the opportunity to voice experience and suggest areas where care could be improved may provide participants with a sense of contributing towards the benefit of future consumers.

Results

Seven main themes were discovered within the data:

They were (in no particular order):

- The hospice as a place of comfort and refuge
- Demystifying the role of the hospice
- Empowering through shared values
- Maintaining good communication
- The staff member as a respectful friend/companion/guide
- The importance of expertise at all levels and consistency of staff
- The effectiveness and impact of volunteers

The hospice as a place of comfort and refuge

- Several participants indicated that the hospice represented a place that they could feel 'at home':

"Hospice, the word means to most people that's where they go at the end of their life and they get good palliative care, and this is what it's about...it was such a... relaxful [sic] pace" (MP 005, p. 12).



- The hospice as a comforting, restful place:
"like a motel", "better than hospital", "better than home" etc.
- The hospice as a refuge during a time of major crisis
- The availability of space *"to be oneself"* ...alone or with others

Demystifying the role of the hospice

- The theme that the hospice is for dying people was a common one that was only dispelled after familiarisation with the service:

“I came in to see the Hospice, to be shown around, to be explained to me how it works and, you know, what can happen while you are here... I stayed there for a while, it was a real eye opener for me because I felt like you come into the Hospice and die, you know, you walk in at one end and you get carried out in a box at the other end, and they look after you during that process. Nothing could be further from the truth” (MP008, p.3)

- The misconception theme (the hospice is for dying people, ‘the unknown’, etc.).
- The notion that dying and death is not a secret or to be mystified...

Empowering through shared values

Several sub-themes emerged in this category:

- The empowering theme (*I talk to the doctors...not family...the Dr/Nurse/Social worker, others, spent time with me, etc.*)
- The power of the people (doctors, nurses, volunteers, etc) to share their values... through the hospice infrastructure
- The value of all the supportive staff, i.e. *“mood conscious”* non-invasive, holistic and coordinated care...is passed on to the client/s.
- The dissemination of shared of values through actions, words – *“on the walls”* – language, etc.).

Values and themes

The five values of Mary Potter Hospice:

- Hospitality
- Compassion
- Dignity
- Respect
- Stewardship

The seven themes (rearranged):

- Demystifying the role of the hospice
- Maintaining good communication
- Empowerment of others through shared values
- The staff member as a friend/companion/guide
- The hospice as a place of comfort and refuge
- The importance of expertise at all levels and consistency of staff
- The effectiveness and impact of volunteers

Maintaining good communication

- The bridging theme (talking the talk, filling the gaps, the value of a liaison person, etc.) This was most often done by one person (commonly the nurse), i.e. The Palliative Care Coordinator).
- The need for effective communication theme, or as one participant put it, *“Full explanations delivered in a generally undramatic fashion.”*
- This process enables adequate decision making:
“The staff here encourage you to make your own decisions and arrive at a point that you feel like you’ve made a decision about that treatment and that you are in control of it, they certainly don’t want to take that away from you” (MP008, p. 7).

Effective communication - “The right touch...”

“The right touch is they’re not going to flinch away from the fact that you’ve got an incurable disease that is going to knock you off. They don’t sort of go all weepy and wailing and smother you in the way that family members might, for example. They’re quite blunt, they quite professional, quite clinical in how they deal with things, but they’re very cautious not to use emotive, non-PC language. For example - and they have a lot of respect for the patients - they don’t try to force anything on to people, things that you might not want to do” (MP008, p. 4).

The staff member as a respectful friend/companion/ caring guide

- The shared companionship/friendship theme - through the ambiance, atmosphere, the communal nature, not wearing uniforms, the use of Christian names, etc.:
- *"... and she's been very good to me, very, very good to me and she's also become a very good friend..."* (MP005, p.5).
- *"Well, we never really had any support[before she went to the hospice], nothing, but they just made it so lovely to go, that somebody cared, and they do care...X [husband] ... but that's the part that their care that kind of lifted up... we had been through some pretty hard times and the Hospice seemed to lift us up over the massive hurdles..."* (MP005, p.11).
- *"They always treat you with respect, you know. I've been sick in the hospital and you don't know from one day to the next what nurse you are going to get, or how well they're going to look after you, you certainly don't get the same level of personal attention that you get in the Hospice"* (MP006, p. 6).

The importance of expertise at all levels:

Consistency of staff

- Data revealed a high degree of appreciation of professional expertise at all levels – e.g. nurses, doctors, social workers, spiritual advisors, occupational therapists, etc. ...but also evidence of practical wisdom within the ancillary staff, cooks, cleaners, volunteers, clerks, etc. (the shared values).

- It's not just medical or nursing expertise that was appreciated... E.g. coordination with community services was seen as very important:

“X [social worker] arranged coordination between the health carers and they came up with a package, and they implemented that and it wasn't until they were able to implement it that I came home. I was a bit worried initially until I experienced it and then it was great”

(MP006, p. 5).

The importance of expertise at multiple levels...

- Excellent treatment and symptom control through combined efforts:

“Oh yes, everything ... every bit of treatment that I’ve had from the day I was crook has been excellent both with the public and with Mary Potter Hospice” (MP004, p. 2).

- The value of a good support group:

“I’ve got this terrific support group all around me with the palliative care nurse, the Hospice, the Blood and Cancer ward and also my GP, and my family. I want for nothing” (MP003, p. 6).

The effectiveness and impact of volunteers

- Hospice volunteers were often praised by several participants for their kindness and altruism:

"I like their volunteers, they're very generous with their time which makes a big difference, but still it also makes a nice atmosphere too, having volunteers there, that's very nice." (MP002, p.7).

"Despite all that there is a phenomenal base of volunteers that help the place to run. I am just so impressed. It sounds to me for funding and logistics issues it would be really difficult for the place to run without them and they need more people helping out... it's a very kind and positive thing to be doing, there is an air of kindness about..." (MP008, p.10).

Limitations/future plans

- Only a small study with ten participants.
- Uses clients who were...mainly effusive in their praise, although there were a few complaints...e.g. ...the 'evangelists visit' (1); sharing rooms (2); the need for GP education about the role of the hospice (3).
- Not particularly a study of the opinions of *the carers* of palliative patients.
- Future plans include a more formalised, possibly survey based, approach to consumer opinion about the services.

Recommendations

- This project has provided consumer feedback regarding the relevance and appropriateness of the inpatient unit and community based care for patients, family, whānau and/or carers, from the perspective of patients
- It has revealed aspects that worked well and areas where care could be improved.
- The findings will be used to develop and implement an action plan for further defining and/or improving best practice care for patients who access Mary Potter Hospice services.



*Preparing for the
future to ensure
people:
get the **right care**,
at the **right time**,
by the **right team**
and in the **right place***

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Contact us

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- He aha te mea nui o te ao?"
- "He tangata, he tangata, he tangata."
- "What is the most important thing in the world?"
- "It is people, it is people, it is people."