Do you really see me?

Or just my disability...

Engaging with patients
with disabilities/tāngata whaikaha

BAY OF PLENTY
DISTRICT HEALTH BOARD
HAUORA A TOI

This booklet has been prepared as a resource to help staff understand the importance of communicating with patients and their families in a way that is patient-centred and timely and fulfils the needs of the patient.

Do You Really See Me?

Do we really see the patient or just their disability? Are we engaging with patients in a manner that fits their needs?

This booklet contains information about seven patients with a disability/tāngata whaikaha, who face daily challenges, and what has mattered most to them.

The questions asked of the patients whose stories are written here were:

- How do you prefer to be greeted?
- How do you like to be engaged with?
- What do people do that helps you?
- What do people do that hinders you?
- What do people do that annoys you?
- What do people do that makes you feel unsafe?
- What behaviours are absolutely unacceptable to you?
- What could be done better?
- What could be done differently?

For each patient there is a story and then their (or their family's) answers to the questions.

Every patient is different, so not all these personal preferences will apply to other patients, but there are common themes here. If we apply the general principles and consider the common themes identified in this booklet (below) when engaging with patients with a disability/tāngata whaikaha, we will be on the right path to providing our patient's with the ideal patient-centred patient journey.

General Principles

- ***Social value*** - don’t devalue a person, don’t take points off because they are different
- ***Treat age appropriately*** - treat people for the age they are and not what you think they are
- Always show “***unconditional positive regard***”
- Get information by ***directly focussing on the person*** - only seek family or carer input if the person isn’t able to provide the information or if more information is needed.

Common Themes

- ***Initial greeting*** – when greeting a person please make eye contact and use the person’s name
- ***Respect and courtesy*** – please treat a person with respect and courtesy
- ***Engagement*** – please talk with the person and not with others around them
- ***Listening*** – please listen to the person – give the person time to express themselves and repeat what they have said; then given them time to understand what they have been told and to ask questions
- ***Treat the person*** – as an individual and not just the disability; don’t judge the person on their appearance or on their needs
- ***Routine does matter*** – when a person has a disability, a routine and familiar items around them help them feel safe
- ***Trust*** – a person needs to trust the people around them to tell them the truth and to do what they say they will
- ***Communication*** – please be careful what is said and how it is said; a joking comment may be a trigger for a person

Providing Culturally Responsive Care

The following concepts – gleaned from the Cancer Treatment Pathway for Māori*- are examples of how we can enhance and develop the way we show aroha and manaakitanga in our interactions with everyone who crosses our path and to be inclusive of whanau in our approach to the care for patients with a disability/tāngata whaikaha.

Whanaungatanga – relationships and connections

Hold whānau hui

Awareness of Māori diversity

Never make assumptions

Always give time and space for decisions

Understand whānau dynamics

Acknowledge culture

Respect patient values and beliefs

Open your heart

Holistic wellbeing

Affirm the mana of every patient

Make yourself available

Ask for support

No patient should feel alone

Awareness of Māori services and support networks

Access to services and information

Kindness / manaakitanga

Inclusiveness

He aha te mea nui o te Ao? (What is the most important thing in the world?)
He tangata, he tangata, he tangata (it is people, it is people, it is people)

* (McDonald M, Rolleston A (2018), *Cancer Treatment Pathway for Māori: Best Practice Guidelines*, Tauranga, NZ: Bay of Plenty District Health Board)

Our participants who have shared their stories here are:

(1) from birth
(2) result of an illness or injury - now recovering
(3) result of an illness or injury - on-going / permanent disability

> *"Some people come into our lives and quickly go,*
> *Some people stop for a while and leave footprints on our hearts*
> *and we are never the same"*
>
> [From a poster on Stephen Bennett's wall]

Visual Impairment: Scotty Saunders

I am Scotty Saunders. I have been an outdoors man all my life with a love of the sea – fishing, swimming, surfing, and pretty much all water pursuits. I also love movies and reading. At the beginning of 2012, using my skipper's ticket, I got the best job of my life – Barge Master on the Brisbane River. I was set – great job – good life.

Then on 19 June 2012 – it all came crashing down around me. I was on my push-bike on the way to work and I was hit by a truck doing 70km per hour. Massive head trauma, damage to my optical nerves, multiple skull and face fractures – almost died three times – finally stabilised on day 12. I was six weeks in hospital in a coma fighting for my life and a further six weeks in the Brain Injury Unit at Princess Alexandra Hospital in Brisbane.

I had to learn to do everything again and, this time, without my sight. Learning to live again has been stressful and I was full of anxiety – I was too scared at first and was forgetting things all the time. But gradually, with the amazing support of my Mother, I was able to start living again. After six months I made it back to the beach – I followed the noise of the sea and my sense of smell to find my way there.

I can now fish with help; I swim on my own and can travel to and from town using the local bus service. I have joined a church community where I am treated as family and I have special technology to allow me to read again.

Best of all, I have Gracee – she is my Thai Ridgeback service dog. She walks beside me and steers me away from obstacles and, most importantly, she is my rock when the Post Traumatic Stress Disorder [PTSD] comes to call – Gracee can sense it before it takes hold and she sits close to me in support.

• How do you prefer to be greeted?

Clear voice communication is good with a gentle tone and words. I have PTSD – so any aggressive behaviour can be a trigger. Because I am having to concentrate hard level tones are easier to understand. Being respectful is essential.

• How do you like to be engaged with?

I like my own space so please don't come too close. Please sit across from me so I can hear you properly. If necessary, I will invite people into my personal space.

Scotty with Gracee on Ohope Beach.

• What do people do that helps you?

Be supportive by asking what I need assistance with, but don't just assume I will need help. I currently have a support worker who helps with shopping, goes fishing with me, takes me to medical appointments, changes light bulbs for me. I also have some housework assistance. I do appreciate help to orientate me when I am in new surroundings.

• What do people do that hinders you?

When you move things around – even a small distance can be frustrating – it makes them harder to find. Familiarity is good – with people and with surroundings. Misplacing things is a problem – so everything needs a place to be stored.

• What do people do that annoys you?

I need to be able to trust people to do what they say they will. Being a Visually Impaired Person [VIP] makes me very vulnerable – so I need to be able to trust people to be truthful and have integrity.

• What do people do that makes you feel unsafe?

Sneaking up on me or walking up behind me without letting me know you are there. Being led into unsafe places, like alleys or large places, or being left in a vulnerable position with strangers.

- **What behaviours are absolutely unacceptable to you?**

People who treat me disrespectfully; people who are cruel and nasty just because they can be. When seeking help / assistance from people who should help and they are unhelpful and even demeaning - sometimes deliberately being obstructive by moving things or placing things outside my reach.

Scotty drawing attention to the difficulty in crossing the road in busy Ohope.

- **What could be done better?**

There is a real lack of advocacy support for the disability support sector so having much better advocacy support is a must. Ensure that all staff in the healthcare sector are well aware of how to engage with people who have a disability or those who are challenged. The Queensland model provided me with excellent support from when I was first injured.

- **What could be done differently?**

For patients to be linked into the long-term support services earlier in their journey – being grounded with support supplied early on.

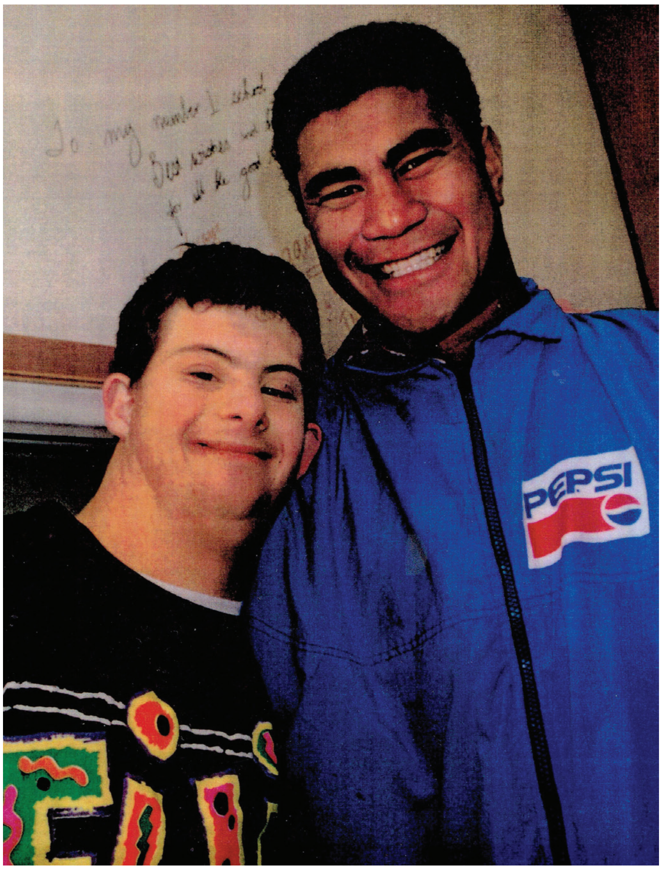
Have more psychological support – links to lifeline etc. Having PTSD I was very depressed and needed all the support I could get to help me out of that darkness.

Ensure that any newly disabled person knows to engage with GP, Mental Health, relevant disability sector organisations, churches, community centres, government agencies – anything that will help.

Intellectual Challenges: Stephen Bennett

I am Stephen Bennett and I have Downs Syndrome. But that never held me back, although there were challenges for me. I loved to both play and watch sport - I was proud to participate in the Special Olympics and won medals for athletics and cups for ten pin bowling.

Stephen's Special Olympics Medals



I loved rugby and was pleased to have my photo taken with All Black Inga Tuigamala. I learnt to Kayak and went boating through mangroves and overcame my fear of heights to conquer the luge at Rotorua. Despite chronic health conditions I managed to work for most of my adult life. I spent a lot of my time with healthcare providers and I have respect for the staff who treated and cared for me. I passed away on 11 November 2017, and my life was celebrated by family and friends at a service on the Northshore where I lived with my family before we moved to Tauranga.

• How do you prefer to be greeted?

Call me by my given name - short versions and nicknames are for family and close friends. Please do not ignore me, please ask me how I am. I will greet people with a handshake if that feels right to me. I am not a hugger - I save that for special family moments.

• How do you like to be engaged with?

I like my own space - I prefer to initiate any physical contact. Side by side or across from me but please not too close. I engage more closely with people as I get to know them better. I am well abled although I have some challenges and I am able to look after others as well as myself.

• What do people do that helps you?

Treat me as an equal - just because I have challenges is no reason to dismiss me as being unable to understand. Please sit down beside me - don't stand over me - and engage with me by explaining what is going to happen and why.

Treat me age appropriately please - just because I may not understand all that you say, I do have capacity to consent for myself if things are explained to me in plain English. I am interested in what is happening around me, particularly when decisions are being made about me. Please help me to orientate when I am in new surroundings.

• What do people do that hinders you?

Disregarding me or talking down to me, making assumptions about me or talking to me as if I do not understand - those things are all disrespectful. I have a lot of knowledge about my own condition and I can answer questions about my own needs. I will answer as much as I can before asking my family to help me. I have a lot of respect for and trust in the healthcare sector and I appreciate having my dignity and independence maintained.

• What do people do that annoys you?

I have a routine that helps me feel safe and I like to have that routine applied even when I am in a healthcare situation. I can rise to expectations, so I find it demeaning when people disregard me and don't treat me age-appropriately. I have great potential but unfortunately my physical ailments overshadow that and people don't see me, just my disability.

• What do people do that makes you feel unsafe?

I may be intellectually challenged but my parents have raised me as they did my brother to value myself, do my best and respect others. I was always encouraged to


Kayaking


Conquering the luge at Rotorua.

be as independent as possible and I can care for myself; but, sometimes if I can't do that, I need to know that I can trust the people who are looking after me. I don't want to be a nuisance and I need to know what you want me to do. When I am uncertain of expectations I can get scared.

• What behaviours are absolutely unacceptable to you?

Being handled roughly and being spoke to roughly. Please engage WITH me and not at me. I appreciate not having my physical privacy breached. I don't like to be the centre of unwanted attention or to be embarrassed or humiliated - those behaviours are very upsetting for me. I get embarrassed or feel unsafe by others inappropriate behaviours, for example being placed in a four bed room with confused or cognitively impaired patients.

• What could be done better?

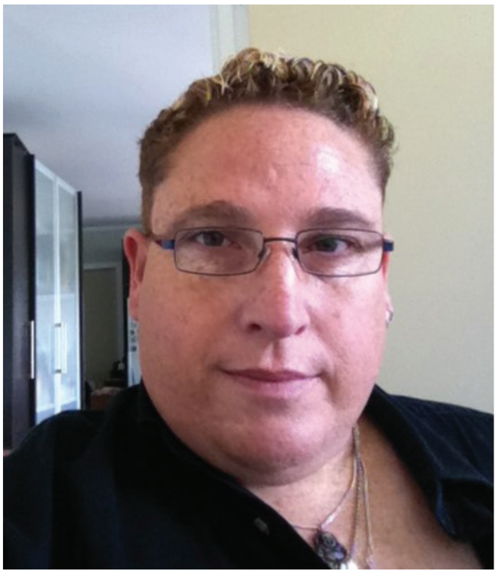
Please ask me what my routine is and try and fit that routine into my care plan - helping me to keep to a routine will help me fit in and feel safe.

• What could be done differently?

Communication is always important and when your patient has challenges communication is even more important. Because it is not always possible to have the same clinical staff each time I visit hospital there can be a lack of continuity of care. If I am not able to answer you or am not able to understand sufficiently to meet the 'competent to comprehend' and 'capacity to consent' criteria than please immediately engage with my family – ask them to tell you what I might have answered had I been able to.

Stephen's cups for bowling.

Physical Disability: Doug Nichols (1)



I am Doug Nichols and I have a disability I have had since birth. I was born with spina bifida and did my schooling in Auckland. I moved to Kawerau with my parents when they moved there. After losing my leg from an infection I needed a wheelchair and because our house in Kawerau was not wheelchair accessible we moved to Whakatane to live.

I work in graphic design as a hobby business, mostly designing logos. I enjoy music - R&B, Hip-Hop, Blues, instrumental, watching TV and Netflix and playing on my playstation. I do read a bit, but probably not as much as I should. I have been privileged to travel to China, Hong Kong and Australia.

• How do you prefer to be greeted?

When greeting me please say hi or hello and use my name if you know it. Please introduce yourself and be respectful.

• How do you like to be engaged with?

Please sit or stand in my line of sight so that I can see you and hear you. I don’t have a sensitive personal space but I do prefer not to be crowded.

• What do people do that helps you?

Please treat me like a normal person. Ask me if I need assistance don’t just assume I will need help. Please speak to me in plain English and when using medical terms please explain them or give me hardcopy information I can take away to review later with family.

As for any person in a strange environment I do appreciate help to orientate me to unfamiliar surroundings.

• What do people do that hinders you?

I get frustrated and annoyed when people treat me as if I am dumb and when they talk over me as if I am not even in the room.

- **What do people do that annoys you?**

I need to be able to trust people to help me. I am vulnerable because I am disabled but that is no reason to tell me I can't do things without even letting me try. If I can't do it, at least I know I gave it a good shot and tried my best.

- **What do people do that makes you feel unsafe?**

I am lucky to have never been in an unsafe situation. However, I can imagine I would feel most unsafe if I was left to fend for myself or was not asked about my preferences or given sufficient information to make informed consent.

- **What behaviours are absolutely unacceptable to you?**

People who breach the code of rights by being disrespectful, people who are physically abusive or intimidating or make me feel demeaned. I hate to think that my family and friends might be subject to racist or abusive behaviour.

- **What could be done better?**

When I come to the hospital in pain, having staff who stop and carefully listen to me and how I feel.

Be totally honest with me about what tests or care I might need and don't prejudge me. I don't need to hear "oh, it's you again". I don't turn up at hospital for fun; I only come because I cannot cope at home anymore.

- **What could be done differently?**

I understand what is wrong with me because I live with this disability and this is my reality.

Please understand that I might well be different to all the other patients you see with my condition and co-morbidities, so if you would just take the time to read more about my condition or talk to your colleagues that would be appreciated.

I don't mind having to wait to be seen, if I know that someone is looking out for what is best for me.

Physical Disability: Penny Gatenby (2)


Recovery at home.


Learning dexterity

I am Penny Gatenby and I am recovering from a physical disability as a result of Guillain Barré Syndrome. I had been a teacher's aide for seventeen years, working with children who have special needs and others who need support to make learning easier. My life changed forever when Guillain Barré Syndrome struck. I was devastated by my loss of movement and ability to be the wife, mother, grandmother, work colleague and friend I had always been. But I picked myself up, learnt to get on with my new life and I am recovering. I was always busy and always on the go, cleaning and tidying and sorting things, meeting with my marching team colleagues and being with the grandchildren - I was mostly never at rest.

My childhood and teen years were filled with ballet and ballroom dancing and skating and marching. I had taken for granted all the movements and skills I learned as a child and they had to be retaught to my limbs as I now had to learn to do everything again. I was no longer the old Penny; I had to become the new Penny. Things have changed but I have new things to do now and I am, at last, enjoying my recovery. I have also conquered my Everest – I have re-joined the marching team.

• How do you prefer to be greeted?

When greeting me please say hi or hello and use my name. Ask me how things are going. Don't stare at me please - make eye contact and then move on if you are not stopping to engage with me.

• How do you like to be engaged with?

Please sit in my line of sight. I don't mind appropriate physical contact - a touch to the top of my arm as part of the hello. Please repeat your name and position and other contact details at the end of the meeting as I may have forgotten them from the beginning.

Ballet

Ballroom

Roller Skating

• What do people do that helps you?

Please treat me like a normal person. At the end of the conversation ask me if I understand. Sometimes I can miss bits and if they are not repeated I miss important information, particularly if my support person isn't with me. Give me time to take in all that you tell me – ask if I understand.

I do want to engage with you but sometimes I feel uncomfortable to do so. I find it less stressful to talk with older staff about personal matters.

• What do people do that hinders you?

I get frustrated and upset when constantly told "you can do it" - I felt like a failure if I don't succeed. I prefer "let's give this a try" or "come on, let's try" - that is far less stressful for me.
When meeting with Doctors the information goes straight over my head if you use medical terms and then I end up more confused than before you arrived.
Telling me how I will feel - rather than asking me how I actually feel - is upsetting as I am left with the thought that the staff members don't really understand what is actually happening for me.

• What do people do that annoys you?

Don't tell me constantly what I should do without clearly explaining why and the consequences if I choose to decline the advice.
I feel you rely solely on your textbooks and don't take into account that I am an individual who may be different from what you have learned - your perception compared to my reality.

Please treat me age-appropriately otherwise your actions are disrespectful. Don't treat me as a child, I am old enough to choose when to do things that aren't clinically indicated as being urgent or time critical. If I want to shower at a different time or have a drink then I should be allowed to do so if I am not interfering with clinical need.

I also would have appreciated being asked if I was okay to have a male nurse help me with my toileting and showering. I would have preferred to wait for my family to come rather than have male attention when I was feeling particularly vulnerable and embarrassed.

- **What do people do that makes you feel unsafe?**

I am lucky that I never felt physically unsafe. I had a period of depression as a result of my illness, but was assisted by the appropriate staff who listened and advised.

- **What could be done better?**

Please don't have one blanket rule that you try to fit everyone under. It is very upsetting and breaches the right to dignity and independence when you are treated as child and not allowed to make decisions for yourself.
Don't be bossy - please mind how you say things, they can have a big impact.
Please don't use the experiences of other patients to influence your decisions for me without asking me first how I feel and what I wish to have happen.

- **What could be done differently?**

Please ask me what I need. Please let me make my own decisions and don't pester me to make my mind up without all the information to hand. I have a routine that works for me at home and I'd like to follow as much of that as I can when in the hospital. If what I want to do is not impacting on your work then please let me make my own choices.

- **What behaviours are absolutely unacceptable to you?**

Handing me the meal tray when I was unable to properly use my arms and hands and leaving me to cope without any assistance.

Overall my time in hospital was good, I had some amazing staff members who looked after me - but not every day was a good day.

Physical Disability: Pehi Te Rangi (3)

I am Te Rangitaupehi Te Rangi a father of four, youngest son of June and George Te Rangi. I was a member of the Mongrel Mob, a community man who liked to fish and dive. I was a gatherer who was outspoken, honest and an all-round good guy. I had goals – I was doing a mentoring course and was working with support workers. I had a vision for the future and had been looking after bees and Manuka. I had a contract with a Canterbury lady for Manuka oil.

This is what was important to ME:

Te whānau – *the family*
Waiora – *total wellbeing for the individual and family*
Wairuatanga – *spirituality*
Hinengaro – *the mind*
Taha tinana – *physical wellbeing*
Whanaungatanga – *extended family*
Mauri – *life force in people and objects*
Mana ake – *unique identity of individuals and family*
Hā a koro ma, a kui ma – *breath of life from forebears*
Whatumanawa – *the open and healthy expression of emotion*

• How do you prefer to be greeted?

When greeting me please use my name. Please make eye contact with me and give me time to respond before continuing your comments. Please greet me first then anyone accompanying me. Talk with me first, then them.

• How do you like to be engaged with?

Please sit or stand in my line of sight. Please respect the restrictions I have with my movement and make sure you can see my face when talking to me.

• What do people do that helps you?

Please treat me as an individual and not just my disability. At the end of the conversation ask me if I understand and please ensure my carer has had a chance to record information that I may need later.

I want to engage with you but sometimes I feel too tired or sick or uncomfortable to do so. I find it less stressful to talk when I am wide-awake and not in too much pain.

- **What do people do that hinders you?**

I get frustrated and upset when I am expected to respond to orders from staff without being told why. Sometimes I can do things and other times not and I feel like I have failed when I can't do things.

Please give me time to digest new information and time to think about my decision.

Being able to consent myself is very important to me and I can't do that when rushed or when not all the information is available. Please listen when my carer tells you something about me - my carer is speaking for me. I need to know that you all understand my diagnosis and my prognosis.

- **What do people do that annoys you?**

Not listening properly to what I am saying or disregarding the comments made by my carer on my behalf. My carer has become my physical being in order for me to function, and my carer knows me now and what works and what doesn't work for me.

I am an adult who has a disability and not a child. You are disrespectful to me when you don't treat me age-appropriately. Please, talk with me and not about me as if I am not even there. Remember that I can still hear you even if I cannot move.

- **What do people do that makes you feel unsafe?**

Not answering the bell in a timely manner and ignoring my concerns - two things that make me feel very unsafe.

I am vulnerable because I cannot get out of tricky situations - I feel very unsafe when left on my own with no means of communication with anyone.

- **What could be done better?**

The routine I have at home is in place to keep me safe and ensure that everything I need is taken care of. I don't expect my needs to be met before other patients, but I would like for my routine to be followed when it can so that I feel safe in this different environment.

- **What could be done differently?**

Please allow my carer to speak for me when I can't, please trust that my carer is answering your questions just as I would if I could. Although I cannot move I can fully understand and consent to accept or decline assistance or medical care.

If what I want to do is not impacting on your work then please let me make my own choices. It may be as simple as letting me listen to music or having a drink when I want it.

- **What behaviours are absolutely unacceptable to you?**

Don’t judge me before engaging with me. Everyone is entitled to their own life-style choices - and everyone is different.

> *Please, give me a fair hearing, don't discriminate against me on grounds of ethnicity, education, gender, marital status, nationality, cultural or spiritual beliefs, or anything else that could be discriminatory or that might be contrary to your own personal beliefs.*

Mental Health Issues: Kevin Cooper

I am Kevin Cooper and I am a father of three sons, a grand-father, a partner and a friend. From birth I was a victim and I am now a survivor who has PTSD. For many years I was diagnosed with a personality disorder and that coloured the way I was treated by people. I experienced flashbacks reliving the horror of the abuse I suffered. My reality is just that and can never really be understood by anyone else - it is all very complex with many issues to unravel. I am in control now; situations from my past have no power over me. I am never going back to what I was; I am reborn since I gained the skills to take control of my life. I want to pay that forward by using the insights I have gained into what can happen to traumatise a person and how that influences their engagement with others and what can be a trigger for anxiety, stress and anger.

• How do you prefer to be greeted?

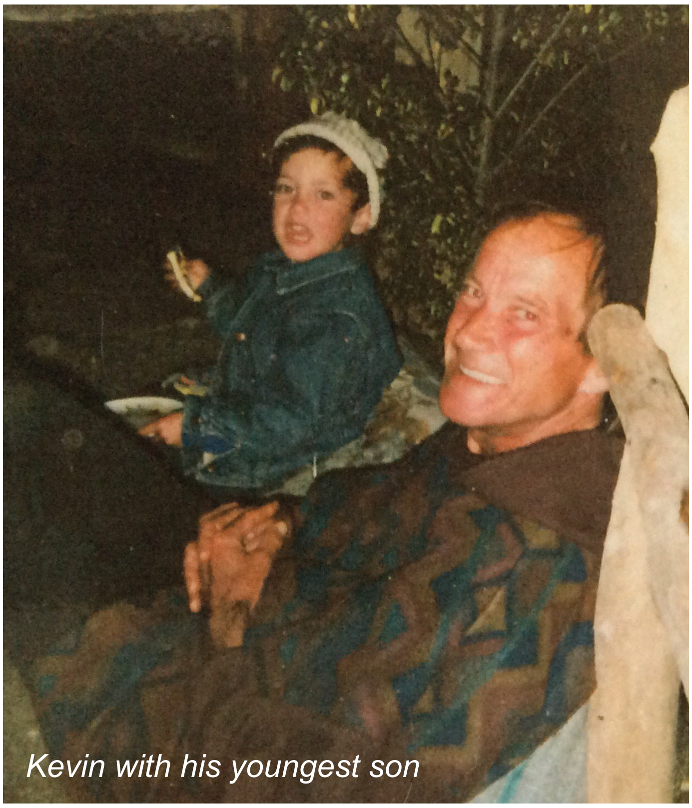
Call me by my name please - or say “hello, how can I help you”. Please treat me with respect and courtesy. No false looks and no judgement please. Allow me to be who I am and please treat everyone kindly.

• How do you like to be engaged with?

Please face me when talking with me - I like to look a person in the eyes. I maintain my own personal space but I accept appropriate physical contact such as a hand on my upper arm for support. Experts tell us communication is 80% visual and only 20% verbal so please take the time to learn how to read a person rather than making an instant judgement. Body language, fidgeting, looking around or everywhere but at you, are signs that show you how the person is feeling.

• What do people do that helps you?

Please listen to me better and hear what I am saying. Please give me a chance to explain my needs and what is important to me. It may take me a little while to get my story out particularly if it is part of my PTSD. When your mind is all-a-whirl it is hard to find the right words and to do that quickly. Please don’t dismiss me as having a mental health problem - that is cruel.



Kevin with his youngest son

- **What do people do that hinders you?**

When you prejudge me that stops me coming in for help - particularly if I need to come for physiological reasons unrelated to my PTSD. I fear what has happened to me before so it influences me coming in now. Being seen by one person is the best way to help me until I feel safe to settle down.

When I am given no information or the wrong information or only some of the information I need, that all changes my patient journey and in a bad way.

- **What do people do that annoys you?**

When I arrive at the hospital to attend an appointment or to visit ED and staff turn away before engaging with me - they are prejudging me. When staff say “you again” or “what are you doing here” in a way that makes me afraid to engage with the staff as I might be ridiculed.

When people are not honest in telling me what is going to happen or what is not going to happen.

- **What do people do that makes you feel unsafe?**

When staff don’t tell me who they are and what they are about to do to me. Please, ask for my consent before you prod and poke me and start treatment. I have a fear of the unknown and some phobias that can cause me to be stressed if they are triggered. I need to know what you are going to do and why. If you just start without engaging properly with me and checking to see I consent then that can make the whole situation worse for me.

- **What behaviours are absolutely unacceptable to you?**

When people are not open and honest about what will and won't happen for me. When staff members are judgemental and make assumptions about who I am and what I are here for. I value my dignity and independence and being treated in that manner is objectionable.

- **What could be done better?**

Apply the organisation's CARE Values - staff learning to read people - no need to accuse a person of drug seeking immediately you see them. Let them explain what they are here for and then make a diagnosis based on signs and symptoms and not simply assumptions or other staff members' prejudices.

- **What could be done differently?**

For patients who have chronic problems or who are complex, a management of care plan is very useful. I have had a plan in place for some time now and my concerns and phobias are always handled very sensitively by the staff. That was not always that case and I dreaded having to come to the hospital. The management of care plan quickly allows the clinical staff to understand that there are issues that need to be taken into account immediately for the patient they are currently seeing.

> *Please take the time to find out who I am*
> *by asking me and reading my notes;*
> *- please don't judge me or*
> *make decisions about me*
> *without knowing me.*

Elaine's cochlear implant is evident in this photo.

Hearing Impairment: Elaine Secker

I am Elaine Secker and I am a wife, mother, nana, daughter, sister and aunt. I have a hearing impairment that is a result of a strong genetic defect that came down through my Mother's line. I enjoy gardening and fishing, relaxing with family and friends.

I had almost perfect hearing until my early 40's and then I suddenly needed two hearing aids. The problem became obvious when I was missing hearing the phone ringing because of the high pitch of the ring tone. I missed bird sounds and other noises that we take for granted. My audiologist suggested that I think about having a cochlear implant. That was a mission, because adult patients are not given the same grading for urgency as children and young people, but I did get the implant in 2006.

The process was very involved – psychologists and technical staff and the surgeon, all engaging with me and my family to ensure this was the right option for me as this was not just my journey it also involved the impact on my husband and children and other family members. I had to do some tests, one of which involved watching and listening to a well-known newsreader. I aced the test when I was watching her but when I had to listen only, I could not make out the words. It was obvious then that I had been 100% lip-reading on the first occasion.

The operation was done and it was a success and then came the hard work. Things are different for me now. I had to re-learn every sound again so that my brain could tell me what I was listening to. The first thing I heard was my grand-daughter. I had always thought she was such a quiet baby – but now I could hear her I found that was not entirely true.

I used to love music but now it sounds tinny. I am now very aware of the sounds of nature and will admit that I was frightened after my implant when I first heard a helicopter flying by as that was such a scary sound.

Had I known what the impact of my hearing loss would be on communication with family and friends I would have learnt sign-language. Having that additional means of communication would have been a boost to my confidence.

My return to work after the implant was stressful and I realised that having to re-learn all the sounds and voices of my colleagues was very tiring. While my colleagues were mostly very supportive of my new hearing ability there were times when I felt stressed and alone as I tried to fit back in where I had fitted so well before.

• How do you prefer to be greeted?

Please say my name when you say hello. If you don't know my name say good morning or hello, smile and mean it. Please face me so I know you are talking to me.

• How do you like to be engaged with?

If I am standing – please stand opposite me. If I am sitting – please sit down opposite me to talk with me. If you stand over me it is intimidating for me. Please attract my attention by touching my upper arm. Speak slow and in a low tone

• What do people do that helps you?

Look directly at me if we are talking one to one. If I am in a group with you please speak slowly and clearly and attract my attention if you are directing comments to me personally.

Please give me time to understand the message – I have to decipher the sounds and then identify the words. You may need to change the words you say so that they are easier for me to understand. Words that sound alike are a problem.

• What do people do that hinders you?

Please don't talk with your hands over your mouth or turn you head away while talking to me. Mumbling and talking quietly are also problems but please don't shout at me as that doesn't help at all.

Having fun with her grand-daughter.

If I don’t know you are talking to me specifically, it can seem I am ignoring you and that is never my intention so please attract my attention. It is often difficult to understand accents until I am used to them. Please don’t be offended if I have to ask you to slow down or repeat yourself.

- **What do people do that annoys you?**

I find it very difficult to accept when people deliberately talk quietly so that I can’t hear even when I am part of the group conversation. That is disrespectful to me and leaves me feeling demeaned.

The other thing that is annoying is when I miss something that has been said and when I ask for it to be repeated I am told “it does NOT matter” or, worse, “I have already told you twice, are you deaf?”

- **What do people do that makes you feel unsafe?**

Walking up behind me or in such a manner that I don’t know who people are until they are almost right on top of me.

Also when people whisper and deliberately make sure that I miss information that I need. Or decide, because I have a hearing impairment, that I don’t need to be engaged with or have relevant information.

- **What behaviours are absolutely unacceptable to you?**

Talking down to me – making me feel small and demeaned, not being respectful, treating me as if I have an intellectual disability alongside my hearing impairment. Telling me or making me feel I can't do something when, in fact, I was never given the opportunity to try and prove whether I can or can't.

- **What could be done better?**

Use clear and precise language when engaging with me. Perhaps have a written copy already available that I can read or you can use to point things out to me.

When there are meetings and presentations, don't leave the front rows empty. I always feel as though I am sitting apart from everyone else because I have to sit close to the front in order to hear.

Yes, I have a hearing impairment but I do a full day's work and complete my tasks on time and when I have to attend appointments I listen and engage and seek advice. Please respect my efforts – allow me my dignity and independence.

- **What could be done differently?**

Please don't assume that because something didn't really matter to you it doesn't matter to me. Please take the time to explain things clearly and repeat the message so that I can feel included and not excluded. Having a hearing impairment doesn't mean my other faculties are impaired as well. When you exclude me I miss out. When I am left out, I lose my confidence.

Educating youngsters to be considerate of people with disabilities would be great – they can see that we are really just the same as them but with some differences.

People with hearing impairments are very diligent – we are hard to distract so can be very hands on and get a job done quickly and accurately once we know what is expected of us. Please – touch me appropriately to attract my attention and treat me as a fellow human being who has a disability.

> *Hearing impairment is UNSEEN – until you engage with me and I don't respond, you are unlikely to know anything is wrong. It can be very diminishing of my worth for me to be treated poorly.*

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DISTRICT HEALTH BOARD
HAUORA A TOI

This information booklet was prepared to assist
staff to understand the importance of
Patient-Centred Care -
through timely and appropriate engagement with
patients with a disability / tāngata whaikaha

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