**Felicity’s story: shared goals of care**

**accessible transcript**

**Visual**

**A woman with short grey hair, Felicity, wears a vibrant blue long-sleeve top and an ankle-length dark coloured skirt. She holds a wicker basket as she moves amongst a lush garden of pink and white flowers. The fronds of a ponga tree reach towards an overcast sky behind her. In close-up, Felicity is interviewed. She wears rectangular earrings and a gold chain necklace.**

**Audio**

(RELAXED MUSIC)
If it's important to you, then you actually have to...to keep trying and keep making the effort and keep insisting and saying, 'I really need to have a say here.'

**Visual**

**Back in the garden, Felicity bends down to harvest some bright green lettuce leaves.**

Audio

And do what it takes to get your say heard and to get your relative's needs met.

**Visual**

**A white logo appears on an emerald coloured background. It is comprised of two swooshing shapes and a circle forming a stylised figure leaping into the air. Text beside the logo reads ‘Waitematā District Health Board. Best care for everyone’. On a white screen, a title appears in bold black text: ‘Felicity’s story. Caring for older adults.’ Felicity sits on a deck and rolling bushland can be seen behind her. Text appears beside her reading ‘Felicity. Marie’s daughter’.**

Audio

My mother was a remarkable woman. Every morning, summer and winter, she would go down at dawn or predawn and swim the length of the beach. She was very tough.

**Visual**

**Two sepia-toned photos appear. One shows a small girl in a black button-up swimsuit. The second shows the girl, now older, with her arm around a younger boy, standing on the beach with a metal bucket in hand. Black text on a white background reads ‘Marie was born in 1918.’ A black and white photo shows Marie in her 20s with a group of men and women standing triumphantly on a pile of rocks. One of the men has a climber’s rope wound around his torso from shoulder to hip. Marie stands with her hands in the pockets of her tramping coat, her hair tied up under a scarf. Another photo shows Marie riding a camel beside a man on horseback. Both wear uniforms consisting of shirts and ties. A final black and white photo is a smiling portrait of Marie in military uniform. Felicity moves through her garden and plucks some more lettuce leaves.**

Audio

Over the last 10 years, her health had started to deteriorate, and she was getting progressively more immobile, difficult to walk very far and a lot of pain at night. It got to the point where we felt she really wasn't able to live on her own in the apartment, and she agreed to go into the retirement village. We moved her in there for respite care. She lasted two days and discharged herself. And that happened a couple of times. And she'd forget during the day just how distressed she'd been at night. She was starting to get some short-term memory loss, although she was still very with it, and she was still totally able to do her Justice of the Peace work. She didn't have any slippage in her mind for that sort of stuff at all.

**Visual**

**A photo of elderly Marie in a maroon and purple raincoat standing on a swing bridge above a river. Text appears beside the photo: ‘Marie lived well into her 90’s.’ A photo shows white-haired Marie sitting in the cockpit of a yellow fighter plane. A man in his late 60s wearing khaki overalls with a NASA patch on the right shoulder helps her. A pair of photos appear. The one on the left shows Marie in a sunny room leaning against a wooden table beside an arrangement of pink flowers. The one on the right shows Marie in a blue floral printed shirt and skirt standing under some trees. She holds a small white flower and clutches an envelope. A photo shows Marie with Felicity outside Takapuna Citizens Advice Bureau. In this photo, Felicity has dark brown hair and wears a red leather jacket. She holds the leash of a trainee guide dog, a black Labrador.**

Audio

The manager of the rest home hospital at Northbridge said that what we really needed to do was to get her needs assessed for residential care. And I had rung up and tried to get this to happen through the outpatient system, but it had not happened. So they said next time she got short of breath, we really needed to say that she ring the buzzer there, and the caregiver would come. So that's what happened; caregiver came, they called an ambulance — because that's their policy if someone's short of breath — so she ended up in North Shore Hospital. And so our reason for her wanting to be there was to get this multidisciplinary assessment done. First time she had an assessment, and they decided she was quite OK to go home. We knew she wasn't going to be OK to go home. So she went home and, two days later, ended up back in hospital. So, by the time she got in the second time, she was more short of breath, and so she did need to have some frusemide — it's the medication that helps reduce some of the fluid and make your lungs less wet. And so that I thought was fine. I mean, that's palliative care, that you need to make someone more comfortable. But by the time she got on the ward, the focus was really on doing lots more investigations. You know, she must have had I don't know how many chest X-rays and ECGs in those two weeks. And the focus was always on... on her acute condition, which was a deteriorating condition of heart failure or of shortness of breath. She was at the point of needing palliative care. So there was... there was a disconnect between the sort of care they were offering and the sort of care that she and us as her family were wanting.

(GENTLE ACOUSTIC GUITAR MUSIC)

**Visual**

**Filling her basket with lush lettuce leaves, Felicity makes her way along the cobbled path between beds of white flowers. Ferns populate the garden behind her as well as a plant with an explosion of bright red flowers.**

Audio

They gave her good care, but it was the wrong sort of care. So their care was about, 'Let's keep her alive at all costs.' And that was not what she wanted. She was terrified of having a stroke, but she wasn't at all scared of dying and she was actually ready to die.

**Visual**

**Black text on a white background reads: ‘Trying to speak to the Consultant.’**

Audio

I kept leaving messages all the time to say, 'I'd really like to speak to the consultant,' but I never got to speak to him until... One evening, he rang me to say that my mother's breathing was getting worse. And... And I said, 'Well, look, we had this place for her at Northbridge.' They had actually then done the needs assessment. I hadn't had the result, but they had done it. And I said I wanted her to discharge in the morning. I was going to come and pick her up, and we wanted her to go to... a room in Northbridge that was waiting for her. But what he was doing was he was doing ECGs. He was sending her off for another chest X-ray. He said, 'Well, 'maybe she's had a heart attack and that's why she's short of breath. Maybe she's got pneumonia. We're going to do these blood tests 'called troponins to see if she's had a heart attack.' And I said, 'We don't want any of that. We expect her to get more short of breath, because she's in heart failure, and she's dying. And even if she's had a heart attack, what are we gonna do? She's 97 now.'

**Visual**

**Black text on a white background reads: ‘Taking control as next of kin.’**

Audio

I went in first thing in the morning. I got there about 7, 7.30, on the ward, and she was
incredibly distressed. She didn't know where she was. She had... had had ECG monitor. She had... an IV infusion of frusemide. She had a catheter in. She had oxygen. So she had tubes everywhere. And they said, 'Oh, we're going to have to move her to another room, because the other patients are finding her distressing.’ And I said, 'No, we're going to discharge her. I insist that we— I'm going to discharge her. I'm gonna take her right away, 'unless I can talk to the consultant.' And I managed to calm her down, and she realised where she was, and she said, 'Yes, I wanna go to Northbridge.' I was just at the point of, 'I need to extract her — what do I need to do?' And then I finally met the first specialist for the first time. He said, 'Well, we need to do this, and we need to do that.' And I said, 'No. We want all the tubes out. I want her to go home.' He agreed reluctantly to discharge her.

**Visual**

**In her garden, Felicity plucks some sprigs of parsley from amongst the flowers. Felicity places the parsley in her basket with the lettuce leaves. Black text on a white background reads: ‘Being listened to and made to feel welcome.’**

Audio

You try and do it in as respectful a way as possible, but it can be quite hard to try and engage the doctors and the nurses and the other staff at the hospital. They really didn't want to be bothered with a relative. And there wasn't... I can't really recall any occasions where I felt really welcome there. I felt tolerated sometimes. (CHUCKLES)

**Visual**

**Stepping over some flower beds, Felicity picks some frilly lettuce leaves that have a brown and green colouring.**

Audio

Most of what we do is aimed at extending life and reducing suffering. Because our whole hospital system is really focused on acute care, it needs to get better at recognising when it's time to stop that and time to look at palliative care and looking at... at how we best look after this person in their end of life.

**Visual**

**Black text on a white background reads: ‘Much better care for mum back at the rest home.’**

Audio

The most important thing was that she was getting the care she needed to make her as comfortable as possible, and the focus was on... on that sort of care. But the focus was not on trying to extend her life. And that was the contrast, that it was just love and care and time for people to come and say farewell.

**Visual**

**A close-up photo of elderly Marie shows her smiling, wearing pearl earrings with a matching necklace and a black shirt with red polka dots.**

Audio

It was incredibly dignified. She was treated with dignity. It was what she wanted that was the focus, and what we wanted, and not what somebody else thought she needed.

(BRIGHT, PERCUSSIVE MUSIC)

**Visual**

**The leaping figure logo on the emerald coloured background appears along with the words: ‘Waitematā District Health Board. Best care for everyone.’ Felicity smiles as she sits on her deck. The screen fades to white, then three photos appear side by side. The first is a black and white family photo. The father wears a suit, the mother and their two daughters wear frilly white dresses with flowers pinned to their chests. The second photo shows Marie in her 70s wearing a hat and a purple dress suit standing beneath a large painted portrait of a young Queen Elizabeth the II. The final photo shows Marie in her 90s. A woman in a graduation robe holds a certificate and has her arm around a smiling Marie. The screen fades to white then text appears: ‘Felicity’s mum passed away surrounded by friends and family at her rest home.’**

Accessible transcript by Able.

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