



HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

Nau mai, haere mai ki tōku kainga hou | Welcome to my home



**He kōrero mai i ngā tāngata e noho ana ki te tiakitanga ā-noho mō
te pahake | Stories from people living in aged residential care**

Written by Malatest International for the Health Quality & Safety Commission | I tuhia e
Malatest International mō te Kupu Taurangi Hauora o Aotearoa

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Foreword | Kupu whakataki

I am pleased to share a collection of personal stories about ‘what’s important’ to people and their families/whanāu when entering aged residential care (ARC) in Aotearoa New Zealand.

As the national clinical lead for the Health Quality & Safety Commission’s quality improvement programme in ARC, we consider it vital that people are always at the heart of our work.

From the beginnings of our programme in 2018, one of the key messages we heard was that people wanted a stronger resident and family/whānau voice. We often hear negative stories about ARC, but these reports are less often balanced out by stories of the great work that is done by so many clinicians and care staff every day. This collection aims to present a more balanced view of the care provided by those who are endeavouring to make the experience of residents the best it can be.

This story compilation and report, undertaken for us by Malatest International, presents a range of stories from those willing to share first-hand their experiences of living in ARC. In general, we find that, for the most part, people are very happy and comfortable in their supported living environment. You will be touched by the ‘small things’ that really make a difference.

I hope the power of people’s stories will bring a fresh perspective to what is often presented negatively – life in ARC. While ARC may never be a preferred place to live, there may come a time when it may be the best place for a loved one, or even ourselves, when home is no longer the safest place to meet our living needs.

We are hugely grateful to everyone who came forward and took part in this project – residents, family and whānau members, staff and management. The stories are ‘magic’ and we have committed to respect the narratives in their entirety (see [Resident and whānau stories | Ngā kōrero a ngā kainoho me ngā whānau](#)). We acknowledge and thank all participants for helping us capture these wonderful insights.

It saddens me to say that one of the residents interviewed has since passed away, but the family is thankful that their presence has been recorded. They are happy to continue to have their loved one’s voice shared as part of our project to identify ‘What is important to me?’

This report is accompanied by a short video (available at www.hqsc.govt.nz/our-programmes/aged-residential-care/publications-and-resources/publication/3757), which summarises some of the stories, includes video footage of resident interviews and presents discussion topics for the purposes of quality improvement, based on themes drawn from the interviews. We hope the discussion topics will provoke thinking among providers, as well as residents and families and whanau, about how the resident experience can be improved. But to truly harness the feelings, passion and honesty of the experiences, we present the full and unaltered stories within this document.

We hope you enjoy the read and reflection.

Dr Michal Boyd

National clinical lead, quality improvement programme – aged residential care
Health Quality & Safety Commission

Document purpose | Take o te pukapuka

This report was written for the Health Quality & Safety Commission by research and evaluation specialists Malatest International. Firstly, it summarises the stories of 13 people and whānau experiencing life in aged residential care in Aotearoa New Zealand, based on a series of questions focusing on 'What's important to me?' It then highlights common themes drawn from the residents' stories and discusses each theme individually, including quotes from residents to illustrate key points. Lastly, it includes a discussion guide, written by our clinical lead Dr Michal Boyd. This is a series of topics for the purposes of quality improvement, based on themes drawn from the interviews. The topics aim to provoke thinking, for example, during resident and family/whānau quality forums, about how to enrich wellbeing at the care home.

The resident stories are written in their own voice and presented in full. The rest of the report is written from the perspective of the authors.

Acknowledgements | He mihi

Malatest International

Malatest International is grateful to the residents and whānau who shared their stories with us. You were generous and candid during your time with us, contributing a wide range of different experiences and thoughts. We had a lot of fun meeting you and enjoyed your company. Thank you for your allowing us to hear what is important to you.



Thank you to the managers of aged residential care facilities who connected Malatest with residents and whānau. We saw first-hand how incredibly busy you are. We were touched see with our own eyes, and hear from others the warmth and depth of relationships that you have with staff, residents and whānau.

Thanks also to the staff who welcomed and accommodated us into their busy day. We heard so many examples of your kindness and we appreciated the time you took to chat with us.

Health Quality & Safety Commission

The Commission would like to thank Malatest for providing a rich resource in response to our brief. The voices of the residents and the themes drawn from their stories will help to inform the future work of our aged residential care quality improvement programme.

We also acknowledge and thank the many residents and whānau who were so open to sharing their stories, and all the aged residential care facilities and staff who helped to make it happen. Ngā mihi nui.

What we did | Ngā mea i mahia e mātou

The Health & Quality Safety Commission asked us to talk with residents and whānau, and hear their stories about what it is like to receive aged residential care, and what is important to them. The intention of this document is to share the stories of residents and whānau to help bring awareness of human experience from a resident perspective.

We met with 13 aged residential care residents and whānau from four aged residential care (ARC) facilities. Three of the facilities were based in main centres and one was a small, rural facility. We liaised with ARC managers and they distributed information about this project to the residents and whānau. Those who expressed an interest in sharing their story with us were followed up with an interview. Before the interviews began, we talked with residents and whānau about the reason for the project and explained their rights as a participant. We asked residents to sign a consent form and sought their permission to be video- and audio-recorded. Four residents did not want to be filmed.

We had a list of questions to ask residents that were grouped around the four domains of wellbeing in te whare tapa whā.¹ These are: taha wairua (spiritual health), taha tinana (physical health), taha hinengaro (mental health) and taha whānau (family health). By asking residents and whānau about themselves across the different domains, we were able to explore what was important to them.

We spoke with some residents in their room; others met with us in different parts of the home such as dining rooms, a boardroom or other common areas.

Resident and whānau stories were transcribed. These were edited for publication as case stories. Where feasible, we re-connected with residents and whānau to read their story back to them. Because these are selected resident and whānau stories, they are not representative of all residents and whānau.

¹ www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha

Resident and whānau stories | Ngā kōrero a ngā kainoho me ngā whānau

Jim

Resident

The people who serve here make it a home. They talk to you and they make something special for you like the ones who make my herring and my whiskey. That's not necessary, but they do it voluntarily, and that's a home.

I was married for 72 years. My wife died just a few months ago here, so there's that. I was born in Belgium, Antwerp. I've lived in many places and served in many air forces during the war, and I was eventually discharged to New York. And I married my wife, who was born in [city name], and that's how we eventually finished up here. She served in the New Zealand Air Force too, amongst other things.

We were anti-militant, so certainly not an air force family, but during the war you get drafted and you do whatever you have to do. Well, most people obeyed it. I've known people who were conscientious objectors. That's a different story, but the average person gets drafted and that's it. I was actually not drafted. I volunteered. Just a small detail.

I have one child. Very peripatetic, he is. All over the world, he travels. On business, mainly, and he's in Sydney just now. Next week, he'll be in Bali and so forth. So that's that. That's the family. The grandchildren live, one in Melbourne and one a bit older in Auckland, and the oldest in Shanghai. Between them, they have four great-grandchildren. That's enough.

I lived in the centre of the city in a very nice apartment. I had a few falls and I needed outside help, so I got some nurses and the like, which I paid for myself. Then I had a big fall and I went to hospital. One, I could see that I couldn't keep on doing that, and two, they told me I had to find a place like this to stay, so I had no option really. I knew about this place because I'm a member of the Rotary Club for 50-something years. Longer than anyone else as a matter of fact. And we used to take the people who live here out for excursions, and we used to meet here in the boardroom. So I got in touch with [ARC manager] and she joined my Rotary Club and she became not only that, she became the president last year, so I was talking to her frequently, you know, that sort of thing, and she told me good things about it here, so I joined, and I'm not sorry.

My wife heard about the food here, which was not very good, and it's still not perfect but it's getting better. Now, she heard people say that [name of different ARC], it's called a retirement village. It prides itself on its food, so I said to her, well, don't take this for granted. Go and stay at the other place. She did, and she didn't like the attitude of the staff.

Now, the attitude of the staff is a major thing here. The culture of the staff is unbelievable. They go to any amount of trouble. The proportion between residents and staff is also very high on the side of the staff. That makes a difference. You just ring them up, they come. They do! They clean, they do everything. They'll get my pills sorted out. I'll ring the bell.

One of the girls here makes me my drink at 4 o'clock, my whiskey, and makes me something to go with it. Herring on some bread or something this evening. I eat very early here. In most places they eat at 5 o'clock, which is not practical. I have to chase most of my visitors away

because they come around 4:30 or so. They don't know that they have to go half an hour later. It's become a joke really. They come and they have to say hello... But that's just a small disadvantage, and the service and the care and all of that is 100 percent here.

I've compared notes with other people who live here too, and that's the same opinion that they have. You can say that people come here to die. That's probably so. That's because it's the nature of the place. My wife caught pneumonia, she was sent to the hospital, and she was neglected there in my personal opinion and the family's opinion. She was sent back here again, and in a few days they had to send her back to the hospital, and a few days later again, back. It was certainly not the care that you'd expect.

They could do a lot better here, but they've got restrictions. They can't keep certain artificial things like breathing support. But the care that they took for her was amazing, so I can't be more favourable in my assessment. It's really great. I think [ARC manager] has something to do with it, because the whole atmosphere is... I spoke to staff that work here and they've worked somewhere else, and they say it's amazing; there's a culture here of looking after people and loving people, and that's what's happening, so I'm certainly not sorry I'm here.

Although at other places you would have more intercourse with people, more conversation, except with people who can't converse, and you'd have more entertainment. There's films. We haven't got that. That's a shame, particularly since I'm by myself now. I'm getting a bit worse in my health. It makes a lot of difference, taking pills and so forth, but anyway, there you are. Just my assessment. I make it voluntarily all the time. There are no plush seats here and no crystal chandeliers all that, but I don't have those at home either. That's alright.

You see, I'm not very mobile. When I go out, I go in a wheelchair. That's only since I really got here. I'm getting worse. I've got Parkinson's, and Parkinson's gets worse. I've got to live with that or die with that is the proper expression. What's important to me is that we're helped to go to the toilet, and we're helped back again by someone who knows what they're doing and stops me from hurting myself. It's only happened once and it was not serious at all, and that's what I like here.

The company, I can't say too much, but there's a few people I like because I can converse with them. Other people, I have help to talk to them because they can't talk. It's a limitation. There are certain activities here, but I don't participate in many. They have a discussion group. That has stopped in the meantime, but I'll join it again. There's an exercise group, and there's a knitting group and there's all of those things. A film occasionally, and then they sing songs. That sort of thing. I've never sung. The family sings around the piano – it's not for me. I'm tone deaf, so I can't sing.

I like to talk. Not so much now with this problem with my throat, but normally. I liked the discussion groups when they were happening. We talked about whatever they wanted to talk about. I can remember one thing, I had to talk about myself, where I was born, why I was here, just as you asked me – a bit more elaborately. Someone who was a moderator was a doctor and we took up a medical subject like your heart or the size of your heart or something like that, just to keep on talking. It was alright, but I understand there's a better group operating downstairs. I was going to join it, but their moderator is not well just now, so it's not disbanded but it's been delayed in the meantime. But they're always having knitting, singing, music appreciation groups. On Friday afternoons they have a happy hour that gets combined with the music appreciation. I don't go to the happy hour. It's my own choice. They bring me the wine here. It's easy.

I like reading, particularly about current affairs. I read of course the usual *Listener* and *Time* magazine, and all of that sort of thing. This is happening to me now... just slowing down. That annoys me. It's all there. The whole bundle.

They wake me up with a certain medication at seven o'clock, half past six. Then I eat breakfast and I read the paper. Then about half past nine, quarter to ten they give me a shower, and then I sit here and that's all. I used to be able to walk more. I had a physiotherapist up to yesterday who came in twice a week and he told me better ways of getting out of this chair and better ways of walking around, which are supposed to counteract the effects of Parkinson's, and I'm just experimenting with it. That's all I can say. And when I go out, I get pushed in a wheelchair. I usually use Driving Miss Daisy [taxi service]. There's another one, a new one, too – and that's what I do to go out. It's usually for dinner. For lunch, really. Usually, people come to pick me up, or rather to meet me at the hotel for lunch, and my daughter's coming at the end of next week, and my sister's daughter, my niece, and her husband, they come to pick me up and take me for dinner or lunch. That's what I do. Nothing very exciting.

Up to now, I've been getting a lot of visitors. Too many, really, but I've always maintained that they came to see my wife rather than me, and I've always been denied but now I can see that it's so. Since she died, I've had fewer visitors, so I was right. My wife was very good company. Much more than I. Very vivacious and very... Laughing and happy. So that's probably why they're not visiting me so much anymore. They give me a telephone call from time to time. You don't want to expect too much. We're not entitled to it.

Well, I don't know if there are people I could connect with here. I've only been here for a year and a half, but connect with... There's one lady here who I can connect with, because our brains still work. That's a limiting factor. A lot of them have brains that don't work very much, and I notice that this is starting to work now also with me. The not working is starting to work, but that's a fact – which I'm very sorry about. I used to do most of my own personal books and investments, and things like that, and I start to feel that I'm getting a little bit on doubtful ground. I'm trying to do something about that. You can never predict... I thought I was here to be able to operate like that until I was 110 years old, but no. I don't even think I'll make 110 now. But who wants to be that?

I don't know whether it feels like a home here. It's hard to beat. I've never looked at it as a home, but it really is a home. Home and hospital, they call it. The people who serve here make it a home, they talk to you and they make something special for you like the ones who make my herring and my whiskey. That's not necessary, but they do it voluntarily, and that's a home. For some people, if you have a TV, that's home too.

Another thing that makes a home for me is nice meals, because my wife was a very good cook and I don't think... With due respect, I know that cooks and others here are working very hard to get the meals right. They assure me it's not a lack of finances, but they just don't get the meals right. Usually those people get referred to me. I've become the food guru. They sent the cook to me to say, 'Why are you unhappy?' I haven't used the word yet for what it looks like to me. It was at the tip of my tongue yesterday. They sell you chicken and the biggest piece of chicken is that big. It's chopped up like that... I never hesitate to say what's wrong with it, but I don't use vulgar terms that I should use. I can't do that. There are people who get paid for a living and they're all doing the best presumably. Not good enough, but they do their best.

What I've started to do here is I've got a fridge and in there I've got apple sauce, beetroot, tomato sauce, all of those condiments that I used to get at home. A lady that sits across from me in the dining room, she does exactly the same, so between the two of us we come with all sorts of things and the other people just use them because they don't buy them. They're not used to them, but who wants mint sauce with lamb, and who wants tartare sauce with fish? We do. So, we give the others what they should have. I'd feel at home if I had more of that.

See, the lady there, she still walks so she's more mobile. She can walk and do the shopping, and she's offered to do the shopping for some of us. She came back, I think it was yesterday and today, with grapes and she distributed them to everybody, and I've been sending out mandarins and fruit like that too. It's a pleasure to do that, but some of these people don't really require it. They're not oriented that way. That's not a criticism. That's just a fact.

What's important to me as we've mentioned is food, and I think it's important to acknowledge that it's being worked at. Also it's clear to say that it's failed really. I don't know why. I have never seen anything here that is in the class of fancy food, whatever you like to call it, but I'll say to the others, if you want better, you have to pay for fancy food.

Here, [food is] done with care and the people come from all over the world, which is interesting in my book. They sit with us at the table and take part in the conversation, and that's all good stuff. They're not hoity toity. They just sit with us, and we can ask them all sorts of things. One or two have even done voluntarily some shopping for me, but that's not usual, because I'm lucky to have a lady coming in. She came in today. She comes in twice a week, first of all for my wife and then for me, and now only for me. She takes me shopping or takes me sitting in the sun or anything like that. I pay for that, but that's a pleasure. So, it's simple. It's nice to know there's someone here to do these things for me, and it's very limited at this rate, but she does. She keeps my fridge defrosted. You see, that's one thing. Last night, one of the fellows came to put me to bed – that means going to the bathroom and getting washed and put to bed. I asked him to get something out of the fridge, and he noticed straight away that the freezing compartment was frozen over. He took that thing there, it's actually an emergency thing for if you get caught in a car to break through the glass, and he hacked it all away and he cleared it up. The lady who comes for me twice a week, she defrosted it further, so everything works alright. I can find many faults, but that's easy. I think it's easier to find the good points.

One thing I've not participated in is on Tuesday mornings; they have a car or a little van available to carry people who want to be driven around town. Three people at my table use that service. I get up too late to do it, so I don't do it, but it's a good idea. They drive to the botanical gardens and things like that, so that's quite good.

To be honest, I haven't got a religious faith. I belong officially to the Jewish religion and I've been president of an outfit and all that, which I usually do in all of the things I belong to, but I'm not really a religious person. If this were a religious organisation, it wouldn't suit me. Not even my own religion would suit me. That's just the way it is. That's a good question.

People don't talk about their faith here. I don't know. They've got church services and they've got other services, but all general. To me, I belong to every religion. I belong to the world. I've lived in many parts of the world, and that's my view.

No parting words. Keep up the good work.

Raina

Whānau

We do it on Wednesdays and Fridays now. It's kaumātua kapa haka waiata – you can see them starting to try to interact with the singing and movement. It's beautiful.

A lot of – especially Māori people – we don't like nursing homes. We don't like putting our whānau in here. I didn't want to but I had to, because Mum's paralysed on the right side of her body. I wanted to take her home, because that's what we do. We look after our own. But they said it would be best to put her in here.

Before my mum got sick, she had a gambling problem in Australia, and it made her get Alzheimer's. They were studying Mum for like three months for her type of Alzheimer's. And then she said she wanted to come home so I brought her home. And then somehow the Alzheimer's made her go back to a really young age and she started drinking. She hadn't drunk for 40 years – smoking marijuana, and then she had the stroke and then that put her in hospital.

I was living in Australia all this time and I was just coming back and forward to see her, and then she had the major stroke. We came back, then they said she had to go into nursing home care, so we picked this place. And I mean, I really looked because I wanted to make sure that she went into a good place. And then she was here for the first six months and really depressed, just really, really depressed. So, I was flying back every month just to get her sort of eating properly, drinking properly. Me and my husband decided to move home from Australia. We've been home for four years now and I come here every second day. I look after my sister – my sister's also disabled, so I'm with her in the morning and then I'll come up here to spend time with my mum.

They had a little sing-song thing going on here and I'd sit in with Mum and then we'd start singing along, and some of the residents here like [resident name], he was good then. He was playing the guitar, and then we started singing old Māori songs, and it's got to be a thing. So, I said to [staff name], can I put some old Māori songs together and bring them in? And she said, yes, that'd be great! And so I started coming in on Wednesdays, and then [resident name], his arms got really weak. So, I started to bring recorded music and we'd sing along with it and it was awesome. And I tell you, some of the residents who are not fully communicational, they'd always bring them in. We do it Wednesdays and Fridays now. It's kaumātua kapa haka waiata. The residents that I see who just – you know, they're not communicational, they'll just be lying in their chairs – you can see them starting to try to interact with the singing and movement. It's beautiful. It's like an awakening.

My kapa haka group tutor has a business to do with education and communities, and she gives me funding every month to do books and printing and whatnot for this kaumātua waiata. I think we've been doing it for about a year and a half now, and that's every Wednesday and Friday. It's been awesome, you know. Just to come here and get to know them.

One thing I will say about the nursing home thing – I'm glad this is going on camera – is the residents here. Like I said at the beginning, our Māori people don't do this. We don't put our kaumātua in nursing homes. We look after them ourselves. A lot of them have asked me, how's Mum? And how's it having her in a nursing home? And I tell them it's been awesome.

I tell them I could not do all the things that she does here if we had her at home, because I look after my sister, you know. I have my own life.

At least here, you know they're having the activities, they're getting fed, they're getting their medication on time, they're getting doctor check-ups all the time. But one thing that I have to say is that family needs to visit regularly, so that they see them and they know that. Because I feel sorry for a lot of family kaumātua that I see here – kaumātua, kuia, koroua. It doesn't look like anyone visits them. Maybe some of them don't have any family out there, but if you put your family in these sorts of places, it's up to you to visit them regularly, spend time with them. Some people come and they're only here for like, five minutes with their mum or their dad.

When we're having our waiata, some come and sit and join in with the waiata, which is awesome. Even the staff join in on the waiata. But for me, I'm glad we put Mum here, and I even say sometimes, Mum, do you want to come home to live or do you like being here? And she'll say, nah. I don't want to come home. It's alright here. And she's got a couple of boyfriends too. It makes her happy, you know what I mean? It makes her happy. Sometimes it makes her a bit sad, but I think that's just... When you become elderly, that sort of thing happens. It's something to do with that Alzheimer's situation, eh?

It does feel like a home for her here, but because of her Alzheimer's she still says to me every day when I come and see her, what am I doing here? And then I tell her, you were unwell. You had a stroke, and then you've been here for a while now. And then she says, oh, okay then. And you know, it's that rule of, don't say remember? But just tell them where they are and then they accept it.

When I first came here, I think my mum's been here for five years now, it wasn't all that great. But in the last two years, and I'm saying this straight out, since [staff name]'s been the manager here, it's been like, awesome. She made a great change to this place, and she's one of those genuinely caring people. She gets around there and she sits with them, she helps feed them, she gets in with the work. I think that she's the third or fourth facility manager here since my Mum's been here. The first two, I didn't really see them as often and that's how you know, eh? I like her. She's how I think a facility manager should be. I don't want to say that too much so that they take her from here. I said to her, don't you go getting a promotion or something and moving up! And she just laughed.

The staff? Yeah, they're great, and as you very well know there's no perfect staff. I think the older ones lead the new ones really well. I remember when Mum first came in, when I did come over for visits I was a bit of a bitch because I didn't think she was getting cared for properly. I think we all get like that, and I was on their backs and I was kind of an on-your-back daughter. I think they ended up accepting me and seeing that I was just trying to make sure Mum's looked after properly. Because if you saw my mum's room it's got notes all over the walls, just like reminders, sort of thing.

I can tell the new staff because they sort of just do their work and then go off and probably look for something to do, but they could just sit right there with the resident and interact, eh? Just socialise with them. I've seen a few lazies, and I've always said something. Not to them. I write it on a sheet. I'm a tell-tale, so it's like, if they see me it's like, better move. And I don't care what anyone thinks because I think, you treat the people who live here how you would want your grandparents or your parents treated if they were in this sort of a facility.

I do, however, think there should maybe be more security cameras outside there, because I see people come and go and I wonder, are you a criminal? It worries me that one day someone will just come in off the road, walk in and take something or do something. That's only me. I've been meaning to write it down on a list. That's a great thing about it, too. If ever you have a query or a complaint, you've just got the suggestions box. It's not a complaints box. It's just a suggestions box, and that's awesome, and I've meant to put that on there. Nah, but this is a good area.

It makes me feel a little guilty sometimes, because knowing that Mum is okay here I might not come back and see her for three or four days, and that's the most I haven't been to see Mum unless I'm overseas on holiday. But I think in the first place I've taken those extra days off because I know Mum's alright, so yeah.

I know my mum. If she doesn't like a place or someone, she will tell me, and she will be straight up about it. Like when she got better from the depression they were telling me, oh, your mother – sometimes she tells us to shut up or get out! And I'm like, she's just being herself. She's just relaxed, and she can talk to them like that. She's just hard case.

I always come here with a positive mind. If something outside here is upsetting me, I don't come in here with it because you've got to be positive around the kaumātua, because they sense it, they know. I think that's the same with the staff. That should be their number one priority. When they come to work, same goes. Positive attitude, positive vibes, positive life, and positive makes happy, you know? Negative is so ugly. Yes.

This has impacted my relationship with my husband, and I don't mind answering that question because it has. When Mum got sick, that was one thing. We brought her home but because we were living in Aussie, the move back home had a big impact on us.

Yeah, it is rough, but I'm okay. I have to be, and my mother-in-law says to me that God is watching me and God is watching what I do here with the kaumātua, how I look after my mum and my sister, and put up with my husband. Because I see it in a Christian sense. It makes me feel stronger. And she just says, God is watching you because of the good you do. He makes me stronger... Oh, it's getting weird now. Even when we do our waiata with the kaumātua, we always open with a prayer and we always close with a prayer. And for me that's just to protect and watch over everyone, and a lot of the waiata we sing are from Māori composers who have passed on, so we have the prayer to be thankful and just cover us for the waiata that we do. We don't just do Māori songs. There's the odd English song in there, 'Ten Guitars', and then there's the odd Samoan song, and then we've put a Tongan song in there too and a Cook Islands song.

They have cultural days here for all cultures. Yes, I suppose they focus on the Māori because we're in New Zealand and it's in respect for tangata whenua, but they have all sorts of cultural days and I love coming to them. Mum loves them too. I've come to the Tongan cultural days, Samoan, the Filipino, and the Indian, and it's been awesome. I must say, they don't that in Australia. None of that happened in Australia. I think we win. New Zealand wins because of the cultural thing. Yeah.

If this was an advertisement for television, to make people feel at ease about putting their family in rest homes, residential care, nursing homes, I would probably say, yeah, they're fine. Just go regularly, at least weekly, and visit your family so that they know you're still there for them, and involve yourself in their activities. The place is not just an 'old people's home'. That's what we used to say when we were little, eh? Oh, that's an old people's home!

You know, it's boring. It's just an old people's home. And for staff members, I would say there's a few rules for dementia that are really important to maintain when interacting and communicating with the residents.

I know she's safe here, she's happy. I really still wish she would be at home with me but I know that if she ended up living with me at home, she'd probably end up going early. Look how long she's been here for. Man, we had so much worries about her in the past, that we were going to lose her. My brothers would come up and they're like, is she alright? And then I'll say to them in the end she's going to probably outlive us. And we have a little laugh.

Luke

Resident

When I first came here I was passive, I didn't really think anything. I thought it was quite good to be alive.

My history here is very atypical, but I'm sure you're aware of that. I didn't exactly choose to come to this care home. I had a health collapse. Until that happened I thought I was in very good health, and then one day I slid down some external stone steps on my spine. I was taken into the hospital. I had a lot of things wrong with me, I had pneumonia, I had spinal fractures and a number of other things. And they started treating all these, but the people in charge of me discovered that I have a rare form of bone marrow cancer called multiple myeloma, and I probably had this for quite a while.

When they treated the pneumonia and had done what they could do for the spinal fractures and treated the other things they started treating me for the cancer. By that time they had decided that I didn't actually need to be in the hospital taking a up a bed for these treatments to continue, and the hospital was quite keen to get me out of the hospital. They recognised that I needed to be in care of some sort, but not in the public hospital care where the focus is on diagnosis and intensive treatment.

The hospital social worker liaised with a very good friend of mine, and they had discussions with me. And I was only cognisant to a certain extent about what was going on, because I was receiving quite a lot of pain relief and I was getting the chemotherapy and I was disoriented. So, this woman looked at rest homes. I was going to have to continue treatment at the hospital, so it was convenient for me to be moved to a place that was easy to get to the hospital.

So that's what happened, I came here. It wasn't a case of me deciding perhaps I should move into some form of care and so on. I acquiesced, but I wasn't an active participant in this because of my condition. When I came here, I was in very bad shape, I was practically helpless. I couldn't bend at the waist... I was progressing well, but that was simply a matter of time and I needed to be cared for. I had to be semi-carried. I could be supported vertically, I couldn't bend and to go to the lavatory. So, I was in quite a bad way both physically and not particularly cognisant of what was going on in the initial stages. In that respect I wasn't different from many residents here, but most people here are on a visibly downward trajectory in terms of problems that brought them into here, and all of these things.

I went from being very physically restricted when I came in here, to being able to walk quite comfortably now. So that's improved too. I've got an exercise programme that I need to keep

up to exercise the joint, and physiotherapy exercises which I've kept up to strengthen the muscles and keep it mobile. So that's improved too. Someone who saw me now, walking here and sitting down and talking to you, and had seen me when I came in here, wouldn't really recognise me now, and this is very atypical of people here. Others are on a downward spiral, whereas I'm going from strength to strength.

When I first came here I was passive, I didn't really think anything. I thought it was quite good to be alive. Because it was a shock, when I was first told that I was in a public hospital, that I had the cancer, and they explained the nature of this particular sort of cancer. I was in a state of great uncertainty. I have a sister-in-law who had been a nurse, and she said if things go well for you, you could live for many years, and if they went badly I could be dead in a few months. So, I was taking each day as it came.

I was being well looked after physically. It was a lot of work to keep me clean, and toilet me and so on. A lot of effort was being put into this. Not only was effort being put into this, it was very effective. And I couldn't really have, I wasn't aware of anything that wasn't being done, anything that could be done wasn't being done, or anything that was being done that could've been done better. I felt secure in that treatment, I felt I was in good hands.

The other thing about it and I became more aware of this as time went on, was that the staff – both the nurses and the carers – were very supportive. They went a long way beyond just seeing me as a job, seeing me as someone who needed to be flannel washed. They would chat away, they were friendly, they were well trained. For example, there is a lot of touching. And it seems in some ways fairly artificial, because I'm sure they are trained to do it. You know, if I am walking up the corridor with a carer, she'll probably put her hand on my back and it's quite nice, you know?

The whole place has got a supportive, friendly atmosphere. I've never felt neglected, or that I'm just getting the cursory minimum of care. And I was impressed, a bit surprised really. You must remember I had been in the public hospital for several weeks, and they've got a completely different regime there. I would have completely different nurses every day, so the nurses didn't know me at all. I couldn't get to know them. And they were very confident, but they were doing the job that they were trained to do. When a nurse was attending to me there, she was attending to me for some particular purpose which she was efficiently doing. They weren't engaging with me, but they weren't not engaging. Their job was purely the nursing task. And same thing with the doctors, when the doctors would do inspections and there would be groups of doctors that would come around, they were there for a particular purpose, and I was involved in that purpose.

Well the atmosphere was different here. You had the same group of carers, I learned their names, they address me by name. They got to know me and my foibles, such as they are. It was much more personalised. That was a contrast.

One thing about the regime here is that it encourages contact between residents and their friends and their families. It's quite active. For example, if someone visits me over meal time, the visitor will be offered a meal. And in various ways, the regime encourages that sort of contact. It doesn't make it difficult to come at particular hours. It bends to people's individual requirements. I have friends that come and visit me... And it's good in that respect.

Of course, this is not an issue for many people, because they're not particularly aware. People with dementia, for example, it just might not be something that is possible. Others are in a sort of semi-stupor a lot of the time, so they're not conscious in this area of life. And I

have a cell phone which was given to me by one of my daughters shortly after I came in, which was I dubious about, but which has been invaluable in enabling me to keep contact with people. I keep in contact in different ways for different people.

I don't know if this is important to me or not, but I've really become very impressed with the administration here. There is someone here who is a very effective person, she's a very definite person, she's a personality. And I think she's excellent, she does an excellent job. She keeps track of what the staff are doing, she's supportive of the staff, she's not oppressive. I have a sort of relationship with her, she keeps close track of my situation. I have little chats with the general manager. And she again is very receptive. Her job doesn't really involve being in contact with residents, but she likes to keep track of not just the pure administrative aspects of the situation, but the tenor of things. So, the place is well run. For example, every now and then, there will be a news story, a horror story about people being left lying in urine, and people being hit, or being completely neglected for long periods and so on, and I just can't imagine any of those things ever happening here. The whole management is just oriented to ensuring that those things don't happen.

I never thought that I might ever be in aged residential care, I was in good health. I had a good diet, I got a lot of exercise, I was vegan, and I thought had no particular health problems that I was aware of – although for a while, the multiple myeloma was working its insidious way in my bone marrow, unbeknownst to me.

I eat very slowly. I had an interest in Buddhism for many years, in fact I was reasonably active at one point in my life. I went on Buddhist retreat weekends and so on. And vegetarianism is a tenet of Buddhism. But I became vegetarian because I thought it was a good diet. When I came here, an inventory was taken of my food preferences and if I had allergies and things like that. And they classified me as a vegan. Before that I hadn't described myself as that, but they have elaborate classifications of people's food needs and they popped me in the vegan category, and that was fine for my point of view. It got the results. And it led to quite a lot of trouble, to extra effort needed to meet my food requirements. I had got into the habit of eating slowly, savouring each mouthful which is a sort of meditative form of eating. So, for that reason, I eat much more slowly than the bulk of people. In fact, many people in the dining room don't eat very much. Meanwhile I like food I enjoy, and I enjoy it to the fullest by this way of eating. So, it suited me to have my meals brought to my room, and to eat them in my room, and the regime here was very accommodating to that. That's one of the things that's very good about this.

I became a meditator in my 30s, and this gelled very well with my interest in Buddhism, because particular types of meditation are part of Buddhist practice. I used to meditate twice a day when I first woke up in the morning and do a morning meditation. And then after I finished working and got home. I think I benefited greatly from meditation... The meditation practice was completely broken, destroyed really, by this illness. Because I found quite early on once the practice was established that most drugs interfere with meditation. If I wanted to meditate here, I'm not sure if it would be possible. I'd have to try. I might be able to arrange something... But I've never taken that up. I'm sure they would be accommodating about me meditating here. The question is whether – no, I could probably adapt. Maybe I might do something in that area.

I'm not unhappy with myself, but we're in a world that has many problems, and these concern me. I don't want to detach myself from an interest in the world, and responding to other people's problems and so on. There is a Buddhist tenet that no-one can be truly happy

until everyone is happy. And I think there is an element of truth in that. To insulate yourself from the condition of other people is to an extent a destructive way to seek contentment.

They have a very active activities programme as you probably know. There are activities morning and afternoon. Every afternoon there is something going. Most of these don't particularly interest me, and I listen to the national [radio] programme a lot of the time which has got a lot of coverage of current affairs, and I find that very interesting. So, I find that more interesting than most of the activities here. I go listen to some musical items, but I also enjoy just communicating with people via text. I've done this for a long time in one way or another, but I also write little, humorous poems and I send these as long texts to the people I'm in regular communication with. There is a person involved in a lot of the activities in the activities programme, and she discovered this and become very interested. Normally each week I send a poem, so she's included in that circle, so if you're interested in seeing the sort of stuff I'm producing, you could see her and she's got them all on her phone, it's an interest. It's something I have a facility for, they are probably quite good.

How do I define home? I feel there are quite a lot of people here, who are in sort of wretched conditions and I feel a link to them. There is nothing I can do, but I feel a sort of sympathy. There are people constantly dying here which is the nature of the place. Some of these some of these I really didn't know of their existence until I learned that they had died, but there are other ones who I've been aware of and had little talks with. And then then they've died, and this saddens me. It can become a slightly oppressive aspect of the place, that there are so many people who are in a wretched state who can't be ameliorated or relieved and die. But it's the nature of the place. This is not the sort of experience one ordinarily thinks of in relation to being in a home, in one's own home. But it gives me a sense of connection to the place. It's a feature of having a home, it's part of the idea of the home that you shape it in your own way. You select the furniture, you arrange it. In fact if you saw my room you'll see that I've got some pictures that I own, I own quite a lot of pictures, and some of these are up in my room and I've personalised it to a very limited extent. One can't shape the environment here in the way in the one shapes one's home environment. You can't have a garden with native trees, so in that sense it's not very home-like. It's accommodation. I don't see it as a home in that sense. I don't see it as a fault, a weakness, that it doesn't achieve the things that can be achieved living in your own home.

All things considered, at the moment I'm reasonably contented. Given that I'm quite cognisant of my surroundings, more so than most people here, you might say that's quite an achievement of the place. It's not the most ringing of endorsements, but that's quite positive. I feel to an extent in a sort of a limbo, but that's because of my stage of life. I was very involved in my professional work and I was good at it, and I thought that some of it was quite valuable and was quite beneficial, so I had a life where I had professional goals. I was doing work that I thought contributed to the effectiveness of the government to the extent that it wasn't ignored and produced valuable knowledge. And that was satisfying to me.

The occupational work was completely gone, finished with that. That stage of my life is completely gone, but that leaves a sort of a hole because I've been very oriented towards developing projects and bringing them off and so on, and there won't be any more of those. And the recreational things in my way of looking at things, were in a way ancillary, they're like the dessert of a meal. I'm at a particular stage of my life which is different from all earlier stages in my life. I see life is being a matter of various stages really.

Berys

Whānau

The children come up and sing songs for them. I went right, this is it. This is what I believe in. More community involvement in something such as this.

He was born in England, came out here when he was 17 as an assisted immigrant. In those days they used to call them '10 pound Poms'. Because you'd sign up in England and had to pay £10 to come to New Zealand. And you had a job to come to, which for him was with the railway. He worked on the railway and my brother was on the railway as well. So, I met him through my brother at these social functions. That was how we got together. We married in 1960 and had three children.

In those days it was steam engines. His first job was preparing the fires to get the steam up for the engines, and he progressed through to engine driver. For the last couple of years before he retired, he was in the office doing rosters and things like that. One of his claims to fame which has recently come up again, is that he was the mentor and tutor for the first woman engine driver in New Zealand. His hobbies were fishing, and he was very much into amateur radio, communication all around the world. We had contact with people he met on the radio during that time. He loved chatting to people and that's hard to see now. No communication at all.

With his Alzheimer's dementia, it was just a deterioration. Originally it was more for his safety, but as a family member who is the primary caregiver, you feel so guilty about putting someone into care. The mental health nurse was very good. He said to me, it's now becoming a safety thing and you have to have him put into care.

One day he was sitting in the lounge which is upstairs. We have a huge wall full of ranch sliders and we can see the planes coming into the airport, so he used to sit there and watch the planes. He was sitting on a couch and fell asleep. And I thought I would whip downstairs and put a load of washing on. And so I did, and when I got back he wasn't sitting on the couch. He was out on the balcony which is two storeys high and he was trying to climb over. Within a couple of days of that happening, I found him trying to climb over a banister.

It really became a safety issue, he had to be somewhere secure. That was the reason really, but it is not easy, and you still have that guilt feeling. I didn't want to make the decision. It's easier if someone else makes it but that doesn't happen. Within a couple of weeks, we were able to get him into here.

One of the things I said to them at the time, to me it felt like making a euthanasia decision for him, that this was for the rest of his life. They said to me we've never heard anyone explain it like that, but we understand what you're saying. For all that it became, like, not a choice. We had to have him somewhere he was safe. The minute I drove in, it looked like a motel to me more than a care facility, and so far it's just been amazing.

The day I came here with him I thought, what am I going to do when it's time for me to go? If he says take me with you, I'm not staying here. But it never happened. I am so thankful for that and it's never happened the whole time he has been here. It's full credit to the facility and the staff. The staff member that came out to meet us when we arrived is still here and he responds to her really well. Just so many things to be grateful for really. The environment and the atmosphere is just amazing, and not just for him but to me as his primary ex-

caregiver, as the primary person in his life. But the staff care for me as much they care for him really. I was in the hospital recently recovering from an operation. I got the hugest bunch of flowers, and they were from the ARC staff. I think that shows how much they care. They are like a family really.

He has been here for almost two years. For a long time that guilt feeling was still there, and at the end of last year I realise now I'm feeling guilty about not feeling guilty. But yeah, it's hard to see the deterioration and just not the people you knew for all these years, been married nearly 60 years. It's not that person anymore.

One of the other residents in his unit, the other gentleman's daughter, we met during visiting and that. We would go for coffee, which we do on a regular basis, and one of the things that she said to me during one of our coffee sessions is that her mum had been diagnosed with cancer, terminal cancer and given about six months. She said, you grieve and it's sad and you have the funeral and do what you have to do. But she said for her it is harder to come and see her dad like he is, than to have had that six months with her mum.

I thought that was a really good analogy, really. I often think about that. It is like that. At home I've still got things, one of them is a little dog whose head wobbles, but it was in his car, a little ornament in his car. And because he hasn't gone I don't feel like I can get rid of anything. You haven't got that grieving. I understand exactly what you mean, you haven't got that finality to the situation, it's ongoing.

I did visit several homes. The first impression of the environment was a big factor for me. One of the other things is that I worked in early childhood for 27 years and for me it's been a lot like working with under five-year-olds. Teach them to wash their hands, it's the same thing. I think in a sense it's been easier for me than a lot of people, my expectations haven't been perhaps like other people's expectations. I've heard other people say I've told him 20,000 times. Well, yes, but I've done it with 20,000 children. But with children they eventually learn, but with this it's just an ongoing thing.

What sealed the deal for me is that they have children from the kindergarten down the road coming up for a visit. For me that's part of what I would love to see, more of that in terms of both the children and the residents here. The children come up and sing songs for them. I went right, this is it. This is what I believe in. More community involvement in something such as this. Just because they've got dementia, doesn't mean they don't enjoy seeing children or seeing dogs or people playing the piano or that sort of thing. They play housie with the residents but he's well past that sort of thing. One of the things they say to you with Alzheimer's, with dementia, is to keep up your exercise and he used to walk 8 km every day.

Through my early childhood experience, I've made things that I can bring for him to do. I was here one day and they have bibs when they have food. He had the bottom of the bib and he was rolling it up. I got bits of material and I sewed them together so there was a picture on both sides and brought them up and gave him those to fold. I say you've made a square or triangle or whatever he did with it. The activities coordinator went through and asked where I got it and I said I'd made it, and are you hinting that you'd like me to make some more? I've done 20 for them and they use them with the residents. There are things like that. That's just one example of what I've done. I always bring up magazines when I'm leaving. I give a magazine, and I was just saying to someone today that the libraries here, they cull their books and magazines every so often and get 10 magazines for a dollar. If they tear the pages it doesn't matter.

One of the ladies from the needs assessment team said to me one day I wish we could bottle you and give you to other people who find it difficult. I can understand that. I didn't find it as difficult as what other people have. I didn't realise my early childhood background would help me with my husband and coming here.

Mata

Resident

I think the most important thing when I'm here, is the visits of your family, or family visiting you.

I don't know why I chose this place. It's a place. Place to remember, to think later on of your life. As the time goes on, you remember all sorts of things. And some of those things, it has to be told to someone. I've been here for a long time I think. For how long, exactly I don't know. The first time when I got here, I think I was saying that I like it. I don't know what I liked, numerous things. To name one, I don't remember exactly. But time goes on – you start to think.

I have family here in [city name]. I have a daughter down here, and grandchildren. They visit me here, and I can go out with them too. That's one thing I like about here, no restrictions. You can go any time you like. There is no stopping you from going to do what you like. I don't know if that's the right thing to do or what. But as far as I know, I was able to do things like that without being told. I would like to think what I like to do, and what I want to do will go down into the book and sign. No-one else will know.

I think the most important thing when I'm here is the visits of your family, or family visiting you. There is nothing else. My family do visit me here, and I can go outside if they want me to go. I do go to church over here too. I don't phone my family, they just come. They just arrive, they sit there and they talk and you listen to them. And perhaps one day you'll remember something you want to tell them. That you've got to tell them about the things you want. Otherwise you just go without.

The most important thing for me is if the family is allowed to visit, and you're allowed to visit your family, and family comes in and visits you. But above all the things that I really miss is my mother, and I can't remember much about her. She's dead, and sisters. So many sisters I can't remember. The only thing I do remember about them is the things that we used to do when we were kids back home in Rarotonga. That's where they were, and some of them grew up here in New Zealand. And grew fast, grown up and become independent. One has passed away, just a few months ago. Another sister passed away at 55 I think, and a girl she passed away about six months ago I think. I try not to remember, because you can't forget. You remember so many things that have happened.

As a child in Rarotonga you do all sorts of things, and you become independent. You choose to like things. And it's safe where you live and as you grow up, times goes with you. I don't remember how old I was when I came to New Zealand, I think I was 17 or 18. I can't remember the exact date, that's a long time ago to remember. There was a sister here who liked to think all her sisters would come to New Zealand would stay with her. And so we did.

I think I have a big family in [city name], yeah. The relations in New Zealand. The cousins and all that, there is a lot of them. I've also made friends living here. As you grow older you

forget about being afraid and so on, and you remember about things when you were kids, and you do things when you were kids.

From the time I get up in the morning, the time I get out of bed, we have exercise one day. And of course before you do that, you wake up in the morning, you'll have someone to come and wash you and make you what you want to wear and then go onto the exercise, and when that's done you'll be on your own all day.

There's activities here. Some of the things we do – there's the art and craft shop, you do that without anybody telling you what to do, you just do it the way you want it. I haven't done that, but if you want to you can. I would like to knit, and to do other things. To make some other things, you need the time. And perhaps some material. I've done a lot of knitting in my life. I've knitted a jersey for myself, and the kids. And so on. How long it takes to make depends on the size of the jersey you knit. If I do one that will fit a man, that will take four weeks to do it, yeah. Four weeks. For a child's jersey, it takes less than that. Also lots of cooking. That was in the time when I was alright. I'd come home from work, do the cooking, to provide for those who stay home.

It's different having someone else cooking for me now. I like it after a while. The cooking is not really like the one you want, the flavours of the cooking is not there, but you just have to eat it. There's a lot of things that I miss, but I can't do it. If I could do things that would make my own, I would be happy.

I have other things I like to do here. I don't deal with things like singing at the piano, they're beyond me. I do like to listen to the radio and news, and on TV to see what goes on. I don't go into the garden here. In my own home I do that, go out in the garden, do some planting. I don't go on the day trips here, but maybe one day they will choose me to go, and I'll go. I think you have to be chosen to go, you can't just get up and go.

I do feel content within myself, yeah, but if I don't it'll be my own fault. You'll have to do things that you like the best and then you drop everything. I wish I could do my sewing now, but I can't. But one of the things I don't like is that my eyes don't work like they used to. I would like to do the things that I used to do, but that was a long time ago. Things that liked to do were my sewing, I like sewing. Wonderful sewing. And I would like to do that. I sewed kids' stuff, and things for myself. If I could do some of the sewing now... I like to do the cutting, and make my own and the children's things or anyone that comes along to ask you to make something for them. I was always very busy, but that's the life. Sewing, would make me feel more valued now, just sewing. Doing like that, sewing.

My sewing is very important to me, but I can't do it now. One thing I remember about my sewing is to prepare the things you want to do, and it was cloth that comes in yards, and it's cut up into fashions and style. And you put it over the sheets of different coloured material, and you sew, and you go on sewing and that's it. I like to remember all those things that I can't do it anymore. You have to have the patience to do that, without that, no good.

My daughter showed me in the room, she said look, you made all of these for us. I sewed them, and they go on. They are still there. Yes, it is part of me that they can keep.

Lena

Whānau

It is kind of like family when we are not. It's contributed to that whānau-ness that is around here. I like to hear the caregivers refer to the people here as Whaea, Mama, Papa, all those lovely endearments, and I think that makes a difference in their life.

He was a school teacher. He did really well. And he did a spot of politics. He's done quite a bit with his life – he's always been involved in the community and cultural activities. The school he was at, they actually started Polyfest. His school started that in 1977, they were the founders of it, and it just grew. It was specifically for Māori schools in the beginning, and for a little while it just grew and became this huge dynamic diverse cultural thing that they have now. He was involved and always busy. Before he retired he did a short stint in a kaupapa secondary school, and that wasn't for long. He retired, and this is the him we have now. It was soon after that. It was devastating for me as well and for him too, because it was a very quick backwards slide.

I took him with me to Melbourne before he was diagnosed and I didn't realise how serious the problem was until we got there, because I went to look after my daughter who passed from cancer. That was the hardest three months of my life, one eye on my daughter and one eye on him. Luckily, I had my little security posse who was either chasing him when he'd gone out the door or locking places up to keep him inside with us.

We came back and had a chat to a doctor, but he regressed from that point on. It just went backwards really fast. The decision to bring him here was really not mine, it was a family collective one, plus the doctors. If I had all the resources they have I'd probably keep him at home.

Bringing him here was extremely hard. I was forced to bring him in the end, because I tried really hard to keep him at home. But lifting and transferring him from bed to different places in the house just got impossible and I was hurting myself. His doctor was getting quite cross about it and said, you have to take him in here before you seriously injure yourself. It was the hardest decision, it took months of tears and tantrums. They were all on my case, the whole family, so frustrating – and I just dug in. It took me a long time. I was getting sick, actually. And so, I had to give in and say okay.

That was the hardest decision, it really was. The most heart-breaking thing I've ever had to do was to leave him here. I still find it hard today. I've never not been here, I'm here every day. I'm here after work and go home 8:30–9 o'clock and then I hardly live in my house because I'm here most of the time.

We took him home Christmas day. My son and his family helped with transporting him to the house and into the building. It was lovely, he just sat there looking at them all, giggling and chucking and laughing and reaching out to touch and reaching with that hand. They had a Christmas party here, that was lovely – he enjoyed that, because they all came. Everyone just got together and chatted and talked about their families. And asked, how long had they been here, and because of those things, you make connections. And every day you see them, everyone stops and has a chat, or sit down and chat with each other. That's what it does for people, their little parties bring everyone together.

It definitely is really, really hard walking out of here. I know he's getting really good care here, but there is still that element that makes it difficult to leave him. I guess doing the job I do helps a little bit – I work with children, the other end of the scale. You can take from there what you know and use it in this setting. There are some similarities, like passion for a start, patience, empathy, all those things are involved.

This residential home was recommended to us by other people. We kind of looked at somewhere else, and then we met this person who gave us background of this place. When we first came in to meet the manager and the staff, she wasn't what I expected. She was very welcoming, a very lovely, people person. And that's what you want. I think that's what brought me here in the first place, the cultural aspect of it. And the fact that there were quite a number of Māori people here. And some of them are native speakers, which was lovely for him.

I didn't realise how diverse it was here, I really did not. I had in my mind that it was only for a certain section of society which you always read about. And when I came here and saw how diverse it was, I went, 'wow!' I was quite impressed by that. Impressed in that it's so diverse, but sad that we're all in here and our families couldn't keep us at home for one reason or another. That was the reason I brought him here, had a lovely vibe to it. Very whānau-oriented. There are rules, obviously, but generally it's quite open and everyone is accessible and they're not all at their offices or stations as one might think. That's what I liked about it, that personal touch.

Everyone talks to each other here, and it feels like a real whānau. We've liked it for him and I guess in a way he has thrived here. Saying that, we're here every day. I think it helps having other families around you in the same situation. It helps that you get to meet them and talk about your own feelings, talk about the situation you're in from one day to the next or any given time. You meet with the residents and have a chat with them, rather than just walk by and say 'ugh'. It gives you the opportunity to see different things that are happening to us, and to be able to think about what can you do about it, what can you contribute to make their life a little happier, brighter, more positive, and I think that's what it does for me.

There is a lady down the hall here, I've known her for many years – she looks forward to my visits and we chat about old times and grandchildren, children and it's always lovely. And she's always happy to see me, and that means a lot if you can do that for someone. At the moment she's grieving, so I've tried to be there for her every day. And she has really appreciated that.

It is kind of like family when we are not. It's contributed to that whānau-ness that is around here. I like to hear the caregivers refer to the people here as Whaea, Mama, Papa, all those lovely endearments, and I think that makes a difference in their life. You've made their day a little happier, a little brighter, and to me that's important. I think everyone should do that. I think for me that's helped me go through this process of living here, his daily life, evenings. Everything he is experiencing here.

Everyone here has a respect for each other first and foremost and they have this lovely bond. We deal with pretty much everyone – with management, nurses, with the caregivers, with the residents. We don't just come and sit in his room, we walk around and visit and end up over there, we push him around in his wheelchair and go and see residents and just experience things outside of his little environment.

I always thought you had to keep to yourself when you first came, that's your boundaries but don't go beyond that, but that's not the case. You are able to mix and mingle and have a chat and just share time with somebody. You have this coffee room here where you meet someone, and it's surprising how many we've met here. I like that there are two chappies here that we went to school with. We're all from the same area, so they generally come and sit with us because we can converse in our language and speak Māori with each other. And that's lovely for him, because his way of recognising, and responding to things is by laughing, giggling or chuckling, that's how he communicates. When he does that, we know he's listening and following as best he can what we're saying at the time.

This is absolutely the best environment for him, I wouldn't have it any other way. Someone suggested another place, and we did go to another place for two weeks that I wasn't happy with – it didn't have any of what they have here, and they were just completely different. I brought him back here, it was lovely. I think he noticed the difference. Like every other place you have problems, but you talk about them, which we do. You approach those people responsible and have a chat about it and that's sorted. Responsibility goes both ways is how I'm looking at it. So, we talk and hope to come to some nice conclusions for whatever is going on, nice outcome.

It's definitely the diversity of this place lends itself to the way it is, this lovely atmosphere. Everyone gets involved, the staff all know each other well. We all know each other from one end to the other, and you do shifts and go 'there is so-and-so', you really get to know them. And they probably know you in and out as well. I wouldn't have it any other way.

Being a preschool teacher, you learn all about activities. I've brought him a whole range of things to do, to play with, to interact with. So, I supply that myself – because they do activities, but I'm never here for their activity days. I don't get here until late in the afternoon and I've missed most on that. But if they have a cultural day, I'll take time out to come to that to be with him.

That's just one of many things I get for him, all the Rubik's cubes there. There are quite a few, and lots of other activities, interactive stuff that I buy that are good for manipulatives skills to keep his hands moving, and his brain active. And he just plays around with them. They have lovely music days, which he loves. I did actually listen one day. I was here for one of the music activities. I knew he didn't know the words of this song, because he is tone deaf and doesn't know how to play an instrument. But on this particular day I heard him sing and it was perfectly in tune with the song that was playing, and I could not believe my ears. They said they would tape it for me, so I would believe the nurses. And I said, no, that's not right, he's tone deaf. All the family would tell you he's tone deaf, no rhythm, no timing, no anything. And well, blow me down if he didn't, he was singing beautifully.

Another thing I like about here is you can bring a meal for them. It is a distance to get here. I train or bus over, and then my son takes me home every night when he comes to put him to bed. There is always someone here to put him to bed. The only time I'm in my house is to sleep. Have a cup of tea and sleep, that's it in a nutshell.

It is safe for him. Safety is a priority and it is safe for him, and that's what I like about it. The manager is fabulous. It makes a difference, it does because I half-expect to come in and find this straight-laced person, going 'yes, can I help you, please?' That kind of attitude. When I came here, I said I'd like to speak with the manager, and I almost fell over when I saw this

little lady coming, really inviting. You felt at home straight away. That's pretty much what everyone is like here, you're just part of this family.

All up I'm happy, I'm happy with him being in this place. I'm not happy being without him, but that's just the way things are now.

Joseph

Resident

It helps to be listened to. That is why I like the place. It's clean also, this place is hygienically clean.

I was first pushed into a care home at a private hospital. It was certainly bad there, profiting was their main idea. I started searching and I visited all these places and then kept in touch. When someone called saying we've got a position if you want to come, immediately I came down here. I found this place a little better than the other places. It's a corporate operation, so naturally you will find things are more superior here.

I was in the last place by mistake. When I was in the hospital they keep you for a certain number of weeks, then they transfer you to your home care or community care. Then they ask where you would like to go – and I'm alone, so I said I don't mind going anywhere. I had no idea about care homes or anything. That [aged residential care home] was selected and I stayed, and then it was not good. Smelling human faeces all day in the corridors and all that, health-wise and social relationship-wise they were not good at all. I was not happy. Then the room that was offered to me was a small room which I couldn't manage.

When I got this place I came here, and there was a person who showed me around, and with her being an Indian, I could sort of communicate better with her and clarify things. And once I came here I got myself accustomed to this place. There are certain difficulties here also, but this has got a particular corporate standard. They are making an effort here to maintain the management side with the principles and all that and the rules.

It is the caregivers individually which hampers things here. If the caregiver is good, you are well taken care of, but if the caregiver is bad, a bit lethargic or lazy or not communicative, then you are suffering. My main concern here is if I have to go to the toilet and press the bell, there are certain people who are quite efficient and immediately they come for assistance. But certain people are so lethargic that for one hour you won't get anywhere. Can you imagine one hour, you are suffering in your stomach, you have to go to the toilet, it becomes difficult at that time. Staff members are busy somewhere else, they have their own reasons. I told them to train me up to walk to the toilet and I'm doing my best at the moment, trying to go to physio to learn to walk to the toilet and be independent. Once I finish with that I will be in a better position. But at the moment, I'm like a cabbage. For anything I have to depend upon someone to move around.

This is not because of the management. Management is better, they have maintained that standard, but it is down to the individuals. Like I can see when the cat is away the mice are at play. That is the situation. I've learned to live alone, I was living alone for 10 years, I am alone.

I have my son visiting sometimes. At the moment he's in [city name], and anywhere he goes he drops down to see me. One benefit of this sickness I have, is that me and my wife were

separated for the last 10 years, and now she comes to visit me. That is a big thing now, something that is sort of a problem that has been cured to a great extent, though there is a difference, there is a line of communication, but at least she visits maybe once a fortnight or once a month.

I've been here for more than a year now. My wife's visits depend upon her time and all that stuff. Yes, I'm happy she visits, nothing more than that. Financial problems are all I have. I've got really good help from a budget manager. It's very helpful to have that support. She visits me and that is the highlight of my day. And she's nobody to me in fact, I just went down there to get a budget and she came to my rescue.

It's very hard, because I have worked for 28 years in service and I always wanted to work. I'm not a person who could sit at home and do nothing, I always tried to work my way out. Even now I can work even though I've got these disabilities. I'm looking for work – if I can work somewhere I can forget that I am a cabbage. Spend my days on Facebook or something to keep myself busy. I do have certain projects that I'm trying to do independently – at the moment I'm under this scheme of raising plants from seed. I sow the seed and take care of the seed until the plant is raised to a certain height and then I transfer it down from the garden side or something. I completed one earlier project for avocado seeds, made them into plants this side and then sold them. Now I've got seeds, but I need help.

I'm an outdoor party man, party animal. I worked for a five-star hotel, and I was a manager for a discotheque. Now I can't. Now it becomes very difficult even if I have to drive away a fly, my hand doesn't work so well, the fly will still be living there. That is a difficulty at the moment.

It helps to be listened to. That is why I like the place. It's clean also, this place is hygienically clean. One drawback of this place is that sometimes the corridors are smelling – that is because there is no exhaust there. If you see, and you are getting the smell, maybe someone is moving a dustbin. If there was an exhaust it would not react so much. I have told them but no one has taken action for it.

Positive statements help give me meaning in life. I have this willpower that one day I will walk and go to my toilet. And this a very embarrassing position. Young workers sometimes find you very awkward to deal with in such situations. I want to get out of that predicament. Early on I used to go out and play ball, I used to visit pubs, but now I can't do that. I've got private physio because the government is not funding me for that. I've written to the prime minister. I've spoken and they're not funding me, they want me to sit still and improve.

I was a well-known photographer myself. I used to operate five cameras. I have received a presidential award from the president of India for my photography. It is very difficult not being able to do that anymore. I have seen this man working on photography, I don't know him but I try and pick up a little conversation, and see if he needs a photographer for something. But I keep myself busy with reading and watch some documentaries or something like that. I'm too lonely – I told them I had a dog. Me and my dog could communicate easily. We lived together and that friendship with him it kept me quite a bit. And now I'm dead lonely, looking for some improvement. I want to improve from my present situation, then I can move, it's like a car stuck in the muck, you have to push it with your hands. That is my situation.

I have to keep good relations with the staff and that is must, if I am to get myself well serviced and be in a comfortable position. Staff is family to me at the moment where I tell

them to hold out your tears for me. Certain staff are very good, especially the coordination staff.

I have great bouts of depression. But I keep exercising, and I feel a little revived at the blood circulation. Simply once I start moving, and I will move, and sitting in chair and moving is not going to help me at the end of the day. The physio keeps me going – it has to because I'm paying through my nose for that physio, and that's the physio I can afford. Without any improvement I'll be a nutter.

We're communicating, and when there are people who are ready to listen to you and you speak upon that issue, you find solace in that. At the moment I'm in this situation because I'm not getting alright, I'm trying my level best and I can't keep myself fit. And loneliness is eating me, there are no friends sitting here. I'm fed up with the types of entertainment I have – watching TV, read the newspaper. And just thinking about the situation... I believe in God so there is something. That helps me most. At least if there is nothing else, there is a little bit of hope. That is what religion is built on, faith and hope. I have hopes.

Chiae

Whānau

I think maybe if we were still in Cambodia, he would not still be alive now. It's much better here. He can eat a lot.

My husband fell down and got brain damage so now he can't stand. He can't do anything by himself. I can't help him, so him staying in a rest home is better than at my house. I can't help him because he's very heavy and he can't stand. He can't do anything.

The first time leaving him here was very, very hard, but now it's okay because I see that now he is better than before. He is better than the first time when he was in the incident, but now I see that here, he's okay. It's good for him here.

They take very good care of him here, because the staff always help him. I come here every day, so I know they take care of him like family, and they help people. I come here to visit him, and I see all the staff look like my sister, my brother, just like that. Because they're very good. Yeah, the staff are like family. Sometimes we got some problems but that's okay. Never mind, because people thinking not just them, but I always see them as our family too, and they really, really love us too.

I come here to visit him sometimes. I want to talk with him because you know, sometimes he can understand things people say to him, but sometimes he can't understand at all. And I can translate and explain for him, just like that. Because you know, people have limits. Sometimes they cannot explain that they want something, and I can help him. Sometimes the staff don't know what he wants to do and I can say, he wants to... Yeah. Because I know him so well, I can speak for him. If I can come here to talk with him, he's happy, so to keep him happy is our job.

He's got Parkinson's disease, and he fell down very, very heavily. His brain is damaged now, so he got some dementia. But not really dementia at all, because he can understand me. He can know who I am, and sometimes if a friend comes here, he can know them too, who he or she is. He knows. Sometimes my friends come to visit. His kids from overseas come to see him. He knows. For many, many years we didn't see them but when they come here, he

knows it's his daughter, his son. He knows. They don't visit a lot, because they live very far from here.

We are married. This year is 20 years for us. This is my second marriage. His first wife passed away, and then I married him, and now we've been married for 20 years. At Christmas time I had a Christmas party, a small party for him at the rest home here, and I'm planning to do a birthday party for him too because it's nearly his birthday, in February. So, I told [staff name] I want to have a birthday party for him. [Staff name] said, okay. So, it's okay. I always tell him, this is your home here. I think him staying here is very good.

Before, in my country, he was a teacher. He was teaching Chinese language and Cambodian language. He can translate Cambodian to Chinese and Chinese to Cambodian. Yeah. He was a very clever teacher, but not now.

I think it's just different now. Before we were teaching and we could see a lot of students. It was okay, but now we came here and the government really takes care of us, so it's good. If we were in Cambodia, never. I think maybe if we were still in Cambodia, he would not still be alive now. It's much better here. He can eat a lot. I just want to keep him happy. Yeah, he is happy here.

Maybe he cannot have conversations with residents here, just the staff sometimes help him to change something and he knows... When the staff come here to speak with him, he just smiles with the staff. This morning the nurse here, he told me he that he used to be his student, because his face was very similar to one of his students. And I told the nurse and the nurse said, okay, I can call you teacher again! So, when the nurse comes and sees him, he says, teacher! He's very happy. He smiles. I said, can I ask him if he still remembers you? And I told nurse and he said, okay, I can call him teacher again, and he was very happy.

There's no one else here from our country. There's one staff member, but she's lived here since she was a kid so she can't speak our language. She can just speak a little, like, how are you? Just like that. She can just speak a little, but not too much.

I am Chinese Cambodian, so I think other people maybe don't know very much about this culture. But that's okay because we have been here for such a long time. I've lived here 21 years, nearly 22, so it's okay. Sometimes I forget when our New Years is too, our cultural events. Sometimes I don't know, and my friends tell me about them. Because when we came to New Zealand, we became Christian, so I love our culture. I don't really care.

I'm not sure what he likes doing here. Before, he always wanted to grow some vegetables, but now he can't, so maybe he forgot. Yeah, it's hard, but I just know this is... God wants him to have a rest, relax. Just relax now. I always tell him... Sometimes he thinks he wants to do something. I say, no. Now, you just relax, because God really loves you. What God wants you to do now is relax. Don't do anything.

My friend comes to visit him and he always knows. He knows that if he comes here, he must speak Mandarin. Some Cambodian friends come to see him and he speaks Cambodian. He knows, but he can speak Mandarin so he speaks Mandarin with us and when my Cambodian friend comes, he speaks Cambodian. And when I speak with him, we speak another Chinese language, China's got a lot of languages, and sometimes I speak Khmer with him.

I do get to visit him a lot. It's okay because I have nothing to do at home. I just come here to talk with him, so I still come every day. Just on Sunday I go to church. Maybe I rest for one day, or I come for an hour or two and then go back. I do miss him at home a lot, yeah.

Paul

Resident

What do I get up to here? I read mostly. I love reading.

I've only been here six or seven months, but before that I stayed with my daughter, the one I didn't know I had. I'm very independent. I said to my daughter, I'd like to find a place – and she found this place for me. She kept coming over and asking if I was happy and I'd tell you if I wasn't happy. I love it here, fantastic.

I play jazz guitar, used to play by ear but this guy, he was a school teacher and a jazz guitarist and he picked up straight away that I couldn't read. We had a trio in Australia and our leader came from Whangarei. As far as playing a jazz piano, my God, he was good. The keyboard, he could span six keys. I could only do about four. I didn't tell him I was jealous and I wanted to punch his bloody head in.

What do I get up to here? I read mostly. I love reading. My son said to me, because I was reading the *Reader's Digest*, he said, I know the magazines you like. Your favourite is *Reader's Digest*. I said you read the Bible! There is some curly stories in there, mate. Just because it's a religious book, it's not all about religion.

I said to my mate, I've got a pet name for that cat. They said, what? I said, breakfast. He said, do you eat cats? And I said, nah. Did you know we used to eat opossum, very similar to cats? Possum has got a slimy taste. I didn't like it.

Mum said if she put anything in front of me, I'd eat it. I said, Mum, do what you want, I'm not going to eat that. She said, alright, baby. And I hated being called baby, I was the youngest. And I said, don't call me baby. And she asked what she should call me. And I said, Bubba. That seems a bit more manly.

I get on with a lot of the residents here. There is a fellow here, we're related. When I first met him there were two young fellows who used to live here were moving out. I spoke to them and said, you see that big guy, I bet you anything I know where he comes from and what tribe he belongs to. And I told them where he came from and the tribe he belonged to. I finally met him officially and we're related. It makes a difference. We sit together at the same table and we gossip.

A lot of the Māori people here don't know how to speak Māori. Yeah, but I feel so sad for them and they said to me, who taught you Māori? I said, nobody taught us. Mum wouldn't allow English in the house. Because I overheard her talking to these other grown-ups. If we don't speak te reo, it'll fade out. And when I went to school, my religion, I was baptised Church of England, but here (in my heart) I'm a Ringatū. That's a Māori religion, it means handstand.

This guy, he was Catholic and he goes, what makes you think Ringatū is better than Catholic? And I said, what makes you think Catholic is better than Ringatū? And he said,

you're a cheeky bugger, and I said, yeah, anytime you want. I knew I won the argument because he changed the subject.

Sometimes we're in the meal room and somebody might swear, f's, b's and c's and a's. And they said, but you swear, and I said, yeah, but we do it in Māori. Actually, we don't swear at all, there is no swear word.

The food is good here, but the cooks or the waitresses, they know what I like. They know what someone else likes, we both eat the same things. That's interesting conversation, it really is. My favourite biscuits are Arnott's cracker biscuits. They are beautiful and I like, we call it penupenu. Penupenu, you mash it up and I've got a soup mug, it's big and very heavy, good when you're fighting. And I like Arnott's cracker biscuits. Beautiful, they are. I like putting it in a mug with tea, let the tea soak it up. Put a little butter in it. Mum said you are a fussy bugger, and I said, Mum, don't blame me, blame yourself – because she said how to do it.

I always feel at home here.

Thomas

Resident

It's hard to know what's important to me. I just take each day as it comes and then if I get help here and there along the way, it's handy, I suppose.

I'm always happy when my wife comes. She's the main person in my life, I suppose. Yes. We've been together since September 1965, I think it was. And still very close. We got married in [name of town].

I came here because I was just falling over. I fall over, and the funny thing, I've had some terrible falls back home. For instance, you know, shopping trolleys in the New World? I would take one, I'd load it up with stuff, and get back to the car before her and I'd empty everything off, and my wife would come afterwards and put my trolley away, you see? Well, this time I came back and there was no trolley and here's me lying on the ground with a pool of blood all around me, with an ambulance taking me in to hospital, and that's how some of them happened. You know, there were simpler ones. That was a graphic one, because I became the hero around the place and all of the ladies looked after me.

One time in there, I thought I'd get a Lotto ticket. Now, my big thing was I had to watch myself that I wasn't standing in one place for a long time, and that was at the Lotto counter and down I went. And they had a big crowd around me, and they thought I'd had a heart attack, but however... People come and ask me, why did I do that? I could never tell them. It just happens, you know? And like yesterday, in my room. But, of course, with so many medics around me, I had no way of escaping.

My daughter chose this place for me. It's quite nice here and I've got used to them. As a person who's forever been at home I don't like being anywhere else but home. We get fairly well looked after here. The food seems nice. Yes. It is mainly the kind of food that I like. Well, of course, I've got to the stage where my teeth have failed me, and so it's chopped up food for me and a couple of us, and some of it seems very nice but I'd sooner be getting into a plate of chips and things like that, you know? Yes.

What I've observed about staff is that it depends upon the ones that have got the inclination to reach out to people. Not everyone is like that. Some of them are away with the willies and they can't do anything much. But the exercise class is on now between half past nine each day, and that one includes that lady that's lost her memory and so forth, and amongst those ordinary people, there are people that care for others.

This dear little nurse – she's a Filipino nurse involved in these sort of things... I'm just thinking. [Name] is the name of this particular nurse. She's a very caring person, and she's too caring with the likes of this. So, she had to make sure I was sorted out and everything. She's not one of the oldest, but she's very... You know, for instance, instead of doing their exercises... she knows I like to take a walk.

I used to be a trumper. I was a trumper and a harrier runner. I used to run from [suburb name] to [city name] for work a couple of days a week, and so I still like walking. I've got a whole lot of things that go through my head now, because having been a trumper, we used to go to different parts of the country and take off from there, and you sort of get a different perspective of other places too. Places like Lake Waikaremoana, that's where the big lake is. That was a nice place. We used to go there a couple of times. And then of course, we all headed down south, tramped the Routeburn, and the Glenorchy. The Abel Tasman, I've done that often. We used to call it something different, but that was great. Beautiful country in places but I think it's being overdone with tourists now. It's gotten so popular because it was an ideal place. You could tramp the whole length of it in one day if you wanted to. I have done that one. I took the kids down there one time. Yes.

And of course, they're very interesting with those thieving little birds... the kea, that's right. One night, I had everything laid out outside my tent, and next thing, I look around the corner and here's this kea taking all of my sleeping bag cover. Yes. Because I came across them at another place, Somes Island... Going up this track and these kea coming out and meeting us and begging us to give them some stuff. Yes. Little characters of birds all together. And then at Kapiti Island...

Instead of doing all the exercises, I'd be able to do a lot of them, although a lot of them involve shattering your hand, because I'm full of arthritis in my hand. But I just like going for a walk, and on the way through the hospital section I noticed [name of nurse] helping some poor old lady that's got nothing left, and then she takes it upon herself to be as caring with that person as anything. And this is what touches me with some of these nurses. Some of the ordinary people. They're all caring for one another, I think. Just some more than others. Yes.

I normally get up at about six. I have an alarm that sets off at six. Then of course we have a procedure where we've got to wash our backsides and so forth and get dressed for the day. They help us with that, yes. Some people are helpless. They can get help alright.

It's hard to know what's important to me. I just take each day as it comes and then if I get help here and there along the way, it's handy, I suppose. Among the nurses, of course, there are foreign nurses, like Indian nurses. They help too. Our beds are made. My bed has been made today, and then a crowd will come through and mop out the place. Yes. It's all very well worked out.

I feel positive about being here, to the extent that... I'm not positive about being anywhere but at home. I'd sooner be home with my wife, but look, it's a good home. Yes, I do things here that make me feel happy. I don't involve myself with a lot of things that other people do.

Some of them have Housie and different card games and whatnot, and I haven't bothered. I should really bother with some of those things, but I just haven't let myself go. Yes. But it's hard to know. I suppose I'm not the best at... I should tell the nurse. It'd give her some better ideas, too, about who she could identify as being more interesting for you.

Feeling connected to our families depends on whether they connect to us. My wife visits me here as often as she can. She'll come and see me on Saturday, because I do a big thing on Saturday. Because you see, we're Catholics, and our church is up on the hill there and I've got to do the big walk. On Saturday night we have the mass and so forth, and then I've got to find myself back to the home afterwards, but it's all worked out. I can manage it quite well. Practising my faith here is no trouble at all, because it's an Anglican organisation, and they're quite good when it comes to other people. Yes, they are.

Do I feel strong in my own identity here? I think so, yes. And valued? I think so. That little lady that brought me here, she's a registered nurse. She's over and above the other nurses. I feel myself that this is a nice place.

Asovale

Resident

There's always, hello, how are you? And they come and talk to me, and we both talk, and make friends. The main thing is to me that I'm around everyone. Because before, there was no one, and I was just afraid.

I didn't even think I was going to come here. It's the way I was living. I wasn't well. I was living alone. I was unwell, and I know I can go to the doctors and can be medicated to take it, but I'm not well at all. And then my son contacted [name of manager] and that's how I got here.

Living alone, I had problems with door knockers. All the time, they're knocking on your door, even though you say you don't want it, but they keep knocking on the door. I felt, I don't know if they were coming genuinely or they just wanted money or what. Because they ask for money. I said, I'm sorry. I can't afford it, and the next thing, five weeks later they're knocking again. They're still the same people, and I thought... you know? I stopped doing anything then, and my health was not the best.

I was in the hospital for two weeks before coming here, and then from there my son contacted [name of manager] and [person 2] because [person 2] was taking me to the hospital to see the doctor, and everything she did for me. I don't think I'd be here now if I was still at home, and then I was in hospital for two weeks, for treatment, and that's how... I think [name of manager] and [person 2], they contacted the people, they questioned me. I said, all I want is just a place I can go so I can see people every day, instead of living alone, especially in the night time.

To me, I feel safe because I believe in God. He's with me all the time, especially the times when I'm not feeling my best, I believe in God. Yeah. That's the reason why I contacted the hospital and came here. I just came here for two weeks to see how I go. I don't want to go back home. I'd be better in here instead of going back. I'm really happy where I am now – because of all the people around me all the time, like the nurses that talk to us, and the staff.

I've met nearly all the residents through exercise, church, and you know the garden, we talk in there. I moved in here... I'm not sure. July or August last year? I think July. About six months ago. I do feel settled in. There are a lot of people. You can see people and meet people and talk to people, enjoy... Yeah. I don't have to worry about... You know?

I get up in the morning, do the routine, same exercise, and do things during the day. If I don't feel like it, I just go for a walk. People help me with my personal cares, and the nurses. They are good staff, looking after people, especially when you really need help. I just tell them what I want and they just come straight away. When I first came here, it was strange having other people look after me, because I don't know them. The longer I was here, I started to get used to them and they got used to me. We talk enough.

I like being here because I'm not worried about... When I was out there, I was worried about sleeping at night. I can sleep through the night here. I don't have to worry about someone knocking on the door during the night, because it's amazing. I was really nervous about people knocking in the night. Sometimes I don't answer the door because I'm scared. I don't know who they are. And then when I came here, I was really happy. My life's got better now from there.

I've got a lot of family that live far away from here, but only [person 2]'s mum. She's the closest to me. And my son and their family live in Auckland, but that's another thing, because I said to my son, you should work in Auckland. Every time I'm not well, he has to come down and leave his work. That was amazing to me, and he said to me, Mum! You know, it's very hard for him. A job. No one to... You know? When his boss is away, he's the one to look after. When I have trouble, he leaves the job to come and see me. That's another main thing to me. Now that I'm here, he doesn't have to do that.

Yes. We have visitors. (Person 2)'s family, they come and visit me, we talk. I haven't been out since I came here – I just go out for a walk and then come back. I just go down to the shopping mall or around here, because the other two... The ladies who do the exercise, they take us out for a walk. Not only me. Whoever who wants to go for a walk, we go for a walk all together. I've made a lot of friends here.

I go to church in here, or on Sunday a member of my church comes and takes me to church and drops me here. It's good. I feel like they miss me because...they're happy when they see me coming to church. I still have that connection with my church, yes. It's not like I've gone away.

I feel that I'm not alone here. Everyone around me all the time at night and in the day. Before, I was really alone during the day and the night time. I know I can go talk to other people, but it's not the same when you're by yourself. I felt isolated at home, whereas here there's people everywhere. People coming in, going out, always people around. It feels like a family. I appreciate being here. Especially the whole staff. Everyone's knocking on doors, are you alright? I say, yes.

I can keep in contact with my son from here, but the number is the room, or they ring me so I don't ring – they'll ring me. I have two grandchildren in Auckland. One boy, one girl. One is going on 10 and the other one is 13. The oldest one is 13. They both go to college. I've got grandchildren on the other side but they won't come and see me. If they don't want to see me, I just leave it.

The things I do to feel happy here are exercise and going for a walk and helping out. Back home I used to do my own work but that's what I'm doing here in my... You know? I ask them to help me with my shower, and I do the rest for myself. I tidy up my room and make my bed.

It is home for me here. Home is having a lot of people around you all the time, eh? There's always, hello, how are you? And they come and talk to me, and we both talk, and make friends. The main thing is to me that I'm around everyone, because before, there was no one, and I was just afraid. The whole time I was by myself. I sort of felt alone, you know? I felt I was far away from everyone. And dealing with door knockers trying to sell things, or they're collecting money for taking to the...you know?

What's important to me is I'm happy where I am. I'm really, really happy where I am. I wake up in the morning and everyone's around each other and they say, good morning! That's the main thing. Everyone's happy and that. It's very friendly. The people are very friendly.

Joan

Resident

I don't have any worries here. Nobody worries you and if anybody's got any upsets you just talk to them, and they come right. I just tell them what I've been through.

I was in the public hospital, and I was taken to [street name], and then I was taken to the hospital. And they took me for a drive one day and said they were taking me somewhere and brought me here. But it didn't matter, they're all so nice – staff and the people. The staff are always very good to you, and top to tail wash in the morning. And clothes looked after and you've got your good clothes. I've had this shirt since the '90s, it hasn't got a hole or anything, it's good material. I've had it since then.

I think I don't know if I've been here since March last year or March this year, I'd have to ask. I think it was March this year, coming up a year. Before that I lived at [street name]. I can see my place from my room. There's sort of a driveway, and I was up there, and I see the different colour things going on the line. I had a chair I used to sit on out on the veranda and I could see right over the beach that side, and the beach this side, and the beach and the hill over there. And I could see all the shops down below at [suburb name]. The shops, I could see people going around. I used to walk down there sometimes and sit on the seat and talk to other residents and that and then come back. I've been into [name of council housing] sometimes. Some of the ladies used to be there, and I used to go in there and talk to them.

I've met a lot of people since I've been in the different homes. Then I went to [town name], I was up there in a home. [Name], but she was a bit elderly, so I was brought back down here to [suburb name], and then out to here. [Suburb name] was very good. They were very good to me out there and the other people. That was good there. Jonah Lomu used to visit out there. He's so tall, he's 6 foot 1. And I had a lot of friends there. The matron and the staff were very good, no hidings or anything. I only used to get hidings from my father. That was one of those things. I was the eldest daughter, I got the blame for everything. My step-sisters didn't matter, because my step-mother wouldn't let him hit them. Then I had the trouble about... that's how I came to be out this way. I was brought out to [suburb name], then I came to [street name] there, and then I came here. But they're very nice here. The staff are very nice, very understanding, you get dressed and washed from top to tail.

There is bowls, and there's the games thing here. Five hundred and snakes and ladders, and we play cards over here. I can play 500, just got to figure out which jack is jack. I'm learning and getting better, the jack of hearts and the jack of diamonds. There is a lot to remember with that game.

And there was another two ladies there playing something else – Scrabble. I love Scrabble. I used to play that years ago, and you could look at letters I V E and think it's 'native' or something like that. That was one thing at the school, my reading was the best, I could read good. I read a lot of books here. There's a library here – I've read all of Katherine Cookson's, and Jack Reicher and Jefferey Archer. I like to read anything.

We've seen *Cheaper by the Dozen*, the films, and a tribal one, and a couple others, I just can't think of them. We go to a film about once a fortnight. We do that here in the hall. I think the thing at the end there might be another hall down there. There's a range of different activities. I play cards, 500 and I like patience – I've played that a lot.

Every morning I take part in exercise. And then over like this, there is a whole lot of exercises, it's good for your body. Most of them do it, they like it, yes. But I quite like it, we keep coming along, they wheel us along sometimes, or we come along wheeling the old go-kart.

I have quite a few friends here. There is nobody we really don't like, and I speak to them all, chinwag. It makes them feel at home because I remember what I felt like when I first came here. I didn't know where I was going, but the staff here made you feel at home and I got to know some of the others, that used to go to Housie meetings over at the mariner and we have a few Housie evenings here. I won a chocolate now and then.

I've been outside here, but I don't go on the van trips and that, because I know [city name] and [city name] off by heart, so I don't go. I leave it for somebody who hasn't seen them. I know [suburb name] – I was at the YWCA there, and I lived in [suburb name], had my auntie there... My sisters and I were in a home, in the home, can't think which one – oh, the YWCA, that's where we were. And they took me for a drive one day and that's how I came here. But as I say, it's never worried me because I fit in anywhere. With the others and that, the staff are very good, I'm not praising them just because they're staff, but they are very good.

They do a good job with the personal cares here. Yes, hold your hand out. My flaps and my roll, that's what I call them! And she says, 'Come on, we'd better do under the flaps.' There is nobody really that gets angry with anyone. Some get upset, you have your days which were upset.

There is a rather plump woman getting around, you might have seen her. Her brother is the one that takes our photos. I think I've got the photos of the cat in there if you want to see them. That's the cat, he's over next door. And he sometimes comes on the path next to our place. That's a lovely one, she's ginger and white and black. The chappie just gave me those. He's a big Māori chap, had he gave some to a staff member, and some to me.

That cat's lovely. It makes our day watching her on the path – the path out the back there, over that fence. She comes under the fence or goes over, and that's the path leading to the gate. We haven't met her parents.

We do meet lots of interesting people here, a lot of things happened in this room, as I say. Snakes and ladders, it's a big material thing they put down. It's about every Thursday or once a fortnight I think it is. And sometimes they play the piano. I've got a friend who comes

to play the piano. We have a good sing-along when she comes. All the different songs. You pick a song. I go through the alphabet, 'Are You Lonesome Tonight?', 'Blue Moon', 'Can I Have the Dance with You', 'Down Street', 'Evening Shadows Make Me Blue', 'Forever and Ever', 'Green Grass of Home' and so forth. The last one is 'Zambesi'. I sometimes lie in bed and say them all, helps me to go to sleep. I do sleep well here.

The food is very good here. They have pork meat or lamb roast, and potatoes and kumara roast, and cauliflower or broccoli is the other one, and the pudding is usually pavlova and cream. I can't seem to have too much cream. But I can take anything in, vegetables. I used to go down to the shops and to [restaurant name], you could order a couple meals from there. I'd order two or three meals and take them home, that was three days. Saves me cooking so much. I don't really miss cooking. I love gardening more. I can't really do that here – they've got a gardener, and there is not much garden. Over there's the vegetables, he does all that. There's silver beet, carrots, cabbage, tomatoes in the back. He gets plenty of carrots – he thins them out.

I go to the Anglican church, but down to the hall there. I can go to the Catholic or the Anglican, there is both. When I lived at [street name], near that was the Catholic church further along. And the Presbyterian church was next to [street name], so I could go to either.

I feel content being here. I'm not worried about anything, let's put it that way. Are you getting up now? Yes... Open one eye up. Yes, I feel positive about being here. When I first came here I had asthma and bronchitis, but the doctor gave me six weeks of tablets for that, and I'm alright now. Touch wood. I haven't got any troubles with health just now. I don't have any worries here. Nobody worries you and if anybody's got any upsets you just talk to them, and they come right. I just tell them what I've been through, and since I've been here we've been alright.

There's only a few that I've had to help, and of course we had someone pass away, and that upset a few of them. So, we had to talk to them and get them right. It wasn't too good seeing her, but I put my hand on her as we always do. I've done that for years. You put your hand on their hand or their elbow. You feel better. We have something each day. We go to bowls and a few things coming in here. And, of course, I've got friends that come visit me, and another friend brings her daughters. They've been to see me lately. This friend was married to the son of a friend of mine. I'd known her for years, and she passed away with leukaemia. And her daughter passed away. And then someone had something with his head. That's the one I used to go with. All gone, left me, but I'm alright.

I've been through a lot, but I haven't let it worry me. I've been helping other people here. They like to talk to you and that. We've got the big lady, she gets upset. She talks about her husband that died. So, I talk with her sometimes, and you feel better when you talk.

Patricia and Margaret

Resident and whānau

I just feel totally relaxed and quite happy about being here. I have no worries being here. I'd suppose you'd say it's a home away from home.

My father used to come in here for respite care. He had his leg amputated from here down. To give Mum a break from him, he used to come in here. I've always sort of known about

this place and how great they are. The staff, wonderful! And then a couple of years back my auntie needed to come in, and then in November 2017 my mother sort of started deteriorating quite quickly. So that was our choice, and close to home for us instead of having to travel half an hour either way. And there was a position available when everything sort of deteriorated with Mum with the dementia.

Also, at that stage it was about two and a half years since my father had died and we noticed a great difference, and it was loneliness. She was very active in the garden. She would go out every day on her mobile scooter, things like that, and she wasn't doing that. She wouldn't do it. It was hard to get her to go out with us, even though I had contact with her every day. Food-wise she wasn't really eating, things like that, so my son and my brother said, we need to do something. So, we moved on it and we were very lucky to get her in here.

Everything just sort of fell into place, and since then she's improved greatly. Happy, yeah. Can't believe the change in her. I really don't think she would be here with us if we hadn't brought her here. Even though, as I said, we tried every day, she wouldn't go out. She used to walk, everything. Just basically lost it all.

My auntie's in here as well. I like the size of the place. I just think the little homes are wonderful. They're more caring. The load's not there, do you know what I mean? Whereas in a bigger home I tend to think they get a little bit left out. At a bigger place I don't think you'd get that, I suppose, one to one. It's not there. Like, I go to see my uncle who is their brother in [town name], and I've never felt... the same as when I walk in here. I just feel totally relaxed and quite happy about being here. I have no worries being here. I'd suppose you'd say it's a home away from home.

Patricia: All the people here are great. They really are. They're all friendly and nice. Really good.

They have a hairdresser come in and cut their hair and all that sort of thing. They have people come in and do their fingernails and paint them up. It's amazing. I think the community itself... little communities I think knit wonderfully together, whereas you get out in your big, open areas and things are not the same, are they? I suppose we're lucky living in a small community and people, they get to know you and they watch out for you. Yeah. They watch out for you, whereas in a bigger place you sort of don't have that as much, do you?

We're very spoilt. We are spoilt, and we take it for granted, but people are there to look after each other. There's some wonderful people that have basically nothing to do with the everyday running of this place, that will come in. They take them down to the RSA. The Lions run a Christmas dinner and all of those sorts of things. So, the ones at the home are always brought down, and people from outside bring them down in their vehicles. So, there's plenty for them to do.

I couldn't wish for a better place and they're so friendly and helpful, and you feel at ease when you come here. Wonderful place, you know? And as I said, everything's relaxed. Nothing's too hard. You just instantly feel sort of relieved. You're leaving your loved ones in somebody else's care where you've sort of done it yourself, you know? Just really friendly and helpful, and they go out of their way.

It's like home away from home. It's basically... Yeah. They grow... It's their home. It's their place. It's like, we can go out for a drive and she'll always say, 'We're home', so she treats it

like her own house and hasn't wanted to go home, back to her own place, which is good. It's wonderful. The food, Mum.

Patricia: Oh yes. Very good. I can't hear properly. No complaints. What do I like? Well, I don't dislike anything. I just enjoy everything. It's very good.

They're very spoilt. The food is beautiful, and if we come up for morning tea, afternoon tea, you always get a cup of tea and something to eat. You can't complain about the meals. They're very healthy, healthy meals.

Patricia: They're excellent. Everything makes me happy. Just everything. I'm quite happy to do anything. They took us over the road yesterday to the park for the entertainment over there. It's was really good.

They had sort of like a Christmas carols in the park thing over here, so the residents go over there. Christmas things, they do, and they have activities every day here. Exercises. People come and play music, play games, the Beatles. All sorts of different... Snakes and ladders and things.

Patricia: My favourite activities - I just like everything. I just go along with what they're doing. I can enjoy it.

She's pretty easy-going. She just goes along. She likes doing word-find and things like that, which we do. She's got back into knitting, where she wasn't doing any of that at home. She just lost all of that. But generally, I'm rapt. It's taken a lot of pressure off me as well. Before, with her being by herself at night... During the day it wasn't a problem because I'd be popping in and out, but at night. Even though she had her alarm, sometimes she wouldn't use it and the thought of going out there in the morning and actually finding her. Yeah. We had a couple of instances like that, but I always had keys so I could get in. It's just taken so much pressure off, and seeing her happy again, it's really good.

As I said, I don't think my mother would be here now. She was just willing herself away, really. It was a real good move. It was a hard one, but yeah. I think it's the best think we could have done.

Patricia: Oh yes. I am doing more knitting. I don't do much now, but I have always knitted jerseys or socks, or hats. And I like to walk. I just enjoy what comes up.

During school term, I visit Tuesdays and Thursdays... and occasionally other times I'll call in as well. It just depends. They'll welcome you any time of the day. And if anything's wrong with Mum, they'll ring. They contact us. If she was really sick or something was drastically wrong, or she had an appointment or something where they might want me to take her.

We had an incident in the middle of the year. It was term break and I took her out to my daughter's for lunch, and unfortunately she had a fall and broke her arm. So, I rung in here and I said what had happened. So [staff member] said to me, you ring the ambulance, I'm on my way. And [staff member] and one of the nurses came out to make sure we were alright. So, they're really very caring. Once the ambulance arrived, [staff member] left us in their good hands and they took Mum off to hospital.

Practising your faith... I know one of the other ladies does go to church. Her family pick her up. Just recently, I brought a Bible up for Mum. I sort of started to clean her house up and found a Bible so I brought that up, but, yeah, she has her own faith, and quite regularly used to go to church at home.

What makes a home? People. The environment, I suppose. People make a home, and feeling warmth, happiness, peace, is what you're about. They are always there for any of your needs if you've got a problem. They're always open. They're willing to be there and support you as a family too. Yeah. And they know, if you're going through hard times. They support us as well. I suppose more so with my father, when we used to bring him in here, because he wanted to be at home. They were there to help me through that, because I always felt guilty about bringing my dad in and sort of saying to him, if you don't give Mum a rest, we're not going to have her, and then where are we going to be? He came here, but he still didn't like coming, and I can understand that. It was pretty hard when he lost that limb, because he was so active with the grandchildren and he used to do patrol work and stuff down at the primary school, so he lost all that. It was pretty hard.

She's always quite happy to come back and go out for the day and things like that. She'll say, oh, we're home. Whereas her sister, she always says, I'm going to go home, and Mum would always say, no, this is our home.

Common themes | Ngā ia kaha te puta mai

The following section teases out common themes from the resident and family/whānau stories. The themes are listed in the table below, and each theme is discussed in the text that follows. The own words of residents and family/whānau members are given in italics.

Entering ARC	<ul style="list-style-type: none"> • Accepting there is no choice • Slow decline or acute crisis • Unsafe at home, loneliness • Whānau guilt • Welcome from ARC staff • Realisation that ARC care is the better option
Settling in	<ul style="list-style-type: none"> • ARC better than expected • New connections • Less loneliness • Increased physical and emotional safety
Meaningful connections	<ul style="list-style-type: none"> • New friends and activities for residents and families/whānau, but some limitations due to cognitive function • Family/whānau not just visiting in bedroom, can go walkabout, chat to other residents and family/whānau • Chatty, genuine, caring staff
Whānau involvement	<ul style="list-style-type: none"> • Some family/whānau visit all day every day, others not at all • Opportunities to contribute, ie resources and waiata • Can be under stress, overzealous with feedback • Appreciate communication from staff
Living conditions and care	<ul style="list-style-type: none"> • Manager sets the tone • Quality of staff, personal cares • Size, cleanliness of facilities • Quality of food
ARC part of community	<ul style="list-style-type: none"> • Kindergarten kids coming in to sing and play • Regular day trips • Community including ARC in their activities, eg, Christmas carols in the park, Lions Club driving residents there and back
Living and celebrating culture	<ul style="list-style-type: none"> • Waiata • Food preferences and eating in your chosen location • Cultural celebration days • Culturally diverse staff • Practising faith

Mental health	<ul style="list-style-type: none"> • Some residents depressed • Loss of skills, ability to sew or knit • Losing a loved one • Death a part of ARC life
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Entering ARC

Residents came from diverse backgrounds and shared a wealth of work and life experience before coming into ARC. There were teachers, a steam train operator, photographer, nightclub manager, social scientist and an Air Force pilot. Residents had raised families both here and in other countries and were involved in their communities.

Resident pathways to ARC began either with a slow decline through dementia, or an acute health crisis leading to a hospital admission. Some expressed surprise at finding themselves living in ARC. Luke felt that he was in good health, had a good diet and plenty of exercise. But a fall, coupled with a cancer diagnosis had led to him living in ARC. Thomas suffered from multiple falls, and Chiae's husband had sustained a serious head injury after a fall. Lena, Berys and Raina described their loved ones becoming less and less able to live at home due to Alzheimer's and other dementia-related memory decline.

Those who had an acute crisis lacked planning and awareness of what was available when entering ARC, whereas when a whānau member suffered from an extended period of decline there were opportunities to plan for the future. For whānau, it was a difficult decision to place their family member in ARC. All whānau described guilt at not having their husband, wife, mum or dad at home. After a number of years, one whānau member said she felt guilty for not feeling guilty. However, they reflected that ARC was the best place for their whānau member to be. There were a number of reasons for this. The first was that they could visit as much as they wanted and be part of ARC life. They could participate in daily activities and this helped whānau accept that their loved one was being cared for. Whānau came to an understanding that the level of care in ARC was better than what could be offered at home.

Before entering ARC, whānau had experienced difficulties with their family member's physical needs. Tasks such as lifting were not possible for some whānau, or the constant surveillance of family members who might wander off and become unsafe. Before moving to ARC, whānau noted that their loved one had become withdrawn and some stopped eating.

Settling in

Once in ARC, residents and whānau found it was better than expected. There were new connections to be made, new activities and opportunities, and capable staff who could assist with personal cares. When Chiae reflected on her husband living in an ARC, she was grateful for care that might not be available in the country they had emigrated from. She suspected that if they lived in Cambodia her husband would no longer be alive. Patricia also believed that her mother was on a downward spiral before moving to ARC and described her mum *willing herself away*. Raina noted that there were many more activities and opportunities available to her mum in ARC and that she *couldn't do all the things that she does here if we had her at home*.

Asovale's story of entering ARC highlighted elements of safety and social connectedness in being part of a new community. Living alone was becoming unsafe for Asovale, with people knocking on her door at all hours of the night. She felt lonely and was unable to sleep. Asovale described relief at living in ARC. She loved that people were around her all the time.

Safety at night was also noted by Margaret, whose mum had an alarm but whānau were not confident she would use it should she have a fall at night. It was comforting to whānau that mum was now safe at night.

Meaningful connections

Some residents and whānau already knew people at the ARC facility before they moved in. Jim's Rotary club had provided transport for residents in the past, and he knew the manager through the club. Patricia's dad had lived in the ARC and her auntie currently lived there with her mum.

It made a positive impact on whānau bringing their family member to the ARC facility when they were warmly welcomed. Berys loved that the staff member who welcomed her whānau was still there years later, and they could build a long-term relationship. Lena was struck by the diversity in the home, and Raina loved hearing waiata. She quickly became part of the waiata group and now runs the weekly kaumātua kapa haka waiata. The group now includes waiata from Germany, the Netherlands and India.

Residents established connections with each other and with staff. Paul found a resident he was related to. They could converse in te reo Māori. Joan had a circle of friends and took pride in welcoming new residents and helping others. Jim joined a discussion group. He had also become the 'go-to' for the cooks, providing advice about the level of food quality. Luke composed poems, which delighted staff members. In this way, residents were valued, which was important to them.

There were limitations to the relationships residents could build, as some suffered with memory loss and other cognitive disabilities. Jim said, *There's one lady here who I can connect with, because our brains still work. That's a limiting factor. A lot of them have brains that don't work very much.*

Whānau connected with other whānau and also with residents. Berys found it comforting to have coffee with another resident's daughter. She could talk to someone who understood her situation. Lena ran into an old friend at the care home and reignited the friendship. Being able to support others was satisfying for both whānau and residents. Raina noted that *it means a lot if you can do that for someone.* Whānau also got to know residents from their day-to-day visits.

Whānau involvement

Whānau who shared their stories for this project were proactive in the lives of their loved ones. They had become part of ARC life and contributed in a number of ways, such as supplying resources or running the waiata group. A staff member noted that Berys had sewn some bibs for her husband to roll up as an activity and asked her to make more. She has now made 20 so that other residents can participate in the activity. Raina took on the singing group, obtaining funding, putting together a song book and naming the group the kaumātua kapa haka waiata group.

Raina shared her own whānau struggles that had stemmed from having a mother with dementia. In the context of this project, whānau who come to ARC may be stressed and under pressure. They may behave in a negative way, for example, Raina called herself a *kind of an on-your-back daughter* who was hard on the staff at first.

Living conditions and care

Everyone who shared their story with us was impressed with the way their ARC facility was run. They emphasised the importance of management who were 'on the ground' getting to know residents and staff. This set the scene for the culture of the ARC. Both residents and whānau described the kindness and genuine connections they had with staff members. Lena described it as a 'whānau-ness' when she said that *everyone here has a respect for each other first and foremost and they have this lovely bond*. Raina thought that although most staff were attentive and caring, there were some who did not appear to be on the ball. *I've seen a few lazies... I'm a tell-tale so if they see me it's like, better move*.

When we asked residents about what it is like to have personal cares undertaken by staff, such as washing and toileting, their responses were very similar. Luke felt that he was seen as a person beyond a body to be tended to: *they went a long way beyond just seeing me as a job, seeing me as someone who needed to be flannel washed*. Jim knew from experience that he was no longer able to toilet himself and appreciated the skilled staff assistance with this: *what's important to me is that we're helped to go to the toilet, and we're helped back again by someone who knows what they're doing and stops me from hurting myself*. Joseph, however, described ringing the bell and waiting for long periods for someone to help him get to the toilet. *Can you imagine one hour, you are suffering in your stomach, you have to go to the toilet? It becomes difficult at that time*. He was determined to build up his strength with the help of a physiotherapist, so that he could perform this task himself. Joan described being washed each morning with good humour.

Residents were for the most part, happy with the food in their ARC. Paul enjoyed a cracker biscuit treat: *Penupenu... I like putting it in a mug with tea, let the tea soak it up. Put a little butter in it*. Joan listed with aplomb the array of meals and desserts available throughout the week and lamented the quantity of cream she was allotted. As part of his Buddhist practice, Luke did not eat animal products and also liked to chew very slowly. He felt valued in that the ARC staff respected his preference to eat in his room, although he also found it amusing they had labelled him a vegan, as he had never thought of himself this way. Food was an important part of Jim's life, and he was unhappy with the quality of the food at his ARC. He had tackled this on two fronts, first by having his own condiments which he and another resident shared with others. His second strategy was to become an advisor to the cooks, who often consulted him on how to improve.

All but one resident were happy with the spaces that they lived in. One commented that the rooms were bigger than other places he had visited. Bedrooms were decorated with art and other pieces that expressed the individuality of the residents. Some residents and whānau commented on the high level of cleanliness, although one resident considered that extractor fans were needed to ameliorate unpleasant odours.

ARC as part of the community

ARC facilities do not exist in a vacuum. They are based in geographic locations inhabited by communities. Most of the whānau who spoke with us chose the ARC for their loved one because of its involvement in the community. For Berys, hearing that local kindergarten children visit *sealed the deal*. Margaret described the small rural community where their ARC was based including the residents and whānau in activities. The local Lions Club would transport residents to events such as Christmas in the Park.

Residents had mixed stories about going out into the world. Some enjoyed occasional shopping or other trips organised by the ARC. Others did not join community outings. For some, this was by choice; for example, Joan said, *I've been outside here, but I don't go on the van trips and that, because I know [city name] and [city name] off by heart, so I don't go. I leave it for somebody who hasn't seen them*. Mata didn't join outings but believed that residents had to be 'chosen' to go: *but maybe one day they will choose me to go, and I'll go. I think you have to be chosen to go, you can't just get up and go*.

Living and celebrating culture

The ARC facilities involved in this project were made up of staff and residents from diverse cultures. Culture can be expressed through food, music, language and other ways. The diverse mix of cultures attracted Lena to her husband's ARC. The culture of connection, relationships and warmth was also appreciated by her.

One of the ARCs has regular cultural days where they celebrate an ethnic culture. This is very much enjoyed by staff, residents and whānau. When we visited one of the ARCs to arrange our visit, it was the week before Christmas. The facility was decked out in festive decorations, and the staff wore Santa hats and Christmas badges.

The kaumātua kapa haka waiata group was another example of a cultural activity uniting residents, staff and whānau. Raina noted that those who were unable to communicate were still able to participate: *they'll just be lying in their chairs – you can see them starting to try to interact with the singing and movement. It's beautiful. It's like an awakening*.

Paul was able to communicate with his relative in te reo Māori. Keeping language alive was very important to him: *if we don't speak te reo, it'll fade out*. Chiaie's husband did not have people around him who could speak his language. One staff member was able to use basic greetings but for the most part, Chiaie translated for her husband. Despite this, the staff made efforts to build a relationship, and Chiaie recounted one of the staff reminding her husband of a past student: *So, when the nurse comes and sees him, he says, teacher! He's very happy. He smiles*.

Some residents regularly attended church. They were collected by friends or family and taken out each Sunday. Others practised their faith in other ways. Some ARC facilities had church services on site.

The cultural diversity of the staff was noted by residents, some of whom never had the opportunity to get to know someone from a different culture than themselves. Thomas noted the different ethnicities of the staff around him and enjoyed having them in his life.

Mental health

Most of the residents we spoke with had not chosen to enter ARC. Joseph described feeling very unhappy. He yearned to leave and re-join the world. Some residents had dementia and found it difficult to reflect on what was important to them in the present moment but raised their sadness and grief for family members who had died a long time ago and more recently. Mata talked about missing her mother and siblings who had passed away. Joan, who was universally optimistic, also reflected on those who had passed. Jim had been married for 72 years and recently lost his wife.

Death is a regular occurrence at ARC. Although most residents were matter-of-fact when they raised this, it was also described as oppressive by Luke: *It can become a slightly oppressive aspect of the place, that there are so many people who are in a wretched state who can't be ameliorated or relieved and die.* Joan shared how she touches the arm of the deceased and it makes her feel better.

Sometimes residents grieved for the things they used to enjoy and were now unable to do. Mata spent decades raising a family and sewing and knitting for them. Her eyesight had failed to an extent that she could no longer enjoy these things and she missed creating beautiful and practical gifts for others. Thomas missed tramping and recounted cheeky keas stealing his gear.

Luke had gone from an autonomous life rich with friends, learning and meditating to limited mobility. But unlike other residents, he was improving: *this is very atypical of people here. Others are on a downward spiral, whereas I'm going from strength to strength.*

Discussion guide | Aratohu kōrerorero

This guide is available online at www.hqsc.govt.nz/our-programmes/aged-residential-care/publications-and-resources/publication/3757 as a standalone MS Word document, to enable providers to freely copy and adapt the topics.

The following topics provide a guide for relationship-centred quality improvement discussions between providers, people living in care homes and their families and whānau, for example, during resident or family/whānau forums.

The topics are grouped according to the themes identified earlier in this report: entering ARC, settling in, meaningful connections, whānau involvement, living conditions and care, ARC being part of the community, living and celebrating culture, and mental health.

One topic could be discussed at each meeting. Record the answers then develop an action plan with the group to work on the matters raised, then follow up with the group about what actions were taken or trialled.

These are suggested discussion topics only. ARC providers are free to adapt them or develop other questions to suit their individual facility and residents' needs.

<p>Entering ARC</p>	<p>For residents and family/whānau:</p> <ul style="list-style-type: none"> • What was behind the decision for 24-hour care in a care home? • What was your experience of coming to this decision? • How did you find your first day? • How welcoming did you find the staff when you first arrived? What makes the experience more positive? <p>For family/whānau:</p> <ul style="list-style-type: none"> • What other feelings did you experience during this transition? Guilt? Sadness? • What advice would you give others that helped you?
<p>Settling in</p>	<ul style="list-style-type: none"> • What surprised you about care home living? • What are the positive aspects? • What differences would you like to see?
<p>Meaningful connections</p>	<ul style="list-style-type: none"> • How are the relationships between the people living in the care home? What advice would you give for improvement? • What activities do you find most meaningful? What would you like to have available to you? • How are the relationships with the staff? What advice would you give for improvement? • How is communication from staff for you?

Whānau involvement	<ul style="list-style-type: none"> • What aspects facilitate meaningful family/whānau involvement at the care home? • How could staff help you with communication with family/whānau? • What would be helpful to support family/whānau?
Living conditions and care	<ul style="list-style-type: none"> • How did you find the management at the care home? What advice would you give to the management for improving the overall 'feel' in the care home? • How do you find the food? What suggestions would you give about the food? • How do you find the staff's care? What suggestions would you give about the care? • How do you find the care home environment? What suggestions would you give about the care home environment (cleanliness, facilities)?
ARC part of community	<ul style="list-style-type: none"> • What would be ways to become more involved in the wider community? • What outings are most meaningful to you and why? • What visiting groups are most meaningful to you and why?
Living and celebrating culture	<ul style="list-style-type: none"> • Do you feel that your individual religious practices are available to you? What advice would you give around this? • Do you feel that your individual cultural needs are met? What advice would you give around this?
Mental health	<ul style="list-style-type: none"> • Some people who are less independent find this difficult and sometimes have problems with depression. What advice would you give to support these people? • Some people are grieving after loss of a loved one. What advice would you give to support these people? • Some people living in care homes are facing the last stage of their lives and death is a regular occurrence. What advice would you give to support other people when someone dies?