Adolescent and Young Adult (AYA) Cancer

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1. AYA - Mia shares her story

My name is Sean McPherson, I'm one of the haematologists here at Christchurch Public Hospital. So that means I'm a blood doctor and that involves various things but one of the biggest parts of the job is looking after patients that have some kind of blood cancer. So things like leukaemia, lymphoma, myeloma and I'm also part of the AYA team. You're going to hear from the most important person in the AYA team in a wee second, that's the adolescent and young adult team. A very small number of my patients fall into that category of adolescent and young adult, they're a really important and rewarding group.

That's enough. Kia ora, I'm Louise. I'm the adolescent and young adult cancer nurse specialist. I work with anyone diagnosed with cancer aged 12 to 24 years of age in the top half of the South Island. And yeah, it's an absolute honour and privilege to work with amazing people like these people. Hi, I'm Nick. I was diagnosed with lymphoma, stage 2. And yeah, I became here because Louise thought I'd be a good advisory. That's what we're meant to do. And I'm just a nurse again. Whatever I want to be. Kia ora everyone, my name is Toihi. I hail from the Wild West Coast. More specifically, Hukatika.

And yeah, I'm from the West Coast. But my family is here. So, kia ora everyone. My name is Toihi. I hail from the Wild West Coast. More specifically, Hukatika. And yeah, I am blessed to be here, I suppose. And I'm just here to offer some kōrero and whakaaro based on my experience with acute myelo leukemia. Toihi. Show off, ma. I do this a lot. Hi, I'm Mia. I am still currently on my journey. I am 23. I got diagnosed with leukemia last year. And yeah, I'm just right in the wave at the moment. So, yeah. Post-transplant, I've had a transplant. I'm good to go. Yeah. And she's looking beautiful. Thank you.

Yeah, absolutely. I have to say, I have a kēnā whaka e kēnā. I look quite... Yeah, I can't really follow Toihi. Mine's much slower. Yeah. I'm not nearly so good. Yeah, yeah. Anyways. Anyways. My tonneau, guys. Best job ever. The first one that you... I think it was with you, Mia. Yeah. And you were going to talk about, obviously, working and then... Yeah, this happened. So, got diagnosed last year in March. And it was like a whirlwind. I was working. Like, I had just graduated. I had just got my job. I was like three months into my brand new job. And I was working all the night shifts because I was just scrambling for cash and everything.

So, I was tired and run down. And I worked in the hospital. And, yeah. Like, I just started to feel really tired one day. And I got a full body rash. And I was like, oh, shit. Like... Oh, no. Oh, no. I was like, oh, no. I was like, oh, no. I've gotten, like, some sort of, like, you know, something from a patient or something like that. And I didn't even have a doctor up in where I was working. And I, yeah, had to go to the after hours. And as part of the after hours, I got blood tests. And that then sent me home with some antibiotics for my rash that I had. Which I didn't really think much of.

It was just, like, a little rash on my leg. And then got a phone call a couple of hours later and was like, oh, your bloods are really not looking good. You should head to ED. And I was like, oh, well, I've actually got my shift in, like, a couple of hours. And they're like, nope. You should definitely go now. And I was like, oh, well, I've got stuff in my locker at work. Which I didn't actually have anything other than I thought I had stuff. So I ended up at work in my little, I had, like, UGG boots and, like, a pair of, like, tiny little shorts. And, yeah, I got, like, taken away to a side room by myself.

Got told, oh, you've got, like, probably cancer. But there's no haematologist here to, you know, to confirm that. So we're going to fly you to the nearest hospital that does have a haematologist, which was Hamilton. So I got in a, like, private chopper. And, yeah, got diagnosed up there. And I was like, I'm completely fine. Like, I'm completely by myself. This is crazy. I need to go home. So, yeah, there was amazing people up in Hamilton Hospital, the AYA team. And they organized for me to get a flight back down to Christchurch. And, yeah, then I arrived in Christchurch. And my first week was, like, hectic.

I had my graduation on Friday. Which I was determined to get to my graduation on Friday. So I was like, okay, I've got diagnosed. I still feel okay. I'm going to do this. It's just cancer. I can smash this. And so I had just, like, the most craziest week of information overload. People coming and seeing you. Handing you pamphlets. And it was just crazy. But I just had, like, the mindset of I'm getting to graduation. I'm going to walk across that stage. And, yeah, I did it all. I had my. I had my graduation at 9 a.m. Walked across the stage. Walked out the door. Straight back here. And was taking off my makeup as I was walking down the halls.

To get my Hickman inserted. And then my ovarian harvest at the same time in the theater. In the afternoon. And that was, like, the most exhausting week of my life. And there was just so much information. So I think, oh, shit. That was just week one. That's a bit of an understatement. That was week one. But, yeah, so I definitely rambled and stretched that out. But, yeah, it was a hectic week. I didn't know all of that. Yeah. The little bits of it. Yeah. But that touches on so many of the issues that we were planning to talk about. That was amazing. Yeah. And a horrible, horrible experience. No.

I just powered through. It was. I feel like it was just so moved so fast that you just, like, can't grasp everything. And I still felt well that first week. Like, you know, that first. Like, I still felt like myself. I still had my hair. I still. Yeah. Like, I was working the week before. Yeah. But, yeah. You weren't feeling 100%, though, were you? No. I was working night shifts. And I was just feeling tired. Yeah. And in your moods, weren't you? Like, sluggish. Yeah. And I kind of, like, was explaining them in other ways. Yeah. And I feel like probably that's just because I was, like, brand new job.

Like, I'm wanting to work hard. I'm wanting to impress people. I'm wanting to make sure that, you know, like, I just push through it and I do my best. And didn't realize at that time that I had just been fit. When you're young and fit. Yeah. You can purify all that stuff. And you will put it down to other things. And it can be. Yeah. And it can delay the diagnosis. Because you're not supposed to get stuff like this. It's cancer. It's not on your radar. It's not something you really have to think about. I hadn't actually known anyone that had had, you know, cancer or anything. It wasn't even on my, like, you know, like, personally.

Like, in my family. You know, we're all fit and well. It just wasn't even on my horizon. Yeah. And cancer. Yeah. It's the, there's a lot of reasons. Because cancer, let's go with cancer. Yeah. This age group, we're talking 12 to 24 in New Zealand. That's the official age group for AYA in New Zealand. If cancer affects less than 1%, sorry, less than 1% of the cancers effect that age group, is what I meant to say. So, it's not supposed to happen. It's not on your radar. It's not on anyone else's radar either.

So, even if you turn up at the GP and you're feeling a little bit run down, that's not going gently, it's really satisfying to do. Yeah.

going to be the first thing on their list either it's not really until you take a blood test often that it becomes apparent because you know you're obviously well enough to go home again and think about going back to work uh and then we we get that result in the lab and some suddenly you know it's action stations we phone you up and say actually you better get in here and there's no easy way of doing that without giving you some sort of alarming information to try and get across the message that you really do need to come in it's not

the best way to tell people things like this but sometimes you have to because it's the only way you can you can get started on on the treatment and you know you're doing the right stuff to get you better yeah well i think like the speed behind it is always why i think i just like kept going the whole time because that was just so fast moving that you just like didn't even grasp it like i think well that's how just so much going on which was crazy and then it's not till you like actually like um now in a hospital room hooked up sitting here that you kind of start to like digest everything and go okay i've got like a hundred booklets in front of me and i've had like a million doctors walk in the room like what's happening and i think that it um quite often and it depends on sort of what type of you know cancer that you are diagnosed can sort of really affect what your diagnosis junior or junior diagnosis is like so for i think all three of you it was quite a rapid sort of you know period from being at work living your life to oh my gosh now i'm in a hospital room and i've got cancer but for quite there is a quite a number of diagnoses that are different to to you guys that we are actually it's quite a long process as well like so for example if it's someone that's got sort of a tumor in their bone or something like that then it can be a lots of uh visits to gps going something's wrong like something i can't you know i'm sore it's painful it feels funny there's a lump something's wrong and because like sean said that you know it's such a small it's so unlikely to be cancer then those the steps that they would do if someone was older doesn't happen and then they um so that sort of gets delayed and they go down the route of well you know have you injured yourself and have you had a sporting injury and have you or have you got a really bad flu or have you got something else and all those things have to be sort of and that's usually that's usually the right approach because usually it's not cancer i think it's like 200 uh aya cancer patients per year yeah in new zealand which isn't it sounds like a lot but it's not it means you've got company um and that makes it even less like reality because you know you're well enough to continue working now you're telling me i've got because i quite often find that if i'm going into a room to meet someone for the first time they're either going to be sort of similar to what you were explaining at mia which is like like this all happened so fast or i'm so relieved that finally i know what's going on and yes it's cancer but i just want to have something done about it because i've known something's been wrong for months and it's almost like your approach sort of changes depending on what that journey to sort of yeah getting their diagnosis sometimes it's just having a diagnosis is a bit of everything itself yeah but it does mean that we've got some do you know where you're going to say i agree gary chur

2. AYA - Nic shares his story

I think you were going to have a chat about, like, when you have to move. Oh, yeah. Yeah, I saw you. Yeah, because there's a nice segue there, because you had to move as well. Yeah. Yeah, so I was living up in Napier at that time when I got diagnosed. Like, getting, coming up to the diagnosis, I kind of was a classic male and really, ah, I'll get over it. I don't need to go to the doctor. I'm too tough to go to the doctor kind of thing. So I kind of had my symptoms for a long time, and then I kind of got fed up with them, really. And I just kind of went to the doctor. They gave me inhalers. They were like, oh, you've just got asthma.

And I went through three inhalers within two weeks, and I was like, hmm, that's probably not the greatest. So I went back to the doctors, and they were like, no, that sounds like a severe asthma problem. It's a traumatic kind of thing. We just don't have the correct ratio for you. So I was like, nice and sweet. And then he heard me cough once. And he was a young doctor, and he was like, no, we're just going to have a check on that cough, do an x-ray. And yeah, I went in, had an x-ray, and we came back, and I didn't even actually sit down in the waiting room. He dragged me in and was like, he's no easy.

He's no easy way of kind of breaking it to you, but you've got cancer. And I was like, oh, cool. That's a good way of doing it. That's an easier way of doing it. There's lots of ways of doing things, and most of them aren't necessarily wrong. Yeah. But I didn't mind it. I was like, sweet, you're up front to me. You're not going to drag me through and all that. And then he was like, what? We were wanting you to go in an ambulance to Hastings Hospital. And I was like, nah, I'll be all right. I'll just drive myself. My phone was literally on 1% as well, so I was like, I need to grab a phone charger as well.

And they let me go, drive there, because at that stage, I didn't know. They didn't really know how serious it was. It was just a soft diagnosis for cancer. And got to Hastings. Sorry. It's a little bit of a cancer. It was a soft diagnosis for cancer. What do you mean they weren't completely sure? They were sure, but it was just soft. Yeah. They just didn't want to, like, we're not jumping into, like, you've got... You're not riding it on your back. I think maybe you have cancer. Maybe. But I mean maybe. It could be cancer. Yeah, a little bit. A little bit. A little bit. A little bit. Was that based on a chest x-ray?

Yes. Yeah. Yeah. Yeah. So there was stuff there that shouldn't have been. Yes. Yeah. Yeah. Yeah. And yeah, so went to Hastings, and they started doing a whole lot of tests, scans and all that sort of stuff. And they found a couple blood clots around the heart and all that sort of stuff. And they're like, sweet, we're going to give you a... Sweet. That's what we do. What is that? What is that? What is that? What is that? What is that? What is that? What is that? What is that? What is that? What is that? What is that? What is that? What is that? Yeah. That's fine. That's fine. It's exactly what you're giving me, right?

People are just going to be like, guess what I found? We should try this. Next patient would be like, sweet. Guess what I found. And yeah, so they gave me... I'm sorry. That's all right. They gave me a blood thinner to fix it. And the doctors literally ran in, and they were like, have you given the blood thinner? And they were like, yeah. And they gave me like a whole lot of liquid.

around my heart and they were more worried about the liquid around the heart than the blood clots in my body so i got bounced around hastings hospital because no one really wanted me because i was in a critical situation did they explain to you what the problem was there that they've given the blood thinner no no i didn't kind of get told that information i just kind of took a pill and have you been told since yes yeah yeah maybe you can explain to us and then yeah i kind of then ended up in icu because they kind of told me i wasn't going to make it and that was that was a big massive shock for me and i was like how can this really happen i'm 23 at the time like just being told i've got cancer the saying make it through the night so it's kind of a lot of things were going through my mind family's not even close to me by yourself i was by myself so it was quite a lot of process going through and then in the back of my mind i kind of was like shit happens really i can't do anything about it now so yeah that night just kind of dragged on kind of tiktok didn't save me at all in killing time and then in the morning my parents turned up they rushed up and i kind of made it noticeable that i wanted to be down in christchurch if anything happens i'm in christchurch with family so the hastings team were really awesome they kind of were like we're going now if we're getting down there they literally jumped just chucked me in the back of my mind and i was like what's going on what's going on what's going on what's going on what's going on what's going on in an ambulance and put me on a plane down to christchurch and then i had all my treatment in christchurch and tomorrow did you come directly to one of our awards or yes or no something's happened we went to cardiology okay yeah started off there and did they put the drain in or did you already have it they already put the drain in yeah yeah they woke me up at when i just got to sleep they woke me up at six o'clock and they put the drain in they were honestly waiting yeah actually they were waiting can you sleep no wake you up yeah yeah that should do it it's so relatable it's like the four o'clock like like 4 a.m bloods and you're like oh yeah i'm sorry you do that a lot don't we yeah and then they come around to fight me like i've just fallen asleep and then they come around at seven o'clock to wake you up yeah as well yeah yeah yes and then i moved into b5 for my first two treatments i think or the first one yeah after that i moved into tomorrow the treatments and tomorrow and then when i relapsed came up to christchurch for the rest of my treatments

3. AYA - Support from families - location of treatment - resources available

I think that that's a really important thing and probably something that's a bit more unique to this age group of people when they're diagnosed with cancer. It's quite often that they are just recently living away from home, so they might be at university or they might have just got a new job. They were away from where they'd grown up, they were away from their key supports, which was totally the place that you were happy and comfortable with when you were well and working and studying or socialising, doing what you wanted to do. But quite often, I think, and you guys will probably agree that when you're diagnosed, you just want to be surrounded by people who you know and can rely on and trust on to be there and care for you.

And sometimes even if that's not what you want, that's actually what you need. Because you aren't able to do some of the things like financially, you can't continue working to be able to pay your rent or you can't continue to study because you need treatment. So then you can't stay at university where you were or any of that. And I think that that can be tough, but also I think you guys are a really good example of the fact that thankfully the health system and everybody that works with young people, will usually do what you want, like, you know, like if you want to be at a certain place, they will do everything they can safely.

It's quite often it needs a bit of stabilising and, you know, sometimes you need to have your first round of treatment or something like that to be able to before you can get to where you want to go. But also, you know, like you said, Nick, you know, like it's about the treatment that you can have as close to home as possible, like you did in Cimarron. True, we'll do, but some of the treatment has to happen in like a tertiary hospital, so sometimes you have to travel. Sometimes you're stuck with here. Sometimes you're stuck in, you know. Which is okay if you live here. Yeah, yeah. I think I actually read that survey, AYA survey, I think one of the points, and it's possibly a take home message, I don't know, I think 79% of AYA patients said that they needed to move somewhere else to get the treatment that they required.

They would do it, yeah, so it's nicer if it can be at home, but, yeah, some things. Yeah, for me, if I, if I lived in Napier, I would have had to go to either Hamilton, Rotorua or Palmerston North, so that's a, that's a long. It's not even where you work. Yeah, it's, it's a longer drive from where I live now to Christchurch, so. And the people, like, you know, like I have faith that. The people that do my role throughout New Zealand and the teams that they work will do whatever is needed. So if it's to get you back to where you want to be, then it is. If it's you decide that you want to stay where you are and that actually you're being with your friends and the people that you're surrounded with is more important, or that you want to keep working, if you can keep working, then they will do the support that they need to, you know, to do that.

So, and be those support for you, so. Sorry, are we just doing it? Yeah, I know, I know. I just hit the hair clip and it was, like, slipping back, but yeah, thanks, all good, yeah, it's on. And we've got, I've got your notes on the phone as well, so you're not, it's not like you're. Yeah, no. No, I'm just trying to steal your phone. Yeah, I was like. You're stealing my phone. I'm actually like, this feels weird. Well, no, like, that was all part, this is a wig, guys, and we're just for real. Yeah, yeah. It's pretty fabulous, huh? Like, I've seen it to you before, I haven't seen that. This one, I've got, I've got a few.

Yes. Oh. So, I just change it up every now and again. It's looking great. Yeah. But that was, like, also, like, part of my journey as well, was, like, change in how I looked and how I felt, and I think that's probably quite important, you know, as a young person. Absolutely. I mean, I try not to care about that sort of stuff. But, you know, those are all, like, questions when you're, like, my body doesn't feel good on the inside, I don't look good on the outside. Like, oh, I just feel like a completely different person. You're like, it's just, like, who am I, what's happening with all of these questions, and that's the thing.

But there are people that help me through that, like Louise, like all the wig people, Cancer Society, or all of the different, well, there's so many resources, it's just, like, yeah. You talked about resources before, I'm feeling like you had, like, 20-something resources in front of you. Yeah, it's just, like, filing through them all and being like, actually, this one is what I need right now. Yeah. Or this is this, and it's, I think, about asking questions as well, like, you know, when you're, like, who do I ask? And I think... Yeah. Sorry, I don't remember. No, it's all right. I don't even know where that was going.

That's all right. That was just a ramble. We were just admiring you. That was just a ramble. I was going to say, but there's, like, the resources that you use might not work for me. Definitely. So it's literally trying to kind of pick the ones that work for you, give them a try, see if they work. If they don't, you kind of really move on to another resource kind of thing until it really works out for you. Especially when you're, like, really smart. And you have, like, a studying health background, which helps a lot of it. Well, it does help. And I think, for me, it definitely helped in regards to a little bit of understanding of, like, medical terminology and kind of trusting the system.

Like, you know, like, oh, I'm going to go for this scan. In my head, I know what that is. Oh, I'm going. I'm going for this. I know what, like, I know what to expect. And so, for me, I think that was really beneficial and it really helped me just work through my journey.

4. AYA - Everyone's journey is different – the challenges of medical terminology

Do you feel you were able to support some of your peers that didn't have the same background and were going through the same thing? Quite honestly, like when I first joined the ward, there was 20 and then there was no one else around my age. The rest of the ward was like 65 plus. That's most of my patients. So the next question is how many people you've aged? Yeah, so I mean, very grateful. She was my neighbor. And yeah, so that was really cool. But I think everyone's journey is just so different. And for me, that was really beneficial in mind because I could kind of work through things because I did have a pretty like rough journey.

Still, you know, a little. But yeah, I think for me, having that background already as a radiographer, I could kind of understand the body a little bit. And so I had a little bit more trust than, I don't know, someone that, you know, hasn't been to the doctor in like six years and, you know, or like mum's rung up and maybe. I had a little bit more trust than, like, you know, someone that, you know, hasn't been to the doctor in like six years and, you know, maybe. And I think that was really helpful. And you're like, oh, I don't, I don't even know what, like, my, like, what, what's this one word?

And you're like, oh, I don't even know that. So for me, it was familiar. But I think that helped. Well, because you had like similar interests with your role, right? Yeah. So you're like, you're finally engaging. So I could kind of like connect the dots a little bit. But like for my family, like my mum didn't even know what a stoma bag was. Yeah. Yeah. Yeah.

had to get a like a stoma and she was like you know I've never even heard of this word before like what do I do like who do I ask and you know she's in the room with me getting all these medical terminology that I'm kind of like nodding my head like yeah yeah I took that off but I look around and everyone's like lost like all these big words and everything like that as a doctor you have to like you know say it medically and you have to say you know that's how you say it and it's just like when they leave the room you've got to like digest that and you're like wow it's just something to translate yeah I know it's like we spend years and years at medical school learning the terminology so that we can speak to each other in code but no it's not it's just so we can communicate properly with each other and then you become a doctor and then there's a real patient in front of you and you've got to be able to translate back into something that's understandable but you still you've noticed that most of the patients in the ward are much older ooh and , they'll have more experience of either being in hospital or knowing people have been in hospital cancer is not it's not a foreign word it's it's something that they'll know lots of people that have gone through that and it means something but I was thinking back to when I was between 12 and 24 which is this age group at what point did I actually know anything about any of it I mean I've heard the words but they meant nothing to me really most of the way through even when it became a even when I was going through medical school when my one of my friends got a horrible day of cancer nothing you didn't get, different one, different one, okay that didn't go well but I didn't really I didn't really get it I had no idea what it meant in terms of the journey that she was gonna take through the health system and the sort of things that could go wrong and what actually the nuts and bolts of it I had no idea I knew a bit about the theory because we both studied together we'd study pathology so we knew the name we knew the names of the diseases and we knew what they looked like under our microscope but we didn't really know what it meant for we might even have known the figures for prognosis and things like that how bad is it but no idea what it actually meant and i i was i was the other things everyone's everyone else's life just carries on

especially if you're at university or something like that everyone else just keeps going and you have to take time out to be sick well while you're treated and that's horrible i had no idea that that's the sort of thing she was going through i went away on my elective to study abroad and then i came but and i had absolutely no idea what any of it meant beforehand and it's you know it's so the point there really apart from um the point there really is that even with background knowledge and studying the subject matter i still didn't know really what it meant at all and it's because of that age because none of my friends have gone through it i've not i've just not experienced it it's like you see it for other people like in my training i was you know i could see it but then i i couldn't picture that for myself i was like whoa this is all going to happen to me like this is crazy i don't know how yeah yeah that's it i think it's that sort of lived experience where until you've lived through it you don't know you can't even like really grasp what that means or what that is going to look like and i would say even for sean and i who have walked many journeys along with you guys and other people and stuff i still haven't done it myself so i still am very aware that you know i've only got so much knowledge you know and it's not the real that you guys have had?

No it's all second hand experience but my problem now in terms of medical jargon is I'll make assumptions because most of my patients are older and they do have that experience or you know second hand or lived experience and I can say words like cancer and know what sort of emotional response it will get and know that they understand what it means and then you have to say well okay there's cancer and there's cancer and you know some of them aren't so bad and you can start the conversation from there quite reliably but that's that wouldn't be in the case for me when if I'd been diagnosed at the age of 18 or 19 I wouldn't have known what it really meant for me and I wouldn't have known what chemotherapy entailed again I can say chemotherapy to older patients and they've all they've all got an idea of what they think it means

5. AYA - Why the service was setup - asking questions, advocating for oneself, support for families

Well, you probably did as well, but what did it mean, how did those conversations go, did I make any sense at all when I was speaking to you? You're looking right at me. I'm looking at you. My advice to everyone, watch Grey's Anatomy. I have watched it like twice before I went into treatment. And you answered it as well. That's terrible. Grey's Anatomy. I mean, don't watch Shortland Strange. Grey's Anatomy. Everything that happens on Grey's Anatomy happens in these hospital walls. Yeah, the on-call rooms, they don't exist apparently, but you know, no scandals. I think what I was thinking was...

I didn't have to hate him, no I'm sorry. But, you know, I think that to some extent that is what the whole purpose of setting up the Al Way Cancer Service was. Like... You know, it was about, okay, this is a hospital system or services that are completely designed for the majority of patients, which are those over 65 years of age. So, setting up this service was about addressing that gap and figuring out a way of really adapting it to this age group. And so I guess, you know, one of the sort of things that we'd want to get across is the fact that, you know, that's where I guess people like my role or...

Yeah. ...my role comes to as, you know, part of the service and we've got other people as well. It's people that have done extra sort of study and spent time thinking about actually, just like, what it would have been like and how would I... How do I need to adapt what I do to make sure that you guys get the information that you need, that you're supported, that, you know, you get through your treatment? Because it's actually a massive ask for... It's a massive ask for someone who's had... ...who's had a lot of life experience and ups and downs and have figured out things where quite often, you know, the people that I'm working with that, you know, this is the big...

It's a major hurdle, but this is the big first almost hurdle that they've actually had to come across. And so they haven't had those times to learn from, to figure out, you know, what their coping mechanisms are or any of that. So I think, you know, the key is to know that we're out there to, you know, to ask. I think, you know, like what Nick was saying is, you know, to talk to the people that can give you that information. There's like resources and there are resources that are specifically designed for young people. So it's about getting your hands on them, which we would hope happens really smoothly.

But I think that sometimes it doesn't and you actually, you know, people who are watching these videos might go, well actually I need to ask that question. I need to ask to speak to a social worker. I need to ask to speak to a young person's nurse, nurse, you know, or whatever their issue is. It's, you know, it's hard to speak up for yourself. But, you know, finding someone that will speak up, you know. Yeah, because there's also like the, I mean, in the, every day, every day you have the doctors come round. But they're different doctors every time. So my relationship with Sean is so different.

We just put different hats on. Yeah. For the whole spirit. Yeah. But even that, because it would be like the way you would talk to me would be different to someone else that will come in. So how would someone navigate that if they don't know how to advocate for themselves? Like it's actually really nerve-racking to be like, I have no idea what you're saying. Yeah. Because as young people, I mean, not that we're proud, but we like to, I mean, have an idea if we understand what's going on. I'm really good at just like nodding along. Yeah. And so was I. Like I was like Madagascar penguin like smiling away, you know.

Yeah. Yeah. Yeah. Yeah. Yeah. I mean, I guess I could say like a whole lot of people like advocate for themselves when they are constantly every day, you know, there'll be a different doctor and then the conversation and things they're saying is really different. Yeah. That's what I struggled with. I didn't realise that was how I was going to go down because obviously I had Sean first and I was seeing him for a bit and then I'm like, who's this random man telling me what's going on now? I don't even, you know, like I don't quite understand that part of it. I think I was a little bit wrecked from the water.

Yeah. I was like, you know, you have your days and your rounds but it's like something like I wasn't prepared for, but how can I go and do this? Yeah. Yeah. Yeah. Yeah. Yeah. Yeah. Yeah.

days in your rounds but it's like something like i was prepared for but how can i guess a young person be an advocate to be like i don't understand yeah and i think in some ways it's really hard to expect a young person to be an advocate like and to be able to advocate for themselves and they shouldn't have to and i think that's where like my role comes in like you know that's a big part of my role is that you know actually you guys were all really good advocates for yourself i was there as a support but for some people i actually really have to advocate for them like that is my role like you know and so it's but it's not only just like patience as well i know like for me um i was on the ward for a really long time and i had like a room with a pull-out bed my mum stayed almost every night because of the doctor's rounds you know she wanted to know she wanted to be involved she wanted to understand and like having the aya like you know rooms and then having the space there's like a little lounge in christ church um and so you've got that like family well for me i was fortunate enough to have my family here and wanting to be a part of my journey and really involved yeah so you know and like the aya provided that but not only did you support me and my i kind of had more understanding than like my mom or my dad and my grandparents didn't even know what like we're supporting well yeah they're like what even is this like you know so it was kind of like it's not just like it is it is for us but like you know you're there to ask like any anyone's there to go to you yeah absolutely um and i think that you know that's a really good point that you know we'd want to get across is that you know as young people going into the health system is that you're entitled to have support you're entitled to have a loved one a support person with you you know to to advocate for you or just to support you just to be there because it's a pretty scary play and you know i mean it's like even at my age i think like you know yeah i like you know you like anybody is entitled to have a support person with them and i know in the hospital system we're quite good at maybe not making that as easy as it should be um i think it's getting better i think it's getting really it is getting a lot better um and i think we've done a lot of work for especially for young people um you know that that is the expectation is that you can have someone with you that's and it's had quite a nice knock-on effect for some slightly older yeah um but also young yeah other people that yeah they're still making they're getting the benefit i think you're finally really important i was like say probably all of you i had less to do with you what you guys want as well and you know so it's advocating for that so you know me it really worked for you to have your family with you and have a support person with you but i've definitely had the other side of the coin where the young person's like i actually just i've been living away from home for the last three years i actually don't like the fact that my mum is here 24 7 like you know i've stopped that that that part of my life is finished and so then it becomes my role to have those conversations and to help that young person to sort of navigate that relationship and their independence because that's really important um sometimes it's having conversations with parents to say hey they really appreciate your support and stuff but we've got to remember that they're adults and yeah i found that hard when i because i've lived since 18 i kind of buggered off i worked over in australia and hadn't been home so i mean i got kind of that having mum there kind of overlooking me all the time that was kind of got like the independence had kind of gone and you can't have your arguments you have your fights and all that but end of the day that's family you're you're going to say sorry at one point of the time through the journey you're going to have multiple fights really with them but that's part of the journey really yeah that's beautiful

6. AYA - Is my cancer my fault_

My question was going to be around when you're first diagnosed in my brain I was like thinking I was playing a bit of a blame game with myself like I was thinking I've done something wrong what could I potentially have done that could have been a preventative from me being in this space and I was like was I working too much was I not exercising was I not eating healthy so I guess what I like would have loved or I probably did hear a lot but I wasn't listening because I just couldn't because obviously I had cancer so I'm like nothing you can tell me is gonna make me feel better but what would I guess for someone that is having it being really harsh on themselves like what would what can you guys say like what it's not the person's fault like they've done nothing wrong specifically but when they when they're in that state of mind like what would you guys be wanting to say to that person or tell them she'll be like are there preventatives you know like no is that is that a thing is it just like random we know that we know that there are things that can predispose to synaptic things if you're excited if you're exposed to radiation or previous chemotherapy even that's always a bit of a sobering thought when you're giving you so much chemotherapy but you know there are things that can cause it they're usually things that other people did it's not usually something you did to yourself and and quite often sorry to add to that you guys are almost too young for that yeah do you see what I mean so like that sort of comes into play when you're you know even if you smoked a couple of cigarettes it wasn't going to be that yeah and that thing about you know cancer and young people is that it is it's nothing that you've done because you know you haven't lived enough life yet to have done that you know what I mean like you know even the exposure like the environmental

exposures that we talk about yeah smoking and alcohol and things like that but yeah you know you could there's no way you're gonna manage to have done that to yourself and it's it's just it's really just a bad luck and it's it's a terrible answer it is it's a real one it's it's real it's it's a terrible answer but it's real there's usually nothing that we can identify that caused it and it's a chance occurrence and it's just check it up well I think that kind of like then also leads into how you choose to have your mind set like throughout your journey as well like you know I always have the mindset um you know I've been dealt these really shitty cards this sucks but you know it's how you play them it's how you you know it's you know you can't what's that quote it's like you can't um you can't change the winds but you can adjust to your sails and it's like that's powerful so I think you know it's like that's that's that's also like you know how how am I going to play this game yeah like how how am I going to keep my head on my shoulders throughout it's completely normal to play that blame game so is there something something that I did is there something I could have done to prevent this and the answer is usually no and you kind of talked about um genetics like I know I mentioned that and I wish I hadn't talked about that as well is it yeah well is it an option like if you because obviously my sister went through this so I see my sister with her through her whole journey which Louise also was a part of sister things um is it could that have been an option and is it an option for like after like my baby like she said it now that she's a girl now and I said do you remember that time I said to my dad I was like you've got cursed daughters because and then she gave me like the deadliest look in the world but I was like you know like I'd lost my sister just months before that and then my first sister passed away when I was a lot younger so naturally yeah because but I was like can I break a curse like is there a curse that can be broken can my daughter be genetically tested to see if that's gonna work yeah if we can speak I'm going to speak figuratively like you can see genetically cursed there are there are things that can be classed on that will freeze both cancers we checked I don't really find anything in your case but we know that the BRCA genes for breast cancer things like that that's quite well understood I'm not going to talk about that because I will make up an awfulature man I'm not going to talk about that because I will make up awful men making off my wife for breast cancer.

an awful mess of it I don't know enough about it but there are there are and there are mutations there are genetic mutations that we can identify like p53 mutation for example if you're unlucky enough to be born with one of those then it's more likely that you might develop a form of cancer as you get older there's things that that we've known about for a long time that can predispose to different kinds of cancer we checked and we didn't find anything there are um we've got really uh fancy techniques now next generation sequencing which we'll do on we've got patient with uh leukemia for example um we can we can run those leukemic cells through the machine and uh and get a sort of genetic profile of all that there might be more than one abnormal mutation that predisposed to looking at that particular type of leukemia and if we find it in uh sometimes we can find it in a particular type of leukemia and we can find it in a particular type of leukemia that uh insufficient quantities to be suspicious that maybe it's something that was inherited and we can check for that and I think we did that in your case moving over anyway that's not something for the video I don't think um sometimes we sometimes we will identify things um and then we can go back and we check uh a buckle swab say from the inside of the cheek and just check and see if that mutation is present in the normal cells um and if it's not then that's fine it's not a genetic thing you can pass on if we do find something like that then then it might be something that you that we need to think about for other family members or when you're thinking about having a family so we're increasingly capable of finding things like that now and that that's gonna that's gonna be something that doctors are gonna have to deal with and and learn how to how to communicate that and understand it themselves so that we can you know we can actually move forward but that that's the future or as part of the future for medicine um it's not it's not a blame thing though is it but I suppose if you're trying to understand um what caused a cancer and that's that's one of the avenues we can go down and it's something that we can if we understand it better then we can do something about it in the future but generally speaking the answer to your question is no there wasn't anything you did wasn't anything that you could have done to have prevented it and you did all the right things you you know you presented when you did and

7. AYA - Positive attitude, the support from the AYA team

And you had an incredible positive attitude that helped you get through, and you had the support of your whānau and friends and all of that stuff's just... Also AYA as well, because... Not my place to say that, but I'm glad you did. Because, just to butt in as well, because I had an amazing team, I was really lucky, amazing nurses and everything like that. But Louise came in and wrote down what this means, you know, when I get my blood sheet every morning, with all my levels and everything, she, you know, Googled it, or not Googled it, she knew. I didn't Google! No Googles, nobody Googles. We do Google.

I also didn't go to TikTok, TikTok didn't tell me. Yeah, ask the right people, ask the doctors, ask the nurses, don't just Google and be like... What? Oh my gosh, not only do I have blood cancer, I've got this, this, this, and this. You know, I like, you know, it's us, like, Louise broke it down and said, no, this is, you know, what this is, and, you know, I think that's also, like, fortunate with the amazing team that's over the road, and you guys. You know, being able to ask the question and then having someone actually break it down for you. Yeah. Because I think people walk in and be like, who's going to actually explain this all to me?

And they're there, and you've just got to ask. Yeah. Yeah. I think that sometimes it's finding that key person for you, and that's what I try and be. Like, you know, I try and be that person for you in regards to, like, you know, I'm aware that, like you sort of said, lots of, you

know, it's different doctors all the time that come in and, you know, even for me, it's different. Yeah. Yeah. It doesn't matter how good and how much training or thought and how thoughtful and approachable that you are, you know, that the team are and the doctors are, you're still the person sitting in the vulnerable position, usually in a bed.

And, you know, it's really hard to talk for yourself when you're that vulnerable. And, you know, I'll have young people that are like, oh, I've got all these questions, so quite often I'll be like, right, write them down, let me know them. So that I can make sure if I'm sitting there. So that I can make sure if I'm sitting there with you that those questions got answered, because like you said, you'll get bombarded with all this new information, and then you'll forget to ask the questions that you needed to ask from the last time that you were seen. And I think that whole writing down questions and taking them with you is important, but also making sure that there's someone else that knows that those questions are wanting to be asked.

Or even sometimes I'm like, if I can't be there, I'm like, actually, there's no harm in you starting off if you can. You starting the conversation and say, hey, you know, when you're at your clinic, I'm going to be there. You know, when you're at your clinic appointment or whatever, it's like, well, I've just got these questions, can we answer these first before you can make any more? When patients come in and the first thing they do is they pull a notepad out and they're like, okay, you got some questions? You look like you've got some questions. And that's why it's just physically producing a piece of paper, even if there's nothing written on it.

That would do it.

8. AYA - Asking the internet_

i was gonna say i found i know you can't trust everything on the internet but i a lot of the time when i went through it i actually looked on the internet through like actually cancer research in new zealand australia uk america and kind of researched what what a pet scan was or a ct scan or abvd what are they actually the formulas of that sort of stuff and all that there so you can trust yeah trust the internet and yeah the truth is out there somewhere yeah no there's some brilliant search engine we use them yeah google stuff all the time as long as you know what you're looking for there's a lot of good stuff out there and if you've got enough of a background in it it's quite easy to navigate what's what's reading and what's not uh if you have less of a background then you you might it's unfiltered and you get stuff that's maybe not relevant and using stuff that you discover um treatments that we can't give you because it's just not available or it's actually not the treatment that would work for your type of cancer well such a massive range of yeah and drugs especially the newer drugs that are coming out are so specific to what they'll work on and i think that is the biggest thing that i come across i'm coming across now as young people is that they'll be like you know or usually their family members it's not so much them but the young people themselves are quite seem quite um as well because you know they feel comfortable that we've got their best interest and we're going to you know what we're suggesting is you know the best that we think for them quite often it's family members or friends or something that like i've found this on the internet i found that on the internet and that can be really overwhelming and it's like we're here like we know that that goes on so bring it to us we're gonna we're gonna look into it we're gonna chat to you about it if you find something really distressing or confusing on the internet like you know bring it to us we'll talk about it so to summarize don't trust the internet 10 minutes use the internet it's a great resource that's what it's for and we use it as well um but yeah if you find something you'll find all the stuff that we do is evidence-based and you'll find it on the internet it's there it's all there and there's some brilliant resources um but if you want to start with the trusted sites like uh leukemia about cancer in new zealand for example that's a good place to start because they've actually filtered out the stuff that's that's worth reading there's some really good stuff for that and young adult camp network i said oh they've got a website and that's all designed for young people like you know and with links off and stuff and canteen um click here to find all the links to all the resources that are available to you love it you're fired i was gonna say it's okay to see me orange today i just let you all know i do lots of filming jobs going on so this is not my first radio

9. AYA - The treatment plan changes – trusting the process

I was gonna say as well um Louise what you said as well um like a little bit further back was uh for me when I got diagnosed I had like a treatment plan mine changed completely from that original treatment plan and it was just evolving the whole time yeah and it like I mean I definitely did the hard road not the easy road um but I think also being like adaptable yeah um to change as well was hard um but with the right support and everything it's like you know and I think that that's I mean I think it's hard for I think understandably it's hard for young people to trust like you know because once again trust is something you develop over time like you know and over life experience yeah and I think that you know like we said earlier this is the first time usually the first big major hurdle that you know someone's come up against and it's massive and um and so we will come in as trying to be as reassuring as we possibly can but everybody is different every young person's journey is different and I think I've used as I say to most people like you know I can have three people sitting next on a couch opposite me who have the same diagnosis at the same age and we get the same drugs too and they will all have a different journey and experience with that they will probably have different side effects they will cope with it differently and their journey will have to be adjusted based on how their body responds and how they as a person respond to it it's

nothing that they do or don't do it's just we all our bodies are all unique to us and and the cancers are all different as well and we get so much information out from all those molecular tests we can not we can almost predict which is find scary um but you know for example um the treatment algorithm for your type of leukemia we've shown you that at the start maybe and and it's an algorithm that sort of it branches and there's all sorts of different yeah it's all over the place and it's like if this happens then that happens and then if this happens then we do that but we don't do that but there's no what ifs no yeah no but um but at the start it's all what if it's a what if that happens and you can start off and go well I hope I go down that rate yeah yeah that looks like the shortest and easiest one yeah and then things change and that's going to inevitably because you can see on that map which way things are going it's like oh god we didn't want to do it it's more or say what if nothing goes wrong yeah I'll be out of here in like what did you say like a year and a half it's almost like there's too much information yeah I didn't want to know that at the start I just wanted to know you know we could maybe fix it yeah and uh we'll just do our best and see what happens and that used to be like that yeah so now we've got so much information yeah it's and the treatment the treatment's got better yeah it's got better through research

10. AYA - Mia, Nic and Toihi key messages

My cool quote? I actually hadn't written enough on my whiteboard for like, I had like rotating quotes. Sounds like it should be in three. Yeah, you can translate. Can you do it? No, not right now. Write it down. I think my, um, my key thing was um positive positive outlook looking forward, positive mindset, like I had a goal, I'm gonna get through this. It's gonna be hard and it's gonna be probably the hardest thing I've ever done in my whole life, but there's gonna be an end and it's gonna be long but, buckle in. Let's go for a ride! It's a marathon, not a sprint. Settle up! Take it easy.

Don't, don't don't let it weigh down on you, just you know, look forward there's, yeah, it it gets better it does, it's bumpy but it gets better, it's hard work, and trust the process trust the people around you all of that, there's you know, I think you said there was light at the end there's light there's a lot at one of the ends of the tunnels don't walk towards it don't walk towards it, but just like look at it and think, I don't wanna go there no, no I mean, I mean what I was trying to say is it gets better, but you know, don't be so hard on yourself there's really down times, and you've just gotta take it easy and just you know, ride the wave it gets better I think that's yeah like, it gets better there's people to ask questions to trust the process what will be, will be yeah nice Mikey takeaways um Mikey takeaways um, just do your best being an advocate for yourself if you feel something is wrong, there's probably something wrong if you go to the doctor and they tell you they think you're all good, don't take it um, keep going back keep pushing because, you know, that's the best you can do for yourself and yeah, trust the process lean on to the people that are around you there will be lots of people lots of people you haven't talked to in a long time message them back reform that relationship if you have family if you have whānau and you are in a culturally safe environment there are people on site that will come and do a karakia for you if you need it as well um, and yeah that's probably Mikey's takeaways I was gonna say the girls have kind of answered it very well for me really it's just trusting the process again and just being positive on the outcome and all that sort of stuff and just always look forward and have the family support really, and friends I think, like, just leaning on having a support system and if you're if you don't have the support system there are people that will fill that for you as well and not to think you're doing it alone because you know, it's hard but you can do it and don't be afraid to admit you're afraid of needles because I am definitely afraid of needles and Louise hooked me up, and Sean and they were able to get me under GA for basically anything I ever needed you know, yeah that's very important so if you're afraid of needles don't worry, it's not too bad because they'll hook it up for everything that didn't even work here straight GA everything I got the sleeper lock yeah that was me with my Daz I was like, my Daz me up yeah, my Daz me up Daz is good I just always got told two nurses would come in one would distract me and they would jab me and then walk off and I'm like, oh, I got jabbed you didn't have the virtual reality headset on at the time no we used to do that we couldn't find it yeah, there's lots of things that we can what did Alex say it's not so much a take home message it's a huge, huge privilege to be able to look at these guys yeah, medicine is quite interesting the diseases are quite interesting but the best thing about medicine is the patients and that's what it's all about you're welcome I would probably echo what you guys have said, it's just like a process but I'd say trust the people even if you're always going to gel with some and not with others that you come across as part of your medical team but I truly believe that everybody who works in the healthcare setting is there because they want to do well for you and they want to have a good outcome for you and they want to make it easier and I think that it's really hard to trust but I definitely know that all the people that I work with they just purely are doing it for the patients and it is, it's an honour an absolute honour thank you and this has been an honour I think we rambled so much and next time on the podcast something more