



WEIGHTLIFTING

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ONE IN 10

It's a lifelong inflammatory condition that takes an immense toll on physical and mental wellbeing, yet many of those with endometriosis continue to suffer in silence. Nicole Saunders investigates Aotearoa's devastating endometriosis epidemic.

PHOTOGRAPHY STEPHEN TILLEY

With an estimated one in 10 women, girls, and those assigned female at birth suffering from endometriosis, this is a chronic health condition that significantly affects New Zealanders' physical and mental wellbeing. Despite endometriosis affecting 10 per cent of those assigned female at birth, it's an invisible disease – with many suffering in silence from debilitating pain for years, or even decades, before receiving a diagnosis.

Tash Crosby, the founder of Talk Peach Gynaecological Cancer Foundation, recalls the pain she experienced throughout her teenage years and adulthood: "I constantly had back pain, fatigue, pelvic and abdominal pain that left me curled up in bed, unable to move." But as many young women do, Crosby brushed off her period pain as 'normal'.

Edie Carrie, who recently underwent surgery to remove stage-four endometriosis from her ovaries, bowel, the lining of her abdomen, and pouch of Douglas, recounts pain so severe that it started affecting her relationships and her overall quality of life. "I just started retreating," says Carrie. "My intimate life suffered too. Sex became quite painful. It was very difficult trying to navigate that with a partner; it wasn't easy." Yet Carrie continued to go about her day-to-day, putting up with the pain, calling in sick to work, and cancelling social plans when it got too hard to cope. "For the longest time, I thought I was overacting and crazy," Carrie says.

It's a common thread and one that doctor Michael Wynn-Williams, an Auckland-based gynaecologist and advanced laparoscopic surgeon, hears frequently. "There's a huge genetic component to endometriosis," explains Wynn-Williams. And for many suffering from the condition, this idea of 'normal' period pain has been passed down through

generations. "It's what they see as normal within their family. They see their sisters, mothers, and grandmothers experiencing severe period pain and think it's normal."

But what is 'normal'? And when should you seek help if you think the pain or symptoms you are experiencing are not within the realms of normal? Wynn-Williams says that it's not uncommon, for those who menstruate, to experience some mild period pain from time to time, but what is considered 'normal' period pain can be relieved by over-the-counter pain relief. "When the pain is affecting what you normally do; for example, if you're young and can't do sport when you have your period, or you're taking time off work or school. When the pain impacts your enjoyment of life, and simple interventions aren't working, seek help."

A SILENT CONDITION

Knowing where to start or who to turn to for help can be overwhelming for many. In this day and age, the plethora of information available with a click of a mouse can be mind-boggling, to the point that simply understanding what endometriosis is can be difficult. "Endometriosis is an inflammatory condition where cells like those from the lining of the womb end up outside the uterus," explains Wynn-Williams. According to Tanya Cooke, chief executive of Endometriosis New Zealand (ENZ), endometriosis is generally considered to affect people in their reproductive years. "For some, it can be as early as their first menstrual period, whereas for others it could begin to occur much later in life and the effects sometimes continue beyond menopause," she explains. Symptoms can include pain with periods, pain during or after sexual intercourse, heavy bleeding, chronic pelvic pain, bowel problems, fatigue, and fertility problems, and it can have an impact on general physical, mental, and social wellbeing. "Some people won't experience any pain or symptoms. About a third of patients with endometriosis may experience difficulty or delay in getting pregnant," Cooke says.

As for how many Kiwis endometriosis affects, according to ENZ, there are over 120,000 people living with endometriosis in Aotearoa. "It affects one in 10 of those identified as female at birth," says Wynn-Williams. Though, he says, recent research has found that the number in Australia is more like one in nine.

However, in Aotearoa, Wynn-Williams says endometriosis research is sparse, particularly concerning Māori and Pasifika communities. "There are significant access issues and differences in ages that these patients are presenting. I see lots of younger, white women getting treated, and I see older women who are Māori and Pasifika who have



JADE KAUKAU

Ngāti Kahungunu

Stage four

Jade first realised something wasn't quite right after coming off the contraceptive pill when they were 19. "I was walking home from work and felt my ovary 'pop'. I immediately told my mum, who had been in her 30s when she had a full hysterectomy, and she said I needed to sort it out straight away. She made sure I pushed for a referral."

Getting diagnosed while Jade was just entering adulthood was tricky to navigate. "I was trying to figure out who I was and what I could deal with as a 19-year-old, trying to figure out how to deal with a chronic illness and take it seriously while enjoying life in my early 20s."

Surrounding themselves with people who could understand and accept Jade's journey with chronic pain has been something they have learnt to embrace along the way. But as Jade identifies as takatāpui – or non-binary – they explain finding a space within the endometriosis support world has taken time, and often they've needed to forge and foster those communities themselves.

"A lot of stuff to do with endometriosis is very pink and feminine, and I understand that people need that messaging, but many people I know are trans or non-binary and have endometriosis."

While Jade says every endometriosis journey is unique, being trans or non-binary adds another element of complexity.

"The whole situation is different. There are different challenges. There are layers to it. And there's often transphobia. It's hard to feel comfortable."

Now stage four, Jade says their endometriosis experience has been one of constant learning. "I had a third surgery last year, and that's when I found out about the pelvic floor. But it took nine years for a doctor to tell me the pelvic floor is related to endometriosis. I felt like I knew all there is to know, but I learn something new each day."

Although navigating each new chapter of their endometriosis journey has its challenges, Jade is upbeat and positive. They hope their looking-on-the-bright-side approach might encourage others suffering from chronic pain conditions to seek help and talk about what they are going through. "I don't want my story to come across like it's been so traumatic and for other people to be afraid. You can talk to me, you can DM me. People need that positive reinforcement. We need to laugh. Everyone who has endo, we all have those hard days but sometimes you need to just spin a yarn with others who understand what you're going through."

struggled their entire life and have tried to get access to treatment without success,” he says.

Wynn-Williams says it’s not an issue that’s easy to unpack. Cultural differences – the taboo of menstruation, access to primary and secondary care, and distrust in the healthcare system – play a role. “But we don’t know; this is all anecdotal. We need more research and more money spent looking at these communities,” he says.

THE GENDER PAIN GAP

It’s not exactly breaking news that there are massive equity issues concerning medical research on women’s health. Although many sufferers still contend with outdated notions of chronic pelvic pain, Wynn-Williams remains positive that change is afoot. The All-Party Parliamentary Group on Endometriosis in the UK was launched in 2018, and its goals are ambitious. According to a recent New Zealand study, the delay in diagnosis averages almost nine years. It’s a similarly heartbreaking statistic around the globe. Still, impressively, the UK parliamentary group has made a commitment to reducing the delay from eight years to four by 2025 and then to one year by 2030.

Closer to home and across the ditch, the Australian Government has started to shine a light on endometriosis. In recent years, there’s been a public apology to people living with endometriosis from the government; a national action plan to improve the treatment of endometriosis; and, more recently, an A\$58 million (approximately NZ\$65 million) commitment to support those suffering from the condition.

Wynn-Williams believes that, here in Aotearoa, dismantling individual DHBs and introducing Te Whatu Ora – Health New Zealand will improve access to care for many. “In New Zealand, we need a national action plan,” he says. Currently, he explains, each DHB has a different referral process. “It needs to be consistent throughout the country. GPs need consistent referral pathways.”

THE PAIN-ANXIETY CYCLE

We still don’t understand much about endometriosis, particularly when it comes to the pain. Another puzzle affecting people living with endometriosis is that pain is not always related to your menstrual cycle or the severity of the disease. “There is poor correlation between the severity of the disease and the symptoms,” explains Wynn-Williams. “We understand that the disease has a genetic component; it has something to do with your immune system and potentially has something to do with stem cells. There are a whole lot of factors that cause endometriosis, but ultimately we don’t know. If we knew we would be able to fix it.”

Then there are the complexities of how our bodies deal with pain, which Wynn-Williams says are still a big mystery. “Any pain experienced is not as simple as ‘I prick my finger; I feel pain’. It’s related to many other things – what my mood is like, how much stress I’m under, how happy I am; all these other experiences in my life reflect on my pain experience.”

Wynn-Williams says that it’s common for those suffering from chronic pain to doubt their experience. “It’s very much an evolutionary thing to how your body deals with pain. Your body wants you to forget the pain.” And for

those with endometriosis, because it can be hard to remember their last period: “They start thinking: was it that bad? Was it all just in my head?”

Ironically, the longer you experience pain, the more likely your central nervous system will rewire itself. “Some people, when they experience pain repeatedly, experience changes in their central nervous system. And you get physical changes you can see on an MRI,” explains Wynn-Williams. While this doesn’t happen to everyone suffering from endometriosis, central sensitisation can occur. “Central sensitisation occurs in the area of the brain near where anxiety and depression occur. The neurochemicals are very similar and start feeding off each other, making your anxiety worse, your depression worse, and your central sensitisation worse. It’s a spiral,” he explains. “If you can’t reach your full capacity, whether it’s fertility, finance, education or career because you have this pain, imagine how that will affect your mental health.”

Wynn-Williams is not wrong: while the pain can be crippling, the impact endometriosis has on the mental wellbeing of those living with it is devastating. “People contact ENZ every day, desperate for help with nowhere else to turn,” says Cooke. She references a recent study, An Aotearoa New Zealand Survey of the Impact and Diagnostic Delay for Endometriosis and Chronic Pelvic Pain, which details the immense toll that the condition takes on people’s livelihood. Eighty-one per cent of respondents avoided sex because of chronic pelvic pain, and 73 per cent of respondents were afraid to tell their employer about their pelvic pain because they feared it might affect their prospects.

LOOKING FORWARD

It’s a complex condition that desperately needs more government funding, research, and attention, but, unfortunately, there is no quick fix for its sufferers. While laparoscopic surgery can help, it’s not a silver bullet. Because of this, Wynn-Williams is a proponent of an interdisciplinary approach to managing endometriosis: “We need to build endo clinics in New Zealand that involve a gynaecologist, endometriosis nurse, pain psychologist, pelvic physiotherapists, pain specialists, and even psychiatrists in some cases. We need specialist units to help these people with multi-organ difficulties.” Wynn-Williams says that the seedlings for such clinics in Auckland have been planted.

Meanwhile, many suffering from endometriosis and chronic pelvic pain will continue to advocate for themselves. “I wish I could tell my younger self to advocate more. Not even just to my GP, but to my friends, to my family. That way maybe I would have got a diagnosis earlier,” says Carrie. Yet, as Crosby reminds us, campaigning for your health is a privilege: “It’s not afforded to everyone. This is why it’s important we are having these conversations. If people can recognise things within themselves through someone else sharing their story, that empowerment helps them feel more confident seeking medical advice.”

TO FIND OUT MORE ABOUT ONE IN 10
VISIT [FQ.CO.NZ/ONEIN10](https://fq.co.nz/onein10)

EDIE CARRIE

Stage four

If you were to pass Edie on the street, it would be impossible to tell that the upbeat 25-year-old had, just three weeks ago, undergone surgery to remove extensive stage-four endometriosis from her ovaries, bowel, the lining of her abdomen and pouch of Douglas – the small area between the rectum and the uterus.

Edie's endometriosis journey is one-of-a-kind, but heartbreakingly, there's a common thread that entwines her story with those of other endometriosis sufferers. Despite Edie's mum, who was diagnosed with endometriosis just a few years ago, her aunt, and other family members suffering from

severe period pain and heavy bleeding, it wasn't something that the women in Edie's family discussed. "I just thought it was normal; no one spoke about it," Edie says. "I recall thinking, all of the women in our [family] have heavy, painful periods from time to time; it's just something we have to deal with."

Despite frequently flooding her bedsheets and clothing due to 'torrential' bleeding, Edie kept quiet. "I felt ashamed of it," Edie says, while admitting she would often find herself in debilitating pain and struggling with the mental anguish that endometriosis caused her: "Everyone else had normal

periods. Why couldn't I control the bleeding? Why couldn't I keep it together?" At times,

Edie even convinced herself that she was overreacting or that what she was going through was all in her head. "I just suffered in silence for quite a while and soldiered on because I felt like that was what I was meant to do," she says.

After a while, Edie was able to open up to her aunt – a fellow endometriosis sufferer – who encouraged her to push for answers and a diagnosis. "There's this cultural taboo that's stuck since the beginning of time," Edie says. "But it's OK to talk about blood, periods, and pain. And when you do, you'll probably find that someone you know has a similar experience. We need to start vocalising the issue more. The more I spoke about it, the more comfortable I got. It's something we need to get more comfortable talking about. It's part of being human."



KAARINA RANGI PARKER*Ngāpuhi**Stage two*

Kaarina's story — a drawn-out and at times discouraging journey to get a diagnosis — will, without a doubt, resonate with many people with the chronic inflammatory condition.

"I had never heard of endometriosis," she says, "all I knew was I was in a disproportionate amount of pain, and it came to a head when I was around 24 years old because it was becoming difficult for me to work and function."

At first, Kaarina assumed that she was having some other abdominal issues — one pain flare-up was so bad that her doctors thought she had appendicitis. "But I didn't. And I was bounced around four specialists before I saw an OB-GYN, and she diagnosed me with endometriosis, which I had never heard of at the time."

"The impact on my mental wellbeing was quite severe," says Kaarina. "At first, when I didn't know what was happening to me, it made me very depressed not being able to work or do normal things when I had my period." And, although a diagnosis often provides solace to many, Kaarina found that her depression very soon morphed into crippling health anxiety. "I found I had health anxiety because doctors would tell me everything was fine whenever anything was wrong with me, and I would think, *Oh, I've heard that all before, so what's going on,*" she explains. "Small problems became blown out of proportion in my head." As a result, Kaarina admits she found it very difficult to trust the opinion of a single doctor. "It's been a hangover of this whole experience."

Kaarina says that her health anxiety is something she's still working through, but there are some learnings she would like to share with others who are in a similar boat: "Seek out medical practitioners that have an empathetic approach, that aren't dismissive, who listen, who may have had similar experiences. Finding people I can trust has made a huge difference to me."

Today, Kaarina has found a gynaecologist she trusts, and she says she's learned a lot from her. "The biggest myth about endometriosis I would like people to unlearn is that pain is normal," she says. "That's something my specialist taught me; she taught me if your period pain is impacting your ability to function, then that is not within the parameters of normal."





TASH CROSBY

Stage four

In 2016, at 36 years of age, Tash Crosby was convinced that her endometriosis was back with a vengeance. After having stage-four endometriosis removed three years prior, the nagging pain that Tash had experienced was plaguing her once again. "When things started feeling off with my body again, I went straight to the doctors," Tash explains. "I told them my endometriosis has grown back, and I want surgery to remove it." Her GP examined her abdomen and pelvic region and agreed that something wasn't right, which prompted a call to the hospital. Although the hospital declined to see Tash, her GP was still concerned. "He said, 'If you feel off in the weekend, I want you to take yourself to the emergency department', so I did." But it wasn't until her third visit to the hospital that Tash's pain was taken

seriously. "We were frustrated, so my mum said put on the waterworks. I finally got sent for a CT scan after having a big cry, and that's when they picked up a suspected tumour on my ovary, which led to a diagnosis of ovarian cancer."

Fortunately, Tash was diagnosed with stage-one ovarian cancer, which is incredibly uncommon. Due to vague symptoms that mimic more common and less life-threatening conditions, ovarian cancer is often diagnosed later, once it has already spread.

"My experience with endometriosis is unique because, in the end, endometriosis is what saved my life," says Tash. And, while the constant doctor's appointments and time spent searching for a diagnosis caused Tash much anguish and frustration over the



years, she says that her immense experience advocating for herself within the health system motivated her to keep pushing once again when the pain returned.

Tash's personal experience with advocating for her health inspired her to do something with all the knowledge she had gained and, today, Tash heads up the gynaecological cancer charity Talk Peach. Nothing is taboo in the Talk Peach world, and that's just the way Tash feels it should be throughout Aotearoa. "We are super positive about discussing anything to do with vaginas, vulvas and uteruses; there's no shame," she says. "Because it's those conversations that have the potential to save lives and empower people to advocate for themselves."

TANNE SNOWDEN*Stage four*

Tanne, now 32, realised that something wasn't normal with her periods from a young age. Although she saw doctor after doctor over the years, it wasn't until she was in her mid 20s that she heard a medical practitioner say, "I think you have endometriosis". Like many searching for a diagnosis, Tanne tirelessly pushed for answers. "No matter what doctor I went to, I would always hear the same thing: take some Panadol, you'll be fine, you're not different from anyone else." But the chronic pain — so severe that Tanne would pass out or fall to the floor in agony — became too much to bear. "I was about 14 when I thought, how will I do this for the rest of my life? I felt like I was by myself. There was so much taboo and shame around discussing your period; you didn't talk about it." Tanne underwent a five-hour surgery in 2013 to remove endometriosis. But she was puzzled and overwhelmed by guilt when the pain returned just three years later: "I found myself asking what had I done wrong?" Endometriosis was taking a toll on Tanne's mental wellbeing once again. Of course, there wasn't anything she could have done to prevent what was going on with her body: a 6cm endometrioma (a type of endometriosis-related cyst) was growing on her left ovary, and her fallopian tube had managed to wrap around it, pull it down, and become attached to her colon.

With a second surgery looming, Tanne once again grappled with the emotional distress endometriosis causes. "You start thinking maybe it's all in your head because that's what I had been told for so many years," Tanne explains. At this point, Tanne was told that a hysterectomy might be the only option for her — something she says she wasn't ready to consider at 28 years of age. Fortunately, Tanne's second surgery — which took over eight hours — was a success, and her surgeon managed to save all her reproductive organs bar a sliver of one of her ovaries. "It was very cathartic to hear that you're right, a lot is going on, and we've removed those problems."

Although it's taken time, Tanne says talking about what she has gone through and finding a support network that understands how her pain affects her life has helped her heal and move forward. "Before I knew about endometriosis, I thought I was one in 500 or one in 1000. I didn't know anyone else was going through what I went through. I'm glad there are so many more different options now for people to seek advice and not feel alone. They are one in 10."





WHERE TO GO FOR HELP

Cooke suggests visiting credible websites and social media platforms, such as ENZ's website, nzendo.org.nz. "Individuals living with endometriosis and their friends, whanau, colleagues, and partners across the country can browse categories looking for the information and contact ENZ for more specific information via submission forms. The website is a vital source of information for individuals when they are struggling to navigate their endo journey."

ENZ also provides 'Endo Helps': free 30-minute support appointments made available to anyone wanting more information on endometriosis in New Zealand.

To learn more or donate to ENZ, visit nzendo.org.nz.

NICOLE SAUNDERS

Stage three

I detest the word 'normal' – what is normal? It's not something that's possible to define; there is no normal, and the word needs to be erased from our vocabulary, particularly when we are talking about bodies, pain, and menstruation. It's a word I tired of hearing over the years, yet it's one I heard frequently as I searched for answers. From a young age, I didn't understand what was going on with my body, and, like many young people, I was told the pain was normal – take some Nurofen and get on with it, or if it's really bad take the day off school and you'll be right. So, like the majority of the those living with endometriosis do, I soldiered on through my teens and into my 20s, and, as many with pelvic pain are, was advised to take the contraceptive pill by my doctor. For years it was OK, and it did help. I skipped the sugar pills and didn't have a period and thought that's the end of my story. But after a while, the pain came back. And it wasn't just pain with my period; there was pain in my ovaries, pain with bowel movements, pain with urination. And it wasn't just when I had my period; it was

most days of the month.

By the time I was in my mid 30s, my pain had come to define much of my life, and although deep down I knew that something was wrong, it wasn't until I was 34 that I heard the word 'endometriosis' while visiting a doctor.

There was such big period anguish for me. It's something that's hard to talk about, and it's something that a lot of women and people with endometriosis go through – not having a diagnosis, and not knowing what's wrong with your body and why it's doing this to you. You get told it's all in your head. You get told, 'deal with the mental-health side of things', and that takes a huge toll. You start to believe that it is all in your head or you start thinking, *No one can tell me what's wrong; it must be the worst possible thing imaginable*. Your mind goes to these really dark places.

At the same time that I was trying to manage my pain and get answers, my partner and I decided we wanted to start a family. We decided to take a two-birds-with-one-stone approach and see a fertility specialist, but it was incredibly deflating. I learned that my

egg reserve was so low, menopause was imminent, and IVF wasn't likely to be successful. Starting IVF didn't seem like a plausible solution to my chronic pain, so I sought a second and then a third opinion. My diagnosis at 36 years of age came as a huge relief. All the pieces of the puzzle fell into place. You go through this period of self-doubt and get told, 'listen to your body, trust your body'. The truth was, I couldn't trust my body, because at the same time I had been told this pain was normal, and to 'work on your anxiety or depression'. But it's such a vicious cycle; the chronic pain feeds the anxiety and depression, and vice versa. While I wouldn't change my journey – my boisterous son is about to turn one in days – I do wish my younger self had the courage to talk about she was going through. Talk with your family, talk with your friends, talk with your doctors. Our experiences are all so unique, but I believe that the more we share and the more we get the word out about endometriosis, the more progress we will make with it. We can empower one another to get answers and to manage pain.

Health Insurance MYTH BUSTING

If the thought of signing up for health insurance leaves you feeling perplexed, we've answered some common questions and concerns to make it all a whole lot easier.

Myth: I won't be able to get coverage because I've already been diagnosed with endometriosis or another condition.

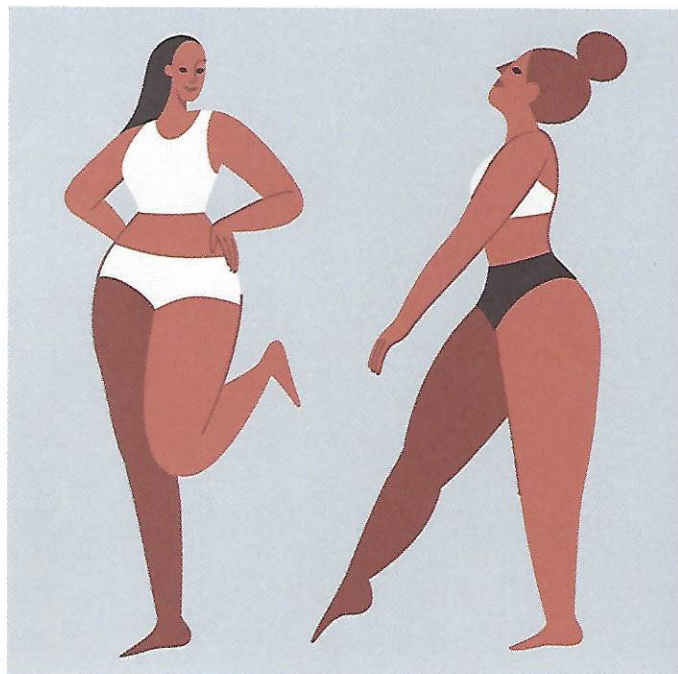
Many of us consider health insurance a safety net for those curveballs life can throw at us. But for those with already diagnosed conditions, the thought of seeking health insurance can be a little nerve-racking. nib knows all too well that pre-existing conditions can often present a hurdle where health insurance is concerned. To put it simply, a pre-existing condition is any injury, illness, symptom, or diagnosis that happened prior to starting your health insurance policy. Pre-existing health conditions shouldn't be a barrier to getting health insurance, which is why nib chooses to cover many pre-existing conditions. Once you've been with nib on either Premium Hospital or Standard Hospital cover for three years, many pre-existing conditions are covered, allowing you to claim on them in line with your policy terms, just as you would with other new unexpected conditions. If you're unsure whether your particular condition may be covered, or want to understand how you may be affected by a waiting period, talk to one of nib's friendly insurance specialists today.

Myth: My preferred health specialist isn't part of nib's First Choice network, so I will need to choose a new specialist.

The nib First Choice network was created to help anyone who has a health insurance policy with nib access Aotearoa's leading health partners who help to deliver the best value. To be part of the First Choice network, nib vets each healthcare provider to ensure that they charge fairly and are able to provide a hassle-free claim experience. nib knows that visiting a healthcare provider you trust and have good rapport with is important. While many of Aotearoa's leading healthcare professionals are part of the network, having the choice to see who you want is important. When you sign up to a nib health insurance plan you can opt to see any specialist – if the specialist you choose isn't in the First Choice network, nib will still cover eligible costs in line with your policy terms but you will need to pay any difference between the fair market price and their fees. Visit provider.nibfirstchoice.co.nz to find a specialist near you.

Myth: My life is already so busy! It's too time-consuming to set up health insurance and make claims.

nib understands that your life is already hectic enough without having to worry about health insurance. With this in mind, nib aims to keep everything as hassle-free as possible. From their knowledgeable insurance specialists, who will talk you through



coverage and any questions you might have, to a seamless claims process, nib makes signing up for insurance and claiming easy for you and your loved ones. At the end of the day, health insurance should give you the confidence to live life to the fullest whilst resting assured that you have cover should the unexpected occur. And if you visit one of nib's First Choice network providers, it can manage your claim with nib directly, letting you focus on your recovery.

Myth: I'm young and healthy enough! I don't need health insurance, and besides isn't that what our healthcare system is for?

Health insurance doesn't replace Aotearoa's comprehensive public healthcare system; instead, it is designed to complement it. Most of us believe that the unthinkable will never happen to us, but health insurance with nib can give you extra peace of mind when you need it the most. You can relax and live your daily life knowing that you're covered should the unexpected occur, and it also could give you the flexibility to decide how, when, and where you receive treatment you require.

Myth: Health insurance is for emergencies and serious health conditions only.

Health insurance should never be about an ambulance-at-the-bottom-of-the-cliff approach. Fortunately, nib takes wellbeing seriously right from the get-go. In fact, nib is committed to helping its members live healthier, more fulfilling lives. To make this possible, nib offers a comprehensive range of Health Management Programmes that are free to eligible members. The programmes – which include Healthier Joints: Pain Management, Healthier Heart, and Cancer Care – take a proactive approach to managing health conditions and symptoms, which might reduce the need for invasive treatments.

Health insurance should give you the confidence to live life to the fullest whilst resting assured that you have cover should the unexpected occur.

Visit nib.co.nz to arrange a callback from one of their helpful insurance specialists. They'll answer any concerns or questions you have and will make the sign-up process seamless and hassle-free.
nib.co.nz | 0800 123 642