

**“It is
devastating”**

**‘Patient co-payment’
prescription fees and their
effect on communities,
as witnessed by
community pharmacists**

Title

“It is devastating”: ‘Patient co-payment’ prescription fees and their effect on communities, as witnessed by community pharmacists

Published by the Independent Community Pharmacy Group (ICPG), New Zealand.

CC BY-NC-SA
April 2023, ICPG

This publication is licenced under the Creative Commons Licence CC BY-NC-SA, which allows reusers to distribute, remix, adapt, and build upon the material in any medium or format for noncommercial purposes only with attribution given to the creator only. Modified material must be licensed under identical terms.

Report prepared by Janet McAllister with data supplied by ICPG and the Prescription Access Initiative.

The publishers wish to thank all the pharmacists, technicians and assistants who took the time to respond to the survey so quickly, with such thoughtfulness, care and perception about their communities.

Thanks also to Vicky Chan, Karen de Roo, Jane Peng, Gemma Perry, Charlotte Schimanski, & Lanny Wong for coordinating the survey and to all the pharmacists who shared and promoted the survey.

The Independent Community Pharmacy Group (ICPG)

Established in 2021, ICPG is an Incorporated Society representing 115 independent pharmacy owners across Aotearoa New Zealand.

Our purpose is to promote, protect and improve owner-operated community pharmacies in New Zealand.

The Prescription Access Initiative (PAI) is a group of passionate pharmacists in Aotearoa New Zealand who:

- care deeply for whānau and our communities;
- believe that all people should be enabled and supported to have the highest attainable standard of hauora, health and wellbeing;
- and work to empower all people to exercise choice, and have access to the highest-level medicine-related care in Aotearoa.

The Prescription Access Initiative is currently working to enact change around 'patient co-payment' prescription fees in Aotearoa New Zealand.

It makes me feel defeated sometimes. I can't make a difference if the person needing medication cannot access it.

Location undisclosed

Contents

01	Foreword
03	Contents
05	Executive Summary
07	Introduction
10	What community pharmacists see: Initial responses and effects Patients affected ¹⁰ Patient responses to unaffordable prescriptions ¹² When patients are children ¹⁶ Communication with healthcare professionals ¹⁸ Community pharmacy responses ²¹

[During the cyclone-related prescription fee waiver], patients were happier and were more engaging, asking more questions about their conditions and medications, and were eager to get better.

Northland

Contents

23	Outcomes of the prescription fee
	Effects on patient outcomes ²³
	Effects on whānau ²⁷
	Generation of Shame/Anxiety/Anger/Despair ³⁰
	The effects of system confusion/complications ³³
	The effect on higher income people ³⁶
39	Our vision - Aotearoa New Zealand without the prescription fee: better, more equitable healthcare

EXECUTIVE SUMMARY

Access to necessary medicines and healthcare in Aotearoa New Zealand, is blocked for many by the “patient co-payment” prescription fee. This government fee – targeted to most patients aged 14 years and over, usually \$5 per item – has recently been shown to significantly increase the number of people admitted to hospital.

It is heart-breaking to see patients trying to choose which medicine is most important.

Auckland

This report shines new light on how some of these preventable hospitalisations come about, as well as less visible effects of the fee, by presenting survey responses from community pharmacists about the prescription fees' effects on their own communities.

Pharmacists told us that the patient co-payment prescription fee has contributed to:

- Patient outcomes such as stroke, heart attack, sight loss, failed kidneys, and amputations (including amputation leading to job loss)
- Patients having to go to hospital due to breathing problems, mental health crises and infections requiring IV antibiotics
- Family stress, including exacerbating abuse and violence; and (separately) families having to choose between medicines and food
- Patients feeling ashamed and whakamā about not being able to afford the fee
- Doctors and other prescribers making treatment decisions without receiving vital information about how prescribed medications have been taken, if at all.

Even for patients who can afford the fee, pharmacists reported the fee and its complexity led to deterioration of patient-healthcare professional relationships, and negative patient experiences of the health system (associated with worse outcomes for patients).

It takes away from the real part of my job when people can't effectively listen or form a trusting relationship as they are worried about the money.

Whānau who would not normally collect their medications are collecting them [thanks to the temporary fee waiver]. One [teenager] was not collecting insulin regularly and now is, her [...] blood glucose levels are [now] well maintained.

Location undisclosed

Community pharmacies assist as much as they can, but fiscal management takes time and resources away from health consultations. Some pharmacies create accounts for patients; this can lead to patients using the pharmacy as a 'bank', making withdrawals for groceries.

Lower North Island

Although the government does not impose the fee on medicines for children aged 13 and under, children are still affected. Pharmacists told us:

- The fee for older children leads to teenagers suffering from conditions such as uncontrolled asthma and eczema.

- Some caregivers don't pick up prescriptions for younger children, either not realising their prescriptions are free, or being too scared to collect them from a pharmacy where they have outstanding bills of their own.

Offering hope, experiences of the temporary fee waiver in cyclone-affected areas show that removing the prescription fee for everyone immediately increases access to basic medicines, producing rapid positive effects for community health and wellbeing.

INTRODUCTION

Right now, access to necessary medicines and healthcare in Aotearoa New Zealand is blocked for many by 'patient co-payment' prescription fees targeted to most patients aged 14 years and over, for almost every item prescribed.¹

I think [co-payment is] a national crisis that is not being talked about enough. There is HUGE inequity going on!

Auckland

For families with high health needs, just one trip to the doctors could result in prescriptions costing \$50-\$70 or more (the government fee is \$5 per item – \$15 per item for private prescribers such as dentists or private specialists – ostensibly up to a ceiling of \$100 per family per year, but system complexity means some families will be paying even more).

Recent research by the University of Otago confirms that prescription fees are significantly increasing the

number of people admitted to hospital – creating high levels of entirely unnecessary and preventable distress. Sometimes the fee means patients cannot access vital medicines at all: 137,000 adults in New Zealand had at least one unfilled prescription due to cost in 2021/22, an increase from the previous year (and likely to have increased again due to the cost-of-living crisis).³ Many others struggle to fill all their prescriptions, for example, by buying less nutritious food.⁴

What do these negative effects look like on the ground in our communities; exactly how do they happen; and what other effects might the prescription fee have on patients and their whānau? Community pharmacists (i.e. those working in pharmacies independently owned, operated and controlled by pharmacists) have an invaluable and unique lens on these questions, given their work gives them a great depth of understanding into the health needs of their communities.

Not only do they dispense medicines and advice about medicines, but they also vaccinate, do outreach such as marae hui, and often refer patients to other health services and social services as necessary. They have trusting, therapeutic relationships with patients that build up over many years.

So in March 2023, the Independent Community Pharmacy Group (ICPG) and the Prescription Access Initiative (PAI) asked community pharmacists to share what they'd seen of the effects of the prescription fee on their own communities. A survey encouraged open-ended responses on: patient responses to unaffordable prescriptions; immediate and knock-on effects of the fee for the patient; effects on patients' family members;

effects on patients with medium and high incomes; and effects on the pharmacists themselves.

The response was overwhelming – this report contains only a fraction of the deep worry, care, and frustration poured out by more than 150 pharmacists from all around the country (all quotes in the report are from community pharmacists). Respondents told us what they were seeing – not only about the effects of unfilled prescriptions themselves but also the detrimental effect on patients' perceptions of the health system (uncaring, not useful) and on patients' self-esteem and wellbeing due to the shame and whakamā of not being able to pay. Reports were very similar around the country - their testimonies add to Aotearoa New

Zealand's collective understanding of the disastrous effects of the patient co-payment on patients; their children, parents and other whānau, family and supporters; their employers and the community as a whole.

All quotes in the report are about experience in community pharmacies. Yet we know community pharmacists are not seeing all the problems that come with the prescription fee. There will be patients that do not even come through the door because of the fee. Hospital and specialist pharmacists see other problems. For example, an oncology centre pharmacist tells us that in most PHARMAC-funded chemotherapy regimens, between 2-10 prescribed pre-medications are required every cycle:

For these patients things can change very quickly too, requiring changes in prescriptions with drug choice, strength, dosing, dose forms (due to swallowing issues that often develop with head and neck cancers). I don't think it is fair for these patients to have to pay a new co-pay for their prescription every time one of these slight changes to their medications may need to be made. They are paying these on a frequent basis. If these patients must choose between paying for a script or suffering in pain, or with severe nausea and vomiting, it could result in an admission to hospital.

The survey also asked those pharmacists working where the co-payment was temporarily waived after Cyclone Gabrielle about the effects of the fee removal. Their experiences give enormous hope: fees-free prescriptions had immediate and profound positive effects. Such instantly improved access to basic healthcare for a short while shows what all of Aotearoa New Zealand could and should enjoy, in perpetuity.



1

For more information and background on the co-payment issue, see ICPG (2023) "Rapidly improve community health via Fees-Free Prescriptions for All". The current report focusses solely on survey responses. "Fees" throughout this report refer specifically to the patient co-payment.

2

Norris, P., Cousins, K., Horsburgh, S., Keown, S., Churchward, M., Samaranayaka, A., Marra, C. (2023). Impact of removing prescription co-payments on the use of costly health services: a pragmatic randomised controlled trial. *BMC Health Services Research*, 23(1), 1-11.

3

Ministry of Health (Nov 2022) Annual Update of Key Results 2021/22: New Zealand Health Survey; and Key Indicators. Statistics NZ (Aug 2021) National population estimates: At 30 June 2021.

4

Norris, P., Tordoff, J., McIntosh, B., Laxman, K., Chang, S. Y., & Te Karu, L. (2016). Impact of prescription charges on people living in poverty: a qualitative study. *Research in Social and Administrative Pharmacy*, 12(6), 893-902.

WHAT COMMUNITY PHARMACISTS SEE: INITIAL RESPONSES AND EFFECTS

Patients affected

People facing serious conditions are among those who have their healthcare put at risk by the fee – particularly as they often have the largest number of scripts to fill, and the cost can rapidly add up. Those with acute medical needs are also affected.

The most common uncollected prescriptions [include] folic acid/iodine supplement during pregnancy [to prevent] babies born with spina bifida or poor neural development; antibiotics - often patients “wait and see” if their infection gets worse; [... and] nicotine replacement therapy.

Taranaki

[People are] not taking their meds if there's a charge i.e. diabetes, heart disease, gout, kidney disease, asthma/COPD [lung disease], mental health.

Auckland

Medications [not picked up] could be antibiotics, antidepressants, antipsychotics, heart medications, inhalers, insulins, diabetic medications, medico packs.

West Coast

Unfilled prescriptions due to cost "is a very typical scenario for [...] hospital discharges" (Wellington). And pharmacists told us of at-risk organ transplant patients:

[The patient] has now ran out of his [anti-rejection drug] but he still can't afford to pay for it. He requested for 3 days worth until he gets paid. He was very worried about his conditions and knew he shouldn't stop [taking the drug] but he didn't know what else to do ...

North Island

**The issue is not isolated;
it affects many people.**

[T]his year, there has been a significant rise in the number of people unable to afford the cost of their medication. This is probably a result of the ever-increasing cost of living, particularly after 24 months of inflation. Things are getting worse. [...] I struck off \$15,000 of unpaid copayment last financial year and this year it looks as if it will be over that level.

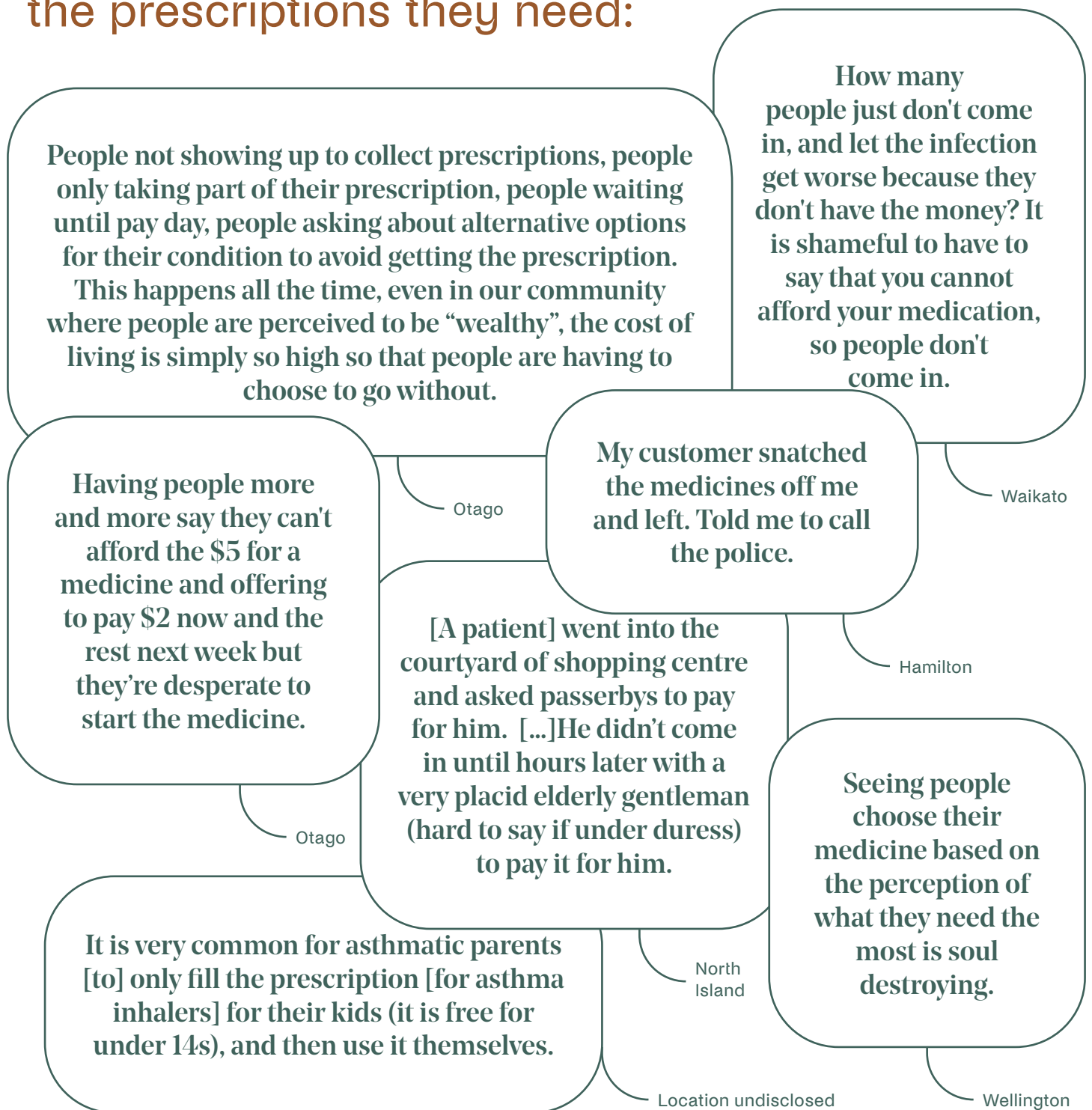
Location undisclosed

Every week we go through the shelf and check for Rxs [prescriptions] not collecting we fill two big baskets with items not collected and when we ring them they all say the same thing (can't afford it)

Rural

Patient responses to unaffordable prescriptions

Patients use multiple strategies to deal with the unaffordable cost of the government fee for all the prescriptions they need:



For patients who can access only one or two prescriptions out of a whole list of medicines they need, prioritisation strategies differ:

A patient came in [under 25 years old, with] strep throat and she was in so much pain but only had \$5. She wanted to get [prescribed anti-inflammatories] instead of the antibiotic but I encouraged her to get the antibiotic due to rheumatic fever risk. I put the pain killers on her account but she hasn't come back to pay it.

This pharmacist then went on to explain the effects:

North Island

Patients would pick [...] antibiotics and not take any pain relief even when they are super sore.

Location undisclosed

It is heartbreaking to see patients trying to choose which medicine is most important.

Auckland

Patients should not have to choose between treatment and pain relief. Our most vulnerable populations are suffering with pain when they should be able to access analgesia [pain relief] easily. When patients are in pain it impacts on their physical and mental [health] and often impacts on education and work.

It absolutely crushes me. It's inhumane.

Auckland

Most of the strategies mean medicines are not being taken in evidence-based ways:

Auckland

We also see people who don't bring a hospital discharge script in until they have finished their old (now obsolete) meds as they think they are saving themselves money.

Waikato

Hawke's Bay

[Some patients] don't come to collect their medicines until they have money so antibiotics are used way too late.

Some will take their medication every 2nd or 3rd day to spread out the cost.

Patients taking someone else's medicines at home to try "help" their conditions.

I know of a patient who said they had been "eking out" what they had of their antidepressant/anti anxiety medicine because of script cost and ended up coming in as they had worsening anxiety and were struggling.

South Island

Location undisclosed

Asking advice over the phone that if they can self-medicate by taking old medicine from cupboard which was prescribed a while back or lending medication from friend who may have similar condition. This trend is getting common and is very harmful as it can lead to further medical complications for patient.

Often they will say 'can I pick up pay day?', sometimes they don't come back, often we give [a few days worth] to get them through [until pay day] but they don't turn up to get balance - especially in the case of antibiotics - resistance occurs.

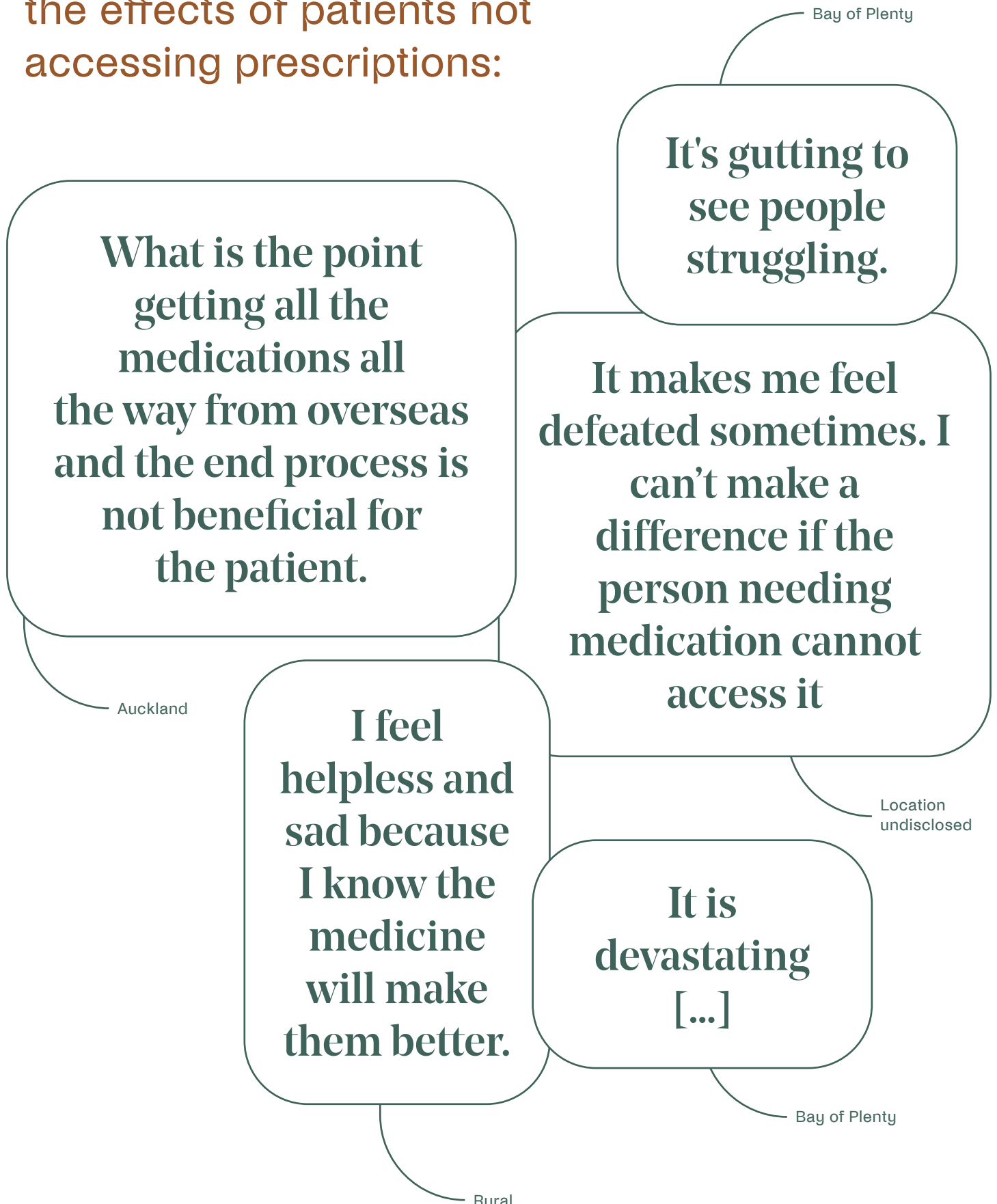
North Island

Northland

Northland

One family didn't treat their whole house for threadworms [as is strongly recommended] because they could only afford the copaymen for 3 out of 5 people.

Pharmacists worry about the effects of patients not accessing prescriptions:



When patients are children

Not all dependent children are exempt from the prescription charge: while children aged under 14 years are exempt, teenagers are not.

Auckland

Sometimes the children (if over 13yrs) will have to pay for the medicines, out of their own pocket money, or if they can't, they may go without altogether. Or, in one case I have heard a parent say to their child, "Its either medicine or food, we can't afford both".. Heartbreaking!

Children with uncontrolled asthma and eczema not being treated as can't afford it. [...] still seeing older kids with huge issues.

Bay of Plenty

[...We] have parents trying to get funded scripts under younger free siblings so incorrectly labelled doses if we and the doctor think the meds are for the prescribed patient.

South Island

If they have a number of teenagers who are asthmatic, they will often all share inhalers and then inevitably run out [...] One person gets the Rx for inhalers and shares them but then dispensing history doesn't show inhaler use for other family members if they end up in hospital.

North Island

Contraception charges for young teens can be difficult

Bay of Plenty

An adolescent with really bad scabies- the family was poor and chose the antihistamine over the A-Scabies solution. I paid the dispensing fee on their behalf because I couldn't bear to think of this poor child scratching all day/night long.

Pharmacist who had worked in multiple locations

The prescription charge can also prevent healthcare for children under 14, even though their prescriptions are free of the charge:

[I've seen] children not collecting medicines that are free as the patients are frightened to collect their children's meds from a pharmacy where they have run up an account of unpaid prescription copayments.

Bay of Plenty

I have seen parents decide to not give their children antibiotics because they mistakenly thought that they would need to pay the co-payment in order to get them.

Canterbury

Communication with healthcare professionals

The government fee also has a detrimental effect on vital trust, and the therapeutic relationship, between the primary healthcare provider (the pharmacist) and the patient:

It takes away from the real part of my job when people can't effectively listen or form a trusting relationship as they are worried about the money.

Location undisclosed

It makes me feel awful! [...]It's exhausting! By the time you spend 15 minutes explaining the co-payment to them and they have to walk away without their medicines..... enough said.

Canterbury

It takes away from the real part of my job when people can't effectively listen or form a trusting relationship as they are worried about the money.

Waikato

Staff [take] mental health days due to abuse from patients.

Auckland

It also adds strain between us as health professionals and patients, patients now perceive us as those would want to take their money, rather than those they trust for advice. This has resulted in strained relationship to the detriment of patient health.

The copayment makes my job unpleasant. [...]It puts a barrier up between me and my patients.

Hawke's Bay

Often the prescriber (for example, the doctor) has no idea that the patient has not been taking the prescription due to cost –

with the result that the patient's health can be put at further risk due to inappropriate additional prescriptions:

We see this time and time again where patients with multiple co-morbidities struggle to come up with a large amount of money to pay for their meds as one dispensing easily cost over \$60. They don't pick up their meds, and then end up in the hospital but they didn't want to tell doctors that they haven't been taking their meds. They then get discharged with even more medications and also higher doses, with the assumption that the previous meds weren't effective.

North Island

Often doctors are [...] are puzzled why the treatment is not working

Location undisclosed

Patients having to switch back-and-forth between discounters and their preferred pharmacies can also lead to miscommunication and health professionals missing vital information.

Accessible only to some patients, corporate pharmacies pay or discount the fee themselves as a "loss leader" commercial strategy. Many pharmacists told us they see patients with high health needs who go to discounters early each

year until they reach the 20-item ceiling, when the government no longer charges them the fee, at which point they switch back to the pharmacy they prefer (due, for example, to a long-term positive relationship with "their" pharmacists, convenience and/or

additional services such as instruction translation).

Having to move between affordable prescriptions and preferred services interrupts continuity of care. If people switch between pharmacies then:

Whenever there's a change in medical conditions and medicines, the local pharmacies don't have their full medicine history, and thus could not give a proper consultation and suggestions, which to me, is disheartening as we couldn't help much when they needed the most help.

One elderly patient, who could not speak English, went to a discounter after a hospital discharge: their prescription had changed and they were supposed to stop taking one anti-coagulant and start another – but instead they took both drugs together for a day. This could have been dangerous if it continued, as it would have put the patient at risk of a

potentially life threatening bleed. But they went to their community pharmacist for advice:

Bay of Plenty

Auckland

"Luckily I found out and informed them, explained all of the hospital medication instruction in Chinese to them so they understood. [...] Patient should go to a regular pharmacy for monitoring and consultation for changes. [...] Patients should [be able to go] to pharmacies at their choice, for the sake of good decent pharmacy service, consultation, not because of the cost.

Community Pharmacy Responses

Pharmacists sometimes pay the fee themselves (out of their own employee wage) or the community pharmacy itself absorbs the cost – costing some pharmacies tens of thousands of dollars a year.

This is unsustainable for most community pharmacies.

The worst situation was a whānau who tossed up whether to buy milk or their script. When I removed the co-payment they burst into waiata, truly moving and humbling.

North Island

Mental Health Patients [...] find it a struggle to afford their prescription - particularly challenging for those who have a lot of acute changes to their conditions and circumstances. [...] We know all of our Mental Health patients and never allow them to run out of medicines due to financial barrier. This also means that as a business, we are constantly balancing how we operate and how we serve our communities.

I once had a young woman who couldn't afford the morning after pill co-pay. I paid on her behalf hoping to save the course of her life. I think she was 15. Unintended pregnancy could have been the consequence if not. I couldn't do nothing.

Location undisclosed

Auckland

I had a woman who opened up about domestic violence and the hardships she was facing and didn't have the 5 dollars to pay for a medicine that she needed to start immediately [...] She was about to leave as she could not afford it, so I paid for it and she cried and was very thankful. I then bawled my eyes out when she left because she reminded me of my mum and the struggles we had growing up.

North Island

Many pharmacists feel they have no choice – particularly in situations where lack of medication could be life-threatening.

Hawke's Bay

[When a patient visiting from elsewhere was told the cost (over \$30)] she immediately broke down and I rushed to comfort her, she said she has no money and needed the medications as she has been discharged from the crisis team due to self harm and suicidal attempts. I comforted her and gave her the medication with no charge (which meant we made a loss). [...]If I wasn't there to help this lady out, who knows what may have happened. Obviously the co-payment was a huge barrier here to a very sick unwell person."

North Island

I have personally lost track of the number of copayments I have paid personally over my 10 year career so far. There are a number of situations where we need to "do no harm" and to do this appropriately people require the medicine they need & we know this as health professionals- should it land on us personally, no, but it does as we are at the coal face.

Auckland

Many community pharmacies also offer to set up weekly accounts for patients,

to spread the cost load over the year, or spend time researching whether funding is available via Work and Income, or charities. One pharmacy noted that setting up an account for a regular patient means:

North Island

Weekly payment also mean precious staff time are taken up to set up accounts and chase up payments when these resources could be used to actually provide beneficial face to face counselling , advise, consults for the patients

"we can now talk to her about her complex medicine needs without her being embarrassed or stressed about paying. [...]The disadvantage of this system though is administrative. She is forever coming and asking how much credit she has with us , sometimes asking to make a 'withdrawal' so she can use that money at supermarket. We have become her proxy bank."

OUTCOMES OF THE PRESCRIPTION FEE

Effects on patient outcomes

The effect on patient health is unnecessary and disastrous, both in terms of long-term health declines, and in terms of health crises.

Northland

We have noted people are in a ping-pong-type system between primary and secondary health, i.e. they get sicker if they do not collect scripts and then end up in prison, hospital, other care facilities to get them sorted. Happens all the time.

Waikato

[The patient's] shortness of breath was evident during his visit. Without being able to afford to pick up his inhalers, his shortness of breath cannot be alleviated.

Once an infection of cellulitis took almost about a year and regular district nurse dressing changes to heal. [...] I would not be surprised if he had delayed picking up his antibiotics because of cost. To him its medication or having food for the week.

Suburban, location undisclosed

I have first-hand experience of a diabetic patient who had a heart attack because they were not compliant with their diabetes medication due to cost.

Location undisclosed

The main knock-on effect of [the prescription fee] is that the customer has a negative experience with the New Zealand health system and is less likely to engage with doctors and pharmacists for their health needs, leading to worse health outcomes.

Hawke's Bay

The health effects can be serious and permanent.

[When I worked at a pharmacy administering anti-psychotic injections, I saw that] under Mental Health Act [mental health outpatients] got free medicines, however when they became well enough to be released from the act they couldn't afford their medicine, so would have worsening of schizophrenia and again end up under the MHA. Since with each episode of schizophrenia the impact of the illness gets progressively worse it was heartbreaking to watch.

Location undisclosed

The worst case I know of is a man who didn't pick up meds because of the price. He didn't tell anyone (even his whānau). Then one day he had a massive stroke.

Wellington

[I've had a patient with] failed kidneys due to uncontrolled diabetes.

North Island

I knew someone who frequently chose between groceries and her insulin. [...] She was losing her sight because of poor diabetes control.

Location undisclosed

We had a chap with diabetes have 2 separate toe amputations!!

Inner-city,
location undisclosed

The government prescription fee is responsible for an estimated tens of thousands of unnecessary hospital bed nights a year.⁵

People end up in hospital! All the time! It's particularly noticeable when people do not collect their heart medications and then later come in with a hospital discharge prescription.

I particularly remember a young man unable to pay for his flucloxacillin prescription. He ended up in hospital on iv antibiotics for a few days.

During winter, not being able to afford inhalers or medications for respiratory conditions have caused patients to be hospitalised.

Northland

North Island

Auckland

Mental health in-patient: [...] Can't afford next prescription - prioritises benzo [benzodiazepine) over antipsychotics and antidepressants. Reaches crisis point and then ends up back as an in-patient.

72 year old: unable to afford antibiotics for a post-surgical wound, did not collect and then ended up back in hospital on IV antibiotics for a deteriorating infection.

A particular example that stuck in my mind was of a young adult who came in for his insulin only to be surprised by the copayment cost for 1 months supply (the doctor wanted to see him before his next 3 month Rx). The young man said he couldn't get it that day but didn't pick it up at a later date. We later learned that he had been admitted to hospital a few days later with severe DKA [a serious diabetes complication].

North Island

Auckland

Unnecessary ill health due to the prescription fee means the patient cannot live their life the way they want to, and the way they expect to be able to – with knock-on effects on family and work and income.

I could write 100 examples! Here’s one from just the other day, one of our patients had a gout flare up because he couldn’t afford to collect his allopurinol, he then had to take time off work, something he really couldn’t afford.

The whole situation, the pain, the added financial stress, and the knock on effect on his employer and workplace could have been easily prevented.

[I know of family] being beaten up / stabbed because a family member has not collected their mental health meds. [Another Family] calling police because family member has gone missing / psychotic / comatose. Family stress.

South Island

One patient was diabetic, and he would not come to pick up his insulin as he did not have money for his meds and he was admitted to the hospital with multiple complications and ended up with foot amputation. [He] was a sole earner for the family and he has lost his foot and has lost his job.

Rural, location undisclosed

Wellington

Effects on whānau

Some patients end up not being able to care for their children the way they want to.

Parents get sicker as they don't pick up their meds and then find it difficult to take care of their children and family members. I have seen this.

Auckland

[Children] get told that they don't get treats or certain food for their meals as they now couldn't afford it as the family needed to buy medicine.

Northland

The prescription fee leads to stress on patients' children in other ways.

We have one mental health patient [who] has taken to sending her young child (about 7) in with her script. The child is sent in with no money to pay. When we ask to see Mum, she says Mum can't get out of the car; she's scared. [...] We've taken medicine out to the car to explain it to her (and because [we don't feel] comfortable giving [it to the] child). Mum can be aggressive, yelling 'I have no money'. Usually, she will calm down when we say we've come to talk about medicine not the money.

Auckland

We get kids sent in to collect prescriptions so often because they know we can't say no to a kid. [...] When we ask for payment the kid will say they don't know or mum will pay next time. No kid should be put in that spot.

Otago

Whānau end up having to care for the patient.

[People] then have to take time off work to provide additional care to their parents.

Manawatu

The granddaughter of [one patient] was using her own money [to pay for his prescription], despite being younger than 20 years old. Often it is the younger generations caring for their elderly grandparents/parents. This is a difficult task as it is, without the financial burden for them. Whānau support is essential in maintain our elderly populations health and we should be making it easy for them to come in and get their meds, no scaring them away with the cost.

North Island

Concern for patients also affects the wellbeing of their whānau.

Their families are worried and are stressed when the patient ends up in hospital.

Canterbury

I have seen family members become upset when they realise that their loved one has not been collecting or taking their medications.

Northland

While some family members are in a position to pay for the patient's medications "to remove the burden" (Nelson- Marlborough), others cannot – or refuse to do so.

In situations of family breakdown, the prescription fee can exacerbate or lead to family strain or even abuse and violence:

Shared custody forces some parents to make the other parent pay for costs incurred [regardless of income].

Location undisclosed

I've seen people refuse to pay for their elderly parents' medicines, which is so sad. Saying they will just take the antibiotic and skip the pain relief for example. Elder abuse is a real problem.

Auckland

We had one particularly volatile patient (now in prison), and if his wife didn't get his medication he would yell at her in the pharmacy (and we suspect worse at home). We haven't charged the family for anything since witnessing this (easily 5 years).

North Island

Generation of Shame/Anxiety/ Anger/Despair

It's heartbreaking to see how ashamed people are of their lack of ability to pay for simple medical care and prescriptions

Bay of Plenty

Shame is detrimental to people's wellbeing on its own, but it can also lead to decisions which directly impact patients' physical health:

Wellington

The sense of shame when they can't afford [prescriptions] stopped them from asking for help so they risk their health instead.

So many times when they collect their scripts and their card is declined, they get whakamā and say they will be back after they've been to the bank... but they never return.

Hawke's Bay

The most recent is patient was one with worsening heart failure [...]but due to the quantity of medicines and the lump sum co-payment she never came back to collect her blister pack even though I had said I would charge it to an account to pay later. She then ended up back in hospital, such an awful feeling!!!!

North Island

The frustration and shame of having approached the health system when feeling ill and/or in pain and already stressed – and to not benefit – can boil over.

I had one lady throw (literally throw) her medicine at me because she was so angry that I charged her for her funded prescription meds, she thought I stole her money [...]

I personally have been accused by a patient of being a f@#\$% criminal just like the f@#\$ government for charging the fee and accused me for being responsible for her son attempting suicide.

[Y]ou 'brace for impact' never knowing when you say what's owing what the response will be ... it's an emotional response that you get back ranging from outrage , frustration , anger , to confusion [...]

Auckland Manawatu-Whanganui Wellington

Having payment options such as a pharmacy account can sometimes assist with the prescription pick-up but do not alleviate the deep shame people are made to feel by social values for not being able to pay (sometimes very large) bills all at once.

Many patients have had to come in a different day after picking up their medicines to pay off unpaid bills which has resulted in them feeling embarrassment and stress.

Only choosing some meds - we always say, take them all and come back and pay later (which can cause whakama).

Canterbury Bay of Plenty

There have been a number of initiatives started by the DHB to waive copayments for high need individuals but when you focus on the action part of these initiatives they are patronising / cause whakamā and assume that the service user does not know how to budget- it is not a pharmacist's job to act as budget advisor or to act as a laybuy company - something is very wrong with this model.

Hawke's Bay

Anxiety

We had one young mother that had extreme anxiety/depression about coming to the pharmacy to pick up her pack and having to pay for her psych meds - leading to even more depression and mania. She had no money for a phone so the nurse/doctor was unable to contact her, I tried to get in touch with her Mother to help pay for the meds, but she was struggling too.

North Island

We have a gentleman who refuses to deal with anyone but me, because he is so embarrassed about not being able to afford his packs. [...] he needs compliance packaging as he has very low literacy and health literacy. We try to help him as much as possible.

North Island

The effects of system confusion/complications

The system is so complex, pharmacists have to spend time explaining and managing it.

If co-payments were removed, it would free up so much more time for our pharmacists to consult with the patients on their meds instead of trying to explain how the system works.

I spend more time managing patients fiscally than medically.

Hawke's Bay

Location undisclosed

Auckland

Elderly couples are the main people we see struggling to pay, as they tend to see the doctor at same time, often their \$100 comes up in 1 go, it can take some people a long time to get back on track after \$100.

The prescription subsidy system means prescription fees for people with high health needs are concentrated in the weeks after 1 February every year, until they reach the annual ceiling of 20 items (\$100).

People will often be shocked at the price of their medication, especially during February, March and April when they are no longer exempt like the year before. They do not have to expect to pay such a large lump sum [...] People simply do not remember it and do not understand it. [...] there is often a lot of anger and frustration from people about this.

Wellington

A “family” does not include adult children over 18 years – so one household may have \$200 or more to pay early in the year.

While a fee is required for repeat prescriptions, repeat dispensing (when a prescription is dispensed at intervals over a period of time) is exempt from the fee. However – just as with the fee exemption for under 14-year-olds – not everybody is aware of this.

One example - family with elderly parents who have a disabled son. The father mentioned to me the other day that one of the reasons he still has to work is to pay for the costs associated with their son. This was in the context that the son had to get to 20 items himself before [he became] exempt [from the fee]. He was arguing that the parents and disabled son were a family. The son is still dependent on them. Hard to argue that it doesn't count as a family, but once again we have to be the bad guys.

Auckland

We have a number of customers who will not return to pick up their free repeats as they think they have to pay another \$5. [...] When repeats are not collected (even though free) [...] patients have been admitted to hospital due to complications of very high blood pressure.

Auckland

The fee for mental health patients being treated compulsorily “under the Mental Health Act” is usually paid by mental health service. Once they are not so unwell, the patients themselves are required to pay the fee again.

Once [patients] are discharged from the mental health service and no longer under the Mental Health Act, their prescription costs become their own. Time and time again, we have to explain to the patient that there is now a \$5 cost for each prescription item. This frequently results in the patient leaving the pharmacy without their medicines, and we later hear they have been readmitted to the mental health ward at the hospital. I have had 2 such patients just this week alone. [...]

Taranaki

We have some Forensic patients. During their community re-integration, the government pays their co-payment and all med costs. After a while, the government stops paying and these patients have never paid for years so why would they start? They just disappear. 90% of the time, they are on long-term mental health meds.

Auckland

The effect on higher income people

Even those who can easily afford the fee have their healthcare diminished by it.

There is an indirect impact on healthcare provision for all [regardless of income], as the small fee actually takes a lot of time to discuss, negotiate, explain and pay so everyone misses out on that 5 mins extra with a pharmacist, and it changes the relationship of pharmacist to a tax collector from a health provider. [...]

For whatever reason, rich and poor patients [both] want to discuss the fee and ask about it and take time to process it. [...]

It changes the entire therapeutic relationship. [...We] would much rather be able to say "and where are you at with vaccinations?" rather than a long discussion around the \$5.

Pharmacist with experience at multiple locations

Some pharmacists noted that difficulty in paying the fee for those with medium or high incomes was a growing issue.

I know of a Dad with medium/high income but resulting high child support payments that has difficulty with copayments for his meds sometimes.

[I] have noticed more and more families/people that are considered "middle/working class" are finding it harder and harder to afford their medication.

South Island

Auckland

With the cost-of-living crisis at the moment, I have been surprised with some of our customers needing to delay picking up some meds due to cost - people that I didn't think would struggle with payment.

Northland

You hear about the high costs of daycare and loans for cars and maybe they had been over extended with mortgages and they say they can't afford to take time off work if they get sick. But then a copay charge for their asthma medicine is too much so [...] they end up have asthma flare ups and needing time off work anyway.

Otago

For families who find themselves in a situation of vulnerable health, the fee can be a direct barrier even for those on higher incomes.

People with high income but struggling with addiction or a family member with some kind of addiction [have found the co-payment a barrier]. I've seen lawyers and even a doctor once whose card declined on a \$5 fee.

Pharmacist who had worked in multiple locations

Lots [of our medium or high-income patients struggle with prescription costs]. Pretty much ALL of our high-risk patients. I work in a GP practice, so I see both sides of this. Not only the side that's obvious to the pharmacy, but the side where they don't even get to the pharmacy. All of our high-risk patients are vulnerable to this.

Hawke's Bay

[We see struggles with many higher income] people! We have a gentleman in renal failure waiting for a transplant. His wife works full time, but with both his and hers (more than 20) items all prescribed at once, they struggle [...], again I offer for them to pay it off [on account].

North Island

We have many people [even on higher incomes] with disabilities, cancer or multiple medical conditions that find it very hard at the beginning of the year to pick up their meds [before their \$100 cap kicks in]. Some are very embarrassed, some cry, some only pick up a few of the 'more important' ones. We have several clients who are taking 15 to 20 meds so it is a big cost for their first yearly script.

Auckland

High and medium-income people [...] also struggle to pay for their medicines, especially when [the] subsidy finishes on 31st January and it is time when their kids' school starts. They compromise on their medicines as they have higher bills to pay for their children's books and uniforms etc.

Rural, location undisclosed



OUR VISION

Aotearoa New Zealand without the prescription fee: better, more equitable healthcare

In 2023, we have seen on the ground in real time the benefits that fees-free prescriptions can achieve.

The patient co-payment prescription fee was temporarily waived after Cyclone Gabrielle in cyclone-affected areas for four weeks in February/March 2023. Pharmacists working in these areas told us about the difference the waiver made to their communities:

Hawke's Bay

Hawke's Bay

Northland

Our shelves aren't full of uncollected prescriptions as patients can take what they need.

It's been amazing to see the difference - it has had a much more significant impact during this time than I ever thought it would. [...] I've been able to focus on the patients rather than having to discuss how to pay for their medicines!

Patients are definitely surprised and happy to save on medicines, especially at the start of the year when the exemption card expires and some have to spend \$100 upfront in 1 day when they renew their 20-items scripts.

Our shelves are clear as medication has been collected. People appreciate that the barrier has been removed & we can let them know that the government is looking after them.

Whānau who would not normally collect their medications are collecting them. One [teenager] was not collecting insulin regularly and now is, her [...] blood glucose levels are [now] well maintained.

North Island

Compliance packaging patients we had not seen in months, were present at the pharmacy with new prescriptions and asking to be put back on packs.

Hawke's Bay

Northland

Hugely beneficial in enabling us to sort out complex medication regimens. [...] Several cases of people with multiple hospital admissions have had input and medication alignment and then remained stable.

Deliveries were easier to organise immediately.

It has been great! [...] Easier to facilitate getting medications to [non-mobile] patients, e.g social working collecting or deliveries to patients without having to worry about it getting paid for.

Hawke's Island

Improved access because other people eg care givers, aunties, neighbours, kids can pick up the medicines without the cost being a barrier.

Northland

Patient wellbeing, and patient-healthcare relationships were immediately improved – even before medicine adherence started.

My interaction with my patients has changed dramatically. No angry financial conversations. More medicine-related conversations.

Hawke's Bay

Improved patient mood. Has made dispensing a lot easier. I've had more time to talk to patients.

Tairāwhiti

The staff have been happier and the whole vibe at the pharmacy has been relaxed and allowed us to focus more on the important work.

Northland

Patients were happier and were more engaging [during the waiver], asking more questions about their conditions and medications, eager to get better.

Northland

Felt amazed about the new position that we were in that helped so many affected people and took another burden off them!!

Waikato

Lot more happy patients and far more engaged about their health.

Rural

This is our vision come to life: Aotearoa
New Zealand without the prescription fee –
and therefore better, more equitable healthcare.

**[Removing the fee] would help
to redress the balance of the
"haves and have nots" in health
where it should be equal.**

Northland

**Having the co-payment removed
has been a huge blessing.
Customers have a more positive
experience in the health system,
are more likely to pick up all
their medicines at once.**

Hawke's Bay

**I want to do so much more for those
who come through my pharmacy door and
offer the high-quality community pharmacy
care to everyone - not just the ones who
can afford the co-payment.**

Auckland

Thank you for reading