



Living with

EMAZINE

A report on the
real-life impact
of eczema on
New Zealanders

About This Report

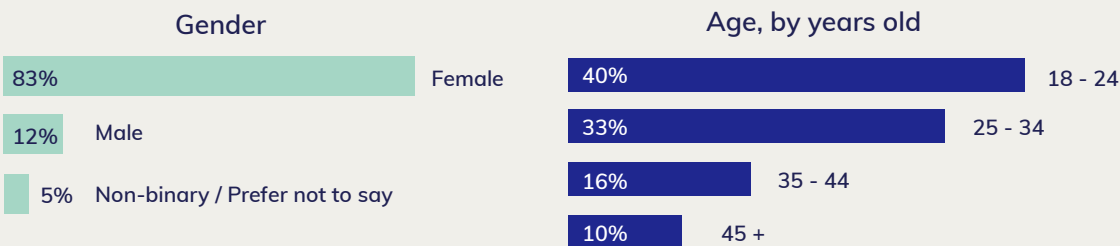
The Living with Eczema report was developed by the Eczema Association of New Zealand (EANZ) and AbbVie and has been funded by AbbVie. It features a summary of results from a survey, the first of its kind in Aotearoa New Zealand providing an insight, direct from patients, into the burden of living with eczema (atopic dermatitis).

The survey captures the experiences of 517 adults and 98 parents and carers of people with eczema in New Zealand, making it the largest survey on the lived experience of New Zealanders with eczema.¹

The online survey was conducted by Elbow, an independent market research consultancy. The survey was distributed to EANZ members and promoted to the general public via social media. Participants were surveyed between 19 December 2023 and 1 March 2024. As a convenience sample was used, results may not be generalisable to the New Zealand population.

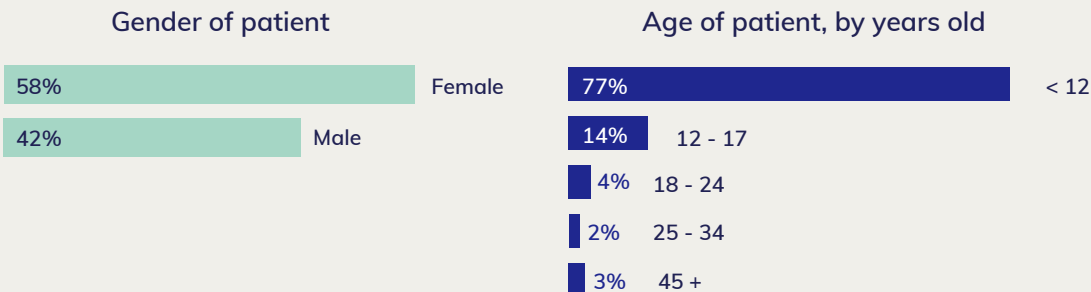
Adults with eczema

n=517



Parents & carers of people with eczema

n=98



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Summary

Foreword

Vanessa Jenkins

Eczema Association
of New Zealand



As both a representative of the Eczema Association of New Zealand and a long-term carer for my husband who has eczema, it is my privilege to introduce the largest survey on the lived experience of New Zealanders with eczema – *Living with Eczema: A report on the real-life impact of eczema on New Zealanders*.

Eczema, a chronic and often misunderstood condition, affects the lives of thousands of individuals across New Zealand. Despite its prevalence, data on the true burden of eczema has been scant, particularly concerning adults. This survey marks a significant milestone in our understanding of the lived experience of those with eczema, shedding light on the challenges they face in their day-to-day lives.

The findings presented here are not just numbers; they represent the unseen struggles, the sleepless nights, and the relentless pursuit of relief that characterise daily life with eczema. Many people assume that eczema is 'just a rash' because that's what they see on a person's skin, but what they can't see is the significant socio-emotional, mental health and financial burden that comes from living with eczema.

From the physical symptoms and pervasive impact on mental wellbeing to the never-ending search for relief that involves trying multiple treatments and seeing various healthcare professionals, this survey reveals the profound toll of eczema on individuals and their families.

One of the most striking findings is the challenge people face in finding treatments that work for them in the long term, meaning that many Kiwis continue to grapple with uncontrolled symptoms in a perpetual cycle of frustration and despair.

Waitlists for dermatologists are long and appointments can be costly. Currently, there are also no reimbursed advanced treatment options for people with moderate-to-severe eczema in New Zealand.

Improving access to care by increasing the number of public dermatology services and funding new treatments for patients with eczema remains critical. By increasing the budget available to Pharmac, New Zealand has a chance to improve access to medicines. New Zealand is currently one of the lowest ranked countries in the Organisation for Economic Co-operation and Development (OECD) when it comes to access to publicly funded medicines.²

This survey underscores the urgent need for healthcare providers and policy makers to prioritise the needs of those living with eczema by taking steps to improve access to timely and effective care, particularly for those who live with moderate and severe eczema.

It is my sincere hope that the findings presented here serve as a catalyst for change, sparking dialogue, helping to inform public health decision making, driving improvements in the delivery of care and inspiring action to better support the eczema community in New Zealand.

By elevating the voices of those affected, we can dispel misconceptions, reduce stigma, and foster a more supportive environment for individuals navigating this complex condition.

Together, let's work towards a future where every individual living with eczema feels understood, supported and is empowered to live their life to the fullest.

Vanessa Jenkins

Eczema Association of New Zealand

Living With Eczema

Survey Summary

Eczema is the most common chronic inflammatory skin disease.³

212,000 **193,000**

Adults

Children

may live with eczema in New Zealand^{4,5}

Survey participants

N=517

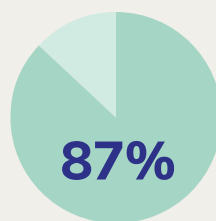
adults (18+ years) living with eczema

N=98

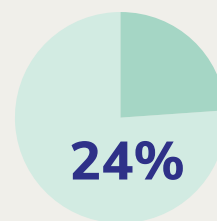
parents/ carers of those with eczema



Eczema can be a long term condition...



of adult respondents have lived with eczema for over 10 years



of adult respondents have lived with eczema for over 30 years

Physical eczema symptoms

% of adult respondents who have experienced...

Itchiness

97%

Dry, cracked skin

94%

Raw, sensitive skin

91%

Pain

74%

Symptoms cause negative impacts on daily life



51% of adults and 65% of parents & carers reported a significant or moderate **impact on day-to-day life**



63% of adults and 71% of parents & carers said **itchiness had a significant/ very significant negative impact**



16% of all respondents have been **hospitalised for eczema complications or infections**

Mental health and relationships are affected

46%

Almost 1 in 2 adults reported a significantly **negative impact on their mental health**

79%

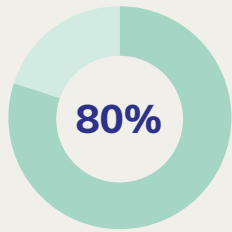
Almost 4 in 5 adults reported **low self-esteem** and confidence

70%

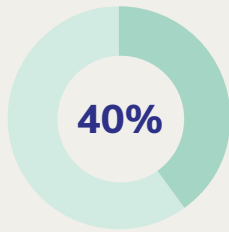
70% of adults reported **negatively impacted friendships**

Survey Summary

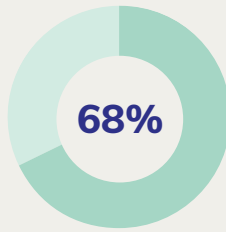
Eczema can curb ambitions, career, and hope for the future



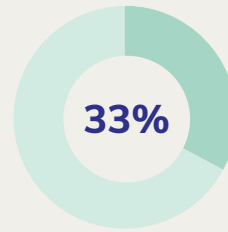
4 out of 5 adults said eczema negatively impacts their ability to work



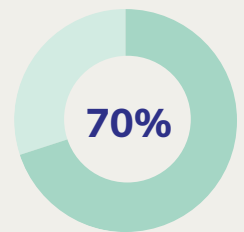
2 out of 5 adults missed an average of 7 work days a year due to eczema



68% of adults said eczema impacts their ability to fulfil career ambitions



1 in 3 parents & carers said it impacts the ability to go to school or university



70% of adults said eczema impacts their hope for the future

Not enough healthcare support available

Only 1 in 10 adults are currently seeing a dermatologist. Challenges accessing dermatologists included: long waiting lists and cost

55% of adults and 49% of parents & carers do not feel they can get help from a doctor for eczema when they need it

72% of parents & carers are not satisfied with the help they get from their doctor

73% of adults feel their doctor does not understand the impact eczema has on their life



Controlling eczema is challenging

25%

1 in 4 respondents have tried more than 20 eczema treatments

79%

79% of adults with moderate-to-severe eczema report their eczema is not fully manageable or under control

62%

62% of respondents feel a sense of hopelessness given the number of treatments tried and doctors seen

84%

84% of respondents feel frustrated by an inability to find an effective, long-term treatment

74% of adults, parents & carers reported not being able to bring an eczema flare-up under control

Introducing eczema

Eczema, also known as atopic dermatitis, is the most common chronic inflammatory skin disease worldwide.³ **In New Zealand approximately 212,000 adults and 193,000 children live with eczema.**^{4,5*}

About 20-40% of children diagnosed with eczema will continue to be affected as adults and live with the condition for most of their life.⁶ Eczema is also **more prevalent among Māori and Pasifika** children compared with European/Pākehā children.⁶

Eczema is characterised by **itchy skin that can appear on any part of the body**, leading to an urge to scratch for relief. Other symptoms include skin that is **dry, sensitive, inflamed, scaly, oozing or crusting and areas of swelling**. Infections can also result due to broken skin and may require treatment with antibiotics or hospitalisation. Symptoms range from mild to moderate and severe and cause significant discomfort and pain.⁷ They also have a **major impact on people's quality of life** and emotional wellbeing, with disruptive itching making working and socialising difficult, causing loss of sleep, and contributing to anxiety and depression.^{8,9}

Eczema is not contagious and is the result of an overactive immune system. While the main cause of eczema is unknown it is thought to be influenced by the combination of genes and environmental triggers, such as **stress, some foods and alcohol, as well as irritants such as weather and allergens.**⁷

There is no cure for eczema, however over-the-counter and prescription treatments are available to help manage symptoms, but results vary from person-to-person and can depend on severity.⁷



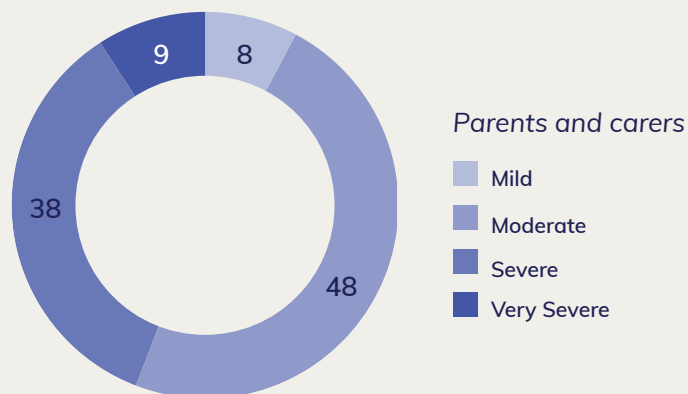
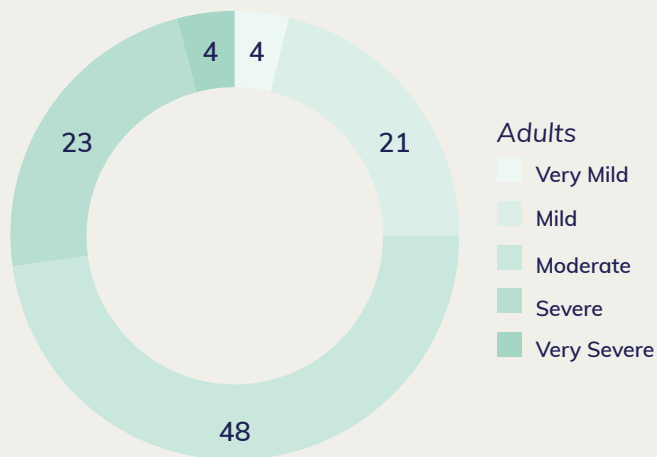
*In line with definitions used in the New Zealand Health Survey, adults are people aged 15 years old and over.

Survey key results

Of adults who responded to the survey, **75% self-reported having moderate-to-severe eczema**. The majority of parents and carers (92%) who responded to the survey indicated they cared for someone with moderate-to-severe eczema.

Reported severity of eczema

by % of survey respondents

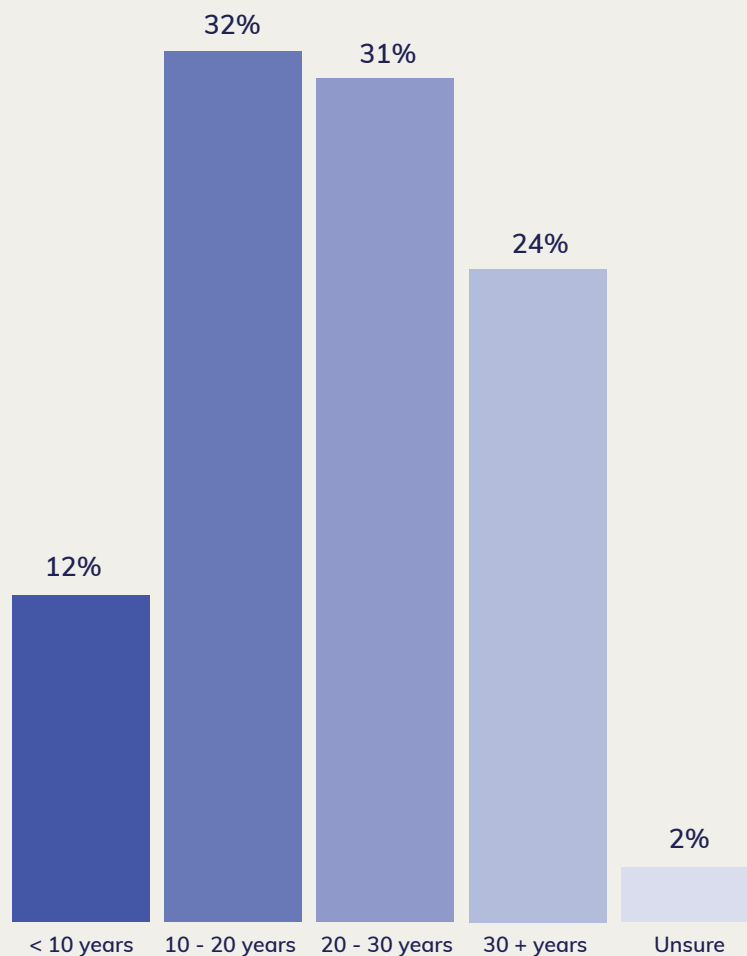


Eczema can be a long-term chronic condition

Of adults who responded to the survey, 87% reported living with eczema for **over 10 years**, nearly a third (31%) for **20 – 30 years** and almost a quarter (24%) for **more than 30 years**.

Reported duration of eczema

% of adults who have had eczema for...

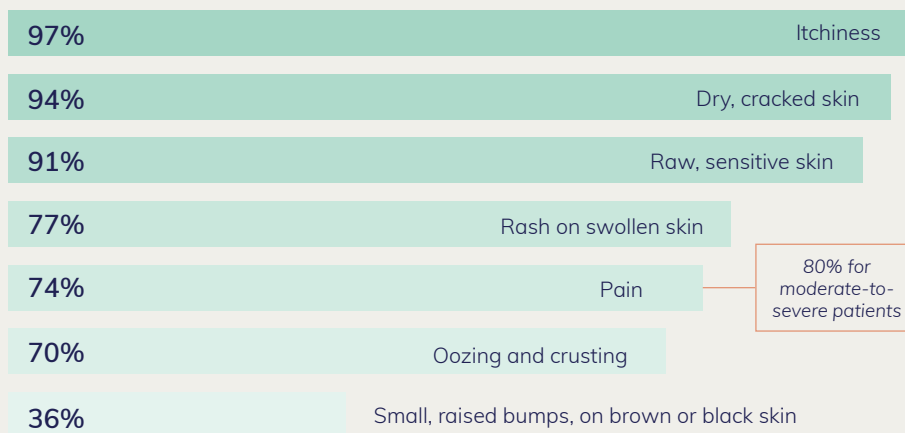


People experience challenging physical symptoms

Respondents reported experiencing (currently or in the past) a wide range of eczema symptoms with itchiness, dry/cracked skin and raw/sensitive skin being the most common. Symptoms were also **worse for those with moderate-to-severe forms of eczema**.

Physical eczema symptoms

% of adults who have experienced each symptom



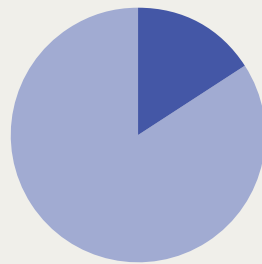
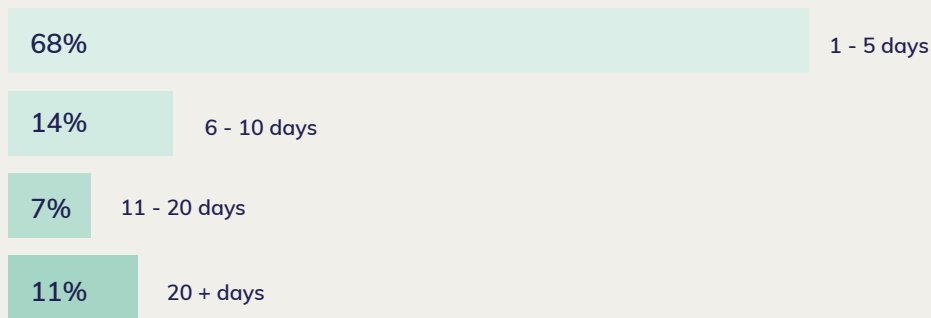
With eczema causing the skin to crack and break, it can become infected with bacteria or viruses leading to complications.¹⁰ Around **16% of those surveyed have experienced hospitalisation** due to eczema complications or infections.

“ 91% of adults living
with eczema reported
experiencing **raw,**
sensitive skin and
74% experienced **pain** ”



Hospitalisation due to eczema complications

% of survey respondents who reported being hospitalised



16%

of respondents have been hospitalised due to eczema complications/ infections

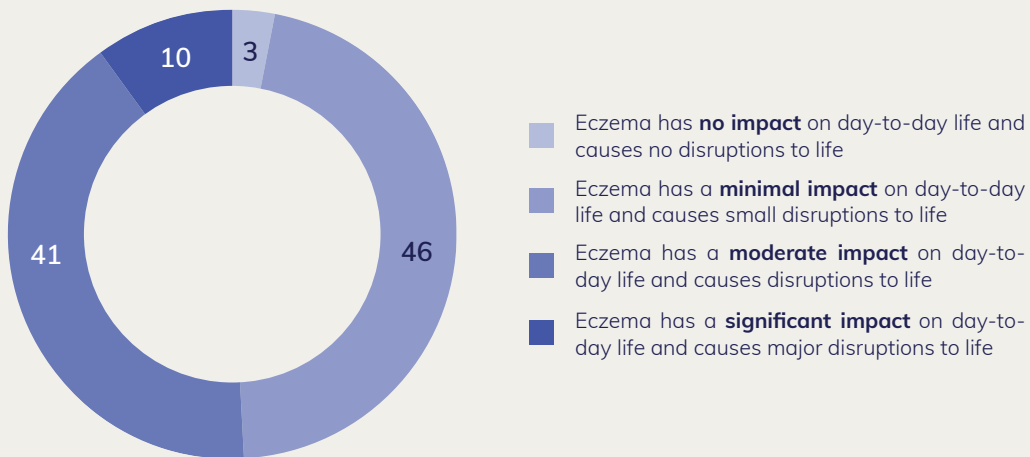
Symptoms cause negative impacts on daily life

One in two (51%) adults acknowledged the **moderate-to-significant negative impact** eczema has on their day-to-day life. This increased to 65% for parents and carers of those with eczema.

Some eczema symptoms were more likely to cause interruption to daily life including **itchiness**, with 63% of adults and 71% of parents and carers reporting significant or very significant negative impacts from this symptom. **Raw, sensitive skin** also had a negative impact with 54% of adults and 57% of parents and carers reporting it to be significant or very significant. These symptoms also **impacted an adult's ability to be physically active** with 85% of adults saying it had a negative impact.

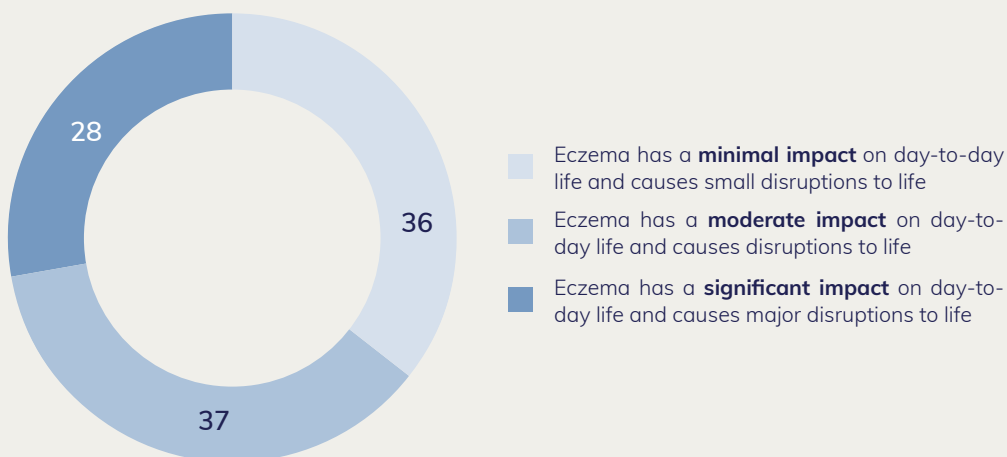
Impact of eczema on daily life

% adults who stated...



Impact of eczema on daily life

% of parents and carers who stated...



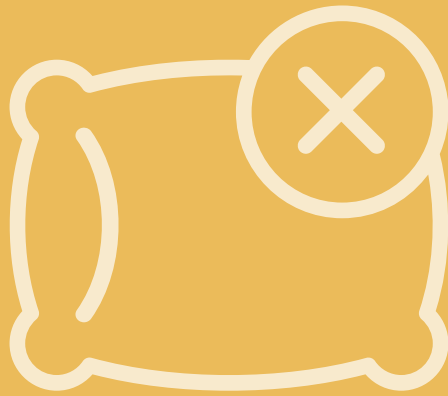
Mental health and relationships are affected

Eczema symptoms along with the **uncertainty of when flare-ups may occur** can create feelings of **helplessness and frustration**, taking a toll on mental health and impairing quality of life.⁸

Of the adults surveyed 97% acknowledged that eczema has a **negative impact on their mental health**, with almost half (46%) reporting that impact to be significant or very significant. Mental health was also noted by parents and carers with over one third (37%) reporting the impact to be significant or very significant. Adults also reported experiencing **anxiety, stress and depression. Loss of sleep was noted by parents and carers as the biggest challenge** with 64% reporting it as an issue and, this was also supported by 66% of adults with eczema.

The physical appearance of eczema, especially if it is visible on the face and hands, can also **impact self-esteem and confidence**, with 79% of adult respondents reporting **low self-esteem and confidence related to eczema**.

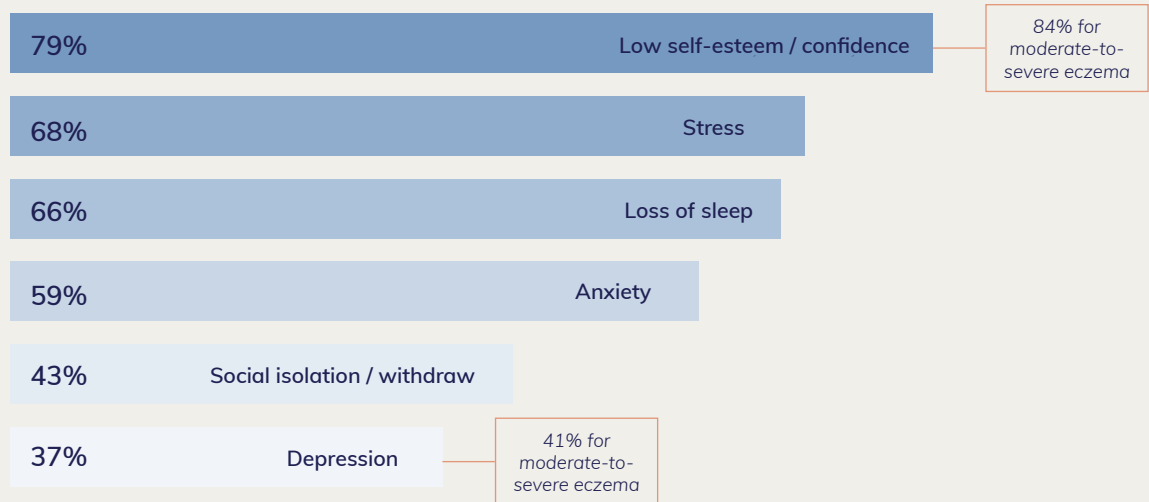
“ 97% of adult respondents say the condition has a **negative impact on their mental health** ”



“ Loss of sleep is a challenge for 2 in 3 people with eczema **”**

Mental health challenges of eczema

% of adults who have experienced each challenge



Eczema was found to affect the quality of relationships people had, with 70% of adults surveyed saying **eczema has a negative impact on their friendships**. Social isolation was also identified as a negative outcome of eczema, with 43% of adults indicating they struggle with this. **Relationships with spouse/partners were also negatively impacted** with 62% of adults experiencing this.

“ 70% of adult respondents believe eczema has **negatively impacted friendships** ”

Eczema can curb ambitions, career, and hope for the future

Eczema is known to impact people's **ability to participate in employment** and is associated with sick leave, changing jobs, and receiving benefits or pensions.¹¹ A multi-country study found an **average work productivity loss of 34.2%** in employed adults with moderate-to-severe eczema.⁹ The symptoms people experience can **impact the use of their body**, while the **loss of sleep** at night can make it **difficult to concentrate** at work.^{7,10}

Results from the survey provides further insight into these experiences. Four in five (80%) of adults said eczema has a **negative impact on their ability to work**, and two in five (39%) reported **missing on average seven workdays** per year due to eczema. Notably 68% of adults felt it **impacts their ability to fulfil work and career ambitions**.

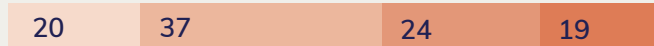
Respondents also noted **impacts on ability to study and pursue academic ambitions**. One third (33%) of parents and carers reported that eczema had a **significant and very significant impact on the ability to go to school or university**. With ambitions seemingly curbed by eczema, 70% of adults said living with the condition **impacts their hope for the future**.

“ 70% of adults said eczema impacts their hope for the future ”

Impact of eczema on work and education

% of adults who rated...

Ability to work



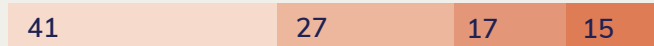
Ability to go to school / university



Ability to fulfill work & career ambitions



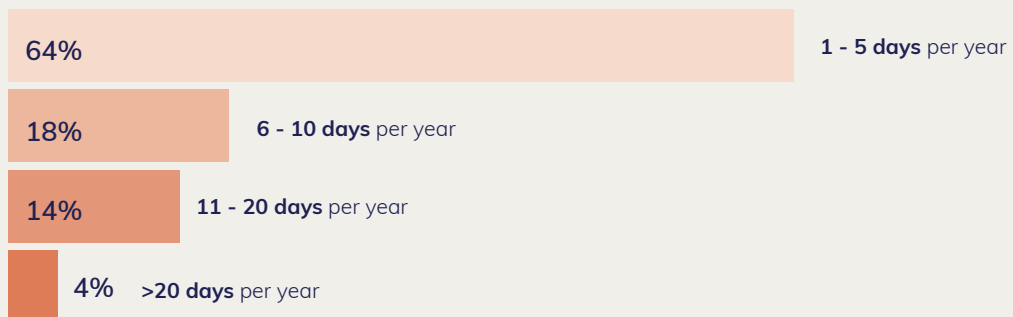
Ability to fulfil school & academic ambitions



- No negative impact at all
- Slight negative impact
- Moderate negative impact
- Significant/very significant negative impact

Impact of eczema on work absenteeism

% of workdays missed reported by adults who missed work due to eczema



39%

of adults have had to
miss workdays due
to eczema

7

days missed, per year
on average

Rebecca's story



Rebecca, 20, Taranaki, New Zealand

"I've been living with eczema since I was three months old. From really early on I can remember the itching. It was constant; 24/7. I can remember having oozing skin, bleeding skin and broken skin.

"When I was a newborn, mum would have to get me out of the bassinet and soak the bedding and clothing off my skin because it had oozed and would stick to me.

"As I got older, it was more about how the social side of physical symptoms were impacting me.

"My body was covered in severe eczema"

"My body was covered in severe eczema. It was open, raw and bleeding, there were marks from scratching on it. It was bright red and inflamed, really dry, and often weeping and that would come with infections as well. So, I'd be covered in welts and pustules all over my body.

"I remember I was in hospital for one of my friends' 16th birthdays. I had been looking forward to this party and I was in hospital hooked up to an IV pump so I couldn't go. There were many times like that throughout the years.

"When my flares were really bad, I was feeling really isolated. At that point as a teenager, I wasn't going to school because I couldn't keep up with my school work.

"My whole life was focused on what treatments I had to do and when the next one was due. I couldn't go out and see my friends on the weekends. It was just really isolating.

"I think I probably spend around four-to-six hours a day caring for my eczema and doing different treatments which was also why I couldn't go to school at that time because there weren't enough hours in the day.

"The range of treatments available for people with eczema in New Zealand at the moment is incredibly limited compared to other parts of the world"

"I always had to be with someone else who could help me put wet wraps on, put the emollients on, the topical steroids. I was taking oral steroids, I was injecting immune suppressant medications, I had tried everything that was available in New Zealand and none of it had worked for me, so I was at a loss.

"The range of treatments available for people with eczema in New Zealand at the moment is limited compared to other parts of the world. And I don't think people in the medical community and people in public in general realise the impact that something like eczema can have not only on the person with it, but their entire family as well.

"It's important that research is done and funding is put in to support medications for people with eczema.

"I'm looking forward to carrying on my career. I've gone into nursing primarily because of the experiences I've had and I know I want to work with children and young people who have eczema and allergies just like I did.

"I'm also looking forward to travelling and just to having a typical life that people take for granted."

Managing eczema costs time and money

Eczema can impose a **significant financial burden** on individuals and their families. Many people living with eczema – in addition to medication – may need to purchase specialist moisturisers or emollients, skincare, makeup, deodorant, hair products, hypoallergenic clothing and bedding, bandages, antihistamines, and pain relief, among other products. While some products may be helpful for some, they **may not work for others**. People may need to trial several products to find things that work for them.

One quarter of adults surveyed estimated they spend **up to or over \$100 per month trying to manage their condition**. The expense to see a private dermatologist was also raised as a challenge facing people with eczema.

The time burden of managing eczema can also be significant including time to attend appointments or undertake **self-care at home during a flare-up**. Over a quarter of adult respondents (27%) and over one third (35%) of parents and carers noted spending up to or over **20 hours per month managing eczema**.





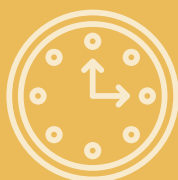
25%

of adults surveyed estimated they **spend up to or over \$100 per month** trying to manage their condition



\$

the **expense of private dermatologists** was raised as a challenge



27%

of adult respondents noted spending up to or over **20 hours per month** managing eczema



35%

of parents and carers noted spending up to or over **20 hours per month** managing eczema

Rhys' Story



**Rhys, 46 years,
Auckland New Zealand**

"Over 33 years of living with eczema, my symptoms have been severe and can change day to day. It can be red, bumpy skin, bleeding, weeping, itchy and cracked. It's been a long time to have to live with it. It's unpredictable and can flare up at any time.

"To explain it to someone, I'd say that there's something hovering over you all the time that affects your confidence, will affect you physically, emotionally, mentally.

"My parents first took me to a dermatologist at the age of 12 and would have spent tens of thousands of dollars on treatments, dermatologists and alternative treatments. Some of them made my eczema better for a little while, but it always came back or got worse. I had to leave school at 16 years old and even though I did a few courses, I struggled to keep it up because I was always sick with eczema.

"To be honest, eczema has made me sad for most of my life. "

"I got used to getting jobs and having to leave them because of the mental and physical side of my eczema. If you're flaring and you're at work, you can't concentrate, even if you try really hard.

"Eczema affects all of the skin on my body from my toes, my ears, and between my fingers.

"My family have supported me over the years with my eczema journey with understanding and love. Our kids have grown up not knowing any different.

"If you're flaring and you're at work, you can't concentrate, even if you try really hard. "

"Dealing with depression is a big thing when you're living with eczema and your family understands that there's going to be good days and bad days.

"To be honest, eczema has made me sad for most of my life. For a treatment or medication not to work or be successful is devastating; it's gut wrenching. It's hope taken away from you.

"What do I imagine when I think about a life without eczema? It's hope."

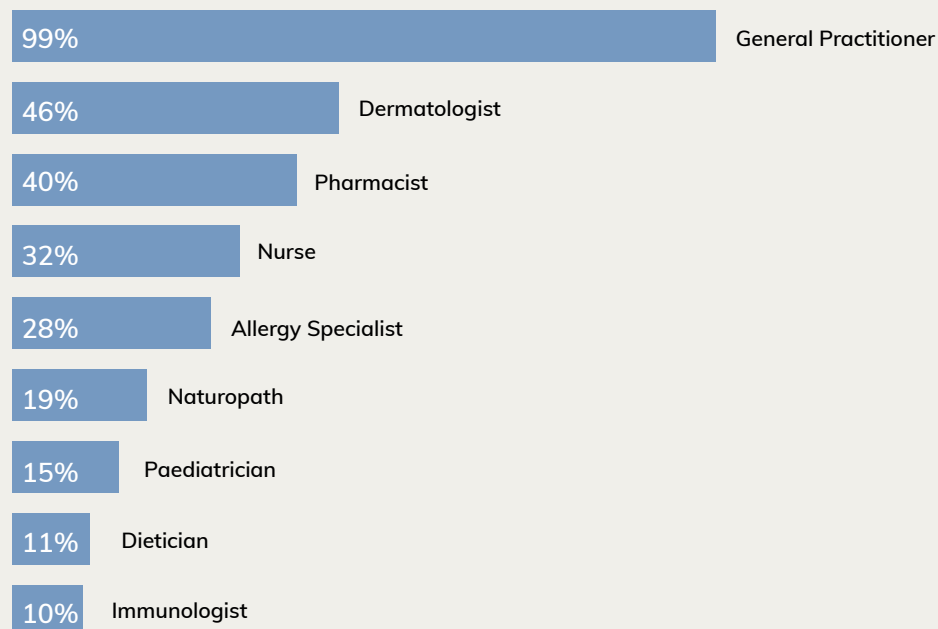
Not enough healthcare support available

People living with eczema may see a range of healthcare professionals to help manage and treat their condition. These commonly include general practitioners (GPs), dermatologists, and pharmacists. From the survey GPs remain the main healthcare professional people with eczema see, with dermatologists the second most popular healthcare provider, with **46% of adults either currently or in the past having seen this specialist.**

However, **only 1 in 10 adults surveyed are currently seeing a dermatologist**, with slow referral processes, long waiting lists and cost raised as challenges facing people with eczema in accessing specialist care.

Healthcare professionals seen for eczema management

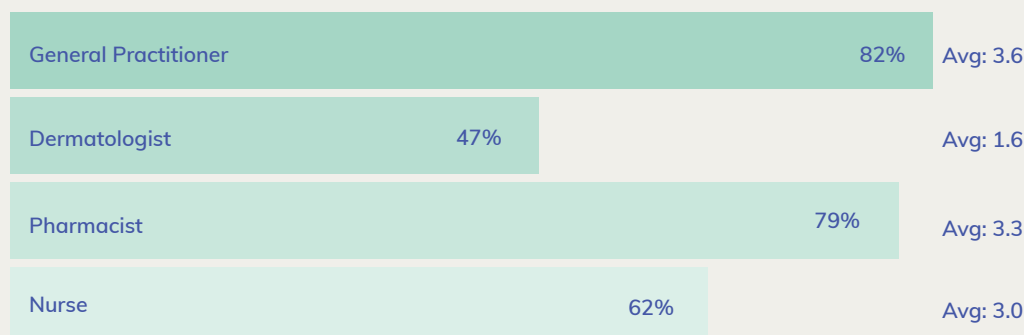
% of adults who have seen each healthcare professional, currently or in the past



In search of support, patients are trying **multiple healthcare professionals** from the same specialities. From the adults surveyed, on average people see approximately **3-4 different GPs and 2 different dermatologists**. This may be because they are **not getting the support they need**, with 73% of adults indicating they feel their doctor does not understand the impact eczema has on their life. While 68% of adults and 72% of parents and carers reported not being satisfied with the help they get from their doctor. Over half (55%) of adults and 49% of parents and carers **do not feel they can get help** for eczema when they need it.

Multiple healthcare professional appointments

% of adults who have seen more than 1 person from each specialty...



Perceptions of healthcare professional support

% of adults who rated...

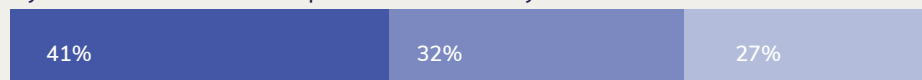
I feel I am able to get help from my doctor for my eczema when I need it.



I am satisfied with the help I get from my doctor.



My doctor understands the impact eczema has in my life.



1/2 - Disagree / strongly disagree 3 - Neutral 4/5 - Agree / strongly agree

“74% report that they are not able to bring an eczema flare-up quickly under control with the available treatments

”



Controlling eczema is challenging

There is **no cure for eczema**, and for some it can be a lifelong condition. Treatments can assist in managing symptoms and reducing inflammation. Treatments include over-the-counter topical treatments such as emollients and moisturisers, prescription topical treatments such as topical steroids, and light therapy. Oral corticosteroid and immune suppressant medicines available by prescription are also used. When patients experience a flare, wet wrapping, bleach baths and oral antihistamines may be used along with other therapies.¹²

Skin infection is a common complication of eczema, where a virus or bacteria can get into cracked or broken skin.¹⁰ People may require antibiotics or may be admitted to hospital for treatment.

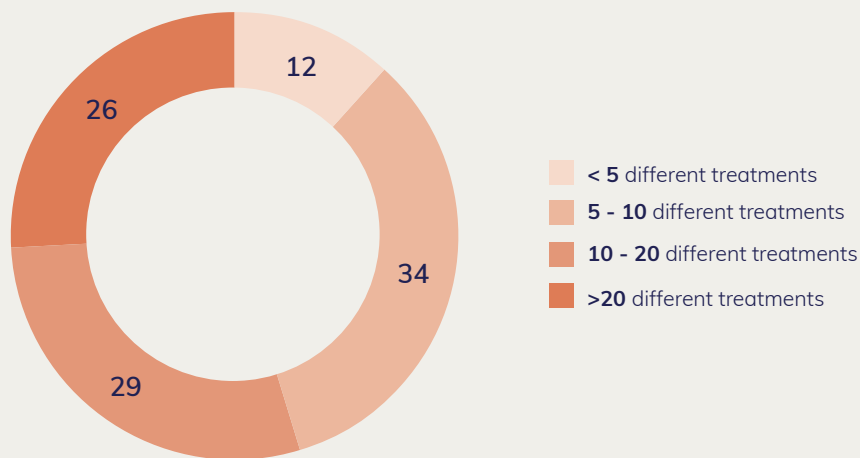
For patients with moderate-to-severe eczema, **management can be difficult** with many patients cycling through different treatments to try and find relief from symptoms.¹³ Currently, **there are no reimbursed advanced treatment options** for people with moderate-to-severe eczema in New Zealand.

“Currently, there are no reimbursed advanced treatment options for people with moderate-to-severe eczema in New Zealand”

Results from the survey showed that on average, people living with eczema try at least five different treatments for their symptoms, while one in four have tried more than 20 treatments.

Number of treatments tried for eczema management

% of respondents who have tried...



Prescription topical treatments, like steroid creams, have been used by **99% of people living with eczema**. Over-the-counter topical treatments are the second most common. **Oral corticosteroid tablets have been used by 43% and wet wrapping by 40%.** Only 17% of respondents are currently using or have previously used immune suppressant medicines.

Wet wrapping is a time intensive procedure that involves placing wet bandages over emollients and/or topical steroid creams on inflamed, weeping and sore skin to cool it, support moisturising and steroid absorption.¹²



26%

of respondents have tried
more than 20
eczema treatments



73%

of adults feel their **doctor does**
not understand the impact
eczema has on their life



60%

of respondents feel a **sense**
of hopelessness given the
number of treatments tried
and doctors seen



84%

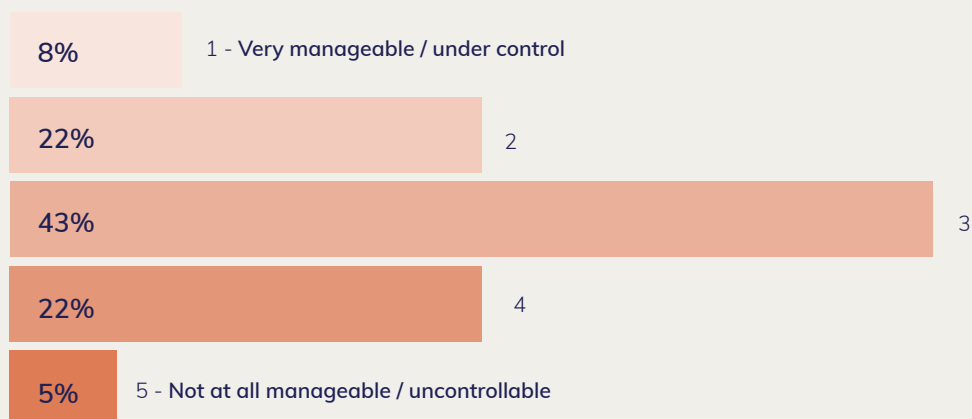
of respondents said they **felt**
frustrated by their inability to
find an effective, long-term
treatment for their eczema

Despite multiple treatments tried, 70% reported their **eczema is not fully manageable or under control**. This increases to 79% for adults with moderate-to-severe eczema. 74% report that they are **not able to bring an eczema flare-up quickly under control** with the available treatments.

The survey uncovered feelings of **frustration and sense of hopelessness** when it comes to treatment, with some treatments only working in the short term and some people unable to find something that works for them. Of the adult respondents 60% feel a sense of hopelessness given the number of treatments tried and doctors seen, and 83% feel frustrated by their **inability to find an effective, long-term treatment**.

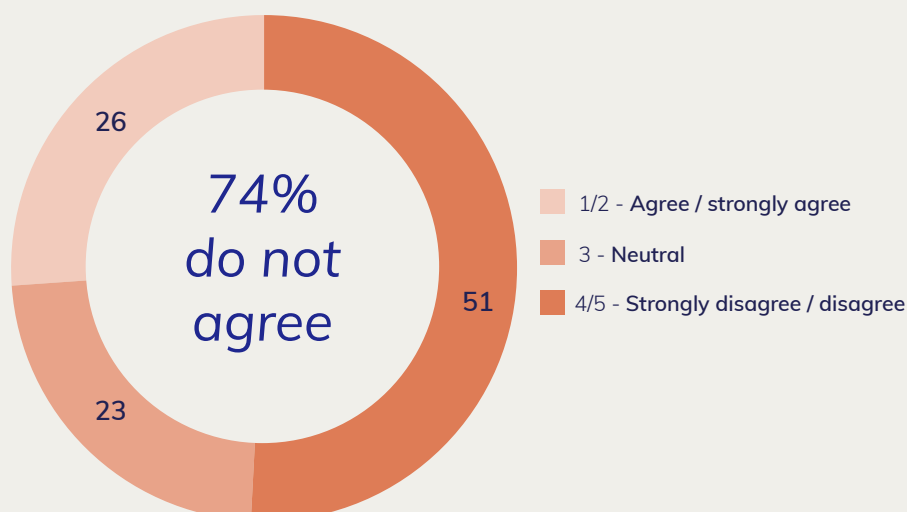
Reported control over eczema symptoms

% of respondents who rated their control over symptoms after as...



Ability to control eczema when experiencing flare-ups

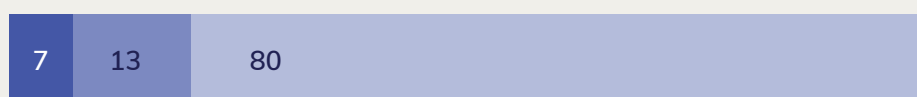
"I am able to bring my eczema quickly under control, when I have a flare"
% adults who reported....



Attitudes to treatments for eczema

% of adults who rated...

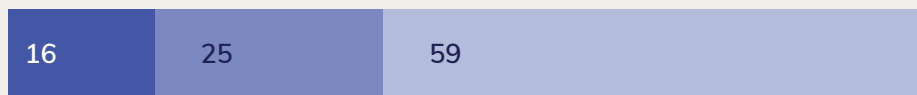
1/2 - Strongly disagree / disagree 3 - Neutral 4/5 - Agree / strongly agree



I find many treatments for eczema will work, but only for a short period of time and aren't as effective long term.



I feel frustrated by my inability to find an effective, long term treatment for my eczema.



I feel a sense of hopelessness with my eczema, given the number of treatments I've tried and different doctors I've seen, without a successful outcome.

Survey Summary



The **physical symptoms** of eczema are burdensome with **itchiness, dry/ cracked skin and/ or raw/ sensitive skin, significantly impacting people's lives.** The extent of this impact correlates to the severity of eczema, with those with moderate-to-severe eczema struggling more with these symptoms.



Eczema has a significant impact on **mental health, self-confidence and relationships.** It also impacts people's ability to work, study and pursue future ambitions.



Patients spend time and money searching for relief trying different treatments and seeing **multiple healthcare professionals.**



For many their eczema is **not fully manageable,** and when eczema flare-ups occur, they are **not able to get them under control.**



The lack of consistent symptom control leaves people feeling **frustrated and lacking hope for the future.** They also feel their doctors **do not understand the impact eczema has on their life** and that help can be hard to find when they need it.

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If you or someone you know is living with eczema and need support, contact the Eczema Association of New Zealand or a healthcare professional.

www.eczema.org.nz

Email: eanz@eczema.org.nz

Phone: 0800 300 182

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