Eczema Support
AUSTRALIA

The Burden of Eczema – Evidence for a National Strategy

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Eczema Support Australia Ltd is a national support network established late 2015. Originally named Hands to Hold, Eczema Support Australia (ESA) is registered as a Public Benevolent Institution and is an Australian registered charity and endorsed as a deductible gift recipient.

Our mission is to:

- **Connect Australians living with eczema to reduce feelings of isolation.**
- **Inform and educate Australians living with eczema to successfully manage their condition.**
- **Advocate for practical support to improve the lives of Australians living with eczema.**

Our vision is for all Australians living with eczema to overcome difficulties and thrive in their community through connection, information and advocacy

This paper has been prepared by Eczema Support Australia in conjunction with an expert advisory group including Australian researchers and health professionals with a special interest in eczema, and in the fields of adult and paediatric dermatology, psychology, general practice and nursing. The aim of this paper is to provide an evaluation of what is known and what is unknown of the overall financial and humanistic burden of eczema in Australia in 2023, identify current challenges that exist with eczema care and make a call to action to address the most pressing of those challenges. This includes recommendations for how, collaboratively, key stakeholders and policy makers can support improvements in eczema management to improve better disease control, thus reducing the costs and associated burden placed on individuals, society and the Australian economy.

This paper has been developed using literature and data sourced from searches of Pubmed, CINAHL, the Cochrane Library, Australian federal and state government websites and Australian University thesis libraries. It has also been informed by personal communications from Australian medical and allied health research professionals.

Acknowledgements:

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Foreword

As the peak body representing Australian dermatologists, we welcome this report into the burden of atopic dermatitis (eczema) in Australia, and the opportunity to shine a spotlight on this common and often under-recognised condition.

For many years, eczema has been the ‘poor cousin’ of other allergic and immune system diseases when it comes to recognising and addressing its impact. While many living with the condition hide it and suffer in silence, it presents a heavy burden both on patients and Australia’s health system. This report seeks to bring eczema out of the shadows and to show that Australia can, and must, do better.

First and foremost, the report reveals that eczema affects nearly three million Australians, making it one of the 10 most common health conditions in Australia.

Second, the report highlights the profound impact of this disease on everyday life. As dermatologists who support thousands of Australians with this condition, we can attest to the distress and pain caused by severe eczema and the domino effect this can have on other aspects of life.

As dermatologists, our concern is to reduce skin irritation and protect the skin barrier. We understand that proper management of eczema not only prevents life-threatening infections but restores normal daily functioning for those affected.

We also endorse the report’s finding that there is a nationwide shortage of dermatologists, with just over 600 dermatologists to meet the skin health needs of 26 million Australians, and limited levels of dermatology education in medical schools and in general practice, where the majority of people with the condition are managed.

The good news is that many of the issues identified in this report can be addressed with a coordinated national response. Take for example widespread corticosteroid phobia – the common but misplaced fear of topical corticosteroids which often leads to the underuse of these valuable therapies, resulting in unnecessary disease flares. This has long been a concern of the College. However, until there is a coordinated effort to change these perceptions in general practice and pharmacy, Australians will experience avoidable and unnecessarily severe disease flares.

We recognise that there will always be constraints on the national health budget. We therefore acknowledge the need for an efficient, coordinated use of resources to not only address the education gaps and specialist shortage, but to also support improvements in consumer health literacy, as eczema is a condition which requires a high level of self-management.

A coordinated response will go a long way to ensuring all Australians with this condition have optimal and equitable access to treatment and care, which is why the College has no hesitation in commending this report – and the evidence for a National Eczema Strategy.

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President
The Australasian College of Dermatologists

Executive Summary - Evidence for a National Eczema Strategy

This report reveals the devastating and far-reaching impact of eczema in Australia and calls for a National Eczema Strategy to end the treatment maze that causes many to miss out on essential treatment and support.

Eczema (atopic dermatitis), is a common, often dismissed, incurable immune dysregulation skin disease that recent research[1] indicates affects up to 2.8 million Australians. It imposes a high burden on individuals, society and our healthcare system. Eczema causes red (darker brown, purple or grey on skin-of-colour), dry, scaly and often bleeding skin lesions, which are **painful, itchy and prone to infection.**

Often starting in early infancy and affecting up to 35.6%[2] of Australian children aged under six years old, **eczema is the most prevalent chronic inflammatory skin condition globally** and is associated with pain, severe sleep disturbance, impaired quality of life, mental illness and a higher risk than normal of many other serious chronic diseases.[3]

Children with eczema are at greater risk of being developmentally vulnerable at school entry[4]. As eczema often persists throughout a person's life, there is generally a need for long-term management by individuals and health professionals[5] with emollients, wet wraps and corticosteroid creams as a first line of daily treatment. **Managing eczema can be complex, expensive and take a psychological, social and economic toll** on the children, adolescents and adults affected and their families.

Eczema is an expensive disease, costing our Medicare system more than $593 Million in 2019-2020. Persons with eczema and their families incurred up to $336 million out of pocket costs for medical visits and an estimated additional $1.2 billion for the medications, emollients, special food and clothing needed to manage eczema symptoms on a daily basis. The income and capacity of working age individuals with eczema is affected with regular absenteeism and impaired productivity at work. This also reduced Australia's economy by an estimated $4 billion in lost productivity in 2022.

Currently, there is no cure for eczema and one in five Australian patients with moderate to severe eczema frequently find that their disease does not respond to conventional treatments. In the last five years, new medications offering significant symptom relief have been made available internationally, with the first of these listed on the PBS for eligible patients in Australia since March 2021.

Currently, however, there is limited approval to treat infants, children and adolescents who comprise a considerable proportion of those living with severe eczema in Australia. Many patients with eczema in Australia are undertreated, resulting in uncontrolled symptoms and increased burden. This white paper identifies the burdens that this disease places on Australia and Australians.

International research has shown that **timely management** of eczema flares and associated skin infections can significantly reduce the physical and mental health burden, and increase the financial burden and risk of severe co-morbidity.[7] Early intervention and joined-up support services can minimise the negative effects and support families.[8] In this paper, we draw attention to existing barriers, including lack of access to specialist dermatologists for Australians with eczema who require optimal/critical treatment.

We recommend that the barriers that need to be addressed most urgently are fears about the safety and side effects of long-term corticosteroid treatment, the nation-wide paucity of dermatology education for medical undergraduates and primary care health professionals, and the lack of education and support provided to patients and their families to assist in treatment adherence and eczema self-management.

A dedicated National Eczema Strategy is needed to:

1. **Standardise care to end treatment maze.**
2. **Address steroid phobia which leads to eczema flare-ups .**
3. **Prevent hospitalisation and manage co-morbidities.**
4. **Ensure equitable access to treatment.**
5. **Increase health literacy through patient education**
6. **End isolation via government funding to Eczema Support Australia.**
7. **Bolster dermatology training for GPs, nurses, and Aboriginal health workers.**
8. **Improve transitions from paediatric, adolescent to adult care.**
9. **Address dermatologist shortage (only 2.3 specialists per 100,000 Australians).**
10. **Establish an eczema registry.**

For full recommendations, see page 28.

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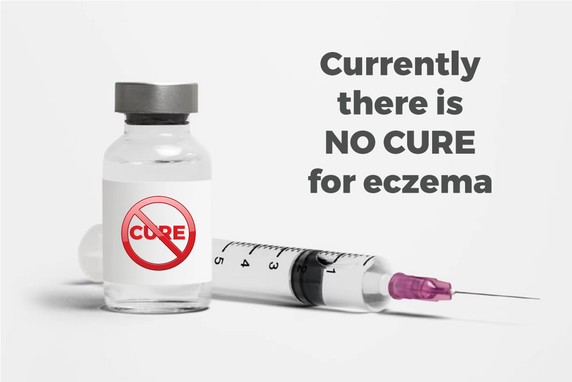
Eczema – A serious and incurable condition

What is eczema and how is it caused?

Eczema, also known as atopic dermatitis or atopic eczema, is the most prevalent chronic inflammatory skin condition globally. It is a chronic immune dysregulation disease that often begins in infancy and can progress in severity, but also affects a substantial number of adults.[9] Eczema is associated with significant, sometimes lifelong, ill health (morbidity). The disease interrupts the skin barrier[10] leading to inflamed, red (darker brown, purple or grey on skin-of-colour), rough, dry flaky skin. which is profoundly itchy and painful to touch. The constant itching and scratching can cause weeping and bleeding making skin vulnerable to infections and skin thickening and hardening[11]. This chronic, intense itch-scratch cycle is the hallmark of eczema and is persistent with flare-ups that can last 6 weeks or more.

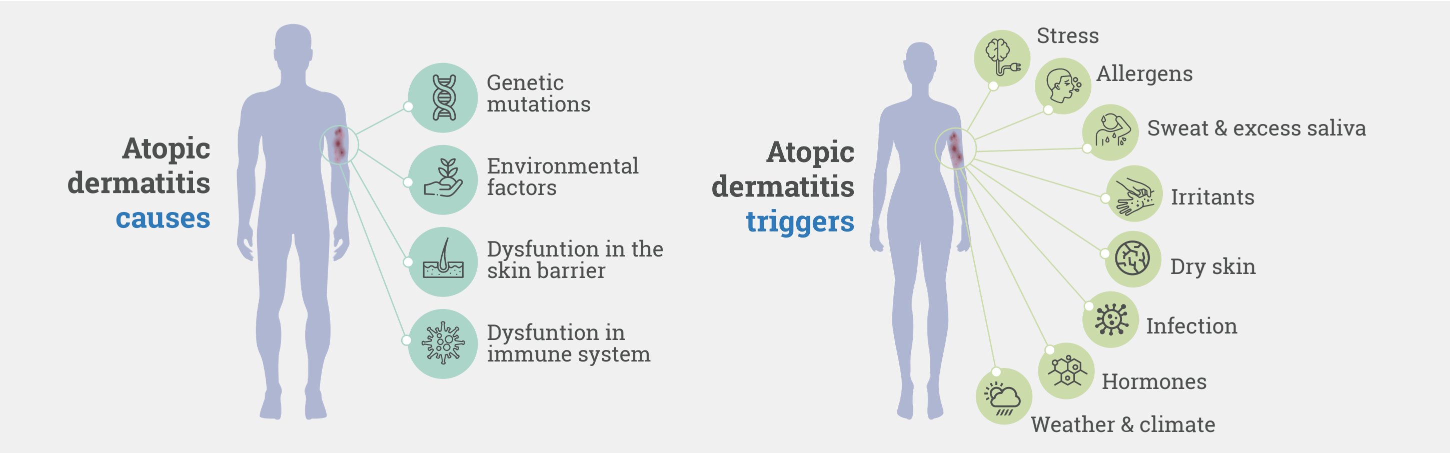


Eczema is a complex condition with a number of contributing causal factors including both genetic and environmental factors[12] (Figure One). Causal factors contributing to eczema include:

- Genetic mutations resulting in skin barrier defects characterised by reduced hydration and increased water loss.
- Genetic mutations resulting in immune system defects and dysregulation that increase the risk of eczema in infancy and childhood.[13]
- Climatic conditions including humidity, UV index, temperature, and precipitation that influence the prevalence of paediatric eczema.[14]
- Bacteria (especially Staphylococcus aureus),[15] viruses and fungi.
- Long term exposure to air pollution.[16]

Eczema flare ups can be caused by a variety of triggers (Figure One) including airborne allergens (dust mites, pollen, pet fur and dander etc)[17] , chemicals, heat, humidity, stress, hormonal changes, dry skin, sweat, saliva, skin infections, food allergens and short term exposure to air pollution (dust storms, bush fires etc).[18]

Figure One - **Causes of eczema and triggers which exacerbate eczema flares.**



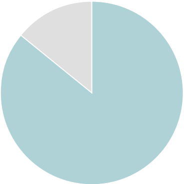
Source: AtopicDermatitis.net 2023

Eczema increases the risk of mental illness and behavioural disorders

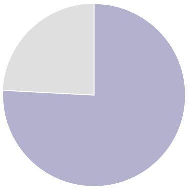
The evidence shows that good sleep is vital to maintain physical[19] and mental health and perform at our best.[20] The intense itch-scratch cycle of eczema often causes severe sleep disturbance, leading to daytime sleepiness[21] and can reduce an eczema patient's ability to move, work and think properly (functional impairment).[22,23] This has a profound adverse effect on quality of life, and can lead to unsatisfactory school and/or work performance, as well as a general reduction in health and safety. The ensuing financial costs are high.[24]

In addition to dealing with the debilitating medical aspects of eczema, patients also cope with a significant mental health burden. The sleep disturbance caused by eczema increases the risk of mental illness,[25] chronic headaches, and speech disorders[26]. Eczema is strongly associated with decreased quality of life, low self-esteem, bullying at school, career discrimination[27], low work productivity, irritability, decreased physical intimacy[28], disturbed sleep, anxiety, depression[29], suicidal ideation[30/31], attention deficit hyperactivity disorder[32] and conduct disorder.[33/34/35/36]

Severe eczema in children and adolescents results in:



86% of infants and young children with significant sleep disturbance[37]



76% of infants and pre-schoolers with disturbed sleep on at least five nights per week[38]

Approximately 50% greater risk of attention deficit hyperactivity disorder as a result of itch related sleep impairment[39/40/ 41]

Research shows children with eczema are also more likely to have cognitive dysfunctions such as memory impairment and developmental delays than children without eczema.[42] These studies[43] also show a significant increase in behavioural problems at age 15 years when eczema persisted at ages 5, 9 and 15 years. Eczema was associated with psychological disorders (anxiety, depression, worrying, being withdrawn, attention problems) and 12 aberrant behaviours, particularly fighting, physically attacking people, being sullen and threatening others.

Australian data from 2017-2018[44] showed adult eczema patients had an increased risk of insomnia, anxiety and are three times more likely to have depression[45] compared to those with no recorded eczema. The prevalence of suicidal ideation exceeds 20%[46] in adult eczema patients.

Furthermore, because this is a disease often starting in infancy and childhood, the mental health of family members, especially parents, is also affected by the condition.[47] Caring for a child with a chronic, unpredictable skin condition is stressful, requires a large time investment, and takes a toll on a family's finances and social networks.[48/49/50] These stressors are compounded by sleep disturbance and fatigue[51] and high levels of exhaustion, worry, isolation and helplessness.[52/53]

Recommendations are that the diagnosis and treatment of sleep disturbances and mental illness should be routinely factored into the management of eczema for both child and adult patients in Australia. However, only 3% of adult patients in a 2018 study[54] reported receiving any information about psychological help from their treating GP.

Eczema is a gateway disease to many other serious physical conditions

Adults and children with eczema often develop one or more co-morbid diseases including allergic conditions.[55] Recent studies of the large-scale adult and paediatric eczema population have shown that both paediatric[56] and adult[57] onset eczema sufferers are associated as having a higher risk of developing various psychiatric and systemic co-morbidities. This emphasises the systemic nature of eczema and the need to closely monitor patients for symptoms of other serious illnesses.

Eczema is commonly associated with elevated levels of immunoglobulin E (IgE) and can be the first disease to present in a series of allergic diseases (the atopic march), including food allergy, asthma, allergic rhinitis, allergic conjunctivitis and eosinophilic oesophagitis, in order.[58/59] Further related conditions are described in the next section.

Eczema co-morbidities extend well beyond this atopic march to other serious conditions. Recent research shows links between eczema and a higher risk of developing the following range of acute infections, chronic diseases and auto-immune conditions:

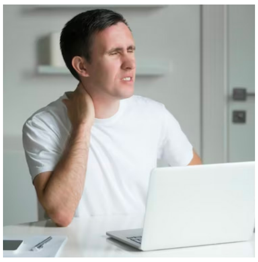
Skin infections[60] including cellulitis, impetigo, methicillin resistant and sensitive Staphylococcus aureus infections,[61] molluscum contagiosum, carbuncle / furuncle, erysipelas, cutaneous warts, herpes simplex and zoster viruses,[62] eczema herpeticum, dermatophytosis, and candidiasis of skin/nails and vulva/urogenital organs. Eczema patients of all ages are more than twice as likely to present to an emergency department with a skin infection.

Other chronic skin conditions including vitiligo and alopecia areata.

Immune dysregulation disorders - eczema was associated with 18 of 32 autoimmune disorders examined in adults, and 13 of 24 examined in children, including disorders of the skin, endocrine, gastrointestinal, hematologic, and musculoskeletal systems.[63]

An increased risk of other chronic inflammatory and systemic diseases including ocular disorders, lymphoid/hematopoietic malignancy, atherosclerosis, metabolic syndrome, diabetes and obesity.[64]

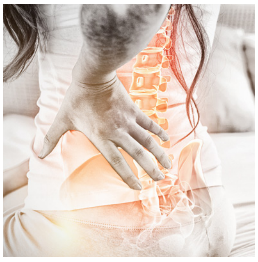
Cardiovascular disorders and cardiovascular risk factors including obesity,[65] metabolic syndrome,[66] hypertension, diabetes mellitus with complications, vascular, cardiovascular, and cerebrovascular disease, including peripheral vascular disease, peripheral and visceral atherosclerosis, pulmonary circulation disorder, congestive heart failure, a history of transient ischemic attack and cerebrovascular disease.[67]



Venous thromboembolism, especially deep vein thrombosis and pulmonary embolism.[68]

Infectious disease, especially hospitalisation for Herpes Zoster.[69]

Bone loss and associated bone fracture.[70]



How many people have eczema in Australia?

Eczema is a disease which can affect people of all ages, genders, ethnicities and socio-economic backgrounds. The worldwide prevalence rate of eczema is rising, and eczema affects up to 42% of children in some countries[71] and 2-10% of adults[72], with up to 60% of some paediatric eczema populations suffering from moderate-to severe forms of the disease.[73].

The short answer for Australia is that we don't have reliable government data available for how many people in Australia currently have eczema (prevalence), how frequently it occurs (incidence), how many people have long lasting (chronic) disease and what proportion of patients have mild, moderate and severe forms of eczema. This is partially because, unlike some other countries, Australia does not have a disease registry, like those for melanoma for example, or any other system for recording diagnoses of eczema outside of hospital settings.

The Australian Institute of Health and Welfare (AIHW) and the Australian Bureau of Statistics (ABS) have both drawn attention to this problem, rating the accuracy and reliability of data provided in government reports as variously 1/5 stars, having a greater than 50% error rate and too unreliable for general use. For example, the internationally published Australian burden of disease for eczema in 2018 was based on prevalence rates from a very small-scale community-based study conducted in regional Victoria in the late 1990s[74] and adjusted for increased 2018 population numbers.[75]

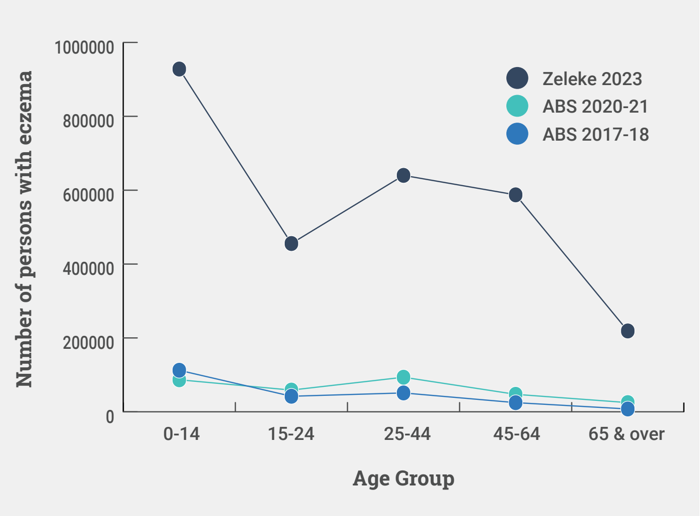
What we do know

1. A just published (February 2023) paper,[76] which analyses data collected on eczema from four Australian cohort studies – HealthNuts,[77] Melbourne Atopic Cohort Study,[78] Tasmanian Longitudinal Health Study[79] and the Australian[80] arm of the European Community Respiratory Health Survey – indicates the following prevalence rates of eczema by age group in Australia:
    - between 28.8% and 35.6% of Australian children under 6 years have had eczema with 16.7% - 24.7% having current eczema at the time of the study.
    - Between 14.6% to 24.7% of children aged 6 to 12 years had current eczema.
    - Between 12%-18% of children aged 6-10 years had a moderate to severe form of the disease.
    - Between 13.8% and 48.8% of adults surveyed have had eczema at some time in their life with current rates of eczema for at least the last 12 months being 15.1% at age 18, and 8.8% at an average age of 53 years.
2. These high rates of eczema are consistent with international findings. Assuming this data to be correct, our extrapolation using June 2022 figures from the Australian Bureau of Statistics for each age group would indicate as many as 2.8 million Australian may currently have eczema. We arrived at this estimate by multiplying the number of people in different age groups of the June 2022 Australia population of 25,422,788[81] by prevalence rates of an average 20% for children under 14, 15% for teens and young adults aged 15-24, 9% for adults aged 25 to 64 and 5% for adults aged over 65.

Figure Two contrasts this estimate that we have developed with age group data from the ABS and AIHW[82], on long term health conditions by age and sex, which estimated the total number of Australians with eczema to be respectively 238,000 in 2018-2017 and 311,000 in 2020-2021. Optionally volunteered answers to a question about "any other long-term illness" the respondent may have from Australia's National Health Surveys and National Census were used to estimate government figures. Unfortunately, this data discrepancy suggests the very real likelihood of governments and health service planners and funders severely underestimating the resources needed to address this common, incurable condition in Australia.

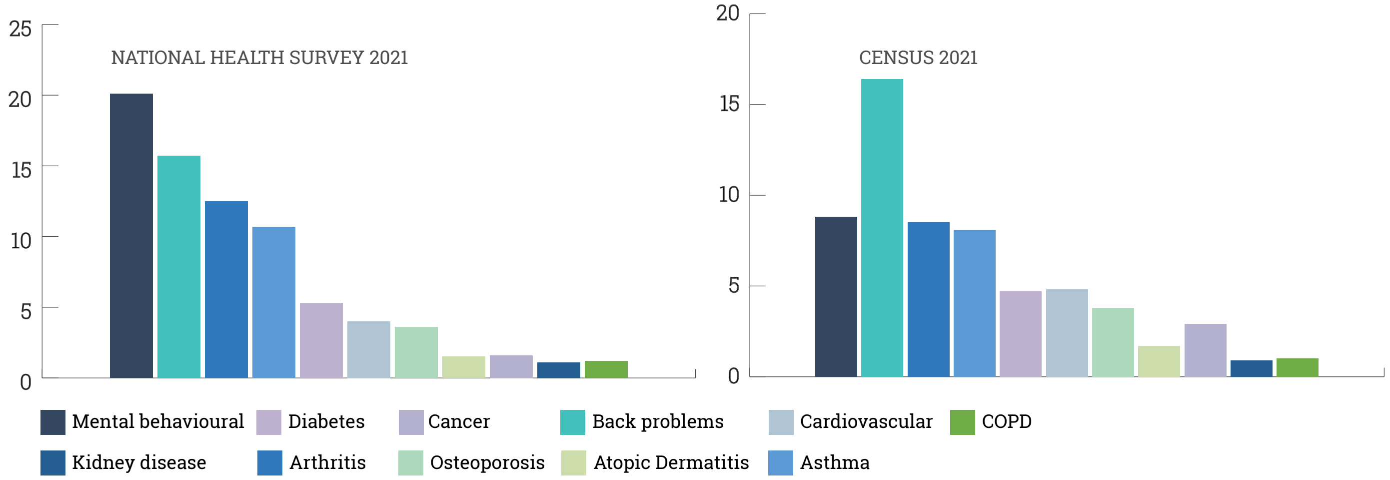
Despite these seemingly low figures, the ABS still found that, at 1% of the population, eczema (atopic dermatitis) was the 10th most prevalent chronic condition reported by people in Australia in 2020-2021 (Figure Three). If the actual average prevalence rate is 12%-15%, as suggested by the recently published research, then eczema would actually be the second or third most prevalent condition after mental and behavioural illnesses.

Figure Two – Contrasting current estimates of eczema incidence by age in Australia



Source: Disease prevalence data tables Australian Bureau of Statistics 2017-18, 2020-21 and Zeleke et al 2023

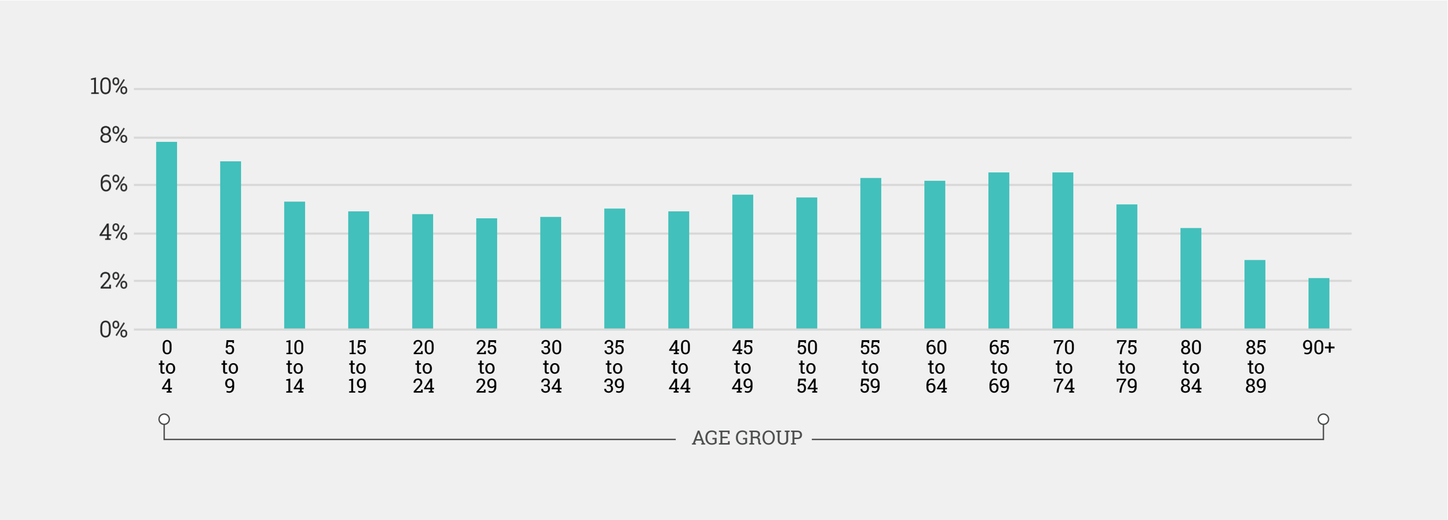
Figure Three: **Most prevalent chronic conditions experienced in Australia in 2020-2021**



Source: Australian Bureau of Statistics National Health Survey 2020-2021

3. General practice data[83] from a geographically and demographically representative cohort of 2.1 million patients seen across 494 general practices in Australia from 1 January 2017 to 31 December 2018, estimated that 16.4% of Australians will suffer from eczema at some time in their life. Of those diagnosed with eczema, 21.4% (around 600,000 Australians) were classified as having moderate to severe disease (Figure Four).

Figure Four: **Proportion of patients ever having dermatitis by 5-year age group Australia 2017-2018**



4. A 2008-2011 Melbourne based study of paediatric eczema[84] showed that a clinic observed prevalence of 20.3% at 12 months old while parents reported a cumulative prevalence of 28.0%.

5. Data from the Longitudinal Study of Australian Children (LSAC), which looked at the prevalence and persistence of 19 paediatric conditions among the same group of children from infancy to mid-adolescence (aged 14–15), demonstrated eczema prevalence declines as children grow older.[85]

6. Genetic heritage can impact prevalence. Eczema has been found to occur more frequently in people with an ancestry from the Asia and African continents.[86] For example Asian children born in Australia are more likely to have eczema compared to non-Asian children.[87]

How is eczema diagnosed and managed in Australia?

Eczema is diagnosed clinically based on history, symptoms, lesion morphology, and distribution. The majority of Australian eczema patients are diagnosed and managed in a general practice setting. General practitioner discomfort diagnosing and managing eczema leads to suboptimal patient outcomes.[88/89]

54% of Australian patients living with severe or very severe eczema in 2018 stated that doctors had told them there was nothing that could be done about it.

PEEK Study 2018

The chronic nature of eczema characterised by flares, exacerbations and periods of quiescence, requires a multipronged approach aimed at reducing itch, pain, skin inflammation and the appearance of secondary lesions. In addition, varying levels of maintenance therapy may be required to avoid exacerbations such as skin irritation and infection.[90]

The use of clinical practice recommendations by all healthcare professionals involved in eczema care is essential for delivering optimum healthcare for patients. Their intention is to describe the available options of care, with their benefits and possible harms and provide diagnostic and treatment options, based on the best available external evidence. They also permit integration of clinical expertise and patients' values and preferences[91] in a shared decision-making approach, which allows the best personalised referral path or treatment strategy to be chosen.

There is significant global variation in current treatment practices for eczema with management influenced by differing health-care systems, variable climate, access to medical care, access to medications and cultural diversity. Australia does not currently have a single best practice guideline for eczema management. While the Asia Pacific (Australian context) expert consensus recommendations for the management of eczema in adults[92] were updated in 2020 to include new treatments becoming available, most hospitals and professional bodies such as the Australasian College of Dermatologists and the Australasian Society of Allergy and Immunology (ASCIA) have their own recommendations and resources.[93]

Eczema management involves a stepwise approach from basic skin care with regular emollient for maintenance and prevention of flares to additional specific treatment of active eczema depending on its degree of severity (Table One). Eczema lesion distribution and morphology, disease impact, personal preferences, comorbid conditions, psychosocial factors, past therapies, and treatment accessibility all affect treatment choice, tailored to individual needs. Most patients with eczema can be adequately managed with effective eczema education[94], trigger avoidance, topical anti-inflammatory management of symptoms and phototherapy.[95] Education and psychosocial support of patients and carers is also critical for optimal treatment outcomes.

However, existing guidelines make no recommendation as to treatment order or treatment target, and criteria for the assessment of treatment success are not always well defined, creating a treatment maze. Consequently, decision making to select a treatment and to guide the assessment of its benefit in individual patients can be complex, and often subjective, and patients may not receive optimal management necessary for disease control.[96]

Many patients on topical eczema therapies have uncontrolled disease and report decreased quality of life and impaired work productivity, while physicians often report dissatisfaction related to control.[97] Currently, few treatments exist for childhood eczema and many parents report poor control with current medications.

88% of patients suffering from severe eczema say the disease compromises their ability to face life

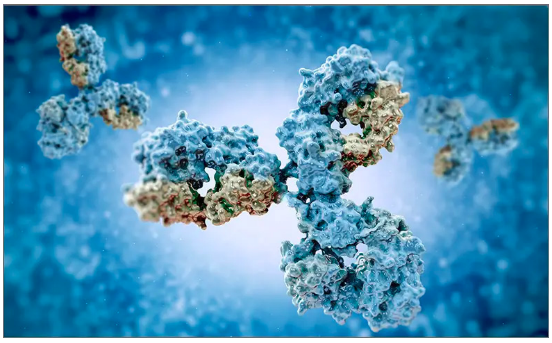
Ring et al 2019

Table One - **Stepwise management of eczema:**

Regular maintenance	Mild to moderate atopic dermatitis	Clinical infection	Moderate to severe atopic dermatitis	Severe to refractory atopic dermatitis
• Skin care (regular emolient). • Avoidance of triggers (detergents, irritants and allergens).	Add on: • Topical corticosteroids, calcineurin inhibitors, and/or crisaborole.	Add on: • Bleach baths. • Antibiotics if needed.	Review: • Diagnosis. • Adherence. • Infection. • Allergies (eg, patch testing). Add on: • Increased potency of topical corticosteroids and/or calcineurin inhibitors. • Wet wrap occlusion (short term, focal) • Phototherapy (especially non-facial atopic dermatitis, skin of colour). • Dupilumab (noting PBS criteria). • Systematic immunosuppressants (cyclosporin, methotrexate, mycophenolate mofetil, azathioprine, JAK inhibitors).	Review: • Diagnosis. • Adherence. • Infection. • Allergies • Referral to dermatologist. • Consider hospitalisation. • Consider clinical trials for new agents.

Source: Goh et al 2022 Management of atopic dermatitis: a narrative view[98]

New treatments can make a difference



Since late 2021 a number of new treatments are becoming available in Australia, including biologics and JAK inhibitors. Recommendations for a treat-to-target approach to guide optimal use of biologics and JAK inhibitors in eczema were recently developed via an international consensus.[99] This included a proposed clinical algorithm to guide shared decision making for systemic treatment in adults with eczema.[100]

Currently not all patients with moderate to severe eczema in Australia are eligible for these treatments, especially infants and children. The Therapeutic Goods Agency (TGA) is currently assessing a number of medications and their safety and efficacy for infants and children.[101] At time of writing, some of the available medications have not yet been subsidised under the Pharmaceutical Benefits Scheme (PBS).

There have been a number of clinical trials and other real world evaluation studies on the use of biologics for the treatment of moderate to severe eczema in adult patients over the last five years. Some significant findings from these include:

- **Rapid and persistent improvement in eczema,** including difficult to treat anatomical areas, with reduced disease severity and improved quality of life.[102/103/104/105/106/107]
- **Significantly reduced hospitalisation** and length of patient stay for both eczema and its co-morbidities.[108]
- **Improved quality of working life** with reduced absenteeism and increased productivity.[109]
- **Reduced itching, improved sleep quality**[110] **and reduced anxiety and depression** for both patients and their caregivers.[111/112/113]
- **Improved skin barrier function** with long term efficacy for moderate to severe eczema not controlled by topical corticosteroids or cyclosporine.[114/115/116]

Eczema taking a toll on individuals, families and the health system

Preventable treatment failure and suboptimal management of eczema is very common

In 2022, Eczema Support Australia participated in a patient survey across eight countries (Australia, Canada, Denmark, France, Germany, Italy, United Kingdom, United States) undertaken by the Global Patient Initiative to Improve Eczema Care.[117] Australian eczema patients were often dissatisfied with eczema treatment (av score 2.88/5) and struggle to achieve long term control of their symptoms (Figure five A). Australian patients and caregivers don't feel included in decision making about treatment (Figure five B). and more than half (53%) are dissatisfied with help they have received from doctors and other medical professionals. [118]

Figure Five A – **Long-term control of symptoms**

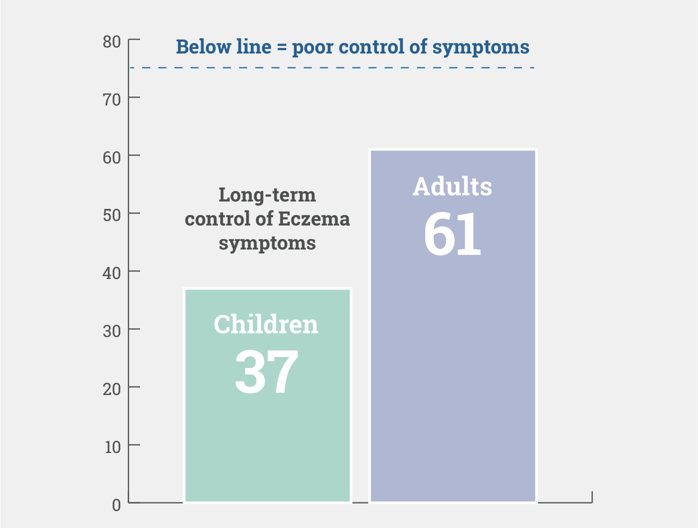
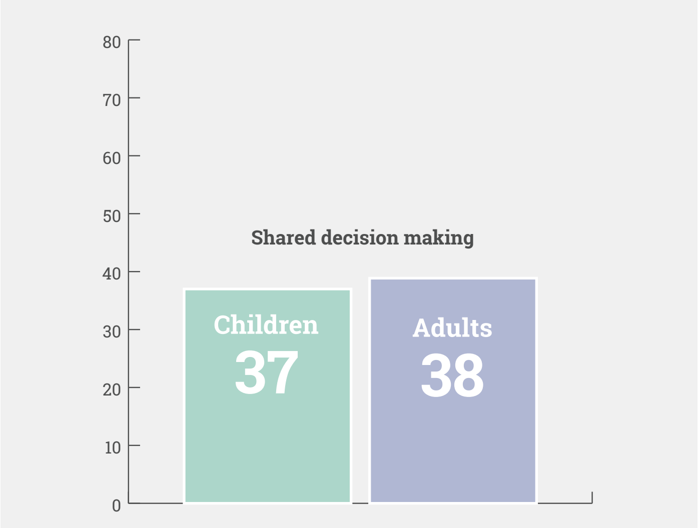


Figure Five B – **Involvement in shared decision making**



Source: www.improveeczemacare.com/Australia

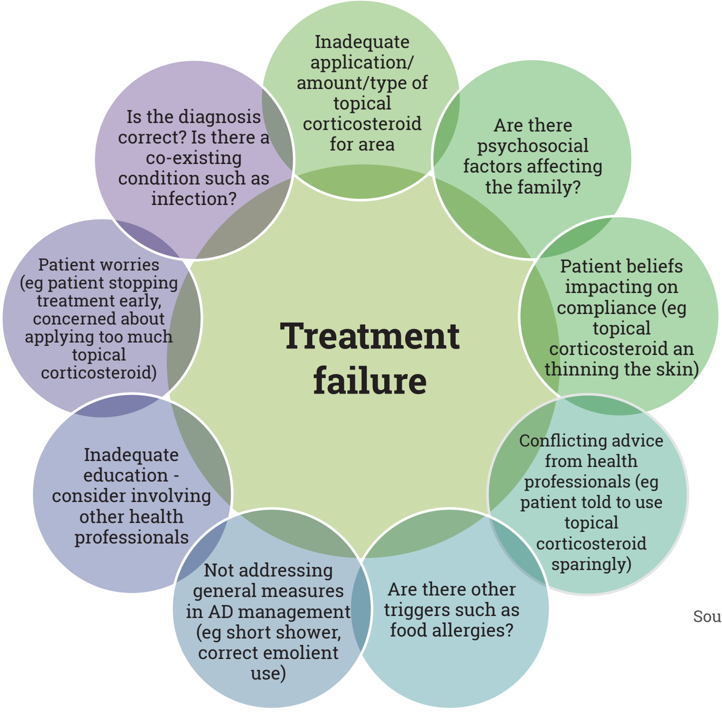
Topical corticosteroids (TCS) are the mainstay of treatment in eczema flares, with 94% of Australian adult patients surveyed in 2018[119] reporting current treatment with corticosteroids. Fear and anxiety about the safety of TCS, known as corticophobia, is common in patients with eczema,[120/121] the parents of children with eczema, and the treating health professionals,[122/123] with many people believing the treatment to be dangerous.[124] Corticophobia is a major source of treatment non-compliance and treatment failure in eczema patients internationally and in Australia.

Internationally, pharmacists, general practitioners, nurses,[125] public healthcare physicians, paediatricians and dermatologists have all displayed significant levels of corticophobia ranging from almost 50% in primary care to up to one third of dermatologists.[126] This is also common among Australian GPs[127] and pharmacists.

Patients and their caregivers[128] don't understand how topical corticosteroids work and what the side effects can be. Information about corticosteroids,[129] often conflicting, is provided by friends, relatives, broadcast media, print media, social media and the internet[130] as well as the medical specialists, GPs, nurses and pharmacists involved in their care. When patients consistently receive negative messages about topical corticosteroid risk from social media in particular, as well as their GP or pharmacist, their corticophobia and poor understanding of TCS safety can lead to treatment non-compliance. On the other hand, parents and caregivers who have received information emphasising the beneficial effects of TCS from dermatologists and paediatricians, demonstrate less concern about using TCS and consequently their children have a lower number of disease flares.[131]

The right amount of TCS to use and the frequency of applications are some of the concerns that should be addressed with patients as part of patient/carer education.[132] An Australian study[133] has demonstrated that appropriate use of topical corticosteroids in mild to moderate eczema can minimise mild eczema symptoms without side effects. In general long-term, TCS treatments are considered safe in both adults and children.[134] However, a 2017 survey of Australian GPs[135] showed up to 48% regularly provide patients with instructions to minimise the amount, coverage and duration of application of topical corticosteroids, contrary to recommended treatment guidelines.

Figure Six – Corticophobia and other causes of treatment failure in childhood eczema.



Source: Australian Family Physician 2016[136]

Patients need to be capable of selecting and filtering reliable information content in order to make accurate health decisions. Health literacy is responsible for the capacity and critical choice in health behaviours. A recent study has suggested higher health literacy is associated with lower corticophobia[137] across patients, caregivers and healthcare professionals. The promotion of eczema and corticosteroid health literacy to all these groups is essential for correct use of TCS and good control of eczema.[138] Whether intentional or unintentional, non-adherence to treatment can limit patient outcomes for a variety of reasons.[139/140]

Other challenges contributing to suboptimal eczema treatment or treatment failure in Australia include:

- A lack of dermatology training and exposure in undergraduate (average 5 hours or less) and general practice medical training in Australia, despite the majority of treatment being centred in primary care.[266]
- Under Australia's fee for service model, there is a financial dis-incentive for GPs undertaking a consultation where time is taken to provide patient education, especially as eczema may be only one of a number of issues discussed in that consultation.
- Disconnects exist between different treating sectors in the health system which compounds the treatment maze.
- Disconnects in transition of care for adolescents from paediatric to adult services in the public sector.
- Barriers to accessing specialist dermatologist treatment if needed. A long-term national acute shortage of dermatologists has resulted in only 2.3 specialists per 100,000 Australians. The shortage is not due to a lack of doctors interested in becoming dermatologists but rather to insufficient public investment in dermatology services and in the registrar and consultant positions needed to grow the dermatology workforce.Added to this, the majority are based in the central areas of large cities. This means patients have long waiting periods for both public and private dermatology treatment. For regional, rural and remote zone patients, the distance, time and cost needed to attend an appointment in person may be prohibitive.[141]

  www.dermcoll.edu.au/about/dermatologist-workforce/

- Limited eligibility to access the most recent systemic treatments – currently Dupilimab (Dupixient), Baricitinib (Olumiant) and Upadacitinib (Rinvoq) has been approved by the TGA for treatment of eligible adults and adolescents aged 12 and over (2021).[142] Some treatments have an age limitation, and some are not yet subsidised by the Pharmaceutical Benefits Scheme (PBS). Dupilimab and Upadacitinib can be accessed at a subsidised cost under the (PBS). Treatment with these medications can only be initiated by a dermatologist or immunologist after an eczema flare has been inadequately controlled for 28 days or more.[143]
- High out of pocket costs for patients, especially those with severe eczema, can lead to patients delaying medical appointments and not filling necessary prescriptions,[144] nor purchasing emollients and other products necessary for ongoing management of their condition.

Identified factors leading to poor treatment adherence include: complexity of treatment regimen, lack of knowledge, dissatisfaction with treatment strategies, infrequent follow up, corticosteroid phobia, fear of medicated baths and the use of complementary and alternative medicine.

Effective strategies to increase treatment adherence include: caregiver education and utilisation of educational resources, optimisation of the patient/caregiver–clinician relationship, to help patients navigate their way through the treatment maze early and frequent follow up and improvement of patient and caregiver quality of life.[145]

Eczema can lead to a very poor quality of life

Eczema has substantial effects on the psychosocial well-being and quality of life of patients. In addition to significant morbidity, eczema is associated with impaired health-related quality of life and considerable financial cost. Recent studies[146] show that a higher proportion of adults with eczema report having poor overall health (26% vs 16%) than a control group with worse scores for both physical and mental health. Eczema was found to limit lifestyle, led to avoidance of social interaction and impacted daily activities.

Caring for children affected by eczema can be an extremely time-consuming task that can impair personal relationships, decrease psychosocial functioning, and cause sleep loss among family members of affected patients.[14] Additionally, eczema may result in work absence or decreased work productivity for caregivers. Special diets, irritant and allergen avoidance strategies, and alternative therapies are commonly used by patients to manage their disease and require large amounts of family involvement.

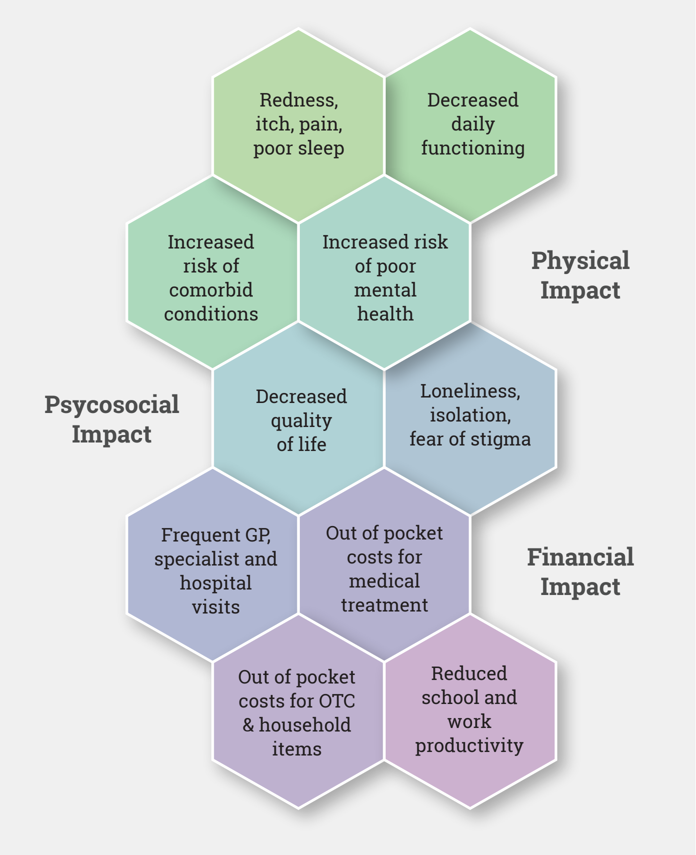
Research[148] indicates that the family stress related to the care of children with moderate to severe eczema is significantly greater than that of the care of a child with type 1 diabetes mellitus. The factors contributing to family stress include sleep deprivation and loss of employment. Time taken for eczema care and financial costs are compounded by inconsistent eczema information and a lack of paediatric practice guidelines..

Having an understanding of the burden of eczema is important for healthcare professionals as they assess and manage eczema in the clinical setting. Early intervention and psychotherapy may be needed in some patients to address these quality-of-life impairments.[149]

> **Hearing your child screaming in pain for hours on end is beyond heartbreaking**
>
> **Capozza et al 2019**

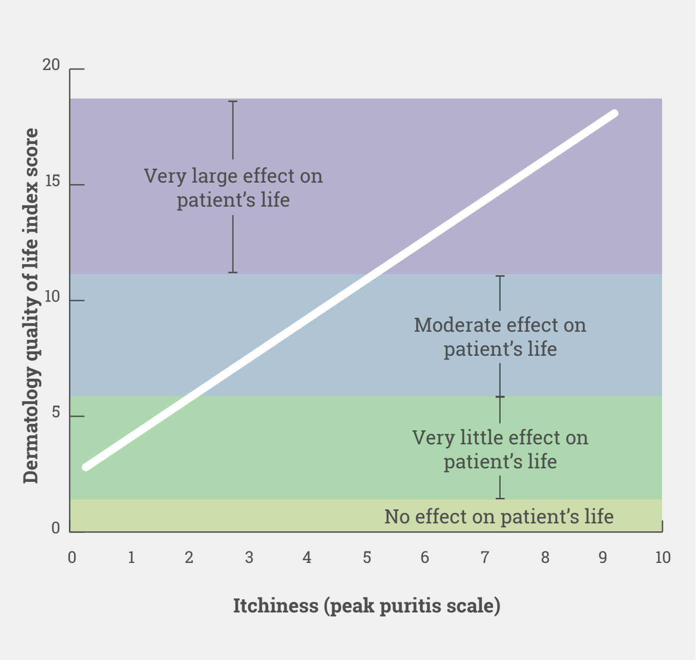
Figure seven illustrates the numerous ways in which moderate to severe eczema can impact the physical, mental health, social and financial wellbeing of patients .

Figure Seven – The personal impact of Moderate to Severe Eczema



Research has shown that the more severe eczema and its related itchiness (puritis) becomes, the worse a patient's quality of life becomes (Figure Eight).[150/151/152]

Figure Eight – Relationship between rating of itchiness and eczema related quality of life



Gooderham et al 2021[153]

Having eczema can be very expensive

Having eczema, particularly in childhood, comes with a high financial burden. Given the increasing global prevalence of eczema in recent decades, and what looks to have been a considerable underestimate of the number of people in Australia with eczema, understanding these costs is becoming even more important.

The economic burden of eczema in Australia includes direct and indirect factors. Direct costs includes medical and hospital visits, costs of medicines and other items used in treatment. Indirect costs come from reduced performance in school and at work, and the associated loss of employment and career opportunities.

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Costs for the health system

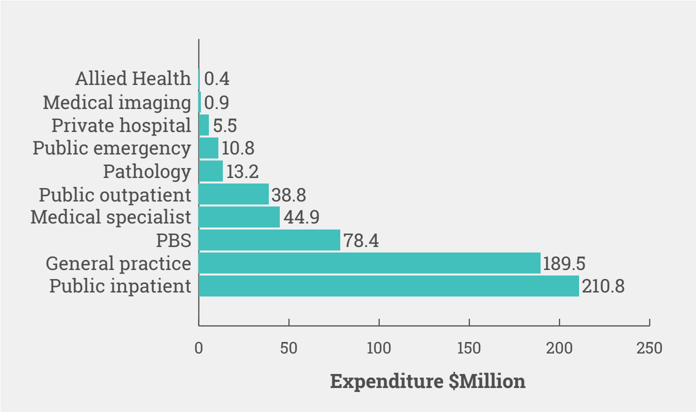
Under the Medical Benefits Scheme (MBS), the Pharmaceutical Benefits Scheme (PBS) and state based public hospital funding, government health departments absorb a considerable proportion of the cost of medical treatment for eczema in Australia.

The latest Australian Institute of Health and Welfare annual data estimating disease-specific health expenditure[154] available is for the 2019-2020 year. This data shows that, out of a total health spend of over $140 billion, $4.8 billion (3.42%) was spent on skin disorders (excluding skin cancers).

When looked at in more detail, skin disorders were ranked 12/21 for overall health expenditure but ranked 8/21 for primary care expenditure. Skin disorders, at 16.67% had the largest increase in health expenditure between 2018-19 and 2019- 2020 of all disease groups.[155]

Expenditure on eczema in 2019-2020 was $593 million, with the highest spends on hospital admissions and general practice visits (Figure nine). Unlike other skin conditions, eczema incurred significant expenditure across all age groups of Australians (Figure ten). With the introduction of expensive new medications, a major cost driver for Australia in the next five years will be the additional PBS costs associated with the use of systemic biological treatments for severe eczema.

Figure Nine – Eczema and Dermatitis Australian Health System Expenditure by type of service 2019-2020

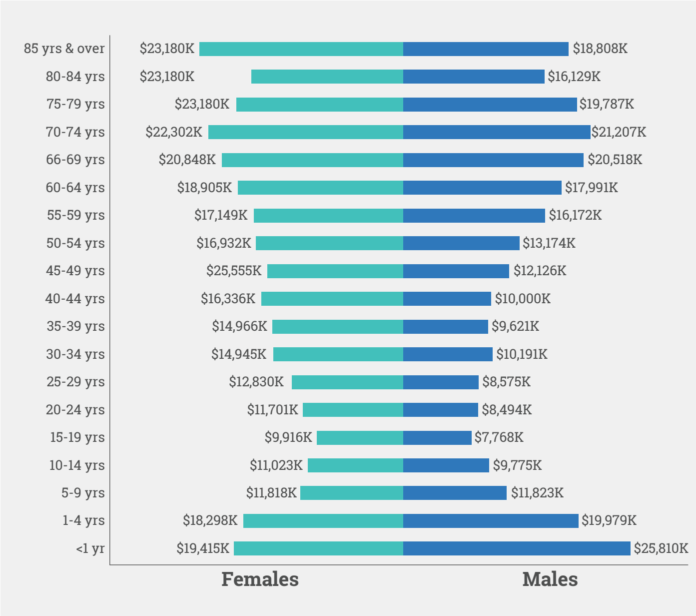


Data Source: Disease expenditure in Australia 2018-2019 AIHW August 2021

The Australian Institute of Health and Welfare estimated eczema as a cost to the health system of $70 per case in 2018-19,[156] which is significantly lower than other chronic diseases such as psoriasis ($363), asthma ($287), coronary heart disease ($3,496), stroke ($2,880), anxiety disorders ($1,056) and depressive disorders ($2,549).

> **While treatment with biologics is the main new health system cost driver in eczema management, patient related benefits of therapy with highly priced biologics are reflected by significantly better clinical outcomes compared to traditional therapies**
>
> **Mohr et al 2019**

Figure Ten – Australian government expenditure (thousands) on eczema by age group and gender 2019-2020



Source: Australian Institute of Health and Welfare 2022

The cost for individuals and families

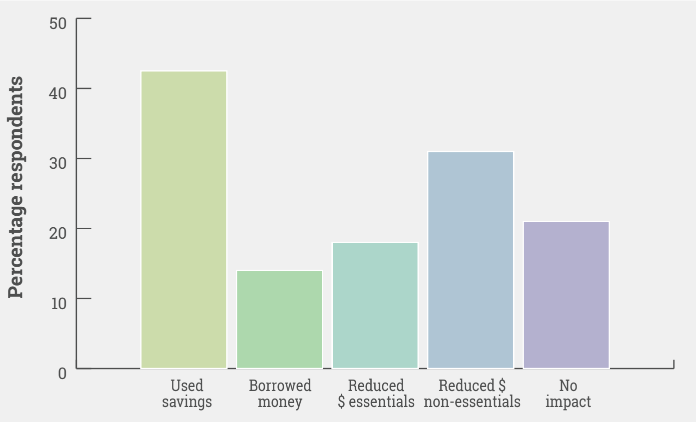
Out of pocket expenditure on healthcare as a proportion of the total household expenditure on all goods and services increased by more than 25% between 2009-10 and 2015-16, when the average annual out of pocket expenditure was A$4290 per Australian household, representing 5.8% of the amount spent on all goods and services.[157] Although we do know that out of pocket healthcare expenditure is relatively high in Australia, little is known about what health conditions are associated with the highest out of pocket expenditure[158]. Rising co-payments for medications, prescription medications for chronic conditions, private medical consultations, poorly subsidised health support, non-health logistics (e.g., transport) and eligibility barriers for existing social support, pose a substantial financial burden to many households, particularly those with low incomes and general pharmaceutical subsidies.[159/160]

People with chronic disease in Australia struggle to afford healthcare,[161] particularly if they are already under financial stress. As a result, individuals and families skip medication doses and pathology tests, and delay or cancel filling a prescription or visiting a doctor.[162]

Out of pocket costs are an additional day to day financial burden for adult eczema patients and the caregivers of paediatric patients. Additional costs can include emollients, moisturisers, medications, bandages, special clothing, special foods, cleaning products, gloves, bedding, personal hygiene products, washing powders, medical practitioners, hospital outpatient costs, travel expenses, phototherapy, hospital inpatient treatments and much more.[163]

In a 2022 global survey[164] of adults and caregivers, 75% of Australian respondents said eczema had placed an additional financial burden on their family. Many had to use savings, borrow money, spend less on food and other essentials or spend less on non-essential items (Figure eleven). Australia ranked 7/8 participating countries (with 1 being best) with only the United States ranked worse.

Figure Eleven - Financial impact on families living with eczema in Australia 2022



Source: www.improveeczemacare.com/Australia

International research indicates that the indirect costs[165] of eczema may substantially exceed the direct costs for healthcare, medications and other treatments.[166] Childhood eczema can have far-reaching and profound impacts that affect parents' decisions to work or to have more children. Household finances may be reduced by loss of income as well as the many costs involved with eczema management.[167] In addition, the loss of productivity from absenteeism to care for a sick child can be three times that of an absence due to a worker's own illness.[147]

Indirect costs of eczema include loss of current and future income through absenteeism and reduced productivity at both school and work. Average days of absenteeism due to care of a child with eczema or worker's own illness range from 10 to 20 days a year.[168/169/170]

We estimate that, based on 15 days average absenteeism for the approximately 1 million working age (15-64) Australians with eczema, would be $3932 each or up around $4 billion in lost productivity for Australia, calculated at the 2022 average wage of $34.95 per hour.[171] For those with very severe eczema, absenteeism averages 1 day a week plus another 19 hours of reduced productivity.[172] These indirect costs of eczema can be significantly reduced by early diagnosis and appropriate treatment.

There is little evidence-based information to quantify current out of pocket costs for eczema patients in Australia, with a 2004 publication being the most recent we could find. This study showed a relationship between increased morbidity, severity of eczema and increased cost, and the average annual out of pocket costs for products used for treatment was $425 (up to $2000), and for medical consultations was $120 (range from $0-$800).[173] Using this, nearly two decades old average data, would equate to current Australian out of pocket costs of $1.19 billion for treatment products and a further $336 million for out of pocket medical costs for 2.8 million people with eczema.

We do know that Australia ranks among the highest OECD nations for out of pocket healthcare spending.[174] As a proportion of the total household expenditure on all goods and services, healthcare out of pocket increased by more than 25% between 2009-10 and 2015-16.[175] In 2014 seniors in Australia with one chronic condition had average annual out of pocket expenses of between $1744 (emphysema) and $2808 (cancer).[176]

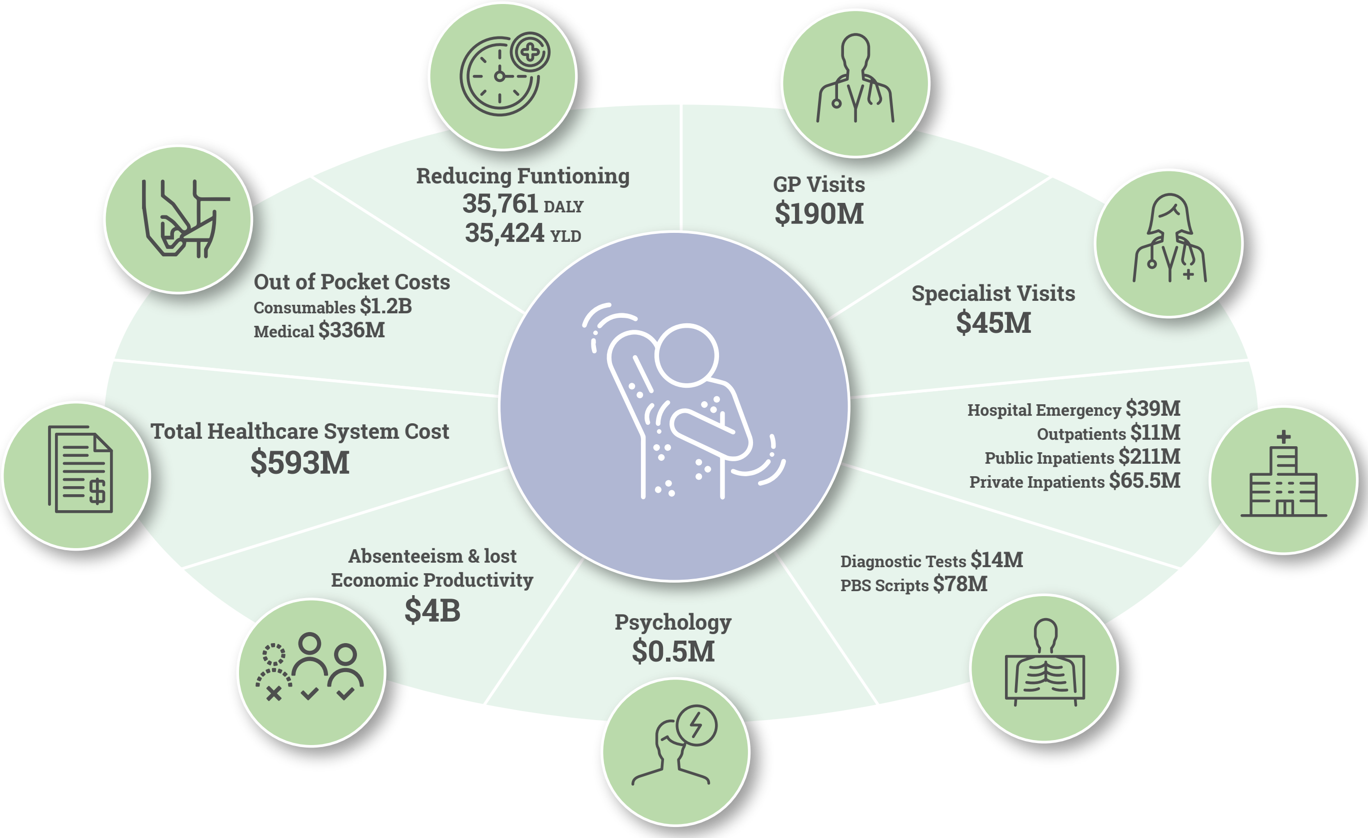
There is a lot of recent international evidence, particularly from North America and Europe. However, because of large variations in healthcare system subsidisation and costs for example, it has been difficult to use these in the Australian context. **Some recent international out of pocket costs for patients with severe eczema are:**

- Up to $US5000 (AUD$7800) in the USA[177] in 2019.
- Up to E2300 (AUD $3600) for medications in Ireland[178] in 2019.
- Average E20983 (AUD$32,000) if using biologics and E2470 (AUD$3950) without biologics in Germany[179] in 2019.
- Average E463 (AUD$720) on non-medical out of pocket costs in France[180] in 2018.

This would indicate that the real out of pocket economic impact on Australians with eczema might be even higher than the calculations above, especially for those with severe disease.

Figure Twelve is our attempt to bring an estimate of the total economic cost together in an understandable way. Calculation of data included is explained throughout this paper.

Figure Twelve – **Estimated economic burden of eczema in Australia - 2019-2020**



Eczema places stress on the capacity of the Australian health system

Medical treatment of eczema can involve hospital and community based medical practitioners, psychologists, nurses[181], pharmacists, dieticians and other allied health and alternative therapy providers. Eczema places a significant capacity burden on the Australian health system as well as a financial burden on patients, caregivers and the community.[182]

In 2011, eczema was found to be the third most frequent new diagnosis in paediatric outpatient practices, with 20% of cases referred for specialist treatment.[183] Eczema was also the 9th most frequent reason for patient review.

We have found that Australian economic data may significantly underestimate health system and out of pocket costs, given that prevalence, incidence and burden of disease figures are considered very unreliable. Added to this, data around GP visits for diagnosis / management and corticosteroid dispensing in pharmacy are not recorded in analysable registries. This makes it difficult to quantify both the financial and capacity impact, as well as unfulfilled healthcare needs of eczema and its preventable co-morbidities in Australia.[184]

Analysis of a representative 20% cohort of children and adults of hospitalisation (70 million) and emergency department visits (200 million) in the United States over a ten-year period (2002-2012) [185/186/187] showed significantly longer and more frequent inpatient stays and related costs for co-morbid conditions in patients with eczema.

This would indicate that investing in efforts to improve the management of disease flares in patients with moderate to severe eczema, and thus preventing exacerbation to hospitalisation and co-morbidity, will provide significant personal, societal and economic benefit to Australia.

Eczema has the highest burden of all skin disorders

Burden of disease analysis measures the impact of different diseases or injuries on a population by measuring how many years of life Australia loses to diseases either due to people: dying early (fatal burden) or living with ill health (non-fatal burden). Burden of disease is measured in disability adjusted life years (DALY) and years lived with disability (YLD).[188]

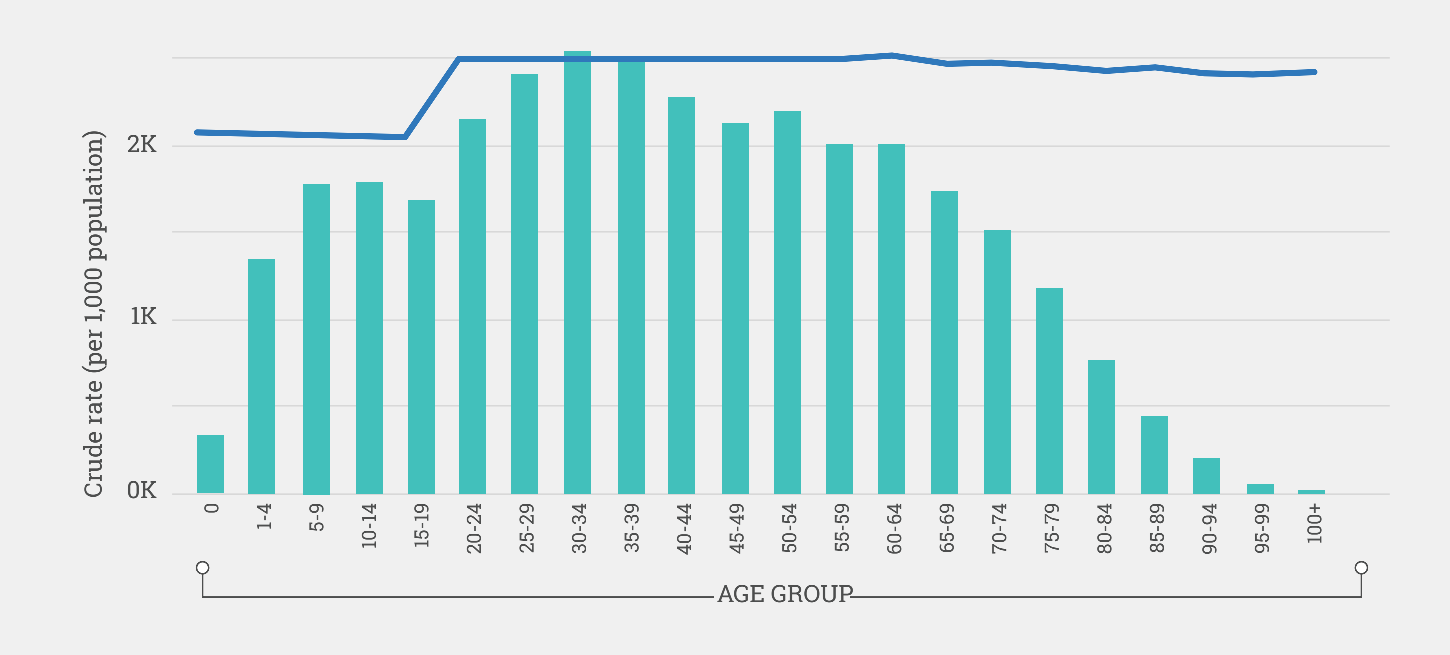
Burden associated directly with eczema is almost always non-fatal. Eczema was the 20th highest cause of non-fatal burden in 2022[189] , estimated to be 37,228 DALY – equivalent to 1.43 DALY per 1000 persons, making up 0.7% of the total disease burden. Eczema carries a similar burden across both genders and for Indigenous and non-Indigenous Australians. The leading causes of non-fatal burden were back pain/back problems, anxiety disorders, depressive disorders and asthma.[190] Figure thirteen shows that the non-fatal burden of eczema impacts all age groups in Australia, with a peak burden on adults aged 20 to 50 years. It is also the only single skin disease with a similar burden on Australians, no matter their age or gender.

Burden of disease data for eczema is very unreliable

Burden of disease data (DALY, LLD, YLL) is generated by using prevalence rates for a disease, ideally with current prevalence data being available including age, gender and geographic variations in prevalence if available. Unfortunately, AIHW data quality notes[191] for Australia burden of disease studies alert us to the fact that all burden of disease data on eczema since the 2003 report have derived national prevalence rates and severity distribution from the results of a small-scale community based study of school-aged children conducted in regional Victoria in the late 1990s.[192] The report rated the accuracy and reliability of its eczema data as 1/5 stars – compared to data reliability for psoriasis @ 4/5 stars. Unfortunately, this has resulted in a flat rate of disease burden rate of around 1.4 DALY per 1000 people for the last 20 years. Any increases in total DALY and YLD figures are purely related to the increase in Australia's population.

Based on the knowledge that prevalence of eczema has been increasing worldwide in the last two decades, we expect that the actual 2022 eczema burden of disease may be much higher than reported.

Figure Thirteen – The estimated burden of disease for dermatitis and eczema in Australia 2022 by age group.



Source: Australian Institute of Health and Welfare 2023 Australian Burden of Disease Study 2022: Interactive data on disease burden.

The compelling case for a National Eczema Strategy

With nearly 3 million Australians impacted by eczema, there is a compelling need for a National Eczema Strategy to address the challenges families and individuals face dealing with eczema. Because this is primarily a disease of infancy and childhood, family members, especially parents, are also affected by the condition. Individuals and family members are burdened with a time-consuming treatment regime for eczema management as well as dietary and household changes. The financial impact of eczema on families can also be large and the cost to society and our health system is also significant.

> **Our current health system is not optimally set up to effectively manage long-term conditions.**
>
> **Department of Health 2015**

Having timely access to health-care professionals when a person needs it is crucial to preventing, treating and managing health conditions.[193] Patients with a chronic disease such as eczema may require support navigating barriers in Australia's complex healthcare system. They will often require healthcare from a range of disconnected providers. Responsibility for funding and delivering these services may be spread across the public, private and non-profit sectors. This can result in confusion for patients, poorer health outcomes and a lack of continuity of care.

As identified in the 2015 report Better Outcomes for People with Chronic and Complex Health Conditions,[194] Australian patients often experience a fragmented system, with providers and services working in isolation from each other rather than as a team. Care is often not co-ordinated and patients / caregivers have difficulty finding the services they need. Patient access is worsened by lack of system knowledge, high cost of services, distance from providers, lack of transport, language barriers / cultural barriers and mobility issues. This can result in feelings of disempowerment, frustration and disengagement.

Australia's Primary Healthcare 10 Year Plan shares a vision for enhanced access to primary healthcare services for all Australians to support health and well-being in the community. However, from a health system perspective, there are no specific federal initiatives in place for eczema as it is not currently a national health priority area, despite being identified as the 10th most prevalent chronic disease in Australia in 2021.[195]

Unlike other prevalent long-term conditions such as asthma, arthritis, diabetes and back pain, the impacts of eczema on the health of Australians and costs to the health system, both through the disease itself and the increased risk of co-morbid physical and mental health conditions, are not well recognise in the Australian strategic health policy, service planning and funding landscape.

This has significant impacts on many aspects of care such as funding of disease registries, funding of specialist dermatology training places, inclusion in medical and allied health training curricula, recognition of mental health impacts, provision of public hospital services, provision of specialist outreach to regional and remote Australia, funding of PBS access to specialised medications, funding of research and the implementation of models of shared care.

Even with advances in treatments such as biologicals and JAK inhibitors, which have only recently become available in Australia, a large percentage of patients with moderate to severe forms of the disease are considered to be undertreated and / or have inadequate control of their symptoms.

Considering the shortfalls in the current treatment of eczema which leaves many Australians undertreated, a National Eczema Strategy is needed to:

- Standardise care to end treatment maze.
- Address steroid phobia which leads to eczema flare-ups.
- Prevent hospitalisation and manage co-morbidities.
- Ensure equitable access to treatment.
- Increase health literacy through patient education.
- End isolation via government funding to Eczema Support Australia.
- Bolster dermatology training for GPs, nurses and Aboriginal health workers.
- Improve transitions from paediatric, adolescent to adult care.
- Address dermatologist shortage (only 2.3 specialists per 100,000 Australians).
- Establish an eczema registry.

Priority One – Eczema management education and support for patients and their families

Undertreatment and poor treatment compliance are significant barriers to eczema patients being optimally managed in Australia.

The goal of this priority action is to empower eczema sufferers, their caregivers and families with the knowledge, skills, confidence and support needed to better understand and self-manage their condition.

Reducing the burden of eczema on Australia must take into account the full breadth of its burden. Targeting parents and caregivers with education and psychosocial support can decrease family and personal burden, which in turn may decrease the cost of treating the condition because of better medical, psychosocial, and family outcomes.

Patients and their caregivers want to understand eczema and its treatment

Treatment adherence improves as health literacy increases

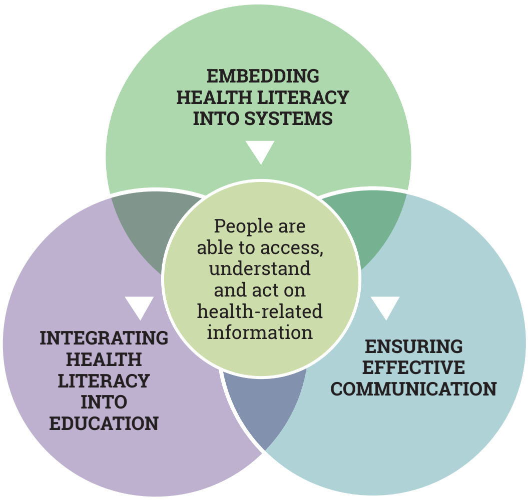
The Better Outcomes[196] report found many factors that contribute to patients experiencing poorer quality care and increased rates of adverse outcomes. Key factors include variation in care provided between clinicians, services and geographic locations. A patient's choice, expectation and participation in their care can also significantly influence their health outcomes, especially when the patient or their caregiver has low health literacy.

Poor patient-related clinical outcomes have been linked with low health literacy for many chronic diseases of childhood. If a patient / caregiver can't fully understand the diagnosis and treatment regime, their ability to self-manage the condition may be compromised. Low health literacy can also negatively influence interactions with healthcare professionals and peers.[197]

Internationally, low health literacy is recognised as a public health challenge, which is modifiable through effective educational intervention and health system improvement.[198/199] As health literacy increases, so does a patient's treatment adherence. Adequate health literacy is also significantly associated with patients' preferring to be involved with treatment decision making.[200]

The National Statement on Health Literacy 2014[201] was endorsed by all federal, state and territory health ministers signalling their in-principle commitment to addressing health literacy in Australia using a coordinated approach (Figure Fourteen).

Figure Fourteen – A coordinated approach to health literacy for Australia.



Source: Australian Commission on Safety and Quality in Healthcare[202]

Eczema health literacy in Australia is poor

Knowing the level of health literacy in a disease community, can offer health and community organisations insights into the challenges people experience when trying to access and engage with their services. The 2018 Australian PEEK (Patient Experience Expectations Knowledge) adult eczema patient study[203] identified significant gaps in knowledge and understanding of their disease and a lack of confidence in themselves and the professionals managing their treatment. For example, 45% of respondents knew nothing about eczema at diagnosis and only 54% understood that eczema can be an incurable lifelong condition. More significantly, only 3% of respondents had received information about the potential psychological impacts of eczema and the need for additional professional support in this area.

Three out of four (75%) of PEEK study[204] respondents used the internet as their main source of information rather than their treating health professional. They identified charitable or not for profit organisations such as Eczema Support Australia as their most trusted sources of information. Patients and caregivers wanted more advice on where and how to find information on their disease and its treatment and for that information to be more easily available and accessible.

Despite having experience of eczema since childhood, teenagers and young adults with eczema express uncertainty about treatment and how it affected their bodies. They often perceive the availability of healthcare and knowledge of treatments among primary care providers to be limited. They do not usually receive support from health professionals to self-manage their care, which affects young adult's possibility to take full control of their eczema management.[205]

Proven ways to improve eczema health literacy and self-management outcomes

Health coaching[206] or patient education helps patients gain the knowledge, skills, tools and confidence to become active participants in their care so that they can reach their self-identified health goals.

Self-management is defined[207] as "the active participation by people in their own healthcare". Self-management involves consumers adopting attitudes and learning skills that facilitate a partnership with carers, general practitioners, and health professionals in treating monitoring and managing their condition".

Therapeutic patient education (TPE) programs have become indispensable for managing chronic diseases and should be an important part of healthcare for eczema patients. TPE approaches depend on considerations that include the clinical setting, the country and its organisation of health services, and socioeconomic and cultural factors.

Multiple publications have shown the positive effect of TPE on the course of the disease, the prevention of complications, and the autonomy and quality of patient life.[208] In eczema, TPE is increasingly proposed as a means to increase treatment adherence, to avoid treatment failure, to support/enable their ability to cope with the disease and to improve the patient quality of life. TPE led by a multi-disciplinary healthcare team covers the complex causes of the disease, trigger factors, nursing and dietary issues, and the broad variety of treatment options available including psychological and behavioural aspects. Randomised, controlled studies[209] have demonstrated the beneficial effects of delivering structured group training to children, their caregivers, and adult patients with eczema. Improved understanding and treatment adherence is key to achieving substantial improvements in quality of life and objective clinical disease parameters.

Corticosteroid safety education

Corticosteroid phobia (corticophobia) in parents is a significant barrier to treatment compliance. This corticophobia is not associated with any particular disease condition, steroid use, age or education level of the caregiver / parent. However, female caregivers have been shown to be more likely to have higher levels of corticophobia.[210] Educating parents and carers about the safety of gold standard corticosteroid therapy and the importance of day-to-day skin maintenance measures and environmental modifications, is central to treatment success and maintaining remission.

The establishment of a strong relationship between health professionals and the patient's family, with focussed education on the use and safety of the new generation of topical products is important. Assistance in negotiating many of the associated considerations, such as minimising the cost of treatment and suggesting simple solutions for when the child is at school, make the world of difference to the wellbeing of children with eczema.[211/212]

To encourage corticosteroid treatment compliance, psychological and educational interventions have been used as an adjunct to conventional therapy for children with atopic eczema, to enhance the effectiveness of topical corticosteroid therapy. Psychological and educational approaches have been used to complement medication in managing eczema, for example, by using simple psychological techniques to manage itching and scratching or sleep disturbance.

Nurse-led educational interventions for paediatric eczema

Effective child and parent education is the key to successful self-management of paediatric eczema. When diagnosed, children and parents should learn to understand the condition through clear explanations, seeing treatment demonstrations and receiving ongoing support to learn practical skills to control eczema.[213] Educational interventions, provided to individuals and groups by nurses or teams of specialists in hospital or community settings, have been used to help parents and children to understand the condition and their role in managing it successfully.[214/215]

The timed payment structure of doctor-patient interactions and medical practitioner workforce shortages in Australia does not easily lend itself to medical specialists and GPs dedicating the time needed for individual patient / carer education. However, only 14% of adult and 20% of child eczema patients surveyed in Australia[216] in 2022 said that their healthcare provider had suggested they attend a training program outside of medical visits and only 9.5% had received more than 6 hours of education / training.

The most cost-effective way to manage eczema is to provide adequate time for education and demonstration of treatments, which the literature suggests can be achieved through nurse-led clinics,[217] which include education of children and their parents/caregivers.[218/219]

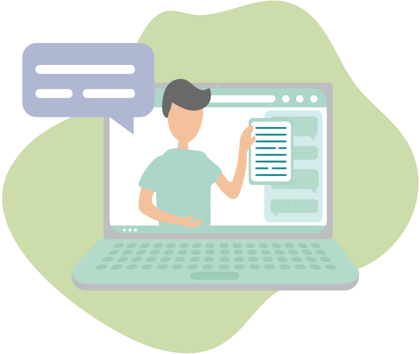
Dermatology nurse specialists can play a central role in the assessment and management of moderate to severe atopic dermatitis patients and families. This places them in an ideal position to build strong and often long-term relationships with patients and parents. Such engagement promotes trust, assists in setting realistic expectations of treatment and outcomes, and enhances self-management and engagement in their own care. Providing emotional support, as well as formal and systematic education (including individualised practical advice) all contribute to improved treatment adherence and can enhance the quality of life of patients and their families throughout the course of this long-term condition.[220]

Successful dermatology nurse-led intervention for the education of children with atopic dermatitis and their parents[221] is provided by a number of Australian public hospital dermatology outpatient clinics – these interventions could be used as a model for nurse-led intervention in other practice settings.[222/223/224]

Successful models include parent-child dyads attending nurse-led eczema education programs[225] and nurse practitioner treatment models for childhood eczema.[226] These have proved effective, resulting in statistically significant improvements in infant quality of life, child quality of life and parental self-sufficiency.[227] There is scope for these nurse-led interventions to be used as a model[228] to expand the role of nurses in cost effective, timely and local care and management of patients with eczema in primary care, regional and rural settings.[229/230]

An international review[231] of randomised control trials of interventions with children and their parents demonstrated significant reduction in disease severity and improvement in quality of life for both nurse and medical practitioner led interventions. This suggests that there is scope for both multi-disciplinary teams and suitably qualified individual clinicians, such as nurses, to deliver educational interventions in conjunction with conventional therapy.

Online educational support



Parents/carers report multiple barriers to managing childhood eczema, including limited information about eczema, its treatments, and child treatment resistance, which could potentially be addressed through online interventions. Eczema Care Online[232], designed by people with eczema, parents and carers of children with eczema, and a team of health experts using the most up-to-date research evidence, is a recently developed United Kingdom website resource[233] using plain, easy to understand language. The website's aim is to help individuals and families address key barriers to effectively manage their own or their child's eczema. It supports self-management by adults and young people and a parental co-management approach with the aim of facilitating the child's later transition to self-management. The effectiveness and cost effectiveness of these educational interventions is currently being trialled.[234]

The Way Forward - Patient issues

Proposed partnerships to improve patient and caregiver eczema health literacy in Australia

It is vital that health literacy levels of Australian eczema patients and their caregivers be raised through effective interventions to ensure better adherence to treatment.[235/236] The experience we have with providing information and support to the eczema patient and caregiver community in Australia places Eczema Support Australia perfectly to play a significant role in providing in patient education and support resources across Australia.

Eczema Support Australia currently provides evidence - The Way Forward – proposed partnerships to eczema health literacy in Australia

Eczema Support
AUSTRALIA

Eczema Support Australia currently provides the eczema community with evidence-based information, offers interactive dermatologist and psychologist led patient and caregiver webinars and runs a number of patient, parent and teenager support groups. We are currently working in partnership with the developers of Eczema Care Online to offer this resource tailored to the Australian context via our organisation's website.

Eczema Support Australia has strong relationships with healthcare practitioner organisations such as the Australasian College of Dermatologists, The Australian Dermatology Nurses Association. We aim to partner with these organisations along with additional key stakeholders such as the Royal Australian College of General Practice and the Australian Practice Nurses Australia and Primary Health Network, to develop educational resources to support practice nurses across urban, regional and remote Australia to provide patient and caregiver education.

Priority Two – Provide eczema education and management support for primary care health professionals and junior doctors

The immediate goal of this priority is to equip front line primary healthcare professionals dealing with eczema on a daily basis, with the knowledge, skills and support systems needed to diagnose, manage and appropriately refer patients. This will ensure that Australians impacted by eczema receive the standard of care, and the right medicine at the right time, regardless of where they live.

1. Reliance on primary care professionals with little or no formal dermatology training.

Our Australian healthcare system is under challenge. Many emergency departments, specialist hospital services and private specialists are overloaded and have long waiting times.

At the same time, primary health services (GPs, practice nurses, psychologists and pharmacists) are facing growing demand for their services.

A 2020 consumer survey[237] showed general practitioners (86%) and pharmacists (62%) are the most frequently accessed health service providers in Australia, with fewer than a quarter of respondents (23%) seeing a medical specialist outside of the hospital system. Those with chronic conditions were significantly more likely to access a GP (88%), a pharmacist (71%) and a private medical specialist (32%). Those residing outside of metropolitan areas, especially in rural or remote locations, have significantly higher reliance on pharmacists and GP or nurse practitioner run public hospitals for their healthcare.

Australians deserve access to a quality, comprehensive and connected primary care sector that provides them with coordinated care led by their general practitioner. However, timely and equitable access to general practice services, particularly in rural and remote areas, is a growing issue. There is unprecedented demand for health services as the population ages and the rates of chronic disease and psychological distress increase. The COVID-19 pandemic and recent natural disasters have compounded these issues, highlighting the gaps and inequities in the current delivery of primary care.[238]

In the face of these challenges, primary health professionals should have easy and ready access to evidence-based resources as well as access to specialist help if needed to deliver best-practice care for the myriad of health conditions they see in their broad-based practice. This includes the diagnosis and management of acute and chronic skin conditions.

Medical undergraduates in Australia receive little or no training in dermatology. A 2016 survey[239] of the 18 Australian medical schools found dermatology as part of the core training of 15/18 medical schools with a mean of 5 lecture hours over the entire degree period. Only 4/18 medical school curricula included attendance at one or more compulsory dermatology clinic session and only 6/18 required undergraduates to satisfy dermatology examination requirements. Dermatology placements are also infrequent in junior doctor rotations and, as such, the bulk of dermatology learning takes place in a practice setting after graduation.

2. A lack of confidence diagnosing and managing eczema in primary care

Eczema is a common presentation in the general practice setting with skin diseases being the main reason for around 17% of Australian GP visits.[241] Research indicates that the mean amount of time spent on skin problems in a GP consultation is under five minutes.[242] With complex management options available according to severity of eczema disease, it is important for GPs to have confidence in diagnosis and guiding the early stages of management and in recognising disease severity as well as having a good understanding of the indications for referral to a dermatologist

An essential skill for Australian GPs and registrars is having an appropriate referral pathway for eczema in place. Unfortunately, recent findings[243] indicate eczema is often a low priority in general practice as it is not viewed as a chronic condition and lacks government funded treatment incentives. Many GPs still use a treatment approach developed early in their career, despite rapid changes in treatment options and updated guidelines.

Many GPs have difficulty and lack confidence diagnosing and managing eczema and other skin diseases due to a lack of formal training throughout undergraduate, post graduate and specialist GP registrar training. [244/245/246] GP registrars who may be exposed to managing eczema less frequently than their more senior GP counterparts, find skin conditions challenging to manage and are more likely to lack confidence in eczema management.[247/248] Skin disease remains a learning-need for GP registrars, and GP registrars find skin consultations problematic compared to non-skin consultations.[249] This is a serious problem for Australian primary healthcare.[250]

Community pharmacists also play a primary role in the management of atopic dermatitis. They are easily accessible and have knowledge to clarify dosing instructions and the opportunity to emphasise the importance of treatment adherence in compliance with the therapeutic regime for the effectiveness of treatment.[251]

Corticophobia among primary health professionals further reduces their skills and confidence in managing eczema, especially prescribing to meet TCS treatment guidelines and reinforcing the need for treatment compliance with patients. The PEEK 2018 study[252] identified that 3 in 4 patients used the internet as the main source of information on their condition and not their treating health professional. Evidence-based information on the safety of topical corticosteroids is needed to empower GPs to improve treatment outcomes in paediatric eczema as parents commonly cite TCS phobia as a major impediment to treatment adherence.[253]

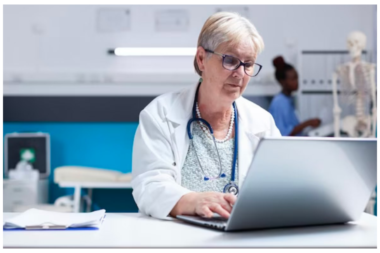
Primary care interventions that work

International studies provide evidence of the need to focus education for all healthcare professionals involved in the management of eczema on the appropriate and safe use of topical corticosteroids. Healthcare professionals can then dedicate time to inform patients and caregivers about the safety of the new generation products, whose main advantage is a clearly improved health outcome.[254] Interventions that led to significant patient outcome improvement included dermatology-trained nurse consultations for patients, instructing GPs to follow treatment guidelines based on patient eczema severity, and an educational module followed by employment of an eczema action plan in the clinic.[255]

Education on topical corticosteroid use

Studies have shown considerable knowledge gaps on the safety of topical corticosteroids use in Australian GPs and pharmacists.[256] This demonstrates the urgent need for formal continuing professional development (CPD) for these groups. Current attitudes to TCS use appear modifiable through targeted, evidence-based education delivered by a dermatologist. Trials have shown significant reduction (from 54% to 8%) in the recommendation of sparing use of topical corticosteroids to treat paediatric eczema Additional beliefs that side effects such as skin atrophy would occur from appropriate use of topical corticosteroids dropped from 56% to 11% post CPD.

Formal online education in dermatology



Recent research[257] has shown that undertaking an interactive digital masterclass in paediatric dermatology, including the treatment of eczema and use of topical corticosteroids, was an efficient tool to achieve long term significant improvement in confidence managing eczema, improved knowledge about TCS and significant reduction in corticophobia. Interventions that lead to significant improvement in clinician knowledge include a standalone educational module by itself, an educational module paired with a treatment algorithm, and an educational module paired with eczema action plan use.[258]

Clinical experience and access to dermatology advice

GPs undertaking an online educational model combined with the use of clinical action plans and experience in joint consultations with a dermatologist, and with ongoing access to dermatologists guidance by text or email, show significant improvement in their clinical management of eczema. They advise more appropriate use of corticosteroids, use a greater number of treatment modalities and make fewer referrals to specialist dermatologists.[259]

Training health professionals how to educate patients and caregivers

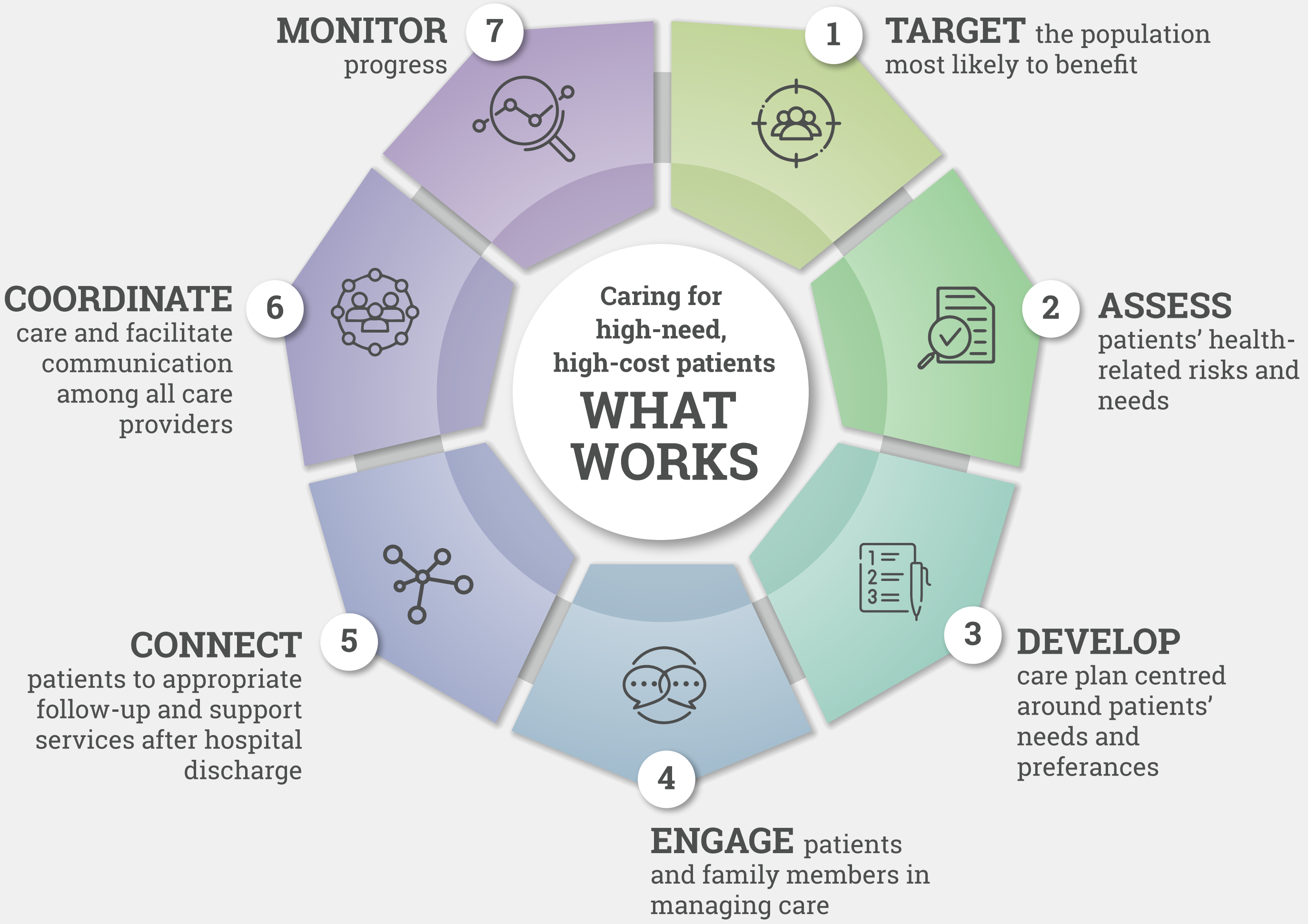
Health literacy interventions for patients and caregivers must increase health learning capacity, which refers to the cognitive and psychosocial skills patients and family members must draw on to effectively promote, protect and manage their own or their child's eczema. By understanding this concept, healthcare professionals, especially nurses leading therapeutic eczema education programs, can more effectively design health-education materials, develop instructional strategies, and deliver healthcare services to support patients and families across their life span.[260]

Proposed partnerships to improve patient and caregiver eczema health literacy in Australia

Primary care professionals in Australia are overloaded with work and have little time available to undertake professional education on the myriad of conditions they treat in general practice and community hospital settings, especially if the time taken away from their work to undergo training leaves them significantly out of pocket or requires additional travel time.

Eczema management does not receive specific government support at either National or State level. Simultaneously the Australian Government has implemented a number of cost-subsidised primary care initiatives aimed at improving coordination and care for people with chronic and complex conditions. These include MBS incentives for care planning and assessment and the Healthcare Homes 2017-2021 trial.[261] Eczema and other chronic skin diseases are not recognised as eligible chronic conditions under these incentives. The Australian Department of Health has identified what works in the Australian setting to improve health outcomes for patients with chronic complex conditions.

Figure Fifteen – Caring for high-need high cost patients: what works?[262]



Source: Department of Health better outcomes for people with chronic and complex conditions

Providing GPs, and other primary care professionals with the professional development desperately needed to improve their eczema health literacy and gain the knowledge, skills and confidence to properly diagnose, treat and refer patients with mild, moderate and severe eczema in Australia fits perfectly with this model of care.

Eczema Support Australia urges State and Federal Departments of Health to subsidise formal education and CPD in dermatology for GPs, GP practice nurses, nurse practitioners and Aboriginal health workers, especially those in regional, rural and remote settings where there is little or no access to either public or private specialist dermatology care.

There are a number of existing evidence-based professional eczema educational courses available which could be included in a coordinated approach to improving primary care skills and confidence:

- **Dermatology Australasia,** the primary care education arm of the Australasian College of Dermatologists, runs a **12-course program in its Advanced Certificate in Dermatology**[263] (fee $4,970), which requires 235 study hours. The eczema online course from this certificate is also offered separately for a fee of $400.

- **The Australian Dermatology Nurses Association** offers its members access to a graduate certificate in dermatology nursing and CPD courses covering a range of skin conditions and dermatology techniques.

- **The Skin Health Institute website** includes an range of **GP resources, an Eczema Awareness Hub, a maternal and child skin health resource about eczema.** The Institute is running a CPD course on diagnosing and managing eczema in general practice as part of a 5 event inflammatory diseases workshop series in 2023. It also provides an advanced therapeutics education portal for dermatologists, dermatology registrars and dermatology nurses.

- **In 2023 the Royal Australian College of General Practice is offering a certificate in dermatology**[264] (fee $13,500) with a 25 unit online course, a two day dermatological surgery workshop and three full or six half days of clinical experience.

The compelling case for a National Eczema Strategy

Despite high prevalence and burden, many Australians with eczema are lost in a treatment maze, which is why a dedicated National Eczema Strategy is needed to:

- Standardise the care of Australians with eczema so they receive access to the right medicine and services, including psychological support, at the right time, regardless of where they live.
- Address steroid phobia which results in the underuse of corticosteroid therapy, leading to unnecessary eczema flare-ups and treatment failure.
- Prevent hospitalisation and manage co-morbidities associated with eczema flare-ups in patients with moderate-to-severe eczema.
- Ensure all Australians with eczema benefit from timely and affordable access to effective and well tolerated therapy.
- Increase the health literacy of Australians with eczema and their families, by providing patent education and support, in order to improve the self-management of the condition.
- Support Australians with eczema to feel less alone by referring individuals and families to Eczema Support Australia and provide government funding to support this organisation.
- Bolster dermatology training for GPs, practice nurses, nurse practitioners and Aboriginal health workers.
- Improve the transition of care from paediatric and adolescent to adult care.
- Address a shortage of dermatologists which means there is only one specialist for every 50,000 Australians with eczema.
- Establish an eczema registry to collect reliable data on the prevalence, severity, treatment, and hospitalisation rates due to eczema.

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