

ECZEMA SOCIETY OF CANADA

ATOPIC DERMATITIS: PATIENT INSIGHTS REPORT

- MILD-TO-MODERATE DISEASE -



PATIENT INSIGHTS BY THE NUMBERS:

Adult Atopic Dermatitis (AD)

In the past two years, **29%** of respondents have seen a doctor four or more times due to their AD, and 22% have seen three or more different doctors to manage their AD

One in four adults with AD report having lived a decade or longer without adequate treatment



Only 13% of respondents reported that their AD is well controlled

37% of respondents have treatment needs that are not being met by current therapies

82% of respondents report that their day-to-day life is negatively impacted by their condition

The three most important aspects of atopic dermatitis to control were rated as: 1) Interrupted or lost sleep 2) Anxiety related to AD 3) Missed work or important events

Children's Atopic Dermatitis (AD)

In the past two years, **28%** of respondents have **seen a doctor four** or more times related to their child's AD. and **17%** have seen three or more different doctors

One in four reported having to wait six months or longer for their child to see a dermatologist



One in four children who miss school due to their AD miss ten or more days each year

20% of children find treatments **painful** to apply

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Less than **1/3 of parents** surveyed indicated their child's AD was well controlled

The three biggest challenges of treatment were rated as: 1) Fears of medication safety 2) Pain and discomfort of treatments 3) Complex routines that are difficult to follow

ATOPIC DERMATITIS: MORE THAN JUST DRY, ITCHY SKIN

Atopic dermatitis (AD), a common form of eczema, is a life altering symptoms. AD can range from mild to severe, chronic, inflammatory skin condition characterized by dry, and all forms of the disease can have significant quality of itchy skin that goes through periods of flares and periods life impact on patients, caregivers, and their loved ones. of clearing. During times of flare the skin can become very AD is often diagnosed and managed by primary care itchy and painful, and skin becomes red and inflamed. AD physicians and nurse practitioners.¹ While Canadian data patients can have periods of remission; however, some is not available, AD is estimated to affect 11% of children², and 7% of adults ³ in the United States. patients never experience complete remission from these

INTRODUCTION: OUR PATIENT INSIGHTS REPORT

Eczema Society of Canada (ESC) is a registered Canadian of dismissively as simply dry, itchy skin; however, even charity dedicated to improving the lives of Canadians mild disease can have significant impact on sufferers. The living with eczema, through our mission of education, adult survey gathered data from 137 adults who live with support, awareness, advocacy, and research. In late 2016, moderate AD, and the children's survey gathered data ESC set out to better understand the burden of disease on 384 children who live with mild or moderate AD. This of Canadians living with AD, and the existing barriers to report contains the data and insights gathered that are better care. specific to mild and moderate patients.

ESC conducted online surveys of Canadians living with AD The content of this report details the survey data collected and had a total of 1,035 respondents from all provinces from both the adult and children's survey, and reflects across Canada. Of those respondents, 377 were adults the insights gathered through survey responses from living with AD and their caregivers, and 658 were children Canadians impacted by AD. and their caregivers. Mild or moderate AD is often thought



MILD

Areas of dry skin, infrequent itching, with or without small areas of redness.

Areas of dry skin, frequent itching, and redness with or without broken skin or localised skin thickening.

These definitions of atopic dermatitis were used within the surveys to define disease severity.

DEFINITIONS OF ATOPIC DERMATITIS SEVERITY



MODERATE



SEVERE

Widespread areas of dry skin, incessant itching, and redness with or without broken skin, extensive skin thickening, bleeding, oozing, cracking and alteration of pigmentation.

ADULT SURVEY INSIGHTS



Atopic dermatitis (AD) is often thought of as a childhood condition, however many children who suffer with AD continue to suffer into adulthood.⁴ Data presented in this section is based on responses from Canadian adult respondents (18 years of age and older) who suffer with moderate AD.

Survey respondents were asked to indicate all health care providers who diagnosed their disease, and respondents indicated that the family physician and dermatologist were most often the health care providers diagnosing their AD, with 62% of respondents having been diagnosed by a primary care physician, and 59% diagnosed by a dermatologist. The management of AD is similar, with just over half of respondents (55%) reporting that their AD is managed by the primary care physician, and a third (36%) reporting that their AD is managed by a dermatologist (again, respondents were asked to check all that apply).

Who manages your atopic dermatitis?*



In the past two years, 29% of respondents have seen a doctor four or more times due to their AD, and 22% of respondents report having seen three or more different doctors to manage their AD. Wait times for dermatologists

are long, with 62% waiting three months or longer and 21% waiting six months or longer. Access to primary care physicians is better, with 43% of respondents experiencing no wait time to see their family physician.

1 in 5 survey respondents have **waited six months** or longer **to see a dermatologist**

TREATMENTS

AD is a chronic condition for which there is no cure, and therefore patients are caught in a cycle of treating recurrent flares. Only 13% of respondents report that their AD is well controlled. Additionally, nearly three quarters (74%) of respondents have been suffering for

Only 13% of respondents report that their AD is well controlled

98% of respondents have used topical corticosteroids
44% of respondents have used topical calcineurin inhibitors
57% of respondents have used oral antihistamines
24% of respondents have used phototherapy

1/3 of survey respondents have tried **systemic medications**

Bathing and moisturizing techniques used in AD can reduce dryness and therefore reduce itching. 86% of respondents reported using bathing and moisturizing techniques to manage their disease. Although moisturizing skin is important for AD management, medications are typically required to manage the inflammation of AD. Topical corticosteroids (TCS) are a first line therapy for AD and almost all (98%) of respondents report having used TCS Datient fears about TCS (compating referred to

Topical corticosteroids (TCS) are a first line therapy for AD and almost all (98%) of respondents report having used TCS. Patient fears about TCS (sometimes referred to as "topical corticosteroid phobia") is a common problem and a barrier to care as confirmed by recent medical literature.⁵ AD sufferers commonly cite fears related to side effects of the TCS, such as thinning of the skin, and this may contribute to the under-treatment of AD.

48% of respondents **find treatments uncomfortable 47%** of respondents report it is **difficult to dress after applying treatments 22%** of respondents find it **physically painful to apply treatments**

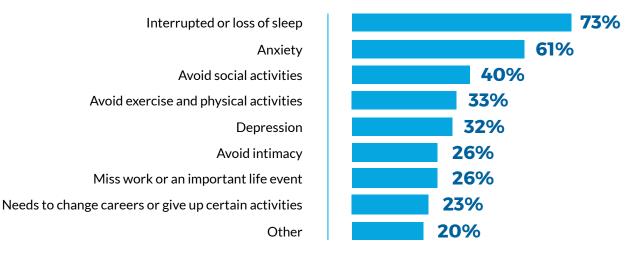
> **37%** of respondents report treatment **needs** that are not being met by current therapies

QUALITY OF LIFE IMPACT

AD has a significant impact on quality of life with 82% of respondents indicating that their day-to-day life is negatively impacted by their condition. Sleep, anxiety, and avoidance of social activities were the three most common areas of life affected by AD. Nearly three quarters (73%)

of respondents experience loss of sleep related to their AD, and of those respondents, 72% report a loss of three or more nights each month, and 38% lose eight or more nights each month.

Has your atopic dermatitis contributed to any of the following in the past two years?



*Respondents were asked to check all that apply.

The three most important aspects of atopic dermatitis to control were rated as:

(1) Interrupted or lost sleep (2) Anxiety related to AD (3) Missed work or important events

CHILDREN'S SURVEY INSIGHTS

91%

of responses pertain to children **12 years of age** and younger





Paediatric atopic dermatitis (AD) is primarily diagnos by family physicians or primary care providers w 62% of children having been diagnosed by the prima care provider. Pediatricians and dermatologists are a important members of the medical team with 33% 23%, respectively, making the diagnosis. The managem of the AD is primarily done by parents and/or caregiv with 85% reporting that they manage their child condition. Nearly a third (31%) reported that their fan physicians or primary care provider manage their chil AD, and dermatologists and paediatricians were cited managing the condition for 17% and 14% of respondents

Who manages your atopic dermatitis?*

The parents/caregivers Family Physician or General Practitioner Dermatologist Pediatrician The child Pharmacist Allergist

Natural health care practitioner

*Respondents were asked to check all that apply.

25%

of responses pertain to mild atopic dermatitis

75%

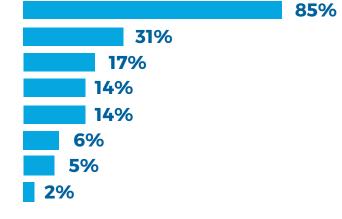
of responses pertain to moderate atopic dermatitis





CARE OF ATOPIC DERMATITIS

osed with	respectively. This data indicates that parents are the most frequent manager of a child's AD.
nary also and nent vers ild's mily ild's d as	Respondents indicated that in the past two years 28% have seen a doctor four or more times related to their child's AD, and 17% have seen three or more different doctors. In one-on-one interviews ESC learned that seeing multiples doctors is common as the chronicity of the disease often has parents seeking second opinions and new treatment options in hopes they can "cure" the disease.



WAIT TIMES

Wait times are a common concern within the Canadian health care system, and access to specialists and wait times were also a concern for survey respondents. While 62% report experiencing no wait time to see their family physician, and 54% of respondents experience no wait time

to see a paediatrician, wait times to see a dermatologist were longer. Nearly half of the children (46%) waited three months or longer to see a dermatologist, and one in four (24%) waited six months or longer.

CHALLENGES WITH TREATMENT

It is well documented that patients with AD have difficulty adhering to recommended treatment plans.⁷ Of caregivers surveyed, 39% indicated that their child finds the treatments uncomfortable, 35% reported difficulty

dressing after applying topical treatments, and 20% of respondents find the treatments physically painful. Patients interviewed indicated that pain from topical medications includes stinging and burning of the skin.

67% of caregivers experience challenges following their **child's treatment plan**

TREATMENT

65%

of respondents' have used **four or** more different treatments to manage their child's atopic dermatitis

The majority of parents surveyed are dissatisfied with the management of their child's AD with only 29% indicating their child's AD is well controlled. Families of children, including very young children, have tried multiple treatments to try and gain control of their child's disease, with more two thirds (65%) having used four or more different treatments, and 19% having used 10 or more different treatments.

Bathing and moisturizing techniques are a common method of AD management, used by 94% of respondents. Topical corticosteroids (TCS) are a first line therapy for AD to manage inflammation, and almost all (94%) of respondents report having used TCS. Caregivers cited fears related to side effects of the TCS and this may contribute to undertreating the AD. 14% of respondents indicated they don't follow the regimen as prescribed by the doctor.

Fear of TCS is sometimes called "topical corticosteroid phobia" and is a common problem and a barrier to optimal care.⁵ Although TCS have been used for more than four decades, AD sufferers and caregivers commonly cite fears related to side effects, such as thinning of the skin, and this may contribute to under treating the AD.

One fifth (21%) of respondents have used topical calcineurin inhibitor (TCI)s. In Canada, TCI medications have a black box warning from Health Canada for Adherence is a challenge with TCI treatment as well, potential cancer risks. While recent studies have with 17% indicating that they don't follow the regimen as supported the safety of these medications,⁶ caregivers prescribed by the doctor. Children with AD who do not have concerns surrounding their safety and the cancer respond to topical therapy may be prescribed systemic warning contained in the product monograph. therapies, even for moderate AD, with 2% of respondents reporting the use of off-label systemic medications.

Which treatments has your child used to manage their atopic dermatitis?*

Topical corticosteroids

Bathing and moisturizing techniques

Oral antihistamines

Topical calcineurin inhibitors

Systemic corticosteroids

Light therapy / Phototherapy

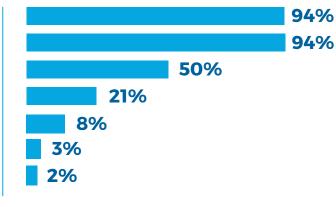
Other systemic medications that suppress the immune system

The three biggest challenges of treatment were rated as:

(1) Fears of medication safety (2) Pain and discomfort of treatments (3) Complex routines that are difficult to follow

QUALITY OF LIFE

Quality of life is negatively impacted by mild and moderate Caregiver sleep is also significantly impacted, with 44% AD. A common concern among sufferers is that AD is not experiencing sleep loss. Anxiety was also a significant considered a serious medical concern, and it is reduced concern, with 27% of caregivers experiencing anxiety to simply "dry itchy skin". Just over a third (37%) of specifically related to their child's AD, and 21% of respondents indicated their child's daily life is negatively children with AD experiencing anxiety related to their impacted by atopic dermatitis. More than half of children AD. Participations in sports and physical activity is also experience interrupted sleep, with 58% of respondents impacted, with 16% of children experiencing limitations being impacted. More than half of children with mild to related to their AD. AD can also lead to school absences, moderate AD experience loss of sleep related to their with 9% of children missing school specifically related to disease. Of those, 24% experience sleep loss 8 nights per their AD, with 25% of them missing 10 or more days of month or more. school per year.



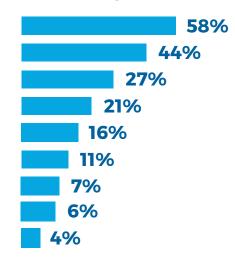
*Respondents were asked to check all that apply

One in four children experience **sleep loss** 8 nights per month or more

25% of children who miss school due to their AD miss ten or more days per year

Does your child's atopic dermatitis contribute to any of the following?*

Interrupted or loss of sleep for the child Interrupted or loss of sleep for parents/caregivers Anxiety for the caregiver/parent Anxiety for the child/youth living with eczema Difficulty participating in sports or physical activities Avoidance of social activities Being bullied and/or picked on by peers Depression for the caregiver/parent Depression for the child/youth living with eczema



*Respondents were asked to check all that apply

The three most important aspects of their child's atopic dermatitis to control are:

(1) Pain and/or discomfort (2) Interrupted or loss of sleep (3) Anxiety related to AD

What challenges do you face in caring for your child with atopic dermatitis?*

Time management and/or competing demands Physical, mental and/or emotional stress Lack of support from the health care system Financial challenges Other Lack of support from family members and friends **Employment challenges**

52% 29% 17% 15% 11% 7%

60%

*Respondents were asked to check all that apply.



Mild or moderate AD is more than dry, itchy skin and While some patients with mild or moderate atopic dermatitis (AD) are well managed with current therapies, Canadians deserve relief from the anxiety, pain and for other patients current therapies are inadequate to complexity associated with this condition. This report manage their condition as indicated by survey results. sheds light on the unique and often overlooked needs The insights reflected in this report demonstrate a clear of these patients, and opportunities for change. As we need for additional treatment solutions to help with the sit on the cusp of a new era in care for AD patients, ESC management of AD. The impact AD has on quality of life is hopes this report drives change by initiating a discussion significant, whether it is associated sleep loss, time away among patients, caregivers, healthcare professionals, from work, school, or social activities, or frustration with government decision-makers, scientists, researchers, and finding help and control of the disease. the general population.

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SUMMARY

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