



ECZEMA SOCIETY OF CANADA

ATOPIC DERMATITIS QUALITY OF LIFE REPORT

— MODERATE-TO-SEVERE DISEASE —



2016/2017 Survey Results

ABOUT THE ECZEMA SOCIETY OF CANADA

Our mission is simple: education, support, awareness, advocacy, and research.

Eczema Society of Canada (ESC) is a registered Canadian charity dedicated to improving the lives of Canadians living with eczema. ESC's mandate is that of education, support, awareness, advocacy, and research. ESC offers patient and health care provider education, has support volunteers across the country, and funds research efforts through a competitive research grant program.

ESC also advocates for Canadian eczema sufferers to ensure access to the best treatment and care. In late 2016 ESC hosted an online survey to gather insights on the impact of atopic dermatitis on Canadian adults. In early 2017 ESC hosted a similar online survey to gather insights on the impact of atopic dermatitis on children living with atopic dermatitis, and their caregivers.

TABLE OF CONTENTS

About Atopic Dermatitis.....	1
Quality of Life Insights Project.....	2
Adult Survey	
Adult Survey Demographics	3
Definitions	3
Access to Care and Treatment	4
Wait Times.....	5
Disease Management	6
Atopic Dermatitis Treatments	6
Systemic Medications	7
Quality of Life Impact	8
Sleep Loss	9
Mental Health	9
Children's Survey	
Children's Survey Demographics	10
Definitions	10
Access to Care	11
Treatments	12
Quality of Life.....	14
Sleep Loss	15
Impact on Caregivers	16
Summary	17
Acknowledgements	17
References	17

ABOUT ATOPIC DERMATITIS

Atopic dermatitis, commonly referred to as eczema, is a chronic, inflammatory skin condition characterized by dry, itchy skin.

Patients with atopic dermatitis experience acute worsening of their condition, which are referred to as flares. During flares the skin becomes red, with lesions that can blister, ooze and crust. Scratch marks can often be seen on the skin, and long term changes to the skin, including skin thickening can result. Atopic dermatitis flares can be extremely itchy, painful and uncomfortable, can cause psychological distress, and can negatively impact the individual and their family.¹ Atopic dermatitis can have periods of remission; however some patients never experience complete remission from these life altering symptoms.²

Atopic dermatitis can range from mild to severe, and all forms of the disease can have significant quality of life impacts on patients, caregivers, and their loved ones. Atopic dermatitis is often managed by pediatricians or primary care physicians whereas moderate-to-severe atopic dermatitis is often managed with the help of a dermatologist or allergist. While reliable estimates are not available for Canada, atopic dermatitis is estimated to affect 11% of children, and 7% of adults in the US.^{3,4}



QUALITY OF LIFE INSIGHTS PROJECT

In 2016/2017 ESC undertook a quality of life insights project to better understand the burden of living with atopic dermatitis, the quality of life impact, and the needs of those living with atopic dermatitis.

ESC conducted online surveys of Canadians living with atopic dermatitis and had a total of **1035 respondents**. Of those respondents, 377 were adults living with eczema, and their caregivers, and 658 were children and their caregivers. ESC also interviewed atopic dermatitis

sufferers and their families, from provinces across Canada, conducting 22 one-on-one interviews to gather additional insights. Some key concerns emerged from the one-on-one interviews and the commentary provided in the surveys.

KEY CONCERNS

- Pain and itch
- Significant quality of life impact
- Lack of health care provider knowledge in the management and treatment of atopic dermatitis
- Difficulty in obtaining dermatology referrals
- Long wait times to see specialists
- Geographic inequality in access to dermatologists and other specialists
- Lack of effective treatments to adequately manage the physical symptoms and the itch



ADULT SURVEY DEMOGRAPHICS



Respondents were from all provinces

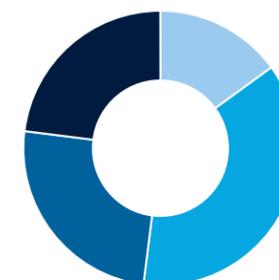
49%

of respondents suffer with **moderate atopic dermatitis**

39%

of respondents suffer with **severe atopic dermatitis**

AGE OF RESPONDENTS



- 18 to 29 years old – **15%**
- 30 to 44 years old – **37%**
- 45 to 59 years old – **25%**
- 60 years and older – **23%**

The survey data reported in the remainder of this section includes only the responses regarding adults living with moderate and severe atopic dermatitis

DEFINITIONS OF ATOPIC DERMATITIS SEVERITY



MILD

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



MODERATE

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



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.

ACCESS TO CARE AND TREATMENT

While atopic dermatitis is typically managed by the primary care physician, patients with moderate-to-severe disease often need the help of a dermatologist to manage their disease.

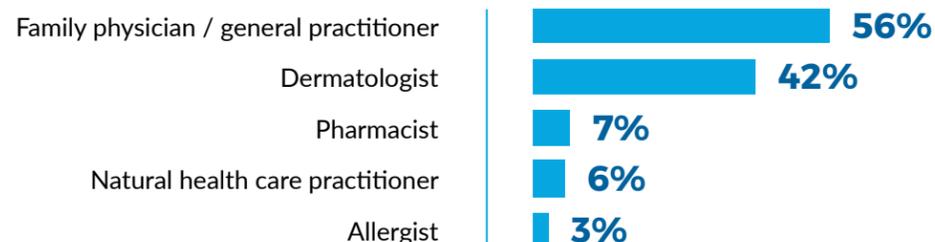
While atopic dermatitis is typically managed by the primary care physician, patients with moderate-to-severe disease often need the help of a dermatologist to manage their disease. Of our respondents, with moderate or severe disease, only 42% are managed by a dermatologist. This indicates that access to specialists may be a significant barrier to optimal care. Patients from across Canada share challenges and frustration with accessing a dermatologist in their local area, accessing a dermatologist in a timely manner, and for some Canadians in remote areas, accessing a dermatologist at all.

Due to the chronicity of atopic dermatitis, sufferers make frequent visits to the doctor for disease management.

42% of respondents have visited a doctor four or more times in the past two years to manage their atopic dermatitis.

For patients who do receive care from a dermatologist, wait times are long. Survey data indicated that 69% of respondents have waited more than 3 months to see a dermatologist for atopic dermatitis treatment, and some wait longer than a year. When suffering with recurrent atopic dermatitis flares, these wait times could result in months of suffering without relief. Survey results also demonstrated that patients are seeing multiple doctors to seek care, as 28% of respondents have seen more than three different doctors in the past two years to manage their atopic dermatitis.

Who manages your atopic dermatitis?*



*Respondents were asked to check all that apply.

Only **42%** of respondents are **managed by a dermatologist**

28%
of respondents have seen **three or more different doctors** to manage their atopic dermatitis in the past two years



42% of respondents visited a doctor **four or more times** in the past two years to manage their atopic dermatitis

WAIT TIMES



69%
of respondents have waited **3 months or longer** to see a dermatologist

27%
of respondents have waited **6 months or longer** to see a dermatologist

“Wait times are so long, and I can never see my dermatologist when I’m in the middle of a bad flare.”

Sometimes going to the emergency department is the only way to get help when I need it.”

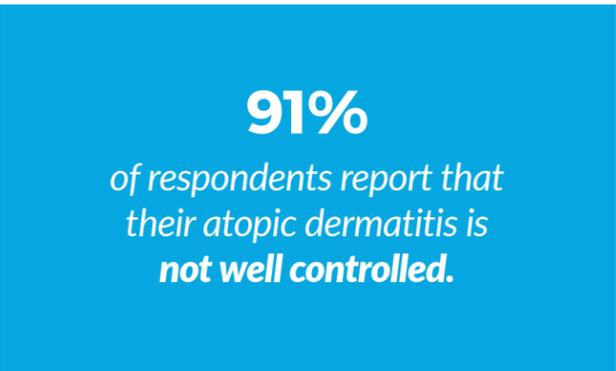
— Adult suffering with severe eczema

DISEASE MANAGEMENT

For many people with atopic dermatitis, management with moisturizers and prescription topical anti-inflammatory treatments such as corticosteroids and calcineurin inhibitors is adequate to control their disease.

For many with moderate-to-severe atopic dermatitis, those treatments are inadequate. Phototherapy can be effective for some people, but it is often difficult to access. Some patients must turn to off-label use of medications that suppress the immune system, including cyclosporine and methotrexate. These medications are not always effective and can have significant side effects.

91% of respondents report that their atopic dermatitis is not well controlled and 78% report that they have lived without adequate treatment for a year or longer.



41%
of respondents have treatment needs **that are not being met** by current atopic dermatitis therapies

SYSTEMIC MEDICATIONS

For some patients with moderate-to severe atopic dermatitis, topical medications do not adequately control their disease. These patients may use systemic medications to try and manage their atopic dermatitis.

There are systemic medications which suppress the immune system and work to quiet down the inflammatory process within the body. These medications (such as Cyclosporin and Methotrexate) are not indicated for atopic dermatitis, their use is off-label, and these medications carry significant risk for side effects. Systemic corticosteroids (e.g. Prednisone) are also sometimes used to help patients manage severe flares. Systemic corticosteroids are very different from topical corticosteroids, and carry significant, life altering side effects when used long term. Atopic dermatitis is a chronic condition and this treatment is not safe for long term management.



ATOPIC DERMATITIS TREATMENTS

Which treatments have you tried since being diagnosed with atopic dermatitis?*



*Respondents were asked to check all that apply.

43%
of respondents have used **10 or more different treatments** to manage their atopic dermatitis



29%
of respondents have used **15 or more different treatments** to manage their atopic dermatitis



“My entire body is covered with my eczema. My eyelids burn, my arm creases crack and weep, and it’s painful to flex my knees and open my hands. I itch all the time. I wish I was someone else.”

— Adult suffering with severe eczema

QUALITY OF LIFE IMPACT

Itch. Burning. Pain.

The physical symptoms of atopic dermatitis have significant quality of life implications.

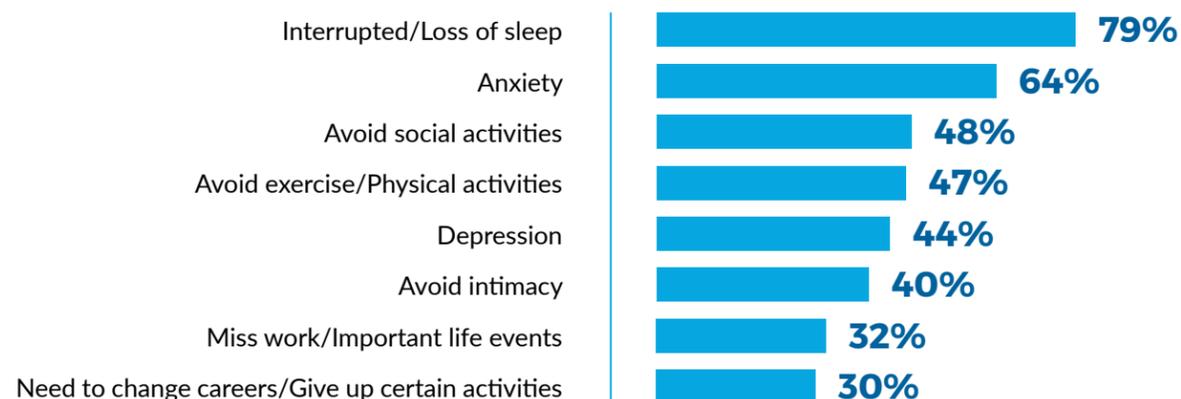
For people suffering with moderate-to-severe atopic dermatitis, the quality of life impact of the disease is multi-faceted and can be constant.¹ Much of this impact is related to its major symptom (itch), its effect on sleep, its outward visibility and the expense and time-consuming nature of prescription and topical treatments. Atopic dermatitis affects social, sexual, academic and occupational functioning. It is also associated with increased rates of depression and anxiety.⁵ **32% of respondents miss work or important life events due to their atopic dermatitis, and 30% have had to change careers or give up certain activities due to their atopic dermatitis.**

Loss of sleep and poor sleep quality is perhaps one of the most significant quality of life impacts related to atopic

dermatitis. It is well documented that atopic dermatitis disrupts sleep, with 79% of respondents reporting impact on sleep. Often, sleep disruption can affect partners and caregivers as well.

87%
of respondents' **daily life** is negatively impacted by their atopic dermatitis

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



*Respondents were asked to check all that apply.

47%
of respondents **avoid exercise or physical activity**

48%
of respondents **avoid social activities**

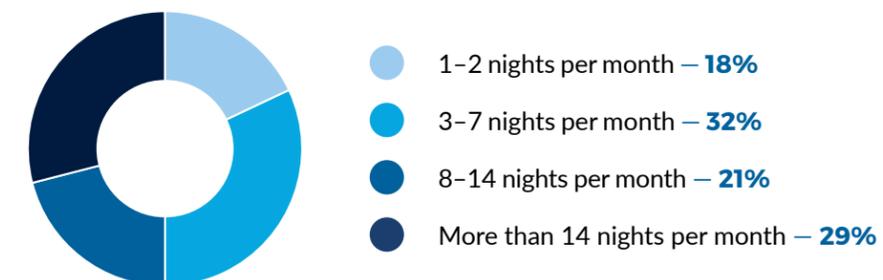
40%
of respondents **avoid intimacy**

SLEEP LOSS

79% of respondents **experience loss of sleep**



Nights of sleep affected by atopic dermatitis per month:



50% of respondents **experience loss of sleep 8 nights or more per month**

MENTAL HEALTH

Atopic dermatitis is so much more than just dry, itchy skin. It can significantly impact the mental health of the sufferers and their caregivers. 64% of respondents report experiencing anxiety specifically related to their atopic dermatitis, and 44% report experiencing depression specifically related to their atopic dermatitis.

64% experience **anxiety**
44% experience **depression**

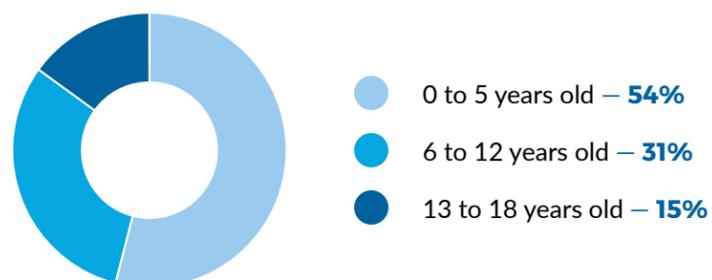
CHILDREN'S SURVEY DEMOGRAPHICS



53%
of respondents
suffer with **moderate**
atopic dermatitis

29%
of respondents
suffer with **severe**
atopic dermatitis

AGE OF CHILDREN IN THE SURVEY



The survey data reported in the remainder of this section includes only the responses regarding children living with moderate and severe atopic dermatitis

DEFINITIONS OF ATOPIC DERMATITIS SEVERITY



MILD

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



MODERATE

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



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.

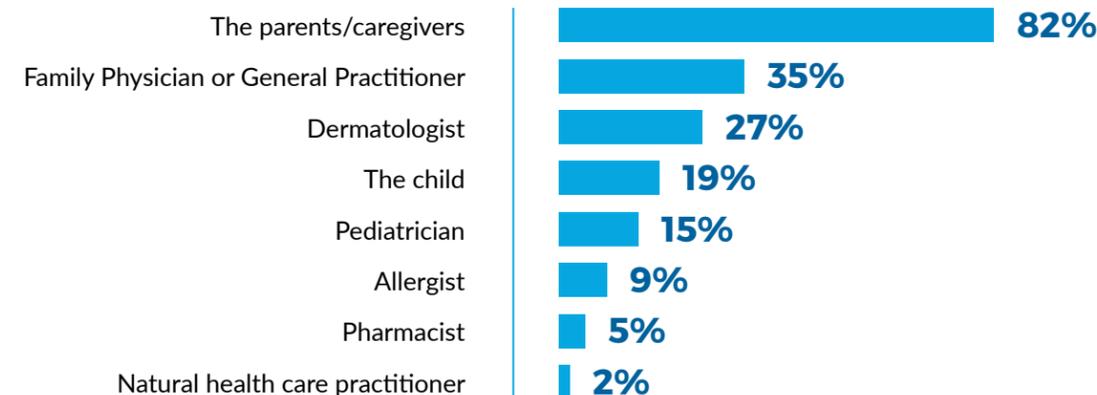
ACCESS TO CARE

Access to specialists and wait times are a concern to those who care for a child living with atopic dermatitis.

In our survey, only 27% of children living with moderate-to-severe atopic dermatitis are managed by a dermatologist. 40% of respondents indicated that their child has seen a doctor four or more times in the past two years related to the management of their atopic dermatitis, and 27% have seen three or more different doctors to manage their atopic dermatitis in the past two years. Wait times can also be long, with 46% having waited 3 months or longer to see a dermatologist, and 25% having waited 6 months or longer. Of the children in our survey, 48% have been living without adequate treatments for a year or longer.

85%
of children in the survey are
living with atopic dermatitis that
is **not well controlled**

Who manages the child's atopic dermatitis?*



*Respondents were asked to check all that apply.

Only **27%**
of children with
moderate or severe
atopic dermatitis
are managed by
a dermatologist

Of children surveyed:

46%
have waited **3 months**
or longer to see a
dermatologist

25%
have waited **6 months**
or longer to see a
dermatologist

TREATMENTS

The survey results reveal that topical corticosteroids are the most common treatment for atopic dermatitis; however parents and caregivers report that they fear side effects of topical corticosteroids.

Topical calcineurin inhibitors are also used to treat the inflammation of atopic dermatitis flares. Survey respondents reported that they have fears related to the safety of topical calcineurin inhibitors. Caregivers surveyed also report that these treatments may not necessarily manage their child's condition well. Among those who use topical corticosteroids and calcineurin inhibitors, respectively, 22% of caregivers report that topical corticosteroids manage their child's atopic dermatitis very well, and 9% report that topical calcineurin inhibitors manage their child's condition very well.

For some children with severe atopic dermatitis, their disease does not respond to topical therapies. In some of these cases oral systemic medications may be prescribed by a specialist. Prednisone, a systemic corticosteroid taken by mouth, is sometimes used, but this medication has significant adverse effects when used even for short periods in children. 18% of the children in the survey have used systemic corticosteroids at some time in their lives. 5% of children surveyed have used other oral systemic therapies to manage their eczema. These other systemic agents are oral immune suppressant drugs, and also carry significant side effect risks.

78%
have used **4 or more different treatments** for their atopic dermatitis



34%
have used **10 or more different treatments** for their atopic dermatitis



19%
have used **15 or more different treatments** for their atopic dermatitis



TREATMENT ADHERENCE

Adherence to treatment plans can be a significant challenge for children living with atopic dermatitis. 80% of caregivers find the treatment regimen somewhat challenging or very challenging, and have difficulty keeping up with the regimen. Applying topical therapies can also be uncomfortable, painful, and can make

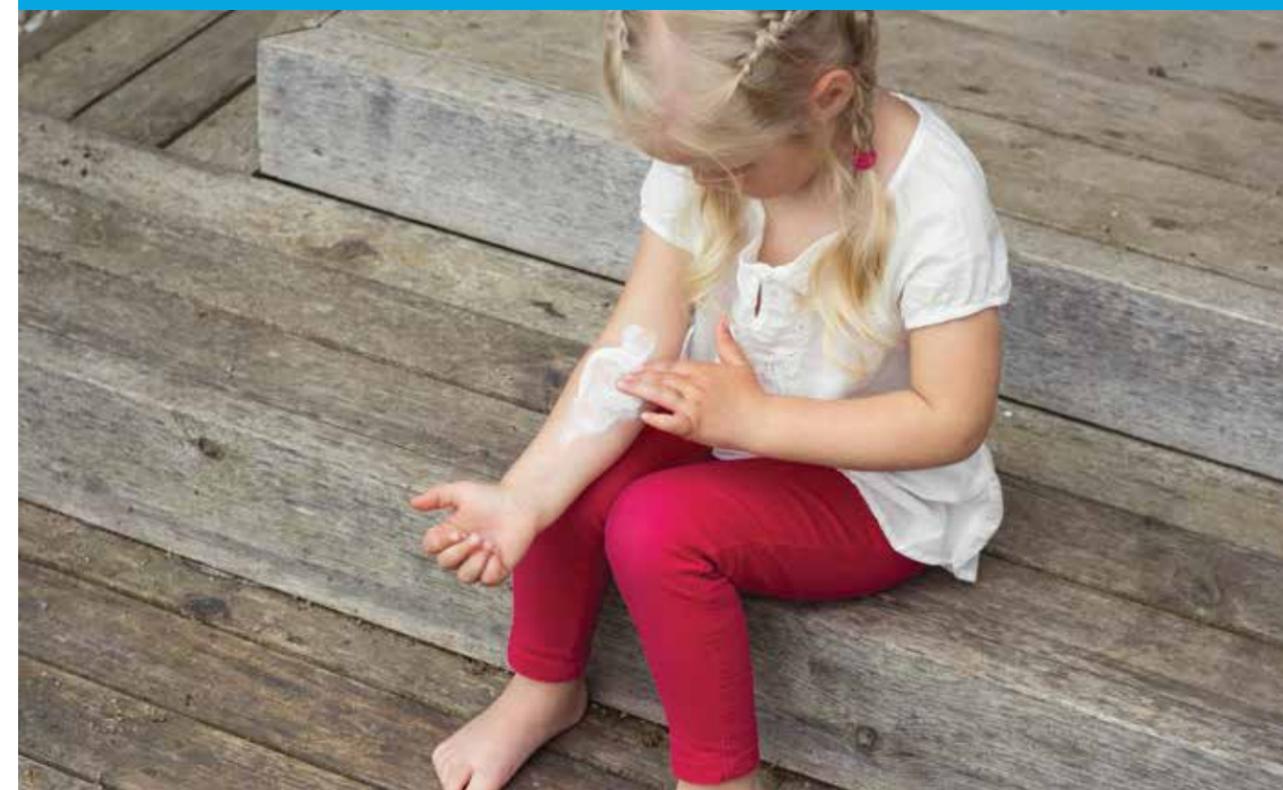
applying the treatments. 51% of survey respondents indicated treatments are uncomfortable for their child, and 32% report that their child's current treatment is painful to apply. 48% of respondents report that their child finds it difficult to dress after applying the treatments.

35%

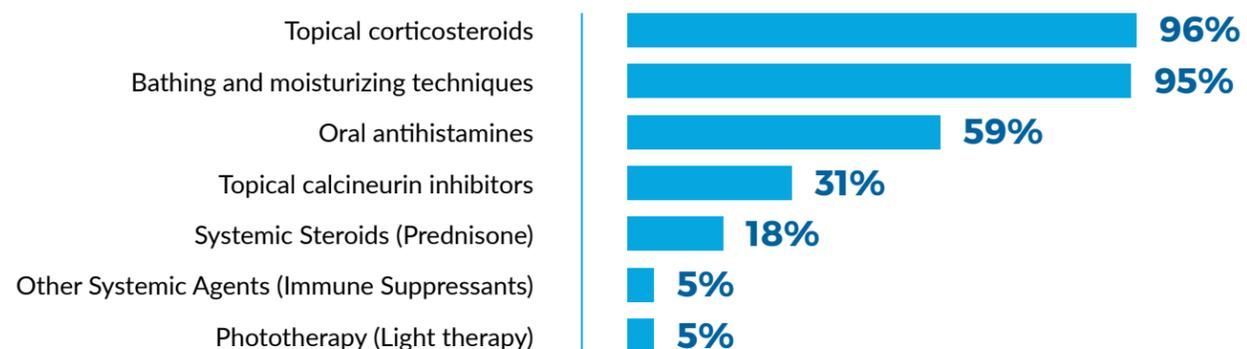
of children surveyed have treatment needs that are not being met by current available therapies



80% of caregivers find the treatment regimen **challenging**



Which treatments has the child tried since being diagnosed with atopic dermatitis?*



*Respondents were asked to check all that apply.

QUALITY OF LIFE IMPACT

Children with atopic dermatitis can suffer significantly with itch and pain, however the impact goes far beyond those symptoms.

The daily life of 52% of the families in our survey is negatively impacted by atopic dermatitis. 70% of children experience loss of sleep. 30% experience difficulty participating in sports or physical activities, and 21% avoid social activities. 30% of children experience anxiety related to their atopic dermatitis. The disease

also impacts the child at school. 20% of children miss school days specifically due to their atopic dermatitis, with 23% of those respondents missing 10 or more days of school per year, and 12% missing 20 or more days of school per year. The caregiver reported rate of bullying of children related to atopic dermatitis is 14%.

Of those children:

20%

of children miss school specifically due to their atopic dermatitis

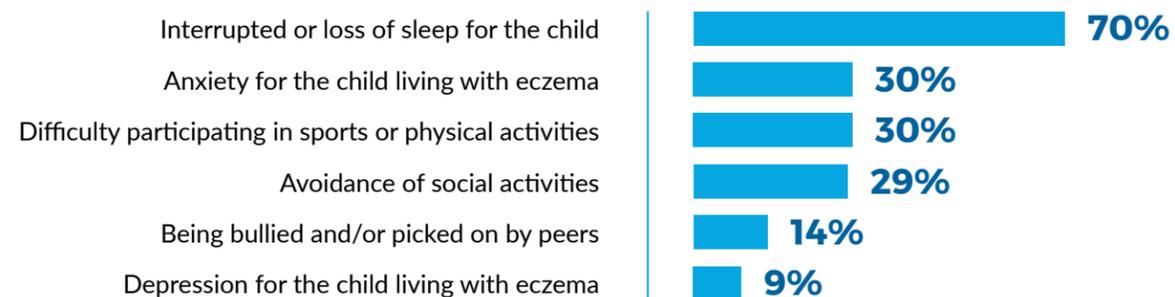
23%

miss 10 or more days of school per year

12%

miss 20 or more days of school per year

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



*Respondents were asked to check all that apply.

30%

of children have difficulty participating in sports or physical activity

21%

of children avoid social activities

30%

of children experience anxiety related to their atopic dermatitis

Respondents reported that **pain or discomfort** is the most important aspect of the child's atopic dermatitis to control

SLEEP LOSS

Good quality sleep is essential for the growth and development of children, and poor quality sleep can negatively impact mood and behaviour.^{6,7}

70% of children experience sleep loss related to their atopic dermatitis, and 55% of caregivers also experience sleep loss related to their child's atopic dermatitis.

70% of children surveyed experience loss of sleep



Nights of sleep affected by atopic dermatitis:

54%

of children have 3 or more nights affected per month

29%

of children have 8 or more nights affected per month

18%

of children have 14 or more nights affected per month

IMPACT ON CAREGIVERS

Atopic dermatitis can contribute to significant quality of life impact for the caregivers.

Survey results indicated that 55% of caregivers experience sleep loss due to their child's atopic dermatitis. 69% of caregivers report experiencing anxiety related to managing a child with atopic dermatitis, and 25% reported to experiencing depression related to their child's atopic dermatitis. Caring for a child with atopic dermatitis can also take a toll on the caregiver's lifestyle, with 23% reporting having little or no time for social activities, 23% reporting having little or no time for intimacy, and 29% reporting having little or no time for exercise and physical activity.

Additional challenges reported by caregivers include time management, stress, and feeling that they lack support to manage their child's disease. 62% report that time management is a challenge when trying to care for their child with atopic dermatitis. 63% report experiencing physical, mental, or emotional stress. Caregivers also report feeling a lack of support, with 36% report feeling a lack of support from the health care system, and 19% feeling a lack of support from family members and friends. Caring for a child with atopic dermatitis can also cause financial burden, with 30% of respondents reporting financial challenges related to managing their child's disease.

69% of caregivers experience **anxiety** related to their child's atopic dermatitis



“Managing our child’s eczema is exhausting and stressful. I try not to put my feelings of frustration and hopelessness onto our son, but it’s hard, and the worst part is I know how much he is suffering.”

— Mother of child with moderate eczema

SUMMARY

These survey results of Canadians suffering with moderate-to-severe atopic dermatitis and their caregivers clearly demonstrate the burden of this chronic, debilitating skin disease.

New treatments and solutions are needed for patients who are suffering and for whom current therapies are inadequate.

The impact on sleep, quality of life and mental health demonstrate that for many people living with the disease, atopic dermatitis is more than “just a rash.” Many Canadians with moderate-to-severe atopic dermatitis have difficulty accessing specialty care and appropriate treatments.

Unfortunately, the treatments they do use are often inadequate for this patient population. Safe and effective treatments for moderate-to-severe atopic dermatitis are desperately needed.



ACKNOWLEDGEMENTS

ESC would like to extend our gratitude and acknowledge the contributions of Amanda Cresswell-Melville, Executive Director, ESC, Aaron Drucker, MD, ScM, FRCPC, and Panteha Eshtiaghi, HBSc, MD Candidate, on the quality of life surveys and the creation of this report.

This project was supported by an unrestricted grant from Sanofi Genzyme.

REFERENCES

1. Drucker AM et al. *J Invest Dermatol.* 2017 Jan;137(1):26-30.
2. Margolis JS et al. *JAMA Dermatol.* 2014 Jun;150(6):593-600.
3. Silverberg JI et al. *J Invest Dermatol.* 2015 Jan;135(1):56-66.
4. Shaw TE et al. *J Invest Dermatol.* 2011 Jan;131(1):67-73.
5. Cheng CM et al. *J Affect Disord.* 2015 Jun 1;178:60-5.
6. Gregory AM and Sadeh A. *Sleep Med Rev.* 2012 Apr;16(2):129-36.
7. Meltzer LJ and Mindell JA. *Psychiatr Clin North Am.* 2006 Dec;29(4):1059-76.



ECZEMA SOCIETY OF CANADA

411 The Queensway South
PO Box 25009, Keswick, Ontario
L4P 4C2 Canada

Toll-free line: 1-855-ECZEMA-1

E-mail: info@eczemahelp.ca

Website: eczemahelp.ca



[facebook.com/
EczemaSocietyofCanada](https://facebook.com/EczemaSocietyofCanada)



[twitter.com
@EczemaSocietyCA](https://twitter.com/EczemaSocietyCA)



[youtube.com/
EczemaHelp](https://youtube.com/EczemaHelp)

