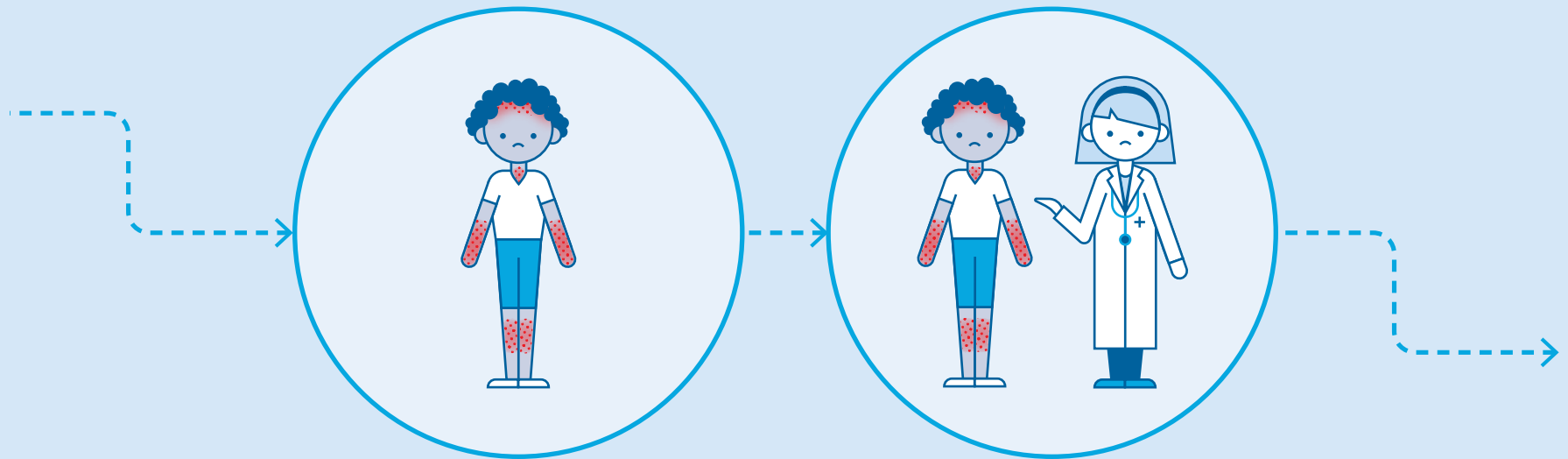


ECZEMA SOCIETY OF CANADA

THE ATOPIC DERMATITIS PATIENT JOURNEY



INTRODUCTION

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AN ITCHY LIFE: ATOPIC DERMATITIS

Atopic dermatitis (AD) is a chronic inflammatory skin disease that is characterized by dry, red, itchy skin that can crack, ooze, and bleed. The symptoms can lead to lack of sleep, low self-esteem, and cause a significant negative impact on quality of life. It is estimated that 11% of children and 7% of adults live with the disease.

As a chronic condition with no cure, AD requires daily management, typically consisting of time consuming and often painful topical treatments. For some patients, despite their best efforts to manage their condition and avoid triggers, their AD remains uncontrolled.

ABOUT THE REPORT

This report is based on information gathered via patient and caregiver interviews and focus groups. A 2020 patient journey survey was also conducted and included responses from 1057 AD patients from across Canada, including both adult patients and caregivers of children living with AD.

The journey aims to accurately represent the experiences of the AD patient, however this content does not represent all patient and caregiver experiences. It is our hope that those living with AD see their experiences reflected in this report, and that all relevant stakeholders can understand the journey, the barriers, and the gaps in care for Canadian AD patients.

ATOPIC DERMATITIS SEVERITY

Defining and understanding AD severity is a complex task. AD severity is often described by physical symptoms and the amount of body surface area involved. Patients report that the location of the rash, and impact on sleep and quality of life, also affect 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 localized skin thickening



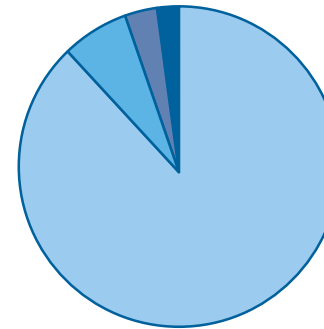
SEVERE

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

WHAT'S IN A NAME?

Eczema is the umbrella term for dermatitis, or inflammation of the skin. When we refer to the chronic, itchy form of eczema that is hereditary and linked with other conditions such as asthma and allergies, we are referring to AD. The most common form of eczema is AD, and patients typically refer to their condition as eczema.

WHAT DO PATIENTS AND CAREGIVERS CALL THE DISEASE?



- 88% Eczema
- 7% Atopic Dermatitis
- 3% Atopic Eczema
- 2% Other

FLARES

FLARE CYCLES

AD patients experience periods of flare (worsening of the disease) and periods of remission (less disease or periods of clear skin). Some patients always have a baseline level of disease activity and never experience clear skin. Topical treatments are typically used for the duration of the flare, and then stopped when skin is clear. Patients and caregivers cite concerns and challenges with their treatment plans that can drive them to stop treatment.

Common reasons for stopping treatment before the skin is fully clear include: lack of efficacy, discomfort and pain upon application, and medication safety fears. Lack of efficacy is the leading cause for patients to stop using a treatment. Only 8% of severe patients surveyed report that topical medications are always able to manage their flares.

INTERMITTENT FLARES

More than half of the survey respondents report experiencing intermittent flares, which are acute flares with clear skin in between. This flare pattern is much more common among mild patients. The most common flare frequency among mild AD patients is four flares per year or less.

A CONSTANT STATE OF FLARE

Other patients live in a more constant state of flare; 41% of survey respondents report some level of baseline AD at all times with additional varying periods and degrees of worsening. These patients may experience improvement of their symptoms, but may never have periods of fully clear skin. This pattern of flaring is common for moderate and severe patients and much less common for mild patients.



80% of patients and caregivers experience frustration during flares



43% of patients trust their health care provider's treatment recommendations



44% of patients and caregivers feel let down by their treatments



41% of caregivers feel like failures when they cannot control their child's flares

Patients and caregivers also report their access to specialist care is limited and wait times can be long. They also worry about the timing of their appointment in relation to flares – by the time they see a specialist, the flare may be temporarily improved and not indicative of the true level of severity. Patients also report frustration when health care providers do not fully assess their skin and specific needs. For example, when health care providers don't take time to examine areas of skin that may be covered by clothing, or don't recognize the unique needs of individuals with AD and skin of colour.



37% of adult patients worry their health care provider won't see their skin during a flare



42% of caregivers worry the health care provider won't see their child's skin during a flare

ACUTE FLARE CRISIS

Patients report experiencing a “flare crisis” – a significant flare that was not manageable and required immediate medical intervention. Almost half of the patients surveyed (48%) have experienced a flare crisis. Of those patients surveyed, 89% have moderate or severe AD, while only 11% of mild patients reported experiencing a crisis.

Patients report seeking urgent medical care during a flare crisis, and/or an adjustment or escalation in treatment as a direct result of a flare crisis. A flare crisis takes a tremendous emotional toll on patients, as well as the physical impact which typically includes painful and extensive rashes, open wounds, and infection.



72% of respondents report emotional stress due to a flare crisis



The survey revealed **THE MORE SEVERE** a patient is, the more likely they are to give up on treatment

“During my worst flare crisis, my life fell apart and I couldn't take care of myself. It was so bad that my parents had to come and help me. This is when I knew I couldn't continue to manage my eczema; it was time for a major change in my treatment.”

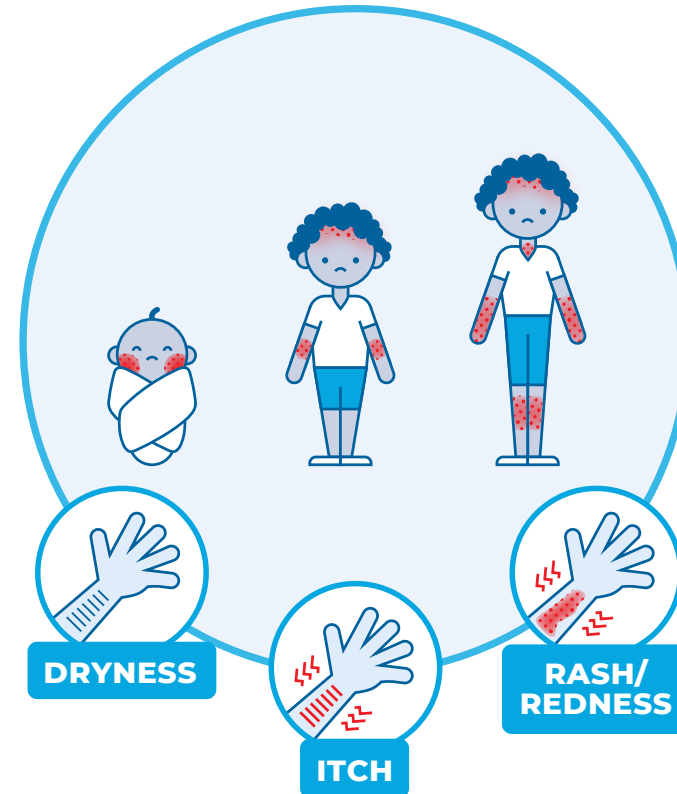
— Adult patient with AD

ABOUT THE PATIENT JOURNEY

This patient journey map is designed to articulate the shared experience of patients living with AD and the journey from diagnosis onward to seeking management.

While the information contained in this report has been validated by patients and survey data, and aims to accurately represent the AD patient experience, this content does not represent all patient and caregiver experiences.

It is our hope that those living with AD see their experiences reflected in this report, and that all relevant stakeholders can understand the journey, the barriers, and the gaps in care for Canadian AD patients.



THE ATOPIC DERMATITIS PATIENT JOURNEY

The patient journey map has been divided into the following three distinct sections that can work independently or as a continuum. It should be noted that during their lifetime, patients may cycle back and forth through these phases and experience periods of managed and unmanaged AD.



THE ATOPIC DERMATITIS PATIENT JOURNEY

The first phase of the journey follows the patient from first symptoms, to diagnosis, and on to initial treatment. Some patients achieve management of their AD, enter a period of remission, or outgrow the disease and their journey ends. For others, the disease is not managed, and they suffer through cycles of flares, which typically prompts a request for specialist care.



LIVING WITH RECURRING FLARES

The second phase of the journey includes treatment escalation, often under the care of a specialist. At the end of this phase, some patients are able to manage their flares, while others are still unable to achieve management. As flare cycles persist, suffering increases and quality of life deteriorates.



CRISIS DRIVES ACTION

The final phase is that of a crisis. Patients who experience a crisis, primarily moderate and severe patients, are the most desperate and seek emergency intervention. In this phase, patients have exhausted topical treatments and are ready to escalate therapy again. They experience very poor quality of life due to intense and intolerable itch, painful and open skin rashes, poor sleep, and social isolation.

COMMON CARE TEAM MEMBERS:



PRIMARY CARE PROVIDERS
(e.g. family physicians, general practitioners, nurse practitioners, etc.)



PHARMACISTS



DERMATOLOGISTS & DERMATOLOGY NURSES

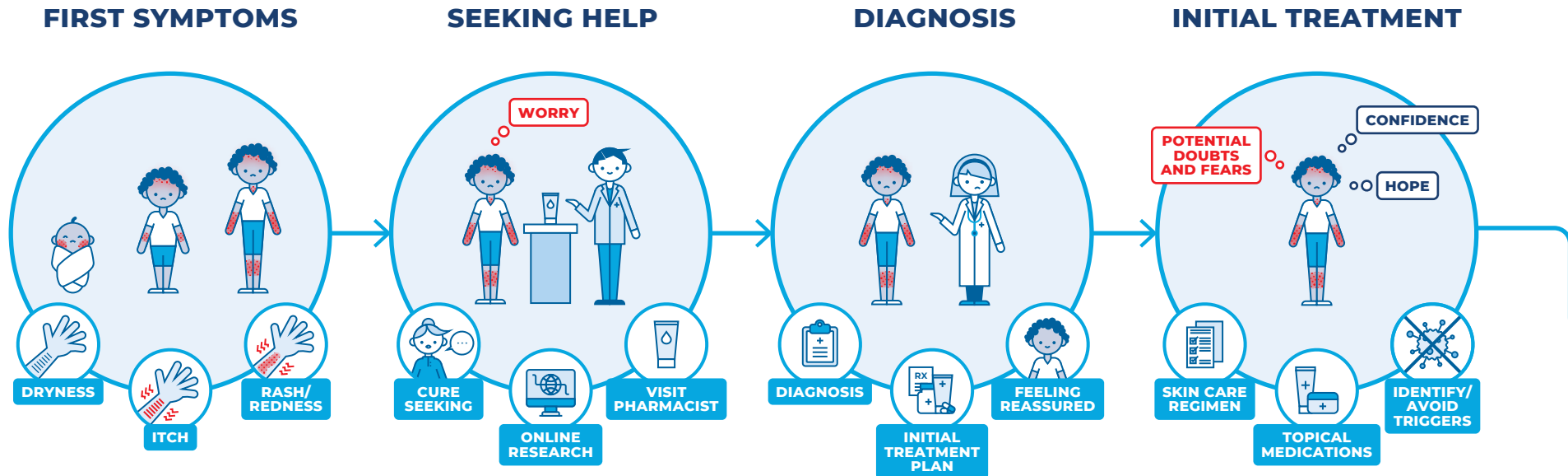


PAEDIATRICIANS



ALLERGISTS & IMMUNOLOGISTS

THE ATOPIC DERMATITIS PATIENT JOURNEY



Atopic dermatitis (AD):

- Typically begins in infancy or childhood and can continue into adolescence and adulthood
- May seem to first appear well into adulthood
- May be outgrown, have long periods of remission, or be a lifelong condition
- Caregivers may think early AD is a heat rash or caused by food
- Patients often try to attribute symptoms to a cause or trigger, such as diet or environmental triggers

At first, it's common to feel concerned yet hopeful that AD could be simple to treat or even cured. Patients and/ or caregivers:

- Often seek a cure
- Seek early advice from trusted friends and/or family
- Receive unsolicited advice which can be frustrating
- Book an appointment with a primary health care provider

Patients and caregivers typically seek a diagnosis from a primary health care provider.

- Many receive quick access to diagnosis and medical care from primary health care providers
- Some feel satisfied with their primary health care provider and confident with their treatment plan
- Others may feel dismissed

Initial treatment commonly includes topical medications. It may include counseling on bathing, moisturizing, and trigger avoidance, however, for some patients this does not occur until specialist care later in the journey. Patients and/ or caregivers:

- Often try to determine and eliminate potential triggers or the "cause" of flares
- May report non-adherence to topical medications due to safety and/ or efficacy concerns



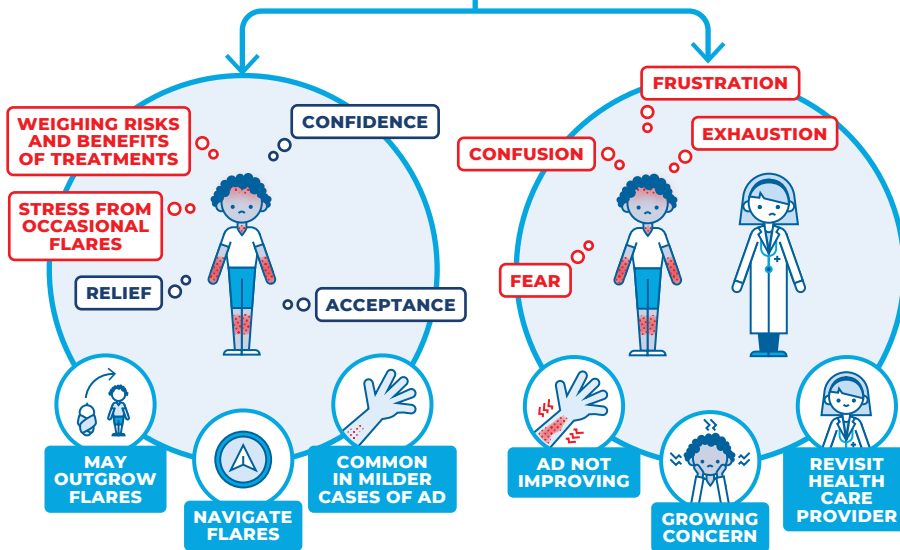
DIAGNOSIS TYPICALLY OCCURS QUICKLY



DURATION MAY VARY

MANAGED

Some patients will be able to manage flares as they occur, using topical medications and skin care, and may be satisfied with their AD management. Their health care provider is able to provide support for their AD management.

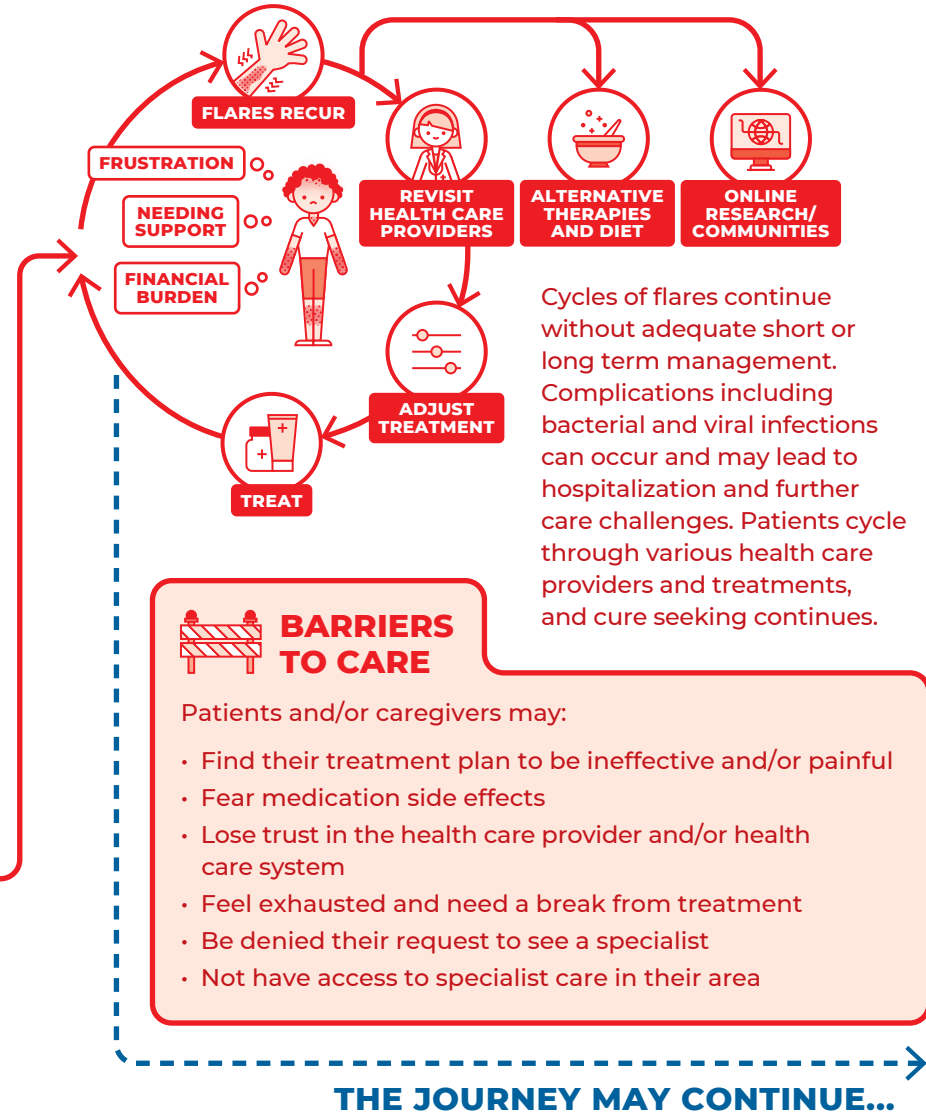


NOT MANAGED

Other patients will not achieve optimal management from an initial treatment plan, and the cycle through health care providers and various treatments begins.

- AD does not respond to mild topical medications and/or bathing and moisturizing
- Patients and/or caregivers may seek a re-evaluation from their health care provider

FLARE CYCLES



Cycles of flares continue without adequate short or long term management. Complications including bacterial and viral infections can occur and may lead to hospitalization and further care challenges. Patients cycle through various health care providers and treatments, and cure seeking continues.

BARRIERS TO CARE

Patients and/or caregivers may:

- Find their treatment plan to be ineffective and/or painful
- Fear medication side effects
- Lose trust in the health care provider and/or health care system
- Feel exhausted and need a break from treatment
- Be denied their request to see a specialist
- Not have access to specialist care in their area

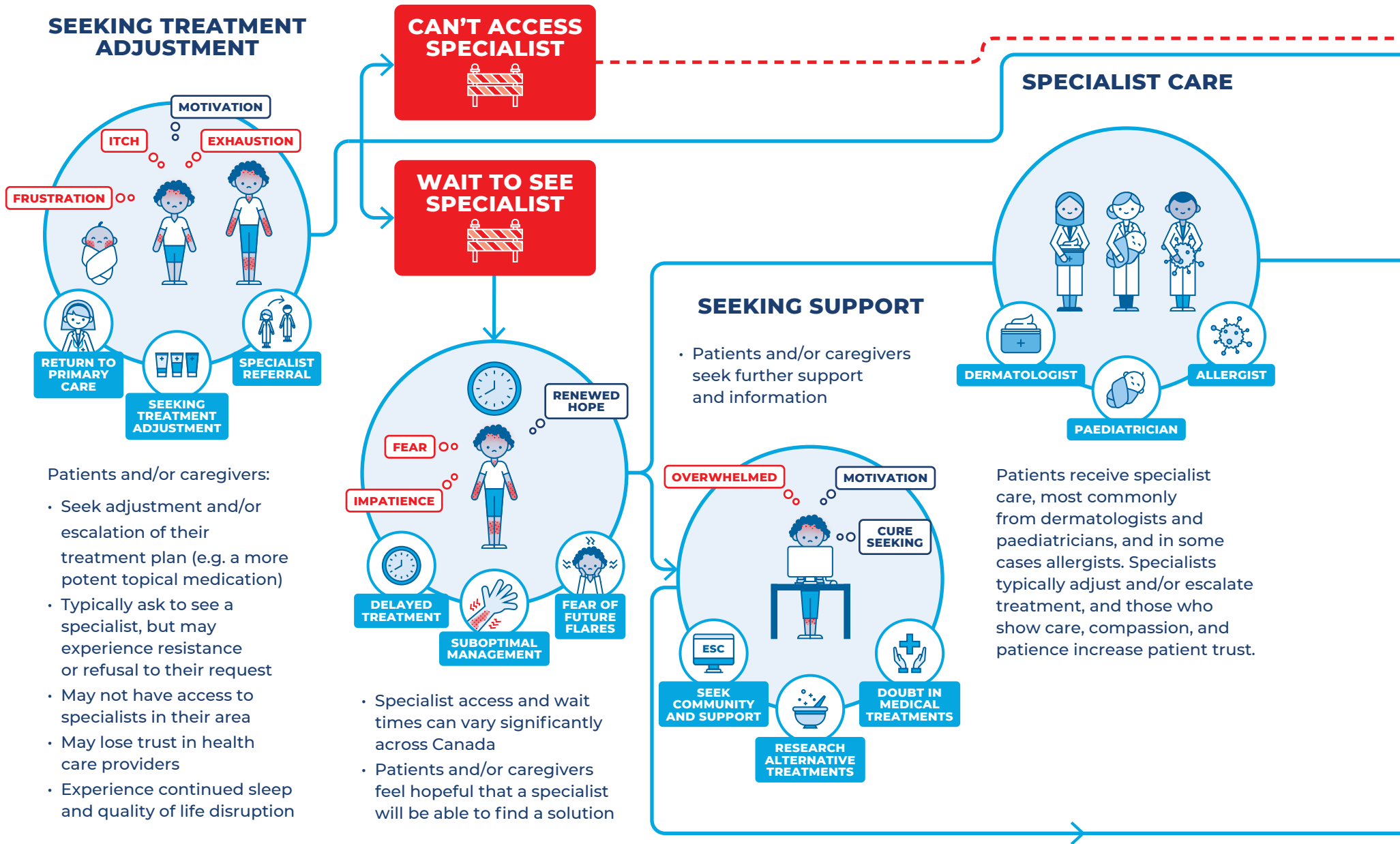
THE JOURNEY MAY CONTINUE...

DURATION MAY VARY

DURATION MAY VARY

DURATION MAY VARY SIGNIFICANTLY

LIVING WITH RECURRING FLARES

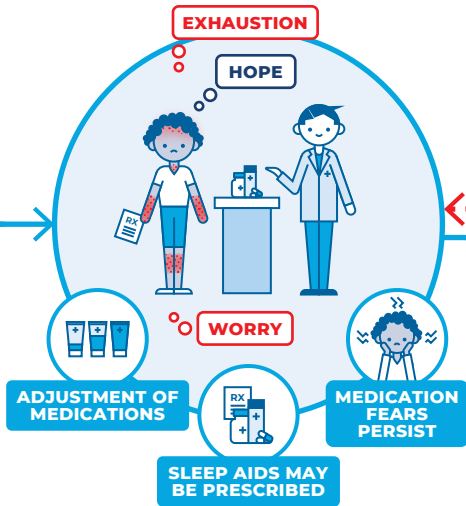


TYPICALLY A SHORT DURATION



DURATION MAY VARY

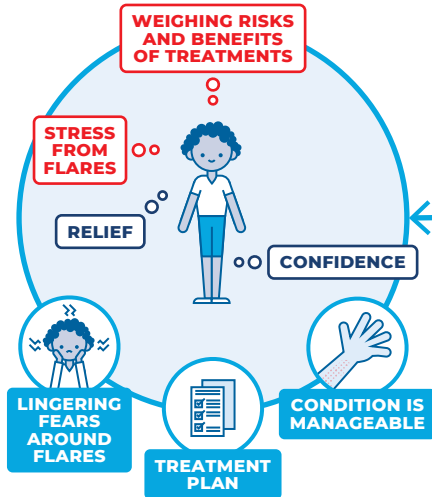
TREATMENT ADJUSTMENT



Medication safety fears may continue alongside the desire for a stronger medication that will manage flares. Pharmacists may support or contradict the prescribing health care provider recommendations. As suffering increases, health care providers may also prescribe medications to help manage infection, itch and/or sleep.

MANAGED

Ideally an effective long-term strategy is established for managing flares as they occur, minimizing triggers, and escalating treatment when needed. The condition is generally manageable with primary care and intermittent specialist care, and patients and/or caregivers feel relief and in control. Sleep, quality of life, and self-esteem may improve.

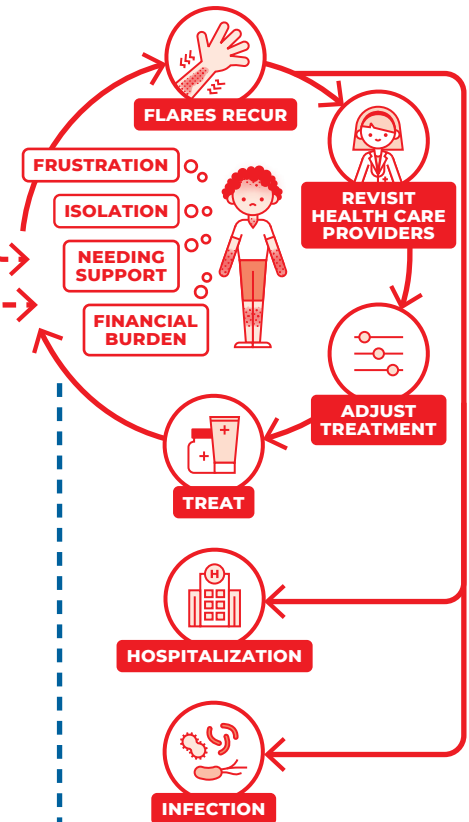


NOT MANAGED

Many patients never experience periods of clear skin and/or remission, especially those with moderate or severe AD. Chronic itch, sleep loss, skin rash, and pain further impact patient quality of life and mental health. Social relationships and family life continue to suffer, and caregivers report feeling like failures.



RECURRING FLARE CYCLES

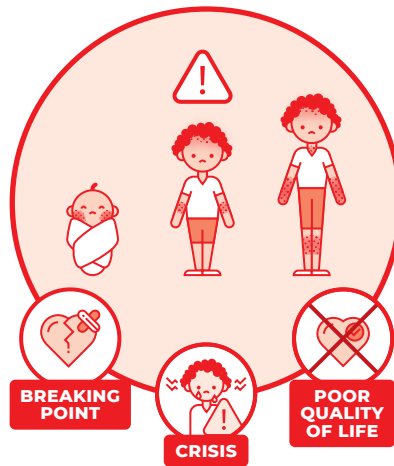


THE JOURNEY MAY CONTINUE...

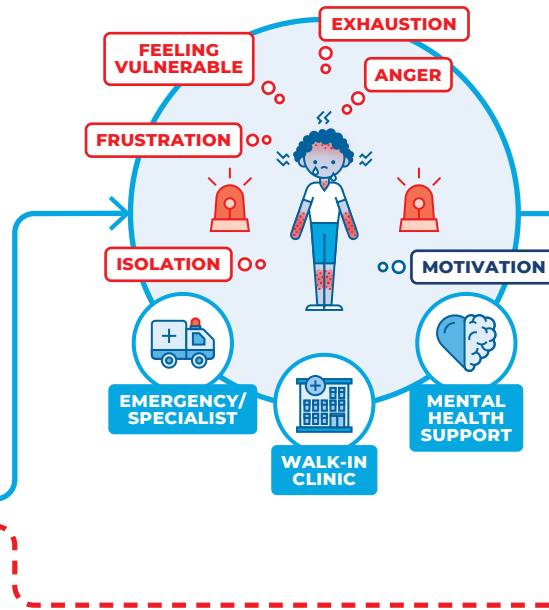
CRISIS DRIVES ACTION

CRISIS!

Many patients and/or caregivers report experiencing a flare crisis (i.e. an acute or gradual worsening of the condition that can no longer be tolerated and requires immediate medical intervention). A crisis drives action to improved, adjusted, or escalated care and treatment.

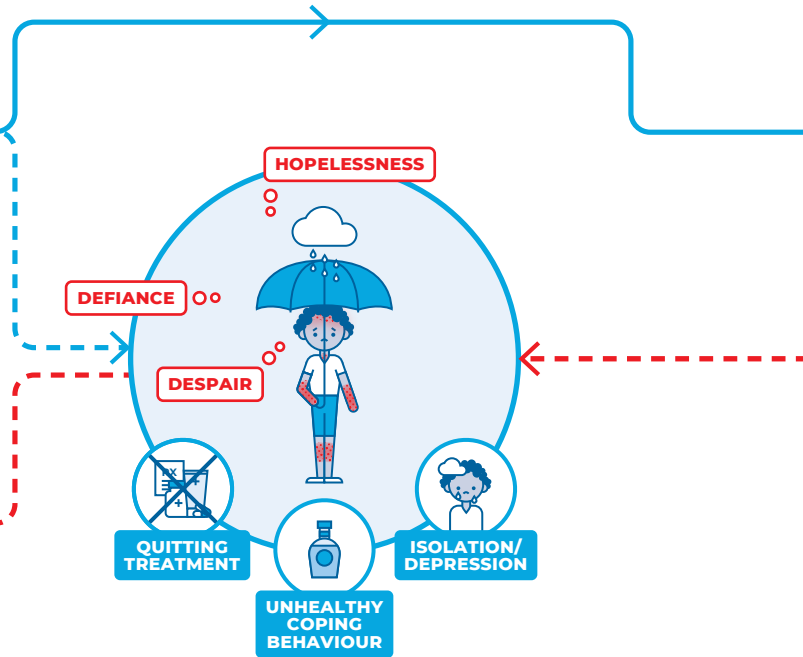


SEEK URGENT INTERVENTION

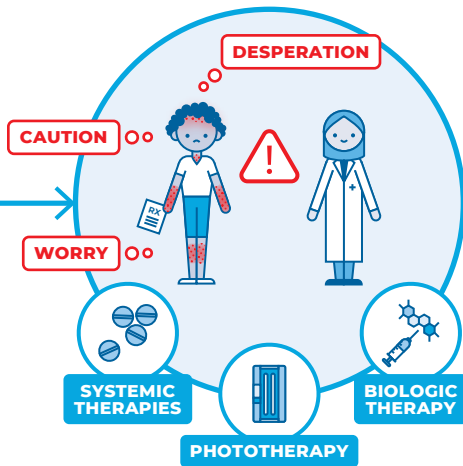


QUIT TREATMENT

Patients and/or caregivers may quit treating AD anywhere from weeks, to months, to years at a time. The main reasons for quitting treatment are lack of efficacy and safety fears. Some begin to believe that no effective treatment exists, and/or accept a life with suffering.



TREATMENT ESCALATION

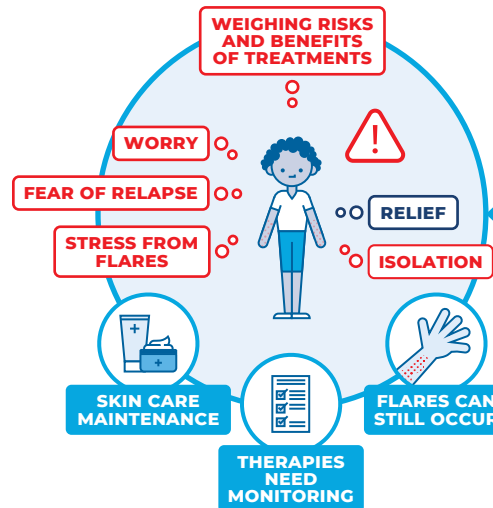


Patients and/or caregivers weigh the risks and benefits of stronger medications, which may include more potent topical medications or systemic therapies.

- Oral corticosteroid and systemic immunosuppressant therapies may be prescribed for short periods of time, but safety fears and blood monitoring may be prohibitive
- Phototherapy may be prescribed but access to a clinic may be a significant barrier
- New biologic therapies may be prescribed; cost may be prohibitive depending on access to drug coverage and reimbursement

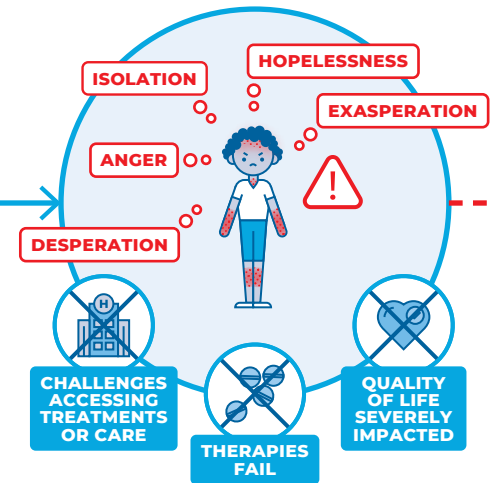
MANAGED

Some patients are managed at this stage, but it may be temporary. Relationships and quality of life begin to improve when AD improves. At this time there is no cure for AD.



NOT MANAGED

For individuals who reach this stage, treatments may only offer temporary relief, if any. Itch and sleep, along with AD symptoms, continue to impact quality of life, mental health, relationships, and work.



MAY LAST MONTHS, YEARS, OR A LIFETIME

MAY LAST MONTHS, YEARS, OR A LIFETIME

MAY LAST MONTHS, YEARS, OR A LIFETIME

SUMMARY



CHALLENGES

- Conflicting and/or inaccurate information can derail and/or delay treatment.
- Understanding the chronicity and the lack of cure is essential.
- As patients and caregivers experience treatment failure, they report their trust in their health care providers decreases. Only 43% of adult patients trust the recommendations of their health care provider.
- Patients report disconnection and contradiction across their various health care providers.
- Patients report their primary health care provider delays specialist referral or waits until there is a crisis before referring.
- Timing to see a specialist during a flare is also a challenge, and 37% of adult patients and 42% of caregivers worry they won't actually see the health care provider during a flare or at a flare peak.
- Patients often report a renewed sense of hope when they receive specialist care.



TREATMENT CONCERNS

- Patients with a milder form of AD are often able to manage their condition with topical medication and guidance from their health care provider, while moderate and severe patients experience greater treatment challenges related to efficacy.
- Safety fears related to AD medications persist; 29% of adult patients and 64% of caregivers report fears around medication safety.
- Some patients with severe or persistent flares find topical medications ineffective even when used as prescribed.
- Some patients seek alternative therapy; 35% report they have researched alternative therapies.
- Only 7% of patients report having used alternative therapies instead of their health care provider prescribed treatments.



FLARES

- Mild and moderate patients typically experience flares as exacerbations of AD after periods of clear skin.
- Moderate and severe patients often experience flares as a worsening of AD on top of a constant baseline of disease activity.
- Patients can live in a constant state of flare, with 41% of patients experiencing some level of baseline AD at all times along with additional intermittent flares.
- Frustration during flares is reported by 80% of patients and caregivers surveyed.
- Complications such as bacterial and viral infections can lead to emergency department visits and make the disease significantly more difficult to manage.
- 48% of adult respondents have experienced a flare crisis that has required immediate medical intervention, and 72% of patients report emotional stress due to a flare crisis.



QUALITY OF LIFE IMPACT

- Itch is consistently reported as the most bothersome symptom of AD.
- Long term AD can impact sleep, mental focus, work and school productivity, ability to exercise, travel, interpersonal relationships, self esteem, and mental health.
- Patients report a need for mental health support, as well as a desire to connect with peers and seek support from organizations like Eczema Society of Canada.
- Patients report significant quality of life impact from incessant itch and skin symptoms, affecting every facet of life. As the disease worsens, patients fear they may never be well managed.
- The more severe the disease, and the longer the patient suffers over time, the more significant the quality of life impact.

ABOUT THE ECZEMA SOCIETY OF CANADA

The Eczema Society of Canada (ESC) is a national registered charity dedicated to improving the lives of Canadians living with eczema through education, support, research, and awareness.

ACKNOWLEDGEMENTS

ESC thanks the patients and caregivers who gave their time and expertise to this project, and for sharing their experiences of living with atopic dermatitis. ESC thanks and acknowledges AbbVie Canada, Bausch Health Canada, LEO Pharma Inc., Pfizer Canada, and Sanofi Canada who provided funding for this project.

This report is dedicated to patients and caregivers living with atopic dermatitis.



ECZEMA SOCIETY OF CANADA

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