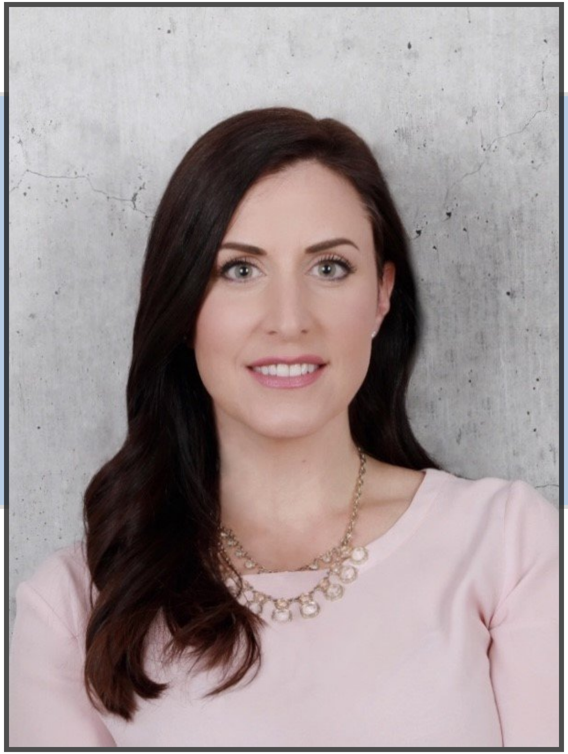
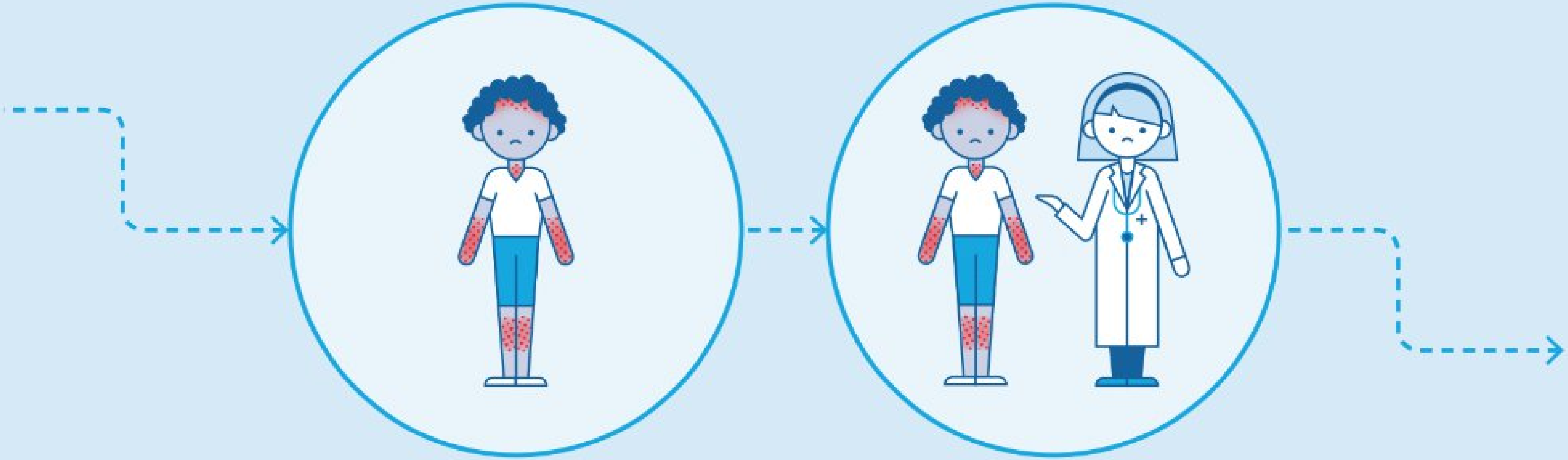


AMANDA CRESSWELL-MELVILLE
EXECUTIVE DIRECTOR
ECZEMA SOCIETY OF CANADA

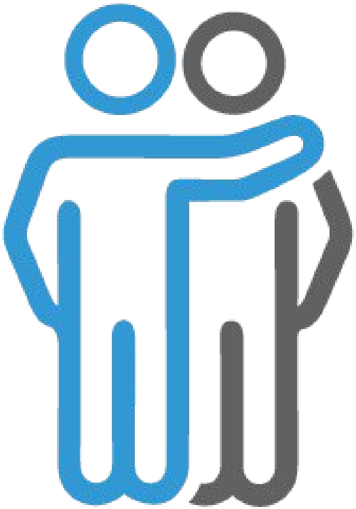
Eczema Society of Canada
Société canadienne de l'eczéma
TM/MC

THE ATOPIC DERMATITIS PATIENT JOURNEY PRESENTATION



OUR GOAL

- Better understand the experiences, care, treatments, pain points, and gaps in care along the patient journey
- Represent patients and caregivers authentically, and have their experiences honoured and validated
- Help multiple stakeholders understand the journey, the barriers, and the gaps in care for Canadian AD patients



METHODOLOGY

- Based on patient and caregiver interviews, focus groups, and surveys

- A 2020 validation survey included responses from 1,057 patients and caregivers from across Canada

- Journey iterations were validated and edited along our process

MAPS

J

THE ATOPIC DERMATITIS PATIENT

LIVING WITH RECURRING FLARES

CRISIS DRIVES ACTION

THE ATOPIC DERMATITIS PATIENT JOURNEY

FIRST SYMPTOMS

Atopic dermatitis (AD):

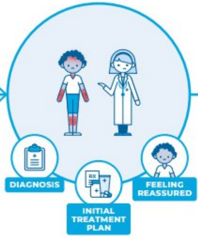
- Typically begins in infancy or childhood and can continue into adolescence and adulthood
- May seem to first appear well into adulthood
- May be outgrown, have long periods of remission, or be a lifelong condition
- Caregivers may think early AD is a heat rash or caused by food
- Patients often try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

SEEKING HELP

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

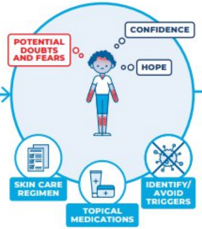
DIAGNOSIS



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



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:

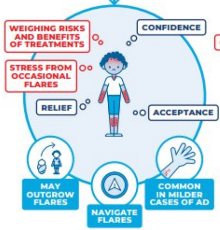
- Often try to determine and eliminate potential triggers or the "cause" of flares
- May report non-adherence to topical medications due to safety and/or efficacy concerns

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.

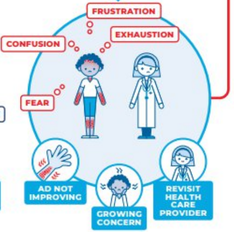


DURATION MAY VARY

NOT MANAGED

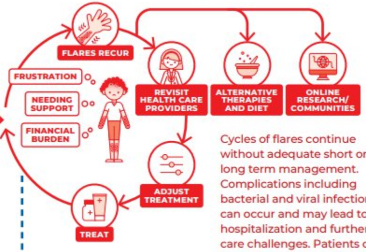
Other patients will not achieve optimal management from an initial treatment plan, and the cycle through health care providers and various treatments begins.

- 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



DURATION MAY VARY

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

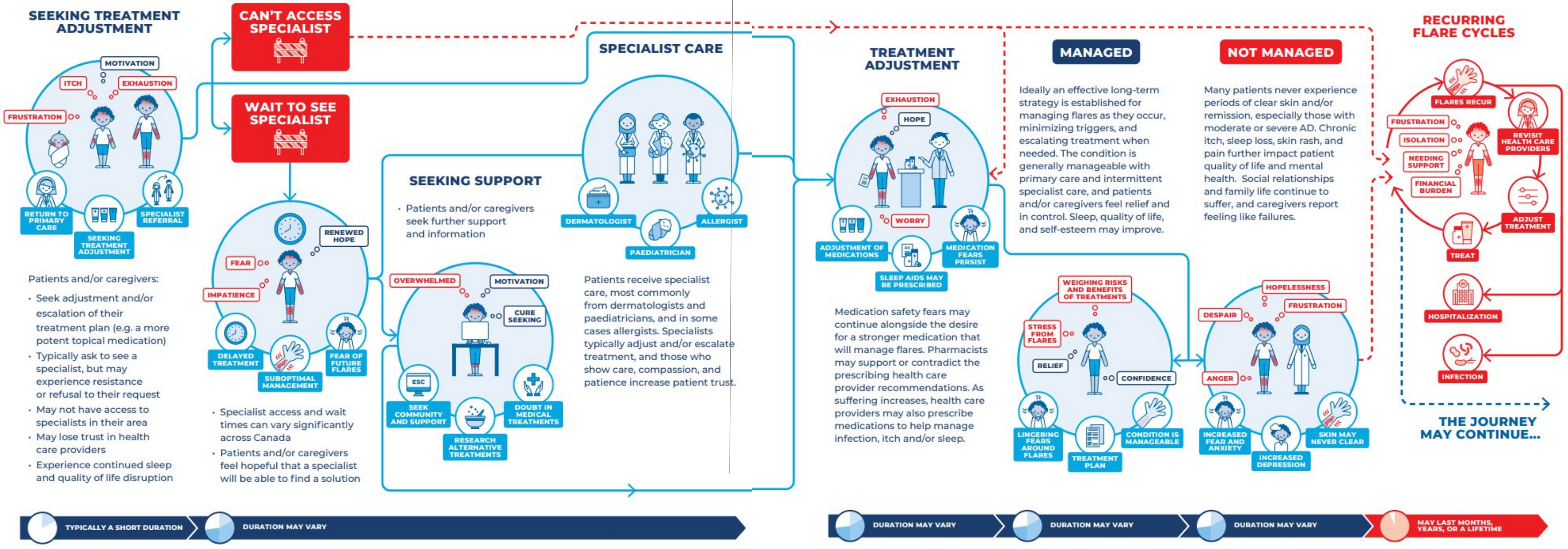
Patients and/or caregivers may:

- 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 SIGNIFICANTLY

LIVING WITH RECURRING FLARES



SEEKING TREATMENT ADJUSTMENT

Patients and/or caregivers:

- Seek adjustment and/or escalation of their treatment plan (e.g. a more potent topical medication)
- Typically ask to see a specialist, but may experience resistance or refusal to their request
- May not have access to specialists in their area
- May lose trust in health care providers
- Experience continued sleep and quality of life disruption

CAN'T ACCESS SPECIALIST

WAIT TO SEE SPECIALIST

- Specialist access and wait times can vary significantly across Canada
- Patients and/or caregivers feel hopeful that a specialist will be able to find a solution

SEEKING SUPPORT

- Patients and/or caregivers seek further support and information

SPECIALIST CARE

Patients receive specialist care, most commonly from dermatologists and paediatricians, and in some cases allergists. Specialists typically adjust and/or escalate treatment, and those who show care, compassion, and patience increase patient trust.

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.

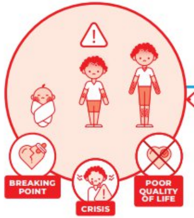
RECURRING FLARE CYCLES

THE JOURNEY MAY CONTINUE...

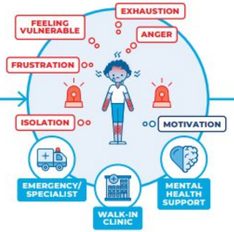
CRISIS DRIVES ACTION

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.



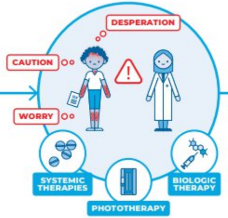
SEEK URGENT INTERVENTION



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.

TYPICALLY A SHORT DURATION

TYPICALLY A SHORT DURATION

DURATION MAY VARY SIGNIFICANTLY

MAY LAST MONTHS, YEARS, OR A LIFETIME

MAY LAST MONTHS, YEARS, OR A LIFETIME

MAY LAST MONTHS, YEARS, OR A LIFETIME

FLARE PATTERNS

INTERMITTENT FLARES

- More common for mild patients

CONSTANT STATE OF FLARE

- More common for moderate and severe patients

DATA HIGHLIGHTS

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

DATA HIGHLIGHTS

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

DATA HIGHLIGHTS

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

DATA HIGHLIGHTS

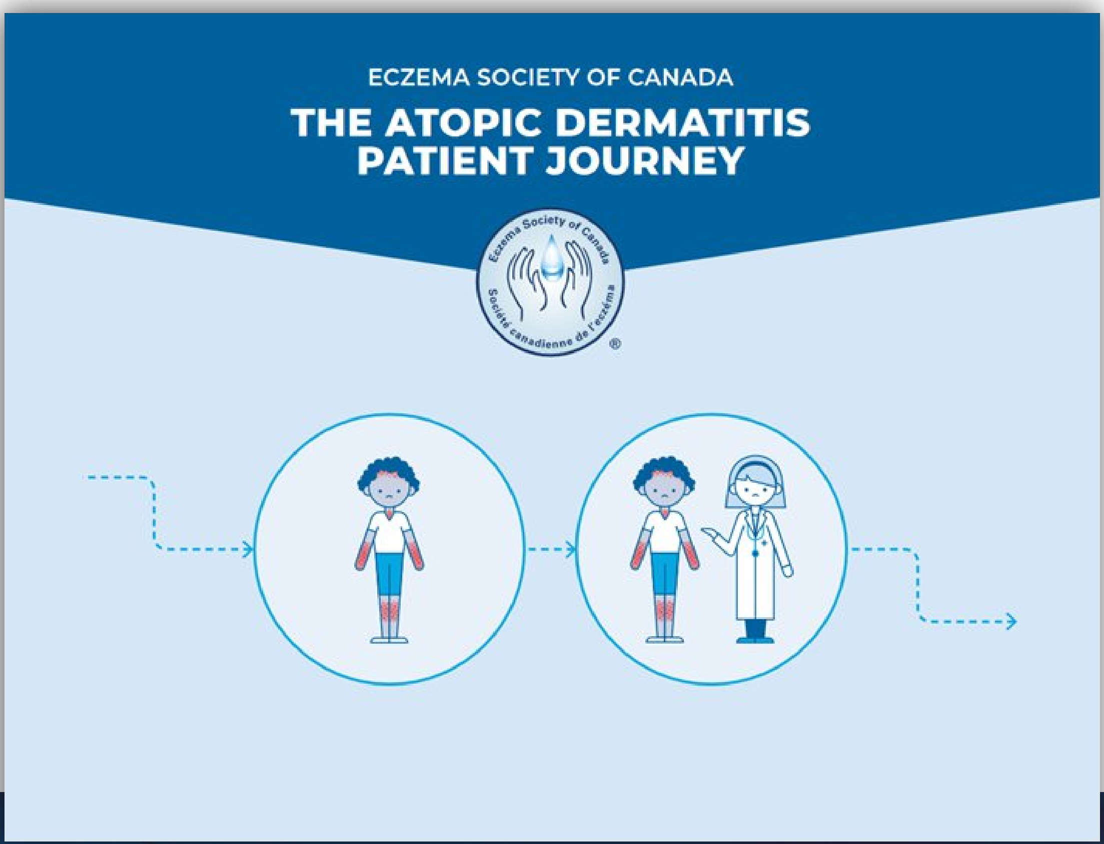
PATIENTS AND CAREGIVERS WORRY THAT HEALTH CARE PROVIDERS:

- Won’t see their skin during a flare
- Won’t actually examine their skin
- Don’t understand or address the needs of patients with skin of colour

AD PATIENTS NEED AND DESERVE

- Compassion, empathy, and understanding
- Education
- Appropriate and timely care
- Customized care plans with provider integration
- Treatment adjustment BEFORE a crisis
- Mental health support
- More research
- More treatment choice

eczemahelp.ca/journey



ECZEMA SOCIETY OF CANADA

THE ATOPIC DERMATITIS PATIENT JOURNEY

THANK YOU