

This content is not meant to replace a conversation with a healthcare provider.
A healthcare provider can evaluate your symptoms and make appropriate clinical decisions.

In the management of
hereditary angioedema (HAE)

WHAT IF YOU COULD

deflate HAE

WITHOUT DEFLATING
EXPECTATIONS?

**Life with HAE can be a burden.
Its management shouldn't be.**

Real person
living with HAE.

WHAT EVERY FAMILY NEEDS TO KNOW:

**THE BURDEN AND TRADE-OFFS
OF LIFE WITH HAE**

See inside to expand your HAE knowledge.

HAE IS A RARE, UNPREDICTABLE DISEASE THAT CAN BE LIFE-THREATENING

An HAE attack may
cause various parts of
your body to swell



Real person
living with HAE.

During an attack, people with HAE may experience many complications

FACE

- Problems speaking clearly
- Poor vision from swollen face causing eyes to close
- Swells may cause fear and shame

LEGS & FEET

- Difficulty walking or running
- Cannot fit into shoes

HANDS & ARMS

- Lack of ability to hold objects (phone, pen, glass/cup)
- Difficulty texting or typing
- May make it difficult to give oneself an injectable or IV HAE medication
- Embarrassment being seen in public

STOMACH

- Mild to severe stomach pain with nausea, vomiting, and/or diarrhea
- Abdominal pain can restrict ability to move

THROAT/AIRWAY

- Shortness of breath
- Difficulty speaking
- Choking and fear of death from being unable to breathe
- Highest emotional impact compared to other attack locations
- Hospitalization more likely to occur

GENITALS

- More-frequent attacks during periods, giving birth through C-section, and breastfeeding
- Estrogen-containing birth control pills can trigger HAE attacks
- Potential attacks during childbirth

#deflateHAE

FOUR REAL PEOPLE WITH HAE. FOUR UNIQUE STORIES.

deflate HAE TOGETHER



Real people
living with HAE.

DISCOVER HOW HAE AND ITS MANAGEMENT BURDENS THEIR LIVES



ANDJELA

Real person living with HAE.

Married with two sons, trauma nurse,
diagnosed with HAE at age 27

"Some people didn't believe I had a disease; they thought I was exaggerating my pain or that it was all in my head."



WATCH
ANDJELA'S STORY



EMMA

Real person living with HAE.

Medical school student, diagnosed
with HAE at age 24

"If I am starting to have a swell, I tend to stay home. I just don't like to be seen in public because it's not something I can hide."



WATCH
EMMA'S STORY



GABBY

Real person living with HAE.

Recently engaged, diagnosed with HAE at age eight

"I predominantly swell in my hands and in my stomach. And hand swells make it difficult to start your own IV."



WATCH
GABBY'S STORY



JAMIE

Real person living with HAE.

Married with three sons, two have HAE,
language arts teacher, diagnosed at age 20

"HAE has disrupted my job, my friendships, and my everyday life."



WATCH
JAMIE'S STORY

#deflateHAE

FOR PEOPLE WITH HAE

LIFE CAN BE FILLED WITH BURDEN



Real person living with HAE.

EMOTIONAL BURDEN

- Some people with HAE may potentially experience near-constant anxiety about their next attack, causing them to cancel plans
- They may experience embarrassment and/or feelings of shame in front of friends, co-workers, or strangers

“So if I’m swelling, emotions are heightened, absolutely. There is a sense of panic that occurs during a swell.”

— Gabby, real person living with HAE



Real person living with HAE.

OCCUPATIONAL BURDEN

- Possible worry over limits on job options and perceived lack of career growth
- Possible fear of being seen as undependable or unproductive by co-workers

“Medical school is very competitive, and I do not want to be considered a weak link by my colleagues.”

— Emma, real person living with HAE



Real person living with HAE.

SOCIAL BURDEN

- Avoiding social events out of fear of having an attack and feeling embarrassed in public
- Difficulties dealing with the stigma of having a rare and isolating disease
- Problems managing the negative attention of others during an attack

“HAE also made me lose friends, because we would make plans and then I would end up canceling because I was sick.”

— Andjela, real person living with HAE



Real person living with HAE.

BURDEN ON CHILDREN

- Concerns over children missing classes, practices, or events, resulting in repeatedly being held back from important childhood milestones
- Children may not understand why they are unable to participate in contact sports, such as American football, rugby, or the martial arts

“For me, the biggest burden with these medicines is traveling with them. Two of my sons have HAE, so between all 3 of us, our medications and supplies take up a whole carry-on!”

— Jamie, real person living with HAE

IS HAE MANAGEMENT

FORCING YOU TO MAKE TRADE-OFFS?

Living with HAE can be complicated and frustrating.
Knowing how and when to take your medication shouldn't be.

“[An] injection makes you feel like you're very sick, and people see you more sick when you have injections around.”

— Andjela, real person living with HAE



TRADE-OFFS WITH HAE INJECTIONS

FEAR OF NEEDLES

Needles may cause anxiety

TRAVEL PLANNING

Injections can be difficult to carry, require more planning, and take up space

FAMILY PLANNING

Treatment options should consider impact on personal choices in family planning

SIDE EFFECTS

May cause pain and/or a reaction at the injection site

REQUIRES TRAINING

Learning to give oneself an injection can take time and require training

TIRED OF NEEDLES

Some people may get tired of giving themselves injections and may avoid treatments as a result

“I did try an oral [medication], and the side effects made me feel miserable.”

— Gabby, real person living with HAE



TRADE-OFFS WITH HAE ORALS

EFFECTIVENESS

On average, currently available orals may not provide injection-like efficacy™

SIDE EFFECTS

Currently available orals may have side effects that could lead people to stop therapy

“It's not an immediate medication. It takes time and for me it takes usually 30 minutes to an hour. And so in that time, I could still have progression of my disease, and so it's a waiting game as well. That anxiety is always there. That dread is always there.”

— Emma, real person living with HAE



TRADE-OFFS WITH HAE INFUSIONS

TIME CONSUMING

May require travel to an infusion center

HARD TO SELF-ADMINISTER

May be hard to find a vein or get IV to work

CONFLICTS WITH PLANS

May interfere with personal and work plans

SIDE EFFECTS

May cause headaches, nausea, rash, and fever

NEED ASSISTANCE

May need other people for help giving IV

TRAVEL ISSUES

When away from home, hard to give oneself an IV

10 FACTS ABOUT HAE YOU CAN SHARE WITH THE PEOPLE IN YOUR LIFE

01

HAE is a rare disease that causes parts of my body to suddenly swell up

02

These attacks can affect different parts of my body, including my face, arms, hands, legs, feet, genitals, or stomach

03

If an attack affects my throat and prevents me from breathing, it can be life-threatening

04

These attacks may be caused by anxiety, injury, surgical procedures, or other reasons. Attacks can even happen from happy excitement, like a wedding or birthday party. Sometimes, the attacks happen for no known reason

05

About two people in 100,000 have HAE in the United States

06

There are about 7,000 people living with HAE in the United States

07

HAE is typically passed down from parent to child

08

HAE is not contagious, and I cannot pass it on to you

09

The attack from HAE is not the same as swelling from an allergic reaction

10

The medications that treat allergic reactions are not effective in treating an HAE attack. One way of treating an attack is to give myself an injection of a medication prescribed by my doctor

Discover more about this rare disease at deflatehae.com

YOU'RE NOT ALONE CONNECT WITH THE HAE COMMUNITY



ANGIOEDEMA CENTERS OF REFERENCE AND EXCELLENCE (ACARE)

acare-network.com

A joint initiative by GA²LEN and HAEi with the aim of developing and accrediting an interactive network of centers of excellence in angioedema management.



HEREDITARY ANGIOEDEMA ASSOCIATION (HAEA)

HAEA.org

A non-profit advocacy organization serving people with HAE and their caregivers. They offer a wide variety of services and resources that further HAE education, clinical research, community engagement, access to medications, and personalized support networks.



HAE INTERNATIONAL (HAEi)

HAEi.org

A global non-profit network of patient associations dedicated to improving the lives of people with HAE. They are a group of compassionate HAE patients and caregivers who make it their life's work to raise awareness of HAE.



HAEi LEAP

youngsters.haei.org/leap-welcome-program/

An educational program, developed by HAEi, that allows young people to learn new skills and develop as individuals and advocates.



NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)

rarediseases.org

A comprehensive resource for people with a rare disease and their caregivers, including rare disease facts and statistics, information on living with a rare disease, mentoring organizations, improving clinical care, and community support.

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#deflateHAE



Real person living with HAE.

PEOPLE WITH HAE

MAY NOT BE LIVING THEIR LIFE TO THE FULLEST

IF TRADE-OFFS GET IN THE WAY

While current HAE management may help,
you may be making trade-offs among:

EFFECTIVENESS

How well
it works

SIDE EFFECTS

How well it is
tolerated

CONVENIENCE

How easy it is to
take or carry around

Discover more about this rare disease at deflate**HAE**.com

#deflate**HAE**



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