

SPEAK YOUR TRUTH

ABOUT MANAGING YOUR HEMOPHILIA A

**Are you making trade-offs
by compromising on bleed
protection or ease of
administration?**

Advocate for both bleed protection and
ease of administration—because your care
should never be compromised

**BREAKTHROUGH
BLEEDS**

**TOO MANY
INFUSIONS**

**PAINFUL
INJECTIONS**

**ACHES AND
PAINS**

Nikola lives with hemophilia A.

SpeakYourHemTruth.com

Are you making trade-offs when managing your hemophilia A?

You may be making **trade-offs by compromising** on bleed protection or ease of administration. While trade-offs are part of everyday life, accepting them in hemophilia A management can mean:

- accepting difficulties related to administering treatment to help prevent bleeds
- sacrificing bleed protection for easier administration—you may feel less protected for certain activities

Making trade-offs can be frustrating— do you ever have thoughts like these?

**“NOBODY
UNDERSTANDS**

how hard it is to help my child
infuse so often...”

“I feel like my concerns
are not worth talking about
because my healthcare provider
DIDN'T REALLY HEAR ME
in the past...”

**“I WISH
I FELT MORE
PROTECTED**

from bleeds between
doses, because my aches
and pains worry me...”

“I wish treatment were
LESS OF A HASSLE
so I could do more
fun things...”

Speaking up about administration challenges may help create change

When thinking about your hemophilia A management, do you ever feel frustrated by any of these common **treatment challenges**?



Large needles for injections and infusions



Injecting large volume doses frequently for better bleed coverage



Refrigeration requirements



Too many administration steps and supplies



Wasted product

Concerned about whether your current treatment is doing enough?

If you get **anxious or worried** about being protected from bleeds with your current management, you are not alone. Studies have shown that breakthrough bleeds with either current Factor 8 replacement or nonfactor therapy that works like Factor 8 (Factor 8 mimetic therapy) are still happening. What about for you?

In a real world study,

47%

of people with severe hemophilia A **using Factor 8 replacement** felt anxious at least sometimes about having adequate protection from bleeds^a

33%

of people with severe hemophilia A using **nonfactor therapy** that works like Factor 8 felt anxious at least sometimes about having adequate protection from bleeds^a

Learn about speaking your truth around trade-offs in hemophilia A management



^aFrom June 6, 2020 to June 15, 2022, 472 people with hemophilia participated in a survey. Among a subset of patients with severe hemophilia A, 83 patients receiving Factor 8 replacement prophylaxis therapy and 75 patients receiving nonfactor therapy.

Speak your truth: Tips for discussing trade-offs with your provider

Advocating for yourself or your loved ones is crucial when managing hemophilia A. Everyone's circumstances and treatment experiences are unique, so having effective shared decision-making conversations with your healthcare provider may help you make sure you are getting the best care for your situation.

Get ready to make the most of your next healthcare provider visit:

TRACK TRENDS

Keep track of how much and how often you are dosing, as well as any bleeds or side effects you may have (no matter how minor the bleed).

ASK QUESTIONS

Don't be afraid to ask your healthcare provider, your hemophilia treatment center (HTC), or members of the community about what you may be looking for in your hemophilia management.

GET SUPPORT

While others in the hemophilia A community can understand your experiences and offer support, you can also access qualified mental health professionals through foundations such as the National Bleeding Disorders Foundation (NBDF) and Hemophilia Federation of America (HFA).

KEEP EVALUATING

Consider what aspects of your hemophilia A management may be frustrating, so you can communicate with your healthcare provider about what can be simplified without sacrificing bleed protection.

[Visit our website](#) to connect with a **Novo Nordisk Rare Blood Community Liaison** and receive resources and updates



How to prepare for your upcoming appointment

Use this checklist as a starting point to track important information about your current management experience. There is also space below where you can track bleeds and write down any questions or concerns you want to bring up at your next visit.

Bring this information to your healthcare provider when discussing your hemophilia A management plan so they can get a clearer picture of what challenges you may be facing.

- ☐ **Treatment schedule**
How frequently do you administer treatment?
- ☐ **Treatment dose**
How much product are you injecting or infusing?
- ☐ **Bleeding episodes and other symptoms**
Examples: bruises, bumps, aches, and pains
- ☐ **Satisfaction related to hemophilia treatment**
How often do you feel frustrated or worried?
- ☐ **Things you haven't liked about previous or current treatments**
Example: dosing too often
- ☐ **Things you would like in your treatment**
Example: less painful injections


General questions and concerns

"I am worried about my vein health; are there ways to adjust or optimize my current therapy, and what factors should I consider when thinking about my future?"

Track your bleeds

"Fell and scraped my knee on October 1; bruising and pain in my right arm week of December 7"

EXAMPLES



Nikola lives with hemophilia A.

SPEAK YOUR TRUTH

Now you can feel confident knowing that you have the tools to have deeper discussions with your healthcare provider about your hemophilia A management.



You may be making trade-offs by compromising on bleed protection or ease of administration



You may be experiencing administration challenges despite current prophylaxis (including both Factor 8 replacement therapy and nonfactor therapy that works like Factor 8)



If you are anxious about bleed protection despite your current management, you are not alone—people still have breakthrough bleeds



Keeping track of your treatment experiences, including dosing, bleeds, and other symptoms, can help show evidence of your concerns to your healthcare provider



Staying connected to the wider hemophilia community is key to staying informed

You deserve fewer compromises—speaking up can help you better manage hemophilia A

FOR MORE RESOURCES, VISIT
SpeakYourHemTruth.com



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