



In Your Own Words

Reflections on Living with, or Caring for Someone with, Hemophilia



in Your own words

IN YOUR OWN WORDS

People living with hemophilia and their caregivers write back to their younger selves, to share personal insights and reflect on their experiences living with, or caring for someone with, hemophilia and starting on therapy.

Contents

The letters in this book have been written by people living with hemophilia, or who have a loved one living with hemophilia, and edited by Ellyn Spragins. The views and opinions expressed are not representative of Novo Nordisk and should not be considered as treatment advice.

Novo Nordisk has permission from all participants confirming their consent to use their letters and personal details in the *In Your Own Words: Reflections on Living with, or Caring for Someone with, Hemophilia* book.

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Introduction from

Ellyn Spragins

How many of you have looked back at a difficult passage in your life and wished you'd known then what you know now? Most of us, probably. This desire is so common that we have a shorthand for it: 20/20 hindsight. Who knows better than you exactly what your younger self was struggling with—and that perfect piece of wisdom that would have smoothed the way?



For me, this yearning for the insights that lay in the future became a creative project. What if I asked smart, accomplished people what they would say to their younger selves if they could somehow post a letter back in time? Even better, what would they say about a critical or challenging moment in their lives?

These questions led to three books filled with letters that I collaborated on and a speaking career which allowed me to bring the Letters to My Younger Self experience to life for hundreds of people in seminars and workshops. From the letters that emerged, I learned that everyone, even the seemingly invincible, has struggles. I discovered that what is difficult has as much to do with the fears and beliefs surrounding a particular obstacle as it does with the obstacle itself. Wonderfully, the lessons in the letters felt very approachable because the letter writers were not lecturing the reader—they were addressing themselves at a younger, less experienced age.

Very few letters, however, were about a physical or health problem. And yet, wouldn't it be extremely helpful to know how other people have handled—or mishandled—a health challenge so that we could gain from their experience? At the very least, it seemed to me, reading about someone who has faced a condition or situation like your own would make you feel less alone and better equipped to move forward.

This is the thinking that led to *In Your Own Words: Reflections on Living with Diabetes*, a book published in 2018 containing letters from people

with type 1 and type 2 diabetes. Though they all have diabetes, it wasn't a surprise to find that their experience with it varied tremendously. Some were diagnosed quite young, while others were diagnosed later in life. Some had suffered serious complications, while others had not. Some found it easy to manage their blood sugar, but others had to search painstakingly for the right combination of diet, exercise and medication that worked for them.

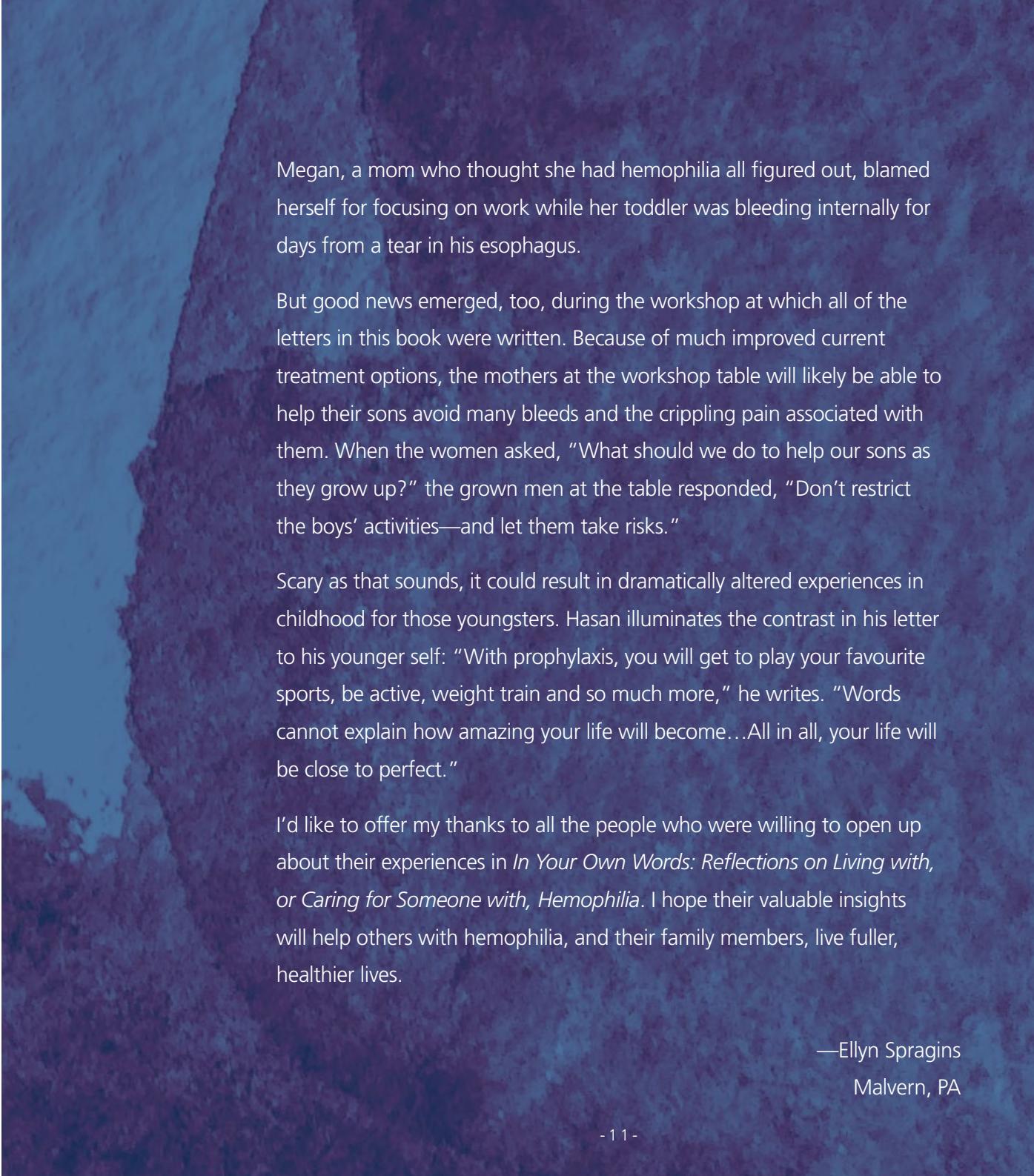
The success of those letters in revealing both the physical and emotional hurdles of diabetes led to *In Your Own Words: Reflections on Living with, or Caring for Someone with, Hemophilia*, the book in your hands. Though this book also contains letters, it differs from the previous book in two ways. The health condition being addressed is hemophilia and the letter writers include not only patients with hemophilia but also mothers of young boys living with hemophilia.

The resulting letters illustrate how formative hemophilia is. Because many people with the disorder are born with it and diagnosed as infants or toddlers, childhood experiences around it are particularly potent and long-lasting. Pain plays a leading role. I think of Chad, a talented athlete who learned to be very secretive about his bleeds and pain because he feared being barred from playing sports if coaches and other players knew what was happening. The feeling of being different, the need to endure hurt rather than get help and the practice of bottling up his feelings eventually brought him to the point of explosion in his early 40s. What Chad wishes he'd known as an eighth grader: Asking for help is not weak and don't keep everything inside.

Loneliness and the need for secrecy were even more pronounced for 23-year-old Hasan. He lived in Dubai, where there were very few treatment options for most of his childhood until age 14. His activities were extremely restricted, and he worried about being an outcast if his peers knew about his hemophilia. Living with depression and agonizing joint bleeds led him to consider taking his own life more than once.

The letters show that hemophilia tests relationships, too, introducing an array of issues that a so-called normal family does not have to face. Matthew, a 63-year-old community developer who prefers to be upfront about his disorder, discovered that his brothers, also hemophiliacs, strenuously objected to revealing their conditions.

Parents are enormously affected by a child with hemophilia. Mothers, particularly, often feel corrosive guilt because they are the carrier of the gene that causes it. What's bewildering are how many categories of guilt exist. Sally, who discovered her son's disorder after a stressful, long night at a hospital, felt horribly crushed for having "caused" her son's hemophilia.



Megan, a mom who thought she had hemophilia all figured out, blamed herself for focusing on work while her toddler was bleeding internally for days from a tear in his esophagus.

But good news emerged, too, during the workshop at which all of the letters in this book were written. Because of much improved current treatment options, the mothers at the workshop table will likely be able to help their sons avoid many bleeds and the crippling pain associated with them. When the women asked, "What should we do to help our sons as they grow up?" the grown men at the table responded, "Don't restrict the boys' activities—and let them take risks."

Scary as that sounds, it could result in dramatically altered experiences in childhood for those youngsters. Hasan illuminates the contrast in his letter to his younger self: "With prophylaxis, you will get to play your favourite sports, be active, weight train and so much more," he writes. "Words cannot explain how amazing your life will become...All in all, your life will be close to perfect."

I'd like to offer my thanks to all the people who were willing to open up about their experiences in *In Your Own Words: Reflections on Living with, or Caring for Someone with, Hemophilia*. I hope their valuable insights will help others with hemophilia, and their family members, live fuller, healthier lives.

—Ellyn Spragins
Malvern, PA



chad

Lives with hemophilia A | 46

If you met Chad today, it would be hard to guess that he has endured enormous challenges from hemophilia. Now 46, he's a team leader in the cylinder head machining department at Ford Motor Company and counts soccer, golf, bodybuilding and bowling among his leisure activities. The father of four, who lives in Windsor, Ontario, has also become a sought-after public speaker on hemophilia at events across North America.



Yet, only three years ago, he says, "I had a lot of depression, anxiety and all-round hated myself. I was treating my wife and my kids terribly." Years of pain from hemophilia had built up to the point of explosion.

Chad punished himself, but did the most damage to his wife, Jocelyn. "I only thought of my own problems. I never put her first," he admits. He needed help, which he finally got at a treatment centre. Now, he finds that sharing his story and addressing the mental trials of hemophilia is therapeutic. He inspires others, and speaking out helps him get everything off his chest.

As he looks back, Chad realizes that his mental anguish had its roots during his teen years, particularly around eighth grade when he switched from playing baseball to soccer. He was a talented athlete, despite having been told that he couldn't play sports due to hemophilia. To defend against coaches and parents warning him against—or preventing him from—playing, he developed the habit of ignoring his bleeds and simply enduring the pain. If no one knew about his bleeds, he figured no one would stop him from participating. Hiding his secret isolated him from his peers and teammates.

By the time he was finishing high school, his talent had earned him a shot at a sports scholarship and, later, a tryout with a professional soccer team. On both occasions he was told that having hemophilia would prevent him from winning those coveted prizes. So he didn't pursue them.

Today, Chad describes that behaviour as "taking 'No' for an answer." Here, he writes to himself as an eighth-grader attending Camp Wanakita, a camp for children with hemophilia. ❤️

Dear Chad

You need to know that even though there is going to be a lot of pain in your life, it can be managed. Relationships will be easier for you if you let people in. You cannot keep your feelings inside.

You will find it hard because you don't know many other hemophiliacs. But here at Camp Wanakita there will be many. You need to bond with other kids like yourself. This will help you deal with upcoming struggles.

Chad, learn to self-advocate. The side effects of hemophilia are nothing you can't handle, but, take it from me, you will need help. You may think you are alone. You may think you are being strong if you don't ask for help. But you need to ask. You need to know that you are never alone.

IN YOUR OWN WORDS

Your parents don't know much about hemophilia. So you have to tell them what you need. Dad will always be there for you. Just ask him. If you do, your mental health will be much better than if you don't. Take care of the mental side as well as your physical health. Chad, Dad is the go-to! Let him help you.

I never pushed for more factor until I was in my late 30s—a mistake. You need to have Mom push for you now. Treatments should never be put off. If they are, you will suffer too much. Eventually, treatments will improve dramatically and you will have home infusion and prophylaxis.

You are going to have a great sports career. Do your best but understand that you don't need to always be the best, in every sport on every team, to hide your hemophilia. You're putting way too much mental pressure on yourself by thinking that way. When you get to high school it will be okay if people know of your hemophilia. The times when you get hurt, you need help. Don't hide it. Go to the hospital, no matter the wait.

You will get some great opportunities in soccer. Do not let anyone tell you that hemophilia will hold you back. Trust me, you will regret it forever. Get that scholarship.

“The side effects of hemophilia are nothing you can’t handle”

Go to that pro tryout. Don't take "No" for an answer. You are the master of your dreams. Hemophilia is your sidekick, not the ruler of your world.

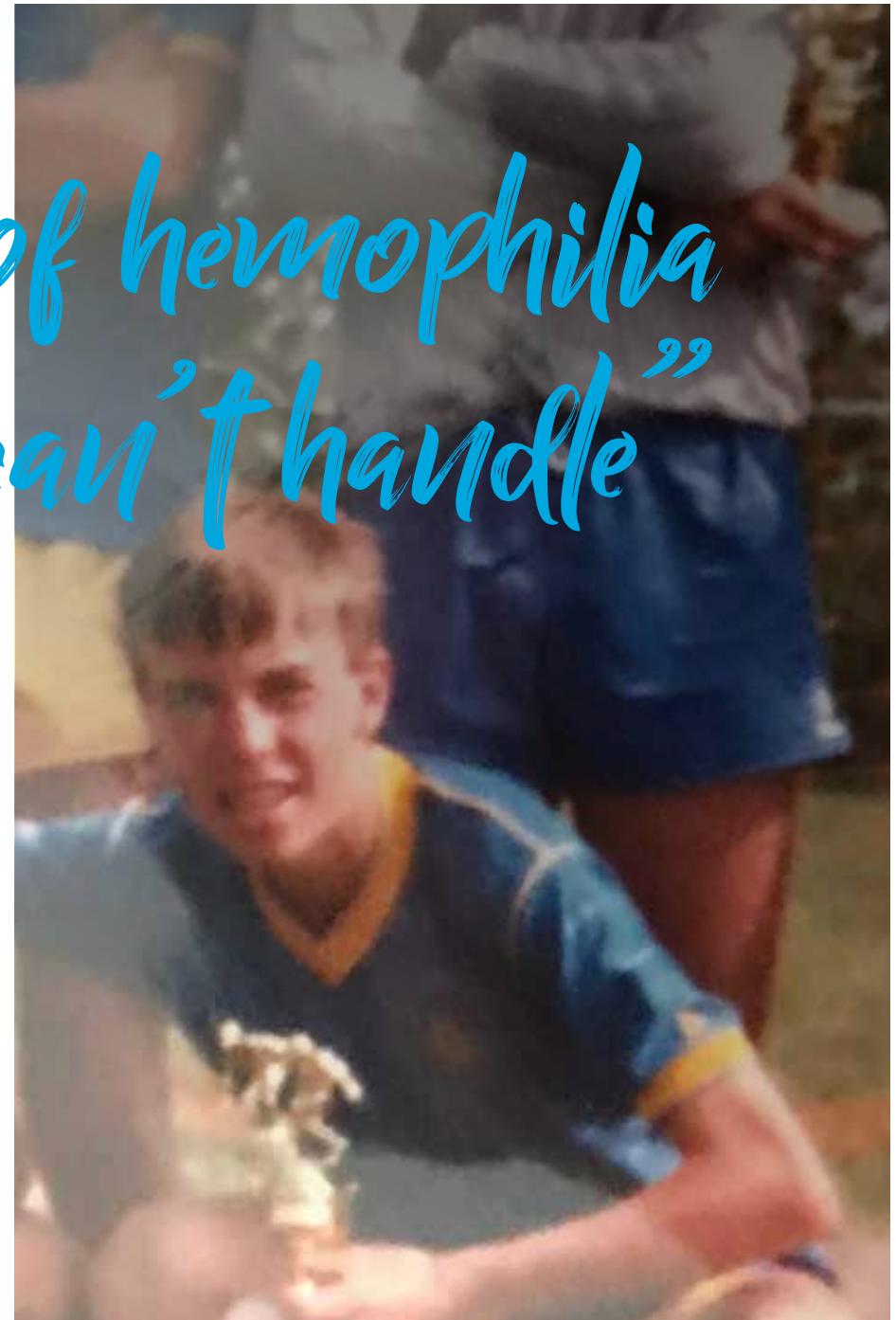
You don't need to alienate your friends. They are great guys. I waited too long to realize that and lost some as a result. Life will be full of ups and downs with hemophilia. Wavy, if you will. You sometimes can't control the waves, but what you can do, buddy, is "learn how to surf."

In closing, Chad, as well as learning how to surf, remember Jocelyn is always there for you. She is your rock. Treat her well and remember "You are not alone." You will grow to tell your story to people. Start early. People will love your journey.

Love yourself. You are worth it.

Love,

Future you, Chad



IN YOUR OWN WORDS

Hasan

Lives with hemophilia B | 23

Hasan, a 23-year-old bodybuilder and fitness trainer with a friendly manner, was diagnosed with hemophilia B at six months old while living in Pakistan. Pakistan offered little to no treatment and Dubai, where Hasan and his parents moved shortly after the diagnosis, did not provide much more.



As a result, the best way Hasan's parents could protect him from bleeds was to place extreme restrictions on his life and behaviour. Hasan explains that his parents felt that "if I wasn't in their sight, I was at risk... I couldn't hang out with friends, wasn't allowed to run or lift things." At school he was prohibited from participating in physical education class and had to watch instead. The little cross beside his name on school documents (indicating a medical condition) felt like a brand. As much as possible, he kept his condition a secret.

The constraints meant that he led a very isolated, lonely life, mostly at home. Despite his parents' efforts—and Hasan's own endeavours to not bleed—he became a spontaneous target joint bleeder. He tried so hard not to make his parents upset, but of course he had no control over his hemophilia. Trips to the hospital were frequent enough that it became the place he knew best after his own home.

In 2011, when Hasan was 14, his family received news that they had been approved to emigrate to Canada. After moving there in 2012, Hasan finally received prophylaxis and was able to have both knees, damaged from repeated bleeds, replaced. Life was transformed dramatically. The young teen who had occasionally thought about taking his own life suddenly had a world of possibility open to him. The idea of living a normal life had been a remote fantasy, but no more!

Here, Hasan writes to himself at 14, just before learning that he and his family would move to Canada. 



Dear Hasan,

I know that things are difficult with you right now. Ever since your diagnosis, imagining a world without bleeds has been nearly impossible. No one really understands what you are going through. From kindergarten until high school, life has been just rules and depression. You hate that terrible feeling of being left out during phys. ed. and the looks you get from your teachers or peers because your name has a cross beside it.

You wake up every day to the fear of another spontaneous bleed. I know it drives you crazy. I know that the weekly visits to the hospital make you feel more at home there sometimes than at your own home. The worst part is that the treatment you are getting is barely enough. Your joints hurt a lot.

IN YOUR OWN WORDS

Running or walking is a challenge some days. Explaining why you are limping due to a bleed is very frustrating as it serves as a constant reminder that you are different, I know.

The part that hurts the most is not your physical pain, but the emotional torture for your parents. You cannot control your bleeding no matter how careful you are. And your parents cannot help you, no matter how hard they try. Trust me, I know!

As terrible as things are, I am writing to let you know that things will be close to perfect for you. But before I do that, I want to make sure you are okay. I know I am from the future and you may think I have forgotten how hard things are for you now. But I assure you, you will no longer have to be anxious about waking up in the middle of the night to pain. Things will be close to perfect. You will no longer have to worry your parents. Things will be close to perfect. You will no longer have to dread spontaneous bleeding. Things will be close to perfect. You won't be alone forever. So please, don't think about hurting yourself, more pain will not make the real pain go away.

“Words cannot explain how amazing your life will become”

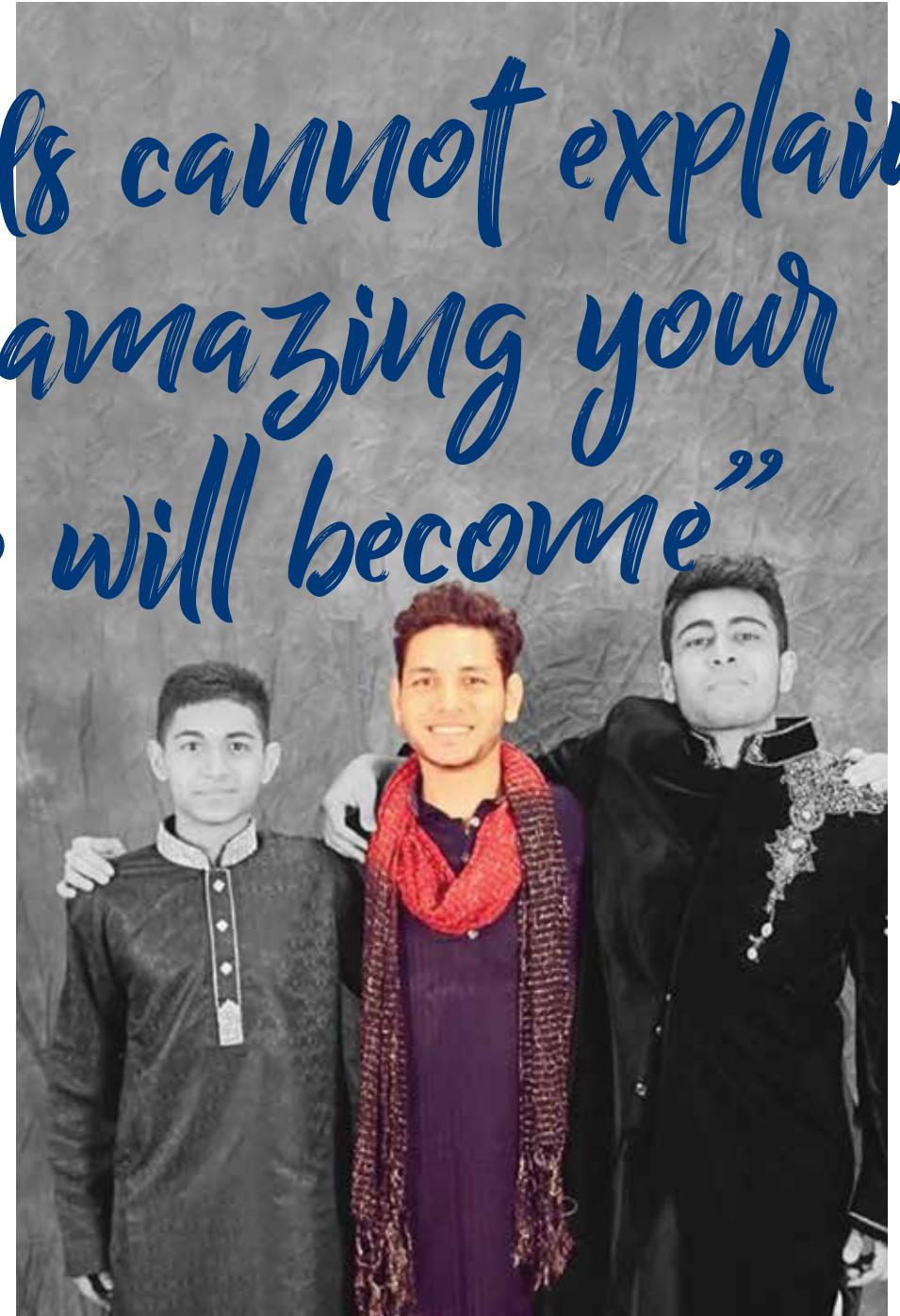
Now, as I am sure you are aware, your family applied to move to Canada. Surprise—you will get accepted! This is the turning point! This is the part where you get to live a little. The most important part of all of this is that you get access to prophylaxis.

Now, fast forward to 2019. By then you will have had only a handful of bleeds. That is pretty amazing compared to weekly bleeds. With prophylaxis, you will get to play your favourite sports, be active, weight train and so much more. Words cannot explain how amazing your life will become. You will become a dependable person that is respected by your family, friends and peers. You won't be lonely forever. You will become a personal trainer—with a good physique, might I add. Another cool thing you should know is that you get to become part Terminator, because you will get two artificial knees.

All in all, your life will be close to perfect. You will finally be able to do the things you wanted to as a child. Granted, you will never get your childhood back, but you do get to make the rest of your life fun, interesting and free of worries.

Before I go, I just want you to know that you won't be average or different forever. You will do amazing things and achieve greatness. The idea of living a normal life was a fantasy, but no more!

Hasan



A portrait of a man with grey hair and a mustache, smiling. He is wearing a white button-down shirt under a dark blue denim jacket.

IN YOUR OWN WORDS

Matthew

Lives with hemophilia A | 63

Matthew, a gentle, thoughtful 63-year-old who works as a community developer, has endured many losses in his life as well as the challenges that come from having severe hemophilia A. Though this has made life difficult, he enjoys a rich array of activities and interests, including sailing, gardening, do-it-yourself projects, birdwatching and Indigenous art and spirituality.

He's also developed an admirable way to appreciate the disorder. He feels he's been graciously supported by many people—wonderful individuals and organizations. When he reflects upon them, he says hemophilia seems less overwhelming, and he is able to give tribute to the many small miracles and blessings he has experienced.

Matthew came from a highly unusual family. He was one of four children growing up in London, Ontario: three boys and a girl. All three boys had hemophilia, despite there being no family history of the disorder. Because his father was a physician-in-training, and later a doctor, Matthew and his brothers were able to get home care, which was very uncommon in the 1960s.

As a result, Matthew did not grow up feeling alone or different because of hemophilia. The three brothers competed and roughhoused as brothers do—sometimes causing one another to need treatment—but supported each other consistently as they matured.

There was one noticeable difference in their attitudes toward their conditions. Where Matthew felt quite open about revealing his hemophilia, his middle brother, Mark, and youngest brother, Paul, preferred to keep the disorder a secret.

By the time Matthew was 45, Paul had died due to complications related to HIV, which he contracted through an infusion. Mark, who also had HIV, was ill. So was Matthew's father, who had cancer. Matthew faced many demands at the time—a new job, a new relationship and settling in Guelph, where he

had recently moved. Nevertheless, he spent every weekend in London, caring for his father and Mark.

Mark died in 2001. Matthew went to the funeral understanding that his brother did not want anyone to know that he had contracted HIV—or that he had hemophilia. Here he is writing to himself as he attends Mark's funeral service. ❤



Dear Matthew,

I know this is hard. It doesn't seem that you or anyone else here is prepared to be real and authentic. In the middle of your brother's funeral you are wondering about all of these hundreds of friends, family and business associates: *Who knows the truth of your brother's death? Do they even know their own truth?*

You chose your path, and, by the way, it is a good road, but definitely different than the one your brothers picked. When you were in business together, Mark was selling while you were building relationships. Your integrity called for you to make full disclosure. He wanted to reveal only just enough to get the deal. In some ways you were so very different.

“Having self-respect can magnify your strength and bravery”

It's confusing to think about because it feels like one way must be the correct way, and the other wrong. But Matthew, there's all kinds of approaches in business, health and life. Mark's was okay for him—and your method is okay for you.

And here's what's most important to know: For you, transparency about hemophilia—and other things—helps you stand in your own power. Speaking the truth might not change a situation for an individual or a family or for you, but it certainly changes how you move through difficult times with the disorder. You cannot change the outcomes but having self-respect can magnify your strength and bravery for all that is to come.

So, have those hard conversations with your brother, your doctors and your co-workers. Ask the difficult questions. Don't settle for minimal truth.

With respect for your choice,

Matthew



IN YOUR OWN WORDS

in your
own words





Megan

Mother of **Robbie** who
lives with hemophilia A | 36

A self-confident 36-year-old red-head with an unflappable temperament, Megan is a store manager at Walmart Canada—a job that requires a lot of careful attention and long hours. Despite the importance of her work, she is crystal clear about her most critical job: “Robbie, my son, is my Number One responsibility,” she says.

That clarity was hard-won, only a year ago. At the time, Robbie, who has hemophilia A, was almost two. He had had a port implanted and was receiving prophylaxis at home. He was getting his factor every three days and, besides a few small blips, everything was going smoothly. This treatment approach meant fewer trips to the Hemophilia Treatment Centre and fewer interruptions of a new job that gave her more flexibility to treat Robbie from home. Megan also counted herself lucky to have great, helpful in-laws.

"We thought we had everything under control," recalls Megan. "We knew enough, we thought, to be able to take great care of him."

In late October of 2018, everything changed. She had been away from home at a work conference for two days. Upon her return, she was excited to have some quality time with her husband, Rob, and son. Robbie hadn't felt well for a week or so, with a bad cough. She speculated that it was perhaps because he was new to daycare, but didn't worry because toddlers get colds all the time.

He also hadn't been eating, which Megan attributed to his cold. When he finally ate dinner that night, his parents were pleased. Success, they thought. *He is getting better.* But at 10:15 pm, Robbie threw up. It was like a scene from a horror movie: blood on the carpet, the walls, the couch and all over her baby. She rushed him to the hospital, where Rob met them in the emergency room. Robbie had had a severe internal bleed and had lost a very significant amount of blood. He needed a transfusion immediately

or it would be very dangerous for him. He had a tear on his esophagus and had been bleeding internally for at least a few days.

That night changed everything. Megan writes to her younger self as she is absorbing the news at the hospital. 



Dear Megan

To date, this has been the scariest moment in dealing with hemophilia, the closest you have come to your son being in a critical state—and possibly losing him. You and Rob are supposed to be his protectors, the people that ensure Robbie will grow up to be happy and healthy.

Will Robbie be okay? Can they treat him?

IN YOUR OWN WORDS

You feel corrosive guilt that you didn't see this bleed sooner. Robbie was giving you signs that he wasn't okay, that he was in pain and that he was bleeding. You feel terribly at fault for being focused on work while Rob and Rob's parents were taking care of him. You feel you are to blame that even after doctors' appointments and medication, Robbie's cough wasn't improving. You didn't push harder to have him checked out again. You didn't want to keep "bothering" medical staff if Robbie had a mere cold. And you thought you had this "hemophilia thing" under control!

Megan, it's okay. You may have days like this again in your future, but all of these feelings are natural. You are used to being very self-sufficient and independent. So, it's especially uncomfortable to ask for help, to push for more attention. You see that now. You see that and from now on nothing will deter you. You will do everything in your power to make sure Robbie is getting the best care possible. You will dig in, asking the right questions and seeing the right people, rather than assuming the first answer is the correct one.



IN YOUR OWN WORDS

“It’s especially uncomfortable to ask for help”

Also, this experience has caused you to reorder your priorities. You’ll still work hard at your job, but Robbie comes first. You won’t let yourself be overly distracted by work.

Rob is amazingly supportive and you have each other to see you through this challenge. This moment will help both of you uncover some other health and development issues that you will be able to start addressing. You and Rob will have deeper discussions and make better plans about what to do if or when something like this happens again.

Robbie will have a long road back to better health but he will get there. He feels safe, he knows his parents love him and he has a great safety net with his family. He is happy. He is healthy. Hemophilia is part of who we are but not all that we are.

With confidence,

Megan

IN YOUR OWN WORDS

Melissa

Mother of Cole who **lives with hemophilia A | 38**

Melissa is a 38-year-old mom from Toronto who works behind the scenes in television production as a traffic coordinator.

Two years ago, she thought she had the world conquered. She was happily married, enjoyed a great job and was raising two beautiful boys, Isaac, 3, and Cole, 1. But in the back of her mind she knew there was something wrong with Cole:

"He was covered in bruises, dark bruises with hard lumps," she recalls. "I thought it might be cancer."





Her answer arrived on a snowy December night, though it was an agonizing process. Believing that Cole had broken his leg, Melissa's husband, Mikey, took Cole to the hospital. Hospital staff could not get a line into him, despite poking him 30 or so times. By 2:00 pm Melissa joined Mikey at the hospital, where the three waited for three hours and staff tried, again unsuccessfully, to draw blood.

At this point, the anxious parents were advised that they had an hour to get themselves, Isaac and Cole to child services at SickKids downtown. "They thought we were abusing Cole because he was covered in bruises," Melissa explains. Once they picked up Isaac, the family was put into one room, while Cole was in another with a staffer, who counted his bruises. The hours crawled by, during which they had dinner at the hospital, Isaac was returned home to stay with relatives and Cole had a bone-by-bone ultrasound—which revealed blood flowing into the knee joint of the leg Melissa had thought was broken. Finally, at 11:30 that night a doctor gave Cole's parents his diagnosis: hemophilia. By 1:30 the next morning, with Cole's blood finally analyzed, Melissa and Mikey were told that it was type A.

Melissa is writing to herself at this moment.

Dear Melissa,

You are relieved and freaking out at the same time. No, they won't take your kids away. And you were right: Something is wrong with Cole. It's hemophilia.

Right now, everything changes. Everything you knew about being a mother changes. You will confront fears you never thought you would have to face. You hate needles but you are going to have to use them.

Who would have thought in a million years that you, Melissa, would be okay with needles and poking them into your son with life-saving medications? But I've got news: Before long you *will* be able to poke your son without so much as a blink of an eye.

Needles, it turns out, are the least of it. Melissa, you will learn of a new fear. Inhibitors, the phenomenon that could cause Cole's small body to fight off the essential clotting factor that he needs, become your new nightmare. If the inhibitor wins it will be terribly difficult to stop Cole's bleeds. Your terror about this development will overshadow every other concern for quite a while.

And there's something else, completely unexpected. You thought you'd have the support of some people close to you, but you won't. They will think you're overreacting to this thing called hemophilia. It feels like a profound betrayal at the worst possible moment.

“You will become
a fierce mama
bear to these
two little boys”

But take heart. Your son beats his inhibitor. You will become a fierce mama bear to these two little boys—one who is free of hemophilia and the other who is not. It’s a lot of hard work, but you’re stronger than you realize. You can take care of and protect your kids and you don’t need approval from the critics around you about how you are doing it.

You and Mikey will create a tight family unit, doing everything together: camping, hiking, canoeing. You will instill in the boys that the four of you will always have each other’s backs, come what may.

With pride in you,

Melissa



IN YOUR OWN WORDS

Sally

Mother of **Zieven** who **lives with hemophilia A** | 36

In the summer of 2012, Sally was 29 years old, grappling with an abundance of intense experiences. A petite brunette who had grown up in Manila, Philippines, she was by now a new mother with an eight-month-old son, living in a new house in Scarborough, Ontario, and preoccupied with growing her career in IT.



IN YOUR OWN WORDS



Everything felt overwhelming. But that mental state was serene compared to how she suffered during a crisis that unfolded late in the evening of August 22nd. Her son, Zieven, had developed unusual bruises on his arms and legs during recent weeks. So, Sally and her husband, Paul, took him to SickKids Hospital in Toronto. While attempting to draw blood for lab analysis, medical staff had to poke Zieven's arms multiple times before finding a vein.

After they returned home, Zieven's arms began to swell alarmingly, growing to twice their normal size. They rushed back to the emergency room where doctors told them that if they could not quickly determine the cause of the swelling, they would have to slice open Zieven's arms to relieve the pressure.

Horrible pain cut through Sally's heart at hearing this. She had no idea what was wrong with her own child. But she couldn't bear the thought of her baby going through such a procedure. Soon, she learned that he had severe hemophilia A, which she knew practically nothing about. Now 36, she is writing to herself seven years ago, after receiving the diagnosis on this dreadful night. ❤️

Dear Sally,

You feel awful. You are in distress. You are thinking of ways how to fix this. There are many questions running through your mind right now.

"Why did this happen?"

"Why my son?"

"Did I do something wrong during the pregnancy?"

"What do I need to do to cure my son?"

"When will this nightmare be over?"

Emotions are tumbling through you: sadness, anxiety, disappointment and guilt over your incompetence as a parent.

IN YOUR OWN WORDS

You've always been a problem solver. You always try your best to analyze a situation and strive to make it better. But at this moment you feel helpless. You're struggling to come to terms with this condition of your precious son, your firstborn. You are denying that this is real. And refusing to accept that your son will never be like a normal kid who has unrestricted options when it comes to sports. You are worried about his development and when he starts school.

I get it. But trust me in saying this:

YOU ARE DOING A GREAT JOB AS A MOM!

You may not feel like it right now because you are blaming yourself for passing on the hemophilia gene to him. But it is not your fault. Still, you need to reflect on this guilt. Acknowledge it. Feel it. It's okay to feel it. But don't burden yourself with it for years to come. And strongly strike back by deciding that this doesn't define you—or your son.

“You are blaming yourself for passing on the hemophilia gene”



Everything is going to be okay. Zieven will grow up to be a kind, generous and video-game-loving kid. He will tolerate his sister's antics most of the time. And, amazingly, he will learn to accept his hemophilia with open arms. He actually will take great pride in his pain tolerance by enduring not one, but up to five pokes a day for infusions.

In closing, I will leave these words of encouragement. Don't be too hard on yourself. You and your family will get through this with flying colours. And never doubt that you are being a good parent, because your family loves you unconditionally.

You can do it,

Present-day Sally

*in your
own
words*

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