

# INFUSING

BONDED BY BLOOD | WINTER 2023



## Co-Parenting a Child with a Bleeding Disorder

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Co-Parenting a Child with  
a Bleeding Disorder

How to Get and Stay  
Motivated in the New Year

Can CBD Help People  
with Bleeding Disorders ?

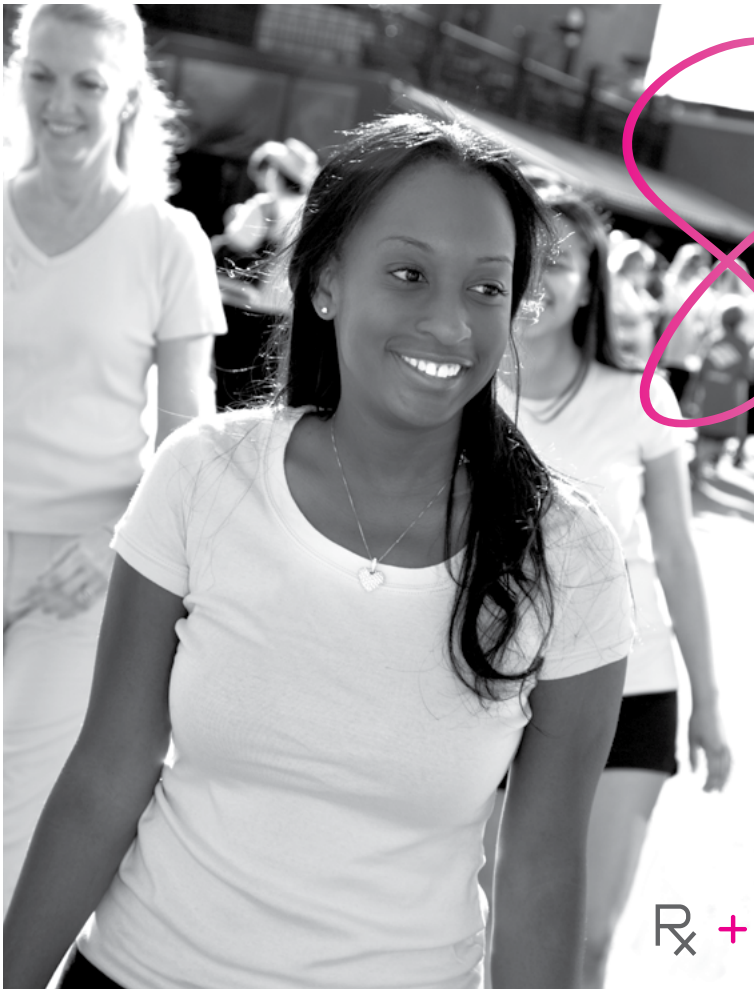


# Our Story

## BONDED BY BLOOD

At an early age, our founders Kevin and Scott, met at hemophilia summer camp. As blood brothers, their friendship has spanned three decades of experiences in the bleeding disorders community and healthcare challenges. Over time, they shared each other's struggles and victories of living with a bleeding disorder. As they became professionals, they resolved to create the healthcare experience they wished they had. In mindful pursuit of this dream, they created **BROTHERS HEALTHCARE**, a unique specialty pharmacy, built around exceptional care, personal experience, and integrity. Kevin and Scott are committed to providing pharmacy care experience that is second to none.

**BROTHERSHEALTHCARE.COM** | 800.291.1089 | *Se habla Español* 866.591.3955



# Sisters

## Leading the Charge

With a growing awareness of women's treatment needs, **Brothers Healthcare** is a leader in advocating for women with bleeding disorders. Historically, women's unique needs are often overlooked when compared to their uncles, brothers, or sons. We support women getting the care they need to be their best selves. **We serve women by listening to their stories and finding creative solutions.**



## FROM THE EDITOR

I want to take a minute to share our gratitude for an incredible 2022 year!



*Stay healthy and safe,*  
—Kelle Carthey, RN  
Editor

I hope you had a wonderful holiday season, and we're excited to bring you a fresh new year of ideas, inspiration, and knowledge. As 2023 gets underway, we can remember all the things that happened in 2022 (and be very grateful for them!) and look forward to what's ahead for us. There's always something special about the beginning of a new year—it's like a fresh start. Thank you for riding the 2022 waves with us and proving that we are **BONDED BY BLOOD.** 🌊



INFUSING LIFE  
WINTER 2023

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## ASK US!

Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.

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# 2023

## How to Get & Stay Motivated



Olena Sergienko/Unsplash

As another new year starts, you might feel unmotivated and not know where to turn. These are normal feelings, and there's no shame in seeking help when you don't feel your regular self!

The good news is that there are loads of research backed tips that can help you get motivated—and stay that way. Various studies and insights prove that it's possible to overcome the feeling of not wanting to do anything or succeed at something. You'll learn about these studies in this email and discover how to improve your mental health in 2023 and beyond. Read on to learn more.

### **Take on Tasks on the Edge of Your Abilities**

One way to stay motivated is to take on tasks that are not too hard but that are also not too easy. That might seem like an odd concept, but tasks just beyond your comfort zone can motivate your brain and make you feel inspired again. This phenomenon is called the Goldilocks Rule, popularized by the author and motiva-



tional speaker James Clear.

Clear says:

***“The Goldilocks Rule states that humans experience peak motivation when working on tasks that are right on the edge of their current abilities. Not too hard. Not too easy. Just right.”***

Clear argues that working on tasks that comply with the Goldilocks Rule is a great way to maintain motivation in the long term. That’s because jobs that are too easy or hard can cause you to give up on that goal or drift into boredom.

So think about something you want to accomplish but make it achievable. Climbing Mount Everest or going to the moon might be on your bucket list, but learning a new language or taking up a new sport will be more likely to make you feel motivated again.

can achieve by surrounding yourself with positive people, as mentioned earlier. In addition, working on competence and autonomy might help you feel like you are more in control of your life, which will improve motivation:

- Rewarding yourself after a task, no matter how small, can improve competence, especially if you don’t get positive feedback from others. For example, you can treat yourself when you reach an important milestone. Working toward that milestone will motivate you and make you feel energized.
  - Exercise, meditation, or practicing self-awareness can improve self-regulation and help you control your behavior. That can achieve autonomy in your life.
- demeaning tone tends to increase our feelings of self-hatred instead of motivating us to change undesirable actions in a constructive manner.”***
- Here’s how to silence your critical voice and become more motivated in your life:
- Pay attention to negative thought patterns and what triggers them. Certain situations might cause you to doubt yourself, affecting your motivation. Avoid situations (or even people) that make you feel like this.
  - Distract yourself from critical thoughts that impact motivation. This is easier said than done, but with the right techniques, you can clear your mind, at least temporarily. For example, walking the dog or phoning a friend might divert your mind from negative thinking.
  - Mindfulness is another technique that can overcome self-criticism. This method involves pausing to acknowledge your negative thoughts, realizing how they make you feel, and diverting attention to your breathing. Regular mindfulness can lead to neurological changes that benefit your mental health. It can also help with any pain you experience if you have a bleeding disorder.
  - Stop comparing yourself to others. Instead of looking outward, be grateful for the positive things in your life—whether that’s friends, family, education, or something else.

tivation. Finding a mentor who provides support and life guidance can help you view your life from a new perspective and find inspiration to reach your goals. You will still make the final decisions in your life, but a mentor can offer a helping hand and encourage growth.

Here are some of the things a mentor can motivate you to do:

- Find a new job or career path
- Deal with personal relationships
- Identify gaps in knowledge
- Become a more confident person
- Make better life decisions

You might also want to consider becoming a mentor yourself. Guiding someone else and providing ongoing support might motivate you to make meaningful changes for yourself. Plus, this new-found responsibility will add structure to your life and give you a sense of purpose.

## Set Short Deadlines

Earlier, you read about the Goldilocks Principle and how taking on tasks that are not too hard or too easy can improve motivation. Setting short deadlines might go against this advice, especially if it takes you far out of your comfort zone. However, setting deadlines for the short term rather than the long term can create a sense of urgency.

Think of it this way. Say you have a life goal but haven’t set a deadline to complete it. You might procrastinate and tell yourself that you will achieve that goal at some point in the future. Setting a deadline for a specific point in the short-term future, however, will encourage

# in the New Year

## Self-Determination Theory

Researchers say you need to fulfill three psychological needs to improve motivation:

1. Competence
2. Autonomy
3. Relatedness

Competence refers to the need to produce desired outcomes, autonomy relates to self-regulation and controlling your behavior, while relatedness is the feeling of being connected to other people. These things can improve self-determination—the ability to control your destiny.

Relatedness is a concept you

## Silence Your Critical Voice

Your inner voice might hold you back from being a motivated individual, especially if it’s a particularly critical one. Perhaps you tell yourself that you are doomed to fail or will never achieve your dreams. These negative thought patterns can influence how you behave and drag you down.

PsychAlive says:

***“The critical inner voice is not a conscience or a moral guide. What most distinguishes the inner voice from a conscience is its degrading, punishing quality. Its***

## Find a Mentor

There is an intrinsic link between mentorship and mo-

Continued on page 10

# Co-Parenting

## a Child With a Bleeding Disorder



**“The romance that we had is over, but the bond we have between our kids shall remain till eternity.”**

Co-parenting can throw up multiple challenges. Any conflict between you and your ex can have a long-lasting impact on your child.

But, co-parenting can be particularly hard if a child has an ongoing medical condition, such as a bleeding disorder. Managing a condition like hemophilia or von Willebrand disease requires consistent habits and routines that are sometimes difficult to maintain after a separation or divorce.

Read on to learn more about how to co-parent a child with a bleeding disorder, discover our top tips for co-parenting a child, and how to overcome challenges when creating new daily healthcare routines.

***“The romance that we had is over, but the bond we have between our kids shall remain till eternity.” — Anon***

## Establish a Care Plan

A care plan will help you and your ex-partner manage your child’s condition and improve bleeding disorder management in both households. It will specify the care your child requires to live a near-normal lifestyle. Your plan might be a short paragraph or several pages.

You can include the following information in your plan:

- The name of any medications your child takes, when they take them, and which parent will be responsible for giving them.
- The support and services your child requires to manage their bleeding disorder. That might include regular hospital visits and appointments at an infusion pharmacy.
- Any equipment your child needs to manage their disorder.

- A list of emergency contacts for bleeding disorder management. These contacts might be your child’s primary care doctor, the pharmacy where they pick up medication, a specialty pharmacy that helps your child manage their conditions, and your child’s school.

Even if communication has broken down between you and your ex, a well-written plan will maintain consistency when caring for your child.

***“Remember you are not managing an inconvenience. You are raising a human being.” — Kittie Frantz***

## Know What To Do in an Emergency

Perhaps you or your ex-partner were solely responsible for managing your child’s condition before you broke up. After separation or divorce, both you and your ex will share childcare responsibilities. Communication between households—and keeping things amicable between you and your ex—will help your child receive the right care in an emergency.

Here are some things to consider during a crisis:

- Look for symptoms that might require your child to go to the hospital. These symptoms include vomiting blood, blood in your child’s stool, and nose bleeding that lasts an hour or more. You might want to discuss which symptoms require certain treatments with your partner.
- Contact your ex-partner if your child’s symptoms worsen or visits the

hospital. It’s important to maintain some kind of relationship with your ex when co-parenting a child with a serious medical condition. Remaining cordial can improve everyone’s mental health, including your child’s.

- Contact your child’s teacher or principal if they require time off school for their bleeding disorder. Your school can provide your child with learning resources during hospital and specialist pharmacy visits.
- Learn about co-parenting a child with a bleeding disorder by regularly checking resources from organizations such as the American Society of Hematology, the National Hemophilia Foundation, and the Hemophilia Federation of America.

## Decide on Who’s Carrying the Costs of Your Child’s Healthcare

Managing a child’s bleeding disorder can be expensive. You might need to pay for visits to a specialist or hospital, transportation to healthcare providers, and equipment that manages your child’s condition.

If you were married to your ex-partner, you might have shared a healthcare insurance plan that covered most or all costs associated with managing your child’s disorder. If your partner put you on their insurance, you probably have to apply for a brand new healthcare insurance plan. As well as any additional expenses, signing up for a healthcare plan can be challenging. You need to find a provider that covers as many of the services your child requires as possible. Out-of-

network healthcare companies might be the only service providers who offer the treatment your child needs, which could result in a higher co-pay when accessing treatment.

Regardless of healthcare insurance, you and your partner need to decide who will be responsible or pay for the costs involved in looking after your child with a bleeding disorder. Those costs will include expenses not covered by any insurance company, such as transportation fees to and from healthcare facilities.

## Apply for Emergency Assistance

You or your ex might suffer financially after a separation or divorce, impacting your child with a bleeding disorder. Your child might need expensive specialist equipment to manage their condition or require transportation to a hospital or other facilities during your visitation schedule.

You might be eligible for emergency financial assistance for situations caused by an ongoing bleeding condition.

*Continued on page 11*



# Can CBD

## Help People With Bleeding Disorders?

You might never hear about the medical advantages of cannabidiol (CBD) at a Hemophilia Treatment Center (HTC) or hospital facility. However, research shows that CBD—whether taken orally, sublingually, or topically—can provide multiple benefits for those with a bleeding disorder. Learn more about how CBD could potentially improve mental health, sleep conditions, and chronic.



### **What Is CBD?**

Cannabidiol (CBD) is an active chemical in cannabis (marijuana). It's legal to sell CBD products made from hemp—a type of cannabis plant—in the United States. Federal law says CBD can only be sold in “cosmetic” products, not in foods or dietary supplements.

U.S. states have different laws for CBD usage. CBD is

completely legal in the following states:

- Alaska
- Colorado
- Illinois
- Maine
- Michigan
- Nevada
- Oregon
- Washington, D.C.
- Vermont
- Washington

Other states have restrictions or conditions on CBD. Idaho, Nebraska, and South Dakota are the only states where CBD from marijuana is illegal.

CBD doesn't contain a psychoactive ingredient called tetrahydrocannabinol (THC), meaning users can't get “high” from consuming the chemical. However, proponents of CBD claim it can improve mood, reduce anxiety, and help with



chronic pain. Other benefits of CBD might include inflammation reduction.

## Mental Health

Managing a bleeding disorder can be mentally challenging for patients and their loved ones. However, research shows that CBD can improve depression, anxiety, and other related conditions.

One study reveals that CBD can have similar effects to antidepressant medications that work on serotonin receptors in the brain. Low serotonin levels can cause someone to feel depressed and develop mood disorders. While CBD doesn't boost serotonin levels, it could influence how the brain reacts to serotonin in the body, making users feel more relaxed and able to deal with life's challenges. The study also found that the effectiveness of CBD usage for depression depends on serotonin levels in the central nervous system.

In another study, Brazilian researchers tested anxiety levels in men giving public speeches. The men received either 150mg, 300mg, or 600mg of CBD or a placebo. Those who received 300mg experienced reduced anxiety when giving their speech compared to the placebo group. Subjects who received 150mg or 600mg of CBD experienced more anxiety than the 300mg group.

## Sleep Conditions

Between 30% and 48% of older adults suffer from insomnia—just one of many sleep conditions that can negatively impact health. Bleeding disorders are often associated with bad sleeping habits because of the potential for chronic pain and the likelihood of patients

worrying about their symptoms and health outlook instead of getting a good night's rest.

Research has explored the effects of CBD on sleep conditions. While further research is needed regarding this topic, one study discovered that 65% of adults who suffered from poor sleep experienced improvements after taking an average of 25mg of CBD every day for a month. (However, sleep quality declined over time.)

Other research on animals suggests CBD acts as a "wake-inducing drug" that could potentially help people who suffer from excessive daytime sleepiness. Further research is required to ascertain which CBD methods and doses can positively affect wakefulness.

## Chronic Pain

Many people with bleeding disorders such as hemophilia and von Willebrand disease (VWD) can experience chronic pain, making living day-to-day life an ongoing challenge. Bleeds can be extremely painful for people with bleeding disorders, while damaged joints might result in constant and chronic pain, resulting in a decreased quality of life. Traditional pain management methodologies for bleeding disorders—such as rest, ice, compression, elevation (RICE), physiotherapy, and complementary techniques—might not provide enough relief for any pain lasting more than a few months.

Research suggests that CBD can relieve chronic pain, making it a potential treatment for various areas of the body. Exogenous and endogenous cannabinoids bind to receptors attached to the body's cells, stimulating cell responses

that positively influence pain-signaling pathways. One study on mice reveals that CBD might communicate with receptors in the spinal cord and help with chronic inflammatory pain.

In a separate study, most people agreed or strongly agreed that CBD products decreased how much pain medication they took. Moreover, CBD products helped reduce the amount of opioid medication taken for pain management.

## How to Use CBD

CBD is available in various forms, including gummies, oral capsules, and topical patches. Oils, creams, salves, and balms might be particularly effective for people with bleeding disorders who suffer from chronic joint pain. Individuals can rub these products on aching joints and experience pain relief for up to several hours, depending on the strength and quality of the product.

Here are some tips for choosing the right products that might help with chronic pain associated with bleeding disorders:

- Follow the dosage information listed on the product. Taking too much CBD orally or sublingually (under the tongue via a tincture) can sometimes lead to unpleasant side effects such as nausea, stomach upset, diarrhea, dry mouth, and disorientation. Liver damage can also occur when someone takes excessive CBD amounts for long periods.
- CBD might interact with other medications taken for bleeding disorders, resulting in undesired side effects. Consulting with a medical professional can help

individuals decide whether CBD for pain management is right for them.

- Choose CBD products that contain high-quality ingredients free from mold, pesticides, heavy metals, and other potentially dangerous components. CBD product manufacturers should display all ingredients on product labels.
- Look for CBD products that have undergone third-party testing for contaminants. Manufacturers should have a certificate of analysis or list quality protocols on their websites or product labels.


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**“Research shows that CBD can improve depression, anxiety, and other related conditions.”**

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## Before You Go

CBD could provide people with bleeding disorders with multiple benefits. Taking CBD orally, sublingually, or topically could improve mental health, sleep conditions, and chronic pain. Follow the tips above when choosing a CBD product to ensure safety and quality.

**Brothers Healthcare provides individuals with bleeding disorders access to an integrated healthcare team, helping them manage their conditions more effectively. Contact the organization now to learn more.** 

you to take quick action and ensure the task gets completed.

You might also want to set deadlines in days rather than weeks or months. Research suggests that a 10,950-day deadline creates more immine-  
nence than a 30-year one, even though both timeframes are the same. That's because of manip-  
ulated time metrics, which can make a deadline seem shorter than it is. In other words, setting a 30-day time limit instead of a 1-month time limit can energize and motivate you.

### Create a 'Ta-Dah' List, Not a To-Do List

To-do lists might help you maintain a little motivation, but a 'ta-dah' list is more effective, according to one leadership training provider. At the begin-  
ning of every day, write down all the things you have achieved since your last list or are on the verge of completing. These might be mundane achieve-  
ments like making a phone call, taking your pain medication, or walking your dog. The idea is to recognize every small accom-  
plishment in your life, which improves pride and self-com-  
passion.

The psychology behind a 'ta-dah' list makes sense. Instead of writing out all the complicat-  
ed tasks you need to achieve at the beginning of the day, you congratulate yourself for things you have already done or are nearly done. That can motivate you to tackle your more compli-  
cated to-do list!

### Surround Yourself With Positive People

Negative people can make you feel unmotivated—it's a scien-  
tific fact. The Longevity Project

studied 1,000 people over 80 years and found that the groups you associate with decide what type of person you become. Surrounding yourself with moti-  
vated and inspired people can lift you out of your slump and help you think differently about your ambitions and goals.

Meeting new people who have a zest for life can be hard when you are feeling seriously unmotivated. However, online social networks can provide friendship opportunities, allow-  
ing you to meet new people with shared interests who can help you reach your goals. You can transform your social circle and develop long-lasting and valuable relationships that en-  
hance your mental well-being.

Depending on any medical con-  
ditions you have that impact mobility, you could also:

- Join a local book club
- Join a sports team
- Volunteer in your community
- Reconnect with old friends who are ambitious and motivated
- Talk to your neighbors

These opportunities might give you access to a network of people who not only provide you with the support you need when feeling unpmotivated but also inspire you to become more successful.

### Visualization

Feeling unmotivated can be a symptom of not feeling good about yourself, perhaps because of the challenges you face with a medical condition, family problem, difficult work scenario, or other life event. Visualization can change how you think about yourself and achieve your goals. It involves creating pictures in your mind of the results you want to



**"The good news is that you can change this state of mind by making changes to your life right now."**

accomplish. That could be any-  
thing from getting a new job, losing weight, or controlling the symptoms of your disorder.

Motivational speaker Jack Canfield—author of the "Chicken Soup for the Soul" series—has researched the effect visualization can have on motivation. He says:

***"Once you make visualization and motivation a non-nego-  
tiable part of your daily prac-  
tice, you'll find it so much  
easier to stay motivated and  
focused. You'll be working to-  
wards creating your ideal life  
and making all your dreams  
come true."***

Here are some visualization tips that might improve motivation:


- Write down what you want to achieve on a piece of paper. Accurately describe your goals in detail.
- Think about the emotions you will experience when achieving each goal. Will you feel content? Excited? Powerful?
- Take proactive steps every day to accomplish your goals. If your goal is to get

a Master's degree, work toward it by researching programs, contacting colleges, and figuring out how financially support your studies. Completing each of these steps might make you feel more motivated.

- Continue to visualize the goals on your piece of paper regularly. Think about the emotions you will experi-  
ence and the steps you will take to turn your dreams into reality.

### Final Word

Feeling unmotivated is normal. You aren't the only person to feel this way! The good news is that you can change this state of mind by making changes to your life right now. Taking on achievable tasks, surrounding yourself with positive people, silencing your critical voice, and creating a 'ta-dah' list are just some of the ways you can enhance motivation and feel inspired again.

**Learn more about managing your bleeding disorder with Brothers Healthcare.** 

The Hemophilia Federation of America manages one of the biggest assistance programs, providing funds for specialist equipment, transportation, and other expenses you or your partner might not be able to afford. After applying for assistance, the organization will be in touch with information about your application within 2-3 weeks. You can check the eligibility requirements for the program [here](#).

***“The best security blanket a child can have is parents who respect each other.”—Jane Blaustone***

## Maintain a Good Relationship With Your Child’s HTC

Your child’s hemophilia treatment center (HTC) provides comprehensive care and treatment that reduce the risk of serious complications associated with a bleeding disorder. An HTC can help you manage a condition like:

- Hemophilia A
- Hemophilia B
- Factor VII deficiency
- Von Willebrand disease

Maintaining a good relationship with an HTC is essential for your child. You should schedule regular check-up appointments and take your child to the facility for recommended services such as gait assessments, pain management, joint measurements, and strengthening exercises.

If you live far from your ex-partner, you might want to enroll your child in an HTC nearer your location and take them to the facility during your visitation schedule. (You can

discuss this with your ex-partner first.) Your ex can take your child to their original HTC during their schedule.

## Maintain a Good Relationship With Your Child’s Infusion Pharmacy

A specialist or infusion pharmacy will help you manage any home infusion treatments for your child during your visitation schedule. A pharmacy like Brothers Healthcare assists you when navigating your

involving children. That can impact everyone in the family, including a child with a bleeding disorder. You don’t have to be best friends with your ex-partner. However, effective communication can help you manage your healthcare plan and the responsibilities of looking after your child.

Here are some ways to improve communication between you and your ex:

- Want to learn about co-parenting a child with a bleeding disorder? Counseling can help.



child’s disorder and provides a helping hand when you need it the most.

Brothers Healthcare partners with medical providers to create an integrated healthcare service for your child based on clinical expertise and experience. Our friendly team will deliver a personalized care plan for your child and help you learn about co-parenting a child with a bleeding disorder.

## Improve Communication With Your Partner

Communication problems often happen after a breakup

Talking to a professional about why your relationship broke down and its impact on your child can manage stress, improve the atmosphere in home environments, and help you mentally process your breakup.

- Avoid situations that could lead to conflict. These situations include talking about post-breakup financial affairs or bringing up any new current partners. Another way to avoid conflict or confrontation is by not checking your ex-partner’s social

media pages. These pages might include photos of your ex’s new lifestyle or partner.

- Communicating about your child through means other than face-to-face conversations could prove beneficial. You might want to exchange healthcare information about your child through email or text messages. Both of these communication methods allow you to think about what to say to your ex-partner rather than exchanging information on the spot.
- Don’t talk about the past with your ex-partner and concentrate on the future of your child. Bringing up old experiences might cause an argument in front of your child, which might trigger mental health problems.

## Before You Go

This email includes several tips for co-parenting a child with a bleeding disorder. Establishing a care plan, knowing what to do in an emergency, applying for financial assistance, and maintaining good relationships with your HTC and infusion pharmacy can help you manage your child’s condition and provide them with the specialist care they deserve. Consistency in care and keeping things communicative and amicable between you and your ex will serve the best interests of your child.

**Need more advice? Learn about co-parenting a child with a bleeding disorder by reaching out to Brothers Healthcare.** 