

(HTC interview continued)

Colleen: We already know that people with hemophilia have a higher incidence of low bone density and joint damage. NHF recently released a news bulletin citing a study out of the University of Arkansas for Medical Sciences on over 20,000 people with vWD and women carriers of hemophilia which showed a “significantly higher” risk of osteoporosis, osteoarthritis, and fractures. It highlights the importance of the patient and the HTC focusing on bone health.

Linda: Yes, and I should also mention that anyone with joint pain should report changes as early as possible to avoid further damage. This goes for the younger patients as well, so please see your treatment center annually and call any time you see any changes outside of your annual visit so that you can avoid further damage.

Care Coordination

Colleen: When we talk about screenings for cancer (skin, prostate, breast), joint, liver, and kidney diseases as well as cardiovascular screenings, most specialists provide those health tests, but can you talk a little bit about ways that the treatment center can help coordinate care?

Linda: One of the most important things an older person can do is visit their primary care physician annually for a thorough check-up, blood tests, and screenings so you can catch and address “older-age” issues early or get any referrals you need to see a specialist. In the old days, your hemophilia treatment center could make referrals for routine tests or to see specialists. Some insurance plans don’t allow us to do that anymore. You may be required to see your primary care doctor for those referrals that aren’t related to the bleeding disorder.

Once the referral is in place, we work very closely with each specialist as it relates to the bleeding disorder. Fear of medications to treat cardiac issues is common in the bleeding disorder community, and we coordinate with the cardiologist to balance the medication with factor.



As in Cathy’s case, we also coordinate with knee, elbow, and ankle replacement surgeons to ensure that we all agree with the treatment plan. Excellent coordination between the treatment center and the surgeon ensures fewer bleeding problems.



Advocacy

Colleen: I know that many women, such as Cathy, and some men living with a bleeding disorder have had trouble at times convincing a practitioner/doctor or surgeon to work with the Hemophilia Treatment Center. Women more so because of the lack of knowledge about women with bleeding disorders. How do you recommend women advocate for themselves if they’re faced with a provider who minimizes the need to coordinate care with the hemophilia providers?

Linda: Well, first, it’s extremely helpful to have your procedures or any surgery in the same medical system as your hemophilia treatment center. Sometimes that can’t be helped, which makes coordination most important.

Ellen: Communication prior to a procedure or surgery is really a three-way street between the patient, the specialist, and the HTC. Never assume that the HTC knows about other procedures even if they are scheduled within the same health system. Always call your HTC team to coordinate your care prior to the procedure. If you have a provider that isn’t willing to work with your HTC, this is a red flag and an indication that you should give us a call.

Colleen: Thank you both for speaking with our readers today. There are a few important messages we’ve learned from you and from Cathy McCarthy. Being proactive regarding our health by scheduling annual health exams will most likely prevent more complicated health issues down the road. Coordinating your care and any procedures or surgeries with the treatment center will avoid unnecessary bleeding issues post-surgery. And equally important, learning to advocate for yourself even in intimidating medical circumstances may just save your life. Thank you all for sharing these messages.



Language assistance services are available free of charge. Call: 1-800-996-2575.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-996-2575.

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Aging Successfully with a Blood Disorder



Colleen Joiner, LMSW, CCM
Clinical Care Manager

Dear Readers,

In our last issue we discussed some important aspects of growing older including the importance of staying active. In this issue, we’re going to continue the conversation with Henry Ford Hospital social worker Ellen Kachalsky and nurse coordinator Linda Mueller. We’ll also hear from Cathy McCarthy, a woman in our community who has a long and, unfortunately, all too familiar history of medical treatment as a woman with a bleeding disorder.

It’s important to take care of our bodies and our minds as we age. Although we may physically change, we’re still essentially the

same person inside and should enjoy the high quality of life we had while we were younger. Staying current with health screenings for heart, breast, liver, prostate and bone density, and joint disease are one way to stay ahead of the game in order to live a long and active life.

Learning to advocate for yourself in the healthcare arena is also one of the more important skills to hone, particularly if you live with a bleeding disorder. As we age, we generally visit the doctor more often for routine health screenings, procedures or surgeries that arise from joint issues or other naturally occurring illnesses. Just know, you don’t have to navigate the system alone, and with the support of your hemophilia treatment center (HTC) and an occasional dose of self-advocacy when needed, you’ll get the best care possible. Take care of yourself, and enjoy...

Colleen

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Aging Successfully: An Interview with Cathy McCarthy

Younger Years

Cathy McCarthy was born in Detroit in 1951 and grew up in a large family in St. Clair Shores. From the beginning, she suffered with more bruising than the rest of the family. She was a “rough and tumble” tomboy who fit right in with her five brothers. Her mom, who was a nurse, simply figured that Cathy was the kind of kid who would forever be falling out of trees or wiping out on her bike, so when she came home with a swollen elbow after a fall, her mom simply recommended she take it easy. There was no known history of a bleeding disorder in her family, and nobody suspected a thing.

Cathy had other unusual bleeding episodes throughout the years including heavy nose bleeds. And her gums would bleed uncontrollably after having a tooth pulled. But the most troublesome symptoms started as a teen because she suffered from long and heavy periods, bleeding more days out of the month than not. Cathy often became severely anemic requiring several dilation and curettage procedures. Throughout the 1960's, the doctors sent her home telling her that she most likely comes from a “delicate” heritage. There was no relief as even birth control pills were not an option for her, and the diagnosis was unsatisfying.

Starting a Family

Cathy was thrilled to start her family in the late 1970's and during her first pregnancy her abdomen quickly grew; so much so that her doctor's questioned the baby's due date and decided to induce labor. Once induced, they found a womb filled with blood and a 2.5-pound baby girl. Cathy had experienced a concealed placenta abruption and her enlarged abdomen was actually a terrible bleed. It was a traumatic delivery, but she and her daughter survived.

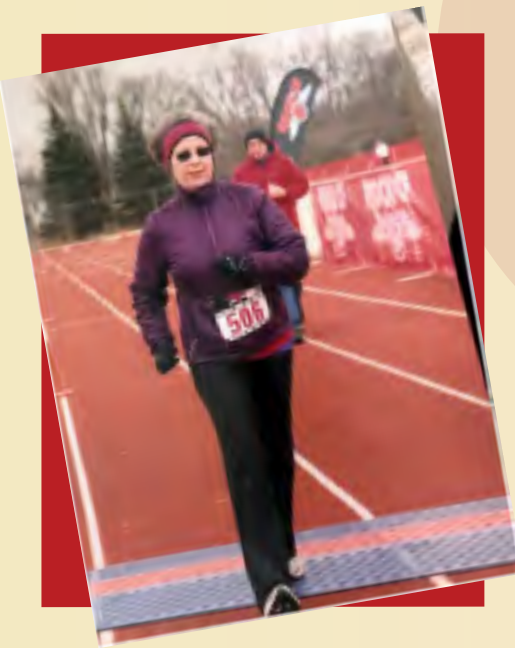
Cathy had similar and often frightening complications with her next two pregnancies, but her son and second daughter made it through. Her son, Mike, was born in 1980 and at birth he was transferred to Detroit Children's Hospital for respiratory issues. After a needed blood transfusion, he was understandably circumcised without issue. But four months later, while playing “patty-cake” his hand swelled to twice the size. Catherine took him to St. John's Hospital where he was diagnosed with Hemophilia B.

Unfortunately, Cathy did not receive her own diagnosis until 1985. She'd visit the library to learn about her son's bleeding disorder but couldn't find any information at all related to women carriers. Her doctors told her that “women cannot have hemophilia,” but she had significant bleeding symptoms and was tired of being labeled “delicate.”

Advocacy

Over the next 20 years, Cathy had five surgeries including a torn meniscus, gall bladder surgery, jaw surgery and a hysterectomy. With each surgery, there was little coordination of care, and not much awareness in the medical profession of women living with a bleeding disorder. She'd receive fresh frozen plasma on occasion, but after having her hysterectomy, her hemoglobin dropped to a dangerously low level and because of that they declined to administer morphine for pain.

By the year 2015 when Cathy needed a spine fusion, things had drastically changed in the medical field. The surgical team worked closely with her hemophilia treatment center at the Detroit Medical Center. She was given pre- and post-surgical factor to control the bleeding. Subsequent surgeries were equally well coordinated with one surgeon stating, “Have Dr. Anderson tell us what to do, and we'll do it.”



(Cathy McCarthy interview continued)

But the other thing that has changed is Cathy's confidence in advocating for herself. She knows first-hand how difficult that can be, particularly when someone in the medical field is not listening. Had she had the necessary information, she would have walked away from those early surgeries. She's learned a lot over the years.

Cathy says that women really need to find that internal voice and ask themselves, “Am I going to be able to tolerate their lack of knowledge? There's a lot of information available to physicians now. Ask your doctor what his/her plan is regarding a surgery and coordination of care.

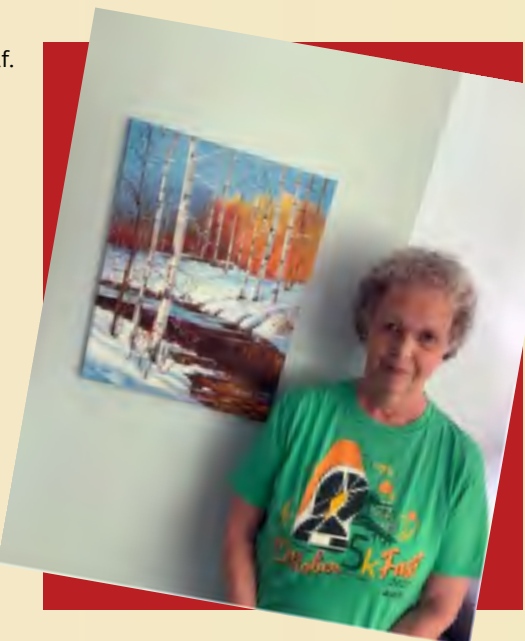
Doctors don't know everything, so it's important to speak up and say, “Let me tell you something about myself: You want to trust your doctor, but don't let yourself be hurt because you want to save their feelings. If they aren't going to listen, or if they don't have a plan to coordinate your care, walk away and find another doctor who will.”

Cathy Today

Cathy retired in 2014 after an extensive career as a NICU nurse at St. John's and Beaumont Hospitals, and now spends her time in more creative and therapeutic ways. She is an artist, painting in oils and acrylics throughout the winter and selling her artwork at local Michigan art fairs each summer. She is also extremely close with her adult children, Valerie, Mike, and Stephanie who are all now in their 40s. Cathy is proud of the people they have become.

When asked for a few words of wisdom on healthy aging, Cathy had some sage advice for her peers:

- ▶ Keep yourself moving, in whatever activity you enjoy.
- ▶ Trust your hemophilia staff, and be an active participant in your treatment. Ask questions and keep asking until you are certain you understand how your treatment works.
- ▶ Learn all that you can about your bleeding disorder and take advantage of every educational opportunity you can, like seminars and all educational opportunities offered.
- ▶ Living and aging with hemophilia is a challenge, but one you can embrace and not walk away from. Stay on top of your health with vigilance and don't let small things become big things.
- ▶ Find your voice and use it, and most of all, be kind to yourself!



Cascade Hemophilia Consortium Mission

The Purpose for Which the Corporation is Organized

To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their disease; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care.

Aging Successfully How Can Your HTC Support You?



Linda Mueller, RN



Ellen Kachalsky, LMSW



Colleen Joiner, LMSW

Staying Healthy: Age-Related Health Screenings

Colleen: Thank you both for joining me for the second part of our discussion on aging. It's really such an important topic for everyone, not just for “baby-boomers.”

There are some benefits to getting older. Hopefully, we know ourselves a bit better and feel more comfortable in our own skin. One additional bonus is that we don't tend to care quite so much about what other people think! But to age gracefully, we also want to think about our health. There are a lot of people who put off age-related health screenings and even needed surgery for a variety of reasons. However in the bleeding disorder community, there is the added fear of a procedure causing bleeding complications such as some of those that Cathy experienced. Can you address that?

Ellen: Please don't delay out of fear! Your hemophilia treatment center can coordinate pre- and post- factor and/or medication for colonoscopies, prostate cancer screenings, mammograms, or other necessary health procedures if needed. We're here to help.

Linda: As you know, we recommend treating prior to a procedure to avoid any bleeding, not only because procedures are invasive at times but because they may want to take a biopsy during the procedure. If you haven't treated before you have a colonoscopy for example, and they need a biopsy, you may need to reschedule. Nobody wants to repeat the prep for a colonoscopy, so we prepare you for that with each procedure.

Colleen: I was reading studies published in *Haemophilia*, that having hemophilia doesn't prevent you from having cardiovascular disease as some people believe. High blood pressure appears more commonly in this community which is interesting. There are active research studies to determine why that may be the case.

Linda: There's a misconception that because you have a bleeding disorder you aren't at risk for hypertension or cardiac disease. Because of advanced treatments over the years, people are simply living longer and seeing other conditions that our community hasn't seen in the past. And on top of that, joint issues can lead to a sedentary lifestyle putting you at equal risk for heart disease as the general population. You want to be screened, particularly if you have a family history. It's better to address these issues early.

Colleen: Of course, the earlier prostate, skin, or breast cancer is addressed, the better the outcome. I remember speaking with a woman who was told by a nurse that she should avoid mammograms because of bruising. But this was obvious misinformation.

Linda: Many women will get bruising with mammograms, but that isn't a reason to put them off. Consult with your treatment center beforehand, so that you can adequately treat to avoid or minimize those bruises.

