

Controlling the Pain

Colleen: Of course, many older people with hemophilia have had repeated joint damage over the years, and we know inactivity can complicate that even more. I know the past couple of years have been difficult on everyone physically and emotionally. But according to research, people with chronic pain are four times more likely to have depression or anxiety than those who are pain-free. What do you recommend?

Linda: Yes. Pain due to severe joint arthropathy is an issue with many people we see. Unfortunately, opioids alone only work to a point. Simply adding more rarely solves the problem. A person builds up tolerance, requiring a higher dose over time. There are only so many milligrams of pain medication you can ingest before it becomes harmful.

Because of that, we usually treat pain with several approaches, including selective serotonin reuptake inhibitors (SSRIs) because they can decrease pain and treat the anxiety or depression that comes with it. Realistically, pain doesn't always go away completely, but our goal is to help you get to a point where you can live with the least pain as possible.

Colleen: A lot of people in the community use medical marijuana for pain control which is legal in the state of Michigan and Ohio. It's not legal in Indiana at this point.

I generally recommend that if someone is interested in medical marijuana to control pain, they should talk with their hemophilia treatment center. I've been told by one treatment center that some pain clinics will not work with patients who are using medical marijuana.

Ellen: Yes, I advise anyone interested in using medical marijuana to discuss it with their HTC and medical providers, so that they can review any opioids being taken and cross reactions. The patient and the clinic may try to taper down on

opioids, because of the side effects. I don't recommend marijuana use for those under 25 years of age, and certainly not if pregnant. For seniors, they will need to monitor the dosing.

Another option is to work with a pain clinic on a combination of medications along with other holistic pain management techniques, including hypnosis or guided imagery, which may work well together. These techniques, used along with talk therapy, exercise or just getting out of the four walls of your house can be helpful.

Spirituality can also play an important role for some people. If you have a belief in a higher power, it can be calming and give a sense of

purpose. Going to a church, synagogue or mosque or other religious gathering place can also bring less isolation and a sense of community.

Colleen: Some people don't follow a formal religion but consider themselves spiritual. Connecting with others, taking a slow nature walk, or doing anything that fills your cup can make a big difference in your emotional outlook and have other positive outcomes.



Staying Safe

Colleen: Let's talk about safety. We know that joint disease or osteoporosis can sometimes lead to falls. I've always loved working with seniors but when it came to suggesting Lifeline or medical alert system, it was one of the most difficult safety items to convince someone to use - even when it could truly help. People are afraid of the cost or that 911 will be called unnecessarily and they will end up in the hospital.

Ellen: That's true, but this is an excellent option to have if you or someone you know is at risk of falling. It's definitely better than spending a day or two on the floor, which can cause further damage! What's nice about them is that when you push the button, the service calls a family member or friend. It will also call 911 if you don't answer the service's call. There are many variations of settings, and some have GPS features.

Actually, many hospital systems have them at lower cost; they may average about \$1/day so it's not really that bad for safety and peace of mind.

The i-Watch has an app that serves as a lifeline. It includes a heart monitor and can detect A-fib or other concerns. And it will contact someone of your choice if you have a fall. You can also speak to Siri (apple products) and Alexa to call 911 if you do not have your cell phone handy in the event something happens. Technology is much more advanced these days!

Colleen: That's a lot of interesting information, and there are many more good things to talk about. Let's keep the conversation going in our next issue! Thank you both for being with us. And thank you Paul for sharing your interesting story!



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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,

Many years ago, actually too many to mention, I became a social worker. A big part of why I've loved the field for so many years, is that I get the opportunity to listen to the life stories and experiences of other people. There's something to be said about sharing and learning from another person's experiences. Not only is it a wonderful way to feel a connection, but also a way to glean helpful insights.

In this issue, we're focusing on "successful aging." That undoubtedly means something different for everyone, but in our community, and for some of the older adults reading this newsletter, growing older is a success in and

of itself. Life-saving synthetic factor products were not available until the 1990s and in the past kids did not treat prophylactically as they do today. In earlier years, many young people with hemophilia wondered if they were going to live past 18; to reach the age of 30 was only a dream.

The 1980s brought tragedy to the community with 90% of people with severe hemophilia succumbing to HIV after receiving tainted blood products. This community has had a long and sometimes tragic history. Fortunately, because of advanced treatments, many have reached their golden years and strive to live their best lives possible.

To look at the many aspects of aging, we're dividing this topic into two newsletters. In this issue we'll hear from Paul Huggler who reflects on what has helped him live his best life over the years as a person with severe hemophilia. We'll also talk with nurse, Linda Mueller and social worker, Ellen Kachalsky, from Henry Ford Hospital to discuss various aspects of aging and ways that your HTC can support you as you age.

Regardless of your current age, we're hoping you enjoy the conversation.

Colleen

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Aging Successfully: An Interview with Paul Huggler

Younger Years

Paul Huggler grew up in Alpena with three brothers and a mother who tried her best to let her two boys with hemophilia live their lives, albeit with a big dose of caution. It wasn't an easy task. Paul's older brother was the first diagnosed with Hemophilia to the surprise of the Hugglers who had no family history. In the 1940s, there definitely wasn't the support we have today. The concept of Hemophilia Treatment Centers were decades away, and treatment options were limited to whole blood or plasma derivatives.

From an early age, Paul found ways to remain active and lead an "average" life for a young boy. But he also learned his boundaries through trial and error. "My mom didn't want me to ride a bike because I might get hurt or get a bleed. We just didn't know what to expect in those days.

Paul, being a typical young boy, would sneak over to a friend's house to borrow his bike. He also played baseball out of his parents' sight with other kids in the neighborhood. "I wanted to do the things that other kids were doing. But I did suffer for it later. I just never wanted to be babied."

Paul had many bleeds during those years and spent many days at University of Michigan hospital. But speaking to him, one gets the feeling that he wouldn't have changed a thing. He'd be "down" for two weeks sometimes, but he still had the urge to stay active. Eventually, he learned what he could and couldn't do.

Paul had lots of ankle, knee, and elbow injuries over the years. In 5th grade, Paul's right knee was frozen at a 90-degree angle after an injury. He was put into a cast which was adjusted each day to slowly straighten the leg. He missed ¾ of his school year and was required to wear a brace and use crutches. "The kids would tease me and call me Chester, the Deputy from 'Gunsmoke'. Chester walked stiff-legged too."

One of Paul's more critical bleeds occurred when he was rear-ended by a car in his teens. His arm was badly injured, and he eventually headed back to U of M. The hematoma was deep and wide, and his arm swelled to 20-30" in diameter indicating possible compartment syndrome. While eating a popsicle, the large "bruise" broke open around the edges leaving muscle and bone exposed. Paul hasn't eaten a popsicle since.

Paul has dealt with plenty of pain over the years. He believes he was fortunate to meet Michelle Witkop, the nurse (at the time) for Munson Medical Center's HTC in Traverse City. She consulted with the pain clinic in Alpena and helped work with him on his pain medications. He is now one of their patients and attends clinic there once a year.

He's also had numerous surgeries including 3 knee and 3 elbow replacements. He feels his joint replacements have helped to decrease his pain levels. "I know joint replacements are scary for a lot of people. It was for me too, but I would recommend it to anyone. It's made a dramatic difference in my life."

Paul Today

Paul has an excellent relationship with his primary care physician and with her help has cut his dosage of pain medication in half. "I just didn't think I needed as much pain medication. I wanted to lower the dosage, and my local doctor was willing to work with me. I trust her and she trusts me to know my own body." It took a long time to titrate down, but he says he's now satisfied with his medication and pain level.



(Paul Huggler interview continued)

Paul has a philosophy, "I strongly feel that you have to stay as active as you can. Even if you go on an easy walk every day, take one step at a time, and just keep moving. It hurts at first, but if you work past the pain, it gets better and better."

Many people have a difficult time accessing veins as they age, and more recently Paul felt that he needed a port. As a person with Hemophilia B, he doesn't use injectable products, and his veins were getting more and more difficult to access. Fortunately, Paul advocated with the HTC to have a port placed. The HTC coordinated the procedure, and Paul and his wife are much happier with his weekly infusions.

Paul's relationship with his primary care doctor has helped him to connect with other providers for care that he needs. After having Hepatitis C in the 90's, Paul eventually took Interferon and cleared the virus after 9 months. He still gets his liver tested every year by a specialist. Paul goes in for those annual health maintenance exams that are recommended for all of us as we age and is pleased to share that, other than high blood pressure and hemophilia, his doctor says he's in excellent health.

Paul retired a couple of years ago after a successful 48-year accounting career, and he's happy with retirement. He spends his time with his wife, Cindy, 3 adult kids, and his grandchildren and is enjoying his life. "I've always tried to have a positive attitude."; it seems to make a difference.

Paul attributes successful aging to his positive attitude and a refusal to be "babied" throughout his life. "I never wanted any of that." But he attributes his success most of all to Cindy. "She loves me, and cares for me, but if I ask for a glass of water, she tells me to get it myself," Paul laughs. And that's true love!



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 Gracefully: How Can Your HTC Support Your Goal?



Linda Mueller, RN



Ellen Kachalsky, LMSW



Colleen Joiner, LMSW

Colleen: Thank you both for joining me for this discussion on aging. Some aspects of getting older are universal while others are particular to the bleeding disorder community. I know people are interested in hearing your perspective and how the HTC can help.

Staying active is a challenge for many of us, but with joint arthropathy and concurrent pain it can seem like an uphill battle at times. Paul Huggler mentioned that although it isn't easy, he feels better by staying active.

Do you believe that staying active as you age with a bleeding disorder can be a reality?

Ellen: Definitely. Unfortunately, less activity means increased weight gain and less joint mobility which becomes a vicious cycle. It's important for physical and mental health to stay as active as you possibly can. If you're just getting back to a routine, take it one step at a time.

Linda: Most of our older folks didn't have the advantage of prophylactic treatment when they were younger and suffered joint damage as a result. The younger people in the community have better treatment but can also help protect their joints by being active. If someone sees changes in their joints, regardless of age, you need to let us know right away. We'll ask you to see orthopedics as soon as possible to evaluate and treat, watch for changes, and try to prevent further damage. The earlier it's addressed, the better the outcome.

Ellen: Working with your PT to develop a plan can be helpful. Some people do chair exercises if they aren't ambulatory. Swimming, yoga, and Tai Chi are great exercises for older people with hemophilia. The buoyancy and low impact of swimming prevents injury from sudden moves and allows you to strengthen the muscles for better joint support, while keeping your heart healthy. And I've seen actual improvement in range of motion after regular, low-impact exercises like walking or Tai Chi.

Physical activity is also a big serotonin booster. Serotonin is the natural chemical in our brain that appears to play a role in mood, emotions, appetite, and digestion. It's also an effective component in controlling pain, or how we perceive pain.



Colleen: I think the point is to keep moving. The key is to start slow and build on that as you can. And, yes, work with your physical therapist to develop a plan that works for you if needed.

Safe Low Impact Exercises

Chair Aerobics

Yoga

Tai Chi

Swimming

Dancing