UPMC
LIFE CHANGING MEDICINE

UPMC Adult Spina Bifida Clinic Winter 2027 Newsletter

A Message from Your Peers: Living with Spina Bifida and Emotional Wellness - Part 1

As two adult women with spina bifida, Abby McCormick and I [Sara Izzo], have shared several conversations with each other about how our emotions can become rollercoasters as we manage both our circumstances and the environment we are in.

These experiences led us to invest our education in psychology to have a deeper understanding of emotions, thoughts, and behaviors so we can help ourselves and others have better emotional wellness. This article is a two-part series about how emotional wellness can be managed from a spina bifida perspective.

As adults with spina bifida, we are both grateful to have degrees in psychology with Abby focused on music therapy and mine in counseling. So, what is emotional wellness and what does spina bifida have to do with our emotions?

According to Dr. Diana Rabb from the National Center of Emotional Wellness, "emotional wellness is an awareness, understanding, and acceptance of your emotions. This understanding and acceptance give you the ability to manage effectively through challenges and change." Your body and emotions are connected and are controlled through your nervous system.

If you were born with spina bifida, you were born with a spinal cord that was affected before your birth. This can result in needing assistance with walking, having bladder and bowel issues, and sometimes having to treat hydrocephalus or "water in the brain." What Abby and I learned in college while studying psychology is that the nervous system is divided into two main parts: the central nervous system (the brain and spinal cord) *and* the peripheral nervous system, which connects the central nervous system to the rest of the body, including the eyes, skin, arms, legs, and organs such as the lungs, heart, bladder, and bowels. Together, these systems communicate with one another and help the body respond to its environment as effectively as possible.

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Welcoming Winter

"In the midst of winter, I found there was, within me, an invincible summer." French philosopher and author Albert Camus wrote those words, and they capture the resilience we see in our community every day. As the season turns colder, we hope this edition helps you tend to that inner strength and remember that you have a whole team behind you.

Written by ***Brad Dicianno, MD***

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When it comes to our body's response to something we fear in our environment, that conversation can feel very overwhelming if we encounter it too often. Most books and websites that talk about the body's automatic response to fear within the nervous system use examples of people without disabilities, similar to the one by Glen Getz (2025), *"Imagine you are hiking in the woods and suddenly see a large, venomous snake coiled nearby, and your body is now deciding to fight-flight-or flee."*

Your eyes see the threat, and your *brain* immediately prepares your body to respond. Your *heart* begins to beat faster, pumping more blood into your *arms and legs*, while your muscles tense up to prepare you to run or fight. At the same time, your *skin* begins to sweat because the increased blood flow from your *heart* raises your body temperature. Your *lungs* also expand, causing you to breathe more quickly as your body prepares to run.

Stress can trigger many of these same physical responses, even when there is no immediate danger in our environment. When we experience too much stress for a long time, these reactions can develop into anxiety, panic attacks, and depression. Depression may develop when people begin isolating themselves or avoiding situations that make them feel uncomfortable or distressed (like pain, incontinence, or just feeling overstimulated).

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Well, I don't know about you, but Abby and I have never run anywhere in our life, and we never fought any danger off either, yet we still feel all these changes in our bodies, as if we are being prepared to run or fight. When I am talking to Abby and other peers, I realize our history of medical procedures and surgeries made our bodies familiar with stress before we could even talk and communicate our fears to our loved ones and even doctors. Having these medical experiences every year and sometimes several times a year, made some of our bodies respond this way so much, so we feel the fight-flight-flee response to the smallest inconvenience. We call this an *overactive alarm system* (Beckner, 2025).



When Abby and I started to talk to other adults with spina bifida we realized how hypersensitive we are to our environment and how difficult it was for us to communicate our fears, worries, and frustrations when trying to get our needs met by family, friends, and even ourselves. As adults with spina bifida, we also have issues with executive function and combining these two truths we now understand that our hypersensitivity impacts our emotional control, impulse control, flexible thinking, and self-monitoring skills.

As adults with spina bifida, we have more power over our emotions than we think, and in our next article we will discuss what grounding techniques are and provide 3 key things that have helped us with our own emotional wellness. As peer navigators, we don't have the answers to your problems; however, we do help to make it easier to find the language to ask for help and even assist you in connecting with someone who can help you on your journey of emotional wellness.

Can't wait until the next article and want to know more about how to manage emotional wellness, feel free to contact me, Sara Izzo at **sai20@pitt.edu**, and I will be happy to connect you with Abby or another one of our adult spina bifida peers.

*Written by **Sara Izzo** and **Abigail McCormick***

Beckner, V. L. (2025, February 12). Anxiety Gets a Bad Rap: Understanding Your Healthy Alarm System. Psychology Today. **Anxiethttps://www.psychologytoday.com/us/blog/harnessing-principles-of-change/202104**

Getz, G. E. (2025). Applied biological psychology: Chapter 3: Nervous System and Brain Structure. (2nd ed.). Springer Publishing.

Raab, D. (2022, March 7). What is Emotional Wellness and How it Leads to Happiness. **Mind Journal**.

Darcie Petrillo Honored with Award



We are thrilled to announce that Darcie Petrillo, MPAS, PA-C received the UPMC Advanced Practice Provider (APP) Excellence in Leadership Award at UPMC, in celebration of the 2026 National APP Week. Darcie is a physician assistant and Program Manager for the UPMC Adult Spina Bifida Clinic. This award recognizes her commitment to patient care, teaching, research, advocacy, innovation in bowel management care, and her leadership in developing the Spina Bifida Transition Clinic— a program designed to support patients as they move from pediatric to adult services. Congratulations, Darcie!



Disability Pride PA in Pittsburgh

This fall, Disability Pride Pennsylvania brought its celebration to Schenley Plaza in Pittsburgh, with live entertainment, community resources, accessible games, and guest speakers. The 2026 theme, "We Belong Here and We're Here to Stay," was a fitting reminder that disability is a vital part of our community's identity and history. Monica Albert Still, RN, BSN and Cheyenne Hennen staffed a table at the event on behalf of our clinic and in partnership with the Human Engineering Research Laboratories and other organizations, joining thousands of Pennsylvanians in celebrating disability pride and advocating for an inclusive community.

The Disability Lead Institute

The Disability Lead Institute is a year-long fellowship program designed for emerging and established disabled professionals. Fellows engage with a committed peer group to explore their disability identity and refine their personal leadership styles, with the ultimate goal of advocating for change and fostering an equitable society.

As a fellow in the 2026 inaugural Southwestern Pennsylvania cohort, I had the privilege of collaborating with like-minded leaders throughout Pittsburgh. The program offered a safe environment where I could actively engage in meaningful dialogue about disability advocacy while collaborating with my peers to cultivate more accessible and inclusive spaces for the community.

Navigating professional environments that are built without disability in mind can be challenging. However, this fellowship expanded my leadership capacity by teaching me to embrace the power of community, collaboration, and impactful storytelling. Ultimately, this fellowship provided me with a new-found confidence and a supportive network that continues to empower my advocacy through ongoing mentorship and connection.

Disability Lead is more than just a networking opportunity, it is a transformative experience that provides invaluable insights, practical wisdom, and the confidence to lead with authenticity and pride.

Written by ***Cheyenne Hennen***





Opportunity to Make a Difference: Challenge Accepted

When Governor Josh Shapiro appointed me to the Governor's Advisory Commission on People with Disabilities, I was truly humbled.

As a person born with spina bifida, a registered nurse, and someone who has spent much of my life advocating for disability rights, this appointment is both an incredible honor and a tremendous responsibility.

I am especially honored to serve as the Co-Chair of the Healthcare Working Group. Improving healthcare for people with disabilities has become my life's work. Every day in the UPMC Adult Spina Bifida Clinic, I see both the resilience of our patients and the barriers they continue to face. I believe everyone deserves healthcare that is accessible, respectful, collaborative, and informed by the lived experiences of disabled people. I am eager to help shape recommendations that move Pennsylvania closer to that goal.

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Governor Shapiro established the Commission to ensure that the voices of Pennsylvanians with disabilities help guide state policy. The Commission's charge is to identify barriers, advise the Governor on issues affecting people with disabilities, recommend solutions, and help improve programs and services across the Commonwealth. Most importantly, it recognizes that the people most affected by disability policy should have a meaningful role in creating it.

I am honored to serve alongside my fellow commissioners, who are some of Pennsylvania's most dedicated and accomplished disability advocates. Their expertise, passion, and lived experience inspire me, and I look forward to learning from and working with each of them.

This appointment is also deeply personal. I often think about my mom, who spent my childhood encouraging me to be independent, speak up for myself, and believe that I could make a difference. She challenged expectations, refused to let disability define what I could accomplish, and instilled in me the confidence to advocate—not only for myself, but for others. I only wish she were here to see this moment. I think she would be proud.

Finally, I want to express my sincere gratitude to Governor Shapiro for creating this Commission. His commitment to ensuring that disabled voices are not only invited to the table, but truly heard, sends a powerful message. Meaningful change happens when people with lived experience are recognized as partners in shaping policy.

I am grateful for this opportunity to serve and excited to get to work. I hope to represent our patients, the spina bifida community, and all Pennsylvanians with disabilities with integrity, compassion, and the belief that together we can build a healthcare system—and a Commonwealth—that works better for everyone.

Written by ***Monica Albert Still, RN, BSN***



Osteoporosis is a condition in which bones become weaker, which causes a higher risk of breaks called fractures.

As we age, bones get weaker because old bone breaks down, but new bone does not form in the same way as it did when we were young. This makes bones weaker on the inside, though they still seem hard on the outside. Up to 50% of adults with spina bifida are at risk of "early onset" osteoporosis (occurring in the 20s or 30s instead of at older ages). Risk factors include being female, family history of osteoporosis, immobility, prior ileal diversion surgery, long-term use of corticosteroids, or kidney failure.

There are some steps you can take with your diet to help reduce the risk of osteoporosis.

Calcium:

Calcium is an important building block in bones that helps keep them strong. Calcium needs vary by age and gender:

- Women ages 18-49 years, and men ages 18-69 years: 1000 mg calcium per day
- Women ages 50+ and all adults ages 70+: 1200 mg calcium per day

Dairy products are a common source of calcium (including milk, yogurt, and cheeses). If you do not consume dairy, check that your dairy substitutes (such as soy, almond, or oat milks/yogurts) are fortified with added calcium. Non-dairy sources of calcium include dark green vegetables (kale, collards, mustard greens), nuts/seeds, calcium set-tofu, canned fish with soft edible bones, fortified breakfast cereals, and beans.

If you do not regularly consume about 3 servings of dairy or calcium-fortified dairy substitutes daily, you may need to take a calcium supplement. Talk to your healthcare provider about a calcium supplement before starting. A few things to think about:

- More calcium is not always better. Long-term, too much calcium from supplements can have risks such as kidney stones.
- Some people find calcium carbonate (the most common type of calcium supplements) constipating. Calcium citrate is a less constipating alternative. Using smaller doses per sitting spread throughout the day can also help.
- Calcium carbonate must be taken with food for absorption. This is optional for calcium citrate.
- Our bodies don't absorb more than about 500 mg of calcium from food or supplements at one time. Spread your calcium throughout the day.

Vitamin D:

Vitamin D both helps our body absorb calcium. Our body can make vitamin D when our skin is exposed to the sun. However, people who live in northern climates or spend a lot of time indoors often can't make enough vitamin D on their own. Foods higher in vitamin D include dairy, fortified dairy alternatives, fortified cereals, salmon and tuna, egg yolks, and sun-dried shitake mushrooms. Discuss if you need a vitamin D supplement with your healthcare provider.

To learn more:

- Spinabifidaassociation.org
- Bonehealthandosteoporosis.org

*Written by **Jacquelyn Klunk, MS, RDN, LDN***



WINTER WELLNESS Checklist

As the days become shorter and temperatures drop, it's natural to spend more time indoors. For individuals living with Spina Bifida, cold weather and snow can create additional barriers to getting out of the house, making it even more important to stay connected with others and prioritize your mental health.

Why Staying Connected Matters

Social connection plays an important role in both physical and mental health. Whether it's a phone call with a friend, a video chat with family, attending a support group, or participating in a community event, maintaining relationships can help reduce stress, improve mood, and remind us that we're not alone.

Here are a few ways to stay connected this winter:

- Schedule regular phone or video calls with family and friends.
- Join a virtual support group or community event.
- Participate in hobbies that connect you with others, such as online book clubs, crafting groups, or gaming communities.
- Reach out to your healthcare team or social worker if you're feeling overwhelmed or isolated.
- If weather allows, enjoy a short outing to a local library, coffee shop, or community center to safely interact with others.

Take Care of Your Mental Health

Winter can sometimes affect our emotional well-being. Pay attention to how you're feeling and remember that it's okay to ask for help. Consider these simple wellness habits:

- Stick to a regular sleep schedule.
- Stay physically active with exercises that are safe for your abilities.
- Spend time near natural light or open your curtains during the day.
- Practice relaxation techniques such as deep breathing, meditation, or journaling.
- Celebrate small accomplishments and be kind to yourself.

Winter Assistance Resources

Winter can also bring higher household expenses. If you're struggling with heating costs or utility bills, assistance may be available.

- **LIHEAP** (Low-Income Home Energy Assistance Program) will open in November 2026.
- **CAP** (Customer Assistance Program) offers emergency help for households experiencing heating emergencies, such as broken heating equipment, fuel shortages, or utility shutoff notices during the winter season.

If you think you may qualify for these programs or need help applying, please contact me. I am happy to connect you with available resources and answer any questions. We wish you a safe, healthy, and warm winter season!

*Written by **Olivia Hughes BSW, MSW***

Staying Connected

Feeling lonely from time to time is part of being human. But for many adults with spina bifida (SB), loneliness can become a regular part of life, and when it does, it can wear on both your mood and your health.

If you often feel isolated, left out, or like you do not have enough people to turn to, you are not alone in that experience, and there are things that can help.

Loneliness is not the same as being by yourself. Some people spend a lot of time alone and feel just fine. Others can be around people all day and still feel disconnected.

Loneliness is the gap between the connection you have and the connection you want. It can show up as feeling misunderstood, feeling like a burden, or slowly drifting away from people without meaning to.

Adults with SB may face extra hurdles to staying connected. Getting to social events can be harder when transportation or accessibility is a challenge. Medical appointments and daily routines take time and energy. Friendships from school can fade in adulthood, and building new ones is not always easy. Over time, it can start to feel simpler to stay home, even when part of you wants company.

Connection matters more than most people realize. In earlier newsletter articles, I have written about depression, anxiety, and sleep. Loneliness is tied to all of them. When we feel disconnected, mood tends to dip, worry tends to grow, and sleep often suffers. The reverse is also true. Strong relationships help protect our mental and physical health, and they make hard days easier to get through.

The good news is that connection is something you can build, a little at a time. You do not have to overhaul your whole social life at once. Small, steady steps tend to work best.

Here are a few things to try:

- **Start small and regular.** A short phone call, text, or coffee with one person on a set day each week can matter more than one big event a year.
- **Do things you care about, with others.** Think about what is meaningful to you, whether that is a hobby, a cause, a faith community, or a class, and look for a group built around it. Shared interests make connection easier.
- **Look for peer support.** Connecting with other adults who have SB can help you feel understood in a way that is hard to find elsewhere. The Spina Bifida Association and United Spinal are two great places to start.
- **Be patient with yourself.** Reaching out can feel awkward or tiring at first, especially if it has been a while. That is normal, and it usually gets easier with practice.

If loneliness is weighing on you, you do not have to sort it out on your own. Please bring it up at your next visit to the SB Clinic. Your providers can listen, help you think through your options, and connect you with resources. Our SB Clinic social worker can point you toward groups, programs, and services in your area.

Loneliness is common among adults with SB, but it does not have to be permanent. Connection takes time to build, and you deserve it. The first step can be as simple as reaching out to one person you trust.

*Written by **Ted Allaire Barrios, PhD***







Sample workout to try 2 to 3 days per week:

2 sets, 10-15 reps, 30 seconds to 1 minute rest between sets

- **Banded External/Internal Rotations**
- **Banded Face-Pull**
- **Dumbbell Overhead Press**
- **Dumbbell Lateral Raise**
- **Dumbbell Bent Over Fly**

Strong Shoulders for Healthy Living

Our shoulders help with reaching, dressing, transferring, pushing a wheelchair, using a walker or crutches, and lifting objects.

Whether you are a wheelchair user or walk with or without devices, keeping your shoulders strong and healthy can help you stay independent and reduce pain.

How the Shoulder Works

The shoulder is very mobile, which makes it useful but also easier to irritate. It moves in several directions: lifting forward, lifting out to the side, moving backward, turning inward, and turning outward. The shoulder has the three main muscles of the deltoid itself as well as four supporting muscles known as the rotator cuff muscles.

The main muscles include:

- **Anterior/Front deltoid:** lifts the arm forward and helps turn it inward.
- **Lateral/Middle deltoid:** lifts the arm out to the side.
- **Posterior/Rear deltoid:** lifts the arm backward and helps turn it outward.

Rotator Cuff Muscles:

- **Supraspinatus:** helps to lift the arm and keeps the shoulder stable.
- **Infraspinatus:** turns the arm outward and helps keep the shoulder stable.
- **Teres minor:** turns the arm outward and helps keep the shoulder stable.
- **Subscapularis:** turns the arm inward and helps keep the shoulder stable.

Keeping these muscles strong and healthy as long as possible will allow us to live stronger and healthier lives overall and provide us with the strength we need to be active members of our community and experience more out of life!

*Written by **Dan McCoy, MS, CPT, PLY***

Understanding Chiari II Malformations

Many people with Spina Bifida also have a Chiari II Malformation. This is when part of the brain extends downward past the base of the skull and into the spinal canal. Nearly all people with Myelomeningocele (a type of open Spina Bifida) have a Chiari II Malformation.

It is possible for someone to live their whole life with a Chiari II malformation and never have any issues from it. Only 10-33% of people with Chiari II develop symptoms that need treatment. However, everyone with a Chiari II should know to watch for warning signs including difficulty swallowing, choking, trouble breathing or sleep apnea, changes to your voice, new weakness, worsening or changing headache, or changes in balance or coordination. If these symptoms were to be present, you should reach out to your medical team right away. They will want to do a thorough examination and may want to order imaging as well.

Maintaining regular follow up with your medical team can help you feel confident about catching symptoms if they happen. You should seek emergent care by going to the emergency department for symptoms such as sudden severe headache, difficulty breathing, seizures, rapid change in strength, or a loss of consciousness. If you have any questions, we would be happy to try to answer them!

*Written by **Darcie Petrillo, MPAS, PA-C***

Do you have ideas for our Newsletter?

If you have particular topics you'd like to see in our newsletter, please reach out and let us know.

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Check out our other newsletters and clinic information at:
UPMC.com/SpinaBifida

SIGN UP HERE
to receive our newsletter in your email.

Your Voice Matters — Get Involved with SB-CAN!

The **Spina Bifida Care Advisory Network of Western Pennsylvania (SB-CAN)** brings together people with spina bifida, parents, family members, caregivers, and members of the health care team to help improve care and strengthen our spina bifida community.

SB-CAN gives people with lived experience a voice in what matters. We talk about barriers to care, resources our community needs, current research, transition from pediatric to adult care, community events, and ways we can make care better for children and adults with spina bifida at the UPMC clinics.

We are looking for new members! We especially want to hear from parents and families connected with the pediatric clinic, as well as adults with spina bifida. You do not need any special experience—just an interest in making things better for our community. **Beginning in the first quarter of 2027, SB-CAN will meet quarterly in the evening** to make it easier for more people to participate. Interested in getting involved or learning more? Contact the UPMC Adult Spina Bifida Clinic at 412-232-8902, or reach out to Sara Izzo at izzos@upmc.edu or Monica Albert Still at stillm2@upmc.edu.

*Written by **Monica Albert Still, RN, BSN***



United Spinal Association of Pittsburgh

United Spinal Pittsburgh welcomes people with spina bifida and other mobility disabilities into its community. This partnership can give children and adults with spina bifida more opportunities for peer support, advocacy, education, recreation, social events, and connection with the broader disability community.

*Written by **Monica Albert Still, RN, BSN***