

## Spina Bifida Awareness

Spina Bifida Awareness Month, observed every October, and World Spina Bifida and Hydrocephalus Day, which occurs every October 25, are great opportunities to educate, raise awareness, and show support for those affected by Spina Bifida. There are many ways to celebrate and raise awareness.

Consider joining **initiatives at our clinic**, such as:

- **The Peer Navigator Program (PNP):** partner with and learn from a peer with similar lived experiences. Please reach out to Sara Izzo ([izzos@upmc.edu](mailto:izzos@upmc.edu)) or Monica Albert Still ([stillm2@upmc.edu](mailto:stillm2@upmc.edu)) if you are interested. You can also join our **Group PNP meetings** on the 1st and 3rd Thursday of every month at 7pm ET.
- **The Healthcare Navigator Program:** a new initiative to help you better manage your health and more effectively navigate the healthcare system. Through group and one-on-one sessions, you can learn how to advocate for yourself, understand your medical needs, and access care and resources for health and wellness. More information about this program will be in future newsletters.



**Participate in research** by visiting this **website** or the kiosk in our waiting room. **Host a local event**, such as a fundraiser. **Donate** to programs that provide clinical care or research related to Spina Bifida. **Explore events and resources** from the **Spina Bifida Association**, **United Spinal PGH**, or the **Spina Bifida Association of Western Pennsylvania**. **Social media campaigns** are also effective; you can use hashtags like **#AdultSpinaBifida**, **#SpinaBifida**, or **#SpinaBifidaAwarenessMonth**. We encourage you to choose an initiative that is right for you and commit to making a difference this October!

*Written by Brad Dicianno, MD*



## Fall Again

As autumn paints the world in warm colors, and cooler breezes sweep in, we have an opportunity for planning and reflection. The fall season encourages us to nurture our well-being and welcome change with open arms. In this edition, we'll help you plan accessible travel, recognize and seek treatment for depression, learn about reducing utility expenses, and manage migraines. We also provide ideas for advocacy, getting involved in the community, and making small steps toward a health goal. So grab a cozy blanket, settle in, and let's enjoy this season of transformation together!

*Written by Brad Dicianno, MD*

*"Life starts all over again when it gets crisp in the fall." – F. Scott Fitzgerald*

## Low Income Home Energy Assistance Program

The Low Income Home Energy Assistance Program helps families living on low incomes with energy bills, energy crises, weatherization, and minor energy-related home repairs in the form of a cash grant. Households in immediate danger of being without heat can also qualify for crisis grants. The cash grant is a one-time payment sent directly to the utility company/fuel provider to be credited on your bill. These grants range from \$300 to \$1,000 based on household size, income, and fuel type. For more info visit the [LIHEAP](#) website, [People's Usage Reduction](#) website, and the [People's Assistance Program](#) website.



## Secure Your EBT (Electronic Benefit Transfer) Funds from Theft

EBT stands for Electronic Benefits Transfer. It is a benefit delivery system that provides public assistance recipients with electronic access to their cash and Supplemental Nutrition Assistance Program (SNAP) benefits.



Unfortunately, some users of EBT cards have been victims of theft when the card is accessed fraudulently. A new feature called Card Lock allows you to lock your EBT card when not in use. Locking your EBT card blocks all purchases, balance inquiries, and transactions to keep your funds secure. You can Lock your card when it's not in use, then simply Unlock your card before making a purchase. You can also use the Auto Re-Lock feature to automatically Re-Lock your card in 30, 60, or 90 minutes after unlocking. Read more about EBT and the Card Lock feature at the [Dept. of Human Services](#) website. The [Connect EBT](#) website can be used to access your account and view your transaction history. You can also download the official [myCOMPASS PA](#) mobile app for free, which allows users to view their EBT balance and transactions, update personal information, view eNotices, submit documents, and more.

*Written by Brad Dicianno, MD*

## Welcome to Olivia Hughes

We're excited to welcome [Olivia Hughes](#), Social Worker, as the newest member of our UPMC Adult Spina Bifida Clinic team. Olivia holds a Bachelor's degree in Social Work from Slippery Rock University and is currently pursuing her Master's degree in Social Work there, with an expected graduation date of July 2025. She is also working toward a certificate in Cognitive Behavioral Therapy. Olivia comes to us from the Department of Human Services – Office of Children, Youth, and Families (OCYF), and brings a strong background in the non-profit sector. She has extensive experience in case management, community resource navigation, rapport building, and trauma-informed care. Please join us in giving Olivia a warm welcome to the Spina Bifida community!







## Depression in Spina Bifida

Depression is something that many adults with Spina Bifida experience. If you think you may be depressed, it's important to know that you are not alone and that there are many effective resources available to you.

All humans sometimes feel sad. Sadness (and its cousin, grief) are normal human emotions. However, if feelings of sadness, hopelessness, and helplessness linger for more than a couple of weeks, this may mean that you are experiencing an episode of depression – which, despite its name, is not some moody new TV show.

One of the tricky things about depression is that it can look very different from person-to-person. It can even look different over time within one person! For example, in addition to the feelings mentioned above, people who are depressed may lose interest in activities they typically enjoy. They may also find themselves simply doing fewer and fewer things in their daily routine. They might find it hard to get out of bed, have trouble making decisions, or feel more easily overwhelmed by simple tasks. As people become less engaged in meaningful and enjoyable activities, they might also notice concentration difficulties, as well as changes (more or less) in appetite, energy level, weight, and sleep.

Recognizing these signs is an important first step in getting help. If you think you might be experiencing depression, please mention this during your next appointment with the UPMC Adult Spina Bifida Clinic. Providers in the Clinic are trained to offer non-judgmental support, guidance, and recommendations to all patients,

including those who are experiencing challenges related to mental health, like depression. If you find yourself in a crisis situation related to symptoms of depression, please know that you can always dial 9-8-8 to speak with a skilled, judgment-free counselor who can provide free, quality, one-on-one crisis support 24/7 all 365 days of the year. You can also dial 9-1-1 or seek emergency care in the Emergency Department at any hospital.

The best option, however, is to establish care with a provider or team of providers who can engage you in mental healthcare services, with a goal of preventing you from ever reaching a point of mental health crisis. Cognitive-behavioral therapy (CBT) is an evidence-based treatment for depression that is non-medication-based, meaning there are no side effects! CBT for depression focuses primarily on shifting the relationship that someone has with their thoughts and feelings, while at the same time also boosting time spent in those meaningful and enjoyable activities I mentioned earlier. Therapists who provide these services can be found by searching the *Psychology Today* [website](#), which allows you to filter providers by location and insurance coverage. On the other hand, some people prefer medication-based approaches to depression treatment, either instead of or in addition to CBT. If this is you, then this would be a great topic to bring up during your next visit with either the SB Clinic or your primary care doctor. If you find yourself experiencing depression, please remember that you are not alone and know that there is hope for a brighter future – The first step is to ask someone that you trust for help!

*Written by Ted Barrios, PhD*

# Traveling with Spina Bifida: Tips for Navigating the World with a Wheelchair or Mobility Device

I love going back to Connecticut to see the autumn leaves along the shore. Traveling can be a deeply rewarding experience, offering the chance to explore new places, meet new people, and gain fresh perspectives.

However, mobility challenges and specific medical considerations mean that thoughtful planning is essential to ensure a safe, smooth, and enjoyable journey. Whether you use a wheelchair, crutches, or another mobility device, here's a guide to help you travel with confidence.

Spina Bifida is a condition that varies widely from person to person, affecting mobility, continence, and other physical aspects to different degrees. Knowing your personal health and accessibility needs is key to planning a successful trip. There are so many things to consider. Let's break them down.

## General Considerations

- ▶ **Mobility requirements:** Will you need full wheelchair access or partial support for walking?
- ▶ **Medical management:** How will you handle routines like catheterization, skincare, and medication on the road?

## Destination Research

Choosing an accessible destination is crucial. Research cities and countries that are known for good disability access.

Look into:

- ▶ **Accessibility of tourist sites:** Are there ramps, lifts, and accessible bathrooms?
- ▶ **Terrain and climate:** Avoid destinations with steep hills or extreme weather if these might present extra challenges.
- ▶ **Healthcare availability:** Check where the nearest medical facilities are located in case of emergencies.
- ▶ **Online communities and blogs** by travelers with Spina Bifida or similar disabilities can offer invaluable, real-life insights.

## Accommodation Tips

When booking accommodation:

- ▶ **Request detailed descriptions:** Ask for photos and measurements of doors, bathrooms, and room layouts to ensure true accessibility.
- ▶ **Ask about bathrooms:** Roll-in showers, grab bars, and enough space to maneuver are essential.
- ▶ **Location matters:** Choose a hotel close to public transport or attractions to minimize long transfers.

## Medical Planning

Medical preparedness is a top priority when traveling.

- ▶ **Bring extra supplies:** Pack more catheters, incontinence products, and medications than you expect to need.
- ▶ **Carry documentation:** Bring medical letters explaining your condition and needs, prescriptions, and emergency contact details.
- ▶ **Portable medical devices:** If you use assistive devices like a portable toilet chair or cushion, confirm they fit in your transport and accommodation plans.

(Continued on page 5)



(continued from page 4)

## Getting Around

Mobility planning is crucial to minimize obstacles:

- ▶ **Air travel:** *Inform airlines of your needs well in advance. Airlines often provide assistance with boarding, wheelchair storage, and priority seating. Don't forget your REAL ID!*
- ▶ **Ground transport:** *Book accessible taxis or transport services ahead of time. Some cities have accessible public transportation, but it's best to confirm routes and access points in advance.*
- ▶ **Rental vehicles:** *If you drive, look for companies that offer adapted vehicles.*

## Managing Fatigue and Comfort

Travel can be tiring, especially with mobility challenges. To stay comfortable:

- ▶ **Plan breaks:** *Include regular rest periods in your itinerary. Plan for realistic travel days to avoid fatigue and overexertion.*
- ▶ **Hydrate and eat regularly:** *Staying nourished helps maintain energy.*
- ▶ **Protect your skin:** *Use your wheelchair cushion when sitting on other surfaces, and inspect your skin regularly, especially on long travel days.*

## Legal Rights and Support

Different countries have varying laws regarding disability access. Familiarize yourself with:

- ▶ **Disability rights laws:** *These define your rights in transport, accommodation, and public access.*
- ▶ **Support services:** *Find local disability organizations that can offer support or advice if you encounter difficulties.*

## Stay Flexible and Positive

Even the best-planned trip can have hiccups. Keep a flexible mindset, and don't hesitate to ask for help when needed. Many people and places are willing to assist travelers with disabilities when they understand your needs.

Traveling with Spina Bifida and using a wheelchair or mobility device presents unique challenges, but it also offers unique rewards. Each trip helps build confidence, creates new memories, and can inspire others with similar challenges to pursue their travel dreams. With thorough preparation, a supportive network, and a spirit of adventure, the world is yours to explore.

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

## Small Wins Lead to Bigger Wins!

When we have a goal for ourselves, whether it is fitness, nutrition or life-related, we often spend a lot of time thinking about how we want to achieve the goal, or how it will feel once we do achieve it. We may even meticulously plan out every step in the process before we even begin. But just getting started by doing *something small* is the most important first step. This could be doing one set of movements like a shoulder press, lateral raise, or a bicep curl, or simply going for a roll or walk!

Whatever your goal is, just doing something, especially when you don't feel like doing it, can lead to much bigger wins in the future. The smallest steps, no matter how small, when stacked up, can lead to big wins in the future. Eventually this can lead to healthier, stronger, and more fulfilled lives. Starting small helps us but will ultimately help others around us too, as we lead by example.

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

## Exciting Partnership Announcement!

The UPMC Adult Spina Bifida Clinic is proud to announce a new collaboration with the United Spinal Association of Pittsburgh! Together, we are expanding our commitment to not only provide top-quality medical care but also to enhance the lives of our clinic members through advocacy and community engagement.

This partnership will create new opportunities for our members to participate in advocacy efforts that promote disability rights and awareness, as well as a variety of social outings designed to build connections and foster a sense of community.

Want to know more about United Spinal PGH? Check out their [website](#). Stay tuned for upcoming events and initiatives—and get ready to connect, advocate, and thrive with us!

For more information, please contact Monica at [monica.still@unitedspinalpgh.org](mailto:monica.still@unitedspinalpgh.org).

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



# Migraine Health

Migraines can be challenging and can affect your ability to navigate everyday tasks. For many individuals, migraines can cause blurry vision, nausea, and light sensitivity.

Not only can these side effects alter your mood, but they can get in the way of completing important tasks, engaging in conversation, and meeting daily goals. Although you may not be able to eliminate migraines completely, maintaining a consistent self-care routine and managing your health are the first steps to managing migraines.

Medications are a common way of managing migraines. But lifestyle factors like diet, exercise, and sleep are also important tools to help control migraines. While there is a lot of interest in different diets and supplements for migraines, not everything is backed by research. Below are a few of the current common nutrition topics related to migraine management:

- **DIETARY PATTERNS:** While many diet patterns are studied for migraines, research tends to show that diets that are more balanced (high in fruits, vegetables, whole grains, nuts/seeds, beans, low-fat dairy, and lean meats) are more helpful for reducing how often and how severely a person has migraines. Diets that are less healthy (high in added sugar, salt, red meat, fried foods, and ultra-processed foods) are usually linked to worse migraine control.



- **MEAL TIMING:** Eating regular meals and not skipping meals has been shown to be helpful for migraines. Some research also shows that it is extra important not to skip breakfast.
- **SPECIFIC DIETS:** There is some research that shows that the DASH diet (Dietary Approaches to Stop Hypertension), the Mediterranean diet, and a lower glycemic index diet may be helpful for migraines. Each of these diets resembles the balanced diet pattern listed above that is high in fruits, vegetables, whole grains, nuts/seeds, beans, low-fat dairy, and lean meats and lower added sugar, salt, red meat, fried foods, and ultra-processed foods. There is also some evidence that a ketogenic diet may be helpful for migraines. However, a ketogenic diet is not recommended for people with a neurogenic bowel because it can worsen constipation.
- **DIETARY TRIGGERS:** Common dietary triggers often listed for migraines include alcohol, caffeine\*, chocolate, aged cheeses, fermented foods, MSG, artificial sweeteners, nuts and nut butters, and cured meats. However, research has not been able to show a consistent link between these triggers and migraines. This means we cannot say for sure that these foods will cause migraines for everyone. Each person may have different triggers that are unique to them. This means that you should not cut out all of these foods. It may help to keep track of what (if any) foods or drinks make your symptoms worse/better, rather than follow a lot of generic restrictions for

*(Continued on page 7)*

a long time. This can lead to decreased diet variety and sometimes nutrient deficiencies.

*\*While caffeine may help headaches for some people, it can be a trigger for others, particularly in amounts that are different from what an individual normally consumes.*

- **SUPPLEMENTS:** Though evidence is not concrete, there is some evidence that the following supplements may help with migraines:

- **Riboflavin (vitamin B2): 400 mg daily**
- **Magnesium: 400-600 mg daily**  
*A common side effect of magnesium is a laxative effect (this means it makes you poop more often).*
- **Feverfew (dosage varies)**  
*Important! You should always ask your medical provider before starting a new supplement to make sure it is safe for you. Vitamins, minerals, and herbs can interact with medications that you take or may not be good to use because of other medical problems that you have.*

Please remember that if you have new headaches, you should contact your medical provider. This is especially important for people who have a shunt to manage hydrocephalus (pressure on the brain due to fluid build-up in the skull). There are other kinds of headaches, too, so getting a diagnosis from a medical provider is the first step in treating them.

Written by **Jacquelyn Klunk, MS, RDN, LDN**  
and **Cheyenne Hennen**

#### References:

Moskatel LS, Zhang N. Migraine and Diet: Updates in Understanding. *Curr Neurol Neurosci Rep.* 2022 Jun;22(6):327-334. doi: 10.1007/s11910-022-01195-6. Epub 2022 Apr 28. PMID: 35482279.

Gazerani P. Diet and migraine: what is proven? *Curr Opin Neurol.* 2023 Dec 1;36(6):615-621. doi: 10.1097/WCO.0000000000001204. Epub 2023 Sep 19. PMID: 37865855.

Schwedt, TJ and Garza I. Preventive treatment of episodic migraine in adults. In: *UpToDate*, Connor RF (Ed), Wolters Kluwer. (Accessed on April 8, 2025.)



## Upcoming SBAWP Events

**Sept 20, 2025**

**Noll-Spratt Golf Scramble**  
*Beaver Valley Golf Club*

**Nov 15, 2025**

**Girlfriends for Good Purse Bash**  
*Divine Parish – St. Ferdinand's Oldenski Hall in Cranberry Twp*

For more information regarding events and/or camps and retreats, please visit our website at <https://sbawp.org/events> or call 724-934-9600.



## 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.

#### Contact us

**UPMC Adult Spina Bifida Clinic**  
UPMC Mercy Pavilion  
1622 Locust Street, 4th Floor PM&R Clinic  
Pittsburgh, PA 15219  
Phone: 412-232-8902

Check out our other newsletters and clinic information at: [UPMC.com/SpinaBifida](https://UPMC.com/SpinaBifida)



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