

Healthy Holiday Shifts

The holiday season is full of celebrations and delicious food. While it's important to enjoy our favorite holiday foods in moderation, it can be easy to overdo it. Incorporate small shifts into your routine so that you can enjoy holiday foods while still keeping up with healthy habits.

Balance your plate!

Keep MyPlate portions in mind: $\frac{1}{4}$ plate starch (pick whole grains) + $\frac{1}{4}$ plate protein + $\frac{1}{2}$ plate fruits and non-starchy vegetables. Remember that corn and potatoes both belong to the starch part of your plate! Limit fried meats and remove the skin from turkey or chicken before eating to reduce added saturated fats. Use less gravy, butter, and creamy sauces.

Don't skip meals!

Skipping meals to "prepare" for the holiday can lead to overeating later. Eat a balanced breakfast and a lunch or midday snack before your main dinner meal.

(continued on next page)



Home is where the Heart is

Edith Sitwell, a British poet, once wrote, "Winter is the time for comfort, for good food and warmth, for the touch of a friendly hand and for a talk beside the fire: It is the time for home." Although many of us spend more time indoors in the Winter months, it does not mean that we have to be sedentary, bored, or socially isolated. Winter can be the time to set new physical activity and nutrition goals, rekindle friendships, and plan for the future. This newsletter is full of information that aims to help you make the most of the Winter season.

Sip smarter!

Emphasize calorie-free drinks such as water, unsweetened tea, sparkling waters/seltzers, or diet drinks. Dress up your water or sparkling water with a squeeze of lime/lemon juice or a splash of 100% fruit juice.



Enjoy desserts mindfully!

Have a dessert you enjoy but take a smaller portion. Be mindful to savor the flavors of the dish. Choose your favorite dessert you look forward to each year but skip out on other desserts that may be “just there” on the table and that you won’t miss.

Try cooking swaps!

Use herbs and spices to help reduce the salt content of dishes. For many baked goods, you can often reduce the amount of sugar in the recipe (start with decreasing the sugar by 1/3). Additions like vanilla extract and cinnamon can boost flavor without extra sugar. To reduce the fat content of cookies or cakes, you can replace ½ of the butter or oil in the recipe with the same amount of pureed fruit (unsweet applesauce, banana, or pumpkin).

Stay active!

Include some holiday traditions that keep you active, such as getting outside for some fresh air or playing active games with family and friends.

Written by Jacquelyn Klunk, MS, RDN, LDN

Article References:

1. https://www.diabeteseducator.org/docs/default-source/legacy-docs/_resources/pdf/general/ThanksgivingPlateResource.pdf
2. <https://www.usda.gov/media/blog/2013/12/20/myplate-holiday-10-tips-make-healthier-holiday-choices>
3. <https://www.heart.org/-/media/aha/h4gm/pdf-files/hheatingguidefinalnohobloglo.pdf?la=en&hash=8D07B2B796438093C7DC7DEF12DA978C8DFF5893>



Pegasus Dream Tour: a new Adaptive Sports Video Game

The Pegasus Dream Tour is a new video game that allows players to participate in adaptive sports, similar to the Paralympics, and connect with other players. You can create your own athlete and enter “Pegasus City,” an online virtual city where diversity and inclusion are important values, and where the individuality of each person is respected. This ultra-positive and energetic game allows players to equip themselves with prostheses and wheelchairs and train in a number of para-sports including basketball, bocce, track and field, and others. This game is available in the [Apple App Store](#) and [Google Play](#).



A Shoe that Fits

Having trouble finding shoes to fit over your braces? The Spina Bifida Association recently published this blog containing advice from people with spina bifida and their families. Check out the information specifically for adults at the bottom of the list.

Written by Brad Dicianno, MD

How do you manage Neurogenic Bowel Dysfunction?



Neurogenic bowel dysfunction can be a huge burden to people with spina bifida. Chronic constipation and fear of having an accident in public prevent many people from doing the things that they love. It is possible however that you can take control of your bowel and stop letting your bowel control your life!

While signs and symptoms of neurogenic bowel dysfunction can vary, the underlying cause is the same: damage to the nervous system's control of the bowel. This results in slow transit time which increases the risk of chronic constipation.

So how can you take control of your bowel?

First, you need to make sure you have the basics down:

- **Diet:** Generally, it is recommended that you get at least 20 grams of dietary fiber and 60 oz of water daily. Your medical team can help you find the best way to meet these goals.
- **Routine:** Attempt to have a bowel movement (BM) at a planned time daily. Take advantage of the gastro-colic reflex, which is a mass movement of the bowels that occurs after eating a meal. You should sit on the toilet about 20 minutes after the same meal every day.
- **Position:** The best way to position yourself to encourage a BM is to be flexed at the hips and knees. You can accomplish this by putting a stool or a stack of books under your feet while on the toilet.
- **Physical Activity:** If you are sedentary, odds are that your bowels will be too. Increasing physical activity can help improve bowel regularity.

I'm doing all that! What is next?

The above-mentioned basic strategies are essential. However, even if you are incorporating these into your daily routine, if you have neurogenic bowel dysfunction, you likely will need to add some additional interventions. Lucky for you, you have a team of people who are available to help you find a bowel routine that works. It will take patience though!

Keep a bowel diary:

We will want you to keep a bowel diary for at least 5 days, noting daily:

- The frequency or number of BMs per day
- The consistency of the BM using the Bristol Stool Chart
- The volume or size of the BM
- Time of day of the BM
- Whether or not you had an urge to go at time of the BM
- Whether or not you were able to make it to a bathroom to have the BM

The bowel diary will allow us to understand what you're currently doing so that we can make suggestions for improvement. We will need to communicate regularly to figure out a plan together. Expect to talk with someone from the Spina Bifida Clinic team at least once every 2 weeks while we work on fine-tuning your bowel routine. To reach us, call 412-232-8902 and ask for Darcie, or message us via the [MyUPMC app](#).

Written by Darcie Illg, PA-C

WHEELCHAIR WORKOUT



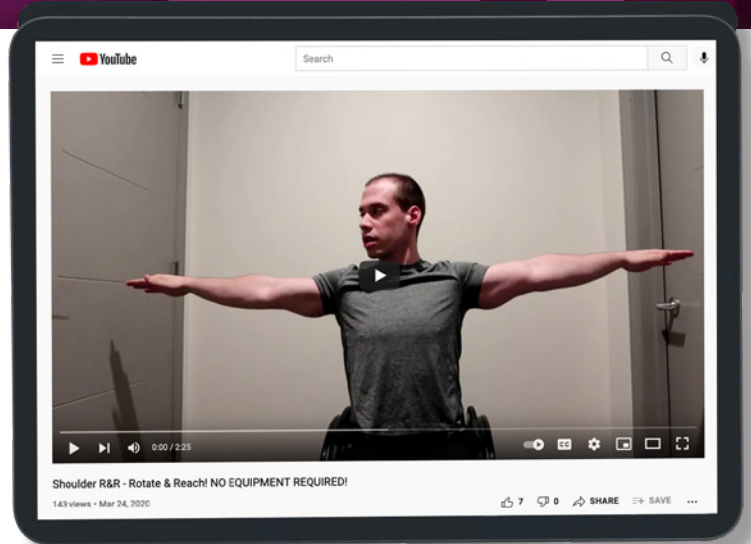
Reach and Rotate to Healthier Shoulders

No Equipment Needed!

As individuals with Spina Bifida, our lower body musculature is often weaker than that of our upper body due to the incomplete formation of the spinal cord and nerves associated with the lower body. This causes us to have to use our upper body, specifically our shoulders, as our means of mobility more often than our lower body. We therefore need to be aware of the stress we put on our shoulders.

This is not to say that we should not train or exercise our shoulders, but the exact opposite! We NEED to exercise our shoulders to preserve our strength and mobility. We have talked about shoulder **strength** in earlier newsletters which is a major aspect of shoulder health, however that is only half of the equation. The other half of the shoulder health equation is shoulder mobility. This has to do with not only the muscles of the shoulder, but the joint capsule of the shoulder as well. One of my favorite shoulder **mobility** movements is the Reach and Rotate.

The Reach and Rotate starts with your arms out to your sides lifted at shoulder level with the palms of your hands facing the sky. From here, all you have to do is keep your arm straight out to the side, elbow locked out, and try to touch your fingers to the nearest object around you while rotating each arm one at a time at the shoulder joint as you reach. During the rotation part of the movement, whichever side you are reaching toward, make sure you rotate that palm up and rotate the opposite palm down. You can think of it like you are trying to squeeze the water out of a sponge or a towel. As you do that, one of

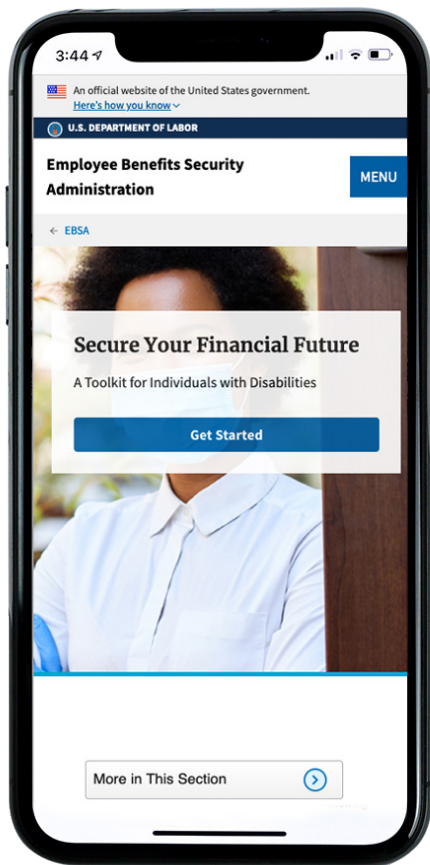


your palms naturally rotates up toward the sky, and the other naturally rotates down toward the ground. This movement is very similar, except you are rotating with your shoulder joints and not your wrists. Make sure to point your fingertips toward a wall or object next to you and pretend you are trying to touch it without bending your elbow.

Complete this movement for 2 sets of 20-30 reps at the beginning of your day or the beginning of your workout. Remember, rest is also very important for joint and muscle health so resting anywhere between 30 seconds to 1 minute will give your joints time to recover before your next set. Give this a try before your next workout or tomorrow morning and soon your shoulder mobility and strength will benefit greatly!

Click [here](#) for a video demonstration of this movement along with other upper and lower body movements to help you increase your mobility and strength lead the healthiest life possible.

Written by Dan McCoy, ACE-CPT



Securing Your Financial Future Tool Kit

The “Secure Your Financial Future” toolkit was specifically designed for individuals with disabilities and walks you through finding full-time or part-time employment to getting your finances ready for retirement. It was created by the U.S. Department of Labor and the Employment Benefits Security Administration. The toolkit was created because of the many changes individuals with disabilities have encountered throughout the pandemic.

The tool kit provides individuals with the most recent, relevant information from agencies such as the Social Security Administration, Consumer Financial Protection Bureau, and Internal Revenue Service, among others. The toolkit is filled with resources such as worksheets and “how to” guides. The toolkit breaks down and explains information and buzz words from other sources that can be overwhelming or difficult to read. It may help people secure and use their disability related benefits and find a job.

The Secure Your Financial Future toolkit can be located by visiting this website: <https://www.dol.gov/agencies/ebsa/secure-your-financial-future>

Written by **Libby Powers**

Good News! Medicaid Coverage of Ramps, Glides, and Lifts Expanded in PA

Just like the Spina Bifida Association advocates nationally for people born with Spina Bifida, there are groups in Pennsylvania who advocate on behalf of all people with disabilities within the state. Disability Rights Pennsylvania (DRP) is one such group. Not only do they go to the legislature to discuss how different laws being considered might affect the disability community, but they also have lawyers who file lawsuits for their clients. The settlement of one of these cases has recently been decided. It is very good news for those of us living with Spina Bifida.

A few years ago, DRP filed a class action suit on behalf of children with disabilities who need removable medical equipment. The case was settled in June 2021. “The settlement provides that Medical Assistance now covers wheelchair lifts, stair glides, ceiling lifts, metal accessibility ramps, and other items that are used by a beneficiary with a mobility impairment to enter and exit the home or to support activities of daily living and are removable or reusable without damage to the item” (Disability Rights PA). Although the original lawsuit included only children with disabilities, the settlement includes both children and adults. The settlement applies to removable medical equipment requested from April 1, 2020, forward. If you were denied coverage for an item, it is recommended that you reapply for that item. At the time this article was written, specific details on how to apply, determination criteria, and other specifics were still being worked out by the Department of Human Services (DHS). If you require assistance or further information about the settlement, please Contact Disability Rights PA via email equipment@disabilityrightspa.org or call 800-692-7443, Option 6.

As a side note, Pennsylvania is the first state to have Medicaid pay for this type of removable equipment. DRP was the first to successfully advocate through litigation, and other states are expected to follow suit. It is a wonderful thing when advocacy works.

Written by **Monica Albert Still, RN, BSN**
Monica is a member of the Board of Directors of Disability Rights PA.

A Sweet Holiday

Monk fruit is a fruit that was discovered by monks over 1,000 years ago. Today, it is used as a zero-calorie sweetener that is employed as a sugar substitute for your everyday uses such as in coffee, smoothies, and baked goods. For most natural sugars, the sweetness comes from glucose that contains calories which turns into carbohydrates for your body's fuel. Unfortunately, most of us are consuming too many calories and an amount of carbohydrates that is too high for our bodies to burn off. This is why sugar substitutes are so popular. The great thing about monk fruit is that its sweetness comes from antioxidants called mogrosides instead of glucose. This makes monk fruit a no-calorie and zero-carbohydrate sweetener. As the holidays approach, we often eat large amounts of sweets and high carbohydrate



“What good is the warmth of summer, without the cold of winter to give it sweetness.”

John Steinbeck

side dishes. Monk fruit sweetener is so easy to use, its substitution has a 1:1 ratio, and it tastes exactly like regular sugar. This is why it's a great alternative for your favorite holiday recipes without altering your dishes flavor, and your guests will never know!

Here is one of my favorite “chocolate” recipes. Its gluten free, sugar free, and uses carob powder which also makes it caffeine free!!

Written by Sara Izzo

Gluten- Free “Chocolate” Zucchini Bread

Makes 12 slices | 10 minute prep time; 45-55 baking time

- 1 cup Gluten- Free baking flour
 - $\frac{3}{4}$ cup Monk Fruit Sweetener
 - $\frac{1}{3}$ cup carob powder
 - 1 tsp. baking soda
 - $\frac{1}{4}$ sea salt
 - 2 cups grated zucchini
 - 2 large eggs
 - $\frac{1}{3}$ cup vegetable oil (*I prefer sunflower oil*)
 - 1 Tbsp. carob chips (*optional*)
- Toothpick for testing



Preheat oven 350°F.

Grease or butter a loaf pan (may use a 9x9 brownie pan). In a bowl, whisk together GF flour, monk fruit sweetener, carob powder, baking soda, and sea salt. Add grated zucchini, eggs, and oil, and mix with a spoon (no need for a hand mixer). Let batter rest for 2 min (Do not skip this step). Stir batter one more time, making sure no flour is left unmixed. Pour into desired pan and sprinkle any leftover grated zucchini and optional carob chips. Bake on middle rack for 40 minutes. Check for doneness with a toothpick; if batter is still seen, bake for an additional 5 minutes until the toothpick is clean. Cool on a wire rack for 15-20 minutes. Slice and Enjoy!!

Written by Sara Izzo

If You Need a Disability Related Accommodation, Let UPMC Help You (LUHU)

Accommodations are available free of charge for patients and visitors (support persons) with a disability. UPMC is committed to giving the best care possible to those who have a disability, making sure that all patients, support persons, and guests have equal access to health care.

Types of Accommodations Available

- Accessible exam/treatment/inpatient rooms
- Assistance with self-care tasks like eating, bathing, and toileting
- Help with patient transfer
- Accessible parking and bathrooms
- Accessible medical equipment
- Communication and storyboards
- Help with navigation
- Signature guides
- Tactile interpreters for individuals who are deaf and/or blind
- iPad® with communication apps
- American Sign Language interpreters

To take part in the LUHU program, contact the **Disabilities Resource Center** at 412-605-1483 or LUHU@upmc.edu. For more information, visit www.UPMC.com/LUHU

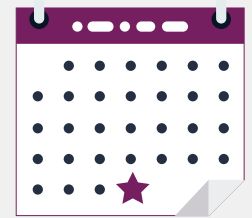


COVID-19 and Spina Bifida

Many people contact us with questions about COVID-19 and vaccination and how they relate to Spina Bifida. A good source of information is located on the SBA website: [here](#) and [here](#).

Upcoming Events at SBAWP

Some of the upcoming events for adults at the Spina Bifida Association of Western PA (SBAWP) include:



Camps & Retreats:

December 3-5 Youth and Teen Retreat
December 10-12 Adult Retreat

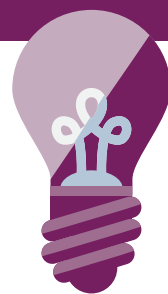
For more information regarding events and/or camps and retreats, please visit our website at <https://sbawp.org/events> or call 724-934-9600.

Access Kaleidoscope (SBAWP's newsletter) [here](#).



Help to Pay your Electric Bill

Having trouble paying your electric bill? Grants, payment plans, emergency rental and utility assistance programs are available. Check out the resources at this [website](#) to see if you may qualify for these programs.



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

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