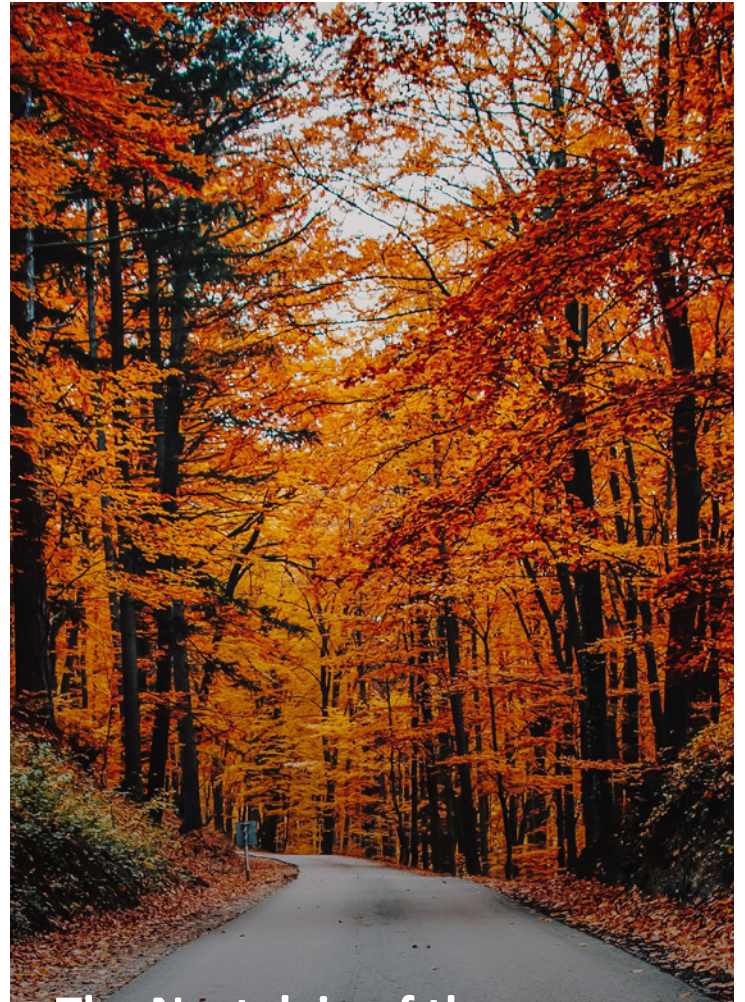


## New App Available to Help with Self-Care

The Interactive Mobile Health and Rehabilitation System (iMHere) is a new app developed by our team to help you with your daily needs.

The app allows you to set reminders to take medications and do your bowel and bladder routines, record mood symptoms, and track nutritional intake and physical activity. It also has educational materials about spina bifida and a personal health record to help you keep track of your medical problems and health care providers. The app also connects to the electronic medical record so that at your visit your health care providers can view information about your self-care routines. If you would like to use the app, contact Dr. Dicianno. It needs to be registered with our clinic in order to have full functionality. You can read more about the app [here](#).

*Written by Brad Dicianno, MD*



## The Nostalgia of the Fall Season

The word “nostalgia” was created in the 17th century by a medical student when describing soldiers’ memories of home. There’s no doubt that Autumn brings back memories, from the smell of fallen leaves to the first sip of a pumpkin spice latte. However, remembering the past can be easier than remembering to do the things we need to do every day to keep ourselves healthy. This edition of the newsletter provides many tools and suggestions for good health, even when our memories aren’t as crisp as the fall breeze.

*Written by Brad Dicianno, MD*



## Staying Warm this Fall and Winter

Two programs are available to help some individuals with problems with furnaces or with paying heating bills.

- **Heat the Burgh** is for those with low income who cannot afford a new furnace. This charitable group made up of local Carrier factory authorized dealers will provide a limited number of furnaces including the installation for eligible individuals who have been selected. After the applications have been received, the board will look over the applicants and decide who the recipients are and where the furnaces will be installed. Selection of recipients and installations will take place in November. Anyone can apply or nominate someone in need to receive a new furnace.
- **Low Income Home Energy Assistance Program (LIHEAP)** helps families living on low incomes pay their heating bills 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. This is a grant and does not have to be repaid.

*Written by Brad Dicianno, MD*



## Do You Need Incontinence Supplies?

We've received generous donations of incontinence supplies. We have a variety of products of different sizes for both men and women. If you are in need of these supplies, please contact me.

*Written by Monica Albert Still, RN, BSN*

## Have You Ever Wanted to Teach Medical Students?

Standardized patients are individuals from the community, hired and trained to portray a real patient, client, health professional, family member, or other individual for the purpose of in role play type formats. With proper training they can add objectivity, believability, and diversity to the learning of medical students and other trainees. Standardized patients are educators rather than actors. The University of Pittsburgh is always looking to hire standardized patients from a variety of diverse backgrounds. You read more about the position and how to apply [here](#).

*Written by Brad Dicianno, MD*



## I Can't Remember What I Forgot to Do Today

We all have some difficulty remembering things, and this is an unavoidable issue as we age. However, there are many components to remembering something: paying attention, rehearsal, storage, and retrieval, to name a few.

Adults with Spina Bifida are at increased risk for and often have difficulty with retrieving things they have learned in addition to organizing, planning, maintaining attention, and keeping up with materials or appointments. These processes are called **executive function**, and when we have difficulty consistently doing these things, it is called **executive dysfunction**. Executive functioning refers to cognitive abilities that allow a person to successfully plan, organize, carry out tasks, and reach a goal. Other abilities that are executive functions include emotional and behavioral regulation, thinking before you act or impulse control, monitoring one's own performance and how well you are doing at a task, and working memory or holding something in your mind long enough to do something with that information.

But as I said, we all forget things and for very different reasons. Many adults with Spina Bifida have executive dysfunction that interferes with remembering something. Executive dysfunction's role in memory is primarily

related to holding something in your mind long enough to rehearse it and then store it for later use. If you aren't paying attention or don't rehearse something you want to know, then you often "forget it" because it never got stored in your brain. That is not memory loss but a working memory issue. Because you didn't rehearse and store the information, it is not there when you go to pull it out of (retrieve it from) your brain. That is considered executive dysfunction. That information is not there in your brain when you go to find it because you either didn't rehearse and store it - OR - you didn't store it effectively and you can't find where you stored it in your brain. So, you think you have forgotten it.

Here are some strategies for managing executive dysfunction:

- **Posting reminders in a prominent location.** Which items or tasks do you forget most often? A written note can help. For example, someone who frequently forgets their keys may post a reminder to remember the keys, as well as designate the same place each day to hang your keys in sight, by the door when you first get home.
- **Finding ways to organize your time and your thoughts.** When your brain "loses" information, putting this information somewhere else can help compensate for the challenges of executive dysfunction. Paper and digital planners, detailed checklists, and digital apps can help.
- **Breaking tasks into smaller component parts.** People with executive dysfunction often struggle with large, complex tasks, but smaller 5–10-minute tasks can feel more manageable.
- **Taking frequent breaks from challenging or frustrating tasks.** Try setting a timer for 10 or 20 minutes. You may find your brain can work better after it has had a rest.
- **Developing a routine.** Executive dysfunction often gets worse when a person's schedule is unpredictable, or their routine is chaotic. Create a ritual surrounding the most important tasks of the day and stick with it.
- **Discuss strategies with your peer navigation team or in a support group.** Sometimes other people have a good idea of strategies that have worked for them and can share those with you. Having a support system, like your friends and family, can help hold you accountable for following new strategies to improve executive functioning.

*Written by Lisa D Stanford, PhD, ABPP*



## Growing Pains and Medical Trauma

As an adult with Spina Bifida, approaching the age of 40 has been an *interesting* journey. Adults with Spina Bifida are trying to understand pains related to aging, pains related to spina bifida pains, and possible new health issues.

Even as a person who has worked in the medical profession for 17 years, I still avoid practicing what I preach. I did not seek care as an adult until I began showing signs of a symptomatic tethered cord. I repeated this behavior in my mid 30's by going to the doctor but then not following up on their suggestions. It wasn't until I began searching for a therapist to deal with my pain when I heard the terms "medical trauma" and "medical anxiety."

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*"Control leads to compliance;  
autonomy leads to engagement."*

**Daniel H. Pink**

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According to Gary Walz and Jeanne Bleuer (2013), authors of *When Treatment Becomes Trauma* published by the *American Counseling Association*, medical trauma is a "set of psychological responses of patients and their

families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences." While not an official diagnosis, medical trauma can lead to conditions like PTSD, anxiety, depression, or chronic pain. They go on to mention qualities and situations that may cause re-traumatization as adult, which can include:

- A medical professional ignoring your symptoms
- Receiving a lower standard of care due to your disability, race, ethnicity, identification, or appearance
- No one informing you of what to expect before a procedure
- Your wishes not being respected during an operation or procedure
- Being separated from your primary support person during a procedure

Chances are you or a family member has experienced or witnessed medical procedures and invasive treatments including surgeries and bowel or bladder treatments. As we get older and face new situations, sometimes alone or with less support than we are accustomed to, we can feel less prepared to handle new experiences as adults. I personally have felt this way this past year and found some helpful tips that might benefit you as well.

*(Continued on page 5)*



## Adult SB Peer Navigation Program

Virtual Group Meetings Every Month  
2nd and 4th Thursday at 7 pm

<https://pitt.zoom.us/j/93733996022>

Meeting ID: 937 3399 6022

### Ways to deal with medical anxiety:

#### Prepare Before Your Medical Visits

- Before going to your appointment, take a moment and think about all the issues you have been dealing with and make a list so you can address all of your concerns. Be as specific as possible. For example: if you are dealing with pain, describe your pain in detail utilizing a 7-day diary, listing info such as:
  - *the feeling of your pain (aching, tingling, throbbing)*
  - *the direction it travels*
  - *the time it takes to go away and what helps*
  - *the activity you were doing when you experienced your pain*
  - *the time of day you experience it the most*

#### Get Clarity on your Concerns

- Utilize the notes you made while you are in the exam room and ask your doctor if they can include notes in your after-visit summary. This will make you feel reassured that your concerns were taken seriously and with clarity and provide you with documentation you can take home.
- Don't leave the doctor's office without a genuine understanding of their directions. Have a support person present who can receive your information on your behalf if it helps you. Review your after-visit summary before you leave, or follow-up with a telemedicine visit in case you aren't sure.

#### Communicate Effectively

- Try your best to follow your doctor's past suggestions and be honest with them about what worked and what didn't work. Talk openly about whether your lifestyle could be contributing to your health issues. Make goals and follow through with them, so you aren't missing opportunities for effective treatments.

#### Talk To a Professional

- Ask your Spina Bifida care team or your primary care physician for information about counselors in your healthcare network.

People with Spina Bifida are born with bodies they never had full control over. We've had strangers poking and prodding our whole lives -- all while our bodies refuse to do what our brains tell them to. Feeling in control is a feeling everyone desires, and we have been fighting for this our whole lives. Having someone to talk to who can validate your feelings and frustrations can give you a sense autonomy over your care, while you continue to fight for control over your body.

*Written by Sara Izzo, Coordinator and Mentor for the Adult Spina Bifida Peer Navigation Program*

Walz, G. R., & Bleuer, J. C. (2013, March 24). When treatment becomes trauma: Defining, preventing, and transforming medical trauma. American Counseling Association. 73. [https://www.counseling.org/docs/default-source/vistas/when-treatment-becomes-trauma-defining-preventing-.pdf?sfvrsn=4735f21\\_13](https://www.counseling.org/docs/default-source/vistas/when-treatment-becomes-trauma-defining-preventing-.pdf?sfvrsn=4735f21_13)



## Milk Mystery



With so many types of “milks” on the market, it’s hard to make a decision in the grocery store. This article will help you break down the mystery so that you can choose what works best for your health, budget, and taste preferences.

### Cow’s Milk

Cow’s milk comes in whole, 2%, 1%, and skim versions. The only difference between these is the fat content: whole milk contains all the fat naturally found in milk (3.25% milkfat), while 2% or 1% milk contains only 2% milkfat or 1% milkfat respectively, and skim milk has no fat. This is a reduction in mostly saturated fat, which is the type of fat that is associated with higher cholesterol levels. Less fat also means there are fewer calories in the milk. Choosing a lower fat milk can be helpful if you are watching your diet for heart health or trying to reduce your calorie intake for weight loss. Whether you are buying whole, 2%, 1%, or skim milk, the protein content remains the same. Vitamin and mineral content also remain the same – though some fat-soluble vitamins such as vitamin D are removed when the fat-content is reduced, these vitamins are added back

into the milk later. Cow’s milk is generally less expensive than plant-based “milk” alternatives.

### Plant-Based “Milks”

Plant-based “milks” are typically made from nuts, seeds, or grains. Beverages made with nuts or seeds are usually made by soaking the nuts in water, grinding them down finely, and then straining out the remaining nut pieces. Oat milk is made by mixing oats with water, grinding them down finely, adding enzymes to break down the starch so that the oats do not gel (think about how oatmeal gels – you would not want your oat milk to do that!), and then straining out the solid pieces. Rice milks are usually made from finely milled rice that is blended in water and filtered. Once the base liquid of a plant-based “milk” is created, manufacturers might then add oils, sweeteners, flavorings, or stabilizers. Lastly, the product may be homogenized (making it so that the fat particles don’t separate out from the liquid – cow’s milk is homogenized too!) and heat treated to give the product a longer shelf life. Storebought plant “milks” usually last about 7-10 days after opening, but homemade versions usually last no longer than 5 days.

*(Continued on page 7)*

## So, What is the Best Choice?

There is no simple answer to this question. It depends on what you need! Here are a few things to know:

- Cow's milk, soy milk, and pea milk contain protein. Other plant-based milks are low in protein.
- Grain-based milks such as oat or rice milk are highest in carbohydrates. Cow's milk contains some carbs. Nut/seed milks tend to be lowest in carbs.
- Some plant-based milks are fortified to meet (or even exceed) the amount of calcium and vitamin D in milk, but others are not. You need to read the label and verify!
- For both cow's milk and plant-based milks, it is best to look for options that are unsweetened. Flavored milk contains a lot of added sugar. It is also good to look for simple ingredient lists without a lot of additives (vitamins and minerals are okay in the ingredient list though!).
- Plant-based milks are an option for people with health conditions that require them to eat less potassium and/or phosphorus. While cow's milk is high in potassium and phosphorus, many rice and almond milks are lower in both nutrients.
- Lactose-free milk is an option for people with lactose intolerance, which is caused by the body

being less able to digest lactose (the carbohydrate in milk). Lactose intolerance is harmless but can cause uncomfortable symptoms such as gas, stomach upset, and diarrhea. Lactose-free milk has lactose filtered out or pre-digested (depending on the brand), which allows people with lactose-intolerance to tolerate it. However, a person with a dairy allergy cannot consume lactose-free milk. This is because they are allergic to the protein in milk, not the carbohydrate (lactose). While an intolerance is harmless, an allergic reaction can be life threatening depending on the severity of the allergy. A person with a dairy-allergy will need to use a non-dairy milk alternative.

- You can substitute plant-milks for cow's milk in a 1:1 ratio when cooking or baking. You will need to consider the flavors of what you're making. A sweetened nut milk may taste much better when baking a dessert while unflavored nut milk may go better in a savory dish. If you are swapping a plant-based milk for whole milk, you may need to add additional fat into the recipe.

**TIP:** If a cooking recipe calls for coconut milk, they are often referring to canned coconut milk. Refrigerated coconut milk is used for drinking rather than in cooking; it is made with more water and has a weaker coconut flavor.

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

Milk and Plant "Milk" Nutrient Comparison (per 1 cup)

	CALORIES	CARBOHYDRATES	PROTEIN	TOTAL FAT	SATURATED FAT	CALCIUM
<b>WHOLE COW'S</b>	150	12 grams	8 grams	7.8 grams	4.5 grams	300 mg
<b>1% COW'S</b>	100	12 grams	8 grams	2.4 grams	1.5 grams	300 mg
<b>SOY MILK</b>	80- 110	7-9 grams	7-8 grams	2.5-4.5 gm	0 grams	300-450 mg
<b>PEA MILK</b>	70	Less than 1 gram	8 grams	4.5 grams	0 grams	465 mg
<b>RICE MILK</b>	120	23 grams	1 gram	2.5 grams	0 grams	20 mg
<b>OAT MILK</b>	120	16 grams	3 grams	5 grams	0.5 grams	250 mg
<b>ALMOND MILK</b>	60	8 grams	1 gram	2.5 grams	0 grams	450 mg
<b>COCONUT MILK</b>	60	5 grams	1 gram	4.5 grams	4 grams	62 mg
<b>HEMP MILK</b>	80	1 gram	2 grams	6- 8 gm	0.5-1 grams	300 mg

Nutrient Data from: FoodData Central ([usda.gov](https://www.usda.gov))

## Did You Remember to take your Meds?

Forgetting to take your medication can cause serious problems such as breakthrough symptoms or negative health outcomes. However, most people often miss doses of their medications regularly. Studies have demonstrated that about 50% of people who are prescribed medication do not take their medicine as they should. Whether missing a dose or doubling a dose, medication misuse can be hazardous to health. There are many tools for helping to improve medication compliance including simple pill boxes, setting reminders on your phone, our iMHere app mentioned in this newsletter, and individually packaged daily medication packets straight from the pharmacy.

Smart medication container lids (smart caps) can be another helpful tool. They can do things such as alert you that it is time to take your medication, remind you that you already had your dose, and even contact your pharmacy when you are due for a refill. Below are two examples of smart medication container lids.

**PillsyCap** is priced at about \$40 for each cap (which will add up quickly for those who take multiple medications). The Pillsy smart cap can be placed on any pill bottle from the pharmacy. It automatically tracks when the bottle is opened and will mark the dose as “taken” if you have a scheduled dose. You can also set up the device for “as needed” medications. It links to an app that can allow an individual to track their own medication compliance as well as permit caregivers and or family members to monitor timing of medication administration when appropriate. It can help prevent accidental repeat dosing by informing you that a dose has already been given.

**TimerCap** is a bit simpler in design and therefore has a less expensive price tag. It can be found at pharmacies or on Amazon for less than \$16. TimerCap’s intuitive design simply shows the time the pill bottle was last opened, displaying the time directly on the cap.

Medications work best when they are taken as directed, but there are many reasons why we do not always do what we are told. Smart caps are another tool out there that can give you a bit more control over your health.

*Written by Darcie Petrillo, PA-C*



**GET STRONGER  
ONE ARM AT A  
TIME!**

The most popular way to lift weights is to use both arms (or legs) at the same time and move them in conjunction with each other in order to produce the most force possible. An example is the bench press. This is a great strategy for building total body strength. However, many people have muscle imbalances from birth, due to wheelchair use, or for other reasons. When we train with dumbbells, resistance bands, or machines, we can use a technique called **unilateral training** to even out these imbalances over time. Unilateral means “one side,” and this technique involves working the muscles of one side of the body at a time. See below for an example of a workout and give it a try in your next workout!

### **EXAMPLE UNILATERAL WORKOUT:**

*Do 3-4 sets with each arm, 8-12 reps in each set, with 1-minute rest*

**Single Arm Seated Machine Chest Press**

**Single Arm Dumbbell Bench Press**

**Single Arm Dumbbell Shoulder Press**

**Single Arm Dumbbell Side (Lateral) Raise**

**Single Arm Overhead Triceps Extension**

*Written by Dan McCoy, CPT, PLY*



## Finding a Career

[Career One Stop](#) is a great website for helping you explore career options. Figuring out which career will fit you best may be intimidating. But this site has many resources that can help.

### How can you get there?

- An [Interest Assessment](#) will help you identify careers that meet your interests.
- Use the [Skills Matcher](#) to create a list of your skills and match them to careers that use those skills.
- Identify your own work values with the [Work Values Matcher](#).

### Find the education and training resources you need.

- Through education and training options, learn about GED's, Adult Basic Education, Certificate programs, low-cost/free training options, Licenses, Schools, Financial Aid, and scholarships.

### Search for thousands of job listings in your area or across the country.

- Review digital job search tools.
- Identify local employers.
- Attend job fairs.
- Browse online job banks and newspaper job ads.

### Find workforce services in your neighborhood or across the country.

- Resources in your neighborhood, [Find American Job Centers](#), Employment and [Training](#), [Unemployment Benefits Finder](#), & state services ([vocational rehabilitation office](#)).
- [Networking](#), [Resumes](#), and Interviews & more.

### What disability employment programs are available?

- The [Ticket to Work Program](#) helps people who receive Social Security due to a disability find work and keep their health coverage.
- Centers for Independent Living (CILs) provide job coaching, training, and information on disability in the workplace to help people with disabilities maintain their independence. [Find your nearest CIL](#).

### Find the tools you need to research career information, training, or jobs.

- Also providing targeted resources such as [mySkills myFuture](#), [ReEntry Program Finder](#), [Older Worker Program Finder](#), [Worker with Disabilities](#), [State Resource Finder](#), [Career Advisors](#), and [Job accommodations](#).

Written by **Amy Kiska, BSW**

## SBA “Join the Conversation” Zoom Calls for adults with Spina Bifida

<https://fb.me/e/2gWe3dbFU>

<https://bit.ly/2SpBEom>

First and third Thursday of every month at 7pm ET

## Upcoming SBAWP Events

### [Soup and Salad Fundraiser](#)

October 22: 11:00 am - 2:00 pm

Cranberry Community UP Church

### [10th Annual Girlfriends for Good Purse Bash](#)

November 11 - April 2: 12:00 pm - 3:00 pm

St. Ferdinand's Oldenski Hall

### [Giving Tuesday](#)

November 28 - April 2: All Day Virtual Event

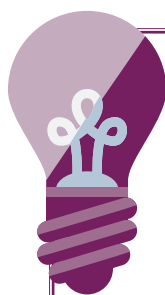
### [Adult Retreat](#)

December 1-3: All Day Camp Guyasuta

This form **MUST** be completed, downloaded to your computer, and emailed to Sue Garver at

[sgarver@sbawp.org](mailto:sgarver@sbawp.org).

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

1400 Locust St.

Building D, Suite G-103

Pittsburgh, PA 15219

Phone: 412-232-8901

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