THE EMPOWERMENT ZONE

A publication of the

SPINA BIFIDA RESOURCE NETWORK

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In This Issue . . .

- *From the Desk of Roberta Kestenbaum*
- *When is Telehealth Appropriate?*
- *Connect with Others through SBRN Virtual Events*
- *Are You in Need of Masks?*
- *How Can we Adapt Holiday Celebrations to Fit the Times*
- *SBRN's DERA Fund Helps People with Emergent Needs*

84 Park Avenue, Suite G-106
Flemington, NJ 08822

908-782-7475
info@thesbrn.org
www.theSBRN.org

From The Desk Of *Roberta Kestenbaum*

As we wind down an unforgettable 2020, we feel very grateful to have such a wonderful community of supporters, volunteers and participants.

With generous support from some wonderful volunteers, SBRN has held numerous virtual events. We are so appreciative of Millie Gonzalez, our Board Chair, who has established and coordinated our fabulous weekly *Virtual Empowerment Series* and our *Afternoon Chats*. We give sincere thanks to Millie and all of the presenters who have graciously offered their time and expertise. We also thank Millie and Colleen Roche for coordinating and leading this year's virtual *Empowerment Retreat* for adults with disabilities.

We also held three fun fundraisers in October. Five comedians (Steve Way, Mike Cotayo, Tina Friml, Tim Grill & Mike Favor) performed at our very funny *Hilarious Healthcare Hacks Comedy Show*. Four disabled female small business owners (Michelle Filippa-Robb, Beth Kasper, Natalie Anderson & Katie Horsham) donated parts of their commission from sales of their products. And dozens of supporters participated in our *Express Feedback for Good* campaign. Through these events, we raised over $2,000 and we are so appreciative to those who gave their time, talent and support.

As we move into 2021, we hope for better, safer, healthier days ahead. Here at SBRN, we plan to continue our supportive and creative virtual events and services as well as our financial assistance programs to help those in need.

This year the holidays will be different due to COVID but we hope that we can all find some cheer and camaraderie even if we have to do it virtually!

Happy New Year!

Giving is a Simple Act that Changes Lives

We know that 2020 has been hard on all of us, but if you are able to, please consider giving to SBRN this holiday season. Your contribution will strengthen our creative and supportive virtual events and services, as well as our financial assistance programs. *Together we can make a difference!*

Go to www.thesbrn.org to learn more and to donate.

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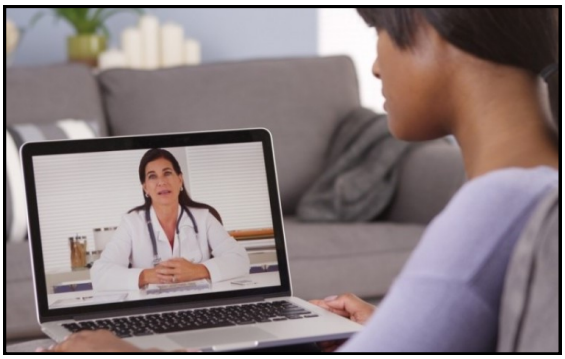
When is Telehealth Appropriate?



One of the many changes that we have taken on during the current pandemic is switching from in-person doctors' appointments to telehealth, either through phone or video. Some are delighted with this option (you don't have to travel!) while for others, it's more of a struggle (the doctor can't see what's really going on!)

Moving forward, even beyond the pandemic, telehealth will likely continue as an accepted practice, at least for some types of visits. It's important to know when it can be helpful and how to best prepare for these appointments.

What Are the Benefits of Telehealth?

The most obvious benefit of seeing your doctor through video is that you don't have to leave home – no worries about transportation and parking. This can save time, energy and money. Access is also easier since there are no concerns about accessibility in the office.

Another advantage that people have noted is that video appointments offer face-to-face interaction at eye level, which may give a greater feeling of equality and the provider may be more attentive. It may also be easier to see a specialist more quickly, at least for an initial visit.

People with disabilities have also noted that it is easier to have family members and caretakers available during discussions of follow-up procedures as well as during demonstrations of self-care and other techniques.

What Is Not So Good about Telehealth?

Some things may just be more difficult to accomplish at home. For example, movements and positioning that a provider may need for a physical exam may be difficult to do at home. Providers may also miss seeing things that they might have noticed in the office, for example, an unusual gait or movement that would not be seen if you are sitting and not mobile. It may also be difficult for them to get a good view of sensitive body parts or small anomalies.

Technology can also be a problem. Not everyone has access to the equipment needed for a video conference or has the know-how to use the equipment effectively. And then of course, there can be technical glitches even when everything is in place.

When is Telehealth Appropriate? *(continued)*

When Is Telehealth a Good Option?

Some visits lend themselves to telehealth fairly easily:

- In general, appointments that mostly involve conversation, such as medical histories, some follow-up meetings, and mental health visits
- Chronic disease management that is fairly stable such as diabetes or migraines
- Renewing prescriptions
- Situations that primarily involve describing symptoms such as earaches, nausea, vomiting or diarrhea, or straightforward urinary tract infections
- Discussions regarding diets and exercise
- Symptoms that can easily be seen such as conjunctivitis (pink eye) or some skin conditions that are readily visible and accessible

What Should Be Done in Person?

Clearly, some conditions and situations require in person and hands on assessment and treatment:

- Surgery (obviously!) although instructions for preparing for surgery could be done through a telehealth visit
- Procedures that require touch such as gynecologic or urologic exams, thorough physical exams, checking the abdomen or breast exams
- Lab tests, radiology and other imaging
- Physical and occupational therapy that require hands on assistance (other types may be done through video)
- Some allergic reactions and breathing problems
- Head injuries or other traumatic injuries from falling or other accidents
- Listening to the heart or lungs
- Skin conditions where video or photos are not good enough; excising skin lesions; biopsies

Your healthcare provider will make the determination whether telehealth is warranted or whether they want to see you in the office. It may be that you begin with a telehealth appointment and then make an office appointment if necessary.

Getting Ready for a Telehealth Appointment

Now that you and your provider have determined that a telehealth appointment is appropriate, you will need to prepare yourself and your location to make the most of your time.

- Find out from the provider how they will provide the information for you to connect. Will they phone, text, email? You will also need to know whether the appointment itself will be by phone or video, and if there are any apps that you will need to download. Be sure to ask for them to provide clear instructions.
- Determine where in your home or setting you will do the appointment. Consider comfort, privacy and visibility. Choose a place with enough light so that the provider can see you and anything that you need to show them.
- On the day of the appointment, make sure that is generally quiet for the appointment. Turn down music and TV and ask others to keep the noise down. You may prefer to use headphones or earbuds.
- Test out your equipment. Check out your video view. Unless the provider specifies otherwise, you will likely want to be at eye level with head and shoulders in view. You may also need to show other parts of your body, so make sure that you can move around.

When is Telehealth Appropriate? *(continued)*

- Consider who else needs to be present or available for the appointment, such as family members or caregivers, and make sure that they are available. In terms of privacy, consider how much you want the others to hear or participate and be sure to let them know beforehand.

What to Have Available for the Appointment

- Have your medical information available, including your medical history, a list of medications and any other information that the provider has asked for.
- Prepare lists of your symptoms and your questions. It's best to have them written down or recorded.
- If you have a rash or wound, find out from your provider whether they would like a photograph of it.
- Also ask your provider what medical devices you should have available and what readings you should do beforehand, such as temperature, blood pressure or glucose.
- Have a notepad and pen with you to write down instructions or guidance. You can also ask the provider to send you written follow-up instructions.

Some Helpful Tips for Your Telehealth Appointment

- Read the instructions sent by the provider well in advance of the appointment so that you have time to prepare.
- Check with your insurance company to make sure they cover telehealth appointments.
- Connect about 15 minutes early so that you can fix any problems and set up your view.
- Dress as you would for an in-person appointment. Wear loose clothing if you will need to show different body parts.
- When the time comes, focus on the appointment and don't try to multitask.

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This information is presented for the purpose of education and is not meant as a substitute for medical advice or care from a physician or other healthcare providers. Contact your healthcare provider with questions about care.

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Connect with Others through SBRN Virtual Events

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VIRTUAL EMPOWERMENT SERIES

Adults with disabilities looking to meet up with others, learn new skills, become empowered and make new friends - Join us for our virtual events and conversations:

* Our weekly ***Virtual Empowerment Series*** features interactive workshops with adults with disabilities as speakers, experts and discussion leaders. Sessions are held Wednesdays starting at 7:00 pm ET.

* Our ***Afternoon Conversations*** are virtual chats where adults with disabilities share stories, resources and laughter. Sessions are held on Mondays at 3:00 pm ET.

Sessions are free. Join by computer, tablet or phone. Go to https://www.thesbrn.org/news-and-events/teleconferences/ to learn more or visit our Facebook page at https://www.facebook.com/TheSBRN/.

ARE YOU IN NEED OF MASKS?

SBRN has acquired packages of 5 white cloth masks from the U.S. Department of Health & Human Services which we can mail to households. The masks are FREE.

If you are a person with spina bifida or other disability or live in a household with a person with spina bifida or other disability and you are in need of masks, please fill out the information on our website and we will send you a package. Limit one per household. Click Here To Learn More

Please note that we can only deliver within the U.S.

Help stop the spread of COVID-19! Protect yourself and others!

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How Can We Adapt Holiday Celebrations to Fit the Times?

This holiday season, travel is probably not happening, so no worries about how to transport that wheelchair. But with less traveling and getting together in person, how do we stay in touch and feel connected to our loved ones?

This year is certainly different and we may need to throw out expectations that our celebrations will be the same as always. The trimming of the tree, the lighting of the candles and the celebratory meals may still happen but on smaller scales and with less people. Although this may seem disappointing, instead of bemoaning what is different or missing, we can try to embrace new customs and activities while staying safe, joining in with our friends and family and making sure everyone is included.

What Can We Do?

Get Creative with Technology! By now many of us are used to connecting through video platforms like Zoom and Google Meet. These are excellent ways to host "parties" with family and friends. It doesn't have to be just talking - you can up the fun factor in many ways:

* **Meals** – You can simply eat together virtually or you could share recipes and have everyone cook the same meal. You could even cook together over video.
* **Crafts** – Pick a craft, send everyone the materials list and then get together online to create new masterpieces. Both kids and adults can have fun with this.
* **Music** – Gather a group and listen to Christmas carols, other holiday music or any music you choose. You can sing and dance along or just use it as a time to relax.
* **Games** – Pick a fun online game that your friends and family can do together.
* **Gifts** – Share the joy of giving by opening gifts virtually. Ship the presents, join in online, give everyone a turn and be sure to thank the givers.

Comfy or Dressy? For some, it may feel good to dress as you would if you were all together – maybe that's putting on dressy clothes or wearing festive or silly sweaters. Others may welcome the opportunity to wear comfy sweats or pj's for the festivities!

How Can We Adapt Holiday Celebrations to Fit the Times? *(continued)*

Bond One-on-One. Group chats can be festive and merry, but sometimes it's nice to just relate to one person. Speaking one on one by phone or video may allow you to dig deeper into how you are feeling and to share your joys and misgivings this holiday season. We know it's not the same as seeing someone in person, but we can strive to feel grateful for what we do have, and do what you can to feel pleasure, love and acceptance.

Connect on Social Media. Another way to connect this holiday season is through social media. Browse your friends' posts and comment or message them if you'd like. One nice thing about social media is that you can get on anytime – no scheduling needed. It's not as interactive but it can cheer you up to see what friends are up to or thinking about. They may have some good suggestions for what to watch or participate in. Of course, if it just depresses you, sign off. If it doesn't feel good, don't do it.

Get Personal with Snail Mail. Take some time to write heartfelt (or funny!) cards and letters. Reach out to those who you think may be lonely or reconnect with someone you haven't spoken to in a while. Emails are great too but they don't have quite the same personal touch. Mail cards and letters and imagine the smiles on their faces when they receive your special message.

Hopefully next year everything will feel "normal" again and we can resume old traditions. But maybe we'll happily include some of the new ones as well. Let's all be grateful for the people in our lives even if we only see them virtually!

SBRN's DERA Fund Helps People with Emergent Needs

The SBRN Disaster/Emergency Rapid Assistance (DERA) Fund helps individuals from NJ with acquiring medical supplies, covering non-reimbursable medical costs, assisting with adaptive equipment or other basic needs (e.g., food or other supplies) in response to an urgent need during the pandemic. There is a maximum award of $300 and this is one-time only assistance. Due to limited funding, we may not be able to fund all requests.

CLICK HERE FOR MORE INFORMATION