



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

December, 2022

Our Mission:

To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.

Inside this Issue:

December is the Holiday Season. Polio survivors all over the world share a common theme during this season of joy and thanksgiving. We wear ourselves ragged and discover we're very, very tired. This month, we are focusing on how to wake up on January 1st feeling GREAT.

When Is it Time to Stop (or Start) Hosting the Holidays?

- With some help from AARP, we're bringing up what can be a difficult subject. Passing the baton and changing traditions can be difficult for families but worthwhile on many levels once it happens.

Richard L. Bruno, HD, PhD likes to say: "Treat the cause, not the symptom."

- With the holidays coming and bringing extra stress, it's a good time to talk about controlling high blood pressure.
- In his newly updated article "Vampire Relatives", he answers the question: "How do I treat the high blood pressure caused by my relatives?"

Getting the most out of our health care visits. Wanting to start the new year right, many of us are making appointments with our health care professionals. Of great importance is how do we get the most out of those health care visits. Healthy Aging and Disability from the University of Washington can help.

PPS – WHY is it so hard to diagnose? PPS is *always* a diagnosis of exclusion. What does that mean? We are ending the year with Part 6 of this series. We sent your questions to primary care physician Marny K. Eulberg MD. She did a video with us that explains the answers to those questions about Post-Polio Syndrome and how it's diagnosed. Her written work is significant, and very popular. You will enjoy her comfortable, professional approach as she explains.



From Survivor Leigh Lewis Trimble:

"I keep reading all of your comments about hurting and being tired. When I was first diagnosed with post polio I was told to stop walking and use a wheelchair to save what I had.

I tried to follow this. I got a power chair. I have not had the pain from over usage nor have I had the fatigue. I did have to adjust my life to my new reality. I have used a chair for a good 25 years.

During this time I have been in business with first one son and then another. I believe when life gives you lemons, you make lemonade.

Take care of yourself, follow the rules and your pain and fatigue will go away."

Everyone expects
"Ho-Ho-Ho"

Sometimes it's okay to say "No-No-No"



When Is it Time to Stop (or Start) Hosting the Holidays?

Passing the baton and changing traditions can be difficult for families

Robin L. Flanigan, AARP

“Hosting for the holidays can be a marathon sport. There’s planning the meals, buying the groceries, [cleaning the house](#), cooking the food. It’s a lot of work, especially for older adults who have been at the holiday helm for two - sometimes three - generations.

When is it time to call it quits and let the younger generation take over?

That’s a difficult question for all involved. It can be difficult to give up the role of host after so many years; on the other side, it can be hard to take over that role, especially after a lifetime of baking, decorating, game-playing and gift-giving traditions.

‘It’s a very emotional topic,’ says Andrew G. Celli Jr., a 57-year-old attorney in Manhattan.

The traditions at his mother’s house - the home where he grew up in Rochester, New York - have ‘a rhythm and a regularity that makes it incredibly special and specific to her and the way she does things.’ But their family is large. Celli and his two siblings each are married with multiple children, some of whom have significant others, which means gatherings draw nearly 20 people. It’s a lot of work for Dolores Celli, who lives alone and is approaching 90, to make her usual lasagna; prime rib, or chicken with lemon, garlic and rosemary; pizzelles; and the apple pie recipe her grandmother always used in Italy.

‘It means taking the house apart and putting extra tables out, but I enjoy every moment of it,’ she says, adding that she also provides breakfast for guests in the mornings. ‘Fortunately, I’m healthy enough to do it. Every year is a blessing as far as I’m concerned, even though I’m sure one of these days one of the kids is going to say, ‘No more.’

While Andrew Celli says neither he nor his siblings have put their foot down once and for all just yet, he will be hosting Christmas at his home this year. His mother ‘is incredibly strong and somewhat stubborn, but at the end of the holiday weekend, she is pretty tired,’ he says. ‘We want her to enjoy the traditions that we can re-create at my house, without her having to do all the work.’

The Importance Of Holiday Rituals

Going to the same house, eating the same food and interacting with the same people for decades brings a sense of comfort and belonging.

‘Traditions help create meaning in our lives, and help find and establish family connections,’ says William C. Torrey, the Raymond Sobel professor of psychiatry and interim chair of psychiatry at Dartmouth Health and Dartmouth’s Geisel School of Medicine in New Hampshire. ‘Any change in how you celebrate the holidays can easily feel disruptive, but it also creates an opportunity for more conversation and expression of appreciation.’



That’s not so easy for Evey Meyer, 76, to believe. ‘I will be at the edge of my grave when I stop hosting,’ says the former biology professor from St. Louis. Rather than a chore, Meyer views hosting [Hanukkah](#) (‘It wouldn’t be Hanukkah if I didn’t make potato pancakes’) as an act of survivorship, ‘something the Jewish holidays are partly about.’

She points out that her generation may resist relinquishing the holiday reins in part because subsequent generations are less likely to engage in religious rituals – a worldwide phenomenon confirmed by a Pew Research Center analysis in 2018.

Meyer says that providing meals is linked to her self-image: ‘I’ve always been the feeder. When people think of me, I hope they think of food.’

At some point, however, the duties can become too much. It may take an older person days to recover, and younger adult guests may start to feel guilty for remaining on the receiving end. When this happens, it’s time for an honest, and possibly tough, conversation.

Adjusting to new holiday approaches

The loss of a tradition requires both an emotional and a cognitive adjustment, in part because our brains



are wired to resist change. One way to adapt may be to mark the transition and even celebrate it. 'Maybe that's gifting the apron you always wore when [cooking holiday meals](#) to the new family member who will take over that responsibility,' says Kasley Killam, a leading expert in social health, including the science of human connection. 'Or maybe it's making a toast at dinner where you share one thing you've learned from hosting over the years and officially pass the baton to the next generation.'

Gay Strickland is trying to figure out what her family's holidays should look like these days, as the grief from her mother's death a year ago melds with her grief over lost traditions that spanned generations at her childhood home.

'I keep thinking, We did this, we did that,' says Strickland, 66, who lives in Tabor City, North Carolina. 'It's going to be very hard to do something different.'

This brings up the idea of impermanence - the reality that nothing stays the same forever.

'Once we change the tradition,' she muses, 'what other changes will follow?'

Continuing to honor some of the family history you appreciate most may help preserve a sense of familiarity. Or consider putting your own spin on an old favorite.

Regardless of the reason holiday hosting may look or feel foreign this year, Killam recommends reflecting on the reason for gathering in the first place: 'The holidays are about spending time with loved ones.

Remind yourself of that and savor the chance to connect with family or friends.'

Focus on what matters most

Andrew Celli envisions going back to his childhood home for another Christmas or two if possible, but he also hopes to find other times of the year for everyone to get together there and celebrate family traditions. In the meantime, his mother still will be baking her legendary lasagna and apple pie this Christmas to bring over to her son's house.

'If the children someday insist that they don't want me to ever host again, I would just have to accept it,' Dolores Celli says. 'I would rather have them here, but more than that, all of us being together is the most important thing.'"

Robin L. Flanigan is a contributing writer who covers mental health, education and human-interest stories for several national publications.

Article Source:

www.aarp.org/home-family/friends-family/info-2022/hosting-for-the-holidays.html?cmp=SNO-ICM-FB-HF&socialid=8367593013



PPS is *always* a diagnosis of exclusion. What does that mean?

In July, Marny K. Eulberg, MD started off our series with her article

[PPS - One Doctor's Visit Does Not A Comprehensive PPS Evaluation Make.](#)

In her clear and remarkable writing style, she explained the importance of the lengthy process that goes into this diagnosis. You had questions and we sent them to Dr. Eulberg. She did a video with us that explains the answers to those questions about Post-Polio Syndrome and how it's diagnosed. You will enjoy her professional and comfortable approach as she explains.

These additional articles help round out this conversation.

[Diagnosing Post-Polio Syndrome.](#)

[Muscle Pain, Post-Polio and The Importance of Being a Medical Detective](#)

[Post-Polio Syndrome: A Diagnosis of Exclusion](#)

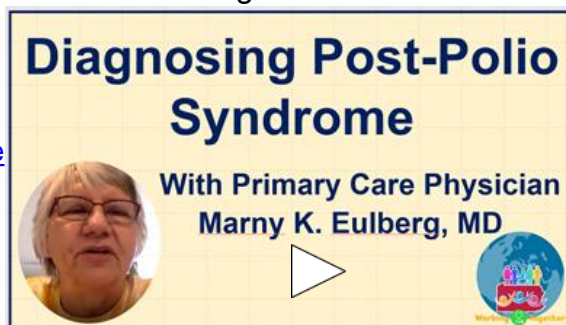
THANK you to each and every contributor in this series.

Richard L. Bruno, HD, PhD

Marny K. Eulberg, MD

Mark A. Lopatin, MD

Post-Polio Health International



Just "click" on the triangle.
You can find this video on Vimeo:
www.vimeo.com/771655346

You can find their biographical information in the "[Professionals](#)" section of our website.

Vampire Relatives

By [Richard L. Bruno, HD, PhD.](#)

Director, International Centre for Polio Education

Question: "With the holidays coming and bringing extra stress (re: relatives) it's a good time to talk about controlling high blood pressure." You always say, "Treat the cause, not the symptom." How do I treat the high blood pressure caused by my relatives?

Dr. Bruno's Response: Dealing with your relatives is lot harder than finding a drug to treat high blood pressure! When PPS rears its ugly head, some relatives stop being nice to you when you stop doing what you've always done for them. I call those folk "Vampire Relatives," people who have become used to your meeting their needs regardless of how *you* feel, physically or emotionally. Some polio survivors try to educate Vampire Relatives about PPS, hoping that understanding will lead relatives to meet their own needs. But more polio survivors continue to meet relatives' needs and thereby trigger more PPS symptoms.

What do you do when Vampire Relatives deny PPS symptoms are real, refuse to listen to your needs and call you lazy, crazy or selfish because you're not meeting *their* needs? There's only one solution for "deaf" Vampire Relatives: Divorce.

There are three types of Relative Divorce:

Silent Divorce

"Silent" means you don't announce the divorce. You just don't answer Vampire Relatives' phone calls. Use caller ID to screen the number and let Vampires' calls go to voicemail. Answer your phone when and if you want to. If relatives show up and ring your doorbell, don't answer it.

When relatives ask why you're no longer responding to the bell like Pavlov's dog, you just say, "My doctor told me to rest. I was resting." There is tremendous power and savings in emotional energy in repeating a brief statement like, "My doctor told me to rest," without having to come up with different answers to Vampires' inevitable complaints, like "Why have you become so selfish?" and the ever popular "Why don't you love me anymore?"

Sometimes, Vampire Relatives respond to silent divorce and stop making demands of you. More likely, relatives will complain more loudly that you're not meeting their needs. If that happens, there's a another kind of Relative Divorce.

Conditional Divorce

If relatives refuse to even acknowledge your needs, you can simply say, "Until you understand that I have PPS, I can't talk to or be with you." When they ask "why?" you just repeat that simple statement, "My doctor told me to rest and avoid stress."

Where's the "conditional" part of the divorce? Conditional is the "Until you understand . . .". You don't allow Vampires back into your life until they understand, acknowledge and meet your needs. For Conditional Divorce to work you have to be patient. *Really* patient. Vampire Relatives are used to decades of having *their* needs met and ignoring *yours*. A few weeks (or months) of separation may not change your relatives' behavior. During the separation you will likely feel whopping guilt that will push you to end the divorce. After all, guilt is what made you take care of Vampires in the first place. The only way divorce can work is by staring down the guilt and staying away from your Vampire Relatives, "until they understand ." But, if "until" never comes, there's only one other option . . .

Permanent Divorce

When Vampire Relatives show that they are never going to acknowledge your needs, you need to cut them off. Whether you tell them or not, Permanent divorce means you never again answer phone calls,

continued . . .



the doorbell, letters or queries sent by other relatives. For your own good, you "finalize" the divorce. I know this sounds really difficult, and it is.

So you should rightly ask, "Does divorcing relatives work?" I have had a number of patients who divorced a Vampire Relative, usually their mothers. At first their guilt was almost overwhelming. But, eventually relief overcame the guilt -- relief of not meeting others' demands, not being interrupted by a dozen phone calls each day, no longer going shopping for them several times a week and no longer cooking every holiday dinner. I have never seen patients so relieved -- and so proud of themselves -- as when the guilt burned away and they were free of the Vampire Relatives.

And here's an amazing fact. All but one Vampire Relative eventually acknowledged my patients' needs, although it sometimes took years for relatives to come around. Yes, relatives did backslide and tried to resume their Vampire ways. But a simple, "I divorced you once, I'll divorce you again" reminded them that my patients meant business, and relatives Vampire behavior stopped again.

I can't guarantee that Vampire Relatives will respond to any type of divorce. And I know it's hard to divorce relatives, even if they are Vampires. You may think you can't live without them. But, ultimately, there is only one person you can't live without: **You!**

Happy *Vampire* - Free Holidays!

[Richard L. Bruno, HD, PhD](#)

Rev 2022



And more on this timely topic:

Exorcism of Emotional Vampires

By [Leslie Davenport, Contributor](#)

Author, 'Healing and Transformation Through Self-Guided Imagery'

"Emotions are contagious. Have you noticed how some people are chronic complainers or often emit anger and irritability? How do you feel around them? [Scientists have discovered that we have mirror neurons](#) that trigger us to directly experience the emotional atmosphere of others. Take an inventory of people in your life that drain you. Then take the initiative to end toxic relationships, surrounding yourself with positive ones.

There are also situational vampires. So you volunteer at your kid's school, but only in time to get the other one to soccer practice, before taking all the kids along with you to the market and, oh yeah, the dry cleaners, before throwing together that dinner tonight so you can meet your friend that you're hoping to open a side business with since you're not all that happy with your part-time job, but not staying out too late because you haven't finished that book and book club is tomorrow or wrapped your sister's birthday present, but you can't forget to leave a note for the babysitter first about helping the older one with the school project, being sure to find the links to the online research articles he needs and... on it goes. The superhuman lifestyle, and there are many varieties, are a core cause of fatigue.

Set limits -- learn to say no.

Prioritize those people and things that you want to really come first."

The full article is available:

www.huffpost.com/entry/chronic-fatigue_b_1013186



“Health care providers are the most common source of health information so it is important to get the most out of each health care visit. Visits with health care providers are usually brief, packed with information and many health care decisions are made.

Research has shown that people who are organized for their visits, take an active role in their health care decisions, and have good communication with their health care providers tend to be more satisfied with their care and have better results.

What to expect during a health care visit

Knowing the typical structure of the visit will help you make the most of every minute and take part in making important decisions about your health care. Health care providers often use the following steps during a visit.

- Setting the agenda for the visit.
- Asking about your symptoms and concerns.
- Giving you information about your treatment options.
- Understanding your preferences.
- Making healthcare decisions such as a change in medication or further testing needed.
- Ending the visit by reviewing health care decisions made and checking for your concerns.

Not all health care providers will follow all these steps at every visit. Regardless, it is important that you feel comfortable asking questions and expressing your concerns. If you consistently feel like your questions and concerns are not addressed by your health care provider, you may want to find another health care provider that is a better fit for you.

Tips for your health care visit

Remembering the abbreviation PACT will help you organize health care visits.

PACT stands for **P**repare, **A**sk Questions, **C**reate a Plan, and **T**ake-Away Materials.

P – Prepare

Make getting ready for visit a habit. Being prepared is particularly important for your first visit to a new health care provider.

What to bring:

- Your insurance card, the names of your other health care providers, the phone number of your pharmacy.
- A list of medications and supplements you are currently taking and dosage, including over-the-counter and alternative medicines.
- If you have an Advance Directive make sure that your health care provider has a copy.
- Your glasses, hearing aids or other things to make communication easier.
- If you need special equipment (because of mobility limitations) or more time (because of communication limitations) be sure to let the person who schedules the appointment know.
- A friend or significant other as an extra set of ears. You can also use an audio recorder if you get permission from your health care provider first.
- A brief written description of your health problems and your symptoms. Be prepared to respond to questions your health care provider will ask about your symptoms, including:
 - What are the symptoms?
 - When do you experience them? Are they constant?
 - Do they affect your daily activities? If so, how is your life affected?

Other tips:

- Find out how much time you will have with your health care provider so you can decide on how many questions to ask.
- Most importantly, be on time by planning to get to your appointment a little early.

A - Ask questions

Your questions will inform your decisions and help your health care provider understand your perspective.

Some suggestions include:

- Write down questions to bring to your visit.
- Place your questions in order of importance so the things that matter most to you can be dealt with first.
- If you don't understand what your health care provider is saying or the information is going too fast, ask for a repetition or more explanation.
- If you have questions about health information you found in other sources such as the Internet, make sure the information is trustworthy and bring a brief summary and name of the source to your health care provider.

Possible questions to ask about medical tests:

- Why is the test being done?
- What steps does the test involve? How should I get ready?
- Are there any dangers or side effects?
- How will I find out the results? How long will it take to get the results?
- What will we know after the test?
- May I have a copy of the test results?

Possible questions to ask about medications:

- What does the medication do?
- What are the benefits of the medication?
- What are the side effects?
- What will happen if I don't take the medication?
- How long will I need to take the medication?
- Will the medication have an interaction with other prescriptions or over-the-counter medications or supplements that I'm taking?

C – Creating a plan

Creating a plan involves making decisions with your health care provider on how to address the issues that are bothering you.

- Let the health care provider know how much you want to be involved in the decisions.
- Understand the decisions that need to be made.
- Be sure you know all of the options that are available to you and the pros and cons of the various options.
- Remember that deferring the decision might be an option.
- Tell the health care provider if you have concerns about the decisions made.
- Make sure you understand the plan.

T -Take-away materials

It is important that you have information to review after you leave the appointment to help you remember what decisions were made. Take-away materials might include:

- A written version of your health care decisions.
- A written follow-up plan, including return visits and appointments with other health care providers.
- Contact information in case you have questions after the visit.
- Brochures, articles, audio and video recordings that provide additional information.
- Recommendations of useful and trustworthy websites.”

Source: Yorkston, K. (2012). Getting the Most Out of Health Care Visits [Factsheet]. Aging and Physical Disability Rehabilitation Research and Training Center. NIDRR/U.S. D.O.E. grant #H133B080024. University of Washington. www.agerrtc.washington.edu



THANK YOU for your kind words and generous [donations](#).
We truly appreciate it.

Some Holiday Fun



Thank you survivor John Nanni

Knock, Knock!
 Who's there?
 Honey!
 Honey who?
 Honey-kah is my favorite holiday!

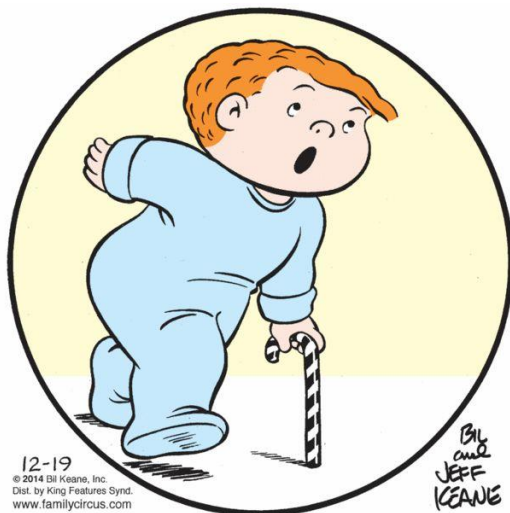
Knock, Knock!
 Who's there?
 Atomic
 Atomic who?
 I have a tomic ache from
 all this candy !

Which hand do I light the Menorah with?
 Neither – use a candle !

How do you know when Santa's at the North Pole?
 You can sense his presents

Who works construction at the North Pole? Crane-Deer

Why is the person who runs Times Square in New York always
 sad on January first?
 Because he always drops the ball !



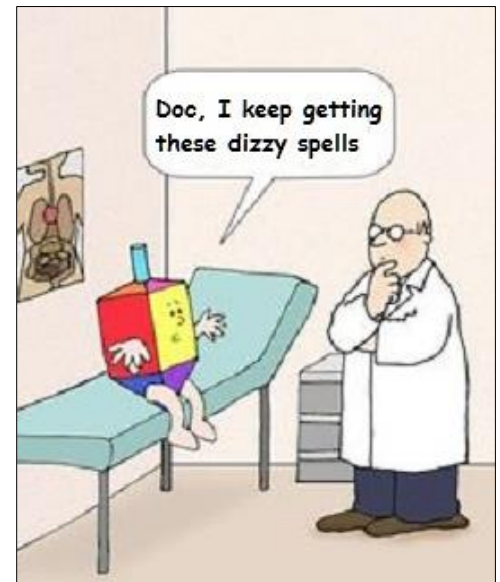
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Bill
 and
 JEFF
 KEANE

"I think the elves made this cane
 to fit them, not me."



HILARY B. PRICE



GLASBERGEN

It's fine. I'm fine
 everything is fine



Be good to yourself this
 holiday season.



Polio survivors KNOW that the pain and disability of this terrible virus can last a lifetime.



We wish everyone a peaceful holiday season.



December

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