



PA Polio Survivors Network

Information and Inspiration
for All Polio Survivors and Their Families

Serving the Keystone State and Beyond

www.polionetwork.org

December 2018

Our Mission:

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



To quote a famous song – “It’s the Holiday Season”

As part of that, Polio survivors often struggle with extraordinary fatigue, both mental and physical.

Have you ever heard the word “vampire” used at this time of year?

[Richard L. Bruno, HD, PhD.](#) does so in a way we can help rid ourselves of some significant holiday stress.

[William M. DeMayo, MD](#) is back with us this month.

He’s written an article, in answer to a question, that addresses breathing issues and the “deconditioning” that comes to so many Polio survivors.

Self Care – it’s especially important at this time of year.

We have some suggestions to help with the overwhelming fatigue that comes to so many of us. Let’s not forget to laugh, love, find something to be grateful for and strive to keep our cups full.

Here’s a “Self Care” holiday reminder from Dr. William DeMayo, MD

“The holidays are a particularly difficult time when it comes to these activity decisions. In order to avoid chronic overuse activities, some helpful questions to consider this holiday season may include:

- Do I want to continue to push myself to prepare the big family dinner (and risk creating pain and exhaustion) or do I **Want** to put my relationships with family first and preserve my energy by asking for help?
- Do I **need** to climb that ladder to put up decorations despite the obvious risk?
- Do I **have** to bake 12 dozen cookies or do I **Want** to avoid overdoing it and dial it back a bit and ask for help?
- Should I “shop ‘til I drop” or do I **Want** to be a better example to my kids and grandkids by purchasing or even making one special gift.”

All these questions center around individual values, desires, and goals. It is my hope, especially during this holiday season, that we can all focus on our real **Wants** and be less driven by passing desires/wants, “have to”, “need to”, and a “should” mentality.”

(From his article – “Conserve to Preserve, What does it Mean?”)

www.polionetwork.org/demayo



COPD and Polio

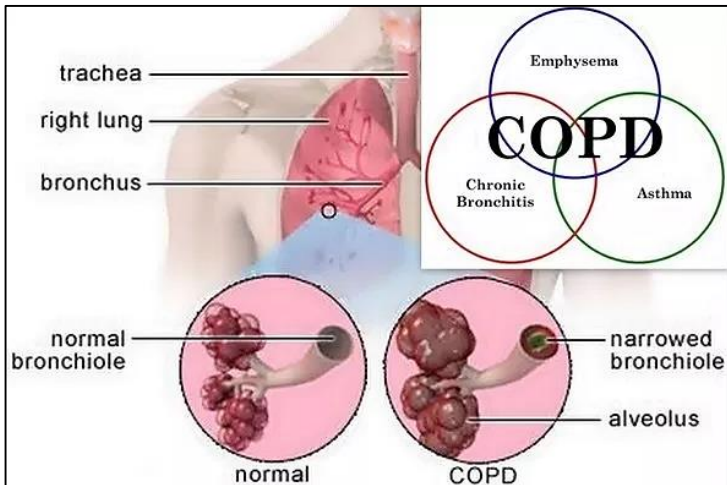
[William M. DeMayo, MD](#)

DeMayo's Q&A Clinic

www.polionetwork.org/demayo

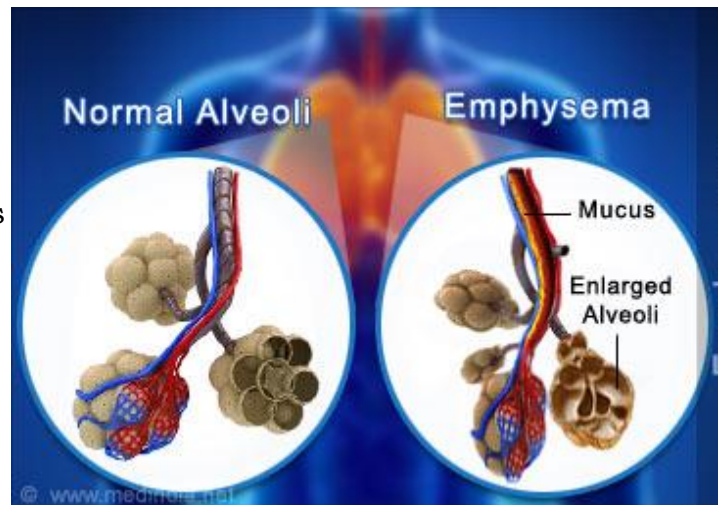
Question: "I started smoking when I was in college, and smoked steadily until I quit at age 30. I am now 80 and have had some breathing problems. I am being checked for COPD. Are polio survivors being diagnosed with COPD a lot? Is it one of the post-polio medical issues we face? I really think the smoking has something to do with it. Thank you."

Answer: This is a great question that has a very short simple answer and a much longer answer all at the same time. The short answer is "No", COPD itself is a lung disease and not a Post-Polio medical issue.



I'm guessing that most readers would like a bit more so I will give the longer answer as well. Although COPD is a lung problem, alterations with progressive PPS can increase the functional impact of COPD. First let's talk about the lung issue. COPD (Chronic Obstructive Lung Disease) is a problem that includes elements of Chronic Bronchitis, Emphysema and Asthma. For different people some elements may be more prevalent than others. Many factors influence each of these elements including genetics, allergies, medications and, obviously, smoking.

Unfortunately, smoking has many other risks and some can be permanent. Smoking can cause permanent physical harm to the lungs such that a distant 12 year history of smoking could be one part of the cause of your COPD. Nevertheless, given the fact that the smoking was 50 years ago, a good primary care physician and/or pulmonologist needs to look closely at other causes for COPD. It may be that the problem is not at all COPD or it may be that there is a large allergic asthmatic component that is easily treated. The evaluation and management of COPD is beyond the scope of this article. At the same time, it is a good example of the fact that it is extremely important to fully evaluate medical issues that are impacting function and I encourage you to ask detailed questions so you can understand the specifics of your Pulmonary work up.



Having said that, it is important to know that the symptoms of COPD include cough, sputum production, wheezing and shortness of breath. Many of these symptoms can be activity / exertion related. It is also not uncommon at all for an individual with Post-Polio to have activity / exertion related shortness of breath. This symptom may be a functional limitation and thus when it is caused by both COPD and PPS, there is a "Double Whammy" that can impair overall functional status. So in addition to looking at the presence or absence of COPD and managing it well (if present), it is important to look at how PPS can influence shortness of breath.

PPS can have a profound effect on an individual's mobility and activity. This in turn leads

to deconditioning and deconditioning soon leads to shortness of breath with activities that were formerly routine. It's a bit of a vicious cycle. Additionally, biomechanical changes in gait can lead to less efficient ambulation and an increased reliance on the upper extremities. This is more strenuous and another common cause of shortness of breath. In some cases, adjustment to bracing or introducing bracing can restore biomechanical support and reduce the effort of standing and walking. Lastly, increase in weight that comes with aging and reduction in activity also increases the work of standing and walking, especially if an elderly person has any level of heart disease.



In summary, this question is a good one to think about the interaction of many medical issues above and beyond PPS that can all impact shortness of breath (and function). In addition to working with a good primary care physician to manage these medical issues, regular exercise and weight loss is always a good idea. For further information, consider reading my prior article "Exercise and weight loss for the polio survivor". <https://www.papolionetwork.org/demayo-articles.html>

As far as smoking is concerned? It's NEVER too late for anyone to quit (regardless of whether or not they are a Polio survivor). Give yourself a gift this holiday season and get rid of the cigarettes once and for all.

The warmest of holiday wishes to you all, William DeMayo, MD.



American Disabilities Act
July 26, 1990

"Some see leadership as high drama and the sound of trumpets calling, and sometimes it is that. But I see history as a book with many pages, and each day we fill a page with acts of hopefulness and meaning."

President George H. W. Bush
January, 1989
(Six months before he signed the ADA.)

This is a page in his history book that holds *true* meaning and hope.

Vampire Relatives

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

Director, International Centre for Polio Education

Question: You have written, "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?

Answer: 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 make Vampire Relatives understand PPS hoping that understanding will lead to relatives meeting 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 it. You just don't answer Vampire Relatives' phone calls, or you use the answering machine to take calls when and if you want to. If relatives show up at your door, you 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 questions, 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 second 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."

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 those weeks or months 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." 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, the doorbell, letters or queries sent by other relatives. For your own good, you "finalize" the divorce.

(continued . . .)

I know this sounds really difficult, and it is. But the question is does divorcing relatives work? I have had a number of patients who divorced a relative, usually their mothers. Their guilt was huge at first. But, eventually, so was the relief of not or meeting others' demands, having to take a dozen phone calls a day, going shopping for them several times a week and 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!



And more on this timely topic:

By [Leslie Davenport, Contributor](#)

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

Exorcism of Emotional Vampires

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 here --

https://www.huffpost.com/entry/chronic-fatigue_b_1013186

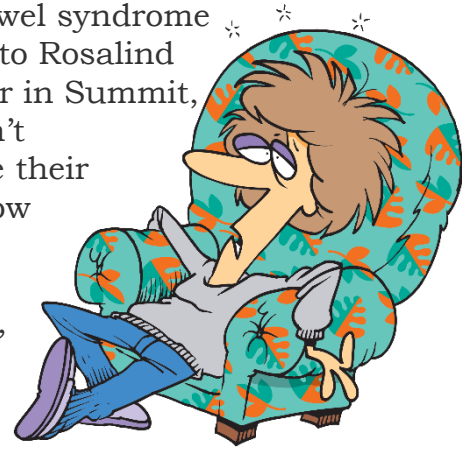


Chronic Disease Doesn't Have To Be Exhausting. Here Are 5 Ways To Combat Mental Fatigue.

Kate Silver, Pfizer

brought to you by 

Illness can be exhausting, and not just in the physical sense. When someone learns they have a chronic disease, whether it's arthritis, diabetes, irritable bowel syndrome or another condition, it can be a life-altering experience, according to Rosalind S. Dorlen, Psy.D., a clinical psychologist at Overlook Medical Center in Summit, NJ. "It's rare that I come across a person, post-diagnosis, who hasn't experienced shock, fear, or denial," says Dorlen. Many can feel like their prior sense of comfort, joy and connection with the world is somehow violated. "It can often create feelings of chaos and confusion, which can lead to a complete mental overload."



Not to mention exhaustion. There are doctor's visits, treatments, possible complications, insurance and financial concerns, appointments with specialists, excessive online information and worrying about what the present and future hold. With all these burning questions surrounding chronic disease – which Dorlen refers to as a person's "new normal" – it can bring on profound sense of emotional fatigue. "When we are dealing with this kind of fatigue, it means a person is likely experiencing really difficult thoughts, feelings and attitudes," says Dorlen.

Just as the fatigue, itself, can be a result of mental exhaustion, the response to it may be a matter of mental conditioning. Dorlen shared this advice on how to cope with chronic illness and the psychological fatigue it may bring:

Attitude can make a difference.

How a person copes with bad news isn't just about the bad news, itself.

The person's own thoughts and perceptions make a big difference as well, advises Dorlen. "It's our attitude that may determine how resilient or not resilient we are, or how we react to a health crisis," she says. According to Dorlen, there are certain traits that can help you cope better with illness, and one of those is flexibility. "Maintaining a flexible mindset can give you a better capacity for resilience," she says. Maybe flexibility isn't your thing? The good news – it can be learned. Dorlen says start by mixing up your routine. It could be writing with your non-dominant hand, taking a different route to work or shopping at an off-the-beaten-path store. "Though simple, these small experiments are activities that can help you enhance your flexibility and turn it into a skill," she notes.

I feel good.
I feel great.
I feel wonderful.
I feel good.
I feel great.
I feel
wonderful.

Cultivate gratitude.

"I ask most of the people I work with to think about [gratitude](#) every day," says Dorlen. She asks her patients to keep a journal and write down three things each day that they appreciate. These could be simple things, like the sunrise, a tasty meal or a beautiful flower. "When you are challenged with life circumstances that are beyond your control, a dose of appreciation can help change your outlook," she says.

Take care of yourself.

When you're exhausted, everything feels a little more difficult. A cheeseburger might sound better than a salad. Making it to the gym



might seem like a feat of impossible strength. If you're stressed and worried, even getting a full-night's sleep might sound like a fantasy, despite your exhaustion. But it's important to strive for a healthy routine. "No matter your circumstances - self-care must be a priority," insists Dorlen. By eating a nutritious diet and working towards quality sleep, you may improve not only your outlook, but your energy levels. Also, by incorporating some kind of physical activity you may also see big returns. "Exercise reduces anxiety and enhances wellbeing, and I tell that to every patient I see," says Dorlen. (**Note: *Always* consult a doctor before starting any new health routine.)

Lower your stress levels.

A chronic illness can add a whole new level of stress to your life. Dorlen encourages engaging in [mindful meditation](#) as a way to manage stress. "You don't have to go to a dedicated meditation studio either, there are many different apps available that help you practice mindfulness in your own home and throughout the day" she says.

Spend time with others.

Being around other people can help you become more understanding, and that, in turn, can inform you on your own journey, notes Dorlen. "We found that one thing that may help people cope with illness and the potential side effects of illness has to do with nurturing their own empathy," she says.

She suggests a number of ways of connecting with others: find a support group that helps people with your illness; visit your local community or senior center and spend time with new faces; lend a helping hand at a volunteer organization; and reach out to friends and family to schedule get-togethers. You can't control being ill, but you can control how you respond to that illness, and that response can empower and energize you. Dorlen says that when people get over the initial shock and isolation of chronic illness, there may be a silver lining. "It can move you to 'rally your resources' and reach out," she says. "Often before you know it, you've created a new community." That, in turn, can lead to growth, understanding and a deeper appreciation for all that you have.

*Note: The information contained within this article is based upon the knowledge and opinions of the author and experts.

<https://www.getold.com/chronic-disease-doesnt-have-to-be-exhausting-here-are-5-ways-to-combat-mental-fatigue?linkId=54186958>



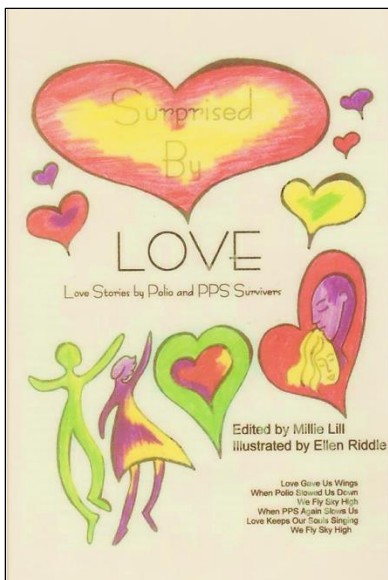
A Book Review from Kathy Galletly



Surprised By Love

Stories of Love and Support by Polio Survivors
Edited by: [Millie Malone Lill](#) Illustrated by Ellen Riddle

Love and support is such an important part of everyone's lives. For people with disabilities some days our struggle can be so much more difficult. It's especially on those days when the emotional support and love you get is invaluable. This book is a collection of many different types of love. Marriages that stood the test of time, second time loves. Support of strangers through letters, the kindness of an orderly to a child, the love of parents, and my personal favorites the friendships and love between polio survivors. Each story is as unique as the person who tells their special stories. Some bring a tear; some a smile but when you finish you have the one thought: Isn't love and support just grand!



(Surprised by Love is available on [Amazon](#)).

Joyful Noise . . . Some Holiday Humor

One night a Viking named Rudolph the Red was looking out the window when he said, "It's going to rain." His wife asked, "How do you know?"
"Because Rudolph the Red knows rain, dear."

Q - What do you call a shark that delivers toys at Christmas? A - "Santa Jaws!"

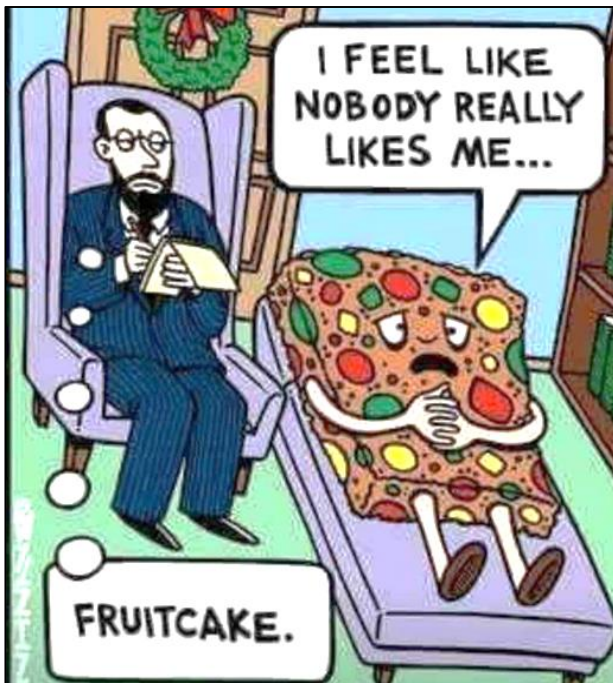
Q - What do snowmen like to do on the weekend? A - Chill out.

Q - Where do snowmen keep their money? A - In a snow bank.

Q - Where do polar bears vote? A - The North Poll!

Knock, knock.
Who's there?
Murray.
Murray who?
Murray Christmas, one and all!

Knock, knock.
Who's there?
Pizza.
Pizza, who?
Pizza on earth, good will toward men!





THANK you for your kind words and very generous [donations](#).
You are the reason we will be going forward into the new year.

**Our Pa. Polio Network Professional Contributor,
[Daniel J. Wilson, PhD](#) was interviewed for an outstanding PBS Documentary:
“The Case for Vaccinating Children”**

You can see this interview (and many others)
in our Polio Vaccine Video Library

The Encyclopedia of Polio and Post-Polio Sequelae

This document on our website contains the entire library of updated
articles written by Dr. Richard L. Bruno, HD, PhD.

When you access the primary Encyclopedia page, just go to the “Red” buttons
(after Dr. Bruno’s Introduction) and “click” on your topic of choice.

It is divided by:

Articles, Books he has authored, Bruno Bytes by month,
the Encyclopedia Index, and a Video Library.

The Encyclopedia is easily accessed either through our website
polionetwork.org/encyclopedia
(or) by going to Dr. Bruno’s website. <http://postpolioinfo.com>



Do you have a topic you would like us to cover? Please let us know.

Always feel free to contact us.

[The Polio Network Team](#)

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Contact us: Email: info@polionetwork.org Phone: 215-858-4643

PO Box 557, Doylestown, Pa. 18901

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