Nebraska
NPSA
Polio
Survivors
Association

GLEANINGS

ISSUE #3, SUMMER 2021

Change

By Millie Malone Lill

As a polio survivor, I have learned to adapt. That is one of our superpowers: Adaptation. A task will be set before us, and we will set about finding a way to make it doable. We have done this for so long that it is now second nature.

First, we had to learn to walk again after polio knocked us off our feet. Or, if polio took away the use of an arm or our breathing muscles, we had to learn to survive and thrive without that piece of equipment. Not survive? That was never an option. Polio took a lot away, but it left behind a good supply of determination. If the "normal" way was blocked, we created a detour.

Personally, I've learned to walk several times and I'm still not good at it. That does not mean I'm helpless. Absolutely not. It was hard at first to have to go back into a brace. I'd worn one from age 4 to age 10, first a full-length brace and then a shorter one. At age 10, surgery made it possible for me to walk without the brace. I thought I was done with polio. Wrong. At age 13, I needed another operation. Another chance to learn the fine art of walking.

I swam, I tried to roller skate, with far-from-perfect results. I took ballroom dancing lessons, also with mixed results. I was no athlete, but I enjoyed games of softball at recess and loved to read. As a result of not being good at sports and physical things, I became an exceptionally good student. I've enjoyed learning new things all my life.

In my mid-forties, I got tired of falling so often. I thought my knees were just a tad too old to be constantly skinned and the callous on the side of my polio-affected foot was too often torn and bloody by the end of the day from being twisted as I walked. I talked to an orthopedic doctor, who recommended a brace. "Say what? No! I tossed out my brace at age 10!" But I gave in and got a brace. What a difference that brace made. Far less pain, maybe even a little more energy.

Then, I stepped on something in my kitchen and fell, twisting my body over that leg that was kept immobilized in the brace. The result was a spiral fracture just below my knee. My doctor did not think it needed a cast, so I struggled along using crutches and a manual wheelchair. If there is anything more frustrating than trying to be a farm wife using crutches and wheelchair, I hope I never run into it.

(Millie's Column, continued Page 2)

June NPSA Meeting Topic: Durable Power of Attorney for Health Care

By Elaine Allen, Gleanings Editor

An Illinois attorney and past president of Post-Polio Health International recommends everyone have a Durable Power of Attorney for Health Care.

"Having a Durable Power of Attorney enables someone you know to make decisions for you when you are unable to make decisions for you," Saul Morse told the June attendees of NPSA's Zoom meeting. A polio survivor himself, he is the Legal Counsel for the Brown Hay & Stephens law firm in Springfield, Illinois.

The Durable Power of Attorney does not relate exclusively to end of life; it can be triggered by other medical situations like coma or if a person becomes unconscious from an accident or illness.

(Durable Power of Attorney, continued Page 3)

Millie's Column

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It took 18 months and a few different braces before I could learn to walk yet again. I'd lost some strength by then and my usual leather and metal brace was too heavy. I couldn't lift it. But I found one that worked. Was I done now with all the changes? No. Fatigue became an awfully familiar companion. I eventually went into a power chair, kicking and screaming denial all the way. Not full time, though. I could still walk short distances if I used the chair for any lengthy forays.

Now I am facing another change. My good right hip has done its best as long as it could, but it is now very arthritic with a little bit of bone-on-bone cha-cha-cha" going on. I'm experiencing considerable pain daily. I might be using my chair full time now.

In typical polio survivor fashion, I am not giving in easily. I am not kicking and screaming this time, though, because kicking hurts my hip. Maybe I'll give in more easily this time. I am still a survivor, so I will always find a way to live my best life. I've learned from long association with other polio survivors that there is always a way. Don't be afraid of change!

For as long as we live, we will find ways to accommodate our disabilities to our necessities. If that means more time in the power chair, then that's what must happen. I recently heard from a friend who has gotten a new power chair with an elevating seat. Now there is a change I can get behind. With an elevating seat, I could cook, do dishes, and even reach my shelves.

That would be a good change and one I can really use.

ZOOM with NPSA!

We are meeting on Zoom for the rest of 2021. In addition, we may move to a "hybrid" model by meeting in person for those who are in the Omaha area, if we are able to meet in our previous meeting place.

With Zoom telephone/video conferences, all our members can attend safely from anywhere. As a Gleanings subscriber, you are invited to attend our Zoom meetings, no matter where you live!

You have two options to participate in our Zoom meetings:

- Call in via one of the phone numbers listed below.
- Or, to join via video, download the Zoom app onto your mobile device or computer.

We meet from 2:00 – 4:00 Central (U.S.) time on the following Sunday afternoons with topics to be announced via email and on our Facebook page at least one week in advance.

Date	**Topic**	**Zoom Meeting Details**
8/1/2021 and 9/12/2021	To be announced	Zoom web address: *https://us02web.zoom.us/* Meeting ID: 825 6010 0877 Meeting passcode: 661946
10/3/2021	Annual Reunion	Call-in phone numbers (using the same Meeting ID and passcode):
11/7/2021 and 12/5/2021	To be announced	+1 346 248 7799 US (Houston) +1 312 626 6799 US (Chicago)

We encourage our readers who value this newsletter, or those who want to honor or memorialize a polio survivor, to send a tax-deductible gift to the address below:

Nebraska Polio Survivors Association
PO Box 6076
Omaha, NE 68106

Durable Power of Attorney

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Morse said dementia is growing exponentially in the U.S., citing these statistics:

- 37% in U.S. have Durable Power of Attorney documents
- Only 55% of nursing home residents with dementia have them
- Approximately 5.8 million have incurable condition and it is expected to grow by 2050 to over 14 million people.

He said a Dementia Provision (Advance Directive Addendum) can be added to a Durable Power of Attorney document.

Morse also recommended checking state laws on living wills and palliative care, which can have great limitations. Without a Durable Power of Attorney document, he explained that physicians are reluctant to honor a family's wishes. According to Morse, all states have online versions of this document. You don't have to have an attorney to fill it out, but you will need to have witnesses when you sign it.

During the Zoom meeting, he urged attendees to talk to the person they have designated at some length about your wishes. Some questions to discuss:

- Are you willing to have surgery?
- Do you want to be hooked up to machines?
- Are you willing to undergo general anesthesia? This question is especially for polio survivors, Morse said.

Morse also explained the difference between the Durable Power of Attorney and Advance Directive: The **Advance Directive** includes non-legal aspects, such as personal preferences, religious beliefs, etc.

A Gentle Death: This is a letter you can send to your health care provider that expresses your preferences for what your future will be like. See the Online Resources for the **Compassion & Choices** website where you can download a copy of the letter.

He also discussed the controversial movement toward **Medically assisted Death**. Not the same as assisted suicide, medically assisted death is a very uniquely personal decision, which allows the methods for a person to end their own life. Currently, only a couple of states permit the practice.

In addition to being controversial, it's also a matter of ethics. Morse explained that very few health care providers are willing participate in a medically assisted death because it violates the Hippocratic Oath, which says the highest priority is to maintain a life.

Online Resources

Compassion & Choices resource page: This page includes links to "**A Gentle Death**: Proposed letter to send to health care provider", "COVID-19: Dying in the Age of the Pandemic" and "COVID-19: Impact on underserved communities".

http://www.compassionandchoices.org/resources

Post-Polio Health International's Post-Polio Directory: Available as a PDF download or for purchase: *https://post-polio.org/education/publications/*

Post Polio Health International's

POST-POLIO DIRECTORY 2021©

Physician Turns to Mindfulness during the Pandemic

By Elaine Allen, Gleanings Editor

A past president of Post-Polio Health International (PHI) retired as a physician in 2019, just before the Coronavirus Pandemic began in early 2020. He turned to a practice of Mindfulness and Meditation to cope with the challenge of COVID.

Dr. Martin Wice, who retired from the *Center for Advanced Medicine Neuroscience Center in St. Louis, Missouri*, spoke to 14 attendees of the May 2nd NPSA Zoom meeting.

What brought him to Mindfulness and Meditation? He began to feel a loss of freedom and a need for more spirituality. “For me, that was a good thing. There was room for improvement,” he said.

What is Mindfulness? Dr. Wice defined it as “paying attention to what's happening in the present moment with kindness, and curiosity, without judgment, in service of self-understanding and wisdom.”

One of the most positive impacts of mindfulness: It helps with better brain function, citing statistics that dementia is increasing in the U.S. population. If you are concerned with cognitive decline, Dr. Wice said it’s important to consult with physician.

For those who have been infected with the Coronavirus, a phenomenon called “COVID Languishing” has been described in recent medical literature as “difficulty in concentrating.” Another after effect of a COVID infection is "brain fog", which can also cause concentration issues.

Dr. Wice recommends practicing mindfulness and meditation 5 minutes a day at least 5 days a week. Doing mindfulness consistently 5 times a day for a year, he has found his concentration and focus has improved. “Mindfulness has lessened my stress level. I feel more compassionate to myself and others,” he said. He also said it can help with pain management.

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Mindfulness and Meditation

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Dr. Wice suggested using the acronym **RAIN** to help develop a mindfulness practice.

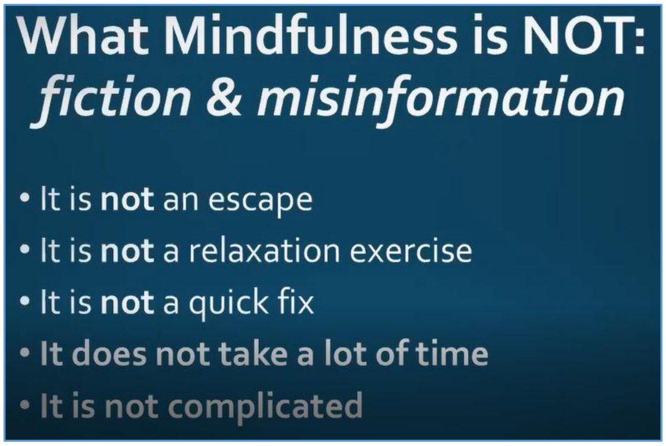
- **R**ecognize: What's going on with you in the moment?
- **A**ccept: Where are you with your life as it is?
- **I**nvestigate your inner experiences/senses.
- **N**urture: Show self-compassion and to those around you.

He offered the following suggestions when beginning a Mindfulness and Meditation practice:

- Stay in the moment: We tend to negativize the past. What happened in the past helped to form who we are. But it is not who we are now.
- Be aware of our body, emotions, thoughts.
- Remember to focus on one thing at a time: Mindfulness helps us to take on one task at a time.

Before he opened his presentation to questions, Dr. Wice guided the group in a five-minute guided session.

Local NPSA members met for the first time since March 2020, when the Coronavirus Pandemic began. Attending the Annual Ice Cream Social was held at Culver's Restaurant in LaVista, Nebraska (clockwise from left to right): Fred and Eunice Jalass, JoAnn Keller, Barbara Johnson, Penny Jewell, Stanley Johnson, Karen Dulany, Elaine Allen, and Dipakkumar (Dr. Dipak) Prajapati. This photo was taken by Dr. Dipak's second-grade daughter, Adaa Prajapati.



What Mindfulness is NOT:
fiction & misinformation

- It is **not** an escape
- It is **not** a relaxation exercise
- It is **not** a quick fix
- It does not take a lot of time
- It is not complicated

How to Begin

COMMIT TO A CONSISTENT DAILY PRACTICE

DEDICATE A SPECIFIC SPACE

FIND A GROUP WITH WHOM TO PRACTICE

GET A WELL QUALIFIED INSTRUCTOR

Donor List

The following donors sent gifts from April 1 to June 30, 2021:

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NPSA Mission Statement

The mission of the Nebraska Polio Survivors Association is to educate the public and the health care community concerning polio and post-polio syndrome and to respond to the needs of individuals who suffer from the syndrome through group meetings, educational programming and newsletters, financial and other support of research concerning the syndrome and the circulation of research results.

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