

Paulette, Mark, and Ann Talk about How Life Has Shifted during the Pandemic

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In late October, I interviewed three individuals who experience life with a disability from polio. They, like the rest of us, have had to manage and reinvent life during the COVID-19 pandemic. Currently living in three different American locales, they thoughtfully and candidly answered my questions about their quarantine experience. Paulette Bergounous lives in Nevada. Mark Mallinger is from California. Ann Crocker resides in Maine. Their personal introductions follow.



Paulette Bergounous

I had polio in my right arm at the age of two. I was taken from my family and hospitalized and placed in isolation in Cook County Hospital, Chicago,

Illinois. I was there for almost two months. Over the years I had gained some mobility and strength to the point that most people did not even know I had any disability. But 15 years ago, I started experiencing loss of strength and mobility because of post-polio.

I was fortunate over the years to be in a profession that gave me great satisfaction and in many cases was a lifesaver. I have a master's degree in the field of Communication Disorders and was a speech-language pathologist for over 40 years. Once I retired, I began to pursue an interest in developing a business that took my skills in another more personal direction. During the last two years, I have created a business that not only allows me to share my experience with polio but also help others who have lost the function of an arm or hand. "One-Handed Solutions" (<https://onehandedsolutions.com>) meets those two goals.



Mark Mallinger

I am a polio survivor who contracted the disease in 1951 at the age of eight. Polio affected my left leg and left me with a limp. Since the year 2000, I have relied

on a brace for support. When I initially heard the news about post-polio syndrome in the mid-'80s, I assumed I had dodged the bullet, for I experienced no new symptoms. However, by the turn of the century I began to feel pain in the affected limb and soon after it was suggested that I be fitted for a brace. I have lived in Los Angeles County for most of my life. I am a retired academic, but still engaged with Pepperdine University in a part-time capacity. Recently I've been involved with the Rancho Los Amigos Support Group in Los Angeles. The pandemic had caused them to cancel their monthly in-person meetings. For the past few months, I have been hosting Zoom sessions with the membership. Richard Daggett, the group leader, and I have collaborated to create an opportunity for members to continue their active fellowship.



Ann Crocker

In September 1952, I was diagnosed with polio just after starting kindergarten. I had paralysis from around my chin down to my toes. I was away from home for about a year, mostly at the rehabilitative

center in Bath, Maine. By that time, I only needed a lower leg brace and one cane. After a few months, the brace and cane were removed. While I never could do extensive physical activities, such as sit-ups or running more than a very few feet, I could get around adequately.

After about 25 years, I began noticing some subtle changes in my strength and physical endurance. Around 1983, my son saw an article in *Newsweek* magazine about other polio survivors experiencing changes, and Dr. Lauro Halstead was quoted in that article. I wrote to him, and he kindly responded with wonderful information and told me to contact Gini Laurie (the founder of PHI). Wow! This was an eye-opener for me and a great relief.

We got together with a few other polio survivors and went on to form our own group called the Post-Polio Support Group of Maine. At present, there is one small group around the Portland area which, before the COVID-19 shutdown, had been gathering for lunch once a month during good weather. The rest of our group members are scattered across the state. Now we all stay informed through our regular newsletter, which I edit.

During my adult life, I was lucky that I had jobs that interested me. Most of them involved helping others. Eighteen years of my career were at the State Housing Authority where I served as Director of the Homeownership Division, Manager of Special Assets, and Senior Officer for Project Oversight. Upon the strong encouragement of my physiatrist, I retired two days after my 52nd birthday. The long hours appeared to be weakening my physical condition. That was 21 years ago, and I have used my time since then doing volunteer work and helping family members. At present, walking is still possible but limited.

Each interviewee was asked the same questions about their pandemic experience. Their answers follow.

Interviewer: *Please describe your living circumstances during these lockdown months.*

Paulette: I currently live in Sparks, Nevada, with my two dogs Elsa and Mia, both rescue dogs. They have been a blessing during these lockdown months. Being able to take care of them during this time has really helped with being isolated from friends and family. They are also great listeners with no opinions! I have been on my own now for over 12 years as a result of divorce. I have been able to live independently with no assistance. But I am grateful for my neighbors, who during the winter remove snow from my sidewalk and driveway. My schedule every day is to wake up and meditate for at least ten minutes. Then I have breakfast and take my dogs out. After that I will begin to work on tasks that are related not only to my business but to my personal life, as well. This was a pattern that I had even before the lockdown. The only difference now is that I don't go out for meetings or speaking engagements. I use Zoom.

Mark: I live in a condominium on the west side of Los Angeles County with Arlene, my wife of 36 years; and I don't require outside assistance. Since the beginning of the pandemic we have lived, to some degree, in isolation. We visit the market about once a week, along with an occasional trip to Trader Joe's or Costco—obviously wearing masks while I carry a small bottle of sanitizer attached to my belt buckle. Prior to the onslaught of the pandemic, we were very active. Frequent visits to the theater, museums and getting together with friends had been our typical lifestyle.

Ann: I live in a small town near Augusta, Maine. My husband and I have lived in our current home for 40 years. Some modifications have been needed over the years, such as building another driveway in the back

to eliminate the need to climb stairs and putting in a small ramp to make entry and exit very easy, whether walking or using my scooter. We don't have any regular outside help. For the first five or six months of the COVID shutdown, our son and daughter-in-law insisted on doing our grocery shopping, but now I do about 80% of that. While the risk hasn't really lessened, I felt it necessary to restore some normalcy in meeting our day-to-day needs. We never leave the house without our face masks and hand sanitizer.

Interviewer: *What has been most difficult for you to deal with throughout this time of constraint?*

Paulette: I think the most difficult to deal with is not having opportunities to be with friends and other business owners. I have adapted very well to going out grocery shopping and to attending doctor appointments. But I miss the one-on-one contact when I was able to get together with friends. I have been creative, though, by using Zoom and by calling friends on the phone. But it's just not the same as being able to sit down in my living room and chat with them person-to-person.

Mark: I miss the freedom to get in the car and head off without concern about having to deal with the virus. Up until mid-March, there was no thought about restrictions of what I could do or where I could go. Certainly, I wish for that active lifestyle we led. However, I have found our new "life" has several benefits: I feel less rushed not having to juggle the numerous events we once planned. Again, having more time to work in the kitchen has led to us discovering a number of new recipes. With respect to the unexpected outcomes of the quarantine, having less patience with my spouse is one example. Given that we are together almost 24/7, there are times when we "lock horns," sometimes over trivial matters. Although my wife has been a wonderful partner and nurturer, spending more time together can lead to increased incidents of disagreement.

Ann: Daily living now involves careful planning to be sure we have all the essentials. My husband has been in the hospital twice this year, and his health condition is requiring more attention and care from me. Some of our grandchildren usually visit for part of the summer, and we pay them to help with seasonal and cleaning work. But this year that was not possible. I have really missed the loss of spontaneity, as we must be so careful and protective of ourselves and those around us. We can't merely decide on a whim to stop somewhere and visit or check out a new store or restaurant. The other thing that I miss very much is the abundance of hugs that

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were once in my life. Not being able to visit and hug my dear grandchildren and other family members is a big and unpleasant change for me.

Interviewer: *What has sustained you throughout these months of self-isolation?*

Paulette: My close friends and my canine companions. I talk to my best friend on the phone every day. It's not the same as when we used to meet on Sundays at my home, but it still keeps us connected. My dogs have been a godsend because I need to focus on something other than myself during this time, and the dogs require attention and affection. The routine with them has been critical in getting me through these times.

Mark: The sustainers during the past eight months include cooking, eating, exercise, streaming shows on TV, plus recognizing that the pandemic life will end sometime in the near future. My guess is that a vaccine is around the corner. It may not be available until mid to late 2021, but it will arrive.



Cooking offers a creative expression that is not only fun (usually) in the process, but in the outcome. It's a great experience to be able to enjoy my own creations. Exercise, especially swimming, for me has multiple benefits. I

like being in the water, freedom to push aside outside thoughts and concerns, and the sense of accomplishment when I reach my 30-minute goal. I do also find time for reading, either hard copy, digital or audible, but evenings are set aside for entertainment. Twenty-first century technology allows us to select from a very wide set of program content. It is not only entertaining and intellectually stimulating (depending on the choice of venue) but offers a distraction from the plight of the current environment. One evening, we especially enjoyed watching "Rising Phoenix" on Netflix.

Ann: Both my husband and I are relatively self-reliant. I always have supplies in our freezer and cabinets to maintain us for a few weeks at least. My strong faith enables me to get past some of the worst

hurdles—and I don't feel alone. Our wonderful family ties are a great comfort for both of us, and we stay in contact via phone, texting and Facetime.

Interviewer: *Upon reflection, what are three unexpected, good things that have come out of this quarantine experience—for you or others?*

Paulette: I have learned who my true friends are. I have also learned more about individuals with regard to what they value in life. I learned how to pivot my business during times like these, and in several ways the pandemic is the best thing that could have happened to my business. Now because I'm focused more on connecting via the internet, I can share information with more people than I could have by just going out and talking to groups as in the past.

Mark: The positives of the quarantine must include more available time, a greater sense of appreciation for what I have, and recognition of the importance of a loving relationship. With so many people in the US and around the world struggling with their health, their finances and their sanity, I am lucky that I do not face those challenges. My hope is that my wife and I can continue to remain healthy.

Ann: Despite all the negativity that is often portrayed in the media, I have seen goodness all around me. The kindness of neighbors and even strangers coming forward to help is so rewarding to witness. Even many businesses have stepped forward to offer free delivery services or modified production to provide much-needed medical supplies, such as face masks and testing kits.



Interviewer: *What advice would you pass along to our readers who have a disability from polio and are still forced to self-isolate? How to get through it? How to make the best of it?*

Paulette: My advice is to find a purpose and have a routine. So, how do you renew your purpose? Think about something you enjoy doing that is fun for you, which is a solitary task, obviously. Maybe you are good at knitting. Maybe you have a friend who is interested in learning how to knit. I would suggest that you google "how to teach knitting." You could



learn more about this skill; then, if they want, show your friend what the steps are involved in learning how to knit. You could then establish days and times in which you will go on Zoom to practice knitting together.

I always need to start my day with some type of reflection or silencing of my mind to focus and stay grounded. Then I can set up at least three things to accomplish that day. Maybe you'd enjoy painting; maybe you could make jewelry. It's also an ideal time to write. Do you have a book you have always wanted to write? This is the perfect time. Go for it! There are lots of hobbies out there that can get you focused and get you into a routine, but most of all, they will provide an important sense of purpose.

Mark: My three "pearls of wisdom" include staying active, committing to a positive attitude, and seeking support. Given the limitations we face, engaging in activities can be productive, while also allowing the passage of time.

I believe attitude has a huge influence on our psyche. Dwelling on the negative only exacerbates feelings of helplessness. Ask yourself, what can I do today that will make my life more meaningful or interesting. What do you like to do that is available to do? How can you incorporate that into your daily life? I'm not suggesting you deny feelings of doubt and concern, but don't let those thoughts dominate. Having supportive relationships is crucial. Those of you who live alone can be in contact with family, friends and workplace associates. Being able to share the positives, as well as your concerns, will open the space for valuable conversation that lets you know you are not flying solo.

Ann: As winter approaches, we all need to be more cautious in getting around. We can still communicate with others through so many social media outlets. Try to look for joy in our lives—it's there—we just have to value more of the little things. I'd like to sort out all my loose pictures and add them to picture

albums I already have. Reading is a big part of my entertainment, and once the wind and snows return to Maine, our jigsaw puzzles will keep us busy.

Interviewer: *Is there a question that I didn't ask that's important to answer? Please say more.*

Paulette: *What is your vision for the future?*

I've only lived in Sparks, Nevada for 2½ years. I came here to be close to family in Sacramento and to live by my dear friend and her husband of over 45 years. I thought that this was going to be my permanent residence for the rest of my life. But these last few months have forced me to look at whether this is the best place for me. I live at an elevation of 4500 feet above sea level. I've never lived at that high an elevation ever. At the beginning I adjusted, but due to the smoke from the fires in California, the high levels of ozone and UV, the winds and brand-new allergies, I am having to consider moving again. I have moved a lot over the last 12 years since my divorce. I'm quite good at the steps you need to take to make a move. It is not easy as you get older, but at the same time, my health is my priority.

Mark: *Has the pandemic brought back feelings you had when you contracted polio, in terms of helplessness, fear and anxiety?*

Following my hospitalization in 1951, I struggled with feelings of abandonment. I didn't recognize those feelings as such for many years. I did experience fear but did not understand the underlying source until many years later. At eight years old, I was taken away from my parents, friends and family. There were many episodes where fears of abandonment showed up in my life (e.g., relationships ending, parents dying). When watching TV or reading the news about COVID patients isolated in the hospital and passing away without visits from family, it brought back distressed feelings associated with my early polio struggles.

Ann: *How do we nurture our loved ones and take care of ourselves at the same time?*

All of us have stressors in our lives. These worries can be financial, environmental, family-related or include a variety of other issues. Some of us are caregivers of others or have family issues that are very taxing. Still, we also have our individual personal issues that we can't ignore. I think it is important to find a daily balance of giving others what is needed and giving ourselves some essential time, care and attention, too. ■