

AJC Home Edition
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As children they fought off illness, but new pains, problems arise when Polio strikes again

M.A.J. McKenna / Staff,
Warm Springs

On a breezy spring morning in a historic building in Middle Georgia, a group of men and women catch up on gossip, nibble fruit and coffee cake and complain about their bodies betraying them.

It could be any gathering of older adults, a bridge club or a Bible study group, pausing to lament the inevitabilities of aging. But small signals --- the glint of a brace below a freshly pressed trouser cuff, a pair of crutches lying beneath a chair --- suggest it is something more.

"Does anybody else have fever at the end of the day?" asks Jan Snider, 71, the perfectly coiffed wife of a retired minister.

"My throat just slams shut, " says Jill Harman, 52, a computer specialist. "If I didn't have my husband there to hit me between the shoulder blades, I think I would die."

"For one hour, just one hour, I would like my husband and my daughter and my son to experience what I've been through, " says Carolyn Haege, a Thomaston grandmother.

Their common complaint is an old foe, forgotten by most of their friends and neighbors but painfully vivid to them: polio.

It has been more than four decades since vaccines relieved most Americans of the terror of polio, which could leave a healthy toddler limp and crippled overnight. To those born after 1956, when the Salk vaccine went into use, the paranoia of the epidemic years --- more intense than the early days of AIDS hysteria --- is almost unimaginable.

But to the 1.63 million polio survivors in the United States, the fear and panic of polio are not merely a memory. Up to 40 percent have developed, or are expected to develop, the severe muscle weakness, pain and deep fatigue that are collectively called post-polio syndrome.

The new disability, not life-threatening but frequently life-altering, usually comes as a shock. It can take away the ability to cradle a grandchild, to walk without assistance, sometimes even to breathe freely. There is no cure, although adaptations can make life easier and slow the syndrome's progression. Survivors are left feeling twice victimized by polio --- and this time round, there are no national campaigns to help them and no poster children to draw attention to their plight.

Snider, who lives in Riverdale with her husband of 48 years, doesn't remember her initial experience with polio. She was only 6 months old, the daughter of farmers in southeast Alabama, when it struck. The virus weakened many of the muscles in her legs and left her with a deformed foot and an unusual spinal curvature.

Despite those effects, Snider brimmed with energy. She refused to use crutches or even wear corrective shoes. She was a high school cheerleader. She became a typesetter for several Southern newspapers, including The Atlanta Journal, and conducted choirs and Bible schools in her husband's congregations.

"I just sort of forgot I'd had polio, " she said. "Then in my 50s, I began to go backwards. I became very frustrated because I thought when you have had polio, it is over and done with."

So did her doctors.

But then, decades after believing she had beaten polio, she began to experience aches and pains, nightly fevers and overwhelming fatigue. She was falling --- she has broken her legs and ankles five times --- but complete physicals at Piedmont Hospital turned up no explanation for her symptoms. Then by chance, in May 1986, she watched part of the ABC News magazine "20/20" and caught the closing remarks by anchor Hugh Downs.

"He said, if you have these four symptoms --- fatigue, flu-like aches and low-grade fever, and you are falling without stumbling first --- you should go to San Francisco, the Mayo Clinic or Warm Springs," Snider recalled. "So the next morning I called Warm Springs, and they had already had such an influx of calls they could not see me till August."

The clinic staff confirmed her suspicions: Post-polio syndrome was taking away the control she had painfully regained over her remaining leg muscles. They cut back her activities, asking her to stop swimming for exercise and to use an electric scooter. With some reluctance, she has complied.

"I don't do much, and I use my scooter. That way I can avoid the fatigue and fever," she said.

Snider's husband, T.W. --- at 91, a strikingly handsome man with a shock of pearly white hair and a voice so strong his preaching never needed amplification --- cleans and vacuums and maintains their huge vegetable garden. Snider says she has learned "to slow down in my mind. I have had three doctors tell me that I have no walking muscles, and they cannot believe that I walk at all. But I am not at the stage where I want to stop walking."

Groping for a definition

Post-polio is as surprising to some physicians as it is to patients. It is a relatively newly recognized problem. The first scientific meeting about it, at which the syndrome was formally defined, occurred 16 years ago at Warm Springs. Researchers still disagree on the symptoms, definitions and degrees of severity. On the same morning the Warm Springs Post-Polio Support Group met last month, a contentious conference on post-polio was taking place in the building next door.

"It is actually a very common problem; it is just not recognized," said Dr. Barbara Vickrey of the University of California at Los Angeles, citing federal research in which only 28 percent of former polio patients said they were "still at their physical best." But survivors who have lived for years with polio disability often suffer from a slate of problems --- arthritis, obesity, intractable pain --- that arise from their limited mobility and use of crutches and canes. Those symptoms are difficult to tease out from the symptoms of post-polio syndrome, making it hard for researchers to find pure cases of the syndrome to study. "We still don't understand the pathogenesis of post-polio syndrome," said Dr. Lauro Halstead of the National Rehabilitation Hospital in Washington. Halstead, who chaired both the recent Warm Springs conference and the first one in 1984, is considered the father of post-polio syndrome. He himself is a polio survivor, and he began to study the syndrome after he developed its perplexing symptoms in the early 1980s.

"There hasn't been a tremendous amount of research," he said. "There is not a lot of funding."

Warm Springs is an appropriate setting in which to struggle to define post-polio syndrome. Once a fading 19th-century spa, it was remade by Franklin Delano Roosevelt into a treatment center for polio and a refuge for patients. And although FDR concealed the extent of his disability while outside Warm Springs, his willingness to be publicly identified with polio and Warm Springs redefined the disease itself.

Polio had been recognized by medicine for centuries, but emerged as an acute American problem only in the 1900s. It was initially blamed on immigrants and the poor. FDR's advocacy, along with the upper-class patients he drew to Warm Springs for treatment, changed polio's image. It became a malady that did not respect income or status and did not deserve to be stigmatized.

That stigma could be extreme: The discovery of a polio case could cause a family to be ostracized, and quarantine notices could close off streets and neighborhoods. Haeger, who comes from Little Rock but moved to Thomaston to be close to both her family and Warm Springs, was never told she had had polio. Then in the 1990s, she found herself losing strength without knowing why.

"My father saw a program about post-polio syndrome on TV and called me and said, 'You must have this because you had polio when you were 5,' " she said. "I never knew that. I just knew that I had headaches and that I hurt all the time."

Painful memories

Most of Warm Springs --- now called the Roosevelt Warm Springs Institute for Rehabilitation --- no longer focuses on polio. But former patients still flock there because it is one of the few places in the United States working to define and treat post-polio.

They come with mixed emotions. Children who were sent to Warm Springs found themselves in a society where almost everyone looked like them: in wheelchairs, on stretchers or crutches. It was a relief from being kept in protective isolation, but the treatments they received were agonizing.

"I had a great time here," said Chris Cash, the former publisher of the Atlanta alternative paper *Southern Voice*, who was at Warm Springs for six months in 1955. "We had wheelchair races, we went to movies on campus; it was like a spend-the-night party all the time. But the pain after the surgeries was just incredible. There's nothing like bone surgery. And the physical therapy was grueling."

Cash, now 50, contracted polio when she was a year old. It destroyed the motor nerves in her lower right leg, immobilizing the muscles. Within a few years, tendons in the leg contracted, curling her foot around and down. As part of her treatment, her right ankle was frozen in a procedure called a triple arthrodesis. She can flex the foot, but not point it or move it from side to side.

Another common remedy for polio deformity was called heel-cord lengthening done by partially slitting the Achilles' tendon and forcing it to stretch as it healed. Judge Frank Cheatham of Savannah, who lost the use of his left side to polio before he was 2 and underwent surgeries at Warm Springs for five summers in a row in adolescence, had it done twice to each leg.

"Your feet would drop, so you would be walking almost on your tiptoes," he said. "They would put you in a plaster cast and put a block inside it, and then they would come back a day or two later and force a larger block inside. It was extremely painful."

Patients at Warm Springs were forbidden to focus on their disabilities. By the time they returned to the real world, they were expected to be as good as the able-bodied, or better.

"The whole push was for you to be as 'normal' as possible," Cash said. "You were not allowed to express any feelings of grief or what they would have called self-pity. We were expected to excel."

That unconquerable spirit served them well. As a group, polio survivors have higher rates of marriage and employment and more years of education than most U.S. residents. But the same toughness also may have betrayed survivors by predisposing them to post-polio syndrome.

A marathon every day

To live seemingly normal lives, polio survivors expend extraordinary effort --- by one researcher's estimate, the equivalent of running a marathon every day.

"The way they learned to fit in was to deny they had even had polio," said Dr. Richard Bruno of Englewood Hospital and Medical Center in New Jersey. "They can make themselves walk without muscles, and they can hide that they hurt all the time. But they can't do it forever."

Bruno is a leading researcher in the psychology of post-polio. In three national surveys, he found former polio patients were more likely to have been physically or emotionally abused as children, more sensitive to criticism and failure and much more likely to be Type A personalities: hard-driving, overachieving perfectionists.

"The more Type A they are, the less likely they are to even acknowledge that they have post-polio syndrome, let alone be evaluated for it and adhere to treatment," Bruno said. "Everything they were taught in order to be safe has to be turned on its head."

Cash is still learning that lesson. At 12, she threw away her leg brace. She had the last of five surgeries at 13. She was left with a slight limp that grew worse when she was tired.

"I've always had a tremendous amount of energy: played tennis, played softball, played soccer, go, go, go," she said. "Then a few years ago, I noticed I was just exhausted at the end of the day. I started having lots of muscle twitches, not just in my leg but everywhere."

She began to lose the grip in her left hand, the one she uses to throw a ball, hold a tennis racket and write. She was diagnosed with post-polio syndrome at Warm Springs in 1997 and soon after sold her newspaper and moved to the Florida coast with her partner. She sells real estate part time and fights the impulse to make it full time.

"I have to pace myself," she said, "which has been a really hard thing to learn how to do."

Bruno has heard that before. "Post-polio syndrome is eminently treatable if people take care of themselves," he said. "If they can learn to go from the old model of 'use it or lose it' to 'conserve it to preserve it,' they will plateau or get significantly better. The problem is getting them to adhere to that treatment."

Patients in the Warm Springs post-polio program are treated by a team --- a nurse, a physical therapist and a brace maker --- headed by Dr. Anne Gawne. Typically, they undergo a two-day evaluation, then return periodically for physical therapy, testing and help with assistive devices.

"It is an overuse syndrome, so we try to avoid overuse," Gawne said. "We get them to rest, we treat their pain, we deal with any degenerative problems they have developed. It is a lot of brace work, a lot of prescription wheelchairs, a lot of tuning up. There is no magic medicine."

The lack of a silver bullet is a source of bitterness for many post-polio patients. Many feel ill-served by medicine, because doctors often miss or misdiagnose the syndrome, and underserved by the pharmaceutical industry, because few drugs have been explored.

"Understanding of this is still quite poor; patients get bounced from doctor to doctor," said Halstead of the National Rehabilitation Hospital, who supervised Gawne's training. "It is the worst

feeling in the world, to recognize changes in what you can and can't do and be told it is all in your head."

But awareness of post-polio is likely to increase, largely because the number of patients experiencing it is expected to explode. It takes, on average, 40 years from the time of polio infection for the symptoms of post-polio syndrome to appear. The Salk vaccine ended new U.S. cases of polio 44 years ago. The last American generation of polio survivors is just about to reach the age when post-polio appears.

"There were big epidemics in the U.S. in the '40s and '50s," Gawne said. "Most of those patients are just starting to get into problems now. Post-polio is not going to kill them. They are going to live on into their 80s. So we have another 40 years of treating post-polio patients, whose problems over the next 40 years will just get worse."

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POLIO NOW: THE SYNDROME: 'I am headed for a wheelchair'

M.A.J. McKenna / Staff,
Waverly Hall

Bill Crowell remembers the day he developed polio. He was almost 8 years old, a bantamweight redhead growing up in Minnesota, when he stood up in his family's home and one leg crumpled under him.

But if that day ever slips from his memory, he has plenty of reminders. A spine fused with bone chips. An ankle locked in a right-angle bend. A sheet of polyester implanted in his abdomen to hold his internal organs in place. Nine feet of surgical scars up and down his body.

It took almost four years of surgeries and hospital stays to undo the damage that polio did to Crowell, but the torturous treatment eventually left him strong enough to make it through adulthood using only a leg brace and a cane. He moved to Georgia, raised a family, taught public speaking for almost 30 years at Columbus State University and planned a retirement sailing the Caribbean on his 38-foot boat.

And then the past caught up with him.

Crowell had fought the effects of polio to a draw, but in 1988, at age 50, the first symptoms of post-polio syndrome began to emerge.

"I thought I had beaten post-polio, and then I began to suspect I hadn't," he said. "But what do you do when your body lets you down? You have to go on."

Today, he uses two crutches inside his ranch-style house and an electric scooter with fat tires and a green-flake finish to navigate the garden outside. The boat has been sold; the proceeds bought the 23-acre hilltop property where Crowell, 62 and retired, lives with his second wife, Rita.

Coming to terms with post-polio has been a difficult struggle for a man so intolerant of limitation that "I used to race people to the door so I could hold it open, as a gentleman should," he said. "My racing gear no longer works. When someone opens the door for me now, I smile and thank them --- but oh, that is hard to take."

About 12 years ago, Crowell began to notice his energy ebbing. That was followed by muscle tremors, first in his weaker leg, then in his upper body --- an ominous sign for anyone who depends on a crutch or cane. One day, without warning, his legs gave way in his bedroom. In the following months, he fell several times more.

That launched him into the process of relearning that many survivors face: If they expend the extraordinary effort they have always used to counter the effects of polio, they accelerate the rate at which their post-polio symptoms get worse.

Crowell's response has been to prepare for what he believes to be the inevitable: the day he can no longer get along under his own power.

He is making his new home, where he and Rita live with two dogs, a cat, three Pekin ducks and two donkeys, as maintenance-free as possible. He used 6x6s instead of 2x4s, telephone poles for fence posts and a roof with a 25-year guarantee.

"I expect I am headed for a wheelchair, " he said with a catch in his voice. "It's important I get all of this done first."

With foresight, he also has begun to turn his property into a sort of adult playground for the disabled, complete with a pond, a small pistol range and a nature trail wide enough for scooters and wheelchairs. He has laid out a 1,400-foot runway and plans to order an ultralight --- a small-scale plane that does not require a pilot's license, for which he would not qualify medically. And he has cleared enough land for airplane hangars --- not just one for himself, but six.

"I spent my professional life communicating, and now I am sometimes alone here 12, 14 hours a day, " Crowell said. "I'd like to encourage people to come visit."

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POLIO THEN: THE VIRUS

'He is allowed to sit up an hour a day'

M.A.J. McKenna / Staff,

In the peak years of polio, Warm Springs kept patients safe from stares and snickers while they worked to regain their health. But for all the protection it offered, it also was a place of pain and isolation: The surgeries were excruciating, rebuilding strength took extraordinary effort, and patients were forced to live far from their families for months at a time.

Most left without looking back, but a few recorded the experience. One was Bertram Paul Schmitt, known as Paul, who contracted polio at age 17, just days before he was to enter college in 1939. He arrived at Warm Springs on a gurney in January 1940, paralyzed from the shoulders down, and left at Thanksgiving, walking on crutches and with a brace on one lower leg.

During his stay, he wrote home every week; when his mother, father or younger brother visited, each wrote to those who had stayed behind. Reading the letters, preserved in crumbling scrapbooks in the Roosevelt Institute's archives, provides a glimpse into the patience and determination that polio treatment demanded.

Paul arrived at Warm Springs by train Jan. 8 with his mother, Edna Diehl Haines Schmitt. They had been traveling for almost 24 hours; Paul was encased in a cast from hips to toes, topped by a tightly laced corset to support the weakened muscles of his trunk.

"Nearly everyone you see is apparently hopelessly crippled, " Edna wrote to her husband, Bertram, and younger son, Bob, that first day. "Just after dinner, a few minutes ago, they all got out of their wheelchairs and with an attendant before them and behind them, they (tried) to walk a few steps with crutches. I nearly wept in front of them."

"Dear Fish-face, " Paul wrote to his brother several days afterward. "I thought I was heavy, but since I have been lifted on and off stretchers by an orderly and a nurse, I have changed my mind." In a note to his father, at the end of the month, he confided: "I guess I'll be in bed for about a month yet. It seems they don't, as a rule, let patients sit up for six months."

"I'm beginning to want to sit up in a wheelchair, " Paul wrote on Feb. 16. "The (exercise in the pool) isn't hurting as much anymore. I guess my muscles have just decided to quit." Three weeks later, he announced: "They are going to let me sit up. I don't have to wear my night splints any more. As soon as they refit the corset and make (arm) splints for the chair, up I go."

On March 17, Bertram Schmitt visited his son. "Paul looks very well and is very cheerful, but I'll tell you frankly I came back and cried for the pity of it, " he wrote to his wife. "He is allowed to sit up an hour a day."

A month later, Paul was still unable to move on his own. "I had a muscle test today instead of next week, " he wrote hopefully on April 26. "I should start to get motion now because the muscles are almost strong enough for it." By the end of July, he could report: "I can put myself in my chair now, and get out again, too. . . . I'm also starting to dress myself."

In mid-August came big news: "I'm going to get a walking brace, (but) I don't think the brace will be finished for a few weeks, so I won't be walking before September." He added, a few days later: "I've been trying to swim. . . . You never realize how much you use your legs until you can't use them at all."

By the end of September, Paul began walking short stints with full-length crutches, graduating in late October to the shorter forearm version. "They are pretty hard, " he reported. "I'm still working on steps, but I'm not having an awful lot of luck as yet. . . . I want to be able to do them well before coming home."

Paul Schmitt left Warm Springs on Nov. 27, 1940. Four years later, he was awarded a bachelor's degree in marine engineering from Massachusetts Institute of Technology. He married twice, had no children and died in 1982.
