

POLIO NETWORK NEWS

International Polio Network

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A Review of Swallowing Difficulties in Post-Polio Individuals

Roberta Simon, R.N.

In response to a request in the Spring *Polio Network News* (Vol. 6, No. 2), I received several letters from individuals experiencing swallowing difficulties (dysphagia) that I would like to share. First, I would like to say that most letters were from people who knew they had had bulbar polio. A few individuals were uncertain because they were young at the time of their original illness, and they had not been told of any such problem by their family members or had not obtained their hospital records. One individual had hospital records but felt they were vague as to the involvement.

In looking at some of the personal experiences shared with me, I found that swallowing difficulties are no different than other difficulties we are experiencing. They vary greatly with each individual. It is pretty obvious that we are just as unique with these experiences as we are with all other aspects of the late effects of polio. In other words, an individual evaluation and a treatment plan must be developed for each one of us.

Swallowing is a complex mechanism involving many functions. If any of these areas are affected, different symptoms develop. (We will discuss this aspect in detail later.) First, I want to share with you a summary of the letters I received.

One person had a hiatal hernia and symptoms were controlled with medication. (The author would like to
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"Prescription for Pain" from Fifth International Polio & Independent Living Conference in Saint Louis

Polio survivor, **Sunny Roller**, Ann Arbor, MI, introduced the topic of pain by sharing her experience and personal point of view. A panel of physicians then offered thoughts and solutions to the problem of pain. The panelists included **Ernest Johnson, M.D.**, The Ohio State University College of Medicine, Columbus, OH; **Thomas P. Anderson, M.D.**, Spaulding Rehabilitation Hospital, Boston, MA; **Frederick Maynard, M.D.**, University of Michigan Medical School, Ann Arbor, MI.

SUNNY ROLLER: New pain, muscle weakness, and general fatigue are common complaints of post-polio individuals who fought polio once and won, but are now reluctantly having to return to rehabilitation after a 30-40 year reprieve.

Along with muscle weakness and fatigue, new pain is the most common complaint of people with the late effects of polio. It is what drives them to the doctor's door, causes sleepless nights, and eats away at their ability to get through a productive day. My pain came in dual form. It was both physical and emotional, each form feeding the other and gradually increasing over the course of four years, to finally overwhelm me.

It became something I couldn't just get through by minimizing, like I always had in the past. It's hard to clearly remember but I must have continually lived in some kind of pain since contracting polio when I was four years old. During the acute stages I was completely paralyzed: only able to move one finger. The physicians gave me ten days to live.

For the next ten years, I worked with the determination of an olympics-bound athlete coming back from that near-death experience. No pain, no gain, the voices would say. My parents became my primary coaches, providing the encouragement, resources, and training that I needed. How, I wonder, did I assimilate the emotional pain they inadvertently must have communicated at the loss of a healthy child? They were my private rehabilitation team. Nine months in

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a rehabilitation hospital-school. Ten years of exercise routines and five major orthopedic operations.

As I grew, I know they gave me morphine in the hospital, but I don't clearly recall the pain it alleviated. I was scrutinized by tall, well-tailored doctors in gray suits and shiny black shoes once every month. At the age of fourteen I was happy to say good-bye to their alert somber faces and objective eyes. I remember hating to get new shoes because I had to stuff crooked feet into straight shoes. It was the same with new braces that pulled and pinched and poked in new places. But I did manage it all with success, often ignoring the irritations and riding along on my personality.

I went to suburban public schools. I was mainstreamed. I graduated from a state university in 1969. I taught high school college-prep English for ten years, then supervised a university co-ed dormitory for three years while working on my Master's degree. Suddenly, I started to cave in. It was thirty years after I had contracted polio: I was 35. I didn't understand what was happening to me. I started to feel a tremendous amount of new pain in my back and left hip area when I would sit up in bed every morning. All of my physical activity, including standing, sitting, walking, or reclining became more and more uncomfortable, and I was losing much stamina. I resigned from my job at the University because of the pain, weakness, overall exhaustion, and a pervasive new sense of inadequacy.

After seeing five medical specialists who each told me something a little different, and nothing that seemed

conclusive, I was referred to the Post-Polio Clinic at the University of Michigan Medical Center. The following evaluation and prognosis became the ones that I intuitively accepted: post-polio syndrome, inflamed tendons in left hip area, bad scoliosis, rotated pelvis, some arthritis, some deformities, lose ten pounds, take aspirin for musculoskeletal pain, go to physical therapy, use an electric cart, get a right shoe lift, conserve energy.

When the physician told me all the things that were "wrong" with me, my tears revealed relief in that formal knowledge, and initiated my submersion into a whole new set of feelings that I had never experienced with such intensity. As unique as our distinguishable disabilities are, so the intensity of our feeling will vary. Nevertheless, the late effects of polio generate similar emotional responses that do not go away quickly.

One of the first and strongest emotions that I felt when the doctor told me to slow down ... things weren't going to get better ... expect a one percent per year muscle loss ... make adjustments, was an overwhelming amount of emotional pain. Why me? Again? Emotional pain layered on top of physical pain. What did I do to deserve this?

There is an amount of grief accompanying a new sense of loss. So much of me ... gone. Not only had I lost some of my energy level, strength, stamina and functioning; I was starting to lose my earning power. I could never be the yuppie that I always wanted to be. Would I ever own a house? Would I ever be able to earn enough money? How can this be? I was one of the golden, talented, socially-aware baby-boomers! I felt tricked, and hence, very, very sad. I also felt that I had lost my sense of identity. I had been a teacher and I was proud of it. Would I be able to endure a six-hour

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day, trying to stimulate and motivate the typical American teenager? I was lost and my sense of self-worth plummeted to almost zero. Who am I now? Suddenly I was just a sick person: a needy woman with a lost capacity for giving. Would I look so funny that they wouldn't want to be seen with me? Would I have any sex appeal?

Fear becomes an insidious intruder. What's going to happen to me physically in five years? Ten years? What will it really mean to lose one percent a year? Will I lose the use of my right hand? How will I write? I love to write. Will my respiration go next? I don't know. Financially, what is going to happen? Will I be able to get disability pay? Is insurance going to cover me?

Another strong feeling that I have is guilt. Now that I'm more disabled, how much more of an imposition will I be to those around me? I am already more of a burden than I would choose to be: people have to help me constantly, in spite of an achieved amount of independence on my part. Surpassing all of those feelings is anger, sometimes qualifying as rage. Why did nature do this to me? It is not fair.

Due to these unwanted complications that I'm trying to deal with, I feel very high levels of stress. There are so many new changes and adjustments to make. There are so many complexities to deal with physically, emotionally, intellectually, and spiritually. I feel ashamed, vulnerable, and defensive because I've been weakened. Yet I still need to maintain some pride. I am also resistant to any new plans for rehabilitation. I don't want to walk back into a hospital. I was in hospitals for 14 years and they were sad places filled with trapped people in pain.

Pain was all over. Inside and outside. The worse I felt, the harder I fought. The more I fought, the harder I was on myself. "What's wrong with you?" "Get going!" "Quit thinking about yourself so much!"

But today, six years later, the overwhelming pain has subsided. Within nine months of my physical therapy and getting a shoe lift, I was back to minimal, manageable physical irritations. With the help of several kind, patient, respectful professionals and dear friends, I have gradually renewed and found relief from many of the self-doubts and much of the self-abuse. My objectivity is restoring itself. The emotional pain layered on top of physical pain may never go away completely for me, but it can be managed. And that's great to know. There is hope and there is help. One must actively choose to be hopeful and assertively seek that help for it's out there — waiting to be discovered.

DR. JOHNSON: Pain is an impulse along the nervous system until it reaches the sensory cortex of

the brain when it becomes modified and is expressed as pain in your consciousness. One of the things that affects your perception of pain is a memory of a previous experience. If you have never experienced pain, you won't appreciate it as much. On the other hand, if you have experienced it in the past, it can be very severe. The most important consequence of the pain is how you respond to it.

The number one reason post-polio people seek help in our program at Ohio State is pain. Only after we gather history do they say, "I'm losing a little strength, or I can't do what I did before."

The number one treatment method is to find the cause and remove it. This requires some investigation. Once we have determined what causes the pain, we suppress it by overloading the input.

Putting a tight bandage on a cut will alleviate pain. The TENS unit (transcutaneous electrical nerve stimulation) works on the same principal. We use medications to suppress the kinins, which are chemicals that the body releases to stimulate the pain fibers. We can block the transmission of pain by injecting novocain. We can occupy the pain receptors in the brain, so that the impulse will not cause the appreciation of pain. We attempt to increase our intrinsic narcotics so they'll occupy the pain receptors, and then we won't need extrinsic narcotics like morphine.

Fibrositis or fibromyalgia causes some muscle and in our judgment is the most common cause of muscle pain in any population. We diagnose it clinically with these findings: 1) the jump sign 2) a "ropey" consistency under palpation 3) extreme dermatography (which means you can write on the skin and if you wait just a few seconds more, that reddened area will actually raise a little bit) 4) complete relief of pain in about ten minutes when sprayed with ethyl chloride or fluorimethane.

Fibrositis causes pain in the posterior shoulder, the neck, the low back, the lateral buttocks, and the thigh. We have to exclude other reasons for pain, but if it turns out to be widely scattered muscular pain the diagnosis is usually fibrositis.

The onset of fibrositis or fibromyalgia is insidious. Some doctors may say there's nothing wrong with you. We see it often after an acute injury. We call it muscle strain and treat the acute muscle pain with an injection of novocain and a cold pack, or fluorimethane coolant spray, ice massage, and superficial heat.

We also have another technique to raise the threshold of muscle pain. Individuals are put on a low sodium diet and a medication, such as Lasix, for three successive days each week. Of course, we make sure that

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they have plenty of potassium. Dried apricots, bananas, and orange juice are foods that are high in potassium.

Several of our post-polio people go through the sleep lab in order to identify any sleep disturbance which is generally referred to as a non-restorative sleep pattern. Individuals sleep for eight hours or the pain may wake them up a couple times. When they wake in the morning, they feel as if they haven't had any sleep at all. We use Amitriptyline at that time.

DR. ANDERSON: There are many different classifications of pain for people with residuals of polio. It might be an oversimplification to say that there are two principle types; one is joint pain and the other is muscle pain. The joint pain is usually straight-forward and due to mechanical stresses on the joints from weaknesses or deformities or tightness.

But the muscle pain due to fatigue or overuse of a weak muscle is complicated, and I'll leave that for someone else to cover.

What I want to talk about is pain associated with contracture or tightness. I am old enough to have had a lot of experience with acute polio and have been following polio survivors for over forty years. During the acute phase of polio, tightness is often the most prominent symptom. If you ask people, they don't remember the weakness as much as the tightness and that tightness was often quite painful.

After Sister Elizabeth Kenny came to this country from Australia, polio was treated with hot packs and stretching exercises. If one did a survey it would be interesting to see how many of the deformities were due to weakness and how many were due to tightness? There are many people who feel that tightness plays a greater role in producing deformities after polio than weakness.

The tightness that was present in acute polio tends to recur. Many people, including a lot of physicians, tend to overlook this. There's something that can be done about the tightness and it's important not to forget that.

You question people about their care with acute polio, and they recall years of exercises. Generally, people were told that they should go through some exercises, not to get themselves stronger, but to prevent reoccurrence of tightness. Many were told that they should be doing these every day for the rest of their lives. My guess is that very few people took this seriously and after awhile they forgot why they were

doing the exercises. In addition, they were not getting any stronger and wondered why exercise. They discontinued them, and then the tightness tended to subtly sneak back. (I recently reviewed the literature on post-polio and I was disappointed to see how few authors mention the reoccurrence of tightness.)

Recently with one of my residents, I saw a 67-year-old woman who had pain in her calves. I asked if she had heel cord tightness. Obviously, the answer was no because both ankles would come a few degrees above a right angle. Knowing it was supposed to be more than a few degrees, we taught the woman how to stretch her heel cords. She said, "I remember doing that when I was a child." She did the stretches in the office and walked some more. She said, "The pain's gone!" That was rather dramatic, but I don't think the resident will ever forget the point. It's subtle but some people can lose an enormous range of motion in their shoulders due to tightness and experience no pain. Somebody else loses only a few degrees and it becomes painful.

What causes this pain? Is it due to the tightness itself? Is it due to fatigue in the tight muscle? Or is it due to fatigue in the antagonistic muscle?

There is a phenomenon that occurs in polio where the weakness tends to be new. It occurs 30 years or more after the onset of polio and people know they were never that weak in that muscle before. An explanation is that the muscle may be antagonist of one that has tightness. A common example is the dorsiflexor muscles that pulls the foot up to clear the toe while walking. If tightness develops in the calf muscles, the dorsiflexors have to work harder against that tightness to pull the foot up. The dorsiflexors can become weaker over a long period of time.

We see this, not only in polio, but in people who have contractures associated with spasticity or other kinds of problems. The interesting thing is that when a muscle has to work against tightness in its antagonist, it has to work extra hard and it can develop pain and/or weakness.

During the acute phase of polio, even though the stretching exercises were not pleasant and not comfortable, individuals remember that after the stretching exercises were done, they often felt very relaxed and relieved and would take a good nap. So, even though stretching exercise is uncomfortable, it does help relieve pain.

I believe that one of the important parts of the examination is to check the polio patient for tightness because it's an ever present problem with anyone who has ever had polio. This is a phenomenon that is present in the acute stage and it tends to stay with

people who have had polio. My suggestion is that in the management of residuals of polio, particularly pain, we should remember to check for tightness, and if it's present, institute correction. Stretching exercises are quite painful and some heating beforehand helps tolerating the stretching.

DR. MAYNARD: If we are clever enough to find the causes of a pain problem, most of them can be diagnosed and treated. There are actually few mysteries about the pain problems that are occurring among people with a history of polio. I would like to discuss the most frequent kinds of pain problems seen in our Post-Polio Clinic according to the location of pain in the body.

First of all, we see a lot of pain problems in the upper limbs. Many of the people with polio had worse involvement in their legs, and therefore they have been using their upper limbs for most of their life activities. This results in frequent stress and strain syndromes to upper limb muscles and joints. When degenerative arthritis occurs in the shoulder joint, it can be treated with physical therapy, anti-inflammatory medication, and icing. If a shoulder joint is very severely involved, steroid injections can be helpful when used judiciously. Shoulder pain more often results from tendonitis or bursitis and it responds to traditional therapeutic approaches.

Elbow and forearm pain usually results from repetitive strain. In the so-called "tennis elbow syndrome," or lateral epicondylitis, there is a very small ripping of the fibers that attach the forearm muscle to bone, and they get inflamed when their stretched harder than the forces they can withstand. Ripping can also happen in a muscle tissue, particularly when it is "eccentrically loaded." An eccentrically loaded injury occurs when a muscle is contracting at maximum force while it is being elongated. As an example, consider the biceps muscle that flexes the elbow. When it is controlling the fall of a heavy object in the hand, it is much more subject to injury than when lifting the same weight because its maximum contraction force results from shortening of microscopic muscle fibers while at the same time the entire muscle body is being elongated. These eccentric contraction injuries are often subtle, and, if they occur repetitively, can be chronic and very painful.

Pain can respond to heat or ice, but ice is more effective when injuries are acute. A gentle amount of repetitive stretching followed by resting allows the muscle injury to heal. However, although pain subsides when an injured muscle is rested, it then becomes weaker and can be more easily irritated and strained again when it is next used. Thus, rest alone can lead to a vicious cycle of pain and strain.

The goal of curative treatment is not to immediately eliminate the pain but to begin stretching the muscle and its fiber attachments to bone so they can handle higher forces without strain. When this is accomplished, pain will begin to resolve. For the patient, participation in the strengthening exercises takes a lot of patience, persistence, and belief that the pain will get better! A physician also must believe in the effectiveness of the treatment because if he/she does not persevere with this approach and radiate optimism and conviction, then he/she will not be able to support a patient in following through with the treatment program.

Pain in the hand and wrist often results from "wear and tear" arthritis. When using wheelchairs, crutches, and canes, most body weight is transmitted to the thumb side of the wrist and to the lower joints of the thumb. People who depend on their upper limbs for their functional independence can find these pain problems very disabling. Joint injection, short-term splinting to immobilize the joint, anti-inflammatory medications, and judicious use of ice and heat are the best treatment approaches when prescribed on an individualized basis.

Research studies done at the University of Michigan have shown that carpal tunnel syndrome (CTS)* is very common among post-polio survivors and is related to cane and crutch use, wheelchair pushing, and using hands for transfers. During all of these actions, the wrist is generally kept in a fully extended position and body weight is transmitted through the wrist. Large compressive forces are generated at the wrist in the space where the median nerve runs through the carpal tunnel. This can compress the nerve and produce tingling and numbness of the hand and forearm. It can also result in atrophy of the small thumb muscles of the hand or sensory loss around the thumb.

Because thumb damage is such a common sequela of acute polio, it is hard to tell whether its presence is new and whether it is from carpal tunnel syndrome or post-polio muscular atrophy. Traditional treatment for CTS with splints, injections, or surgery is often ineffective in post-polio patients so preventative measures are very important. One preventative intervention is changing how the hands are used. Crutch and cane handles that are much wider, or have rounded and cone shapes, can better distribute weight through the wrist and hand and lead to reduced irritation and pain. Changing use patterns is one of the most important treatment strategies for all of these upper limb problems. If the pain is from repetitive strain, you must change how the injured part is being used.

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In my experience, most hip girdle pain is due to muscle strain. Muscle tightness and myofascial pain must be looked for and does occur, but pain more often results from straining hip muscles repetitively during walking. Again, effective treatment often necessitates changing walking patterns. One of the simplest ways to relieve hip muscle strain is by using a cane. One lady bitterly complained to me about hip girdle pain, and I recommended that she correct her gait abnormality by using a cane. However, she had what I call "canophobia." After lengthy debate, I suggested that if she broke her leg, she would use a crutch until the fracture healed and that her hip pain was a similar problem. I urged her to use the cane long enough to find out whether or not it would eliminate her pain. Afterwards, she could decide whether she preferred the pain or the cane. I think this analogy was helpful because it allowed her to stay in control of her own life and make her own choice.

A common source of pain around the knee is genu recurvatum or "back knee." The cause of this problem is stretching of the capsule on the back of the knee joint which can result from new weakness of the quadriceps muscle, from stretching of the ligaments, and from cartilage degeneration. Knee problems occur when supporting structures are not protected by strong muscles and when people walk with abnormal limbs and gaits. Short-term treatment can involve anti-inflammatory medications, icing and stretching, and range-of-motion exercise. Once again, only changing the use pattern of the knee joint will solve the problem. When the knee pain is chronic and severe, bracing is usually the only effective treatment.

Back pain is common in the general population and also among polio survivors. I use the services of our entire physical medicine rehabilitation department to treat low-back pain. Changing walking patterns can again be very helpful for reducing chronic strain. At other times vigorous joint mobilization techniques and manual therapy is needed to correct vertebral malrotations or other problems of the spinal column. These conditions frequently occur in post-polio survivors with long-standing structural abnormalities associated with scoliosis or a short leg. Another example is a chronically rotated pelvis that may rotate even further and become the source of new pain. Exercise programs can sometimes help resolve chronic back pain if abdominal or hip muscles are sufficiently functional to be further strengthened. Frequently, they are not. Sometimes a simple abdominal support garment or girdle can substitute for severely weakened abdominal muscles and can make just enough of a

difference to relieving back strain that pain becomes manageable, and a person can remain active.

Sitting posture in chairs is also very important. A great deal is now known about the biomechanics of sitting and sitting postures. Engineers, physical therapists, occupational therapists, and seating experts assess structural abnormalities of the back in our spinal cord injury and post-polio populations. They may recommend lumbar rolls, ergonomic chairs, and/or special seat inserts to prevent chronic strain associated with sitting.

When all of these approaches for controlling pain fail, techniques like transcutaneous electrical nerve stimulation (TENS), biofeedback, imagery, and cognitive restructuring are tried. Pain should not always be thought of as bad since it can serve as a warning signal. Psychologists and support groups can help people understand this. Additionally, stress and emotional pain may keep muscles tight and interfere with patients taking appropriate actions for resolution or control of chronic pain problems.

Finally, when polio survivors are facing a difficult and confusing problem that does not fit into one of these categories, they will need to engage themselves with a doctor and therapist who can listen and communicate with them. As a team, they can usually solve the riddle of pain and find an effective management program. On the whole, I have found post-polio individuals willing to engage themselves in such a process and do their half of the work toward discovery of an acceptable solution to pain problems. An acceptable management strategy, rather than a complete cure for pain, is often the only realistic short-term goal. Subsequently, the pain may either slowly disappear completely or fade into the background.

*RECENT, RELATED PUBLICATION

"Coping with Carpal Tunnel Syndrome" by Gunter R. Haase, M.D., Alexander C. Johnson, M.D., and Oscar M. Reinmuth, M.D. Patient Care, July 15, 1990.

NEW POST-POLIO CLINIC

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TIPS TO COMBAT THE STIGMA OF CHRONIC PAIN: AN EVEN DOZEN*

1. Look for health care professionals with training and experience in the field of pain management. Remember that not all health care professionals are skilled in pain management.
2. Join support groups so you can benefit from the advantages of being with others who have chronic pain. Anson refers to the several hundred years of combined experience found in members of a typical support group. "Share with others and the burden lightens," he observes.
3. Communicate honestly about your pain with your family and friends. Heinrich advises other pain sufferers to strike a balance between talking too much about pain and being dishonest about it.
4. Educate others about the experience of chronic pain. "Be honest about what living with chronic pain is like," Gentleman says. "But try to get control over your emotions first because people have trouble absorbing information when it's loaded with emotion."
5. Accept whatever other pain sufferers are experiencing. "Practice acceptance of both yourself and others," Heinrich advises.
6. Don't reinforce negative stereotypes others might have. Also, don't make assumptions about what others are thinking and feeling about you. "Instead, check them out to be sure your perceptions are correct," Baither suggests.
7. Treat yourself with respect. "You have to love and re-spect yourself first, before other people can," Lockaby says.
8. Demand respect from others. Challenge negative stereotypes.
9. Accept responsibility for coping with your pain. "You'll be a prisoner of your pain if you don't take charge of your own life," asserts Filner. You are not responsible for your pain — but you are responsible for what you do about it and how you live your life.
10. "Give your doctors permission to not cure you," Heinrich advises. "I ask them to just help me be as comfortable and functional as I can be."
11. Resist the temptation to blame yourself for your pain. The question, "Why me?" often doesn't have a good answer.
12. "Develop a sense of humor," Heinrich advises. When all else fails, a humorous outlook can be your saving grace.

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OTHER RESOURCES

Chronic Pain Letter is a six-page newsletter devoted to news about chronic pain management. It is geared to both professionals and consumers. A one-year subscription (6 issues) is \$20 for individuals and \$35 for professionals and institutions. For more information, contact *Chronic Pain Letter*, Box 1303, Old Chelsea Station, New York, NY 10011.

Topics in Pain Management is a four-page monthly newsletter for health care professionals. Annual subscriptions are available for \$55 from Williams & Wilkins, 428 East Preston St., Baltimore, MD 21202.

The National Headache Foundation (NHF), 5252 N. Western Avenue, Chicago, IL 60625 (1-800-843-2256 outside Illinois or 1-800-523-8858 in Illinois).

U.S.A. Fibrositis Association, Riverside Hospital North Medical Building, 3545 Olentangy River Rd., Suite 8, Columbus OH 43214 (614/262-8020).

Fibromyalgia Network is a 10-page quarterly newsletter devoted to news about fibromyalgia/fibrositis. Articles include news of current research as well as information on support groups and coping with fibromyalgia. A one-year subscription is \$12. A complimentary copy is available on request. For more information, contact *Fibromyalgia Network*, 7001 School House Lane, Bakersfield, CA 93309.

Arthritis Today is the national consumer magazine of the Arthritis Foundation. It is available only to members of the Arthritis Foundation. Anyone donating at least \$15 can join. Contact the Arthritis Foundation Membership Center, P.O. Box 96012, Washington, DC 20090-6012 or your local Arthritis Foundation chapter.

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