Pressure sores



What you don't know can hurt you.

by Aviva Patz

Jennifer Digmann, of Mount Pleasant, Michigan, learned that she had multiple sclerosis at age 23, but the disease progressed quickly, and just five years later, she began using a wheelchair. It was one of those generic little folding numbers you could buy at a local pharmacy, and Digmann soon found herself squirming in discomfort. She didn't know yet that a wheelchair should be professionally fitted and customized to her needs.

"I'd be constantly wiggling and trying to shift to get the pressure off my butt, and I wasn't able to do it," says Digmann, now 42. "It was incredibly frustrating." When she started complaining about an especially sore spot, her caregiver took a look. "She was like, 'OK, this is not good,' " Digmann remembers. It turned out she had a severe pressure sore that took months of nightly treatments and weekly visits to a doctor 20 miles away to heal. "It was so painful and annoying," she recalls. "I'm gueasy just thinking about it."

Pressure sores (also called bed sores, decubitus ulcers, pressure ulcers or pressure injuries) are a breakdown of the skin after prolonged pressure, and occur most commonly on the tailbone, sacrum, hip or other bony area, from sitting or lying for a long time in the same position, especially in people who are mobility-impaired. "The pressure causes mechanical stress on the soft tissue and disruption of blood flow, or ischemia, resulting in an ulcer," explains Dr. Francois Bethoux, associate staff director of Mellen Center Rehabilitation Services at The Mellen Center for Multiple Sclerosis at the Cleveland Clinic.

In a very small 2015 study, researchers learned that pressure sores affect quality of life for

people with MS, causing physical, psychological and social difficulties. But they're more than just a hassle.

"Pressure sores can be an entry zone for infection, and they can go deep, into muscle, bone and blood," explains Dr. David E. Jones, assistant professor of neurology with the University of Virginia Health System. "If an infection gets into the blood, it can be a potentially fatal complication."

The sores are categorized by stages of severity from one, a persistent red skin discoloration, to four, in which the ulcer may go all the way to the bone.

By some estimates, more than half of people with MS who need advanced care are at risk for pressure sores. "Pressure sores are an underrecognized—and very concerning—issue in the MS community," Dr. Jones says, "and they're largely preventable." The key, he says, is to know how they develop and how to prevent them.

The causes

As MS progresses, so do the odds of developing pressure sores, due to the following factors:

Decreased mobility. The No. 1 cause of pressure sores is reduced ability to shift positions when sitting or lying down. "Most of us readjust our center of gravity frequently—squirming in our seats, leaning forward or backward," Dr. Jones explains. "But if you have weakness in your legs or core, you may not be able to do that."

Karen Jackson, 55, of Alexandria, Virginia, is a full-time wheelchair user who developed a pressure sore on her right hip from sleeping the same way every night on an unforgiving mattress. "Rolling over and turning are issues for me, so I kept sleeping on my right side, because it was easier to get into that position," Jackson says.

Reduced sensation. When you have less feeling in your lower half, it's easy to miss the pain signals associated with pressure. "People may just not feel it," says Jean Minkel, a physical therapist and seating specialist, as well as senior vice president of rehabilitation services at Independence Care System in New York. "Or they don't feel it with the same intensity, so they don't have the same responsiveness."

Jackson didn't feel the pressure sore on her hip until her physical therapist happened to stretch out that area. By the time Jackson inspected her hip that night at home, not only was there a pressure sore, but there was already dead tissue that was starting to slough off, meaning the sore was already at stage three.

Dampness. Incontinence, a common symptom of MS, means moisture, which leads to skin irritation and potential infection. "You can imagine how sitting on a wet wheelchair cushion increases the risk of skin breakdown and infection much more than if you were dry," Dr. Jones says. "Dampness makes skin more vulnerable."

Spasticity. Muscle stiffness from spasticity is a common symptom of MS. "When stiffness is severe, you can develop contractures—shortening of muscles and tendons that often causes a limb or a joint to become partially or completely 'frozen' in a certain position, creating pressure points," Dr. Bethoux explains. "And muscle spasms associated with spasticity can cause shearing, which is when two surfaces, in this case, bone and soft tissue, move in opposite directions."

Transfers. Every time you get help changing positions, there's potential for friction when you're sliding across a surface or possibly bumping into things. "It may be quick," Dr. Jones says, "but think about how often you're doing it, how long it takes and what you're transferring across."

Body weight. Being overweight can add extra pressure (it also contributes to skin breakdown when moisture gets trapped in skin folds), but being underweight is no better. "It leads to more prominent bony surfaces," explains Dr. Bethoux, "and decreases the thickness of the soft tissue between the skin and the bone," setting the stage for pressure sores.

Diet. Poor nutrition—especially a diet high in saturated fat that potentially clogs arteries—can lay the groundwork for pressure sores. "Blood flow is important, so issues that may develop with years of an unhealthy diet can reduce blood flow, making it hard for injuries to heal," Dr. Jones says.

Lack of essential nutrients, especially iron and vitamin D, he says, can contribute to poor wound healing, as can low amounts of protein. Common dietary recommendations include lean sources of protein, such as fish and poultry, and adequate fluid intake. People at risk should talk to their doctors about a proper diet to prevent pressure sores.

Older age, smoking, tight clothing, dehydration and a history of pressure sores also up your risk, Dr. Bethoux notes.

Preventing pressure sores

Just being aware that you're vulnerable is a helpful first step, according to Minkel, because you're more likely to take precautions, including these:



An alternating air pressure seat cushion has airfilled channels that alternately fill and empty to keep weight off bony prominences. It is designed for people who are unable to shift their weight frequently. Photo courtesy of Apex Medical Corp.

Move around. If pressure is the problem, relieving it is the solution, whether you're aware of the sensation or not. "It's essential to make sure that pressure is relieved at regular intervals, particularly if a person stays in the same position throughout the day," Dr. Bethoux says. "Lifting the body off the wheelchair seat, turning the body in bed ... sometimes it requires help from another person or the use of special equipment."

Digmann's caregiver shifts her position in her wheelchair about three times an hour, and sometimes more, as needed. If spasticity is limiting movement for you, work with your care providers to address it through medications or physical therapy.

Gear up. Specialized tools can help with repositioning: Look for mattresses made of supportive materials (such as memory foam) that allow you to sink in and spread your body weight over a broader surface. Your therapist or seating specialist can help you find the right size and type of wheelchair, and can modify it with cushions made of gel, high-quality foam, air or some combination, which work similarly to keep weight evenly distributed.

Some cushions and mattresses can automatically shift the pressure periodically—but you'll need a prescription from your doctor in order for insurance to cover these. A wheelchair with power seating that tilts back can give your rear end a break.

Not everyone will benefit from every solution—for example, some people may find it difficult to shift their weight on a memory foam mattress. "Your healthcare team can help you understand the pros and cons of any given recommendation, assist you in making a more informed decision and, hopefully, reduce the trial-and-error method of finding a solution that

works for you," Minkel says.

After Digmann developed a pressure sore, her insurance provided an individually configured wheelchair with vital accessories, such as tilt-in-space power seating, which she credits with saving her from developing further sores. This type of equipment is known as "complex rehabilitation technology," or CRT. After Jackson's pressure sore developed, she too was able to purchase a CRT bed that allows her to raise and lower her back and legs, and that's topped with a mix of supportive, weight-distributing materials.

Health insurers may cover these products only after pressure sores have developed. However, the National MS Society and MS activists like Jackson and Digmann have been lobbying Congress to pass bills that would help Medicare beneficiaries access medically necessary CRT and related accessories to prevent, and not just treat, these costly and painful conditions.

Check yourself. Skin inspections are critical, says Minkel. "When you move from one surface to another, examine the weight-bearing areas," she advises, paying special attention to the buttocks, the outside of the legs on top of the hips, and the sacrum or base of the spine. "Look for any area of redness that doesn't go away within 20 to 30 minutes," Minkel says. On people with darker complexions, redness is less visible, so also feel for warmth or a "spongy" consistency to the skin. Do skin checks daily, ideally several times a day, with the help of caregivers as needed. If caregivers aren't available or if you're embarrassed, use a cellphone on a selfie stick to snap pics of your backside, and review them carefully.

Stay dry. If incontinence is a problem, work with your doctor to find medications and behavioral strategies that will get it under control as much as possible. But the goal is to stay dry, so if necessary, wear absorbent undergarments and change frequently. "You don't want to be sitting in wetness at any time," Minkel says.

Treating pressure sores

If you suspect that you may be developing a pressure sore, have it looked at right away, as early intervention is critical. "It can take as little as one hour of not moving for a pressure sore to develop and then progress," Dr. Jones says.

Treatment depends on the severity of the injury. If the skin is open, the wound must be cleaned, dried, treated with medications to prevent infection, and dressed in special non-stick gauze at regular intervals. If there's dead tissue, it will need to be removed—with special dressings and chemical agents, or surgically—to promote healing, in a process known as debridement. If a pressure ulcer is deep and isn't healing well, your doctor may need to close the wound surgically.

Even after you've healed, there's one more key step: "Figure out what caused the pressure injury or you'll just repeat the problem and get more injuries," Minkel says.

Use the services of a physical or occupational therapist who specializes in seating issues to identify any new equipment or modifications to your existing equipment you may need, whether it's a cushion, a lift chair, gel overlays for your bed, an air mattress, a hospital bed or something else. "If you get the wrong equipment, it may take a long time for your insurance company to approve new equipment," warns Dr. Jones, so it pays to consult a pro and get it right the first time.

Aviva Patz is a freelance writer in Montclair, New Jersey.

To find a seating specialist in your area, visit <u>RESNA</u>, the Rehabilitation Engineering and Assistive Technology Society of North America, for a directory of certified practitioners.

Learn more about the Complex Rehab Technology bill or get involved.