

# Swelling of the Feet and Legs

By PALS Diane Huberty, CNRN

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Swollen feet and legs are a common problem for neuromuscular patients. Although it is probably impossible to prevent swelling entirely because it is due to the lack of muscle action in our legs, it is very important to do what we can to minimize it from the first. Left unaddressed, it quickly becomes a vicious cycle of swelling leading to damage leading to increased swelling. As a nurse, I knew that, but still had to learn it the hard way! My legs are ghastly. They look fine when I am lying down, but the minute I sit up they turn hideous shades of red and purple and blue and grey. If I am not careful to prevent as much swelling as I can, they are swollen like sausages by noon, miserably uncomfortable and absolutely painful by evening. It is worse in hot weather and in cold weather they are impossible to warm up if they get cold.

In order to understand how to minimize it, it is important to understand why the swelling occurs, so let's begin there. (No quiz, I promise!)

## The Cause of the Swelling

The heart pumps blood through the arteries under high pressure. As the arteries branch out into smaller arteries and then into tiny capillaries, pressure decreases. Oxygen is removed from the blood in the capillaries and then the "used" blood flows into veins for the trip back to the lungs for another load of oxygen. Unfortunately, the pressure generated by the heartbeat has been lost by then and the blood relies on simple back pressure to move back up to the heart. This is aided by muscle activity - ordinary muscle movement "squeezes" the veins and pushes the blood along. The veins have little one-way valves all along the way that keep blood from draining backward as it is pushed upward.

When muscle movement is lost, it becomes much harder to get the blood back up from the legs. It pools in the veins and causes them to get distended. Water seeps from distended veins out into the surrounding tissue and your legs and feet swell (edema). With repeated episodes of swelling, the little veins become damaged - leaky - and water seeps into the tissues even more easily. At the same time, the valves are collapsing under the heavy weight of all that blood that is pooled on top of them. That damage to the valves is permanent. Without the valves, the blood pools in the feet even worse than before and remaining valves are under even more pressure and more likely to fail.

## Complications

As miserable as swollen legs are, things can get worse. . .

The most common complication of swollen feet is a burning discomfort that can be downright painful. I haven't read a full textbook explanation for this but my interpretation is that the excess fluid that comes between the capillaries and cells deprives the tissues of an adequate blood supply. The burning sensation is sort of the "needles and pins" feeling we get from cutting off blood supply to an arm or leg -- but on a micro-level because it is primarily the skin layers that are affected, not the deeper muscle tissue as when arteries are compressed. This doesn't happen ordinarily -- people with good circulation in their legs can

handle the temperature changes much better because the microcirculation is not damaged and functions properly to regulate temperature.

The lousy circulation allows the blood to pool and, when not in motion, blood tends to start to clot. A blood clot (thrombus) can form and not only further impede circulation, but break loose and travel to the brain (A stroke - just what we need - more paralysis and speech problems!) or to the lungs (A pulmonary embolus. Painful, and can land you in intensive care on a ventilator if it doesn't kill you outright). Luckily, that doesn't seem to happen to us as often as it seems like it should, but we need to let our doctor know immediately if one leg suddenly seems more swollen or if the swelling doesn't go down overnight as it usually does, and especially if the leg becomes painful. If you even suspect that you may have a clot in one leg, **DO NOT MASSAGE THE AREA!** Elevate it and call your doctor. To reduce the risk of blood clots, we also need to be sure we drink enough to stay well hydrated.

Long term, the lousy circulation begins to affect the skin of the legs and feet. It becomes fragile and heals very slowly when injured. If the problem continues over many years, the skin becomes yellow-brown in color. Even without injury open wounds called “stasis ulcers” can appear. They are extremely hard to heal because the blood flow to the skin is so poor.

## Treatments

Doctors aren't very good about helping with swelling. The first thing they will say is to put your legs up to minimize the swelling but they don't tell you how to do that effectively. They will offer prescriptions for TED (elastic or compression) hose (somewhat helpful) and “water pills (which should be used as a last resort only).

The first thing to look at is the chair you sit in. A recliner may seem like the ideal way to keep your feet up and swelling down but it is NOT! There are two big problems with most recliners. First, the footrest section is made in such a way that all the weight of your legs rests on the calves. That is really bad for circulation. Second, putting your feet up - even way, way up - without “unfolding” at the hips is very minimally helpful, possibly even detrimental as that bend interferes with the already difficult job of moving blood upward to your heart. Lift chairs are wonderful and most of them are recliners, but if you spend most of your time in a recliner, I strongly recommend that you bring the footrest up **only** when you lower the backrest.

Whether you sit in a regular chair, recliner, or a wheel chair, it must be properly fitted to you. You need to make sure that your leg to floor/footrest distance is short enough that there is minimal pressure at the back of the lower thigh and knee. Having your legs “dangle” is a sure-fire way to cause swelling! Put a box/platform under your feet (an old hard side suitcase worked great for me - lightweight and had a handle) or raise your footrest an inch or so. The objective is to make certain there is **minimal** pressure on the back of your knees/thighs. If you have added a ROHO or other cushion you need to adjust your platform/footrest upward to make up for the height of the cushion.

The best treatment for leg swelling that I have found is something that I discovered entirely by accident: *More time in bed.* When my husband was working, I spent about seven hours in bed at night and then would lie back in my recliner for another two or three hours in the afternoon. Even with that, my legs were swollen by noon, miserably uncomfortable by evening and absolutely painful by bedtime. Last year when my husband retired, I was able to go to bed at the usual time, listen to books on tape for an hour or two, and then sleep late in the morning. Instead of spending 10 hours lying with my feet up in two separate sessions, I began spending 10 hours or more in bed all at one stretch. Within a matter of days after starting this routine, I noticed that the swelling was minimal. Now I don't even have to lie down in the afternoon in order to be comfortable in the evening. I don't know if this is due to spending more time lying down at one stretch, spending all my lying down time in a bed rather than a recliner, getting

more sleep, or some combination of the three. All I know is that in this has made an incredible difference for me. Not only has it made my problems with swelling minimal, I feel better in general. Now I simply stay in bed until I really feel like I am ready to get up rather than trying to catch up with naps. I seem to need about 10 hours of sleep these days. Even though my sleeping in is inconvenient at times, it is much easier for my caregivers if I spend a longer stretch in bed rather than going back and forth, I prefer not having to take time out to lie down in the middle of the afternoon, I am not too tired and miserable to do anything in the evening, I sleep much better at night since I don't nap during the day, and I have more energy and stamina.

Another thing that helps is *muscle activity*. Granny's old rocking chair served a real purpose besides putting babies to sleep! I find that on days when I am most active (Interpret that as days when I am frequently hauled in and out of my chair and forced to stagger a few steps, whining all the way!) the swelling is minimized. I guess I have some muscle left in my legs, even though I sure can't feel 'em! Even passive range of motion exercises help.

Keep cool. A few minutes of sitting in the summer sun is all it takes to turn my feet into balloons. (Blood vessels dilate when we are warm.) Simply keeping my legs in the shade makes a difference, but I have also been known to pour cold water over my feet on really hot days when I need to be outside. Wet socks and tennis shoes are still more comfortable than that miserable burning sensation of swollen feet!

Sometimes I also have problems with a burning sensation in my feet in bed at night. It doesn't start until my feet began to warm up. This is very consistent with what happens during the day if my feet get too warm (sitting near a heater or, in the summertime, sitting with my legs and feet in the sun). It can get really bad in the middle of the night if I have the electric blanket on and my feet get really warm. That is a real nuisance because the rest of my body gets really chilled and I can't move at all if I pile on extra blankets. So, in cold weather I end up sleeping with the electric blanket on, but my feet sticking out!

For some people, this burning pain becomes severe and doesn't seem to be relieved by getting the swelling down. This might be the end result of long term or severe swelling. Some people find that aspirin (not Tylenol) helps. Do not take aspirin if you are on anticoagulants (medications to thin the blood). If burning pain is felt when swelling has not been a problem, discuss it with your neurologist.

Limiting salt intake used to be high on the list of things to do to minimize swelling, and your doctor may suggest it, but the need for that is questioned these days. I guess it is enough to say don't over-indulge with salty foods.

Hospitals often use *devices to improve blood flow* to the feet of patients who are going to be stuck in bed for a while in order to reduce the risk of blood clots. TED (elastic or compression) stockings are by far the most common. By simply squeezing the legs and feet a little, they help keep the veins from getting distended. You can ask your doctor for a prescription for these stockings, but unless you have strong hands and arms, you will need help getting them on.

Hospitals also use types of "boots" that inflate and deflate to help pump the blood along. One study apparently showed that simple alternating pressure on the soles of the feet greatly improves flow, so some brands of boots simply apply waves of pressure to the bottom of the foot. With help from your doctor you may be able to get your insurance to cover the cost of this equipment. It is not complicated to use, but you must be very careful to make sure that it is not rubbing anywhere and causing breakdown of the skin.

If you complain about swollen ankles and feet to your doctor, odds are he will whip out the old prescription pad and put you on *diuretics*. I have real reservations about this because many of us are borderline dehydrated half the time anyway. (Another contributing factor for the development of blood clots.) It gets hard to reach a drink, or hard to swallow, or it is simply too hard to get to the bathroom (you men have it made!) so we don't drink as much as we should. Diuretics cause your kidneys to remove

more water from your blood stream. The “thicker” blood is then able to “sponge up” more water on its travels through the body so it does reduce the edema. It does nothing about the cause of the edema -- poor blood flow – however. Using diuretics for swollen legs is kind of like taking a diuretic to lose weight - sure it “works”, but it doesn't really solve the problem.

I certainly won't say diuretics should never be used -- if nothing else works well enough to keep the swelling under control, they need to be used because the swelling further damages the veins and valves and the situation just gets worse. But all the things described above should be implemented first before diuretics are even considered.

### **About the Author**

Diane Huberty is a retired RN. She worked general Med-Surg units, then 5 years in Critical Care where she began specializing in Neuro and earned Neuro Certification (CNRN). Diane was diagnosed with ALS in 1985 at the age of 37. When her hospital opened a Neuro Unit, she was selected for the position of Neuroscience Educator. She was able to continue working in that position until 1995, when arm weakness and fatigue made it too difficult to continue and she retired. Through the Internet, Diane communicates daily with other ALS patients and keeps up on research, treatments and care issues. In addition to maintaining and posting a set of ALS Frequently Asked Questions on the ALS newsgroup (sci.med.diseases.als), she has her own ALS website (<http://home.att.net/~liveletdie5/ALS/home.html>) which focuses on nursing care rather than research. Diane can be contacted by email at “liveletdie@att.net”.