

WHAT TO EXPECT: PHYSICAL HEALING

Author: Jill Sproul

Time can be your best friend and your worst enemy as you recover from a burn injury. In the beginning, it may seem like there's no progress, like you're never going to have a normal life again. You may feel frustrated and impatient like things aren't happening quickly enough.

But it's important to remember that **how you feel and what you can do right now is not your permanent reality**. As time goes by, you will make more progress than you can imagine. When I see patients for follow-up visits, they often forget that they could barely walk five steps when they came home—now they're walking around the block.

When you go home, you're forced to do so much more than when you were in the hospital. Over the course of a month, your physical improvement may be dramatic. But trying to do too much or move too quickly can set you back.

I always tell my patients to set realistic goals and take baby steps forward.

It's a journey, with many ups and downs, and it can be hard to stay motivated to do the hard work of healing—exercises, pressure garments, follow-ups—without something to work for. If you're trying to do too much or move too fast, you might actually set your recovery back.

Don't Let Infection Fester

Signs of infection include heat, pain, and swelling. If you put off getting it checked out, the infection can become much worse! If you think there's something going on, either with an open wound or under your scar tissue, see your team right away.

Your burn care team will help you navigate the journey.

The frequency of your follow-up visits will depend on your wounds and the burn center's distance from your home. During these visits, the care team's goal is to make sure your healing is on track.

- During follow-up visits, your care team will:
- Assess the status of wounds and scarring
- Help manage symptoms such as pain, itch, immobility, or infection
- Assess overall progress
- Check in about your mental health and emotional wellbeing, and refer you to the appropriate resource for support or counseling if needed
- Invite you to join a support group or connect with a Peer Supporter
- Some questions I recommend asking in your early follow-ups:
- How have my nutritional needs changed since my initial treatment?
- How can I keep my skin moisturized? What products do you recommend?
- How long will my immune system be compromised? When can I stop being so vigilant about infection?
- How can I move the narcotics to other pain meds/pain management techniques?
- When can I... (go to the beach, play with my dog, go for a run)?

Don't Suffer In Silence!

Your care team understands that going home after a burn is really scary, so don't hesitate to reach out with any questions or concerns. If it's not urgent, keep a list of your questions for your next visit—this will help you remember what you meant to ask, even if you're overwhelmed in the moment.

Transportation For Appointments

If transportation is a challenge, here are several strategies to consider:

- Check with your team to see if a telehealth visit may be an option.
- Check with the social worker/case manager on the burn care team, who often have connections with ride services.
- Contact your local foundation or burn unit to see if they can offer gas cards or recommend transportation services.

- Dial 211 – they can provide a list of transportation services available in your region, some of which may be free.
- Ask a Friend – many people in your community want to support your recovery, and transportation is a concrete way they can help.
- Contact a local non-profit organization. Many churches, senior centers, community centers, etc., work with volunteer drivers to help with medical transportation needs.

Scars thicken as they mature, so it is critical that you follow your discharge plan from your PT/OT. The exercises they prescribe will help keep your scars soft and increase your mobility. During outpatient appointments, the PT/OT will assess your range of motion and help you keep moving forward. If you don't move, your scars may thicken, and your range of motion may decrease.

Another Goal Of Physical Therapy Is Strengthening And Conditioning Your Body.

After laying in bed for a long time, your muscles will be sore and deconditioned. Follow your discharge plan from the PT/OT--if one wasn't prescribed, try to keep increasing your physical ability in baby steps. Walking, stairs, exercise reps—the goal is to keep progressing.

This isn't always easy. If you're frustrated, struggling with pain or itching, or just having a bad day, you can give yourself a break—but don't give up. **Every day is not going to be a bad day.**

As hard as it is, family members need to let the burn survivor struggle a bit. Many families and caregivers think they're helping by doing everything for the survivor, but it's not helping them regain independence. Let the survivor do as much as possible by themselves—getting dressed, going to the bathroom, taking a shower—and be on standby to help if necessary.

It's not good to be dependent on people for everything, especially if you're an adult.

When I was burned at 7 years old, my mom did a lot of my care. She was a nurse, and she didn't cut me any slack. When I came home, I could barely walk from the car to the house, but instead of bringing me things, my mom made me get them myself. She did everything possible to promote independence. As a little kid, I hated how hard she pushed me—but as an adult, I am so grateful.

Your Journey May Include Reconstruction Or Revision Surgeries.

The amount of reconstruction needed will depend on your individual case and priorities. Some reconstruction helps with physical mobility, and some are intended to improve appearance. Sometimes it does both, such as in the case of a severe neck contracture. Typically, burn surgeons will prioritize mobility in initial reconstructions.

If you're thinking about reconstruction, have a conversation about your goals with your burn surgeon. Based on your scars and your goals, the surgeon will plan a series of revision surgeries.

Often, burn surgeons want to wait and see how your scars mature to determine whether you'll need revision surgeries. Over the first year to 18 months, your scars will become thicker and change appearance.

As your scars are maturing during this period, you may need to wear pressure garments. It is so important that you wear these as directed because the compression helps significantly with scar formation that can impact both appearance and mobility. Pressure garments also help with circulation, especially if your legs are burned.

When patients tell me they've been wearing their pressure garments all the time, I can always tell if they're not wearing them as prescribed. There is a drastic difference in how the scars form and thicken.

Running Hot And Cold?

Skin plays an important role in helping us regulate our body temperature, so burn survivors often struggle to stay cool or warm-up. Don't be surprised if you're the only one in the house who's freezing and be careful to avoid overheating. Over time, you'll get to know your body and your limits.

Pressure garments can be uncomfortable at first, but it's critical that you get over the initial hurdle of getting used to them and wear them religiously. Your future self will thank you.

"I love the beach," one of my patients said. "I'm never going to be able to go to the beach again."

"Why not?" I asked.

"Because I can never be out in the sun again."

"You have to take precautions," I replied, "but just because you're burned doesn't mean you can never go to the beach again. Who told you that?"

"I'm never going to be able to wear a bathing suit, I'm never going to be able to run again, I'm never going to have sex again, I'll never wear a dress..."

I can't tell you how many "nevers" I've heard. My response is always the same: "WHY NOT?"

Three months after I went home, my parents helped me get on my bike again. Once I got the hang of it, I rode that bike for hours--to the point that I could hardly walk the next day. Regardless, I was on Cloud 9. I was so afraid I'd never be able to ride my bike again, but I had done it, and I knew I would be able to do it again.

When you're recovering from a burn injury, you have a lot of time to think and anticipate. Not knowing the future is often the hardest thing, and when you're worried about something, you always think of the worst-case scenario.

You Can Do The Things You Love Again. A Burn Injury Does Not Define You.

There will be good days and bad days, leaps forward and stumbles backward, but you can achieve your goals. You can go back to school, return to work, get back to your normal routine or create a new normal. You can go on to have meaningful relationships and meaningful work. You can do what brings you joy.

There is life after a burn injury.

Jill Sproul, MS, RN, has been working in burn care for the past 28 years. Currently, she is the Chief Nursing Officer at Santa Clara Valley Medical Center (SCVMC) in San Jose, California. In addition to working clinically in burn care, Jill's passion has been outreach and aftercare. Jill has been involved with Phoenix Society since 1994. Her contributions include serving on the National Advisory Committee for Phoenix SOAR, the organizing committee for Phoenix World Burn Congress, and former Treasurer on Phoenix Society's Board of Directors. She has also served on the boards of the American Burn Association (2013-2016) and the Alisa Ann Ruch Burn Foundation (2016-2018). Jill and her husband, Kevin Cook, who is also a burn survivor, have two teenage children together and two older children from Kevin's previous marriage.