

REALIZING THE POWER OF COMMUNITY

SPECIAL EDITION | 2022

Journey

MAGAZINE

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AFTER MY BURN
INJURY: WHAT
I WISH I'D KNOWN
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YOUR POWER
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PHOENIX SOCIETY
FOR BURN
SURVIVORS

PHOENIX SOCIETY FOR BURN SURVIVORS is the leading resource, connector, and go-to place for those impacted by a burn injury. We understand the healing journey, and we are with you, survivors, loved ones, and care teams, every step of the way. Together, we want to ensure that no one facing the life-changing effects of a burn injury is forced to journey through healing alone.

Contact us anytime at:

✉ info@phoenix-society.org

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Journey

MAGAZINE

Journey Magazine is a publication written by the burn community, for the burn community. The magazine is completely free for readers and is filled with resources, stories, and updates delivered directly to your mailbox. Sign up to start receiving your copy today: www.phoenix-society.org/magazine-signup.



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The following stories are all written by survivors or loved ones.



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- AlloSource
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- The Tony Gonzalez Family



Amy Acton's career started as a burn nurse and later as a nurse manager at the Spectrum Health Regional Burn Center located in Grand Rapids, MI, where she herself was treated at the age of 18 for an electrical burn injury. In 1998, Amy was named the CEO of the Phoenix Society for Burn Survivors, where she has dedicated her career to advocating for the expansion of burn recovery services and resources for burn survivors and their loved ones.

Since joining Phoenix Society, Amy and the team of dedicated staff and volunteers have developed and expanded several national programs that have significantly increased access to long-term recovery resources for those in the burn community. She is the Chair of the National Fire Protection Association's Board of Directors, a member of the Home Fire Sprinkler Coalition's Board of Directors, and has served on numerous American Burn Association committees.

Amy is grateful for the opportunity to work with the Phoenix staff and so many devoted hospital partners and colleagues serving those impacted by a burn injury. Her family's deep love and support have always been the touchstone that fuels her purpose and passion.

THE JOURNEY AHEAD

A Message from Amy Acton, Burn Survivor
+ CEO of Phoenix Society for Burn Survivors

Dear friend,

As you explore this magazine, think of it as an open door to Phoenix Society for Burn Survivors and the burn community. Inside, you'll find lots of information and many invitations to get support. You may choose to take advantage of these resources right away, or you may not be ready for some time. Whatever you do, remember one thing: **you are not alone.**

Every article in this magazine was written by survivors, for survivors and their loved ones. People impacted by burn injuries share the information, advice, and tools that helped them through their journeys—or what they wish they'd known—so you don't have to start from scratch (If you don't find what you're looking for or need additional support, never hesitate to reach out to us).

With the help of our community, we've identified some common threads and key issues people face as they learn to live with a burn injury. Every article may not be relevant to your individual experience or current concerns. Still, your story is unique. Take what you need and use what works for you.

It's your journey, and we're here to support you however we can.

As for me, my journey began at 18 years old, when an accident at my summer job left me with burns over 35% of my body. During the initial injury, I had an incredible burn team taking care of me 24/7. Focused on whether I'd survive, my family and I didn't give much thought to what came next.

When I got home from the hospital, I couldn't see a path to regaining the freedom and adventurous spirit I'd lost. I had no stamina. I had limited use of my hands and injuries to my feet that made it difficult to walk. I was certain my friends wouldn't want to hang out with me. It didn't matter if they did because I was too self-conscious of my chin strap and missing fingers to imagine a casual outing anyway.

I'm not the only burn survivor to struggle during this phase of the journey. We've heard time and time again that **going home from the hospital** is something we look forward to, yet it's one of the greatest challenges for burn survivors and their families. I had so many questions my burn team couldn't answer and no idea how to find the information I needed.

It was not in my nature to ask for help, and it took me a long time to engage with the resources and support available in the burn community. Throughout my **ongoing healing**, I struggled because I felt alone.

Then, one day, my brothers took me sailing. Ignoring my protests and my mother's concerns, they grabbed me and got me out on the water. As the wind filled the sails and I took the helm, I felt something I hadn't felt for a long time. Hope.

I was alive, I could still do this thing I loved, and maybe—just maybe—my burn injury did not have to define my future.

And so began my slow shift into **living and thriving with a burn.** I reached out to my friends, signed up for classes at the community college, and learned to juggle my need for independence with asking for help. I began to build a new normal.

This wasn't the end of my journey. The emotional, social, and physical impacts of a burn injury can last a lifetime for some. As James Bosch says in *What to Expect: Mental Health*, "healing is a spiral, generally moving upward, with lots of twists and turns."

Through all the twists and turns, Phoenix Society and the burn survivor community are here for you. Our goal is to build a hub of experts, opportunities to get support, and resources for burn recovery: everything you need in one place. And if we don't have what you need, we'll tap into our network to help you find what you're looking for.

That's what community means to us. Together we are stronger.

A place where you're seen for the person you are and the potential you possess. Where your story is heard because it's yours, and you matter. We understand the healing journey, and we are with you and those who love you every step of the way.

Together, we believe in the endless potential of what can be.

Amy Acton, RN, BSN

WHAT TO EXPECT: PHYSICAL HEALING

Author: Jill Sproul, MS, RN

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.

WHAT TO EXPECT:

PHYSICAL HEALING CONTINUED

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.

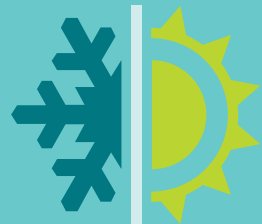
Often, burn surgeons want to wait and see how your scars mature to determine whether you'll need revision surgeries. **Over the first year to 18 months, your scars will become thicker and change appearance.**

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. Every author in this special edition of Journey Magazine is living proof.



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.

GOING HOME AFTER MY BURN INJURY: WHAT I WISH I'D KNOWN

Author: Amber Wilcox

After my burn injury, my husband and I were surrounded 24/7 by nurses, doctors, therapists, and other care professionals who took care of everything for us in the hospital. What we didn't think about was that once I was discharged, we would have to take on all those roles ourselves.

No matter how long you've been in the hospital, the transition to home might be exciting and terrifying all at the same time. To help you better navigate this transition, I've reached out to the burn community and compiled stories, advice, and information for you to take this important step.

"I assumed 'discharged' from hospital meant a person was fixed. But I actually thought I was "kicked out" because I was sent home still bandaged, hurting, and struggling in my recovery. My parents were totally ignorant of their ability/right to advocate for this situation, and the family was evidently unprepared for the intense treatments and maintenance required for my homecare."

- Dennis Gardin, burn survivor

At-Home Care & Aid

Just before you are released from the care of your burn team, you may work with the hospital team about what home-life will look like in regards to your current physical needs. This might include at-home care teams, outpatient therapists, and other providers who can assist with this transition.

Talk to your care team about at-home health care, a service often covered by insurance companies. The home care team is composed of nurses, PT/OT, social workers, home health aides, etc., and the composition of the team that will support you depends on your unique needs.



The idea of finding at-home care as a 29-year-old burn survivor both infuriated and frustrated me. I had no idea what to expect with a stranger visiting my home and was provided with a list of at-home providers my insurance would cover and told to select one. In some cases, this may be provided for you, but before navigating the at-home care or aide experience, my biggest piece of advice for this time would be not to be afraid to ask any questions.

Consider asking questions like:

- Have you had experience caring for patients with skin grafts or burn wounds before? Would you be willing to stay in communication with my burn care team – including video chats if appropriate?
- What does your schedule look like? How will you and I come up with a schedule that meets both of our needs?
- How do you handle supplies required for my medical needs?

Once you select a home health agency, they'll schedule your first visit. An admission specialist will assess your function, your medications, your burn wounds, your support systems, amongst many other things. Plan to ask what to expect from various members of your home care team. Likely, you will get visits from the home care team only a few days per week, which is different than the daily care that you received on the burn unit – and one of the main goals of your home care team is to increase you and your caregiver's comfort and independence with your care.

"Both a burn survivor and their caregivers [should] be ready to immediately take on responsibility for wound care upon leaving the hospital. I recommend [not solely] relying on the home care nurses that help."

- Carlos Ward, burn survivor

Preparing with Supplies

One of the biggest pieces of advice I can give as a survivor would be that what may have been easy before may not be easy right now.

My husband, Tyler, went by the motto, "we'll do whatever it takes to keep you safe and comfortable." Another helpful tip I received shortly after returning home was to think outside of the box. Pants don't fit your swollen/bandaged legs? Get larger ones. Shoes hurt too much from rubbing against your scars? Wear slippers. If it doesn't work—consider reaching out to other survivors for suggestions or looking for an alternative option.

"Third-degree burns on my buttocks created a condition of constant pain. For a year, I could not sit for more than 5 minutes. To drive anywhere, I needed to lie on my stomach on a child's mattress in the rear of our SUV."

- William "Chip" Crawford, burn survivor

Medical Supplies

In addition to supplies used to make things easier, medical supplies are definitely needed in excess during this time. Thankfully, our hospital sent us home with enough supplies for a few days, which allowed us time to figure out where we could get the volume we needed.

To start, we searched for local medical supply businesses that could support the amount required for my wound care. You may also want to ask your provider for a script to be able to access these types of facilities to purchase volume supplies. Once we understood what was required, we began searching Google and Amazon for bulk options that could ship within a few days. In addition, we spent a few minutes speaking with our doctor for suggestions we could use and purchase. Although a "gauze pad" seems like a straightforward requirement, we began to familiarize ourselves with brands we liked better than others with each dressing change.



If you're having trouble paying for supplies or insurance doesn't cover the cost, it can be challenging to know where to turn. Here are a few ideas:

- Stay in communication with your care team. If one supply type isn't covered by insurance, perhaps a different one will be. Don't be afraid to ask for alternative options. They may also have access to coupons or sites that offer the supplies at a discount.
- Reach out to a regional foundation and ask if they know of any supply resources
- Reach out to Phoenix Society for Burn Survivors – as a connector for the burn community, we may have ideas or resources that can help

Assistive Devices

Insurance may or may not cover the cost of assistive devices such as walkers, a taller commode seat with armrests to help get on/off the toilet, etc. In good condition, pre-owned devices can be an economical way to meet your needs. Just be sure to have the device checked by your care team to ensure it's safe and in good condition, and sanitize all equipment before using.

- Check with family and friends – they may have or know someone that has a device that is no longer being used or can be loaned for a period of time
- Online listings – places like Facebook Marketplace or Craigslist are great sources for used equipment.
- Community service groups – organizations like the Lions Club, Salvation Army, VFW, etc. often will collect and store used equipment to loan out
- Consider posting your needs on social media – often, word will get spread on what will help with your recovery, and someone will have what you need

Track Your Progress

We've all been there. You might be so happy to have returned home only to realize how exhausting (whether a caregiver or survivor) the process of recovery actually is. You're in what seems like days on days of dressing changes only to take off a bandage that looks like it hasn't come close to healing.

CONTINUES ON PAGE 12

“Be patient with yourself. Take baby steps, and celebrate small victories.”

-Lauren Grove, burn survivor

During my moments of anguish, I was given the advice to track my progress. This might look different for every survivor. For Lauren and myself, it meant taking daily pictures of our wounds to see improvement over time. This might also be journaling or asking a caregiver to remind you what you can do now that you can't do yesterday.

As a survivor of a kitchen accident, it took me several weeks before I was even willing to be in my kitchen. For me, physically walking into my kitchen was a victory worth celebrating.

Feeling overwhelmed? Most survivors agree that the biggest advice during this time is to BE KIND TO YOURSELF. Practice mindfulness, or find something to make you laugh.

You are Your Best Advocate

In my darkest hour of one of my darkest days, I reached out to Phoenix Society for Burn Survivors for help. My husband and I were exhausted, and the itching was uncontrollable. I remember looking at my husband and thinking I couldn't possibly be the only one dealing with this.

I joined my first virtual support meeting that following Saturday. I vividly remember jumping on that call just to see what they could do to provide answers to our many survivor questions. I felt relief—knowing someone finally understood what I was going through. As a caregiver, my husband also felt relief knowing he wasn't alone, and I had a friend or two who understood.

With advice from Phoenix Society, my husband and I quickly learned that we had to be our own advocates and speak up. We needed to voice concerns and not be afraid to ask lots of questions. As a survivor or a caregiver, you must advocate for your own journey. If something doesn't feel right—trust your gut and ask questions.

Find Your Cheerleaders

As a survivor, communication with my caregiver was vital. Even on the days when I wanted to do nothing but scream and cry—I let him know it was just a “bad day.” As a caregiver, Tyler never backed down. Even on the days I had it rough, he was there to cheer me on or just be there to listen and not fix.



Tyler learned what worked for me and my journey. Here are just a **few of the things that came out of our journey:**

- Dressing changes were both long and sometimes quite miserable. To get through, here are a few tips:
 - › A distraction during changes. For us, we watched every episode of The Masked Singer or found something on Netflix to binge on.
 - › Have a plan for mealtime. After hours of changing dressings, we were both tired and did not want to make dinner. Pizza delivery became our go-to.
- During times of intense pain or fear of the unknown, music became my motivator and my means of focus.
- A little encouragement went a long way. I'd been active in yoga prior to my injury, led a very busy lifestyle, and one of my biggest fears was not being able to get back to what I knew and loved. Just a few weeks after I returned home, Tyler knew I needed all of that. He'd help me work out a plan for returning to work on my terms and would put me on a chair in front of the TV to do yoga.
- Give yourself a goal. I wanted to succeed, but I wanted it to happen overnight. The truth was, it wasn't going to. I set micro-goals for myself to help continue to motivate me to move forward.



Throughout all of our ups and downs—Phoenix Society for Burn Survivors and its community of fellow survivors were there to cheer me on. There were some weeks I just didn't have it in me to talk, and others where I didn't want to join virtual peer support chats, but after I did, I'd always feel less alone.

You, my friend—survivor, supporter, or caregiver—are not alone. Every survivor's journey is different, but we all share one common theme: a need for support and resources. When you're ready, the burn community is standing by to help.



➤ Amber Wilcox is a burn survivor, yoga instructor, and marketing professional from Ormond Beach, Florida. After her kitchen accident in 2020, Amber faced burns on 20% of her body from a hot caramel spill. After two skin graft surgeries from Orlando Regional Burn Center, Amber experienced hypertrophic scarring and underwent a series of laser burn surgeries from Tampa General Hospital. As a Marketing Strategist for SmartBug Media, Amber enjoys helping a wide range of industry clients with their marketing needs. When not marketing, Amber enjoys volunteering for Phoenix Society as a Peer Supporter, teaching yoga for Kula for Karma supporting youth in Florida detention centers, or providing free yoga for peers on her website, yogaamber.com.



SELF-CARE FOR CAREGIVERS

Author: Carly Bowers

Most of us aren't trained professional caregivers. We were thrown into this role because of life's unexpected twists and turns. We try to do our best, but it's easy to feel like you aren't doing a good job or burnout because of the stress and exhaustion.

Here are some helpful hints on how to take care of yourself when you're caring for a loved one, drawn from my own experience after my husband, David, was burned. I hope it gives you some practical ways to take care of yourself—or offer ways to support a friend or family member who has taken on the huge responsibility of caring for someone after a burn injury.

1. Learn as much as you can so you can be your loved one's advocate.

Trust your instincts. If you have a concern or notice something that just doesn't seem right, it's ok to speak up—and do so immediately. Speak to someone directly involved in the care of your loved one, such as your doctor, physical therapist, burn nurse, or nurse manager. Be specific and clear about your concerns and expectations, so the hospital knows how to best help.

When David was in the burn unit, there was an aide that was a bit brash and tended to be a little too rough with her patients. I went to the unit's Nurse Manager and explained my fears and concerns. I told her I didn't want this particular aide working with my husband. My concerns were heard, and changes were made.

2. You don't have to do it all. Ask for help from family and friends—and be willing to accept help!

Trust me, I know this is not an easy thing to do! We like to be the ones helping others as opposed to having people help us, but don't let pride get in the way. Accept assistance with transporting kids to their activities, allow neighbors or friends to drop off meals, and accept help with yard work, housework, or even laundry. If you have kids, assign them appropriate tasks as well. If possible, consider hiring medical staff or other professionals to assist with home health care such as daily wound care, physical therapy, and bathing.

3. Help your loved one maintain as much of their independence as possible.

When you allow your loved one to do some things for themselves, it helps them maintain a sense of dignity and control, and it allows you to do one less thing. I used to purposefully turn David's t-shirts inside out when I was folding laundry so he would have to turn them the correct way before trying to dress himself. I wasn't doing this to be mean. He needed to move his hands and arms, and this was a way he could get some extra therapy in. It also gave him a sense of accomplishment! I found times when it was safe for me to step back and let him do things.

4. Take Care of yourself physically, emotionally, and spiritually.

Get rest, eat, and get some fresh air every day. Call a friend. Exercise. Go for a walk. Read. Watch a movie. Pick what works for you. It sometimes felt like I was being selfish by putting my needs ahead of David's or our kid's needs. However, if I didn't take care of myself, I wouldn't be of any use to any of them.

It's not being selfish—it's being practical. Simple exercise and activity can help alleviate stress. Make sure you eat regularly. Take a break and go for a walk. Go outside and get some fresh air. Just a shift in your physical setting can help give you a mental break. And don't forget to get sleep! Sleep is critical for your physical and mental health so you can best care for your loved one.

5. Get support from counseling or support groups.

It's difficult to effectively care for your loved one if you are suffering emotionally and physically, too. Find a network with others who've experienced a similar situation. It just helps to know you're not the only one that's ever been through this.

We found Phoenix Society for Burn Survivors within the first year. Phoenix Society offers trained peer supporters for survivors and loved ones. Teaming up with them gave us an instant sense of community. We belonged simply because we'd all gone through a similar experience. I didn't have to explain anything to anyone because they knew what we were struggling with on a daily basis.

Don't hesitate to seek professional help from your physician or other professional if you are struggling with emotions that feel "out of control," or that don't seem to be getting better, or if you're having physical signs of illness or stress. Remember that it's ok to ask for help.

6. Deal with your feelings.

It's ok to have feelings of anxiety, worry, anger, guilt, fear, despair... Grieve over what you've lost. Find what is healthy and fits you best in terms of expressing or coping with your feelings. This might be talking with a close friend, writing a list of fears vs. realistic options, or writing in a journal.

I kept a journal to try to sort out my feelings. Sometimes I didn't feel like I could voice my feelings to anyone because I wanted to make sure everyone thought I was ok, but in order to deal with my emotions, I needed to release them on paper. This practice helped me not suppress my emotions. I also had regular visits with a counselor.

7. Try to stay connected to your friends and life outside of caring for your loved one.

It's ok to take a break, as hard as it might seem. Don't cut yourself off from the outside world. It may be tempting, especially when you're overwhelmed with everything that needs to be done. On occasion, we would have a "Girls' Night Out / Guys' Night In" evening. David's friends would come over to our house to grill steaks and watch action movies while I went out to dinner with my friends. Those were great moments, and it gave us a chance to laugh once in a while.

Here are some other ways to stay connected:

- Go out for lunch with a friend or have them bring lunch to you so you can visit.
- Call a friend, parent, or other close relatives just to chat. Take time to reach out and hear a friendly voice.
- Take a mini-trip. Maybe leave the hospital and go home for a day or two. Go visit a friend if someone else can stay with your loved one.

Although this list is simple, I hope that it may offer you some practical help to a situation that may seem too big to handle. Taking care of others is no small task, but it's a precious one. It's important for caregivers to take care of themselves so they can continue to care for their loved ones. If we aren't healthy, we can't help others heal.



Carly Bowers and her husband, David, are the founders of Bowers Ministry and co-authors of *Walk Through Fire: One Couple's Journey of Finding Joy in the Midst of Tragedy*. In 1999, their lives were forever changed when David was severely burned in an oxygen flash fire and was not expected to survive his injuries. The healing process has been an ongoing battle, but through it all, they have learned that there is a purpose for their pain. They try to encourage others facing hardship, especially families impacted by a burn injury. Carly and David are long-time volunteers with Phoenix Society for Burn Survivors and love to travel and share their story with groups.

RECLAIMING YOUR POWER AFTER TRAUMA

AUTHOR: HUYEN "KIKI" VO, MSW

I believe that each of us is born with unlimited power and potential. But sometimes, circumstances beyond our control can make us lose sight of that inner power. Trauma can cause profound feelings of longing and a great sense of loss, often forcing hurtful thoughts and questions about self-worth, existence, and the future.

At nine years old, I was severely injured in a house fire that resulted in third-degree burns all over my body. I spent more than ten years in and out of the hospital and had over 30 reconstructive surgeries. For years, I felt hopeless and angry. I often cried and asked, "Why me?"

Why did bad things happen to me? Why did I have to deal with such awful pain from all the surgeries? Why did I have to look different than everyone else?

What I didn't realize was that I was **grieving**. When we go through something that alters our world, we often go into shock and denial. We feel like it's not fair, and it's hard to accept the change.

I was grieving the "old" me and the "old" life I had before the injury.

Over time, I could fully grieve, regain my strength, and reclaim power over my trauma. It was not an easy road, but I am here to tell you that **it is possible**.

Below are some tools and strategies that helped me recover and heal.

1. Find Community

Tap into your communities for support, whether it's a burn organization like Phoenix Society for Burn Survivors or other community-based organizations. Within these communities, I met other survivors who had been through similar life experiences.

I believe **nothing heals people like other people**. When we come together to share our stories, struggles, and triumphs, we create a space to learn to navigate life together—healing and regaining our strength are not easy feats. It takes a lot of hard "heart" work. **You don't have to do it alone.**

2. Keep Learning

Whether through formal education or informal exploration, knowledge can open doors to endless opportunities that in turn challenge your mind, build capacities, and focus on your potential. It can help you develop and gain confidence—something that nobody can ever take away from you.

For me, education is one of the most powerful tools I have ever acquired. Through my study in social work and mental health, I have gained a deeper understanding of my own trauma and healing process. I am able to develop coping strategies and tools that work for me. I know that emotions and uneasy situations don't last forever. Even on the days I don't feel my best, I can ground myself and remain emotionally resilient.

3. Focus on Hobbies

Another strategy to help you find your strength is focusing on your hobbies and passions. When you focus on what you can do best, you nurture your gifts while building confidence. The more consistent your efforts, the better the results and, ultimately, the greater the chance you'll feel better about who you are as a person.

Whenever I feel down, I turn to cooking, working out, or dancing to release my stress. Over the years, focusing on these hobbies has made me realize **I have the power to choose joy and happiness**. I learned that I could take control by choosing what to focus on, and I can be in control even in hard times.

4. Get Active

Staying active is super important for feeling good about yourself. There is scientific evidence indicating that when you are active (walking counts!), your brain develops serotonin, otherwise known as the happy chemical.

When you stay active, you're more likely to feel confident about who you are, and your body will thank you for it. Our bodies keep account of what has happened to us, including and especially past trauma. The accumulation of all the stress over the years shows up physically, in the form of headaches, stomachaches, body aches, and more.

> Huyen "Kiki" Vo is a burn survivor, social worker, and motivational speaker. She has a master's degree in Social Work with an emphasis on Community Mental Health. She is also a Certified Trauma Professional (CTP). She currently serves families with histories of homelessness, mental health, and substance use challenges. She is also a psychotherapist-in-training with a focus on trauma-informed care and strengths-based healing. During free time, she is a mental wellness coach who helps those who have experienced trauma learn how to overcome self-doubts and negative beliefs, build confidence, navigate emotions, and ultimately, thrive in life. Check out www.thrivewithkiki.com to learn more about her story and work.

Trauma and its effects can have a lifelong impact on our overall health, so let's be kind and make sure our body receives the support it needs to **sustain, survive, and ultimately thrive in life**.

5. Write in a Journal

Journaling can decrease stress and anxieties while promoting mindfulness and allowing introspection. Try to start each morning with five to ten uninterrupted minutes of journaling to set your intentions for the day. If you are not a morning person, you can also do it before bed at the end of the day.

It's helpful to use a timer and set devices like phones and computers aside. I know journaling isn't easy for everyone, but our brains absorb so much throughout the day that holding everything in with no release can be very overwhelming and stressful.

When we take time to write out our thoughts, we can challenge whether or not our thoughts are true or if our emotions simply cloud them. Finding strength is a process that requires introspective work; it may cause us to sit and rumble with discomfort. Journaling is a great way to release pressure and gain strength.

6. Therapy or Coaching

It's not easy to identify strengths when you feel hopeless or overwhelmed with pressure. **Being strong is knowing when it's time to be vulnerable and allow professionals to support us.**

If you feel sick, you go see a doctor, correct? Well, therapists and coaches are doctors for our minds. When life is tough, our mind tends to make up stories about scenarios that might or might not be true. Professionals can provide a safe space and help us challenge our own inner critics, navigate uncomfortable emotions, and ultimately, help us feel empowered to thrive.

At the end of the day, there's no blueprint for what exactly will help you find your strength. But one thing is for certain: it's harder to do the work of overcoming trauma, healing, and regaining strength by yourself. **Communities exist so we can be each other's source of guidance and support.**

Remember, you are not on this journey alone.

Tools for Social Confidence

Based on the work of Barbara Kammerer Quayle, MA

We can influence how people respond to us when meeting strangers; entering new social, work, or school situations; or going into public places. Using **STEPS** helps to build our confidence and send the message to others that we are self-assured—even if we're still getting there!



S – Smile: Warm and kind.

P – Posture: Stand up straight/shoulders back.

E – Eye Contact: Look 'em in the eye.

T – Tone of Voice: Friendly and enthusiastic.

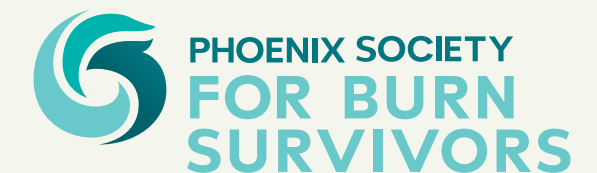
S – Self-Talk: What we say or believe about ourselves.



Be Seen. Be Heard. Belong.



Phoenix Society is the leading resource, connector, and go-to place for those impacted by a burn injury. Here, you're **seen for the person you are** and the potential you possess. **Your story is heard** because it's yours, and you matter. We understand the healing journey, and **we are with you**, survivors, loved ones, and care teams, every step of the way. Together, we believe in the **endless potential of what can be.**





BURNS IMPACT THE WHOLE FAMILY

Author: Justina Page

On March 7, 1999, my husband James, our six sons, and I experienced a horrific house fire. We awoke to our home completely engulfed in flames. My husband threw me out of our bedroom window, then got our four oldest sons out of the house. They all suffered varying degrees of burn injuries.

When James tried to rescue our youngest sons, twins Benjamin and Amos, the house caved in before he could grab them both.

We lost everything we owned. Most devastating of all, we lost Amos on site.

Everyone processed the trauma differently.

My husband dealt with severe survivor guilt. He felt it was his responsibility to keep his family safe, and he was not able to rescue Amos. Through faith, prayer, and counsel, he was able to reconcile with what happened.

My oldest son, Jonathon, was angry at God for a tragedy he believed shouldn't have been allowed to happen. Joseph compared his actions to his older brother, who tried to run back and save his brothers, and concluded that he was a coward because he didn't try to save anyone but himself. Caleb became very sensitive about his self-image as he dealt with teasing at school.

As for myself, I was debilitated by the grief of losing a child.

Our journey was long, but we were able to heal, thrive, and find purpose in helping others who suffered similar tragedies.

Whether multiple family members experienced a burn injury or a single individual was hurt, every family member is touched by the trauma of a burn injury. Every one of you is on a unique journey of recovery, dealing with the trauma in your own way.

If you are struggling and feel guilty because you weren't the one who experienced a burn—please don't! What you suffered—emotionally or otherwise—is valid. You deserve to get support.

Many burn recovery programs, such as Phoenix SOAR Peer Support, are available to family members as well as survivors. There are resources for caregivers, spouses, parents, and children of burn survivors and siblings of young burn survivors.



Support is vital for the whole family. Hearing the experiences of those who have traveled the road your family member is currently on will empower you on how to better take care of your loved ones and yourself.



➤ Justina Page is an international speaker and natural storyteller who speaks with a bold and refreshing honesty that touches the hearts of audiences. She now inspires audiences worldwide with a powerful message of hope and triumph. She is the author of the award-winning book, *The Circle of Fire* and 11 other literary works. She is the Founder and Executive Director of The Amos House of Faith, a non-profit organization that provides post-burn support to children and families affected by burn trauma. She is a supporting actress in the award-winning faith-based movie *We Are Stronger* and the highly anticipated upcoming TV series *Breaking Strongholds*.

Tools for Coping with Guilt



Of all the emotions families endure in a crisis, guilt seems to be one of the hardest to resolve. Help your family develop healthy coping strategies with these tips from social worker and Phoenix Society volunteer Jennifer Harris:

- Validate the thoughts and feelings of each family member.
- Maintain normalcy and routine (as much as possible) at home, particularly when children or teens are involved.
- Provide honest and accurate information about the injury.
- Sustain positive self-talk and self-affirmations.
- Stay connected with family, friends, community, and school.
- If talking becomes overwhelming, keep a family dialogue book, where everyone can share their feelings without the intensity of having to talk about it.
- Remember that your loved one most likely does not blame you for what they are going through, and if you asked, they would probably tell you just that.

WHAT TO EXPECT: MENTAL HEALTH

Author: James Bosch, MA, LMFT

At 8 months old, I was burned when a hot water humidifier fell into my crib. This was more than 50 years ago—there were no comprehensive burn centers with social workers and peer support. My parents were young, from families that didn't talk about mental health issues.

As a result, I was left to navigate the hostile landscape of being a kid with visible differences alone. Since no one talked to me about possible emotional challenges, I didn't have the vocabulary to talk about them myself.

I went inward, suffering in silence. I tried to medicate my feelings with unhealthy behaviors and substances. This led me down many paths, and I eventually found healing through therapy and peer support.

My experience led me to become a therapist who works with burn survivors. Though my adversity may have led to me becoming a gifted healer, many of my struggles could have been prevented by knowing what to expect and where to get support.

If you hear nothing else, know that you are not alone, and you do not have to suffer in silence.

In this article, I hope to highlight some of the common responses to burn trauma and some of the mental health challenges you may face on your journey.

The emotional recovery after a burn often does not begin until we get home.

During the acute phase of healing, your focus is on surviving your injuries and physical healing. There is often a huge network of burn staff and visitors to keep us distracted. When we go home, we're faced with caring for ourselves for the first time. We're finally alone with our thoughts.

Don't be alarmed if you fall into fear or depression shortly after arriving home (or wherever you'll be staying for the early rehab stages). This is a common experience once the reality of your journey sinks in.

Depression and anxiety are normal responses to a horrific life-altering event like a burn injury.

It is okay to acknowledge how hard it is, talk about your feelings, and reach out to your burn team with questions. You and your home support team will be figuring out a lot of things you never expected having to think about!

Shame is one of the most prevalent emotions in burn recovery.

We are often full of self-judgments: "I should be able to get through this on my own." "I need to be strong for others." "I can't show weakness when everyone is rooting for me." The most common one I hear is, "I should be past this by now!"

But when you're recovering from a traumatic injury, emotional healing isn't a straight line.

Just when you think you're doing great, something triggers you, and you're back in the darkness of depression, or you're full of fear and anxiety. I don't say this to scare you, but to prepare you if it happens. I like to look at healing as a spiral, generally moving upward, with lots of twists and turns.

Acknowledge this journey is hard and give yourself lots of breaks and self-compassion.



Sleep and pain management are two of the big issues once you are home.

One is often the result of the other. Many things can help with sleep, such as looking up sleep hygiene practices and over-the-counter remedies. Explore relaxation apps and YouTube for sleep hypnosis and guided imagery to help with both sleep and physical discomfort.

It is easy to want to play pharmacist and try to adjust your own medication, but be sure to call your doctor if your pain is not being managed. We are often given open prescriptions for pain medicine—but not told how to ween off them.

Once the physical pain decreases, survivors often discover the medication also numbs emotional pain.

This is a pathway to addiction. Talk to your burn team about how to move off of the narcotics to other pain meds or pain management techniques.

Post Traumatic Stress Disorder (PTSD)

PTSD refers to certain symptoms a trauma survivor experiences that persist over 30 days after the traumatic event. Symptoms include hypervigilance, easy startle responses, flashbacks and nightmares of the event, avoiding topics, or anything that reminds you of the event, and mood disturbances.

Some of these things are normal after a life-threatening experience and the traumatic experience of burn treatment. Not everyone who has a trauma develops PTSD, but it is important to get professional help if you're having a hard time moving past feeling frozen or fearful all the time.



Accepting changes in our appearance and the structure of our bodies can be the most difficult part of emotional healing.

Once the wounds heal, the rehab phase of your recovery begins.

Around this time, self-motivation is very important—and often very difficult! We get exhausted by daily physical therapy, massaging, and stretching. The work on our body and relearning to do things independently is frustrating enough, yet the physical changes to our body are often the most emotionally taxing in this time.

Developing a sense of identity with a visible difference or coming to terms with an altered body image is hard but important work. Lots of self-love and self-compassion are needed in the path to seeing our differences as beautiful and accepting ourselves. As Sonya Renee Taylor says in her book of the same name, “Your body is not an apology!”

Phoenix Society has many resources to help with image and body acceptance. From make-up tutorials for burn survivors and fashionable ways to cover up to social media campaigns like #BurnsAreBeautiful, there are many ways to foster confidence and self-love.

Today I accept my scars, but that was not always the case. I’m a big proponent of not only focusing on what’s beautiful on the inside but also finding things we love about our outside—scars and all.

Connecting with other burn survivors is so important.

After all, no one can relate with losing a body part or having a scar if they haven’t been there. Being able to talk to someone who knows exactly what you mean and doesn’t get all awkward trying to offer sympathy is life-changing. It removes shame by letting us know we are not alone and offers hope by providing a role model for life after a burn.

Phoenix Society holds this at the heart of their mission and will help get you connected to a trained peer supporter or burn support group.

Professional help is incredibly important and helpful, but in my own journey, it wasn’t until I met other burn survivors and found others who related with my experience that my healing truly began.

You are on a courageous journey with many hills and valleys.

I hope these few words on navigating the early emotional land mines after your burn has given you some solace. There is a large community of burn professionals and burn survivors that are here to walk the journey with you!



➤ Burned as an infant, James Bosch has dedicated much of his professional life to helping other burn survivors, and their families heal and find meaning after a burn. Acceptance of new life, new body, and finding new meaning are at the core of his work. James is a Licensed Marriage Family Therapist practicing in California and a member of the Mental Health Support Team at Phoenix Society.

THE POWER OF PEER SUPPORT

Author: Rich Casias



In June 1989, I was injured in an aircraft accident in southern Oregon and began treatment at the Oregon Burn Center ICU.

After about two months in the burn center, one of my nurses commented that I was “smiling a lot more” and even becoming “more talkative.” Maybe it was a coincidence, Nurse Tom said, but I seemed to be in a generally better mood—why was that? Could it be related to “that pretty girl who stopped in to see you the other afternoon?”

Tom was referring to a visit from Pam Maxon, who had come by to introduce herself at the request of my burn surgeon. I vaguely remember my surgeon saying something like, “I’m going to have one of my former patients come by to show you how good your legs can look.”

One afternoon, not long after my surgeon’s announcement, a nurse stopped in my room and said I had a visitor. Following behind her was this confident young woman in a white sundress.

Nurse Tom was absolutely right—meeting Pam and listening to her share the story of her burn injury and recovery process was motivating. Her ability to empathize with my challenges and to understand the frustrations of my seemingly slow recovery process made all the difference in my own outlook. Pam shared how discouraging it was for her to try and learn to walk again on legs that looked like “hamburger meat,” but she found the strength to keep moving forward, and so would I.

Pam went on to become one of my best friends, and I never forgot how powerful her visit was for my recovery.

After my years of physical and emotional recovery, I responded to my own desire to give back by volunteering at the UC Davis Med-Center Burn ICU. When the hospital adopted Phoenix Society’s SOAR Program, I learned what it meant to be an effective peer supporter.

Through Phoenix SOAR, I learned the skills necessary for in-person and online peer support. I have had the honor to participate in many peer support sessions with “newbie” burn survivors and sessions with many “long-time” survivors.

As survivors, we already understand burn injuries are physically, emotionally, socially, and economically traumatic events with the potential for long-lasting impact. From our peer supporter training, we understand a burn survivor’s recovery process requires “the highest level of care and support that can be provided through the collaborative efforts of dedicated medical staff, a local agency, and peer supporters, including the patient’s loved ones.”

As a new or long-term burn survivor, receiving peer support can be motivating, affirming, even magical—just as it was for me many years ago when Pam visited my hospital room. Today, there are many opportunities to meet one-on-one or in group settings (both in-person or virtually) with a Phoenix SOAR Peer Supporter.

It takes enormous courage to start your journey of recovery after a burn injury. We only ask that you give one of us the opportunity to inspire you and walk by your side.

“In-person or online, one thing remains clear: peer support is a carefully managed two-way relationship.”



➤ Rich Casias studied groundwater resources and earth science in college and continues to work as a California Professional Geologist based in the northern California region. As a Phoenix SOAR Peer Supporter and Peer Support Trainer, he is energized by assisting burn survivors to learn to rebuild their self-confidence and advocate for themselves and others in the burn community.

WHAT TO EXPECT: GETTING BACK OUT THERE

Author: Blake Tedder, MSW, RYT

When I visit people in the hospital as a peer supporter, one of the most pressing questions is how their injury and appearance will affect their life and relationships when returning to the world.

Of course, I always say that no one's recovery is the same, just as no one goes into a burn injury with the same story.

Still, having an altered appearance from a burn injury in our image-obsessed society can be challenging and sometimes emotionally painful. People may stare, ask intrusive questions, and make snap judgements. They may have trouble looking at your scars. Even people who know you and love you may react poorly to your appearance.

But that's not the whole story.

It helps to recognize that this reality is not something to fight against, wishing it wasn't true. After all, it's human nature to be challenged by difference.

How others respond to your appearance is out of your control.



I think knowing this takes a lot off your plate. You can skip a lot of heartache and focus on learning to be comfortable in challenging situations. With the right mindset, your personality can outshine any visible differences you have.

While my return to the world hasn't always been graceful or easy, it has been real. I did a lot by trial-and-error. With my fresh red scars, glistening skin from oily lotions, and pressure garments on my arms and legs that didn't match my skin tone, I felt like I had a big sign over my head reading, "LOOK HERE."

When people stared, I would often stare back aggressively. When someone asked invasive questions, I might lie to them with some overblown war story involving flamethrowers. In an intimate moment with a partner, I would try to distract them from my scars.

These strategies gave me emotional protection and space, but truthfully, I just felt vulnerable 100% of the time when out in public, passing groups of children, meeting new people, or dating. I became very familiar with the heat and sweat of anxiety and relentless negative inner voices.

My brash reactions helped me feel less vulnerable, but deep down, I knew I would have to face up to my changed appearance. I was never going to change human nature and magically make people not see my scars.

This process didn't happen overnight. I had to learn how to feel the hurt in my body, resolve some of my trauma, and stretch some of my scars. Yoga, meditation, and massage were tremendous tools that helped me do just that. Simple yoga movements and stretches, finding stillness, and the warm touch of a skilled massage therapist all helped me become more comfortable in my mind, in my body, and about my appearance.

As I felt better about myself from the inside, people seemed to feel better about me. The new comfort with myself spilled into my social life, career, friendships, and intimate relationships. I felt confident in who I am, so much that I began to embrace the opportunities my scars gave me to connect with others.



Whether it was an honest conversation with a new intimate partner about what to expect with my body or the unexpectedly deep conversations with curious strangers, my scars have given me a special key to connect heart-to-heart with others.

It turns out everyone has scars—inside or out.

I encourage anyone embarking on the journey to a full life after a burn injury to learn how to feel good first, and trust that the rest will follow in time. People tend to reflect about us what we feel about ourselves, so find some mind-body skills to help you feel better from the inside out.

Phoenix Society has many resources to get you started in building confidence, managing social interactions, and cultivating self-love. You may also find professional support from burn professionals, including physical/occupational therapists, social workers, psychologists, and recreational therapists.

And remember – you are not alone. The burn community is here to help you build confidence and get back out there.



Blake Tedder, MSW, RYT, is a burn survivor from Hillsborough, NC. In 2001, he and his father survived a plane crash in the Rocky Mountains of Colorado. Blake's long journey through disfigurement and PTSD has created a desire to help others heal their own physical, emotional, and soul wounds. He is a certified yoga teacher. Blake is a long-term volunteer with Phoenix Society and the UNC Jaycee Burn Center's Aftercare Program. His Blake Tedder Burn Endowment funds healing initiatives for burn survivors in North Carolina. Blake enjoys writing and playing music, being in nature, podcasting, and spending time with his wife, Amelia Vogler. He currently works for Duke University.

UNLOCKING YOUR CAPACITY FOR RESILIENCE

Author: Dr. Lise Deguire

Burn recovery is more than a physical ordeal—psychological healing can take as long, or longer, than physical recovery. The journey may not be quick, but most people are capable of a resilient recovery after being burned. Resilience (the capacity to bounce back from adversity) was once thought to be rare. But researchers have found that resilience is actually surprisingly common, although that does not mean recovery will be easy.

I am a psychologist and also a childhood burn survivor. At 4 years old, my mother and I were engulfed in flames from a barbecue fire. I underwent years of surgical procedures, as they reconstructed my lip, chin, neck, arms and grafted my tiny body again and again. I had so many operations that my grandmother stopped counting. I had third-degree burns on two-thirds of my body and am disfigured for life. I endured most of these procedures alone because my parents, although loving, were intensely self-absorbed and unable to care for me.

This is my story, and it is all true. So, how is it that I am now a happy, well-loved, successful psychologist? I lead a beautiful life, happily married, the mother of two, with rewarding work and many friends. No one would have predicted those odds.

Many components contribute to resilience. Some factors are beyond our control, such as genetic or economic factors. Having financial resources grants better access to quality health care, education, and support. Having a supportive family and community also supports resilience.

However, much of resilience rests in our own mindset, in the way we view ourselves, our world, and our future. Happily, we can improve and enhance this mindset.

I have developed an acronym to explain these mental resilience skills: **G.O.A.L.S. + M.M.**

G is for Gratitude

The capacity to notice and appreciate your blessings in life.

The simple act of acknowledging your blessings can have a quick and positive effect on mindset and physical wellbeing.

Being discharged from the hospital, you may find yourself

overwhelmed. There will likely be pain, dressing changes, scarring, and many disruptions to your routine. Still, it is important to notice the good around you. Are you healing? Are you able to walk around? Is the sun shining?

Try noticing three things every day for which you are grateful. Even better, write those three positive things down every day and start a “gratitude journal.” You will probably notice that you feel better whenever you notice the good in your life instead of focusing solely on your challenges.

O is for Optimism

The capacity to look forward, to anticipate something positive and to have hope—even during challenging times.

Sometimes the call for optimism can sound fake or superficial. However, focusing solely on gloomy “what-ifs” can spiral into demoralization.

It is vital to imagine that things could turn out well for you. Recovery from burns can happen. It is possible to have a great life as a burn survivor, take it from me. Your life can still be full of joy, adventure, and love. It won't be easy because being burned is not easy, but it is still possible. Holding onto an optimistic vision is key. Because when we have hope, we will be more motivated to do the hard work necessary for recovery.

A is for Active Coping

The ability to do something productive to help solve our problems.

There is much about life right now that you cannot change. If you are burned, then you are burned. That cannot be undone; you are now a burn survivor.

But there are other things you can change! You can follow your doctor's instructions and optimize your recovery. You can wear your splints and do your physical therapy. You can give your body the nutrition it needs to heal. You can listen to music or sit outside to improve your mood. There are many ways to actively cope with trauma and promote a better future.

L is for Love

Surround yourself with loving relationships and good support systems.

Resilient people tend to have good support systems, though support may not come from expected sources. Parents may be neglectful; marriages may be disappointing. But support can still be found in friends, neighbors, coworkers, and the burn community.

Many survivors notice that some relationships change after the burn. Some friends and family really come through for us, showing tremendous love and care. Other friends and family do not. Perhaps they are overwhelmed, perhaps they are emotionally limited themselves. Perhaps they simply don't have that much to give. Many of us over-focus on the disappointing people, feeling aggrieved and hurt. And yes, this is natural.

But it's important to notice the people who have come through for you.

Try to celebrate and appreciate them instead of dwelling on the disappointing people. If we mostly focus on the people who have failed us, we won't even notice all the people who have been heroes.

S is for Social Skills

The capacity to form and keep positive relationships.

Resilient people tend to be good at relationships. They connect well with teachers, neighbors, friends.

Utilizing good social skills will help you build positive relationships.

It's important to smile and say “please,” “thank you,” and “you're welcome.” You will probably need a lot of help as you return home. Caregivers get overwhelmed too, as do medical providers. The more you show appreciation and gratitude for the people in your life, the stronger those relationships will be.

You may also face some social challenges as you head back out into the world. Your own social skills will help you build confidence and make connections.



Dr. Lise Deguire graduated from Tufts University and earned her doctorate in clinical psychology from Widener University. She is the author of the multiple award-winning memoir, *Flashback Girl: Lessons on Resilience from a Burn Survivor*. She is a blogger for Psychology Today and has appeared on NPR, NBC, ABC, FOX, Sirius XM, and numerous podcasts. Dr. Deguire writes a blog about psychological resilience issues and is a national keynote speaker. She lives in Bucks County, Pennsylvania, with her husband, two wonderful daughters, and one rambunctious dog. To learn more about her work, visit www.lisedeguire.com.

M.M. is for Meaning Making

The ability to find meaning and purpose from the experience of suffering.

At some point after trauma, it is vital to make sense out of what you've been through. Sometimes faith helps us make meaning, but it is not necessary to be religious to find meaning.

Many burn survivors make meaning out of their suffering by giving back to the burn community.

Some of us volunteer, visiting newly burned people in the hospital. Some of us help to run summer burn camps for children. Some of us are peer counselors. You don't need to be an active part of the burn community. There are so many ways to give back to the world, through church, or charity, or simply helping a neighbor. Still, please know that the burn community is here if you wish to join us, making meaning out of our own trauma by helping others.

Notice anything about G.O.A.L.S. + M.M.?

All these skills and mindsets can be strengthened and improved. Most of us fear that resilience is a gift that we either have or we don't. Luckily resilience is both common and possible. You can improve your likelihood of a resilient outcome by working on being grateful, optimistic, a good problem solver, noticing the love around you, using good social skills, and giving back in a meaningful way.

Like many of you, I am a survivor. With help from loved ones and professionals, I grew the qualities of resilience that kept me thriving. The meaning I take from my trauma is that I am now here to help others.

Now it's your turn to think about G.O.A.L.S + M.M.

- **What are you grateful for?**
- **What gives you hope?**
- **Who loves you?**
- **How can you connect with others?**
- **What can you learn from your experiences, and how can you give back?**

Responding to Questions + Comments

It may be awkward, embarrassing, or frustrating when others ask questions about your burns. By memorizing and rehearsing a simple response, you can stay in control of what you share and how you manage these moments.

Craft Your Response

Sentence 1: About your/your loved one's injury. Can be broad or specific.

Sentence 2: How you/your loved one is doing now.

Sentence 3: End the conversation.

"I survived a burn injury. I'm still going through treatment. That's all I feel like saying about it."

"I was burned in a car crash. I'm doing a lot better now. Thanks for asking."

"I don't feel up to talking about it today. Thanks for understanding."

Low Energy: Prepare another version for when you don't feel up to questions.

Tip: Practice these tools in front of a mirror. It takes practice until it becomes authentic, natural, and part of your daily life.



When athlete and Army Guardsman Jalen Richardson was 20 years old,

another motorcyclist hit his bike's back tire projecting he and his bike down the highway, causing the gas tank to explode. He was rushed to the Grady Memorial Hospital's Marcus Trauma Center. Two months later, he woke from a coma with his left forearm amputated and 60% to 70% of his body covered in third-degree burns.

By 2020 – four years after the accident — Jalen had not only returned to his unit at the Georgia National Guard, but he was also named the 78th Aviation Troop Command's "Soldier of the Year."

Dr. Juvonda Hodge, assistant medical director at Emory University's Grady Memorial Hospital Burn Center, treated Jalen and pushed him forward, even when he wanted to give up. Jalen and Dr. Hodge have developed a special relationship over the last six years of Jalen's recovery and would like to share some inspiring tips on living life *after* the hospital.

Questions & Answers

Jalen

Q: Describe the importance of being committed to your recovery. What can patients do to speed up their recovery?

A: "Listen to your physical therapists and doctors! I didn't wear compression garments right away and my skin was really rough. Once I started wearing them, I realized how helpful they were with laying down the scar tissue and just looking better in clothes. Also, try and encourage yourself to get back to the things you like to do as fast as you can because if you allow yourself to dwell on all that's happened, it won't put you in a good place."

Q: When leaving the hospital, are there questions you recommend asking the staff/providers before going home?

A: "Make sure you're aware of what your at-home duties are: what therapy exercises you need to be doing, stretches, good care routines for your burns, things you can put on your skin to help the rejuvenation of the skin. You don't want to have to guess about these once you're home."

Q: What's the first thing you realized that was different when you got back home?

A: "I needed everybody to do everything – to walk, to get out of bed, to go to the bathroom, to wash myself, to brush my teeth – every little thing. That was the biggest eye-opener for me: my loss of independence."

Q: What's the one piece of advice you would give anyone leaving the hospital after this type of injury?

A: "You're not alone. When you're going through this trauma, a main question is: Why me? It helped to hear the stories of people that have been in my shoes—or even worse shoes—and how they overcame it, living prosperous lives and making a new normal."

Dr. Hodge

Q: What's the most important thing to you for your patients to remember when they leave the hospital?

A: "Have grace with yourself. It's okay to mourn your past life but remember to also look forward. This kind of self-acceptance is a process for sure."

Q: Do you have any recommendations to track progress once a patient is home?

A: "I advise using a physical reminder like a FitBit or an Apple Watch—something that shows how much activity you're getting to gauge your strength, progress and overall recovery."

Q: What may surprise recent burn survivors about what can make an impact to recovery after the hospital?

A: "I've seen what the human body and mind can do when they're aligned. My job is to get you to the finish line. When we get to the 4th quarter, I'll hand the ball over to you for the touchdown – but it's a team sport. You need to start motivating yourself again. I have patients write down goals of what they want to do and what they are working towards to help motivate that journey and keep a positive mental state."

Beyond the mental journey, once at home, nutrition is key as is daily rehab while tracking progress. It's important that your PT routine not only happens at the therapist's office but at home too. Support is totally key as well, whether from peers or family."

HOW TO RESPOND TO QUESTIONS + COMMENTS ABOUT YOUR BURNS

Author: Amber Wilcox



During my stay at Orlando Regional Hospital's Burn Center, I didn't realize my life had changed forever. Not just from this traumatic experience mentally, but also learning that my appearance would likely change.

When I returned home and had the chance to really look at my burn scars and grafted skin, I realized that I would no longer look the same. This can be a difficult part of the journey of a burn survivor, and once you're ready to get back out there, questions and comments from people who haven't been part of your healing journey can make it feel even harder.



Responding to Others About Your Scars

How, as a survivor, do you deal with these questions or comments? Every survivor's journey is different—but we all have a variety of ways to respond or react to these comments and questions. I've asked other survivors how they respond to reactions, and here's just a few of the different responses or options available to you:

Inform & Educate

Before my burn injury, I was ignorant of the many types of burn injuries or the events that could cause them. When I saw someone with a burn injury, I truly didn't understand.

Ignorance can lead to some uncomfortable moments for survivors, but these can be countered with information and education.

Bill Alexander was burned at 9 years old after spilling paint remover on his shirt. The fumes flashed when he struck a match to light an outdoor BBQ pit.

Recently, he shared this story with an old friend:

"[My friend] proceeded to tell me how incredibly stupid it was not to stop, drop, and roll—much less be lighting a BBQ fire at nine years old.

I took a big breath and said that in 1960, stop, drop, and roll wasn't taught. Even today, I see videos of firefighters running with their suits on fire; it's an automatic fight or flight response. I also explained that my dad had passed away in 1953, and I had been lighting the BBQ for the past year.

After that, [my friend] changed the subject with no remorse evident. Moral of the story? Even a highly educated, 68-year-old man can act stupid and keep going."

Sometimes friends, family, or complete strangers may say hurtful things out of ignorance. Bill chose to patiently educate his friend, but that's not the only way you can respond.

Unexpected Humor

It took me a long time to feel comfortable using humor when asked about my scars. However, I've found making light of a heavy situation can break up a tense moment.

Jon Zawislak can relate to not wanting to use the same rehearsed response:

"When people asked me about my scars, I got tired of giving a long answer, or a few sentences like I had practiced. Whenever I get asked about my facial burns now, I simply reply: 'I survived a home explosion in 2019. What did you do that year?' 100% of the time, they laugh, and that is the end of that conversation."

Not everyone is comfortable with this approach, but it's a huge relief to laugh together instead of telling a traumatic tale for some.

Take Action First

Sometimes, I can sense a question coming before it happens, or someone is staring but too afraid to ask. I could ignore them and let it be, but this can be frustrating. You're left wondering what was so fascinating. Have you seen scars before? Are you staring because you want to know what happened?

Instead, I like to address it head-on:

"I noticed you might have been looking at my legs, and well, I know they look different. I was burned in a kitchen accident last year, and my legs are healing great, but as you might have noticed, I do have skin grafts and scars."

Taking action first gives you control of the situation. You can tell the story you want and move on quickly with the reaction you want.

Set Boundaries

While there are some days that I'm happy to talk for hours about my journey as a burn survivor, there are certainly days where I want nothing more than to have you ignore me and move on.

On those days, when I get questions, my response is short, sweet and I quickly change the subject:

"My legs? Yes, I had a burn injury in April of 2020. What you see are skin grafts; I'm doing great now, thanks for asking."

If they press for more information, be ready to set a boundary by saying something like, "That's all I want to share right now."

Walk Away + Regroup

I remember my first time in a bikini on the beach. My husband's family had been incredibly positive, and all were aware of what happened—but understanding is a lot different. One of his aunts came over to ask to see my scars, then proceeded to say, "how great they looked."

To a non-survivor, this might sound positive, but as a survivor, the last thing I'd like you to do is inspect my legs and tell me how you think they look. Sure, maybe they look great to you, but these legs worked really hard and, depending on the day, don't always look so great to me.

When uncomfortable situations occur, you may want to remove yourself from the situation and take a moment to regroup. For me, this has been a better approach than sitting with my emotions in a situation where I'm already uncomfortable.



Talking to Kids

I was playing with a young relative when she touched my skin grafts and asked what happened. With the most innocent concern imaginable, she noticed the visible difference between my skin and that of others.

Even though I knew this would happen, I was unprepared to respond:

"I got hurt in the kitchen; something hot touched my legs. I'm okay, and my legs just look a little bit like a mermaid's now, don't they?"

A fellow survivor had given me the mermaid tip, and it stuck with me. Mermaids? Yep, totally relatable. She sat there for a moment, looked at my legs briefly, recognized I was indeed okay, and that was that. The moment was over just as quick as it came.

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Your Story, Your Choice

Shortly after connecting with Phoenix Society, I was provided with resources on how to share my story and how to rehearse my response. I began writing down my story, practicing telling it with my husband, and starting to just use it with others.

No matter how much I rehearse my story, I'm still thrown off by someone saying something that makes me angry, frustrated, or annoyed. On these days, I try to reframe my perspective: "This person just doesn't understand." There

are some days where I just want to be Amber, the girl without scars, because I don't want stares or questions. Sometimes I wear my burn survivor shirt and hope others will...take the hint.

But the more I share my story, the easier it becomes to tell. It helps to remember that I'm in control of my narrative. For some, this might mean you don't want to talk about it at all. And you know what? That's completely okay. It is your story to tell.



➤ Amber Wilcox is a burn survivor, yoga instructor, and marketing professional from Ormond Beach, Florida. After her kitchen accident in 2020, Amber faced burns on 20% of her body from a hot caramel spill. After two skin graft surgeries from Orlando Regional Burn Center, Amber experienced hypertrophic scarring and underwent a series of laser burn surgeries from Tampa General Hospital. As a Marketing Strategist for SmartBug Media, Amber enjoys helping a wide range of industry clients with their marketing needs. When not marketing, Amber enjoys volunteering for the Phoenix Society as a Peer Supporter, teaching yoga for Kula for Karma supporting youth in Florida detention centers, or providing free yoga for peers on her website, yogaamber.com.

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ADDITIONAL RESOURCES

American Burn Association

<https://ameriburn.org>

The American Burn Association offers resources and tools related to burn research, education, care, rehabilitation, and prevention.

American Chronic Pain Association

<https://www.theacpa.org>

Provides resources and education for people living with chronic pain so that individuals may live more fully despite their pain.

Amputee Coalition

<https://www.amputee-coalition.org>

The Amputee Coalition provides resources, support groups, peer support, and more for amputees and their families.

Crisis Text Lines

<https://www.crisistextline.org>

Text HOME to 741741 from anywhere in the United States to receive free 24/7 support from a crisis counselor (Also available on WhatsApp).

EMDR International Association

<https://www.emdria.org>

Eye Movement Desensitization and Reprocessing (EMDR) therapy is an extensively researched, effective method proven to help people recover from trauma.

GoodRx

<https://www.goodrx.com>

Compare prescription prices, get free coupons, and save on your prescriptions.

Lotsa Helping Hands

<https://lotsahelpinghands.com>

Coordinate help and support and communicate updates to your friends and family.

National Alliance for Caregiving

<https://www.caregiving.org>

A national nonprofit dedicated to improving the quality of life and assisting caregivers and those in their care.

Northern Alliance of Mental Illness (NAMI)

<https://nami.org>

NAMI provides support and education for individuals and families affected by mental illnesses.

Substance Abuse and Mental Health Services Administration (SAMHSA)

<https://www.samhsa.gov>

SAMHSA will get you connected with reliable, reputable sources for assistance with substance abuse.

Social Security Disability Insurance + Supplemental Security Income

<https://ssabest.benefits.gov>

<https://www.ssa.gov/ssi>

The Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs provide financial assistance to people with disabilities.

Suicide Hotline

1-800-273-8255

<https://suicidepreventionlifeline.org>

The lifeline provides 24/7, free and confidential support.

United Way

211

<https://www.unitedway.org>

A free and confidential service that's available 24/7 to help you find local health, education, and financial resources.

Explore our entire resource directory and find local resources by visiting www.phoenix-society.org/directory.





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