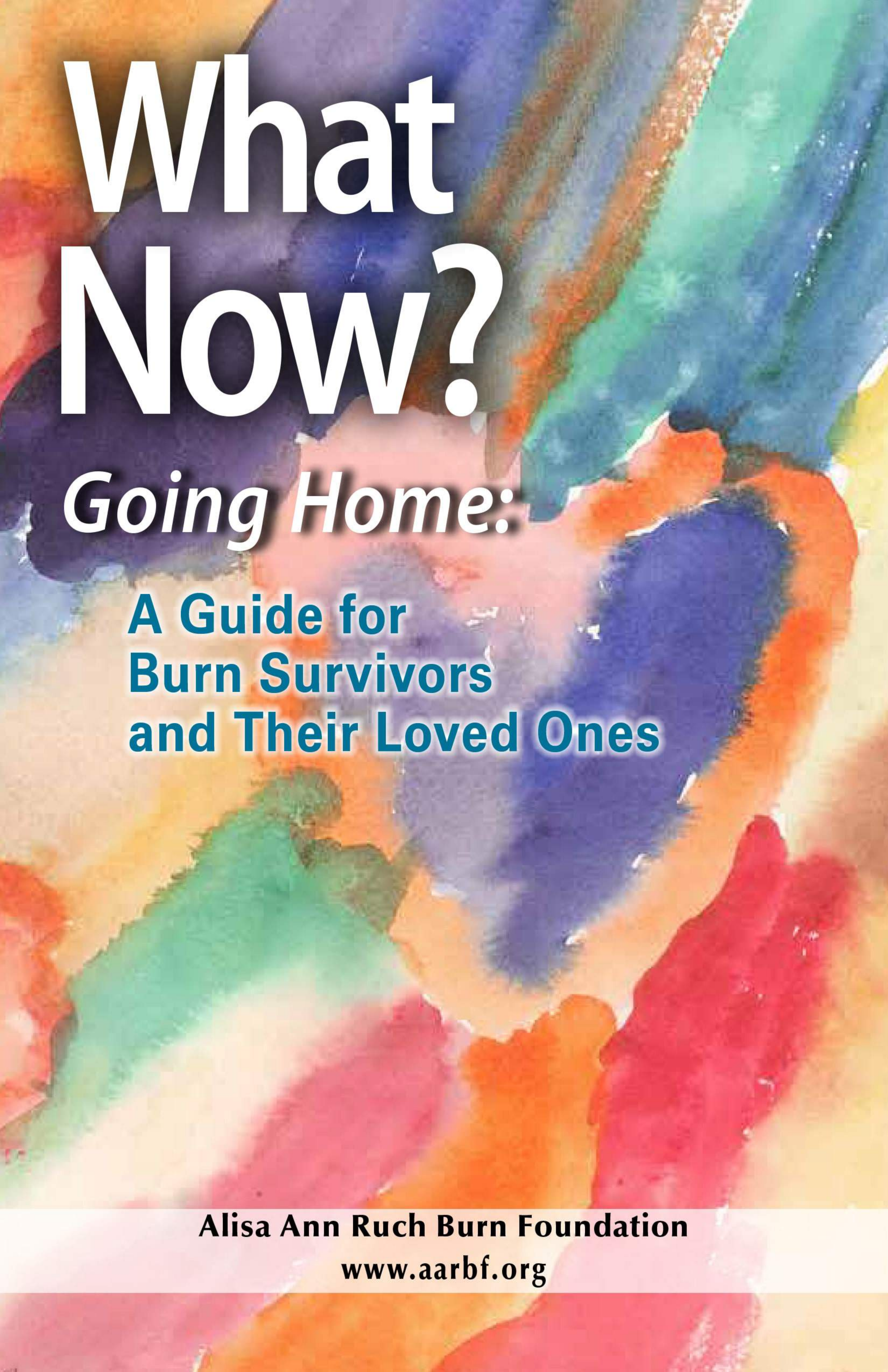




What Now?

Going Home:

**A Guide for
Burn Survivors
and Their Loved Ones**

Alisa Ann Ruch Burn Foundation

www.aarbf.org



**This booklet is from
burn survivors
to you.**

DEDICATION

To all the courageous burn survivors who have contributed to this booklet. It is through your example that there is life and hope after the trauma of a burn injury.

This publication is also dedicated to the families and loved ones of burn survivors who have shown tremendous strength, dedication, sacrifice and support.

This booklet has been developed by burn survivors, family members, and burn care professionals.

**Cover painting by Alice Becker
In memory of the joy she brought to so many lives.**

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INTRODUCTION

This booklet has been written by burn survivors who have been through the process themselves and want others to know that, although the recovery may be difficult, there is a full life to be lived after a burn injury. This booklet is a starting point for finding resources and support. We hope that the information will offer you practical advice on ways to move forward.

A severe burn injury can alter one's sense of safety, mobility, independence, appearance, and feeling of self-worth. Survivors must navigate both the burn recovery process in the hospital and the challenges involved in returning home to their everyday lives. Through reading this booklet, we hope survivors and their loved ones will feel more supported as they heal.

Burn recovery begins in the hospital and continues after you return home. Knowing what to expect will help you prepare for the challenges ahead. For some it may take months, and for others the process may take years. While your life following a burn injury may be different from the life you previously envisioned, over time your new reality can be equally meaningful and rewarding.

Even if you feel you do not need support today, it may be helpful to you down the road. We invite you to fill out a referral form to stay in contact with the Alisa Ann Ruch Burn Foundation after your hospital discharge. You can use the list of resources provided in the back of this booklet to seek out additional services.

Finally, we hope that by reading this booklet you will understand ***you are not alone***. There are places to get help and people who understand the difficulties you may be facing. From physical rehabilitation to emotional healing to regaining control of your life, this booklet offers perspective on the burn recovery process. We are available to share advice, offer support services, and help you figure out . . . What now?

GOING HOME

Leaving the hospital after a burn injury can feel frightening as you enter an uncharted part of your recovery. While the departure is an important milestone in your recovery, you will be faced with a new set of challenges as your healing continues outside of the hospital.

"I knew right away this was a life-changing event."

- Josh

"The ride home seemed like an eternity. I felt nauseous and it hurt to sit upright."

- Jesse

"I felt lost when I got home and didn't remember a thing I was supposed to do. I had to get re-educated on my first clinic visit. Those last few days in the burn unit were just a blur."

- Carol

"I felt like I was an adult in an infant's body. I couldn't open milk bottle tops. I couldn't eat. I could barely walk. I thought my life was forever going to depend on others to help me with the simplest of tasks."

- Nils

Don't be afraid to ask your doctors and rehabilitation team any questions you may have about returning home. Your medical team is there to guide and support you. No question is unimportant. Keeping a notebook on hand can be a useful way to record medical advice from your hospital team and track any questions that arise when you return home.

During your hospital stay, a team of staff was there to assist with your medical care. At home, you and your loved ones will take on that responsibility. At first, you may find that you are unable to perform tasks you were once able to do with ease. It is normal to feel sad, angry or discouraged about needing help with mundane daily activities. Over time you will increase your independence and regain your sense of control.

Remember, you don't have to do it all by yourself. For now, allow others to do their part in assisting you and don't be afraid to accept help. Burn injuries take time to heal. Short-term setbacks are common along the way and do not necessarily reflect on your long-term recovery. Tracking your recovery over months or years, instead of days or weeks, can be a helpful reminder of your continued progress. Remember to keep in mind how far you have come since you were first admitted to the burn unit.

When you return home from the hospital:

- 🌍 **Mixed emotions are normal when leaving the hospital.** The burn unit is a place where you can develop a daily routine that helps you feel safe and accepted. Many survivors feel resentful, frustrated, and helpless when returning home. Naming your feelings can be a useful tool to help identify ways you might benefit from additional resources and support.
- 🌍 **Stay in contact with your outpatient medical staff as you navigate your pain management and homecare routines.** It is not uncommon to experience continued pain and discomfort after hospital discharge. Consult with your doctor if you notice any unexpected physical changes when you return home. Ask your medical providers for advice about making your daily routines more realistic.
- 🌍 **Ask for professional help if you think you can't manage emotional stress without pain medication.** Reach out to your medical team or meet with a therapist to learn other coping skills. Talk to your doctor about pain medication and learn how to taper off in a safe way. If you find yourself self-medicating with drugs or alcohol, know that help is available to you and reach out for support as soon as possible.
- 🌍 **Many people experience feelings of isolation or loneliness after the transition home.** Adjusting to your home routine can be discouraging at first. Some survivors will experience mobility limitations that require new ways of navigating their home setting. Many people feel frustrated because of the slower pace of home life. It is helpful to talk to people who understand your feelings and who validate your experiences. Attending a burn support group in your local area or asking for a peer support visit can be a powerful tool. To learn more about burn support groups contact the Alisa Ann Ruch Burn Foundation or refer to the national resource list at the end of this booklet.

After a burn injury, you may feel overwhelmed with friends or family members contacting you to express their concern. People will want to know how you are doing, and some people won't know exactly what to say to you. Others might say things that upset you without meaning to do so. Identifying someone you trust to handle the questions from your friends and family can help you stay focused on your own recovery. Talk with others only as much as you feel comfortable. There is always time to discuss what happened to you in detail, but only when you are ready to do so.

PHYSICAL REHABILITATION

Physical healing requires time. When you leave the hospital you may be asked to attend an outpatient clinic or do daily exercises at home. It can be challenging to adhere to your physical therapy regimen, since the results of your hard work might not be immediately apparent. Some survivors feel discouraged because progress is slow. Be kind to yourself during this important phase of recovery.

"Rehab is tough. I cried a lot, but I lived through it. Although sometimes I didn't see it that way. But because I made it through, I can walk upright instead of being bent over and I can move my right arm."

- Thelma

"I have to be careful about staying in the sun too long. I tend to overheat and get faint. I always carry a water bottle with me."

- Cindy

"This was the point when I decided I owed it to myself and my body not to give up. Missing one day would set me back two or three."

- Josh

"Don't ever get down if your therapy doesn't help from the beginning. You have to give it time. Success needs time to bloom."

- Anonymous

Following through with outpatient medical appointments will enable you to gain the most from your outpatient care. Many survivors find it helpful to bring along a friend or family member to outpatient medical appointments. Others have benefited from asking for assistance from a roommate, friend or loved one during homecare therapy routines. The benefits of the physical effort you put in now may not be immediately apparent, but they will pay off in the long run.

As you begin the process of physical recovery, here are some tips to keep in mind:

- **Physical Rehabilitation.** In the early stages of recovery you may find that you become exhausted and overheated from physical activity. Your body simply needs time to adjust and you will build up your tolerance as the healing process continues.
- **Pain Management.** If you are having difficulty with pain management there are pain management specialists at your hospital who can help you gain a better relationship with your pain and your body. Johns Hopkins University has an online "Take Charge of Pain" interactive program that can help you learn more about managing chronic pain. The Resources section of this booklet includes a link to the "Take Charge of Pain" online resource.

- **Sun Exposure.** Burns and skin grafts are susceptible to sun damage in the early stages of recovery. It is very important to ask your doctors about sun exposure! While sun protection is a necessary part of regular burn care, keep in mind that a burn injury need not prevent you from enjoying the outdoors or maintaining an active lifestyle in the future.
- **Pressure Garments.** You may be asked to wear pressure garments to reduce scarring and leave your skin more flexible. Many survivors find that they become more accustomed to wearing the pressure garments over time. As your body recovers you will need to update your garments. Some providers have color options that give you more choices in the style of garments you wear.
- **Itchy Skin.** Healing skin can itch! Rather than scratching, try tapping, stretching or distraction. Apply water-based lotions to lubricate the skin or ask your medical team about medications. Some survivors report that wearing their pressure garments helped decrease the itching.
- **Temperature Adjustments.** If your burns are on a majority of your body surface area, weather may affect how your body feels. Adjusting to the way you regulate your own temperature can help you feel more comfortable. In hot weather, it is especially important to seek shade when needed and drink plenty of fluids. Wearing breathable clothing can help your body adjust to changing temperatures or new climates.
- **Developing a Morning Ritual.** Allowing extra time for your morning routine can help you feel more comfortable as you prepare for the day. Try establishing a routine consisting of a shower, lotion and scar massage, movement or stretching, and putting on your pressure garments. Creating simple routines like listening to your favorite music can make the transition more tolerable and set the tone for your day.
- **Exercise Routine.** Create consistency with your physical rehabilitation regimen. Find what works for you and stay with it. Physical therapy and regular exercise will enable you to regain as much flexibility and movement as possible. Use your movement during hospitalization as a point of comparison instead of your movements before to your burn injury as you reflect on your physical progress.
- **Physical Appearance.** The redness and swelling of a new burn injury may fade over time, but burn scars will always be different from your previous skin. Most survivors find it hard to accept that their appearance has permanently changed. Many survivors continue to struggle with their physical appearance for quite some time after their injury. Although challenging, it is important that you continue on the journey towards acceptance of your new you.

- 
- **Scar Visibility.** After your burn injury has healed, you may be able to find new cosmetics to complement your scars. Some makeup will no longer work with your new skin texture, but there is a wide selection that is created specifically for scarred skin. Every person is different, so some experimentation may be necessary. The *Phoenix On-Line Learning Creative Cosmetics Program* offers creative make-up techniques to assist people with skin discoloration and scarring. The Resources section of this booklet includes a link to the Phoenix Society for Burn Survivors website. Whether you use makeup or not, feeling comfortable with your scars and embracing your new appearance can improve over time.
 - **Reconstructive Surgeries.** Plastic and reconstructive surgery can sometimes enhance symmetry, mobility, and functionality of your burn injury. The results of laser surgery may improve scar appearance, but surgery can never return damaged skin to its original condition. Techniques for treating burn injuries are advancing all the time so ask about the latest treatment options. It is important to get different opinions from doctors with burn experience before making big surgical decisions.
 - **No One Told Me About This.** Absorbing information doctors and nurses give you when leaving the hospital is hard when you are concentrating on going home. Many questions will arise when you leave the hospital, and there are many more topics than can be adequately covered in this booklet. If you have questions or concerns, write them down and call your doctor for an appointment or phone consultation.

EMOTIONAL HEALING

The effects of a burn injury are not just physical. Traumatic injuries can impact an individual's sense of safety, self-esteem, social interactions, and many other aspects of their emotional well being. Even after survivors have healed physically, emotional reactions may occur. Common reactions to a traumatic injury may include:

- 🌍 Denial and/or ignoring that the injury has occurred;
- 🌍 Focusing on or obsessively thinking about the accident;
- 🌍 Feeling sad or tearful much of the time;
- 🌍 Having difficulty sleeping or eating;
- 🌍 Feeling irritable or angry;
- 🌍 Wanting to avoid reminders of the injury;
- 🌍 Fears about personal safety;
- 🌍 Fears about going out in public;
- 🌍 Anxious feelings;
- 🌍 Feelings of guilt;
- 🌍 Loneliness;
- 🌍 Difficulty accepting physical appearance;
- 🌍 Difficulty adjusting to physical limitations;
- 🌍 Nightmares;
- 🌍 Hypervigilance or a feeling that something is about to happen

It is important to remember that if any of these reactions persists or begins to affect your relationships, work, or mood, there is help available.

"Because I didn't want to show any signs of enduring pain, I had chronic headaches. Not until I finally let my emotions escape did I have any kind of relief. My advice is to shed your emotions freely. Don't bury them. Join a support group and seek as much contact with other patients as possible. Family and friends should do the same."

- Ed

"My daughter suffered the physical pain, and I as a parent suffered emotionally and psychologically."

- Alisha

Many survivors find it useful to talk with other survivors about their experiences. Hearing from a burn survivor who may be five, ten, or twenty years from their burn injury can generate hope and create perspective. It is easy to lose sight of future life opportunities when you are struggling in your recovery.

A support group is a safe place where you can gain strength and hope through speaking with other burn survivors, loved ones, and hospital staff about specific challenges. It is also an opportunity to support others. Bring your burn recovery questions to a local burn support group or participate in an online burn support chat. See the Resources section in the back of this booklet for where to look for local, national, and online peer-support resources.

"Although it has been 22 years since I was burned, I can still remember that horrific night in great detail."

- Tanya

"I remember that for several months after the fire, all I did was talk about it. Then I began to realize that I was gradually talking less and less about it and had lost all the fears I'd developed after the fire. I would tell other survivors to keep on talking -- no matter how long it may take."

- Chrissy

"When I was first burned, I found myself in awkward situations. I would volunteer to tell others about my injury right away. It seemed to set them and me more at ease."

- Arthur

Many burn survivors and loved ones have found that attending the Phoenix World Burn Congress can be motivating and empowering at any stage of recovery. The Phoenix World Burn Congress is an annual, international conference that brings together over 900 burn survivors, their families, caregivers, burn care professionals, and firefighters. At the Phoenix World Burn Congress, people can come together to offer support, increase their knowledge of burn recovery, and share stories. See the Resources section in the back of this booklet for burn survivor scholarships and additional resources.

There is no set schedule or prescription for healing the emotional scars that come along with the physical trauma of a burn injury. Allow yourself lots of time and space to experience all the feelings that may come up as you continue healing.

While talking about your experiences may help, there are other ways in which people cope with emotional reactions:

- **Routine.** While you may not be able to return to all your previous activities as quickly as you would like, getting back into familiar routines provides a sense of normalcy.
- **Belonging.** Attend a burn support group, meet with a peer support provider, participate in an online burn support chat, or attend the Phoenix World Burn Congress.
- **Humor.** Laughing can provide a good break from your worries. Laughter has been shown to reduce stress hormones such as cortisol and epinephrine. When laughing the brain also releases endorphins that are believed to enhance mood and may relieve some types of physical pain.
- **Distraction.** Keeping yourself busy can help your mind get much needed rest and restoration. It is important to take breaks from thinking about the burn injury.
- **Document.** Keep a journal or diary. Writing down your thoughts and feelings can be very therapeutic. It can also be a great way to look back and reflect on your journey of recovery.
- **Creative Expression.** Find a productive way to express your feelings or emotions through an artistic medium. Drawing, painting, poetry, writing, singing, chanting and playing music are some of the many examples of creative expression.
- **Meditation.** Mindfulness practices can help with anxiety and difficult thoughts. In mindful meditation, you can begin to observe your thoughts, emotions and bodily sensations without judging them as good or bad. A meditation practice is believed to help decrease anxiety and improve overall wellbeing.

While in the hospital, survivors are so focused on healing their bodies, it is often not until later that the emotional issues surface. Be aware of this and ask for help if you need it. You are not alone! It is not uncommon to think you are doing great and then be flooded by confusing emotions such as anger, sadness, frustration. It is very common to take these feelings out on the people closest to you. Know that this is normal and learning to pause, identify your feelings and express them in healthy ways is part of the healing journey.

GRIEF AND LOSS

Returning home is often the first time survivors are able to think about the aftermath of their injuries. Many survivors are confronted with losses that may

“One month after returning home, I was still sad and depressed about the loss of my ‘former’ face. It seemed like every time I expressed my concerns or feelings, people would say, ‘You should just be happy you’re alive.’ They didn’t realize that I was worried about what kind of life I was going to have.”

- Anonymous

“My sons and my family almost had to deal with the loss of me. We all grieved for the person who used to go to jazzercise and used to take hikes in the mountains. I was fortunate I had a very close and supportive family and we grieved together.”

- Cindy

“People kept asking me about my scars, but they didn’t realize what I was really grieving was the loss of my toes and wondering how I was going to do the things I enjoyed doing before.”

- Anonymous

include property or treasured belongings, the ability to perform certain physical activities, like doing your job or even simply walking, a change in your physical appearance, loss of faith in people or your spiritual practice, or the death of a friend or a loved one due to the circumstances of your injury.

Emotional reactions to loss may include feelings of:

- **Shock.** There is no way to prepare for sudden loss. It may be very difficult at first to think about what you have lost. You may even find yourself denying it actually happened.
- **Devastation.** Experiencing overwhelming feelings and struggling with often unanswerable questions is a part of the grief process.
- **Emotional Swings.** Survivors and loved ones often feel strong emotions such as anger and sadness. Survivors may lash out at those who are close to them. Such feelings are part of the grieving process and normal reactions to the experience of traumatic loss.
- **Acceptance.** There is no timeline and no wrong or right way to deal with your injury. Acceptance will take time and does not happen overnight.
- **“Get Over It.”** Others may not comprehend your experiences and may confront you with a “get over it” attitude.

Rebuilding your life is going to take time, patience, compassion, and a lot of help from outside resources. Some people find it very helpful to talk to someone about these issues. Whether it is a family member, a friend, a counselor, or another burn survivor, letting someone know how you are doing can make a big difference. Others take great comfort in their religion or their own spiritual beliefs. Some survivors find that online support with other survivors in remote locations can be beneficial if a local support group is unavailable. Connecting with others who understand your experiences can give you strength and hope during a time of grief and loss.

Although there are many theories about grief recovery, there is no one way to grieve. We must respect our mind and soul's timetable in accepting some of the losses we have encountered as a result of the injury. Grief support groups can be very helpful and provide a special type of peer support if you have lost a loved one. Talking about your feelings is one of the most challenging, yet incredibly healing resources.

STEPPING OUT

There will come a time when you are ready to go out in public for the first time after your burn injury. You may be concerned about how others will react to your

changed physical appearance. Survivors might find themselves having a strong emotional reaction, like getting angry every time someone stares at their burn scars or asks a question about their injury. Other survivors may feel isolated or shut down when they begin to engage with the public. It is normal to experience worry about how to talk with others about your burn trauma.

"At first dealing with others' reaction to my appearance was very difficult. It's not easy to have someone stare at you, but I learned to understand that they don't really know what happened to you. They are just curious, I guess."

- Mark

"In the hospital, the nursing staff protected me from looking at my scars. I got home and I was confronted with mirrors. I needed a lot of support in accepting my scars. I couldn't have done it without the help of my family."

- Anonymous

"Stepping out was not easy. When others asked me how I was burned, it motivated me to tell them. Now, I believe it was truly therapeutic to tell my story. People know what you go through and MOST people can see through your scars. The more I told my story, the more my 'old self' started to come through."

- Arthur

It is helpful to mentally prepare yourself for these inevitable situations. Having standard answers ready for these encounters can help ease the transition. Some survivors find it easier to have the support of family or friends when they venture out in public for the first time. Go out with people you trust and who care about you.

Here are some things to try when facing the public:

- 🌍 **Consider not looking away.** Practice maintaining eye contact with the person to whom you are talking. Using confident body language and tone of voice can help you feel more empowered as you navigate new social interactions. Practice some prompts that express confidence, such as smiling when you say hello or looking at someone in the eyes when speaking to them. Accept that it is hard at first. The fear of rejection can be a very scary feeling.
- 🌍 **Tell your story. Educate those who ask questions with genuine concern.** Practice the story of how you were burned in a way that feels safe and comfortable for you. Having a couple of versions of your story ready can enable you to tell the short or long version of your story depending on your comfort level.

Remember, you don't have to spend your time explaining your story to people who are negative or unsympathetic. You can set boundaries by redirecting the conversation to another topic when you're ready to move on or if you prefer not to share your own experience at that moment.

- 🌍 **Remember it is normal for people to be curious about others' appearances.** While adults may conceal this curiosity or limit it to just staring, children may express their curiosity in a much more overt manner, such as pointing or asking questions. If you feel comfortable doing so, tell them what happened to you using simple language. Children are rarely judgmental, but they are quick to notice appearances that differ from what they are used to seeing. Help them understand that all people and bodies look different.
- 🌍 **Try striking up a conversation that is not burn related.** Starting a conversation that is not burn related can be a powerful way to take control of any social interaction. Letting others know you are comfortable talking with them about other topics can lead to authentic conversation that goes beyond your identity as a burn patient.
- 🌍 **Have a personal mantra.** Prepare a personal mantra that will get you through a tough moment, such as "I can do this" or "I have overcome so much already." Spend time with fun, supportive, and genuine people. Keep your mantra to yourself or considering sharing your personal mantra with friends and family. Exchanging ideas with people you respect and trust, and discussing how to deal with difficult moments, can lead to a useful and inspiring dialogue.
- 🌍 **Some days you feel stronger emotionally than others.** Go at your own pace, but don't limit yourself. Respect your process and pace yourself as you get to know your new appearance. With time and practice, you will find that stepping out becomes easier and more comfortable.

The Phoenix Society for Burn Survivors has a social skills training program called *Beyond Surviving Tools for Thriving After a Burn Injury*. The training teaches survivors and families the skills to use when faced with stares, questions, setting boundaries, and unwanted attention in school, work, or social situations. More information about the social skills training can be found on the Phoenix Society website in the Resources section in the back of this booklet.

"I decided that I needed a long version and a short version of my story. I use the short one when I really don't want to talk about it, and the long one when I feel connected to the asker or when I see that they are genuine in their concern. It helps me to feel in control."

- Anonymous

"At the beach one day, I forgot to put my shirt back on to walk to the snack bar. That's the day I realized it was going to be okay."

- Jim

SEXUALITY AND INTIMACY

The idea of sexuality and intimacy can be overwhelming for a new burn survivor. Sex and sexuality are important parts of everyday life. Sexuality is a very important part of who we are and how we see ourselves. It is a part of what makes us feel attractive, confident, and close to others. Intimacy is defined as mental, emotional, or physical closeness.

Survivors who are already in relationships may be concerned about a partner's reactions to their burn injury. Survivors who are single may experience fear about dating or concerns about initiating physical contact with someone new after a traumatic injury. While it is normal for sexuality and intimacy to be impacted by a burn injury, there are many ways to feel more comfortable as you navigate these important topics. It helps to talk about your questions with other burn survivors who have been through a similar recovery process. Members of your medical care team and referrals to professional therapists can be helpful resources. Over time, many of these concerns can be addressed and overcome.

Physical factors that can affect sexuality and intimacy can include:

- 🌍 **Energy Level Variation.** Many survivors experience decreased energy after a burn injury, which can temporarily affect your intimacy and stamina.
- 🌍 **Alteration of Skin Sensitivity.** Understanding what feels good and doesn't feel good must be relearned and communicated. Skin may be hypersensitive or hyposensitive. There may be different textures and colors to the skin now. Find safe ways to touch and show affection that feel comfortable to both of you.
- 🌍 **Mobility and Pain Need to Be Addressed.** You may have mobility and positioning issues that were not present before the burn injury and you will need to learn new positions that are more comfortable during sex or physical intimacy.
- 🌍 **Professional Counseling.** Couples counseling or sex therapy with a trained professional can help prevent silent suffering and improve intimate relationships.

Decreased interest in intimacy and physical contact are common in the aftermath of a burn injury. The loss of intimacy and sexual desire may result from feelings of depression, anxiety, sadness, fear of rejection, and self-consciousness. The many medications and treatment regimes you are on may also lower your libido. Communication can help survivors regain physical comfort and confidence. Starting out slow, working together to accommodate the physical changes, and

incorporating humor into the process can make it easier as you reconnect. Time is a great healer as you move through your recovery process. If these feelings do not go away, it is important to talk to your doctor or professional counselor.

Navigating the way back to sexuality and intimacy can be equally overwhelming as a spouse, partner or significant other in a relationship with a burn survivor. Communication is key in achieving a sense of intimacy and sexual activity again. There may be fear that whatever you are doing may cause more pain for your loved one. Taking baby steps and going slow to learn about the new body can be beneficial for both of you.

"The little things that got to me the most were not the big things that you'd expect. The hardest thing I experienced was giving my burned husband a hug."

- Karen

"I know I was supposed to be her biggest supporter, but I was dealing with terrible guilt of my own feelings of grief because I was unable to touch my wife in the way I used to because her skin was so sensitive. It was not until I spoke to her about these feelings that I realized she was also missing my touch. It's like we are getting to know each other all over again."

- Anonymous

"Dating was really hard for me once I was fully recovered from my injury. I dreaded that first moment that I had to face someone. Luckily there are people out there that see beyond my scars. I am having a great time dating and meeting people now."

- James

"Tell the burn survivor how much you love them, and show them in every way you can."

- Thelma

FAMILIES AND LOVED ONES

"Dealing with my loved ones is the hardest part. I honestly feel my family experiences the effects of my burns every day."

- George

"I can't seem to put into words how much comfort I felt having my mother with me through all my surgeries. I knew that she was the last person I saw before I closed my eyes each surgery and the first person I saw when I opened them."

- Sylvia

"They felt so helpless. Even though I don't have any physical scars, there were emotional scars. I could not have made it without the support from my family and friends."

- Mark

"My advice is to let them know you love them. Walk with them, talk with them. Listen to what they say. Don't pressure them and let them take it at their own pace."

- Paul

"Every time I looked at my son's scarred skin, I wanted to cry. I felt I was responsible for his safety at all times. I felt like I let him down. I realized that, until I dealt with my own feelings, I would not be able to help my son deal with his injuries and recovery."

- Anonymous

Family members and loved ones who have witnessed a burn injury or cared for a survivor during their recovery process are also survivors of trauma. It is traumatic to see someone you love injured in any way, and it is difficult to watch someone suffer. From caring for the survivor to dealing with their own feelings of grief, families and loved ones face many challenges for which they are not always prepared. Often, a loved one can be just as affected as the person with the burn injury. This booklet is as much for families and loved ones as it is for the person who experienced the injury.

The experiences of family members, spouses, and loved ones may include:

 **Assisting the Survivor.** Often, family members feel out of control and helpless in the face of a loved one's injury. You might wish to discuss with medical staff ways you can be included in a patient's physical rehabilitation. Assisting survivors with physical or occupational therapy activities helps families feel included and useful, and reduces possible feelings of helplessness that many family members experience. Even young children can participate in small ways, such as counting the number of exercises completed.

 **Feelings of Resentment.** When a burn survivor comes home, they may exhibit feelings of anger, guilt, and hopelessness. While emotional reactions of this kind are normal, they may be confusing to family members and difficult to manage. It is not uncommon for survivors to go through a short period of regression, in which they may become too dependent on the care of a loved one or act in childlike ways.

 **Role Reversals.** As a caregiver, you may catch yourself feeling sad or resentful that the injury happened in the first place. These are normal reactions, and they do not mean that you do not care about your loved one. Many caregivers experience role reversals in their relationship with

the survivor following a burn injury. Helping the burn survivor maintain a sense of dignity and control can support a healthy transition back to daily life.

-  **Family Support.** Coping and assisting in the care of the burn injury may mean that you have not been able to give attention to other family members as you normally would. Try to set aside a small amount of time each week to devote to activities with other family members. Even one or two hours a week can go a long way in maintaining relationships within your family. This is particularly important with siblings of child survivors, who are more prone to feeling “left out” or forgotten during the course of a survivor’s recovery.
-  **Helping Children Adjust to a Parent’s Injury.** When a parent experiences a burn injury, there are many ways to support their children in adjusting to the change in appearance and physical ability. Some children will accept the changes with few questions and others will respond with varied emotional responses such as confusion, fear, acting out behavior or complete avoidance of the topic. It will take time for children to process the injury of a parent and there are many medical professionals, such as Child Life Specialists or psychologists, who can support children as they accept the scars and the new appearance of the loved one.
-  **Financial Concerns.** You may have missed significant time at work as a result of your loved one’s rehabilitation and may now be experiencing financial strain. Financial concerns are very common and can add to what is already a very distressing situation. Many hospitals provide information on financial advisors or advocates who assist in dealing with insurance companies, disability, and worker’s compensation. Don’t be afraid to ask questions and utilize such resources.
-  **Self Care.** Remember, while you can play an important role in supporting your loved one, you also need support. This is a difficult time for everyone. Make sure you have experiences in your life that refresh and replenish your spirit. Taking walks, spending time outside of the family, and talking with families of other survivors can help give you the strength and support needed to assist you in your loved one’s healing.
-  **Talking about the Injury.** Be there to support emotional recovery by not inhibiting your loved one and let them talk about burn-related issues. Encourage your loved one to participate in activities that he/she enjoys — it helps bring a sense of normalcy back into daily life. Keep in mind that it may take time for the survivor to feel comfortable talking about the trauma or going out in public where they may be faced with questions about their burn injury.

A burn support group is a great way to meet other families of survivors who have been through this difficult process and have already navigated many of these topics in their own lives. Many family members have found peer support to be extremely helpful. You can get in touch with other families through local and national burn foundations listed in the Resources section of this booklet.

BURNS AND CHILDREN

FOR PARENTS AND CAREGIVERS

A child's reaction to a burn injury can be very different from that of an adult, and every child will respond differently to their particular injury. Depending on the age of the child, the severity of the injuries, and the details of the accident, the child may experience varying degrees of difficulty in coping with and accepting the

reality of having been burned. Some children may not seem at all distressed about their burns, while others may experience great difficulty in adjusting.

"As I was growing up, school was tough because of the children constantly making fun of me. Then as I was becoming more mature, I realized that the children making fun of me was their way of understanding and coming to terms with what had happened to me."

- Linda

"Sometimes kids would make fun of me. It was nice to know that my parents were there to talk to about it."

- Brian

"I overheard my grandmother tell my mom - 'Can't they fix her face with surgery?' Doesn't she realize I have already had 13 surgeries? My doctor says that I have the best face she can give me."

- Erica

Being open and accepting as a caregiver can make a world of difference in a child's coping. Is the topic of the injury welcome in the household? How are you talking about the burns or accident with other adults in the child's life? How much are you involving school staff and others who interact with your child in the recovery process? The more accepting you are of your child, the more likely they will accept themselves and their visual differences. Some parents feel they are protecting their child by not talking about the burn openly, yet many child survivors later report that they felt their burn was something secret to feel ashamed about.

Here are a few common reactions that child burn survivors may experience following their injury:

- **Regression.** Regardless of age, many children and adolescents have difficulty with hospitalization and the temporary loss of freedom caused by their injuries. Children and teenagers often become dependent on their caregivers when they arrive home and may act younger than their actual age. They may act angry and defiant. This is normal behavior and may reflect the child's attempt to gain more control over their lives and come to terms with their losses.

- **Insecurity.** Teenagers are prone to body image issues and are more likely to have a difficult time accepting changed physical appearance. They may also have a hard time being unable to do things for themselves. Injuries incurred during childhood may take on new significance as teenagers become more self-conscious about their physical appearance.
- **Worries about Peer Acceptance.** School-aged children and teenagers may focus more on how peers and those outside their families perceive them. If they worry that pressure garments, splints, and other burn rehab tools may set them apart from their peers and highlight their differences, they may be less willing to comply. Parents should emphasize the importance of after-burn care while providing their children with as much control as possible. Helping your child stay involved in normal childhood activities is important; it lets them know they are not completely different from their peers. Pay attention to symptoms of your child having trouble with their appearance such as hiding their scars, avoiding activities that they used to enjoy, acting irritated or depressed when peer oriented activities are discussed or suggested.
- **Rebellion and Curiosity.** Young children base their reactions on those of their parents or caregivers. They may rebel against physical rehabilitation or their natural curiosity might lead them to participate in the process. Parents can take the lead in educating children about the importance of participating in physical rehabilitation, and there are many professional medical staff such as Child Life Specialists who can support and empower parents during this process.

Below are some helpful coping mechanisms that child burn survivors may utilize:

- **Play Is the Language of Children.** Children use play to express emotions, problem solve, rehearse situations, and master difficult situations. When children channel their thoughts, worries, and questions through the modality of play, their play becomes an outward expression of an internal narrative. It is how children tell their own stories and process their experiences, and it can be a tool for healing and resiliency as well as joy. Every child is capable of play, regardless of their physical or mental capacities, and even a child who is unable to move due to a burn injury can benefit from playing vicariously with a trusted adult.
- **Medical Play.** Medical play is a means through which children can explore medical materials, prepare for or reflect on frightening procedures, develop coping plans, and gain mastery over their experiences in a familiar and non-threatening way. Providing children with the tools and opportunity for medical play allows them to be active participants in a process that might otherwise make them feel helpless. Rather than having things constantly done to them, children are able to reverse roles and be a doctor or nurse within the safe world of their imagination.

- 
- **Examples of Medical Play.** For young burn survivors, medical play prior to new medical procedures such as dressing changes or surgeries can offer a chance for the child to ask questions, process fears, and gain a sense of agency. These sessions can be facilitated by a professional such as a Child Life Specialist or a trusted caregiver. A session might include the opportunity to change bandages on a stuffed animal, clean pretend wounds, or help a teddy bear fall asleep for surgery. Coping strategies can also be introduced or practiced during play, and medical play can be beneficial before, during, or after a procedure.
 - **Processing Trauma through Repetition.** Young children learn about their world through repetition, and just as a child might ask to read the same book over and over, a child may play out the same situation repeatedly as they work hard to gain understanding and mastery over it. These repetitive play sessions allow children to approach future medical procedures with a greater sense of familiarity and control, while continually processing the changes in their lives through a safe and comforting modality.
 - **Developing Coping Skills.** Remember that the child is working with whatever coping skills they have available. Offer reassurance, patience, and unconditional love while setting limits around unacceptable behavior. The best thing that you can do is create an environment where talking about problems is okay. Make an effort to encourage social interactions and physical activities that are within safe boundaries. Often your presence can be the difference between a demoralizing outing and a positive, successful one.
 - **Creative Expression.** Creative expression can be a powerful outlet for restoring psychological and spiritual well-being following a traumatic event. Making original artwork can help children and teenagers process the trauma they have experienced through a non-verbal means of communication. A therapeutic art-making session in a safe and supportive setting can enable young people to release distressing emotions, organize fragmented memories, gain inner strength and resilience, and use their artwork to share their burn story.

When an adult is burned, they have the task of redefining how they see themselves in the world. Children and adolescents are still in the process of maturing and must develop a personality and a place in the world with a burn injury. Although transitioning can be difficult, it can be made easier with compassion and support from parents, primary caregivers, extended family and community members. With adequate support, children and teenagers can incorporate a burn into their identity and their story in an empowering rather than a defining or a limiting way.

GOING BACK TO SCHOOL

Going back to school can create serious anxiety and worry for children. How will their friends react to the way they look? How will they talk about what happened? How will they perform tasks they were once able to do with little or no help? Parents worry that their child will not be accepted or will be made fun of when they return to school. Generally, this is not the case. Returning to their daily school routine as quickly as possible, along with their parent's verbal acceptance of the child's injuries, allows them to realize that they will be accepted for who they are.

Practice before returning to school:

- 🌍 **Plan an Outing.** Take your child with you when you go shopping or out to eat. Being in public prior to school re-entry can assist in reducing a child's fears about others' reactions.
- 🌍 **Invite a Friend to Visit.** Invite a close friend to visit with your child as a first step in normalizing social interactions.
- 🌍 **Playing in the Neighborhood.** Playing in public provides situations in which the child can explore what it is like to interact with their peers.

Other factors that impact children when returning home:

- 🌍 **School Re-entry Programs.** School re-entry programs involve educating the child's peers and teachers about the nature of burn injuries. The parent's and child's fears of returning to school are also addressed. The goals of these programs are to educate the students and teachers about burns and to create a supportive environment where the burn-injured child can learn and thrive. The Alisa Ann Ruch Burn Foundation and several other foundations listed in the Resources section offer back-to-school programs. The Phoenix Society for Burn Survivors has created an online library entitled *The Journey Back*®, which includes downloadable resources to assist school reentry after burn injury or traumatic loss.
- 🌍 **Reactions to Your Child's Appearance.** Parents may have a hard time coping with others' reactions to their child's new appearance. It is important to get support on how to deal with rude or tactless comments about your child's injury. Don't give up on the dreams and expectations you have for your child because his/her appearance has changed. A parent's acceptance of the child's injuries is essential to facilitate the child's acceptance of them. The reality is that the beautiful child is still there and needs your approval and support more than ever.

- 🌐 **Practice Information-Sharing Together.** How a child tells and shares their story can be a powerful and important moment with peers who will ask about the incident or the resulting burns. Practicing answering simple questions together

"I'm so glad I went to camp and met other kids just like me. I now know that I am not the only one who was burned."

- Kyle

"Camp was so much fun and I didn't have to worry about anyone staring at me. They had scars just like mine."

- Jennifer

"At camp I have been able to become friends with other kids that are going through some of the same things I am."

- Anneka

"There were adults at camp that had been burned when they were little, and they are okay now."

- Jake

"I was really scared about going back to school. I had pressure garments and a chin strap. The nurse and firefighter went to my class and talked to them. When I returned to school everyone was so great."

- Jessica

like "What happened?" "How did you get those?" or "Why do you look like that?" can help your child feel more comfortable and confident when responding to these questions. These moments can help educate peers and form deeper connections instead of feeling threatening or isolating. If your child does not want to share information about their burns with others, you can practice how to tell others this as well, such as "I don't feel like talking about my burns right now, but I would like to play Legos with you." Practicing navigating these situations with a caregiver in a safe environment can support the child's communication and connections with others.

- 🌐 **Follow-up Surgeries.** Those who are burned at a very young age are likely to need more follow-up surgeries as they grow older. Burned or grafted skin does not continue to grow as the child does. Some doctors will delay cosmetic or reconstructive surgery until a child is older for optimal results. This is not the case for everyone, but it is important to remember that future hospitalizations often throw a child back into feelings or behaviors that you thought had been resolved. Recovery is not always a linear process.

- 🌐 **Child Burn Survivors Are Not Alone.** It is crucial for children, teenagers and young adults to realize that they are not alone. Many survivors have benefited tremendously from taking part in social activities with other burn survivors their own age. Organizations such as the Alisa Ann Ruch Burn Foundation offer a variety of opportunities for burn-injured children, adolescents and young adults to get involved and meet other survivors who understand their experience.

 **Make Connections.** The Alisa Ann Ruch Burn Foundation provides annual events, including Champ Camp and Regional Retreats, for children and parents to meet other children and families who have experienced a burn injury. Use the Resources section of this booklet to connect with other organizations and make use of such opportunities. Fill out a referral form to stay in contact with the Alisa Ann Ruch Burn Foundation and learn more about their ongoing activities.

Children and teens hear and pick up on feelings more than most people realize. The more you talk about what they are going through, the more successful they will be in overcoming the obstacles facing them. It is a journey upon which the entire family will embark. Support each other, ask for help, and remember, your lives may never be the same but they can still be rich and meaningful. In many instances, traumatic experiences such as burn injuries bring families closer together and lay the groundwork for added depth and greater trust.

MOVING FORWARD

This booklet has touched upon many issues you or your loved ones may face as you continue on the road to physical and emotional recovery. You have faced challenges that few people have faced and it is proof of your strength and courage. These characteristics will serve you well as you continue to heal.

Here are some things to keep in mind as you return to daily life:

- **Your Burn Injury Does Not Define You.** It is simply a part of who you are, an adversity you have had to face in your life. There are many elements that define you as a person. Continue to participate in activities that interest you and develop new interests. Remember to keep developing goals and dreams for the future. A burn injury can change your life, but it should not prevent you from continuing to grow and thrive.
- **Set Attainable Goals for Yourself.** Do not expect too much too soon. Setting small goals will provide you with a sense of accomplishment and allow you to see real progress. Perhaps your goal is to get back to work, or just to be able to brush your teeth on your own. Whatever your personal goal, have patience; you will not be able to do everything all at once. You may have to learn completely new ways of doing things. Slowly, you will regain control of your life.
- **Many Survivors Continue to Struggle with Their Physical Appearance.** It is normal to struggle with your new appearance for quite some time after your injury. In the beginning, it will be difficult for you and others to look beyond your scars. While it is true that many people may stare or react to your scars, ultimately how you feel about yourself and the confidence you present to the world will define how others perceive you. Although sometimes challenging, it is important that you continue on the journey towards acceptance of your new you. You are much more than just your physical appearance. Experience has shown that over time, the burn scars become less of a focus for you and people close to you.
- **You May Ask Yourself, “Will the Feelings of Pain, Fear, and Loss Ever Go Away?”** Many burn survivors who are now living happy, functional lives say that they feel self-conscious about their burns on some days more than others. This may not be completely due to the burn injury itself. Some days you may not be feeling good; your self-esteem may be low. These are times when a stare or a comment will bother you more than usual. Try to keep positive and encouraging thoughts in mind, while recognizing that there will still be difficult days. You cannot change what has happened to you, but you can control how you react.
- **Reflect on How Far You Have Already Come.** It helps to reflect on how far you have come since your burn injury occurred. Some survivors feel the challenges they have faced have made them more aware of the strength and resiliency they never

knew they had. If you continue to suffer from pain or depression on a daily basis, you may find it helpful to identify the areas of your recovery in which you are unhappy and make small, daily changes to improve your overall well being. Over time, you may be surprised by the ways in which new and unexpected outcomes that will come your way as a result of your injury. For additional support and resources, refer to the resource list at the end of this booklet.

- **Paying It Forward.** Some survivors find that once they have reached a place of acceptance around their injury, volunteering and giving back to other survivors is very healing and rewarding. For example, you can become a burn camp counselor, attend a support group and share what has worked for you, or become a Phoenix SOAR volunteer by participating in the Phoenix Society's *Survivors Offering Assistance in Recovery*® training program. Others feel a need to remove themselves from burn-related activities for a while to concentrate on their own healing. Remember, everyone copes differently.
- **Connect, Connect, Connect!** There is no medicine or therapy as powerful as being with others that know exactly what you are going through. Whether it is online, through a foundation, at a World Burn Congress or meeting with another survivor one to one. The greatest healing is often reported having come from these relationships with other survivors and other family members.

Finally, it is important to be patient with yourself and realize that healing takes time. Everyone adapts to change at a different pace. As you continue to recover, be open to all the possibilities that may come your way and accept support when it is offered. Progress may be slow and difficult at times, but experience has shown that many burn survivors will continue to grow and thrive long after their burn injury.

"One day I went out and completely forgot about my scars for the first time. It was so refreshing. I realized that would happen more often the more I kept pushing forward."

- Sheila

"My first burn-support group was very scary. But after I saw all those people who were living full lives, with burns much worse than mine, I knew that one day I would get my life back together."

- Susan

"One day it hit me that people will see me exactly how I see myself. If I am withdrawn, they will pull away from me. If I am open and enthusiastic, they will be drawn to me - burns and all!"

- Tammy

"I no longer dread the anniversary date of my injury. I treat it as a kind of celebration of the life I have created."

- Jill

"I want to tell every burn survivor that is just starting on this journey, that it will get better. I never believed it at first, but it does. My accident has opened up a whole new life for me."

- Sam

A TIMELINE - ONE SURVIVOR'S STORY

When will things get back to normal? What kind of timeline can I expect? Every burn injury is unique and therefore the timeline will be different for every burn patient. I was burned as a child and 65% of my body was burned.

Discharge from the hospital for the first two months

When I was discharged from the hospital it felt like an extension of the hospital routine. I still had daily dressing changes and could not walk or do anything independently. I still depended on my family to help me do everything. There were frequent trips to the hospital (3-4 times per week) for occupational and physical therapy.

Two months to six months after discharge

After I had been home for a few months I started to build up my strength and endurance and started doing things independently. Increasing my independence became my focus. I was able to walk for longer distances, stand for longer periods of time and do things like eating and dressing more independently. I started venturing out in public. I started wearing my pressure garments from head to toe. It was hard to go out in public with the garments. It was also hard to go out in public without them as people stared. The more I went out in public the easier it became.

Six to twelve months after discharge

This was a time period when I wanted my life to get back to normal. I wanted to be around kids my own age and play, play, play. I would get frustrated when I could not do all of the things that the other kids could do, but I still wanted to participate. If I overexerted myself then I would overheat, start itching, and be wiped out for the rest of the day. I learned to pace myself and know my limitations. I started to see a great deal of progress. My wounds were healed and I was able to play for longer periods of time. I could go swimming and ride a bike. I had a year of homeschooling with a tutor and could not wait to go back to school. I was able to go back to school 18 months after my injury.

Thirty years after my injury

It has been 36 years since my burn injury and now I am living a very busy life with four kids and a challenging career. When I was first injured I did not think I would ever be so active and happy. Now I can not imagine slowing down. Time has been a friend to me and my family.

Jill Sproul, RN

RESOURCE LIST for HOSPITAL DISCHARGE

Alisa Ann Ruch Burn Foundation, www.aarbf.org

The mission of the Alisa Ann Ruch Burn Foundation is to significantly reduce the number of burn injuries through prevention education, and to enhance the quality of life of those affected by burn injuries in California.

(San Francisco) 1-800-755-2876

(Fresno) 1-888-492-2876

(Pasadena)) 1-800-242-2876

Alisa Ann Ruch Burn Foundation resources include:

- 🌐 Recreational Events
- 🌐 Support Groups
- 🌐 Peer Support
- 🌐 Financial Support
- 🌐 Scholarships

Phoenix Society for Burn Survivors, www.phoenix-society.org

The mission of the Phoenix Society for Burn Survivors is building a community for transformative healing.

A national resource for burn survivors.

(National Hotline) 1-800-888-2876 or 616-458-2773

Phoenix Society for Burn Survivors resources include:

- 🌐 Phoenix World Burn Congress
- 🌐 Phoenix World Burn Congress George Pessotti Scholarship
- 🌐 Phoenix SOAR Survivors Offering Assistance in Recovery[®] Program
- 🌐 Phoenix On-Line Learning School Reentry Program
- 🌐 Phoenix On-Line Learning Creative Cosmetics Program
- 🌐 Phoenix On-Line Learning Beyond Surviving -Tools for Thriving After Burn Injury
- 🌐 Phoenix On-Line Community

American Burn Association, www.ameriburn.org

The American Burn Association is dedicated to improving the lives of everyone affected by burn injury.
(Nationwide) 312-642-9260

Burn Questions Hotline

Answers to medical questions about burns. Torrance Medical Center, Torrance, CA.
(National Hotline) 1-800-500-2876

John Hopkins Medicine, www.takechargeofpain.org

John Hopkins offers a “Take Charge of Pain” interactive online program.

National Suicide Prevention Hotline, www.suicidepreventionlifeline.org

The Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you and your loved ones, and best practices for professionals.
(National Hotline) 1-800-273-8255

MentalHealth, www.mentalhealth.gov

One stop access to mental health information, advice and support.

Psychology Today, www.psychologytoday.com

Find detailed professional listings for psychologists, psychiatrists, therapists, counselors, support groups and treatment centers in the United States and Canada.

Angel Flight West, www.angelflightwest.org

A nonprofit organization that provides transportation via small aircraft to doctor appointments and follow-ups.
(Serving 13 Western States) (888) 4-AN-ANGEL or 1-888-426-2643

Americans with Disabilities Act Hotline, www.ada.gov

The ADA prohibits discrimination and guarantees that people with disabilities have the same opportunities as everyone else to participate in the mainstream of American life.
(National Hotline) 1-800-514-0301

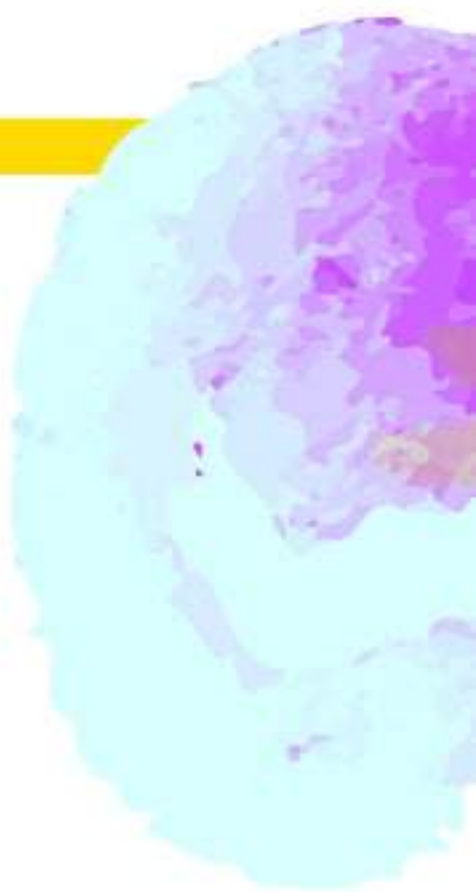
California 211, www.211california.org

Quick and easy access to information about health and human services.

Red Cross, www.redcross.org

The American Red Cross prevents and alleviates human suffering in the face of emergencies by mobilizing the power of volunteers and the generosity of donors.

See the “Picking Up the Pieces After A Fire” Online Brochure.



REFERRAL FORM for HOSPITAL DISCHARGE

The Alisa Ann Ruch Burn Foundation’s mission is to significantly reduce the number of burn injuries through prevention education, and to enhance the quality of life of those affected by burn injuries in California.

- Monthly peer-led support groups
- Regional events and recreational activities
- Scholarships and financial assistance

By releasing your personal contact information, you are allowing the Foundation to contact you directly. Please print contact information below.

Patient Name: _____

Patient Date of Birth: _____

Address: _____

Email: _____

Phone: _____

Family Member/Guardian Name: _____

Name of Hospital: _____

Type of Burn Injury (optional): _____

Any other information that you would like to share with us?

Signature of Release: _____

Date: _____

☐ Yes, please share my contact information with Phoenix Society for Burn Survivors and any other regional burn organizations that provide burn survivor services in my area.

Fax your completed form to (818) 848-0296 or Email to info@aarbf.org

Alisa Ann Ruch Burn Foundation www.aarbf.org

(San Francisco) 1-800-755-2876 (Fresno) 1-888-492-2876 (Pasadena) 1-800-242-2876

CREDITS

The “What Now?” booklet is a publication of the Alisa Ann Ruch Burn Foundation. In the making of this booklet, we have received invaluable input from burn survivors at many different stages of recovery, family members who have been impacted by the burn injury of a loved one, and burn care medical professionals. We want to express our gratitude and appreciation to our many contributors. A special acknowledgment is extended to all those who contributed to the 2009 and 2011 editions of this publication.

Sadie Wilcox & James Bosch
Editors of the “What Now?” Booklet, 3rd Edition
August 2017

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