

# TIPS FOR PARENTS + CAREGIVERS OF YOUTH BURN SURVIVORS

---

- During hospitalization, ask your medical team if there is a Child Life Specialist who can work with your child. They can help you educate, support, and advocate for the needs of your child.
- With any age group, keep the conversation open and honest. There is no shame in being a survivor, and keeping the conversation open will help make sure of that.
- It is normal for caregivers to feel guilt, but living with that feeling can impact your ability to support your child. Caregivers need support too. Try to find a support group or system to work through these feelings.
- Connect with the burn community—your entire family will need support for their unique experiences as you navigate this journey.
- Invisible or hidden scars can be just as impactful as visible ones.
- Don't compare your trauma to anyone else's—allow yourself to process and work through your own experience.
- As your child goes through changes in their development, continue to ask what they need in terms of advocacy from you. This changes over time!
- Siblings and family members left at home will also struggle with separation, changes in routine, and stress. It is important to remember that they will need your support on this journey as well.
- Rehearsing your responses is a powerful tool for the whole family to use. Responding to staring with a quick explanation can help demystify the story and give you control.



# 0 - 6 MONTHS

reflexes are leading to intentional movement • attachment develops  
physical/cognitive and language skills start to develop



Creating a secure bond in the midst of a traumatic event can be challenging, but your infant will still be able to benefit from your presence. Even if you can't hold them, being able to look in your eyes and hear your voice will help them understand that you are there for them. Continue talking to them and playing within their view to nurture the bond, stimulate their mind, and motivate their rehabilitation.

During infancy, the child will not have awareness of any differences between themselves and other children. During this stage what they need the most is a secure attachment and opportunities to build their skills and explore their environment. This will create a sense of trust that will eventually grow within their community.

**WHAT TO EXPECT WHEN YOU NEVER EXPECTED THIS:  
NAVIGATING BURN + SCAR CARE FOR AN INFANT**



## CHALLENGES

- Separation
- Disruption of routine
- Lack of developmental stimulation
- Multiple / changing caregivers
- Reduction of bonding opportunities
- Secondary stress (from caregivers)
- Doubts with trust

## SUPPORT

- Advocate for consistent schedule
- Replicate routine as much as possible
- Bring comfort items from home
- Play games to normalize separation (peek-a-boo)
- Offer play + bonding opportunities
- Help distract + comfort during and after procedures
- If possible, breastfeed for comfort

# 6 MONTHS - 2 YEARS

learning independence • learning how to control bodily functions  
starting to achieve early physical, cognitive, and language milestones



Children this age will have difficulty understanding what is going on and why. They will not be able to understand that painful bandage changes or surgeries will eventually lead to healing. They may develop fear of medical personnel and equipment. To help with this, children should be given opportunities to explore medical equipment in order to become more comfortable with it. Playing with children and medical equipment can also give us opportunities to correct any magical thinking or misunderstandings they have about what is happening.

Grow your child's confidence and ability to adapt by letting them figure out how to do things themselves. If everything is done for them or if they are not given opportunities to be independent, they could lose confidence and their skills may possibly regress. Children need opportunities to feel successful, and they benefit from positive reinforcement and praise when achievements are accomplished. Hospitalized children sometimes do not have as many opportunities to be independent, so it is important to find safe ways to provide these moments.

Once healed, your infant/toddler will have very little awareness of additional challenges they may have due to their injury, and they will find ways to achieve their developmental milestones as long as they are given opportunities to mobilize and problem solve. It may be tempting, during this time, to make things easier for them, but they will adapt better and develop more confidence if they are allowed the opportunity to problem solve the challenge themselves. You can support this by providing reassurance and positive reinforcement as they explore and adapt.

**HELPING TODDLER BURN SURVIVORS  
UNDERSTAND THEIR EXPERIENCE**



## CHALLENGES

- Separation
- Lack of independence
- Regression of developmental skills
- Lack of ability to explore / practice / mobility / play
- Misunderstanding what is going on and why
- Fear of bodily injury / pain
- Confusion surrounding procedures

## SUPPORT

- Provide consistency with routine
- Provide positive reinforcement only
- Help child understand what is happening
- Offer realistic choices so child feels in control
- Allow child to explore + adapt independently during play
- Continue separation play (peek-a-boo, hide-and-seek)

# 2 - 7 YEARS

independence • purpose • able to understand more  
see things from their perspective only • magical thinking/confusion  
mastering physical, cognitive, and language skills through play  
begin developing social skills through play

Preparing a child for procedures and surgeries is very important during this stage. Preparation helps the child feel more in control and it can benefit them to feel like part of the medical process. If they are constantly surprised by procedures, they will likely develop high anxiety and mistrust for the team and caregivers, so giving clear explanations, expectations, and control (where possible) is key.

Children in this stage of development may also think their hospitalization/injury was because of their bad behavior. To help reduce stress from these misunderstandings, ask child about what they think is happening and why. Knowing what they are worried about will help you prepare them better and allow you to clarify the situation.

It will also be important at this age to maintain any expectations and limitations you would have for them at home. During hospitalization, it is tempting to relax the rules, but children this age benefit from boundaries and knowing what the rules are. It will also make the transition back home easier. While limits need to be maintained, they may need to be adapted depending on your child's condition. As your child continues to heal and take on challenges, encourage and provide plenty of positive reinforcement.

Children this age also struggle to understand differences how others may be different from themselves. This kind of thinking from your child's peers may cause them to fear your child if they appear different from themselves. They may fear that a condition is contagious, which could lead to them avoiding interaction with your child as a result. Generally, these misunderstandings can be easily corrected with a simple explanation. Helping your child prepare a rehearsed response can help get them ready for questions from peers, and school re-entry programs are also very helpful. Caregivers can also prepare their own rehearsed response to share with other parents and teachers, who can give that information to other children as well.



## CHALLENGES

- Hospitalization / condition are seen as punishments
- Loss of independence + decision-making
- Regression
- Separation anxiety (fear that bad surprises will happen while caregivers are gone)
- Fear of bodily injury / pain

## SUPPORT

- Honest, clear, + simple explanations
- Validate feelings
- Establish / maintain routines + boundaries
- Provide social + play opportunities
- Provide support + positive reinforcement
- Reassure that behavior is not the cause of hospitalization / condition

# 7 - 12 YEARS

self awareness of status among peers • desire to be proficient at multiple tasks  
independence and privacy • adjusting to academic load  
feelings of success are imperative • logical thinking allows for rational thought  
rules and structure • learn through observation • information seeking



As children at this age are beginning to think more logically and rationally, preparation, accurate expectations, and opportunities to participate in procedures (where possible) are very important. Help your child create a plan during their procedures using realistic choices and coping strategies to help them feel in control, and allow them to gain mastery over their experience. This can boost their overall confidence and can create a more positive hospital experience for them.

Giving your child some input on adaptations to the rules while in the hospital can help them feel more in control, just make sure the choices you give them are realistic and enforceable. Children this age like to test boundaries, but also feel safe when they know exactly where they are. Maintaining limits will also make the transition back home easier.

Children this age are starting to have more needs/concerns socially, and may feel very isolated from peers while in the hospital. Where possible, encourage interactions with other children in the hospital, as well as scheduling video chats and interactions with friends from home. Encouraging your child to continue with school work (where possible) may keep them from feeling like they are falling behind.

If your child has lost skills or their appearance has changed due to their burn injury, this can be a major loss and they will need to grieve before being able to move forward. They will likely be highly concerned with what this means for their future, and also how they will fit in with peers after discharge. You can help by validating their feelings and listening to their concerns. It might also help them to speak with other survivors, whether it is in a hospital based support group, chatting casually with other patients, or talking to a Phoenix SOAR peer support volunteer. Once they are ready to move forward, you can help them find ways to adapt and boost their confidence by setting them up for success with daily and recreational activities.

## CHALLENGES

- Loss of control
- Loss of peer interaction
- Regression of cognitive skills
- Disruption of routines
- Self-esteem / self-identity crisis
- Fear of being different than peers
- Fear of bodily injury / pain

## SUPPORT

- Be honest about what is happening
- Validate emotions and expressions of pain
- Provide positive reinforcement
- Maintain schedule, routines, limits, + expectations
- Help child establish coping skills
- Encourage social interaction
- Provide choices and control where possible

# 12 - 18 YEARS

exploring self-identity • trying to establish role in society + with peers  
exploring thoughts on ethics, politics, etc • socializing may be awkward as peer groups shift  
peer interaction is life • need for privacy • sexuality is emerging  
heightened self-awareness + body awareness • highly concerned what peers think of them



Children this age are starting to realize who they are as people and what their role in society might be. They will be capable of understanding more abstract and complex ideas, and should be allowed a more active role in their medical plan where appropriate. Procedures should be fully explained and clear expectations should be set. This will encourage confidence and mastery with their role in their healthcare experience, and will lead to more trusting relationships with medical personnel.

It is important for this age group to maintain expectations and limitations you would have for them at home. Structure and continuity of daily routines like school, time for privacy, and recreation time, can help normalize the hospital setting and will help make the transition back home/to school easier. Working together with your child to come up with a plan about how this looks in a hospital setting will increase their buy-in to the plan, will give them a sense of control, and will help them feel like part of the process.

Peer support an interaction is highly important for this age group. Allowing your child time to socialize in person, on the phone, video chat, or social media (with clear limits, of course!) will help them feel connected to things happening at home and in school. If their school allows them to attend classes virtually, encourage their participation in as many classes as possible during recovery. During hospitalization, encourage interactions with other patients their age, and see if they would like to talk to a Phoenix SOAR peer support volunteer to help gain perspective about their future as a burn survivor.

When returning to school, you can support your child by keeping an open dialogue about their concerns, interactions, and support needs from you. Encourage them to prepare a rehearsed response before they return to school, and see if a school re-entry program might be available for them.

## CHALLENGES

- Loss of peer acceptance + interaction
- Depression / anxiety / anger
- Regression in school
- Loss of trust
- Lack of privacy + independence
- Fear of loss of competence
- Fears about the future

## SUPPORT

- Opportunities for choices + independence
- Give opportunities for emotional expression
- Encourage peer interaction
- Encourage questions
- Maintain limits / expectations at home
- Positive reinforcement
- Talk openly about future plans

# EXPLORE MORE RESOURCES

---

CAREGIVERS >

GUILT + SHAME >

KIDS + TEENS >

SCHOOL >



COMMUNITY CALENDAR >

