



Model Systems
Knowledge Translation
Center

Free Research-based resources from
the MSKTC to support individuals with

Burn Injury

Edition 10
August 2022



www.MSKTC.org/TBI



Offered by the MSKTC To Support Individuals Living With Burn Injury

**Edition 10
August 2022**

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About the Model Systems Knowledge Translation Center

The Model Systems Knowledge Translation Center (MSKTC) summarizes research, identifies health information needs, and develops information resources to support the Model Systems programs in meeting the needs of individuals with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury (Burn). The health information offered through the MSKTC is not meant to replace the advice from a medical professional. Users should consult their health care provider regarding specific medical concerns or treatment. The current MSKTC cycle is operated by American Institutes for Research® (AIR®). The Center is funded by the U.S. Department of Health and Human Services (HHS), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) under grant number 90DPKT0009. To learn more, visit <http://www.msktc.org>.

About the Burn Model Systems Program

The Burn Model System (BMS) Program is funded by NIDILRR in the U.S. Department of Health and Human Services. The BMS began in 1994 and continues its mission to improve care and outcomes for individuals with burn injuries. Currently, there are four BMS centers, each providing a multidisciplinary system of rehabilitation care, including emergency medical, acute medical, and post-acute services. In addition to providing direct services, these centers play a pivotal role in building the national capacity for high-quality treatment and research serving persons with burn injuries, their families, and the communities in which they reside. To learn more, visit <https://msktc/burn/model-system-centers>.

Burn Injury Model Systems

2017–2022 Funding Cycle

Boston-Harvard Burn Injury Model System

Spaulding Rehabilitation Hospital, Boston, MA

Northwest Regional Burn Model System

Harborview Medical Center, Seattle, WA

The North Texas Burn Rehabilitation Model System

The University of Texas Southwestern
Medical Center, Dallas, TX

Pediatric Burn Injury Rehabilitation Model System

University of Texas Medical Branch, Galveston, TX

About the National Data and Statistical Center for the Burn Model Systems

The National Data and Statistical Center for the Burn Model Systems (the National BMS Data Center) advances medical rehabilitation by increasing the rigor and efficiency of scientific efforts to assess the experiences and outcomes of individuals with burn injury. Specifically, the National BMS Data Center:

- Maintains the national longitudinal database (BMS Database) for data submitted by each of the Burn Model Systems Centers (BMS Centers).
- Facilitates the entry of high-quality, reliable data in the BMS Database by providing training and technical assistance to BMS Centers.
- Facilitates the entry of high-quality data collected from database participants of all racial and ethnic backgrounds by providing knowledge, training, and technical assistance to the BMS Centers on culturally appropriate methods of longitudinal data collection and participant retention.
- Supports rigorous research conducted by BMS Centers and investigators from outside of the BMS network who are analyzing data from the BMS Database by making statistical and other methodological consultation available.
- Improves the efficiency of the BMS Database operations through collaboration with other entities, such as the National Data and Statistical Center for Traumatic Brain Injury Model Systems, the National Data and Statistical Center for Spinal Cord Injury Model Systems, the Model Systems Knowledge Translation Center (MSKTC), and the American Burn Association.
- Improves reports for the public from the BMS Database.

The National BMS Data Center is operated by the University of Washington Department of Rehabilitative Medicine and is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research.

<http://burndata.washington.edu/>

Contents

Overview of Burn Injury Products Offered Through the MSKTC	4
Opportunities to Participate in MSKTC Activities	5
Delirium After Burn Injury	6
Employment After Burn Injury	11
Exercise After Burn Injury	17
Going Back to School After a Major Burn Injury.....	20
Healthy Eating After Burn Injury—For Adults.....	25
Healthy Eating After Burn Injury—For Kids	28
Help Your Child Recover—Build Your Child’s Resilience After a Burn Injury.....	31
Itchy Skin After Burn Injury.....	33
Managing Pain After Burn Injury	38
Outpatient Opioid Management for Adult Burn Survivors.....	42
Post-Traumatic Stress Disorder (PTSD) After Burn Injury	46
Psychological Distress After Burn Injury	49
Scar Management After Burn Injury.....	54
Sexuality and Intimacy After Burn Injury	58
Sleep Problems After Burn Injury	62
Social Interaction After Burn Injury	66
Sun Protection After Burn Injury	70
Understanding a Burn Injury	75
Understanding and Improving Body Image After Burn Injury	81
Wound Care After Burn Injury.....	86

Overview of Traumatic Brain Injury Products Offered Through the MSKTC

The Model Systems Knowledge Translation Center (MSKTC) offers a variety of free resources on traumatic brain injury (TBI) to support people with disabilities and their caregivers, researchers, practitioners and clinicians, and policy makers. The following resources are available at www.MSKTC.org/Burn.

Burn Factsheets

The MSKTC collaborates with Burn Injury Model Systems to produce evidence-based and consumer-friendly factsheets.

Burn Slideshows

The MSKTC develops traditional and narrated slideshows based on information from select factsheets. These resources are developed for users who prefer a format with more images, less text, or an audio option.

Burn Hot Topic Module

The MSTKC developed a Hot Topic Module, which is a collection of resources such as videos, factsheets, and slideshows to support individuals who live with Burn Injury.

Burn Quick-Turnaround Reviews

The MSKTC provides quick reviews of Model Systems research studies funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). Those reviews offer timely summaries of newly released Model System research studies using lay language for easy access.

Burn Systematic Reviews

The MSKTC collaborates with Model System programs to conduct systematic reviews on high-priority health topics to inform clinical practice. Results of a systematic review provide the best information for making decisions about treatment, practice, or behavior.

Burn Database

The MSKTC maintains a database of over 350 Burn citations and abstracts of studies funded by NIDILRR.

Burn Infocomics

The MSKTC translates contents from the consumer factsheets and presents them in a comic-styled storyboard format.

Burn Audio Factsheet

The MSKTC narrates the consumer factsheets to develop audio factsheets to enhance user accessibility.

Opportunities to Participate in MSKTC Activities

Engaging people with lived experience in our work helps make the MSKTC resources more useful. Periodically, we recruit individuals with traumatic brain injury and their family members, caregivers, and clinicians to participate in MSKTC activities. We sometimes offer a small financial token of appreciation to participants. Examples of activities include:

- ◆ Providing feedback on factsheets
- ◆ Offering input on videos
- ◆ Participating in a conversation about the needs of caregivers

If you are interested in learning more about these activities or participating, please email MSKTC@air.org or call 202-403-5600.

Collection of Burn Factsheets Offered by the MSKTC

This section contains Burn factsheets offered by the MSKTC as of August 2022. These and other resources are available at no charge on MSKTC.org/Burn

- ◆ Delirium After Burn Injury
- ◆ Employment After Burn Injury
- ◆ Exercise After Burn Injury
- ◆ Going Back to School After a Major Burn Injury
- ◆ Healthy Eating After Burn Injury—For Adults
- ◆ Healthy Eating After Burn Injury—For Kids
- ◆ Help Your Child Recover—Build Your Child’s Resilience After a Burn Injury
- ◆ Itchy Skin After Burn Injury
- ◆ Managing Pain After Burn Injury
- ◆ Outpatient Opioid Management for Adult Burn Survivors
- ◆ Post-Traumatic Stress Disorder (PTSD) After Burn Injury
- ◆ Psychological Distress After Burn Injury
- ◆ Scar Management After Burn Injury
- ◆ Sexuality and Intimacy After Burn Injury
- ◆ Sleep Problems After Burn Injury
- ◆ Social Interaction After Burn Injury
- ◆ Sun Protection After Burn Injury
- ◆ Understanding a Burn Injury
- ◆ Understanding and Improving Body Image After Burn Injury
- ◆ Wound Care After Burn Injury

Delirium After Burn Injury

April 2020

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains what delirium is and what you or your friends and family can do about it.

What you need to know about delirium

- What is delirium?
- What are the symptoms of delirium?
- After a burn injury, who develops delirium in the hospital?
- What can the health care team do to help?
- Does delirium go away?
- What are the long-term effects of delirium?
- What can you do to help someone who has delirium?
- Frequently asked questions about delirium

What is delirium?

Delirium (dee-leer-e-um) is a ‘disturbance in mental abilities that causes confused thinking and reduced awareness of one’s environment.’¹ It is usually caused by an underlying health problem, such as an infection. Other causes include changes in the sleep cycle, an illness, medicines, or drug withdrawal. Delirium does not mean that your loved one is “crazy” or has a permanent mental illness.

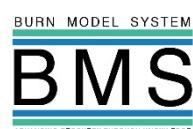
Three types of delirium have been identified:^{1,2}

- **Hyperactive** delirium. This is likely the easiest type to recognize. Signs include feeling restless or agitated; people may pace. People may have rapid mood changes. They may also hallucinate, or see things that are not there. They may not cooperate with care and pull at intravenous (IV) lines and tubes or try and get out of bed.
- **Hypoactive** delirium. Signs of this type may include inactivity (slow and/or limited activity). People may feel sluggish or more tired than normal. They may seem to be in a daze and may not recognize loved ones.
- **Mixed** delirium. This type includes both hyperactive and hypoactive signs and symptoms. The person may quickly switch back and forth between these two states.

What are the symptoms of delirium?^{1,2}

Symptoms of delirium may begin over a few hours or a few days. They may come and go throughout the day. Other times, people may have no obvious symptoms. Symptoms tend to be worse at night when it is dark. Some of the main symptoms include the following.

The Burn Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <http://www.msktc.org/burn/model-system-centers> for more information).



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Reduced awareness of the environment. This includes:

- Not being able to stay focused.
- Being easily distracted.
- Being withdrawn, with little or no activity or little response to the environment.

Poor thinking skills. This includes:

- Having poor memory and attention. A person may not recall instructions. He or she may ask for questions to be repeated.
- Being disoriented. A person may not know where he or she is or what is happening.
- Problems with speaking. This may include rambling or nonsense speech.
- Problems with reading or writing.

Changes in behavior. This may include:

- Seeing things that are not there.
- Being restless, agitated, or even aggressive.
- Calling out. This may include moaning or saying words that do not make sense.
- Being withdrawn; this is common in older adults.
- Having or showing little or no feeling or emotion.
- Not sleeping well.
- Reversing day and night cycles. This causes trouble sleeping at night and daytime drowsiness.

Emotional disturbances or changes. These include:

- Having a wide range of emotions. People may feel anxious, scared, or paranoid. They may also feel sad, cranky, or angry.
- Having sudden mood swings that cannot be predicted.
- Having personality changes.

After a burn injury, who develops delirium in the hospital?

Only a few studies have looked at delirium in burn patients. One study found that as many as 77% of burn patients who need a breathing tube develop delirium in the intensive care unit (ICU).³ Delirium may also develop after an operation. About 15% of burn patients develop delirium after an operation.⁴ Older age is a risk factor for developing delirium in the hospital. In some cases, delirium may have no known cause.

What can the health care team do to help?

Doctors and nurses use several screening tools daily to help identify delirium. They may ask the same questions when they see the patient each day, or even during every nursing shift.

The health care team knows that delirium may develop, especially in patients in the ICU. They will try to prevent it. This may include having the patient walk around the nursing unit or sit up in a chair. Patients should walk as soon as they can and often (make sure the burn team okays this type of activity). The team may also have the patient stay awake during the day and look for ways to help the patient sleep at night. The team may ask you to help with this by adjusting lights and noise in the room at certain times of day.



The team will try to manage your loved one's pain from their burn injury without over- or under-treating them.

The team may limit medicines that can make people feel confused. If your loved one is breathing with the help of a breathing machine, the doctors and nurses will try to decrease the use of medicines that make your loved one drowsy.

They will treat infections, correct fluid and electrolyte imbalances, and promote normal sleep and wake cycles.

They will try to limit interruptions by grouping nighttime care (medication administration, vital signs, and other assessments).

The care that a patient with delirium receives or the strategies used by the health care team to treat or prevent delirium may differ.

What can you do to help someone who is experiencing delirium?

The health care team may ask you about your loved one's medical history and usual behavior. Often, patients with delirium cannot provide an adequate medical history. Helping the team to understand how your family member's mental state is different from usual is a big help. It is also important that you tell your loved one's doctors and nurses if you notice a sudden change in the patient's behavior or emotions.

It is helpful to tell the health care team about your loved one's home routine and habits. This may include what time they wake up and go to sleep, their hobbies, and their likes and dislikes. Doing familiar tasks can help make a long hospital stay feel more normal.

Minimize daytime naps to help reset the day/night sleep cycle. Keep the lights on and the blinds open during the day. Turn the TV and lights off at the same time every night. Using an eye mask, ear plugs, or headphones (that play calming music) can help drown out the noise of the hospital. These habits can also help improve the patient's sleep.

Make sure to bring your loved one's glasses and hearing aids to the hospital. This will help them recognize you and their surroundings, which improves delirium. Bring a few photos of the patient and their loved ones, including pet photos, to help reorient them. Bringing in a favorite toy or stuffed animal may also help the child who experiences delirium.

Do not argue with your loved one if he or she is confused. This will lead to frustration. Instead, gently reassure the patient and remind them that they are safe in the hospital. It may also help to remind your loved one of the date, day of the week, and year. Keep instructions simple and give your loved one time to process directions. If you get frustrated, it is okay to step away from the bedside to take a break.

When your loved one is delirious, limit noise and visitors. Identify a small group of trusted friends or family members who can be with the patient to reassure them. During these quiet times, limit talking, touching, or other stimulus.

Does delirium go away?

For most patients, delirium gets better when they get treatment for the underlying cause of the change in their mental state. This could be a medical issue, a sleep disturbance, or side effects from medicine.



What are the long-term effects of delirium?

For some patients, the effects of delirium linger after their hospital stay. These effects may not be obvious. Patients may be much improved but still have problems with certain tasks that require focused thinking.

In a study of burn patients treated at an inpatient rehabilitation facility after their hospital stay, about 25% of patients had some difficulty with memory or thinking through a new problem when they left the rehabilitation hospital.⁵

Studies with non-burn patients have found that patients who had more days of delirium while in the ICU had the most severe long-term issues with their cognition⁶ and some have trouble with activities of daily living and functioning.⁷

Frequently Asked Questions About Delirium

1. **Is delirium a kind of dementia?** No, but it may be hard to tell the difference between dementia and delirium sometimes. A person can have both. ‘Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person’s daily life and activities.⁸
2. **How can I tell the difference between dementia and delirium?** Signs of delirium start over a few hours or a few days; dementia begins with minor symptoms that slowly get worse over time. With delirium, staying focused is difficult. A person in the early stages of dementia is generally alert. Symptoms of delirium may shift or change often throughout the day. With dementia, people have fairly consistent memory and thinking skills during the course of a day.

Comparison between delirium and dementia⁹

	Delirium	Dementia
Timing of onset of symptoms	Develops quickly, in hours or days	Develops over months or even years
Impact on memory or thinking	Delirium can make memory and thinking problems worse	Dementia is a disturbance of thinking
Length of illness/symptoms	Usually clears up after a few days or weeks	Usually a permanent condition

3. **Is delirium a disease?** No, it is a group of symptoms.
4. **What is usually the first sign of delirium?** Sudden confusion about time and place (where they are).
5. **Can delirium occur at any age?** Yes, delirium can occur at any age to include children, but it is more common in the elderly.

Additional Resources

Critical Illness, Brain Dysfunction, and Survivorship (CIBS) Center: <https://www.icudelirium.org>. Accessed January 21, 2020.

Patient Education: Delirium (Beyond the Basics): https://www.uptodate.com/contents/delirium-beyond-the-basics?topicRef=16994&source=see_link. Accessed January 21, 2020.

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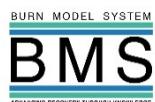
Authorship

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this factsheet were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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Employment after Burn Injury

March 2016

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet covers returning to work after burn injury, including how to know when you're ready to return to work and accessing workplace accommodations.

Returning to work after a burn injury can be an important phase of recovery that helps you return to a routine. Work not only provides you with an income and other benefits, but can also give you a sense of purpose and confidence that is critical in maintaining a higher quality of life. Returning to work, even if you were not injured on the job, can be accompanied by a confusing range of emotions, such as feeling both excitement and anxiety.

- You may not feel you are physically or mentally ready to return to work and do not have the stamina to work the same amount of hours or perform the same physically demanding tasks that you did before you were injured.
- If you were injured on the job, then returning to the same place of injury and/or the same tasks that you were doing when you were injured, may lead to fears or anxiety related to the injury.

Many people have found it was helpful for them to start work gradually, even before they were fully recovered. This is because returning to work can be emotionally and physically therapeutic.

There are many resources available to help you return to work. Some of these resources vary according to your state law and whether or not you were injured on the job. Your eligibility for resources depends on your unique circumstances such as the severity of your burn injury and the demands of your job.

The Burn Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <http://www.msktc.org/burn/model-system-centers> for more information).

Remember that you are not alone. It is important to get assistance from the burn center, your employer, or other community resources to help you take the steps necessary to return to work safely and successfully.

Are You Ready to Return to Work?

There are some important things that you can do to help make the process of returning to work easier:

- See your health care providers regularly and follow through with treatment. Success with getting back to work requires active participation on your part.
- Talk with your health care providers about your readiness to return to work. He or she can help assess your current strengths and limitations and a reasonable time frame for returning to work.
- Spend time during your recovery period to focus on what you need to do emotionally and physically to return to work. This might include doing tasks around the house to build your strength and stamina, participating in an exercise program, or wearing work boots around the house to get comfortable in them again, particularly if you had a burn to the foot or leg.
- Meet with someone who has returned to work after an injury to get support and guidance.



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- Build a supportive network to help you role-play such things as interviews and educating employers and co-workers about your situation.
- Getting prepared may also include counseling to help you cope with psychological and emotional issues you have about returning to work.
 - You may feel uncomfortable about your change in appearance due to your burn injury, especially if your burns are highly visible such as on your face or hands.
 - You may want to learn how to handle questions from your coworkers or employer about your injury and how it happened, or about the way the burn has changed the way that parts of your body look (e.g., scars, pigmentation).
 - If you were injured on the job, treatment for Post-traumatic Stress Disorder (PTSD) symptoms will be important. Treatment might focus on being prepared to return to the place and activities where you were working and other reminders of your accident, such as coworkers who were there when you were injured. It will also include managing nightmares, flashbacks and other symptoms of PTSD.
 - Some people have found it helpful to get in touch with some coworkers they are looking forward to working with again.
- Stay in touch with your employer and express your interest in getting back to work. Keep your employer informed about your recovery to ensure your job will be waiting for you when you are ready to return.
- Ask your health care provider to clearly evaluate your current work restrictions and a time frame for when you may be able to return to work.
- Ask him or her to write a note to your employer with a timeframe and list of supports (workplace accommodations) you may need so that your employer can plan accordingly.
- If you are not able to return to your regular job for a while, talk to your employer about jobs that you may be able to do during your recovery.

Work Conditioning Programs

If your medical team determines that you are ready to return to work but you and they feel you lack the stamina needed to do your work, you may participate in a return to work program that will gradually build your stamina for work, or be encouraged to do fitness training. If your injury happened at work, you might also be referred to participate in a work conditioning (work hardening) program. These are specialized programs run by occupational and physical therapists that aim to improve your strength and endurance to perform your job tasks. Discuss options for improving your endurance for work with your health care providers since there are advantages and disadvantages to various approaches.

Workplace Changes to Help You Return to Work

Your medical team may ask your employer for a job description when you are ready to return to work. This job description is usually provided by the human resources department at your place of employment. The job description helps your medical team determine if you are physically capable of meeting the demands of your job, or if you need changes made at your workplace to accommodate your disability (accommodations). It is OK to ask your employer for accommodations to help you return to work. The Department of Human Resources at your place of work is a good place to start this dialogue. Whether you were burned on the job or not, employers are legally obligated under the Americans with Disabilities Act and many state laws, to provide you with reasonable accommodations as long as it will not cause the business any undue hardship.



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- Under the law, it is your responsibility to make the request for accommodations.
- Be prepared to advocate for yourself or find someone to advocate for you because your employer may not be familiar with the laws that require job accommodations.
- Your medical team may provide you with guidance and supporting paperwork to help you receive job accommodations.
- You have the right to refuse a job assignment that violates your doctor's stated restrictions.

Typical Workplace Accommodations Include:

- A modified work schedule (4 hours per day in the beginning, with a gradual increase to full time).
- Working in a clean and dry environment.
- Limits on how much you can lift.
- Limited exposure to extreme temperatures (avoiding extreme heat or prolonged periods of cold).
- Altering work schedules to accommodate outpatient physical therapy and other medical appointments.
- Special software and hardware so a person with limited or no hand function can work on a computer.
- Adaptive equipment to help you perform your job tasks.
- Consider having your first day at work be in the middle of the week, rather than on a Monday. This short week will be less physically demanding for you.

These accommodations can make the initial transition back to work less demanding on you, and over the long haul, make it possible for you to succeed in your job. You may also need more recovery time when you get home at the end of the workday. It may be helpful to educate your employer and co-workers about burn injuries so they are more understanding to your needs and have realistic expectations of your performance.

On-The-Job-Injury

If you were injured at work, you are likely covered by your state's workers' compensation insurance. Your case manager is responsible for making sure you get the benefits you are entitled to because of your on-the-job injury. Your case manager can help you get the treatment you need and make the transition back to work go more smoothly. He or she can also be a great resource in helping you to navigate the complex workers' compensation system. It is also important that you know your rights and be prepared to advocate for yourself. State workers' compensation insurance differs by state. Your case manager may not provide you with all the information about what workers' compensation benefits you are entitled to such as mileage compensation for doctor appointments.

Here are some things you can do to make this process run smoothly:

- Be sure to keep all your paperwork.
- It is important for you to know your claim number and to be in touch with your case manager regarding your treatment and your plan to return to work.
- Always keep your medical appointments to ensure your claim remains open.
- Remind your health care provider to send in the required workers' compensation paperwork so your claim is not closed before you are ready to return to work.



- Do not ignore calls, mail or other forms of communication from your workers' compensation program. Some of these communications may require you to take action.
- Make sure your case manager knows the name and address of your health care provider. Good communication between your health care provider, you, and your claims manager is essential to the smooth delivery of benefits.

Independent Medical Evaluation

The workers' compensation case manager or your health care provider may request an Independent Medical Evaluation (IME). These are often done when the health care provider feels that you have recovered as much as you are likely to recover. If you receive an IME, you would be referred to an outside health care provider who would independently assess if your condition is stable and no further treatment is appropriate. In that case, your claim is ready for closure.

Permanent Partial Disability Award

If your injury caused permanent loss of physical or cognitive function or a chronic psychiatric illness you will receive something called a "permanent partial disability award." Any permanent partial disability award you receive is based on the degree of physical or mental impairment on activities of daily living, not on whether you can work.

Vocational Rehabilitation

Whether you were injured on the job or not, you may need vocational rehabilitation to help you return to work.

How Does Vocational Rehabilitation Work?

If you are treated at an inpatient rehabilitation setting, vocational rehabilitation usually starts the first day you are admitted and continues after discharge, as the rehabilitation team and counselor continue to follow your employment status and provide help as necessary. Vocational rehabilitation can also take place at any time an individual with a disability needs help finding employment. If your burn injury makes it difficult for you to get or keep a job, you may try to seek assistance from a vocational rehabilitation counselor.

Your vocational rehabilitation counselor may provide the following support to help you find a job:

- Assessing your skills, limitations, health needs, work and education histories, interests and even personality style.
- Helping you develop a plan that includes specific employment-related goals and how to achieve them.
- Setting up a "trial" work situation for you with a potential employer for a specified period of time to see if you are able to do the job, if you like the job, and what accommodations you might need.
- Helping you determine whether a potential job would be a good match for you. He or she can conduct a job analysis to determine the actual kinds of tasks done in that particular job, the cognitive (mental or thinking), social and physical demands of the job, and the need for accommodations.

How You Can Find a Vocational Rehabilitation Counselor

- Ask your health care provider or burn center for a referral to a vocational counselor.
- The State Department of Vocational Rehabilitation agency (DVR) can be found in almost every state (see Resources). The DVR may also be able to help you train for a new career if you are unable to return to the job you had before your injury.

Vocational rehabilitation services vary by state. State DVRs are permitted to enter what is called an "order of selection" during difficult budget times, which means people with more severe disabilities will be given priority to receive services.



Long term disability

Due to the severity of the injury, some people may not be able to return to any type of employment. A person is eligible to receive disability payments from the Social Security Administration (SSA) if he or she is unable to perform any kind of work at a level of "substantial and gainful" activity and the disability is expected to last at least a year. The SSA pays disability benefits under two programs:

- Social Security Disability Insurance (SSDI) is a long-term disability insurance program funded by payroll taxes. In addition to disability, eligibility is based on your past work history and income. After a waiting period, SSDI recipients are eligible for Medicare.
- Supplementary Security Income (SSI) is a federal welfare program for people with disabilities who are unable to work and are poor. SSI recipients are eligible for Medicaid after one month.

If it seems unlikely that you will return to work within a year, we recommended that you apply for SSA benefits as soon as possible. If you have purchased a long term disability policy, you may also be eligible for benefits from that policy provider.

What Will Happen to Your Long Term Disability Benefits if You Return to Work?

Sometimes people are reluctant to start working because they don't want to lose their medical benefits under SSDI or SSI, or because of the extra costs of getting to or staying at work. Several federal programs have been created to help avoid this situation. Federal work incentive programs under SSDI or SSI allow people with disabilities to receive benefits and federal health care (Medicare and/or Medicaid) while still keeping some of their earnings from employment. Two federal work incentive programs that help people with disabilities secure a variety of supports such as job coaches, transportation, equipment, and work-site accommodations, include:

- PASS (Plan to Achieve Self Support) – This program (3 year max) allows funds used in achieving employment goals such as paying tuition for training courses to be excluded in calculating your monthly SSI benefits. Contact your local SSA office or for more information, go to <http://www.socialsecurity.gov/pubs/11017.html>
- IRWE (Impairment-Related Work Expenses) – IRWE benefits can be claimed for your entire working life. In this program, work-related expenses such as adaptive equipment or personal care costs can be deducted from your income so you can retain more of your SSI benefits.

The Law Protects You

The federal Americans with Disabilities Act (ADA) prohibits employers from discriminating against qualified individuals with disabilities who are able to perform the essential functions of the job with or without accommodations. To be protected under this law, you must have a disability that limits major life activities.

- An employer must make "reasonable accommodation" to your disability if it would not impose an undue hardship on the business.
- Whether an accommodation is considered a hardship depends on the business size, financial resources, nature of operation and other factors.
- When you apply for a job, an employer cannot ask you about the existence, nature or severity of your disability, but can ask you about your ability to perform certain job functions, although some elements of your disability may be visible to others.
- An employer can require you to pass a medical examination only after a conditional offer of employment are made and if it is job-related and required of all employees in similar jobs.



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If you feel an employer has discriminated against you, contact the U.S. Equal Employment Opportunity Commission (EEOC). Call 1-800-669-4000 to find the office nearest you, or go to www.eeoc.gov. Many states have powerful disability rights laws as well.

Resources

Benefits for People with Disabilities, Social Security Administration. 1-800-772-1213. <https://www.ssa.gov/disability/>
Find your local Vocational Rehabilitation Agency and other federal and state resources, contact the Job Accommodation Network, U.S. Department of Labor. 1-800-526-7234. <http://askjan.org/cgi-win/TypeQuery.exe?902>

Equal Opportunity Employment Commission (ADA) 1-800-669-3362. <https://www.eeoc.gov/>

The Phoenix Society for Burn Survivors. 1-800-888-2876. <https://www.phoenix-society.org/>

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Authorship

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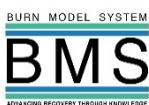
Factsheet Update

Employment after Burn Injury was reviewed and updated by Lynne Friedlander, MED, Spaulding Rehabilitation Hospital in collaboration with Oswald Mondejar, Sr. VP Spaulding Rehabilitation Network; Joan Phillips, Assistant Commissioner of Vocational Rehabilitation, Commonwealth of Mass; Peter Esselman, MD, MPT, University of Washington, and James Fauerbach, PhD, Johns Hopkins. The review and update was supported by the American Institutes for Research Model Systems Knowledge Translation Center.

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Exercise After Burn Injury

February 2021

www.msktc.org/burn/factsheets

BURN Factsheet

This fact sheet explains the importance of exercise or movement after a burn injury. The information describes activities you can do to make your muscles and bones stronger and keep your joints moving.

How does a burn injury affect your body?

A burn injury causes stress to your body. Your heart and lungs may not work as well as before. Your muscles and bones may not be as strong. Remember that muscles get weak or smaller when they are not used—being on bed rest probably caused you to lose some muscle. For each day of bed rest people can lose 1% of their muscle mass.

Also, as your burns heal you may notice that your skin feels tighter. You may not be able to move your joints as far and as freely as before. This tightness and lack of movement may make it harder to take care of your everyday activities like bathing, dressing, and eating.

Why is exercise important?

The sooner you begin everyday activity, the better. Sitting up, getting out of bed, and walking will help you get out of the hospital sooner. Being active or exercising may:

- Help your breathing
- Improve your heart function
- Help your body to fight infections, like pneumonia
- Improve your flexibility and ability to move
- Lower your risk of developing scars or contractures that limit your ability to move
- Make it easier to take care of your everyday activities
- Give you a sense of well-being



What can I do?

The chart below shows the types of exercises that can benefit you. Please consult your physician before engaging in these exercises.

The Burn Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <http://www.msktc.org/burn/model-system-centers> for more information).

Type of Exercise or Activities	
Stretching	<p>Stretching is an important part of your exercise program.</p> <ul style="list-style-type: none">• Stretching increases flexibility, which is important for preventing and treating skin contractures.• The goal of stretching is to move the joint to the point where the skin stretches.• Hold the stretch for 20 seconds to 2 minutes. <p>Relax and repeat three times.</p>
Aerobic activities make your heart beat faster and can make your heart, lungs, and blood vessels stronger and more fit.	<p>Walking is an easy way to get aerobic exercise.</p> <ul style="list-style-type: none">• Walk outside or on a treadmill inside.• Start slow.• Increase the time you walk by about 1 minute per day.• Build up to walking 30 minutes to 1 hour three times a week.• You should feel as if you are working, but you should not be so short of breath that you can't talk. <p>When cleared by your doctor, try using a stationary bike, elliptical, rowing machine or swimming.</p>

Type of Exercise or Activities	
Strengthening activities make your muscles do more work than usual and make your muscles stronger.	Resistance training or muscle strengthening is exercise that uses weights, elastic bands, or your own body weight. Weights don't need to be heavy. They just need enough tension to raise your heart rate and tire your muscles. Yoga, Tai Chi, or Pilates are also ways to make your muscles stronger and keep you moving.
Recreational activities	Playing sports, gardening, and dancing are good recreational activities that can help you build strength and endurance. Children will benefit from playing games that require movement or simulated activities using video gaming technology.

Special considerations

When exercising after a burn injury, keep in mind:

- Pain**—Talk with your doctor about the use of non-opioid medications; if fitted with custom-fit pressure garments, wear them during exercise to minimize discomfort.
- Dry skin**—Apply creams to moisturize skin before stretching. Creams can prevent cracking or tearing of skin. Ask a family member or loved one to massage the area of tightness. Massaging the area gently before exercising can help you stretch.
- Water**—Drink water or fluids so you do not get dehydrated during exercise.
- Exercising in the heat**—Many people with burns are uncomfortable in the heat. Be sure to protect yourself from the sun when exercising outdoors. Cover up with a brimmed hat and long sleeves. Use waterproof sunscreen (for more information, see the MSKTC's factsheet Sun Protection After Burn Injury at <https://msktc.org/burn/factsheets/sun-protection-after-burn-injury>). Start slow and build up to longer times in the heat. Research shows that people with burns can build up a tolerance to the heat if they slowly increase exposure. Listen to your body and how you are feeling!
- Open wounds or exposed tendons**—Talk with your doctor or therapist about what you can do to exercise safely if you have open wounds or exposed tendons.



Stretching exercises to help with tightness

The chart below shows exercises for different parts of the body where skin is tight because of a burn injury. Talk to your primary care doctor or the burn care team about the exercises that are right for you.

Face	<ul style="list-style-type: none"> Look into a mirror and make facial expressions like smiling or looking surprised. Close eyes tightly and massage skin around eyes. Stretch your mouth open and massage the edges of your mouth. Say the alphabet, exaggerating the letters with your mouth.
Neck	<ul style="list-style-type: none"> Combine stretching your neck with face stretching. Stretch in the opposite direction of tightness. Lie on your back on the bed. Look up to stretch the front of your neck. As you get better, let your head jut out over the edge of the bed.
Chest	<ul style="list-style-type: none"> Lie on your back with a ball or cushion in the middle of your back. <ul style="list-style-type: none"> Start with your hands on your hips. Arch your back. Stretch both arms out to the side or over your head to increase the amount of stretch on your chest.
Shoulders	<ul style="list-style-type: none"> Hold a stretch band with each hand. Use one arm to hold the other arm at the point of pull. Repeat to stretch the other shoulder. Prop your arm on the back of the couch or chair when sitting.
Elbows	<ul style="list-style-type: none"> Sit with your elbows all the way straight and your palms facing forward or up.

Hands	<ul style="list-style-type: none"> Stretch each finger at the knuckle to help get the hand into a fist (see photo to the right). For a longer stretch, wrap your hand in a fisted position. To get your hand into an open position, press down against a firm surface. <ul style="list-style-type: none"> Increase the amount of stretch by using the other hand to press down on the back of the open hand. 	
Knees	<ul style="list-style-type: none"> To help get the knees straight, sit with your legs propped up. Increase the amount of stretch by pressing on your thighs or knees with your hands. 	
Ankles	<ul style="list-style-type: none"> Standing helps stretch your ankles to get your feet flatter on the ground. Stand on a step as if you are about to go up the steps. Lower your heel off the step. 	
Toes	<ul style="list-style-type: none"> Toes tend to curl up. First, massage the scar. Then use your hand to stretch the toes. 	

Other Resources

The UW Medicine Regional Burn Center (Seattle, WA) has developed several short videos that demonstrate stretching exercises for specific areas of the body. Visit this YouTube site for 9 videos listed in the Burns300 series. The videos are available in both English and Spanish:
https://www.youtube.com/playlist?list=PLFEMTlzmLeUC-tONmpxadXa_7rusm_B6.



Keeping your body fit and healthy may mean going to a gym, a swimming pool, or being out in public. It's natural to be worried about how you look or how people may react to your burn scars. Check out the links below for resources that may help you.

Body Image After Burn Injury (<http://www.msktc.org/burn/factsheets/Understanding-And-Improving-Body-Image-After-Burn-Injury>)

Social Interaction After Burn Injury (www.msktc.org/burn/factsheets/social-Interaction-After-Burn-Injury)

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Authorship

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Going Back to School After a Major Burn Injury

October 2020

www.msktc.org/burn/factsheets

BURN Fact Sheet

This fact sheet helps you plan for your child's return to school after a burn injury. It gives tips on when to start planning and how to prepare your child. It also offers resources and programs that may help you and your family with the changes.

Introduction

Going back to school is a very important step in a child's healing after a burn injury. Learning and being with friends is important to your child's progress. Going back to school helps your child return to a good routine and continue learning important social and academic skills. It is normal for you or your child to feel stress and be worried about going back to school. This stress can be due to changes in the way the child looks or changes in what he or she is able to do. The stress could simply be due to the time away from normal schedules. Although this step might be stressful, we encourage the child to return to his or her familiar school environment as soon as possible. For example, if your child is in a regular public school, we recommend that he or she go back to that school. Extra help and other accommodations are available in schools.



When Should My Child Go Back To School?

- After spending many days, weeks, or even months in the hospital, the sooner your child gets back to his or her routine the better.
- While each child's injury is unique, on average most children go back to school between 7 and 10 days after going home from the hospital.
- Many things affect how your child feels about going back to school – changes to the body, changes to abilities, the size of the burn, and level of self-confidence. None of these things should keep your child from going back to school as soon as possible.
- If going back to school full-time doesn't seem possible at first, starting with a schedule of half-days or every other day may be a good way to start.

The Burn Model Systems Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <http://www.msktc.org/burn/model-system-centers> for more information).



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How and When Should I Start Planning for My Child To Return to School?

The plan for your child to go back to school should include your child and family, the school, and all members of the health care team, including the physicians, nurses, therapists, and child life specialist. Start talking about a back-to-school plan as soon as your child is medically stable and out of immediate danger. It may seem early, but the sooner the better! Starting early gives you time to put a good plan in place.

- Call your child's school and let them know that your child is in the hospital. Try to call within 2 or 3 days after the injury. If you can't make the call, ask a friend or someone on your child's health care team to call the school. Make sure the school's principal, guidance counselor or social worker, and your child's teachers are all aware of the situation. Ask them to designate one person with whom you should continue to communicate about your child's progress.
- Many children appreciate staying connected to their classmates while they are away from school. Consider asking the school to coordinate sending cards, letters, or pictures.
- Talk to your child about going back to school. Start the conversation early, while your child is still in the hospital. It will comfort your child to know that he or she will be able to get back to familiar routines and be with friends.
- Talk with the health care team about the kind of help your child will need at school and how your child's current school can best provide that help.
- Get your child's schoolwork. Ask to have schoolwork sent to the hospital. This may seem early, but having schoolwork lets your child know that he or she will get his or her life back again. It also keeps your child in contact with the outside world and gives him or her hope.



What Can I Do To Prepare My Child?

The first priority is to get your child back to doing everyday activities. Friends are also very important.

- Check with your child's health care team to see if and when you can set up short visits with close friends. If visiting in person is not possible, try other ways to get them together. Think about video chats, instant messaging, or telephone calls.
- Talk with your child about what he or she would like to share with others.
- If your child is able, suggest that he or she keep a diary or draw pictures of life in the hospital. This may help later in explaining to friends and classmates what happened.
- Children with visible wounds or scars may have questions or worries about seeing their friends for the first time. The health care team can help you prepare your child for these social interactions.
- Be supportive if your child wishes to share feelings, worries, and wishes about going back to school.
- Many burn care centers have on-site school and fun activities for children. Help your child to take part in these activities.
- For assistance with preparing you and your child for his or her return to school, consider consulting a child life specialist, psychologist, social worker, or a national organization such as the Phoenix Society for Burn Survivors.



What Are Accommodations?

Schools are required by law to provide “reasonable accommodations” for children who have been injured. The school guidance counselor or social worker is typically the person responsible for coordinating this process. These accommodations may be available to your child as he or she recovers from the injury:



- **A flexible schedule.** For example, your child may go to school for half a day and then slowly build to a full day.
- **Help taking notes.** This may include the use of a special computer or equipment or having another person take notes if their dominant hand has been affected by the injury.
- **Personal assistance.** Your child may get help with going to the bathroom, putting on a coat, or other everyday activities at school.
- **More time to take tests.** Your child may be allowed more time to take tests if he or she has trouble remembering, learning new things, or concentrating.
- **Changes to physical education.** Your child's physical education class may be adjusted or changed.
- **Help with care of the injury during school hours.** Your child may get help with stretching or putting on splints or pressure garments.
- **Visits to the school nurse.** The school nurse may be available to give your child medicine as required by you and your doctor. Many of these accommodations will be short term. Your child will need less help as he or she gets stronger and moves more easily. The steps to set up accommodations may differ from school to school. Some schools will ask you to fill out forms, while others may not. If you need an advocate, call the Special Education Department in your school district and talk to them about your child's rights and what accommodations you are requesting.

Structured vs. Informal School Re-Entry Programs

The purpose of a school re-entry plan is to provide the child, the family, and the school community with the information and support necessary to ensure a smooth transition back to school. Based on conversations with the burn care team treating your child and your child's classroom teacher(s), you should decide whether your child needs a more structured school re-entry program or simply an informal plan. A **structured program** would have a curriculum that might include sample letters to send to teachers and classmates, videos, worksheets, role plays, guest speakers and other classroom activities to raise awareness about your child's burn injury and recovery. It could be a program developed by your child's burn center or a national program such as The Journey Back developed by the Phoenix Society for Burn Survivors. You can use some or all of the components of the program as appropriate.



In contrast, an **informal school re-entry plan** may simply involve having your child's physician or another member of the burn care team, such as the child life specialist, make phone calls, send a letter, or visit the school. The hospital therapy team can help the school understand what your child can and can't do. This information can help to make sure that your child is not kept from doing school activities with the other students, such as physical education class and eating lunch. It can also make sure your child does not have to go through unnecessary infection control practices, such as not being allowed to play on the playground or not being exposed to other children in a classroom. Some things to consider when deciding whether or not you want to use a more structured program are the specific nature of your child's burn injury, whether he or she is shy and quiet, or more outgoing and comfortable with attention. It will also depend upon whether or not your child will be returning to school with pressure garments or splints, their level of endurance, and whether or not they are returning to the same school or a new school.



A good example of a back to school program is *The Journey Back: Navigating School Reentry* developed by the Phoenix Society for Burn Survivors:

<https://www.phoenix-society.org/resources/the-journey-back-navigating-school-reentry>

Complementary Programs

Many schools have developed other programs that may help as children return to school. Teachers and students can use the skills they learned in these programs to help your child get back into school. These programs may be called anti-bullying, disability awareness, and social and emotional learning. High schools may offer tutoring, counseling, violence prevention, and peer mentorship programs.

What Can I Do After My Child Goes Back to School?

No matter how much planning you do, you and your child may be worried about going back to school. This is natural. Reach out for help.



- **Remember to take care of yourself.** Going back to normal activities yourself is an important step for your child. It may be stressful for both of you. Make sure that you look for support for your own feelings. Keeping yourself healthy will be a big help to your child.
- **Speak up for your child.** Schools have many children who receive special services.
- **Be your child's advocate,** and ask what services are available for you or your child.
- **Check in.** In the first few weeks after your child returns to school, check in often with teachers and counselors to see how things are going. Also check in when things change, like when your child switches grades or schools.
- **Help your child work through problems.** Ask your child to be specific about problems. Then work with him or her to come up with solutions for dealing with the problems. For example, if he or she gets teased about looks, come up with different ways of handling it. Take the time to see what your child feels most comfortable doing. Then help your child practice what to say or do.



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Summary

Children with burn injuries want to get back to their everyday life. Getting back to school is an important part of getting back to normal. Work with your child's health team, hospital or burn center, and school to set up a school re-entry plan so that everyone knows what your child needs. A good re-entry plan will give your child the medical and school services that he or she needs, and it will help your family adjust and heal.

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Authorship

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Healthy Eating After Burn Injury— For Adults

September 2016

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains the importance of proper nutrition as you recover and heal from a burn injury. It describes the nutritional needs during your recovery in the hospital and at home, and offers tips for balancing your diet as you heal.

This factsheet is intended to inform people with burn injury and their families about nutrition during hospitalization and after they return home. Burn injury dramatically increases your nutrition needs. The larger the burn size, the more nutrients you need to heal. A diet high in calories and protein:

- supports the immune system to decrease risk of infection;
- helps wounds heal faster;
- maintains muscle mass; and
- minimizes weight loss to support rehabilitation.

How are nutrition needs determined?

A dietitian and the medical team decide how much nutrition (e.g., calories and protein) you need. They set your nutrition needs based on your weight, height, age, and burn size. Vitamins and minerals are also important for healing and preventing infection.

- Vitamin C, zinc, and copper help burns heal.
- Vitamin E, vitamin C, and selenium are antioxidants. They help to reduce the body's stress response after an injury.
- Vitamin C, vitamin D, and zinc help to prevent and treat infections.

If you eat a healthy, well-balanced diet, you may not need extra vitamins. Ask your doctor if you have concerns about your nutrition needs.

How do I meet my nutrition needs while hospitalized?

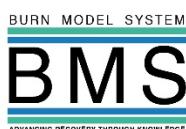
Healing from a burn injury requires more calories and protein than any other type of injury. You may need more nutrients than what you get from eating only by mouth. If this is the case, tube-feedings can deliver more nutrients. A soft, flexible tube inserted through the nose reaches the stomach and delivers liquid formula that contains all of the nutrients needed for healing. Tube-feedings continue as long as necessary.

You may need to add nutrient-rich snacks and beverages in between meals. For example, drinking milkshakes or smoothies may help you meet your calorie and protein needs. High-protein foods include meat, fish, eggs, legumes, milk, yogurt, cheese, and nuts. You should eat high-protein foods at every meal and as snacks. If needed, vitamins may be recommended by the health care team.

The health care team also monitors the level of salt in your blood. If your level of salt is low, you may need to reduce the amount of water and fluid that you drink. This keeps you from diluting the level of salt even more. The team may also ask you to eat foods with higher salt content.

In the hospital, a dietitian may work with you to make sure you are getting enough nutrients to heal. The dietitian follows your weight, nutrient intakes and outputs, wound healing, and levels of protein and vitamins in the blood. After leaving the hospital, maintaining a stable weight is the best way to make sure you are staying nourished.

The Burn Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/burn/model-system-centers> for more information).



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After leaving the hospital, eating a balanced diet is the best way to make sure you stay nourished but do not gain too much weight.

What if I have diabetes or high blood sugar?

After a burn injury, stress forces the level of sugar in your blood to increase. High blood sugar interferes with healing. Even if you don't have diabetes, you may have high blood sugar. Your health care team may prescribe insulin which lowers blood sugar. Until your blood sugar improves, you might have to limit the amount of foods you consume that are high in carbohydrates, such as bread, juice, potatoes, fruit, and desserts.

What should I eat at home?

Remember, your body requires fewer calories than when you were hospitalized. If your burn wounds are still open, your diet should include extra protein. As you continue to heal, your nutrition needs will be like they were before the injury. At the hospital, you likely ate large meals, drank nutrition supplements, and ate a lot of snacks. So your appetite may be big when you get home. Now focus on a balanced diet. Avoid foods with little nutritional value, such as sugary beverages, desserts, candy, fatty meats, whole-fat dairy, and white breads or crackers. Eat more lean meats, whole grains, vegetables, fruits, and low-fat dairy.

Ask your health care provider about exercise to help maintain a healthy weight. Exercise is important for long-term health and avoiding chronic illnesses, such as high blood pressure, diabetes, and heart disease. For more information, refer to the Exercise After Burn Injury Factsheet (http://www.msktc.org/lib/docs/Factsheets/Burn_Exercise.pdf).

Tips for a well-balanced diet

- Eat small, frequent meals and snacks to keep from feeling so hungry that you eat too much at one time.
- Include protein with each meal and snack. Protein helps you stay full and your body stay strong. Good sources of protein are beef, chicken, pork, eggs, beans, nuts, milk, yogurt, and cheese.
- Slice fruits and vegetables for an easy snack on the go. They provide many key nutrients for healing and overall health.
- Change the flavors of the foods you eat to keep them tasty, and fun. Cook with spices and herbs, such as rosemary, mint, garlic, cayenne pepper, and basil.
- Drink water during the day to stay hydrated and avoid unnecessary calories. Many drinks have fat and sugar that your body doesn't need. Read the nutrition facts on food labels.
- Choose whole-grain breads and other foods that are high in fiber. These will help keep you feeling full between meals and can support regular bowel movements.
- Try to eat only when you're hungry. Avoid eating for other reasons, such as boredom, lack of control, anger, or hopelessness. Keep a food log and track your mood to see if you're eating for the wrong reasons.
- Talk to your doctor about any vitamins and supplements you would like to take at home.

Sample menu

This menu provides about 1,750 calories and 103 grams of protein per day. This sample menu should be balanced with physical activity.

Breakfast	2 scrambled eggs 1 slice whole-wheat toast 1 tsp. butter 1 medium banana 8 oz. nonfat milk	Dinner	3–4 oz. baked salmon 1 cup mixed vegetables ½ cup brown rice 8 oz. nonfat milk
Lunch	Turkey sandwich: 2 slices whole-wheat bread, 2 slices deli turkey, lettuce, tomato, and mustard 1 cup nonfat yogurt 8 oz. water	Snack	½ cup ice cream ½ cup sliced strawberries
Snack	1 medium apple 2 Tbsp. peanut butter 8 oz. water		



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Additional resources

Contact your local burn center and ask for an appointment with a dietitian who will create a nutrition action plan to meet your specific lifestyle and nutrition goals.

The MyPlate website (<http://www.choosemyplate.gov>) contains nutrition information, healthy eating tips, and ideas for increasing physical activity.

U.S. Department of Agriculture. (n.d.). MyPlate. Retrieved from <http://www.choosemyplate.gov>

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Authorship

Healthy Eating After Burn Injury was developed by Megan Nordlund MS, RD, CD, Clinical Dietitian and Nicole S Gibran MD, FACS, UW Medicine Regional Burn Center, Harborview Medical Center, Seattle, WA in collaboration with the Model Systems Knowledge Translation Center.

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this factsheet were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0012). The contents of this factsheet do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the federal government.

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Healthy Eating For Kids with Burn Injury

September 2016

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains the importance of proper nutrition as your child recovers and heals from a burn injury. It describes the nutritional needs during recovery in the hospital and at home, offers tips for a healthy diet for healing, and includes a few kid-friendly recipes.

This factsheet is intended to inform families of children with burn injury about nutrition during hospitalization and after they return home. Your child needs adequate nutrition to grow and develop. Having a burn injury dramatically increases the need for proper nutrition. The larger the burn size, the more nutrition your child needs to heal. A diet high in calories and protein:

- supports the immune system to decrease risk of infection;
- helps wounds heal faster;
- maintains muscle mass; and
- minimizes weight loss to support rehabilitation.

How are nutrition needs determined?

For a child with burn injury, a dietitian and the medical team decide how much nutrition (calories and protein) your child needs based on his/her weight, height, age, and burn size. Vitamins and minerals are also important for healing and preventing infection.

- Vitamin C, zinc, and copper help burns heal.
- Vitamin E, vitamin C, and selenium are antioxidants. They help to reduce the body's stress response after an injury.
- Vitamin C, vitamin D, and zinc help to prevent and treat infections.

There is no need for vitamin and mineral supplements if your child is eating a healthy, well-balanced diet. Ask your child's doctor if you have concerns about your child's nutrition needs.

How are nutrition needs met while hospitalized?

Healing from a burn injury requires more calories and protein than any other type of injury. In the hospital, a dietitian makes sure that your child is getting enough nutrients to heal. The dietitian monitors your child's weight, nutrient intakes and outputs, wound healing, and levels of protein and vitamins in the blood. So, your child may need more nutrients than what he/she gets from eating only by mouth. If this is the case, tube-feedings can deliver more nutrients. A soft, flexible tube inserted through the nose reaches the stomach to deliver a liquid formula that contains all of the nutrients needed for healing. Tube-feedings continue as long as necessary.

In the hospital, your child may need to add nutrient-rich snacks and beverages in between meals. For example, drinking milkshakes or smoothies may help your child meet his/her calorie and protein needs. High-protein foods include meat, fish, eggs, legumes, milk, yogurt, cheese, and nuts. You should include high-protein foods for your child at every meal and as snacks.

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After leaving the hospital, you can monitor your child's nutrition status by watching his/her weight, growth and wound healing. Take your child to regular doctor appointments where they will chart your child's growth.

What should your child eat at home?

Remember, your child requires fewer calories than when he/she was hospitalized. If your child's burn wounds are still open, his/her diet should include extra protein. As your child continues to heal, his/her nutrition needs will be like they were before the injury. At the hospital, he/she likely ate large meals, drank nutrition supplements, and ate a lot of snacks. So your child's appetite may be big when you get home. Now focus on a balanced diet. Avoid foods with little nutritional value, such as sugary beverages, desserts, candy, fatty meats, and white breads or crackers. Eat more lean meats, whole grains, vegetables, fruits, and dairy. A child with burn injury needs the nutrients from these foods to continue healing and maintain a healthy weight.

Your child may also need extra vitamins. For example, the health care team may ask your child to take a vitamin D supplement because of extended hospitalization, immobility, and decreased exposure to the sun.

Ask your child's health care provider about exercise to help maintain a healthy weight. Playing and exercising is great for the mind and body. In general, your child can do many of the things that he/she did before the injury. But listen to your child's doctor about any limitations. Protect your child's skin from sunlight when he/she is outside. For more information, refer to the Exercise After Burn Injury Factsheet (https://msktc.org/lib/docs/Factsheets/Burn_Exercise_Fact_Sheet_508.pdf).

Tips for a well-balanced diet

- Offer your child small, frequent meals and snacks. Let him/her decide how much to eat at one time.
- Prepare balanced meals that include all five foods groups: fruits, vegetables, grains, protein, and dairy.
- Give your child foods that are high in protein with every meal and snack. Good sources of protein include beef, chicken, pork, eggs, beans, nuts, milk, yogurt, and cheese.
- Make smoothies or milkshakes for your child, if he/she isn't interested in food.
- Offer your child water between meals. Sugary beverages such as soda and sports drinks add too many calories with little nutritional value.
- Get creative! Try combining new foods.
- Be a role model: Make extra and eat with your child.

Ideas for increasing protein

When your child eats:	Add or use:
Fruit and vegetable sticks	Peanut butter, almond butter, hummus or cheese
Whole wheat bread or toast	Peanut butter or melted cheese
Oatmeal	Milk instead of water and add nuts
Crackers or chips	Choose whole grain and eat with peanut butter, cheese, or hummus
Milk	1 cup of regular, dry milk powder to 1 quart of milk
Broth-based soups	Cream-based soups
Soups and casseroles	Diced or ground beef, chicken or turkey
Ice cream or yogurt	Nuts and granola with seeds

It is best to add protein to the diet with whole foods; protein powder supplements are generally not needed.



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Kid-friendly smoothie recipes

Monkey Shake (485 calories, 14 g protein)

1 banana
2 tbsp. peanut butter
2 tbsp. chocolate syrup
½ cup whole milk

Creamsicle Smoothie (455 calories, 13 g protein)

1 cup orange sherbet
½ cup whole milk
6 oz. vanilla yogurt

Dinosaur Juice (310 calories, 9 g protein)

½ cup vanilla ice cream
1 or 2 handfuls fresh spinach leaves
2 cups frozen fruit: pineapple, mango, or berries
2 tbsp. wheat germ or flax seed

Summer Vacation Smoothie (370 calories, 9 g protein)

½ cup vanilla ice cream
1 package vanilla Instant Breakfast
½ cup orange juice
½ cup frozen fruit (e.g., pineapple, mango, etc.)

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Additional Resources

Contact your local burn center and ask for an appointment with a dietitian who will create a nutrition action plan to meet your child's specific lifestyle and nutrition goals.

The MyPlate website (<http://www.choosemyplate.gov/kids>) contains nutrition information, healthy eating tips, and ideas for increasing physical activity.

Authorship

Healthy Eating After Burn Injury—For Kids was developed by Megan Nordlund MS, RD, CD, Clinical Dietitian and Nicole S Gibran MD, FACS, UW Medicine Regional Burn Center, Harborview Medical Center, Seattle, WA, and Maggie Dylewski, PhD, RD, LD, Research Consultant, Shriners Hospitals for Children, Boston, MA in collaboration with the Model Systems Knowledge Translation Center.

Source: Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the Burn Injury Model Systems.

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Help Your Child Recover—Build Your Child's Resilience After a Burn Injury

July 2022

<https://msktc.org/burn/factsheets>

BURN Factsheet

This factsheet provides information and tips to help you and your child after a burn injury.

Having a burn injury is a hard experience for children, their parents and guardians, and their families. But it is also an opportunity to build resilience. Resilience is the ability to adapt and overcome challenges. Resilience also refers to the ability of other people and systems to help the child overcome challenges. Children who are resilient often have caring and engaged parents or guardians, a supportive extended family, support from a burn center and their community, and supportive schools. This fact sheet is meant to help parents and guardians understand possible emotional reactions after a burn injury and to provide strategies that promote resilience.



What to Expect After a Burn Injury

Burn injury can be stressful on children and their families. Some children may have dramatic changes in behavior and emotions after a burn. Anxiety, sadness, irritability, and adjustment problems are some of the many changes that children experience and parents often see. For some children, these changes last only a short time, but other children may struggle for weeks or months to adjust to life after a burn. No two children respond the same way. A child's response to a traumatic event can vary based on their age, personality, developmental stage, and the social support they receive. Several reactions are common following a burn injury:

- **Sadness and withdrawal.** Your child may be quiet and may not want to talk to others. They may appear sad, have little interest in activities, or seem more emotional than normal.
- **Regression.** Your child may act younger than his or her age. For example, a preschool-aged child who was toilet-trained may go back to using diapers. An older child may be less independent or suddenly rely heavily on a parent or guardian.
- **Loss of independence.** Your child may be needy and less sure of themselves.
- **Fear.** Your child may be afraid of being alone and may have strong reactions to anything that reminds them of the burn.
- **Separation anxiety.** Your child may get upset about being away from parents or loved ones.
- **Sleeping problems.** Your child may not be able to fall sleep or stay asleep.
- **Nightmares.** Your child may have nightmares.



The Model Systems Knowledge Translation Center works with Burn Model System centers to provide free research-based rehabilitation resources for people living with burn injury (See <https://msktc.org/burn> for more information).



- **Irritability or aggression.** Your child may be angry or moody or lash out.
- **Appetite changes.** Your child may not want to eat or may want to eat too much.
- **Adjustment difficulties.** Your child may have a tough time adjusting to the hospital or to changes that have occurred because of the burn.

These changes in behavior may recur, even after treatment. Some children may have new emotional changes or changes in behavior as new stressors arise.

What Is Acute Stress Disorder and Posttraumatic Stress Disorder?

Some children have strong reactions after a traumatic burn injury, including

- Feeling like the burn is happening all over again,
- Having nightmares,
- Feeling edgy or overly anxious,
- Being overly on guard about getting burned again, and
- Trying to avoid anything that reminds them of the burn.



All these reactions, called acute stress symptoms, are normal in the first three days after the burn injury. The reactions typically go away with time and support. If they don't get better or if they interfere with the child's ability to function, the child may develop acute stress disorder (if occurring within one month of the injury) or posttraumatic stress disorder (PTSD) (if the symptoms persist for months after the injury). The good news is that there are several effective treatments for posttraumatic stress, and most children recover fully. **Parents and siblings may also experience symptoms of PTSD.** To learn more about the symptoms of acute stress disorder and PTSD, please see the following fact sheet: <https://msktc.org/burn/factsheets/PTSD-After-Burn-Injury>.

Building Resilience In Children

Parents and guardians are an important part of a child's emotional recovery. Positive family support is one of the biggest predictors of a child's recovery and adjustment. You can help your child by being present and available, listening to them, and validating his or her concerns. It is also important to model a positive, hopeful, and adaptive way of reacting to challenges. Children look to their parents and guardians for cues on how to react to difficult situations; you can serve as a model for your child as they navigate this difficult time. One of the best ways to model positive coping is to return to a normal routine as soon as possible, and wound care, stretching, etc. can be worked into this routine. Children thrive in environments that are predictable. Having a predictable schedule and routine that closely mirrors what they were doing before the burn is important. This includes returning to school as soon as they can and the parent(s) returning to work as soon as possible after the burn.



Some children may want to talk about the event and/or burn; for these children, it can be helpful to let them talk about their experiences and answer questions. It's also helpful to gently make sure that the child ends their burn story with the understanding that the burn event is over and that they are safe. Other children may not be ready to talk about their burn, and that is okay. There is no need to push your child to talk. Respect how your child responds and watch for signs of anxiety or discomfort. Some children may not be able to communicate their needs verbally, but you can still watch their

behavior for clues of what they need. Reach out to your burn care team or pediatrician who can put you in touch with a mental health professional with training in trauma care if your child:

- Has a change in behavior that lasts for one month after coming home from the hospital. There is a typical period of adjustment after a burn injury. However, if your child's behavior hasn't returned to what it was before the burn within a month after their injury, think about getting help.
- Has behaviors that get in the way of returning to normal routines. For example, your child may be physically ready to return to school, but they may be scared and not want to leave home.

There are several ways to help your child build resilience after a burn:

- Spend time with your child through play, talking, fun activities, and shared activities. Make sure that your child feels loved, safe, and valued.
- Build self-esteem and confidence in your child by allowing them to have as much control and independence as they can handle in a responsible way. Encourage your child to make choices after the burn, even if they are small choices. Encourage your child to problem solve when faced with difficulties. Praise your child when you see them trying to respond well to challenges.
- Model how to respond to challenges in a positive way. It may be helpful to think out loud to help your child understand your thought process. Accept that your child may look differently now. Your child may have a difficult time accepting that they look different from their peers. What your child needs first is acceptance from you—the parents.
- Have the same rules and expectations for your child after the burn as you did for them before the burn. After a burn, parents might have the tendency to go easy on their child or not enforce rules about behavior. This can cause a child to worry. For example, they may start thinking, "I must be really hurt if my mom/dad is letting me get away with this." Your child may not be able to do the same chores that they did before the burn. But you can find appropriate chores that your child can do to contribute to the family.
- Help older children find meaning in what they have been through. Many older children struggle with how much their lives have changed after a burn. But over time, these children may also experience some positive changes, called posttraumatic growth. **Dealing with adversity leads to growth.** Help your child to identify personal strengths and new activities and help them feel hope for the future.
- Connect with family, community, or religious supports. Make sure that your child has support from close family members and loved ones. Consider introducing your child to other children who have had a burn injury. Your area may offer summer camps for children with burn injuries. Ask your local burn provider for a list of these camps.
- Ask if your hospital has school re-entry services. Work with your child's school to make sure that staff are ready to support your child when they return to school.



Parental and Sibling Reactions to a Child's Burn

Parents or guardians and siblings may also have stress symptoms after a child's burn. This is known as secondary traumatic stress. These feelings are expected and common. It is important for parents and guardians to recognize their own emotional reactions to their child's burn injury and to take care of themselves and seek help if the reactions don't go away with time.



Things you can do:

Take time for yourself. Get back into the activities that relax and energize you. Socialize with friends, meditate, take walks, and connect with your spouse. It is important for your child to see that you are getting back into your normal routine.

Make sure that you eat well, get enough sleep, and exercise. It is important for you to be physically and emotionally healthy so that you can be the best support for your child.



Recognize when you feel sad or guilty about your child's injury and recognize when these feelings affect your parenting. For example, if you feel guilty, you might be more lenient and less strict about your child's behavior. You might let them get away with talking to you disrespectfully. You might allow your child to make demands or give them a lot more gifts than you normally would. These changes in your parenting style can have a negative impact on your child. Instead, say, "I love you enough to know that you will get through this and we will be cheering you on." If you always rescue your child from discomfort and frustration, they may not learn how to handle such emotions and challenges. Believe in your child's strength, and they will believe in themselves.

Consider peer support by asking your burn center to introduce you to other parents who have a child with a burn injury. The Phoenix Society trains peer supporters through its SOAR program and offers online support groups for parents of children with burn injuries.

Consider seeking counseling for more support.

Siblings are also affected by the burn injury. Consider the following when supporting siblings:

- Always include siblings in discussions about the burn injury. Never blame siblings for the circumstances of the burn.
- Give extra attention or spend one-on-one time with your other children if you are able.
- Seek out camps or support groups for siblings of survivors of trauma.
- Consider getting siblings involved in caring for your child with a burn. Let siblings help IF THEY WANT TO, but don't force them to help. Encourage siblings to get back to their own activities.
- Consider seeking counseling for siblings if they are struggling.



Stressful life events, such as a burn, will happen. But you can choose to use those events to build resiliency in your child, so that they don't feel like a victim or more vulnerable.

Resources

The National Child Traumatic Stress Network: <https://www.nctsn.org/audiences/families-and-caregivers>



The Phoenix Society: <http://www.phoenix-society.org>

The Knowledge Translation Center Fact Sheet on PTSD: <https://msktc.org/burn/factsheets/PTSD-After-Burn-Injury>

Authorship

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider about specific medical concerns or treatment. The contents of this fact sheet were originally developed under a grant (number H133A110004) from the U.S. Department of Education, National Institute on Disability and Rehabilitation Research. It was updated under the American Institutes for Research Model Systems Knowledge Translation Center, with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90DPBU0004, 90DP0082, and 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). The contents of this fact sheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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Itchy Skin After Burn Injury

September 2016

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains itchy skin after burn injury, why it occurs, ways to talk about it with your health care team, and strategies for managing it.

Introduction

As skin heals from a burn injury, it may get itchy. Almost everyone recovering from major burns has problems with itching—especially on or around the burn, graft, or donor site. The medical term for itchiness is “pruritus” (proo-ri’tus).

Itching is a normal part of healing. The reasons it happens are likely complex and poorly understood. Itch intensity (how bad it is) and frequency (how often it occurs) are not necessarily related to the size or depth of your burn injury, but itching may cause you to scratch and open up fragile skin that previously had healed.

Itching can also get in the way of doing everyday activities, including:

- Sleep: Itching tends to worsen at night, making it hard to fall asleep and stay asleep.
- Work and school: Persistent itching may make it hard to concentrate when performing these activities.
- Physical activities: Exercise, sports, and play (for children) may increase itching.

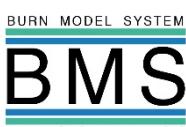
Itching can make you anxious, which can make itching worse. Fortunately, itching decreases over time. In the meantime, there are treatments to help reduce itching. To find the best treatment for you, talk with your health care team about how bad your itching is and how it is affecting your life.

Ways to Describe your Itching

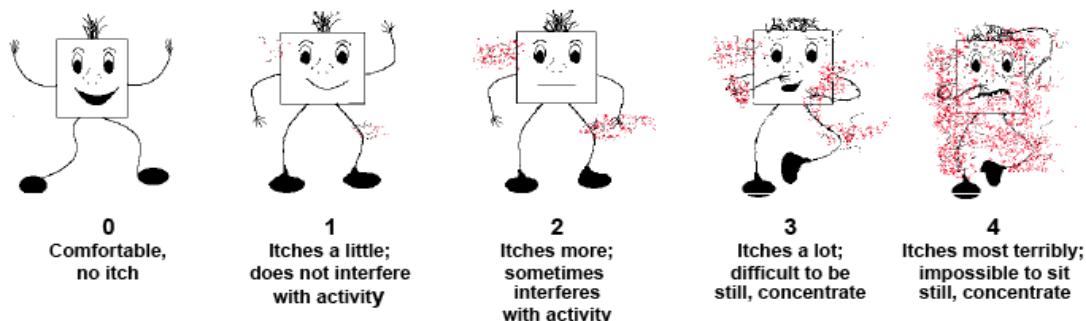
Your health care team may ask you to describe the **intensity** and **impact** of your itch:

- To describe **intensity**, or how strong the itch is, adults are usually asked to rate the itching on a scale of 0 to 10, where 0 is “no itch” and 10 is “worst itch imaginable.” Children are often asked to use the Burn Man Itch Scale to describe their itch (see below).¹

The Burn Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services’ Administration for Community Living. (See <http://www.msktc.org/burn/model-system-centers> for more information).



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¹ Itch Man Scale to rate itching intensity in children, designed by Blakeney and Marvin 2000 at Shriners Hospital for Children. (Reprinted with permission of Shriners Hospital for Children.)

To describe how itching may be affecting your life, your health care team may use the 5-D Itch Scale. This is a set of questions that asks you about the:

1. Duration (number of hours per day)
2. Degree (intensity)
3. Direction (whether it is getting better or worse)
4. Disability (impact on activities)
5. Distribution (location on your body)

You can also use the questions in the 5-D Itch Scale to initiate conversations with your health care providers.

Treatment

No treatment stops itching completely, but several may help.

Topical Therapies

Creams and lotions

- Moisturizers help to maintain skin moisture and hydration. They may help reduce itching if your skin is dry, because itching increases with dry skin. Use unscented or fragrance-free moisturizers. Applying moisturizers more frequently may be helpful.
- Diphenhydramine (pronounced dai-fen-hai-dremine; abbreviated **DPH** or **DHM**) cream blocks histamine and is sometimes helpful. Histamine is a naturally occurring compound in our bodies that triggers the inflammatory response. It is available over the counter and does not require a prescription.

- Doxepin cream (e.g., Zonalon or Prudoxin) has been used with some success. It decreases itching by blocking histamine receptors in the skin. Doxepin creams can be used only in small amounts and must be prescribed.
- Capsaicin (pronounced cap-SAY-sin) cream (e.g., Capzasin, 0.025%) may provide temporary relief. It is best to test this cream on a small area of your skin first because it may cause a stinging or burning sensation, particularly with the first few applications. Avoid getting capsaicin cream in your eyes and other mucous membranes or on broken skin. Wash your hands with soap and water after applying (unless your hands are within the treatment area). If applying to your hands, wait 30 minutes before washing your hands.

Baths

- Bathing may or may not help with itching. Lukewarm water is best and tends to dry out skin the least.
- Bath additives such as oatmeal, powdered milk, or baby oil can be helpful.
- Cooling the skin with water provides some temporary relief.

Oral Medications

- **Antihistamines** work by blocking histamine, which triggers itching. Common antihistamines used include diphenhydramine (e.g., Benadryl), cetirizine, loratadine, and hydroxyzine. They can be purchased over the counter, either as pills for adults or elixirs or liquids for children. Dosages (how much you should take) vary, so talk with your health care provider before taking any over-the-counter medications.
- **Gabapentin** (pronounced gab-ah-pen-tin) is an oral medication that must be prescribed. It acts centrally—in your brain—to help decrease itching and has shown promising results in several research studies.
- **Sleep medications** are used to treat sleeplessness (insomnia). Medications can sometimes be helpful to get to sleep and stay asleep. If itching makes it difficult for you to sleep, talk with your health care provider about safe sleep medications that can help.
- Before taking any medication, talk to your doctor about the side effects.
- Other medications may be helpful in decreasing postburn itching – talk with your healthcare provider about your options. Ask your doctor or health care provider to review all your medications as some medicines can cause itching.

Other tips

- Custom-fit pressure garments and other supportive dressings (e.g., Tubigrip Elastic Tubular Bandage) or tight fitting sport clothing may help during the first months to year following burn injury.
- Skin massage with lotion and/or touching with firm pressure on healed areas can help reduce itching. Make sure you check with your healthcare provider if your itching remains bothersome. In some cases, other treatments such as steroid injections, laser treatments or even surgery can be helpful.
- Distractions such as television, games, and low-impact or mild exercise or activities can help take your mind off the itching.
- Short fingernails, especially for children who tend to scratch at night while asleep, can reduce injury to fragile skin.
- Use unscented laundry detergent.
- Use unscented or fragrance-free lotions (including sunscreens).
- Protect your skin from the sun by wearing appropriate clothing (e.g., a hat and long sleeves) and using sunscreen.

For more information

- The Phoenix Society for Burn Survivors
<http://www.phoenix-society.org/>
- American Burn Association
<http://www.ameriburn.org/>
- In addition, you can contact your health care providers about local support groups and other resources.



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Authorship

Itchy Skin After Burn Injury was developed by Gretchen J. Carrougher, R.N., M.N., and Walter J. Meyer III, M.D., in collaboration with the Model Systems Knowledge Translation Center.

Factsheet Update

Itchy Skin After Burn Injury was reviewed and updated by Gretchen Carrougher MN, RN, Northwest Regional Burn Model System; Karen Kowalske, MD, University of Texas Southwestern; Jeffrey C. Schneider, MD, Colleen M. Ryan, MD, and Barbara A. Gilchrest, MD, Boston-Harvard Burn Injury Model System. The review and update is supported by the American Institutes for Research Model Systems Knowledge Translation Center.

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Managing Pain after Burn Injury

February 2017

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains how to understand and manage your pain as you recover and heal from a burn injury. It describes different types of pain, and medical and behavioral techniques to help you cope.

Introduction

Pain and discomfort are an unfortunate part of burn injury and recovery. Many of our patients tell us that ongoing pain continues to be a problem long after discharge from the hospital.

Continued pain can interfere with every aspect of your life, including:

- Sleep: pain can make it difficult for you to fall or stay asleep.
- Ability to work: pain can limit your ability to function or concentrate on the job.
- Mood: pain can cause depression and anxiety, especially when the pain is severe and lasts a long time.
- Quality of life: pain can keep you from being able to enjoy time with loved ones or do activities that are meaningful.
- Healing: pain can get in the way of healing if it keeps you from being able to sleep, eat or exercise enough.

If you are having pain, tell your physician.

Things to remember:

- Burn pain is complex and requires careful assessment by your health care provider in order to find the best treatment.
- Pain management often requires a multidisciplinary approach that may include both medication and non-medication treatments and involve a team of health providers, such as psychologists or physical therapists, working with your physician.
- Pain severity is not necessarily related to the size or seriousness of the injury. Small burns can be very painful, and some large burns not as painful.

Step 1: Understanding your pain

There are many different types of burn pain, and each person's pain is unique. Understanding the type, intensity and duration of your pain is important for getting the best treatment.

Your health care provider will ask you about several types of pain:

- **Acute pain:** short-term intense pain that typically happens during a procedure like dressing changes or physical therapy.
- **Breakthrough pain:** pain that comes and goes throughout the day, often due to wound healing, contractures (tightened muscles) or repositioning.
- **Resting Pain:** also called "background" pain that is almost always present, even at rest.
- **Chronic pain:** ongoing pain that lasts for 6 months or longer after the wound has healed.
- **Neuropathic pain:** pain that is caused by damage to and/or regeneration (re-growing) of nerve endings in your skin. It is often described as pain that is shooting, burning, feels like pins and needles or stabbing.

The Burn Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/burn/model-system-centers> for more information).



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You might also be asked to describe the pain in the following ways:

- **Intensity:** how strong the pain is, often rated on a scale of 0–10, with 0 as “no pain” and 10 as “worst pain imaginable.”
- **Duration:** how long it lasts (for example—hours, days, etc.).
- **Timing:** when it gets worse (during the day, night, or during certain activities).
- **Quality:** how the pain feels (for example—stinging, throbbing, itching, aching, shooting).
- **Impact:** how the pain affects your emotions and your ability to do things.
- **Itching:** whether pain is related to itching, which may be a sign that the skin is still healing

Other important information that can help your health care providers plan the best treatments for your pain:

- Your experiences with either acute pain or chronic pain before your burn injury.
- Your experiences with insomnia, depression, or anxiety before or after your burn injury.
- Pain medications you have taken in the past.
- How much your pain limits your ability to do certain things.
- Any activities that make your pain worse or better.

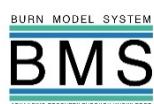
Step 2: Treating your pain

Medications

- **Opiates** are the most common medications given in the hospital setting. Some examples are morphine, hydrocodone, hydromorphone, and fentanyl. Opiates may be less effective for chronic pain, however. Side effects, such as constipation and low mood, can also become a problem. Opiates are potentially addictive. For this reason, your physician will help you taper off opiates when appropriate to avoid withdrawal symptoms.
- **Over-the-counter** pain medications such as Acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs; ibuprofen and Naprosyn are examples) can be used for long term pain relief. They are not addictive. These medications are effective for treating muscle pain. Use of NSAIDs for long term pain management may cause serious side-effects and should be used only under the supervision of your health care provider.
- **Anticonvulsant medications**, such as gabapentin and pregabalin, have been useful for managing neuropathic pain in some situations. These medications work by changing the way the body experiences pain.
- **Sleep medications:** if pain is interfering with sleep, talk to your physician about sleep hygiene and safe medications for sleep.
- **Antidepressants:** some antidepressants provide pain relief for some people, even if they are not depressed. Antidepressants can also help with sleep. You might talk to your health care provider about trying antidepressants as one way to manage your chronic pain.

Behavioral approaches

Rarely do medications take away all of the pain. You may also need to use behavioral approaches to help make pain more manageable. A psychologist with expertise in pain management can work with you to find non-medication approaches that can help. These may include:



- **Relaxation:** a burn injury puts immense stress on the body that continues for many months during the recovery phase. This stress causes muscle tension that can increase pain. Relaxation techniques can be used to lessen the stress placed on your body.
- **Cognitive (thinking) techniques** use the power of your thoughts to relieve stress. These techniques include meditation and a process called “cognitive restructuring,” which helps you change the way you think about your pain and reassure yourself that the pain is temporary and manageable.
- **Somatic relaxation techniques** use physical methods, such as deep breathing, yoga, and progressive muscle relaxation, to relieve tension in your muscles.
- **Hypnosis** has been shown to be a powerful tool in relieving both acute and chronic pain. A psychologist can teach you how to do self-hypnosis so you can include it in your daily routine.
- **Physical activity** can help manage pain. Although it may seem counterintuitive to increase your physical activity when you are in pain, it is important to remember that not all pain is a signal of harm and needs rest. Research has shown that the more physically active we are, the less pain that we have and the more we are able to do. It is important to establish a regular exercise routine as soon as your doctor says it is safe. This will increase function, decrease pain and enhance your mood and self-esteem.
- **Mindfulness Meditation** has been shown to be a very effective treatment for pain. The technique is easy to learn. There are programs online that can guide you in a mindfulness exercise, or you can work with a mental health provider. To get started, simply sit in a chair with your feet firmly on the floor and take some deep breaths. Notice what it feels like to inhale, notice what it feels like to exhale, and notice the quiet space in between your inhalation and exhalation. Count your breaths up to 10 while focusing on what this feels like. If thoughts come into your mind, gently push them aside and continue to focus on your breathing.
- **Pacing of activities:** daily activity and regular exercise are crucial in order to rebuild your strength and stamina and increase your range of motion. But pushing yourself too far can increase your pain.
 - Pace yourself by gradually increasing your physical activity over time. If you are too sore to move comfortably the day after an activity, you have probably pushed yourself too hard.
 - It is best to reduce your activity level until you are more comfortable. This is a difficult balance as burn recovery can be painful, and some pain may be necessary in order to progress to your previous level of function. Work closely with your physical and occupational therapists to set up an activity program that is appropriate for you.

Step 3: Coping with pain

People have different ways of coping with difficult situations or physical discomfort. Your coping “style” can have a large impact on how much pain you feel or how much the pain bothers you.

In any difficult situation, a person can react by choosing to either change the situation, change themselves, or simply “give up.” The first two options are considered “active” coping styles and are highly effective in managing stress. The third option often results in withdrawal or depression.

Research has shown that it is best to determine how much of the situation is under your control and then pick the appropriate coping style. If the situation is out of your control, changing how you think about and respond to it can be the best coping style. A psychologist can work with you on developing this kind of coping skill.



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It is also important to look for aspects of the situation that are under your control. For example, you cannot change the fact that you have suffered a burn injury that has resulted in ongoing pain. “Wishing” the injury had not occurred and dwelling on the “what-ifs” won’t help your pain and may lead to feeling more helpless and depressed. However, focusing on the part of the situation that you can control—such as your own rehabilitation, time spent in physical therapy, doing your daily range-of-motion exercises, and following the pain management strategies suggested by your doctor—can be a highly effective coping strategy.

For more information

- The Phoenix Society for Burn Survivors
<http://www.phoenix-society.org/>

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Authorship

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Factsheet Update

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Outpatient Opioid Management for Adult Burn Survivors

Update for Community Providers

March 2021 | www.msktc.org/burn/factsheets

BURN Factsheet for Clinicians

INTRODUCTION

People hospitalized for a burn injury often describe it as one of the most painful injuries one can experience. Opioids are frequently prescribed to help alleviate this pain.

Although there is not one standard approach to acute burn pain management, a goal is for the hospitalized patient to be awake, alert, and comfortable.¹ Although unrealistic to expect 'no pain' after a burn injury, significant and enduring in-hospital pain has been shown to be a predictor of poor post-discharge adjustment, well-being and lower health-related quality of life.^{2,3}

However, the opioid crisis in the United States is not going away. Overuse of prescribed opioid medications is increasing and misuse is on the rise.⁴ The Centers for Disease Control and Prevention (CDC) report that in 2017, 47,600 people died from opioid overuse in the United States and opioids were involved in 67.8% of all deaths from drug overdose.⁵

Postdischarge pain management

Between 86%⁶ and 90%⁷ of hospitalized adult burn patients are given opioid prescriptions at discharge. Two weeks after discharge, 90% of patients no longer use opioids,⁶ and most patients no longer use opioids 30 days after discharge.⁷

For those that are discharged from the hospital with an opioid prescription, consider the following opioid prescribing practices:

- Lower daily amounts of prescribed opioids;⁶
- Prescribe only short-acting opioids;⁶
- Educate patients about opioid use;⁶
- Ask patients to complete a risk assessment;⁶
- Check the Prescription Monitoring Program to identify other medications or drugs of concern.⁸

Aim: To provide information about opioid management for adults after they have been discharged from a hospital for treatment of their acute burn injury. This information will help community healthcare providers in their provision of comprehensive care in the setting of a national opioid crisis.

The Burn Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/burn/model-system-centers> for more information).



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Other Options and Factors to Consider:

Scheduled use of nonsteroidal anti-inflammatory agents (NSAIDs) and acetaminophen is an option for non-opioid pain medication. NSAIDs help with pain relief and inhibit cyclooxygenase and prostaglandin synthesis.^a When added to opioids, NSAIDs produce superior pain relief and an opioid-sparing effect (reduced opioid doses without loss of analgesic efficacy) that is associated with a decrease in some opioid-related adverse side effects.⁹ Together, scheduled use of NSAIDS and acetaminophen in outpatient settings may help to reduce opioid use.

Gabapentin may be prescribed to treat neuropathic pain and itching in burn patients. Gabapentanoids (gabapentin and pregabalin) were originally designed as anticonvulsants but have been used to treat chronic neuropathic pain.^b Gabapentin is increasingly used in burn care. However, the data do not support an opioid-sparing effect with the use of gabapentin.^{10,11} Gabapentin remains in the body for 1 or 2 days after stopping use, and withdrawal symptoms can occur a few days later. Tapering is generally not needed for patients who take lower doses—that is, 300 mg/day or less. If tapering is necessary, daily doses should be reduced at a maximum rate of 300 mg total every few days and based on feedback from the patient.

When added to opioids, NSAIDs produce superior pain relief and an opioid-sparing effect that is associated with a decrease in some opioid-related adverse side effects.⁹

Non-pharmacologic or adjunctive treatment strategies may help to relieve pain and itching. Although the majority of the studies cited below were performed with inpatients, findings may be helpful during outpatient recovery and help when opioids are tapered.

- **Scar massage** (with hypertrophic scarring^c): Preliminary evidence suggests that scar massage may be effective in treating pain and itch in persons with hypertrophic scarring¹² and promotes wound desensitization. However, because the evidence is of poor quality, more controlled clinical trials are needed.¹³
- **Cognitive Behavioral Therapy** such as cognitive restructuring, mindfulness, meditation, relaxation, hypnosis, and virtual reality have been used to reduce acute and chronic pain.¹⁴
- **Moisturizer for healed grafts and burn wounds:** Dry, healed burned skin and grafts are associated with increased itch intensity and discomfort. Thus, healed wounds should be kept moisturized with fragrance-free ointments.¹⁵
- **Interactive gaming:** Interactive gaming has been shown to reduce pain during rehabilitation sessions for minor burn injuries.¹⁶
- **Other options to consider:** Acupuncture, acupressure, laser therapy.
- **Assessment for other concerns:** Assessment and treatment of coexisting problems that impact pain is recommended. These may include pruritus, insomnia, post-traumatic stress, depression and anxiety.



a NSAIDs have an analgesic ceiling and may be associated with platelet dysfunction, gastrointestinal irritation or bleeding, and renal dysfunction. Like NSAIDs, acetaminophen should be administered on a scheduled basis. When added to opioids, acetaminophen produces better analgesia and an opioid-sparing effect associated with a decrease in some opioid-related events, such as nausea/vomiting and sedation. The maximum dosage of acetaminophen for a normal-sized adult is commonly quoted at 4 g/d, but the manufacturer of Tylenol® in the United States has dropped the maximum daily dose to 3 g/d (<https://tylenol.com/safety-dosing/usage/dosage-for-adults>). Acetaminophen is hepatically cleared and should not be used by patients with liver insufficiency.

b Gabapentanoids are associated with several adverse effects, including sedation, dizziness, and peripheral edema. In elderly patients, these agents should be used with caution or the dose should be decreased. Gabapentanoids are renally excreted; thus, dosage should be lowered in patients with renal dysfunction.

c A hypertrophic scar is a thickened, raised, red scar that develops where the skin has been injured, as with a burn.

Other Options and Factors to Consider:

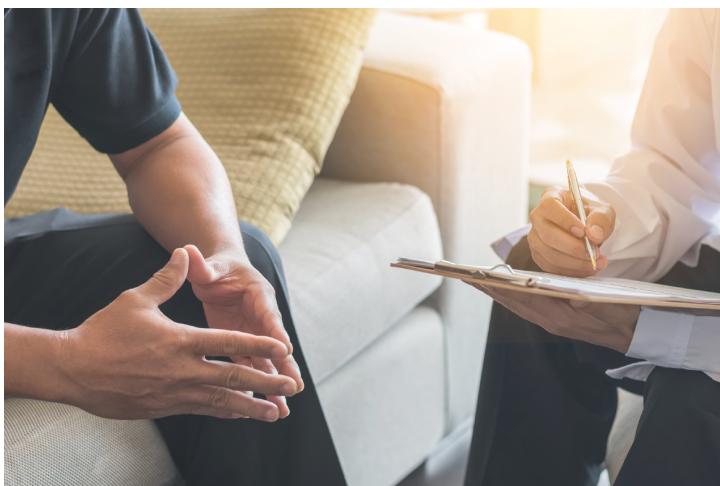
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c A hypertrophic scar is a thickened, raised, red scar that develops where the skin has been injured, as with a burn.

Other Resources

- Burn-specific factsheets on pain; pain (<https://msktc.org/burn/factsheets/Managing-Pain-After-Burn-Injury>), itching (<https://msktc.org/burn/factsheets/Itchy-Skin-After-Burn-Injury>), and Sun Exposure (<https://msktc.org/burn/factsheets/sun-protection-after-burn-injury>).

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Authorship

Outpatient Pain Management for Burn Survivors—Update for Community Providers was developed by Gretchen J. Carrougher, MN, RN (Northwest Regional Burn Model System); Samuel P. Mandell, MD, MPH, FACS (University of Washington Medicine Regional Burn Center, Seattle, WA); and Katherine D. Travnick, MD (Pain Institute of Nevada, Las Vegas, NV) in collaboration with the Model Systems Knowledge Translation Center.

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Post-Traumatic Stress Disorder (PTSD) After Burn Injury

July 2017

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains post-traumatic stress disorder (PTSD) after burn injury and common symptoms that may occur.

What is PTSD?

Mental and physical reactions are common after a traumatic event, like a burn injury. For some people, reactions may last more than 1 month and lead to PTSD. Reactions that occur sooner are called acute stress disorder. Symptoms of PTSD and acute stress disorder are a common response to a burn injury. Think of it as a way for the brain to let the body know it needs to stay safe—these symptoms can actually protect us. Symptoms can develop after witnessing a traumatic event (e.g., as a bystander or first responder) or by learning of a bad injury involving a loved one. If symptoms of PTSD do not go away, they can cause more problems. PTSD can affect adults and children.

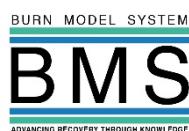
What are the symptoms of PTSD?

- Nightmares related to trauma that disrupt sleep or cause restless sleep. Children may not remember the content of the nightmares, but remember that the nightmares are frightening.
- Feeling like you're in a daze or detached, or that the burn is not real.
- Intrusive thoughts of the burn injury or feeling as though it's happening again (flashbacks).
- Children may engage in repetitive play in which they "act out" the traumatic event.
- Avoiding reminders of the injury, such as talking about it, watching similar events on TV, or not wanting to return to the place where the trauma occurred.
- Being very easily startled or feeling constantly on guard. New fears may develop, such as fear of the dark, crowds, or elevators. Some people will develop anxiety or a feeling of being on edge or not being safe.
- Negative changes in mood or cognition, such as being irritable or not being able to concentrate.

Who gets PTSD?

About 90% of both adults and children with burn injuries report at least one symptom of acute stress disorder right after the traumatic event, but only about 30% develop PTSD. PTSD is more likely to occur if the burn injury is an assault or a repeated trauma (such as ongoing abuse).

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Burn survivors most at risk for PTSD are those with a history of anxiety disorders (generalized anxiety, panic disorder) or depression. Burn survivors who have a history of traumatic events and past PTSD are also at risk for developing PTSD from the current burn injury. In fact, a current burn injury can trigger nightmares and flashbacks from a past traumatic event. Burn survivors with high levels of pain and anxiety while in the hospital may be more at risk of developing PTSD after discharge. Caregivers and the burn team should effectively manage pain and anxiety from a burn wound to avoid future distress. Children are more at risk of developing PTSD if their parents are experiencing such symptoms.

What should I do if I have symptoms of PTSD?

Symptoms of PTSD are common reactions to trauma, and they usually go away over time. After a burn injury, it is important to stay calm and connect with family and friends. You may find it useful to get information and details about the trauma. Only talk about your feelings when you feel ready to do so. Retelling the details of the trauma can actually be re-traumatizing and you can tell friends that you do not wish to talk about it. Let caregivers and the burn team know if you're worried about how you're coping with the burn injury.

Most early traumatic stress reactions get better over time as you return to a normal routine and start to develop ways to cope. For some people, early reactions may get worse. After the burn injury heals, the emotional trauma may not go away. The intensity and length of PTSD symptoms are not related to the severity of the injury. Seek treatment if symptoms of PTSD last for weeks or months and start to interfere with your quality of life.

Very good treatments are available for PTSD. The most effective treatments involve a type of counseling called cognitive behavior therapy (this may also be called Trauma-Focused Cognitive Behavioral Therapy). This is a short-term treatment in which you learn ways to relax and manage anxiety, to gradually be exposed to the traumatic event, and to think differently about the event. Your doctor may prescribe medicine for a short time to help with anxiety, depression, or sleep problems. While awaiting treatment, you can do several things to treat each symptom:

- **Nightmares.** Wake up and remind yourself of where you are. Reassure yourself that you are safe and go right back to sleep. Try not to get up, turn on the TV, or get something to eat—these will keep you awake longer. Try changing the end of your nightmare by imagining a better outcome.
- **Flashbacks.** Try to stop flashbacks right away by imagining a stop sign or a red light and thinking about something more pleasant.
- **Anxiety and arousal.** Practice a relaxation technique to reduce your anxiety. Deep or rhythmic breathing, mindfulness meditation, muscle relaxation, yoga, and exercise can all be helpful.
- **Avoidance.** If reminders of the trauma are interfering with your normal routine—such as not wanting to return to work if that is where the accident occurred, or not wanting to go outside near the gas grill—then consider a fear hierarchy. This is a list of steps that slowly expose you to the normal things. For example, consider going back to the workplace for a very short period of time for a casual visit, such as having lunch with a coworker. Then, gradually increase the time you spend in the workplace until you can be near the accident site for an entire shift. Practice relaxation techniques as you work through the fear hierarchy. You may need professional assistance to help with this.



Always talk to the burn team about PTSD symptoms that you may be having. They can help you to find a mental health provider for treatment.

Additional resources

- National Child Traumatic Stress Network: <http://www.nctsn.org>
- National Institute of Mental Health: <http://www.nimh.nih.gov/health/topics/post-traumatic-stress-disorder-ptsd/index.shtml>

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Authorship

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Psychological Distress after Burn Injury

November 2016

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains some emotional recovery challenges that burn survivors may face after a major burn injury and treatment options.

Introduction

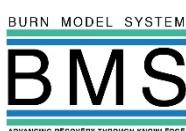
The purpose of this factsheet is to describe some of the emotional recovery challenges that patients may face after sustaining a major burn injury. It is important to point out that most burn survivors do very well psychologically after surviving a burn injury. However, even though we are optimistic about long term recovery, burn survivors may face several challenges in the aftermath of their injury. Whereas each individual experiences psychological distress differently, people with burn injuries often report:

- Feeling...
 - Sad, anxious or irritable
 - Helpless
 - Hopeless
 - Upset about depending on other people for assistance
 - Distant from family, friends or the general public
 - Alone
 - As if the injury was happening again or reliving it
 - A physical reaction (e.g. heart pounding, trouble breathing, or sweating) when something reminds you of the injury
 - Jumpy or easily startled
 - “Super alert” or watchful and on guard
- Difficulty falling asleep due to thoughts like:
 - “I worry about bad things that might happen”
 - “I keep thinking about the way I was injured”
- Difficulty finding enjoyment in things that used to give pleasure
- Difficulty staying asleep
- Avoiding situations that remind you of the accident
- Avoiding thinking or talking about the injury and how it occurred

While in the hospital, survivors may find they have a lot of time to focus on their burn injury. Many people report having psychological distress several days or a few weeks after they were injured. For most, periods of distress become less frequent and less upsetting after a couple of weeks to a couple of months. However, problems that continue for more than a month or two, or thoughts about wanting to die or hurt oneself, indicates a need to seek treatment.

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Causes of psychological distress after burn injuries

Major burn injuries can be extremely upsetting and distressing for the survivor, as well as for family members, and friends. Depression or anxiety before the burn injury increases the chances of those symptoms after the injury. Common causes of distress include:

- Thinking about the event itself – both in sustaining the injury and/or witnessing others who were also seriously injured or died
- Worries about the future
- Concerns about finances and the impact the injury has had on family members
- Changes in appearance because of scars and contractures
- Physical discomfort
- Pain while the wound is still healing (especially during the repeated dressing changes) and pain that continues for months afterward as nerves are healing
- Itching
- Difficulty adhering to range of motion and Physical Therapy exercises
- Limitations in physical abilities
- Loss of independence
- Difficulty in returning to work or school
- Loss of property, residence, pets, etc.
- Interruption of daily life activities and roles
- Challenges with sexual interests and intimacy

Effects of psychological distress on health and recovery

Psychological distress has been shown to affect the way the mind works (e.g., poor memory, short attention span) and the ways the body functions (e.g., immune system, digestion). Distress can also worsen other medical conditions (e.g., blood pressure, glucose control) and can interfere with recovery from the burn in many ways, such as:

- Making pain and itching feel even worse
- Reducing your effort and persistence in participating in rehabilitation therapies and wound care
- Making communication with burn team members difficult
- Reducing your interest and pleasure in daily activities
- Disrupting sleep
- Causing tension in interpersonal relationships



Treatment options

It is critical to seek emotional support from professionals and other survivors to help with your psychological distress. There is a caring community that understands your experience. Always let your burn team know about challenges in your emotional recovery.

- Keep connected with friends and family and ask for support
- Take one step at a time during the recovery process. Acceptance of your injury and the changes in your life take time, and recovery (psychological and physical) can proceed at a slow pace
- Get sufficient sleep and eat healthy foods
- Try to avoid napping during the day so that you will sleep better at night
- Avoid tobacco, illicit drugs and/or excessive use of alcohol because they can lead to low mood and increase anxiety
- Stay focused on tasks that you can do rather than those things that are no longer possible because of your injury
- Stay active and exercise regularly
- Return to a normal routine as soon as possible. Get up, get dressed, groom yourself and get out of the house every day to avoid feeling more depressed
- Engage in one positive, pleasant activity every day
- As soon as you are medically cleared, get back to doing the things you did before the injury like going to work or school and doing chores around the house

Peer Support

- Seek support from professionally led support groups. Ask your health care provider how to locate the right group for you
- Seek support from other survivors. You can find survivors who have been trained by the Phoenix Society's SOAR program to provide peer support (www.phoenix-society.org/resources)
- Participate in regularly scheduled peer support on-line discussions offered through the Phoenix Society (www.phoenix-society.org/chat)

Psychotherapy

Mental health professionals are trained in methods for assessing and treating psychological distress. Professional help is particularly important if the distress is severe and interferes with things that are important to you.



There are many health care practitioners such as psychiatrists, psychologists, social workers, and pastoral counselors that can help. It is best to work with a mental health professional who has experience in treating people with severe injuries and expertise in treating the problems you may be experiencing (e.g., body image, social discomfort, post-traumatic stress disorder (PTSD)).

Here are a couple of the effective methods that health care providers may use to help reduce your distress:

- Cognitive Behavioral Therapy (CBT). Ask your health care provider for more information
- Stress Management: Learning practices like deep breathing, meditation, or staying “present in the moment”
- Coping strategies such as active problem solving
- Communication and social skills: For example, changes in appearance may require that you learn new skills for managing distress that may arise when other people ask about your accident or when they react to changes in your appearance due to your injury

Medications

Consult your primary care doctor or the burn care team to determine if medications may best address your symptoms. Certain medications have been shown to help psychological distress for disorders such as:

- Depression (e.g. low mood, low energy, suicidal ideation, isolation, guilt, irritability towards self and others, loss of interest in things you used to enjoy)
- Anxiety (e.g., worry, recurring and disturbing memories)
- Sleep (e.g., nightmares, difficulty relaxing)

For more information and resources

The Phoenix Society for Burn Survivors: www.phoenix-society.org/

Changing Faces: www.changingfaces.org.uk/

American Burn Association: http://www.ameriburn.org/resources_links.php

Face IT Online: www.faceitonline.org.uk

MSKTC NIDILRR Factsheets: www.msktc.org/burn/factsheets

National Center for PTSD: www.ptsd.va.gov/PTSD/public/treatment/therapy-med/index.asp

Anxiety and Depression Association of America: www.adaa.org/

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Authorship

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Scar Management After Burn Injury

November 2016

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains scarring after burn injury, including different types of scars and information about how to manage them.

Burn survivors can become frustrated that they still have issues with scarring after their initial burn injury has healed. Hypertrophic burn scars (raised scars in the area of the original burn) are the most common complication of a burn injury and can limit a survivor's ability to function as well as affect their body image. It is difficult to predict who will develop scarring. Research shows that less severe burns that heal in less than 14 days generally have no scarring. More severe burns heal in 14 to 21 days and put you at a risk of scarring. Burns that take more than 21 days to heal are at very high risk for scarring and may require skin grafting.

Why do scars form?

Scarring is related to age, ethnicity, and the depth and location of the burn. Scars form when the dermal or lower layer of the skin has been damaged. The body forms a protein called collagen to help heal the damaged skin. Normally the collagen fibers are laid down in a very organized manner, but in hypertrophic scars these fibers are created in a very disorganized manner, which gives the new skin/scar a different texture and appearance. Scar healing can take a long time. Scarring usually develops within the first few months after the burn, peaks around 6 months and will resolve or "mature" in 12-18 months. As scars mature they fade in color, become flatter, softer and generally less sensitive.

What are hypertrophic burn scars?

Hypertrophic scars:

- Stay within the area of the original burn injury
- Develop within the first few months after the injury
- Often have a deep red to purple color and are raised above the surface of the skin
- Can be warm to touch, hypersensitive and itchy
- Are more prominent and noticeable around joints where skin tension and movement are high

Common problems with hypertrophic scars

- Scars across joints can cause a decrease in your ability to move. These are called contractures.
- People with visible scars may feel self-conscious and avoid social situations. This can lead to isolation, depression and lower quality of life.
- Scars can be dry and result in cracking or breakdowns in the skin.
- Scars are more sensitive to sun and chemicals.

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Contractures

Contractures can affect your ability to move and take care of yourself. If your contractures involve your legs, you may have difficulty squatting, sitting, walking, or climbing stairs. If your contractures involve your trunk and arms, you may have difficulty with grooming, eating, dressing and bathing as well as working with your hands. Some contractures are unavoidable, but many can be prevented with active involvement in your rehabilitation program. Here are a few reminders:

- Stretching should be performed a minimum of 5-6 times per day. To make stretching easier, first moisturize your scars with a moisturizer recommended by your doctor.
- Your therapist may make a cast or splint to help position your scar in a stretched position. It is important that you wear the cast or splint as prescribed and tell your therapist if it becomes painful or causes skin irritation.
- Do as much for yourself as possible such as getting dressed and self-grooming. It may take longer than you are used to, but movement and activity will improve your ability to move and take care of yourself.

Itching

Burns can damage or destroy the oil glands that normally keep skin from getting too dry. Partial thickness burns have few oil glands and full thickness burns or skin grafts have no oil glands. The lack of oil glands leads to dry skin. The chaotic organization of collagen in the healed skin may trap nerve endings, which also contributes to itching.

Many patients experience intense itching after their burn. Studies have shown that the larger the burn, the more likely that itching will be a problem.

Ask your doctor for recommendations on what moisturizer is best for you. Moisturizers with high water content—such as those that come in a bottle—generally soak into the skin faster and will need to be applied more frequently. Moisturizers that come in a tube or jar are generally thicker and have less water, so they need to be applied less frequently. Be sure to avoid products that you may be allergic to, such as perfumed lotions.

- Moisturizers can be applied to all healed areas frequently throughout the day.
- Moisturizers should be applied in thin layers and massaged in gently while the scars are more fragile. As your scars mature, you can begin to add more pressure to help your scars loosen so that they are not so stiff.
- Hot showers remove the natural oils from the skin. Therefore it is essential to re-moisturize well after showers. Bathing may feel good but also removes the natural oils. Adding baby oil to the water may alleviate some of this effect.

The approaches for itching are varied. Keep skin moist is the starting point. Also massage or pressing down firmly on the scars may help. Scratching increases inflammation and will make itching worse. Elastinet garments or custom pressure garments may also help with itching.

Medications such as gabapentin or pregabalin (which are commonly used for nerve pain) have been shown to be the first line medication for itching. Antihistamines may also be helpful. Talk to your doctor about what medication is right for you. You should never use mineral oil, Vaseline or antibiotic ointments to moisturize your skin. These can lead to allergic reactions and skin breakdown. Do not use antibiotic ointment to lubricate after the wound is healed.



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Sun Exposure

You should avoid exposing your healing scars to sunlight. Scars that are discolored and have not matured burn easily. If you go out in the sun, we recommend:

- Planning activities in the early morning or late evening when the sun is the least intense.
- Apply sunscreen with SPF level greater than 15 frequently to maintain protection.
- Reapply sunscreen every 2 hours.

Treatment of hypertrophic scars

You will need to work closely with your doctor and therapy team to make sure your scars heal as completely as possible. A strong commitment is required from you and your family member to follow through with the treatment plan to ensure the best scar result.

No single treatment is ideal for treating scars. For many years, custom pressure garments were thought to be the best treatment for hypertrophic scars. Custom fit pressure garments may be useful for decreasing postburn itch and scar formation.

- If you and your medical team decide to use **custom pressure garments**, they should be worn 23 out of 24 hours/day. Even though the use of pressure garments may not improve your scar, they can decrease itching and protect the skin from injury. Some burn survivors also feel that the pressure garments look better than the scars themselves.
- **Silicone gel sheets** are pieces of thin, flexible medical grade silicone that are placed over the scars and may decrease itching and dryness. They are generally durable and comfortable to wear. They can be worn alone or underneath pressure garments, splints, or casts. Some people find they are sensitive to silicone, so check your skin frequently for irritation or rashes.
- Your therapist may recommend **custom-made inserts** to be worn under gloves, compression bandages or custom garments to increase pressure on the scar and improve healing. These inserts can be made from a variety of substances, ranging from soft foam to a rubber consistency.
- **Massage can help soften and desensitize the scar.** When combined with stretching, massage can make the scar looser, softer, and more comfortable. Talk to your therapist to learn about specific massage techniques.
- **Surgical treatment including laser treatment may be an option** if scarring prevents you from performing certain activities. It is important to stay in contact with your treating burn physician for evaluation.

What can you do?

- Be actively involved in your recovery by asking questions and participating in decision-making about your care. Take a list of questions or concerns to your medical appointments for your health care provider to address.
- Always keep your skin clean and well moisturized.
- Keep up your exercise program as recommended by your doctor.
- Massage your scars with lotion to keep them moist, make them less sensitive and make your stretching easier. This may also prevent skin breakdown.
- It is important to follow your providers' instructions for using pressure garments, inserts, splints or silicone gel sheets. If they do not fit properly or if they cause problems such as pressure or skin breakdown, let your health care provider know right away.

The healing process can often seem long and frustrating for a burn survivor and his or her family. If you have concerns or questions about your healing process or treatments, contact your health care providers.

Additional Resources for garments and scar products: For more information regarding compression garments, wound care, and scar management products, please contact your doctor or therapist so that they can make recommendations based on your specific needs.



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Authorship

Scar Management After Burn Injury was developed by Sandra Hall, PT, Karen Kowalske, MD, and Radha Holavanahalli, PhD, in collaboration with the Model Systems Knowledge Translation Center.

Factsheet Update

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Sexuality and Intimacy After Burn Injury

March 2021

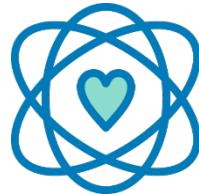
www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains how a burn injury may affect sexuality and intimacy.

Introduction

A burn injury can change the way your body looks, feels, and functions. In some cases, these changes in your appearance may be permanent. After a burn injury, the initial focus is on addressing your immediate, physical needs for survival. Once these needs are met and you are on a path to recovery, issues such as sexuality or intimacy may come up.



What Is Sexuality and Intimacy?

Sex and sexuality are important parts of everyday life. Sex refers to biological and physiological characteristics of your body, and is often used to refer to sexual intercourse. Sexuality refers to how you express yourself, your gender identity (the gender you feel you are), and your sexual identity (your desire for the opposite sex, same sex, or both).

Intimacy is a way to connect closely with oneself or another person on an emotional or physical level. Intimacy with oneself includes, for example, getting comfortable with one's own body via masturbation. You may have different types of intimate relationships; not all intimate relationships are sexual.



Sexuality After Burn Injury

People have different sexual desires and use different ways to express them. Defining what is typical or common is hard. It is whatever gives you and your partner pleasure. It is important to have an open line of communication with your partner to deal with your sexuality.

It is normal to have doubts and fears during this time of healing. These feelings are a natural response to returning to a life of sexuality and intimacy. You are not the only one to feel this way after a burn injury. Talking about body image, sexuality, and intimacy can be hard to do. Sexuality and intimacy are possible regardless of your burn injury.

This factsheet includes information on how changes in your body after a burn injury may affect sexuality and intimacy, suggestions for how to adjust to the changes, and other resources that may help you.

Physical Effects of Burn Injury on Sexuality and Intimacy

Burn survivors may have physical problems or limitations that affect sexuality and intimacy. Here are some things you can do:

- **Keep skin moisturized to lessen friction, blisters, or skin tears.** You may need to try different positioning during sexual activity or different forms of intimacy. After a burn injury, newly healed skin may be fragile and prone to shearing.
- **Good communication with your partner is important.** Newly healed areas may be sensitive to touch. Areas with skin grafts may have little or no feeling. Areas with nerve damage may be more sensitive or may have no feeling. Communicating to your partner about your trigger points may be helpful. It is important to know that it may take time through trial and error to find what works for you and your partner.



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- Consider trying different positioning or different forms of intimacy. Contractures or tightness that limits movement, amputations, surgeries, and general weakness may have a big impact on positioning during sexual activities.
- Talk to your doctor if you have lower energy or decreased desire. Most survivors of a severe burn injury have lower energy levels that may improve over time. Other issues that may affect stamina include changes in hormone levels, such as decreased testosterone or increased estrogen. Medicines – particularly those that treat depression and high blood pressure – can affect desire and stamina. They can also affect a man's ability to get or keep an erection or to ejaculate. Do not stop taking any medicines suddenly because of side effects. Talk to your doctor about other medicines. Ask about blood tests to check hormone levels and nutrition status that may help your energy level and stamina after burn injury.

Psychological Effects of Burn Injury on Sexuality and Intimacy

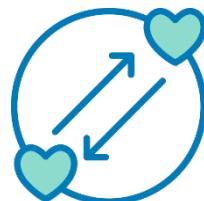
Burn survivors may also have issues with sexuality and intimacy that relate to their mental, social, and emotional well-being. They may have reduced sexual desire and function. This may be due to the following:

- **Body image effects:** You may have changes in body image. Some individuals describe feeling:
 - Distress, shame, embarrassment, or anger. You may also feel inferior.
 - Abnormal.
 - Anxious about hiding or showing burns.
- **Emotional effects:** You may have changes in your emotional health. These may include changes in your ability to accept changes and manage your feelings as you work through challenges. These feelings may cause:
 - Fatigue.
 - Lack of sleep or changes in sleep patterns.
 - Stress and fear about having sex.
 - Mood changes.
 - Anxiety, depression, and sadness.
 - Feelings of sadness about the changes in your body.
 - Use of drugs or alcohol.
 - Boredom with your sexual routine.
- **Role change effects:** You may have changes in roles and relationships after a burn injury that can lead to:
 - A sense of not being needed, or not having control over your life.
 - Feeling like you have lost your place in your home, school, or workplace.
 - Low self-esteem due to relying on others to get through the day or due to the difficulty to fill other roles, such as being a mother, a father, a husband, a wife, or a breadwinner.
 - Ending a romantic relationship or a marriage in separation or divorce.



How can you adjust to the changes in your body after burn injury?

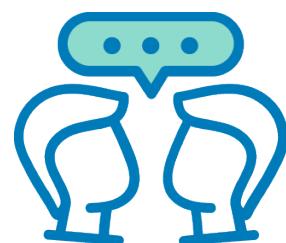
How can you help your partner adjust to these changes?



- You can show your interest in sex in many ways. You may want to have your partner sit or lie next to you. Just touching and holding your partner can be fulfilling. It's important to remember that you can touch, cuddle, and caress someone without needing to have an orgasm. Sometimes just feeling loved and secure without feeling the need to perform can be enough. Over time, you will become more confident and feel more comfortable with yourself and your partner.
- Take time to learn what you and your partner find enjoyable and exciting. The kinds of things you did before your burn injury may not work for you now. Try to be creative and open to finding new ways to explore sexual satisfaction.
- Be playful. Using humor when appropriate and having fun can make your romantic relationship more interesting and enjoyable for you and your partner.

- **Keep the lines of communication open.**

- **Think about how you feel and what you want to communicate.** This will require self-awareness and self-exploration to understand what you want or need sexually after your injury.
- **Talk about your needs and wants together.** Talking about sex can be hard. Talk about things in a way that makes you both feel comfortable and secure. It might be helpful to write about your needs. The goal is to work through issues and concerns together. Your health care provider may help you resolve physical problems and concerns. Don't be afraid to ask for help.
- **Take time to listen to each other.** Good communication takes work. Listen and be open to what your partner says. Listening to each other without judgment can help solve problems in ways that satisfy both of you. Pay attention to body language. Don't assume that something will be uncomfortable; ask.
- **Be flexible.** It may take time for you to become comfortable with each other again. You may have a few setbacks. For example, you may have issues with skin sensitivity, skin breakdown, or your energy level. You and your partner will learn to manage these issues as you continue to communicate, listen, and remain flexible.



How do you keep your romance alive if your partner is your caregiver?

Be patient. Try to keep the caregiver role separate from that of a lover. This will make it easier for you and your partner to appreciate each other when you want to be intimate and allow you to keep the passion in your relationship. Here are some other suggestions:

- **Be as self-sufficient as you can.** Do as much of your self-care and other daily living activities as possible. This will help to lessen the care you need from your partner. It will also help to bring your relationship closer to how it was before your burn injury.
- **Set aside time to have fun and go on a date where you can enjoy romance without caregiving.** Keeping these roles separate will help you to avoid confusion and mix-up of the different roles.
- **Show your appreciation for each other.** Burn care can be stressful for both the patient and the caregiver.
- **If you can, hire a caregiver.** Ask a family member or friend to help with some of the daily caregiving duties. If you don't have help, see if you qualify for intervention programs that can assist you. Contact your state vocational rehabilitation agency or your church. If you are a veteran, contact the Department of Veterans Affairs.

If you are single:

- You can still have a sex life.
- If you start a new relationship, it may be hard to tell a new partner about your burn scars, and that's okay.
- You may feel anxious about hidden scars being discovered. Take your time and when you are ready, have an open and honest talk with your partner.
- Fear of rejection in a romantic relationship may affect your self-esteem. It is important to have friends who support you and listen to you.

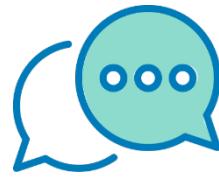
Whether you are single or currently in a relationship—Remember the following:

- Focus on your own needs, wishes, and desires.
- Explore and communicate what gives you and your partner pleasure.
- Your sexuality is about how you feel, and your feelings may change.
- You can change your mind about how you feel, find new things that are enjoyable, and relate to your partner in new ways.
- You can aim to feel good about who you are and how you choose to experience your sexuality and intimacy.
- It's common for sex to not be on your or your partner's mind, especially in the early stages of your recovery. Some people do not want to have sex or need to have sex and that's okay too.



Where can you go with questions?

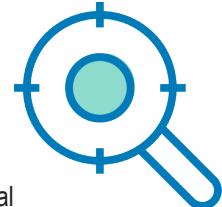
Talk to your health care provider about how the burn injury may have changed your body, your energy level, or your sense of touch. This factsheet is a starting point to help you and your partner understand that it is normal to worry about how your body may have changed after a burn injury. Each person is unique; some of your issues may be unique, too.



- Doctors who specialize in sexuality and physical and emotional trauma can help with your fears or problems. They can also give you correct information and talk openly with you. They can also make sure that you get the therapy, treatment, and information you need to help with any concerns you have about sexuality and intimacy. Your local burn center doctors can help you locate or refer you to the specialists.
- Your occupational therapist or physical therapist can be helpful as well. Occupational therapists can give you tips for how to position your body during sexual activity without causing harm or injury. Reach out to a counselor, psychologist, social worker, or sex therapist. They help people and couples identify and work through problems. They can also help you find resources.

Helpful Resources

- Your local burn center may have aftercare resources as well as events and programs to support you during recovery. For example, they may have peer support volunteers, burn survivor support groups, or survivor retreats.
- The Phoenix Society for Burn Survivors (<https://www.phoenix-society.org/>) has many resources in various formats. These include weekly chat sessions, online learning programs, workshops, and an Annual World Burn Congress.
- Factsheets and multimedia resources from the Model Systems Knowledge Translation Center on various topics related to burn injury such as *Understanding and Improving Body Image after Burn Injury*, *Social Interactions after Burn Injury*, and *Sexuality and Intimacy after Burn Injury*. Learn more at: <https://msktc.org/burn>.
- Find a provider who is familiar with sexuality topics and sexual concerns on the following websites:
 - Society for Sex Therapy and Research (STAR)—STAR is a community of professionals who have clinical and research interests in human sexual concerns. Use the link www.ssarnet.org/find-a-therapist.
 - American Association of Sexuality Educators, Counselors and Therapists (AASECT)—Search for a sexuality counselor or sex therapist in your area. Use the link www.aasect.org/referral-directory.
- Disability rights and activities organizations offer resources for sexuality for specific disabilities.



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Authorship

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Source: Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the Burn Model Systems.

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Sleep Problems after Burn Injury

October 2020

www.msktc.org/burn/factsheets

BURN Factsheet

This fact sheet explains the causes of sleep problems after burn injury and provides treatment options.

Introduction

Sleep problems occur in more than 50% of people who have had severe burn injuries. Insomnia is the most common type of sleep problem. Insomnia can take many forms, including:

- Difficulty falling asleep.
- Difficulty staying asleep.
- Poor quality sleep.
- Waking too early.
- Nightmares.

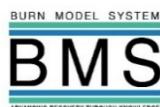
Sleep problems are especially common right after burn injury and during the healing and recovery stages. Insomnia can come and go over the years and may require different solutions at different times. Everyone has a different experience after burn injury, and some of the following information may not apply to you.

Causes of Sleep Problems after Burn Injury

Many factors can disturb sleep after burn injury. Some may continue to affect you long after leaving the hospital and healing.

- Anxiety and post-traumatic stress disorder (PTSD), including fear of falling asleep to avoid nightmares or to remain on the alert against threat.
- Depression.
- Constantly thinking about the burn event.
- Pain.
- Itching.
- Many medications prescribed to treat any of the above problems can also disturb sleep.
- Burn injury can change hormone levels and other chemicals in the body that regulate or affect sleep.
- Sleep apnea (pauses in breathing during sleep)—symptoms include day-time sleepiness, snoring, and agitation.
- Contractures caused by scar tissue—this can limit the ability to move and get comfortable.
- Difficulty breathing, if the respiratory passages (nose and throat) were affected by the burn injury.
- See your health care providers regularly and follow through with treatment. Success with getting back to work requires active participation on your part.

The Burn Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <http://www.msktc.org/burn/model-system-centers> for more information).



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Poor Sleep Can Cause Serious Problems

It is important to get treatment for poor sleep because it can be harmful in a number of ways. It can be extremely distressing and debilitating, and actually interfere with your recovery from the burn injury. Poor sleep can:

- Make pain worse
- Slow down wound healing.
- Cause restlessness, irritability, and changes in behavior.
- Cause problems during the day such as:
 - Low mood or depression.
 - Trouble handling stress.
 - Lack of energy.
 - Difficulty concentrating.
 - Increased risk of accidents.

Role of Melatonin

Melatonin is a natural hormone made by your body that is released into your blood stream to trigger sleepiness. A decrease in light signals the body to release this hormone. The light from electronic screens (blue light) such as that from your TV, computer, smart phone, or electronic books can interfere with the production of melatonin. These devices should be turned off at least one hour before bedtime. Melatonin can also be taken by mouth to promote sleep. Talk to your doctor about this treatment option.

Treatment Options

There are many different approaches to solving sleep problems. The choice of treatment depends on the cause, type, and severity of the problem as well as your stage of recovery from burn injury. Your doctor or medical team may talk to you about your past sleep habits and other factors that affect sleep in order to better understand your sleep problems. If necessary, your doctor may refer you to a sleep specialist.

Treatments That Do Not Involve Medications (also called behavioral or nonpharmacological treatments)

Good Sleep Hygiene

- Sleep hygiene is the practice of following sensible guidelines for promoting regular, restful, good-quality sleep.
- Daytime naps can disrupt normal sleep patterns. Naps may be needed in early stages of recovery, but should gradually decrease as your health improves.
- If naps are needed, they should be at the same time every day and last no more than 30 minutes.



- Maintain a regular time for getting up in the morning, regardless of when you fell asleep. If you have trouble falling asleep after 15 minutes, you should get out of bed and do something else (reading, word puzzles, listening to music) until you get sleepy.
- Do not go to bed until you are tired. Establish a consistent bedtime routine to cue your brain that it is time for sleep.
- Avoid stimulant-containing drinks, food, and drugs in the late evening. Caffeine is in many soft drinks, chocolate, candy, coffee, and bakery products.
- Steer clear of stimulating activities late in the evening, such as surfing the Web, watching exciting or frightening movies, or playing video games.
- Start increasing physical activity and exercising regularly as soon as your doctor says it is okay. Exercise is especially helpful if you suffer from anxiety as well as trouble sleeping.
- Vigorous exercise should be done earlier in the day, at least 6 hours before bedtime.
- Mild exercise should be done at least four hours before bedtime.
- Don't go to bed hungry, but avoid large meals close to bedtime. If you have trouble staying asleep, a light snack an hour before bedtime may help you sleep through the night.
- Alcohol can cause you to sleep poorly. Also, alcohol can be dangerous if you are already taking medications that make you drowsy. Ask your doctor if it is safe for you to drink alcohol.
- Avoid smoking or using other forms of nicotine close to bedtime. Nicotine is a stimulant.

Stimulus Control

If trouble falling asleep goes on for a long period of time, sometimes people develop a “habit” of thinking they won’t fall asleep, and these thoughts keep them awake. Stimulus control can help “re-program” you to associate the bedroom and bedtime with only sleep-promoting (calm and pleasant) activities rather than failure to fall asleep.

Guidelines for stimulus control:

- Go to bed only when sleepy.
- Set a regular wake-up time, no matter what time you actually fall asleep the night before.
- Get out of bed whenever you are awake for longer than 15-20 minutes.
- Avoid reading, watching TV, eating, or worrying in the bed and bedroom.
- Do not nap during the day.

Relaxation Training

Relaxation techniques reduce anxiety and tension at bedtime to help you fall asleep. They can also be used to fall back asleep if you awake in the night. There are several techniques.

- Progressive muscle relaxation
- Meditation training



- Imagery training
- Biofeedback
- Hypnosis
- Yoga

For any of these methods, a practitioner will teach you the formal steps or exercises involved. These methods are most successful when practiced regularly at home. Apps can also be downloaded onto a smart phone or tablet that promote sleep by using relaxing sounds, relaxing music, or even sleep casts or sleep stories. Many of these apps are free.

Cognitive Behavioral Therapy (CBT)

Cognitive behavioral therapy for insomnia (CBTi) teaches sleep hygiene, employs stimulus control techniques, and trains in relaxation methods/practices. In addition, sometimes people with sleep problems develop thoughts and beliefs about sleep that keep them from falling asleep. Examples of such thoughts include “I will never be able to fall asleep,” or “I will not be able to function tomorrow since I cannot fall asleep,” or “I cannot sleep well without alcohol.” A cognitive behavioral therapist can work with you to address and eliminate the thoughts that may be keeping you from being able to fall asleep.

Light Therapy

Our body's chemicals and hormones vary in a natural 24-hour cycle that promotes sleep or wakefulness at certain times. If this natural cycle (called “circadian rhythm”) gets disturbed for any reason, sleep problems can occur. Light therapy uses exposure to daylight (or “light boxes” that mimic daylight) to “reset” the circadian rhythms for sleeping and waking.

- Different ways to do this are using light boxes in the morning, taking daytime walks outside, or using light machines called “dawn stimulators” that mimic a gradual sunrise.
- Light therapy is often used along with sleep hygiene.

Medication (Pharmacologic) Treatment

There are effective medications that can help you sleep better. These may include sleep aids, antidepressants and/or anxiety medications. They can be used alone or in addition to one of the above approaches to improve sleep. As with any medications, it is extremely important to take medications for sleep only as your doctor has prescribed and discussed with you. This includes over-the-counter sleep medications.



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Authorship

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Factsheet Update

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Social Interaction After Burn Injury

June 2019

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains challenges with social interactions after burn injury. It describes some strategies you can use when meeting new people or going into new social, work, school, or public situation.

Some burn injury survivors have changes in their appearance. They may worry about how people will react to them when they leave the hospital and go out in public.

Understanding challenges with social interactions

Some of the social challenges that burn survivors face after they leave the safe zone of the hospital and return to their communities include

- Stares, startled glances, or double-takes;
- Nosy questions or comments about their injury; and
- Bullying and teasing.

If your burns show, everyday activities like going shopping or taking a bus or the subway may involve being stared at and having to deal with people's curiosity. If your burns are hidden, you may worry about how people will react when they are exposed, such as when you take off your shirt at the beach.

The way people react can make it hard to feel confident during social interactions. People may react verbally, with words. People may also react nonverbally, through body language or gestures. Some burn survivors aren't bothered by the reactions of others. But you may find it helpful to learn skills to face these challenges.

Do you sometimes feel uncomfortable in social situations?

Some burn survivors may avoid social situations because they think that people may react to their appearance. Other burn survivors may

- Feel nervous or on edge when they meet new people or when they're with strangers;
- Feel isolated and alone; or
- Feel emotional distress, including depression.

Finding help to improve social interactions

If you feel nervous or on edge in social situations, you can learn skills to help you gain control, comfort, and confidence. Some resources that may help include:

- Members of your burn team can talk with you and provide resources to help you.



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- The Phoenix Society for Burn Survivors has a peer support program called Survivors Offering Assistance in Recovery (SOAR) for burn survivors and their loved ones. This one-on-one program connects people with new burn injuries to other survivors and family members who can share their experiences and offer support.
- The Phoenix Society also offers an online learning program called Beyond Surviving: Tools for Thriving After Burn Injury. This program teaches strategies to help you gain control, act and feel comfortable, and confident.
- The Phoenix Society also offers a weekly peer support chat. This live chat is held on Wednesday nights from 9:00 p.m. to 10:30 p.m. (EST). It covers common concerns and questions facing burn survivors and their loved ones. See <https://www.phoenix-society.org/?modal=what-we-do> for more information.

It's okay to feel nervous when interacting with people after a burn injury. Here are some strategies you can use when meeting new people or going into new social, work, school, or public situations. In all social interactions, it's helpful to act positive and use confident body language.

The "STEPS" strategy may help you feel more confident when facing old or new social, work, and school situations. It was developed by Barbara Kammerer Quayle, a burn survivor.

- **Self-talk**—This is what you say to yourself and believe. Examples include "I love and accept myself the way I am and the way I am not," "I meet people easily and feel comfortable with them," and "I can do it!"
- **Tone of voice**—Use a friendly, warm, and enthusiastic tone of voice.
- **Eye contact**—Look people in the eye, even if just for a few seconds.
- **Posture**—Have a confident posture. Keep your head up, your rib cage lifted, and your shoulders back.
- **Smile**—A smile makes you look confident and approachable.

Ways you can respond when others react to you

If someone stares at you

People who stare are often just curious because they haven't seen someone with a burn injury. They usually don't mean to be rude. If you look back and smile and say, "Hi" or "Hi, how are you doing?" the staring usually stops. Always use your STEPS to look confident and comfortable.

If someone asks what happened to your burn injury

When strangers ask about your burn injury, remember that you are in control. You can offer as much or as little information as you want. You don't owe strangers the whole story of your burn injury experience.

Rehearse your responses. This requires writing and then saying three short sentences about your injury, smiling at the person asking, and walking on. For example:

- I was burned in a house fire.
- I am doing better now, or I am still recovering.
- Thanks for your concern, or thanks for asking.



Write and rehearse three sentences that feel just right for you and use this tool when people ask questions.

Respond in a positive way.

Change the subject if you don't want to continue to talk about your burn.

Use humor when appropriate to lighten the moment.

You can find more information about the Rehearse Your Responses strategy at <https://www.phoenix-society.org>. Look for: Find Resources/Beyond Surviving Tools for Thriving.

If someone teases you:

- Stand up straight and hold your head high.
- Count to 10 slowly and stay calm.
- Shrug your shoulders, act bored, smile, and walk away.
- Say to the teaser, "I'm wondering why you would say something like that?" or "you must be pretty insecure to pick on other people." Shrug your shoulders and walk away.

Social Skills Training

Social interaction skills training programs may also help you

- Get ready for social situations after you leave the hospital
- Understand what goes on in social interactions
- Practice effective ways to manage social interactions

Two well-known social interaction skills training programs are described below.

- Beyond Surviving: Tools for Thriving After a Burn Injury," (<https://www.phoenix-society.org>) which is available through the Phoenix Society and described in this factsheet
- The **3-2-1-GO! strategy**—This program was developed by James Partridge (<https://www.changingfaces.org.uk>). It includes
 - Three things to do if someone stares at you
 - Two things to say if someone asks what happened
 - One thing to think if someone turns away

Resources

The Phoenix Society, Inc.
525 Ottawa Ave NW, Front
Grand Rapids, MI 49503

(800)888-2876 or (616) 458-2773
info@phoenix-society.org

Changing Faces The Squire Centre
33-37 University Street London, WC1E 6JN
<https://www.changingfaces.org.uk>

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Authorship

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Sun Protection After a Burn Injury

September 2018

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains the importance of sun protection as you recover and heal from a burn injury. It describes how sun exposure affects your skin, ways to limit sun exposure, and offers resources to learn more about protecting yourself.

The sun has many beneficial properties, but the sun emits three types of ultraviolet (UV) light that can harm skin and has been linked to skin cancers (basal and squamous carcinoma, melanoma) and vision problems (cataracts and macular degeneration). Healed burns, donor sites and skin grafts are more sensitive to sunlight.

Your Burn Injury and Sun Exposure

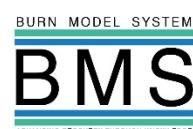
Burn skin sensitivity. Healed burns or skin grafts may be extremely sensitive to sunlight and may sunburn more severely even after short periods of time in the sun compared to before your injury. Sun sensitivity after a burn injury may last for a year or more. In addition, some medications can cause you to be more sensitive to the sun.

Pigmentation. The color of our skin is related to the amount of melanin that each of us has in our skin. When someone has a second degree or deeper burn injury, the pigment of the skin is affected because melanin is located in the epidermis (the outer most layer of skin). With a burn injury, that pigment is lost. With healing, the pigment may return, but this process is unpredictable. Often, newly healed skin appears pink and unpigmented. As the scar matures, the skin may regain pigment. The deeper the burn wound, the slower the re-pigmentation process. We cannot predict if there will be a color difference once the healed skin has matured. Some people will have lighter skin (called hypo-pigmented) and some, darker (called hyper-pigmented).

The Burn Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <http://www.msktc.org/burn/model-system-centers> for more information).

Because re-pigmentation can be affected by UV light (sunlight), suntans in newly healed skin may not fade when the rest of the tan goes away. For a burn that needs a skin graft to heal, the grafted area may become darker than the surrounding uninjured skin. The reason for this is not clear, but sun protection is encouraged to prevent pigment changes that may result in permanent, darker skin coloring within the burn wound for at least one year after a burn injury.

People with dark skin. Even if you have never had issues with sun exposure or sunburn in the past, your areas that were burned or skin grafted are now susceptible to sun burn and pigmentation changes.



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Heat stroke/ Dehydration. Your body uses sweat glands as a way to cool itself when overheated. Sweat comes out of your pores and cools your body as it evaporates. In deep second degree burns or burns that required a skin graft, your healed skin may not have sweat glands, and your ability to sweat may be limited. People with large burn injuries who do not sweat normally might have an increased risk for heat exhaustion or heat stroke with exposure high temperatures or physical exertion. Heat exhaustion or stroke happens when your body overheats. Symptoms of heat stroke include: throbbing headache, dizziness, feeling light-headed, nausea/vomiting, lack of sweating despite the heat. You might also become dehydrated. Dehydration happens when your body does not have as much water as it needs. If you feel like you are overheating, move to a cooler temperature or into the shade and drink cool water or a sports drink.

How can you protect your skin from exposure to the sun?

Returning to your normal activities (e.g., walking outside, hiking, swimming, biking, gardening) after a burn injury is important and strongly encouraged. However, if you plan to be outside for long periods of time, using all methods of sun protection is the best way to protect your skin. Dermatologists (skin doctors) recommend using a combination of sun avoidance, protective clothing, and sunscreen/sunblock to limit sun exposure and to combat sun damage.

Sun Avoidance

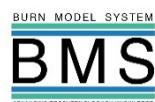
It is nearly impossible to stay out of the sun and be active. But you can choose when you are outside. The sun is strongest from 10 a.m. to 4 p.m. or when your shadow is shorter than your height. Don't let clouds fool you. Up to 80% of harmful UV sunrays can penetrate clouds. Also, keep in mind that UV rays reflect off sand, water, snow, and ice. Certain types of UV light are stronger at higher altitudes. Thus, limiting peak sun exposure and being aware of your environment are key to preventing sun damage to your skin. Seek shade when you are outside.

What about tanning beds? Tanning beds should be avoided, as they emit the same amount (if not more) cancer-causing UV light. And they will cause pigmentation that might not fade.

Protective Clothing

Protective clothing is a good way to protect yourself and your healed skin from the sun. It is important to know that not all fabrics and clothing are protective. When choosing clothing as a means to provide protection from harmful UV rays, consider the following:

- The tighter the weave of the fabric, the better the protection. For example, fabrics such as denim and wool have a tighter weave and provide better protection than lighter fabrics like linen.
- Loose clothing tends to provide better protection than tight or stretched clothes.
- Wet fabrics provide less protection than dry fabrics.
- Synthetic and semi-synthetic materials tend to provide better protection than bleached or refined cottons.
- Dark clothing provides better protection.
- Specialized, sun-protective clothing made from fabric that has been embedded with chemicals that deter or absorb harmful UV rays is increasingly available at sporting stores and online. An Ultraviolet Protective Factor (UPF) rating system that is listed on the tag describes the degree of protection the clothing provides against UV light. Specialized clothing with ratings of UPF 30 or higher is recommended.



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Other Protective Wearable Options

Other types of protective options include wearing sunglasses and wide-brim hats. Recommendations include:

- Sunglasses with 99–100% UV protection that completely cover the eyes and eyelids.
- Hats should have at least a 3-inch brim all the way around to protect the neck, ears, and face. Baseball caps do NOT provide adequate protection for facial and neck burns.
- Hats with a neck flap option have better coverage of the neck.

Sunscreens

Sunscreens are a third line of defense. Keep in mind that sunscreens should be used TOGETHER with protective clothing and sun avoidance. A sunscreen's ability to protect you against a sunburn is measured by a number called SPF or Sunburn Protection Factor. SPF refers to how long it takes for skin with sunscreen to burn compared to skin without sunscreen. Generally speaking, the higher the SPF number, the greater protection against sunburn.

Sunscreens come in multiple forms: gels, sprays, creams, and sticks. Gels tend to work best on hairy areas, while creams work best on the face and dry skin. Sticks work well around the eyes and lips. FDA regulations and standardizations do not apply to spray sunscreens; it is important that the spray covers all exposed skin, is not inhaled or used near a heat source, while smoking or near an open flame. Some sunscreen products contain alcohol, which can be drying to recently healed skin or grafted areas. Sunscreens are also available within face creams and make-up (e.g., foundations). Although convenient, they must be applied frequently to achieve the most sun protection. Some insect repellents also contain sunscreen. The American Academy of Dermatology recommends that insect repellent be applied separately from sunscreen, as the repellent should be applied minimally and sparingly, while sunscreens require generous and frequent applications.

What is the difference between a sunblock and sunscreen? Sunscreens are more common and they filter or screen the sun's ultraviolet rays. They keep most rays out but do let some in. A sunblock reflects the sun's rays and is considered a physical barrier. Most sunblocks use titanium dioxide or zinc oxide, which can make them thicker and somewhat opaque (not transparent) when applied to the skin. Many products commonly referred to as sunscreens combine agents. The American Academy of Dermatology does not recommend one type over the other as long as the product protects your skin from *both* UV-A and UV-B sun rays, has a SPF of 30 or higher, is water-resistant, and is applied according to the directions on the bottle.

Can I use a suntan lotion instead? No. Often the SPF levels in a suntan lotion are only 4 or 5, which is *not* enough to protect your skin from the sun.

Many studies have shown that people apply sunscreen incorrectly, resulting in inadequate protection. The following tips regarding sunscreen use will help you avoid a sunburn and sun damage:

- Apply sunscreen every day, all year, even on overcast or cloudy days.
- Use a sunscreen with SPF 30 or greater.
- Use a broad-spectrum sunscreen to protect you from both UV-A and UV-B light.

- Use water-resistant sunscreens.
- Generally one handful of sunscreen covers all uncovered areas of your skin.
- Keep babies out of direct sunlight. The American Academy of Pediatrics recommends using sunscreen on infants for small areas such as the face and back of the hands where protection from clothes is inadequate. Generally, products with zinc oxide or titanium dioxide are less irritating.
- Apply sunscreen 30 minutes before going outside to allow the sunscreen to absorb into your skin.
- Reapply sunscreen every 2 hours and immediately after swimming/sweating heavily/drying yourself with a towel. This also applies to the use of water-resistant sunscreens.
- Cover your lips with a sunscreen-containing lip balm of SPF 30 or greater and reapply frequently. Avoid petroleum jelly-based products that do not include sun protection.
- Don't forget about your ears, feet, back of your hands, neck, and bald spots when applying the sunscreen.
- Sunscreen designed for the face usually does not clog pores and cause pimples and may be better than other sunscreens.

Frequently Asked Questions About Sunscreen Use

- *Will it ever be safe for me to wear short sleeves again?* We understand that in hot weather long sleeves and pants can be uncomfortable. Short sleeves and bathing suits are OK if you are careful about using sunscreen and limiting how much time you spend in the sun.
- *What should I do if I have a reaction (like a skin rash) to sunscreen?* Stop using the product immediately and try another one with different ingredients. Talk to your doctor or healthcare provider if the reaction persists.
- *How long is my bottle of sunscreen good for?* Based on FDA reports, sunscreens are typically good for 3 years. Many sunscreens will have an expiration date on the bottle. If there is no date, write the purchase date on the bottle and discard after 3 years. If the consistency or texture of the sunscreen changes, discard the bottle.
- *What is a PABA-free sunscreen?* PABA is the abbreviation for para-aminobenzoic acid and related chemicals. PABA-containing sunscreens was an UV-B absorbing type of sunscreen used in the early 1940s. Since then, PABA has been removed from most sunscreens due to reports of allergies and reactions. PABA-free sunscreens do not contain PABA or any related chemicals.
- *Does a higher SPF sunscreen work better than a lower SPF?* No sunscreen blocks 100% of UV sun rays. SPF 30 blocks 97% of UV light when used appropriately. The increased SPF does not imply that you can use a smaller amount or apply it less frequently. All sunscreens should be applied generously every two hours or as directed on the bottle, no matter the SPF number.
- *Can sunscreens cause cancer?* Recent studies have shown no link between sunscreen use and melanoma (a form of skin cancer).
- *Are sunscreens toxic?* Sunscreens undergo extensive testing to ensure that they do not cause harm to humans. The safety of the chemicals used is based on studies with humans but not specifically with people who have experienced a burn injury.

- *Do sunscreens cause Vitamin D deficiency?* Sunscreens theoretically prevent Vitamin D formation because they block the UV-B light rays that are needed to form Vitamin D. However, no studies have shown any physical consequence or difference in Vitamin D levels of people who use sunscreen when compared to people who do not use sunscreen. We encourage a healthy diet that is rich in Vitamin D (fatty fish, cheese, egg yolk, fortified milk and yogurt, beef liver).
- *Am I more susceptible to skin cancer after a burn?* There is no good information about risk of skin cancer with healed burn wounds.
- *When should I be concerned about skin cancer?* From the American Academy of Dermatology, you should “check your birthday suit on your birthday” for skin changes or itchy or bleeding skin. If you have a burn wound that does not heal or breaks open often you should see your doctor or health care provider.

Other resources:

- Phoenix Society Website: <http://www.phoenix-society.org/resources/entry/enjoy-sun-care>
- American Cancer Society Website: <https://www.cancer.org/cancer/skin-cancer/prevention-and-early-detection.html>
- Skin Cancer Foundation: <http://www.skincancer.org/prevention/sun-protection/clothing/clothing-our-first-line-of-defense>
- FDA Fact Sheet: Tips to Stay Safe in the Sun: From Sunscreen to Sunglasses: <http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm049090.htm>
- American Academy of Dermatology: Sunscreen FAQs: <https://www.aad.org/media/stats/prevention-and-care/sunscreen-faqs>
- U.S. Environmental Protection Agency: Sunscreen – The Burning Facts: <https://www.epa.gov/sites/production/files/documents/sunscreen.pdf>

Authorship

Sun Protection After Burn Injury was developed by Gretchen J. Carrougher MN, RN; Nicole S. Gibran, MD; Maria Caceres, BSN, RN, and Cathie Cannon RN in collaboration with the Model Systems Knowledge Translation Center.

Source: Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the Burn Injury Model Systems. Because there is limited research on sun exposure following a burn injury, this fact sheet was developed based on studies and information for the general population.

Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this fact sheet were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this fact sheet do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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Understanding a Burn Injury

February 2018

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet offers important details about burn injuries to burn patients who are admitted to hospitals. This content may also be helpful to the family members and friends of burn patients.

The Burn Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/burn/model-system-centers> for more information).

What is a burn injury?

A **burn injury** most often damages layers of skin. Deeper burn injuries may damage tissue (fat and muscle), or even bone.

What are the main causes of burn injuries?

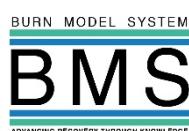
Burn injuries can happen in many ways. Common examples are:

- **Flame:** contact with fire or flames
- **Flash:** resulting from the heat of an explosive blast
- **Scald:** contact with hot liquids or hot steam
- **Grease:** contact with hot grease
- **Contact:** prolonged contact with something hot
- **Electrical:** electricity passing through the body and heating the skin and underlying tissue
- **Chemical:** contact with chemicals, such as acid or alkalis

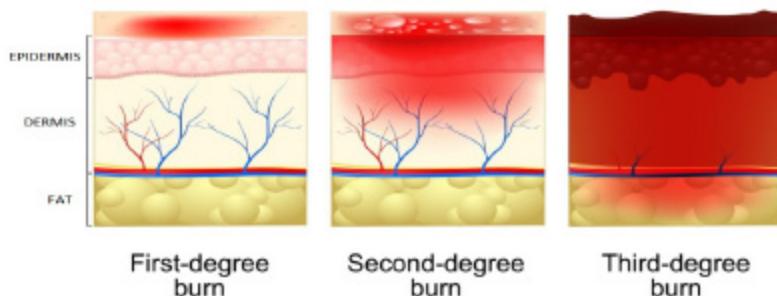
What are the different degrees of burn injury?

Clinicians measure depth of burns in degrees:

- **First degree** burns are the mildest type of burn. They are also called superficial burns. First degree burns damage only the epidermis, which is the first layer of skin. First degree burns usually don't get infected or leave a scar. The skin may get red but won't break, and they heal within 3–5 days.
- **Second degree** burns are also called partial thickness burns. This type of burn damages the epidermis and the dermis. The dermis is the second layer of skin. Second degree burns are painful. The injured area can swell and appear red with blisters. The damaged skin usually grows back unless it becomes infected or the injury gets deeper.
- **Third degree** burns are also called full thickness burns. This type of burn goes through the epidermis and dermis and affects deeper tissues, which may also be damaged or destroyed. The injured area can appear charred and may be black, white, or deep red in color. This area is often numb to light touch. Third degree burns don't heal by themselves, so skin grafting is often necessary (discussed later).
- **Fourth degree** and deeper burns destroy the skin plus fat, muscle and sometimes bone.

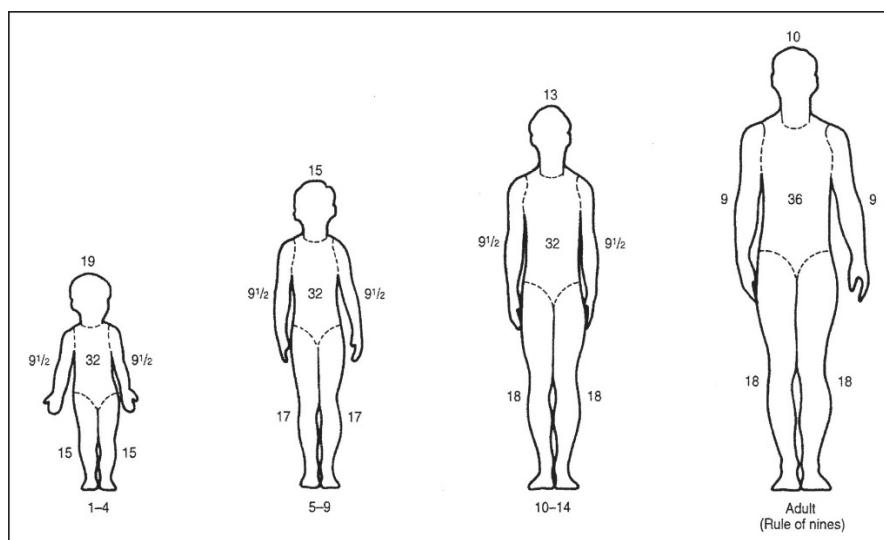


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How is the size of the skin burn estimated?

Total body surface area (or TBSA) burned is the percent (%) of the body that is burned. To estimate burn size, clinicians use a formula that considers the age of the injured person and a diagram called the Rule of Nines (shown below). This is the most common way to estimate burn size. First degree burns are not included in the calculation of percent TBSA burn.



Can lungs be burned?

When breathed in, smoke or toxic gases can harm the lungs. Clinicians call this an **inhalation injury**. This type of injury often occurs when the injured person is trapped in an enclosed area for a long amount of time. Damage depends on the type of gas and smoke particles inhaled and on length of exposure.

How is the severity of the burn assessed?

Clinicians consider many factors to determine the severity of a burn injury:

- **Degree** (depth) of the burn,
- **Size** (percentage) of the skin that is burned, and
- **Age** of the injured person
- **Other factors** include:
 - Location of the burn on the body,
 - Inhalation of toxic gases or smoke,
 - Type of burn,
 - Other traumatic injuries (bone fractures), and
 - Other health issues (such as diabetes, heart problems, or alcoholism).

What are skin grafts and donor sites?

Skin grafts are thin layers of skin that surgeons take from an unburned area and then surgically place on the burned area. The area where the skin is taken from is called the donor site. Common donor sites are the thigh and the back but may be taken from any uninjured area of the body other than the face. The donor site generally takes about two weeks to heal.

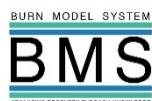
What are the different types of skin grafts?

Surgeons consider many factors when deciding what type of skin graft to use. They look at the condition, thickness, and size of the wound and where the injury is on the body.

- **Autografts** are permanent skin grafts that replace burned skin. With this graft, surgeons remove skin from one place on the body and place it on the burned area of the body. There are two types of autografts:
 - **Split-thickness skin graft** involves removing the epidermis and a shallow layer of the dermis and then placing it on the burned area.
 - **Full-thickness skin graft** involves removing the epidermis and dermis and placing it on the burned area.
- **Allografts and homografts** are temporary grafts to cover the wound. Donor skin comes from another person (usually a cadaver).
- **Xenografts** are temporary grafts to cover the wound. Donor skin comes from a pig.
- **Meshed grafts** are grafts in which donor skin is perforated with small slits or holes. Surgeons can then expand the mesh to cover a large burned area of the body. All four types of grafts can be meshed.
- **Sheet grafts** are grafts that are placed on the wound directly from the donor site without being meshed.

What about infection?

Burned areas can get infected, at the time of the injury and during the healing process. To prevent infection, people with burn injuries should follow the treatment orders of their health care team. They should also follow the hospital's infection control guidelines, such as using gloves and gowns when recommended. Practicing good hand hygiene (clean hands) can help prevent infection. This applies to both the injured person and their family members, friends, and caregivers.



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What about nutritional needs?

Eating well is a key part of the recovery process. Healing from a burn injury requires more calories and protein than healing from other types of injury. **Nutritionists** may be available to provide information about a well-rounded diet.

What about mental health?

It is common to feel anxious or upset after a traumatic injury. Burns can put tremendous stress on the patient and family. Burn teams include psychologists and psychiatrists who can help with feelings and concerns. **Psychiatric and psychological services** address issues like depression, anxiety, post-traumatic stress, addiction, and sleep problems. **Social services** can help families with managing housing, finances, and navigating the healthcare system.

What about rehabilitation?

- **Rehabilitation** is the process of using education and therapy to help a patient reach his or her maximum potential for recovery after an injury. Rehabilitation may also include physical therapy or occupational therapy. Physical therapy treats physical impairments. It aims to improve a person's ability to walk and move, do daily tasks, and live independently. Treatment may include exercise, splinting, bandaging, medicine, and use of assistive devices (such as crutches or walkers), massage, and joint mobilization.
- **Occupational therapy** uses everyday activities and materials to help patients in their own recovery. For example, a patient could practice dressing, bathing, and feeding themselves or cooking.
- **Speech-Language Pathology** helps with swallowing, voice, cognitive issues, and communication.

Several types of facilities provide rehabilitation services to patients with burn injuries.

- **A burn center** often provides intensive physical and occupational therapy during acute hospitalization. The burn team will also follow the patient long-term, prescribing additional therapy if needed.
- **An inpatient rehabilitation facility** is a specially designed medical rehabilitation facility. Patients stay at the facility full-time after discharge from the burn center and must be able to do at least 3 hours of therapy per day.
- **A skilled nursing facility** is a place where patients may go after they leave the burn center. Patients live in these facilities and receive medical and nursing care to help them recover.
- **An outpatient rehabilitation center** is a medical facility that provides physical and occupational therapy services to people who are living at home.



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What should patients expect?

The recovery process differs for everyone. Most patients report feeling pain, fatigue, and itching during recovery and rehabilitation.

- **Pain** is common. Third degree burns are painful with deep pressure. Second degree burns are painful with air movement or changes in temperature. First degree burns are painful on the surface of the skin. Health care providers treat pain in different ways.
- **Fatigue** is common. The more severe the burn injury, the greater the level of fatigue.
- **Itching** is a common part of the healing process. Moisturizers and antihistamines can help make the burned area less itchy. Patients should never scratch their wounds.

Patients may have a tough time dealing with these symptoms. But health care providers can offer at least some relief. Patients should always let health care staff know how they feel. *Space is provided at the end of this factsheet for patients and family members and friends to write down questions.*

What can family and friends do when a loved one is injured and hospitalized?

In addition to care from medical staff, patients can also draw support from family and friends. Visitors and caregivers play an important role during the recovery process. It is important for family members and friends to also take care of themselves (for example, housing, food, and care of children). It can be helpful to coordinate visiting times amongst friends and family members.

Family members should also assign one person to be the main point of contact with medical staff. This person should be an adult who is available to talk with the burn team.

What resources are available?

Factsheets about burn injuries are a great source of information. Factsheets from the Burn Model System discuss many topics related to burn injury, such as sleep problems, body image, social interactions, and nutrition.

Factsheets are available online (<http://www.msktc.org/burn/factsheets>) in English and Spanish. **Videos** are also available online (<http://www.msktc.org/burn/videos>). They cover exercise and employment after a burn injury.

Feeling anxious and afraid is common after a traumatic injury. Several local and national support systems offer support and suggestions about burn injuries. Patients and family members and friends should ask the health care team about options for support systems.

For example, the Phoenix Society for Burn Survivors (<https://www.phoenix-society.org/>) is a national **peer support** system. This group is made up of burn survivors and their family members. They are trained to offer support and can schedule a visit and share their recovery process. The Phoenix Society offers a support program in more than 60 hospitals and burn clinics throughout North America.



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Questions for the burn team

Use the space below to write down questions about the burn injury, treatment options, concerns about hospital care, and anything else to ask the health care team.

Authorship

Understanding a Burn Injury was developed by Laura C. Simko, BS, Boston-Harvard Burn Model System; Emily A. Ohrtman, BA, Boston-Harvard Burn Model System; Gretchen J. Carrougher, MN, RN, Northwest Regional Burn Model System; and Nicole S. Gibran, MD, FACS, Northwest Regional Burn Model System, in collaboration with the Model Systems Knowledge Translation Center.

Source: Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the Burn Injury Model Systems.

Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider about specific medical concerns or treatment. The contents of this factsheet were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082). The contents of this factsheet do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the federal government.

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Understanding and Improving Body Image After Burn Injury

July 2017

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains issues of importance for burn survivors concerning body image and practical strategies for use in social situations.

Major burn injuries can change how the body looks and works. Burn injuries can also lead to body image concerns. Body image refers to how happy, comfortable, and confident a person is with how he or she looks. About one-third of burn survivors have severe distress about changes in the way their body looks, feels, and works when they are first hospitalized. Almost everyone has ups and downs as they heal. But most children and adults get used to the change in their appearance over time.

What causes body image concerns?

Many factors may cause body image concerns after a burn injury. These include how a person feels about his or her burns; flawed coping strategies; and a person's gender, mental health history, and support network. Body image distress may involve

- Grief or sadness about changes in appearance and physical abilities,
- Anxiety about social or intimate settings where scars may be seen,
- Anxiety about actual and expected questions and stares from people in the community,
- Worry about how people will react when they see the scars, and
- A desire to be with a trusted person when in public places.

These feelings are normal. The following sections describe ways you can ease this distress and feel more positive about your body.

Phases of healing

After a burn injury, your skin goes through several phases of healing. During each phase, it's important to follow the advice of your burn team to improve how your skin heals.

Wound Healing Phase

What you see: Lighter colored skin replaces open wounds. For darker skinned people, pink colored skin may replace the burn wound at first and then lessen with time. Generally, the faster a wound heals, the less scarring will occur.

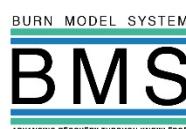
What you can do: Get involved with your wound care as much as possible, such as helping with the dressing changes. A cleaner wound heals faster. The more aware and involved you are with your wound care, the more likely you are to take good care of your burn.

Scar Formation Phase

What you see: After the wound heals, the skin changes over the next 3–4 months. It becomes darker, stiffer, and raised.

What you can do: Scarring can be a problem because of how it looks. Scarring can also make skin stiff and painful.

- Work with the rehabilitation team to lessen scarring. Your team may tell you to wear pressure garments or splints, massage the scar, or do stretching exercises.
- Protect your healing skin from the sun.



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Scar Maturation Phase

What you see: Scar maturation can take up to 1–2 years. During this process, the scarred skin gradually returns to a more normal skin tone. It also becomes softer and flatter.

What you can do:

- The rehab team may tell you to keep wearing pressure garments or splints. The team may also tell you to keep massaging the scar and doing stretching exercises.
- Continue to protect your skin from the sun.
- Ask for help from people trained in using makeup or clothing to make scars less obvious. Some makeup techniques and clothing styles and colors can help improve the appearance of scars. The Phoenix Society has a referral service to help you find a makeup or hair replacement specialist in your area. For more information, visit:
<https://www.phoenix-society.org/resources/creative-cosmetics-for-burn-survivors>.
- You may want to meet with a plastic surgeon who is trained in burn reconstruction. They may have tips for how to improve the appearance of scars and restore function. Some of their techniques may include lasers and cosmetic tattoos.

Burn injuries change how your skin looks. They can also change your appearance in other ways:

- Severe burns can damage structures under the skin. For example, when cartilage in the ears or nose is burned, there can be visible changes in these structures.
- Some burn survivors have many skin grafts and other reconstructive surgeries. These procedures can change the way a person looks.
- Healed skin or grafted skin may be permanently discolored. It may become lighter or darker than your uninjured skin.
- Skin grafts can cause hair loss because hair follicles don't regrow.
- Sometimes burn injuries cause damage that requires fingers, toes, or limbs to be cut off.

Wanting to improve your appearance doesn't mean you're vain. Makeup, clothing, or plastic surgery can help you feel better about yourself and how you look. Even with the best care, rehab, and reconstruction, major burns can cause some permanent changes in how your body looks, feels, and works. Part of the emotional healing process is learning to accept these changes. It may be helpful to focus less on your physical appearance and more on internal strengths and interests that make up your self-image. For example, focus on the accomplishments or roles that make you proud. These may include your education, career, or being a good friend or parent. Accepting your scars doesn't mean you have to like them. While some survivors report being completely at home in their changed bodies, others accept the changes and get their self-worth from a more inner reality.

Here is an excerpt from a burn survivor talking about the change in their appearance:

"I don't *like* my appearance, some things not at all, but I *like* me. The person I am. The contributions I make. The impact I can have on others. The kindness I can show."

Social interactions after burn injury

When seeing or meeting someone with burn scars for the first time, some people may stare, avoid contact, or ask pushy questions.

If This Happens, Here Are Some Things You Can Do:

- To feel confident when you're talking to someone, make eye contact. You should also use confident body language, smile, and use a friendly tone of voice.
- Have an answer ready ahead of time to explain "what happened." For example, "I was burned when I was younger, but fortunately I am back to doing all the activities I did before." Some burn survivors find that talking about their injury helps with emotional healing.



- If you don't want to discuss your appearance, you can say you don't want to talk about it. You also can guide the conversation to take the focus off you. Ask the other person open-ended questions (questions that a person can't answer with "yes" or "no"). For example, "I heard you went on a vacation. That sounds exciting. Tell me about it."
- For those with changes to their face, dealing with the public can be a daily struggle. When people stare or make negative comments, having a *catch phrase*—like "remember to be gracious"—can help you refocus and use social tools instead of reacting in a negative way.

Some burn survivors find it helpful to be with a trusted person when in public places.

Intimacy following burn injury

You may be worried about showing your burn scars during intimate experiences. Here are some ways to help you feel more comfortable and confident:

- Talk to your partner. Learn about the different stages he or she may go through as you recover. These include withdrawal, avoidance, or being irritable with you.
- Encourage your partner to have contact with your skin. Moisturizing or massaging your scars can help both of you to overcome any hesitation or the "fear of rejection." Perhaps your partner can get familiar with the different feel and texture of your skin before you leave the hospital.
- Pursue grooming activities. This helps to improve your well-being and readjustments in body image.
- Get the support you need to address your concerns about intimacy. This may include talking to your health care team or other burn survivors.

Other Resources That Can Help You With Social Interactions

- Image Enhancement Program (<https://www.phoenix-society.org/resources/tools-for-redeveloping-social-skills-as-a-burn-survivor>)
- The following Changing Faces link provides many self-help guides for those who have sustained a burn injury:
<https://changingfaces.org.uk/adviceandsupport/self-help-guides>

Child burn survivors and teasing

Parents and teachers need to closely watch how child burn survivors act and interact with other people. Children often tease each other about even slight differences in appearance. Parents may not be aware of how severely their child is being teased. Children who are teased may become depressed or anxious when meeting new people. Often times, children tease because they are curious or don't understand the situation or why the child looks different.

Adults can intervene early in a child's life to help protect them from teasing by helping the child understand the difference between curiosity and teasing, and by educating other children. For example, it is helpful if adults explain to their child the differences between curiosity (questions asked based on curiosity) versus teasing (malicious or mean intent). Children can feel like they are being teased when kids are simply being curious when asking about their scars. Second, adults can give other children some basic information about burns. This might satisfy their curiosity in a more positive way. They can also teach children how to treat a burn survivor with respect. This can help create a supportive environment for child burn survivors.

Schools should have policies in place to minimize teasing and bullying and create a supportive learning environment. Parents should have an honest talk with the school administration about these policies. They should also ask how the policies are going to be used with their child.



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School reentry and burn camp programs

Burn centers often have programs to help burn survivors return to school. Such programs may ask a burn expert to visit the burn survivor's school before the child returns. The burn expert explains the burn recovery process to the survivor's teachers and classmates. The burn expert also encourages students to be kind and supportive of the burn survivor. Many families find this process helpful in creating a supportive environment for the burn survivor.

The Journey Back: Resources to Assist School Reentry After a Burn Injury has helpful information about the school reentry process. For more information or to order this resource, visit <https://www.phoenix-society.org/resources/the-journey-back-navigating-school-reentry>.

Some burn centers offer burn camps for children. These camps are often free. These camps give children a chance to play and interact with other children with burn injuries so they don't feel so different.

Finding help

Recovering from a burn can be tough emotionally. Get help if you feel anxious or depressed, have nightmares, or relive how you were injured. Many burn survivors find it helpful to talk to a mental health provider who has experience with the challenges of recovering from a burn. Your local burn center or health care provider can refer you to a mental health professional in your area.

Getting the support you need

With burn injuries, emotional healing is just as important as physical healing. You should get support from family, friends, colleagues, health professionals, and other burn survivors who may share your experience.

The Phoenix Society, a nonprofit organization based in the United States, offers the Phoenix Survivors Offering Assistance in Recovery (SOAR) program. This program connects people with new burn injuries to survivors and family members who have been impacted by a burn injury. Trained burn survivors are available across the United States to offer support. For more information, visit <https://www.phoenix-society.org/phoenix-soar>.

You may want to talk to your health care provider about the following treatment options:

Cognitive behavioral therapy (CBT): CBT is a treatment approach used in behavioral health. CBT shows people how to understand and improve the connections between their thoughts, emotions, and behaviors. It is effective in treating severe depression and anxiety. CBT also helps people with body image distress.

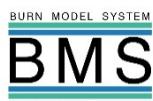
Physical activity: Exercise may improve a person's body image. Exercise can increase energy and build confidence. It can also lessen feelings of hopelessness and lead to an appreciation of one's body. Even if you have never been physically active, you can start with 20 minutes of walking every day. Talk to your health care team about a structured exercise program.

Additional Resources

The Model System Knowledge Translation Center website has many resources available, one that may be helpful for parents is the "Help Your Child Recover - Build Your Child's Resilience after a Burn Injury". See: <https://msktc.org/burn/factsheets/Build-Childs-Resilience-After-Burn-Injury>.

The Phoenix Society is "dedicated to empowering anyone affected by a burn injury." For more information, visit <https://www.phoenix-society.org/resources> or call 1-800-888-BURN. The Phoenix Society offers the following resources:

- Weekly online chats with moderators (<https://www.phoenix-society.org/what-we-do/peer-support-chat>); and
- A catalog of books, videos, and CDs for burn survivors (<https://www.phoenix-society.org/resources>).
- Social skills online courses (<https://www.phoenix-society.org/resources/beyond-surviving>)



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Changing Faces is an advocacy organization in England. Its mission is “to create a better and fairer future for everyone who has a disfigurement to their face or body from any cause and their families.” For more information, visit <http://www.changingfaces.org.uk/Home>.

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Authorship

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Factsheet Update

Understanding and Improving Body Image After Burn Injury was reviewed and updated by Nadia Quijije, MD (Massachusetts General Hospital, Psychiatry); Shelley Wiechman, PhD (Northwest Regional Burn Model System/NWRBMS investigator and UW Medicine Regional Burn Center Psychologist); Mona Krueger (Aftercare Coordinator, Oregon Burn Center); and Claudia Baker, BA (UW Medicine Regional Burn Center SOAR volunteer coordinator). The review and update was supported by the American Institutes for Research, Model Systems Knowledge Translation Center under a grant (number 90DP0082) from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The contents of this factsheet do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the federal government.

Source: Our health information content is based on research evidence whenever available and represents the consensus of expert opinion of the Burn Model System directors.

Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment.

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Wound Care After Burn Injury

September 2017

www.msktc.org/burn/factsheets

BURN Factsheet

This factsheet explains how to take care of a burn injury. It gives an overview of the three degrees of burns and the standard treatments for each. It also discusses the types of products available to treat burn injuries. The wound care described here is following discharge from the hospital.

Understanding the Extent of Your Burn

Burn injuries are caused by fires or flames, hot liquids or steam, contact with a hot object or agent like grease or tar, chemicals, or electricity. When evaluating a burn injury, doctors look at two factors: how deep the burn is and the burn size which is measured by the *percent total body surface area (% TBSA)*. The burn depth depends on how hot the agent was and how long the burned area was in contact with the agent and how thick the skin is in the area. There are three levels of a burn injury:

- *First-degree burns* affect the top layer of skin, called the epidermis (ep-i-DUR-mis). These burns cause minor damage to the skin. Skin may be red and tender or swollen. An example would be a mild sunburn that turns red and may peel. First-degree burns can generally be treated at home.
- *Second-degree burns* (also called partial thickness burns) go through the second layer of skin, called the dermis (DUR-mis). These burns cause pain, redness, and blisters and are often painful. The injury may ooze or bleed. They usually heal within 1 to 3 weeks. After healing, skin may be discolored. These burns generally do not leave raised scars. Treatment for second-degree burns varies. It may include ointments or special dressings. Surgery may be necessary for very deep second degree burns or those that are slow to heal.
- *Third-degree and more severe burns* (also called full thickness burns) damage both layers of the skin and may also damage the underlying bones, muscles, and tendons. Injured skin may turn white, black, and/or gray. It may feel dry and leathery. Sometimes there is no pain because the nerve endings under the skin are destroyed. Third-degree burns have a high risk of infection. They are usually treated with skin grafts. This surgery, done with general anesthesia, removes the injured skin and replaces it with healthy skin from an uninjured area of the body. Full thickness burns that are not grafted may take months or even years to heal. Third-degree burns likely leave raised scars. Burn survivors may have a combination of first, second, and third degree burns. Talk with your health care providers to better understand your specific injuries.

The Burn Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/burn/model-system-centers> for more information).

Treatment Options for Burn Injury

Wound Care

Antibiotic (an-ti-bahy-OT-ik) ointments or creams are often used to prevent or treat infections in patients with second-degree burns. Using these ointments may require the use of bandages. Dressings may need to be changed daily. This can be a painful process. Your doctor can assist you in coordinating the dressing changes with your pain medication. Dressings can be soaked off with water in a sink or shower. The skin and the burn wound should be washed gently with mild soap and rinsed well with tap water. Use a soft wash cloth or piece of gauze to gently remove old medications. A small amount of bleeding is common with dressing changes. Your doctor will decide on the appropriate dressing and ointment. This will be based on the location of the burn, the need to control drainage, and your comfort.



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There are many “advanced wound care products” available for burns. These products don’t require daily dressing changes and can be left in place until the wound heals. This can make pain control much easier and may decrease anxiety about wound care. These types of dressings include impregnated (im-PREG-neyt-ed) gauzes, foams, honey, and silver dressings. Many of the currently available dressings are combinations of these categories. There are many different brand names. Your burn care team will determine the most appropriate product to use. They will also decide when to apply and remove it.

Skin Grafts

Larger areas of third degree (full thickness) burns are treated with skin grafts. This surgery removes dead skin and replaces it with healthy skin from another part of the body. The grafted skin is often treated with an antibiotic ointment and a nonstick dressing. There are three types of skin grafts.

- *Sheet grafts* are usually applied to the face or hands for better cosmetic effect. Sheet graft uses the whole piece of skin without the holes in it. It gives a better cosmetic appearance but requires much more skin to cover a specific area. Newly healed grafts are very fragile. Special care should be taken to protect them. Be careful not to bump, rub, or scratch them. Do not wear rough clothing or anything that rubs; this can cause blistering.
- *Meshed grafts* are used for larger wounds. For permanent wound coverage, a piece of your own skin is taken from another part of the body (donor skin) to close the open area. When the donor skin is taken off the body, it shrinks. To stretch the donor skin, it is put through a machine that makes small slits or holes in the skin. This stretched skin covers a larger area than an unmeshed sheet graft, but leaves a permanent mesh pattern similar to stockings. The wound heals as the areas between the meshed graft and the holes fill in with new skin. Once the mesh sheet sticks to the skin and the drainage stops, the wound is considered healed and can be left open to air. Lotion can be used to keep it moist.
- *Full-thickness grafts* are used for reconstruction of small areas that are prone to contracture such as the hand or chin. It consists of the full thickness of the skin and shrink the least compared to other grafts.

The area of the donor site is similar to a second-degree burn. Most burn providers use one of the advanced wound dressings that can be left in place for 7–14 days while healing occurs. Any remaining small open areas on the donor site can be treated with antibiotic ointment. Notify your burn provider of any areas of redness, warmth, and increased pain. These can be symptoms of an infection.

Moisturizing

Moisturizing will be very important after burn injury.

- Once the skin is closed and no longer draining, it is important to keep it well moisturized. This decreases the chances of developing blisters or skin tears. It also decreases itching and can make movement easier.
- There are many different lotions available.
- Lotions in bottles have a higher water content. They are also easier to apply. They often need to be applied frequently.
- Lotions in tubes and jars are thicker. They need to be massaged in more thoroughly. They last longer on your skin.
- Unscented lotion should be applied and massaged into the scar several times per day. Unscented lotion is important – ask your doctor for recommendations.
- Applying lotion is a good time to touch your scars using light pressure; touching your scars is helpful in keeping them from getting sensitive. It is also a good time to do a little stretching. This factsheet has more information about stretching:
<http://www.msktc.org/burn/factsheets/Exercise-After-Burn-Injury>.

Blisters

- Newly healed skin is fragile. Minor shearing (rubbing force) on the scar can cause blisters. Blisters also can develop from clothes that fit too tightly, shearing while putting on pressure garments, or rubbing or scratching the burn scar.
- Blisters should be pierced and drained as soon as you notice them. Use a sterile (STER-il) needle to make a small hole. Then drain the blister onto a piece of gauze. Put a little antibiotic ointment on the area.
- If a blister opens up, you might need to bandage it with a nonstick dressing. Do not use adhesive or sticky bandages or tape that is difficult to take off. Your skin might tear.
- Over moisturizing especially on face can occlude pores and cause pimples. If this occurs, reduce moisturizing and consult your doctor or the burn team.



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Skin Tears

- Skin tears occur when you bump into something such as a doorway, a counter top, or a piece of furniture. They can also be caused by scratching.
- If the area bleeds, put firm pressure over the wound for about 5 minutes until the bleeding stops.
- Wash the area gently and thoroughly with mild soap and water.
- Use a small amount of antibiotic ointment and a nonstick dressing and allow the wound to heal. If the surrounding area becomes red and warm, you might have an infection. Contact your health care provider for further evaluation.
- If the wound continues to crack open, get bigger, or deepen, your health care provider may recommend a splint or cast. This will keep the wound area still.

Ulcerations

- Ulcerations (uhl-suh-REY-shuhns) are breakdowns in the skin. They usually occur across bands of scar tissue around your shoulder, the front of your elbow, and the back of your knee.
- These areas can be difficult to heal. Physical movements like exercise can cause the wound to continuously crack open or get bigger.
- Keep the wound covered with a thin film of antibiotic ointment. Keep the surrounding skin well moisturized, especially when you are exercising and stretching.

Allergic skin reactions

- Be sure to let your doctor know if you have any skin allergies.
- Allergic skin reactions can be caused by using antibiotic ointments for a long time. Other causes include changing the type of lotion or soap that you use, changing laundry detergents, or changing the elastic in pressure garments.
- If you have an allergic skin reaction, stop using all soaps, lotions, and ointments for 2 to 3 days.
- Once the reaction has gone away, you can start using soaps and moisturizers again. Add these products back into your daily routine one at a time.
- Allow 2 to 3 days in between adding each product back into your daily routine. This will allow time to see if the reaction returns.

What Can You Do?

- Be active in your recovery. Ask questions and help make decisions about your care.
- Take a list of questions or concerns to your medical appointments for your health care provider to address.
- Follow your provider's wound care instructions.
- Always keep your skin clean and well moisturized.
- Avoid bumping, scraping, or scratching.
- Start exercises as soon as possible. Refer to this factsheet for more information about exercise after your burn:
<http://www.msktc.org/burn/factsheets/Exercise-After-Burn-Injury>

Additional Resources

For more information regarding the care of your wounds, please contact your doctor or therapist so that they can address your specific needs.

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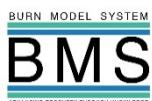
Authorship

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