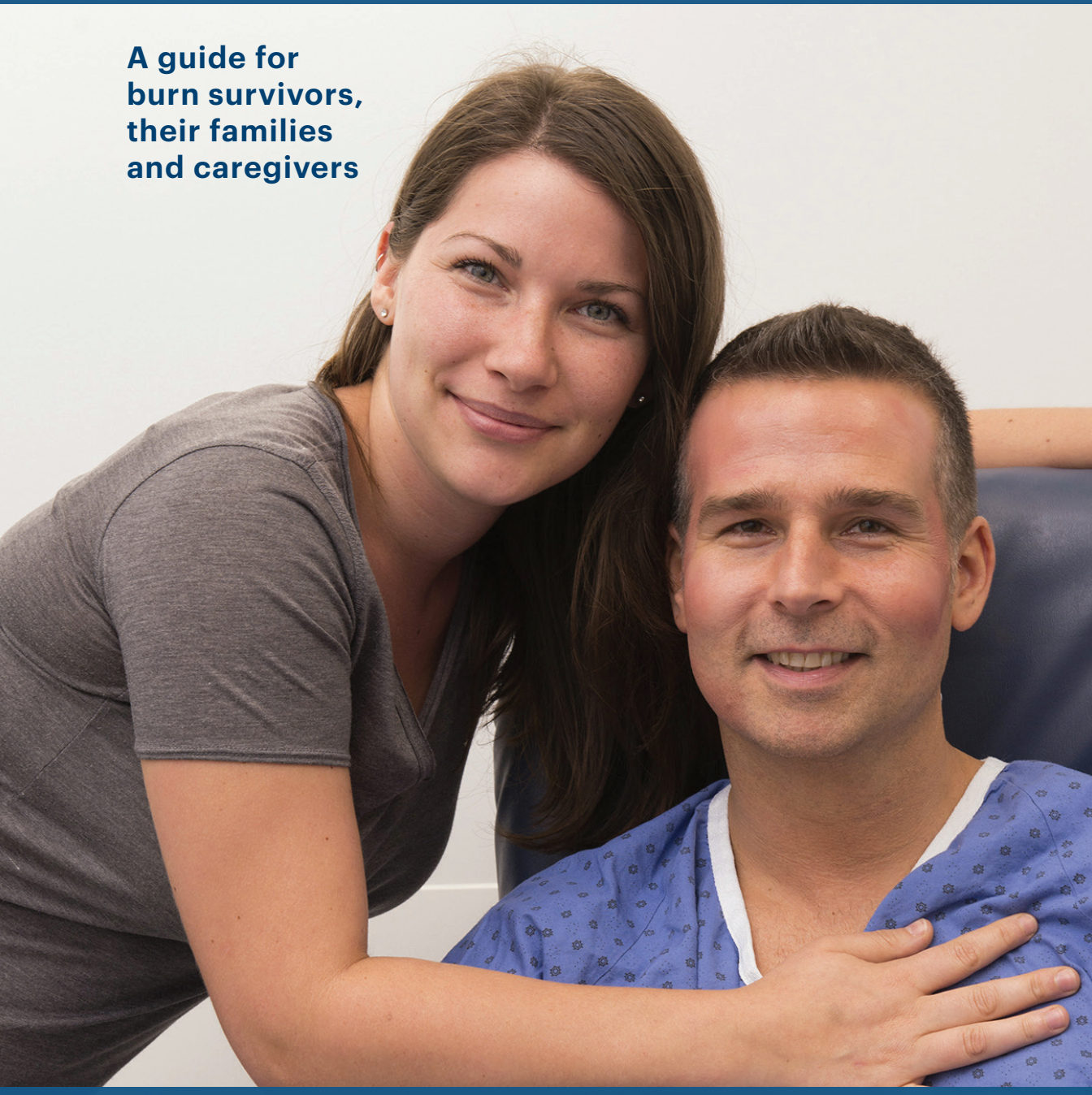
UNDERSTANDING BURN INJURIES

A guide for burn survivors, their families and caregivers



Suzie Bond, PhD
Isabelle Perreault, MD FRCSC

Les Productions Odon inc.

Understanding Burn Injuries

A guide for
burn survivors,
their families
and caregivers

Suzie Bond, PhD
Isabelle Perreault, MD FRCSC

Les Productions Odon inc.

ISBN 978-2-9812691-4-0

Publisher: Les Productions Odon Inc.

Cover design and layout: Julie Sangollo

Mock-up design: Louis-Philippe Verrier

Artistic direction: Suzie Bond

Language editing: Marina Badani

English translation: Nguyen & Murray associées and Maureen Magee

Proofreading: Les Productions Odon inc., Nora Cristall

Photos:

Luc Lauzière (cover page, pp. 36-39, 41 [photo in the center], 42-58, 61, 70, 80, 101, 111, 117-128, 134-153, 161, 173, 180-184);

Shutterstock (pp. 24, 28-29, 59, 67-69, 72-79, 86-97, 102-105, 113, 131, 156, 162-170, 176);

iStockphoto (pp. 25-27, 31-35, 41, 62-65, 82, 109, 157).

Aussi disponible en français sous le titre : *Les brûlures : comprendre pour mieux accompagner. Guide destiné aux grands brûlés, aux proches et aux intervenants*.

We would like to acknowledge the financial support of the Fondation des pompiers du Québec pour les grands brûlés (research and development of the guide).

We would like to thank the Fondation du CHUM for its financial support (editing of the guide).

We would like to thank the Canadian Burn Association for its financial support (computer graphics).

Legal Deposit – 2021
Bibliothèques et Archives nationales du Québec (BANQ)
Bibliothèque et Archives Canada (BAC)

To our husbands,
so loving and accommodating,
who understand our dedication
to patient care.

Preface

Each year, more than 30,000 people in Canada and the United States are referred to a specialized treatment centre for their burns. Today's state-of-the-art technology makes it possible for the majority of burned persons to survive their injuries. However, recovering from a severe burn is challenging, both for the person and for those who support them.

Studies have shown that what family members need most is to receive information in clear language that they can understand. We have developed this guide to better meet this need. We believe it is important to properly equip loved ones to enable them to support their loved one throughout their recovery.

A first version of this guide was tested with about twenty families. Most readers reported that they found the guide useful and would recommend it to other families. Although the majority of loved ones were satisfied with the information received, many said they would like to learn even more. Thanks to their comments, we are now able to present you with this revised and improved version.

Although we recommend reading the entire guide, readers may choose to consult individual sections, depending on their needs. The guide includes information, for example, on skin and burns, medical and surgical treatments, and healing and rehabilitation, as well as a section on the psychological aspects of burn injuries.

The information contained in this guide is intended to promote quality communication between loved ones and the healthcare team. However, please note that this guide is not a substitute for medical advice. Do not hesitate to ask the members of the healthcare team for details on the situation of the burned person and for reassurance.

Suzie Bond, PhD
Psychologist

Isabelle Perreault, MD FRCSC
Plastic surgeon

“Alone we can do so little; together we can do so much.”

— Helen Keller

Table of contents

4 - Intensive care

5 - A severe burn is hard for loved ones too

6 - Burn treatment

7 - Pain

8 - Medication

9 - Healing and scarring

10 - Rehabilitation

11 - Adjusting to a severe burn

12 - What's next?

13 - Because life goes on

Resources

Tables list

Figures

1

BECAUSE EACH PERSON'S STORY IS DIFFERENT

Each severe burn takes place in particular circumstances and becomes, forevermore, part of the personal story of the burn-injured person and that of their loved ones. The personal stories that Jorge, Simon, Frédéric, Richard and Paul so generously agreed to share with us bring this guide to life, giving it a human face. They will stay with us throughout the guide, talking to us simply and directly about what happened to them.

Don't forget to read how their stories turn out at the end of this guide!

Jorge

On August 1, 2004, I woke up in hell.

A job in Canada.
The dream of a better life.
My wife and two children waiting in Mexico, for two years now.
Exhaustion, loneliness and despair.
Tossing and turning in my sleep.
A forgotten cigarette.
Engulfed in flames.
Third degree burns to 90% of my body.
Several months in a "coma".
A miracle.

Jorge, 42 years old

Simon

On March 25, 2012, I defied death.

A nature lover, outdoorsman and thrill seeker.
The challenge of climbing a hydro tower.
A lack of knowledge.
A 330,000-volt transmission line.
An electric arc.
Clothes on fire.
A 20-metre (75-foot) fall.
A fractured jaw.
Third and fourth degree burns to 52% of my body.
Including my face.

Simon, 28 years old

Frédéric

On November 12, 2006, my life changed forever.

My wife, pregnant with our third child.
Enjoying a celebration with friends.
A crash on the go-kart track.
A vehicle on top of me.
The smell of gas.
Fear. And then, oh no, no, no!
Intense fire shooting up.
Third degree burns to 50% of my body.
The start of a long battle.

Frédéric, 29 years old

Richard

On March 16, 2011, I went to work but didn't come home.

A day working at the garage.
A gas pump to replace.
A misunderstanding.
Pressurized gas on my face.
A work light not up to safety standards.
A spark.
A human torch.
The fear of burning to death.
24 months of physical and psychological rehab.

Richard, 57 years old

Paul

On October 27, 2012, I went to sleep, only to wake up.... in a nightmare.

Halloween time.

At a party with friends.

Home to a deep sleep.

An apartment on fire.

Jumping through flames.

Third degree burns to my body.

Intensive care.

Fear of dying.

Chaotic thoughts.

Then, finally, waking up.

Paul, 20 years old

2

SKIN AND BURNS

You may be surprised to learn that the skin is the human body's largest organ. Skin is like an envelope that covers us and protects us from head to toe. Its flexibility and resistance protect the body from the environment. Burns damage the skin. They make an opening in this envelope that protects our bodies. Without skin, the human body would quickly dehydrate and be open to germs. This is what happens when a person is badly burned.

The skin, a complex organ

Layers of the skin

The skin has two layers – the *epidermis*[1] and the *dermis*.

The epidermis

The epidermis is the part of the skin that you can see. It is constantly replacing itself.

The dermis

The dermis is located beneath the epidermis. It does not replace itself and so, the healing process leaves a scar. It contains the small blood vessels that nourish the skin, the nerve endings that make the skin sensitive and collagen and elastin fibres that make the skin flexible and resistant. The dermis also contains the glands that secrete sebum, sweat and the natural oils that give the skin moisture.

Structures and tissues beneath the skin

Beneath the skin are fat, muscles, bones and tendons.

Depending on the severity of the burn, one or more of these layers can be damaged, that is, the epidermis, the dermis or the structures and tissues beneath the skin (see Figure 1 below). That's why we talk about the *degree of burn*, which is explained further below in this section.

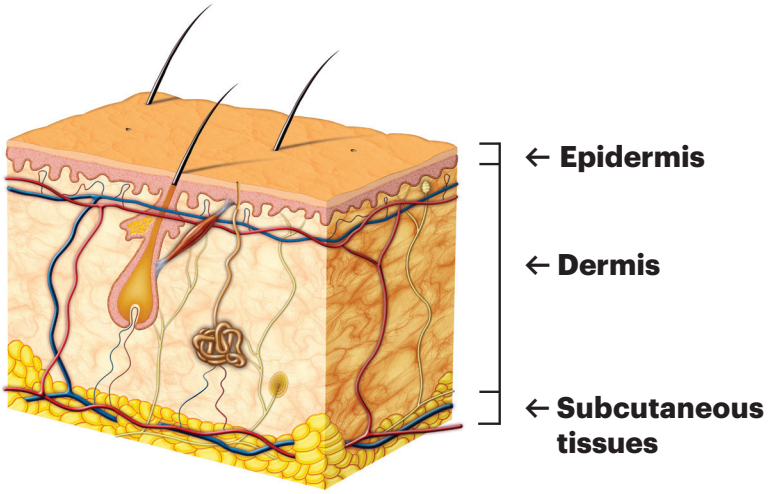


Figure 1. Layers of the skin

[1] See Glossary (p. 190) for the definition of words in italics.

What's the purpose of skin?

Figure 2 below shows the roles played by the skin that can be affected by a burn injury.

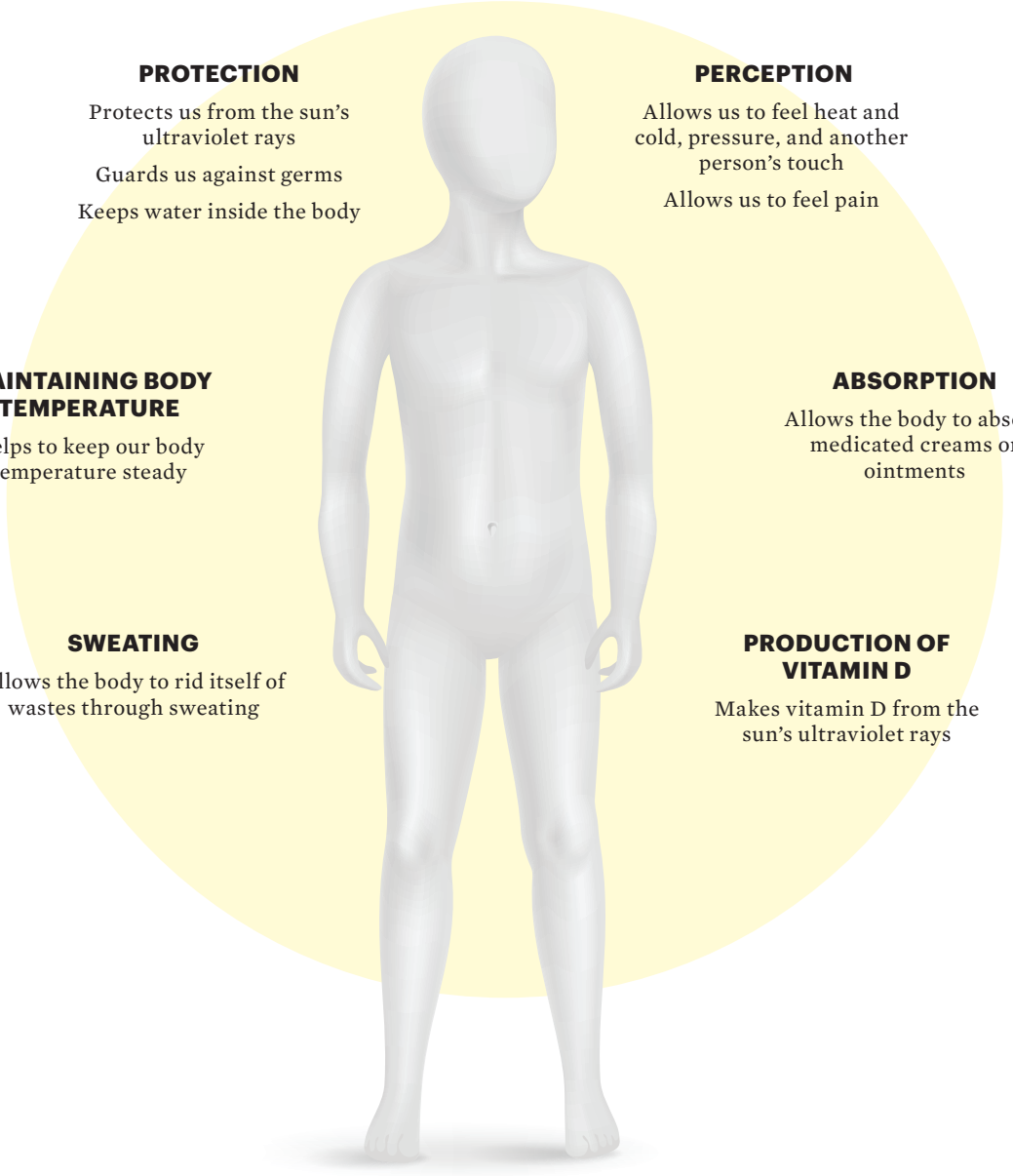


Figure 2. Roles played by the skin

What causes a burn?

Several things in the environment can burn the skin. Most often, burns are thermal, which means that they are caused by a heat source like flames or hot water. A burn can also be caused by contact with electricity or a chemical product, or by being in the sun too long.

More than 90%

Thermal burns

They happen when a person comes into contact with a heat source such as:

- flames;
- steam;
- a scalding hot liquid;
- hot fat or oil;
- hot metals.

A thermal burn can also happen when the skin gets scraped on a rough surface like asphalt (e.g., in a motorcycle accident).

Frostbite is also a kind of thermal burn; it is caused by being in the cold too long.

Did you know

The lungs can also be burned

In certain situations, the inside of the respiratory tract can be damaged. Heat from the smoke and toxic fumes of a fire can cause severe burns to the lungs. These burns are called *inhalation burns* or *inhalation lesions*. This happens most often in enclosed spaces, for example, in a house fire.

Less than 5%

Electrical burns

They result from an electrical current travelling through the body or on the skin.

When the electrical current travels through the body, the person is said to have an *electrical burn*. A burn to the skin can often be seen in two places, at the current's point of entry and at its point of exit. Even if you can't see it, the damage caused by the current travelling inside the body can be very severe. Electrical burns can interfere with the functioning of the nervous system, kidneys and heart. The electrical current can also damage blood vessels, nerves and muscles.

Less than 5%

Chemical burns

They result from the skin coming into contact with a chemical product, or when a chemical product is swallowed or inhaled. Oven and drain cleaners are examples of such products.

Chemical burns are often a problem as they continue to cause damage and deepen the wound if the chemical agent has not been removed. For example, if a worker has acid splashed on their arm and the burn has not been treated properly, the affected skin can continue to deteriorate for several hours after the accident.

Less than 1%

Radiation burns

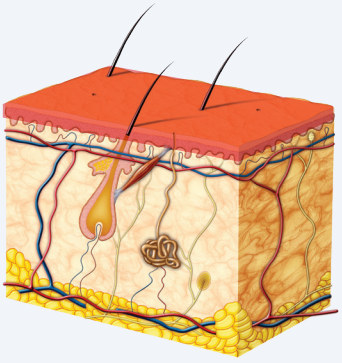
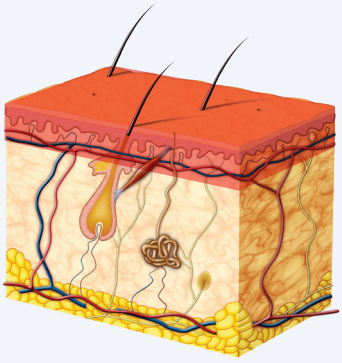
They result from:

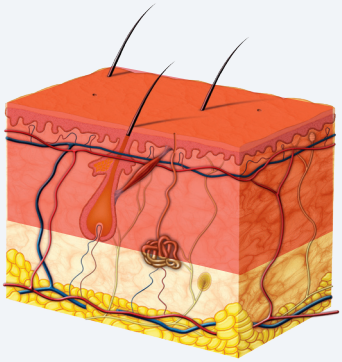
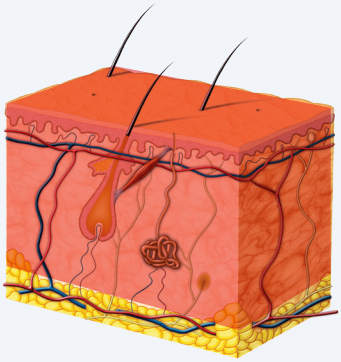
- prolonged exposure to ultraviolet rays (e.g., sunburn);
- contact with radioactive material (e.g., radiation therapy).

What is a 1st, 2nd, 3rd or 4th degree burn?

Table 1 below and p. 29 shows the characteristics of these *degrees of burn*. First degree burns are the least harmful and heal without leaving scars. Fourth degree burns affect structures beneath the skin, like muscles and bones. So, the degree of burn depends on how **deep** the damage is.

Table 1. Degrees of burn

	1st degree burn	2nd degree superficial burn
Depth	*Epidermis*	*Epidermis* and a small part of the *dermis*
Appearance	Skin is red and not broken (looks like a sunburn)	Blisters; the skin beneath the blister is usually shiny, red or pink
Pain	Painful	Very painful
Time needed to heal	5 to 7 days	10 to 14 days
Scarring	No	No, but the skin may be permanently discoloured
Surgery	No	No
Pictures		

	2nd degree deep burn	3rd degree burn
Depth	Epidermis and more than half of the dermis	Epidermis and all of the dermis
Appearance	Blisters (sometimes) Skin may be pale, but can also be purplish-red or brownish	Can be stiff like cardboard or leathery; skin can be several colours: white, brown and sometimes black
Pain	Painful, but less painful than 2nd degree superficial burn	No pain
Time needed to heal	21 to 35 days	The wound cannot close on its own
Scarring	Yes	Yes
Surgery	Yes	Yes
Pictures		

Did you know

Fourth degree burn

A burn can be so deep that it damages the tissues and structures beneath the skin, such as fat, muscles, nerves, blood vessels, tendons and even bones. These are called fourth degree burns. They happen when a person is exposed to flames for too long, for example, if the person is unconscious. It is very complicated to treat these wounds; they will require a lot of surgery. Sometimes, the surgeon must amputate, or remove, the burned area if it is so badly damaged that it cannot be reconstructed.

What is a severe burn?

The *degree of burn* is only one of several factors used to determine the severity of a burn. The following elements also influence the severity of the burn:

- size (%) of the body surface affected by the burn (2nd and 3rd degree)
- area(s) of the body affected;
- whether the respiratory tract or lungs have been burned;
- age of the patient;
- lifestyle;
- medical history.

Can you rank the following people according to the severity of their burns?

Spaghetti sauce

Janet is 87 years old and retired. She slipped when lifting a large pot of spaghetti sauce. She suffered second degree superficial and deep burns to 25% of her body. She is diabetic and has a heart condition.

Gas can

John is a 21-year-old sports coach. He put gas into a barrel to burn some papers. The gas can exploded in his face and his sweater caught fire. He suffered third degree burns to 30% of his body (mostly his trunk and forearms) and second degree superficial burns to his face.

Electric wire

Jake is a 53-year-old electrician. He received an electric shock after touching a high voltage wire with a tool. The current entered his body through his left hand and exited through the big toe on his right foot, burning 3% of his body, at the current's entry and exit points.

Janet has the most severe burn. She may not survive. Because she is elderly and already had health problems before the burn, it is harder for her injuries to heal.

Even though **Jake** has a better chance than Janet of surviving, his burns will probably have serious effects. Because the electrical current went through his body, it may have damaged muscles (e.g., left arm), nerves and internal organs. Depending on how bad the damage is, he may have to have several surgeries, or even an amputation (e.g., hand, arm, toes).

John's case shows that many different things can affect the severity of a burn. Even though he has a very deep burn (third degree), covering more of his body (30%) than Jake or Janet, a number of things are on his side. He is young and in good physical shape, and his burns are on parts of his body that will not stop him from returning to his usual activities. His joints (e.g., elbows, neck, armpits) were not burned. But like anyone who has been severely burned, John is at risk of having psychological problems. He could also find it hard to adapt to his new appearance.

Children and older people have more delicate skin.

- ❍ Ask to meet the doctor.
- ❍ Find out more about your loved one's burns.
- ❍ Take notes.
- ❍ Share the information with other family members.

Notes

The type of burn my loved one has is:

- ❍ thermal
- ❍ thermal (frostbite)
- ❍ electrical
- ❍ chemical
- ❍ radiation

My loved one has a:

- ❍ 1st degree burn
- ❍ 2nd degree superficial burn
- ❍ 2nd degree deep burn
- ❍ 3rd degree burn
- ❍ 4th degree burn

My loved one has burns on

____% of their body.

My loved one has burns on the following parts of their body:

3

THE BURN CENTRE

Being admitted to a hospital burn centre is like taking a trip to a foreign land, a trip you didn't plan to take and were totally unprepared for. Burn patients and their loved ones have to get used to two things: the burn itself and being in hospital.

The information below should help you learn more about how things work in a hospital burn centre.

When the nurse told us, "We're going to take care of your son as if he were our own.", it made all the difference. I thought, "Paul couldn't be in better hands."

— Maureen

What is a burn centre?

Burn centres provide specialized care for all the different aspects of severe burns. This care includes everything from medical to psychological care, and from nutrition to rehabilitation. Each staff member is trained to provide the best care and must keep their learning and skills up to date.

Burn centres are often located in university teaching hospitals. Although the main goal of these centres is to provide high quality care, they also aim to advance the treatments for people who have severe burns. So, often burn patients and their loved ones are asked if they would participate in one or more research projects.

Burn centre referral criteria

Not all burns are so bad that the person needs treatment in a burn centre. The following information is used to decide whether a person needs to be sent to a burn centre:

- burns to more than 10% of the body's surface area;
- burns to the face, hands, feet, genitalia, *perineum*, or major joints;
- third degree burns;
- electrical or chemical burns;
- burns to the lungs or respiratory tract from inhaling smoke;
- burn injuries in a person who will need specialized social or emotional support.

These criteria are established by the American Burn Association (ABA) and are used by North American and European burn centres.

Admission to a burn centre

When the patient arrives at the burn centre, they are taken to the admitting room where their treatment is managed by a team of professionals dedicated to burn patients.

When a burn is very severe, the first goal is survival. Specialized doctors and nurses work together to maintain or re-establish the burn patient's vital bodily functions.

During admission, the doctor and specialized team:

- clean and examine the wounds;
- note which parts of the body are burned;
- evaluate the size of the burns, that is, what percentage of the body surface area has been burned;
- evaluate the depth of the burns (first, second, third degree);
- evaluate other factors to determine how severe the burn is;
- cover the wounds with antimicrobial bandages;
- decide whether the patient should be sent to *intensive care*.

During admission, the doctor decides what type of care is needed based on how severe the burn is, that is, whether the patient should be admitted to intensive care (see section entitled **Intensive Care**, p. 36) or *intermediate care* (see section entitled **Intermediate Care**, p. 37).

Admission to a burn centre.

Intensive care

Intensive care is needed when the person's overall condition is unstable or needs continuous monitoring.

When a person:

- needs to be on a *respirator* (see p. 48);
- has burns to a large part of their body;
- has suffered an electrical burn which may affect the functioning of their heart;
- has severe burns to the face which may cause their airway to swell.

The burned person is connected to different pieces of medical equipment that can detect complications and this allows health care staff to act in an emergency. Nurses monitor the burned person's condition 24 hours a day.

If your loved one is in intensive care, please read the "Intensive Care" chapter, p. 47, to find out more.

Intermediate care

Patients are sent to *intermediate* care when their health is stable but when they need surgery or special care for their wounds. For example, a person with burns to both hands from hot oil will be admitted to a room in intermediate care.

A burn patient who has been cared for in intensive care, but no longer needs 24-hour monitoring, may also be transferred to a room in intermediate care. This allows the patient to recuperate and continue to receive specialized care until they are discharged from hospital.

Find out more...

Evaluating burns is not that easy

When the injured person is admitted, the doctor examines the burns to see how deep they are and how much of the body surface area they cover. It is difficult to tell exactly how deep the burns are when the patient is first hospitalized. This is because the damage to the skin and other tissues can continue to progress in the days following the burn. So, the doctor has to wait at least 48 to 72 hours after the patient is admitted before it is possible to tell how deep the burns are. This evaluation helps the doctor to decide how best to treat the patient, for example, whether to let the skin heal on its own naturally or to use *skin grafting*.

The role of loved ones when a person is admitted

Being hospitalized for a severe burn is very hard for both the patient and their loved ones, who feel powerless and that they can't do anything to help. But in fact, family members and friends can help with treatment, even in the first few hours after the patient is admitted to the burn centre.

Did you know

Providing information about the injured person helps the doctors treat them

It's important for the health care staff to learn a lot about the patient (e.g., their lifestyle, medical history, drugs taken, and allergies) and to know how the accident happened. For example, if the burned person was taking blood thinning drugs such as anticoagulants, it is important to tell the medical staff so that they can adapt their treatment to this new information.

The information provided by the burn patient's loved ones is essential when the injured person is incapable of providing this information.

- Give the health care staff the information they ask for.
- Ask to meet the doctor.
- Make a list of questions.
- Choose one contact person who can call the burn centre to get news and then pass the information on to the rest of the family and other loved ones.

The information provided by loved ones can be helpful in adjusting treatment (photo opposite).

The burn team

Many things affect how the patient heals and how long they stay in hospital. They may have an infection, be in a lot of pain, or feel scared about surgery. All these things require the help of different kinds of professional staff who work together to help the burn patient recover (see Figure 3, p. 41).

Doctors

An **anaesthetist**, or **anaesthesiologist**, is a doctor who specializes in delivering an anaesthetic and must be present when surgery is being performed. This doctor puts the patient into a deep sleep and monitors their vital signs during surgery. The anaesthetist is responsible for the respiratory tract, pain control, and the administration of blood transfusions, if needed.

An **intensivist** is a doctor who specializes in resuscitation. These doctors care for patients whose vital organs (e.g., the heart, lungs or kidneys) are in danger of failing to function. They make sure the patient remains stable while in intensive care.

A **plastic surgeon** specializes in skin reconstruction and other tissues (e.g., tendons) damaged by the burn. The plastic surgeon decides on the best treatment for the burn injuries and, if needed, what kinds of surgery to do and in what order. These specialists follow up with patients after they leave hospital and perform further reconstructive surgery if needed.

A **psychiatrist** is a doctor who specializes in the diagnosis and treatment of mental disorders. These doctors detect and treat *delirium* (see section entitled **Delirium**, p. 63). If needed, they will continue to see patients after they leave the hospital.

Nursing staff

Nurses provide continuous bedside care, evaluating the state the patient is in and taking action as needed. They take care of all aspects of caring for the burn wounds and change the patient's bandages. They assess pain and administer drugs.

Figure 3. The burn team

Other health care professionals

Orderlies or health care aids provide personal care related to hygiene. If needed, they help patients to eat and move around. They assist nursing staff with caring for wounds and changing bandages.

Pharmacists evaluate and monitor the medications taken by patients when they arrive at the hospital and throughout their hospital stay. They work with the burn team to make sure the medications are used and administered safely and effectively.

Nutritionists assess the nutritional needs of patients and make sure these needs are met. They consider each patient's particular situation and the medical treatments they are being given.

Respiratory therapists evaluate and monitor the patient's breathing when they are on a *mechanical respirator*.

Pharmacist keeping track of medications taken by patient.

The rehabilitation team

Occupational therapists help patients maintain or regain their autonomy while they are recovering physically. They use tools like orthotic devices (e.g., *splints*) and pressure garments to facilitate aesthetic and functional healing. They focus on activities that involve fine motor skills (e.g., eating, brushing teeth, and shaving).

Physiotherapists assist patients with moving joints to maintain range of motion (e.g., lifting arms). They design exercise programs to maintain the burn patient's muscle strength and help them get around on their own (e.g., walking, going up and down stairs).

Psychosocial professionals

Psychologists help patients and their loved ones adjust to the burn injury. They give them information on post-traumatic reactions and help them handle these reactions. They give patients ways, in addition to the medication they are taking, to deal with pain and anxiety. If needed, they continue to treat the burn patients after they leave the hospital.

Social workers give patients information about their rights (e.g., to financial assistance) and help them apply to organizations that provide funding. When needed, they help patients with housing problems and put them in contact with community workers. They are often the contact for family members.

Spiritual care providers and hospital chaplains help patients and their family members by listening to them and supporting them. This service helps patients with the spiritual side of the burn experience and healing.

Infection control

Burn teams pay special attention to preventing infections. Severe burns create an opening in the skin through which germs can enter the body. People with severe burns can get infections very easily.

Here are some examples of how burn centres try to lower the risk of infection:

- requiring burn centre staff to put on their uniforms after they arrive at the centre and take them off before they leave the centre;
- frequent hand washing;
- frequent washing of contaminated surfaces (e.g., floors, doorknobs);
- wearing gloves, mask, cap and *isolation gown* when cleaning wounds;
- not allowing gifts and flowers in the patients' rooms.

What is one of the biggest challenges of a burn centre?

Fighting germs and bacteria every day to prevent infections.

Nurse makes sure that spouse puts on isolation garments before entering room.

- Find out the burn unit's rules for infection control.
- Wash your hands every time you go into the centre and into the burn patient's room.
- Wash your hands every time you come out of the burn patient's room.
- Tell family members and friends not to bring flowers or gifts to the hospital. Suggest that they send a get well message instead.

Did you know

Every visitor carries millions of germs

Would it surprise you to learn that you have millions of germs on your clothes, accessories (e.g., purse) and skin? Even though most of these germs would not harm a healthy person, some of them could cause an infection in a burned person. Infections make it harder for the wounds to heal and the patient then has to stay in hospital longer. **This is why it is very important for visitors to follow the rules for infection control.**

Checklist

Burn Centre

Reception: ☎

Visiting hours:

Resource nurse:

Doctors

Intensivists (intensive care)

Dr. ☎

Dr. ☎

Dr. ☎

Surgeons

Dr. ☎

Dr. ☎

Dr. ☎

Psychiatrist

Dr. ☎

Other professionals

Occupational therapist:

☎

Physiotherapist:

☎

Psychologist:

☎

Social worker:

☎

Spiritual care provider or chaplain:

☎

4

INTENSIVE CARE

Having a loved one in *intensive care* can often be very stressful for family and friends. What they find hardest is the uncertainty about the burned person's condition.

The following section aims to help you to better understand aspects of intensive care and find answers to your questions.

Answers to your questions

Why is intensive care needed?

Intensive care is needed when the burned person's condition is unstable or needs continuous monitoring.

When a person:

- needs to be on a *respirator* (see section below);
- has burns to a large part of their body;
- has an electrical burn (which may affect the functioning of their heart);
- has severe burns to the face (which may cause their airways to swell).

The burned person is connected to different pieces of medical equipment that can detect complications, and this allows health care staff to act in an emergency. Nurses monitor the burned person's condition very closely, 24 hours a day (see photo opposite).

What does the mechanical respirator do?

The respirator, also called a ventilator, is a machine that allows the burned person to breathe. The doctor must first put a tube through the mouth down into the *trachea*. This procedure is called *intubation*. The tube is then connected to the respirator, which sends air to the lungs. At this point, we say that the patient has been *intubated*.

A respirator needs to be used when:

- the airways are burned or damaged;
- the medications being given to the patient affect their ability to breathe;
- the burns are very deep or cover a large part of the body;
- the patient's overall condition is unstable.

In most cases, medications are used to put the intubated patient into a deep sleep because it is uncomfortable for them to have a tube in their throat. The intubated person can't speak or eat.


HAMILTON-G5
LIFT TO RELEASE SIDERAIL

Does the burned person feel pain?

As long as the burned person is kept in a deep sleep, **they are not conscious of the pain**. The brain can still perceive discomfort, which may be shown by changes in their heartbeat or in their facial expressions (e.g., making a face or frowning). The health care team pays special attention to these signs, and adjusts the medication to ease the discomfort felt by the burned person.

You have tubes coming out everywhere, but you seem to be sleeping comfortably.

— Extract from diary kept by Julie, Frédéric's spouse

What causes so much swelling?

The way the burned person looks changes a lot during their first days in intensive care and their loved ones may find this upsetting. When a person has burns to a large surface area, the body gets dehydrated. So, a lot of liquids are injected into the burned person to keep their blood pressure steady and make sure the blood keeps circulating to their vital organs, like the heart and brain. This procedure can cause swelling in the whole body, but it is temporary.

Did you know

Why does the team say that a burned person is in a coma?

When strong doses of medication are given to a person with severe burns to put them into a deep sleep, we say that they are in a *coma*.

This is different from a "real" coma when the patient isn't aware of what is going on around them and doesn't react, no matter what means are used to communicate with them. In a real coma, the brain isn't functioning properly. **This is not true for a person with severe burns** (with some exceptions). The health care team can use medication to cause the burned person to go into a deep sleep or to wake them up.

The uncertainty of intensive care

When someone close to you is in serious condition, it is hard to deal with uncertainty. Family and friends ask a lot of questions to try to decrease this uncertainty. Often, the answers to their questions begin with “It depends…” which they may find very frustrating. The changes in the burned person’s health condition are influenced by many complex factors. This means that the situation has to be re-evaluated from hour to hour. For example, a surgery that was planned for one day may have to be cancelled because the patient’s condition has changed.

Intensive care doctor providing spouse with information.

Does it help to visit the burned person when they are in a coma?

Yes, for sure! It has been shown that even if the burned person is unconscious, having a loved one at their bedside is helpful. But be careful not to tire yourself out! **It takes just a few minutes** to reassure the burned person. It is recommended that you visit the burned person regularly, touch them (e.g., lay your hand on their arm) and say encouraging things to them.

Can the burned person hear me?

In intensive care, how awake patients are varies a lot. No matter how awake the burned person is, you should talk to them because we know that the brain can recognize a familiar voice and this helps the patient to heal. But the person who is in a coma won't understand what you are saying and won't remember your words at all.

When he was in the coma, we talked to him, calling him by his name, and said over and over: "Don't be afraid, Paul. You're in the hospital and we're here with you."

— Maureen, Paul's mother

Why is the burned person attached to the bed?

If the health care team judges that the safety of the burned person or the people at their bedside is in serious and immediate danger, cloth ties called *restraints* may be placed on the wrists, ankles or chest. For example, a person with *delirium* may have restraints placed on their wrists (see photo, p. 53) to prevent them from pulling out the tube that helps them breathe. The team then monitors the patient more closely, and regularly re-evaluates the need for the restraints.

Did you know

What do the alarms in the intensive care room mean?

The pieces of equipment in the intensive care room make sounds that are called "alarms". The alarms tell the health care team that it's time to do something for the patient. An alarm may simply mean that it's time to change an *IV* bag. So, there is no need to worry or panic every time an alarm goes off in the room. It doesn't mean that the burned person is in danger.

Nurse explaining advantages of using restraints to spouse.

Will the burned person remember this period?

In most cases, persons with severe burns remember little or nothing about their stay in intensive care. Any memories they do have are hazy. These may be feelings, impressions, snatches of conversations, or distant sounds. More often, the burned person remembers the delirium (see section entitled **Delirium**, p. 63), especially when it is linked to strong emotions, like fear or feeling powerless.

Often the person has memory problems in the days immediately following their stay in intensive care, and these are most often caused by the medication they were given. Try to be understanding!

Before I woke up, nothing was happening. No dreams, no fantasies, no thoughts. Just a vague impression of dying. And no emotions associated with this impression. Then, gradually, I became aware of perceptions. It felt like I was coming out of a deep sleep. The lights seemed too bright, my vision was blurred, sounds were confused, I was feeling confused… It was hard to think, to remember, and I couldn't talk. It made me really angry.

— Simon

What should I say when the burned person wakes up?

The period when the burned person is waking up is very stressful for their loved ones. On the one hand, they are happy that their spouse, relative or friend is coming back. On the other hand, they are afraid that they won't know what to say or do. If you as a support person prepare for this stage, it will be easier.

A gradual awakening

A burned person doesn't wake up in the same way that we wake up after a good night's sleep. Medications are decreased over several days or weeks, depending on the person's condition. During that time, the burned person may be confused or feel lost (see section entitled **Delirium**, p. 63).

Their eyes may be open, but you won't be able to just pick up the conversation where you left off and talk to them the way you did before.

It is important to use reassuring words and simple gestures, and to focus on the present.

I wondered if my son would be the "same Paul" once he woke up.

— Maureen, Paul's mother

Waking up in stages

When the burned person wakes up, they are not at the same stage as their loved ones. You know that several days or weeks have gone by since the burn happened. You have had the time to think about it, react emotionally and start to get used to it. The burned person still has to learn about what happened to them, the effects of the burn, their stay in *intensive care*, etc. That is a lot to deal with. You should put off talking about complex or stressful situations. If the burned person shows signs of worrying, it is important to reassure them by telling that them that everything is being looked after, and that their main job is to get well.

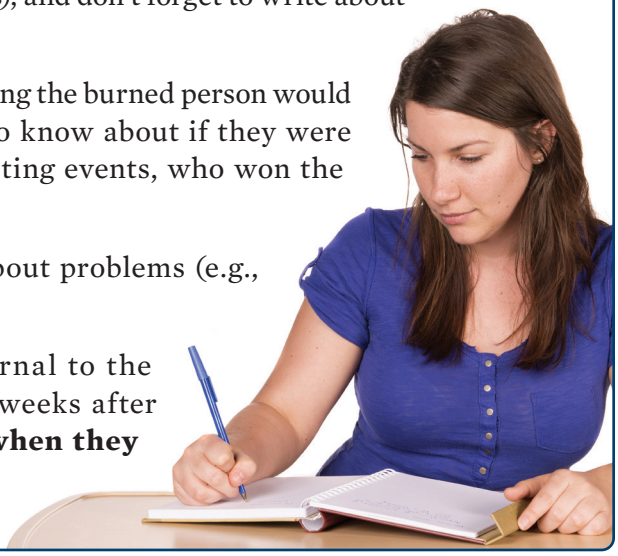
Intensive care journal

Keeping a journal about the burned person's stay in *intensive care* can help them recover psychologically. By reading the information in the journal, they can get a sense of what happened while they were unconscious since they will have few memories of that period.

Here is how to go about creating your journal

- Buy a small notebook.
- Begin by writing about how the burn happened (date, circumstances, arrival of the ambulance, etc.).
- Every day, write down what the nurses tell you about the burned person's condition.
- Note down what you observe about their condition (e.g., that they seem less agitated, opened their eyes, etc.).
- Write about what family members and friends are doing (e.g., children, relatives), and don't forget to write about yourself.
- Talk about anything the burned person would normally want to know about if they were awake (e.g., sporting events, who won the game).
- Avoid writing about problems (e.g., money worries).

You can give the journal to the burned person a few weeks after they leave hospital, **when they feel ready to read it.**



I went to the doctor today. Everything's fine! Our future baby girl has a beautiful little heart that's beating nicely.

— Extract from diary kept by Julie, Frédéric's spouse

What you can do

Intensive care

If the burned person is conscious, but unable to talk

- Look into the person's eyes reassuringly.
- Ask simple questions that they can answer with a simple "yes" or "no" by shaking or nodding their head or blinking.
- If it is hard to communicate with the burned person, you shouldn't insist, because this could make them feel exhausted or annoyed.
- Ask the health care team about the tools they have to help you communicate with the burned person (e.g., picture or word cards).
- Keep a journal of the *intensive care* days.

I know that if I talk too much, I'll start crying. So, I stroke your hair, kiss you through my mask and tell you that I love you.

— Extract from diary kept by Julie, Frédéric's spouse

Providing support and comfort

- Look into the burned person's eyes.
- Touch their arm or hand (making sure to follow the health care team's instructions).
- Speak softly and reassuringly.
- Use this opportunity to tell them how important they are to you and how much you love them.
- Tell them they are safe, and that they are being well cared for.

The hardest thing was feeling powerless. It felt like I was imprisoned in my own body. I couldn't move or talk. My only comfort was having my family by my side.

— Jorge

Be honest

- If the burned person asks what happened (e.g., how they were burned, what the burn looks like), give them the information, with sensitivity and gradually, but be honest. If you need to, you can also ask the doctor or nurse to come help you answer questions.

Advice from the experts

The key message is:

"I'm with you, I love you, don't worry: you're safe now."

What is most important is that the burned person knows you are there to support them in this difficult time. This message comes from your being at their bedside (or talking to them on the phone), smiling at them, looking at them lovingly, and being affectionate.

Helping the burned person find their bearings

- Explain where they are: “You are at the burn unit in X Hospital.”
- Say why they are in the hospital.
- Describe the circumstances of the burn, but without going into detail.
- Tell them the date, day of the week and time of day.
- Say when you last visited.
- Repeat this information often because the medication and shock they have experienced can affect their short-term memory.

Spouse helping the burned person understand what day and week it is.

Keeping connected to life outside the hospital and life before the burn

- Tell the burned person about what's going on outside the hospital to reassure them about the things that seem to be worrying them (e.g., bills getting paid, how the children are being cared for).
- Tell them good news (e.g., about children doing well on exams).
- Bring in photos of their loved ones.
- Ask family and friends to write encouraging messages that you can then read to the burned person.
- Bring in favourite foods (if allowed).

When I woke up in intensive care, I asked my wife to bring me photos. One of the children and me, and another that was taken on a bike tour. I'd found my source of motivation! I'd just set my two most important goals: returning home as soon as possible so that I could resume my family life; and re-establishing physical health (represented by the bike). From that day forward, I saw each minute, each meal, each bandage change as one more step towards my goal.

— Frédéric

Instilling hope and motivation

- Be optimistic: comments that are positive, but realistic, motivate the burned person and help them to accept their treatments.
- Encourage small steps forward (e.g., lifting their arm, scratching their nose).
- Focus on the present: say how important it is to take one day at a time.
- Encourage the burned person to get involved in their recovery (e.g., asking questions, eating all of their meals, following the health care team's advice, doing their exercises).
- If the burned person complains about not being active or feeling useless, help them realize that recovering from a severe burn is a full-time job.

Eating, drinking, sitting up in bed or just having a conversation for more than 15 minutes had become a feat.

— Frédéric

Did you know

Talking about what happened helps the burned person get used to the burn

Talking about the event with loved ones can help the burned person develop a more realistic view of what happened and piece together this puzzle. So, you shouldn't prevent them from expressing their ideas and feelings about what happened to them, **even if it is painful and makes them cry or become angry.**

In other words, be available and attentive if the burned person talks to you about what they experienced when the burn happened, how they feel now, and what they find hard.

Don't be afraid to talk about the event with your loved one who's been burned when they are ready to talk. It's helpful and liberating. It also gives us another point of view about what happened.

— Richard

Delirium, or episodes of confusion

by Dr. Nicolas Bergeron, MD, FRCPC, Psychiatrist

About 20% of severely burned persons experience confusion while they are in *intensive care*. The health care team sometimes refers to this as *delirium*.

Is the burned person experiencing delirium?

Delirium can appear in different ways (see Table 2, p. 64). A person with delirium is less aware of their surroundings and what's happening to them. Their ability to perceive and think is disturbed. They may seem lost or confused or act strangely. They can have *hallucinations* and become very suspicious.

Is delirium a normal reaction?

Just like a child who has a fever, a person experiencing delirium is not in their normal state. But delirium is very common among seriously ill people who are being given a lot of medications. Luckily, it is temporary.

The burned person can be so confused that they don't recognize their loved ones.

Table 2. Signs of delirium

Sign	Description
Loss of awareness	They don't understand what is happening to them and what is going on around them.
Loss of concentration	They can't follow conversations and are easily distracted.
Disorientation	They lose sense of time. They don't know where they are. They don't recognize certain family members or staff members who have been taking care of them.
Memory problems	They can't remember what they are told or things they should normally know.
Disordered thoughts or language	They talk in a way that doesn't make sense or is mixed up, or they find it hard to write.
Hallucinations or illusions	They appear to see or hear things that don't exist, or imagine things (e.g., insects, people, moving walls, strange voices).
Paranoid delirium	They imagine that the staff is carrying out experiments on them or that people want to hurt them.
Agitation	They are tense or impatient, or make sudden movements for no reason. They may pull out tubes or bandages, or hit a staff member.
Moving slowly	They don't move or barely react to stimulation. They seem numb.
Fluctuation	Their state changes or fluctuates throughout the day, and they may have periods that are almost normal.

Is delirium like Alzheimer's disease?

Like people with dementia or Alzheimer's disease, those experiencing *delirium* have memory loss. But Alzheimer's disease develops very gradually, over many months, and it doesn't improve. In contrast, delirium appears quickly and goes away after a few days, usually without any after-effects.

It should be noted that people who already have memory problems before being burned are at risk of developing delirium. A person can suffer from both delirium and dementia at the same time.

Is delirium like psychosis or schizophrenia?

A person suffering from *psychosis* has lost contact with reality. Common *psychotic symptoms* are *hallucinations* (seeing or hearing things that don't exist) or *delusions*, which are often paranoid (feeling spied on or persecuted). Although psychosis is often observed during delirium, it changes and is temporary. Schizophrenia is a chronic psychotic disorder. **There is no risk that delirium will cause a person to develop schizophrenia.**

Paul told me he thought the nurses wanted to hurt him.

— Maureen, Paul's mother

If the person is agitated, does it necessarily mean they are suffering from delirium?

The hallucinations or paranoia experienced by a person suffering from delirium often make them fearful and agitated. But agitation can also be related to pain, the discomfort caused by tubes and *catheters*, anxiety, or not understanding what's going on. In other words, the burned person **may be agitated for a reason other than delirium.**

Sometimes, the person experiencing delirium seems to slow down, as if they are in a cloud. They may become agitated, then slow down, then become agitated again, and so on and so forth. The state of numbness can also be a side effect of medication or a dissociative reaction linked to the trauma (see section entitled **Post-traumatic reactions**, p. 164).

To sum up, some conditions may appear to be delirium. A psychiatrist can help the health care team make the right diagnosis and develop a plan of care.

During the night, you were restless. You were having hallucinations. You really wanted to leave the hospital. They had to tie you down because you were trying to get out of bed. You were trying to use your hands to stop things. They gave you sedatives to relax you. In the morning, you were still confused. You said the children were with you, in your room. You thought we were in a swimming pool. You asked me to leave so I wouldn't get cold.

— Extract from diary kept by Julie, Frédéric's spouse

How long will the delirium last?

On average, delirium lasts from 5 to 15 days, but it can last, in rare cases, longer than 4 weeks.

Why is the burned person experiencing delirium?

A severe burn is thought to put a lot of physical stress on the burned person's brain. One explanation of delirium is that it may be hard for the brain to absorb this stress. Emotional stress does not cause delirium, but it can make the experience more difficult to go through.

Certain people are more likely to experience delirium:

- children;
- elderly persons;
- individuals who have already had brain disease or damage (e.g., dementia, stroke [CVA], or Parkinson's disease);
- people who have a problem related to alcohol or drug misuse.

Delirium in burned persons is generally caused by the combined effect of several factors: the severity of the burn, medications, an infection, or alcohol withdrawal.

Persons who abuse alcohol or drugs are more likely to experience delirium.

Is delirium dangerous? Will it have lasting effects on the burned person?

In general, delirium does not have negative effects. Even if loved ones find the symptoms of delirium shocking and difficult, there is no cause to worry.

Nevertheless, some persons continue to have problems with concentration and memory after they leave the hospital. If this happens, it is important to discuss it with a doctor.

Most people remember their experience of delirium and recover well emotionally. Sometimes the memories are not clear, and they have the impression they were on a strange trip or mixed up their dreams and reality. Some people say they had a really bad nightmare, one that was even more terrible than the events that caused the burns.

In general, after receiving information about delirium and getting support, the burned person recovers from this experience without any effects.

I started to make up stories, probably to distance myself from reality. At one point, I thought I was connected to a cell phone and that I couldn't move because my battery was dead.

— Jorge

How do we deal with delirium?

Preventing

Let the health care team know right away if the burned person regularly consumed alcohol or took medications (e.g., for anxiety or insomnia). The team will then be able to control withdrawal from these substances and lower the risk of delirium. They will stop administering certain medications that the person was taking before being hospitalized if they increase the risk of delirium.

Detecting delirium

The health care team is trained to detect the signs of delirium. Loved ones can help the staff by telling them if there are any changes in the normal behaviour of the burned person, such as acting strange, reacting inappropriately, or talking incoherently, etc. (see Table 2, p. 64).

It was December, but I remember that I thought it was the middle of the summer and I was sleeping in my bed, in a park. I realized afterwards that it was probably because the sun was shining through the window of my hospital room. It was as if reality was getting mixed up with my imagination and I was making up my own reality based on these two things.

— Frédéric

Protecting the patient

If the health care team judges that the safety of the burned person or the people at their bedside is in serious and immediate danger, cloth ties called *restraints* may be placed on the wrists, ankles or chest. For example, restraints are often put on the wrists of a person experiencing delirium to prevent them from pulling out the tube that allows them to breathe. The team then monitors the patient more closely, and regularly re-evaluates the need for restraints.

The support and presence of loved ones reassures the burned person and helps ease the negative experience of delirium.

Treating delirium

The medical team first treats everything that could be causing the delirium. For example, they make sure that the burned person is receiving the right level of oxygen, that any infections are treated, that medications are adjusted, and that alcohol withdrawal is controlled, etc.

Then, they use antipsychotic medication to shorten the episode and make it less intense, and to reduce the psychosis and agitation. Certain antipsychotic medications have the advantage of controlling pain and nausea and helping the burned person sleep. These medications are given only as long as the delirium lasts and side effects, such as tremors, are closely monitored.

Nurse reassuring the person with delirium.

Maintaining an emotionally healthy environment

We can help the burned person recover by providing an environment in which they feel safe, can get their bearings, and are stimulated and able to communicate.

Help keep the burned person safe.

- Tell the health care team right away if you notice any behaviour that could be dangerous such as trying to get out of bed.

Help the burned person become aware of what's going on around them.

- Remind them often of where they are, the date, and the time of day.
- Repeat the names and roles of the staff who are taking care of them.
- Tell them about the care they have received and what will happen next.
- Give them news about the family.

Help the burned person to communicate.

- Help create a calm atmosphere by talking gently and moving calmly.
- If possible, get the burned person to wear their glasses or hearing aids.
- Ask simple questions.
- Give the burned person only a small amount of information at a time, and repeat it often.

Help the burned person return to reality.

- Don't try to fight against or deny any strange ideas or weird visions that the burned person has.
- Suggest that certain medications could be affecting how they see things or that their imagination may be playing tricks on them.
- Say that you feel safe with and have trust in the health care team.
- Limit the number of visitors.

Help the burned person understand what's happening to them.

- When the burned person seems to have a better grasp of reality, give them some information about *delirium*.
- Reassure the burned person by telling them that the delirium is temporary and will go away.

Staying in intensive care: conclusion

A stay in *intensive care* is an ordeal not only for the burned person, but also for their loved ones.

Too often, spouses, relatives and other family members neglect their own needs, focusing only on the needs of the burned person. Spending hours and hours at the hospital, not eating, not sleeping and not relaxing for weeks or months can lead to exhaustion. **It is hard for a loved one who is exhausted to give the burned person the support they need.**

Loved ones who take the time to rest and continue to take care of themselves are able to give better support, and for a longer period. The next section of this guide is devoted to loved ones and their physical and psychological well-being.

Don't forget that you need support as much as the burned person does, and that it is important to also take care of yourself!

5

A SEVERE BURN IS HARD FOR LOVED ONES TOO

In the days and weeks following the injury, the burned person's loved ones seem very shaken. And for good reason! When someone you love is severely injured, it's normal for them to take over our thoughts. It's as if our world has stopped turning. Our daily lives are turned upside down. Between work, our children and hospital visits, it seems like we can't find any time for ourselves.

While other chapters focus on the burned person, this section focuses on their loved ones. The purpose is to help you too as you adjust to the shock of the burn.

One Saturday morning, I got a phone call from Paul's father. He was calling to tell me that there had been a fire at Paul's place. At that point, he didn't have any more information. He was on his way to the hospital.

For the next twenty minutes, I didn't know if my son was still alive.

They were the worst twenty minutes of my life.

I feared the worst. It was as if I couldn't breathe. I couldn't talk. It's hard to put into words the intense anguish that I felt. I was in a state of shock. I thought, "This is a nightmare. This isn't really happening." Not knowing was unbearable.

— Maureen, Paul's mother

Adjusting to what happened: an emotional rollercoaster for loved ones

Learning that someone you love has been severely burned often brings on a cascade of emotions. No matter what these emotions are, you should **welcome** them and not resist them. It's **normal** to cry if you feel overwhelmed by what's happening. It's **normal** to feel tense and anxious when you don't know if the burned person will be alright.

Some people will, instead, feel detached from their emotions, or emotionally numb. Feeling detached from emotions can be useful if, for the moment, the shock is too much to absorb.

My new motto is: "I think, therefore I cry."

— Extract from diary kept by Julie, Frédéric's spouse

No matter what these emotions are, you should welcome them, not resist them.

Loved ones of severely burned persons report experiencing the following reactions in the days after the injury occurred.

Which have you experienced?

- Impression of feeling overwhelmed by events.
- Anxiety, stress and dread.
- Not sure what will happen.
- Feeling disorganized.
- Feeling that you have lost control.
- Powerless in the situation, feeling like there's nothing you can do.
- Confusion, feeling that you're "not there" that this is "not really happening".
- Angry with the burned person.
- Angry with whoever or whatever you think caused the burns (employer, co-worker, destiny).
- Feeling guilty about how you reacted when it happened (e.g., "I froze.").
- Feeling responsible for what happened, feeling that you could have prevented it from happening.
- Difficulty making decisions.

It's normal to take time to adjust. Give yourself that time.

Preparing yourself to help

The family members and friends of those hospitalized for a severe burn often "forget about themselves" in order to take care of the burned person: "I'm not important! We have to focus on her (or him)!"

Some loved ones spend hours wandering around the hospital or at the burned person's bedside, and forget to eat or rest. They put their lives "on hold."

It is normal to feel the need to be present during the first hours or days of hospitalization. However, once the immediate danger has passed, it is important to take time for yourself.

"Never forgetting my mantra—Sleep, eat, fresh air—helped me to carry on. I knew that otherwise I couldn't stay strong for my son."

— Maureen, Paul's mother

Even if you find this hard to do in the situation, it is strongly recommended that you take care of your health and conserve your energy. **Remind yourself that your ability to support the burned person depends on your own physical and psychological well-being.**

Advice from the experts

Save your energy so you can carry on

In some ways, recovering from a severe burn is like running a marathon. It takes a lot of energy over a long period of time. If the burned person's loved ones run a sprint during the period of hospitalization, they'll become exhausted in no time and run out of the energy they need to finish the race. So, you need a strategy! Take care of yourself from day one so that you can continue to support the person once they return home and throughout their rehabilitation.

Some advice to help you get through this difficult period

Keep yourself informed

The members of the care team—the doctors, nurses and other professionals—are there to answer your questions. Reading this guide can help you understand the information they will give you about the burned person's condition.

The nurses and doctors gave us a lot of information about our son's condition. We also met with the psychologist, who helped us prepare for Paul waking up from the coma. She explained what delirium is and reassured us about it. She also told us what we could say and do to support Paul and help him to get back in touch with reality.

— Maureen, Paul's mother

Get organized

Ask your relatives and friends to take care of the children, run errands or take your place visiting a relative that you may have been caring for before the burn happened. Ask your employer for a more flexible schedule or for a temporary leave of absence. If you live far away from the hospital, find out about the resources that are available for loved ones (e.g., accommodation).

Respect visiting hours

Visiting often, but for short periods, helps the burned person get the support they need to get better. Why not use the time when the burned person is resting to relax? Leave the hospital! Take a stroll in the surrounding neighbourhood. Stop for a bite to eat or, for example, to relax in the park. These are good ways to recharge your batteries. A loved one who is rested will be able to provide more active and effective support.

Maintain a healthy lifestyle

It's very important to eat several times a day. This helps your body and brain to work well, and you need them in this difficult time! If you don't feel hungry, pack small snacks that will give you energy.

- Have food on hand that is both nutritious and easy to eat; cheese, nuts, breakfast bars, dried fruit, or yogurt are good choices.
- Avoid drinking coffee, alcohol, and soft drinks or energy drinks because they will most likely make you feel more nervous and tired.
- Be careful not to react to this difficult time by smoking too much or drinking too much alcohol.

It is also important to go to sleep and wake up at regular times. If you have trouble sleeping, read the section entitled **A "how to" guide to sleeping**, p. 83.

Find time for yourself

Some people simply cannot think about taking time for themselves or doing anything fun when someone they love is seriously ill or injured. But taking time to relax or have some fun can help you recharge your batteries so that you can better support the burned person. Schedule things like taking a walk or having lunch with a friend, just like you schedule your hospital visits. And stop feeling guilty: you have the right to take care of yourself!

I'm going shopping with your mom and the kids, just to take my mind off things. I'm going to buy you a new wallet.

— Extract from diary kept by Julie, Frédéric's spouse

Use the resources offered by the burn unit

Find out what kind of professional help is available (e.g., psychologist, psychiatrist, social worker, spiritual care provider or chaplain) and ask to see the professional that you think will best meet your needs.

Burned person's mother and spouse meet with the burn unit psychologist.

Keep in contact with family and friends

Ask your family members and friends for support and talk to them about your worries. They can take turns coming to visit the burned person rather than coming to the hospital together. This will give you more breaks.

I didn't want all our family and friends to come to the hospital. I wanted to conserve my energy so I could concentrate on my son. So, at the end of every day I would send out an email to everyone who wanted news. This gave me time for myself rather than exhausting myself by repeating the same information over and over.

— Maureen, Paul's mother

Talk about what happened

Having to deal with a serious burn is very hard. Trying not to think or talk about it won't change what happened. Talking about it will help you organize your thoughts and "let off steam." Try to put your feelings into words, even if you find it hard to do. If you are worried, if you feel that life has been unfair, or if you feel discouraged, talk about it.

I try to look on the positive side. My son survived the fire. He's being cared for in a specialized burn centre, he's responding well to the treatments and he's getting better and better every day.

— Maureen, Paul's mother

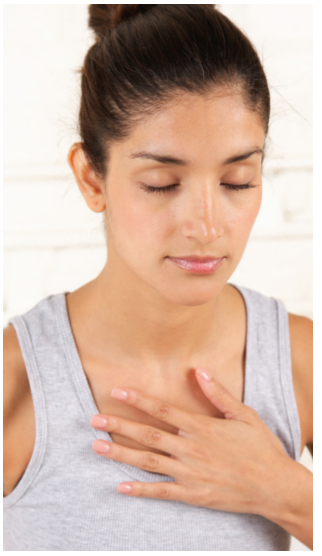
Stop and breathe

When we experience stress, our breathing changes and goes into "survival" mode. Our breathing becomes more rapid and shallow, which keeps the body in an alert state. Air stops at the chest rather than reaching the belly (abdomen). Our muscles become tense and we feel anxious and dizzy. This is why it is very important to try to breathe properly.

Breathing deeply

Deep breathing from the belly is a simple and effective way to relax. It helps you breathe slowly and deeply.

Here are some tips on how to breathe from the belly.



1. Find a quiet place.
2. Close your eyes.
3. Put one hand on your stomach and the other hand on your chest.
4. Take a few minutes to watch how you are breathing: picture the air going into your lungs and the air coming out of them.
5. Try to slow down your breathing.
6. Breathe in SLOWLY through the nose (3 seconds) and try to inflate your stomach.
7. Breathe out SLOWLY through the nose (3 seconds) and say to yourself "Relaaaax."
8. Repeat this as many times as you like (or until you fall asleep!).

For this exercise to work, you should do it for 5 to 10 minutes, several times a day. If you do this exercise often, it will become easier and more pleasant to do and you will feel its positive effects.

When we are stressed, our breathing changes and enters "survival" mode.

A "how to" guide to sleeping

When you are going through a hard time, it is normal to have trouble sleeping, to wake up often, or to have bad dreams.

I was finding it really hard to sleep. I tried to read to get my mind off things, but I couldn't focus. What worked for me? Every night I watched an episode of my favourite TV show. This helped me relax and fall asleep more easily.

— Maureen, Paul's mother

Tips to help you fall asleep

- Burn off energy during the day: keep doing your usual activities (swimming, biking, running). Or just walk!
- Don't nap more than 30 minutes at a time.
- Relax for at least one hour before going to bed. Use this hour to do something pleasant that takes your mind off things, for example, reading a book or watching television.
- Don't go to bed unless you feel like you're getting sleepy.
- Only use your bedroom to sleep or for sexual intimacy (no television, computer, or other electronic devices).
- Avoid smoking, alcohol, coffee, soft drinks or energy drinks after 6:00 p.m.
- Drink warm milk or herbal tea before going to bed.
- Use a breathing or relaxation technique to help you fall asleep.
- Let your thoughts go, abandon yourself to sleep.

If you didn't have trouble sleeping before, then this insomnia should be temporary. If you continue to have trouble sleeping, don't hesitate to talk to a doctor about it.

When the burn injury is traumatic for loved ones

As soon as I shut my eyes, I see my husband going up in flames and then trying, alone, to put them out. This horrible image upsets me every time...

It feels as if my heart's going to burst out of my chest, my hands begin to shake, and I break down in tears. I'm afraid that every time I fall asleep, I'll see this image again. I can't get it out of my mind.

— Susan, Andrew's spouse

Just finding out that someone they love has been seriously injured can be traumatic for family and friends. Some may have witnessed the burn; they may have seen the person in flames and have had to help them. Memories of the burn can keep coming back over and over in the days following the burn and cause extreme distress.

Common reactions of loved ones

- Having repeated and upsetting memories of the event.
- Feeling overcome when something reminds them of the event (e.g., seeing a fire or explosion on television, seeing signs of the fire at home).
- Trying to avoid thinking or talking about the event.
- Losing interest in things that they used to enjoy.
- Having trouble sleeping.
- Finding it hard to concentrate.
- Feeling more nervous, sensitive.
- Acting irritable and impatient.

Even though you find it unpleasant, it is completely normal to think about the burn! Memories, flashbacks and bad dreams give you a sense of what happened and help you get used to it. It is better to let yourself have these thoughts than to try to resist them. As time goes on, these memories will be less frequent and, eventually, they will stop altogether.

If you find that the memories are upsetting you to the point that you are unable to calm yourself down, **don't hesitate to ask the care team for help**. They can direct you to the resources you need.

- Ask family members and friends for help.
- Keep reading this information guide.
- Do deep breathing exercises in the waiting room (see p. 82).
- Talk about what happened with people around you and try to express your feelings.
- Do something fun to take your mind off things.
- Create the right conditions to help you sleep (see p. 83).
- Bring nutritious snacks to the hospital.
- Give yourself time to rest.
- Make an appointment with one of the unit's professionals—the psychologist, psychiatrist, social worker or spiritual care provider.

Selected resources

To help you relax:
Apps (telephone or tablet): Guided meditation & relaxation

To breathe better:
Apps (telephone or tablet): Breathe or Breathing Apps

To help you sleep:
Hauri, P., & Linde, S. (1996). No more sleepless nights (rev. ed.). John Wiley & Sons.

Available on the Internet:
https://medical.mit.edu/community/sleep/resources
http://wellness.mcmaster.ca/resources/relaxation/relaxation.html

When children are involved

By Caroline Berthiaume, PhD, Psychologist

You have children? If so, you may feel that, despite your best efforts, their lives are being turned upside down while the burned person is in the hospital. Children can also feel confused, worried, sad, etc. What should you do to help them? Because you are often feeling shocked yourself, you may be afraid to do the wrong thing... Should you protect them from it all? Should you discourage them as much as possible from thinking about this so that they won't worry even more? Should you talk to them about it? What should you say and how should you say it? These are the questions parents most often ask themselves.

First of all, trust yourself as a parent!

The main thing to remember is that you of all people know your children best. You know how to recognize the signs if they need to talk, be alone or get things off their minds. Trust yourself and use the strategies that have always worked with them (reassure them, give them objects that make them feel safe, spend more time with them, etc.) Each child is different! There are no magic recipes or step-by-step instructions to follow. The only rule is to do your best to support your children so that they feel safe and secure.

Tips to help your children adjust to what has happened

Figure 4 below will help you visualize what will help children adjust to a difficult situation.

Figure 4. Helping your children adjust to your loved one's burn

1 Look after their basic needs

In the first few days after the injury, children feel as disoriented and confused as adults. This is because they are in a state of shock. At this point, no one wants to have long discussions, so you shouldn't try to have one with the children. Instead, focus on looking after their basic needs: eating, sleeping, getting exercise and getting out (try to have the children participate in calm activities as well as physical ones).

2 Try to get back to your usual routine

It is important to try to keep things calm at home. Children will be reassured by familiar things: their toys, their room, and their usual routine. These are points of reference for them. For example, if you normally read them a bedtime story, you should continue to do so.

- Maintain stable routines (morning and bedtime routines, meals, homework), and make sure that the children go to school and participate in their leisure activities (e.g., Scouts, sports, music).
- Try as much as possible to maintain family "traditions" (e.g., Friday movie nights or special weekend breakfasts).
- Respect the same family rules (e.g., following instructions, cleaning their rooms).

3 Focus on your relationship with your children

When a family is shaken by an experience like this, the thing that children fear most is that they will be alone. They also fear that life will never get back to normal. They can become more dependent on adults and not want to be separated from them. You can make your children feel more secure by reassuring them about the bond between you. Take the time to talk with them quietly, looking them in the eye.

- Show your affection through physical contact and comforting gestures. Just being calm and reassuring will often be enough to put your children at ease.
- Accept that your children may be less independent (e.g., need help getting dressed), or that they may need objects to help them get through this period (e.g., blanket, stuffed animal, soother).
- Let your children sleep with you (if you are comfortable with this). Be sure to tell them that this is temporary and that they will have to sleep in their own bed in the near future.
- Take the time to make your children feel secure at specific moments in the day (e.g., leaving for school, or other times when they are separating from you, or going to bed) (see box below).
- Reserve special moments and quality time that are just for your children (e.g., to play with them), times when they have your complete attention.

Advice from the experts

What should I say to reassure my children?

- *I'm here for you. I won't leave you. I won't go anywhere without telling you first.*
- *I'm going to (say where). You're going to stay with (person's name).*
- *Even though (burned person's name) is in the hospital, we're going to do what we usually do.*
- *I expect you to focus on what you normally do: playing, seeing your friends, going to school, doing your chores around the house, etc.*
- *We (grown-ups) have things under control. You don't have to worry about (burned person's name); it's a problem for grown-ups.*
- *The thing that burned (burned person's name) is over. You're safe. (Burned person's name) is safe. The people at the hospital are taking care of him/her.*

4 Surround yourselves with loved ones

Make sure your children feel the support of close family and friends, not just their parents! It is important for your children to get social support from your extended family and friends to take their mind off things. But it is also important for you to have others care for the children so that you get a break when you need it (e.g., sleeping over for a night, going out).

- Put the positive relationships that your children have with other adults to use (e.g., grand-parents, uncles, aunts, family friends).
- Encourage them to be with friends (e.g., get them to invite other children over to play, visit their friends, and play outside).
- Let their school or day care know what happened and keep them informed.

5 Make this experience part of your lives

The approach described above will help most children, no matter how old they are, to cope with the situation.

Supporting your children in the right way will also help create an environment in which you can absorb or "digest" this difficult experience. Figure 5 below shows ways to do this.

Figure 5. Helping your children assimilate the experience of the burn

Did you know

It's all about attitude!

Children often do not have the maturity or experience needed to understand upsetting events. Their reactions will therefore depend more on those of the adults around them. Also, studies have shown that it is mainly the attitudes of adults that help children deal with such events. When the adults stay calm (or relatively calm) and confident, and seem willing and open to meet the children's needs and answer their questions, children are better able to cope.

Follow your children's lead

While some children will need to ask a lot of questions, others won't want to talk about the situation. It is important to follow their lead and not force them to talk about it. There's no need to hurry! Children will absorb what happened at their own pace. Instead, remember to always be ready to listen and show that you are open by keeping a confident attitude.

Talk about what happened

What's most important is to encourage your children to express their own point of view. Encourage them to say what they think, from start to finish, **without interrupting them**. Think about the information they need to feel better. You should give few details at a time, and based on their reactions, decide how much or how little to say. Children don't need all the details about the event. But you should make sure they don't have the wrong impression of events or misinformation about what happened. Examples are thinking that it was their fault, or that someone hurt the burned person, when this is not true. You should correct any misinformation.

Advice from the experts

Help! My children are asking me questions!

- Answer their questions directly, but don't give them details they haven't asked for.
- Give short answers so your children can absorb the information and ask questions.
- The amount of detail you give them may be influenced by the type of incident (e.g., accident vs. violent act), and the child's personality (e.g., avoids or seeks out information), age and maturity.
- Make sure they have understood by asking them to repeat what you have just told them in their own words.

The following conversation and Table 3, p. 94, give examples of what children might ask and how you might reply.

The day Daddy didn't come home

A mother has to explain to her four-year old daughter why her father has not come home from work. There has been a work accident and he has been admitted to a hospital burn unit. He is in *intensive care*.

Daughter: *Mommy, why isn't Daddy home?*

Mother: *Daddy got hurt at work. They're taking care of him at the hospital.*

Daughter: *Can I talk to him?*

Mother: *Daddy's taking medicine that makes him sleep all day. It's helping him rest and get better. When he wakes up, you can talk to him then.*

Daughter: *Does it hurt?*

Mother: *No, it doesn't hurt now because he's sleeping. They're taking good care of him at the hospital.*

Daughter: *When will he wake up?*

Mother: *We don't know yet, but as soon as he wakes up, I'll tell you. The people at the hospital are letting me know about everything they're doing to take care of Daddy. Do you want to ask me any more questions right now?*

Daughter: *No, Mommy. But I miss Daddy a lot.*

Mother: *I have an idea—would you like to make a drawing for Daddy? I can take it to the hospital next time I go.*

Table 3. How to talk with your children about what happened

Situations	Advice
Children want to know all the details, even the most upsetting ones. **What happened involved violence (e.g., suicide attempt).**	If you are not comfortable telling them, or if you know it could upset them, answer: *You don't need to know all the details right now. Maybe we can talk about it again another time. Right now, the important thing is that we're here with you, and you know that we're all safe.*
Everyone tells them that they should not think about what happened.	Don't tell them to forget or to not think about what happened. It is precisely by talking about it that they will be able to absorb this difficult experience.
Children ask the same questions over and over.	They are trying to understand what is happening (or what happened). Just keep repeating what you said, patiently and in a reassuring tone.
You don't know the answer to some questions.	Simply say that you don't have all the answers yet to all of the questions.
You are too upset right now to talk about what happened.	You and your children can choose another time to talk about it. Reassure them by putting into practice some of the suggestions above.
The children have overheard the adults talking	When talking with other adults, be careful about what the children might overhear. Make sure they don't misunderstand what they have heard.

Today, our oldest daughter had an appointment to get vaccinated. At the end of the appointment, her brother told the nurse, "You know, my daddy's in the hospital. He had fire on him and he has big boo-boos."

— Extract from diary kept by Julie, Frédéric's spouse

Encourage your children to express their emotions

It is normal for children to show changes in behaviour and more intense emotions than usual in the days and weeks after their relative has been severely burned. This is an "assimilation" phase during which children are "digesting" and understanding what happened. Parents should not try to prevent their children from expressing their emotions. It is these emotions that help children deal with what has happened. **Your role is to support your children** as they experience and manage their emotions, not to do it for them.

How can you talk about emotions?

The idea is to make your children feel safe in expressing their emotions. Try to make them feel that they can say what they want and not be afraid of worrying or hurting you. You should also encourage them to express their emotions completely (in other words, until the intensity of their feelings has eased).

What should you say?

Again, you should not worry about knowing exactly what to say ahead of time. What children need is for you to be open to their feelings of distress, not for you to calm them down at all costs. Table 4, p. 96, gives suggestions to help your children express their feelings.

- Listen to your children without talking, let them vent.
- Let them express their emotions and acknowledge them (e.g., "You feel angry."), and tell them that their feelings are normal (e.g., "It's normal to feel the way you do when something like this happens.").
- Help them find a solution if they are having a problem or talk more about their feelings so they can release them (e.g., by talking, writing a letter, drawing).

Talk about what's going to happen

Use simple words to tell the children what to expect (treatments that the burned person will receive, how daily activities in the family will change, etc.). Tell them that you are confident in their ability to adjust to these things.

Table 4. How to help your children express their emotions

Situations	Advice
Children refuse to talk about their emotions.	Make sure they are not just avoiding upsetting you. Children may tend to ignore their own distress so they don't further upset their parents. Refer to the box **What to say to reassure your children**, p. 89.
Children can't put their feelings into words.	Suggest that they can use writing, drawing or other forms of art or games. These are all good ways to express feelings!
Children seem to be experiencing intense emotions.	Make sure they can let out all of their feelings until they seem calm again (using the methods described above). You can then reassure and comfort them.
Children are more anxious or stressed than usual. They find it hard to control their emotions.	Show them how they can calm down by breathing deeply and slowly (see p. 82). Explain that these are normal reactions to something that is abnormal for them (something out of the ordinary). Help them to identify what they are afraid of. Give them accurate and realistic information that they can use to reassure themselves. If a problem needs to be solved, find solutions. Tell them that feelings of anxiety eventually go away on their own.
Children express guilt (feel guilty about what happened).	Reassure them by reminding them that they are not in the wrong, and they are not responsible. Get them to put into words why they are feeling guilty. Correct this by giving them the facts.

When is it time to worry? When should you seek advice from a professional?

In spite of the efforts of family and friends in the first weeks, children may still have trouble dealing with what happened. If they continue to show strong emotions and behaviour changes for more than four to six weeks, and if these emotions and behaviours get more intense, you should contact a professional who can help them adjust to what has happened.

Once I was home, a nurse from the community health centre came to change my dressings. The children looked closely at my arms and legs, which weren't the same as before. They seemed to be shy about it, and stayed close to their mother. At one point, I asked my oldest child to come help me. He came over and I gave him the scissors so he could cut through the dressings. From that point on, every morning my son came to help me change my dressings, under the watchful eye of his little sister. Slowly, the children learned to live with Daddy's "boo-boos" and understood that I was the same father they had before, and that I'd get better.

— Frédéric

Notes

6

BURN TREATMENT

The skin acts as a barrier that protects the body from attacks from the environment, such as cold and bacteria. When a burn damages the skin, it makes an opening in this barrier. Without this protection, the body becomes vulnerable. It is therefore important to act fast. An untreated deep burn can become infected and quickly make the person's condition worse.

The aim of this section is to give you information about the main treatments for burns. But each case is different and if you need more information, you should feel free to ask members of the care team more questions.

What is involved in burn treatment?

The aim of burn treatment is to repair the skin as quickly as possible to rebuild the body's defences against bacteria and other invaders from the environment.

This is done in the following main ways:

- washing the wounds and removing the skin that has been damaged by the burn (*debridement*);
- changing dressings regularly;
- replacing the skin that is too damaged to heal on its own with healthy skin (*skin graft*).

The following information will help you prepare for meetings with the doctors and members of the care team. It will help you better understand the care being given to the burned person.

Dressings

Dressings are a very important part of burn treatment. They protect the wounds as they heal. They must be changed very often to prevent infection.

Steps in changing dressings

1. Old dressings are removed.
2. Wounds are checked.
3. Dead skin is removed.
4. Wounds are cleaned and disinfected.
5. Wounds are covered with a clean dressing.

Changing dressings can take a few minutes to a few hours. It all depends on the extent of the burns. Even if the patient is given medication to lessen pain and anxiety before starting this procedure, it is difficult to ease their pain completely. So it is normal for the burned person to feel tired afterwards, and want to rest.

Surgery

Not all burned persons need a skin graft. A burn that is not deep can heal on its own, but is still protected with a dressing. For a deep burn, surgery will speed up the healing and make it easier to control scarring and reduce problems related to scarring.

The surgical team will first carry out a complete evaluation and then decide on a plan of action. In most cases, they decide whether or not to operate in the days following the burn, once the burn stabilizes and they can see exactly how deep it is (see section entitled **Evaluating burns—not so easy**, p. 37).

Preparing for surgery

What is a surgical permit?

The patient must give their consent before each surgery. The plastic surgeon explains to the burned person what is involved in the surgery, the expected results and possible complications. Given that there can be a large loss of blood during certain surgeries, the burned person is also asked to give their consent to allow the doctors to do a blood transfusion, if it is needed. If the patient is not capable of giving their consent, a designated person (e.g., parent, spouse) is asked to do so.

How is the burned person prepared for surgery?

On the night before the surgery, the patient must fast from midnight onwards. If the burned person is awake, the nurse will show them breathing exercises to help them cough up mucus. This will decrease the risk of them getting pneumonia, which can occur with the surgery.

How long will the surgery take?

Surgery can take a few hours because it involves many steps. First, the patient is moved to the operating room and evaluated by the anaesthetist. The surgeon then operates, sometimes on several different parts of the body. Finally, new dressings are put on. **So, you should not worry if it takes a long time for the patient to return to their room.**

This morning, you get your first grafts. You are first on the list. I am with you in spirit!

[...]

Everything went well. Your nurse is nice and answers all my questions. She showed me what a graft looks like.

— Extract from diary kept by Julie, Frédéric's spouse

How many surgeries will the burned person need to have?

The deeper the wounds, and the bigger the body surface area that is burned, the more surgeries will be needed. In addition, if the burned person's condition is unstable, surgeries will be done "little by little" to avoid making their condition worse. Finally, sometimes the surgeon must redo a graft that has not taken well, or has become infected.

Types of surgery

The most common types of surgery for persons with severe burns are *debridement* and *skin graft*.

Debridement

In order for the burned area to heal, it is important to remove the skin that is so damaged that it cannot heal. This is called debridement. It also prepares the burned area for a skin graft.

Skin grafting

Skin grafting or *cutaneous graft* means replacing the skin that has been destroyed by the burn with healthy skin.

The skin used for grafting can come from two places:

- Skin from another part of the patient's own body can be used. This is called *autograft*. The part of the body from which the healthy skin is taken is called the "harvesting site" or the *donor site*.
- Skin can also come from another person who has died. It comes from an organ/tissue donation bank. This is called *homograft* or *allograft*, or "donor skin". This is a temporary graft, which must be replaced later by an autograft.

Table 5. Source of skin and use by type of graft

Type of graft	Where the skin comes from	What it is used for
Autograft	The burned person's own body Healthy skin taken from a *donor site*	To heal wound and form scars.
Homograft/ allograft	Organ/tissue donation bank	To cover wounds with a biological dressing until all the surgeries have been done. To shorten surgery time for severely burned patients. To prepare the burned area for a final graft (autograft), and thus increase the chances of success.

Tracheotomy

If a patient needs to be on a respirator for more than a few weeks, a *tracheotomy* will usually be needed. A hole is created in the front of the burned person's neck and into the trachea (windpipe). A tube is inserted through the hole directly into the airway, bypassing the mouth. This tube is then connected to the respirator to help the burned person breathe. Figure 6 below shows the many advantages of a tracheotomy.

When they did my tracheotomy, I could finally talk to my family and tell members of the care team what I needed. I would let them know that I wanted them to insert the little device so that I could talk.

— Jorge

When the person is able to breathe on their own, the tube is removed and the opening in the neck is covered with a dressing. The small hole left by the tube closes on its own within two to three weeks.

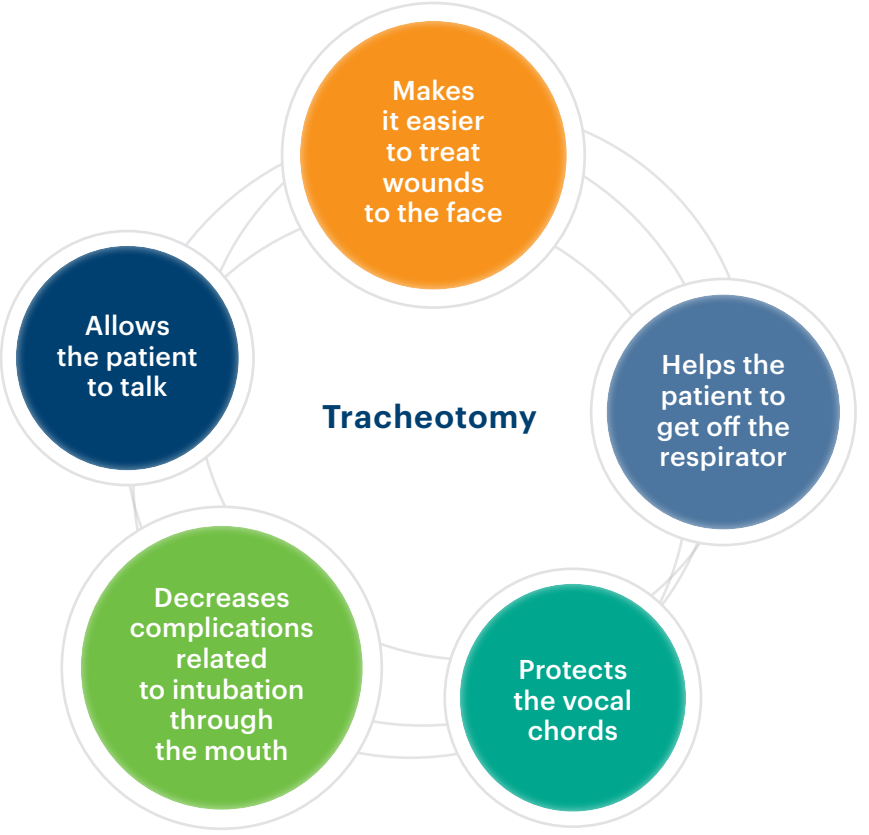


Figure 6. A tracheotomy has many advantages

Secondary reconstructive surgery

Secondary reconstructive surgery is performed after the patient is first discharged from hospital, either months, or even years later. The goals of this surgery are to correct problems caused by scarring and improve their appearance. More delicate areas like the nose or ears can be reconstructed through this surgery.

Flap

Flap surgery is a technique where tissue is removed along with its blood vessels to "repair" an area of the body that was badly damaged by the burn. Tissues may be harvested from skin, muscle or bone. A flap can be used to reconstruct areas where it is unlikely that a conventional skin graft would succeed.

Release of contractures

Contractures are caused by stiff scarring that prevents a joint from moving or causes deformity in a body part (see section entitled **Healing and Scarring**, p. 133). To solve this problem, the surgeon makes an incision in the scar or removes it completely, which releases the hard skin. The surgeon reconstructs the area using skin grafts, a flap or artificial skin (e.g. INTEGRA®). This reconstruction is done to restore normal movement of the joint, or to correct deformities caused by the contracture.

Advice from the experts

Immobilizing the graft after surgery increases the chances of success

A graft has succeeded when it is well attached to the graft site and being fed by the small blood vessels. It is important to not move the graft in order for it to "take". A *splint* or cast can be used to help keep the grafted limb (e.g., arm) immobile. Another way to prevent the graft from moving without immobilizing the patient is to use a *V.A.C.*®. The V.A.C.® is a special dressing attached to a machine. This machine delivers a negative pressure (vacuum) to the wound and helps it heal.

Depending on the area of the body grafted, the patient may have to stay in bed until the dressing is opened, that is, for a few days following the surgery. People who were very active before the burn may find it very hard to stay still. But it is worth it because not moving makes it more likely that the graft will succeed.

Donor site

The area of the burned person's body from which skin is taken to replace the damaged skin is called the *donor site*. Figure 7, p. 109, shows a *skin graft* from a donor site.

What areas are used as donor sites?

Good areas of the body to use as a donor site are those that have smooth, thick skin, for example, the thighs, back and scalp. They are also preferred because the marks left after removing the skin are hidden or are hard to see.

Other areas can be used as a donor site when a large part of the body has been burned and no more skin is available from the thighs, back and scalp. In fact, any unburned part of the body—except for the face, hands and major joints—can be used as a donor site.

If the scalp is used as a donor site, will the hair grow back?

When the head is used as a donor site, usually just a thin layer of skin is removed. This means that the hair root remains on the head, allowing the hair to grow back. It also means that hair will not grow on the graft that has been taken from the scalp.

Why is the donor site so painful?

Most often, only a thin layer is removed so that the donor site can heal as quickly as possible. Removing the skin creates a wound that looks like a superficial second degree burn and leaves the skin raw. This also exposes small nerve endings in the skin to the air, which causes pain.

How long does it take for the donor site to heal?

The donor site heals in 7 to 21 days. How long this takes depends on several things, such as age, hairiness, the patient's health, and the area of the body where the skin was removed.

Will the donor site be scarred?

The donor site usually heals without leaving any scars. But sometimes the skin can change colour, even once it is healed. Certain circumstances make it more likely that there will be scarring at the donor site:

- the donor site has been used several times;
- a problem occurs with healing;
- the patient simply tends to have abnormal scarring.

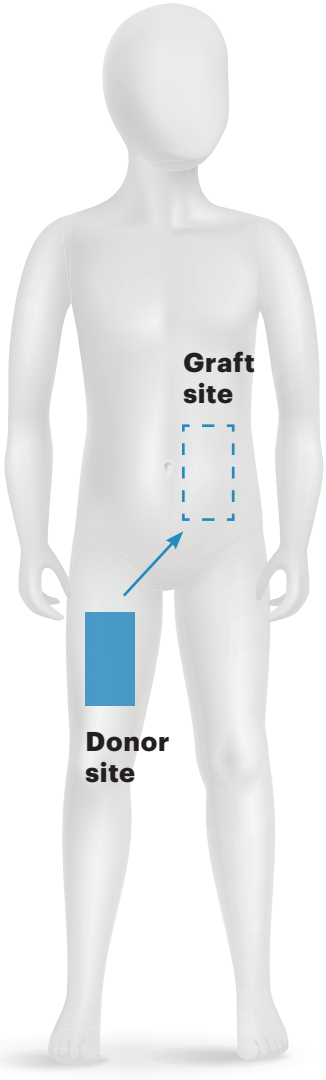


Figure 7. Donor site and skin graft

Find out more...

Circumferential burns, escharotomy... new words to discover

Deep full thickness burns cause the skin to dehydrate and become as tough as leather. If the burn completely surrounds a body part (e.g., forearm, leg) it is called a *circumferential burn*. If the burn is both deep and circumferential, the skin squeezes the limb like a tourniquet. The surgeon must therefore cut into the deep burn to relieve the pressure and allow the blood to flow freely. This surgical procedure is called an *escharotomy*.

They made small incisions so that the blood in your hands could flow.

— Extract from diary kept by Julie, Frédéric's spouse

And a few more new words

When the blood stops circulating in a burned limb (e.g., arm) because of high pressure in the tissues, it is called *compartment syndrome*. This can occur in a number of situations: circumferential burns (tourniquet effect), electrical burns (internal swelling of tissues such as the muscles) and very serious burns to the hands.

This problem can be corrected by an escharotomy, which is described above, or by a *fasciotomy*, which means that the muscle compartment is cut open to relieve pressure and allow the blood to flow again.

An escharotomy allows blood to flow freely when a deep burn completely surrounds a body part.

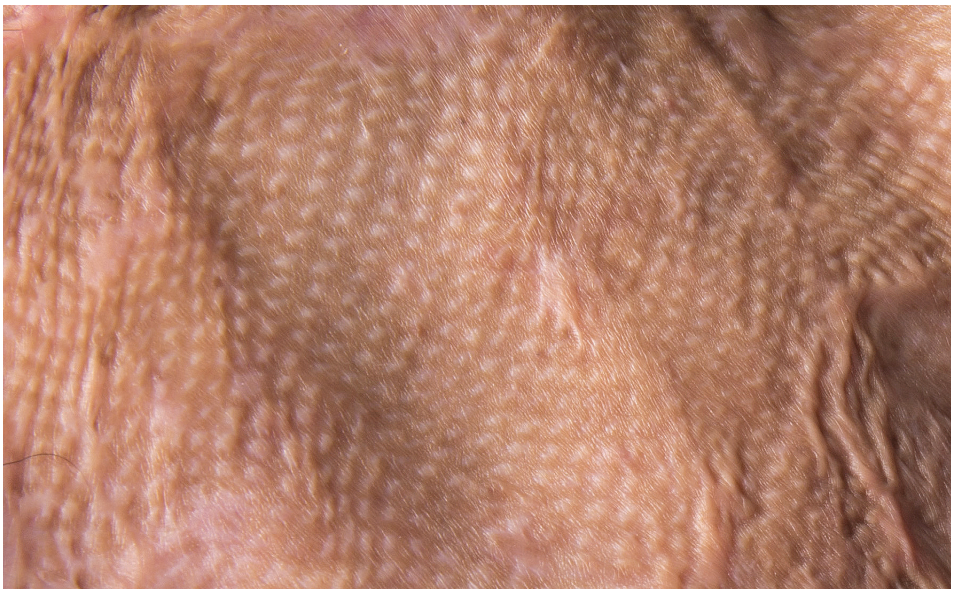
Answers to your questions

Why does the grafted skin look like it has holes?

Grafted skin that looks like it has holes is called a *meshed graft*. This technique involves making evenly spaced slits in the skin taken from the *donor site*, which makes it look like a trellis.

Using meshed graft has several advantages. First, these slits allow the graft to be stretched to cover a larger part of the burned area. This can be very useful when the burn is very large and there few places left on the body where skin can be removed. Using meshed graft also makes the surgeon's work easier when the area to be covered is uneven (e.g., hip). Finally, the small slits in the graft allow drainage of accumulated fluid, which helps the graft to take.

But using meshed graft also has disadvantages. The mesh or trellis pattern can still be seen on the skin even after it heals (see photo below). This type of graft is therefore less attractive than an unmeshed graft.



A meshed graft leaves small marks on the skin.

When are sheet (unmeshed) grafts used?

A *sheet graft* does not have holes. It is more attractive than a meshed graft. For this reason, it is used for areas where appearance is very important, such as the neck and face. Sheet grafts are less likely to contract (shrink), so they are sometimes used to cover the joints, for example, the elbows and knees. These areas play an important role in everyday activities and need to move easily.

Why can't they make the face look the way it did before the burn?

Loved ones often ask why the plastic surgeons cannot use their talent to make the face look like it did before the burn. Aesthetic plastic surgeons work on healthy skin to reduce its imperfections. Specialized plastic surgeons in burn centres work on skin that has been damaged by burns. This is why it is impossible for them to reconstruct the skin so that it looks like it did before it was burned.

Did you know

A math problem

Burn treatment consists in covering the body's burned areas with healthy skin that has been taken from areas that have not been damaged. If 60% of a person's total body surface area has been burned, that leaves only 40% with healthy skin that can be removed—to cover 60%. Not an easy problem to solve!

One method used is to make small slits in the skin that has been removed so that it can be "stretched", but skin can only be stretched so far. Another method is to wait until the first donor sites have healed and to remove skin from the same area again. This would leave the wounds exposed for several weeks, increasing the risk of infection. Instead, skin from a donor (*homograft*) can be used as a "biological dressing" and the burned person's wounds can be covered quickly until a donor site is ready for an *autograft*. It is a temporary solution to the problem because the donor's skin is a foreign body that will eventually be rejected by the patient's immune system.

The patient's condition is monitored more closely in the hours following surgery.

What happens after surgery?

The care team monitors the patient's condition more closely in the hours following surgery. They take vital signs more often, and they monitor the appearance of the dressing for any abnormal bleeding.

Loved ones should expect the burned person to be drowsy and should limit visits on the day of surgery. The stress of the operation and medications given for pain can make the patient sleepy.

Day 31

You couldn't stand not moving any more, surgery after surgery. You were afraid that the doctor would tell you that you needed more grafts. Then finally, it was over!

— Extract from diary kept by Julie, Frédéric's spouse

Don't hesitate to ask members of the care team questions. They are there to help you!

Notes

7

PAIN

All burned persons experience pain. Sometimes this pain can be so bad, it is hard to tolerate—hard not only for the person experiencing the pain, but also for the people who witness it, like their family, friends and members of the care team.

The aim of this section is to help loved ones better understand pain and the things that influence it.

Understanding pain

Where does pain come from?

There are three main types of pain—background pain, post-operative pain and treatment-related pain. Together, these three types can add up to a very intense feeling of pain.

Table 6. Types of pain

Types of pain	
Background	
When is it felt?	Continuous (day, night, when resting).
Where does it come from?	Tissue damaged by the burn.
Intensity	Low to moderate.
Post-operative	
When is it felt?	In the days following surgery.
Where does it come from?	New injuries caused by surgery (e.g., *donor site*), staples, uncomfortable bandages, orthotic devices.
Intensity	Moderate to high.
Procedural or treatment-related	
When is it felt?	During and after certain activities: • cleaning of wounds; • changing of bandages; • doing rehabilitation exercises; • moving around or being moved.
Where does it come from?	Damaged tissue, donor sites, adhesive bandages, stiff joints, etc.
Intensity	Moderate to very high.

Pain is a daily challenge in the burn unit!

When the pain is "all in your head"

One day, I was at a patient's bedside when he said, with disappointment and anger, "It hurts, but the doctor thinks it's all in my head." I answered, "You're completely normal, because pain always comes from our head!"

In fact, hundreds of scientific studies have shown that pain is a **perception** that is constructed in the brain. Of course, the brain first receives pain signals that come from the physical injury, but it then analyzes and modifies these signals. In the end, the pain **felt** is influenced by many things that are specific to the person and their situation (see Figure 8, p. 119).

Did you know

Each pain is unique

Some patients with a small burn describe it as "torture," while others with burns to over half their body tolerate the pain very well. A burned person will feel more pain if they feel powerless to control it and believe that there is nothing they can do to decrease the pain. Patients who are more pessimistic by nature or who are generally more anxious or tense tend to feel the pain more. This shows that pain is a perception that is influenced by many things that are specific to each person.

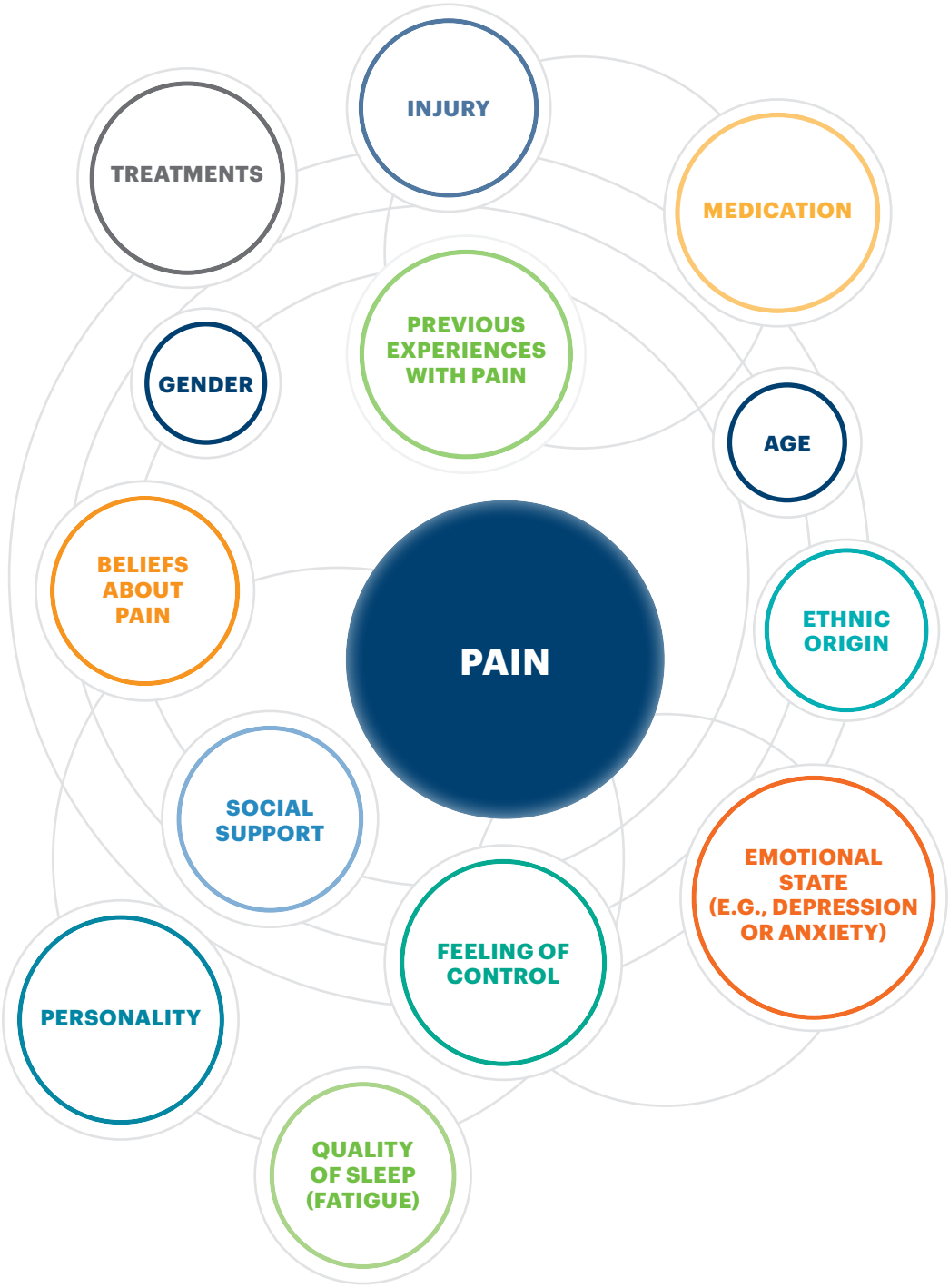


Figure 8. Factors that influence pain

Consequences of pain

No one likes to feel pain. Our natural reflex to pain is to avoid moving. Most of the time, this is the right thing to do because it gives an injury time to heal (e.g., sprained ankle).

Patients with severe burns are the exception to this rule. For their wounds to heal properly, they must move or be moved from the outset of their admission to hospital. Indeed, not moving to avoid pain can have serious consequences for their ability to take up their activities when they return home (see section entitled **Rehabilitation**, p. 149).

Not moving is the worst thing a person can do when recovering from a severe burn.

It is therefore important to **move even if it is painful**. The next section describes ways to help the burned person manage their pain.

Burned person's spouse encourages him to walk despite the pain.

When fear of moving becomes a phobia

Sometimes a burned person may be so afraid of the pain that they refuse to move. This is called *kinesiophobia*. Fear of pain can be a serious problem for burned persons if it prevents them from participating in their rehabilitation. Figure 9 below shows how fear of movement can increase pain. The burned person must understand that pain is not harmful and that by continuing to move rather than not moving, they will be much better off in the long term (see Figure 10 below).

Figure 9. Phobic approach to pain

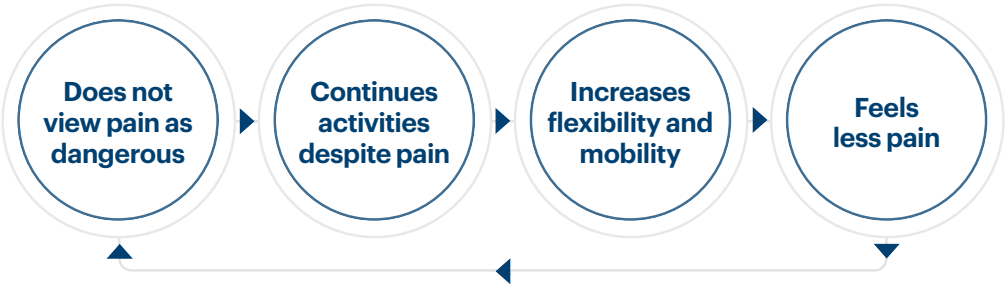


Figure 10. Constructive approach to pain

Did you know

Anxiety increases the feeling of pain

The burned person often feels anxiety because of the burn trauma, medical treatments and pain. A person who is anxious will feel the pain more than a person who feels relaxed. Their muscles tense up and their breathing becomes rapid and shallow. This increases the pain, which then increases anxiety, creating a vicious cycle.

Burned persons are often given an anti-anxiety medication to help them manage pain. But they must also work actively to decrease their anxiety by practising the techniques that they have been taught by the care team.

Managing pain

It is very important to manage pain. This allows the burned person to put all their energy into their treatment rather than wasting that energy to fight intense pain.

Two different approaches, which go hand in hand, are normally used together to control pain:

- pharmacological interventions (medication);
- non-pharmacological interventions (e.g., relaxation).

Controlling pain with medication

Different types of medication are used to help manage pain (see Table 7 below). Some of these medications are so strong that the burned person will need a mechanical ventilator to help them breathe. In these cases, they will be placed in intensive care where they can be monitored by nurses 24 hours a day.

An extra dose of medication is given before the patient's bandages are changed and before they do their rehabilitation exercises. This helps to manage the pain caused by these activities. Patients are also given recommended doses of pain relief medication as needed.

Because anxiety often increases the feeling of pain, anxiolytics (antianxiety medication) are also used to manage pain (see box **Did you know?**, p. 121).

Table 7. Medication used to control pain

Class	Medication	Purpose
Sedative	PROPOFOL VERSED®	Reduces level of consciousness and agitation Relieves anxiety
Analgesic	DILAUDID® FENTANYL MORPHINE® TYLENOL®	Relieves pain and discomfort
Anxiolytic	ATIVAN® RIVOTRIL®	Relieves anxiety Promotes sleep

Can the medication take away all the pain?

A severe burn injury is one of the most painful injuries a person can have. Often the only way to relieve this pain is to keep the person asleep in *intensive care*. This is what is done if required by the patient's condition. But the burned person must be woken up so that they can rebuild their strength and do their rehabilitation exercises.

Can the burned person be given medication whenever they seem to need it?

Morphine and its derivatives are very strong medications that can cause cardiac and respiratory arrest if they are taken in large quantities. Nursing staff are responsible for the patient's safety and must follow the recommended maximum dosage.

Can the burned person become addicted to pain relief medication?

People being treated for a severe burn very rarely become addicted to pain relief medication. This is because, in this context, the medication relieves pain and is not associated with the pleasure or "high" sought by people who are addicted to drugs.

However, if the burned person **already had an alcohol or drug dependency problem BEFORE the burn,** they could have a relapse or develop a new dependency. If this is the case, the medical team should be told about the dependency so that they can adjust the burned person's treatment.

Additional ways to control pain

The following strategies are used together with medication to help patients control their pain (see box below). The aim is to give the patient a sense of control over their pain.

Pain management techniques

- Giving patients information about pain.
- Helping patients view pain in a different way.
- Teaching patients how to deep breathe and relax.
- Teaching patients how to take their mind off pain.

These are safe strategies with no side effects and can be used throughout life. Once patients understand the information they have received about pain and learn the relaxation and distraction techniques, they can use them to manage pain when they return home.

I think that keeping my sense of humour while I was in the hospital helped me to endure all of it. Joking and laughing with the staff and other patients every day helped me to relax.

— Jorge

Because the medication cannot take away all the pain, burned persons must be **actively involved** in managing their pain and apply the techniques and methods they have learned (see Figure 11, p. 126).

The psychologist teaches the burned person a breathing technique (see photo opposite).

What pain means

Pain usually means that there is a danger. For example, pain can signal to a person swimming that they have just walked on a sharp rock. In this situation, pain is very useful because it allows the swimmer to quickly lift up their foot, decreasing the depth of the injury, and to apply first aid.

Our brain is programmed to avoid pain. This is exactly what happens when the burned person must have their bandages changed. On top of being unpleasant, the pain is viewed as "bad" pain that should be avoided.

Even though it is very unpleasant, the pain felt when bandages are being changed **is not dangerous**. It means that the person's wounds are being cared for properly and are healing. Thinking of pain this way helps the burned person to not feel powerless and to tolerate the pain. **We should therefore encourage the patient to view the pain in a different way.**

Figure 11. Other ways to control pain

When I saw the nurse coming to change my bandages, I knew that it would hurt. But I had a choice between seeing my glass as half empty or half full: each bandage change got me closer to my goal of getting out of the hospital and going home to my family.

— Frédéric

Find out more...

Managing pain with virtual reality

By wearing a special helmet linked to a computer, patients can experience virtual reality, immersed in an imagined or "virtual" 3D world. Cut off from their surroundings, they can focus their attention on a video game, for example.

SnowWorld software was designed by psychologists to help burned persons control their pain during bandage changes. In this game, points are scored by throwing snowballs at penguins. Studies have shown that the burned person becomes so absorbed in the game that they are able to forget about the pain.

Virtual reality is effective because it provides **distraction,** which the virtual world makes even more effective.

Source: http://jyliou.blogspot.ca/

The burned person becomes so absorbed by the game that she forgets about the pain.

- Share what you have learned about pain with the burned person.
- Talk about subjects that interest the burned person (to distract them).
- Encourage the burned person to take their medication.
- Encourage the burned person to use pain management techniques (e.g., breathing, distraction).
- Bring entertainment for the burned person (sudoku, movies, video games)[1].

Do you know what helped me with the pain? Getting my mind off it! Watching movies on my laptop, getting involved in my treatments, and visiting with my family and friends. While they were telling me their news, showing me photos or playing a game with me, I had less time to think about my pain.

— Simon

Loved ones can help take the burned person's mind off the pain.

[1] Always ask what infection control measures you should follow before you take an object into the burned person's room.

8

MEDICATION

The care team uses several types of medication to help the person heal and tolerate medical procedures. This section provides an overview of the main medications used to treat burn centre patients.

Medication and burn treatment

The pharmacist helps the care team choose and adjust the medications given to the burned person while they are in hospital. Table 8, p. 131, lists the medications used to treat burns. Several of these medications are only prescribed as needed (e.g., antidepressants).

Did you know

What to do about medications prescribed before the burn injury

It is important to tell the doctor and nursing staff if the burned person was already taking medication before being hospitalized. The medical team will renew these prescriptions while taking into account the medication they are using to treat the burns. **It is very important that the burned person not take any medications brought from home while they are in hospital.** The care team alone will decide which medications are needed. In this way, they can prevent overprescribing or interactions between several different medications taken together.

Table 8. Medications used to treat severe burns

Class	Medication	Purpose
Analgesic	DILAUDID™ FENTANYL MORPHINE™ TYLENOL™	Relieves pain and discomfort
Antacid	NEXIUM™ PANTALOC™ PEPCID™	Protects stomach
Antibiotic	ANCEF™ CIPRO™ PIPTAZO™ VANCOMYCINE	Prevents and treat infection
Anticoagulant	HEPARINE LOVENOX™	Thins blood and prevents development of clots caused, for example, by lack of mobility
Antidepressant	CELEXA™ EFFEXOR™ REMERON™	Treats symptoms of depression
Antihistamine	ATARAX™ BENADRYL™	Relieves itching as skin heals Treats allergic reactions
Antioxidant	MULTIVITAMINS	Helps heal scars
Antipsychotic	HALDOL™ NOZINAN™ SEROQUEL™	Treats agitation and *delirium*
Antipyretic	TYLENOL™	Reduces fever
Anxiolytic	ATIVAN™ RIVOTRIL™	Reduces anxiety Promotes sleep
Diuretic	LASIX™	Eliminates excess fluid Reduces swelling
Sedative	PROPOFOL VERSED™	Reduces consciousness and agitation Reduces anxiety
Laxative	SENOKOT™ LAX-A-DAY™ COLACE™ FLEET™ GLYCERIN	Prevents and treat constipation
Antinauseant	GRAVOL™ ZOFRAN™	Treats nausea

Note. The names of medications are given only as examples. This list does not include all the medications used in burn treatment.

Notes

9

HEALING AND SCARRING

The scarring process is different for each person. It depends on a number of things, such as the depth and size of the burn, and the burned person's age, genetics, and physical condition. The scarring process goes through a number of stages and can last for more than a year following the burn.

It is normal for the burned person and their loved ones to be worried about how the scars will look. The following section should help you to better understand the scarring process and how scars are treated.

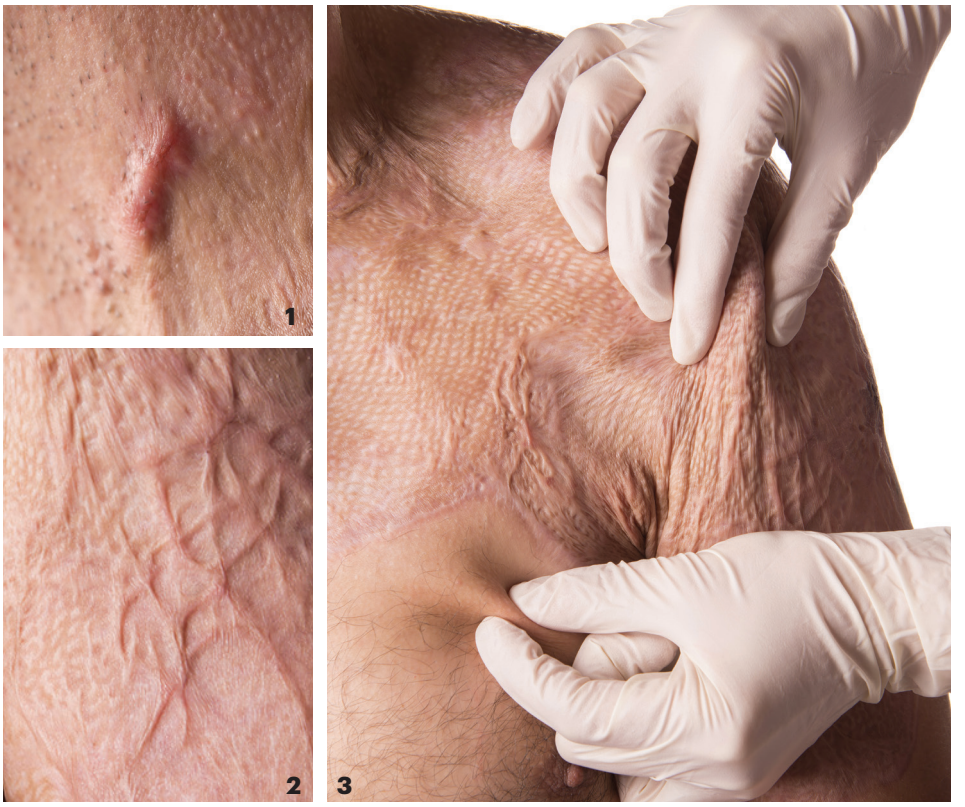
Let's first answer the most frequently asked questions

Will the scars leave permanent marks on the skin?

First and second degree superficial burns usually heal without leaving any scars. However, a 2nd degree superficial burn may leave the skin paler or darker than before. Finally, 2nd degree deep burns and 3rd degree burns leave scarring.

What is a scar?

A scar is a long-lasting change in the skin's appearance. The skin's colour, suppleness or thickness may change (see photos below).



A scar is often more red (1), raised (2) and stiff (3) than healthy skin.

What will the scar look like?

It is hard to predict how a scar will look. Scarring and the scar's appearance are affected by the burn's location on the body, its depth and size, the time it takes to heal, as well as the age and genetics of the burned person.

Burned persons and their loved ones often ask to see photos of scars left by burns or *skin grafts*. It is difficult to meet such requests because no two scars are alike. Seeing the scarred skin of another person could give patients and their loved ones false expectations. The photos in this section are simply examples of possible results.

Apart from its appearance, in what other ways will the scarred skin be different?

A deep burn changes the skin forever. Burned persons notice that their scars:

- are more sensitive or insensitive to touch;
- are sensitive to cold and heat;
- perspire very little or not at all, which makes it more difficult to tolerate hot temperatures;
- do not have hair;
- are more delicate.

Sometimes the scarred skin, which is taut, may make a burned person feel like they are wearing tight clothes.

How long does the scarring process take?

Scarring occurs in several stages and can take from a few months to a few years. People are often surprised to see how much the scar's appearance changes in the first weeks after the burn. **It could take over a year before the scar stops changing.**

Treating scars: a race against time

The natural scarring process: on your mark, get set, go!

All of us have hurt ourselves at one time or another (e.g., scrapes or cuts). These small injuries usually heal without leaving any mark (or almost none). In general, **the faster a wound heals, the smaller the scar.**

In the case of a severe burn, the wound is deeper. The deeper the wound, the more time it takes to close. The longer healing period produces a more visible scar if the wound is left to heal on its own. But using a *skin graft* speeds up the healing process and produces a better result.

The scarring process starts as soon as the person is burned. Scar treatment must therefore begin as soon as possible!

Role of the rehabilitation team

To get the scarring process off to a good start, the rehabilitation team (occupational therapists and physiotherapists) start their work as soon as the burned person arrives in the burn unit. Their most important role is to act as a GUIDE. These rehabilitation experts teach the burned person what they need to do to improve the scarring process.

Did you know

A scar can make it harder to move

Scars that form from a deep burn are not only easier to see, but can also make it harder for the burned person to move if they are on parts of the body that need to move, like the neck, underarms, hands and other joints. If this happens, the burned person will find it hard to return to their usual activities once they have returned home. But by acting fast, this type of problem can be prevented.

The patient is the key person in the treatment of scars

The burned person plays the most important role in the treatment of their scars. They must be **actively** involved and do the exercises they are given by the rehabilitation experts **every day,** from the beginning **to the end of the scarring process**.

It goes without saying that patients who are unconscious or confused are treated by the rehabilitation team until they are able to take care of their scars themselves.

The burned person plays the key role in the treatment of their scars.

Burned person doing exercises to increase finger strength.

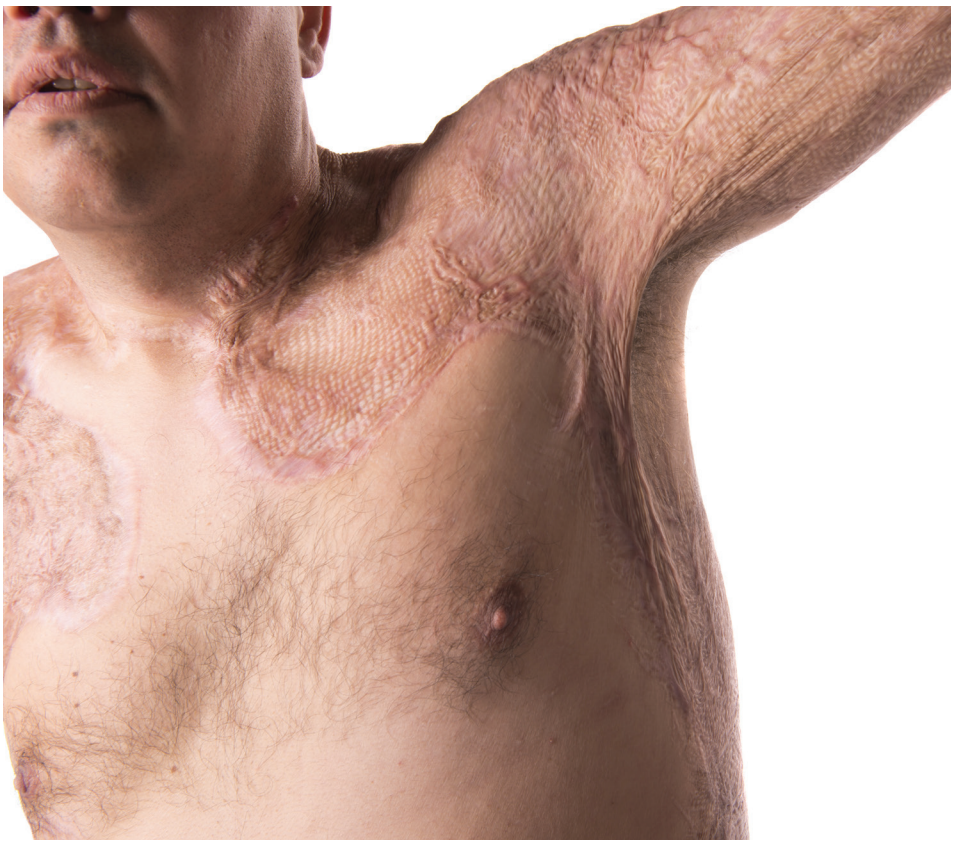
What problems are linked to scarring?

Tightening of the skin

When the body is injured, it tries to close the wound. This pulls on the skin around the wound, making it "contract."

Once the wound heals (on its own or with grafting), the scar can get tighter. It is as if the scar "shrinks." This can continue for weeks, months, or even more than a year.

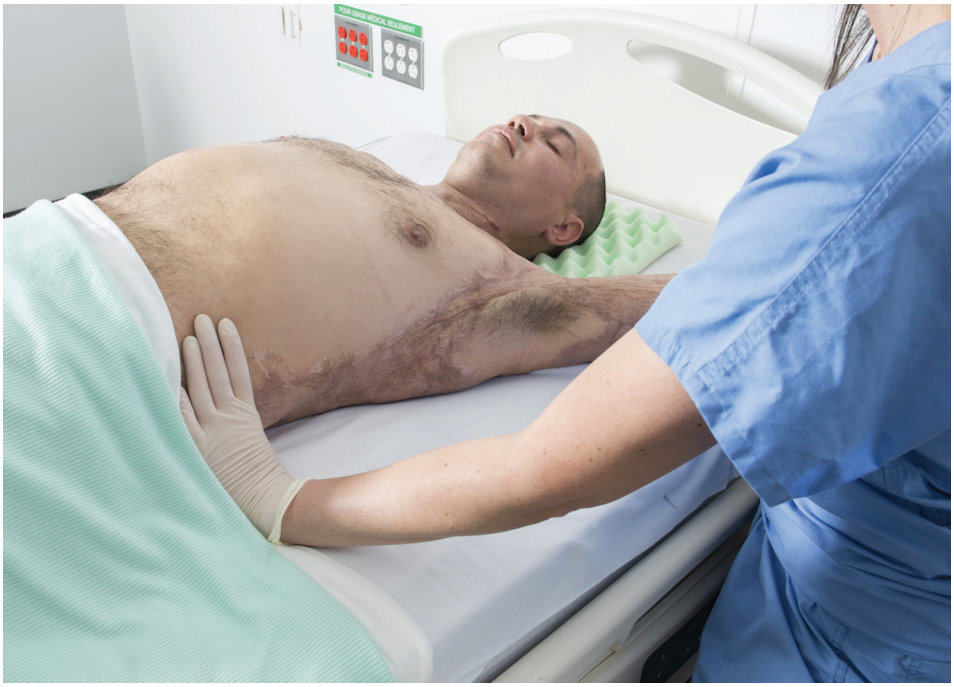
To sum up, as the skin damaged by a deep burn heals, it shrinks. It can become so stiff that it limits the burned person's ability to move. For example, a patient whose underarm was burned may no longer be able to completely lift their arm (see photo below). This loss of movement is called *contracture*.



Underarm contracture.

Methods to reduce tightening of the skin

- Stretching the scar, using exercises taught by the physiotherapist.
- Placing the body in a position that stretches the skin and/or ligaments when in bed.



Physiotherapist stretches the scar to make the skin more supple.

Hypertropic scar

A *hypertropic scar* is raised, stiff and very red (see photo opposite). These scars can appear from a few weeks to a few months after the burn, so it is very important for the burned person to **continue to take care of their scars even if the scars seem to look fine.**

This type of scarring is more common among people who have deep burns, and among younger patients, those who have darker skin, and those whose wounds take longer to heal.

I'm still not sure. What will my scars look like? I wonder if I'll be as strong as before or weaker, and I wonder whether or not I'll be able to move the way I did before.

— Frédéric

Methods to improve the scar's appearance

The following methods are used to improve the appearance of scars (see Figure 12, p. 141):

- wear *pressure garments* **at all times** (see section entitled **Advice from the experts**, p. 142);
- massage the scar 3 to 5 times a day, or as instructed by the rehabilitation team;
- moisturize the scar 3 to 5 times a day with an odourless, colourless moisturizing cream;
- use SPF 60 sunscreen for 2 years following the burn.

The rehabilitation team starts working on the wounds as soon as the wounds can benefit from their work, even before the patient leaves their hospital bed. If grafting was used on the burned area, the team will have to wait a few days, until the graft is stable enough, before beginning their work.

It's normal to find the first few months hard because you can't see the results of the rehabilitation exercises right away. You have to keep at it and persevere to reach your goals!

— Frédéric

Did you know

The sun has a negative effect on the appearance of scars

It is very easy for scars to get sunburned. Scars that are exposed to the sun can turn brown (hyperpigmentation) up to two years following the burn. This happens as soon as the person is exposed to daylight. The sun's rays pass through clouds and glass (e.g., windows or car windshield).

But life must go on! It is important for the burned person to continue to do the things they like, such as going to the beach with friends or participating in outdoor activities. When doing these things, the burned person must protect their scarred skin by wearing thick or sun-protection clothing, or by applying SPF 60 sunscreen to their skin.

Massage the scar

Moisturize the scar

Wear a pressure garment

Figure 12. Methods to improve the skin's appearance

Pressure garments

Pressure garments are elastic, very tight and tailor-made to fit each individual's body. They are designed to compress the scar, which softens and thins it. Pressure garments are always used when the skin has been grafted or if there is a risk of a hypertrophic scar forming. For pressure garments to work, they must be worn **day and night, 7 days a week.** Of course, the burned person can remove their pressure garments to wash themselves, have a bath, take care of their wounds, or while having intimate relations.

A burned person removes his pressure garment to wash (himself or herself).

Advice from the experts

Getting the most out of pressure garments

Pressure garments should not be removed for more than **60 consecutive minutes** at a time and it is best to wait another **2 hours** before removing them again. This allows the pressure garment to do its job and makes it more effective.

Obstacles to scar treatment

In an ideal world, scars would be treated properly, every day, until the scarring process is complete. This would produce the best possible result.

The rehabilitation team teaches the patient what to do to help the scars heal properly. The burned person must then **continue to care for their scars just as carefully and regularly** when they return home.

Unfortunately, a number of things can work against the burned person caring for their scars properly, both while they are still in hospital and once they leave (see Figure 13 below).

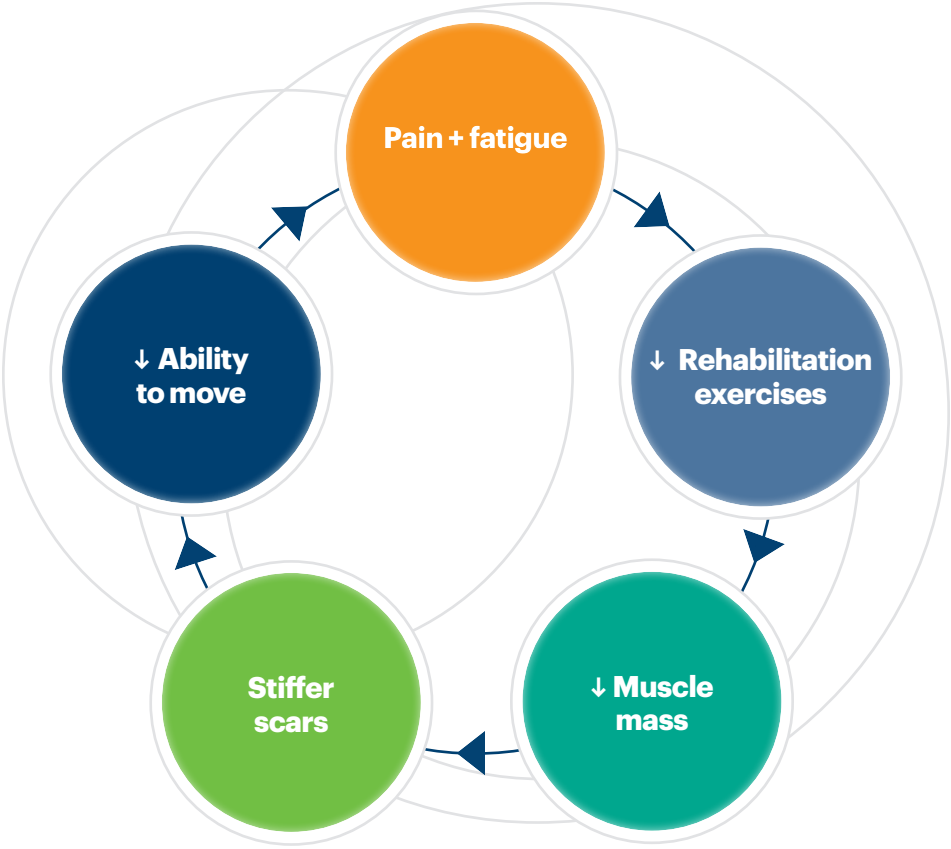


Figure 13. How pain and fatigue can work against scar treatment


POUR USAGE MÉDICAL SEULEMENT
LIFT TO RELEASE SIDERAIL

Obstacle #1: Pain

Doing exercises and caring for scars can be uncomfortable or painful. So it is normal for the patient to want to avoid this pain. They might tell themselves, "I'll do the exercises when I've healed or when it's less painful." That is the worst thing they can do! For example, a person with burns to the hands must continue to open and close their fists as their scars heal. If not, they may not be able to bend their fingers. So patients **must be convinced to do their exercises even if they find it uncomfortable.**

Obstacle #2: Mental and physical fatigue

Rehabilitation exercises must begin in the days immediately following the burn, while the person is still in shock over what happened. In addition, they may be tired and sleepy because of the medication they are taking, making it even more difficult to get organized and be disciplined about doing the exercises recommended by the rehabilitation team.

Obstacle #3: Mistaken belief that the exercises are pointless

Some patients think that the recommended exercises cannot help them. They think they can "do it on their own" even though they have been given information on the consequences of not taking care of their scars.

The scars may at first look fine, giving the burned person the idea that they can stop caring for them and doing the exercises. This is a big mistake! It is important to **continue the treatments,** because *hypertrophic scars* can begin to form a few months following the burn.

Given these obstacles, all members of the care team as well as family and friends must join forces to encourage the burned person to put in the effort needed to care for their scars.

Why does the rehabilitation team put emphasis on the burned person doing the recommended exercises?

Burned persons often do not feel like moving because they feel tired, because it hurts to move, or because they are still in shock over what happened. Despite all of this, why is it very important to convince them to move?

There is a very short window of opportunity for preventing or decreasing loss of mobility caused by scarring. Once the damage is done, it is very difficult, if not impossible, to undo it. So, it is better to work hard early on, **even if it is painful and uncomfortable**. This will increase the burned person's chance of one day being able to return to their activities of daily living (see Figure 14 below).

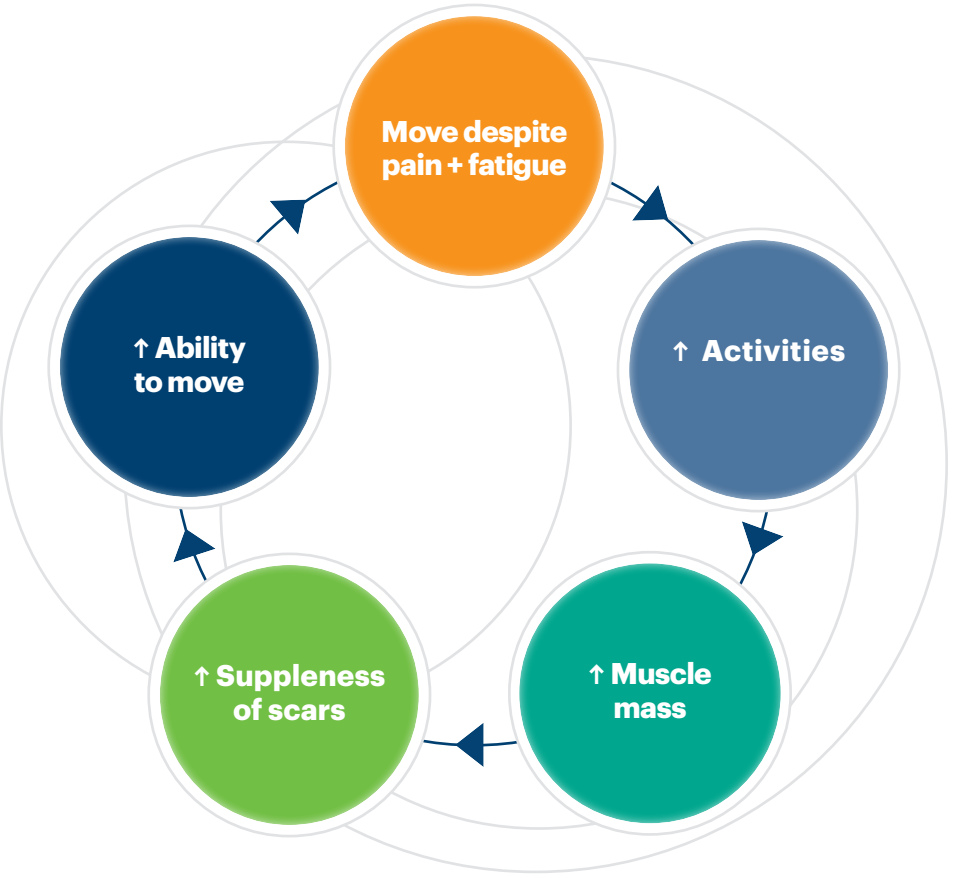


Figure 14. Benefits of moving despite pain and fatigue

- Open the curtains and turn on the lights in your loved one's room.
- Find out about the exercises recommended by the rehabilitation experts and encourage the burned person to do them.
- Let the burned person do things by themselves (e.g., eat, pour a glass of water, use the phone), even if doing so is painful or takes a long time.
- Encourage the burned person to sit up in a chair or visit with them outside their room (in the burn unit) if it is allowed.
- Ask the burned person about the progress they have made with their activities (e.g., brushing teeth, walking) and encourage them to carry on.
- Bring the burned person things that they like to do (e.g., Sudoku) and follow the unit's rules for preventing the spread of infection.
- Make sure that the burned person does not expose their wounds/scars to the sun.

Advice from the experts

Loved ones can help with scar treatment

A family member or friend can help the scars to heal properly by letting the burned person do things on their own. Ask the care team what the patient is allowed to do. By encouraging the patient to hold their own utensils and eat on their own, you are allowing them to fully use their fingers. That's the best gift you can give your loved one!

My friends took a group photo of themselves making funny faces and my mother put it up in my room. I looked at it often, and it cheered me up.

— Simon

Notes

10

REHABILITATION

A burned person may sometimes have to stay in bed for several weeks, or even a few months, when they are in the hospital. Staying in bed for such a long time does not agree with the human body. Remaining in one position can cause problems, for example, pressure sores, joints that become *ankylosed* (fused) and muscle weakness.

The rehabilitation team works to prevent these problems and help the burned person function as close as possible to the level at which they did before they were burned.

My family motivated me: "Things will be fine, you'll be able to teach your grandson to play soccer!"

— Jorge

The role of the rehabilitation team

Preventing pressure sores

Pressure sores are caused when pressure is placed on a part of the body for a long time. This can happen if a person stays in bed for several days. So, they are sometimes called "bed sores".

The occupational therapist uses different tools, such as foot positioning boots and cushions, to take the pressure off areas of the body that rest against the bed, for example, the heels, tailbone, elbows and head (see photo below). They can also use special mattresses.

The physiotherapist also helps to reduce the risk of getting pressure sores by moving the patient as soon as possible. Getting the burned person to walk, asking them to sit up in a chair, and encouraging them to do their exercises are all ways to get the patient out of bed and prevent pressure sores.

Did you know

Staying in bed causes muscles to waste away

The longer the burned person stays in bed, the smaller their muscles become. The body does not like to feed things that are not being used. That is why muscles get smaller or larger depending on how much they are used. But do not worry—the burned person can regain endurance and muscle strength by doing the exercises that are prescribed for them.

Preventing ankylosis

A joint that does not move tends to become more and more stiff (ankylosed). Not moving can damage the joints, making the person unable, for example, to extend their arms or bend their knees.

Even when the burned person is confined to bed, every day the physiotherapist moves (mobilizes) their joints to prevent *ankylosis*. And the occupational therapist encourages the patient to carry out activities of daily living (e.g., eating) on their own. Carrying out these activities moves the joints, which also helps to prevent ankylosis.

- Encourage small day-to-day victories (e.g., sitting, lifting arm, scratching nose).
- Encourage the burned person to:
  - do more things themselves (e.g., eating, blowing nose);
  - do the exercises that they have been taught by the rehabilitation team;
  - do the suggested respiratory exercises and cough to get rid of secretions;
  - sit in a chair (e.g., for meals) and spend less time in bed **if the care team approves of this.**
- Walk around the room and up and down the corridor with the burned person **if the care team approves of this**.

In short, encourage the burned person!

The secret to successful rehabilitation is … moving!

When walking becomes a feat

The doctor told me that there would be no more surgeries. Wonderful, I'd soon be able to go home! But first, I had to get out of bed... and walk. I'd hardly moved for 35 days. Feeling happy, I tried to move to the edge of the bed, but I couldn't do it. I managed to prop myself up on my arms for five seconds before falling back to sit on my bed. Unable to try again, and exhausted, I slept for at least an hour.

The next day, my physiotherapist brought me a walker. But my legs wouldn't work and this upset me. My muscles didn't have any strength and I had no sense of balance. The orderlies finally helped me to get up. Enough for one day!

The next morning, I was able to reach the chair. Five small steps and I was drained. So, I had to have a rest before I could make the return trip to bed.

I could have been discouraged, because it is discouraging! But instead, without telling anyone, I decided to surprise everyone and use my own two feet to get to the rehabilitation centre. So, I exercised as much as I could, with my wife's help, with the physiotherapist, and, finally, on my own. The day I left the hospital to go to the rehab centre, I walked behind the wheelchair. What a victory!

— Frédéric

Advice from the experts

Focus on achievements

Focusing on **small** steps forward motivates the burned person and encourages them to get involved in their rehabilitation. In contrast, those who compare what they can do now with what they could do **before** the burn can get discouraged, slowing down their progress.


EASE SIDERAIL

Notes

11

ADJUSTING TO A SEVERE BURN

A person who has been severely burned experiences a trauma that is both physical and psychological. So, it's normal for them to feel shaken by what has happened.

The burned person must not only adjust to the burn, but also get used to being in the hospital, which is made even harder if they are in *intensive care*.

The aim of this section is to give the burned person's loved ones information about the less visible, psychological sides of being severely burned.

Adjusting to being in the hospital

A person who is going through a bad experience wants, more than anything else, to be in the comfort of their own home, surrounded by their loved ones. But because a severely burned person needs specialized care, they find themselves in the hospital, surrounded by strangers. The medical procedures are intrusive and often painful: tubes and sensors, needles, surgery, and bandage changes. Even if the aim of this care is to help the patient get better, it is still unpleasant.

Burned persons often experience the following reactions:

- anxiety, nervousness;
- trouble sleeping;
- nightmares or bad dreams;
- difficulty concentrating and forgetfulness;
- fatigue;
- irritability or aggressive behaviour;
- frequent mood swings;
- lower appetite;
- anxiety about medical procedures.

These reactions are stronger and happen more often for those in *intensive care*.

You can't stand having any more surgery, and being in the hospital. You realize that your life has been turned upside down. You're afraid of what's going to happen in the next months. You'd like to be home, and have our old life back.

— Extract from diary of Julie, Frédéric's spouse

- Be reassuring: “You’re being taken care of in a specialized unit.”
- Be there by their side, hold their hand, and say “I’m here.”
- Be understanding when they get irritable or have mood swings.
- If the burned person is in *intensive care*, consult the **Intensive Care** section, p. 48-72, to find out how you can provide support.
- Take them drawings made by their children, messages of encouragement and photos of loved ones.[1]

Advice from the experts

Put yourself in the burned person’s shoes

Often what loved ones think does not match the real needs of the burned person, which may be very basic, like being able to drink water, sleep, or get to the toilet on their own. But their loved ones are already thinking about next steps, like rehabilitation and returning to work. This is why you will often hear members of the care team say, “We’ll wait and see, we’re not there yet.”

[1] Always check with a member of the care team before taking an object from outside into your loved one’s room.

Adjusting to a severe burn, one step at a time

Studies of the psychological reactions associated with severe burns have identified the following stages of recovery[2]. The burned person goes through each of these stages at their own pace. Because each person is different, psychological healing can take a few days to several years.

1 Feeling anxious about survival

I recognized the hospital from its colour and the sound of the machines. I couldn't feel my arms or legs. I imagined the worst. When I found out that I had been asleep for a month, I realized right away that I was in a coma. That made me panic.

— Simon

2 Coping with pain

Every day brings pain, but along with it, the comforting knowledge that this means one less day of tolerating pain.

— Frédéric

3 Looking for meaning

I ask myself the same question over and over: why... me? I am looking for a reason, for an explanation that could prevent me from seeing the reality: sometimes, life is simply unfair.

— Frédéric

[2] Based on Watkins, P.N., Cook, E.L., May, S.R., & Ehleben, C.M. (1988). Psychological stages in adaptation following burn injury: A method for facilitating psychological recovery of burn victims. *Journal of Burn Care and Rehabilitation*, *9*(4), 376-384.

4 Playing a full part in recovery

We can dream about what we were before and live in the past and have regrets, or we can choose, and I want to emphasize CHOOSE, to focus on what we want to regain and set goals to do it. This is how we can overcome obstacles and make the impossible a reality.

— Frédéric

5 Accepting what has been lost

Little by little, I'm realizing that life will never be the same and I have to deal with it. Refusing to accept this new reality—as sad as it may be—and to get involved in treatment, will only delay returning to a normal life.

— Frédéric

6 Playing a full part in rehabilitation

I spent several months in the rehab centre so that I could regain my mobility and physical abilities. Every day, I accepted help from the staff and I worked hard to get back what was dearest to me: my family life.

— Jorge

7 Developing a new identity

Your life is not over; it's just different. What do you want to do with your new life? What do you want to contribute to the world? What is really important for you?

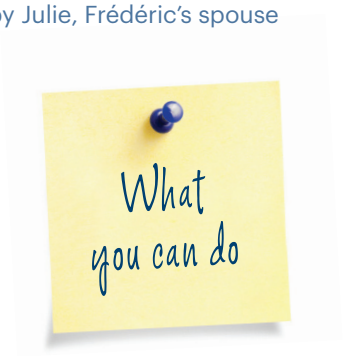
— Simon

When support makes all the difference

The support of people around you (family, friends, co-workers, employer, medical staff) is one of the best predictors of how a person will adjust to burn injury. In other words, the support you give to the burned person will have an effect on their physical and psychological healing. Giving them good support involves simple acts: being by their bedside, holding their hand, smiling, listening, and saying "I love you."

When we are alone, you start crying. I don't know what to say any more to make you feel better. I often have the impression that there's not much I can do for you. But you tell me that just having me there makes you feel better. Just the fact that I stay with you while you eat supper means a lot to you.

— Extract from diary kept by Julie, Frédéric's spouse



- Show the burned person that you support them with affection, a smile and encouraging words.
- Listen to the burned person's feelings about the burns and their effects without judging them.
- Avoid criticizing the burned person.
- Ask family members and friends for messages of encouragement so that you can read them to the burned person.

My brother set up a Facebook page where my friends, family and acquaintances could send words of encouragement. Some of them posted photos and videos of good times we had had together. My parents printed out the comments and brought them to me until I had access to the Internet. It was so encouraging and made me feel so good.

— Simon

Learn to embrace emotions

Loved ones often find it hard to let the burned person talk about their feelings freely, especially when the feelings are negative. But this is an important stage in adjusting to a burn injury. It's normal for the burned person to be angry when they believe that another person is responsible for what happened to them. It's normal for them to cry when they realize that they have changed forever and will have to live with limitations every day (e.g., not being able to bend a limb, looking different). But talking freely about their emotions will help them let off steam and relieve pressure.

Is the burned person crying? In this situation, it may be best to put a hand on their shoulder and tell them, "You can cry, I am here to support you."

I was so angry with my employer. I was boiling inside. I'd told him so many times that the work lamp wasn't safe. If he had listened to me, all this would never have happened!

— Richard

Even the strongest feelings will eventually become less intense, as long as they can be felt, accepted and expressed.

How should you react if the burned person is angry?

Loved one: *How're you feeling today?*

Burned person: ... (Silence)

Loved one: *Aren't you happy to see me?*

Burned person: *No, it's not that.*

Loved one: *What is it then?*

Burned person: *I just talked to my boss. He said that he wasn't going to fire that guy who forgot to shut off the safety valve. He says it was just an accident. (The burned person clenches his hands into fists and looks angry. There are tears in his eyes.) I don't understand how they can do this to me after all the years that I've worked for them!*

✔ A loved one who encourages the burned person to talk about emotions may react by...

Giving the burned person room to experience their emotions fully and express them.

For example:

- letting your face and body language show that you understand what the burned person is experiencing;
- putting your hand on their arm to show support;
- acknowledging and validating their emotions: "I understand why you are disappointed and angry about your boss's decision.";
- probing further by asking questions: "What would you like to say to your boss?".

✕ A loved one who wants to shut down emotions may react by saying...

"You shouldn't let them upset you. They're not worth it! Stop thinking about it. Look, I brought you your favourite magazine."

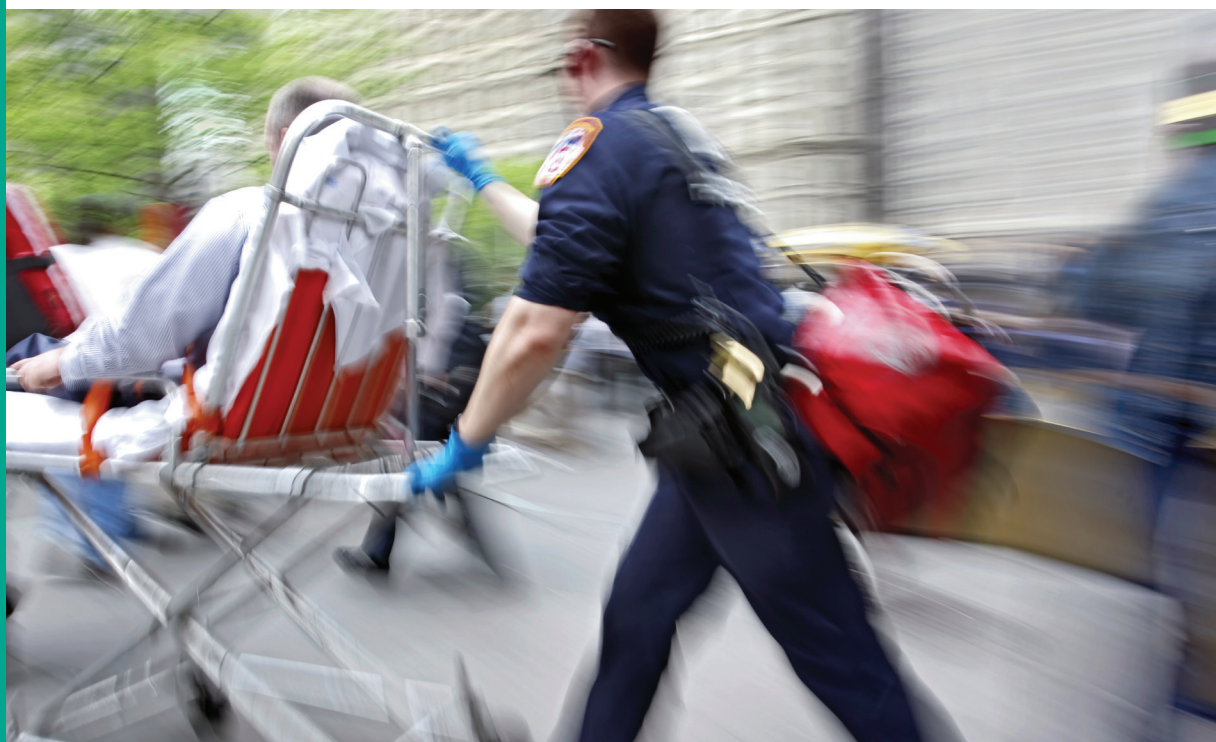
What not to do: encourage the burned person to avoid their emotions, rather than feeling and expressing them.

Post-traumatic reactions

A severe burn can be a traumatic event because the person has been seriously injured. The burned person may also have been afraid of dying or being disfigured. So post-traumatic reactions often occur during the rehabilitation period following the burn (see Figure 15 below).

Figure 15. Post-traumatic reactions

A severe burn is considered to be a traumatic event.



Find out more...

Feeling dissociated or cut off from reality

High doses of medication lower the burn patient's level of alertness. It may seem that they are "not all there." But sometimes the burned person may still seem numb and "in their own world" even after the medication doses have been lowered. Why?

In some cases, being detached from reality is due to *delirium*, a short-term confused state (see section entitled **Delirium**, p. 63).

It felt once like I was outside my own body and was looking down at myself lying in the hospital bed. My imagination helped me travel to several different places and this made me feel very peaceful.

— Jorge

In other cases, it may be due to *dissociation*, a defence mechanism that allows the person to more gradually absorb the nervous shock associated with the event. Does the burned person seem strange, as if they are detached from their feelings and do not realize that their injuries are serious? Are they unable to remember certain facts surrounding the burn and seem to have some blanks? They may be in a state of dissociation.

It is important to note that dissociation is often short term and goes away on its own.

It can be normal to feel detached from our emotions or to forget what happened (amnesia) if, for the moment, we find it too hard to deal with the shock.

Reliving the event

The burned person may feel that they are re-experiencing the incident over and over again. This may take the form of:

- intrusive memories (e.g., remembering rolling around on the ground);
- flashbacks or feeling as if the incident is happening again (e.g., smelling burnt odour, seeing the ball of fire coming towards them);
- nightmares or bad dreams;
- feeling upset when something reminds them of the incident (e.g., seeing a fire or explosion on television, feeling the heat of a furnace or coffee).

Understanding and helping

It is common to relive the event in the days following the burn. This seems to help the person "digest" what has happened and make it part of their life. If the burned person is **willing to re-experience what happened and welcome unpleasant memories** instead of resisting them, little by little, the memories will fade and then disappear altogether.

Being "on edge" or wary

Some burned persons say that they have been feeling like a "bundle of nerves" since the incident. They are on their guard, day and night. Signs of this are:

- problems falling asleep or staying asleep;
- irritability or aggressive behaviour;
- problems concentrating;
- feeling that something bad is about to happen (hypervigilance or mistrust);
- being easily startled;
- feeling agitated, tense or nervous.

Understanding and helping

These reactions mean that the burned person is in "survival" mode and is not yet feeling secure. **Relaxing and stress-reducing activities**, as well as the support of loved ones, can help soothe them.

Avoiding reminders of the event

Some severely burned persons tend to avoid or run from anything that reminds them of what happened. Signs of this are:

- avoiding **the cause of the incident** or something similar (e.g., a person who was burned by boiling water refusing to eat soup, an electrician who got an electric shock staying away from electric wires or sockets);
- not wanting to see **images of the incident or to think about it** (e.g., trying to think of something else, watching television or sleeping more than needed);
- avoiding **feelings** associated with the incident. For example, a person who was burned while trapped under a vehicle could react badly to not being allowed to move following surgery. They may be trying to avoid "feeling trapped" again;
- not wanting to **talk** about the incident. For example, getting angry or changing the subject when people close to them ask questions about the burn; not letting friends, co-workers or their employer visit to avoid having to talk about what happened.

Understanding and helping

Someone who has been in great danger (like being burned) will do everything they can to protect themselves and avoid being in the same situation again. This is a normal survival reaction.

So, it is normal to no longer want to use gas to get a fire going in the fireplace, since this is dangerous. But it becomes a problem if the person avoids doing safe everyday activities (e.g., lighting the fire in the fireplace with paper, cooking, or returning to work).

As soon as possible, the burned person should gradually start to **carry out their normal activities, even if it feels uncomfortable.** This feeling should go away within a few weeks.

- Let nursing staff know if the burned person seems to be acting strange or to be "in their own world."
- **After a few days,** encourage the burned person to talk about what happened, **at their own pace.**
- Be understanding if they become irritable and have mood swings.
- Encourage the burned person not to avoid reminders of the incident (e.g., talking with a co-worker).
- Tell the burn team if the burned person's post-traumatic reactions are intense and persistant over time.

Post-traumatic reactions are seen as normal reactions to an abnormal event. In most cases, they will disappear on their own after a few weeks.

Adjusting to one's new appearance

A severe burn changes the appearance of the burned person's skin as well as their own body image. A number of things affect how the burned person will react to this change:

- their age and sex;
- the appearance of the scarring;
- the location of the scarring (will it be visible or hidden?);
- how important body image was to the burned person and their loved ones before the incident, etc.

Burns to the face

The face has an important role in our social, romantic and professional lives. It is part of our identity. The impact of a burn to the face goes beyond simply healing the skin.

Loved ones often feel worried and helpless when it is time to talk with the burned person about their facial burns. Here are some answers to the questions they most often ask.

Who should tell the person that their face has been burned?

Most patients know when their face has been burned because their wounds are being treated and their facial skin feels different.

But they still have to be told how severe the burn is and whether their face will be scarred. It is better to wait until the burned person asks about it and is ready to hear the answer. The best people to answer their questions are medical staff (doctor and nurse). A loved one should be there to support the patient when they are given this information.

At first, I purposely put aside the fact that my face had been burned. I already had enough to worry about!

— Simon

When is the burned person "ready" to hear how bad their facial burns are?

First of all, the burned person must be capable of **fully understanding** this information. Giving them bad news (e.g., face severely burned, limb amputated, person died in the fire, house written off) should be delayed if the patient is confused, disoriented or experiencing *delirium*. But a patient who is fully awake, oriented in time and space, and asking questions, is considered to be "ready" to hear this news.

The first time the psychologist came to see me, I didn't feel ready to look in the mirror. We just talked about it. I wanted to know more about what my face looked like.

— Simon

What should I tell the burned person if they ask about their face?

Honesty is the best policy, whether the burned person asks nursing staff or a loved one. The simplest thing to do is to describe their face in neutral terms: mention which parts have been burned, describe the skin's colour and texture, etc. **Do not** use words that suggest **judgment**: "It's beautiful/ugly."

What do I do if the burned person asks me for a mirror?

If the burned person is fully awake and says that they are ready to look in the mirror, there's no reason to say no.

The doctor should first tell the patient how serious their burns are and how the skin is expected to change so that the burned person can put their image in the mirror into context. A 2nd degree superficial burn that is just a few hours old can seem frightening (intense red colour, swollen, scabs), but will have completely disappeared in a few weeks.

Finally, when the patient looks at their face, a loved one should be at their side to give them the support they need.

Finding out how badly my face had been burned was really tough. I thought I'd be stigmatized, that children would be scared of me, and that I would be sexually unattractive. My family and friends kept saying, "Of course not, you're handsome!", but I didn't believe them. I would have preferred them to be more realistic rather than trying to gloss over the situation.

— Simon

- When they are ready, talk with the burned person about their reaction to these visible changes.
- Make sure that the burned person has been told how serious their burns are and how the skin is expected to change.
- Be available to support the burned person when they look in the mirror for the first time.
- Stay honest. Do not try to hide the facts or make things sound better than they are.

Helping the burned person adjust to what happened: the role of the psychosocial team

Every major burn centre relies on at least one psychosocial professional who works closely with the medical team.

This professional can be a:

- psychiatrist;
- psychologist;
- social worker;
- psychosocial specialist nurse;
- spiritual care provider (e.g., chaplain).

The role of the psychosocial professional is to support the burned person during their recovery to help them adjust to having been severely burned.

Examples of what members of the psychosocial team can do

- Provide support and be a good listener.
- Decrease the burned person's anxiety about medical treatments.
- Teach pain management techniques.
- Provide information on *post-traumatic reactions*.
- Offer loved ones support.
- Help find and complete forms to apply for disability income (e.g., insurance).
- Help find accommodation if housing was destroyed by the fire.

Psychologist evaluates the burned person's capacity for adjustment (see photo opposite).

When we're in the hospital, we've got a lot of time to think and cry. We don't want to do that with friends and family. Of course, we know that they're sad! But we need to think of other things and have contact with the outside world. So, bring in photos, videos, music, and books on topics that would interest your burn-injured loved one. If they like reading but aren't able to do so, read to them. Tell them about what's going on in your life and give them news about their friends. Bring them good food! Eating good food is sometimes the only thing that will still give them comfort.

So, we need to be encouraged, but also to be understood. When you're discouraged, nothing presses your buttons like talk that is overly positive and far from reality. The best form of encouragement is constant, but gentle. No pressure, no comparison with heroic acts, no nagging. Just be there and encourage your loved one to stay positive, nothing more.

Listen to their frustrations as well. Always remind yourself that they aren't frustrated with you. If the burned person gets mad at you, DO NOT take it personally. They are upset by the situation, THEIR SITUATION. And, after all, this frustration can sometimes be very constructive.

— Simon

Ask the care team which psychosocial professionals are available on your burn unit.

12

WHAT'S NEXT?

Once the surgeries have been completed, the burned person can be discharged from hospital. In some cases, for example, when *delirium* lasts a long time or wounds take a longer time to heal, it will be necessary to wait until the situation improves before allowing the patient to leave the burn unit.

The purpose of this section is to provide an overview of the next steps after discharge from hospital.

Discharge

At last! The surgeries are over and the wounds are healing. The burned person will probably soon be discharged from the unit. If so, depending on the burned person's needs, they will be referred to a rehabilitation center or return home. This decision is based on several factors, such as the severity and location of the burn, the evolution of the wound, the person's ability to move around on their own, and the support available from loved ones at home.

Lots of emotions!

The burned person and their loved ones often report feeling all sorts of emotions as they get closer to the discharge from hospital. On the one hand, they feel joy at moving on to another stage of healing. On the other hand, they feel the stress of having to continue recovering without the daily support of the healthcare team. The burned person may wonder, "Will I have enough strength to get up, get dressed, move around? Will my loved ones be able to take care of my wounds properly?" For some, leaving the hospital will seem like a relief. For others, it may seem that they are leaving the nest, and create strong feelings of anxiety.

Don't hesitate to ask the healthcare team questions.
They are there to help you!

For some, leaving hospital is a relief.

Follow-up

Medical follow-up

Remember that you are not alone! When the burned person returns home, the healthcare team will arrange for follow-up care with community caregivers. For example, home care can be arranged with a local community service center. The burned person may need follow-up for changing dressings, examining wounds or rehabilitation. The healthcare team will provide all the information needed before the burned person is discharged from the burn unit. In most cases, the burned person will need follow-up at an outpatient clinic. This will continue until the goals of wound healing and rehabilitation have been achieved.

Psychosocial follow-up

If this service is available, encourage the burned person to contact a psychosocial professional (e.g., psychologist, social worker, mental health nurse) after they leave hospital to help them through their recovery. The box below gives examples of symptoms that indicate that the burned person should seek help.

When to ask for help?

- Disturbing memories of the event that caused the burn.
- Nightmares that keep coming back.
- Trouble sleeping that will not go away.
- Avoiding situations related to the burn.
- Fear of resuming activities related to the burn.
- Fear of returning to work.
- Anxiety that will not go away.
- Feeling sad, crying often.
- Continued loss of interest in favourite activities.
- Excessive use of alcohol, drugs or medication.

The role of loved ones

No matter what happens, it is important for the burned person to continue to follow the recommendations made by the care team. The box below lists some of the tasks that should be carried out to help wounds heal and the burned person function on a daily basis. Several things can make it hard to achieve these objectives. Fatigue, pain, and feeling fed up or discouraged can lead the person to give up on their treatments. The support of loved ones is therefore as important, if not more important, after the burned person is discharged from hospital than it was when they were still in hospital.

You can show your support in a number of ways: having the burned person stay at your home temporarily, going with them to appointments, keeping in contact to see how they are doing, encouraging them to do their exercises, taking care of the children or preparing a meal.

Some recommendations for the burned person

- Go to follow-up appointments (physician, rehabilitation, etc.).
- Change dressings regularly.
- Consult a health care professional without delay if wounds become infected.
- Wear *pressure garments* every day.
- Take proper care of scars (moisturize and massage) every day.
- Do the recommended rehabilitation exercises.
- Keep as active as you can.
- Before going out in the sun, apply sunscreen to scars and wear clothing that covers them.
- Avoid smoking, drinking alcohol or using drugs.
- Adopt a healthy lifestyle.

13

BECAUSE LIFE GOES ON

It is now time for the five severely burned people who kindly agreed to share their experiences with us throughout this guide to tell us how their stories turned out (see section entitled **Because each person's story is different**, p. 19, to read their stories again).

You may be feeling anxious about the days and weeks ahead as your loved one will soon be leaving hospital. What these severely burned people show us below is that, despite the challenges, life can still be beautiful. Surrounded by their loved ones, they describe how far they have come since being burned.

Every day is a gift

Today, I am thankful to still be alive. The doctors said I had no chance of surviving, but I did. I survived thanks to God, my family, and the caring people who helped me, but also because of my determination.

Ten years on, I have been blessed in another way: my wife, my daughter and I have become Canadian citizens. Since being burned, I've been lucky to make true friends and meet wonderful people, including some who were severely burned, like me. I'm involved in my community: in a support organization for the severely burned, in visiting hospital patients, and as a church animator.

Despite the aftermath of being burned, I continue to make progress. I've returned to work and can once again support my family. When you wake up in the morning with dreams, you have two choices: you can go back to bed and keep dreaming, or you can get up and work toward making your dreams come true. I decided to fulfill my dreams and I succeeded.

Jorge

Jorge sustained burns to 90% of his body when his apartment caught fire.

Choosing your battles wisely

On November 12, 2006, I found out how easy it could be to lose what was most important to me—seeing the beautiful smiles of my three children every morning and being able to simply savour that moment.

It's been eight years since the accident, and my life has got back on track. Today, I realize what an enormous challenge I faced and how hard I've worked to have a normal life again. People still stare when I go by (because of the scarring from my burns), but it's up to me to get used to that. I've realized over time that it's our own attitude about our appearance that influences how people treat us and look at us.

I learned that it's useless to fight against what has already happened. That's just a waste of energy. I decided to roll up my sleeves and set my sights on the future. I'm fighting for my family so that we can once again have a good life full of happiness and joy.

Today I am proud of what I've achieved: I'm happy that I gave myself the time to get healthy and recover what I lost in the accident. Eighteen months ago when I ran just a few kilometres, I was exhausted. But after a lot of hard work and good training, I recently finished my first half-marathon. For me, there's nothing more beautiful than pushing yourself beyond your limits.

Frédéric

Frédéric sustained burns to 50% of his body in a go-karting accident.

Reorganizing yourself so that you can get on with life

I moved in with my parents after three months in intensive care and two months in a rehabilitation centre. I was disfigured, there were bandages to change, and I couldn't wash myself on my own. I had a hard time believing that I could ever become independent again or even that anyone could be attracted to me.

Four months later, I moved into an apartment and met my new partner. My hand still doesn't work properly, which means that I've had to change some of my activities. I can't climb any more, but I do a lot of hiking, biking and snowboarding. I've also had to change my line of work because I used to do manual labour.

Today, three years after my accident, I have completely gotten back my social life. I'm now working with some friends to start up a micro-brewery in my own region. Being successful at these things has given me back my self-confidence.

I've had to reorganize my life and take up other activities, but the most important thing, in my view, is that I've pursued my interests and that I live by the same values.

Simon

Simon sustained burns to 52% of his body while climbing a hydro tower.

Focus on the beautiful things in your life

After two weeks in hospital, many appointments as an outpatient, and psychotherapy to treat post-traumatic stress disorder, I finally learned a new trade, as a technician repairing recreation vehicles (RVs).

I've worked for a few years in this field and am now preparing for semi-retirement. I work a few days a week as a maintenance man in retirement homes. I like this work because I can go at my own pace and I'm surrounded by really nice people. I also have some plans for next year: starting up my own small business repairing motorhomes and offering on-site personalized service at campgrounds.

Being burned turned my life upside down, but some positive things also came out of it. Today, I pay more attention to the beautiful things around me and to everyday small pleasures. But the greatest gift is that because of what happened, my wife and I rediscovered each other and made a fresh start.

Richard

Richard sustained burns to his face, arm and left hand (4% of his body) in a work accident.

A life-changing experience

It has been three years since the fire. This may sound weird, but I can't—and I don't want to—imagine what life would be like if I had not been burned. I have taken this experience with me and it is now part of who I am. I have learned things about myself—about my strength, my courage and my self-efficacy—that perhaps I never would have learned, or learned much later in life. I appreciate my life more than ever. I thought that being burned would be debilitating, depressing and forever limit me, but I was wrong. I thought that wearing pressure clothes would be embarrassing and take forever, but it went by fast. I thought that people would stare at me or be disgusted by my scars, but those people were few and far between. Each time my predictions were proven wrong and with every step, I became happier and stronger. I try to find ways to use my experience and help others confront obstacles, even with minor things. On the morning of the fire, in a literal flash, I was transformed. I became a different person, and I love who that person is.

Paul

Paul sustained burns to 18% of his body when his apartment caught fire.

14

RESOURCES

Each situation is different and some may require actions that are not mentioned in this section. Ask the care team about available resources in your area.

Loss of housing / property

Loss of income / inability to return to work

Loss of ID cards

Support associations and organizations for severely burned persons and their loved ones

Canada

Entraide grands brûlés (Montréal and western Québec area)
www.entraidegb.org (in French only)

Association des grands brûlés F.L.A.M. (Québec City and eastern Québec area)
www.grands-brules.ca (in French only)

Calgary Firefighters Burn Treatment Society
www.cfbts.org and **Facebook**

Camp Bucko, Burn Camp for Kids in Ontario
www.campbucko.ca and **Facebook**

Alberta Fire Fighter Burn Camp
www.efbts.ca/camp

Cape Breton Firefighters Burn Care Society

British Columbia Professional Firefighters' Burn Fund
www.burnfund.org and **Facebook**

Firefighters Burn Fund Victoria, B.C.
www.firefightersburnfundvictoria.ca and **Facebook**

Canadian Burn Survivors Community
www. canadianburnsurvivors.ca and **Facebook**

Mamingwey Burn Survivors Society
www.mamingwey.ca and **Facebook**

Manitoba Firefighters Burn Fund
www.burnfundmb.ca and **Facebook**

Nova Scotia Firefighters Burn Treatment Society
www.nsffbts.ca

Saskatchewan Professional Firefighters and Paramedics Burn Fund
https://spffpaburn.ca

United States

Burn Survivor Resource Community
https://burnsurvivor.com

Burn Survivor Support Group
www.hopkinsmedicine.org/burn/support-group.html

Burn Survivors Support Group for Patients and Families
https://burn.jacksonhealth.org/burn-support-group

Burn Survivor Support Programs
https://burninstitute.org

IAFF Foundation Burn Fund
https://foundation.iaff.org

Messages to Burn Survivors from Burn Survivors
https://scarglobal.org/messages-to-burn-survivors-from-burn-survivors

Phoenix Society for Burns Survivors
www.phoenix-society.org

Survivors for Good
https://survivorsforgood.org

Yuma Child Burn Survivor Foundation
on **Facebook**

Additional information on severe burns

Fact sheets on severe burns
www.msktc.org/burn/factsheets

15

GLOSSARY

Loved ones sometimes find it hard to understand the health care team's explanations about the burn and its treatment. Words they haven't heard before, like *escharotomy, debridement* and *phlyctena*, make it seem like people are speaking to them in a foreign language.

The purpose of this section is to help you understand the words commonly used on a burn unit.

Allograft
See *homograft*.

Ankylosis
Decrease in ability to move a joint because it has stiffened. *Ankylosis* occurs when the burned person remains immobile for too long.

Antipsychotic medication
See *antipsychotics*.

Antipsychotics
Medication that prevents or treats the symptoms of *psychosis*, such as hallucinations. This medication can also be used to treat anxiety or to help the burned person sleep.

Autograft
Surgical procedure where the burned skin is replaced with healthy skin taken from the patient's own body.

Bronchoscopy
Medical examination where an optic fibre connected to a camera is inserted into the bronchi. The doctor can use a *bronchoscopy* to see if the burned person's airways have been damaged by smoke.

Catheter
Long thin tube inserted into a body vessel or cavity to distribute fluids to the body or remove them.

Cellulitis
Skin infection that spreads beyond the wound. It causes the skin to become red and swollen, and it is hot to the touch and can be painful.

Circumferential burn
A burn that completely surrounds a body part (e.g., forearm, leg).

Coma
In the case of a severely burned person, the word coma means a state of deep sleep induced by strong doses of medication.

Compartment syndrome
Medical problem that arises when the blood stops circulating in a burned limb (e.g., arm) because of high pressure in the tissues.

Contracture
Stiff scar that limits movement of a joint or deforms a body part.

Critical care
See *intensive care*.

Cutaneous
Related to the skin. Subcutaneous tissues: the tissues beneath the skin.

Cutaneous graft
Surgical procedure where the burned skin is replaced by healthy skin.

Debridement
Medical or surgical procedure to remove skin that is dead or so badly damaged by the burn that it cannot scar. *Debridement* helps prevent infection and promotes healing. Debridement is also used to prepare the burned area for a skin graft.

Degree of burn
Describes the burn depth. The *degree of burn* depends on the layer(s) of the skin that are damaged. A 1st degree burn is the least severe (e.g., sunburn) while a 4th degree burn may affect the muscles and bones.

Delusion
False perception or belief associated with losing touch with reality. For example, the burned person might believe that others want to hurt them.

Delirium
About 20% of burned persons experience *delirium* while they are in intensive care. The patient is less aware of their surroundings and what is happening to them. Their ability to perceive and think is disturbed. They may seem lost or confused, or act strangely. They can have *hallucinations* or become suspicious. Delirium is temporary.

Dermis
Thick layer of skin beneath the *epidermis*. The dermis contains blood vessels, nerve endings, sebaceous glands and sweat glands.

Dissociated
In a state of *dissociation*.

Dissociation
Adjustment and defence mechanism that allows the person to more gradually absorb the emotional shock. A person in a state of *dissociation* may seem to act strangely, be detached from their emotions, not be aware of the seriousness of their injuries, have the impression that what is happening is not real, be unable to remember the accident, or have some blanks.

Donor site
Unburned part of the body from which healthy skin is taken for an *autograft*.

Edema
Swelling.

Electrified
A person has been *electrified* when an electrical current has travelled through their body. This results in a visible skin burn in two places, that is, at the current's point of entry and at its point of exit.

Epidermis
Visible, superficial part of the skin that constantly replaces itself.

Eschar
Localized destruction of the skin by a deep burn.

Escharotomy
Surgical procedure where an incision (cut) is made in the deep burn (*eschar*) to relieve the pressure and allow the blood to flow freely. This procedure is carried out when a burn is deep and *circumferential*.

Extubated
A person has been *extubated* when the tube connected to a *mechanical respirator* has been removed.

Fasciotomy
Surgical procedure where the muscle compartment, called the fascia, is cut open to relieve pressure and allow the blood to flow freely.

Feeding tube
Used in a medical procedure where the patient is fed through a tube, providing all the nutrients they need.

Flap
Flap surgery is a technique where tissue is removed along with its blood vessels to "repair" an area of the body that was badly damaged by the burn. Tissues may be harvested from skin, muscle, bone or a tendon. A *flap* can be used to reconstruct areas where it is unlikely that a conventional skin graft would succeed.

Full thickness skin graft
Skin graft that includes the entire *epidermis* and entire *dermis*.

Hallucination
Sensory perception of something when there is no real stimulus. For example, seeing people or hearing them talk when they do not exist.

Homograft (allograft)
Surgical procedure where burned skin is replaced with healthy skin from another person who has died. The skin comes from an organ/tissue donation bank. A *homograft* is always temporary because the body will eventually reject it. It must be replaced with an *autograft*.

Hypertrophic
See *hypertrophic* scar.

Hypertrophic scar
A scar that is very red, thick and hard.

Inhalation burn
See *inhalation lesion*.

Inhalation lesion
Burn to the airways caused by the heat from smoke or toxic fumes.

Integra®
Biosynthetic skin substitute produced in a laboratory.

Intensive care
Set of medical procedures aimed at maintaining or recovering the function of vital organs such as the heart, lungs and kidneys.

Intermediate care
Range of care given to patients when their health is stable but they need surgery or special care for their wounds.

Intubated
A person is *intubated* when a doctor has inserted a tube in the *trachea* that is connected to a *mechanical respirator* to help them breath. The person who is intubated cannot talk or eat.

Intubation
Medical procedure where a small tube is inserted through the mouth or nostril into the *trachea*. This tube is connected to a *mechanical respirator* that provides air to the lungs to help the patient breathe.

Isolation gown
Long garment, made of cloth or synthetic material, worn to prevent the transmission of germs between visitors / health care staff and the burned person.

Kinesiophobia
Reluctance to move because of fear of pain.

Mechanical respirator
Machine that provides oxygen through a tube inserted into the burned person's *trachea*. The respirator helps the patient breathe when they cannot breathe on their own.

Mesh graft
Skin graft that has been perforated, giving it the appearance of a trellis, so that it can be stretched.

Perineum
The area between the thighs, from the tail bone to the pubic bone.

Phlyctena
Blister (liquid-filled bubble) formed by fluid lifting the *epidermis* away from the underlying *dermis*.

Post-traumatic shock
A series of manifestations observed following a traumatic event (such as a severe burn). Examples are having nightmares, being "on edge" or wary, and having trouble sleeping.

Pressure garment
Elastic, very tight garment that is tailor-made to fit the body to compress the scar, so as to soften and thin it.

Psychosis
Psychological state characterized by a loss of contact with reality.

Psychotic symptom
Sign of *psychosis*. *Hallucination* and *delirium* are psychotic symptoms.

Restraints
Cloth ties placed on the burned person's wrists, ankles or chest to limit their movements, ensuring the safety of the patient and the people at their bedside. They are used only when there is a serious and immediate danger.

Skin graft
See *cutaneous graft*.

Split thickness skin graft
Skin graft that includes the entire *epidermis* and part of the *dermis*.

Sheet graft
Skin graft without holes, used especially for the joints and areas where appearance is important (e.g., neck, chest, face).

Shrinking
See *skin retraction*.

Skin retraction
When scars heal, the skin tightens and loses its elasticity.

Splint
Therapeutic material used to keep a body part immobile.

Subcutaneous
Beneath the skin.

Trachea
Forms part of the airways between the mouth and lungs.

Tracheotomy
Medical procedure where an incision (cut) is made at the base of the neck and into the *trachea*. This allows a tube to be placed directly into the airway, bypassing the mouth. This tube is then connected to the *respirator* to help the burned person breathe.

V.A.C.®
The *V.A.C.*® is a special dressing attached to a machine. This machine delivers a negative pressure (vacuum) to the wound and helps it heal.

Ventilator
See *mechanical respirator*.

Acknowledgements

First, our heartfelt thanks to the **loved ones of the patients hospitalized** in the burn unit of the Centre hospitalier de l'Université de Montréal (CHUM) who evaluated the first version of this guide. Your comments allowed us to produce an improved version of the guide that truly meets the needs of loved ones.

We would like to thank the **burned persons and their loved ones** who agreed to tell their stories and thus convey a message of hope.

Thanks to **Entraide grands brûlés** for funding the costs of computer graphics and printing for the first version of the guide.

We would like to thank the **Fondation des pompiers du Québec** for funding the research costs related to evaluating the first version of the guide.

Our thanks also go to the **team members of Unité des grands brûlés du CHUM** (CHUM Burn Unit) for their judicious comments.

More specifically, we would like to thank:

Jenny Waloch, Nurse

Magalie Roy, Nurse

Marjorie Lévesque, Nurse

Martin Bergeron, Nurse

Paule-Marie Kirska, Nurse

Perle Arcand, Nurse

Rachel Villard, Nurse

Cathy Dallaire, Nurse and Consultant in Specialized Care

Sylvie Dubeau, Head Nurse

Claude Boucher, Patient Care Attendant

Nathalie Morissette, Intensivist

Louise Duranceau, Plastic Surgeon

Nicolas Bergeron, Psychiatrist

Karine Daoust-Soucaret, Social Worker

Anita Ang, Pharmacist

Geneviève Thériault-Poirier, Occupational Therapist

Maria Calandriello, Physiotherapist

Valérie Calva, Occupational Therapist (Villa Medica Rehabilitation Centre)

Thank you to **our collaborators** who believed in this project and invested their time and energy in creating the guide:

Hugo Rivard-Royer, Deputy Director General, Fondation du CHUM (2012-2015), for funding the publishing and printing costs of the final version of the guide.

Élodie Grange, , Director of Communications, Fondation du CHUM (2011-2015), for her support in the production of the guide.

Nicolas Bergeron, Psychiatrist, **Unité des grands brûlés du CHUM** (CHUM Burn Unit), for writing the section on delirium.

Caroline Berthiaume, Psychologist, Hôpital Rivière-des-Prairies, for writing the section on intervening with the children of a severely burned person.

Geneviève Thériault-Poirier, Occupational Therapist, **Unité des grands brûlés du CHUM** (CHUM Burn Unit), for her collaboration in drafting the chapters on healing and rehabilitation, as well as her thoughtful advice in the choice of photos and figures.

The Direction des communications du CHUM and the **Service de production** (CHUM communications directorate and production service) for authorizing the participation of the medical photographer.

Luc Lauzière, Medical Photographer, for his exquisite photos and the passion that he puts into his work.

The **Centre d'apprentissage du CHUM**, (CHUM Learning Centre) for providing the medical environment needed for the photos.

Éveline Bergeron, Clinical Simulation Specialist, for her attentive support and dynamism.

Julie Sangollo, Graphic Designer, for her immense patience and perseverance in laying out the guide.

Nguyen & Murray associées, and **Maureen Magee,** translators, who volunteered to translate the guide from French to English, a colossal job.

Thanks to **the people in the photos**:

Martin Bergeron, Nurse (cover page)

Claudie Loranger, Psychology Intern (cover page)

Sylvain Bélisle, Intensivist

Rachel Villard, Nurse

Karyne Auger, Nurse

Francine Beausoleil, Nurse

Anita Ang, Pharmacist

Michel Bérubé, burned person

Éric Labonté, burned person

Jorge Medina, burned person, his spouse and their daughter

Frédéric Poudrette, burned person, his spouse and their three children

Simon Bessette, burned person, and his mother

Richard Goyer, burned person, and his spouse

Paul Giles, burned person, and his mother

Finally, our heartfelt thanks to **Louise O'Donnell-Jasmin**, our publisher and editor, for believing in this project and giving generously of her time, far beyond the call of duty.

Notes

Notes