

## Home Care Guidelines

This handout outlines how to take care of your external frame at home after surgery. You will need to know about:

- Pin site care
- Physiotherapy
- Lengthening your limb

Our team of health care professionals will help you and your family with your care and treatment

### Pin Site Care

The nurses will teach you how to clean and care for the skin around the pins that attach the frame to your limb (pin sites).

Keeping the pin sites clean helps prevent infection. If infection starts here, it may move into the bone. Infection in the bone is a serious problem. Your nurse will show you how to check for infection so that it can be treated right away.

You will be given specific instructions depending on what type of frame you have. It takes about 20 minutes from start to finish. You will need to do this pin site care as prescribed until the frame comes off. This takes about 20 minutes. The pin site care is important because it helps prevent infection, which can be a serious set back. While you do the care, the nurse will show you how to check for

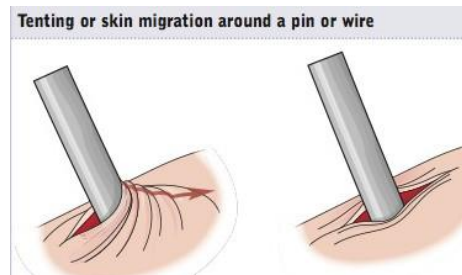
infection so that it can be treated right away.

### You need:

- A large box of Q-tips
- Sterile water (boil tap water and let it cool) Sterile water is important to not introduce any bacteria to your pin sites

### Clean each pin site with sterile water

- Dip a Q-tip into sterile water.
- Press the Q-tip down on the skin around the pin. Make sure the skin pulls away from the pin. Otherwise the skin can “tent” or migrate” around the pin and be painful.



- If there is crusting/ scabbing around the pin, do not remove it unless there is an infection (pain, redness, pus).
  - **Never use the same Q-tip twice.** Clean each of the pin sites with a new Q-tip. The Q-tip picks up germs as it cleans.
3. Check the pin sites for signs of infection.
- Pain or tenderness.

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- Redder, warmer, more swelling than usual.
- Pus discharge.



You can see the redness and pus draining from this pin site.

Infection can happen even when you have been doing pin site care. As soon as you see any of the signs tell your surgeon or orthopaedic nurse. If you get an infection your surgeon will ask you to take some antibiotic medicine. Have the telephone number of your pharmacy ready to give to your surgeon.

Remember to take **all** the antibiotics. The infection may still be there even if it looks like the infection is gone. Do your pin site care more often until the infection goes away.

## Physiotherapy

### Lengthening Your Limb

If you are lengthening your limb, approximately 6 days after surgery

"distraction" (the process of lengthening or straightening the bone) begins. Putting your body weight on your leg will help form new bone. New bone also forms when you increase the gap in the bone by turning the struts on your frame:

- By the same amount (millimetres)
- At the same time each day

When you do the distraction as prescribed, the bone grows approximately 1 mm a day (maximum).

It involves turning the struts on the frame each day at equally spaced intervals. The distraction needs to happen at the same time each day no matter where you are. New bone will not grow well with too much or too little time between distractions. If you can't do this on your own, your parent must come to help you.



An x-ray showing new bone forming in the gap between the frames.

The bone needs some time to fill in and harden. Usually, people spend one month in the frame for 1 cm bone growth. You will have X-rays taken when you come to the clinic. The surgeon uses these X-rays to

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measure how fast the new bone is growing. Your surgeon may suggest that you speed up or slow down the distraction process based on the bone growth.

Talk with your surgeon about how long you need to have the frame on.

## How do you do the distraction?

Turn the strut forward or backward depending on your prescription. You will feel a “click” each time it moves 0.25 mm. You should see the measurement on the strut moved by checking the number.

If you can't do this on your own, your parent/caregiver must help you.

## Your Hospital Stay

The usual hospital stay after your surgery is about 3-4 days. Please bring your crutches or walker with you when you come to the hospital.

You will also need to bring with you the clothing items that you want to be adjusted to fit over your frame.

Physiotherapy begins the day after surgery. The physiotherapist will teach you exercises to help increase your strength, flexibility and keep good movement in your joints. You will have a set of exercises to do each day at home. The exercises should become part of your daily routine. Most people begin standing two days after the surgery with help from the physiotherapist. Little by

little you will learn how to walk and move your leg or arm in the frame.

Before you go home the supplies you will need are:

- Q-tips (lots)
- Sterile water
- Pin site dressing supplies

## Physiotherapy and Exercise Routines



Before you leave the hospital a physiotherapist will teach you stretching and strengthening exercises. If you do these at home each day, it will keep the joints flexible and the muscles strong.

Most people begin standing two days after the surgery with help from the physiotherapist. Little by little you will learn how to walk and move your leg or arm in the frame.

The physiotherapist will arrange for your therapy one to three times a week in the clinic or with another physiotherapist at a hospital near your home. The physiotherapist in the community stays in touch with the health team at BC Children's Hospital, so you have the best care possible.

**Exercise and physiotherapy are important parts of your treatment.**

## What other things do you need to know?

### Splints

The type of splint you will need depends on what bone the limb lengthening frame is on. Your occupational therapist makes the splints. Splints can be used to hold your body in proper alignment. You need to wear it for 12 to 23 hours a day and the occupational therapist will give you written instructions on how to use and care for the splint. There is a rehabilitation assistant who also helps make and check the splint.



An example of a foot splint.

### Walking

Studies show that standing and walking on your legs helps the bone grow strong. The

physiotherapist will help you to stand on your leg about 2 days after your operation. They will show you how to use crutches or a walker to walk.

Walk as much as you can when you get home. It is good to stay active while wearing the frame. Many people hike, shoot basketball and even ride bikes. So – be creative and think of ways to keep moving! The new bone will grow and strengthen and the muscles won't tighten. Your surgeon will advise you on how much weight you can put through your legs.

### Daily Living

- Moving about at home may be a little harder. Keep the floor clear so you do not trip.
- The occupational therapist will help you figure out how to get clothes on over your frame and help you with everyday activities (ex. going to the toilet and showering).
- If you have a frame on your thigh (femur bone) the occupational therapist can give you a special cushion to sit on at home and school.

Your physiotherapist can help you decide how much to walk and how much to rest. It is important to be active and also to rest your leg sometimes. Once you get used to the frame, you will find ways to rest comfortably in bed. You can try different ways of propping pillows around the frame. The metal frame

can damage bed sheets, so use old sheets if you can.

## What about pain?

With time most people find they have less and less pain and can stop their pain medication quite soon. A few people continue to feel aches once they are home. If the medicine does not help the pain, talk to your surgeon. It is good to take your pain medication 30 minutes before your physiotherapy sessions.

## Back to school?

You can return to school about a week after you leave the hospital. It is a good idea to tell your school teacher/principal you are going to have surgery before you come into the hospital. Explain what is to be done. Think about what you do in a school day. You may have some questions for your teacher/principal. For example:

- What will you do during physical education class?
- Can a table and chair be put in the classroom? It may be difficult for you to sit at a desk.
- Can you leave class 5 minutes before the end of class, to get to the next class, before the corridors get too crowded?
- Can you get an extra set of school books so you do not have to carry your books around?
- Can you use the school elevator (if there is one) instead of the stairs?

Talk with your occupational therapist and physiotherapist about the activities that are important to you! They can help you figure out ways to still be involved.

## Follow Up

You will have your first follow-up appointment to see the health care team at the orthopaedic clinic one week after surgery. After that you will have a check up every week or every other week. Once your bone is healing well, your appointments are less often. It is important to come to all the clinic appointments.

- You will have X-rays so the surgeon can see how the bone is growing or correcting.
- The struts on the frame are checked.
- You will have a check up with the physiotherapist.
- Your occupational therapist will check your splint.
- The nurse will check the pin sites and talk with you about day to day issues and your general health and well being.

## Removing the Frame

Once your surgeon decides your bone has lengthened/corrected enough, the clinic team decides when to take the frame off. They decide this by monitoring your born and your walking.

We will give you a date for your surgery and the frame will be taken off under a general

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anesthetic as a Daycare Surgery. Removal of the frame does not take long. You wake up in the recovery room, stay a few hours and then you will go home on the same day. If the leg or arm needs more support, the surgeon may put a cast on while you are asleep.

You will need to bring your crutches or walker with you on the day your frame is removed. When the cast or frame comes off, your leg/arm will feel weak and the joints may be stiff. As you begin to use your muscles they will get stronger. The joints will move more easily.

Remember, we are here to help you anyway we can.



The clinic telephone number at BC Children's Hospital is 604-875-2642. Toll Free Number 1-888-300-3088 ext. 2642.

### It is important that you phone us if:

- You have increasing pain
- You have or think you have a pin site infection
- Parts of your frame are broken or fall off
- You develop a fever

## The Clinic Team

Everyone has different feelings about this procedure. It helps to know there is a health care team at the hospital to help you with

whatever comes up. We are here to make it as smooth and easy as possible for you and your family. The team members helping you are:

**Orthopedic Surgeon:** performs the surgery and guides your care during the treatment.

**Occupational Therapist:** Will help you safely manage everyday activities such as showering and dressing. They may recommend equipment such as a shower chair. They will check the fit of your splint and answer the questions you have.

**Physiotherapist:** helps you with exercises that keep your muscles strong and joints moving well.

**Orthopedic Nurse:** helps you prepare and keep in close touch with you once you leave the hospital to make sure that all is well.

**Rehabilitation Assistant:** helps you adapt your clothing, makes splints and covers for the frame and makes shoe lifts/raises.

At BC Children's Hospital we believe parents are partners on the health care team. We want you to be as informed and comfortable as possible.

This patient handout will answer some of your questions. Please ask us the other questions you have.

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Notes:

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