



**Your Spine Surgery:
Posterior Fusion for
Neuromuscular Scoliosis**

CONTACT US

Orthopaedic Spine Clinic		
Dr. C. Reilly	(604) 875-3711	MOA: Michele Stark
Dr. F. Miyanji	(604) 875-2651	MOA: Valerie Walsh
Dr. A. Ghag	(604) 875-2068	MOA: Valerie Walsh
Dr. A. Simmonds	(604) 875-2345 ext 458207	MOA: Emma Patena
Dr. Andrew Morrison: Anaesthesia Lead	(604) 875-2711	MOA: Yvonne Hardwick
Caitlyn Dunphy: Clinic Physio	(604) 875-2913	caitlyn.dunphy@cw.bc.ca
Chelsea Digney: Inpatient Physio	-	chelsea.digney@cw.bc.ca
Dolly Khanna: Nurse Clinician	(604) 875-2609	dkhanna@cw.bc.ca
Nicole Osborne: Nurse Clinician	(604) 875-2345 ext 7202	nicole.osborne@cw.bc.ca

BC Children's Hospital: (604) 875-2375	
Pre-Admission Nurse (routine inquiries)	(604) 875-3912
Pre-Admission Nurse (if you need to talk to a nurse at the last minute about your surgery)	(604) 875-2191
Switchboard	(604) 875-2345

BCCH Orthopaedics Department
Room 1D – 4480 Oak Street
Vancouver, BC, V6H 3V4

Tel: (604) 875-3187
Toll Free in BC: 1-888-300-3088 ext 3187
Fax: (604) 875-2275

Learn more about:

- Scoliosis care: <http://www.bcchildrens.ca/our-services/clinics/orthopaedics/spine-conditions/scoliosis>
- Anesthesia (pain medicine): <http://www.bcchildrens.ca/our-services/hospital-services/anesthesia#What--we--do>
- Parking: <http://www.bcchildrens.ca/our-services/directions-parking>

ABOUT SCOLIOSIS

What is scoliosis?

Scoliosis is a condition that causes the spine to curve and rotate as you grow. Neuromuscular scoliosis occurs in children with nerve or muscle conditions that affect torso control. You might be able to see the curve in your back. Or, you might notice a change in the level of your shoulders, waist, or pelvis.

If you use a wheelchair, you may slouch or lean to one side. You may have more difficulty sitting, or pressure sores from a tilted pelvis. These symptoms may increase during growth spurts.

How is scoliosis diagnosed?

We will take an X-ray to look at your spine. We can measure the angle of your curve from the X-ray.

Treatment:

When our clinic team recommends a treatment, we consider:

- The size and location of your curve,
- Your age,
- How much more you will likely grow,
- Changes to how you sit or function, and
- How the curve in your spine could affect your heart, lungs, and other parts of your body.

Why am I having surgery?

Your surgeon has likely suggested surgery because your curve is large. Your curve is likely to affect your health. It could affect how you function, or how you sit. It could also affect your skin. Without surgery, your curve will likely increase.

After a successful surgery and recovery, we expect you to:

- Return to your usual activities. You may need to re-learn some activities, as your body will be in a new position.
- Sit more comfortably.

What should I do while I am on the surgery waitlist?

- Keep doing your regular activities.
- See your seating therapist. They may adjust your wheelchair to help support your spine.
- Ensure your skin stays healthy. You cannot have surgery if you have open wounds. The wounds could become infected.
- Reach your best respiratory (breathing) health. Use any equipment that your respiratory team prescribes. Work with your respiratory team, so you can breathe as well as possible before surgery.
- Let your community health team know about your surgery. Make sure you have any home equipment you will need after surgery.

Are there any restrictions while I am waiting for surgery?

No. Keep doing your regular activities!

PRE-OP APPOINTMENT

Before your surgery, your surgeon's medical office assistant (MOA) will call you to book your pre-op appointment. This is a day of tests and preparations for surgery. It can take **4 – 5 hours**, so do not make other plans that day.

At this appointment, you will meet your whole team. The clinic nurse will help you through the whole day. You can expect:

- **To meet** and ask questions of the clinic nurse and your anaesthesiologist, physiotherapist, and surgeon.
 - Tell your team if you were ill over the past year. Did you need to go to the hospital? Did you need any medications?
- **X-rays:** The Medical Imaging team will take x-rays of your spine. They will also take a bending x-ray, so your surgeon knows how flexible your spine is.
- **Pulmonary function test (if possible):** This breathing test will show well your lungs work.
- **Blood tests:** These tests check that you are healthy and ready for surgery.
- **Other tests:** If you see other doctors for different medical conditions, they may want us to do extra tests to make sure you are ready for surgery.

PRE- OP Appointment Date: _____

TIME: **8am** (unless otherwise instructed)

Location: **Orthopaedic Clinic**

YOUR SURGERY DETAILS

Surgery Date(s): _____ Surgeon: _____

Arrival Time: _____ Surgery Start Time: _____

Approximate Length of Surgery: _____ hours

Expected Stay in Hospital: _____ days

Expected Date of Discharge: _____

Location: BC Children's Hospital, TECK Acute Care Centre, Entrance 53
Special Procedures, 4th Floor Anaesthetic Care Unit (ACU)

Do NOT have solid food after midnight the night before surgery

The pre-admission clinic nurse will phone you one business day before surgery. The nurse will confirm your arrival time and explain when to stop eating and drinking before surgery.

If you do not get this phone call, or need to reach the pre-admission clinic, please call the anaesthesia care unit (ACU) nurse at (604) 875-3912.

Call the Orthopaedic Clinic if you develop any of these signs of illness in the 7 days before your surgery:

- Stuffy or runny nose
- Coughing
- Nausea or vomiting
- Diarrhea
- Fever
- A rash

There is always a small chance your surgery will be cancelled (for example, if another patient needs emergency surgery). If this happens, we will reschedule your surgery as soon as possible.

FASTING BEFORE SURGERY

- Eat and drink normally until **midnight** the night before surgery
 - This includes regular g-tube or j-tube feeds
- **NO food (including g-tube or j-tube feeds) after midnight**
- You may have clear fluids (water or apple juice) until 2 hours before surgery start time
- Take your prescribed medications with a sip of water at the usual times (unless we tell you otherwise)

If you eat or drink after these times, your surgery may be cancelled

PREPARING YOUR SKIN FOR SURGERY

You must wash your back and sides **THREE** times before surgery:

1st Wash	Afternoon before surgery	Date:
2nd Wash	Evening before surgery	Date:
3rd Wash	Morning of surgery (Before coming to ACU)	Date:

- Use the chlorhexidine soap sponge to **prevent infection**.
- Use the **soft side of the sponge** (not the bristles).
- After washing, **rinse with warm water** and **towel dry**.
- **Do NOT** use creams or moisturizer.

PRE-OPERATIVE CHECKLIST

- Wash skin **THREE** times before surgery (see above)
- NO CREAMS or MOISTURIZER**
- Shower or bathe and wash your hair the night before surgery
- Braid long hair on either side of your head
- Remove all body piercings
- Remove all jewelry
- Remove all nail polish
- No make-up
- No contact lenses

- No food after midnight the night before surgery
- Clear fluids until 5am



HOSPITAL PACKING LIST

- Wheelchair
- Any usual splints
- BIPAP Machine
- Snacks
- Toiletries
- Change of clothes to wear home
- Underwear or diapers
- Pajamas
- Sanitary pads
 - It is common to get your period when you have surgery, even if it's not your usual cycle timing.
- Your favourite blanket, stuffed toy, or both
- Your cell phone, tablet, or both
- Chargers
- Earphones
- This booklet**

WHAT TO EXPECT DURING YOUR HOSPITAL STAY

Day of surgery

You will go to the 4th floor procedures area at your arrival time to check in.

You will change into a hospital gown and get comfortable in your own room. Your parent or guardian can come with you. Your surgical and anaesthetic teams will come by to confirm details of the surgery and answer your questions.

Your parent or guardian can come with you into the operating room. They will wear hair and shoe covers, and a yellow gown over their clothes.

After surgery, you will go to the post-operative recovery area. Your parent or guardian will stay with you while you wake up. When you are awake and comfortable, a staff member will take you and your parent(s) or guardian(s) upstairs to your hospital room.

Your expected stay

Recovery will look different for each individual. Your hospital stay will depend on your overall health and many other factors. Generally, patients are in hospital for 1 – 2 weeks.

Before you can go home:

- You must be medically stable,
- You must be comfortable with transfers from your bed to your wheelchair,
- Your home equipment must be ready, and
- Your seating specialist must fit your wheelchair to your new posture.

Visitor information

All patient rooms at BCCH are private rooms. You will have a futon couch where your parent(s) or guardian(s) can stay overnight. You will have your own TV, and you can talk to your care team about getting cable, streaming services, and gaming consoles. You can order food by calling the number on your room menu.

What will my day in the hospital be like?

Every day will be a bit different. Each day your surgeons, nurses, physiotherapists, and occupational therapists will check in on you. Your health-care team will change your daily goals to get you ready to go home.

IMPORTANT THINGS TO KNOW DURING YOUR STAY

What will I feel like after surgery?

At first, you will feel groggy. You might have trouble remembering things that recently happened. You will get continuous pain medication through an IV to help with your pain, but you will still feel some discomfort. This is normal.

You may feel nauseous. You can ask for medication to help you feel better. Some people have a sore throat for a little while after surgery. Because you lie face-down for surgery, your face may be swollen (especially your lips and eyes). This will all get better soon.

It is also normal to feel really tired, even weeks after your surgery. This should get better with time. Please give your body a chance to get back to normal. Be patient with yourself.

Girls may start their periods during their hospital stay, even if you would not normally expect your period at this time.

Breathing and Chest Health

Sometimes, after surgery, lungs take time to adapt to the spine's new position. After surgery, you may need extra support with breathing.

A physiotherapist will help you with positioning, moving, and breathing exercises. They may also do hands-on secretion clearance, to help you breathe more easily.

Right after surgery, your breathing may feel more difficult. This can be upsetting. But in time, your breathing should improve.

Your health-care team may suggest breathing exercises for you to do at home after surgery.

Why am I sore?

It is very normal to feel sore after back surgery. Your back muscles and spine have moved. Our goal is to keep you comfortable. Moving is one of the best things you can do to feel better.

Some people find that the second day after surgery is their worst day. At this point, the anaesthesia has worn off. You are also working hard to get moving. It is normal to have ups and downs after surgery. It will get better.

Some patients find that their hips or pelvis may be extra sore after surgery. This can be because you now sit on a different part of your pelvis than before surgery. This should get better with time.

As your pain improves, you can start taking pain medicine by mouth or G-tube, instead of through an IV. This is the same medication, just in a different form. As you recover, you will need less medication, less often.

Most patients find that they only need Tylenol (not the morphine) by about 7-10 days after surgery.

Aches, pain, and funny feelings

- You may have a patch of numbness on your thigh from the pressure on a nerve when you laid on the surgical table
- You may have sensitive skin or feel itchy around your incision
- The muscles in your back and shoulders will be sore from being in a new position
- You may feel off balance as your body gets used to its new position
- *Time and MOVEMENT will help resolve all of these 😊*

Changing positions

Many people struggle to find a comfortable resting position after surgery. It is very important to change positions often. This will make you more comfortable. It also prevents pressure sores from lying in one spot for too long.

Your nurse and physiotherapist will help you change positions until you can do it on your own or with your family's help. This will help keep your pain manageable, and will help prevent you from getting dizzy when it's time to get out of bed.

Changing positions in your chair is very helpful. You can tilt or recline the chair, or move to a different chair. You can rest in bed before you try again.

Eating and drinking

It is very important to start eating and drinking as soon as you can. If you get your nutrition through a G-tube or J-tube, we will gradually increase your feeds back to your normal schedule. Pain medication often causes nausea, and food will help. Drinking lots of water will also help get your bowels moving again, so that you do not feel sore or nauseous from constipation.

Feeding may be more difficult after surgery. If you lean forward for feeds, this will be more difficult when your spine is fused. Your arms may be weaker for a few months after surgery, too. Your physiotherapist and occupational therapist will help you make adaptations. These changes will help you become more independent.

Managing your bowels

A long surgery and pain medications can both make you constipated. Soon after surgery, you will start taking bowel medications to help your bowels move again. Often, people do not poop for a few days after this surgery.

The best things you can do are to take your bowel medications (especially the powder that you put in water), drink lots of water, and move around or sit up. Once you stop the IV pain medications and start moving around, your bowels will get better. Many people poop before they leave the hospital, but not everyone does.

In hospital, it may seem like everyone is asking you if you have passed gas or pooped. This is important information because it tells us if you are on track!

POST-OP ACTIVITY GUIDELINE

What can I do after surgery? What must I not do?

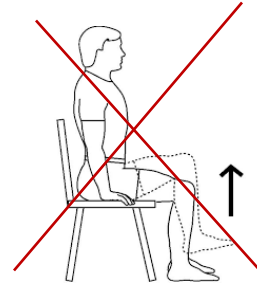
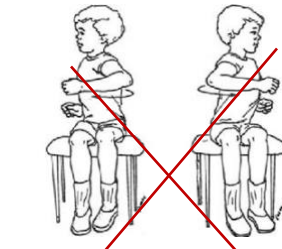
After surgery it is very important to move. Movement helps you heal, and builds muscle, heart and lung health. Moving will also decrease your stiffness and soreness.

For the first **6 months** after your surgery:

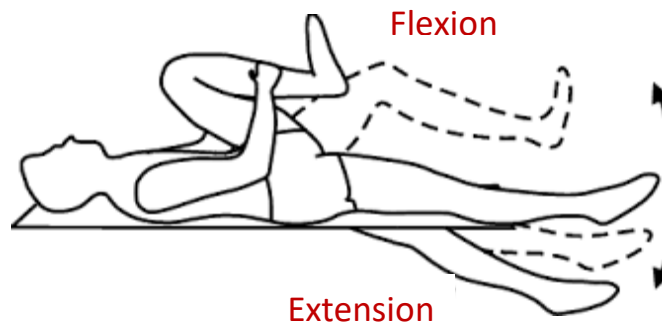
- Do not bend deeply.



- Do not twist deeply.



- If your surgeon put rods and screws into your pelvis, your surgeon may ask you to limit hip movement for 3-6 months after surgery. Limits on hip movement are called **hip precautions**. You will have hip precautions for flexion, extension, or both.

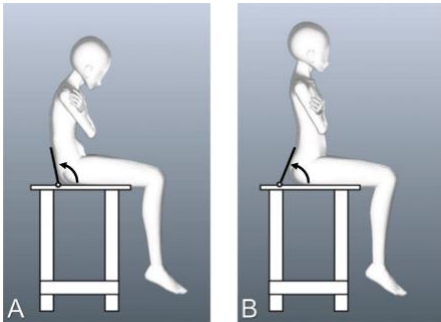


- Your hip precautions will depend on how flexible your hips are before surgery.
- Your surgeon will explain how to move safely after surgery.
- Your surgeon may you not to use your standing frames for 6 months after surgery.

After 6 months, you can slowly resume all activities.

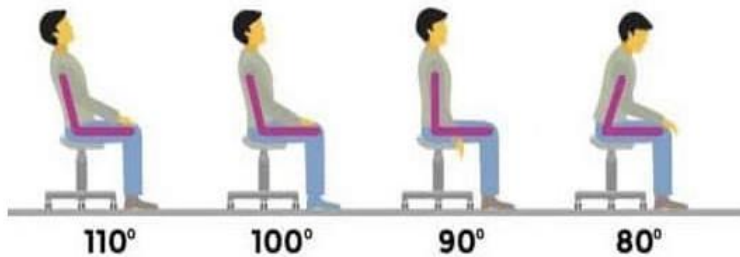
What are hip precautions?

- Hip precautions are limits to the movement in your hips. Your surgeon may ask you to limit hip flexion or extension. Moving your hips can make your pelvis rock back and forth, especially if your hips are tight. If your surgeon placed screws in your pelvis, hip precautions will help you heal more easily.



Moving from the position in (A) to the position in (B) is pelvic rocking. Avoid this if you have hip precautions.

- If you have hip precautions, your knees must not move toward your chest. Your seating therapist may need to recline your wheelchair slightly. You may also need a sling lift, or two people, for transfers



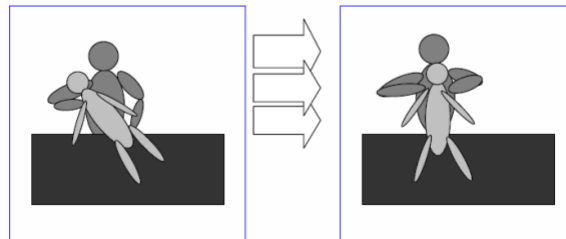
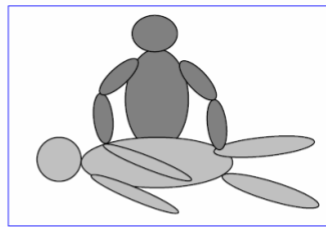
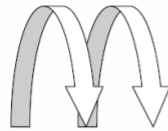
Your surgeon may ask you to have your wheelchair at 90-110 degrees to limit hip flexion.

- Hip precautions generally last 3-6 months. The surgeon will tell you when you can move your hips normally. This will happen at a follow-up visit.

How can I help with hip precautions?

Movement is very important after surgery. To move comfortably and safely:

- Use a lift system, or lift with two people during transfers,
- Recline in your wheelchair, and
- Try log rolling for diaper changes, or when you change positions in bed.



BUILDING UP YOUR WALKING OR SITTING TOLERANCE

After surgery, you may find that activities that used to be easy now leave you tired and sore. In the weeks and months after surgery, you will slowly build back up to everything you used to do.

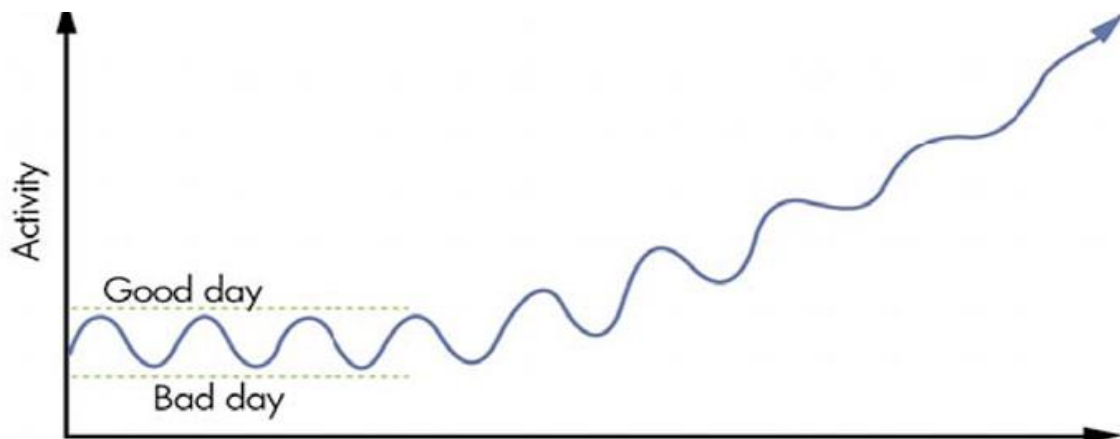
You can do this with a strategy called **pacing**. Pacing means progressing your goals, bit by bit. Do not try to do too much at once. Pacing is the safest way to build your tolerance.

Each individual has a different starting point. Your starting point is your baseline.

For example, if you can tolerate sitting up for 10 minutes, that is your baseline. Start by sitting up for 10 minutes, twice a day. Each day, try adding a bit of time to each session. Continue to progress your goals when you get home.

Some days will be more difficult than others. This process may not always look linear. Overall, though, you will improve each day!

It can be scary to move when your surgeon stops your hip precautions. Work with your community team (if you have one) to build your confidence.



RECOVERING AT HOME

What will my recovery be like at home?

Every patient has a different recovery. Other health issues can affect your recovery after surgery. Generally, our patients report that they feel close to normal 3-6 months after surgery. Other patients take longer to feel normal. You may continue to improve for a year after surgery.

Will I need equipment at home?

This will depend on your current home set up, and your function after surgery. You may also need equipment if you have hip precautions.

You may need:

- A lift and sling for your hip precautions,
- A commode if you do not have a lift in the bathroom, and
- A hospital bed downstairs, if someone usually carries you.

Your hospital team will work with your family to organize your equipment before surgery.

Traveling home

Take a dose of pain medication before you travel home. It is a good idea to fill your prescriptions at the hospital pharmacy, so that you have them for the drive home.

If you live far from the hospital, a discharge planning nurse will help you plan your trip.

Medications

When you leave hospital, the doctors will give you prescriptions for pain medications. We will also tell you how to take any non-prescription medications like Tylenol and bowel medications. It is best to take your pain medications when your pain is around a 4 or 5 out of 10. Do not wait until your pain really bad. Your comfort level should only go up and down a little bit.

You will be ready to start weaning off your strong medications like as morphine in hospital, or soon after going home. Start by decreasing your dose of pain medication. For example, take half a tablet, instead of a full tablet)

Then, space out the doses. You could start taking your tablet every 4 hours, instead of every 4 hours.

After a while, you may find that you only need one dose each day, just before bed. This dose will help you get a good night's rest, so you are ready for the next day!

You can continue regular Tylenol while you wean off your stronger medications. Then, start weaning off your Tylenol as well.

Do not take anti-inflammatory medications, including Advil (Ibuprofen), Aleve (Naproxen), or steroid pills. Some studies show that they can slow bone healing.

Caring for your incision (bathing and showering)

You must keep your incision and the dressing that covers your incision clean and dry. Take sponge baths, until your 2-week visit with the clinic nurse. Your surgeon or nurse will tell you when you can start taking showers. Do not soak in the bath or hot tub. Soaking increases your risk of infection.

Check your incision regularly. You can look in a mirror. Or, ask a family member check for you. Check for signs of infection like a fever, redness, oozing, or increased swelling around your scar. The area may also feel more painful. **If you notice any of these signs, call your surgeon or the clinic nurse immediately.** If you cannot reach them, see your family doctor or go to the emergency room.

To reduce scarring, you must **avoid direct sunlight on your incision for at least one year** after surgery. If you can't keep your incision covered with clothing or a dressing, apply a high SPF sunblock regularly.

Returning to School

Most patients feel well enough to return to school **3-4 weeks** after surgery. If you feel well before this, you can go back sooner. Going back to school is safe and good for you!

Before you return to school, spend time sitting up at home. This will get your body used to sitting for long periods again. You may want to return to school gradually. You can start with half-days for the first week, then return to full days

Tell your school that you **cannot participate in physical education (gym) class** for about 9 months after surgery. Your surgeon will tell you when it is safe for you to join gym class again.

Follow-up Appointments

If you do not have a follow-up appointment booked when you leave the hospital, call your surgeon's office. Usually, follow-up appointments will occur at these times:

- **2 weeks after surgery** (Clinic nurse visit)
 - Wound check, suture or staple removal
 - Date/Time: _____

- **6 weeks after surgery** (Surgeon visit)
 - Date/Time: _____

- **3 months after surgery** (Surgeon visit)
 - Date/Time: _____

- **6 months after surgery** (Surgeon visit)
 - Date/Time: _____

- **1 year after surgery** (Surgeon visit)
 - Date/Time: _____