

HIP SURGERY AND AFTERCARE

Stephanie Bozarth, MPS IV mom
Jennifer Klein, ML III patient

Opting for major surgery like a hip replacement is always trying, but the outcomes have been so successful that it is a good step to take for those with MPS and ML. But the surgery itself is only half the battle; the aftercare is also a major undertaking and requires preparation for the six weeks before the cast comes off and the months after. Here are some things to know about hip surgery from the caregiver and patient perspectives.

Patients

Talk to Your Medical Team

Ask questions, take detailed notes or record your meetings with orthopedists and any surgical team members and consider taking photographs of any information provided to you.

If you are an adult with MPS or ML and of short stature, discuss surgical obstacles and hip replacement parts available for small stature patients. Advise the team of any airway or alert issues. Share any pertinent information about MPS and ML with your surgical team. Remember, you are the expert on these diseases!

Before Surgery

Set realistic recovery goals, using your orthopedic surgeon's recommendations as a guide. A good rule of thumb is to add 25 percent to surgery recovery time and 50 percent post hospital recovery time to the numbers the surgeon presents. For example, if the surgeon expects six to nine weeks of recovery – adding an additional month to this number is typical for those with lysosomal diseases.

Prepare your insurance providers and your surroundings for recovery. In advance, identify obstacles that might prevent you from having a safe recovery. Questions to consider are:

- What will insurance provide for recovery assistance?
- Will I have occupational or physical therapy or both available for recovery?
- Will my insurance pay for nursing or on-site caregiving if I live alone or am alone during any part of the day or night?
- Do I have one-level housing to recover?
- Do I have a bedroom on the first level?
- Will I need a hospital bed?
- What equipment should I have on hand, and will insurance pay for anything?
- Who will be preparing my food and helping administer medication?
- What medications should be considered for recovery - calcium, vitamin D?
- How will I stay stimulated while in a long recovery?
- What activities, movies, art, music and visitors can I line up in the weeks ahead?
- Who will transport me to post-operative doctor appointments?

Recommended Equipment

1. Bed wedge to sit up in bed
2. Trapeze bar – for bedside transitioning and overall repositioning in bed
3. Hip abduction disposable pillow
4. Walker with a walker tray next to bed
5. Walker bag to carry items between rooms
6. Elevated commode at bedside with pads underneath for sanitation
7. Good sheets on bed, tucked tightly to help transitions
8. Shower chair
9. Shower head with a long cord to bathe yourself independently
10. Shower mat and grab bars (Portable grab bars with strong suction cups are available in most home stores.)
11. Wheelchair for safety with board and bottom cushion
12. Hip kit – available at the hospital that has grab pole, sock aide, shoe horn, bath sponges
13. Rolling walker with seat and breaks (Two months' post recovery.)
14. Crutches both forearm and underarm style

Preoperative Procedures/Tests

Your orthopedic surgeon will require a number of tests before surgery, including but not limited to cardiac exam and EKG, MRI or X-rays, pulmonology tests, and bloodwork.

Immediately After Surgery

After waking from surgery, expect to have an IV for intravenous medications, compression hose and a bedpan. Typically, the nursing team will move you out of your bed within 48 hours after surgery to begin moving the muscles and prevent blood clots. The team will also bathe you in bed. If you can manage, using the bathroom on your own with nurses at your side is a good sign that you are on your way to recovery.

Occupational Therapy and Physical Therapy

One of the most crucial steps in the recovery process is occupational therapy (OT). The OT teaches you how to move safely, how to use equipment properly and can provide a sense of optimism. They also assist in a projection recovery timeline based on goals set and accomplished. An OT can visit a patient between one and three times a week based on your individual insurance parameters.

Set an individualized plan for physical therapy. Because some MPS and ML patients suffer from secondary bone disease, it is critical to not overextend your therapy options. You know your body best and can determine what you are capable of doing and monitor your own limitations.

Recovery Process

Prepare yourself for a long recovery, as feeling normal again can take as long as 14 months in some instances. Think about what you enjoy most and plan in advance for your recovery.

Identify hobbies and tasks you can do while bedridden.

Keep a calendar nearby that can help you schedule medications, appointments, visitors, etc. Many people like to keep a blog or a caringbridge site live with current information about your condition. This helps in disseminating information quickly to everyone.

Eat healthy, maintain a good diet and overall well-being. It can be easy to put weight on quickly when you are unable to move or are moving with new physical restrictions. Challenge yourself with new healthy recipes or try homeopathic remedies such as essential oils that can lift your spirits during recovery.

Note: A hip reconstruction is a different procedure than a hip replacement. The reconstruction process is more invasive and usually requires an orthopedic surgeon to complete additional bone modifications. It could be pelvis work, bone grafting, additional screws or plates, but it depends on each individual patient's needs. Usually a hip reconstruction will increase the recovery time of a patient and can include a higher level of pain.

— Jennifer Klein, ML 3 patient

Caregivers

Before Surgery

Arrange for a leave of absence from work. The demands on your time will be severe and trying to juggle both work and home care is nearly impossible.

Think of your child's wardrobe. Shirts and outfits that button in the back or slip easily off and on are the best options to keep your child covered while in a full body cast.

Review the layout of your bathroom. Make sure there is enough space for the patient to use the toilet with the cast on. There should be enough room to straddle the toilet or enough space on either side to lay your child horizontally across it.

Make sure you have sanitary pads or napkins on hand to help keep the cast clean. Try lining the cast opening with the pads to help with this.

Consider buying or renting an electric bed. This allows the patient to sit up during the recovery process so he or she can eat, watch TV, color or any other activity.

Consider buying a bean bag chair. Children in casts can lay on them on their sides, and you can move them around more easily just by dragging the chair.

Make sure you have pillows and blankets for car rides. Pillows can help with comfort and positioning, and blankets can help block the sun in the car.

Immediately After Surgery

Pain management is the primary focus in the aftermath of the surgery. The doctors will prescribe pain medications. Anti-anxiety medications are also a good idea to help keep your child calm and deal with the immobilization of the cast and any discomfort.

You'll need a wheelchair that reclines, which can be rented from the hospital. This makes it easier to transport your child while they're in the cast. The hospital can also rent you a special seat belt so your child can recline in the back seat of the car but still remain safe.

Recovery Process

Keeping the cast clean is difficult, but it's important to do so. Food debris and crumbs can easily fall into the cast, so keeping your child clothed to prevent this is a good idea. Use panty liners or sanitary pads to line the opening of the cast for comfort and cleanliness. Replace these often.

Before the cast comes off, get recommendations for physical therapy, including water- and land-based. This is so important to the recovery process, as full recovery can take on average eight months, and improvements may be seen in a year's time. There is sometimes a waiting list for these types of therapies, so get this information as soon as you can to secure a place for your child. Therapy should be scheduled five days a week.

Sleep schedules may be unusual or disrupted due to the discomfort of the cast or anxiety. Some who've experienced the recovery process describe it as having a newborn again, so sleeping when the patient is sleeping is a good idea.

You don't have to stay inside the whole time. Be sure to get out of the house during the recovery process, as cabin fever can strike both you and your child.

Think of Yourself, Too!

This will be a demanding time for you. Hopefully, your friends and family will be there for you during this process. Let neighbors bring over a meal or have someone sit with your child while you take a break. A support system of friends and neighbors can really help make a difference.

— *Stephanie Bozarth, MPS IV mom and caregiver*