

DSRCT Recovery Pathway: Ileostomy Closure Surgery

Surgery date: _____

Expected discharge date: _____

This recovery pathway goes with the surgery guide *About Your Ileostomy Closure Surgery for Desmoplastic Small Round Cell Tumors (DSRCTs) at MSK Kids*. A member of your care team will give you a copy. You can also find it at www.msk.org/pe/dsrct-ileostomy.

These are goals for your recovery. **Your recovery may not follow this pathway exactly.** Your care team will help you know what to expect.

The day of surgery

What to do

- Once your care team says it's OK, sit up in your bed or chair.
- Use your incentive spirometer or pinwheel 10 or more times every hour while you're awake.

Tubes and drains to expect

You will have:

- A Foley (urinary) catheter.
- An epidural catheter or peripheral nerve catheter (nerve block).
- An arterial line.

You may have:

- A temporary central venous catheter (CVC).
- An intraperitoneal (IP) catheter. This is also called a pigtail catheter.
- A nasogastric tube (NGT).

Tests, procedures, and visits to expect

- You will get chest physical therapy every 4 hours.

Medicines to expect

- Pain medicine through your epidural catheter or nerve block.
- Extra pain medicine such as acetaminophen (Tylenol®) through your CVC or implanted port, if you need it.
- Some or all of your usual medicines.
- Medicine to keep you from feeling nauseous (like you're going to throw up).
- Medicines to protect your thyroid.

Notes _____

1 day after surgery

What to do

- Sit in your chair for at least 30 minutes.
- Do your self-care routines (such as brushing your teeth and washing your face) in bed, with help if you need it.
- Use your incentive spirometer or pinwheel 10 or more times every hour while you're awake.

Tests, procedures, and visits to expect

- You will get chest physical therapy every 4 hours.
- A Physical Therapist (PT), Occupational Therapist (OT), or both may visit you if you need extra help getting out of bed or moving around.

Changes to your tubes and drains

- We may take out your urinary catheter.
- We may take out your arterial line.

Medicines to expect

You will get:

- Pain medicine through your epidural catheter or nerve block.
- Extra pain medicine such as acetaminophen through your CVC or implanted port, if you need it.
- Some or all of your usual medicines.
- Medicine to keep you from feeling nauseous.
- Medicines to protect your thyroid.

You may get:

- Immunotherapy through your IP catheter.

2 days after surgery

What to do

- Get out of bed 3 times today. Stay out of bed for at least 1 hour each time.
- Do activities or exercises while sitting in your chair or walk outside your room. Do this 3 or more times today.
- Do your self-care routines while sitting at the edge of your bed, with help if you need it.
- Use your incentive spirometer or pinwheel 10 or more times every hour while you're awake.

Tests, procedures, and visits to expect

- You will get chest physical therapy every 4 hours.
- A PT, OT, or both may visit you if you need help getting out of bed or moving around.

Changes to your tubes and drains

- If you still have a urinary catheter, we may take it out.
- If you have an NGT, we may take it out.

Medicines to expect

- Pain medicine through your epidural catheter or nerve block.
- Extra pain medicine such as acetaminophen through your CVC or implanted port, if you need it.
- Some or all of your usual medicines.
- Medicine to keep you from feeling nauseous.
- Medicines to protect your thyroid

3 days after surgery

What to do

- Stay out of bed for most of the time you're awake.
- Sit in your chair for 1 to 2 meals.
- Do activities or exercises while sitting in your chair or walk outside your room. Do this 3 or more times today.
- Do your self-care routines while standing at the sink, if you're old enough.
- Use your incentive spirometer or pinwheel 10 or more times every hour while you're awake.

Tests, procedures, and visits to expect

- You will get chest physical therapy every 4 hours.
- A PT, OT, or both may visit you if you need help getting out of bed or moving around.

Changes to your tubes and drains

- If you have an epidural or peripheral catheter, we may take it out.
- If you still have an NGT, we will take it out.

Medicines to expect

- Pain medicine through your epidural catheter or nerve block, if you still have one.
- Extra pain medicine such as acetaminophen through your CVC or implanted port, if you need it.
- Some or all of your usual medicines.
- Medicine to keep you from feeling nauseous.
- Medicines to protect your thyroid

4 days after surgery

What to do

- Stay out of bed for most of time you're awake.
- Sit in your chair for 2 to 3 meals.
- Do activities or exercises while sitting in your chair or walk outside your room. Do this 3 or more times today.
- Do your self-care routines while standing at the sink, if you're old enough.
- Use your incentive spirometer or pinwheel 10 or more times every hour while you're awake.

Tests, procedures, and visits to expect

- You will get chest physical therapy every 4 hours.
- A PT, OT, or both may visit you if you need help getting out of bed or moving around.

Changes to your tubes and drains

- If you still have an epidural or peripheral catheter, we may take it out.

Medicines to expect

- Pain medicine through your epidural catheter or nerve block, if you still have one.
- Extra pain medicine such as acetaminophen through your CVC or implanted port, if you need it.
- Some or all of your usual medicines.
- Medicine to keep you from feeling nauseous.
- Medicines to protect your thyroid.

5 days after surgery

What to do

- Stay out of bed for most of time you're awake.
- Sit in your chair for all your meals.
- Do activities or exercises while sitting in your chair or walk outside your room. Do this 3 or more times today.
- Do your self-care routines while standing at the sink, if you're old enough.
- Use your incentive spirometer or pinwheel 10 or more times every hour while you're awake.
- Change into new clothes. We'll help you if you need it.

Tests, procedures, and visits to expect

- You may have a MOAB scan to check how the immunotherapy spread in your peritoneum.
- You will get chest physical therapy every 4 hours.
- APT, OT, or both may visit you if you need help getting out of bed or moving around.

Changes to your tubes and drains

- If you still have an epidural or peripheral catheter, we may take it out.
- If you have an IP catheter, we may take it out.

Medicines to expect

- Pain medicine.
- Some or all of your usual medicines.
- Medicines to protect your thyroid.

Notes _____
