

Good communication with your doctors BEFORE elective surgery is essential!

OI may complicate some procedures because it makes bones fragile, and also increases the fragility of skin, internal organs, and blood vessels. Lung tissue composition is altered and your breathing may be affected. Some issues, especially concerns about breathing and reaction to anesthesia or pain medications can potentially be more serious for people who are short stature, do not walk, and have rib cage shape differences or spine curves. If the doctor is new to you be sure to provide information about your Type of OI and contact information for your primary OI doctor. Be sure you fully understand what will happen during the surgery, during the hospital stay and during your recovery period at home. Arrange to introduce your advocate to your doctor during a pre-surgery appointment.

1. Discuss a Pre-Surgery Pulmonology & Anesthesiology Consultation

- Neck and chest architecture, breathing, height and weight all affect anesthesia; and underlying pulmonary problems may increase risks. A ventilator may be needed.
- Short statured individuals may also need a cervical spine film.
- Pulmonary function testing evaluates the amount of air you inhale and exhale and how much oxygen gets into your blood. Pulmonary tests to have prior to meeting the anesthesiologist include:
 - FVC (Forced Vital Capacity)
 - MVV (Maximum Voluntary Ventilation)
 - Arterial Blood Gas – or a similar test to measure oxygenation and ventilation
- Report previous experiences with anesthesia including nausea in recovery.

2. Other Topics to Discuss

- **Osteogenesis Imperfecta (OI) and Surgical History**
 - Be specific about any physical differences that may affect your surgery. For instance, is it difficult to lay flat on your back? Is an arm or leg bent and cannot be straightened?
 - Provide a list of rods and other medical hardware.
 - Provide allergy history: medications, latex, sutures, or surgical tape.
 - Mention any excessive bleeding in previous surgeries or post-surgical oozing.
 - Consider providing your doctor with a copy of the OI Foundation fact sheet “**OI and Common Medical Tests and Procedures.**”
- **General Health**
 - Provide a list of all medicines and nutritional supplements.
 - Ask if the dose of medicines, or anesthesia needs to be customized to your small stature.
 - Make all healthcare providers aware if you have a hearing loss.

Take Charge Before Surgery

- **Pain Treatment**

- Provide a list of current pain management strategies and medicines.
- Plan for pain management immediately after the procedure, during the hospital stay and at home.
- Many pain medications especially opioids can repress breathing.

3. Discuss the Hospital Stay

- Nursing, operating room and recovery room personnel need to be fully informed ahead of time about your needs as a person with OI regarding taking Blood Pressure and safe positioning (i.e. moving you, turning you, helping you sit up and taking deep breaths.)
- Ask your surgeon to put a plan in place to handle the gastrointestinal issues that accompany most pain medicines associated with surgery.
- Be proactive and openly discuss with your doctor potential constipation issues. Short stature and the inability to walk makes constipation after surgery more likely. Constipation may delay discharge.
- Make sure the hospital staff takes your smaller size and small bladder into consideration when they calculate how much water you need to drink.

4. Plan for Recovery—Discuss the Need for:

- Adaptations of home, work, and school environments.
- Length of recovery period and restrictions on activities.
- Arrange for a PT and/or OT consultation before leaving the hospital especially if abdominal, chest, arm or shoulder surgery will limit ability to self-transfer.

5. Bring an Advocate

- If possible, do not go to the hospital or outpatient center alone. Bring a relative or friend who understands your OI, and has written permission to talk with your doctor. This person must be someone you trust to make decisions for you if you are incapacitated.
- Ideally an advocate should stay with you day and night during the first days after the surgery.
- Make copies of the OIF Poster, “**Handle Adults with Care**” and post them in your hospital room, near your bed and on your chart.

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