

CAUTION!

I have OSTEOPENIA IMPERFECTA (OI)

This means I have fragile bones, fragile skin, loose joints, and fragile teeth.

Laying flat may be difficult.

I may have respiratory problems.

Please consult me, my parents, or my companion before you move, transport, examine, or treat me. Follow my or their directions on how to handle me safely.

Important information for medical professionals is available:

Osteogenesis Imperfecta Foundation
804 West Diamond Avenue #210
Gaithersburg, Maryland 20878
www.oif.org/MedEd
bonelink@oif.org
(844) 889-7579
(301) 947-0083

Safety Precautions for Medical Professionals

- In osteogenesis imperfecta (OI), fractures can occur easily and spontaneously. **Support my entire body when lifting or turning me.**
- Just looking for signs of fractures, e.g. abnormal mobility or crepitation, can cause a fracture. Use extra caution for rods and possible dislocation. The safest way to determine a fracture is by X-ray examination.
- Symptoms of fractures are not always obvious or identified initially; **pain** often indicates a fracture. In case of pain, even without a diagnosed fracture, **treatment should be the same as for a fracture.**

- Adequate anesthesia is advisable, in children as well as adults. **Dosing for medications and anesthesia should be based on the person's size rather than age.**
- An analgesic and/or a night sedative are recommended the first few days after a fracture.
- Lightweight materials are preferred for immobilization.
- Patients with OI should be mobilized and **start physical therapy as soon as possible.**
- Many patients with OI have hearing loss. They may not hear you clearly with out aids. Ensure accommodations are made and noted for communication.

Adaptive Strategy Checklist for a Safe Hospital Setting

- ⇒ Hospital-admitted OI patients should have a **high level of observation** and consult with a pain management specialist. They should be **close to a nursing station and call buttons should be easily accessible.** Patients may have limited range of motion and pain that limits abilities.
- ⇒ Treating physicians and nursing staff should be aware of and knowledgeable about **possible respiratory and cardiac complications.**
- ⇒ Download, print, and post "Handle me with Care" page from the OI Foundation website (www.oif.org).

X-ray Examination

- In osteogenesis imperfecta the bones may be demineralized. Lower radiation intensity is usually appropriate (as in osteoporosis) to avoid needless repeat films.
- Excessive movements and needless lifting should be avoided.
- Patients or their parents, companions, and other advocates are often experienced with x-ray examinations. They can be helpful in finding the right position for x-rays to be taken.
- A lead shield for the reproductive organs should be used.

Surgery and Anesthesia

- Carefully transfer the patient to and from the operating table, supporting him/her well.
- Be aware of existing deformities or contractures when positioning the patient on the operating table.
- Bend the head gently backwards for intubation, minimizing the risk of fracturing cervical vertebrae; be aware of the vulnerable mucosa of the trachea. The teeth are often fragile as well.

Medical Trauma

- The history of multiple traumas and immobility are extremely stressful and can present as PTSD. Understanding, respect, and dignified care by the entire team are of critical importance.

I have OSTEogenesis IMPERFECTA (OI).

**My bones are fragile.
Handle me gently at all times.**

Contact my Primary Care Doctor:

Contact my Advocate:

This pocket guide was developed with the support and funding from the Thomas Acquafredda Emergency Medicine Education Initiative.

EMERGENCY ROOM CARE

pocket guide for individuals with osteogenesis imperfecta



Osteogenesis Imperfecta Foundation

