

Know Your OI History

- Placement of rods and other metal
- OI Type

Know Your Medicines

- Dates and doses for any bone drugs
- Carry a list of medicines you are currently taking
- Doses for many medicines including pain drugs may need to be adjusted to your size. Standard adult dose may be too much

Know Your Numbers

- Blood Pressure
- Bone Density
- Cholesterol
- Pulmonary Function

Remember: Besides fragile bones, OI makes blood vessels and other tissues more fragile.

Be Aware that OI Changes with Age

Young adult years: fewer fractures but more tendon & joint problems.

Middle adult years and older: fractures may increase again.

Non-union fractures are more common.

Shortness of breath, & other lung problems, may get serious.

Sleep apnea is possible.

Hearing loss may develop or get worse.

Heart valve problems may begin.

Vision may change and risk for retinal detachment increases.

Skin is thin and may become more fragile.

Find a Doctor Before You Are Ill or Injured

Doctors You Need

- Primary Care Doctor
- Orthopedist

Doctors You Might Need

- Pulmonologist
- Cardiologist

Get Annual Screenings

- Vision
- Hearing
- Dental care

You Are at Risk for Respiratory Infection

- Get pneumonia vaccine
- Get annual flu shot

Understand Your Health Insurance

Keys to Living Well with OI

Avoid obesity with weight management.

Maintain a healthy diet.

Be active through appropriate exercise.

Do Not Smoke.

Avoid illness.

Maintain bone mass.

Train an advocate.

Consider wearing medical alert jewelry -for OI and for hearing loss.

Be Prepared to be a Patient

Train a relative or trusted friend to be your advocate.

Have an anesthesia and pulmonology consultation before elective surgery.

Make all health care providers aware if you have hearing loss.

Give Permission—In Writing

Give a spouse, relative, or trusted friend access to your medical information. Your doctor or insurance company may have a form.

In an Emergency CPR is Permitted**Avoid Illness and Injury**

Your basic health needs are the same as other people.

OI does not change your risk for cancer or diabetes .

OI may complicate some treatments or medical tests such as colonoscopy, endoscopy or intubation for anesthesia/ surgery.

Have an annual physical.

Go to the doctor for respiratory infections.

Tell your doctor about changes in pain.

Protect your hearing from noise damage.

Use sun screen.

Develop healthy ways of managing stress & anxiety.

Develop a menu of techniques to cope with pain.

I have
OSTEOGENESIS IMPERFECTA

My bones are fragile.

Handle me gently at all times.

Contact my Primary Care Doctor

Contact my Advocate

Take Charge of Your Health:
Information for Adults
Pocket Guide



www.OIF.org • Bonelink@oif.org

301-947-0083 • 844-889-7579