

Talking With Your Orthopedist

Introduction

People with osteogenesis imperfecta (OI) usually require the services of a health-care team that includes several specialists, along with a primary-care physician. The orthopedist is a doctor who specializes in bone and joint disorders. The orthopedist treats fractures (broken bones) and recommends surgical interventions such as rodding surgery. The orthopedist plays an important role in the lives of children and adults who have OI. Some orthopedists are members of a “team” of specialists at an OI clinic that may also include a geneticist, endocrinologist, nephrologist, neurologist, physical and occupational therapists, and a nutritionist. In some private offices and OI clinics, a nurse or nurse practitioner also is available to answer questions about cast care and orthopedic surgery.

General Principles for Good Communication

- Keep detailed medical records. Include lists of significant fractures, how they occurred, and how they were treated as well as information on all surgeries.
- Keep a brief summary of key points in your medical history. Include surgeries, complications, allergies and a list of any rods, pins or other implanted devices.
- Both OI and your non-OI health information should be included in your medical history.
- Find a surgeon who is knowledgeable about OI and has experience doing procedures for OI patients, or who is willing to consult with surgeons who have OI experience before doing a procedure.
- Find and meet with a new orthopedist prior to having a fracture or other emergency to establish a relationship and ask some general questions.
- Find a doctor who treats you with respect, who listens to you, and is interested in the information on OI that you provide.
- Plan ahead for emergencies. Learn how to contact the doctor, where to go for x-rays, what to do on a weekend or holiday, and which hospital to go to. If the doctor is part of a group, find out if other members are experienced in OI as well.
- When you answer your doctor’s questions, do not exaggerate, deny, or deliberately omit information.
- Be an attentive listener. Whenever possible, bring a trusted person to your appointments.

Prepare for the Appointment

- Make a list of symptoms and the events leading up to the injury.
- Be specific about date, times, location, and type of pain.
- Prepare a list of questions. Be ready to ask the most important question first.
- Bring paper and pencil to write down the doctor’s answers.
- Bring a list of all drugs, vitamins, minerals, other nutritional supplements, nonprescription medicines and alternative treatments you are taking. Include information about dose, reason for taking, and how long you have been on the medication.

The following list of questions is not a script. It is a list of ideas to help you have a productive conversation with your doctor. **Review** this list before your appointment and **select** the questions that are important to you.

General questions:

- What should I do if I suspect a fracture during office hours? What about on a weekend or holiday?
- What does it mean if no fracture shows up on the x-ray? Was resolution high enough to show microfractures?
- Do any of my medications interfere with fracture healing?
- Will any of the medicines I am taking interfere with fracture healing?
- What are my treatment options?

When medications, tests, or treatments are prescribed:

- What is the exact name of the drug, test, or treatment?
- Will my size influence the drug dose you prescribe?
- What are the costs, risks, and benefits?
- Are there any alternatives?
- Will this treatment affect my bone mineral density?

When surgery is recommended:

- What are the success rates for this surgery?
- What complications are possible? How often do they happen?
- How many times have you performed this operation?
- Am I a good candidate for surgery?
- Should I stop taking any of my medications before surgery? How long before?
- Is the procedure done on an inpatient or outpatient basis?
- Exactly what will occur during the surgery?
- How long will the operation take?
- Is the anesthesiologist familiar with OI?
- How long will I have to stay in the hospital after the operation?
- Will the nursing staff know how to treat me? Have they ever cared for a person with OI before?
- What kind of special nursing care will I need at home?
- What will I need to take care of myself at home?
- How long will I be out of work or out of school?
- Will I need a wheelchair or other equipment while I recover?
- Will follow up care with a physical therapist or occupational therapist be needed?

When rodding surgery is recommended:

- What types of rods are available? Which one do you recommend and why?
- What complications are possible?
- If I have been taking bisphosphonates, how long before and after surgery should I discontinue the medication?

When spine surgery is recommended:

- What can I do to prepare for this operation?
- Will this affect growth (if the patient is a growing child)?
- How will a fused spine affect my activities of daily living?
- Will this require a bone graft?
- Is there a chance my bone is too soft to use instruments? What will be done then?
- How much of the curve will the surgery be able to correct?
- Will I continue to be at risk for new compression fractures of the spine after the surgery?
- What risks are involved with this surgery? Is there a risk of paralysis?
- How long will the surgery take?
- How long will I be hospitalized after the surgery?
- How long will I need bed rest after the surgery?
- Will I need to wear a brace after surgery? For how long?
- When will I be able to return to sitting up? To walking?
- When will physical therapy?
- Is there a risk that the rods or other instruments might break?
- How long will it take for the fusion to fully heal?
- Will I need to avoid bending, twisting or exercising immediately after surgery? If so, for how long?
- Will I need modifications to any equipment such as my wheelchair or bed?

When a Cast, Splint or Bandage is applied:

- Can this get wet? Can I swim with it on?
- Will my knee, ankle, elbow or another joint be immobilized?

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- How long will the cast, splint or ace bandage stay on?
- What do I need to look out for while I am in the cast (i.e. changes in skin color, odors, skin sores, and temperature of fingers or toes)?
- What will I need to take care of myself at home? Do I need to rent any equipment?
- How much activity can I do? When can I resume weight-bearing activity?

Other Situations:

- What options are available to treat a nonunion fracture (a broken bone that has failed to heal)?
- Will the type of orthopedic rods, pins, or other implants in my body exclude me from having an MRI?

Pain Management:

- Which type(s) or medications will I need? What are their complications or side effects?
- Will any pain medications interfere with healing?

Physical Therapy and Exercise:

- When can I resume weight-bearing and start my normal activities?
- What type of physical therapy do I need to do to regain strength and function? How many times a week, how long a session, and how many sessions in total are needed?
- Do you keep in contact with the physical therapist?
- Does the therapist have experience working with a person with OI?
- If my insurance company won't cover physical therapy in a medical setting, can I go to a gym?
- What precautions should I take to prevent a second fracture?

Closing:

- How can I reach you if I have questions later?
- When should I return for my next appointment?