



Talking to Your Orthopaedist: A Guide for People With OI

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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 orthopaedist (a doctor who specializes in bone and joint disorders) treats fractures and recommends surgical interventions such as rodding surgery. The orthopaedist plays an important role in the lives of children and adults who have OI. Some orthopaedists are members of a team of specialists at an OI clinic that may also include a geneticist, an endocrinologist, a nephrologist, a neurologist, a physical therapist, an occupational therapist, and a nutritionist. In some private offices and OI clinics, a nurse or nurse practitioner is available to answer questions about cast care and orthopaedic surgery.

General Principals for Good Communication

- Keep detailed medical records. Include lists of fractures, how they occurred, and how they were treated as well as information on all surgeries.
- Keep a brief summary of key points in the medical history. Include surgeries, complications, allergies, and a list of any rods, pins, or other implanted devices.
- 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 orthopaedist before having a fracture or other emergency to establish a relationship and ask some general questions.
- Find a doctor who treats you with respect, 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.

Prepare for the Appointment

- Make a list of symptoms and the events leading up to the injury.
- Be specific about the date, time, and location of the injury and the 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.
- When possible, bring copies of previous x rays that show the baseline status of the bone(s) in question.
- Bring a list of all drugs, vitamins, minerals, other nutritional supplements, over-the-counter 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. Be sure to listen carefully during your appointment. Your doctor may answer many of these questions before you ask them.

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? Is the resolution high enough to show microfractures?
- What is the prognosis? (What can I expect might happen next?)
- Do some medications interfere with fracture healing?
- Will any of the medicines I am taking interfere with fracture healing?
- What are my treatment options?

When tests, medications, or other treatments are prescribed:

- What is the exact name of the test, drug, or treatment?
- Will my size influence the drug dose you prescribe?

- What are the costs, risks, and benefits?
- Are there any alternatives?
- What will happen to me if I don't have the treatment?
- 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?
- How long can I wait before having this 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 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 them?

When spine surgery is recommended:

- What can I do to prepare for this operation?
- What will you be doing to my spine?
- Will the spine be fused?

- If so, where will it be fused?
- Will this affect growth (if the patient is a growing child)?
- How will a fused spine affect my activities of daily living? Will I become less mobile or less able to transfer between sitting, standing, and prone positions?
- What types of rods and other instruments will be used? Will they prevent me from having an MRI (magnetic resonance imaging) in the future?
- 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 in my spine 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?
- Do I need formal physical therapy? When would it start?
- Is there a risk that the rods or other instruments might break?
- How long will it take for the fusion to heal fully?
- 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:

- What types of casts are available?
- Which type of cast do you recommend, and why?
- Can this get wet? Can I swim with it on?
- Will my knee, ankle, elbow, or another joint be immobilized?
- 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, temperature of fingers or toes)?
- Will there be a second cast or something else to protect the bone during the healing process?
- Who can teach me how to take care of the cast and my skin?
- What will I need to take care of myself at home? Do I need to rent any equipment?
- How much weight can I put on the leg? What can I lift with my arm?
- Do I need crutches, a cane, or a wheelchair?
- 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)?
- Would transcutaneous (through the skin) electrical nerve stimulation (TENS) therapy be helpful?
- Would braces, a temporary splint, or other orthotics be helpful?
- Will the type of orthopaedic rods, pins, or other implants in my body exclude me from having an MRI?

Pain management:

- What types of pain treatment are available?
- Which type do you recommend, and why?
- Will any pain medications interfere with healing?
- Can any of the pain medication you are prescribing be addictive?

Physical therapy and exercise:

- When can I resume weight-bearing activity?
- 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?
- When can I resume normal activities?

- What precautions should I take to prevent a second fracture?

Closing:

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

Resources

For information on how to talk to your orthopaedist and other topics on osteogenesis imperfecta, contact the:

NIH Osteoporosis and Related Bone Diseases

National Resource Center

Website: www.bones.nih.gov

Osteogenesis Imperfecta Foundation

Website: www.oif.org

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For Your Information

This publication contains information about medications used to treat the health condition discussed here. When this publication sheet was developed, we included the most up-to-date (accurate) information available. Occasionally, new information on medication is released.

For updates and for any questions about any medications you are taking, please contact the Food and Drug Administration toll free at 888-INFO-FDA (463-6332) or visit its website at www.fda.gov. For additional information on specific medications, visit Drugs@FDA at www.accessdata.fda.gov/scripts/cder/drugsatfda. Drugs@FDA is a searchable catalog of FDA-approved drug products.

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