



Talking With Your Primary Care Doctor: 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 a primary care doctor and several specialists. The primary care doctor is concerned with the overall health of patients. The pediatrician or family doctor also deals with growth and development issues in children. Children and adults with OI have the same general health needs as other people. For example, children with OI need immunizations and may get the usual childhood illnesses. Adults with OI may face minor illnesses and have the same risks as other adults for serious health problems, such as diabetes, cancer, and heart disease.

General Principals for Good Communication

- Keep detailed medical records and lists of fractures, how they occurred, and how they were treated. Include developmental milestones; immunizations; illnesses; surgeries; medical treatments; medicines; allergies; results of urine calcium, bone density, and other routine tests; and any complications from surgery, anesthesia, or treatments.
- Keep a brief summary of key points in the medical history to share with a new doctor or when traveling. Include surgeries and complications.
- Find a doctor who listens to you and who makes you feel comfortable.
- Find a doctor who treats you with respect and is interested in the information on OI that you provide.
- Find a knowledgeable and skilled doctor who has some expertise with OI, or is willing to consult medical literature and specialists to acquire expertise.
- Plan ahead for emergencies. Learn how to contact the doctor, what to do on a weekend or holiday, and which hospital to go to. Discuss with your doctor what to do if he or she is unavailable or on vacation.
- Work in partnership with your doctor: Follow through on prescribed medications or therapies, and provide complete and honest reports to the doctor.
- When you answer your doctor's questions, do not exaggerate, deny, or deliberately omit information.
- Be an attentive listener.

Prepare for the Appointment

- Record any symptoms. Be specific about the date, time, location, and type of pain, and body temperature. It can help to keep notes on a calendar or in a diary.
- Prepare a list of questions.
- Ask questions in order of importance. Never leave the most important one for last.
- Bring paper and pencil to write down the doctor's answers.
- 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. Provide this list to your doctor at each visit.
- Bring copies of any resources you have found, including medical literature or information found online.

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.

Questions about symptoms:

- If the doctor dismisses a symptom by saying, "It's probably the OI," ask how the symptom would be evaluated if you did not have OI.
- If a symptom is persistent or troubling, ask the doctor if it is being treated in the same manner as it would for a patient who does not have OI.

Questions about your general health:

- What can I do in terms of diet that will help me stay healthy?
- What can I do in terms of exercise that will help me stay healthy?
- What other steps toward a healthy lifestyle do you recommend?

After hearing a diagnosis:

- What does this mean?
- What are the possible treatments?

- What is the prognosis? (What can I expect might happen next?)
- What can I do to prevent this from happening?
- What can I do to prevent this from happening again?
- Is it necessary to see a specialist?

When tests, medications, or treatments are prescribed:

- What is the exact name of the test, drug, or treatment?
- Why is it needed?
- 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?
- How do I take this medicine?
- How do I prepare for this test?
- When will I get the test results?
- Will the orthopaedic rods and other implants in my body interfere with this test? (Certain types of rods interfere with an MRI [magnetic resonance imaging].)
- Will this treatment affect my bone mineral density?
- How should I take care of myself at home?
- What warning signs or side effects should be watched for?

When there is a referral to a specialist:

- What will the specialist do about this medical problem?
- Why is this type of doctor being recommended?
- Will you (the primary care doctor) send the necessary records, test results, or x rays directly to the specialist?
- Will the specialist keep you (the primary care doctor) informed about any new treatments?

Closing:

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

Resources

For information on how to talk to your primary care doctor 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 fact sheet contains information about medications used to treat the health condition discussed here. When this fact 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 updates and questions about statistics, please contact the Centers for Disease Control and Prevention's National Center for Health Statistics toll free at 800-232-4636 or visit its website at www.cdc.gov/nchs.