

Talking With Your Primary-Care Doctor

Introduction

People with osteogenesis imperfecta (OI) usually require the services of a health-care team that includes a primary-care physician (PCP) and several specialists. The primary-care doctor is concerned with the overall health of each person. 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 Principles for Good Communication

- Keep detailed medical records. Keep lists of significant fractures, how they occurred, and how they were treated. Include developmental milestones; immunizations; illnesses; surgeries; medical treatments; medicines; and allergies. Include test results for urine calcium; bone density; other routine tests; and 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, and who 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. Include information about how to contact the doctor, which hospital to go to, what to do on a weekend or holiday, and transportation. 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 date; times when symptoms occur; 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.
- Maintain a list of all drugs, drug dosage, vitamin and mineral supplements and alternative treatments you are using and provide this information to your doctor at each visit.
- Bring copies of any resources you have found, including medical literature or Internet information.

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.

Questions about your general health:

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

After hearing a diagnosis:

- What does this mean?
- What are the possible treatments?
- What can I expect might happen next? (What is the prognosis?)
- Is it necessary to see a specialist?

When medications, tests, or treatments are prescribed:

- What is the exact name of the drug, test, or treatment?
- Why is it needed?
- Will my size influence the dosage amount you prescribe?
- What are the costs, risks, and benefits?
- Are there any alternatives?
- What will happen to me if nothing is done?
- How do I take this medicine?
- How do I prepare for this test?
- When will I get the test results?
- Will the type of orthopedic rods and other implants in my body interfere with this test? (Certain types of rods interfere with an MRI.)
- 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 regarding this medical problem?
- Why is this person or type of doctor being recommended?
- Will you (the primary-care physician) send the necessary records, test results or, x-rays directly to the specialist?
- Will the specialist keep you (the primary-care physician) informed about my treatments?

Closing:

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