

# Managing Medical Care When Your Child Has OI

## Introduction

As the parent of a child with osteogenesis imperfecta and a financial services coordinator, I know you will face certain challenges when it comes to coordinating medical care. You may often need to act as an advocate for your child's best interests. To be effective in that role, you'll need to be prepared.

## Diagnosis and Treatment Options

To obtain a complete diagnosis of your child's medical issues, you and your child may need to visit several health professionals. While prenatal and postnatal medical testing has eliminated much of the guesswork around diagnosis, you may still want to ask for second opinions, particularly if your child's condition is difficult to assess. OI is a complicated and variable condition that does not rule out other medical problems. In addition, because doctors don't always agree on the best ways to treat some medical conditions, you may want to get advice on treatment options from at least two physicians.

Your child's health needs may be complex and require multiple services, including medical, psychological, behavioral, and educational help. Talk to your physician about any concerns you have about your child's development, and ask for referrals to other professionals who can provide testing, early intervention services, and treatment options.

## Become Informed and Involved

It is in your best interest (and your child's) to learn all you can about your child's condition and prognosis. Start by asking the health-care providers you've seen to explain what's going on, and insist they do so thoroughly, in language you can understand. In addition, seek out and join organizations like the OI Foundation that are dedicated to the treatment and cure of your child's condition. In addition to the OI Foundation, local organizations may also sponsor support or network groups, and publish

magazines, newsletters, brochures, and other materials that provide helpful information. Browse the Internet for relevant websites like [www.oif.org](http://www.oif.org), and stay abreast of any promising research projects or new medical developments. The more you know about your child's health concerns, the better you can advocate for appropriate treatments.

## Find a Physician You Can Work With

Your child may require specialized treatment and care, but he or she will also need routine care for common childhood ailments. This means that your child's primary physician should probably be his or her pediatrician or family doctor. These providers are trained to care for children with special needs, as well as for those without them. In many cases, particularly if you belong to a managed care organization such as a health maintenance organization (HMO), you'll need to work through your child's pediatrician or primary care physician to obtain referrals to specialists. Since continuity of care is especially important when you have a child with OI, try to find a physician you can work with as your child grows. Look for a physician who:

- Has extensive knowledge of medical condition and treatment options
- Stays up to date on research and available treatments
- Takes time to explain treatment options and procedures to parents and children
- Is accessible and encourages questions
- Takes parent concerns seriously
- Is empathetic and nonjudgmental
- Has a support staff of trained professionals
- Can provide referrals to appropriate specialists and community resources, if necessary

It's also wise to keep your child's pediatrician apprised of all the treatments other doctors recommend

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for your child, particularly if medications have been prescribed. In addition to obtaining copies for yourself, have all reports of treatments indicated by other doctors sent to your child's pediatrician (unless he or she already has access to them).

## Keep Detailed Records

It's always a good idea to keep track of your child's ailments and medical treatment history, and particularly so when he or she has OI. Periodically request a copy of your child's medical records and keep your own lists of doctor's visits, treatments, surgeries, medications, and recommendations. You may also want to keep a daily or weekly log of your child's activities, noting any symptoms that might warrant follow up. In doing so, you may begin to notice patterns of symptoms or changes in your child's condition that otherwise might be missed. This information might help your child's physician refine the treatment plan for your child.

## Paying for Medical Care

Medical care for a child with OI can be costly, and keeping track of all the paperwork involved in paying for it can be complex and time consuming. Make sure you keep complete and well-organized records, especially when it comes to dealing with insurance providers. You should keep copies of correspondence and phone logs that record the time and date of calls and the names of claims representatives you speak with.

## Private Insurance for Medical Care

Private insurance may cover some of the costs of your child's medical care. As soon as you become aware that your child has OI, check your policy. Here are some things to consider:

- Does your child's pediatrician or primary care physician have to make a referral to specialists or other health care providers?
- Can you choose your own providers or must you select them from an approved list?
- Do any limits exist on how much

types of care?

- Does the insurance cover the medications your child may require?
- Will the insurance pay for assistive technology (e.g., hearing aids, prosthetics, wheelchairs)?
- Is preauthorization required for hospitalization, and/or is the length of stay limited?
- Can you work directly with a particular claims adjuster for the purpose of establishing continuity?
- What is the procedure for appealing a decision to deny payment for service?
- Caution: Remember, if you're planning to change insurance policies, examine the new one carefully. Watch out especially for limitations on pre-existing conditions.

## Medicaid

The Medicaid program is the most important source of funding for health services for children with special needs. The program offers:

- A basic health insurance plan for most of its beneficiaries,
- Payment toward long-term care for the disabled, and
- Funding for programs for the developmentally and physically disabled.

Because it's a joint federal-state program administered separately by each state, Medicaid eligibility requirements (and some benefits) may vary from state to state. For specific information on its benefits, see Medicaid. For more information on your state's programs, contact your local health department, your state or county social services office, or your local Social Security office.

In most states, if your child qualifies for Supplemental Security Income (SSI), he or she automatically qualifies for Medicaid. To qualify for SSI, your child must meet certain disability criteria and either have limited income and resources, or come from a home of limited income and resources. If your child meets the disability criteria, but is ineligible for SSI because of income and resource considerations,

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he or she may still qualify for Medicaid if you live in a state that offers a medically needy program. Since their income and resource guidelines are more flexible, these programs may benefit families who are ineligible for SSI but burdened with large medical expenses for their child with a disability.

A child who is chronically ill or disabled is automatically eligible for Medicaid if he or she is institutionalized for over 30 days. In such a situation, your income isn't considered in determining eligibility; only your child's own financial resources are taken into account. Because states want to encourage families not to institutionalize their children, they may award waivers allowing Medicaid to cover the cost of equivalent medical care at home, provided such home care doesn't cost more than the institutional care. Each waiver is individually determined, so ask about the requirements. Your child will be ineligible for this benefit, however, if you have private insurance that would cover the cost of the institutional care.

#### In Case of Emergency

When you're the parent of a child with OI, routine preparedness for an emergency goes beyond keeping fresh batteries in the flashlights. Here are some considerations:

- Learn CPR and other necessary medical skills, such as how to splint a fracture
- Know how to operate any medical equipment that your child may depend on or require in a crisis
- Keep on hand an adequate supply of any medications your child requires, and know how to administer them
- Keep a complete list of emergency numbers (including those of physicians and hospitals) clearly posted in your home, in the glove compartment of your car, and on your person. Give copies of this list to nearby relatives and/or trusted neighbors
- Make arrangements in advance with your pediatrician or primary care provider to allow you to

- specialists in an emergency
- Carry a cell phone
- Make sure a friend, relative, neighbor, or respite care provider will be available to care for your child if an emergency arises and you're unavailable, or to care for siblings while you are caring for your child with OI
- Keep your child's medical records and any other relevant documents (e.g., insurance paperwork, medical letter of intent, will) in a safe place, and make sure someone you trust has access to them
- Draft letters that you can keep on file with child-care centers, the school nurse, babysitters, or family members that describe your child's medical needs and what to do in case of emergency

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