

Social and Emotional Issues of Living with OI

Introduction

Osteogenesis imperfecta (OI) is a genetic disorder characterized by bones that break easily. It has been described as a chronic disorder with crisis periods. Living with a lifelong health condition like OI is stressful at times. Many people with OI and their families cope very well with both the physical and the social/emotional problems associated with OI. They lead happy, interesting and successful lives. Just as it is important to learn how to deal with fractures and other medical aspects of OI, it is also important to develop skills for managing stress and uncertainty. Being aware of potential trouble areas can help people be better prepared, and avoid or minimize some potential problems. By putting support systems in place, additional help will be available if needed.

Strategies for living successfully with OI include:

- Be well informed about OI.
- Develop an effective support network.
- Resolve the social and emotional needs of the person with OI and their family members as they arise.
- Include interesting and fun activities in your schedule.

Issues that Confront Family Members

The Parents

When an unborn child, infant or young child is diagnosed with OI, the parents experience many emotions. Because OI is a rare disorder, an immediate challenge is locating doctors and other health care providers who are experienced with OI. When the diagnosis is not made at birth, it can sometimes come as a relief after months or even years of concern about a child's health. If child abuse allegations were part of this experience, the parents may feel vindicated to receive the diagnosis. Even so it will still be necessary to deal with their feelings about raising a child with a life-long medical condition.

Parents are faced with many emotional issues and decisions.

- An unexpected diagnosis affects all members of the family in terms of their emotions, everyday activities, career choices and finances.
- Life with OI is uncertain – when the next fracture might occur, when a child will reach a developmental milestone such as rolling over, which medical treatment option is the best, what the effects of an experimental treatment might be, or whether vacation or holiday plans will be interrupted by an injury.
- It is important to realize that no matter how careful a caregiver tries to be, it is impossible to protect a fragile child from the pain of broken bones.
- It is a struggle to find the right balance between protecting from harm and encouraging the child to try new things.
- An on-going challenge is balancing the care of a child who has OI, with the needs of other children and adults in the family. Coping with a child who has OI can be more time consuming than caring for other children.
- Coping with fatigue, stress and sadness can affect the parents' health and relationships. Caring for a child with OI can put additional strain on a marriage.

Strategies to help parents cope with the stress of OI include:

- Develop techniques for dealing with risk and uncertainty and a system for coping with broken bones and other medical emergencies.
- Create a support network that includes extended family, friends and professional services. Grandparents often become important parts of the support system. Doctors, nurses, hospital social workers, and genetic counselors can provide information about local services. The OI Foundation offers support, connections to other OI families and verified information on medical care, and daily living.
- Cultivate the habit of open and clear communication between all family members, including the children.
- Pay attention to their own needs for rest, emotional support, and adult friendships.

Parents stress the overall importance of a strong support network for coping with the challenges of OI. People outside the immediate family circle can learn to safely handle the child with OI, help with the siblings and locate support services. A network of skilled helpers gives parents more flexibility, prevents feelings of isolation, and in the long run helps the child with OI develop trust in other people.

When Parents also have OI

When one of the parents also has OI, the couple has insight into what OI is and may already have strategies in place for finding good medical care and coping with fractures.

- As a couple, they will need to develop their own family style for raising a child with physical limitations.
- Over time, the parent with OI will be faced with feelings about his or her own experience with OI.
- Parents who have OI must learn to handle the emotions that arise when their child is in pain or frustrated, and, in some cases, cope with the child who fractures more than the parent did.

Siblings

It is normal for brothers and sisters to feel jealous of the time their parents must devote to caring for the child with OI. They may feel left out, angry, sad, or afraid. They may even feel guilty over not having OI or over causing a fracture. Many siblings worry when the child with OI must be hospitalized, or when their parents are away from home. It is common for children to feel resentment when they perceive that the child with OI is treated differently than the rest of the family.

Parents can address these feelings and help siblings develop a life-long affection and respect for each other. The following strategies can help parents accomplish this goal.

- Communicate openly and calmly with their children. Information can help children feel more secure and reassured.
- Spend special time with their children who do not have OI.
- Be sensitive to the sibling's point of view.
- Expect age appropriate behavior from all of the children in the family.
- Include the child with OI in family projects and daily chores.
- Teach all children in the family what to do in an emergency.

Siblings have a need for information about OI provided in age appropriate language. They also need rules for playing with their fragile brother or sister. At the appropriate age, they will need information about genetics and their future as parents.

Grandparents and Others

As part of the extended family, grandparents, aunts, uncles, cousins, friends and neighbors will all be affected to some extent when a child has OI. They too have a need for information and support. The OI Foundation sponsors a biennial national conference, an interactive web site and publishes materials that can fill this need. The extended family can be an important part of each family's support system.

Issues for People with OI

OI impacts a person's health. It can affect self-concept, family dynamics, relationships and career choices. Children and adults who have OI have the same needs as others to develop a healthy self-image and to understand their personal strengths, abilities, limitations and weaknesses. They need to plan for the future and cultivate personal relationships. Children, teens and adults with OI are just as capable as their peers of having close friendships and loving relationships.

Living with a chronic health condition can affect mental health in a number of ways. People with OI may experience low self-esteem, or anxiety. They may feel isolated, have a fear of early death or feel depressed. Serious problems such as these usually require help from medical professionals. People with OI who experience any of these feelings should discuss their symptoms with their primary care doctor or other trusted professional. Focus groups of adults and teens with OI suggest the following strategies as possible ways to face OI's challenges and develop a healthy outlook on life.

- Stay informed about OI.

- Learn how others have coped with physical limitations and feeling different.
- Develop strategies for coping with pain and medical treatments.
- Develop a personal plan for coping with uncertainty and risk.
- Surround yourself with people who respect you and provide emotional support.
- Learn independent living skills.
- Get a good education and prepare for a career.
- Get information about sexuality and reproduction.

Issues Related to Type/Severity

Each type of OI presents its own set of challenges. Type I OI is often referred to as “Mild OI,” but for many people this is only a relative term – they have fewer fractures than people with other forms of OI, but more than everyone else. Often they have few outward signs of having fragile bones. Their social/emotional challenges involve coping with having a hidden disorder and finding a balance between trying to look and act like everyone else while still protecting themselves from injury.

People with moderate and severe forms of OI face challenges related to short stature and frequent hospitalizations. They often struggle to be treated in an age appropriate manner. The frequent use of walking aides, wheelchairs and the challenges related to driving can complicate friendships, careers and routines of daily living. They may also need to cope with chronic pain related to fractures, immobility and bone deformities.

Hearing loss is a medical complication of OI that can occur at any age and in people with any type of OI. It often results in feelings of isolation and can affect interactions with other people. Information from doctors, audiologists and hearing organizations, such as the Hearing Loss Association of America, will help people cope with the related social and emotional issues.

Issues Related to Age Childhood is a time for laying the groundwork for living independently. It is the time to learn social skills, develop relationships with siblings and peers, begin hobbies and learn self-care skills. Daycare and school play an important role. Frequent fractures, hospitalizations and transportation issues can make it more difficult for children with OI to have these experiences.

Out of necessity, children with OI spend a lot of time with adults. It is worthwhile to deliberately seek opportunities for play dates and other fun experiences with other children. Social skills learned as a child will benefit the teen and young adult. Joining teams, clubs, and organizations such as scouts or church groups can lead to friendships and interests that will last a lifetime and ease some of the problems of adolescence. Developing non-sports hobbies will help children retain a peer group when adolescents begin focusing on competitive sports activities.

Pre-teen and Teen years are challenging for young people with OI and their parents. The early stages of puberty can place additional stress on the child’s growing skeleton and fractures may become more frequent. Hospitalizations will impact school and social life. School issues often become more complex as the child moves to middle school, high school and college or other career training. Like their peers, teens with OI struggle with self-esteem, self-confidence and friendships. Concerns about peer acceptance and physical appearance related to dentinogenesis imperfecta (DI), height and bone deformity may lead to feelings of inadequacy and depression.

Like their peers, some teens with OI may be attracted to various types of risky behaviors, including drug or alcohol abuse in an effort to cope with the challenges of being an adolescent. Coping with being different takes time and loving support from family and friends. If there are signs of depression, or isolation, teens should seek professional help. Talking to a member of their primary care team is often the first step.

Activities, often started in childhood, that help the teen develop and maintain friendships, and participate in school, church or community events can help minimize some of the problems of adolescence. Meeting older teens and adults with OI who can be role models as well as sources of practical information can also help. Like their peers, teens with OI need information about intimacy, sexuality, and reproduction. While dating may be delayed for some people, teens still need to know about safe sex and sexually transmitted diseases and how to take responsibility for themselves and their partners. People with OI can have satisfying sexual relationships. Many get married. Many have or adopt children and raise a family.

During the teen years, issues about the transition to adulthood also become pressing. Besides learning the usual independent living skills, it is important for teens with OI to assume more responsibility for their health and for communicating with their health care providers.

Across childhood and the teen years, parents can help their child with OI grow into a competent adult by providing opportunities that help the child to:

- Learn to take responsibility for self and others
- Socialize with other children and adults outside the family
- Gain experience with nature, and outdoor activities
- Learn about the world of work through volunteering or part time jobs
- Develop good judgment and learn to evaluate risks.

Adults who have OI continue to face the challenges of developing friendships and intimate relationships, finding satisfying work, achieving and maintaining independence and living with confidence. Especially for people with more severe OI, there may be recurring problems of immobility, isolation, and social or financial dependence. Workplace discrimination and access to health insurance are frequent problems for adults with all types of OI. Fracture cycles, increasing fragility, chronic pain and hearing loss can emerge as the person reaches middle age and beyond. As in any population, adults with OI also have risks for health problems such as diabetes, cardiovascular disease and obesity. Staying active, healthy and connected to their communities remains important for both physical and emotional health.

Adults with OI suggest the following strategies for living successfully.

- Be aware of the stressors associated with OI.
- Talk--to family members, friends, other OI families and health care professionals.
- Get the facts about OI and stay up to date on the latest information.
- Be an active member of your medical care team - be your own best advocate.
- Get the best education possible.
- Find employment.
- Make time for hobbies -- do things you enjoy.
- Be physically active on a regular basis.
- Have fun.
- Become a creative problem solver.
- Stay involved with your local community through civic or church activities.
- Stay connected to the OI community; seek opportunities to meet others with OI.
- Seek help from professionals when you notice any signs of an emotional problem; your primary care physician, nurse, or spiritual advisor may be a place to start.

Resources: Getting Information & Support

Family, friends, and other people affected by OI can often provide social and emotional support. At other times, children and adults who have OI or their family members need the kinds of support and guidance only a professional can give.

Health professionals such as psychologists, social workers or clinical counselors are trained to help people cope with fears, stress, depression and sadness. Genetic counselors, nurses, physical therapists and occupational therapists can assist with information about OI. Social workers can help locate services, and provide legal and financial referrals. Marriage counselors are aware of the stress associated with chronic medical problems. Clergy and church members offer other types of support. Disability organizations such as Family Voices or Easter Seals can help families understand their rights, and locate local services.

The OI Foundation is here to help. It provides information about OI, emotional support, and community awareness. Its programs link parents to people with OI and to each other. The CaringBridge program provides personal web sites for people in the OI community who are coping with a medical crisis. On even numbered years, the OI Foundation sponsors a national conference that brings the OI community together to learn, share and support each other. The national conference offers an unparalleled opportunity to meet people with OI of all

ages and their families. The OI Foundation publishes many print and electronic resources. Contact information for the OI Foundation is listed below.