

The type of OI and degree of severity will affect the treatment plan. All people with OI benefit from physical therapy, early intervention programs in childhood and as much exercise and physical activity as possible throughout the life span. Obesity including unhealthy weight gain during adolescence, and low stamina or fatigue can affect people with OI.

Type I (Mild)

Care issues include gross motor developmental delays, joint and ligament weakness and instability, muscle weakness, the need to prevent fracture cycles and the necessity of spine protection. Emotional support is needed at every age to help cope with a disorder that may be “invisible” to peers and the casual observer. Families are advised to carry documentation of the OI diagnosis to avoid accusations of children abuse when taking a child to an emergency room.

Type II (Most Severe)

Care issues include obtaining an accurate diagnosis and management of respiratory and cardiac impairments. Infants who can breathe without a respirator may be candidates for treatment with an intravenous bisphosphonate such as pamidronate or zoledronic acid. Genetic counseling for the parents is recommended. The family will need on-going emotional support as they face the possibility that their infant may live only a very short time.

Type III (Severe)

Care issues include the need to prevent fracture cycles; the appropriate timing of rodding surgery; scoliosis monitoring; respiratory function monitoring and the need to develop strategies to cope with short stature and fatigue. Infants who can breathe without a respirator may be candidates for treatment with an intravenous bisphosphonate such as pamidronate or zoledronic acid. Families will need emotional support and practical guidance particularly during the child’s infancy and when the child is ready to enter school. Important issues to address include difficulties with social integration, participation in leisure activities and maintaining stamina.

Type IV (Moderate)

Care issues include the need to prevent fracture cycles; the appropriate timing of rodding surgery; scoliosis monitoring; the need to develop strategies for coping with short stature and fatigue. The family will need emotional support especially during the child’s infancy. Bisphosphonate treatment is often prescribed. Important issues to address include difficulties with social integration, participation in leisure activities and maintaining stamina. Families are advised to carry documentation of the OI diagnosis to avoid accusations of children abuse when taking a child to an emergency room.

***This information is based on Guide to Osteogenesis Imperfecta for Pediatricians and Family Practice Physicians.
Francis Glorieux, OC, MD, PhD, editor, Osteogenesis Imperfecta Foundation, 2007.***