Adults who have OI are concerned about how their OI might change as they age and how aging may affect their OI. The majority of people who have OI will live past middle age.

**Bone Density and Fracture Risk Protection:** Decreasing fracture risk and maintaining bone mass are priorities for adults with OI. Fracture risk protection is afforded by using physical therapy to maintain muscle strength, use of proper footwear and corrective surgery when indicated. Bone density can decline as a direct result of OI, from immobilization, limited weight bearing, age-related changes in bone and the endocrine system. Smoking overuse of alcohol and certain medications also negatively affect bone mass.

- Treatment with most osteoporosis drugs has been shown to increase bone mass but not significantly decrease fractures in the OI adult.
- Treatment with Forteo® has been shown to improve bone density for those with Type I OI.
- Treatment response with Prolia® has not been reported.

**Cancer:** The incidence of most cancers including breast and prostate cancer appear to be similar to that seen in the unaffected population.

**Cardiac Function:** Mitral valve prolapse is the most common heart valve problem seen in the OI adult. Insufficiency of the aortic valve and dilation of the aorta also may occur but are not common. The frequency of heart problems in individuals with OI is being studied. The occurrence of hypertension is reported to be similar to the unaffected population. High cholesterol and related lipid disorders that may occur in families can contribute to heart problems as well.

- A base-line echocardiogram is recommended for young adults especially if there is a family history of heart problems.
- Medical management of these disorders includes appropriate diet and drug therapies and regular monitoring by a primary care doctor.
- Coronary artery surgery and coronary valve surgery have been successfully performed on people with OI, although precautions are necessary because of tissue fragility.

**Chronic Pain:** Adults may experience pain from nonunion fractures, compression fractures of the spine and age-related bone loss. Unstable joints may increase painful degenerative changes.

- Manage with lifestyle adjustment, medications and alternative treatments.
- Consider tendency of pain medications to depress respiration, increase fall risk, and aggravate constipation.

**Fatigue:** Many adults with OI are concerned about fatigue. Diet, physical activity, pain, weight, respiratory function and health problems that are not OI related may all contribute to both the problem and the treatment.

- Treatment usually begins with a thorough physical.

**Hearing:** Approximately 50 percent of all adults with OI will experience some degree of hearing loss during their lifetime. Hearing loss tends to worsen with age and can become profound.

- Treatment usually begins with hearing aids and may progress to stapedectomy or cochlear implant surgery.

**Mobility Loss:** Upper limb deformity and short stature contribute to difficulties with performing the activities of daily living and with overall independent function. Lower limb deformity may impair mobility. This is more pronounced in those with OI Type IV or Type III. Car accidents and falls can lead to serious fractures and the need to relearn skills. Weight gain is linked to loss of mobility even more often than accidents.

- Treat with referral to rehabilitation professionals for muscle strengthening physical activity programs.
**Musculoskeletal and Joint Problems:** Muscle weakness is documented among people with all types of OI. A higher risk for osteoarthritis is possible where joints are subjected to excess strain due to previous fractures or deformities. Adults often report lower back hip, knee and ankle pain possibly related to compression fractures of the spine, spine curves or joint deterioration. Other problems can include nonunion fractures and joint laxity or excessive joint flexibility. Overuse injuries to shoulders can be serious for the person using crutches, a walker or a manual wheelchair.

- Treatments for lower back pain include exercise and orthotic devises to improve hip, knee and ankle alignment; heel lifts and ankle supports, which can limit joint damage and improve walking comfort.
- Joint replacement surgery may be a treatment option for some, but not all, adults with OI.
- Strengthening exercises and access to different mobility aides may prevent some overuse injuries.

**Pulmonary Function:** Altered lung function affects all OI adults. Incidence of asthma and fatigue due to poor oxygenation are frequent problems. Breathing problems may be more severe in those with OI Type III or Type IV and those individuals with significant curvature of the spine. Sleep apnea is a related problem for some adults with OI.

- Treatments include exercise to promote deep-breathing, use of supplemental oxygen, and CPAP or BiPAP.
- Doctors familiar with OI recommend aggressive treatment of all upper respiratory infections in adults with OI and use of flu and pneumonia vaccines.

**Reproductive System:** OI does not appear to significantly limit fertility in either men or women. Pregnancy related questions should be addressed to physicians who are specifically informed on these matters. Pelvic fractures and deformity may affect a woman’s gynecological health and ability to give birth vaginally. Excessive bleeding in women who have OI during delivery has been reported. Fracture frequency may increase after menopause. Urologic issues for men with OI have not been studied.

**Vision:** OI can affect the shape of the lens and the strength of various eye tissues. Tissue laxity and fragility affect the outcome of surgical procedures. There may be an increased risk for retinal detachment and glaucoma as the person ages.

- An ophthalmologist should be consulted before using contact lenses.
- Laser lens surgery is not recommended for people with OI.

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