



## How Patients with OI Reduce and Cope with their Pain



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### Introduction

Shriners Hospitals for Children houses cutting-edge research and state-of-the-art treatments for orthopaedic disorders, such as Osteogenesis Imperfecta. Our diverse team of experts is dedicated to improve the lives of children by providing outstanding care and support to patients and their families. Our current research efforts target, among other aspects, approaches to reduce and cope with OI pain.

### What is pain?

Pain is a complex multidimensional subjective concept that researchers have organized into three main dimensions: **(1) sensory, (2) affective, and (3) cognitive.**

These dimensions are linked and allow patients and researchers to understand pain as experienced by OI patients.

#### Pain can be described in terms of duration:

**Acute pain** can be viewed as a warning sign to your body to notify it of actual tissue damage. The pain is only endured for a limited time.

**Chronic pain** may arise in the absence of injury or disease and persists beyond 3 months after healing.

## The Multidimensionality of Pain



**Sensory** quality, intensity, duration, location

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**Affective** emotional response, mood, suffering

.....  
**Evaluative** meaning of pain, attitudes & beliefs, coping strategies

### What Have We Found?

We have analyzed studies that have assessed the pain experienced by OI patients and have examined the effects of bisphosphonate treatment on OI pain.

#### Clinicians should further explore treatments for OI pain.

Our study on the effects of bisphosphonate treatment on pain relief reveals that although they increase bone density, they do not reduce pain. Thus, clinicians should move on to looking at other interventions that specifically target pain relief.

#### We need evidence for the effectiveness of non-pharmacological treatments for OI pain.

Although cognitive-behavioural therapy has proven to be successful in reducing pain intensity in other chronic pain disorders, little work has been done to test this in OI patients.

#### There's a need for clinical practice guidelines

Future research should look into patient's preferences in treatments to reduce their pain, and from there formulate appropriate and comprehensive clinical practice guidelines.

## Approaches to Reduce and Cope with OI Pain

Currently, the main goals of medical therapies and interventions are to, (1) reduce fracture rates (2) reduce bone fragility (3) maximize mobility, and (4) improve quality of life. There are many different approaches that can be used to ease OI pain. Generally, patients tend to choose both pharmacological and non-pharmacological interventions.

### Pharmacological Interventions

**Over-the-counter (OTC) analgesics** are the most common pharmacological method used by patients with OI to reduce pain.

For **mild pain**, patients should start with non-opioid pain relievers, such as acetaminophen (Tylenol) and ibuprofen (Advil).

For **moderate to severe pain**, non-opioid analgesics will not suffice, thus patients should additionally use stronger analgesics, such as opioids (ex: codeine).

Although OTC analgesics are relatively safe, if taken for a prolonged duration of time, unpleasant side effects may appear.

**Bisphosphonates** increase bone density, and consequently reduce the rate of bone fractures. However, according to our study on the effects of bisphosphonates on OI pain, they do not reduce pain intensity, nor improve mobility, nor improve the quality of life of patients with OI.

### Surgical Interventions

**Rodding surgery** involves the placement of a rod that is either fixed (non-telescopic) or expandable (telescopic) along the long bone. The rod serves to reduce the risk of bone displacements and fractures.

### Non-Pharmacological Interventions

**Patient Education** is essential as patients should be involved in their treatment by understanding the causes of their pain, the basic anatomy involved, and their treatment plan to help reduce their pain.

**Physical Strategies** may be used along with pharmacological and psychological approaches to decrease anxiety, distress, and pain.

- taking a hot bath, shower, or applying heat
- exercising (swimming, yoga, stretching)
- massaging, rubbing, or applying ice to the painful sites
- sitting up in a chair, short walks, rides in a wheelchair
- opting for bedrest

#### Psychological Therapy

- distractions (listening to music, playing videogames)
- relaxation, guided imagery, mindfulness
- peer support
- consider referral to Child Life Specialist, Clinical Psychologist, Psychiatrist

## What's next in adult-related pain research?

### Long-Term Studies

Studies for OI pain should be done over a prolonged period of time as pain is a long-term symptom and its impact has different repercussions across one's life.

### Capturing Real-Time Data

Methods that capture real-time data, such as pain diaries, are needed to track acute pain and chronic pain.

### Pain Assessments

Studies should follow the appropriate guideline for pain assessments, which examines all three dimensions of pain. For acute pain, a different guideline is available.

If you have questions or concerns in regards to your own pain experiences, talk to your doctor, nurse, physiotherapist or occupational therapist. You can also connect with OI communities, such as:

- OI Foundation ([www.oif.org](http://www.oif.org))
- Brittle Bone Society ([www.brittlebone.org](http://www.brittlebone.org))
- OI Australia ([www.oiaustralia.org](http://www.oiaustralia.org))
- OI Federation of Europe ([www.oife.org](http://www.oife.org))
- Care 4 Brittle Bones Foundation ([www.care4brittlebones.org](http://www.care4brittlebones.org))

Shriners Hospitals for Children® - Canada  
1003 Décarie boulevard. Montréal, Québec H4A 0A9  
514-842-4464

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