

Living with OI

Psychosocial consequences of Osteogenesis Imperfecta

Even if you have OI, you can face questions and challenges at every stage of your life. Everyone has to find a way to deal with obstacles. It doesn't matter whether you have a mild or a heavy form of OI. You don't have to find out everything on your own, feel free to ask for help. In your environment, at the VOI (Vereniging Osteogenesis Imperfecta) or the expertise centers.

Children <12 years

'After my presentation, my classmates understood what OI is.'

Topics that can arise: Obstacles at school, in sports, or when playing with other children. The obstacles are the result of restrictions in movement and fear of broken bones.

Emotions that can arise: Anger and sadness because you have OI.

tips
Tell the class about your OI so they can understand what you've got. Look for sports that you can do, such as badminton/swimming.

Children 12-18 years

'There are quite a few sports I can do perfectly well!'

Topics that can arise: Obstacles at school due to fear of fractures and restrictions in movement, e.g. not being able to participate in gymnastics lessons or in sports.

Emotions that can arise: Sadness, but also optimism about the future.

tips
Get to know your boundaries and dare to express them. Make it easy for yourself: ask if you can work out at the beginning or end of the day. Have 1 book set at school and 1 at home. Look for sports that you can do.

Young adults 18-35 years

'Can I pass OI on to my kids?'

Topics that can arise: Worries about relationship, child desire, study, work. Obstacles due to fatigue and pain. You may experience more barriers in these subjects than peers without OI. This can demand a lot from you. You realize that you may be different from someone without OI.

Emotions that can arise: Aider, fear, sadness.

tips
Talk about it with others or get help. Get to know your limits and dare to express them. See if you can adjust your timetables or if you can take longer to complete your studies. There are schemes for this.

Adults 35-50 years

'I've found work that takes my OI into consideration.'

Topics that can arise: Afraid to lose partner. Fulfilling the desire to have children or not can also cause strong emotions. But there can also be problems with movement.

Emotions that can arise: Loneliness, sadness, fear of broken bones, anger.

tips
Keep an eye on your limits. Talk about it with others or get help. Sometimes it helps to establish contact with other people who also have OI.

Adults 50+

'Often doctors have no idea how OI was handled in the past.'

Topics that can arise: Fatigue, difficulty moving. But there can also be unprocessed traumas from the past. In the past, children with OI were treated differently, in the hospital and at home. The upbringing was sometimes very strict or, on the contrary, very protective.

Emotions that can arise: Fear of the future, loneliness (when a partner is lost).

tips
Talk about it with others or get help. Anticipate ageing with OI. Think about informal care in good time and who can support you as you grow older.

ONTWERP TALLOUT

2018 Survey among people with OI

252 participants

55% <18 years heeft hulp gezocht has sought help for psychosocial complaints

38% >18 years has sought help for psychosocial complaints

You don't have to do it alone

You can ask for help from: → Family/friends → Mentor at school → VOI → Expertise centres OI → Social worker → General practitioner → Mental health nurse → Occupational therapist → Psychologist → Mental health carer

Any questions? Go to www.oivereniging.nl

This information is based on research conducted with 252 people with OI, September 2018

