Living with OI

Psychosocial consequences of Osteogenesis Imperfecta

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.

Children <12 years

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

Children 12-18 years

‘Can I pass OI on to my kids?’

Young adults 18-35 years

‘I’ve found work that takes my OI into consideration.’

Adults 35-50 years

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

Adults 50+

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:
Loneliness, sadness, fear of broken bones, anger.

tips
Talk about it with others or get help. Sometimes it helps to establish contact with other people who also have OI.

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:
Anger, fear, sadness.

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.

Tips
2018 Survey among people with OI
252 participants

55%<18 years
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