



SUPPORTING THE EMOTIONAL WELL-BEING OF CHILDREN LIVING WITH OSTEOGENESIS IMPERFECTA

Practical tips for parents and teachers

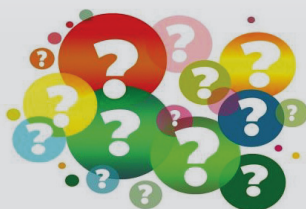
Emotional well-being is vital to our ability to thrive and achieve. It has been described as the ability to cope with the ups and downs of life.



1 in 8 children (5 to 19yrs) now have a diagnosable emotional health problem: that's around 4 children in every classroom. Research tells us that children with disabilities can sometimes struggle with their emotional well-being, more so than children without a disability. For example, children with OI tell us they can sometimes feel 'different' or be seen as 'different' by other children.

Parents can find it hard too. They may try to keep their child safe by avoiding activities and not taking risks; parents do what they can to keep their child free from fracture. Having OI can place limits on the things that children can do. It may restrict them from taking part in some activities that their classmates do.

At times, this may lead to being excluded from play or friendships and may result in feelings of loneliness and isolation. Such experiences are common contributors to children's emotional health difficulties such as low self-esteem, anxiety and low mood or depression.



So, what can we do to help?

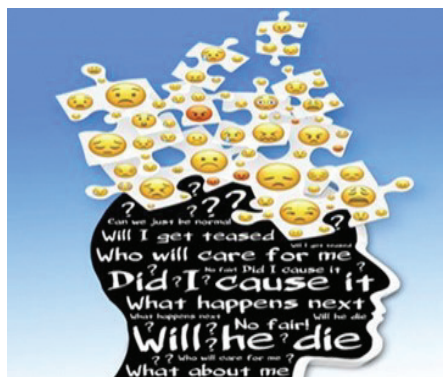


It is important to remember fears and worries are a normal part of growing up and the content of fears change according to a child's age.

For Example:

- ◆ Infants are often startled by loud noises
- ◆ Toddlers often fear strangers
- ◆ Pre-school aged children may fear the dark or being alone
- ◆ Children around the age of 6 to 9 may begin to think about and fear death
- ◆ Between 9 to 12 years they may start to worry about tests or their own health
- ◆ Teenagers often worry about social interactions, 'fitting in'

A child's emotional well-being may be affected when the fear or worry is so high that it starts to impact on activities and/or behaviour or if it is out of context from what we would normally expect for a child of that age.



How can we help children to deal with their feelings?



- ◆ Listen with full attention - sometimes a sympathetic silence is all a child needs.
- ◆ Acknowledge feelings with a word - 'oh' 'mmm' 'I see' - this creates space for a child to explore their own thoughts and feelings and perhaps come up with their own solutions.
- ◆ Give feelings a name - it can be comforting to hear the words for how they're feeling inside, for example 'that sounds frustrating'.



When we try to push away a bad feeling we often feel it even more.



In Summary

- ◆ Fears and worries can be a normal part of growing up
- ◆ Learn about your child's triggers for fearful/negative thoughts - routine can be helpful to manage difficult or negative thoughts
- ◆ Give feelings a name
- ◆ Involve children in decisions on how to manage a situation -work with them not for them
- ◆ Stay calm, supportive and non-judgemental - children mirror behaviour
- ◆ Encourage children to do something they enjoy and aim high - don't think 'you can't', think 'how can you?'
- ◆ Don't take away hope. By trying to protect children from disappointment, we protect them from aiming high and dreaming. The future is unpredictable!



KEEP CONNECTED



RESPECT YOURSELF



CHALLENGE YOUR MINDSET



TAKE A MOMENT



TALK THINGS OVER



GET ACTIVE



MAKE A DIFFERENCE



LOOK ON THE BRIGHT SIDE



BE KIND TO OTHERS



HAVE A GOAL



Finally ... encourage children to do something they enjoy.



- ◆ This could be sports, crafts, singing, playing an instrument, social networking, volunteering.
- ◆ It's often easier to change a behaviour than it is to change a thought.
- ◆ To help to maximise opportunities for success, offer support for what children with OI can do.
- ◆ Research tells us that doing something you enjoy, and that you're good at, helps build confidence and increases self-esteem.
- ◆ This approach helps to build self-confidence and motivation for trying new things.

Try to find activities that are not overly challenging so that children feel a sense of achievement and have the opportunity to build confidence.

Encourage them to build positive relationships with other children who have similar interests; by spending time with positive and supportive children and families, a child living with OI is more likely to have a positive self-image and feel more confident.



By now you may have realised that our thoughts, feelings and behaviour are all interlinked.

To support and strengthen the emotional well-being of children living with OI, it is important to see the whole child, not just the 'OI'.



All children benefit from having positive relationships and feeling a sense of belonging. These positive experiences are especially important for children living with OI.

Remember, it's normal to try to avoid bad or negative feelings but these feelings may often be connected with the things we want to do.

Sometimes feelings such as fear, insecurity or disappointment are unavoidable without giving up doing things we really want to do.

For Example:

Your child wants to go on an outdoor residential trip with school. The risks for children, parents and teachers are:

- ◆ Feeling disappointed that it wasn't as good as was hoped
- ◆ Feeling out of control
- ◆ Feeling fearful
- ◆ Feeling sad when the trip comes to an end
- ◆ Learning about the challenges and unexpected difficulties of day to day life



Keep in mind there is no right or wrong choice.

Sometimes you and your child will choose to take the risk and sometimes you won't. The key point is to keep observing and talking about feelings.

**What about negative thoughts?
How to identify and challenge them...**

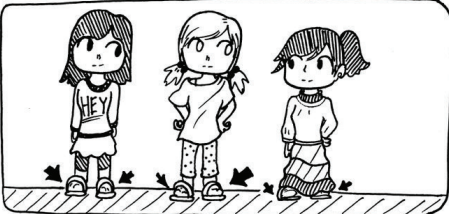
- ◆ Problems are part of everyday life.
- ◆ *Children are often quite good at coping with and resolving problems.*
- ◆ However, some problems may seem more difficult because they happen quite frequently, they never seem to go away, they feel overwhelming or they seem to affect everything we do.

The way we think about ourselves develops over time into strong patterns of thinking, often referred to as our **core beliefs**.

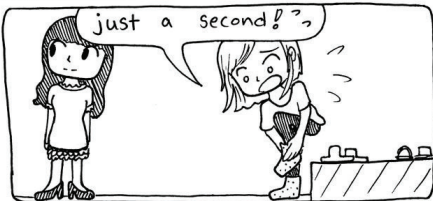
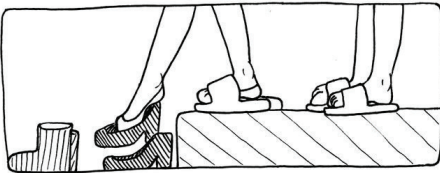
Core beliefs can be extremely useful by helping to predict and make sense of our lives; they can help keep us safe.

However, they can be less helpful when they get out of hand and lead us to make false assumptions about our life such as 'I don't belong' 'I'm useless'.

In Japan, you're not allowed to wear shoes indoors



And people are really good at taking their shoes off and putting them on quickly



Except for me

For Example:

Children with OI often describe how fear of fracture holds them back from taking part in some activities. In addition, they are often fearful of busy or 'dangerous' areas.

This can lead to negative thoughts and 'all or nothing' thinking:

- ◆ I'll **never** be able to go on the bus to school with my friends
- ◆ I'm **useless** at being in the play-ground with other kids...I **don't fit in**
- ◆ I can't go into town on a Saturday afternoon...it's chaos, I'm **bound to hurt myself**
- ◆ I won't be able to go to the football match with... last time it was a **complete disaster**

- ◆ **It's important to remind children that everyone feels like this sometimes.**
- ◆ Use simple analogies - 'we're a bit like the weather, sometimes bright and sunny, sometimes dark and gloomy but we can still have fun'.

Practical tips to help strengthen children's emotional well-being:

- ◆ **Support them to make choices** - children need to practice - making one mistake does not mean they will make the same mistake again
- ◆ **Avoid the use of over-the-top words** which can colour thinking - don't focus on the negatives *'you'll be exhausted by the end of the day'*
- ◆ **Show respect for their struggles** - help them to be kind to themselves *'tying laces takes a lot of fancy finger work'*
- ◆ **Use words like 'should' 'must' 'ought' sparingly** for example *'you ought to be able to tie laces by your age'*
- ◆ **Look for opportunities where they see themselves differently or put them into situations that shows them in a positive light**
- ◆ **Try not to ask too many questions** - you may magnify issues and make them seem bigger than they are
- ◆ **Try not to rush to answer questions** - we can all sometimes jump to conclusions - children need to explore the answer for themselves
- ◆ **Don't assume their emotions reflect what is actually happening**
- ◆ **Model the behaviour you'd like to see**
- ◆ **Be kind to yourself** and you'll become more sensitive to the emotional needs of your child; sometimes unhelpful thoughts cannot and perhaps need not be controlled

USEFUL LINKS:

- ◆ Brittle Bone Society <http://brittlebone.org>
- ◆ Osteogenesis Imperfecta Foundation <http://www.oif.org>
- ◆ Young Minds: Child & Adolescent Mental Health <https://youngminds.org.uk>
- ◆ Nip in the Bud: Learning About Children's Mental Health through Film www.nipinthebud.org
- ◆ How to include children with OI in mainstream PE http://brittlebone.org/wpcontent/uploads/2017/01/110798_Including_Children_In_PE_lores.pdf
- ◆ Find a club <http://parasport.org.uk/find-a-club>
- ◆ Girl guiding <https://www.girlguiding.org.uk/>
- ◆ Scouts <http://scouts.org.uk/>
- ◆ St John's Ambulance Cadets www.sja.org.uk/sja/young-people/cadets-ages-10-17.aspx
- ◆ Duke of Edinburgh Award <https://www.dofe.org/about-us-2/>
- ◆ National Citizenship Award <https://www.gov.uk/government/get-involved/take-part/national-citizen-service>
- ◆ Set up your own toddler group <https://www.childcare.co.uk/information/setting-up-your-own-toddler-group>
- ◆ Infant and toddler swimming lessons <https://www.puddleducks.com/programmes/swim-academy>

OI Parent support forums are also available on Facebook but please contact your GP if you are worried about your child

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The information in this leaflet is correct as at 31st January 2020 but we cannot guarantee that it will be accurate and current at any given time. This leaflet is not intended in any way to replace the advice of your doctor or other medical professional. Leaflets are available online at www.brittlebone.org. This information is available in accessible formats on request.



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*Working with People
who live with
Osteogenesis Imperfecta.*