

“THE MOST IMPORTANT THING IS THAT THE CHILD FEELS ACCEPTED”

Engage the mentor or teacher if necessary but leave contact with the parents of bullying children to the school or the sports club. Provide teachers and pupils with information about the condition. They sometimes do not know how to deal with situations, that discoloration can become worse when under stress for example. When a child is young, you can let them draw, write or play out situations. If the child is older, encourage them to try and face issues they are anxious about instead of avoiding them, but prepare by looking at what is involved (at the swimming pool, for example) and dividing the whole scenario into a few separate pieces so that these can be taken one step at a time as the challenge increases.

5 Social interactions at an older age

When the patient is on the way to becoming an adult, it is important for them to take the initiative in social situations. Do not wait too long with this as they may become dependent on you. Finding social support and feeling supported and appreciated as part of a network (patient association, parents and friends for example) will help considerably. An important question for yourself as a patient is, “What convictions do I have about myself?”, because this will influence your emotional reactions and behaviour. What other things am I missing that could possibly help me? Non-verbal or body language: a physical characteristic can be made more noticeable when the patient unconsciously emphasizes the feature with their behavior. Avoiding eye contact, for example, will attract attention to the face, and could imply a certain level of psychological weakness. Try and make eye contact, shake hands firmly, remember people’s names, speak clearly with confidence and stand upright with shoulders back. Remember that people often listen more to how something is said rather than to what is said.



WOULD YOU LIKE MORE INFORMATION?

For an extended version of this text, much extra information about medical specialists and other similar material, please refer to our website: www.cmtc.nl/en

Website: www.cmtc.nl

Email: president@cmtc.nl

Children’s website: jezz.cmtc.nl



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The psychological aspects of living with a rare disease

This is an information leaflet looking at possible psychological problems that people who live with a rare condition, possibly with noticeable external features, may experience.

Emphasis is usually placed on medical issues, but the psychological and psychosocial aspects of living with a rare disease often receive insufficient attention.

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THE PSYCHOLOGICAL ASPECTS OF LIVING WITH A RARE DISEASE

When children are born with skin conditions or other physical problems, as is the case with CMTC, we can refer to these as Conspicuous External Features (CEF). For someone who has an abnormal appearance, an assumption is often made that they will also have a psychological state deviating from the norm. People with CEF, typically with a reduced level of self-esteem, do tend to try and meet the expectations of society. Dissatisfaction with your own appearance is very common. Sometimes however, people lose their perspective and become obsessed with parts of their body that they consider to be unattractive. This obsession with physical appearance can have a large impact on their own lives and those of their family, a disorder in perception of their own body with significant consequences. Consider several key phases in the life of the patient and their parents, including for example:

1. [The first weeks and months after the birth.](#)
2. [Learning to deal with reactions from the wider community.](#)
3. [Learning to communicate regarding the child's condition.](#)
4. [Helping with problems that a child could experience when starting school and beginning to make friends.](#)
- 5 [Social interactions at an older age.](#)

1 The first weeks and months after the birth

The time from birth to the point of confirmation for a condition differs per patient and depends on the nature of the condition. Any variance in external characteristics can also complicate making a definitive diagnosis and burden the parents with the concerns about the welfare of their child. Although relieved that a diagnosis can finally be made, there follow periods of shock, sadness, anger, unwillingness to accept the situation and concern for the future.

It is therefore quite conceivable that through this process the relationship between parents can itself undergo a change, although this does not have to be a negative experience.

After all, you will need to work together for the benefit of your child. Then comes the time when you introduce them to family and friends and you wonder what to say or whether to say anything at all. Experience tells us that the wider community will quickly become aware of the situation. You will make it easier for them and yourself to tell people something, otherwise an uncomfortable situation for all can develop. For you as parents it is important that you build a level of intimacy with your child, whatever its limitations may be. Direct skin-to-skin contact would be essential for such an emotional bond to develop.

2 Learning to deal with reactions from the wider community

For all kinds of normal activities such as grocery shopping, unexpected problems can arise if comments are made by strangers. You may feel that you should avoid all kinds of social contact to protect yourself from negative reactions, but this would deprive you of highly needed interaction. Parents and children can learn how to deal with probing questions, comments and staring. Give an answer to the question and immediately follow on with a new question to the other person to distract them or dive a little deeper into the subject and see what their reaction is. When people start to stare, look back, smile and keep looking. Usually they smile back and then look away. When they stare for a long time, you can look back and frown your eyebrows to show that you are aware that they are looking. Ask if you can help them or if they know you, you make them aware of their behavior. Avoid an extended discussion but react for example by asking "Are you worried about something?" Do not assume that people are hostile, when they are simply being curious. I heard of a reaction from one mother who said to her child on being questioned by a stranger: "Do we want to answer this today or not?"

3 Learning to communicate regarding the child's condition

Having a child with a rare condition will impact all members of the family and sibling children will also need to cope with this. Parents must therefore pay attention

"IT IS IMPORTANT THAT YOU, AS PARENTS, BUILD AN INTIMATE BOND WITH YOUR CHILD, WHATEVER ITS LIMITATIONS MAY BE"

to what the children experience in terms of reactions from other people. That parents of a patient tend to be over-protective is a very common and natural phenomenon. However, when this is taken to the extreme, a child does not learn to stand up for themselves in a resilient way. Development of a positive self-image and adequate self-confidence is thus not supported. In general, it is advisable not to discuss issues or possible problems before the child raises questions themselves and then not to try and answer these too extensively at first. The child should be allowed to get used to the situation first. How can they estimate the seriousness of the issue? This question will largely determine the behavior of the child and not what is objectively visible. Consider Body Dysmorphic Disorder (BDD) for example. Try standing with the child in front of a mirror and allow them to show you where they may have problems or concerns. Sometimes this does not correspond with the view that the parents had themselves. When the perceptions of parents and the child are not aligned, providing appropriate help and support would be difficult. Above all, mirrors should not be avoided, and they should be used to encourage a feeling of self-confidence. A child is more interested in the present day and is not really concerned with how the future will look like in a few years' time. Their parents naturally are however, but this does not help the child directly. The most important thing is that the child feels accepted, so do ask questions. For example, whether they have personally experienced any bullying.

4 Helping with problems that a child could experience when starting school and beginning to make friends

If there are any problems at school, parents should take these seriously, giving their support and attention. Take care however with well-meaning advice such as "be brave" or "just ignore them". Be clear that the child themselves is not to blame and agree that they let you know everything immediately.