

More than skin deep

Impact of skin disease and visible differences on your child's mental and social well-being

Skin changes might make us look different. This can be a source of psychosocial distress for children and their families.

WHAT IS PSYCHOSOCIAL DISTRESS?

It is an unpleasant emotion that can affect one's thinking, behavior, and/or social interactions. Kids may show sadness and vulnerability or more serious signs of social isolation, anxiety, and depression. Negative reactions are common and normal to have at times. But it is important to recognize and address these feelings early on to prevent them from becoming stronger and more frequent, leading to permanent effects.

HOW CAN SKIN DISEASE OR A VISIBLE DIFFERENCE CAUSE PSYCHOSOCIAL DISTRESS?

The disease or skin difference itself and/or its treatment can cause psychosocial distress and may affect your child's quality of life. For some, the relationships with family and peers, or stigma from society due to appearance may contribute to distress. Aside from teasing and bullying, there are also indirect ways of causing distress. At times, these may not be done on purpose or may just be thoughtless mistakes by people who don't realize their impact. Insensitive remarks and exclusion from school activities or sports can cause feelings of being left out. Frustration, social discrimination and isolation due to skin appearance can lead to decreased self-esteem, increased self-consciousness, and enhanced psychosocial distress.

WHO IS AT INCREASED RISK OF DISTRESS FROM APPEARANCE?

It can affect anyone. Children are most at risk during pre-teen (6-11) and teenage (12-18) years. Lesions or rashes that are larger in size or on more visible areas of the body, like the face, can also increase risk of distress. However, any skin problem or visible difference of any size or severity can cause distress.

HOW TO DEAL WITH APPEARANCE-RELATED DISTRESS?

It is important to remember that a person is not defined by their skin or overall appearance. What does "normal" look like? What makes someone beautiful? The answer changes based on who you ask, the community where you live, the time in history...

It is very important for the family to acknowledge and accept the skin condition of their child. Children take cues of how to feel and behave from their family members and friends. They hear your discussions so please remember to be sensitive when you talk about the skin condition in their presence, even if it doesn't seem like they are listening. They will also often react the same ways they see the trusted people in their lives respond to the comments, questions, and reactions from others.

COPING STRATEGIES

Below are some ways to help your child cope with distress related to their special skin:

POSITIVE THINKING

"Self-Statements:" Create together a list of things your child likes about him/herself. Remind your child to read through it whenever they feel sad or negatively impacted by their skin.

"If-then" scenarios: Encourage your child to think of times when he/she felt anxious, sad, or angry because of their skin. Help them write what they would like to do in response to those feelings. For example: If I feel anxious at a party, then I will improve my confidence by thinking of a relaxing beach scene.

MINDFULNESS EXERCISES

Coach your child through this simple exercise:

"Close your eyes. Concentrate and listen only to your breathing. Take deep breaths in and out, three times. Picture a happy place for one minute as you continue to breathe."

RESPONSE TO INQUIRY AND ATTENTION

Rehearse responses to common questions or scenarios. This can help your child feel confident and prepared for a situation when they are not sure how to react.

SEEKING AND ACCEPTING SUPPORT

Encourage your child to brainstorm a list of supportive people who they can rely on. Have your child think of what would make them feel supported. Acknowledge that asking for help can be hard. This list can guide your child and make the first step toward speaking to someone about their problems a little bit easier.

SHARE INFORMATION ABOUT THE SKIN CONDITION

Another way to deal with uncomfortable questions and stares is through open discussion about their skin condition with peers. If your child feels comfortable, you may contact their school to facilitate an informal conversation to share what your child would like others to know about them.

JOIN A SUPPORT GROUP

Meeting other people with similar special skin can be beneficial for your child. Joining a patient support group has been shown to help patients learn more about their condition and also cope with related distress. Ask your dermatologist for recommended groups. Find a list of national patient advocacy groups at <https://pedsderm.net/for-patients-families/patient-organizations/>

CONFRONTING A DISTRESSING SITUATION

- Take a few deep breaths.
- Use "if-then" scenarios. Reassure yourself with positive self-talk.
- You can use one of your prepared responses:
 - Explain a little bit about your condition.
 - If you prefer, change the subject.
 - Explain that you are fine, but you would rather not talk about it at that time.
- Debrief after with someone in your support network.

OTHER RESOURCES:

Learn more about the topics discussed in this handout:

- » Changing Faces
<https://www.changingfaces.org.uk/>
- » Young Person Face It
www.ypfaceit.co.uk
- » "Building Resilience in Children and Teens. Giving Kids Roots and Wings"
(AAP, Kenneth R. Ginsburg, MD and Martha M. Jarlow)

Embrace your appearance and meet new friends:

- » Camp Discovery
www.aad.org/public/public-health/camp-discovery
- » Positive Exposure
www.positiveexposure.org
- » A Doll Like Me
<https://www.facebook.com/nannysbabiestoodollslikeme>
- » A Children's House for the Soul
www.achildrenshouse.org

Develop a school coping plan for your child:

- » <https://achildrenshouse.org/copingplan/>

Learn and practice mindfulness exercises through smartphone apps:

- » Headspace, Calm – for teenagers and adults
- » Stop, Breathe & Think Kids; Breathe, Think, Do with Sesame Street – for younger children



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