

TALKING TO KIDS:

**How to Talk to Children,
Youth, and Adult Children
About Your Skin Condition**



Canadian Skin Patient Alliance
**Alliance canadienne des
patients en dermatologie**



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You have just been diagnosed with a serious skin condition. This condition may cause physical changes to your appearance. It may cause inflammation in your body, chronic pain, itchy skin, or many other uncomfortable and, at times, debilitating physical and emotional symptoms. “It is tough to have a skin condition. The impact of living with a skin condition is much more than “skin deep”, though. The weight on the emotional and mental health of people affected, and especially those who are children and youth, can be profound.” (CSPA, Shed the Shame, 2022) Perhaps you have been living with your condition for a long

time, but things are changing, and the condition is causing more symptoms. Life as you know it is different and life as your children know it is different.

How do you talk to your children, youth, and adult children about your condition and how it will affect your daily lives? Why is it essential to have these conversations?

WHY TALK?

As parents, all we want to do is keep our children safe. That desire never ends, not even when our children are grown. To our offspring, we will forever be “mum, dad, mummy, daddy, papa, mama...”. We will always try to offer a safe, protective home for them. When our children grow and move out, we want them to continue to be safe emotionally, mentally, physically, and spiritually.

What if your child or youth shares his/her/their concerns, questions, fears, and hopes with a trusted teacher, coach, youth mentor, or adult friend? These special adults act as protective circles around your child or youth. Sometimes, if you are comfortable doing so, sharing and advising these special adults in advance about what is going on with you can help them to respond to your child or youth in a manner that you feel comfortable with. You can also give your child or youth permission to share with the specific special adult person(s) that makes you feel safe. In other words, you pick your team, and you maintain control over choices about what is shared and not shared with your child. By offering permission to your child or youth to talk openly with their particular support people, you offer “wraparound support.” It is a “family-like” team that includes teachers, social workers, nurses, faith groups, friends, and community members you know. Research demonstrates that the “wraparound approach” to support is an effective way to work together to help the young person and family plan steps to move forward positively. It helps the family and young person develop coping strategies. These adults also want your child to be safe emotionally, mentally, physically, and spiritually. You have common goals!

We all know that bad things happen to good people. However, we live with an inescapable truth. Bad things happen in life; sometimes, parents or other loved ones and essential people in a child’s life get sick. In your child’s life, this is related to your skin condition and how it impacts your life.

Our instinct is to shield our children from feeling scared, hurt, different from their friends, or any other of the myriad of big emotions they can struggle with in life. Your diagnosis can lead to many emotions and questions in both the short and long term. Being straightforward, honest, and confident will help your child or youth cope.

Shielding our children is not a good idea.

Children are brilliant, and they are resilient if given the opportunity. They listen and watch everything we say and do! They are like emotional radars, and they sense when the grownups, or others in the home, are anxious or worried. They pick up on all kinds of information and changes in our lives. If left to interpret that information on their own, they can imagine things that are often worse than reality.

When we talk to our children and youth, and even our adult children, we help them understand what is going on, and more importantly, it gives us a chance as parents to teach them coping skills. They need information and coping skills to navigate the skin condition, what it means to them, and how that impacts their lives now and even into the future. When we talk openly with our children, it prepares them to better cope with the big emotions of this new or ongoing situation. When we talk to our children, we arm them. This is the first line of defense in keeping them safe.

When we are willing to tell them about serious things, this gives them permission to ask questions, express their fears and insecurities, and be reassured by us as parents, primary caregivers, and trusted adults in their life. It is our opportunity to achieve our goal of offering psychological safety. This is our opportunity to help maintain the emotional and mental health of our child, youth, or adult child.



BUILD THE FOUNDATION

This is not about one conversation. You do not have to try to address everything all at once. You will have ongoing conversations as you learn more about how your condition affects you or the impacts on you change over time.

Children grow and mature, and you may start with a simple conversation, sharing only basic information. As your child grows and matures, those conversations will become more complex and detailed as your child or youth is ready to absorb the information on more complex levels. They will begin to ask more questions as they try to understand and accept your condition and how it affects the family's day-to-day life.

There are things we need always to consider first before we start the conversations.

We start with “self”, always. It’s important to make sure we are in the right frame of mind. Is this a good day for me, physically and emotionally? Do I feel I can manage the questions and the emotions of my child,

youth, or adult child that may follow or be a part of this conversation? We need to gauge our physical and emotional temperature. If we are in a good place, it is more likely that our child will end up in a good place too.

Next, we need to ensure or assess that our child or youth is also in a good place. Did they have a rough day at school? Was it a great day at school? Are they physically well and not fighting a cold or the flu? Like us, they need to be in the right frame of mind. Gauge their physical and emotional temperature and well-being, and then we can decide to talk with them or wait for a better time.

Using “I” messages is the best practice. When expressing feelings, using the pronoun “I” is to state one’s thoughts and feelings and take responsibility for what you say and what you feel. “I” messages also remove blame from the other person in the conversation. It allows your child or youth to model what you are teaching them.



For example, if your child asks you, “Mum, do you feel scared?” You can reply, “I do sometimes feel scared. I try to be as brave as I can. When I feel scared, I like to ask dad for a hug. I feel better after that.”

Perhaps your teen might express the unfairness of the situation. “I don’t get why you just take this, dad! It’s so unfair that this happened to you, and you look awful. I can’t stand the way you look now!” Reply in a way that acknowledges their feelings and affirms that you will get through this together. “I know it seems so unfair, and I sometimes feel that way too. I feel bad that it’s so hard for you to deal with how I look now. It sure is a big change. I hope we can work together to adjust to these changes. I’m here now, and I love you.”

Engaging our life partner is a good strategy. If we have a life partner, we need to decide what information we want to share and how we want to share it. We need to have that discussion ahead of time, come prepared, and do our best to stay on the same page and offer consistency in our messages. Again, as parents, we are the experts on our children. We need to think about how the news might impact them so that we are ready, as a team, to manage any big emotions or concerns a child or youth may express about how their life will change. If we are single parents, we can consider having a trusted family member or friend stand by for support, or we can choose to have the conversation independently. There is no right or wrong answer here.

We need to choose the best time and place for our children. If you know your child or youth is not a morning person, do not choose Saturday at 9 a.m. to try to converse with them! We need to make sure we are not rushed and can give them all the time they need, so plan for it. If we are rushed or worried about other things, we cannot give our undivided attention. We need to be focused. Where are they most comfortable? Some love car rides, and some love going for ice cream. Another might want the solace of their bedroom. Choose a good place for them and you.

KNOW THE DEVELOPMENTAL AGE AND STAGE OF YOUR CHILD

We need to consider both the developmental stage and the chronological age of our child. A child can be five years old but have the cognitive and emotional prowess of an 8-year-old. A teenaged youth could be 14 years old chronologically but function more emotionally at a 10-year-old level. Alternatively, their development may match their chronological age.

It is essential to understand your child's developmental level. For example, the younger the child, the less likely he/she/they will understand concepts of severe illness or what a skin condition is. However, a teenager will understand more complex concepts. A teen will likely ask more questions and want more details.

When a child is young, they think more concretely. If you tell them, "Mummy is sick," they may believe they will "catch it too." "You must choose your words carefully. Naming the skin condition is fine. You can say, "Mummy has something called alopecia. That is a hard word to say. Do you want to try to say it with me? Al - o - pe - cia! That means that mummy is going to lose her hair. Mummy might be bald."

Offer the information in smaller chunks, and then wait to see how your child reacts. If your younger child wants to know more, they will ask. If they do not ask, stop at that simple answer and wait for the next question, five minutes or five days later! Even youth or adult children can feel overwhelmed. Too much detail all at once is just that, too much. You might tell a younger child, "Daddy has sore skin, and he is going to the doctor so they can help him." You might offer a teenager or adult child more information, "Dad has skin cancer. It is called melanoma. He will have some tests, and the doctors will determine what is best in terms of possible treatments. That is all we know for now. I can answer any questions you have at any time. If I know the answer, I will tell you. If I do not know, I will try to find out." Keeping your messages clear, simple, and straightforward is the best approach.

Children and youth may not be ready and may not want to know all the details. Follow their lead! Be ready to answer their questions and address their concerns as they arise.

Always be truthful.

Always use the correct terminology.

Always start with where your child is at and what they are ready to hear.

Always remember, as parents, we are the experts on our children! We know our children, so approach them "where they are at" developmentally. If you are unsure, talk to your child's doctor, pediatrician, teacher, or others in your care circle for some helpful ideas.



The chart below is helpful to decide where we think our child is “at” cognitively. Jean Piaget (1896-1980) was a Developmental Psychologist. He focused his work on the education of children. Cognition refers to how we learn and come to understand our world.

PIAGET’S STAGES OF COGNITIVE DEVELOPMENT

SENSORIMOTOR

0-2 years old

Coordination of senses with motor responses, sensory curiosity about the world. Language used for demands and cataloguing. Object permanence is developed.

PREOPERATIONAL

2-7 years old

Symbolic thinking, use of proper syntax and grammar to express concepts. Imagination and intuition are strong, but complex abstract thoughts are still difficult. Conservation is developed.

CONCRETE OPERATIONAL

7-11 years old

Concepts attached to concrete situations. Time, space, and quantity are understood and can be applied, but not as independent concepts.

FORMAL OPERATIONAL

11 years old and older

Theoretical, hypothetical, and counterfactual thinking. Abstract logic and reasoning. Strategy and planning become possible. Concepts learned in one context can be applied to another.

If we use this chart to understand where our child is developmentally, we can see that a child who is 11 years or older will be able to absorb and understand more complex concepts and ideas. We will also be able to talk to them about how we plan to manage daily life when things get tough. We can engage our youth and ask them to play a role in planning and coming up with ideas for making things work for them. This will help them to develop coping and problem-solving skills.

TALK ABOUT FEELINGS

We all experience different emotions, and children do too. It is so important not to hide your feelings. Children and youth learn from us. If we “stuff” our feelings inside ourselves, this sends the message that it is not OK to talk about or express our feelings. If we feel sad, worried, or angry at the diagnosis or situation, it is OK to say that. Our feelings are valid.

There is no wrong feeling! This does not mean we stay stuck in our feelings. We will be working with our healthcare team to find healthy and appropriate ways to deal with these natural feelings. Remember, our children and youth are always listening and watching. If we model the healthy expression of feelings and create a safe home environment, our children and youth will know that it is OK to share. When they do, validate their feelings.

They may express sadness, fear, anger, resentment, confusion, or they may not express anything at all. They just might need time to process the shared information. Give them time. Do not push, especially with teenagers. They are working on being individuals, and they want to be competent and confident. Give the older child time to consider what questions they may have for you. We can do a daily check-in and simply ask, “How are you feeling today?” Alternatively, “Would you like an update on dad?” Make sure you are prepared to give them time to respond. We need to be ready to focus and actively listen to them.

Sometimes children struggle to express themselves verbally, you may see a change in behaviors. Perhaps your 6-year-old will start to suck her thumb again. Maybe your teen will be more withdrawn, hanging out in their bedroom. Go with the flow and give them space but ask, “Hey sweetie, does sucking your thumb make you feel better right now?” Wait for the response. Maybe your young one will just give you a nod of his/her/their head or say, “I like it.” Validate the feelings. “It is OK to want to feel safe. Mummy is here to hug you anytime you want.” Take the time to check

in with your teen. Give a knock on the door, wait for permission to “come in,” and then say, “I’m just checking in. You’re in your room a lot this past week. I want you to know I’m available to talk when you’re ready or to answer any questions you may have.” Your teen may say, “no thanks,” but you have planted the seed. Give it time to germinate.

Always encourage them to ask their questions and let them know you will be ready when they are. When they do ask, honesty is always the best policy.

Children, youth, and even adult children can be concrete and practical. They want to know how this condition will affect their own lives. For little ones, routine is crucial. Will they have the same babysitter or daycare placement? Will you still give them their bath? Who is going to cook their supper? Who will watch Paw Patrol with them and take them to the park? A teen may be worried about after-school activities, driving to and from their friends’ houses, or a part-time job. An adult child might wonder if they will end up being responsible for raising younger siblings. All these concerns and questions are valid. Again, be honest, keep it simple, be straightforward, and at this point, you would be reassuring them.

“I have been thinking about that and planning for your basketball games when I’m at the hospital getting treatment or if my pain is bad. I talked with Aunt Sue, and she has agreed to be the driver, so you won’t have to miss any practices or games.”

“Honey, daddy says he’ll watch Paw Patrol with you when mummy is not feeling well. Daddy loves to cook for you, especially your favorite macaroni and cheese!”

“Darling, I know you must worry if something happens to me that you might end up raising your siblings. We can talk about that possibility if you want to. There are several options we can look at together.”

WHAT IF THEY ASK, “WILL YOU DIE?”

If death is a possibility, acknowledge that it could happen, but put it into perspective. You can explain that the doctors, nurses, and healthcare team will do everything they can to make sure you get better. You can tell your teen or adult child that you will keep them informed. “I will keep you updated as the course of my illness unfolds.” You can say to a younger child, “Mummy will always let you know what is happening.” Death is often a topic we do not want to talk about, but we must. Children and youth will ask hard questions like, “Can I catch this?” Alternatively, “Will I get sick too?” A teen or adult child might ask about genetics and if they are at risk. A younger child or teen may ask, “Who will take care of me/us?” “Did daddy get sick because I’m a bad boy/girl?”

These difficult questions need to be answered. We need to answer all questions honestly and be appropriate to the child’s developmental stage. Be patient and know that your child or youth are working on understanding and accepting what is happening to you and them. As they try to process the information, they may ask the same question repeatedly until they can work it out in their mind. They may ask new and more complex questions as time goes on.

Do not lie or make promises you may not be able to keep. It is tempting to minimize your situation or to protect your children. Often, we are quick to respond, “No, mum will not die!” but if you have a potentially terminal illness, you do not want to make a possible false promise. Establishing a trusting relationship is paramount.

When we respond openly, honestly, and directly at their developmental level, we reassure our children that even though life is changing, the adults in their life have got their backs. In most cases, once the child or youth understands the adult is still managing, they begin to relax.



ASK FOR HELP

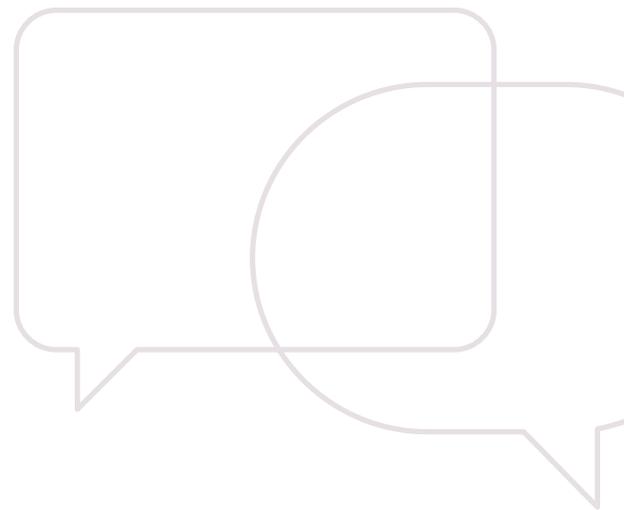
If you do not feel like you or your partner are managing well, reach out for help. You can ask for a referral to a social worker, a psychiatrist, or other mental health providers. Reach out to a trusted teacher or coach. If you do not want to go the formal route, you can talk to your Pastor, Rabbi, Priest, or someone you trust in your faith community. Sometimes a best friend or trusted family member can help bridge the gap between our young child and teen or adult child. Choose someone you know that you, and they, trust and believe loves them deeply. In other words, check in with your wraparound team members.

Start talking with and involve your child, youth, or adult child as early in the process as possible. They

will want to help. They will need time to work things through. They will be much better off if they are not feeling left out or think that adults are “keeping secrets from them.” Knowledge is empowering. When we can learn to understand something, even if it is challenging, it decreases our fears and anxieties. Children and youth and adult children are no different. Helping our children and young adults face life challenges can be difficult at best; however, we need to remember that young people are amazing and resilient, so take their lead, be honest, and you will get through this. The more involved they are and the more they understand and can work through emotions, the more likely our children will become whole and healthy, mentally and emotionally resilient. That is our goal, isn't it?

ABOUT THE AUTHOR

This guide was prepared for the CSPA by Joyce Hamelin. Joyce Hamelin holds two Honours Undergraduate Degrees and an Honours Post-Graduate Degree in Social Work. She has her Early Childhood Education Diploma and a Nursing Assistants Diploma. She has worked with children, youth, and their families for over 37 years in a myriad of health and community care settings. Her areas of specialty include child development and child welfare, and working with children, youth, and adults who are diagnosed with neurodevelopmental exceptions. Joyce has a passion for supporting families to live their best lives and supporting parents to grow and launch healthy, competent, and resilient people. Joyce is a mother of six children ranging in age from 13 to 36 years old. She understands the challenges of parenting!



RESOURCES

Here are some age-appropriate books that might be helpful to support you in your conversations.

For You, The Parent:

Devine, M. *It's O.K. That You're Not O.K.: Meeting Grief and Loss in a Culture That Doesn't Understand*

Hamilton, J. *When A Parent is Sick, 2nd Edition*

Heagaard, M. *When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change*

McCue, D. *How to Help Children Through a Parent's Serious Illness: Supportive Practical Advice from A Leading Child Life Specialist*

For the Two- to Five-Year-Old:

Stamm, J.A. & Kellogg, C. *Some Days: A Tale of Love, Ice Cream and My Mom's Chronic Illness*

Techentrup, B. *The Memory Tree*

Roberts, J. Dr. & Revell, C. *What Happens When A Loved One Dies? Our First Talk About Death*

For the Four-to-Eight-Year-Old:

Herman, S. *The Sad Dragon: A Book About Grief and Loss*

Karst, P. *The Invisible String*

For the Nine-to-Twelve- Year-Old:

Bostrom, K. *When Pete's Dad Got Sick: A Book About Chronic Illness (Helping Kids Heal)*

Leon, J. *Mommy's Going to the Hospital*

Thomas, I. *Worried (Dealing with Feeling...)*

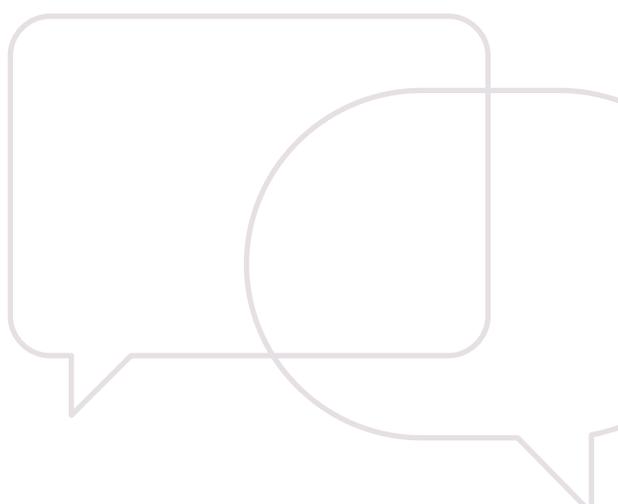
Teens and Older Children

McClintock-Greenberg, T. *When Someone You Love Has a Chronic Illness: Hope and Help for Those Providing Support*

Zoffness, R. MS PhD. *The Chronic Pain and Illness Workbook for Teens: CBT and Mindfulness-Based Practices to Turn the Volume Down on Pain* (This book would be for a teen who is diagnosed with chronic pain, but the exercises can be adapted to help your teen be mindful and better cope with emotions.)

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