



NAVIGATE LIVING WITH MEDICAL CONDITIONS

A Program for Parents



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WELCOME PARENTS!

Living with a medical condition can be challenging for both you and your child. It can be difficult to know how to talk to your family about the condition and how to help your child navigate the emotions they may be feeling. This program is based on the teachings of Dr. Elisabeth Kubler-Ross and is designed to provide guidance and support for parents to help their child through the different stages of grief that can come with living with medical conditions, specifically hyperhidrosis or a neurogenic bladder.

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HOW TO USE THIS PROGRAM



Having a medical condition can be challenging for both kids and parents alike. It's important for parents to have open and honest conversations with their children about their condition so they can understand it and learn how to manage it. However, it can be difficult to know where to start or how to approach the topic. That's where this program comes in. We'll focus on tips for parents, examples of what you can say, and what to expect next as you and your child work toward acceptance. Please reach out if you have any questions.

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STAGE 01: DENIAL

It is common for children to want to deny that they have a medical condition, or to hope that it will go away on its own. This stage can be difficult for both the patient and parents as the family tries to come to terms with the reality of the situation.

TIPS FOR PARENTS:

- Acknowledge that it is normal to feel in denial of the situation, it's a part of the grieving process.
- Seek out information to better understand the condition and how to manage it.
- Share interesting research articles you find
- Talk to your child about the condition and explain it in a way that they can understand.
- Consider using books or toys to help translate technical terms or complex ideas. Using examples are a great explanation so the child can have a better understanding of what is happening.
- Create a support system for yourself and your child.



WHAT CAN YOU SAY?

Examples for parents to explain to their child about living with hyperhidrosis:

- "Sometimes your body will sweat more than usual, and it might feel uncomfortable, but there are things we can do to help manage it. Let's start with making sure you're wearing clothing made of breathable fabrics."
- "It's important that you take extra care with your hygiene to help prevent any skin irritation, but you should know that you are not alone, so many people your age have hyperhidrosis. They just don't often talk about it. But you can talk to us about anything."

Examples for parents to explain to their child about self-catheterizing:

- "Your body works differently than others and sometimes it's hard to empty your bladder completely on your own. To help with this, we'll need to teach you a special technique called self-catheterization."
- "It's not easy, but it's something that you can learn to do on your own, and it will help keep you healthy and comfortable. And remember, you're not alone in this. There are millions of people who self-cath every day. And your family will always be here to help and support you."



STAGE 02: ANGER

When your child is first diagnosed with a medical condition, it's common for them to feel angry and resentful. Your child will have many emotions that they don't know how to express properly so make sure to be patient with them. Parents may even blame themselves or others. This stage can be especially difficult for everyone in the family as people express anger in different ways.

TIPS FOR PARENTS:

- Remember, it's OK to feel angry about your child's condition. But also remember it's not you and your child against each other; it's you and your child against the world together!
- Include your child in any possible discussions about solutions/treatments, as they may feel resentful by being excluded. Remember that they are the ones going through the condition personally, so it is important that they are involved.
- Seek out local and online support groups to discuss your feelings in a healthy environment. Support groups can even be able to give you some advice of how to handle certain situations with your child.
- Schedule fun activities around days or weeks you know may be particularly difficult for the family.



WHAT CAN YOU SAY?

Examples for parents to explain to their child about living with hyperhidrosis:

- "It's OK to feel frustrated that your body doesn't sweat like other people your age, but it doesn't mean that you're any less capable or worthy. We love you just the way you are. People with hyperhidrosis have gone on to great success and have gotten their symptoms under control."
- "It's not fair that you have to deal with hyperhidrosis, but we'll work together to find ways to manage it and make sure that it doesn't hold you back from living your life to the fullest."

Examples for parents to explain to their child about self-catheterizing:

- "It's not fair that you have to go through this extra step just to use the bathroom, but it's important for your health and we're here to support you. There are millions of people who use catheters every day. Soon, it will become just a new part of your routine, like brushing your teeth."
- "Believe me, we're angry too. But we can't let that anger keep all of us from living life to the fullest. We need to rely on each other for support, and together we'll figure out how to make it work."



STAGE 03: BARGAINING

It is common for children to try to bargain with their parents/guardians or a higher power to make their condition go away. Seeing the desperation in their eyes is heartbreaking for any parent. Remain steadfast and strong. Try putting your perspective from your eyes to theirs.

TIPS FOR PARENTS:

- Use statistics or success stories to support the information you've been communicating.
- Acknowledge your child's request before explaining the reality of their situation again.



WHAT CAN YOU SAY?

Examples for parents to explain to their child about living with hyperhidrosis:

- "I know you might be thinking 'if only I didn't eat that' or 'if only I didn't wear that', but it's important to remember that hyperhidrosis isn't your fault. It's something that we can manage together."
- "This condition is not a punishment. There's nothing 'wrong' with you. You just sweat more than other people, and that's OK. We'll find ways to make you comfortable until we find something that works for you."

Examples for parents to explain to their child about self-catheterizing:

- "I know you might be thinking 'if only I didn't drink that' or 'if only I didn't eat that', but this isn't something that you caused, it's something that you have to do to take care of your body."
- "I understand you might have some thoughts of bargaining, like 'if I do this, it'll make it go away' but it's important to remember that this condition is not a punishment and we'll find ways to cope and make you comfortable."



STAGE 04: DEPRESSION

By this stage of the program, parents and their children are often struggling with feelings of hopelessness. You may feel scared to try new solutions if previous recommendations haven't worked out. "We're never going to get through this!" Depression sets in, and suddenly the support system the family had invested so much love into is pushed to its limits. Parents and children start to just give up.



TIPS FOR PARENTS:

- Don't be dismissive of your child's feelings; they're looking for someone to listen and acknowledge how they are feeling, not necessarily just to solve the problem.
- Be open and honest with your child about depression, and don't be scared to share the signs to look out for so they can possibly understand why they are feeling a certain way.
- Remind them (and yourself) that struggling with mental health is nothing to be ashamed of we are all human.
- Consider scheduling a family therapy session with a local mental health professional. They might be able to explain or come up with a positive plan of attack.
- Talk to your child if they start "acting out" in school (such as low grades or even attendance) or lose interest in activities they used to enjoy. These are common traits of someone struggling with depression.

WHAT CAN YOU SAY?

Examples for parents to explain to their child about living with hyperhidrosis:

- "I know it might feel like it, but this isn't the end of the world. There are millions of people with hyperhidrosis. It's just something that's not often talked about. But did you know that Steve Carrell and Cameron Diaz have openly discussed their struggles with sweat? We'll keep working together until we find something that works for you, too."
- "I understand that your sweat may be making you feel down and unmotivated, but it's important to remember that you're a strong and capable person. We love you, and there are more solutions for hyperhidrosis today than ever. We'll keep trying things until we find what works for you."

Examples for parents to explain to their child about self-catheterizing:

- "I know that this self-cathing process has been overwhelming and making you feel sad, hopeless and frustrated. But I promise that it's not the end of the world. If other people have figured out how to live happy lives with a neurogenic bladder, we will, too."
- "I noticed you've seemed unmotivated and down about having to self-catheterize. Believe me, I get it. But I want you to know that we love you very much. And that as long as we have each other, we'll find ways to help you feel better."



STAGE 05: ACCEPTANCE

Acceptance is the last stage of coming to terms with a child's medical condition. Parents are focused on providing support for their child. The entire family may find themselves feeling more confident and capable in dealing with this new normal.

TIPS FOR PARENTS:

- Acceptance is a huge step forward, so take a moment to reflect on the progress you've made and be proud of it.
- Never settle and continue to educate yourself and your child about their condition and new treatment options. Don't be scared to try something new; maybe it'll work better than expected.
- Encourage your child to participate in managing their condition and help them feel empowered in their journey.
- Connect with other families who may be struggling through the earlier stages of the process. Having support and being supportive can be life-changing.
- Be open to seeking professional help such as counseling or therapy if you or your child are struggling emotionally.
- Celebrate your child's progress and encourage them to embrace their individuality; medical condition and all.



MORE ABOUT HYPERHIDROSIS

Hyperhidrosis is a condition characterized by excessive sweating that is not directly caused by heat or physical activity. Symptoms are usually focused around the hands (palmar), feet (plantar), and underarms (axillary). Some common signs of hyperhidrosis may include:

- Persistent sweating, even in cool or air-conditioned environments
- Sweat that affects the whole body, or only specific areas such as the armpits, palms, or soles of the feet
- Sweating that soaks through clothing and causes skin irritation or fungal infections
- Sweating that interferes with daily activities or causes social embarrassment
- A family history of hyperhidrosis, like that relative who always had “clammy hands”

Sweating is a normal bodily function that helps regulate body temperature. But what if your sweat starts to impede daily activities? Living with hyperhidrosis can be challenging for several reasons:

- Social embarrassment from sweat stains on clothing
- Skin irritation and infection, such as chafing, rashes, or fungal infections, which can be painful and unsightly
- Difficulty with everyday activities such as writing, typing, or holding objects, as well as doing manual labor tasks, due to the slipperiness of sweating palms or feet
- Some people with hyperhidrosis may avoid certain types of clothing or materials, such as dark colors or natural fibers, because they show sweat stains more easily
- Hyperhidrosis can cause emotional distress, anxiety, and low self-esteem starting at a young age

Hyperhidrosis makes it difficult to perform everyday tasks, such as writing or shaking hands, and can limit social and professional interactions. This can lead to feelings of isolation, and a sense of being limited by the condition.

SIGNS TO LOOK FOR:

- Avoiding social interactions, or feeling self-conscious in social situations
- Difficulty concentrating or performing daily activities.
- Low mood or feelings of hopelessness
- Changes in appetite or sleep patterns
- Loss of interest in activities or hobbies
- Thoughts of self-harm or suicide

It's important to note that these signs may not be only caused by hyperhidrosis and should be taken as general signs of mental health issues that may need attention, a mental health professional should be consulted for a proper diagnosis.

If you or someone you know is experiencing symptoms of anxiety or depression in association with hyperhidrosis, it is important to seek help from a healthcare professional, who can provide appropriate treatment and support.



MORE ABOUT NEEDING A CATHETER

Urinary retention is a condition in which a person is unable to empty their bladder completely. This can be caused by a variety of factors, including nerve damage, an enlarged prostate, or certain medications. Symptoms of urinary retention can include:

- Difficulty starting to urinate
- Weak urine stream
- Feeling like the bladder is not completely empty after urinating
- Frequent urination
- Urgency to urinate
- Incontinence (inability to control urination)
- Pain or discomfort in the lower abdomen or lower back
- Blood in the urine

A neurogenic bladder is a condition where the nerves that control the bladder are damaged, resulting in problems with the storage and release of urine. Some typical challenges that individuals living with a neurogenic bladder might face include:

- Difficulty starting or stopping the flow of urine
- Incontinence (inability to control the release of urine)
- Urinary retention (inability to empty the bladder completely)
- Frequent urination or urgency
- Bladder infections and/or kidney infections
- Skin irritation or infection caused by incontinence
- Loss of independence or social isolation due to incontinence or fear of accidents
- Bladder spasms or painful urination
- High risk of complications such as kidney stones or damage to the bladder and kidney if left untreated

Self-catheterization is the process of inserting a catheter into the bladder through the urethra to drain urine. It can be a physically and emotionally challenging process for many people, especially if it is something that needs to be done multiple times a day. The constant need to self-catheterize can cause a great deal of anxiety and depression, as well as physical pain if not performed correctly.

SIGNS TO LOOK FOR:

- Persistent feelings of hopelessness, guilt, or worthlessness.
- Persistent feelings of fear, worry, or irritability.
- Difficulty sleeping or excessive sleeping.
- Loss of interest in normal activities
- Difficulty concentrating, or difficulty making decisions.
- Avoiding social events or isolating oneself
- Persistent physical symptoms such as headaches, fatigue, and muscle aches.



Self-catheterization can be very personal and intimate, and the need to do it in public or in front of others can cause feelings of embarrassment and loss of privacy.

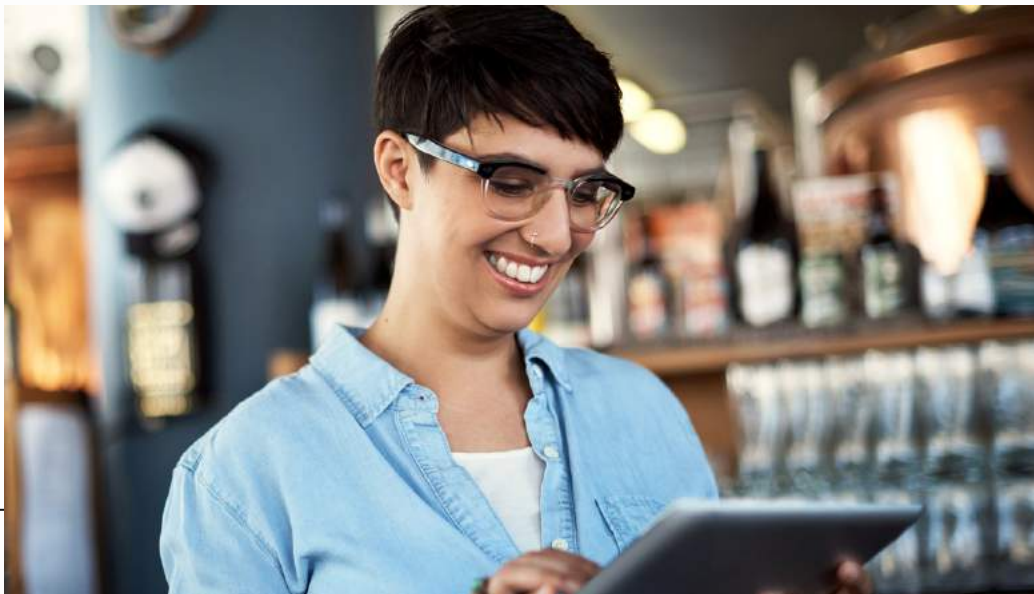
If you or someone you know is experiencing symptoms of anxiety or depression in association with having to self-catheterize, it is important to seek help from a healthcare professional, who can provide appropriate treatment and support.

HAVE YOU HAD SUCCESS WITH THIS PROGRAM?

SHARE YOUR STORY!

Stress is falsely thought of as an "adult problem." However, researchers at Yale Medicine have found that a child as young as 2 years old can experience mental health issues like depression. Sharing your success story could greatly impact the trajectory of someone else's life!

SHARE VIA TRUSTPILOT



*<https://www.yalemedicine.org/departments/child-study-center>

THANK YOU FOR FINISHING THE PROGRAM

CONGRATULATIONS!

As parents, it is important to remember that the journey of managing medical conditions is ongoing, and almost always has its ups and downs. However, by providing your child with the necessary tools, information, and support system, you can help them live a fulfilling life.

