Caregiver Coping Resource

Welcome to the Caregiver Coping Resource from ImproveCareNow (ICN) and the Autoimmune Liver Disease Network for Kids (A-LiNK)

This resource has been coproduced by members of ImproveCareNow (ICN) and the Autoimmune Liver Disease Network for Kids (A-LiNK), including the ICN Parent/Family Advisory Council (PFAC), ICN Social Workers & Psychologists (SWAP) group, and A-LiNK Connections.

Disclaimer:

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About this resource

Welcome to the Caregiver Coping Resource from ImproveCareNow (ICN) and the Autoimmune Liver Disease Network for Kids (A-LiNK)!

Throughout this resource you will read information compiled by both caregivers of children with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Diseases (AILD) as well as psychosocial professionals (psychologists and a medical social worker) who work with pediatric GI patients and families. Larger topics are broken down into smaller sections regarding an IBD and/or AILD diagnosis, handling stress and emotions, self-care, assisting your child's coping, and practical tips and advice from caregivers for everyday life. You may find that some sections apply to you and your family, and some may not. Some sections may apply to families earlier in their post-diagnosis journey, and some sections may apply through other life transitions. We hope that this is a resource that you can return to at every stage of your family's journey.

How to use this resource

- Please be **mindful of how you are feeling as you review this resource** and please pause or stop whenever you need.
- Please **use this resource like a menu** and read any sections that seem of interest; the sections of interest may change over time, and we encourage you to return to this resource if/when of interest.
- As you look through the resource's recommendations for other reputable resources and action steps, please feel empowered to **focus on the resources that feel of interest to you**. Everyone has their own preferences; it is okay if you find that some action steps are more interesting.
- Please **write down any questions you have** as you read through this resource. A notes page has been included at the end of each section.
- If/when you have a question about your child's care or mental health care for yourself, please **talk with your healthcare team about the resources provided here to find the best fit for you and your child.**
- **All links shared in this resource can be accessed online** at: improvecarenow.org/caregiving_coping_links and/or by scanning the QR code located at the bottom of each "Action Items" page, and which we have shared here for your convenience

scan to access all links

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Caregiver Contributors

Brenda Barranco

Brenda is a parent of a son with Crohn's Disease. Brenda lives in Las Vegas, NV and is an active participant with the local ImproveCareNow Center, Pediatric Gastroenterology & Nutrition Associates (PGNA).

Chris Browner

Chris is a nurse and mental health advocate. Her son lives with Crohn’s disease and two autoimmune liver diseases, Primary Sclerosing Cholangitis (PSC) and Autoimmune Hepatitis (AIH).

Maria Lester

Maria is a parent of a daughter with Type 1 Juvenile Diabetes and a daughter with Crohn's disease, Primary Sclerosing Cholangitis, and Celiac Disease. Maria lives in Orlando, FL, and serves as the ImproveCareNow Parent/Family Advisory Council (PFAC) Connections co-lead, a parent partner, and the GI Family Support and Advocacy Coordinator at Nemours Children's Health - Florida.

Tori Levine

Tori is a parent of two boys and lives in Harrisburg, PA. Her oldest son was diagnosed with Very Early Onset Inflammatory Bowel Disease (VEO-IBD) at the age of 2 in 2017. Tori participates with the Children's Hospital of Philadelphia through ImproveCareNow and is passionate about connecting and supporting families of VEO-IBD children.

Ildiko Mehes

Ildiko is an attorney and pharmaceutical executive and a proud mother of two young adults, including a daughter diagnosed with IBD at age 9. She co-leads ImproveCareNow’s Parent/Family Advisory Council, volunteers with several IBD non-profits, and lives in Bryn Mawr, PA.

Caregiver Contributors

Heidi Riechel

Heidi is married with a young adult son and daughter and one preschool aged grandchild. Her son was diagnosed with ulcerative colitis at the age of 16. She has been a pediatric IBD awareness advocate ever since. She has shared her family's IBD journey (surgery, teenage years, transitioning to adult care, college and mental health) and loves to bring hope to other families. Professionally, she is an elementary school substitute teacher and advocate for Alzheimer's awareness as well. She lives in Johns Creek, GA.

Erin Spaulding

Erin is a busy mom of 3 and has been the ImproveCareNow Parent Partner at Boston Children's Hospital since 2017. Her daughter (20 years old) has been living with Crohn's disease for 10 years. Erin worked professionally as a child life specialist at hospitals in Boston and Connecticut, which was an asset as she helped her daughter, family, and herself navigate the often unpredictable IBD journey.

Jane Weyer

Jane is the proud mother of a now 25-year-old daughter who was diagnosed with Crohn's disease and Primary Sclerosing Cholangitis in 2016. Jane is an active participant in ImproveCareNow, PSC Partners Seeking a Cure, and the local group at Cincinnati Children's Hospital Medical Center, "IBDevoted". Jane is a parent co-lead for the Autoimmune Liver Disease Network for Kids (A-LiNK), which she helped launch in August 2021.

Psychosocial Clinician Contributors

Dr. Jennie David

Jennie is a pediatric IBD psychologist at Nationwide Children's Hospital who herself lives with Crohn's Disease and an ostomy.

Dr. Tina Holbein

Tina is a pediatric GI psychologist affiliated with the Center for Pediatric IBD at the Children's Hospital of Philadelphia. She does not have IBD but has been involved with the IBD community in various ways (e.g., research, psychotherapy, quality improvement, Camp Oasis volunteer) since 2008.

Dr. Hannah McKillop

Hannah is a pediatric GI psychologist at Nationwide Children's Hospital who supports young people living their lives with IBD and their families.

Noelle Moore

Noelle is a licensed clinical social worker at Nemours Children's Health, Jacksonville. She is passionate in her work alongside the IBD and ImproveCareNow communities.

1 Diagnosis

A diagnosis of Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) can be overwhelming for both you and your child. A whirlwind of emotions is completely normal, and these feelings may evolve over time. Unfortunately, in this digital age, the vast amount of information online can sometimes increase big feelings, especially when everything about IBD and/or AILD may feel new and frightening. In times like these, it's important to try and focus on the present and what is within your 'circle of control.' Here are a few key points to keep in mind for a resilient, hopeful outlook, whether your child is newly diagnosed, or you have been on this journey for some time.

- Individuals diagnosed with IBD and/or AILD can lead long, fulfilling, and meaningful lives. Today's IBD and/or AILD patients are a diverse group, ranging from Olympic and professional athletes, doctors (including many pediatric gastroenterologists!), entertainers, successful people in business, scientists, parents, world travelers, and more. **IBD and/or AILD does not define your child's potential or future achievements.**

- Early treatment, strict adherence to treatment regimes, healthy lifestyle habits, regular visits with your dedicated care team, and close monitoring of health markers (e.g., stool calprotectin in IBD) can significantly reduce the risk of future damage and complications. **Proactive management can empower your child to live their life to the fullest.**
- While IBD and/or AILD can be challenging, and everyone's experience is unique, it's important to note that some patients experience a milder disease course, and some enjoy years or even decades of remission. Whether your child has a milder disease course or not, **there are an ever-growing number of tools and treatments to help them achieve remission**, which offers a welcome break from the challenges of active disease.
- The fields of IBD and AILD research are continually and rapidly advancing, leading to the development of new treatment options and increased mental health support. **As we learn to better manage the challenges, there is every reason to hope for improved outcomes and a better quality of life for your child.** We anticipate newer and more effective therapies on the horizon, and perhaps even the prospect of being able to prevent and cure these diseases.

Remember your child's journey with IBD and/or AILD is unique, and while there may be hurdles along the way, there is immense potential for a life filled with achievements, dreams, and happiness. By working closely with your healthcare team, staying informed, and fostering resilience, you can provide your child with the support they need to navigate the challenges of IBD and/or AILD and look forward to a bright future.

YOU ARE NOT ALONE, AND THERE IS HOPE.

1 Viewpoints

Diagnosis

From a Caregiver

In the 7 years since our daughter's diagnosis, we have watched her grow into a resilient, mature, capable, and compassionate person. She has rarely missed school, traveled with a medical diet, competed in sports, excelled academically, and has a wonderful group of friends.

- Ildiko, caregiver

From a Psychosocial Clinician

It is normal and human to hope. We can have hope and also have big thoughts and feelings. **Navigating hope in the context of pediatric IBD can be incredibly complex, and having realistic hope can also be a resilient coping strategy.** As Ildiko shares, holding space for hope in the midst of IBD can be difficult and can be impacted by many factors including the IBD phenotype a child has, a family history of IBD, and caregiver mental health. The language we use matters and can impact our emotions, thoughts, and coping, especially as it relates to hope. We can use "and" instead of "but" when sharing our hope - instead of saying, *"I hope the infusions help her feel better, but I worry that the medicine won't work,"* we can say, *"I hope the infusions help her feel better* ***and*** *I worry that medicine won't work."* This later phrasing allows us to hold space for both parts of the sentence and to acknowledge the hope we have.

- Dr. David, clinical psychologist

> THE LANGUAGE WE USE MATTERS AND CAN IMPACT OUR EMOTIONS, THOUGHTS, AND COPING...

1 Action Steps

Diagnosis

- **Gently remind yourself that it is okay to feel any and all feelings;** what you are feeling is human. It is okay to not be okay right now.
- Think of the wonderful things about your child – their humor, athleticism, kindness – and remind yourself that your child's diagnoses does not change **who** they are.
- **Write down your questions or concerns** about your child's IBD and/or AILD to be able to share these thoughts with your child's healthcare team.
- Try to replace the word *"but"* with the word *"and"* where you can, like *"This is scary **and** we can do this"* instead of *"This is scary but we can do this."* **The word "and" increases cognitive flexibility and can support realistic hope and resilience.**
- Try a **mindfulness exercise** like Anchor At the Bottom of a Stormy Sea to validate all of your big feelings and also remember that your love and dedication to your child are the anchor during the stormy sea of an IBD and/or AILD diagnosis.
- Try diaphragmatic breathing**,** a special way of breathing that can help our bodies relax physically and emotionally.
- **Review resources** from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent and learning more about your emotions.
  - Considerations when pursuing finding a mental health support as a caregiver:
    - Some caregivers may be very interested in therapy and some may not, what matters most is what feels like the right fit for you as an individual.
    - Just as it can take more than one try to find a hair stylist you like, finding a mental health professional that is the right fit for you can take time. You may need to meet more than one provider. This can feel frustrating.
  - It can be helpful to consider your goals for therapy – for example, do you want a safe place to share what you are going through, do you want to learn coping skills?
  - Mental health support includes many different types of therapy, like supportive therapy and Cognitive Behavioral Therapy.
    - It can be helpful to ask potential mental health professionals what kind of therapy they are trained in to determine if this will be a good fit for you.

scan to access all links

1 Action Steps

Diagnosis

- **Consider any preferences you have for your mental health professional and advocate for these preferences**, such as if gender of mental health professional or seeing someone through telehealth matters to you
  - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies
- If your child is interested in connecting with others who have IBD and/or AILD, consider sharing these reputable resources:
  - ImproveCareNow's Patient Advisory Council resources (IBD)
  - A-LiNK Connections (AILD) by visiting the "How To Get Involved" sign-up section

scan to access all links

1

Questions, Notes, To-Dos

Diagnosis

2 Navigating the Joys and Challenges of Parenting a Child with IBD and/or AILD

As caregivers of children with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), we have an up-close and personal view of how our children experience and are impacted by chronic health condition(s). We live with them, feed them, nurture them, cheer them on, and witness the ups and downs that IBD and/or AILD presents in their lives. We also handle many responsibilities that extend beyond typical parenting. These include scheduling and going to countless medical appointments, preparing children for procedures, administering medications, and advocating for our children's needs at school, in the clinic/hospital and with insurance companies. We do all of this while striving to provide a sense of normalcy and stability for our child and family. It’s important to recognize our hard work and feel proud of ourselves!

Viewpoints

Navigating the Joys and Challenges of Parenting a Child with IBD and/or AILD

From a Caregiver

Parenting is a journey filled with uncharted territories, many lessons, and immeasurable love. However, being a caregiver to one or more children with IBD and/or AILD adds a unique layer of complexity to this role. **Experiences in the world of IBD and/or AILD caregiving vary widely**, influenced by the severity and type of IBD your child has, family dynamics and support systems, and the age of your child at diagnosis.

- Ildiko, caregiver

> EXPERIENCES IN THE WORLD OF IBD AND/OR AILD CAREGIVING VARY WIDELY...

From a Psychosocial Clinician

Regardless of where you are in your child's IBD and/or AILD journey, being a caregiver requires a lot of time, effort, and emotion – all while juggling life's other demands, including work, caregiving for other children and family members, romantic relationships, friendships, and personal medical needs. Often, self-care falls to the bottom of the priority list. Over time, caregivers may feel overwhelmed by stress or burned out by caregiver roles; in turn, this can make it even more difficult to have the energy and focus for managing children's medical needs and keeping up with the many other demands of life. As the saying goes, the days are long and the years are short! **It is important to create space to reflect on the joys and wonder of being the caregiver to a child with chronic condition(s), like feeling proud of your advocacy at a doctor's visit or the warm fuzzies as you see your child's friends support them.**

- Dr. Holbein, clinical psychologist

2 Action Steps

Navigating the Joys and Challenges of Parenting a Child with IBD and/or AILD

- Consider a mindfulness practice called “Joy Snacking,” this is a strategy of finding the positive sprinkles in daily life like your coffee being at the perfect temperature, arriving to a doctor’s appointment early, not having to wait at the pharmacy to pick up a medicine, your child getting their favorite provider at the lab
  - Prefer listening to information? Check out this 22-minute listen of “Joy Snacking”
  - Prefer reading and visualizations? Check out this read about “Joy Snacking”
  - **Pro tip:** Write down your “joy snacks” each day to make this list of positive sprinkles feel more tangible
- Gently remind yourself to be patient with yourself. Navigating the joys and challenges of being a caregiver with a child with chronic condition(s) is like balancing on an exercise ball, some days may feel harder and this is okay and normal.
- Remember that life isn’t a solo sport and neither is caring for your child with health needs. Reach out to your personal team (e.g., a significant other, a parent, a close friend, a neighbor) and ask for what you need, like being able to vent or asking someone to spend time with your child so you can do something just for yourself.
- If you are interested in connecting with other parents/caregivers of children with IBD and/or AILD to learn from their experiences and find support, consider joining:
  - ImproveCareNow’s Parent/Family Advisory Council (IBD)
  - Autoimmune Liver Disease Network's A-LiNK Connections (AILD)
- Review the “Taking Care of Yourself” resource from the Caregiver Wellbeing Special Interest Group
  - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *“caregiverwellbeingspp”* for other reputable resources and strategies
- Review the “Self Care: A Parent’s Guide to Taking Care of Yourself (as well as Your Child)” resource from the Courageous Parent Network
- Watch this 36-minute video on Taking Care of Yourself When Your Child has a Chronic Condition from the Parent and Caregiver Voices Project

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Notes, Questions, To-Dos

Navigating the Joys and Challenges of Parenting a Child with IBD and/or AILD

3

How Stress Impacts Our Overall Health

We are all human and we all experience stress in our daily lives. For all of us, feeling stress can impact our overall health, such as making us feel more tired, less hungry, more body discomfort/soreness, and more anxious and irritable. Learning to manage stress is an important part of life, and it can be particularly relevant for caregivers of children with chronic health needs like Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD). Learning to manage our stress is very individual and takes time and practice to find the right tools for each of us!

3 Viewpoints

How Stress Impacts Our Overall Health

From Caregivers

It is essential to recognize that being an IBD caregiver is an intensive, unpaid job that requires consistent effort and strength. Whether in remission or not, the role is demanding, carrying a list of persistent worries and anxieties, frequently waiting for another proverbial "shoe to drop." The unpredictable nature of IBD can lead to constant vigilance and stress for both the child and family.

- Ildiko, caregiver

When something scary or stressful happens, our body reacts to help us. Stress hormones are released that make our heart beat faster, and we might feel a rush of energy. Imagine you're being chased by a lion. Your heart would race, and you'd feel super alert. That's your body's way of getting ready to run or fight. **Having a child with a serious illness can chronically trigger our stress response causing us to feel like that lion is always there ready to pounce, which can make us feel constantly worn down.** We may get sick more often or experience mental health issues like anxiety and depression. Sometimes I feel like I'm in a constant fight or flight mode- always waiting for the other shoe to drop. **I have to intentionally practice ways to decrease my stress. For me, things like exercise, meditation, and talking about my feelings help lower the stress hormones in my body.**

- Chris, caregiver

Chronic stress can take a toll on your health, so it's crucial to develop coping mechanisms. These might include deep breathing exercises, mindfulness practices, or engaging in activities that help you relax. Over the years I have assembled a toolbox full of tools to help me cope and stay calm and all I have to do is remember to use it. I even schedule some things like stretching on my calendar! My toolbox includes deep breathing exercises, mindfulness meditations, prayers, stretching, light exercise (walking), listening to music and reading. What's in your toolbox?

- Jane, caregiver

3 Viewpoints

How Stress Impacts Our Overall Health

From a Psychosocial Clinician

Our bodies have an important survival mechanism or stress response. It is also called "fight or flight" (or sometimes "fight-flight-freeze") and involves your autonomic nervous system preparing you to do the best you can to run or fight your way out of a potentially life-threatening situation. When you (or your child) feel a strong emotion, this stress response is activated. Physical symptoms (e.g., abdominal pain, nausea, getting a virus, poor sleep for days) can trigger this response as well. You would want your body to shift into "fight or flight" if you were being chased by a lion. Unfortunately, our bodies tend to activate this response more often than they need to in modern day life. As Chris mentions above, when "fight or flight" is activated, the heart beats faster to prepare your organs for running and complex thinking turns off so that instinct can take over and you can run or fight as hard as you can to survive. However, this isn't the most helpful when you are talking to your child's doctor or are helping your child swallow pills for the first time.

A calming technique called ***diaphragmatic breathing*** can be helpful. This type of breathing lowers your heart rate and is the clue to your nervous system that it does not need to activate "fight or flight." There are also many other great strategies to help you and your child work through stress. Talk to the GI psychologist, social worker, or your child's care team to get connected to additional resources.

- Dr. McKillop, clinical psychologist

Action Steps

How Stress Impacts Our Overall Health

- Remind yourself that **taking care of yourself and managing stress does not necessarily need to take a lot of time**. Even a few moments pause and use a calm-down strategy can make a noticeable difference.
- **Make a list of the coping skills that work for you** – this could be a favorite relaxing song, taking your dog for a walk, praying – and keep this list somewhere that is easy for you to access, like on your phone or in your wallet. When we are feeling stress, it is can be hard to problem-solve in the moment so having a go-to list of coping skills that work for us as individuals can help during a stressful moment.
- Sometimes it is hard to find the right word for a feeling, and we can also feel more than one feeling at a time. **Emojis are a great way to label our feelings** (or support our children in labeling their feelings) without having the 'right name' for the feeling.
- **Relaxation techniques are a great way to calm the mind and the body** during high-stress, busy days. We offer a few selected examples below:
  - Try to **do a body scan** when you feel stressed, what do you notice? Are your muscles tense, is your heart racing, is it hard to breathe, do you feel nauseated? Our bodies give us lots of cues when we feel stressed and it is important to listen when our bodies are communicating.
    - With time, you can begin to notice when these stress symptoms are rising like the beginning of a roller coaster and that is an ideal time to use one of the coping skills below to help reduce stress and calm our bodies and brains (e.g., when you notice a bit of shoulder tension, pause and begin to do some diaphragmatic breaths (see below))
  - Try a **mindfulness exercise** like Anchor At the Bottom of a Stormy Sea to validate all of your big feelings and also remember that your love and dedication to your child are the anchor during the stormy sea of an IBD and/or AILD diagnosis
  - Try a **visualization exercise**, like imagining choppy oceans waves and then imagine the waves getting calmer and calmer
  - Try **diaphragmatic breathing**, a special way of breathing that can help our bodies relax physically and emotionally

scan to access all links

3 Action Steps

How Stress Impacts Our Overall Health

- When it feels like the stressor is outside of your control, try to focus on your 'circle of control' like using a coping skill to calm your body, asking for help, or preparing a comforting snack or drink
- Try to replace the word "but" with the word "and" where you can, like *"This is hard* ***and*** *I will be okay"* instead of *"This is hard but I will be okay."* The word "and" increases cognitive flexibility and can support realistic hope and resilience
- Review resources from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent and learning more about your emotions
    - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies
- Review the "Self Care: A Parent's Guide to Taking Care of Yourself (as well as Your Child)" resource from the Courageous Parent Network

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Notes, Questions, To-Dos

How Stress Impacts Our Overall Health

4

Recognizing Emotions & Coping

While it is very human to experience big feelings, it can often be hard to know exactly what we are feeling and – moreover – how to cope with these feelings. Supporting the psychosocial health of ourselves as adults and also of our children is an ongoing journey, and practicing naming our feelings and figuring out the coping skills that work for us all is an important process. There are no “good” or “bad” feelings, all feelings tell us important information about what we are experiencing, and even rephrasing to “light”/“heavy” feelings or “comfortable”/”uncomfortable” feelings can help us continue to make space for what we are feeling.

4 Viewpoints

Recognizing Emotions & Coping

From a Caregiver

Some may believe that expressing emotions is a sign of weakness or that talking about emotions makes a situation worse or negatively affects our child. These are common misconceptions. Openly expressing fears, anxiety, and frustrations is a sign of strength and is essential for your well-being. Sharing your emotions with a trusted friend, family member, or therapist allows others to offer support, reduces isolation, and allows you to process your feelings to help you think more clearly about your child's care. **Talking about my feelings serves as a release valve for the anxiety, fear, and sadness I often carry. It prevents these feelings from building up and becoming overwhelming. Not only is this vital to my physical and mental health, it allows me to better support my son and the rest of our family.**

- Chris, caregiver

From a Psychosocial Clinician

We all have emotions; this is a normal and healthy part of being human. **While there are not 'bad' emotions, having heavy emotions like sadness or anger can feel distressing to many people.** As Chris mentions, sharing our emotions with people we trust is such a strength and is important to our overall health, especially when your child is having complex medical experiences. **Writing down or talking about feelings is a great way to identify what you are feeling, and this can open the door to learning different ways to cope with big feelings.**

- Dr. David, clinical psychologist

4a Fear & Anxiety

Feeling worried and anxious is a common experience for all people, and we may feel more worried, anxious, or fearful with our children's health. Anxiety is our brain trying to protect us and look out for the 'what ifs,' especially when you have been through hard things with your child in similar situations. For example, you may notice that you begin to feel anxious before lab draws if you know these have been very hard for your child before. **A big part of managing worries and anxiety is 'talking back' to anxiety to help accurately and compassionately reframe an experience.** For example, we may first think, *"Every time my child has a blood draw it is awful,"* to *"Sometimes when my child has a blood draw it is tough and also, they are brave and we get through it each time."*

4a Viewpoints

Fear & Anxiety (Recognizing Emotions & Coping)

From Caregivers

Fear and anxiety with a medical diagnosis (or diagnoses) is normal and common. Our brains naturally consider the full range of possible outcomes, but sometimes you can get stuck thinking about the worst-case scenarios many times over. The more you think about them, the more anxious you may become. It may feel like the worst-case scenario is likely to happen because you've thought about and imagined it so many times, even though nothing outside of your thoughts has changed the likelihood of that occurring. Here, we recommend trying to shift your thinking. You may find it helpful to take things one day at a time and shift your focus to what is within your control (e.g., "how can I help my child meet discharge goals (like drinking water or going for a walk) in the next hour?"). Many parents often feel that they are not doing enough for their child because so much is out of their control. Remember, being there for them and with them in whatever way you can is very powerful. Diaphragmatic breathing is an especially useful tool for times when feelings of overwhelm, anxiety, and fear seem to be taking control. Everyone can benefit from relaxation strategies to calm the body and mind so make sure to take some time to find a few different strategies that work for both you and your child. **There are many emotions that come with an autoimmune disease diagnosis including fear, anxiety, grief, and even relief. Sometimes these feelings are short-lived and sometimes they will linger.** Allow yourself to navigate through all of them but try not to linger in them for long. Know that these emotions may come and go even when everything seems to be going well and even if you are not someone who is prone to it. Build a support system that you can lean on, educate yourself with scientific and vetted information, and ask questions. Many of our fears are of the unknown, so stay informed about your child's illness and treatment options. Understanding their condition can help you make informed decisions and feel more in control of the situation, which can reduce stress and anxiety. Remember to take deep breaths, to pause, seek a bit of nature, journal, retreat when necessary, and explore different ways to cope along the way.

- Heidi, Tori & Jane, caregivers

4a Action Steps

Fear & Anxiety (Recognizing Emotions & Coping)

- Remind yourself that **taking care of yourself and managing stress does not necessarily need to take a lot of time**. Even a few moments pause and use a calm-down strategy can make a noticeable difference.
- **Make a list of the coping skills that work for you** – this could be a favorite relaxing song, taking your dog for a walk, praying – and keep this list somewhere that is easy for you to access, like on your phone or in your wallet. When we are feeling stress, it is can be hard to problem-solve in the moment so having a go-to list of coping skills that work for us as individuals can help during a stressful moment.
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    - Try to **do a body scan** when you feel stressed, what do you notice? Are your muscles tense, is your heart racing, is it hard to breathe, do you feel nauseated? Our bodies give us lots of cues when we feel stressed and it is important to listen when our bodies are communicating.
        - With time, you can begin to notice when these stress symptoms are rising like the beginning of a roller coaster and that is an ideal time to use one of the coping skills below to help reduce stress and calm our bodies and brains (e.g., when you notice a bit of shoulder tension, pause and begin to do some diaphragmatic breaths (see below))
    - Try a **mindfulness exercise** like Anchor At the Bottom of a Stormy Sea to validate all of your big feelings and also remember that your love and dedication to your child are the anchor during the stormy sea of an Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) diagnosis.
    - Try a **visualization exercise**, like imagining choppy oceans waves and then imagine the waves getting calmer and calmer.
    - Try **diaphragmatic breathing**, a special way of breathing that can help our bodies relax physically and emotionally.

scan to access all links

4b Grief

For caregivers and patients with a chronic illness such as Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), grief can part of living with chronic illnesses. Grief is not a straight line and may feel different at different times, like at diagnosis, treatment changes, or at different developmental milestones. Additionally, grief may feel different for each member of the family and some caregivers may not experience grief. While many caregivers share that getting a diagnosis and having a name for the symptoms their children have been experiencing can be a relief, it may also feel like a loss with many big feelings and worries. You may grieve the family life you led before the diagnosis, how you parented your child, the impact the disease has on your child, and the expectations you may have had for your child's and family's future. These are all normal feelings; talking with trusted family, friends, a therapist and/or attending support groups can be helpful. At any point in the IBD and AILD journeys the treatment may change and bring on other waves of emotions; anger that the medication stopped working, the unknown of what a new medication or treatment will entail, worry about another procedure or that a surgery is impending. Some caregivers can also experience anticipatory grief, where you may feel a loss of something before it happens, like feeling grief about missing a family reunion because your child has a planned procedure then.

4b Viewpoints

Grief (Recognizing Emotions & Coping)

From a Caregiver

When my daughter was planning for her prom, not only was I emotional that she was trying on dresses, but **I was also overcome with feelings when she struggled finding a dress to accommodate her protruding g-tube and worried that her medication cycle and side effects would interfere with her big day.** How did I move through that wave? Holding onto the moment of seeing her smiling with her friends during pictures and feeling good about herself on her special day.

- Erin, caregiver

From a Psychosocial Clinician

Grief is often thought about in the context of loss or the death of a loved one. However, grief can occur for many reasons, including within the context of your child's chronic illness diagnosis. When picturing your child's future, chronic illness was likely not part of that. It is in this way you (and your child) experience a loss. Grief is usually described as happening in stages, but the grief experience does not follow a specific pattern and is as unique as a fingerprint. There is no particular order in which one must experience grief stages, and you may feel like you are going through several stages at once or may never experience one of them. The stages of grief include denial, bargaining (e.g., "*if only we had done x, then this might not have happened*"), anger, depression, and acceptance. **Acceptance does not mean that anyone is "okay" with what has happened; rather, the idea is that we recognize there is a new reality and find ways to learn to live with it and even grow from it.** Reaching a place of acceptance takes time and everyone can benefit from support during this process. A sixth stage, called making meaning, involves finding a way to make some meaning from the loss – whatever that means for each of you. **For some caregivers of a child with IBD, this may mean developing advocacy skills in the hospital setting. For others, this may mean volunteering at the hospital, becoming a parent mentor at your center, or joining a group (e.g., ImproveCareNow's Parent/Family Advisory Council).**

- Dr. McKillop, clinical psychologist

4b Action Steps

Grief (Recognizing Emotions & Coping)

- **Gently remind yourself that people can experience grief and a sense of loss at different times during a child's chronic illness(es), and that everyone may experience grief differently.** In other words, you may experience grief about one part of your child's chronic illness journey and another family member may experience grief at another part of your child's chronic illness journey.
- Give yourself the time and space to feel your feelings – this may be writing in a journal, talking with a therapist, or seeking support from a religious leader.
- Try to replace the word "but" with the word "and" where you can, like *"I am grieving **and** I will get through"* instead of *"I am grieving but I will get through this."* **The word "and" increases cognitive flexibility and can support realistic hope and resilience.**
- Try a **mindfulness exercise** like Anchor At the Bottom of a Stormy Sea to validate all of your big feelings and also remember that your love and dedication to your child are the anchor during the stormy sea during the times of grief.
- Try **diaphragmatic breathing**, a special way of breathing that can help our bodies relax physically and emotionally.
- When it feels like you don't have control over the situation (which can happen when people are grieving), try to **focus on your 'circle of control'** like using a coping skill to calm your body, asking for help, or preparing a comforting snack or drink.
- **Review resources** from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent and learning more about your emotions.
- If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies.
- **Make a list of the coping skills** that work for you – this could be a favorite relaxing song, taking your dog for a walk, praying – and keep this list somewhere that is easy for you to access, like on your phone or in your wallet. **When we are feeling stress, it is can be hard to problem-solve in the moment so having a go-to list of coping skills that work for us as individuals can help during a stressful moment.**

scan to access all links

4b Action Steps

Grief (Recognizing Emotions & Coping)

- Consider watching videos of other caregivers who 'get it' from the Parent and Caregivers Voices Project as this can help you feel connected to a community and support you in the grief
- Review the Anticipatory Grief resource from the Courageous Parents Network
- Watch this <1 minute video from a nurse explaining how grief can evolve over time (note: this video is not specific to pediatric chronic illness but the explanation is spot on!)

scan to access all links

4c Guilt

Taking care of your child with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) may involve asking your child to do many brave things that they don't want to do, like taking medicine, getting labs, and going to multiple medical visits and procedures. Some caregivers can experience guilt in asking their children to have brave and potentially uncomfortable experiences for chronic illness(es). Caregivers may also experience guilt if a child – who is understandably upset or nervous about a brave and uncomfortable experience – verbalize their distress. This may be especially hard for younger children or children with developmental needs who may not fully understand why the brave healthcare task is being asked of them. Some caregivers may blame themselves for passing IBD and/or AILD to their child due to a possible genetic link, or they may wonder if they did something to cause their child's IBD and/or AILD. This can be hard and it is important to have strategies to help navigate these feelings.

4c Viewpoints

Guilt (Recognizing Emotions & Coping)

From a Caregiver

There have been many times I have felt guilty about having to stand there or hold my child while he has to undergo a poke for an infusion or even a flu shot. As he is now 10, I've talked to him and try to maintain that I am a safe place for him. My husband and I began this when our son was 3. We always preface a poke or procedure with how we would not do anything that wasn't necessary to help him and keep him healthy. That doesn't make it easy for him or for us. As he grew older, we began practicing more realistic medical play, which has recently involved using (not poking) the same process that occurs during infusions.

- Tori, caregiver

From a Psychosocial Clinician

As Tori shares above, it can be so tough to encourage your child to do a medical task that may be painful, uncomfortable, or stressful to them. You are your child's green-light person, this means that you only agree to medical care that is needed and safe for their body. Continue to remind yourself that you are taking care of their health even if your child does not fully understand why certain medical tasks are needed. **If you know that there are certain medical tasks that are hard for you as a parent, like watching your child get an IV placed, think about a coping plan for yourself to help move through it (e.g., taking deep breaths, putting an earbud in and listening to music, having a chance to journal at the end of the day).** It is okay to have big thoughts and feelings about your child's care experiences!

- Dr. David, clinical psychologist

4c Viewpoints

Guilt (Recognizing Emotions & Coping)

From a Caregiver

Depending on your child's treatment, there may be times when as parents/caregivers we are called upon to learn to place a naso-gastric (ng) tube, change a gastric (g) tube or pouch, give an injection, etc. **There can be some big feelings associated with this shift in roles; as parents first and foremost we are our child's protectors, the ones to give hugs and who chase monsters out from under beds. We are safe, comforting, and the ones who make things better. Until we were not, and we are now the ones doing the medical procedure on our own children.**

When my daughter was 11 and in 6th grade she went into her first flare. She chose exclusive enteral nutrition for 3 months in lieu of steroid induction as she had every side effect in the book at diagnosis. She was admitted for teaching about the ng-tube and EEN; together we practiced on stuffed animals provided by child life until a few days later it was my turn to drop the tube in my daughter. I wasn't prepared for that knife to my heart as she screamed and looked at me like I committed the ultimate betrayal. I dropped the tube and ran out of the room sobbing, finding privacy for myself in an open utility closet on the unit (that I had found the night prior when I needed a safe place for myself to process my feelings away from my daughter). Her kind and supportive nurse found me (guess I wasn't the first parent to cry in the closet) and talked me down. In those moments, I doubted whether I could do this to my daughter and worried that I was traumatizing her. After taking a break (and leaving the closet) the nurse, my daughter and I produced a new plan together which involved my daughter placing the ng tube on me…solidarity at its finest, if you will. **My takeaway advice is keep what is in the best interest of your child at the forefront and involve them in the plan from the start.** I had to change the ng tube 3 times after discharge, and my daughter was in control from beginning to end; she unpacked the supplies, laid them out, we reviewed the steps, picked music to listen to, and we did it…together!

- Erin, caregiver

4c

Action Steps

Guilt (Recognizing Emotions & Coping)

- Zoom out and gently remind yourself of the 'why' – you are asking your child to do a brave healthcare task because it is important for their health. This does not erase feelings of guilt though can ground you in the 'why.' Repeating the 'why' to yourself silently may be helpful to continue to remind yourself of why you are asking your child to be so brave.
    - Depending on the age of your child and your comfort, this may also be something to calmly say aloud to your child like, *"I know I am asking you to do something so brave and I know you are upset and don't want to do this. I want you to be healthy and it is very hard when we ask you to do brave things that you don't want to do. It is okay to feel upset and I'm still going to ask you to do this brave thing because I care so much about your health."*
- Consider giving your child some choice when it is appropriate to their age and situation, this can help the child to feel more control and may make feelings of guilt lighter. For example, this may include asking the child which leg they want their injection in, if they do or don't want a countdown before labs, or want to take their pills before or after breakfast.
- Review the Pain Champions Guide for Parents resource from The Meg Foundation and the SuperMeg Poke Planner to help your child build a 'cope plan'. The It Doesn't Have to Hurt program provides additional evidence-based resources for coping with needle pokes.
- If you are feeling guilty about whether your genetics or caregiver practices caused your child's disease, consider sharing your concerns with your child's medical team so that they can help you to better understand your child's disease. Remind yourself that doctors and scientists are still learning about what causes IBD and/or AILD in the first place. Try to shift your focus to all you have already done to nurture and care for your child's health and well-being, as well as the active role you can take in helping your child take care of their health.
- Give yourself the time and space to feel your feelings – this may be writing in a journal, talking with a therapist, or seeking support from a religious leader or a family support group.

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4c

Action Steps

Guilt (Recognizing Emotions & Coping)

- Try to replace the word "but" with the word "and" where you can, like *"I feel guilty when I ask my child to sit still for their shot* ***and*** *I am doing it because I love them and their body needs this medicine"* instead of *"I feel guilty when I ask my child to sit still for their shot but I am doing it because I love them and their body needs this medicine."* **The word "and" increases cognitive flexibility and can support realistic hope and resilience.**
- Try diaphragmatic breathing, a special way of breathing that can help our bodies relax physically and emotionally.
- When it feels like you don't have control over the situation (which can happen when people are grieving), try to focus on your 'circle of control' like using a coping skill to calm your body, asking for help, or preparing a comforting snack or drink.
- Consider watching videos of other caregivers who 'get it' from the Parent and Caregivers Voices Project as this can help you feel connected to a community of other caregivers.

scan to access all links

4d Medical Traumatic Stress

Medical traumatic stress can happen for patients or caregivers throughout illness experiences where a medical experience creates ongoing symptoms like intrusive thoughts and nightmares. Experiencing medical traumatic stress can make future medical care experiences difficult, such as feeling anxious and sweaty as you drive to the hospital or panicked when you hear an IV pump beep. Medical traumatic stress is very individual; two caregivers may go through the same experience but only one may experience medical traumatic stress. Just as Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD)'s disease course can present itself in many different ways, every individual, even within the same family unit, may experience medical traumatic stress differently.

4d

Viewpoints

Medical Traumatic Stress (Recognizing Emotions & Coping)

From Caregivers

Medical trauma, for a child or the parent, can come in many forms and have many repercussions. When a child is particularly young, it is hard for them to understand why they may be hurting, need to have a procedure, or what is going to happen. This can lead to fear and anxiety around any type of medical appointment, new situation, or experience. **In our experience, it was best to use more realistic looking items for "medical pretend play", try to explain things as simply as possible, and distract as much as possible if needles were involved or procedures were necessary.**

- Tori, caregiver

With our family's trauma, it snuck up on us – a couple years after my son experienced major complications from multiple surgeries. The toll of it all. The diagnosis, the pain & suffering we witnessed as caregivers to our child, the financial toll, etc. It affected our family deeply and we have had to learn to navigate this chapter, but it does and can pass. We sought professional mental health help. We started sharing our story with ImproveCareNow and other IBD communities. **As with all the emotions, remember that you are not alone and there are many resources to help you navigate them.**

- Heidi, caregiver

4d Viewpoints

Medical Traumatic Stress (Recognizing Emotions & Coping)

From Caregivers

As a parent, the moment our daughter was diagnosed with Crohn's Disease, Primary Sclerosing Cholangitis, and Celiac Disease, I was overwhelmed with emotions. It was a shock that hit me deeply, and for a while, I couldn't believe that our youngest daughter also had to live with a chronic illness just like her older sister. Fear and anxiety consumed me, and I couldn't help but worry about my child's well-being. **I realized that each family member had a unique way of dealing with the trauma. I turned to research and education, finding comfort in understanding the condition, exploring treatment options, and feeling like I had some control. I sought solace in knowledge, hoping to find answers and solutions. Our oldest daughter, who also lives with chronic illness, was shocked and confused and found comfort in sitting alone in her room, trying to process the new reality. On the other hand, my husband struggled with guilt and self-blame. He wondered if there was anything we could have done differently to prevent the conditions.** It weighed heavily on our hearts and was a difficult burden to bear.

Throughout this journey, we've learned the importance of recognizing and respecting each other's trauma responses. We've created an environment of support, empathy, and healing within our family. We understand that everyone copes differently, and we're there for each other, sharing the warmth and comfort we all need during this challenging time.

- Maria, caregiver

4d Viewpoints

Medical Traumatic Stress (Recognizing Emotions & Coping)

From a Psychosocial Clinician

Caregivers and children can experience trauma in the medical setting. It is normal to have an acute stress reaction to a scary event, such as hearing your child's diagnosis or observing your child experience intense pain or fear. It is also important to note that the stress reaction felt does not equal the outcome (you may feel that the procedure was traumatic even when the outcome went well). Sometimes the trauma response can last longer and can benefit from professional support. **Symptoms of a traumatic reaction can include difficulty sleeping, nightmares, or flashbacks (sort of like a nightmare while awake) where you re-experience or replay the scary event in your mind repeatedly as if it is happening all over again.** Reminders of the event (e.g., the hospital logo, the smell of the clinic, or hearing your child needs bloodwork) can trigger a trauma response. You may also notice passive or active avoidance of these reminders (e.g., consistently avoiding scheduling follow-up appointments). Mood changes such as sadness and irritability can occur, as well as difficulty concentrating and feeling "on edge." When you first learn about the new IBD diagnosis, you and your family will benefit from maintaining your routine and trying to engage in your typical activities. If you experience several of these symptoms, and they last longer than a few weeks after the event or occur after some time has passed, this may be a sign of a more significant trauma response warranting evaluation and support from a mental health professional.

- Dr. McKillop, clinical psychologist

4d Action Steps

Medical Traumatic Stress (Recognizing Emotions & Coping)

- Consider reading the book "Afraid of the Doctor" about medical traumatic stress in children with health conditions.
- Review the many resources through The National Child Traumatic Stress Network on medical traumatic stress
  - If your child is in the hospital, here is a resource about supporting your child during an admission
  - If your child is recently discharged from the hospital, here is a resource about supporting your child after an admission and another resource on the importance of returning to your child's routine
  - If medical traumatic stress continues to impact your child, consider using this resource to make a plan about how to navigate medical traumatic stress
- If/when comfortable, consider sharing your or your child's experience(s) with medical traumatic stress with your child's care team to help ensure everyone is thoughtful of past difficult experiences.
- Maintaining your schedule and routine as much as possible is very important during times of traumatic stress, this helps to create consistency and increase your 'circle of control.' Finding creative ways to maintain your routine even during busy or stressful times is important, like bringing work to do while your child gets their infusion or listening to audio of outdoors sounds when your child is in the hospital instead of going for a neighborhood walk

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4d Action Steps

Medical Traumatic Stress (Recognizing Emotions & Coping)

- Ask for trauma-informed care during your child's healthcare experiences, this can include:
    - Giving you and your child choices when appropriate
    - Asking the healthcare professional to model asking for consent and assent to help you remain your child's "green light" person (e.g., *"Okay mom, is it okay if I do my physical exam now?"*)
    - Asking the healthcare professional to explain what will happen before anything begins (e.g., *"I'm going to do a physical exam so I will look at your eyes, ask you to open your mouth for me to look in your mouth, then I will listen to your heartbeat with my stethoscope..."*)
    - Asking the healthcare professional to narrate what they are doing as they do it (e.g., *"Now I am using my hands to press on your tummy..."*)
    - Share what works for your child, like if listening to music helps them remain calm during labs or having a stuffed animal have the physical exam first helps them be brave.
- Review resources from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent.
- If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies.

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4e Parental Coping and Self-Care

Learning to cope with our feelings and taking care of ourselves is important for everyone, and especially for caregivers of children with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD). This is a process and like any other skill it takes time and practice.

4e Viewpoints

Parental Coping and Self-Care (Recognizing Emotions & Coping)

From Caregivers

When a caregiver has the appropriate and supportive resources, they are better able to help the child. It’s important that children also have information available to them at a level appropriate for them. ImproveCareNow and other organizations have great toolkits and resources.

- Heidi, caregiver

I started seeing a therapist shortly after our son was diagnosed. She helped me process my own feelings of sadness and worry as well as supported our son as he worked through his own feelings. During a particularly difficult time, my therapist recommended I consider an antidepressant, and it significantly improved both my energy levels and my overall emotional well-being. **Taking care of yourself means different things depending on what's happening in your life.** Sometimes, it's about making sure you sleep well and eat healthy foods to keep your body strong. Other times, it might mean talking to someone, like a therapist or a friend, when you're feeling sad or worried. Therapy and medication can help a caregiver cope with the stress of having a child with a chronic illness. A therapist can help teach coping skills and stress management techniques and offer a safe space for you to express feelings. Medication can also be helpful in treating symptoms of depression or anxiety. Taking care of yourself is like a toolbelt with different tools; you pick the right one for the job depending on what's happening in your life. Just like my feelings change, the things that help me cope with life’s challenges also change. Sometimes my body needs rest, so I’ll lay on the couch and watch a show. Other times, I need to let go of stress, so I’ll go for a walk or run. Sometimes I need to be by myself and other times I need to feel connected to others.

- Chris, caregiver

4e Viewpoints

Parental Coping and Self-Care (Recognizing Emotions & Coping)

From Caregivers

Taking care of a child with IBD or PSC (or both) is hard. One of the most difficult things for me as a parent, is facing the fears and uncertainties of the future for my child. **When I'm having a difficult time, talking to other parents who understand helps me to get through the emotional challenge, and move forward with more hope and positivity.** It's tremendously helpful to me to have a safe space to express my concerns without judgment. One of the best things that we can do is provide insights and tips to other parents based on our own experience caring for our children. In our various PSC/AIH/IBD (Primary Sclerosing Cholangitis, Autoimmune Hepatitis, Inflammatory Bowel Disease) support groups we always start by saying that although we are not medical professionals, as parents and caregivers, we can share our experience, strength and hope with each other. Talking about how to manage symptoms, prepare for a complex procedure or medical appointment or adjust to a new diagnosis is one of the best and most empowering things we can do to support other parents.

- Jane, caregiver

Taking time for yourself is not selfish; it's necessary for your well-being. Getting enough rest is vital to maintain physical and emotional well-being. Sleep deprivation can increase stress levels and make it harder to cope with the challenges of caring for a sick child. Engaging in regular physical activity can help reduce stress and improve your overall mood. It doesn't have to be intense workouts; even short walks or stretching exercises can be beneficial. Find activities that you enjoy and incorporate them into your daily routine.

- Chris & Jane, caregiver

4e Viewpoints

Parental Coping and Self-Care (Recognizing Emotions & Coping)

From Caregivers

Limited check-ins with physicians regarding parental well-being and the absence of parental screening is a genuine concern. As parents, it's vital for us to have regular access to our child's healthcare team to ensure our well-being is taken into account too. Personally, I experienced the immense value of connecting with ImproveCareNow (ICN) when I didn't have adequate check-ins with my daughter's medical team. **Through ICN, I found a supportive community, my ICN family, where I could openly discuss the challenges we faced, seek guidance, and receive the necessary support to cope.** The friendships and support I gained from ICN were invaluable, as they prevented my daughter's diagnosis from significantly impacting my mental and physical health, ultimately improving our quality of life. It's crucial that we foster a system where parents caring for children with chronic conditions feel supported, validated, and empowered and always know they have a welcoming community to turn to, whether it comes from their child's medical team or external communities.

- Maria, caregiver

> IT'S CRUCIAL THAT WE FOSTER A SYSTEM WHERE PARENTS CARING FOR CHILDREN WITH CHRONIC CONDITIONS FEEL SUPPORTED, VALIDATED, AND EMPOWERED AND ALWAYS KNOW THEY HAVE A WELCOMING COMMUNITY TO TURN TO, WHETHER IT COMES FROM THEIR CHILD'S MEDICAL TEAM OR EXTERNAL COMMUNITIES.

Viewpoints

Parental Coping and Self-Care (Recognizing Emotions & Coping)

From Psychosocial Clinicians

As Maria shares above, there can be limited opportunities to talk with your child's healthcare team about psychosocial experiences you are having as a caregiver. While we as healthcare professionals appreciate that caring for a child with medical needs is tough, we may miss checking in and supporting the caregiver. You are allowed to have feelings related to your child's healthcare; this can be overwhelming to so many families! If it feels comfortable, consider asking your child's healthcare team if they can connect you with any resources (e.g., a parent mentor, a therapist). **You can also check out a great resource to find therapy resources for parents of children with medical needs in the resource section of this resource.**

- Dr. David, clinical psychologist

You are human and you have needs too – and that's okay! It's important to have regular check-ins and take time for yourself, allowing yourself to recharge. Below, caregivers provide some excellent examples of practicing self-care. Even if you can take 10-15 minutes a day to do something for yourself – whether it's reading a book, yoga, enjoying a cup of tea, going for a walk, practicing mindfulness – this is intentional time and space carved out for you. There are some helpful tools online to help you get started on your journey, such as the Calm app, Headspace, Elevate, and more. Your employer and community may also offer free resources – you may just need to ask the right person to get connected, whether it's through your job's human resource department, doctor's office, psychosocial provider, school, or community agency.

- Noelle, clinical social worker

4e Viewpoints

Parental Coping and Self-Care (Recognizing Emotions & Coping)

Tips from Clinical Psychologists:

- While it may seem obvious, research has shown that caregivers of children and teens with IBD and/or AILD experience high rates of stress, especially within the first year of diagnosis or when their child is experiencing a flare. Encouragingly, there is also evidence that caregiver stress declines within the first year after the child's diagnosis.
- Finding time and space for self-care can feel challenging, but we encourage caregivers to start with small changes, like setting boundaries about talking about IBD and/or AILD issues during evening time with their spouse or partner, trying a 5-minute guided meditation, going for a walk in the neighborhood, or taking a 15-minute nap.
- **Connecting with other caregivers of children with IBD and/or AILD can be such a validating experience that may help you to feel a sense of community and less alone in navigating IBD and/or AILD.** Group or one-on-one caregiver support programs specific to IBD and/or AILD are available through IBD and/or AILD organizations and some medical centers. You may also find support organically by starting a conversation with another caregiver in the waiting room during an IBD clinic day or at an IBD and/or AILD awareness walk. While social media can be another way to connect, we always caution caregivers to be thoughtful about the content they read. While some posts may be helpful, it is important to keep in mind that some caregivers may use social media to share inaccurate medical information or unhelpful attitudes, or advice based on their experiences.
- While it may not be feasible for everyone, many caregivers find it helpful to have their own therapist or counselor to support them in this journey. With many practices and therapists offering telehealth visits, therapy may be more accessible than before.
- **Therapy is a part of healthcare and is an important resource for many people at different times, especially for caregivers of kids with complex medical needs.** Check out a great resource about finding therapy support in this resource in the resources section! If you are wondering about the role of medicine for worries or mood, talking with your primary care doctor is often a great first step.

- Dr. David & Dr. Holbein, clinical psychologists

4e Viewpoints

Parental Coping and Self-Care (Recognizing Emotions & Coping)

- Consider a mindfulness practice called "Joy Snacking," this is a strategy of finding the positive sprinkles in daily life like your coffee being at the perfect temperature, arriving to a doctor's appointment early, not having to wait at the pharmacy to pick up a medicine, your child getting their favorite provider at the lab
  - Prefer listening to information? Check out this 22-minute listen of "Joy Snacking"
  - Prefer reading and visualizations? Check out this read about "Joy Snacking"
  - **Pro tip:** Write down your "joy snacks" each day to make this list of positive sprinkles feel more tangible
- Gently remind yourself that taking care of yourself is essential to be able to care for your child – you can't pour from an empty cup!
- Remember that life isn't a solo sport and neither is caring for your child with health needs. Reach out to your personal team (e.g., a significant other, a parent, a close friend, a neighbor) and ask for what you need, like being able to vent or asking someone to spend time with your child so you can do something just for yourself
- Review the "Taking Care of Yourself" resource from the Caregiver Wellbeing Special Interest Group
  - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies
- Review the "Self Care: A Parent's Guide to Taking Care of Yourself (as well as Your Child)" resource from the Courageous Parent Network
- Watch this 36-minute video on Taking Care of Yourself When Your Child has a Chronic Condition from the Parent and Caregiver Voices Project
- Review resources from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent
  - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies

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4 Notes, Questions, To-Dos

Recognizing Emotions & Coping

5

The Male Caregiver Perspective

The team that created this resource was made up of caregivers who identified as moms. We reached out to caregivers who identified as dads for their insights on being a caregiver to a child with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD). We know all caregivers can experience big feelings when their children have chronic health needs.

Viewpoints

The Male Caregiver Perspective

From Caregivers

- This is an upsetting diagnosis for caregivers and the newly diagnosed. Be involved and present when needed. And also, help your child (and yourself) understand that this diagnosis does not define your child and your relationship with your child.
- Even if your child doesn’t talk often about their diagnosis, they are thinking about it. As a parent it has been a constant struggle to find the right level of discussion with my child about their diagnosis and associated events. Also, this can be a tremendous strain on you and other family members, in addition to the patient. Constructively communicate and create opportunities for other loved ones to do so.
- There is more research leading to more curative opportunities today than there were when my child was diagnosed. There will continue to be research building on prior studies. So, there is continued better understanding of these diseases. Much of this has been driven by caregiver advocacy. **If you have the capacity, and you might want to, find a way to involve yourself with a caregiver group advancing an issue you feel is important to this disease.**

- John B, caregiver for son diagnosed with PSC/AIH at age 13

- **Take a deep breath, you may be the master of the universe but you cannot control this.** You are going to try but this thing will do what it wants to do. You do not have IBD/PSC/AILD, you have to love and support someone and teach them how to live and love with it. I have even had discussions with my son about how I wish I had this and he could not have it, and he told me no way, he can deal with it, and I will deal with my own stuff. The kids are tougher than we think, even though we don't want them to be. Dr.'s, and family can be a challenge especially when you are eating a specialized diet for your kids condition. They just don't get it. There is nothing you can do to get the Dr. to understand, they have their toolbox and best intention and then we do the rest.
- In terms of family and getting everyone on board for holidays, we took over all the traditions, we do our best to honor all the old ways of doing things, but now there is a new way, and if you don't like it don’t come. My son’s health is more important than a cookie ingredient or two. And remember even kids with IBD get stomach bugs from time to time, not everything is a relapse.

- John L, caregiver for teenage son diagnosed with Crohn’s and Celiac

5 Viewpoints

The Male Caregiver Perspective

From a Caregiver

- Try to do the research but rely on the doctor's and professionals not google. If you go down the google rabbit hole you will immediately find either the worst case scenarios or sometimes just straight nonsense that will give you some sort of unrealistic expectations of a some instant cure. Realize that just because you can't control the situation doesn't mean that you can't control how you react. It is important that you provide calm, realistic, and constant support for not only your child who has been diagnosed, but also for any other children you have.
- Initially there was a lot of concern about having a "normal" childhood and making sure that our son was going to still be able to experience all of the same things that his friends did. It was a straight fear response to the unknown, but it took time for sure to realize that how we react is really the only way that our children know that anything is different, and accepting their normal is entirely normal.
- **Advocate for your child, and don't be too proud to ask for help from the professionals the hospital.** The hospital has the resources to help families through the fights with insurance companies, schools, employers etc. It is a long, exhausting process, and trying to do it without the professionals who deal with this on a regular basis makes it nearly impossible.

- Isaac, caregiver to son diagnosed at age 2 with Very Early Onset IBD (VEO-IBD) and age 8 with Celiac

5 Action Steps

The Male Caregiver Perspective

- Consider a **mindfulness practice called "Joy Snacking,"** this is a strategy of finding the positive sprinkles in daily life like your coffee being at the perfect temperature, arriving to a doctor's appointment early, not having to wait at the pharmacy to pick up a medicine, your child getting their favorite provider at the lab
    - Prefer listening to information? Check out this 22-minute listen of "Joy Snacking"
    - Prefer reading and visualizations? Check out this read about "Joy Snacking"
    - **Pro tip:** Write down your "joy snacks" each day to make this list of positive sprinkles feel more tangible
- **Gently remind yourself that taking care of yourself is essential to be able to care for your child – you can't pour from an empty cup!**
- Remember that life isn't a solo sport and neither is caring for your child with health needs. **Reach out to your personal team** (e.g., a significant other, a parent, a close friend, a neighbor) and ask for what you need, like being able to vent or asking someone to spend time with your child so you can do something just for yourself
- Review resources from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent
- Review the "Taking Care of Yourself" resource from the Caregiver Wellbeing Special Interest Group
    - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies
- Review the "Self Care: A Parent's Guide to Taking Care of Yourself (as well as Your Child)" resource from the Courageous Parent Network
- Watch this 36-minute video on Taking Care of Yourself When Your Child has a Chronic Condition from the Parent and Caregiver Voices Project
- For a Dad-focused resource, check out this 39-minute video from the Parent and Caregiver Voices Project

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Notes, Questions, To-Dos

The Male Caregiver Perspective

6

Navigating Health Conditions and Siblings

Viewpoints

Navigating Health Conditions and Siblings

From a Caregiver

As a caregiver of two daughters with chronic illnesses, my journey has been a delicate balance of love, strength, and perseverance. Navigating the complexities of my daughters' multiple health conditions is no easy task. From managing medications and doctor's appointments to providing emotional support and ensuring a healthy lifestyle, something always demands my attention. I've become a master at juggling schedules, researching treatments, and advocating for the best possible care. It can sometimes be overwhelming, witnessing the pain and discomfort my daughters endure. I've learned to be their rock, offering comfort and reassurance during moments of uncertainty. I'm constantly adapting to their needs, learning about their conditions, and finding ways to improve their quality of life. **But amidst the chaos, there is also immense joy and gratitude. Seeing their strength and determination in the face of adversity inspires me daily. We celebrate small victories and cherish moments of respite from the relentless nature of chronic illness.** Self-care is crucial for me to maintain the stamina needed to provide my daughters' care. I've learned to prioritize my well-being, seeking support from friends, family, and support groups. Taking breaks, getting a good night's sleep, engaging in hobbies, and practicing mindfulness help me stay grounded and rejuvenated. Though the path is challenging, I find solace in knowing that my presence makes a difference. Being there for my daughters, offering them unwavering love and support, and helping them navigate their health journey is a privilege. Together, we navigate the highs and lows, finding strength in our unbreakable bond and the hope for a brighter, healthier future.

- Maria, caregiver

6 Action Steps

Navigating Health Conditions and Siblings

- Review the resource of Mindful Parenting through the Caregiver Wellbeing Special Interest Group
- Read a children's book specifically written for siblings of children with health needs titled "Hi, My Name is Jack" by Christina Beall-Sullivan
- Check out the various articles and videos on sibling coping from Courageous Parents Network
- **Provide explanations that are age-appropriate** if/as needed. Be honest and clear in your language; you may need to review with siblings as they get older and/or as chronic health needs evolve. It can also be helpful to stick to answering the questions your child has and following their lead, while encouraging them to always ask you if/when they have questions!
- Create space to **debrief with siblings** about what they are going through. Talk about what it felt like, as a sibling, to watch an infusion or visit their sibling in the hospital and then validate their experiences (e.g., *"That makes sense that you found that scary to watch your sister cry when she got her labs, it makes me feel sad too."*). When more than one child has a chronic illness, a sibling's experiences may increase worry or concern for another sibling with their own medical need.
- **Model coping** for siblings and problem-solve what works for them when medical experiences come up (e.g., *"It sounds like you get frustrated when we can't all eat at your favorite restaurant because your brother is on a very special dietary therapy for his IBD. It's okay to find things frustrating, I find things frustrating sometimes too! When I feel frustrated, I take a few moments to feel my feelings and share with someone I trust like a good friend, then I take a really deep breath and remind myself that it's normal to feel frustrated sometimes. What do you think we could try when you feel frustrated about not being able to go as a family to your favorite restaurant? Are there any creative solutions like if you and I had a special lunch at the restaurant?"*)
- **Maintain routines and house rules** as much as possible. This may mean consistency with bed times, chores, or continuing to use time-outs or groundings if your family uses these strategies. Sometimes there is the instinct to be more flexible with siblings, like a later bedtime or not giving a time-out, but the research shows that consistency helps children to know what to expect and may help siblings feel less stressed.
- If/when comfortable or appropriate to your family, **consider finding a helping role for other siblings in medical care**. This may mean an older sibling holding a hand while your child with IBD and/or AILD gets their home injection or a younger sibling helping to pack toys and activities for your child's infusion clinic appointment.

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6a

The Impact of a Chronic Illness on Siblings and the Family Unit

Having a chronic illness, such as Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), can impact the whole family system that loves that child, including siblings and others in the family like grandparents. This can also present challenges of knowing what, when, and how to share information with others in your family system. There is no one right answer and this can change over time depending on your child's needs.

6a Viewpoints

The Impact of a Chronic Illness on Siblings and the Family Unit

From a Caregiver

A diagnosis of IBD or related condition does not just impact the child who is living with the disease; its impact is felt by parents, siblings, grandparents, extended family members, and friends. As each of us is unique, so is the coping style and personality of each member of the family unit. There is no right or wrong way to cope and we must remember to respect each others' coping styles as they WILL look different for each individual. When our daughter was in her first flare and fed exclusively through a naso-gastric (NG) tube for 3 months, her sister and brother helped mix the formula, set up the pump, and helped her make frozen formula pops (in different shaped molds that they helped pick out). Including them and giving them a role in her care took the mystery and a little bit of the worry out of the experience and brought them closer together. Additionally, our tech-savvy son got very good at trouble-shooting the pump which ran the continuous feeds. That empowered him and also saved my husband and I a lot of stress and phone calls to the company!

- Erin, caregiver

From a Psychosocial Clinician

It is true that a child's chronic medical condition can add additional stress, worry, financial concerns, disruptions to family routines, and extra demands on caregivers. It is also true that families who have a child with IBD can be quite resilient, close, and thriving.a It is normal for family members to cope with the stresses and challenges of a child's IBD experience in different ways. **Finding ways to unite as a family, communicate openly about thoughts and emotions, and accept support from others outside the family (e.g., community, faith networks, family friends, medical system, behavioral health specialists) can be key for helping families to flourish.**

Here are some tips and tricks related to the siblings and extended family of children and teens with chronic illness.

(...continued on next page)

6a Viewpoints

The Impact of a Chronic Illness on Siblings and the Family Unit

Siblings: The longest-lasting (and sometimes closest) relationship in a family with multiple children is the sibling relationship. **Siblings of a chronically ill child are just as impacted by the diagnosis and should not be overlooked.** It is important to include them in conversations/provide developmentally appropriate explanation, as well as health care experiences (when appropriate), from the very beginning. Feelings of being left out, jealousy, resentment, and an increase of attention-getting behaviors are common responses from siblings. Including them in clinic/hospital visits, procedures at home, and creating a safe space where they can openly ask questions or express feelings will help with their coping and further the sibling bond. Navigating imbalances in caregivers' attention can be a primary challenge for many siblings. For children in elementary school and older, it can be helpful to acknowledge that while their sibling with IBD may require more attention or time, all children in the family are loved equally. Families may also consider ways to recognize siblings without IBD, such as taking a few minutes 1:1 to engage in a favorite activity, going on a special outing with each child, or taking time to attend games, recitals, and other special events. As the sister of a child with a chronic medical condition, my parents expressed their appreciation for me as a big sister with a special treat or privilege on his birthday when I was a child. While children may experience challenges in growing up with a sibling who has IBD, there can also be many strengths that arise from their experiences too. For example, siblings of a child with a chronic medical condition may possess a strong compassion for others, patience, and desire to help others in need.

(...continued on next page)

6a Viewpoints

The Impact of a Chronic Illness on Siblings and the Family Unit

Extended family: Extended family members, such as grandparents, aunts and uncles, cousins, and so on, can be an integral part of your family's support network. Still, many caregivers share how challenging it can be to manage unsolicited advice or suggestions (e.g., "*Your child shouldn't take such strong medication for this long - you should try this dietary supplement I read about*" "*She'll be fine if we get popcorn at the movies just this once*") from well-intentioned family members. **While setting boundaries with extended family members may feel uncomfortable at times, it can help caregivers manage stress around caring for their child and making choices about what they feel is best.** This can be done in a kind way that recognizes the family member's concern (e.g., "*I appreciate how much you care about him, but we're working closely with his doctors to find a plan that helps him feel his best.*" "*I know you feel bad about saying no to her favorite snack, but she has to choose another snack that won't make her sick.*"). Further, caregivers can practice ways to ask for the help they truly need, whether a listening ear for support, practical help (e.g., watching over siblings, running an errand), or problem-solving around a specific issue. This can help family members to better understand how they can best support your child and family.

- Dr. Holbein, clinical psychologist

6a Action Steps

The Impact of a Chronic Illness on Siblings and the Family Unit

- Check out tips and tricks from Dr. Holbein above!
- Review the resource of Mindful Parenting through the Caregiver Wellbeing Special Interest Group
- With family members, **reflect on what you feel comfortable sharing** and what you may not feel comfortable sharing to have a sense of your boundaries before engaging in a discussion with another family member.
- **Practice saying no** in a way that feels comfortable to you, this can be helpful if a family member gives well-intentioned and unsolicited advice to have a well-rehearsed phrase to use like, "*Thank you for sharing that. We only feel comfortable getting information from our child's doctor and appreciate you respecting that.*"
- Read a children's book specifically written for siblings of children with health needs titled "Hi, My Name is Jack" by Christina Beall-Sullivan
- Check out the various articles and videos on sibling coping from Courageous Parents Network
- **Provide explanations that are age-appropriate** if/as needed. Be honest and clear in your language; you may need to review with siblings as they get older and/or as chronic health needs evolve. It can also be helpful to stick to answering the questions your child has and following their lead, while encouraging them to always ask you if/when they have questions!
- Create space to **debrief with siblings** about what they are going through. Talk about what it felt like, as a sibling, to watch an infusion or visit their sibling in the hospital and then validate their experiences (e.g., "*That makes sense that you found that scary to watch your sister cry when she got her labs, it makes me feel sad too.*"). When more than one child has a chronic illness, a sibling's experiences may increase worry or concern for another sibling with their own medical need.

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6a Action Steps

The Impact of a Chronic Illness on Siblings and the Family Unit

- **Model coping** for siblings and problem-solve what works for them when medical experiences come up (e.g., "It *sounds like you get frustrated when we can't all eat at your favorite restaurant because your brother is on a very special dietary therapy for his IBD. It's okay to find things frustrating, I find things frustrating sometimes too! When I feel frustrated, I take a few moments to feel my feelings and share with someone I trust like a good friend, then I take a really deep breath and remind myself that it's normal to feel frustrated sometimes. What do you think we could try when you feel frustrated about not being able to go as a family to your favorite restaurant? Are there any creative solutions like if you and I had a special lunch at the restaurant?*")
- **Maintain routines and house rules** as much as possible. This may mean consistency with bed times, chores, or continuing to use time-outs or groundings if your family uses these strategies. Sometimes there is the instinct to be more flexible with siblings, like a later bedtime or a sibling not getting a time-out, but the research shows us that consistency helps children to know what to expect and may help siblings feel less stressed.
- If/when comfortable or appropriate to your family, **consider finding a helping role for other siblings in medical care**. This may mean an older sibling holding a hand while your child with IBD and/or AILD gets their home injection or a younger sibling helping to pack toys and activities for your child's infusion clinic appointment.

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6 Notes, Questions, To-Dos

Navigating Health Conditions and Siblings

7

Being a Role Model for Your Child Navigating and Coping with Feelings

Just as adults continue to navigate and cope with big and tough feelings, our children are also learning to navigate and cope with their own big and tough feelings. This is an important developmental skill, and modeling from a trusted adult can help children learn that it is normal to have big feelings and learn to cope with them! We can also support the development of resilience in our children through modeling and support.

7 Viewpoints

Being a Role Model for Your Child Navigating and Coping with Feelings

From a Caregiver

As caregivers, a main purpose of our "job title" is serving as a role model to our children. From the beginning, their eyes are on us (non-verbal cues, facial expressions), their ears are listening, and they are learning from our actions. No pressure, right? When you have a child with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), the stakes get a bit higher as they are listening at doctor's appointments, watching our facial expressions, and just when we think we are having a private phone or in-person conversation out of earshot, their supersonic hearing kicks in.

Here are some important tips to keep in mind, no matter the stage of the IBD and/or AILD journey:

- Speak in language and at the level your child understands; if having a challenging time enlist the help of the psychosocial team in the hospital or clinic (e.g. psychologist, a child life specialist and/or social worker) who are great resources for both you and your child.
- Spend time before/after the appointment writing down your questions/answers AND your feelings. Writing is a great tool for processing your thoughts and feelings.
- There may be times of sadness, frustration, anger (with IBD and/or AILD and with life overall). Don't "protect" your child by "sugar coating" and putting on a brave face; rather, use "I statements" and model for your child that it is ok to not be ok (e.g. *"I feel worried today because you're not feeling well."*). In the long run, modeling open and honest communication will in turn be seen in your child.
- Parents/caregivers need time to decompress with friends/family but be mindful of your potential audience. I've been known to toss on my sneakers, head out for a walk, and call my best friend to vent. By the time I get back home, I feel much better, I'm sure a child was not in earshot, and I have gotten my steps in for the day!

- Erin, caregiver

7 Viewpoints

Being a Role Model for Your Child Navigating and Coping with Feelings

From a Caregiver

Model Resilience: It is entirely normal for us as caregivers to feel sad, helpless, anxious, worried, or overwhelmed. Recognize that we are all human and that resilience does not mean we lose our normal human emotions, especially as caregivers. But resilience will help reduce stress, and better equip us to approach obstacles with a problem-solving mindset. It will help us advocate for our children more effectively. **And importantly, modeling resilience to our children helps them grow into more confident and resilient adults, a skill that will serve them in their IBD and/or AILD journey and in life more generally.**

Here are a few specific ways to build resilience:

- Understanding and internalizing that life inevitably provides challenges for everyone, although these may look different for different people or come at different times. Compassion for others and self-compassion are helpful for building resilience.
- Cultivating a positive outlook, even in the face of adversity, embracing optimism, focusing on the fun and positive aspects of life, practicing gratitude and mindfulness, all help build resilience. It is easy for us as caregivers to dwell on and obsess over the negative. Sometimes, it can help just to refocus on being present in the moment, on small blessings, and building positivity from there. In our journey, we prioritized fun: we built a lot of Lego sets, played board games, dressed dolls, and even went to Disney World. We played tag before appointments. When hospitalized, we did art projects and hugged every stuffed animal in the gift shop to find the cuddliest one. Have as much fun as you can.
- Maintaining healthy habits for yourself is also important. As they say in air travel, put your own mask on first, though I will admit to always having found this advice challenging. It's difficult not to put children ahead of everything. But it will help them to help ourselves. Here is the reminder we all need: eat healthy foods, exercise, sleep, and lean on family or friends for emotional support. And also understand that we all fail at these things sometimes, or we may not have the support we would ideally like. In that case, build your own network from other caregivers experiencing similar struggles.
- If you're struggling to cope with the challenges, don't hesitate to seek support from a mental health professional. Therapy can provide you with additional coping skills, strategies, and emotional support tailored to your specific needs.

- Ildiko, caregiver

7 Viewpoints

Being a Role Model for Your Child Navigating and Coping with Feelings

From a Caregiver and Psychosocial Clinician

I think the best thing I've done to model navigating the IBD journey and coping with feelings has been through the work I have done that has led me to become a member of the ImproveCareNow (ICN) Parent/Family Advisory Council (PFAC) and found The Gutsy Network. My son has seen that we raise money and gather toys for other children who may not be able to have a special toy or surprise at each infusion. He sees that I connect with other parents and families through the work I have done with the CHOP Walk for Hope, ICN, and Gutsy Network VEO-IBD Support Calls. He has listened to and heard me attend, even at times he didn't really know what was going on, IBD Education Days. He has also taken part in raising money for IBD walks and has attended some virtual support groups for kids, after seeing that I attend support groups for parents. He now is interested in educating others and raising awareness about VEO-IBD. We worked together to create a video of an infusion day for him to share with his classmates in 3rd grade and he later wanted to publicly share the video. That video has over 80,000 views on YouTube and makes him feel so proud that he has helped other kids learn about infusions. He now wants to create more videos answering people's questions about VEO-IBD to share on YouTube.

- Tori, caregiver

Resiliency is an incredibly important set of skills for a young person with a chronic illness to have, and building these skills can start at home. We may think that resiliency means that our children are always 'coping well' or being tough, but resiliency is arguably the ability to try and keep trying and moving forward with bravery. Resiliency critically includes acknowledging and validating our emotions – resilient people still experience big emotions like sadness and fear. Caregivers have many opportunities to give direct praise to the input and not only the output, such as, *"I'm so proud of you for continuing to try,"* or *"Great job asking for help, we all need help sometimes!"* This is also an important thing to model and look for role models in your child's favorite books or shows. Can you find characters or people who are resilient? What makes these people resilient? When comfortable, modeling resiliency is a great way to narrate aloud for a child how you are resilient, such as, *"Phew that was harder than I was expecting, I'm going to take a deep breath and then try to do that again."* **Resiliency is a muscle, we have to keep using it to strengthen it!**

- Dr. David, clinical psychologist

7 Action Steps

Being a Role Model for Your Child Navigating and Coping with Feelings

- **Remind yourself that it's important to be patient and give yourself grace** in modeling coping for your child – life isn't perfect and we will not always model the 'perfect' way to cope and this is okay! This is a great opportunity to model self-compassion to your child like, *"Goodness, I am reflecting on how I got upset and yelled yesterday when we were running late for your infusion clinic appointment. I am sorry I yelled, I was upset and I wish I had chosen a healthier coping skill. Next time I'm going to try to give us all an extra reminder before we need to get ready and will work on taking deep breaths if I feel upset in the moment."*
- **Notice, validate, and create space for all feelings.** Two things that seem like opposites can be true at the same time, like an intelligent person feeling confused or a brave child feeling scared. Share these observations aloud when comfortable and appropriate for your child.
- **Give labeled praise to your child when they share how they feel.** Saying something like, *"That was so brave of you to share how you feel when we go to see your doctor, it sounds like it makes you nervous."*
- When your child shares a big feeling or a worry, **ask them if they want to be heard, hugged, or helped.** This helps you as the caregiver support your child in the way they want to be supported in that moment.
- **Talk about resilient people in your child's world**, like a family member, a friend, a favorite character in a book, and spend time talking about what makes these people resilient.
- If you are interested in connecting with other parents/caregivers of children with IBD and/or AILD to learn from their experiences and find support, consider joining:
  - ImproveCareNow's Patient/Family Advisory Council (IBD)
  - Autoimmune Liver Disease Network's A-LiNK Connections (AILD)

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Notes, Questions, To-Dos

Being a Role Model for Your Child Navigating and Coping with Feelings

8

Supporting Your Child

8a Talking About Emotions and Coping with Your Child

Learning about feelings is an important part of childhood and getting older. It can also be hard to find the right words for our feelings as adults, let alone for children who feel big feelings but may not know how to label their feelings. There is much that we can do in teaching children about emotions and supporting the development of this skill!

8a Viewpoints

Talking About Emotions and Coping with Your Child (Supporting Your Child)

From a Caregiver

Talking about emotions with your child will differ depending on their age. Our son was a teenager when diagnosed. He and I were very close, and he thankfully talked openly with my husband and I about what he was experiencing. I learned very quickly that this disease was HIS disease, it was his body, and his life/journey that he would have to learn to navigate and make decisions. Talking about emotions changed as he got older, graduated from high school, and entered adulthood. After he would experience something traumatic, it was also more difficult to navigate discussing emotions. **I had to learn to gently push and listen at the same time, to know when to give him space and to accept when there was not going to be any talking about his emotions.** Yes, this was hard, but he is now 24 and we continually learned along the way. He knows, even in young adulthood, that we are always here to support his emotions.

- Heidi, caregiver

From a Psychosocial Clinician

We all have feelings and learning how to identify, label, and share our feelings is a learning process for people of all ages. Talking about feelings is such a powerful way to teach children and adolescents that feelings are normal, even the big feelings! When possible and comfortable, a caregiver sharing their own feelings can be very helpful modeling, like, "*I am feeling so happy that it is sunny outside!*" There are many ways to teach identifying emotions, from trying to identify the emotions in the characters on TV to picking emojis that describe how your child is feeling, this is a developmental skill that takes time and practice for us all! It is okay and helpful to show your child a range of emotions, such as modeling feeling sad and the coping skills you use (e.g., "*I am feeling sad right now, I'm going to take some deep breaths because that helps me feel better.*"). **There are no 'bad feelings,' some feelings are certainly heavier or more uncomfortable, all feelings tell us about ourselves and the world around us and it's important to listen to our feelings!**

- Dr. David, clinical psychologist

8a Viewpoints

Talking About Emotions and Coping with Your Child (Supporting Your Child)

From a Caregiver

Teaching a very young child to relax during a scary medical visit, that may or may not result in a needle poke presents its own set of unique challenges. Our son was diagnosed at age 2. He was amazing at his first blood draw, as most kids are, when they don't know that it will hurt. Any blood draw, procedure, or eventually drive into the hospital parking garage resulted in severe anxiety. In these situations, the child is having a lot of emotions, the parent often is as well. **We all know little kids can throw tantrums; parenting a child having a tantrum is a part of life, but parenting a child having a tantrum because of something that is necessary for health and will also hurt them is NOT easy.** Guilt, your own anxiety, and the physical and emotional stress of carrying a fighting toddler into a lab or having to hold them while an IV is being placed is exhausting. If you can have someone go along with you, that will make things easier for you, and in turn, your child. While it may not seem evident at the time, talking about the way you are keeping yourself calm, can assist your child learn some of those same relaxation techniques in a very relevant setting. Practicing breathing at home and learning the best ways to distract your child, at that stage in their development, can be very beneficial. We have gone through a range of distraction techniques, pretend and more realistic medical play at home, pictorial checklists at infusions, and breathing and muscle tensing and relaxation techniques. These lab draw/procedure/appointment days will be challenging, but coaching your child through some relaxation and techniques while you are also modeling them will be very beneficial. And, after the medical event is over, try to do something fun and special with your child to connect and reward yourselves for using the coping skills during the event.

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8a Viewpoints

Talking About Emotions and Coping with Your Child (Supporting Your Child)

From a Caregiver

I was very tightly wound during those first years after diagnosis. Infusion days with a 3-year-old were and still are, with a 9-year-old, emotionally exhausting. How I cared for myself leading up to, on infusion day, and after, included routines and making sure I was free of other obligations, to the best of my ability. I'd make sure we had fun books, activities, and music ready for the car ride and my son's chosen special construction truck or Paw Patrol shows available on the iPad for during the infusion. This led me to be less stressed going to and during the infusion. Then, after my son went to bed, I either fell asleep right away or took the evening to watch one of my own favorite shows to unwind. **I was able to help support my son's coping skills by reading parenting books about childhood anxiety, talking to my son's doctor about the anxiety leading up to and at infusions, and having a good support and coping system for myself in place.** He was referred to and began meeting with the GI psychologist and we placed him on many counseling center waiting lists in our area to ensure that he will be able to set up a relationship with a local counselor before it may be necessary.

- Tori, caregiver

> I WAS ABLE TO HELP SUPPORT MY SON'S COPING SKILLS BY READING PARENTING BOOKS ABOUT CHILDHOOD ANXIETY, TALKING TO MY SON'S DOCTOR ABOUT THE ANXIETY LEADING UP TO AND AT INFUSIONS, AND HAVING A GOOD SUPPORT AND COPING SYSTEM FOR MYSELF IN PLACE.

8a Viewpoints

Talking About Emotions and Coping with Your Child (Supporting Your Child)

From a Psychosocial Clinician

Your child has likely had pain or other discomforts (e.g., nausea) as well as stress about symptoms, medical tests, and other aspects of their new diagnosis. The good news is there is an easy skill they can learn that will help them with both! Your child may have learned "belly breathing," "deep breathing," or diaphragmatic breathing before (e.g., in band, choir, yoga class). Everyone teaches the skill a bit differently, but the most important part is that your child is taking long, slow deep breaths from their belly. **Even just a few of these breaths slows the heartbeat down a bit. The simplest way to teach it is to take a deep breath in through the nose to a slow count of 3 while the belly expands slightly, then take a long slow deep breath out through the mouth to a count of 4 while the belly goes back to rest.** Younger children can learn to do this with bubbles, pinwheels, or by lying down and trying to make a stuffed animal go up and down on their belly as they breath. Breathing might not dramatically change how they feel at first, but it can help calm the body in the moment. We recommend they take at least a few breaths twice per day because their body gets better at the skill the more they practice it (just like with video games, sports, or any other learned skills).

- Dr. McKillop, clinical psychologist

8a Action Steps

Talking About Emotions and Coping with Your Child (Supporting Your Child)

- **Helping your child notice feelings and how it impacts the body** is an important lesson, like pointing out a character on TV who is sad and how crying can be a clue that the character is feeling sad.
  - The American Psychological Association (APA)'s Magination Press publishes some excellent children's books about all types of emotions and life experiences, including medical conditions.
- When comfortable and appropriate, **modeling how you notice feelings in your own body** can be helpful teaching, like, *"Wow when I feel happy, I notice I feel very energetic and want to dance!"* or *"I think my body is giving me a clue that I feel mad, my shoulders are feeling tense right now."*
  - You can then follow this up with a coping skill to demonstrate the connection between the feeling, physical sensation, and coping, such as, *"I think my body is giving me a clue that I feel mad, my shoulders are feeling tense right now. I'm going to take a deep breath and think of a favorite memory in my mind to calm me down."*
- Labeling emotions with words can be hard depending on the child's age, **using emojis to ask a child how they feel can be a helpful tool**
- If you think your child may benefit from professional support in talking about their feelings, consider using ImproveCareNow's Finding a Mental Health Professional resource
- Consider asking your child's healthcare team if there are any Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) psychosocial resources through the hospital
- Depending on the age of the child, consider watching these brief videos of former Patient Advisory Council members from ImproveCareNow talking about why it's important to talk about their feelings

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8b Seeking Peer Support for Your Child

Living with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) as a child may feel isolating when other peers don't 'get it.' If and when your child is interested in peer support from other children with chronic health needs, it can be very powerful to experience others who 'get it' and others who are also kids first and patients second.

8b Viewpoints

Seeking Peer Support for Your Child (Supporting Your Child)

From Caregivers

Connecting your child with support groups or organizations where they can interact with other children facing similar experiences can be empowering and provide a sense of belonging.

- Brenda, caregiver

Equally as important as sustained clinical remission is prioritizing mental health in the child with IBD. One of the first things we did when our daughter was newly diagnosed at age 9 was to enroll her in Camp Oasis, one of the many programs offered by the Crohn's & Colitis Foundation. We waved goodbye to a quiet, pale and overwhelmed child who was only 6 months into her Crohn's diagnosis. Five days later she returned home a different child, animated and talking about all the new friends she met who were "just like her." She was empowered. Over the years, she continued attending Camp until she aged out, and now is looking forward to going back as a counselor to give back to the program that changed her life. As a family, we rallied around her and formed a team for the Take Steps Walk, a fundraising event for the Crohn's & Colitis Foundation which also brings the IBD Community together. Meeting other children and families who are on a similar journey reduces isolation and instills hope. It's important to share resources like Take Steps, Camp Oasis, the Patient Advisory Council (PAC) within ImproveCareNow (ICN), support groups, etc. with your child. These are the "tools" for their toolbox as they navigate the uncertain world of IBD. A "tool" may work for a while, and then not (and its ok!). Or your child may hear of a resource on their own and explore it (which is ok too!). They need to find what works best for them, sometimes it is trial and error, and nothing should ever be forced. Keep in mind too that what they need in their toolbox will evolve as they move through different stages of development; the same goes for parents/caregivers too!

- Erin, caregiver

8b Viewpoints

Seeking Peer Support for Your Child (Supporting Your Child)

From a Psychosocial Clinician

It is hard to fully put into words how meaningful and – to me – magical it was and continues to be when I meet others with IBD. Well before I was a pediatric IBD psychologist, I lived with IBD since I was 12 years old and even when I had wonderful family and friends, they did not 'get it' and I would feel alone. For me, it took a while until I felt ready and open to meeting others with IBD, for the first couple of years I was not in a space to want this, and I am very glad that my parents respected that and were also encouraging but not forceful about being a part of the IBD community. When I met others with IBD, including the ImproveCareNow's Patient Advisory Council (PAC), it helped me to feel fully seen in my chronic illness experiences and experience such joy in others who finally 'got it.' Now, years later, many of my dearest friends are others living with IBD. I am so, so, so grateful for my gutsy friends and to be a part of the IBD community as a patient and a healthcare professional.

- Dr. David, clinical psychologist

8b Action Steps

Seeking Peer Support for Your Child (Supporting Your Child)

- **Talk (and continue to talk) with your child about if, when, and how they would like peer support from others.** If they are not interested in peer support, that is okay and it is also okay to gently bring it up again in the future as their interest in this may change.
- The Crohn's & Colitis Foundation offers many educational and advocacy events across the country, including walks, races, holiday parties, and educational days, for patients and families to come together. These events can be great "first steps" towards a sense of community and meeting others who know what it's like to live with IBD.
- Consider if the Crohn's & Colitis Foundation's Camp Oasis (a 1-week camp for patients with IBD) would be a good fit
- Consider connecting your child with ImproveCareNow's Patient Advisory Council when they are 14 years and older (IBD)
- Consider connecting your child with the Crohn's & Colitis Foundation's Power of Two program (for children under 18, you as the caregiver can reach out to the Power of Two). If your child is looking for more of a group experience, Crohn's & Colitis Foundation also offers virtual meet-ups for children and teens.
- Consider connecting your child (when 14 and older) with Autoimmune Liver Disease Network's A-LiNK Connections (AILD)
- Consider asking your child's healthcare team if there are peer groups or opportunities through the hospital; this can also include asking if there are other programs or camps in your area for patients with chronic health needs

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8c Checking in with Your Child - When to Push and When Not To Push

Many parts of having a child with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) may feel like a balance, including knowing when to gently push and when to not push. This is a very individual experience for each child and caregiver and may evolve over time.

8c Viewpoints

Checking in with Your Child - Knowing When to Push and When Not to Push

From a Caregiver and a Psychosocial Clinician

As a caregiver, it's essential to strike a delicate balance when supporting children living with chronic illnesses. I check in with my daughters frequently, but I'm mindful not to push too much, or else they will push back. I take the time to listen attentively and create a safe space where they feel comfortable expressing their needs and emotions.

Showing warmth, friendliness, empathy, and understanding that each child's experience is unique is essential. **I constantly remind myself to be sensitive to my daughters' boundaries, offer gentle encouragement, and support them while respecting their independence and autonomy.**

- Maria, caregiver

Just as Maria eloquently shares in her perspectives above, **continuing to be open and available to talk is an important signal to your child that you are there whenever they need or want to talk.** It is okay to check in and share gentle reminders, like, *"That was a difficult medical visit and I imagine you may have some different thoughts and feelings about it, I'm always here to talk when you want to talk."* This is a great opportunity to normalize an emotional response when your caregiver spidey-sense is telling you that your child is having big feelings or worrying about something related to their health, like, *"Gosh that was a tough infusion clinic visit. It would make total sense if you were feeling a bit overwhelmed and upset after that."* Lastly, asking permission seeking questions (e.g., *"Is it okay if I ask about how you felt during your appointment?"*) is another great way to demonstrate that you are there and want to talk while still checking in with your child's comfort and openness to talk. **If you have ongoing questions or worries that your child is having a lot of thoughts and feelings, please talk more with their healthcare team about behavioral health supports.** An appointment with a GI psychologist at your clinic, and outside therapist, or even a trusted coach, teacher, or school counselor may be another way for your child to talk with a trusted adult in a confidential space. Our brains are a part of our body, psychology care is healthcare and matters so much for our young people with chronic conditions.

- Dr. David, clinical psychologist

8c Action Steps

Checking in with Your Child - Knowing When to Push and When Not to Push

- **Periodically check in with your child about how they're feeling about their health** (or life in general). As much as possible, try to do a check in when you are not rushed for time and are in a space that is private and quiet so you could talk more with the child if needed. If your child does not want to share in the moment, allow them their space and provide a gentle reminder that they can come to you at any time if they decide they want to talk.
- **Gently reflect aloud** on past lessons learned, like, *"I remember the last time you had some belly pain in the morning and that your diaphragmatic breathing helped and then you had a great day at school. I think we should try that again today!"*
- **Pay attention to subtle cues** that your child may not be feeling their best or having a big feeling, like your child being more quiet than usual or grumpier than usual. This could be an important point of reflection such as, *"I'm noticing you are seeming quiet and I know you tend to be quieter when you are not feeling well. What do you think about us talking with your coach about doing a lighter practice tonight since you may not be feeling well?"*
- Try using **permission-seeking questions**, like, *"Can I ask about how you felt after that doctor's visit?"*
- If you think your child may benefit from professional support, consider using ImproveCareNow's Finding a Mental Health Professional resource

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8d Supporting a Healthy Body Image and Food Relationship

All children and people have a body image and a relationship with food. Living with a gastrointestinal (GI) condition like Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) can impact a child's body image and relationship with food. There is much that can be done to support a resilient body image and a positive relationship with food!

8d Viewpoints

Supporting a Healthy Body Image and Food Relationship

From Caregivers

There are many dietary therapies and depending on the type of disease or treatment your child's body has, there may be foods that could be 'off limits' for a period of time (stricturing disease where high residue foods like nuts may be restricted, an ostomy bag and the need to support hydration, tube feedings, and so forth). **Just as pharmaceutical and surgical interventions have their own social, medical, and financial features to consider, so does food as it is often a central part of our lives and celebrations.** When considering any of these dietary treatments, make sure you have a full conversation with your child (in a way that is appropriate to their age and development), child's medical provider, dietitian, and social worker or psychologist about the benefits, costs, and challenges of dietary therapies or modifications. This is an important place to talk more about supporting a healthy body image and relationship with food if/when a dietary therapy is a treatment your family is considering.

- Tori, caregiver

Dietary therapy, in our case the Specific Carbohydrate Diet (SCD), has been a very important part of our post-diagnosis journey. When it comes to food, planning ahead and always having a healthy snack on hand is important. It is a steep learning curve but gets so much easier over time as you adapt to simply preparing nutrient-dense whole foods. **If children are on dietary therapies or modifications, food can be prepared and sent for class parties, school trips, social gatherings, or sleepovers. This is no different than many children with food allergies or Celiac Disease.** Even restaurants are typically very accommodating about either making dietary modifications or allowing medically required external food. Most importantly, educating children about healthy eating habits and healthy lifestyles more broadly will serve them well not just with IBD but their overall health over their lifetime.

- Ildiko, caregiver

8d

Viewpoints

Supporting a Healthy Body Image and Food Relationship

From a Psychosocial Clinician

Based on research in pediatric IBD, we know young people with IBD can have more complex thoughts and feelings about their bodies than young people who do not have IBD. We all have a body image – this is how we think and feel about our bodies. Supporting a positive body image and a meaningful relationship with food can come in many different forms:

- What kids see us say and do about our own bodies matters – talking kindly about our bodies is a great place to begin, like, *"It's so cool that my arms are strong enough to hug you!"* Critical or negative comments about your own body or food can impact how your child feels about their own body.
- We often use moral language when we talk about foods, like a "good" or "bad" food, or "junk" food. Using all-or-nothing language like this can convey that some foods are 'wrong.' Instead, we can use more neutral and factual words, like processed foods, foods higher in salt, and so forth. Try to avoid using moral/all-or-nothing words when talking about food.
- Model and teach critical media literacy. We are all exposed to many, many messages about the ways our bodies 'should' look in TV shows, movies, and music, and this perpetuates conventional beauty standards that can be very harmful to young people. Modeling and teaching your child about media literacy – like a social media post that is sponsored by a diet company – is an important muscle for them to strengthen to know which body and food messages to ignore.
- If your young person has access to social media, have open and ongoing discussions about what they are seeing and how it makes them feel about their bodies. Empower them to mute or unfollow any accounts that increase body image dissatisfaction. Help them to curate a social media feed that has body diversity so they can see lots of amazing people of all body types.
- Support your child in thinking about their body's functioning – what can their body do? Like running, playing, reading, learning, their body is an incredible thing! Reducing the focus on how the body looks and emphasizing what the body does is a great way to connect your child to their body. **Remember, a positive body image is knowing your body is *good*, regardless of how it looks!**

- Dr. David, clinical psychologist

8d

Action Steps

Supporting a Healthy Body Image and Food Relationship

- Check out the tips and tricks above from Dr. David!
- Check out the Body Image Toolkit from ImproveCareNow
- The foods and/or dietary therapy (as recommended by your child's team) that work for one child may not work for another, **this is very individual**. It is important to use reputable resources like the Crohn's & Colitis Foundation's Diet and Nutrition page, dietary resources through ImproveCareNow, and Nutritional Therapy for IBD. If you have questions about your child's food intake or if dietary therapy is appropriate for your child, please talk with your child's healthcare team.
- If you notice your child is having a difficult experience with their body image or relationship with food, please **consider sharing with their healthcare team**. If you think your child may benefit from professional support, consider using ImproveCareNow's Finding a Mental Health Professional resource.
- If your child has body image concerns or disordered eating, please consider asking for a **blinded weight** at the doctor's office so that your child's growth can be measured without extra stress (a blinded weight is when a child steps up on the scale backwards so they cannot see the number)

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8e Advocating for Your Child In and Out of the Medical Setting

Finding the right balance between advocating for your child's needs, encouraging your child to advocate for their own needs (depending on your child's age), and maintaining positive relationships with healthcare professionals can be a moving target. Before a doctor's appointment or any critical discussion, write down the most important topics you want to address. Time is often limited during appointments, so being organized can help you make the most of it. Be factual about what you observe in your child, including symptoms, mood, eating habits, and so forth. Discussing topics that may feel difficult, like mental health, changes in medications, or complementary approaches you may be using are also fair game to discuss. Mutual trust between you and your care team is essential for shared decision-making and teamwork in your child's care. Don't hesitate to ask as many questions as you have, and if there isn't time to discuss all of your questions in one visit, write them down and send through the patient portal (if appropriate). Remember that your questions are rooted in a deep concern for your child's well-being. Lastly, know that you are not alone in advocating for your child. Many parents, caregivers, and individuals in medical settings would do the same for their child. Be confident in your role as your child's advocate and remember that you are not alone on this journey. Advocating for your child in medical settings is a skill that can be developed over time which is a testament to your love and dedication to your child's well-being. By recognizing the challenges, approaching discussions with respect and trust, and being proactive in your child's care, you can be a powerful and important member of your child's team.

8e Viewpoints

Advocating for Your Child In and Out of the Medical Setting

From Caregivers

Being a caregiver is a profound and sometimes daunting responsibility. It involves navigating a new diagnosis, mastering a new medical language, and facing significant life changes while advocating ardently for your child's well-being. However, many caregivers, out of politeness or a fear of coming across as confrontational, find themselves hesitant to advocate as strongly as they may wish. And if we are honest, some caregivers may sometimes come across as unreasonably rude or angry, probably out of an understandable feeling of helplessness and worry. **Seek out a healthcare team that you respect and trust and then have open and honest dialogue. Prepare for appointments, ask questions, express worries or concerns politely, and remember that shared decision-making comes from you knowing your child best combined with your care team's more objective expert advice.** We switched providers shortly after diagnosis to a wonderful gastroenterologist (GI) who is evidence-based but supports our use of dietary therapy and has always been open to working with us on selecting medications and dosing for our child. What I appreciate the most in our interactions is the mutual respect and open dialogue.

- Ildiko, caregiver

My best advice when advocating for your child with the medical team is to trust your gut. As parents/caregivers, we are the experts on our children. I took a collaborative approach from the beginning; I need my daughter's care team as the experts in IBD as much as they need me, her mom (and family) to build a holistic, long-term relationship built on trust. But when something felt off, I listened to my gut. There is a balance that is not always easy to strike when speaking up for your children when they cannot; I lead with professionalism, mutual respect, use "I statements", and prepare myself in advance of appointments/meetings by doing my homework. I have used the phrase "agree to disagree" at times when I'm not feeling heard.

- Erin, caregiver

8e Viewpoints

Advocating for Your Child In and Out of the Medical Setting

From a Caregiver

In the first year after diagnosis my anxiety increased around my son's eating and bathroom habits. It also felt like an uphill battle when trying to explain VEO-IBD and what it meant to non-GI doctors, school and camp staff, and babysitters. I felt ashamed that I even panicked about how much or little my child ate each meal, how much or little my child went to the bathroom that day. I worried each time (however seldom they were) that I had to send a message to my son's GI to ask if XYZ was "*normal or to be expected.*" The biggest thing I felt ashamed about was a time when my son was sick with a high fever, and we weren't sure if it was a reaction to his recent infusion. I took my son to an urgent care center and was told something along the lines of "*a child with a high fever wouldn't act as alert as he was and would be lethargic and non-responsive.*" I heard the doctor go to the nurse's station, call my son's GI, and say that my son was fine and had no fever and we were sent home. A few hours later we ended up in the ER, where they actually took his temperature appropriately, and had to give him an IV. I felt ashamed that I didn't advocate more for my child at the urgent care center and felt guilty that I had to take him to get another needle poke and spend the night in the ER. I ran into challenges regarding others understanding how important hydration and food are in making sure an IBD kid is staying healthy when my son began school, attending summer day camp, and even just when spending time with family. I've had to explain that my son is young and has to be reminded to drink and eat, especially if he is enjoying the activity and doesn't want to take a break, even if he says, "*I'm not hungry.*" **I've found that I have continually had to reframe my "*nagging and overbearing*" tendencies, as they have been called, as advocating for my child's health and safety; something no person should be upset with a parent for doing.**

- Tori, caregiver

8e

Viewpoints

Advocating for Your Child In and Out of the Medical Setting

From a Psychosocial Clinician

Doctor-patient/family relationships inherently have power differentials, such that the medical provider is the “expert” who gives the medical plan while the patient and/or family are expected to follow the plan. This power difference can make it harder to speak up with questions or concerns, and many caregivers may experience self-doubt or worries that they will anger or disappoint their child’s medical team. **Remember that as the caregiver of your child, you are an expert about your child!** Medical providers have a responsibility to address family’s questions and concerns, and most actually appreciate opportunities to collaborate with caregivers and patients when making decisions about treatments and problem-solving when issues arise. Consider speaking with your child’s GI team about the best avenues for communicating with them (sending a message through an online portal, calling their office, and so on).

- Dr. Holbein, clinical psychologist

8e Action Steps

Advocating for Your Child In and Out of the Medical Setting

- Check out the tips and tricks from Dr. Holbein above!
- If/when you notice having a different approach than your child's team, consider this resource from Courageous Parents Network
- The healthcare system can feel overwhelming and it can be hard to learn about the different and overlapping roles of healthcare professionals. Consider reading this resource from Courageous Parents Network about navigating the hospital
- When working to advocate for your child in the school setting, review the **Accommodations toolkit** from ImproveCareNow and this Accommodations resource from the Crohn's & Colitis Foundation
- **Keep trying and problem-solving** – after a doctor's visit or a discussion with school, reflect on what went well and what you may want to try differently next time.
- When advocating with people outside of school – like your child's swim coach or school staff – remember that many people may not understand what IBD and/or AILD are. Within your comfort, it can be helpful to **provide background information and share reputable resources** about your child's condition to educate others to help them 'get it' a little bit more!
    - For IBD, consider sharing this resource from the Crohn's & Colitis Foundation for what schools should know about IBD
    - For AILD, consider these other resources and reputable websites about AILD:
        - The A-LiNK Manual (this is an excellent and lengthy resource) under the Tools and Resources section
        - Autoimmune Hepatitis Association
    - PSC Partners Seeking A Cure
- **Keep a record of advocacy conversations**, like emailing a teacher after a face-to-face conversation with a summary of the discussion and action items. This is a helpful way to keep track and to have a paper trail. Keeping records in a secure, cloud-based application can help make your notes easily accessible on the go, like at the doctor's office or during a 504 plan meeting. This can also be helpful to share with any other caregivers in your child's life to make sure that all key caregivers have access to this information.

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8f Teaching Developmentally Appropriate Self-Advocacy Skills

Many caregivers are interested in helping their child to communicate their needs (i.e., self-advocacy skills) to the medical team, teachers, coaches, and friends. However, this process can seem daunting and may bring up many emotions in both caregivers and children/teens, including anxiety and frustration. Sometimes, caregivers may be hesitant to step back from advocating for their child because it can be challenging to give up control, and it may be more efficient at times to complete various tasks without their child involved like refilling a medicine. It is often most effective and manageable to take a slow and steady approach over time. As children and teens learn to better communicate their needs, this process can be very rewarding!

8f Viewpoints

Teaching Developmentally Appropriate Self-Advocacy Skills

From Caregivers

There are so many tools to help teach your child how to take slow ownership of their disease. Start by providing age-appropriate information about their disease to the child, explaining its symptoms, treatments, and how it affects their body. Use visual aids, books, or videos to make it easier for them to understand. Teach the child the importance of taking medications regularly and how to follow their treatment plan as well as other essential self-care skills including proper nutrition, managing stress, and getting enough sleep. As a family, help establish routines to help them become successful in these areas. Help the child understand their symptoms and guide them in recording them. There are apps for medications management, diet therapies, tracking symptoms, etc. Ask for recommendations, try a few out yourself, and help your child find what works best for everyone involved. Sometimes this can be as simple as a notebook or note in your/your child's phone. Keeping a brief record of symptoms that are especially out of the ordinary allows them to communicate effectively with healthcare providers about their condition. Encourage them to ask questions about their medications and involve them in discussions with healthcare professionals. As the child grows older, involve them in making decisions about their treatment plans. This will empower them and develop their decision-making skills. As a caregiver, it may be difficult to release some of this control, but know that eventually your child will be responsible for their ongoing care and this is an important step on the path to being s successful independent advocate. **Children, especially those facing challenging times, are more capable than we sometimes think.** These steps and progress towards being independent with their self-management will vary based on the child's age, developmental level, and individual needs. Consistent encouragement, reassurance, and support are key to helping children be successful.

- Brenda, Heidi & Tori, caregivers

8f Viewpoints

Teaching Developmentally Appropriate Self-Advocacy Skills

From a Caregiver

When my son was presented with the decision to have surgery, we made sure he had access to all the information we were finding. He also was empowered to look for information on his own. He was a teenager, but a younger child can still participate in learning and making choices. First seek out what information your local center has. Use the ImproveCareNow Patient Advisory Council (PAC) and their resources, especially for teens and young adults. Other centers may have resources that are supportive. Trust your child with information, no matter how old they are. This is a wonderful way to slowly teach them to learn and advocate about their disease and body.

- Heidi, caregiver

From a Psychosocial Clinician

There can be so many curveballs in a pediatric chronic illness, like surgery, and it is important to give yourself and your child space to have big feelings. As Heidi expertly shares above, **empowering your child/young person to have as much control as is developmentally-appropriate is a great way to increase their feelings of control.** For example, caregivers can teach young children with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) about the names and reasons for their medications or ask their child to take on a “special job,” like wiping their arm with the alcohol pad before getting an injectable medication. This may also be a forced choice, which means two options where both are okay from your perspective as a caregiver, like, *“Do you want them to take your labs from your right or left arm?”* Ask for any additional supports your child/family needs, like meeting with a psychologist or social worker, taking care of the whole person is especially important during the curveballs!

- Dr. David, clinical psychologist

8f

Viewpoints

Teaching Developmentally Appropriate Self-Advocacy Skills

From a Psychosocial Clinician

A few small steps families can take to develop self-advocacy skills in medical settings over time:

- When writing emails or messages to others in your child's life, have your child or teen join you and provide their input and approve the message. Over time, many teens can begin to write the messages with caregiver input or review.
- Role-playing or rehearsing conversations that your child may have with others in their life about their IBD and/or AILD and related needs can help to increase their confidence in these conversations, and it offers opportunities for caregivers to provider helpful feedback to promote skill-building.
- Praise your child when you notice them speaking up for themselves or taking a step towards independence (e.g., emailing a teacher, asking a question in a doctor's appointment). Praise is a helpful way of reinforcing behaviors you want to see more of, and it's a great way to support the bond between caregivers and children.
- Once your teen is old enough to have access to their medical portal, help them to sign up so they can view lab results, send messages to medical providers, and track appointments. Make sure your teen knows how to log into their portal and find what they need within the site or app.
- The American Academy of Pediatrics recommends that pre-teens or teens have time alone (i.e., 1-on-1 time) with their doctors. To prepare for this goal, start by having your teen prepare some notes (e.g., what questions they have for their doctor, concerns they want to share) before their appointments. If your teen's doctor tends to direct many questions to you, redirect to your teen for their response so they can practice sharing with their doctor.
- Families can have balanced expectations for independence. While youth with IBD and/or AILD learn to be more independent over time, it is still OK – and often appreciated – for caregivers to continue to support their children's medical needs and other aspects of life (education, work, adulthood milestones). As your child enters young adulthood, have conversations together about what kind of support they need from you.

- Dr. Holbein, clinical psychologist

8f

Action Steps

Teaching Developmentally Appropriate Self-Advocacy Skills

- Check out the tips & tricks from Dr. Holbein & Dr. David above!
- **Slow and steady wins the race**, this may mean asking your child to do a small part of a care task like giving their name at the check-in counter at the hospital. Just like any other skill, starting small can lead to building on more and more with time and practice.
- Consider watching this one hour webinar from the Crohn's & Colitis Foundation on transitioning with IBD and strategies for teenagers and young adults
- Consider a **gradual approach of suppor**t, similar to how you likely helped your child to learn how to bike with gradual fading away of your support. This may mean deciding with your child that they will first answer the questions the doctor asks and then you can share any other details that may have been missed. With time, this may be letting your child have part of the visit by themselves as you both get comfortable with their increased independence.
- While it can be very hard to do, **when your child is asked a question about their health, try to wait a few seconds before jumping in with an answer**. The goal is to increase your child's confidence in sharing their thoughts about their health. If you are asked a question directly by the doctor and you know that your child may answer, redirect the question to your child, like, *"Hmm, that's a good question about her pain, Dr. Smith. Let's ask her – Sara, can you tell us more about your belly pain?"*
- Use resources created by members of the ICN Patient Advisory Council
- Consider reviewing The Transfer Toolkit by the Transition Taskforce of ImproveCareNow

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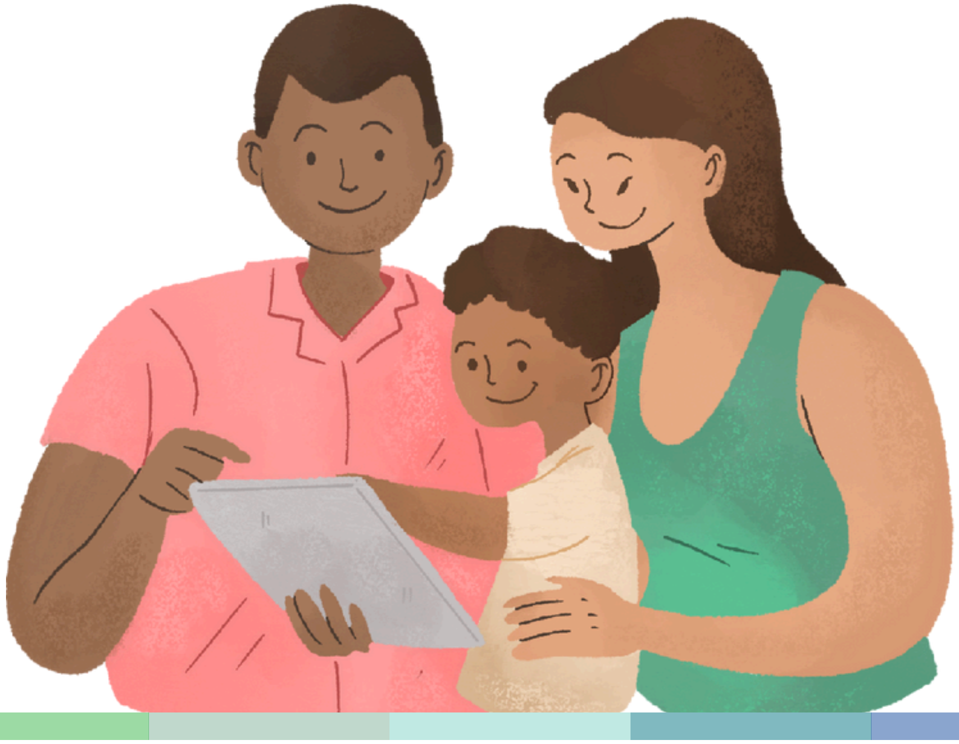
8

Notes, Questions, To-Dos

Supporting Your Child



9

Continuing to Implement Life/Home Expectations and Learning Balance

Life doesn't stop when a child has Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), and other needs like school or your child's chores around the home still need to happen. Having expectations at home is very important for children, especially with unpredictable care needs, and can reduce stress for children and caregivers.

9

Viewpoints

Continuing to Implement Life/Home Expectations and Learning Balance

From a Caregiver

It is only natural to feel torn between wanting to still "parent" our children and "cut them some slack" when they have been diagnosed with a chronic disease. It is important to know doing both is ok. Every family must make the best choice for their child and their own mental well-being. For us, we found that we were not going to stop "parenting" our son after his IBD diagnosis. He was a teen who was still a teen (he vaped, lied, had an attitude etc.). He knew we were still going to discipline and have rules. However, we also knew we had to learn to love him where he was in his journey and it was ok for us to show him grace and let things go from time to time. **Children, no matter the age, infant to young adult, will always need boundaries, rules and structure.** We never wanted the disease to define his life and enable him to not have to deal with consequences. You can ask for advice and suggestions from others, but you must do what works for your family.

- Heidi, caregiver

From a Psychosocial Clinician

Overall, balancing warmth and structure (e.g., setting expectations for behavior, limit-setting, discipline) can feel like walking a tight-rope, especially when caregivers are navigating their own challenging emotions about their child's health. Behavioral health providers typically encourage having similar household rules and expectations for both children with IBD and their siblings who do not have a chronic medical condition. **While living with the unpredictability of IBD, children often appreciate the stability of predictable rules, chores, and expectations (even if they may say otherwise at times!).** For the larger family, this can also "level the playing field" between siblings who may take notice when they perceive that their sibling with IBD gets "special treatment." Of course, families can be flexible and make changes as needed. For example, a teen in the middle of an IBD flare may not feel well enough to help with more physical tasks (e.g., yard work, taking out the garbage) like they typically do, but perhaps they can help the family in another way (e.g., setting the table, feeding a pet) until they feel better.

- Dr. Holbein, clinical psychologist

9 Action Steps

Continuing to Implement Life/Home Expectations and Learning Balance

- See above for Dr. Holbein's strategies!
- **Maintaining routines and schedules** as much as possible can be helpful, with exceptions as needed. For example, if your child usually gets a story read to them before bed, this can still happen during an inpatient admission.
- **Maintain routines and house rules** as much as possible. This may mean consistency with bed times, chores, or continuing to use time-outs or groundings if your family uses these strategies. Sometimes there is the instinct to be more flexible with siblings, like a later bedtime or a sibling not getting a time-out, but the research shows us that consistency helps children to know what to expect and may help siblings feel less stressed.

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9

Notes, Questions, To-Dos

Continuing to Implement Life/Home Expectations and Learning Balance

10 Special Considerations

There can be unique circumstances in Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), like Very Early-Onset IBD (VEO-IBD), surgery, and co-morbid (co-occurring) diagnoses. Below are some perspectives from caregivers and psychosocial clinicians about these scenarios to provide support to other caregivers who are or may experience similar care circumstances.

10a Very Early-Onset IBD (VEO-IBD)

10a Viewpoints

Very Early-Onset IBD (VEO-IBD)

From a Caregiver

It's hard to support a very young child who has undergone lot of medical procedures before they are even old enough to start school. Being direct and using simple language is often the best. For example, whenever our son was sick with a cold, we would explain that germs are "buggies" and started the germ conversations from a young age. Since we had already used the "buggies" for germs term or the phrase "caught a bug" for an illness, my husband wonderfully explained that buggies are in his belly that make it hurt and the medicine is able to chase the buggies away, but it can only keep them away for so long and for this reason, medicine needs to keep being given (initially as pills sprinkled on a teaspoon of yogurt or apple sauce, and later via infusions and daily medications). As my son grew and matured, we began talking more about his diagnosis and calling it IBD. We asked if he had any questions and would answer his questions the best we could. We also began writing down some of his questions so he would be able to later ask his doctor at an appointment, so he would begin to learn about advocating for himself in medical appointments. For infusions and other medical appointments involving pokes, we developed a routine where we had a checklist that helped him take control of the things he could in the situation. For example:

- Calendar and lead up to infusions
- Routine for the day of infusion (take train or drive and listen or watch something)
- Get set up in the infusion room
- Visual Checklist for the process from arriving to IV placement. He would check off the steps and count down for the nurses to insert the IV.
- I'd always try to take something new, like a new book, toy, or Mighty Machines videos to help distract him. We always had a special new toy (little paw patrol figures, later small Lego sets, and even later 30 minutes of a show or kid video game) that our son would earn from having his infusion. Sometimes if worked best to use this as the IV was being placed, later it worked better to have this "earned" by holding still during IV placement. We always made sure to discuss these key points - he is safe and loved and we would not have anything done that would not help him.
- It is okay to be upset and cry and not like the poke because it hurts, but he still may not yank his arm or try to hit/kick to stop the nurses (and this has been more of a school age discussion).

(continued on next page)

10a Viewpoints

Very Early-Onset IBD (VEO-IBD)

When your first, or only child, is diagnosed with VEO-IBD it can also be hard to know what to attribute to IBD and what to attribute to the ages and stages of toddlerhood and childhood. I found it was best to keep an eye on eating, stools, and pain for a few days to a week and then email my child's doctor if the concerns had not been resolved. As in all parenting, I tried my best to not compare my child's eating, growth, height, weight, physical ability to other peers his own age. It took time, but we are now much more comfortable recognizing that food intake can vary from day to day; growth patterns are to be viewed over a span of time and compared to his previous growth curve; and that there is A LOT going on in his body, his physical abilities will continue to evolve as he grows and his health stabilizes.

- Tori, caregiver

From a Psychosocial Clinician

Caregivers of children with VEO-IBD (onset of IBD symptoms before age 6 years) may feel particularly isolated while navigating their child's IBD journey. Many GI clinics have only a small number of young children diagnosed with IBD, and much of the programming and resources available on a national level are targeted towards school-aged children and teens. Although it may take time for the larger IBD community to create resources specifically for VEO-IBD families, **consider existing ways to seek support, such as joining a VEO-IBD-specific virtual support group or asking your child's GI team if they can connect with you another VEO-IBD family**. Caregivers can also create their own opportunities for connection and awareness through their own social media presence, community advocacy (e.g., creating a toy drive for their child's medical center, creating a team to participate in an IBD awareness walk), and connections. Many parents of young children with IBD share about the distress and pain they feel when they have to see their young child undergo an invasive procedure (colonoscopy, MRE, IV placement, NG tube insertion, etc.) or experience pain or other IBD symptoms, especially when their child may not fully understand IBD and cannot speak up for themselves. These emotions are rooted in love and concern, and they underscore the importance of caregivers identifying supports, coping strategies, and outlets for stress that work for them. It can also be helpful to "zoom out" from the present and recognize that children with VEO-IBD and families can learn new, effective coping strategies and communication skills over time as the child matures

- Dr. McKillop, clinical psychologist

10a Action Steps

Very Early-Onset IBD (VEO-IBD)

- See above for excellent tips and tricks from Tori and Dr. Holbein!
- For families where the patient is receiving or may be receiving infusions, consider watching this excellent 9-minute video with Tori and her brave son sharing his infusion clinic experience to help 'preview' what an infusion visit can look like!
- Highlights from their tips & tricks above:
    - **Support your child's understanding** in a way that is appropriate for their age and continue to re-educate and discuss what IBD is as your child grows and may have more questions
    - **Increase opportunities for control** when possible, like asking your child to pick out bandages for their injection medication or packing favorite activities for infusion days
    - **Balancing giving enough notice with not enough notice** for appointments or tests; depending on the age of your child, giving your child a neutral, calm reminder that they have a doctor's visit the day before and then the day of can be helpful
        - This will likely evolve over time and your child may need more or less of a head's up, this is a trial-and-error process to find the right fit for your child!
    - **Support their coping** with procedures like IV placements, such as by using The Meg Foundation's Poke Plan or asking your healthcare team if there are psychologists or child life specialists who can help your child's procedural coping
    - Learn more about strategies you can use to support your child in **coping with chronic pain and symptoms** at the Comfort Ability website. They also provide online parent and teen chats, and participating hospitals offer a one-day workshop to learn these skills and develop a coping plan.
    - Check out these resources from The Meg Foundation on **supporting pain management** in young children:
        - Babies and toddlers (0-2 years of age)
        - Kids (3-11 years of age)

scan to access all links

10b Surgery for IBD

There are many possible treatments for pediatric Inflammatory Bowel Disease (IBD), and the goal is to identify the right treatment at the right time for the right person. Surgery can be one of these treatment options. It is normal for caregivers and patients to have many big thoughts and feelings when the idea of surgery comes up in care.

10b Viewpoints

Surgery for IBD

From a Caregiver

Our family has experienced surgery multiple times. We never imagined at the time of diagnosis, that our son would need surgery, especially 18 months later. **We quickly realized and learned that surgery did not have to be a negative term, and it is common with an IBD diagnosis for some, both in pediatrics and adults.** Our son has had a total colectomy, an ileal-anal anastomosis (simply called a “J Pouch”), an ileostomy closure surgery and abdominal exploratory surgery.

We learned that surgery could be lifesaving and that our son’s voice was so important in the process. Our son elected to have a colectomy, at the age of 17, when his ulcerative colitis (UC) was too severe for any medication treatment and certain drugs were only available per his age. We learned that he was far more resilient than we gave him credit for, that he knew his own body better than any of us (including his clinical team) and that he had a positive outlook on surgery. How might surgery help your child you may ask? For our son, the answer would be, *“It gave me my life back.”* Those were his words after his total colectomy. For us, as parents, *“it gave us hope that our son would be able to have a meaningful life, just one that looked a little different.”* There are many resources out there for surgical procedures with IBD. It is important to understand the facts. Even though there is risk for complications, it is important to understand that surgery is not always a negative experience, but it can be wonderful & positive. There are many types of IBD surgeries, and it is important to understand them all.

- Heidi, caregiver

10b Viewpoints

Surgery for IBD

From a Psychosocial Clinician

Just as Heidi eloquently describes, considering and undergoing surgery for a young person with IBD can be a complex experience for everyone involved. Modern pediatric IBD care is both a science and an art form, with the persistent pursuit of finding the right tool at the right time for the right patient; I often describe this to families as finding the "right puzzle piece fit" for each patient. **Surgery is an important tool in pediatric IBD care, and also is normal for discussions about surgery to come with big thoughts and big feelings for patients and caregivers alike, including feeling overwhelmed, scared, uncertain, angry, and anxious.** When we feel worried, nervous, or scared about surgery in pediatric IBD, we may notice that we temporarily feel better if we avoid talking about the topic. Avoiding talking about surgery often makes us feel more worried, nervous, and scared in the long run. In other words, talking calmly and thoughtfully about surgery can help to reduce nervousness, worry, and fear and help learn more about what surgery could be like and support engagement in medical decision-making. In addition to the stigma associated with GI conditions like IBD, there can be stigma about surgeries for IBD like ostomies. It is important to discuss with your child and care team. In my clinical work, I often ask lots of normalizing, open-ended questions, like, "*Many young people with IBD worry about surgery, like how surgery may impact school, work, or their favorite activities. What are you worried about?*" and this can be a helpful strategy to have these brave discussions about surgery. I am often surprised about the biggest worries young people with IBD have about surgery. Sometimes young people are less worried about their post-operative recovery and more worried about if they can jump on a trampoline, play/wrestle with their dogs, and sleep on their bellies after they've recovered from surgery. **Amazingly, but not surprisingly, when young people and families have calm, open, and non-judgmental discussions about surgery, this often helps everyone to feel less worried, more educated, and more aware of if/how surgery could be an appropriate "puzzle piece fit" for their children.** Involving psychosocial providers in these surgery-related conversations can be very helpful, including talking about a post-operative plan to support pain management (e.g., bringing comfort items from home, learning diaphragmatic breathing to use after surgery to help with pain along with any prescription pain medication while in the hospital) and coping with changes to a child's body like scars or an ostomy pouch.

- Dr. David, clinical psychologist

10b Action Steps

Surgery for IBD

- Check out some great tools from ImproveCareNow, including the Shared Decision-Making tool for surgery in pediatric IBD and the Ostomy Toolkit
- For children with temporary or long-term ostomies for their IBD who are interested in support, consider the United Ostomy Association of America's Pediatric Ostomy Support Group
- Consider proactively creating a **pain management plan** for your child, especially if you know they may normatively feel nervous about being in the hospital, check out the many awesome resources from The Meg Foundation and ask if your hospital has a psychologist or child life specialist who can also help
- If/when planning surgery, help your child in **packing comfort items** (e.g., books, cozy blankets, a picture of the family) and comfortable clothing and footwear (e.g., easy on/easy off clothing, slippers)
- If/when surgery is mentioned in your child's care, continue to **check in with your child about how they feel**. Even if the discussion with a doctor was about the role that surgery could have in the future, this may bring up many worries for children.
    - If your child's worries are very strong and persistent about the idea of surgery and you think your child may benefit from professional support in talking about their feelings, consider using ImproveCareNow's Finding a Mental Health Professional resource

scan to access all links

10c Special Considerations in Autoimmune Liver Disease (AILD)

For patients with AILD, there are important and unique considerations that these families face and can present many psychosocial experiences for caregivers. It is very important for caregivers of a young person with AILD to feel their feelings and know that they are not alone.

10c Viewpoints

Special Considerations in Autoimmune Liver Disease (AILD)

From Caregivers

Having your child diagnosed with AILD is pretty traumatic. You need to have empathy for your child and not overreact no matter how you feel, as these emotions will probably increase the stress levels in your child. You should read up and educate yourself as much as you can on the disease. Typically, there will be the initial phase where you are addressing the current symptoms, but these are lifelong diseases and don't go away. So, you need to be prepared for the long-term nature of this, and how to best be supportive of your child and the rest of the caregiving team. I was ignorant of the long-term nature of the disease. I thought once my daughter was responding to the medicine and was in chemical remission it was victory. However, I did not fully understand the long-term nature of the disease and how to best support my child. It was only after several years that I started to understand. **I did research on the disease and talked to other parents to get a full view of the disease. It was then that I could best support my daughter.** Many of the symptoms are not outwardly evident. My daughter looked fine, but had issues with energy, digestion, and anxiety (among other things). Once I could fully understand that then I could better support her. You need to research the disease. Knowing the facts will provide you with confidence and understanding to best support your child. Talk to other parents. They have gone through what you are now starting. You will get points of view and recommendations that are very helpful. Educate your child's support network (friends, relatives, siblings) on the disease.

- Kent, caregiver

As a parent facing the reality of my child's rare liver disease and the scary possibility of a transplant, my heart is sometimes heavy with a mixture of fear, anguish, and determination. Some days I have a rollercoaster of emotions, from the intense worry for my child's health to the uncertainty about her future. The thought of my daughter undergoing such a major medical procedure as a liver transplant and the fear of losing her or having her life cut short is a weight that never totally leaves my thoughts. **In this challenging journey, I not only seek medical support including information and knowledge, but also the compassion and understanding of those around me who can truly empathize with the turmoil these diseases can cause.**

- Jane, caregiver

10c Action Steps

Special Considerations in Autoimmune Liver Disease (AILD)

- Check out the Autoimmune Liver Disease Network for Kids (A-LiNK) by visiting their website
- For caregivers who are interested in **finding support from others touched by pediatric AILD** and/or who want to stay up to date on the latest research (including clinical trials), please consider joining A-LiNK Connections by visiting the "How To Get Involved" sign-up section
- Consider looking at these other resources and reputable websites about AILD:
  - The **A-LiNK Manual** (this is an excellent and lengthy resource) under the Tools and Resources section
  - Autoimmune Hepatitis Association
  - PSC Partners Seeking A Cure
- Review resources from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent
  - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *"caregiverwellbeingspp"* for other reputable resources and strategies

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10d Co-Morbid (Co-Occurring) Diagnoses

Managing one chronic health condition can be very hard for caregivers and families, and having more than one health condition can be especially challenging. For some patients and families, this may be two or more medical conditions like Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), and for other families it may be medical conditions and psychological conditions like IBD, AILD, and anxiety. Your child deserves whole person health for all of their care needs, which can present additional advocacy needs for caregivers to help their child get the care they need.

10d Viewpoints

Co-Morbid (Co-Occurring) Diagnoses

From Caregivers

When a child is diagnosed with IBD, they may have already had other diagnoses or will have other diagnoses in the future. As an example, my son already had Attention Deficit Hyperactivity Disorder (ADHD) before his IBD diagnosis. He was then diagnosed with anxiety & depression years after. **It is important that the child is supported for all comorbid diagnoses.** Oftentimes this will go back to mental health and making sure they are supported mentally.

- Heidi, caregiver

Navigating the complex landscape of having a child with not just one, but two chronic diseases - Inflammatory Bowel Disease (IBD) and Primary Sclerosing Cholangitis (PSC) - is an emotional journey that feels like being caught in a terrible storm. The weight of this reality sometimes feels suffocating, as each day brings its own set of uncertainties, medical appointments, and treatments. The constant balancing act between managing their symptoms, medications, and trying to provide a sense of normalcy for my child feels like walking on a tightrope. **In this tumultuous journey, what keeps me going is the strength and resilience I see in my child and the unwavering support of those who understand our struggles.**

- Jane, caregiver

As a caregiver for my child with IBD, PSC, and celiac disease, I find that the journey can be challenging at times. Each condition requires a unique approach, making education and awareness essential for receiving effective care. **By understanding the specifics of each condition, I feel empowered to help my child navigate the complexities of treatment and daily management.** This knowledge enables me and my child to advocate for her needs and fosters collaboration with healthcare professionals and support networks. By becoming an informed advocate, I can ensure comprehensive care is tailored to the circumstances, ultimately improving her quality of life.

- Maria, caregiver

10d Action Steps

Co-Morbid (Co-Occurring) Diagnoses

- Depending on the age of your child, talk with your child and/or other caregivers to **make a list of how co-morbid diagnoses may impact their IBD and/or AILD care**
  - For example, if your child has IBD and anxiety, are there accommodations in the medical setting that help them manage their anxiety?
  - **Share the list with your child's healthcare team** to advocate for certain accommodations in the medical setting to support your child's whole person care
- Consider reminding your child's healthcare team about their co-morbid diagnoses and **ask that these diagnoses are accurately reflected in your child's chart**
  - This is especially important if your child received a diagnosis outside of the healthcare system where your child receives GI care, such as if your child received a depression diagnosis from a therapist in private practice
- When relevant, **ask your child's GI provider to share their notes with your child's other medical providers who support their other diagnoses** (e.g., *"I want to make sure Ahmed's hepatologist sees your note about how his ulcerative colitis treatment is going. Can you please route your note to his hepatologist?"*)

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10 Notes, Questions, To-Dos

Special Considerations

11 Health Equity

While all children and families deserve equitable, compassionate, and timely care, we know from research and lived experience that experiences receiving and seeking care can feel very different depending on who your child is and where your child lives.

11 Viewpoints

Health Equity

From a Caregiver

It is critical for healthcare professionals to have cultural sensitivity and humility training, and to never underestimate the power of really listening. There are unfortunately dangerous historical stereotypes that exist in healthcare, such as that Black/African American people and other people of color do not feel pain or can tolerate/endure more pain than others. My young child was subjected to horrendous treatment with adult-sized needles, repeated blood draws, procedures/treatment that made my child very sick and engendered medical traumatic stress that was minimized, dismissed, reduced to my child being anxious when in truth, my child was in significant pain. We changed our child's Inflammatory Bowel Disease (IBD) team three times, and ultimately found the right fit with a private practice gastroenterologist (GI) and pursued patient advocacy before finally having our voices heard and our child's needs met! Patient support, resources, accessible patient advocates, culturally responsive medical staff and social workers need to be built in especially for patients of color and linguistically diverse families. Additionally, inpatient care should have inclusive resources for all patients, such as large-toothed combs and/or brushes for curly hair and shampoo, conditioner, and moisturizer for curly hair (our hospital did not have shampoo for our child's hair as a young person of color), and nursing staff need to be skilled at how to sensitively use the products and affirm each child's beauty and uniqueness.

- Anonymous, caregiver

From a Psychosocial Clinician

I often reflect on how it can be challenging to navigate my own healthcare as an adult living with IBD as a person with privilege, over 20 years of experience living with IBD, and professional knowledge in IBD as an IBD psychologist – I worry and wonder all the time about if navigating my care remains challenging, what is it like for patients and families with less privilege and more systemic barriers to care. **Achieving health equity for all of our patients and families is essential to meaningfully improving the lives of all children.**

- Dr. David, clinical psychologist

11 Action Steps

Health Equity

- Check out the incredible resources and community of the Color of Gastrointestinal Illnesses
  - If you use Instagram, consider following their account *“colorofgi”*
- Check out the excellent resources and community of the South Asian IBD Alliance
  - If you use Instagram, consider following their account *“saia_ibd”*
- Watch the American Academy of Pediatrics’ Stockman Lecture featuring Christian Lawson’s experience as a young black patient with IBD.
- When comfortable doing so, **talk with your child’s healthcare team about any care values, preferences, or needs related to your child’s and/or family’s identity** (e.g., access to personal care products that are appropriate for your child when admitted to the hospital)
- If/when you do not feel like your child is getting equitable, compassionate care, **consider sharing your concerns with your hospital** (this may be a Patient Relations Department) and whether it feels most comfortable to your family to change GI care to a medical provider who is a better whole-person fit

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11 Notes, Questions, To-Dos

Health Equity

12

Practical Tools and Suggestions for Navigating Life and Pediatric Chronic Illness

Dealing with any chronic illness in a family can come with a set of practical challenges that extend beyond medical care. When a child is diagnosed with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), families often find themselves navigating financial, logistical, and insurance-related considerations.

From Caregivers

When my son was diagnosed at 16 years old with ulcerative colitis (UC) he took it in stride and he "rose to the occasion." My son was one of the kids who always dealt with difficult and challenging situations with grace. **Our children are all different and it is ok for them to not rise up and meet their new diagnosis with strength.** That is something that we caregivers must help them with. After 6 years of navigating a pediatric chronic illness, I know that children oftentimes need more support than they may show or express. My son did not start to show any anxiety and depression until years after his diagnosis, when he was in college. I always tried to keep the lines of communication open and give support, but some days it felt like an uphill battle. My son loved art and that was his refuge. He also played sports before diagnosis, and he had to stop some of those. Others he still tried to keep up with even if just recreationally.

- Heidi, caregiver

One of the first steps, after diagnosis, hospitalization, or a flare, is to assess how much care your child will require in the short and longer term. This includes both medical care and daily support. Consider who in the family will be involved in caregiving and whether it will be necessary to hire additional household support. Determine if care can be divided among family members or if you'll need to enlist help or explore hiring additional help for tasks like cooking, cleaning, or childcare.

A few practical tips we have found to be useful:

- If and when children are well enough to go to school, play sports, and socialize—and they will be—let them! Prioritize this normalcy. When feasible, schedule appointments after school hours, during breaks, or at times when the appointments are less disruptive to routines.
- Sports are physically and mentally beneficial, provided children feel up to it and it is cleared by their physician. We like to remind ourselves that there are many successful Olympic and professional athletes with IBD. We have found cross-country and track & field to be incredibly beneficial both mentally and physically.

- Ildiko, caregiver

From Psychosocial Clinicians

Being diagnosed with a chronic illness at any age in childhood or young adulthood is a big thing to go through for a young person, even for the toughest and most resilient young folks. **Reminding your young person that two things can be true at the same time – a young person can be brave and also feel scared – can be an important message.** I often encourage kids and families to be mindful of the word "but" as this can change the message – saying, *"This is hard, but you'll get through it!"* may feel dismissive or invalidating, while saying, *"This is hard, and you'll get through it!"* is a way of holding two things at once. We all have feelings and this can change over time, continue to check in and ask your child how they are feeling and normalize that we all have feelings. Coping and adjusting to a chronic illness is a process, many children have only had discrete illnesses with a start and a stop (like the flu) and having a chronic illness is a shift in how they think about their health. Try to make a list of the amazing things about your child – this could be special skills, how kind and generous they are, having a beloved pet – this list of amazing things is still true with IBD, having IBD does not change who your child is. Sometimes anniversaries or similar experiences can bring up big feelings or memories about healthcare, such as the first anniversary of their diagnostic scope or going to the hospital, remind your child that feelings can be like waves and can rise and fall and this is normal and human and okay!

- Dr. David, clinical psychologist

It can be difficult to adjust with the ups and downs of IBD. I like to use metaphors about IBD that make sense to children and teens. For example, **sometimes life is like a play where IBD is taking center stage – we have to give it more attention and time. At other times, IBD will be in the background or even backstage – it's still part of the play, but we don't have to focus on it as much.**

- Dr. Holbein, clinical psychologist

12 Action Steps

Practical Tools and Suggestions for Navigating Life and Pediatric Chronic Illness

- Check out the great tips from Ildiko above regarding how supporting your child is socializing and doing preferred activities, such as sports
- Try to replace the word “but” with the word “and” where you can, like *“This is scary* ***and*** *we can do this”* instead of *“This is scary but we can do this.”* **The word “and” increases cognitive flexibility and can support realistic hope and resilience.**
- Remind yourself that navigating life and your child’s chronic illness(es) is not a game of chutes and ladders, it is like a mountain range with times where things are on the up and up and times where it feels like you are in a valley. This can be a helpful visualization strategy to remind yourself that it is all part of the journey and the valleys do not last forever!
- Gently remind yourself that **life is not a solo sport, nor is caring for a child with IBD and/or AILD**. Consider making a list of your other ‘team members,’ like family, family friends, neighbors, religious community, and know that it is okay and brave to ask for support. If there are tasks that others can help you with – like asking a neighbor to pick up a few items at the grocery store – it can be helpful to outsource these tasks to someone else on your team.
- If you are interested in connecting with other parents/caregivers of children with IBD and/or AILD to learn from their experiences and find support, consider joining:
  - ImproveCareNow’s Parent/Family Advisory Council (IBD)
  - Autoimmune Liver Disease Network's A-LiNK Connections (AILD)
- Review resources from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent and learning more about your emotions
  - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *“caregiverwellbeingspp”* for other reputable resources and strategies

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Questions, Notes, To-Dos

Practical Tools and Suggestions for Navigating Life and Pediatric Chronic Illness

13 Chronic Illness Burnout and Treatment Plan Challenges

Doing something difficult each and every day – like caring for a child with chronic illness(es) – is very hard. It is normal to feel burnout and have difficult following treatment recommendations at times. This can be especially true with your child is going through a new developmental phase – like supporting your child taking their oral medicine every day may feel very different when they are 10 years old versus when they are 17 years old. **It is okay and normal for healthcare tasks to feel different at different times in life, and important to know how to move through burnout and adherence challenges.**

13 Viewpoints

Chronic Illness Burnout and Treatment Plan Challenges

From a Caregiver

Life with chronic illness is unpredictable, and parent/caregiver/patient burnout is real and often viewed as a negative by medical professionals. But it doesn't have to be, as we have learned the hard way. Burnout can lead to compliance issues, whether in the form of stopping medications, changing diet, missing medical appointments, etc. My daughter stopped giving herself supplemental feeds through her gastric tube (g-tube) when she got to college as she was tired of getting hooked up at night and wanted the freedom of being like other college kids. Her gastroenterologist (GI) labeled her as non-compliant and blamed my daughter, which caused a rift between the doctor and my daughter and led my daughter to feel poorly about herself. **As her parent, I called a team meeting and enlisted the help of the psychosocial team. They, and I, advocated for the doctor to actively listen to my daughter and to dig deeper to identify the root cause of the burnout.** After a few challenging months, my daughter's self-esteem improved, she felt supported by the medical team, and invaluable lessons were learned on all sides.

- Erin, caregiver

From Psychosocial Clinicians

When your child's GI team creates or modifies your child's treatment plan, they may make it seem so easy to follow; once at home, you notice that the combination of oral meds, shots or infusions, suppositories, diet changes, and/ostomy care is more complicated. **It is common for children to struggle to follow their treatment plans for many reasons, including forgetfulness, busy family schedules, difficulties tolerating unpleasant tastes (oral meds, diet supplements) or sensations (suppositories, shots, infusions), concerns for unpleasant side effects, misunderstandings about the plan in general, insurance issues and access to medications and supplements, and feelings of frustration about having to do so much to stay healthy.** Research has demonstrated that teens and young adults are particularly likely to have difficulty following their treatment plans. While you may want to foster independence with your teen or young adult with their medical care, it can be helpful for caregivers to consider ways they can continue to help their child and gradually transition various medical tasks to their child. Pillboxes are one of my favorite recommendations for this age; this can help your teen or young adult stay organized and take their oral medications on their own, with caregiver reminders provided only when it's clear that the medicine has not yet been taken. Being transparent with the medical team and including them in the process of identifying a solution along with you and your child is important. They may be able to modify the plan (e.g., reduce a medication from 4x/day to 2x/day, prescribe a pill instead of a liquid, etc.) or offer strategies to help address barriers. Many families seek additional holistic treatments or diet plans to support their child's IBD and gut health. It is important to share this with your child's GI team, as there are times when holistic treatments may interact with their current medications or present some potential challenges depending on your child's body and type of IBD. **At the foundation, following a treatment plan requires a set of complex behaviors that interact with one's thoughts and emotions. Many caregivers may not realize that psychologists and other behavioral health providers are experts in changing behaviors and setting realistic goals.** Consider consulting with a behavioral health therapist if your child continues to struggle with taking medications, coping with needle-sticks or medical procedures, or following a prescribed diet.

- Dr. Holbein, clinical psychologist

13 Action Steps

Chronic Illness Burnout and Treatment Plan Challenges

- Try to replace the word “but” with the word “and” where you can, like *“I feel so burnt out **and** this won’t always feel like this”* instead of *“I feel so burnt out but this won’t always feel like this.”* **The word “and” increases cognitive flexibility and can support realistic hope and resilience.**
- Try a mindfulness exercise like Anchor At the Bottom of a Stormy Sea to validate all of your feelings when you are feeling burnout
- Try diaphragmatic breathing, a special way of breathing that can help our bodies relax physically and emotionally
- Review resources from the Pediatric Psychology Caregiver Wellbeing Special Interest Group, including free and reputable resources on how to find a mental health professional for yourself as a parent and learning more about your emotions
    - If you use social media, you can follow this Caregiver Wellbeing Special Interest group at *“caregiverwellbeingspp”* for other reputable resources and strategies
- If you notice your child is having a difficult time with burnout and adherence, please consider sharing with their healthcare team. If you think your child may benefit from professional support, consider using ImproveCareNow’s Finding a Mental Health Professional resource
- **Consider talking with your child’s healthcare team to see if any of their care can be streamlined or reduced to help manage burnout and adherence demands** (e.g., asking if labs can be timed with infusions to only have one poke or if any medication can be tweaked, such as a twice a day medicine to become once a day if appropriate)

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13 Questions, Notes, To-Dos

Chronic Illness Burnout and Treatment Plan Challenges

14

How to Talk About Your Child's Diagnosis

Disclosing about Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) or advocating for what will help your child to thrive at school at their activities is a continuous process. These are conversations that are often needed multiple times as your child transitions to different grades or school, tries out new activities, and expands their social network. **As your child grows and changes, what you choose to share about IBD and/or AILD and the accommodations or supports you request will likely change too.**

14 Viewpoints

How to Talk About Your Child's Diagnosis

From Caregivers and a Psychosocial Clinician

Deciding how openly to discuss your child's IBD diagnosis is a personal decision, and it's one that should involve your child in an age-appropriate manner. Families have varied approaches, from embracing openness and seeking a sense of community to maintaining privacy and not letting the diagnosis define their family identity. **Every choice along this spectrum is valid, and these decisions may evolve as your child grows and their needs change.**

- Ildiko, caregiver

My approach with working with the school was keeping the question "what does my daughter need" at the forefront. We also involved her from an early age in her school plan, and as she moved through the grades into college, she became the "expert" on herself and took over the advocacy.

- Erin, caregiver

Many gastroenterology (GI) teams set expectations that children with IBD should continue to strive towards their educational goals, enjoy a range of activities and friendships, and live active lives. Still, it can seem overwhelming or confusing for many caregivers of children with IBD to navigate the practical ways they can support their children. There can be a lot of information and details to keep track of, and specific plans and strategies may need to change depending on your child's age, symptoms, and IBD treatment plan. If you have questions about how to set your child up for a healthy, fun vacation, summer camp experience, sports season, and so on, reach out to your GI team! They have learned a lot through their experiences with children with IBD. Some GI teams may have a social worker or resources coordinator who specializes in identifying appropriate resources, coordinating necessary documentation, and so on. Even with all the tips and knowledge you can gather, it is inevitable that problems will arise, and mistakes will happen. **Try to give yourself some grace and compassion and figure out what you may be able to learn from the experience.**

- Dr. Holbein, clinical psychologist

Viewpoints

How to Talk About Your Child's Diagnosis

From a Caregiver

When it comes to school, it's important to be aware of resources available for children with IBD, such as accommodations provided under Section 504 of the federal Rehabilitation Act (a "504 plan"). You can find information on this topic through resources like the Crohn's & Colitis Foundation (CCF). However, it's also important to consider whether, when, and how much accommodation to seek. Some families, like ours, may prioritize normalcy and avoid labeling or limiting their child with a diagnosis. In such cases, individual conversations with teachers, coaches, and school administrators can be more beneficial than formal plans. But others may require formal plans, which should be prepared by you, in consultation with your medical team, and discussed with your school. Choose strategic moments, such as the beginning of a school year rather than during disease flares, which can be more challenging. Whether you have a formal plan or not, it can be helpful to inform educators, coaches, administrators and school nurses about your child's condition and medications, as well as any special diets. A direct, factual, and informative approach can help everyone understand and align on the best way to support your child. Be prepared to answer questions factually and make it clear that they can contact you at any time with further questions or concerns. **However, it is essential to not assume that others can fully understand the diagnosis and treatment plan or provide the care that you provide at home. Instead, create awareness, maintain open lines of communication, and take an active role in your child's care.** For example, we always supply our own food for in-class events and trips and often volunteer to supply food for kids with Celiac or specific food allergies.

- Ildiko, caregiver

14 Action Steps

How to Talk About Your Child's Diagnosis

- As Ildiko, Erin, and Dr. Holbein shared above, **deciding what, when, where, and with whom to share information about your child's health is an individual decision.**
- **Consider what you and your child are comfortable sharing with others** and what may be very important for another person to know, such as what to do if your child is having abdominal pain while at basketball practice. It can be helpful to have this information written down to be able to easily share the information with another person.
- **Practice declining to answer a question**, like, *"Thank you for asking about that, we don't feel like that's important for others to know."*
- **Support your child in knowing their boundaries** about what to share and practicing saying no, such as, *"I only talk about that with my parents and my doctor."*
- As your child gets older, continue to reflect as a family and consider if what you share about your child's medical needs should change
- Consider reviewing ImproveCareNow's Accommodations for IBD

14 Questions, Notes, To-Dos

How to Talk About Your Child's Diagnosis

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Handling Work While Caring for a Sick Child

Life does not stop when your child is living with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD), which can also mean that managing work and your child's health may be tricky at times. Life can be like a juggling act where there are 'glass balls' (e.g., your child's health) and 'plastic balls' (e.g., things that are important but not critical, like changing the bed sheets every so often), and it is okay for a plastic ball to fall!

15 Viewpoints

Handling Work While Caring for a Sick Child

From a Caregiver and a Psychosocial Clinician

In response to your child's needs, you may, if you are able, make short or long-term changes to your work situation. Some parents opt to reduce their working hours, work part-time, or even leave their jobs to provide full-time care. **This is a reality that needs to be discussed more openly.** Of course, many caregivers continue to work full-time. Some seek out work accommodations. Whatever the financial situation and decision in the household, it’s important to make a plan that works for your family and this plan should also evolve over time.

- Ildiko, caregiver

Your employer may offer something called “Family Medical Leave Act,” also known as FMLA. This is designed to help parents and caregivers who may need to miss work for their child’s medical appointments, hospitalization, or surgery. **FMLA allows for reasonable unpaid leave (up to 12 weeks per year – consecutive or intermittent) for medical reasons, for which you cannot be penalized.** FMLA only applies to employers with 50 or more employees, and only to those who have been employed with the company for one year or more. Talk with your Human Resource Department (HR) for more information and to get the process started if it applies to you. Your doctor’s office will be able to assist with completing the medical certification of these forms. You will also need to contact your GI doctor and provide them with the documents. If you do not qualify for FMLA, we encourage you to still connect with your HR Department and obtain a letter of advocacy from your doctor’s office that may include your child’s diagnosis and expected medical needs.

- Noelle, licensed social worker

15 Action Steps

Handling Work While Caring for a Sick Child

- As Noelle shared, consider talking with your child's healthcare team to see if there is a **medical social worker** who can talk about resources like FMLA (Family Medical Leave Act) to support your family
- Do not hesitate to **ask your medical team for doctor's notes** that you can then provide to your employer.
- Gently remind yourself that **life is not a solo sport, nor is caring for a child with IBD and/or AILD.** Consider making a list of your other 'team members,' like family, family friends, neighbors, religious community, and know that it is okay and brave to ask for support. If there are tasks that others can help you with – like asking a neighbor to pick up a few items at the grocery store – it can be helpful to outsource these tasks to someone else on your team.
- If you are interested in connecting with other parents/caregivers of children with IBD and/or AILD to learn from their experiences and find support, consider joining:
    - ImproveCareNow's Parent/Family Advisory Council (IBD)
    - Autoimmune Liver Disease Network's A-LiNK Connections (AILD)

15 Questions, Notes, To-Dos

Handling Work While Caring for a Sick Child

16 Insurance and Finances

Insurance can feel overwhelming to so many, even families who have been managing Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) for some time. Try to be as patient with yourself as possible, insurance is confusing and frustrating and important to support your own self-care as you manage insurance!

Evaluating your family’s work considerations and insurance will require assessing your family's financial situation.

- Create a budget that accounts for your child's healthcare needs, increases in medical expenses, potential changes in income, and any additional support required.
- Discuss cost-effective treatment options with your child's healthcare team to ensure that you are getting the best care while managing expenses.

- Don't hesitate to seek financial guidance or counseling if you find yourself overwhelmed by the financial aspects of managing IBD and/or AILD.

Financial experts can help you navigate insurance, budgeting, and accessing available resources. Remember that you are not alone in facing these practical challenges. Many families have walked a similar path and can offer advice and support. Connecting with support groups or organizations dedicated to IBD and/or AILD can provide valuable insights into managing the financial and logistical aspects of caring for a child with IBD and/or AILD. Your journey may involve adjustments and challenges, but with careful planning and a supportive network, you can ensure that your child receives the best care while maintaining financial stability and peace of mind.

YOU ARE NOT ALONE IN FACING THESE PRACTICAL CHALLENGES.

16 Viewpoints

Insurance and Finances

From Caregivers

Review your child's insurance coverage carefully. Understand the terms of the insurance plan, including premiums, deductibles, co-pays, and co-insurance. Be aware of any out-of-pocket maximums that may apply. Speak with your care team about what you can do to ensure prompt insurance approvals and avoid unnecessary hassles. In the event of insurance denials, work with your care team and understand your respective roles. For example, we requested all correspondence and then wrote a letter to the insurance company outlining the reasons for the medication pre-authorization request as part of an appeal process. Caregivers can also investigate supplemental insurance programs available for children in your state. Some states offer assistance programs that are not always income based and that can help alleviate the financial burden of managing a chronic illness. Additionally, there are several patient assistance programs offered by pharmaceutical companies, which may provide financial support for medication costs.

- Ildiko & Tori, caregivers

16 Action Steps

Insurance and Finances

- Ask your child's healthcare team if there is a medical social worker who can talk about insurance and financial resources/supports.
- Depending on the kind of medication your child may be on, consider asking your healthcare team if there are pharmaceutical co-pay assistance programs that may help reduce costs or consider using Good Rx to help find pharmacies to fill prescriptions that may be more affordable.
- Consider calling your child's healthcare center's patient accounts/billing department to ask about other resources, like if there are payment plan options.
- When you talk with insurance, make sure to **write down the highlights of the conversation to have a record of this discussion**; some caregivers will email themselves the highlights of the insurance conversation to have a digital record of what was discussed and the outcome (e.g., insurance agent confirming that a prior authorization has been approved on a certain date).
- Remember that i**nsurance and costs may feel different at the beginning of the new year when deductibles reset** and that you may need extra support or problem-solving from your child's medical social worker.
- If you are interested in connecting with other parents/caregivers of children with IBD and/or AILD to learn from their experiences and find support, consider joining:
  - ImproveCareNow's Parent/Family Advisory Council (IBD)
  - A-LiNK Connections (AILD)

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16 Questions, Notes, To-Dos

Insurance and Finances

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Travel with Medical Conditions

Traveling when a child has medical condition(s) can add other stress and considerations, like having enough medication or having a plan in case your child feels unwell during the trip. And yet, traveling with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) is very possible and for many families is an important aspect of life! There are great tips and resources to support your child and family having a wonderful time traveling!

17 Viewpoints

Travel with Medical Conditions

From Caregivers

Travel can seem daunting in the initial stages of diagnosis or even years later if the disease dynamics change. **Traveling with IBD can require a little more advanced planning but is wonderful. Preparation is key.** There are college students with IBD who study abroad successfully. Since every child will have different symptoms and manifestations of IBD, prepare according to your child. There are apps from organizations like the Crohn's & Colitis Foundation (CCF) that help share information about public bathrooms. Additionally, in several states in the United States, Ally's Law or the Restroom Access Act requires businesses with employee only bathroom facilities to grant bathroom access to individuals with IBD if the need arises. Check with your doctor about where you can get a free "I can't wait" card.

- Tori, caregiver

Travel requires planning but is well worth the effort. We prioritize locations with clean water and without common gastrointestinal illnesses. We typically prefer hotels with kitchenettes or home or apartment rentals. And we will work in advance with executive chefs at resorts to plan appropriate meals.

- Ildiko, caregiver

Our son had ulcerative colitis (UC), and urgency and frequent accidents were a regular thing. **We always had changes of clothes, wipes, towels, and ostomy supplies (after his colectomy) in our car.** We traveled around infusions. Otherwise, we traveled all over the US and abroad with few issues.

- Heidi, caregiver

One of the lessons I learned the hard way was not having written medical documentation when leaving the country. We joke about it now, but having to explain every DME (Durable Medical Equipment) device and medical supplies in a special room in customs got old quickly. **Asking your medical team to provide a letter detailing what your child will need and why will be helpful (and can also be used for school trips FYI).**

- Jane, caregiver

17 Action Steps

Travel with Medical Conditions

- When you are scheduling housing accommodations, like a hotel or a rental, **think about if you need access to a kitchen** (e.g., storing foods your child can eat, medications that may need to be kept in the fridge, access to a microwave to heat up a heat pack) and plan accordingly
- If your child is on infusions or injections for their care, look at the schedule to determine when their next treatment is due and **reach out to your child's healthcare team if the trip falls during a planned treatment for guidance on how to manage your trip and your child's health needs**
- **Put your child's GI office number and on call number in your phone** to have a way to reach their healthcare team if any needs arise (e.g., needing a medication called in to a local pharmacy)
- **Look up local hospitals near your destination** to have the peace-of-mind that there is care accessible to your child if an emergency arises
- Remember that if your child has refills on a medication at one retail pharmacy location, **often the medication can be filled at another retail pharmacy location** (e.g., if you live in Philadelphia and fill medication at a CVS, you should be able to transfer a refill to a CVS in Orlando)
- If traveling abroad, make sure you **understand how medical bills are paid abroad** (many countries you pay up front), and know **if your insurance has reimbursements for services abroad**
- When staying at hotels, or going to restaurants at the destination, **contact the restaurant ahead of time to discuss dietary needs** to help ensure there are no issues
    - If you are traveling abroad, **consider making a small sign with the information about the dietary restrictions in English and the local language** to be able to show at restaurants
- For meals during flights, airport security will typically allow medical foods, including liquids, with a note indicating this is for a medical diet but you can always **check with TSA or other security in advance**.
    - An insulated lunchbox, backpack or small cooler can work well for air travel. For road trips, a large cooler stocked with prepared meals is very helpful.
    - Plan ahead and ask your child's medical team to write a letter on official letterhead to be able to show TSA

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17 Action Steps

Travel with Medical Conditions

- If traveling with medications (including injections), **keep the medication in the original pill container** so it will be clear to TSA that the medicine is prescribed to your child. If your family uses pill boxes or other organizer, bring empty ones with you and plan to set up when you get to your destination.
  - If you are traveling with injections, ask your pharmacy or specialty pharmacy about a **travel sharps bin** so you can safely dispose of the needles.
  - If you cannot get a travel sharps bin, consider a hard plastic container like an empty laundry detergent bottle or an empty coffee can.
- It can be helpful to **pack several extra days of medication** in case your travel is delayed, including any extra as needed medication that your child may have (e.g., nausea medication)
- **Pack all medication in a carry-on bag** and avoid packing medication in a checked bag to ensure that you always have access to your child's medication
- Read ImproveCareNow's Travel Toolkit for additional tips and tricks
- Read the Crohn's & Colitis Foundation's travel website for other insights as well

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Questions, Notes, To-Dos

Travel with Medical Conditions

18 Taking Action

There can be a sense of loss that comes with a chronic illness diagnosis or multiple diagnoses. These feelings of loss and grief can occur throughout a diagnosis – for example, years into the diagnosis when your child is having a hard time coping with a treatment or you cannot go on a family vacation because of an infusion appointment. **We often hear from caregivers that active acceptance, seeking support, and finding meaning are key areas that helped with their Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) journeys.** This can be defined differently by all caregivers and can include volunteering with non-profits, becoming a peer-support individual, raising awareness and funds for research, or getting involved in a larger fundraiser. Taking action can increase our circle of control to take care of ourselves and help in building resilience in ourselves and our children.

18 Viewpoints

Taking Action

From Caregivers

In general, **exercise is my greatest way to maintain physical and emotional balance,** but I've adapted and found an immense amount of joy and an outlet for my own emotions by getting involved connecting with other IBD parents and helping facilitate community support groups through the Gutsy Network and in collaboration with Children's Hospital of Philadelphia.

- Tori, caregiver

Taking action, in the form of volunteering, helped me cope and become stronger in my journey as a caregiver. I learned that advocating, sharing my voice and family's story (with their permission) helped me feel less alone, our family's story more understood and I was modeling a positive step for my son with IBD. Volunteering has always been something I (and my family) enjoyed and I found it to be a holistic feature in my healing. **Of course, it is not something that everyone is capable of doing when faced with a life-long illness diagnosis. That is ok. Just know that there is always a place for your voice and advocacy.**

- Heidi, caregiver

A special note - people often handle stress and emotions in different ways; this is okay and normal. For some, being involved and busy may be what helps them, for others, just the driving to and from appointments or calls to insurance and doctors may feel too overwhelming. If it's not the right time or does not feel comfortable - this is okay!

18 Action Steps

Taking Action

- Remember that taking action can mean many different things – like volunteering at a fundraising walk, reposting an IBD or AILD post on social media, and beyond!
- Consider asking your child's healthcare team if there are any volunteer/advocacy opportunities through their clinic or hospital; some hospitals may have parent mentorship programs that you can learn more about
- Consider joining ImproveCareNow's Parent/Family Advisory Council, learn more here
- Consider joining A-LiNK Connections by visiting their website
- Consider the Crohn's & Colitis Foundation's Power of Two program
- Learn about volunteer and advocacy opportunities through the Crohn's & Colitis Foundation:
  - Advocating (e.g., contacting your local legislators)
  - Volunteering and/or fundraising (e.g., Take Steps walk)

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18 Questions, Notes, To-Dos

Taking Action

19 Key Takeaways

Being the caregiver of a child with Inflammatory Bowel Disease (IBD) and/or Autoimmune Liver Disease (AILD) can come with a range of joy and difficult times, and it is important to take care of yourself as a caregiver to allow you to continue taking care of your child. Remember, managing IBD and/or AILD are journeys like mountain ranges with hills and valleys. We are all moving forward in our own journeys.

19 Viewpoints

Key Takeaways

From Caregivers

One of the most important things that I have done for myself since my child was diagnosed with two chronic illnesses was to seek support from parents who have children diagnosed with the same conditions. Not only have I been given validation that my feelings and fears are legitimate, but I have been able to share my experiences and help others. What I have found over the years is that the shared experiences have led to deep personal connections and friendships that will last a lifetime! No one has to go through this journey alone!

By connecting with other parents, there is an opportunity to unite voices and advocate for better IBD/AILD research, treatment options, and healthcare support. Building a strong community can help raise awareness about these diseases and promote understanding among the broader public. Meeting parents who have successfully navigated the challenges of caring for a child with IBD or AILD can inspire hope and provide positive role models. Seeing children who are thriving despite their condition can uplift spirits and provide encouragement during difficult times. **Overall, seeking other parents of children with IBD or AILD provides an invaluable network of support, empathy, and understanding. It can be a source of strength and resilience, helping parents feel less alone and better equipped to cope with the journey of raising a child with a chronic illness.**

- Jane, caregiver

Remember that being a caregiver to a child with IBD is a journey of immense love, resilience, and sacrifice. While the path may be challenging, it is also filled with moments of profound connection and growth. Lean on your support network, including fellow caregivers and healthcare professionals, to share experiences, gain insights, and find solace in the shared journey. Above all, know that you are not alone on this path. Your dedication and advocacy make a significant difference in your child's life, and your unwavering love and commitment are a source of strength for both you and your child.

- Ildiko, caregiver

19 Action Steps

Key Takeaways

- Facing the challenges of IBD and/or AILD may be daunting, **and** it's possible to move through the challenging times with resilience, support, and realistic hope.
- **It is okay and human to feel big thoughts and big feelings as your child lives with IBD and/or AILD.** It's not about pretending everything is fine, rather acknowledging the difficulties and finding the strength to persevere. **Remember that resilience is not the lack of struggle; it's the capacity to move through it.**
- **Leading by Example:** Your response to the challenges posed by IBD and/or AILD can teach your children valuable life lessons, including that it is okay to not be okay at times.
- **Shifting Perspective:** Rather than seeing IBD and/or AILD as a never-ending marathon or crises, try to shift your perspective into as a series of manageable steps. Remind yourself that you're not alone in this journey, and countless others are facing similar challenges, you are part of a community.
- **Cultivate Self-Care Tools for yourself and child:**
    - **Exercise:** Regular physical activity can help reduce stress, boost mood, and improve overall well-being. Even simple activities like walking or stretching can make a difference.
    - **Self-care, relaxation, and mindfulness:** Learning to focus on the present moment can be particularly beneficial during challenging times. Just as the saying goes on airplanes, we have to help ourselves before we can help our children, and we cannot pour from an empty cup. Check out the recommendations in the sections above for evidence-based strategies to encourage self-care, relaxation, and mindfulness.
    - **Seek Support that works for you knowing that this may evolve over time:** Support is critical for us all and can come in many forms – our family members, significant others, religious community, psychosocial clinician like a therapist – to have safe spaces to process big thoughts and feelings. Check out the recommendations above for how to identify a psychosocial clinician for yourself and/or for your child depending on what is the right fit for you and your family.
    - **Take action if and when you are ready:** Learning to take action can help caregivers feel empowered and meet others in the caregiver community. See recommendations above for how to get involved if/when this feels right for you. Remember, this is not required, and it is okay if taking action is not what feels comfortable to you or your family.

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19 Questions, Notes, To-Dos

Key Takeaways