

## WHAT IS A CHRONIC ILLNESS AND HOW CAN IT AFFECT FAMILIES?

- A chronic illness is a physical condition that lasts >12 months and impacts day to day functioning (e.g., asthma, diabetes)
- If a child has a chronic illness, stress can increase for the whole family
  - Children may worry or wonder about their identities and future change
  - Parents can find their roles and priorities shifting
  - Siblings can feel left out and scared
- Physical health and mental health are always related. Feeling sickness or pain can trigger anxiety or depression. Mental health can also affect our physical health directly (e.g., stress increases intensity of physical symptoms of discomfort). It can also impact our motivation to take care of ourselves.
- It is common for families to grieve the loss of opportunities and sense of security they may have had prior to a chronic illness diagnosis.
- Stress can increase, especially during developmental transitions (e.g., entering kindergarten, puberty, going to college).



## HOW DO FAMILIES COPE WITH A CHRONIC ILLNESS?

- Some families find support through illness groups, camps, advocacy programs or friends, and others keep it more private.
- Some families like to learn as much information as possible, while others may want their medical team to manage their medical information.
- Some families find that incorporating healthy behaviors, such as exercise, eating healthy, and using stress reduction techniques like yoga or meditation help them to manage both stress and symptoms of a chronic illness.

## SOME SIGNS THAT YOUR FAMILY MAY NEED MORE SUPPORT INCLUDE:

- Your child has sadness, anger, or worries that begin to interfere with their ability to go to school, take care of their health, keep healthy relationships with family or friends, or their ability to enjoy things.
- Your child has physical symptoms of stress like changes in sleep, appetite, energy level, or unexplained aches and pains.
- Your child's grades are slipping, or a teacher or coach expresses concern.
- Your family is arguing more often, and you are not feeling as close.
- Your child and/or family are having difficulties meeting your health goals like following your medical plan or making it to appointments.

### RESOURCES

<https://www.merckmanuals.com/home/children-s-health-issues/social-issues-affecting-children-and-their-families/chronic-health-problems-in-children>

<https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Children-with-Chronic-Illness-Dealing-with-Emotional-Problems-and-Depression.aspx>

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## TIPS FOR PARENTS

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- **Don't be afraid to talk about the diagnosis.** Children need to process what happened and figure out how it fits into their life as they grow up.
- **Let the child lead the conversation.** Let your child ease into asking questions about their health or long-term consequences. And it's ok to say "I don't know" if you don't know the answer.
- **When the child brings up concerns about bullying,** listen, validate how they are feeling, let them know how much you appreciate them telling you about it, and that you will talk to other adults involved to try to make it stop.
- **We often have no adequate explanations** for why a particular child has a chronic illness, but their sibling or peers do not. Just make sure they know it is not anyone's fault and that they did not do anything to make it happen.
- **It's okay to let children see that you are sad or upset.** In fact, it is a great opportunity to model for them how to express emotions and lets them know that they can talk about negative feelings, too.
- **Keep a routine going for the child that helps them feel safe.** So much about chronic illness is unpredictable, that having a routine helps make a child feel like they know what to expect, at least sometimes.
- **Allow for the child to have a say in their care, when reasonable.** Parents can provide their children a sense of control by offering as much choice as possible (e.g., choosing which arm to receive a poke, picking the music in the car on the way to doctor's appointments, encouraging adolescents to talk more and make their opinions known in their medical visits).
- **Team up against the illness instead of each other.** If a child feels that their parents are upset about their lab values or health behaviors, they may not be honest about what is difficult for them in managing their illness. Find ways to collaborate and tackle the demands of the illness together.

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## WHEN SHOULD I SEEK PROFESSIONAL HELP?

- A family member is having mood or anxiety symptoms almost every day for longer than 2 weeks. Symptoms are not getting better with time or known supports and are interfering with their wellbeing.
- Remember that parents and siblings of youth with chronic illness can also benefit from professional support.
- Don't wait until symptoms become totally unmanageable. No one is born knowing how to cope when a child has a chronic illness, and it is ok to need outside support.
- If you or a family member experiences thoughts of self-harm or harming others, contact 911 or a crisis line (see below) or go to the nearest emergency room.

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## RECOMMENDED RESOURCES

- *Verbal First Aid, Help your kids heal from fear and pain -- and come out strong*, by Judith Simon Prager, PhD, and Judith Acosta, LISW, CHT
- *Wonder*, by R J Palacio, a story of a family's journey living with chronic illness.
- *Digging Deep, a journal for young people facing health challenges* by Rose Offner, MFA & Sheri Brisson, MA and its companion phone game: *Shadow's Edge*.
- *Author Lori Lite* has a series of several illustrated books to help young children manage stress.
- *California Youth Crisis Hotline* 1-800-843-5200, *Suicide Prevention Center* 1-800-784-2433, *Crisis Text Line* 741-741