

# How to Talk to Your Child About Your Chronic Health Condition

Starting the first conversation of many discussions with your child(ren).

## Tips for Starting the Conversation

1. Gather relevant and reliable resources in preparation for your conversation.
2. Using developmentally appropriate language, sit down with your child(ren) and begin sharing information about your chronic health condition—including how symptoms affect your participation in activities.
3. Utilize developmentally appropriate TV shows, books, videos and other resources that depict chronic conditions and other disabilities in a positive way (Ferri, 2021).
4. Let your child(ren) ask questions—if you don't have the answers, pause to collect your thoughts or write down the question and get back to them (Ferri, 2021).
5. Watch your own reactions—your body language and expressions can impact your child(ren)'s view on disabilities (Ferri, 2021).
6. Support your child(ren) throughout the conversation. This conversation can cause a heavy feeling or worry in your child(ren), so remember to offer reassurance and emotional support during and after the conversation.
7. Associate commonalities between people with disabilities and people who do not have a disability—everyone is different and that is okay (Ferri, 2021)!

## When is the Right Time?

Parents expressed that they wish they started the conversation earlier to prevent fear in their child(ren) from unreliable searching and resentment toward them for withholding information. Research shows that the best time to start sharing information about your chronic health condition is after initial diagnosis. Some parents started before kindergarten, while others waited until grammar school or older. The decision is ultimately up to you and when you feel the time is right.



Photo of young girl and mother sitting outside on a porch step having a conversation

## The Environment

- In the home or in the most natural environment where the child(ren) feels most safe
- In the least distracting environment
- In person (as opposed to video or over the phone)
- It is beneficial to have a spouse or supportive family member present.

## On-going support

- Be honest with your child(ren) when discussing your chronic health condition (McDermott, 2017).
- Talk to your provider for further tips on discussing your chronic health condition with your children
- Join a support group for parents with chronic health conditions

## Reliable Resources

**Rare Diseases:** <https://rarediseases.org/for-patients-and-families/information-resources/rare-disease-information/>

**Scleroderma:** <https://scleroderma.org/>

**Rheumatoid Arthritis:** <https://www.rheumatology.org/I-Am-A/Patient-Caregiver>

**Ehlers-Danlos Syndrome:** <https://www.ehlers-danlos.com/>

**Endometriosis:** <https://www.endofound.org/>

**Attention Deficit Hyperactivity Disorder:** <https://chadd.org/>

**Celiac Disease:** <https://celiac.org/>

**Scoliosis:** <https://www.scoliosis.org/>

**Chronic Pain:** <https://uspainfoundation.org/>

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