

How to Talk to Your Child about Your Chronic Health Condition

A Capstone Research Project by Celia Giallanella, MOTS/LEND Trainee

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LEND Competencies Covered

1. Leadership Skills
 - Lead through practice, research, teaching, administration, and legislative systems change.
 - Develop effective communication and teaching skills, as well as accessible presentation skills appropriate for a variety of professional and community audiences.
 - Demonstrate networking and advocacy skills.
2. Interdisciplinary Practice
 - Collaborate effectively with individuals, families, peers, faculty, and other professionals.
3. Knowledge of Neurodevelopmental and Related Disabilities
 - Examine the intersection of disability with other life experiences.
4. Cultural and Linguistic Responsiveness and Diversity
 - Incorporate an appreciation of differences in perspectives into professional behaviors and attitudes while maintaining an awareness of the potential for implicit bias.
 - Demonstrate sensitivity and responsiveness to diverse families in various settings.
5. Person and Family-Centered Care
 - Demonstrate knowledge of the principles of person- and family-centered care.
 - Recognize the primary importance of the family in the life of a child.
 - Discuss and observe the impact of disability on families.
6. Research, Quality Improvement, and Evidence-Based Practice
 - Use science-based judgment, evidence-based practice, and documentation of outcomes in practice, programs and policy.
 - Access and utilize electronic information, resources and databases.
 - Gain experience with framing a problem, researching, developing a product, disseminating to relevant stakeholders, and providing a professional presentation.

Purpose

- Provide resources/support for parents who may be navigating challenging/complex conversations with their children regarding their chronic health condition
- Chronic/invisible illnesses are conditions I hold near and dear to my heart because they are underrepresented, disapproved, and stigmatized conditions across populations. Furthermore, parents with these conditions have experienced disapproval by the general population and some may have been deemed incompetent of caregiver skills.
- Decrease the disapproval and stigmatization around the topic of chronic health conditions, especially regarding parenting.
- Increase the number of education/resources available for parents
 - Lack of guidance on conversations about disabilities from providers
 - Lack of resources on the internet
- Create a generalized resource that can be used all over the USA

Methods of Research

- Reviewed All of my Occupational Therapy Textbooks
- Research through AOTA magazines
 - Found an article that had similarities to my topic
- Searched Internet
 - Blogs on chronic condition websites
- Reached out to Janet Poole PhD, OTR/L, for potential Interviewees
 - IRB not required, all participants' information kept anonymous, no identifiable information collected
- Created Questionnaire with an OT mindset and sensitivity (13 questions)
- Set up 4 interviews (in-state and out of state)
 - Each interview was 1-1.5 hours in length



Parent Questionnaire

Parent Questions

1. Tell me about yourself/family/what you enjoy doing
2. If you feel comfortable, what is your diagnosed chronic health condition?
3. How has your chronic health condition impacted your ability to participate in meaningful activities?
4. How has your chronic health condition impacted parenting?
5. Can you describe an instance where your chronic health condition has been beneficial?
6. Do you share your chronic health condition with family, friends, coworkers and how do you bring up the topic?
7. At what age did you start discussing your chronic health condition with your child(ren)?
8. Did you have the conversation alone or did you have supports?
9. Can you describe the conversation you had with your child(ren)? What was the environmental set up?
10. What age did you decide to talk to your children regarding your condition? How did your child(ren) react? Did they ask questions? Did you answer their questions or refer them to resources? Did they understand what you were telling them?
11. Did this conversation have an emotional impact? If yes, what/who were your supports?
12. Knowing what you know now, would you change anything?
13. If you were to give one piece of advice to providers who are trying to support people with chronic health conditions such as yours, what would you recommend?

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/>

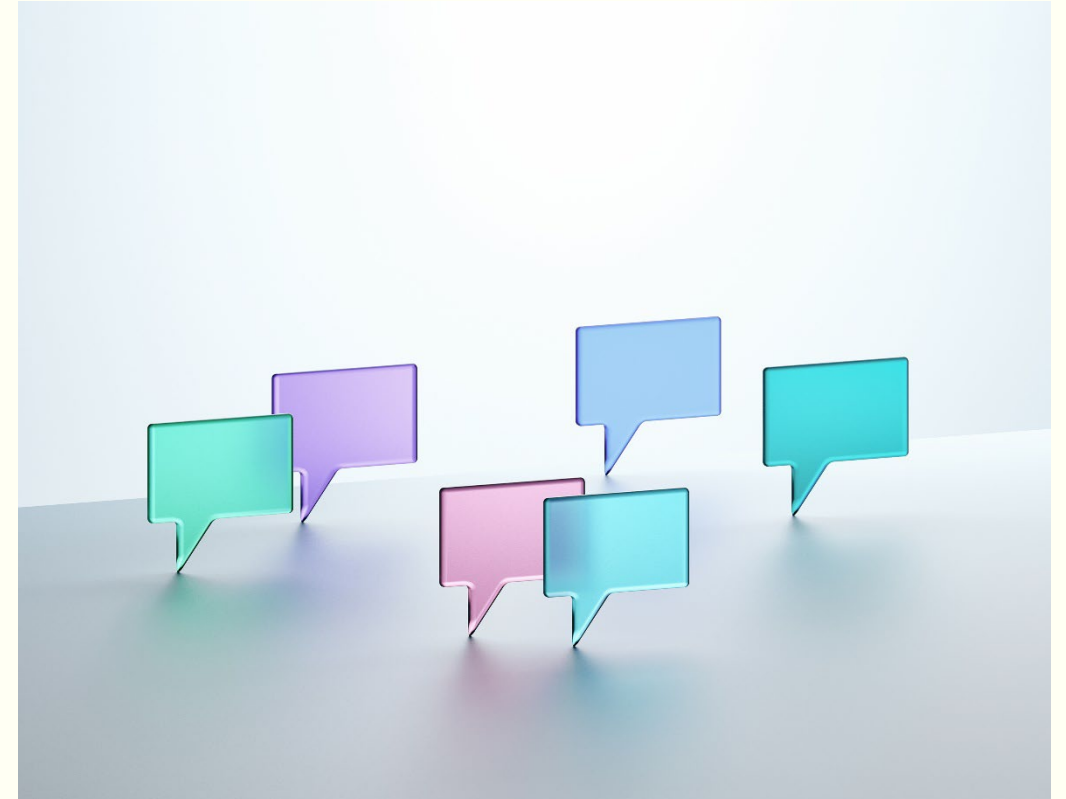
Scoliosis: <https://www.scoliosis.org/>

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

Citations: Resource created by Celia Giallanella, MOTS. Information collected from four parent interviews for first-person encounters on talking with their children about their chronic health conditions. Ferri, B. (2021). Teaching children about disabilities. *OT Practice*, 26(11), 34-35. McDermott, E. (2017, September 14). Teaching your child about your chronic illness. *The Mighty*. Retrieved October 10, 2021, from <https://themighty.com/2017/09/teaching-your-child-about-your-chronic-illness/>. (2022). Mother Daughter. Photo. *The Economic Times*. <https://economictimes.indiatimes.com/magazines/panache/how-to-talk-to-kids-about-war-parents-experts-suggest-telling-children-the-truth-about-nukes/articleshow/90273191.cms>.

Dissemination Plan

- Reach out to Indian Cultural Center and/or UNM OTGP faculty to translate handout to Spanish
- Reach out to UNM CDD Library to utilize as a resource
- Reach out to OT Practice (AOTA Magazine) for publication options
- Reach out to interviewees for dissemination
 - Connect with multiple people for dissemination in clinics around the USA
- Give educational resource out on fieldwork 2 (to applicable clients and to site supervisors)
- Provide handout to UNM OT students and faculty (OT22, OT23)



Conclusions

- All interviewees agreed that this topic is not covered well across the lifespan.
- All interviewees wished they would have had a resource like this at initial diagnosis.
- Healthcare professionals may provide 1 meeting centered around family education, but follow-up meetings are not required—this needs to change!!
- I have gained invaluable knowledge on chronic conditions and their impacts on parenting.
- Healthcare professionals need to improve their active listening skills when providing family-centered care.



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