



Helping Your Children Understand a Chronic Illness Diagnosis

When diagnosed with a chronic condition like Parkinson's disease, one of the most challenging aspects can be explaining your diagnosis to your children. Parents often worry about causing unnecessary fear or anxiety, but research shows that open, honest communication actually helps children cope better. This comprehensive guide provides strategies to help children of all ages understand and adapt to a parent's diagnosis while maintaining family bonds and promoting resilience.

Why Communication Matters

Being open about your diagnosis with your children is essential. Children are remarkably perceptive and will notice changes even if you try to hide them. When left without proper explanation, they often imagine scenarios that are worse than reality^[1]. Cleveland Clinic notes that chronic conditions like Parkinson's disease cause parts of the brain to deteriorate over time, leading to visible symptoms that children will inevitably observe^[2].

Sharing information about your condition:

- Builds trust and prevents misunderstandings
- Reduces fear caused by uncertainty
- Helps children develop healthy coping mechanisms
- Allows your family to navigate challenges together

As the Parkinson's Foundation emphasizes, "With support, they not only adjust but also thrive and can become more self-sufficient, confident and independent" ^[3].

Understanding Children's Reactions

Children's responses to a parent's diagnosis vary based on age, temperament, and family dynamics. Common emotions include:

- Shame or self-consciousness about visible symptoms, especially regarding reactions from friends or strangers
- Anxiety about family stability or changes in relationships
- Sadness, fear, anger, or grief regarding the parent's limitations
- Worry about their own risk of developing the condition
- Feeling overwhelmed by increased responsibilities^[3]

Research shows that a child's outlook is strongly connected to the parent's attitude-when you maintain a hopeful perspective, your children are more likely to adapt positively^[3].

Developmental Considerations

Children at different developmental stages process information differently:

- Preschoolers (3-5 years) may experience separation anxiety, sleep disturbances, and regression to younger behaviors^[4]
- School-age children (6-8 years) may worry about being the cause of family distress and feel rejected when the ill parent cannot participate in activities^[4]
- Adolescents may struggle with balancing their natural pursuit of independence against family needs^[4] ^[5]

When and How to Start the Conversation

Timing the Discussion

Try to tell your children soon after your diagnosis, once you've processed your own initial reactions^[1]. Choose a time when:

- Everyone is calm and relaxed
- There are no immediate distractions
- You won't be interrupted
- Your child isn't already experiencing significant stress (like the beginning or end of a school year)^[5]

Remember that this isn't a one-time conversation but the beginning of an ongoing dialogue. As the Parkinson's Foundation UK advises, "There's no rush to tell them everything in one go"^[6].

Setting the Stage

Cleveland Clinic's specialists recommend:

- Having both parents present (if applicable)
- Creating a comfortable, private environment
- Being prepared for various reactions
- Having basic information ready in age-appropriate language^[7]

Age-Appropriate Communication Strategies

For Young Children (Ages 3-5)

Young children need simple, concrete explanations:

- Use basic terms like "shaky hands" or "slow movements" instead of medical terminology
- Reassure them that they cannot catch the disease
- Explain that the illness is not their fault

- Use picture books or visual aids^[4] ^[5]

For example, you might say: "Daddy has something called Parkinson's, which makes his hands shake sometimes. It's not like a cold-you can't catch it, and it didn't happen because of anything you or anyone else did" ^[4].

For School-Age Children (Ages 6-9)

At this age, children can understand more details:

- Name the condition and explain basic symptoms
- Connect symptoms to things they can observe
- Discuss how treatments help
- Address potential changes in family routines^[5]

You might explain: "Some days I'll have a harder time playing catch with you, but other days I'll feel just fine. The medicine I take helps my body move better" ^[5].

For Teenagers (Ages 10-19)

Teens can understand more complex information:

- Use proper medical terms and basic explanations of the condition
- Discuss how treatments work
- Include them in decisions about family adjustments
- Provide resources for them to learn more independently^[5]

For teenagers, you can explain: "I have Parkinson's disease. That means my brain makes less of a chemical called dopamine, which causes tremor in my hands, stiffness in my muscles, and slowness of my movements" ^[5].

Practical Approaches for All Ages

Be Truthful but Hopeful

Children benefit from honest but optimistic explanations. As the Parkinson's Foundation notes, "you can try to be optimistic about what to expect but not give false hope" ^[4]. Focus on what can be done rather than worst-case scenarios.

Use Consistent Language

All adults involved in the child's life should use consistent terminology when discussing the condition^[5]. Decide together on terms you'll use-whether "PD," "Parkinson's," or even a nickname like "the shakes"-to make the topic more accessible^[5].

Check for Understanding

After discussions, verify what your child has understood by asking them to explain in their own words. This helps identify and correct misunderstandings^[6].

Make it Visual

For younger children especially:

- Use books written specifically for children about chronic illness
- Practice medical procedures on dolls to help children feel more in control
- Create visual schedules for medication or treatment routines^[8] ^[9]

Supporting Children's Emotional Well-being

Maintain Routine and Structure

Children thrive with consistency. The Child Mind Institute emphasizes that maintaining normal routines helps children feel secure during uncertain times^[8]. Continue to:

- Enforce household rules and expectations
- Maintain school and activity schedules when possible
- Involve children in age-appropriate chores and responsibilities
- Celebrate family traditions and create new ones

Encourage Emotional Expression

Create a safe space for children to express their feelings:

- Set aside regular time to talk about emotions
- Validate their feelings without judgment
- Use creative outlets like art or journaling
- Model healthy emotional expression yourself^[3] ^[10]

Build Resilience Through Involvement

Giving children appropriate ways to help can build confidence and reduce anxiety:

- Let them assist with simple tasks related to your care
- Involve them in community events like fundraising walks
- Encourage their questions and curiosity about the condition
- Praise their adaptability and helpfulness^[11] ^[3]

One parent with young-onset Parkinson's reflected: "Parkinson's may sometimes feel like a disease of diminishment, but it doesn't have to be. Some roles, like that of a parent, are too big to be diminished" ^[5].

Resources and Tools

Books and Media

Several resources are specifically designed to help children understand Parkinson's disease:

- "I'll hold your hand so you won't fall" by Rasheed Ali
- "Monica, Mama, and the Ocotillo's Leaves"
- "Shaky Hands - A kid's guide to Parkinson's"
- "Grandpa, what is Parkinson's?" ^[9]

Support Services

Many organizations offer support for families affected by chronic conditions:

- The Parkinson's Foundation Helpline: 1-800-4PD-INFO (473-4636) ^[12]
- Turning Point, which offers research-backed programs for parents and children dealing with serious health conditions ^[7]
- PD Conversations online community for connecting with others in similar situations ^[12]

When Additional Help May Be Needed

Children might benefit from professional support if they show:

- Persistent worry or anxiety
- Withdrawal from activities or friends
- Acting out behaviors at school
- Physical symptoms like headaches or stomachaches unrelated to illness
- Significant changes in sleep or eating patterns ^[8]

Cleveland Clinic recommends consulting with your child's pediatrician or a school counselor if you notice these signs ^[13].

Conclusion

Helping your children understand your chronic illness diagnosis is a journey, not a destination. With honest, age-appropriate communication and consistent support, children can not only adjust to a parent's diagnosis but develop valuable life skills like empathy, resilience, and adaptability.

Remember that your attitude significantly influences how your children will perceive and respond to your condition. By facing your diagnosis with courage and openness, you provide your children with a powerful model for handling life's inevitable challenges.

As you navigate this path together, celebrate the opportunities for meaningful connection that arise, even within the context of illness. Many families report that working through health

challenges together ultimately strengthens their bonds and deepens their appreciation for one another.

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1. <https://www.parkinsons.org.uk/information-and-support/talking-children-and-teenagers>
2. <https://my.clevelandclinic.org/health/diseases/8525-parkinsons-disease-an-overview>
3. <https://www.parkinson.org/library/fact-sheets/children-teens>
4. <https://elunanetwork.org/assets/files/HSCC.SupportingChildren.handbook4.pdf>
5. https://www.michaeljfox.org/sites/default/files/media/document/061218_MJFF_TALKING_TO_KIDS.pdf
6. <https://www.parkinsons.org.uk/sites/default/files/2018-11/FS66 Talking to children WEB.pdf>
7. <https://www.kansashealthsystem.com/news-room/blog/2025/01/talking-about-health-issues-with-children>
8. <https://childmind.org/article/mental-health-in-children-with-chronic-illness/>
9. <https://www.parkinsons.me/books-for-children>
10. <https://www.health.harvard.edu/blog/how-to-talk-to-children-about-the-serious-illness-of-a-loved-one-2019120218468>
11. <https://www.parkinson.org/blog/tips/parenting-with-pd>
12. <https://www.parkinson.org/resources-support>
13. <https://www.merckmanuals.com/professional/pediatrics/caring-for-sick-children-and-their-families/children-with-chronic-health-conditions>