

# Telling Children About a Parkinson's Disease Diagnosis

The age of the child you are talking to will determine how you explain Parkinson's disease to them - the younger the child, the simpler the explanation. Asking a school social worker or therapist to help facilitate this conversation may also be very beneficial. Below are some basic examples of what you can say to children of different ages:

## **Preschool (3-5 Years Old)**

- "My hands are shaky because parts of my brain aren't getting the food they need"
- "It's hard for me to walk fast"
- "I might talk quieter"
- "I may not look happy when I'm with you, but I am!"

## **School Age (5-9 Years Old)**

- "Sometimes I might have a hard time playing catch with you because my hands shake and my movements are slow"
- "My facial expressions may not always match how I feel. If you are ever unsure of how I feel, just ask me!"

## **Adolescents/Teens (10-18 Years Old)**

- "I have Parkinson's disease. That means my brain makes less of a chemical called dopamine. Because I am missing dopamine, I might have some tremors, shaky hands, stiffness in my muscles, slowness in my movements, quietness in my voice, and difficulty expressing my emotions."

# Tips to Guide the Conversation

**Make Sure You Are Ready** – before discussing with children, make sure you have adjusted to and accepted the diagnosis

**Agree on Common Language** – meet with other important adults in the child's life to agree on a common language to use when talking to the children about the diagnosis

**Be Open** – during the conversation, be open about how you are feeling (confused, scared, worried, sad, or a combination of things) so your child knows it is okay to feel and express the same emotions

**Anticipate Questions** – be ready to answer questions that the child asks. Try to spend time before the conversation anticipating what they may ask and preparing age appropriate answers for them

**Parkinson's Is Different for Everyone** – emphasize with the child that Parkinson's Disease affects everyone differently, that not everyone will show the same symptoms

**Prepare Visual Aids** – a lot of kids will comprehend information better with a visual aid. This could be a book for younger kids or a basic diagrams for older kids

**With all ages, it is important to start with broad information and let the child guide how much they want to know with questions.**