

## A FAMILY AFFAIR: TALKING TO YOUR CHILDREN ABOUT PARKINSON'S

Parkinson's disease (PD) is a family affair, meaning that everyone in your family is affected by the disease. As a parent of young children and teenagers/young adults, it is valuable to consider the unique impact that PD can have on your children, and what can be done to continue to live a full family life.

### Telling Your Children

Children are perceptive. They can be quick to recognize when something is wrong, but may often imagine situations to be far worse than the truth. Whatever the age of your child, consider:

- Sharing your PD diagnosis, and openly discussing your experience.
- Providing information and resources on the disease from trusted sources.
- Communicating your best understanding of what the future may hold.

### Providing Accurate Information

A wealth of information is only a few clicks away, and when used properly, the internet can be a valuable resource. However, only certain websites can be trusted. Consider asking your children what they know about PD, and where they get their information. If the internet is mentioned, suggest going online together to websites that are reliable, and work together to establish a "bookmarked" list of trusted internet resources. This may eliminate the many unreliable hits that come from a generic search engine, like Google.

### Possible Impact on Your Family

A Parkinson's diagnosis will present challenges for your family, but it can also provide your children with opportunities to grow, and lessons they may never have encountered without experiencing illness in the family. Having a parent with PD can teach children to become more self-sufficient and independent, but also more compassionate, understanding, and patient with the people in their lives.

Parents without PD should not try to shield the PD parent from involvement with the children. It is critical for children to continue to see their PD parent as a parent with the same expectations, approaches to parenting, discipline, and boundaries. Stability and consistency will foster security and confidence in your children. Do your best to maintain their daily routine, particularly as it relates to sports, friends, and other special interests.

### Respecting Privacy in the Family

Your child may not want to talk to you about PD. However, it is important that they have someone to talk to. This could be a friend, parent of a friend, teacher, coach, relative, or religious leader. The Parkinson Society British Columbia consultation and counselling services are another resource to access if your child has questions about PD.

You may feel uncomfortable with having your diagnosis or disease process shared with members of the community. To balance your need for privacy and your child/teenager's need for support, set up options that work for both of you.

It is generally recommended that you share with your children's school any changes in your home. The staff at the school or sports coaches can be your allies in watching over your children's emotional health and looking out for signs of distress.

## Changes Take Time

Children may need time to grieve the changes and losses in their family life. They should be given permission to do so, and not be expected to always hold it together. Sometimes, your child needs to work through their sadness before they can adjust to a new reality.

Remember that you are the expert on your children. If you sense that something is different or wrong, you are probably right. However, your child may also be experiencing new stages of development both socially and emotionally, and their distress may not be related to PD.

## Helpful Resources

Parkinson Society British Columbia | [www.parkinson.bc.ca/resources](http://www.parkinson.bc.ca/resources)

Parkinson's Foundation | [www.parkinson.org/pd-library](http://www.parkinson.org/pd-library)

Parkinson Canada | [www.parkinson.ca/resources](http://www.parkinson.ca/resources)

Northwest Parkinson's Foundation | [www.nwpcf.org](http://www.nwpcf.org)

## Sources

McCue, Kathleen. (1994). *How to help children through a parent's serious illness*. New York, NY: St. Martin's Press.

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