PD ExpertBriefing:
Parkinson's and Parenting: The Impact on Children and Young Adults

Led By: Elaine Book, M.S.W., R.S.W., Clinical Social Worker
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University of British Columbia, Canada

To hear the session live on:
Tuesday, November 18, 2014 at 1:00 PM ET.

DIAL: 1 (888) 272-8710 and enter the passcode 6323567#.

To also view the session live on the computer by visiting: http://event.netbriefings.com/event/pdeb/Live/parenting/

If you have any questions, please contact: Valerie Holt at vholt@pdf.org or call (212) 923-4700
Introduction

Robin Anthony Elliott
President
Parkinson’s Disease Foundation
Parkinson’s and Parenting: The Impact on Children and Young Adults

Elaine Book, M.S.W., R.S.W.
Pacific Parkinson’s Research Centre
Vancouver, British Columbia
Learning Objectives

1. Understand the issues and challenges commonly faced by children who have a parent with Parkinson’s disease.
2. Learn about current research studying the impact of PD on children and adolescents.
3. Identify practical suggestions and solutions to help children and adolescents to develop coping skills, and avoid negative outcomes resulting from PD in the family.
4. Explore and discuss the types of resources (use of social media, online resources, focus groups) that might meet the needs of parents and children who are coping with Parkinson's disease in the family.
Family Centered Care

• Increased number of children being affected by parental chronic medical conditions
• World Health Organization endorses the incorporation of the patient’s whole family in providing care
Parental Illness Impact Scale (Parkinson’s Disease)

David Morley and Anette Schrag et al. (UK)
Research Update

• 40-50 percent of children felt that they did not have sufficient information about PD
• Close to half of children studied stated that more information would reduce their feelings of uncertainty and insecurity
• Twice as likely to experience low level depression in comparison to children without chronic illness in the family
• With longer disease duration comes a greater impact on family functioning
• 70 percent of respondents stated they have someone to talk to and have support from family and friends
Impact

- Changing roles
- Emotional and practical
- Anxiety re: the future
- Resentment
- Guilt
Adjustment Issues

• Illness characteristics
• Age and gender of person with PD and family members
• Availability of informal/formal supports
• Progressive nature of PD
Common feelings

• Shame
• Anxiety about stress in parental relationship
• Fear and grief
• Loneliness
• Confusion and frustration
• Worry
Positive Outcomes
Common Themes

• Know no other children with parents with Parkinson's disease
• Do not tend to share these issues with their friends
• Do not remember life before Parkinson’s
• Family support is very important
• More information please!
• Feelings of guilt and financial concerns
Quotes

• “My mom has made it as normal as possible. We just make adjustments.”
• “My mom’s outlook has helped us manage well. Her attitude has been the most healing for all of us. She is inspiring.”
• “It is not the end of the world. We are coping.”
• “It’s all a challenge but we have to live with it.”
• “We can’t do things the way we used to. We have to find new ways to spend time together.”
PD Does Not = Adjustment Issues

• Considerations
  – Age and stage of children
  – Presentation of symptoms
  – Social support
  – Preserve the parental role of the person with Parkinson’s disease
  – Share the diagnosis
More Considerations...

- Age appropriate information
- Communicate (family meetings)
- Normal age/stage development
- Your attitude as the parent
- Maintain family life
Key Factors for All Ages

- Provide information and reassurance
- Replace fears with knowledge
- Acknowledge feelings and validate
- Answer questions
- Instill hope and optimism
Suggestions for Your Children

• Ask for help
• Empower
• Connect with others
• Maintain interests
Future Directions

• Research
• Therapeutic services
• Focus group
• Use of social media for children and parents
• RAISE AWARENESS!!!
Resources

*How to Help Children Through a Parent’s Serious Illness* by Kathleen McCue

Parkinson’s Disease Society in UK [www.parkinson.org.uk](http://www.parkinson.org.uk)

[www.designingacure.com](http://www.designingacure.com)

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

Parkinson’s Disease Foundation [www.pdf.org](http://www.pdf.org)
Thank You!
Questions and Discussion
Resources from PDF

Fact Sheets
• Helping Your Children Cope with your PD

PD Resource List
• 750 Resources

Parkinson’s HelpLine
• Available at (800) 457-6676 or info@pdf.org
• Monday through Friday
• 9:00 AM – 5:00 PM ET
Upcoming *PD Expert Briefings*

**The Effects of Exercise on PD**  
*Tuesday, January 13, 1:00 PM - 2:00 PM ET*  
Margaret Schenkman P.T., Ph.D., F.A.P.T.A., Associate Dean for Physical Therapy Education, and Director, Physical Therapy Program, University of Colorado School of Medicine

**More Than Meets the Eye: Vision Symptoms of PD**  
*Tuesday, March 3, 1:00 PM - 2:00 PM ET*  
Daniel Gold, D.O., Assistant Professor of Neurology and Assistant Professor of Ophthalmology, The Johns Hopkins School of Medicine

**Maximizing PD Medications: How to Get the Most Out of Your Treatment Plan,**  
*Tuesday, April 28, 2015, 1:00 PM - 2:00 PM ET*  
Connie Marras, M.D., Ph.D., Associate Professor of Neurology, University of Toronto, Morton and Gloria Shulman Movement Disorders Centre and the Edmond J. Safra Program in Parkinson’s Disease, Toronto Western Hospital, Canada

**Challenges of Advanced Parkinson’s and Tips for Better Living**  
*Tuesday, June 23, 2015, 1:00 PM - 2:00 PM ET*  
Peter Fletcher, M.B.Ch.B., M.Sc., Consultant Physician, Department of Old Age Medicine, Gloucestershire Hospitals NHS Foundation Trust, United Kingdom
Please complete our SURVEY

Your responses help us to improve the work that we do.

Thank you.