

Todd Bischoff
PDTalks, Inc.
304 W. I St.
Ontario, CA 91762
909-996-6997



Children And Parkinson's Disease

From The Forthcoming Book:

Helping Children Cope With Parkinson's Disease: A Clinical, Developmental, And Practical Approach ©Todd Bischoff, PDTalks, Inc. 2007, All Rights Reserved

Factors To Consider

- ❑ Family Dynamic
- ❑ Communication Style Of Family/Child
- ❑ Religious & Cultural Beliefs/Background
- ❑ Child's Temperament (*Easy, Difficult, Slow-to-warm*)
- ❑ Child's Personality (*Distinct Qualities And Characteristics*)
- ❑ Child's Unique Social, Emotional, And Cognitive Growth
- ❑ Child's Past Coping Skills
- ❑ Your Personal Relationship With The Child
- ❑ Your Personal Upbringing
- ❑ Your Personal Morals, Ethics, Values, And Beliefs

Loss and Grieving

- ❑ **Elizabeth Kubler-Ross – 5 Stages of Grief**
 - ❑ Denial
 - ❑ Anger
 - ❑ Bargaining
 - ❑ Depression
 - ❑ Acceptance

“The process of accepting the unacceptable is what grieving is all about.”

Toddlers (0-2)

- ❑ **Developmental Milestones** – Attachment, Sensory/Motor Development, Interactional Synchrony
- ❑ **Understanding** – Limited, Sense Loss/Separation/Environmental Changes
- ❑ **Grief Reactions** – Mirror Primary Caregiver, Eating/Bowel Changes, Emotions
- ❑ **Support** – TLC, Consistency Of Routine, Play



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“I have one daughter who really doesn’t remember Dad before PD. When she started asking questions like, “*why does your arm and hand shake?*” I tried to keep it simple yet truthful. I told her that something went wrong in my brain and for now the doctors don’t know how to fix it.

Don’t try to go into much detail unless they ask for it.

Some of these little buggers are a lot smarter than we give them credit for. I sometimes think one of them will say, “*just do this*” and it will fix the problem.”

- Steve, 42

Preschool (3-5)

- ❑ **Developmental Milestones** – Wernicke/Broca’s Area, “*Learning*” To Control Emotions
- ❑ **Understanding** – Limited, Magical Thinking, Reversible/Temporary, Catch PD
- ❑ **Grief Reactions** – Regression, Separation Anxiety, Nightmares, Difficulty Expressing Emotions
- ❑ **Support** – Language, Not Contagious, Concrete/Short/Simple/Honest Answers, Drawing/Art, Age-Appropriate Books, Play, Role Modeling

“I am 38 and was recently diagnosed with PD. I have a 9 year-old daughter. My daughter is handling my PD very well. When my hand shakes, she calls it my alien hand. When I have difficulty walking, she is right there to help me.

She had a lot of questions at first, which I answered truthfully, and that seemed to help. I keep a very positive attitude toward my PD when I am with her, but I am not afraid to let her know that it is also sometimes frustrating.

My daughter is the one reason I do not just give in to my symptoms. I want to show her that just because Mom has PD does not mean that I have to give up on life!”

-Karen, 38

School – Primary (6-9)

- ❑ **Developmental Milestones** – Empathy, Perspective Taking, Self Esteem
- ❑ **Understanding** – Curiosity, Time And Life Cycle, Illness Not Personal, Irreversibility (9-10)
- ❑ **Grief Reactions** – Regression, Nightmares, School Struggles, Ill Same Age As Parent, Physiological Issues, Aggressive (*Boys*), Clingy (*Girls*)
- ❑ **Support** – Short/Honest/Simple Explanations, Too Much Information Overwhelming, Acknowledge Feelings, Role Model, Have Fun



“All I will say is that I have found my kids remarkably accepting of my PD. They help me when I ask, (e.g. going to the store, I hate packing the bags), and seem generally un-phased.

Considering they were 10 and 12 at diagnosis, they were old enough to know what it meant but still adapted brilliantly, better than some of my adult friends.”

- Michelle, 48

School – Middle (10-12)

- ❑ **Developmental Milestones** - Metacognition
- ❑ **Understanding** – Illness Real, Deeper Interest Biologically, Incurable Means Irreversible/Permanent/Universal And Sometimes Inevitable
- ❑ **Grief Reactions** – School Issues, Acting Out, Over Protective Behaviors, Anger Towards God And Medical Personnel, Fear Of Doctors
- ❑ **Support** – Reaffirm No One’s Fault, Recognize Grief Process And Assist Them Through It, Listen, Let Them Lead Conversation, Use Humor, Role Modeling, Play

“My children, now all teenagers, have a kindness and patience about them which never ceases to amaze me. I truly believe if anything good is to come out of growing up with a parent who has PD it's that.”

- Hilary, 46

“My oldest daughter did comment once, that together we make one brain. LOL!”

- Carol, 47

Adolescence (13-18)

- ❑ **Developmental Milestones** – Physical Maturation, Formal Operational Thought, Personal Fable, Imaginary Audience, Peers/Cliques/Crowds
- ❑ **Understanding** – Death/Illness Very Real, Life Is Fragile, Ponder Implications Of Serious Illness
- ❑ **Grief Reactions** – Depression/Suicide, Severe Anger/Embarrassment, Bad Choice Making, Idealization Of Ill Person, Fear Of Abandonment, Emotional Rather Than Cognitive Difficulties
- ❑ **Support** – Explanations Honest/Accurate, Give Permission To Express Emotions Appropriately, Clarify Expectations, Allow Child To Develop Identity, Encourage Communication With You/Others, Journal Writing/Poetry, Internet With Guidance, Honest But Positive Role Modeling, “I Don’t Know”, Patience



Maladaptive Coping

Seek Professional Assistance If:

- ❑ Intense Reactions Each Time The Situation Is Brought Up
- ❑ Minor Events Trigger Major Responses
- ❑ Develops Same Symptoms As PWP, Convinced They Have PD
- ❑ Withdrawal From Family, Friends, Major Lifestyle Changes
- ❑ Reckless Or Self-destructive Behavior, Violence, Substance Abuse, Driving Too Fast
- ❑ Develops A Phobia About Illness In General (*Hypochondria*)
- ❑ Completely Avoids Any Association With The Illness

Todd's Top Ten Tips

1. **Be Aware Of Your Conversations Around Children** - *Be careful what you say, how you say it, and who you say it to*
2. **No One's At Fault** - *Dispel myths and rumors, it's not your fault, my fault, the doctors fault, etc.*
3. **Communicate With People Outside Of The Family** - *Teachers, school nurse, counselors, pastors, relatives*
4. **Listen To Children** - *They need to talk, not just be talked to, maintain eye contact, acknowledge feelings, assure feelings are normal, thank them*
5. **Ask Simple Questions** - *What have you heard about PD? What are your worries? Open-ended questions are best*
6. **Provide Simple Explanations** - *Often over-answering reflects our own anxiety*
7. **Be Honest** - *Complicated answers can result in confusion and distraction*
8. **Don't Be Afraid To Express Your Own Emotions** - *Children receive permission to mourn and grieve from adults*
9. **Encourage Expressions** - *Drawing, painting, journaling are great ways for children to express emotions and feelings*
10. **Children Do Grieve** - *Remember that each child is unique and individual in their reactions and expressions to loss and grief*

