

PARENT ROADMAP

We recognize that navigating the balancing act of raising a child with a rare disease, in addition to other children is difficult. We hope to help you recognize common feelings, reactions to look out for, and tips to remind your sibling children that they are seen, loved, and supported.

What You Can Do

- Provide developmentally appropriate explanations
- Set aside individual time with siblings doing things they enjoy
- Clear up misconceptions
- Be honest and truthful
- Model appropriate open emotions
- Invite siblings to be involved in care
- Remain consistent with routines, discipline, and schedules
- Provide siblings with choices
- Connect to others in similar situations
- Take care of YOU

Resources

- Children's books
- Parent2Parent USA
<https://www.p2pusa.org/parents/>
- Patients Rising
<https://www.patientsrising.org/>
- Courageous Parents Network
<https://courageousparentsnetwork.org/>
- Sibling Support Project
<https://siblingssupport.org/>
- Siblings with a Mission
<http://www.siblingswithamission.org/>
- Angel Aid
<https://www.angelaidcares.org/>
- National Alliance for Caregiving
<https://www.caregiving.org/>

Signs Your Sibling Child Might Benefit From Extra Support*

- Anxious
- Depressed
- Withdrawn
- Doing poorly in school
- Negatively acting out for attention
- Losing interest in activities they previously enjoyed
- Changes in eating or sleeping patterns

*If you are concerned about your child's behaviors, contact your children's local psychologist, therapist, or resources through your child's school

Common Feelings of Siblings

- Guilt
- Anxiety
- Jealousy
- Anger
- Fear
- Frustration
- Confusion
- Worry
- Embarrassment
- Sadness
- Responsibility

Common Feelings of Parents/Caregivers

- "Blur" after diagnosis
- Isolation
- Guilt
- Disorientation
- Loss of identity
- Anger
- Frustration
- Exhaustion
- Failure
- Confusion
- Uncertainty
- Worry
- Responsibility
- Fear of the future
- Lack of normalcy
- Emotional & financial stress

Connect with resources to help guide you through this journey

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www.ptcinsightfulmoments.com/

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