

Siblings and Loeyes-Dietz Syndrome

AT THE 2016 LOEYS-DIETZ SYNDROME FOUNDATION CONFERENCE, OUR LDS SIBLINGS DECIDED TO SHARE SOME IMPORTANT ADVICE TO OTHER SIBLINGS AND TO PARENTS.

ADVICE FOR SIBLINGS OF NEWLY DIAGNOSED CHILDREN WITH LOEYS-DIETZ SYNDROME

- Be prepared to take care of yourself and be on your own at times
- It's okay to feel frustrated that you don't get as much attention or special treatment as your sibling
- Don't feel sad or guilty that it wasn't you who got the condition
- Be prepared for medical emergencies to happen for your sibling; there may also be sleepless nights because you will worry that an emergency will happen. Have a bag ready for emergency overnight hospital stays for your sibling.
- Appreciate the fun days that you have with your sibling; don't worry that something bad will happen
- Don't feel you have to hide what you're going through; find people who you can talk to
- Have your safe places (school, music, hobbies, friends) where you can just be yourself and not just _____'s sibling
- There will be a lot of difficult, hard roads ahead. You might not think there's any good that will come from it while you're going through it, but you will be able to push through it!

ADVICE FOR PARENTS REGARDING SIBLINGS

- Don't forget us! We're here too and we have needs
- We also have extra responsibilities. In addition to being a sibling, we often take on other roles (caregiving, babysitting, helping out with chores, doing our own homework, making dinner for ourselves, protecting our sibling from bullies at school)

because you are busy with our sibling. We're expected to be more mature to help out, but remember that it's hard sometimes for us to live up to that expectation

- Try to create more equal expectations for me and my sibling; for instance, if we get into an argument with our sibling, try hear both sides of our story, and don't give us a harsher punishment just because we're not the one who has the condition
- When it comes to health issues for our sibling, don't hold information back from us. We need to know the entire truth of what's going on. Don't think that we can't take it; we'll probably have to deal with it eventually
- Remember to celebrate us and our accomplishments!

For a more detailed conversation about sibling topics, please access "What Siblings Would Like Parents and Service Providers to Know" at: <https://www.siblingsupport.org/documents-for-site/WhatSiblingsWouldLikeParentsandServiceProviderstoKnow.pdf>. This resources come through The **Sibling Support Project (www.siblingsupportproject.org)**. The Sibling Support Project was founded in 1990 and is the first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns. They have published books for and about siblings, host online groups for teen and adult siblings, and presented **workshops** on sibling issues internationally and in every state.

