

# SUPPORT FOLLOWING A DEVASTATING DIAGNOSIS



## Discussion points for clinicians and caregivers

- Reassure family that you're not going anywhere and that you are in this journey together.
- Understand the need of whole family care, not simply medical care for the affected child. For instance, be prepared to share advice to help parents support other family members. Offer to talk to siblings or family members.
- Provide resources or directions to other areas of support.
- Understand that families will have to make choices about working outside the home for both practical and emotional reasons. There is no right or wrong answer, as each family is different.
- Encourage questioning and address fears: Although parents may initially feel overwhelmed with that they do not know, as they seek to learn more and cope with the reality on a daily basis, they often ask informed, pointed and relevant questions. This may pose a challenge and could be perceived as a negative, but it can provide opportunities for learning and opening up options to provide the best quality of life and care for their child.
- Be honest about what you do not know.
- Respect family's wishes and be supportive.
- Accept limitations.

*\*adapted and shared with permission from [CPN](#)*

