

THALASSAEMIA

and your family...

Thalassaemia doesn't just affect the person diagnosed with it, the whole family is affected by coming to terms with the disorder, making major changes in schedules and priorities and somehow manage to remain a family.

Parents may struggle with their own feelings about their child's illness and try to put on a brave face. It is normal to feel a sense of disappointment and grief for the way you imagined your child's life would be. Caregiver burnout and stress on relationships in the family can become overwhelming.

Siblings of the child with Thalassaemia may feel left out, and later may feel guilty at any bad feelings they have toward their brother or sister. Less time will be available to spend with the other children in the family; parents need to let them know that they are still special and important.

The most successful families tend to be those who are able to move on from seeing Thalassaemia as an intrusion toward working together as a team to face the responsibilities of managing a long-term condition.

What your family can do:

❖ *Have fun together as a family*

You can expect the whole family to under increased stress at times. Maintaining your commitment to your family and getting support from each other may be harder during times of stress, but is also even more important! Spend time together that is not focused on being sick.

❖ *Involve the shoe family and even an extended support network*

Allow each family member to help in any way that they are willing able. Seek support from people outside your immediate family, such as through your extended family, school, religious community, neighbourhood, or children's hospital. Often people don't know exactly what you need so don't wait for them to offer it. If someone gives you a generic offer of help, tell them what you need specifically, and ask if they can do it for you.

❖ *Teach coping skills*

Parents need to help children learn new ways to cope with the special challenges of living with Thalassaemia. Children and families can learn to build on their strengths and can even develop pride in their abilities to meet the challenges.

❖ *Don't let your kids hear more than you intend!*

If your conversations are adult and private, have them away from your children. Kids hear more than you may think, don't assume they are sleeping when their eyes are closed or that they don't understand!

If you would like to obtain more information, get in touch with other parents or have further concerns about your child please contact the Thalassaemia Centre:

Phone: (02) 9550 4844, Fax: (02) 9519 3517 or e-mail: coordinator@thalnsw.org.au



Thalassaemia Society of NSW

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