

THALASSAEMIA

and children's development

The impact of Thalassaemia on your child's healthy development depends on several factors, including their personality, family and most importantly their development.

Children's understanding, feelings and their skills in coping with Thalassaemia will change as they get older.

This is how some children adjust at different stages:

Infants and Toddlers

The task of this stage in childhood is to develop trust and an overall sense of security. They generally have very little understanding of Thalassaemia. They experience pain, restriction of motion and separation from parents as challenges to developing trust and security.

Preschool Children

They are beginning to develop independence which is crucial to their development. They may understand what it means to be sick but lots of doctor's visits and adjusting to treatment schedules can challenge the child's developing need for independence. The child may try to counter lack of control over their world by challenging limits and boundaries set by their parents.

Primary School Children (early years)

They are developing a sense of mastery over their environment. They can describe reasons for their blood disorder but these reasons may not be entirely logical. Children at this age often have 'magical thinking'. They may believe that they caused their disorder themselves, perhaps by being bad. Children also begin to sense that they are different from their peers. Parents can help by allowing children to help in the management of their treatment (as appropriate).

Primary School Children (later years)

These children are more capable of understanding Thalassaemia and its treatment but they should not be expected to react as adults do. They may feel left out when they miss school or activities with their peers. Parents may feel the need to protect their children by restricting them from activities with other children. This is a natural reaction, but it can interfere with the child's independence and sense of mastery. To the extent that they are able, children should be allowed and encouraged to participate in all school and extra curricular activities.

Adolescents

Adolescence is a time when we begin to develop a sense of identity that is separate from their family. Self image becomes extremely important during these years. That can be a problem when their appearance is altered by illness, medication or treatment. Teens are also beginning to develop a real independence from their families. Parents who have been very involved in their teens care for many years may find it difficult to let go of their roles as primary caregiver.

Many teenagers will go through times of denial and often stop complying with treatment and using their pump. It is important to help them gain control of their treatment and to understand its importance.

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.

Contact details are listed below.



Thalassaemia Centre of NSW

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