Impact on the Family

The Role of Social Work

When a child is diagnosed with a blood disorder it comes as a totally unexpected family crisis for which nobody could be prepared. The social worker is a member of the Haematology/Oncology team who is available to meet with you when your child is diagnosed and can also help you with issues as they arise.

Parents may find it useful to talk with the social worker about their hopes and fears for their child, support for siblings; ways of coping with the change of lifestyle. The social work service is available on an ongoing basis.

The social worker can also provide information about benefits, facilities and community resources.

The social worker can be contacted by Haematology Clinic staff, through the Allied Health Department or directly through the switchboard of the Hospital. If the social worker is not available, a message can be left so that the call can be returned, or an appointment made.

To help parents meet the demands of treatment there are a number of hospital and community services available.

The costs of travel, accommodation and possible loss of income may cause financial pressure. To help with this situation there are some allowances that can be claimed.

Carer Allowance

Parents of children with some severe continuing blood disorders may apply to Centrelink for a Carer’s Allowance. This allowance is intended to assist parents with the increased costs, and the demands of constant care caused by the child’s illness. This allowance is paid each fortnight to entitled parents at the same time as the Family Tax Benefit.

Application forms are available from your social worker and they can assist you with completing the form, if needed. Ask your doctor to fill in the medical section.
Patient Assistance Travel Scheme

Where families live more than 100 kilometres from their specialist medical treatment centre, they are eligible under this scheme to claim from their State Government for partial repayment of their travel and accommodation costs. Application forms are available from your local GP and health centre. They can also be obtained from the receptionist at Paediatric Allied Health.

Families who are unable to gain this assistance, but who have financial or family problems, are asked to discuss these in confidence with the social worker.

How will I cope?

Parents often experience feelings of shock, numbness and disbelief after their child has been diagnosed with a blood disorder. These are the common signs and symptoms of shock, which may be followed by a deep sense of loss – the loss of a healthy child. Later reactions may be denial, anger, guilt, grief, fear and confusion.

These are all natural reactions. In time parents will adapt to the new demands placed on them. Each parent will cope in his or her own special way.

At first parents often feel overwhelmed. There is a large amount of medical information to try and understand and decisions to be made. The hospital routine and difficulties of finding your way around the hospital can be confusing.

Some parents read books / articles and ask questions to find out as much about the disease as possible. They want to understand what the disease really means to their child’s future.

Other parents cope by becoming very practical. They find it comforting to concentrate on specific tasks that help them to feel that they have some control.

Some parents feel a very real need to talk over and over again about the disease and treatment, and they seek out family members and friends to whom they can talk and who can give practical aid or emotional support.

Concentrating on work may also be a way some parents use to try and cope with the disease. Others may avoid any discussions, which centre on the child’s illness. In the longer term this may leave one parent to take a heavier burden caring for the child.
Each parent will need a different time and amount of support to help them come to terms with the diagnosis.

General care

The focus is on assisting the family to live with the illness. The emphasis is on life and the quality of life, not only for the patient but also for the whole family.

The child with a blood disorder should be given the same discipline as other children in the family, and the temptation to shower them with gifts should be resisted. All children need love, affection and guidance – and this includes setting limits on their behaviour. Children with a blood disorder are no exception. Most parents think that in times of sickness they must devote their complete attention to the sick child, and that they may overlook behaviour, which at any other time would be completely inappropriate. It is quite understandable that parents of children with a blood disorder should want to over-protect their children.

However, over-protection can lead to problems as it restricts the child’s freedom and development. Even though the child may have a life long and potentially life-threatening disease, their needs are the same as those of any other child of a similar age. The child should continue to grow and to develop in every way. Brothers and sisters also have the same needs for love and security, and they will be very aware of any signs of favouritism that they might either see or imagine.

Parents who have any problems with the behaviour of the child are encouraged to talk these over with any member of the Haematology/Oncology team.

Telling your child

At the time of diagnosis the illness and the recommended treatment plan are explained to the parents.

The policy of the Haematology/Oncology Unit is one of honesty, and it is recommended that children be told as much about their disease as their age and stage of development will allow them to follow. They need to be told honestly and gently in words that they can understand. Some parents prefer to tell the child themselves with or without the doctor present, while others may want the doctor to do it.

It is important that children know why they must stay in hospital, and why they must undergo procedures that are often unpleasant
and painful – especially when they might be feeling and looking very well.

Experience here and at other centres has shown that a failure to be honest and open can damage the child’s relationship with their parents at the time that they most need communication with and support from them.

Children today have access to so much information and as a result they are more knowledgeable. They can hear about blood disorders from a variety of sources including television, Internet, school friends, parents or friends and also from the hospital. When they come to the McGuiness & McDermott Foundation Children’s Clinic, they often discuss their illness with other children. The only way that this flow of information could be stopped is by isolating them completely.

Knowledge about blood disorders can help to reduce feelings of helplessness and fear. If children are not told about their illness, they may conclude that it is much more serious than it really is.

The initial shock of the diagnosis may make it difficult at first for parents to talk to their children and offer support. However, with time, parents will gain strength and confidence and usually become more able to respond to their children’s need for information, love and security. This is an important and sensitive area, and hospital staff are willing and able to help parents with it.

Older children and adolescents need more detailed information than do younger ones, and they should be encouraged to take an active part in the process of making decisions about their treatment.

**Guilt feelings**

Parents may feel an overwhelming sense of guilt if their child’s blood disorder is the result of a heredity trait. This is a normal and common reaction. Talking to the genetic department can be of help especially when planning to have more children. It may also help to talk to the social worker.

The child, too, might feel guilty about the blood disorder, and need support that he or she has not done anything that could have caused it. Younger children are sometimes tempted to see a stay in hospital or treatment itself as a punishment for something they have done wrong. Young brothers or sisters can also hold this view.
Your child’s reactions

Going into hospital is often a new and frightening experience for the child, and especially a younger child faced with separation from the mother. Children often feel confused and angry not only at the doctors and nurses but often at the parents too. It is quite common for children to act out their anger, or to respond as if they actually blame their parents for the situation.

Young children can be quite overwhelmed by what is happening to them, and sometimes their development may regress as they try to cope with the threats imposed by hospitalisation.

Children younger than about eight might not have the skills to be able to say what they are feeling, and so their fear, sadness and later their anger may be acted out in their play and behaviour.

Some children express these feelings through drawings, working through their feelings about the new experiences to which they are being exposed. Others might simply withdraw, and this can leave the parents feeling shut out of the child’s private world.

Children are as individual as the parents but, no matter what their response, they need comfort, understanding, unconditional love and a sense of security.

Any parents who want to discuss any aspect of their child’s reactions to being in hospital or to the treatment, or who feel that their child might need additional help, are invited to talk about the matter with a member of the Haematology/ Oncology team.

Adolescents

At a time when they are trying to be treated as adults and asserting their independence, teenagers placed in hospital are suddenly faced with real loss of control. This is heightened by their poor health, the increased emotional and perhaps financial dependence on parents. Lifestyle pursuits and planning for the future are suddenly interrupted.

As far as is possible, teenagers need to feel they are a part of the decision-making processes. They need time and space for private talks with the hospital staff, and they need to be able to seek out other adolescents on treatment so that they might share their feelings and experiences.

Teenagers may need and want their parents to be there, but they often find it hard to actually ask them to be. Adolescents usually
want to talk to someone about their illness, but only on their own
terms and in their own time. The family, staff and friends should
respect this need for privacy and some sense of control.

**Brothers and sisters (siblings)**

Just as the child and parents are affected, so too are the brothers
and sisters. Their life is suddenly turned upside down. They know
that their brother or sister is sick, and they are naturally worried.
They can see that their parents are very upset and that their
activities revolve around the sick child – suddenly it seems that
nobody has any time for them. They may display any of the
following behaviours

- Frightened they will catch the blood disorder
- Jealous of the gifts and attention the sick child receives
- Pretend to be sick to receive attention
- Feel rejected by their parents
- Feel sad that their brother or sister might die
- Angry that their normal life has changed and blame the sick
  child, or hospital staff
- Feel guilty and confused about their feelings
- Feel guilty for being healthy

Often siblings will try and hide these feelings from their parents so
not to cause them any further worry.

**How can parents help?**

When the blood disorder is first diagnosed, young brothers and
sisters often need help to understand what it is, and how it is
present in the body even though it cannot be seen. It should be
explained that the blood disorder is not contagious and they will
not become ill.

Here are some suggestions that might help to involve brothers and
sisters in what is happening inside the family.

- Explain as much about the child’s illness as a brother or sister
can understand. Any member of the team will help with this.
- If possible, the brothers and sisters should be allowed to visit the
  hospital. If the child is in hospital it can be arranged that they
  come at treatment time so that they can have explained to them
  what is happening. If the sick child is attending as an outpatient,
then brothers and sisters can come and see for themselves how
the treatment is given.

If the sick child is in hospital, parents might want to be with the
child 24 hours a day. In this case the parents may decide to take it
in turns, while the other gives some time to the other children – it
might also be a good time to involve other family members as
stand-ins.

Find special time to spend with each child. Listen and talk about
their feelings, and share some of your own. Remember that it is all
right to cry with them if you both feel sad. It is important that their
schoolteacher be aware of what is happening so they can give
extra support. Try and keep life at home as normal as possible,
especially school, family meals and other routines. Children are
children and not adults, and they are only capable of reacting,
feeling and thinking as their stage of development allows. Give
them extra hugs and cuddles.

Grandparents
The diagnosis of a blood disorder in a child is particularly upsetting
for grandparents. They not only see a much-loved grandchild sick
and having treatment, but they also have to see their own child
suffering. They might well feel helpless at not knowing how to
handle their own feelings and at the same time respond
appropriately to the needs of the family.

Grandparents can be a great help and support at this time. They
can spend time with the sick child, babysit the brothers and sisters,
and support the parents by attending the clinic with them, and by
being available to listen.

However, if the grandparents cannot cope with the diagnosis, then
it might be that they can be of little real help, and indeed they can
be an additional problem if the parents have to provide them with
emotional support. If this situation arises, the social worker can
offer suggestions as to how to deal with it.
Impact of a childhood blood disorder on couple relationships

The diagnosis of a blood disorder in your child and the stress of treatment are likely to have a major impact on you, the child’s parents, and therefore place extra strain on your relationship as a couple. Having a close and supportive relationship with your partner is one of the most important factors in helping you cope with the stress of a blood disorder in your child. For parents without partners such a relationship with a close and trusted friend or family member can make a great difference in how you manage this challenging time. Here are some suggestions on how your relationship can sustain you and remain strong at the same time.

Emotional

Shock, disbelief, anger, fear, guilt, powerlessness and the need to blame are some of the strong emotions, which commonly arise. These feelings are usually shared with the ones closest to you. Knowing how to share, listen and respond to these feelings is important.

- It is important to talk about your strong feelings and share them, rather than keeping them to yourself. This is especially true for men, many of who believe in keeping feelings to themselves. Not sharing them can lead to further feelings of isolation, frustration and anger and your partner feeling excluded and distant.

- If talking about your feelings is too difficult, writing them in a diary or a letter is often helpful.

- Listen, understand and respect your partner’s emotional state and needs. They may be different from your own.

- Avoid the tendency to judge their response or to tell them to feel differently.

- Don’t try to solve the problem or make the feelings go away. Your partner just wants to feel heard and cared for.

- Be aware that your partner’s own emotional needs may make it difficult for them to support you. At such times, it is useful to have a close friend and confidant to turn to.

- When listening is too difficult at the time, try again later, either through talking or sharing what your partner has written.
• Remember that these emotional responses can recur over the period of your child's treatment for no apparent reason. Don't expect to have gone 'past that stage'.
• You are encouraged to seek help if you feel overwhelmed. Ask a member of the haematology team to advise on options for getting extra help.
• Accept that there may be times when you or your partner feels 'ok' even happy and this is quite normal.

**Information**

During treatment you will receive a lot of information and hear terms that are unfamiliar; it will take some time to absorb and understand this information.
• Wherever possible, be present when the doctor is giving new information or when you want to ask further questions rather than relying on your partner to relay information or answer the questions.
• Make an effort to learn about the disease, the details of treatment and hospital procedures.
• Try to agree on how much information to share with your child and the other children, family and friends.
• Be aware that it is easy to forget what you have been told. To help remember to ask questions write them down and it some times helps to jot down the answers.
• Where you are uncertain or have a different view of information, ask your doctor.

**Lifestyle**

You will have many demands on you:
• Caring for your sick child, including giving them their medicine, taking them to the hospital for appointments, planned or unplanned hospital admissions.
• Caring for other children who need to know what is happening and why life is different. They may experience behaviour changes and become more demanding.
• At the same time normal household and family responsibilities don't go away.
To help you cope:

- Try to share these tasks equally and maintain some normality in your life.
- Discuss how to manage the children’s behaviour, what you will and will not accept. You may need to inform friends and family of your expectations. Be sure to support each other in this.
- Alternate spending time with the sick child and your other children.
- Make an effort to organise normal activities, family outings and holidays, including your own individual relaxation.
- Your relationship is also a priority. Take some time out for yourselves and include this as you plan ahead.

It may mean more time away from work, stopping work for a period, postponing other plans you may have had and restrictions on visitors or outings. It may mean living away from home and even some periods where family members are apart from each other.

- Where you need to change roles in any way, be patient with yourself and your partner. Try to reach agreement on roles that you will share, and those you will fulfil yourself.
- Recognise that you may be reliant on outside resources more than usual. Many families find it a great support to accept help from others as it allows time to spend with their child and family.

Parents who face this beginning period successfully often:

1. Give their partner sympathy and understanding rather than blame and criticism.
2. Make their sick child a priority; both parents come together to learn about the diagnosis and treatment.
3. Recognise that they must continue to share in caring and loving for their other children.
4. Share their own feelings of anger, sadness, sorrow and hope with each other.
5. Accept the help of family, friends and neighbours whom they love and trust.
6. Maintain loyalty to their partner in the face of criticism or blame from relatives or others.
7. Don’t be afraid to ask for help and accept and respect each other’s need to do this.

Support Networks

Every one of us has a social network that we use for support; these can include partners, relatives, friends, church, minister/pastor and community resources.

Parents can benefit by meeting with other parents who have a child with a blood disorder and have had similar experiences.

Having dealt with their own child they can provide valuable support and understanding.

It can be comforting to learn that your fears are quite normal, that you really are coping well, and that others DO care and are willing to help.

Accommodation for Families

Many parents wish to stay with their child while in hospital, and one parent may sleep in the ward with their child. Staff encourage parents to stay because they know the special needs of their child and it will help the child feel secure.

Other accommodation is in the Samuel Way Building in single or double rooms.

This building is part of the hospital and parents are close by if the child wants them during the night.

Located near the hospital, is Ronald McDonald House at 271 Melbourne Street, North Adelaide. Social work will need to make the first booking, but then you can book directly with Ronald McDonald House.