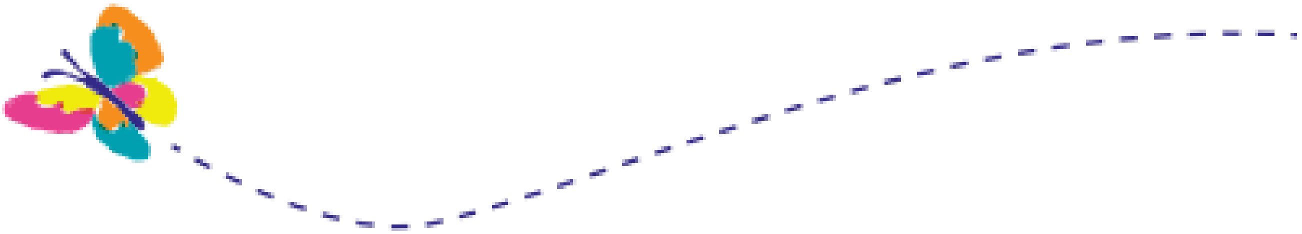
Dealing with Diagnosis and Ongoing Care

Lily x

together for short lives



Stage one: Diagnosis or recognition

Diagnosis & Recognition

Receiving the diagnosis or being told that your child has a life-limiting or life-threatening condition is one of the hardest moments that any parent can face.

Checklist

- Time available for open and honest face-to-face discussions and the opportunity to ask questions
- A private room to talk in
- A partner, relative or friend should come with you to offer support, so you are not alone at the appointment
- Helpful written material to supplement your discussion
- Information conveyed in a language you can easily understand, with interpreters provided if necessary
- Emotional support for yourself and your family
- Information about support groups

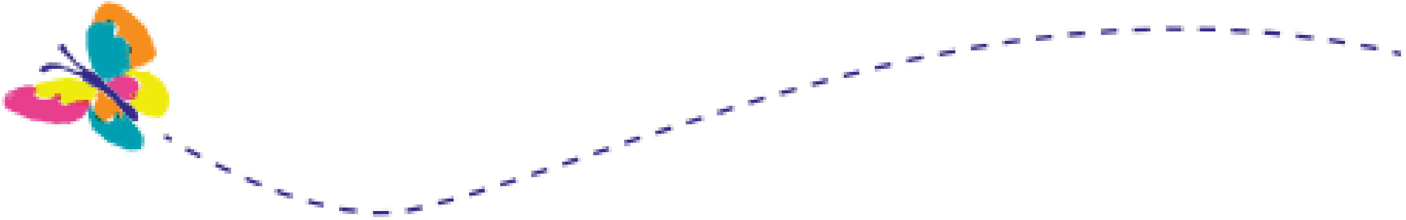
Top Tips

- Ask for copies of any letters written by the medical team about your child, so you always know what's going on.

- Write down questions you want to ask your doctor in advance, so you don't forget. Ask your doctor to write down the answers so you can look back at them.

- If you have other children, make sure their needs are not forgotten during this stressful time. They will no doubt have lots of questions and will need time and support to understand and come to terms with their brother or sister's condition. See our factsheet on Understanding Siblings' Needs.

- If your child was diagnosed within the hospital setting, you should have an agreed transfer plan involving the hospital, community services and yourselves. Make sure you have all the resources and equipment your child needs before leaving hospital.



Stage two:
Ongoing care

Ongoing Care

Once your child has been diagnosed with a life-limiting or life-threatening condition, it is important that their needs, and those of your whole family, are assessed regularly so that the right support is put in place to allow you to enjoy quality time as a family.

Checklist

- A multi-agency needs assessment should take place as soon as possible following diagnosis.
- The assessment process should involve all agencies and providers so that you do not have to repeat your needs to different services and organisations.
- You should be central to the assessment process and expect to work in equal partnership with your professional team.
- Your child should be the central focus of the assessment and be involved in the process.
- Care should be taken to include the needs of the whole family.

Checklist continued

- Your culture and personal beliefs should be respected.
- Straightforward, non-jargon language should be used.
- Issues of confidentiality and consent to share information with identified professionals should be discussed with you.
- You should be given your own copy of the assessment information to keep.
- It should be made clear who is taking the keyworker/lead professional role.
- Professionals involved in the multi-agency needs assessment should have appropriate skills and local knowledge of what is available.

Top Tips

- You can request a review of your child’s care plan if they have to go into hospital, if there is a change in your child’s condition or if something happens within the family that affects your ability to cope.
- It can be helpful to find someone for your child to talk to outside of the family, such as a trusted member of staff at your local children’s hospice. Your care team will be able to put you in touch with a suitable individual or service.
- It is usually a good idea to keep your child’s school informed about the progress of their condition, to enable them to keep up with school work and maintain links with school friends. If you have other children, it can also be helpful to inform their school so that they can provide emotional support as needed
- It can help to keep a diary of your child’s symptoms so that you can share this with members of the care team.

Understanding Siblings Needs

- Coming to terms with your child’s diagnosis
- Building trust
- How do siblings feel about their brother or sister?
- Worrying about talking to your children
- Finding the right words
- Finding the right time
- Finding the right approach
- How siblings may respond
- Remember that you are not alone

Hospice Services

Children’s hospice services help children and young people with life-limiting conditions who are not expected to reach adulthood, and their families, to deal with the emotional and physical challenges they face and to make the most of life. This care can be provided throughout the course of a child or young person’s life.

What Hospices can offer:

- • 24 hour telephone support
- • practical help, advice and information
- • specialist short break care
- • specialist therapies, including physiotherapy, complementary therapies, play and music therapy
- • 24 hour access to emergency care
- • 24 hour end of life care
- • care for a child’s body after death
- • bereavement support
- • information, support and training for parent carers