

Children's Community
Nursing Clinical Psychology
Information for Parents

About us...

Caring for a child with a life-limiting or life-threatening condition and managing the treatments and hospital admissions can be very challenging. Sometimes coping with this affects how you, your child or other members of your family think, feel and what you do. You might feel worried, or you might notice your child is quieter, or your partner feels down or that one of your other children is struggling.

If you notice any of these types of changes in yourself or anyone in your family, it might be good to meet with a CCN clinical psychologist.

What is a clinical psychologist?

We offer you the opportunity to talk through any worries you may have as a result of having a child with a life-limiting or life-threatening condition.

As well as talking and listening, we can offer suggestions for changing things, practical ways of coping and ways forward. We can also work with your child's school, doctors or anyone else you may like to be involved.

What support do we offer?

We can see you or a member of your family until your child with is 18 years old (or 19 in some circumstances).

We aim to work at your pace and we would decide together what kind of support would be most helpful. This may be:

- Seeing you by yourself;
- Seeing you and your family together;
- Seeing your child by themselves;
- Seeing their brother or sister;
- Offering your child the chance to join groups of other young people;
- Supporting your child's doctors, nurses or school.

Our main way of working is through talking but we can also use writing or drawing if your child would like this opportunity as well.

What can we help with?

We help families experiencing all sorts of difficulties. We could offer you or your family support around:

- Coping with sadness, anxiety, depression or anger;
- If you find it hard to talk to others about your child's condition;
- Worries that things are affecting your relationships;
- Managing your child's condition;
- Coping with their treatment;
- If your child worries that their condition makes them feel different to their friends;
- If your child is having problems getting along with their brothers or sisters;
- If your child would like to build up their confidence;
- Any worries you may have about your child's school because of their condition;
- If you or your child are struggling with thinking about the future. For some people this includes time to think about end of life wishes and plans.
- Complicated grief and bereavement work.

Not sure about seeing a psychologist?

Often people feel unsure about seeing a psychologist for lots of different reasons.

If you are not sure or have questions or concerns, do feel free to talk to your children's community nurse, or contact us directly and we can either discuss this with you over the phone or arrange a time to meet with you to do this in person.

Would you like an interpreter?

If you or do not speak English, or have any communication difficulties, please let us know. We can arrange for an interpreter to translate for you.

Any questions?

Please give us a call on: **01225 731624** or ask your children's community nurse for more details

What will happen if you decide to see us?

If you would like to talk to us, we will arrange to come and see you.

and we can

We often find it helpful to meet you with your family for the first time, but sometimes you might like to meet us alone.

If we are seeing your child, we usually see them at home but we can also meet them at school or somewhere else if you prefer.

We sometimes agree that we will meet a number of times or you may find that one appointment is all you need.

We allow 45mins -1 hour to discuss how things are for you and to give you the chance to ask questions and find out more about what psychologists do.

Confidentiality...

We know that what you tell us is very personal and important and we treat all the information you tell us confidentially. We do not tell other people what you tell us without discussing it with you first.

As we work as part of a team with the nurses, we do update your child's nurse, their medical notes and your GP with our general progress.

If we need to discuss what you have told us with anybody outside the team, we will talk about it with you first. The only exception is if we think you or someone else is at risk of harm and we need to tell someone about it in order to help the situation.

How you can support your other children/ Sibling Groups in Lifetime

Lifetime sibling groups are aimed at finding positive ways of helping children express their feelings and develop healthy ways of coping. We know from clinical experience and from the research literature that siblings of children with life limiting and life threatening illnesses may at times experience difficult feelings, which can include:

- **Worry** – about whether they will get ill like their siblings, about whether their siblings may get ill or go back into hospital, or about the impact of the illness on the family.
- **Resentment** – siblings may experience resentment, disappointment and a sense of unfairness, even if at some level they understand the reasons (e.g. the extra attention and time given to their brother or sister, or the limitations imposed on the family such as not being able to go on holiday, have days out, etc.).
- **Sense of loss and isolation** – siblings may feel different from peers who have well siblings, and sad that they cannot have the same relationship with their sibling that they might otherwise have had (Meyer, 2005).
- **Embarrassment** – this may relate to their sibling's differences, appearance or behaviour (which may lead, for example, to a reluctance to invite friends around to play).
- **Responsibility** – siblings may have to cope with increased responsibility and independence as their parents are preoccupied with caring for their brother or sister, or even care giving demands themselves.
- **Guilt** – the child may worry about whether they caused the illness through something they did wrong, they may feel guilty about being the “healthy one” or about their abilities in relation to that of their sibling, or they may feel guilty about other feelings they have towards their sibling or parents.
- **Love and protectiveness** – siblings often have lots of positive feelings towards their siblings too!

These are all really normal and understandable feelings and it is important that children can realise this and feel able to express their feelings and be supported to cope with them. It is also very helpful for children to have clear, age-appropriate information about their sibling's condition and to feel able to ask questions, as children otherwise tend to use their imagination to fill in the gaps.

Our sibling groups at CCN aim to provide a safe, fun environment to explore:

- **Information** - Share information about their brothers' and sisters' condition and identify any misconceptions.
- **Feelings** - Express feelings about their brother or sister's condition and its impact on them and their family.
- **Normalise** - Realise that the feelings they have are normal and share experiences by meeting with other children in similar situations.
- **Coping** - Explore useful ways with coping with their situation and feelings.
- **Friends** - Make new friends and have fun.

If you would like to discuss anything further, or have any queries or concerns about the needs of siblings, please do not hesitate to contact one of the CCN Clinical Psychologists on 01225 731624 or talk to your CC Nurse. The following links also have some helpful information on the needs of siblings:

- www.sibs.org.uk
- www.act.org.uk/families