

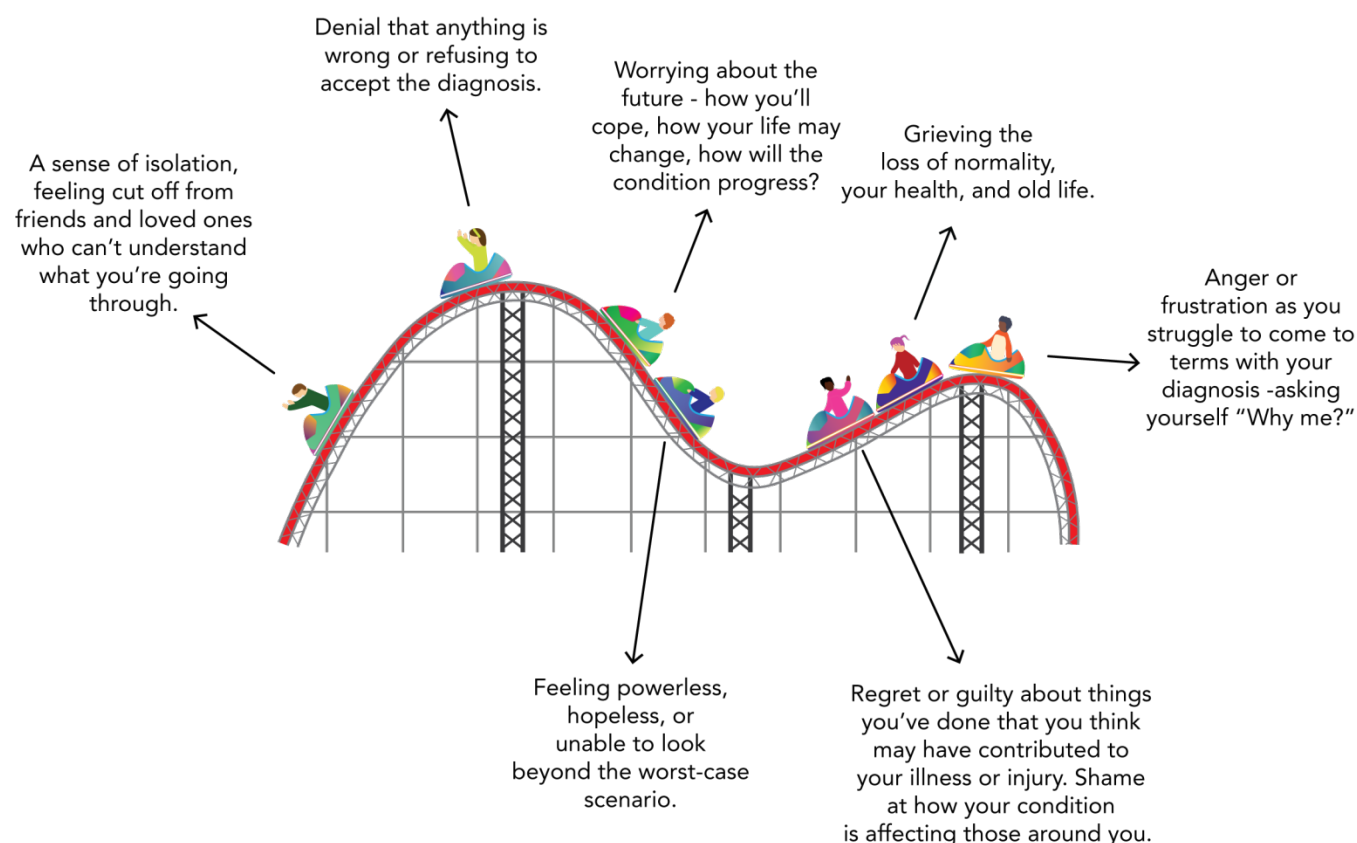
Coping with your child's health condition

Information for parents and carers



Paediatric Psychology and Liaison Service (PPALS) Royal Hospital for Children and Young People (RHCYP)

A diagnosis can happen unexpectedly or can feel like a relief after a long period of your child having unexplained symptoms that will have understandably caused some worry. Processing the information can take some time and can lead to some difficult thoughts and feelings. Some families describe the process as being on an emotional rollercoaster.



You also might experience a sense of relief and feel reassured that your child is receiving the appropriate medical care. However, there is no right or wrong way to respond to your child's diagnosis. We're all different, so try not to tell yourself what you should be thinking, feeling, or doing after a diagnosis. Give yourself time to process the information and be kind to yourselves as you adjust.

It is important to remember that you are not alone; statistics show that 15–20% of families have a child who may have a health issue that involves regular treatment or medical care. Therefore, there are also many parent support groups and services for supporting parental wellbeing. You might find it helpful or comforting to meet other parents/carers who are going through similar things and can offer friendly advice (see a comprehensive list of charities and organisations at the end of this leaflet).

Why is it important to speak to my child about their condition?

Having a physical health condition can be a difficult time for children and young people. Your child may feel disbelief, anger, uncertainty and fear. Children may show their worry through changes in their behaviour, eating, sleeping, schoolwork or friendships. It's important to recognise that these are common and normal reactions. However, talking about these worries can help support your child through the process of coming to terms with their condition.

Talking to your child about their condition will also help them to get helpful and accurate information about their health condition, rather than relying on information from friends or the internet. Helping children to understand their illness needs sensitivity and a good sense of timing. It is something that goes on over many years with the aim of giving them a good understanding that is right for their developmental stage and age. When your child has a good understanding of their health condition, this will help them to become more involved in making choices about their condition in the future and increase how likely they are to follow the treatments or advice their medical team might suggest.

What to do and say depends on developmental stage

Infants will be most affected by changes to routine and separations from parents/carers (for example, if they need to stay in hospital).

There are some strategies that you can use as parents/carers to help reduce your baby's distress. For example, physical touch such as skin to skin contact, swaddling or rocking can help soothe your child and provide a distraction during medical procedures.

Sensory stimulation such as bubbles, music, singing, lights or books, or other transitional objects (toys, teddies, comfort blankets) can also be helpful.

If you are staying in hospital, you can try and get involved in care tasks, so ask nursing staff or your medical team for some advice about this.



Pre-school (approximately ages 3 to 5) children might think illness is caused by something they have done, by catching it or by something magical. They might also think of treatments as punishments, especially if these are painful (for example, blood tests or injections). When talking to your child you could say things such as "You need to take medicine to help you stay strong and healthy".

At this stage it is helpful to start talking to your child about their medical condition and about coming to hospital. This can be done by making stories together, through play or by drawing about how your child feels.

If you are finding hospital appointments to be challenging or upsetting for your child, you can use distraction (such as having their favourite toys available).

It may also be helpful to prepare your child for the appointment so that they know what will happen. Providing this information should be done the day before a hospital appointment. You could try telling your child: "We all need to go to the doctors sometimes to make sure we are healthy - tomorrow we are going to see the doctor together and they will see how you are doing".

You can practice some relaxation techniques with your children to help them to manage anxious feelings. Practice these regularly when they are calm, and they will be easier to use when they are feeling anxious in an appointment. For example, you can try out “teddy bear breaths” or “squeeze the lemons” (see below).

Keeping to a routine and maintaining usual boundaries will help your child feel safe.

Pretend you have a lemon in your hand

- Reach up to the tree and pick a lemon with each hand.
- Squeeze the lemons hard to get all the juice out – squeeze, squeeze, squeeze.
- Throw the lemons on the floor and relax your hands.
- Then repeat, until you have enough juice for a glass of lemonade!
- After your last squeeze and throw, shake out your hands to relax.



Primary school (approximately ages 6 to 11) children begin to have a basic knowledge of body parts and their functions and can understand simple explanations about illness and its effects on the body. They can be interested in why people become ill and can make links between their illness and needing treatment. For instance, they can understand that "Blood tests help us to see if the medicine is working."

It is important to continue to create and read stories about your child's condition as your child's understanding of illness is still developing.

Using simple explanations in small chunks can help your child process this information.

You can give children information up to 1 week before hospital appointments to help them prepare.

Talking about emotions and worries are appropriate at this stage. You could use open ended questions to explore their worries to help find out what the specific difficulty is, and problem solve with your child.

It could be beneficial to explore coping skills and anxiety management. You could ask your medical team about getting a hospital passport that has lots of helpful ideas for coping with appointments and gives you and your child a space to record what helps them during an appointment for their medical team to read. There is also a space for collecting stickers for after their appointment.

You could look at the Hospichill app together for fun relaxation exercises to try out and you could make a checklist of what would be helpful to bring to appointments.



Teenagers (ages 12 to 18) understand that there are many causes of illness and that psychological factors can also influence things. They can understand ideas about prevention and factors that may cause symptoms, such as stress and physical activity. Being diagnosed with a health condition can be particularly challenging during this time as teenagers often seek to become more independent but may need more support compared to their peers to manage their condition. It can help to reassure them that talking about their feelings and worries is a positive way of coping and is how adults often deal with stressful situations.

At this stage, they are likely to be more aware of the difference between themselves and their peers, which can affect their acceptance of their health condition. Feelings of independence are likely to be important. You can encourage your child to ask medical staff questions and support them to become more involved in decision making.

It is important to validate how your teenager is feeling. You could say “it’s ok to feel...”, “it makes sense that you might be feeling...” or “lots of people experiencing...” to help them to feel heard and to reassure them that however they are feeling about their condition is ok.

It is important to be honest when talking to them about their health condition. Support them to identify reliable sources of information on the internet about their health condition. Your medical team can help with this if you are not sure.

Developing coping skills for managing difficult emotions, like anxiety, could be helpful at this stage. Your teenager could learn these with you through self-help guides provided by your team, school, or through the hospital website. Some young people might benefit from support from a mental health professional like a psychologist. If you have concerns about how your teenager is coping, discuss this with their medical team or your GP. Strategies such as using relaxation (deep breathing, progressive muscle relaxation or visualisation techniques) or distraction (computer games, and puzzles or crosswords) can be useful to practice together.

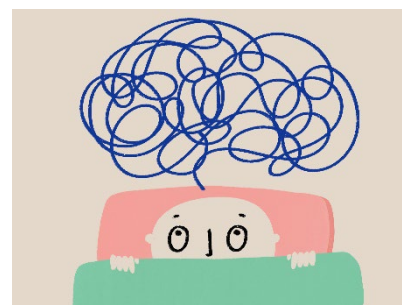
General advice

- If you can, wait for the right time to talk to your child about their health condition. It is better to give yourself time to adjust to before you discuss it with your child.
- If you have to speak to your child about their illness in a moment of crisis, explain things again later on when everything is calmer.
- Firstly, find out what your child already knows about their condition. For instance, you could say “What do you think about what the doctor said?” This will allow you to plan what you are going to say to your child.
- Give information in small chunks and repeat.
- Check your child understands the information you have given them to avoid misunderstandings.
- Seek knowledge together. You can ask your medical team for suggestions of where to get the best information about your child’s health condition.
- Be ready to answer questions which may come from your child. If it isn’t a good time to talk when they ask, promise to make time to answer them later.
- In appointments, remember that it is ok to take in a list of questions with you. You could prepare these in advance with your child if this is helpful.
- Get support from relevant services (details provided on pages 6 and 7).

Thinking about the future

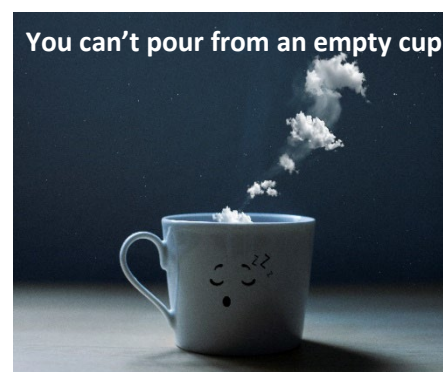
It is important to consider the future when talking to your child about their condition.

- As your child grows and develops, it is important to revisit questions that your child has asked so you can update them with information and check their current understanding of the situation.
- Your child's concerns may change at different points in their development. Be prepared to discuss any new questions and worries in years to come.
- Your child may have questions about life expectancy or quality of life so be prepared for this and plan what you want to say to them.
- Remember your child's perceptions of how illness will affect them in the future will be different from your own. This is because young people's brains are still developing so they are not able to think about future consequences in the same way as adults - this is a skill that they develop gradually.



Taking time for your wellbeing

It's okay to take time out to take care of yourself. We know that some parents/carers feel guilty about taking breaks from parenting duties. It's important that parents/carers feel supported to meet their own needs – like making time to eat and drink well, exercise, see friends, and do fun things. Taking care of yourself will help you care for others.




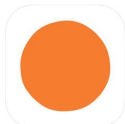

Notes

Suggested resources for parental wellbeing

We hope that some of these resources that other parents/carers have found useful in the past might be helpful for you. If you have any concerns regarding your mental health or if you need further support, contact your GP. In an emergency, contact NHS 24 on 111 or go to your nearest A&E (Accident and Emergency).

Apps

Relaxation and mindfulness can be useful skills to develop to help with coping with stress, anxiety and other difficulties.

App	Helpful for...
Smiling Mind 	<ul style="list-style-type: none"> • Provides different guided relaxation and mindfulness exercises • Free
Head Space 	<ul style="list-style-type: none"> • Provides mindfulness exercises • Has a free trial
Relax Lite 	<ul style="list-style-type: none"> • Provides relaxation exercises including a visual aid for controlled breathing techniques • Free

Supports and websites






Family Support Service is based at The Hub in RHCYP and provides a range of practical and emotional support. Ask your medical team about accessing this service.

Community Help and Advice Initiative is a free service based at the RHCYP, offering independent and impartial advice to people on their income, welfare rights, debt and employment. CHAI is a registered Scottish charity providing advice to people affected by housing, debt and benefit issues in Edinburgh and Midlothian. You can get in touch with the Welfare Adviser (Monday-Friday, 9am-5pm) on 07464 927 716.

Kindred is an organisation providing advocacy and information on services available to children with additional support needs and their carers. Contact details: 0800 031 5793 <https://www.kindred-scotland.org/>

Spiritual and Pastoral Care Department: Members of the Spiritual and Pastoral Care Team offer confidential, non-judgemental support to patients, and families whatever their beliefs or life situations. Spiritual Care is located on the ground floor, next to Castle Mey. Contact details: 0131 242 1990

Voice of Carers Across Lothian (VOCAL) works with carers and family members, offering practical and emotional support, training, counselling and advocacy. Contact details: 0131 622 6666

Kindred Scotland provides practical support and counselling to parents/carers of children with complex needs. https://www.kindred-scotland.org/hospital-support	
This website has a range of self-help resources created by professionals for helping to find new ways to manage different mental health difficulties including anxiety, depression, and low self-esteem, amongst many others. https://www.cci.health.wa.gov.au/resources/looking-after-yourself	
Solihull Online Courses for Parents/Carers <ul style="list-style-type: none"> • Understanding Pregnancy, Labour, Birth and your Baby • Understanding your Baby • Understanding your Child • Understanding your Teenager's Brain. To access these courses for free, families need to use the access code TARTAN . https://inourplace.heiapply.com/online-learning/	
Health in Mind run peer led online support groups for adults living in Edinburgh affected by depression, low mood, stress or anxiety. For more information email edinburghselfhelp@health-in-mind.org.uk or call 0131 225 8508 https://www.health-in-mind.org.uk/services/depression_and_anxiety_support_groups/d101/	
NHS Mental Health Information Station Walpole Hall, Palmerston Place, EH12 5AW Information on a range of adult mental health supports. Speak with an NHS Mental Health professional at the face to face drop in or telephone 0131 537 8688 on Thursdays 10.30am-3.00pm. Email: MentalHealthInformation@nhslothian.scot.nhs.uk https://services.nhslothian.scot/mentalhealthinformationstation/	

Other supports I have found:

Interpretation and translation

This leaflet may be made available in a larger print, Braille or your community language.

Acknowledgements

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