

Dealing with a Diagnosis of Childhood Interstitial Lung Disease (chILD)

The diagnostic process

Finding an accurate diagnosis for your child can take time. Sometimes months or even years pass between the start of symptoms and the final diagnosis. This can be a demanding, stressful and emotional time. Sometimes it is not possible to make a diagnosis.

Working together with the healthcare team during the period of diagnosis will help you and your child move through the process. Ask your doctor why each test is being done, what they are hoping to discover, the potential risks and what the test will be like for your child. The healthcare team will expect you to have many questions and will know that you may need something explained several times. After each investigation, ask your child's doctor to explain the results of the test.

The diagnosis conversation

Preparing for the conversation with the doctor about a diagnosis can be confronting. Request clarification of anything you have not understood. Share what your feelings are about this diagnosis. Often people forget questions that they want to ask their doctor during an appointment. It can be helpful to write down a "shopping list" of questions before you speak with them. Keep a list of any questions you may think of after the appointment so you can follow up at the next appointment.

Explaining the condition to your child

Children have a right to know their diagnosis. It is important not to try to protect children from it. They will know better than anyone else that something is wrong and that they are unwell. Not being informed about what is happening can actually increase their anxiety.

The healthcare team can work with you to explain the condition to your child, in an appropriate way

for their age and at a pace consistent with their level of understanding. It is sometimes helpful to use uncomplicated pictures and diagrams with the explanation, particularly with younger children. Children may be very closed or withdrawn during these conversations. This does not mean that they do not understand what is being said. Commonly, children will ask their questions after the doctor leaves the room, and it is important to write them down and address them at the next visit with the doctor. Sometimes, children cannot clearly put into words things that are weighing them down. Different services may be helpful at this point, such as art therapy, music therapy, or seeing a psychologist specialising in chronic health conditions in children. Discuss these services and their potential role in helping your child understand their diagnosis with your child's doctor.

Explaining the condition to others

Planning for how you might discuss your child's condition with others, such as family members, friends and employers, is important.

It can be useful to have all the family members involved with the care of your child present at the diagnosis conversation. Otherwise, it may be possible to arrange an additional appointment with the doctor, to explain things a second time. If someone cannot attend at all, it can be helpful to bring a list of their questions to the doctor and jot down the answers to inform them later.

If your child has a weakened immune system it can be useful to mention their immunodeficiency to family and friends, and how this may impact your families' participation in social gatherings. For example, if your child's risk of infection is high, at times you may need to avoid certain social situations to reduce their exposure to germs and illnesses. When navigating these discussions, it can be helpful to ask family and friends to let you know in advance if they themselves are unwell before spending time together, so you can make an informed decision about whether your child will attend or not.

If you have other children besides your son or daughter with chILD, it is important to keep them informed with truthful, age-appropriate information about their sibling's health. Ask if they have questions and check for misunderstandings. Provide them with opportunities to talk about their worries, feelings, questions and themselves. If needed, get help from a counsellor or someone who can help them open up about their concerns. See section on Hospital Services for further information.

Advice from a Social Worker may be valuable when having these discussions. Ask your treating healthcare team about how to access the hospital Social Worker.

Explaining to your employer

Your child's condition may impact on your work, depending on the nature of your employment and the severity of your child's illness. Although many children with chILD lead relatively normal lives despite their condition, many will require frequent and at times prolonged hospitalisation, with increased parental support. It is advisable to discuss things with your employer so they are aware of what is happening and can provide you with the appropriate support and assistance.

Things you may be feeling

A chILD diagnosis can have an enormous impact on you, your child and your family.

You will experience many emotions when a diagnosis of chILD is made. Understandably, feelings of sadness, fear, guilt, anger and confusion are common.

- **Grief**

It is completely normal for parents and carers to feel grief, and even intense sadness, when their child is diagnosed with chILD, hospitalised or told that they need surgery. Grief is often strongest in times of crisis but can pop up – sometimes unexpectedly – at other times during a child's life as well.

- **Fear**

Having a child with chILD often leads to being fearful. It's all too easy to fill your head with frightening 'what if...?' scenarios. Fear can rear its head in a variety of situations. One of the biggest fears of parents and carers is that their child will not survive. Other fears include that their child will be exposed to germs and illnesses, or stigmatised and socially isolated.

- **Guilt**

Many parents (and grandparents), especially mothers, feel like they did something wrong to cause their child's condition. These feelings of guilt are real, and you should acknowledge them,

but then let them go. There are factors that make it more likely for you to have a child with chILD, but that doesn't mean you caused your child's condition or that you should feel guilty.

- **Anger**

Anger is a completely normal reaction. You might feel like it isn't fair and wonder why it has happened to you. You might feel resentment toward others who have healthy children, especially if it seems like they don't appreciate how fortunate they are. Most parents and carers experience feelings of anger at some point, and those feelings do not make you a bad person.

- **Confusion**

Feelings of confusion are normal. You may be confused after receiving large amounts of medical information that you didn't fully understand. You might have turned to the internet to learn more, adding to your confusion and fear. Other parents of children with chILD might provide you with additional advice, which could be helpful, but could also add to your confusion because each person's experience is different.

- **Frustration**

Many parents will experience frustration. You may be frustrated that there is no diagnosis for your child and there aren't any answers, frustrated that medical staff have little knowledge on rare lung diseases, or frustrated that you aren't being heard by your child's treating healthcare team.

Taking care of yourself

As parents and caregivers of children with chILD, you must take care of yourself so that you can effectively care for your child. You will be faced with making important choices about your child's care, and you may not make the best decisions if you're too tired, physically unwell or overwhelmed with very high levels of stress or anxiety. That's why it's vital for you to take care of yourself.

- **Ask for and accept help**

Acknowledging and accepting that you need help can be difficult. Remember, your family and friends want to help you and support you during this stressful time, so allow them to do so. They may not be sure when or how to help. It is okay to reach out and ask for help. Make a list of things that need to be done to keep your life running and be realistic about what you have the time and energy to accomplish. Keep the list handy, and when things feel like they might be starting to get on top of you, talk to a family member or friend about how they can help and pick something from the list.

- **Give yourself a break**

You do not need to have all the answers or be with

your child every second of every day. We know it's scary to leave your child's side, particularly after surgery or when they are in the hospital, but you do really need to get away – even for just a little while. For your own mental health, it is essential to schedule time away from the responsibilities of parenting and caregiving. Make plans for a friend, family member or healthcare provider to spend time with your child while you read a book, go shopping, dine out, nap... anything that is truly relaxing.

- **Connect with your healthcare team, support network and other families**

Being the parent or carer of a child with medical needs can be an isolating experience. It is important that you reach out and connect with others who can help you feel less alone during the journey. Ask your healthcare team or social worker to refer you to community support groups or put you in touch with another family that has experienced a similar situation. Connecting with other parents or carers can help ease the fear. Use the internet to keep distant family and friends updated on your child's condition and care. Take advantage of your hospital's support services such as social workers, pastoral care or patient advocates.

- **Take care of your own health**

When you are caring for your child, it's easy for your health to become secondary. But if you aren't healthy, it will be more difficult to meet your child's needs. Regular exercise is important for both your physical and emotional wellbeing. It is important that you eat nutritious foods and drink plenty of water during your child's hospitalisation to ensure you stay hydrated. Keeping up with your favourite hobbies or developing new ones is a good way to take a mental vacation. Knitting, reading, drawing and blogging are easy ways to busy your hands and quiet your mind.

Taking time together

Don't let your child's diagnosis define your family. Recognise that your child's illness places every member of the family under increased stress and makes it more difficult for you to support each other. This is especially true for other children, who may have fears and anxiety that they aren't voicing. It is important for your family to spend time together that is not focused on your child's diagnosis. Plan family game nights, share special meals or attend a sporting event as a family.



FURTHER INFORMATION AND SUPPORT

Contact Lung Foundation Australia for more information, to access our support services and join our mailing list for regular updates and latest news.

Lung Foundation Australia Services

- Information and Support Team
- Lung disease information resources
- Education webinars
- Lung Cancer and Respiratory Support Nurses
- Support groups
- Peer-to-peer connections
- Referral to pulmonary rehabilitation and Lungs in Action exercise programs
- E-newsletter

External Links

- Australian Genomics
www.australiangenomics.org.au
- Consumer Information
www.genomicsinfo.org.au
- US Child Foundation
www.child-foundation.org

Lungfoundation.com.au | Freecall 1800 654 301 | enquiries@lungfoundation.com.au