



Stage: Diagnosis

Questions to ask medical professionals

- How did the CDH occur?
- Are there any other birth defects or concerns?
- Could there be genetic causes to CDH?
- Is this left sided or right sided CDH?
- How severe is my child's CDH?
- How much lung is on the side opposite the hernia?
- What organs have moved through the hernia?
- Is the heart pushed over or affected in any way?
- What do the arteries around the heart look like?
- Do the kidneys look swollen?
- What does the future hold for my child? Will they lead a 'normal' life?
- Will my baby's birth weight be affected?
- What are the next steps?

Advice from parents

- Make sure you speak to a range of doctors after your baby is diagnosed — obstetricians, surgeons, midwives and neonatologists. Each one specialises in different parts of the CDH journey and will be able to provide different insights. Hospitals will usually organise these meetings and appointments for you.
- Don't blame yourself for the diagnosis, there is nothing you could have done to prevent this.
- Remember that each CDH baby is very different and will respond differently after they are born. Take any medical numbers and percentages that doctors give you with this in mind and never lose hope.
- Do what you need to do to look after yourself after this diagnosis. The diagnosis is scary, heartbreaking and changes your excitement to fear. If this means you need to distance yourself from friends or family for a while, or if it means talking to a counsellor then do those things.
- Ensure you know about all of the appropriate support services available — from patient travel subsidy information, to social services and medical support etc.
- Seek clarification if you don't understand what the doctors are saying. Make contact with the social work team.
- Join the CDH support groups. It helped me so much to talk to other parents who had been through this experience before me.