



Information Sheet

Questions for Parents to Ask Healthcare Workers

You will have a number of appointments after your CDH diagnosis where you will have the opportunity to ask questions of different health care providers. The following questions and tips are suggestions by parents of children with congenital diaphragmatic hernia (CDH) to help expectant families.

Pregnancy

“Get second opinions; have someone else with you at appointments; talk to other families affected by CDH and research as much as you can so you can go in armed with knowledge so it’s not so scary and foreign.”

Mum of Harlee

Diagnosis questions

- 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?

Hospital questions

- What survival rates does your hospital achieve?
- How many CDH cases does your hospital deal with each year?

- Can I take a tour around the NICU unit (both hospitals if the baby is going to be transferred)?
- What kind of support is there at the hospital?
- Does the hospital or an association provide long-stay accommodation for me (and my partner/family)?

Treatment questions

- Will I have a fetal MRI?
- Will I need to have an amniocentesis? What are the risks?
- How often will I have appointments during the rest of the pregnancy?
- What are other potential pregnancy complications due to the CDH diagnosis?
- How often will I have ultrasounds?
- Can I get photos from each ultrasound?
- Can we watch our baby in 4D for a while at some of the ultrasounds?
- When will I meet the neonatologists?
- Who are the surgeons and when will I meet them?

“If you have a question write it down and make sure you ask it at next appointment.”

Matthew, dad of Nala

Labour

“Seek clarification if you don’t understand what the doctors are saying. Make contact with the social work team.”

Linda, mum of Emma

- Will I be allowed to go into labour naturally or will I need to be induced or have a caesarean section?
- (If applicable) At what stage of pregnancy will I need to relocate?
- (If you live rurally or remotely) If I was to go into labour in my local town, is my hospital one that is able to stabilise my baby for transport to the appropriate hospital?
- Is it safe to transport my baby between hospitals?
- Can the organs in the chest become damaged from being in the incorrect position? What kinds of issues or challenges could we face from the organs developing in the incorrect position?
- How much monitoring will take place during labour?
- How active can I be during labour?
- What things can go wrong during labour?
- What is your policy on having other people at the delivery? Can I have two people – one to go with the baby and one to remain with me?
- What drugs will be used during labour and are there any that will be avoided as they could have an effect on the baby?
- How many medical people are going to be in the room when I give birth? What are their roles?
- What happens if I give birth on a weekend? Is there always someone on call experienced with babies with CDH?

- Will my baby cry at birth?
- Will my baby look physically different at birth?
- Will they take my baby straight away or will I get to hold him or her?
- Can my partner cut the cord?
- What's the process after a child with CDH is born?
- If I have a caesarean section, and my baby needs to be transferred between hospitals, will I get to see my baby before they leave?

“Ensure you know about all of the appropriate support services available (from patient travel subsidy info to social services and medical support of any relevance, etc.)”

Joel, dad of Kurt

After Birth

“Talk to the nurses and allied health staff. They are the ones who will deal with you on a daily basis and for years to come.”

Rebecca, mum of Jasper

- Who are the different healthcare professionals who will be involved in my child's care? What will their roles be?
- How long is our hospital stay likely to be?
- Can my other children visit their sibling in the NICU?
- Can extended family or friends visit our child in the NICU?
- Do you use ECMO? Under what circumstances will it be used?
- What are the potential treatments that will be used (ventilators, drugs etc.) and what are the risks associated with these?
- How do you decide when to perform surgery? When will you know if surgery will go ahead?
- How long will you give my baby before deciding s/he isn't a candidate for surgery?
- What exactly will the surgeon do during surgery?
- What can go wrong during surgery?
- What can go wrong following surgery?
- How long will surgery take?
- Up until what stage can I stay with my child before they are taken in to surgery?
- How long do I have to wait after surgery to see my child?
- If I can't feed my child, what will happen with my breastmilk?
- Under what conditions will doctors say there is nothing more they can do for our baby and recommend removal from life support?
- At what point would my baby move from NICU to the ward?

“Meet with people who would care for you post hospital, and how the care over the first year or so might look and the complications to look out for.”

Lara, mum of Jackson

At Home

“Ask what is going to happen when we get home. These were some of the hardest times.”

Damon, dad of Liam

- What does my baby need to be able to do before he/she can go home?
- What support will I have once I go home?
- Could my child be sent home on oxygen?
- Could my child go home with a feeding tube?
- Does this hospital offer any follow-up services for children with CDH?
- Will my child have access to a feeding clinic if needed?
- What are the chances of having another child with CDH?
- Do I need to arrange a local paediatrician on top of our hospital one?
- How will my child be different from ‘healthy’ children?
- Who coordinates with other health services (E.g. My local GP, my maternal and child health nurse)?



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