

NO FAMILY TO FACE CDH ALONE



are you
expecting a baby with
CDH?

CDH AUSTRALIA

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REVISED (2018, 2020)

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First Published 2009

First published and designed by Damon Knott of As One Advertising and Marketing

This version published 2018 by CDH Australia

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CDH Australia would like to thank our community of CDH families for their ongoing support of this booklet. Parts of our booklet have been produced with permission from our community.

CDH Australia does not encourage or discourage any medical treatments or procedures. Our purpose is to educate families and medical care providers so that they may make the best decisions in their / their patients' interests.

You cannot compare your child to other children born with CDH; they are all different. The information in this booklet does not necessarily represent the views of all members or staff of CDH Australia.

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- 1. ABOUT CDH AUSTRALIA**
 - 2. WHAT IS CDH?**
 - 3. ABOUT CDH**
 - 4. WHERE TO FROM DIAGNOSIS?**
 - 5. QUESTIONS TO ASK HEALTH CARE PROFESSIONALS**
 - 6. FATHERS**
 - 7. COPING EMOTIONALLY**
 - 8. THE HEALTH CARE SYSTEM**
 - 9. HOW TO WORK WITH HOSPITAL STAFF**
 - 10. FROM BIRTH ONWARDS**
 - 11. SERVICES AVAILABLE TO YOU AT HOSPITAL**
 - 12. YOUR HOSPITAL STAY**
 - 13. THINGS TO THINK ABOUT**
 - 14. THE FUTURE**
 - 15. FAMILY MEMBERS & FRIENDS**
 - 16. ADVICE FOR SUPPORT PEOPLE**
 - 17. SOME ADVICE FROM OUR COMMUNITY**
 - 18. PROFESSIONAL, FINANCIAL AND CRISIS ASSISTANCE SERVICES**
 - 19. RESEARCH**
 - 20. GLOSSARY OF MEDICAL TERMS**
-

CDH AUSTRALIA

about CDH Australia

EXPECTING A BABY WITH CDH?

CDH Australia is a grassroots national health-promotion charity which supports the families of children diagnosed with the birth defect congenital diaphragmatic hernia (CDH).

"One day we hope to be redundant; we see a future where CDH does not exist. Until then, we aim to empower families to survive, thrive and live their best lives."

CDH Australia was established in 1999; we have supported over a thousand families since our inception. In addition to support, we seek to establish relationships with and between medical professionals, and to support CDH research.

Underpinning this is the need to raise awareness of the condition and of our organisation. We believe greater community and political awareness will provide us a firmer footing from which to advocate for our families.

CDH Australia has contact with up to 75% of families who are diagnosed with CDH. The majority of these are located in Australia, although we also have a small community in New Zealand. Our group consists of families, friends and medical professionals who have been impacted by CDH.

We are a registered Health Promotion Charity with Deductible Gift Recipient (DGR) status (ABN: 60 131 315 145).

One of the most important roles of our organisation is to offer support to families raising CDH children, expecting a child with CDH, or families remembering a CDH baby who passed away. We moderate online support groups, which many community members participate in. Our community are generous with their compassion and empathy, and have personal experience with a range of scenarios associated with having a child diagnosed with CDH.

Additionally, we offer limited financial support, care packages, volunteer-led family liaison services which include provision of helpful information sheets, referrals to external crisis support organisations, and facilitation of local events. We also offer annual forums for face-to-face networking and knowledge sharing, as well as fundraising and awareness gatherings.

If you're experiencing difficulties related to your family's CDH journey, please get in touch. We are not able to offer crisis services; however, may be able to assist with other difficulties you are facing or provide you with appropriate referrals.

CDH AUSTRALIA

about CDH Australia

**EXPECTING A BABY
WITH CDH?**



Families, grown survivors, expectant parents and key support people are welcome in our online group. Please note that membership is only for families based in Australia and New Zealand.

"The online support groups mean that there's always someone to connect with."

Many of the supportive relationships that develop are fostered thanks to email and social media. As CDH Australia's workforce are spread throughout Australia and New Zealand, we make the most of the flexibility and responsiveness offered by technology. But if you'd rather talk to someone, you can always pick up the phone. Do not hesitate to contact us with any questions or concerns you may have.

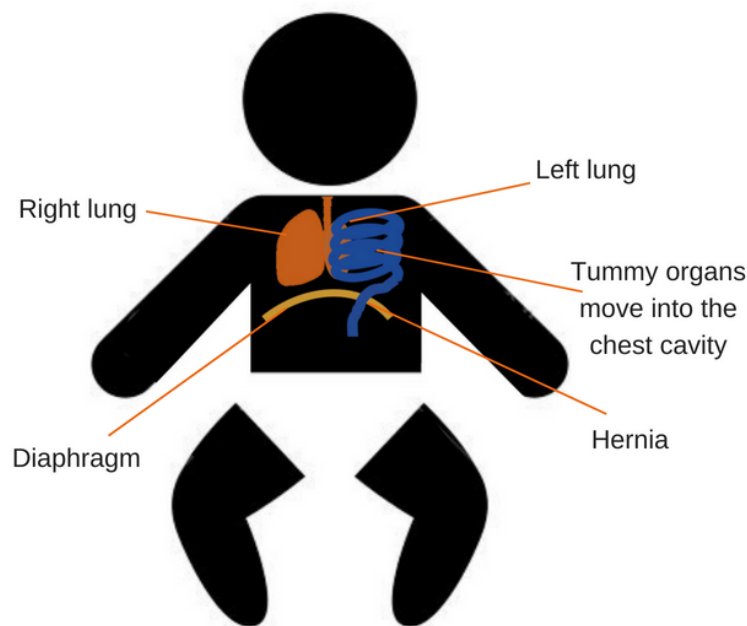


Image: left-sided CDH

The diaphragm is a muscle that helps us to breathe and separates the chest cavity from the abdominal cavity. It develops in early foetal life. Congenital Diaphragmatic Hernia is the absence of the diaphragm or, more commonly, the presence of a defect in the diaphragm. It can occur on the left or the right side, or bilaterally, but is most common on the left (80%).

As there is a defect in the diaphragm, the abdominal contents including the stomach, intestine, liver and spleen can be displaced into the chest cavity. CDH is usually an isolated condition, although other congenital anomalies, most commonly cardiac, may be associated and influence the prognosis.

Since these organs are in the chest cavity and not where they are supposed to be, the lungs have insufficient space to grow normally and are therefore smaller than they should be.

The determinants of survival include the degree of under development/under growth of the lung and the supplying blood vessels, with associated pulmonary hypertension, as well as the gestation of the baby.

CDH occurs in about 1:2500 births. To put it into context, that's 2-3 families being told to expect a CDH child every week, or 125 families every year.



CDHer Baby Jett in hospital

Half of CDH children will pass away in their first year. Sometimes this is during birth or within minutes of birth; sometimes it is weeks or months later.

Every CDH child faces their initial battle in NICU; of the children who survive, many face a raft of ongoing health complications. These are varied, and range in severity. Examples are: ongoing gastroesophageal reflux; failure to thrive and growth problems; scoliosis & pectus excavatum; bowel obstructions & gastrointestinal disturbances; developmental disorders. Our children sometimes require ongoing medical care, including home oxygen or tracheostomies, PEG feeding, nutritional supplements, and/or ongoing medication.

Some children face few, if any ongoing concerns. Many tertiary Australian hospitals now offer families multidisciplinary follow-up care and observation to help surviving children live their healthiest lives.

CDH AUSTRALIA

where to from diagnosis?

EXPECTING A BABY WITH CDH?



Waiting for CDH Her Baby Aylah

Your baby has just been diagnosed with a serious birth defect; it's going to take some time for this to all sink in.

What can you do? Where can you go? What does it all mean?

You are about to enter a world that is not familiar to you; new people, new words, new equipment, and a new concept of having a baby.

You will meet doctors and nurses who will assist you in taking care of yourself and your baby. You will have questions that need answers; you will want things explained again that you haven't understood the first time around.

All your questions are relevant and important. There is no such thing as a silly question, but there is such a thing as an uninformed person. If at any time you are not comfortable or satisfied with answers or treatment, you are entitled to seek other opinions. Sometimes it will feel like the choices are being made for you, but ultimately the choice is yours.

Here are some commonly asked questions that you may find useful to ask at your next appointment with your Doctor.

"Just remember that however you are feeling, and whatever thoughts are whirling in your head, it is almost always 'normal'. There's very little that can prepare you for a CDH diagnosis, so be kind to yourself as you come to terms with it."

- Have you had experience with CDH babies, and if so, how many do you see in a year?

Some doctors have seen and experienced more than others, but this will largely depend on the size of the hospital and where it is situated. Our community members have had babies in hospitals as far north as Townsville, so the largest city hospital is not always necessarily the best for you and your baby. You and your doctor should discuss what is best for you.

- What are the procedures for getting my baby from the birthing suite to the Neonatal Intensive Care Unit (NICU)?

After your baby has been stabilised as much as possible in the delivery room, he/she will then be moved to the NICU. It's good for you to know what to expect, as it's best for you to have as little surprise as possible. Who is allowed to follow the baby down to the NICU? Can they go in with the baby to the NICU? How will you know what's happening to your baby? What communications will occur so you know what is happening to your baby?

- How many people will be in the room as my baby is being born?

For your preparation and mind's eye, it's good to know how many people will be helping you and your baby. There will be many people present and they will include your obstetrician, his registrar, a neonatologist and midwives. Also, an anesthetist and anaesthetic technician may be waiting close by along with an orderly and a few more nurses to help the medical team. Of course your partner will also be there, and it may be possible for you to have another support person present, but you will have to check this with your doctor. Your partner and/or support person will be taken care of by the midwives or orderlies who work in the delivery suite. They will make sure that they are in the delivery room with you. If at any time you are unsure of something, just ask, as the health care team is there for you to answer any questions that you may have along the way.

- What will happen in the first few minutes after birth?

As soon as your baby is born, your obstetrician might hold him up for you to see. You may hear a faint cry but don't be alarmed if you don't hear anything. The obstetrician will then hand your baby over to the neonatologist who will assess, and likely ventilate them (place an endotracheal tube into your baby's nose and down to the lungs to help your baby breathe). Once this has been done, your baby might be weighed and measured. As soon as your baby has stabilised they will be transported to the NICU where other lines and devices will be inserted and attached to help monitor your baby.

- Will I be able to touch or hold my baby after birth?

This will largely depend on how stable your baby is after he/she has been delivered. The fact that you know your baby has CDH probably means that it was diagnosed early in your pregnancy. Because of this, it is very likely that your baby will need to be ventilated as soon as it is born. In this case you won't be able to hold your baby. Once the doctors have stabilised your baby, it may be possible for you to touch it before it is transported to the NICU. Let your doctors know if you would like to do this but remember that your baby's wellbeing is their first priority and they may have to say no.

- Who, and how many people are allowed to see my baby in the NICU?

Every NICU has its own policy on who can visit the babies in the NICU. Usually only 2 to 3 people at any one time may visit the baby and one of them must always be a parent. Siblings can usually visit, but other children less than 12 years might not be allowed in. You will have to check with your doctor about the policy of the NICU your baby goes to.

- Can my baby be christened in NICU?

You may need things in place and people prepared, so asking this question will enable you to tell others what needs to be done and how.



CDHer Baby Aylah at birth

- Can I visit the NICU during pregnancy?

This is a chance for you to see the workings of the NICU, possibly see the machines your baby will be hooked up to, hear the noises that are synonymous with the machines and drips, and meet the staff who work there.

It can be a shock to see sick babies and, if you can reduce the 'surprise' factor, it will be one less thing to deal with when you are the parent sitting beside one of those beds.

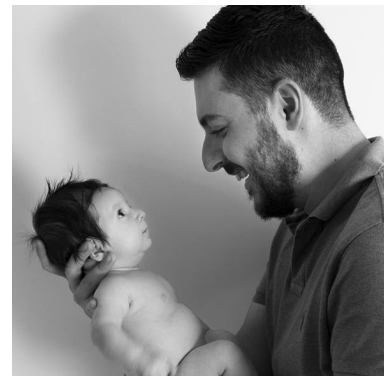
Each hospital is different; from their routines to the way they position their beds, so find out about yours. You will be guided on what to do and what not to do by the staff at the hospital.

Fathers

At the best of times women and men usually scratch their heads and wonder at each other! We all deal with crisis differently and the difference between men and women can start to show during this stressful time.

Men can feel side-lined; the emphasis tends to be on the mother and the child. Men often concentrate on practical issues such as managing workloads, transport needs, etc. Each person will think, feel, act and react differently. If your partner doesn't react the way you do, it doesn't mean they are not involved or don't care.

Be sure to keep the lines of communication open and try not to judge your partner's reactions.



**CDHer Baby Gabriel
& his Daddy**

Coping Emotionally

Now that you know you are having a baby with CDH, how do you get your mind around the fact that while the baby is inside you it is fairly safe, but won't be that way when it enters the world?

Trying to distance yourself from your baby won't protect you from the pain if your baby doesn't live. It's OK to love, sing and speak to your baby. In general, if it feels good for you to do it, then do it. We all walk our own path on this one.

You can do normal things such as set up the baby's room, buy baby clothes, etc. If the worst happens, having these things can be an important part of the grieving process. One mum didn't put the baby's room together for fear the baby would die. The baby died and the parents felt robbed of not having the nursery.

It is often part of the grieving process to get to a certain point and then pack away the baby's things – this mum actually ended up setting up the room and leaving it that way for a couple of months and found it helped.

If you need to talk to someone about your pregnancy and your feelings, you can talk with the hospital social worker or get in touch with our Support Services branch.

You are not alone.

The Health Care System



Your obstetrician can refer you to a neonatologist and paediatric surgeon who specialise in CDH. Your baby will now need to be born in a large public hospital that is equipped to deal with critically-ill infants.

In some states once your baby is stabilised he/she will need to be moved to another hospital for surgery. This could mean - depending on how you delivered your baby and how well you are after the birth - that you will be in a different hospital to your baby.

When you tour the NICU prior to the birth of your baby, it is a good idea to ask to see the transport cot that is used and to ask the doctors some questions about what happens to your baby prior to the transport.

Your baby will be sedated and paralysed with medication before they are placed in the transport cot. This is done to make sure the baby is calm; it reduces their stress. Along with a ventilator, they will also have a few intravenous lines and pumps attached to them, and a monitor that records their vital signs will also be placed inside the cot. It can be overwhelming to see this for the first time. If possible, have a look beforehand to prepare yourself.

Some hospitals can now place the baby straight into the cot that will transfer them to another hospital once they are born. Some hospitals can also perform surgery on your baby while they are in this cot, therefore reducing the amount of movement for the baby. You will have to ask your doctors if this is available at the hospital you are delivering in. If you have any questions about the treatment and surgery your child will undergo after birth, be sure to ask your doctor/surgeon during one of your visits.

You could also have the choice of using private health insurance. This is entirely up to you as the care your baby will receive will not be affected whether you have insurance or not. In some states you may be allowed to choose your neonatologist and surgeon, but this isn't always the case. This is because our public hospitals are teaching hospitals and many of the NICU's have a rotational system where a different specialist doctor is in charge each week.

Some NICU's also have parent rooms set up at the hospital for parents to stay in. They are usually for the parents only and other family members are not allowed to stay. It is best to ask what sort of accommodation is available for you and your partner while your baby is in hospital so you can organise yourself prior to the birth (especially if you have other children). The social worker who works in your hospital can help arrange these details for you.

CDH AUSTRALIA

how to work with hospital
staff / from birth onwards

EXPECTING A BABY WITH CDH?

How To Work With Hospital Staff



**Photo courtesy of Sydney Children's
Hospitals Network**

Dealing with your child's illness is hard. Sometimes we can feel uneducated and intimidated around medical professionals. You do not need to feel this way. Speak up, and ask questions. There are no silly questions at a time like this.

Remember, staff members are also people. Treat them with the same respect you expect to be given.

Parents who remain calm and do not lose their tempers during stressful times get more respect from the staff than demanding, overly aggressive parents. Of course we all want our

children to receive the best medical care possible. Most health care professionals will understand the extreme stress parents are under, but they deserve to be spoken to in the same way we would like to be spoken to.

From Birth Onwards

Once your baby arrives at the NICU, many things will happen to stabilise him or her. Initially your baby will be looked after by one nurse each shift to ensure that they receive the best care possible. The doctors will be keeping a very close eye on how your baby's oxygen levels are going and how well they are coping on conventional ventilation. They may make adjustments to the ventilator to help your baby's oxygen levels and possibly even switch them over to the high frequency oscillator. If your baby's pulmonary hypertension remains too high, the doctors might also start to administer nitric oxide to help bring down the pressure in the lungs and improve oxygenation. Your baby will also have a chest x-ray so that the medical staff can have a look at the size of the hernia and what the lungs look like.

The nursing staff will be recording your baby's vital signs every hour and will notify the doctors of any changes. The nursing staff may also be required to take blood from your baby's intravenous line, attach various intravenous fluids and administer medications.

The medical staff will also liaise with the surgeon and let them know how well your baby is going and when they think surgery should occur. Each baby stabilises at a different rate so surgery could occur in as little as a day or as long as a few weeks. Once your baby goes to surgery, the hole in the diaphragm will be repaired using sutures, and may require the use of a patch, depending on how large the defect is.

If you have any questions about the surgery and treatment your baby will undergo, be sure to ask your surgeon or doctor when you visit them.

CDH AUSTRALIA

services available to you
at the hospital

EXPECTING A BABY WITH CDH?

Services Available To You At The Hospital

When you visit the hospital prior to your child's birth it's a good idea to meet the social workers who work there.

Social workers can help organise accommodation and car parks, provide help with finances and, most importantly, counsel you and your family. They can talk to you about the ways to involve older siblings in preparing for your child's birth and the experiences that could happen afterwards. They can also help you deal with the myriad of overwhelming feelings that you may experience.

The social workers can advocate on your behalf if you are feeling overwhelmed with the medical staff who care for your baby. Some hospitals offer childcare for siblings; the social worker can advise you about this also.

All hospitals have their own antenatal preparation. There will be antenatal classes, tours, and hospital visits. These are designed for the majority of pregnant women and you may find them too hard to deal with now you are in the minority. Some people have found being part of this process has given them a feeling of normality while others have found it challenging.

You can always ask to see the midwives privately. They can go through the antenatal classes with you and let you know what you need to bring into hospital for the birth of your baby. Some of the extra things you may need to know have been mentioned briefly in "The Health Care System" section.



Nurse caring for a baby in NICU

"Some studies have shown that post-natal depression and anxiety, and / or post-traumatic stress disorder are more prevalent in the parents of children who are in NICU. It's often easier to get on top of if you ask for help in the early days. Speak to your social worker or child's care team for support."

Your Hospital Stay

Your care team will be able to provide you with some guidance around what will be provided, and what you need to bring - for you and for your baby. This can differ between hospitals.

- What To Pack For Mum

- Toiletries (toothbrush, toothpaste, shampoo & conditioner, soap, moisturiser, hairbrush)
- Sanitary pads (heavy, moderate)
- Underpants
- Day time maternity clothes (loose fitting, front-opening tops to assist with breast-pumping and soft elastic bottoms. Don't forget that it is often warm in hospitals)
- Slippers and easy on/off shoes
- Nightwear (2 or 3 sets, again front-opening if you wish to express breastmilk)
- Maternity bras
- Pens & diary or notepad (to record your thoughts or questions) and a book or tablet (with charger)
- Favourite pillow
- Camera, memory card and charger / spare batteries
- Mobile phone charger
- A small amount of money for purchasing snacks etc
- Any medication you have been taking
- Extra bags - for your dirty laundry, and for any gifts or flowers that arrive (to assist with transporting them home)
- Try not to take anything valuable to hospital, and if you do, never leave valuable items unattended.

Some hospitals allow dads to stay, too. If this is the case make sure that dad has all his essentials packed, too.

- What To Pack for Dad

- Comfortable clothing, underwear, socks and comfortable shoes
- Sleepwear
- Toiletries
- Snacks
- Pillow
- Mobile phone and charger
- Panadol, water bottle

Your Hospital Stay - What to pack for baby

Your doctor, midwife or social worker can help you decide what to pack for your baby. They will tell you what you are allowed to bring, what you need to bring, and give you some ideas about extras you might like to bring.

If your baby survives, you will have plenty of time to arrange the clothing and blankets you will need. However if your baby dies, you don't have the time to do this. Therefore you should pack an outfit and blanket for your baby. It is nice to be able to dress them in their own clothes and wrap them in their own blanket, and you can keep those items forever (a lot of people store them in special air lock bags with a sheet of acid free paper - such as is used for scrap booking. This can help keep the baby's smell on them for a long time).

You don't get to keep too many 'things' when a newborn dies and some of our community members wish that they had the chance for their baby to wear something of their own and be wrapped in their own blanket.

Parents may like to purchase and take an inkless 'hand and footprint kit' to take prints of those precious hands and feet soon after birth. Another thing to remember is that Heartfelt can come and take photos of your baby in NICU, irrespective of their survival prediction; if you'd like to request this service, mention it to your social worker or nurse.

Some families like to leave a family photo or drawing from siblings in the baby's hospital room. Another idea is to have two small blankets - one should have your smell on it to leave in your baby's cot, and the other should have your baby's smell on it. Not only can this be comforting for parents and baby when separated, it can also assist with milk production, should you choose to express breastmilk. Ask your nurse to help you make sure that the blanket is positioned in a place that will not impede medical care.



CDHer Baby Lucy in NICU with blankets around her

Things To Think AboutBreast Feeding

Breast pumps are usually available in NICUs

It is a good idea to think about whether you would like to breast feed your baby. This is because your baby will most likely be unable to go to your breast directly after birth. If you wish to breastfeed your baby in the future it is important that you hand express in the first 12 hours after birth to help establish your milk supply. Your midwives will support you with this.

While at first your baby will probably not be able to go to the breast, you can still establish and maintain a breast milk supply for when they are able to. Your breast milk can also be fed to your baby via a nasogastric tube until they have the strength to feed.

The nurses at the hospital can give you advice about expressing, and using a breast pump, for when your milk comes in. Although you will have access to expressing equipment at the hospital, It may be a good idea to talk to the staff about hiring a breast pump machine for when you are not at the hospital.

For further assistance on breastfeeding, contact the Australian Breastfeeding Association in your area. They have information and advice on how to feed sick babies, how to freeze your milk, what to use etc. A social worker can help locate the nearest one to you.

Taking a camera

During one of your prenatal appointments, ask the nursing staff on the labour ward about their procedures regarding photo taking during labour and birth. These days many hospitals are quite open about photo taking, but you must find out if there are any limitations (e.g. no video recording, not photographing staff).

You can never get too many photos. If you don't have date and time identification in your camera, you can use a thick pen on the back of an envelope with date/time and have it in the background of the photo. Have the camera (or phone) charged and ready with plenty of space in the memory.

When taking a photo of your baby, sometimes a clarifier is needed in the photo (e.g. a pen or your hand) to give an indication of how small your baby is. Take a photo of the surrounding equipment, the crib, possibly your favourite nurse tending to your baby (with their permission). If the flash is going to fire, remember not to get too close, more than a meter away is good, too close will give you a very white exposure. So step back and zoom in rather than be too close.

Things To Think About

Bonding

Mothers usually have the opportunity to hold their baby and feed immediately after birth. It is unlikely you will be allowed this opportunity due to the importance of stabilising your baby after birth. You may not be able to hold your baby for hours, days or even weeks. This does not mean you will not be able to bond with your baby.

Some families have found it useful to become involved in their baby's everyday care needs. Ask your baby's nurse about what you can do to be involved. This might include keeping baby's lips moist with lanolin, wiping away saliva, or changing baby's nappy.

Parents can sing and read to their baby, and you might like to keep a photo of them with you so you can talk to family and friends about your baby even if they are yet to meet him or her. You can bring in small items from home to talk to your baby about (check with the hospital first). If baby has siblings, they might like to be involved in this.

Keeping A Diary

Some people find keeping a diary is a good outlet for their mental wellness, as well as helping to remember this time in their lives. Recording your feelings and your baby's progress can become an important part of your family history later. Whatever may happen, you can always look back and see how far you've come. You can get other people to write in the book as well (e.g. grandparents, siblings, hospital staff).

One of our community members kept a diary whilst sitting beside her baby's bed, and with her permission, the night nursing staff would read her entries. They said it gave them an insight into the parent's feelings.

You could also write a letter to your baby, or use it to jot down any questions or concerns that cross your mind.

Online

Another way to capture this time is to set up a social media page. This can also take some pressure off you, as you can provide one update to the page, and all of your family and friends can access it.

During your pregnancy you can keep an online diary or blog, including pregnancy and ultrasound photos. After the baby is born, someone can update the page on a regular basis with photos and diary entries. This is not only therapeutic, but allows communication with all family and friends at once. Sometimes one of the parents manages it; sometimes another family member or a friend will do this for the parents.

CDH AUSTRALIA

the future / dealing with
family & friends

EXPECTING A BABY WITH CDH?

The Future

It's a fact that your baby has a life-threatening problem. All of us who have known about our child having CDH during our pregnancy have had to face the reality of our baby possibly not surviving. It is a waiting game you have to face and that in itself can be difficult to deal with.

Talking to other parents who have gone through this can be of great comfort. They don't necessarily have answers, but when you say 'Do you know what I mean?' and they answer 'Yes,' you know they really do.

Some people have found it important to decide how to handle issues before they arise so they don't have to make any important decisions during grieving. Things that you have never needed to think about before may need to be discussed with a partner now. You may want to look into funeral homes, make decisions with each other over burial or cremation, or decide how to discuss death with the children you may already have. You may want to seek help from the hospital social worker; they will have information and guidance you may not have considered. And there is always the CDH Australia community. There is a vast amount of experience in the community and there is usually someone who can relate with whatever decision you're struggling with at that time.

Dealing With Family & Friends

You may find that many of your family members and friends will be uncomfortable with your situation. This does not mean that they don't care. Some may distance themselves while others will rally around you. Some may cry, some may crack jokes. Some with healthy children may even feel guilty.

While you may not understand these feelings, they are all natural and normal. Talk about your feelings and keep your family and friends informed. An easy way to do this at this intense time is to appoint one person as a "go between" for all other family members and friends. This way you only have to update one person.



CDHer Baby Kurt in NICU with his Mummy

Advice For Support People

“Take it seriously, do not say ‘it will be all right’ because it might not be. Let the parents grieve for the loss of their healthy pregnancy. Offer practical assistance, drive them to appointments, cook meals, help out with looking after other kids if they have them.”

“Listen: You don’t have to say anything, just lend an ear and a shoulder.”

“Avoid saying things like “I understand, it’s God’s will, and you just have to accept it and move on,” and other clichés. Stay positive and respect the parents’ decisions and feelings.”

“Offer rides to the hospital, babysitting for siblings, doing laundry, cooking meals, cleaning, picking up mail, making phone calls, etc.”

“Encourage the parents to talk about how they feel, but don’t push them too hard.”

“No matter the outcome, realise that the parents will need support, comfort, and help for many years, not just weeks.”

“Ask questions, find information, seek support for the parents - but recognise that there are certain boundaries.”

“Bring food, books, and magazines to the hospital.”

“Take pictures, videos, and help the parents to accumulate mementos.”

“If the family would like to, offer to throw a baby shower, offer to help decorate the nursery, buy the baby gifts just as you would if the baby was healthy.”

“Don’t be afraid to cry. The parents know that their family and friends are hurting too.”

“Talk to your children about the baby and about what is going on in words that they can understand.”

“Ask the parents what they need and make them feel comfortable enough for them to let you know.”

“Recognise that the parents are grieving the loss of a healthy pregnancy, the loss of a normal birth and instead are dealing with anxiety and worry.”

CDH AUSTRALIA

some advice from our
community

EXPECTING A BABY WITH CDH?

Some Advice From Our Community

"Listen to your baby first and others second."

"Never give up hope, take it all day by day and enjoy every moment you have with them."

"Don't be pressured into terminating your pregnancy."

"Ask lots of questions even if you ask three or four times."

"Get all the information you can, not just from doctors but other parents of children with CDH."

"If you are pregnant with a CDH baby, allow yourself to love them. Withdrawing emotionally will not lessen the pain if your baby dies – it will only cause guilt and regret. Despite the stress involved, try to love and enjoy every minute of your pregnancy while your baby is kept safe inside you."

"Take one day at a time. Do not look forward, just live in the present moment and spend as much time as possible with your baby. Never feel guilty for having time out to be on your own and accept all the love and support you can."

"The best advice we were given when our son died was by a nurse who flew in to our room in the middle of the night and said, 'In the hours, days and months, even years ahead, people will come to you and express their feelings for you, and your situation. Most often they will probably say the "wrong" thing, and you may be hurt or offended, even though that wasn't their intention. See everyone who comes to you as coming to give their love and support, rather than stewing on their words.' This advice was invaluable to us, and has taken us through many other situations."

"Never give up hope. You and your family are your child's best advocates."

"Hang on – it's a rollercoaster."

"Sometimes thinking one day ahead is too far- moment by moment will do."

"Keep your memories close and then your baby will never be far. Ensure you have adequate medical follow up and continued counselling; men and women do grieve differently."

"My advice would be directed to the fathers and is, 'Understand your wife, love her and support her. Give her hope.'"

"We don't know which outcome we will have but I found stealing a look at the grieving sites planted a seed in my mind of some of things I could do, e.g., taking hand and foot moulds, singing lullabies."

CDH AUSTRALIA

professional, financial and
crisis assistance services

EXPECTING A BABY WITH CDH?

Professional, Financial and Crisis Assistance Services

Please note that these services are not endorsed by, or affiliated with CDH Australia in any way. It is up to the individual to research the appropriateness of these services.

Crisis Support Services

Lifeline Free 24/7 telephone counselling service and crisis support.

Ph: 131114

Grief Line Dedicated loss and grief telephone counselling and 24/7 online chat support.

Ph: 1300 845 745

Beyond Blue Free 24/7 support for everyone, delivered by mental health professionals.

Ph: 1300 224 636

Grief Support Services

SANDS

Provides support and education to anyone affected by the death of a baby.

Red Nose

Provides support through the unexpected death of a baby or young child.

The Compassionate Friends

Provides support to bereaved parents and siblings.

Grief Line

Supports people experiencing loss and grief, at any stage in life.

Grief and Bereavement Counselling Service

Provides specialist bereavement service following the death of a loved one.

Mental Health Support and Resources

Relationships Australia

Provides relationship support services to enhance family relationships.

Beyond Blue

Provides information and support to help everyone in Australia achieve their best possible mental health.

Specialised Support for Premature or Sick Newborns

Miracle Babies

Provide support for premature and sick newborns, their families and the hospitals that care for them.

Life's Little Treasures

Provides information, specifically tailored for families of premature or sick babies.

CDH AUSTRALIA

professional, financial and
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EXPECTING A BABY WITH CDH?

Professional, Financial and Crisis Assistance Services continued

Raising Children Network

Outlines early intervention for children with disability and provides national and state contacts.

Creating Special Memories

Heartfelt

Professional photographers dedicated to giving the gift of photographic memories to families that have experienced stillbirths, premature births or have children with serious or terminal illnesses.

Angel Gowns

Provides baby gowns made from donated wedding dresses for angel babies.

Angel Nappies

Provides beautiful cloth nappies for angel babies. Nappies are made in identical pairs, one for baby and one for family to keep in their memory box.

Financial Support and Government Assistance

Miracle Babies

Provides a detailed outline of parental payments and allowances.

DHHS 'Having a Baby'

Provides detailed tools and resources for financial assistance and payments.

DHHS Carer Payment

Provides income support for carers to someone who has a severe disability or illness.

Department of Support Services

Provides information and resources for carers.

NDIS Support for Carers

Information about additional services dedicated to help you in your role as a carer.

DHS Bereavement Support

Provides financial assistance to help if your child has passed away.

DHHS provides support if you recently had a baby who was stillborn.

CDH AUSTRALIA

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**EXPECTING A BABY
WITH CDH?**

Professional, Financial and Crisis Assistance Services continued

Travel and Accommodation Assistance

If you travel long distances for treatment, you may be eligible for state government financial support.

- NSW: Travel Assistance (IPTAAS)
- ACT: Interstate patient travel assistance (IPTAS)
- QLD: Patient Travel Subsidy Scheme (PTSS)
- VIC: Patient Transport Assistance Scheme (VPTAS)
- TAS: Patient Travel Assistance Scheme (PTAS)
- SA: Patient Assistance Transport Scheme (PATS)
- WA: Patient Assisted Travel Scheme (PATS)
- NT: Patient Assistance Travel Scheme (PATS)

Disclaimer: By providing these referrals, CDH Australia is not in any way endorsing the content, or further links, associated with these organisations.

Research

Although many of us have never heard of CDH until our child is diagnosed, there are teams all over the world who are looking at the cause of CDH, and improving survival and wellbeing outcomes of children born with this condition.

“Despite modern neonatal care, 30-50% of babies born with CDH die postnatally and long-term morbidity is common, with survivors at risk for thriving problems, neurological, neurodevelopmental and chronic lung disease.”

- Head of Perinatal Services at Monash Health Dr Ryan Hodges

As of 2020, CDH Australia has been involved with, and contributed funding to, research conducted at Melbourne's The Ritchie Centre, Hudson Institute of Medical Research. This is looking at improving the transition to newborn life for babies born with underdeveloped lungs (CDH).

Other programs in Australia look at long-term outcomes of children born with CDH. These are based out of tertiary hospitals where CDH children are treated and cared for. Research is being undertaken to - amongst other things - look at the efficacy of treatment options, including ECMO and Nitric Oxide.

CDH Australia maintains relationships with research and medical care teams across Australia, and where possible we invite families to be involved with, or support, research if they wish to do so.



CDH researchers Dr Kelly Crossley, Dr Ryan Hodges, Dr Philip DeKoninck and Ms Margaret Polacska, former President of CDH Australia



Information Sheet

Medical Terminology

Artery: a blood vessel that carries oxygenated blood away from the heart.

Arterial Blood Gas (ABG): a sample of blood taken from an artery that allows the medical staff to analyse the gas exchange in the lungs, specifically looking at the amount of oxygen, carbon dioxide, and acid in the blood. These measurements are used to determine how much ventilation support is needed. Normal ranges for ABGs are listed below, however staff may accept different levels depending on the clinical situation:

- Partial pressure of carbon dioxide (PCO₂) is 35-45mmHg.
- Partial pressure of oxygen (PO₂) is 80-100mmHg.
- Saturation of haemoglobin with oxygen (SaO₂) is 96-100%.
- Bicarbonate (HCO₃) level is 22-26mEq/L.
- pH is 7.35-7.45

Agenesis of the Diaphragm: complete absence of the diaphragm.

Alveolus: air sac in the lung.

Amniocentesis: A fine needle is inserted through the mother's abdominal wall and into the amniotic sac, where a small amount of fluid that surrounds the embryo is withdrawn, to test for genetic abnormalities.

Analgesia: medication given to provide pain relief, such as paracetamol (panadol) or morphine.

Antibiotic: a medication given that prohibits the growth of, or destroys micro organisms that cause infection.

Aneurysm: abnormal bulge in the wall of an artery, caused by weakening of the artery wall.

Apnoea: temporarily stopping breathing.

Arterial stab: procedure by which a sample of arterial blood is taken from an artery (e.g. for the purpose of blood gases).

Bagging: a procedure that uses a small mask attached to an oxygen bag to manually pump oxygen into the baby's lungs usually during resuscitation

Blood Transfusion: the administration of blood donated from a healthy individual that is needed to replace blood lost from the patient through surgery or repeated blood tests.

Breast Milk Substitute (BMS): infant formula used as an alternative to breast milk.

Bochdalek Hernia: an opening through the posterior part of the left diaphragm between the abdominal cavity and the chest cavity. It is the most common form of CDH.

Bolus: a single, concentrated dose of a medication (e.g. morphine).

Bradycardia: slowing of the heart rate. In infants this is less than 70 beats per minute.

Carbon Dioxide: colourless waste gas carried in the blood to the lungs where it is exhaled.

Central Venous Line/ Central Venous Catheter (CVC): an intravenous line with two to three tubes enclosed in one larger tube (called lumens) usually inserted into a large vein in the neck or groin or in an arm or leg, which allows fluids and medications to be administered to the baby. Because there is more than one tube (lumen), multiple drugs can be administered, even ones that are incompatible with each other. An umbilical venous catheter serves the same function

Chest Tube (intercostal catheter - ICC): a drainage tube inserted into the patient's chest to drain fluid or air.

Congenital Abnormality: a defect present at birth.

Continuous Positive Airway Pressure (CPAP): a form of noninvasive ventilation support, where soft nasal prongs are placed in the infant's nose, which are then attached to a machine that pushes air or oxygen into the baby's lungs to keep the air sacs (alveoli) open after each breath. Sometimes a mask is used instead. CPAP can also be administered through an endotracheal tube attached to a ventilator.

Cardiotocography (CTG): a machine that monitors fetal heartbeat and contractions during labour.

Culture: a sample of blood, urine, stool, secretion or any other physical matter obtained from the baby and sent to the lab for analysis. If the culture shows an infection is present, it can be treated with various medications to kill the bacteria or fungus present.

Desaturation (oxygen): a decrease in the amount of oxygen ("saturation") in the blood. Can lead to hypoxia (oxygen saturation <90%).

Diaphragm: dome-shaped muscular separation between the chest and abdomen. It plays a major role in breathing, as its contraction increases the volume of the thorax, and inflates the lungs.

Diuretics: medication that increases the volume of urine produced by promoting the excretion of salts and water from the kidney.

Dobutamine: a medication used to treat heart failure and improve blood pressure.

Dopamine: a naturally-occurring compound that has many functions within the body, including as a vasodilator. Dopamine is also used as medication. It acts on the sympathetic nervous system. Application of dopamine leads to increased heart rate and blood pressure.

Dopamine cannot cross the blood-brain barrier, so dopamine given as a drug does not directly affect the central nervous system.

Expressed Breast Milk (EBM): also known as EHM: expressed human milk

Extracorporeal Membrane Oxygenation (ECMO): a machine that takes over the work of the patient's heart and lungs. A large catheter is placed in an artery in the patient's neck. Blood is then removed from the patient's body, oxygenated and returned to the body.

Endotracheal tube (ETT): a tube placed through the nose or mouth into the trachea to provide mechanical or manual ventilation.

Extubate: the removal of a breathing tube from the trachea.

Familial Abnormalities: a birth defect that occurs in two or more family members.

Femoral arterial line: a central line inserted into the femoral artery near the patient's groin as an arterial line to take blood samples easily.

Femoral venous line: This is a form of central venous catheter.

Fetoscopic Tracheal Occlusion (FETO): an in-utero procedure where a small balloon is inserted into the trachea of a foetus in order to help stimulate lung growth. This is mainly experimental.

Gastrointestinal Reflux: a condition where the contents of the stomach "back up" into the oesophagus because the valve at the top of the stomach does not work well. Also called Gastroesophageal Reflux and Silent Reflux.

Gastrostomy Tube (G-Tube): tube or button that is inserted surgically and delivers nutrients directly to the stomach.

Genetic Counseling: counseling that involves providing information to at risk parents who are expecting a child or planning a pregnancy, or who have child with a birth defect or chromosomal abnormality. It informs parents of their risks in future pregnancies and the significance of any differences found on genetic tests.

Goretex: a type of synthetic material sometimes used in CDH repairs (patch).

Hernia: protrusion of an organ or tissue through a weak area in muscle or other tissue that would normally contain it.

High Frequency Oscillator (HFOV): type of ventilation that delivers a small volume of air/oxygen with a fast respiratory rate of more than 150 breaths per min. It maintains adequate lung volume with a constant distending pressure together with the ability to remove carbon dioxide (by “wobbling” /oscillating the chest).

Head to Lung Ratio (HLR): measurement taken in utero to assist medical personnel to assess and monitor severity / progress of CDH.

Hydrocephalus: Enlargement of the brain cavities caused by a build-up of cerebro-spinal fluid (CSF).

IPPV: intermittent positive pressure ventilation. A type of mechanical ventilation that delivers air to the lungs in short bursts under pressure in order to mimic intakes of breath.

In Dwelling Catheter (IDC): a fine tube inserted into the urethra, through to the bladder, to drain urine.

Inotropes: drugs used to control the strength of heart beats (muscular contractions).

Intubate: insertion of a tube into the trachea to assist with breathing (via a ventilator).

In-Utero Procedures: There are some in-utero procedures that can be used on CDH babies. At this stage, they are all experimental and only a limited number of doctors throughout the world perform them. They include fetoscopic tracheal occlusion (FETO) and tracheal ligation. In the past, full CDH repairs were conducted in-utero but have proven to be ineffective. Please read our document entitled CDH Medical Procedures.

Long line: see PICC, CVL, CVC.

Lung Hypoplasia: failure of one or both lungs to develop fully. In CDH, occurs to both lungs to varying degrees.

Lung Displacement: term used to describe the movement of the lung tissue from where it is usually located (e.g. due to CDH).

Midazolam: a sedative medication.

Magnetic Resonance Imaging (MRI): it is a common practice to do an MRI in conjunction with scans prior to the birth as this gives the medical team a clearer picture of where organs are located in the babies chest, it also provides some different angles and images not able to be captured on ultrasounds.

Morgagni Hernia: diaphragmatic hernia that occurs near the front of the body, near the breastbone.

Morphine: a narcotic pain-relieving medication.

Narcotics: drugs used to therapeutically treat pain and induce anaesthesia.

Neonatologist: a sub-specialist Paediatric doctor, qualified to work with newborn babies in intensive care.

Nitric Oxide: a gas used to treat pulmonary hypertension. It relaxes the smooth muscle in the walls of the blood vessel in the lungs, therefore increasing blood flow and increasing oxygenation.

Nissen Fundoplication: a surgical procedure where the opening between the lower end of the oesophagus and the top part of the stomach is narrowed to prevent contents from the stomach flowing back into the oesophagus. It is sometimes used to treat severe reflux.

Naso Gastric Tube (NGT): a fine plastic tube inserted through the nose of the baby into the stomach which can be used for feeding or drainage of stomach contents.

Neonatal Intensive Care Unit (NICU): newborn nursery for critically ill infants.

Oedema: excessive accumulation of fluid in body tissue.

Oxygen Saturation: measures the percentage of oxygen carried by the red blood cells in the bloodstream.

Patent Ductus Arteriosus (PDA) Shunting: changes in the blood flow of the heart due to the foetal duct remaining open.

Permacol: a type of synthetic material sometimes used in CDH repairs (patch).

Percutaneous Endoscopic Gastrostomy (PEG) / Percutaneous Endoscopic Jejunostomy (PEJ): a type of feeding tube, surgically inserted directly into the gastrointestinal tract to bypass the stomach / oesophagus.

Peripherally Inserted Central Catheter (PICC): a small, flexible tube inserted into a vein near the patient's elbow to allow easy administration of fluids and medications. It can stay in place for months to years.

Paediatric Intensive Care Unit (PICU): a hospital ward for critically ill infants, children and teenagers.

Pneumonia: inflammation of the lung caused by bacteria. It causes the alveoli (air sacs) to fill up with pus and become solid. This prevents adequate oxygenation of the body.

Polyhydramnios: excessive amounts of amniotic fluid that can be an indicator of possible fetal problems.

Pre- / Post-ductal Saturations: the measurement of oxygen in the blood, often used to measure PPHN.

Prostin: medication to treat Persistent Pulmonary Hypertension (PPHN).

(Persistent) Pulmonary hypertension (of the neonate)(PPHN): Is a complex condition of the newborn and an important determinant of survival with CDH. It is defined as a failure of the normal fall of pressure within the blood vessels supplying the lungs. It can be very difficult to treat and is related to the degree of undergrowth/underdevelopment of the lung and its supplying blood vessels that occurs with CDH. It is characterised by low oxygen levels in the baby. In essence the baby's circulation remains as it was before delivery and the right-sided heart pressure remains high instead of dropping, which normally occurs at birth.

Pulse Oximeter: a machine that reads the patient's heart rate and blood oxygen saturation levels through a probe placed on the patient.

Scaphoid Abdomen: visually, a concave rather than convex-shaped abdomen (tummy sunken in because the abdominal contents are in the chest).

Special Care Nursery (SCN): a nursery for infants that are healthier and stronger than those in the NICU.

Sildenafil: a vasodilator medication used to treat PPHN.

Sepsis: severe illness caused by an overwhelming infection of the blood stream by toxin causing bacteria.

Suctioning: a procedure during which a small catheter, attached to a suction machine is inserted into a baby's endotracheal tube to remove secretions that the baby can not cough out.

Total Parenteral Nutrition (TPN): high calorie intravenous fluids used for nutrition.

Tracheal Occlusion: involves an operation on the mother during pregnancy, where the baby's trachea is clamped off, causing the lungs to grow and push the abdominal organs back into the abdominal cavity.

Tracheostomy: surgical insertion of a tube to assist with breathing.

Umbilical Venous Line and Umbilical Arterial Line (UVC/ UAC): these are tubes inserted into the vein and artery of the umbilicus. They are inserted as soon after birth as possible and can be left in place for up to 14 days. The umbilical venous line provides immediate intravenous access to the baby, to provide fluids and medications. The umbilical arterial line enables regular blood sampling.

Vasodilators: medications that work on blood vessel walls to stop them from narrowing.

Vein: a blood vessel that carries deoxygenated blood to the lungs from around the body.

Ventilator: a type of mechanical breathing assistance. See HFOV, CPAP.



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