

Facing the "brick wall"

At first, your shock and intense feelings may be very hard to handle, perhaps overwhelming at times. However, as you face your feelings and talk about them, you will begin to find ways of coping with this unexpected event. You will be amazed at your strength and the resources that are available to help you through this "brick wall".

ACCEPTING YOUR FEELINGS

The birth of a baby is usually a time of celebration, excitement, joy, uncertainty and wonder. When you are told that there is a problem with your child's heart, you may struggle to balance your feelings of celebration with your worry and disappointment.

All parents struggle because the baby they have dreamed about is different from the healthy baby they expected. You are not alone in what you are feeling. Many parents have shared their stories with us; some of their feelings are shared below.

Fear

When parents find out their baby has a CHD, many are afraid that their baby will die. They describe feeling "terrified", "frightened", and "scared". Some parents say they feel physically sick, while others say they feel like running away or escaping.

Shock

Most parents are shocked when they learn of their child's diagnosis. Many give reasons why this cannot be happening to them. Parents talk about how healthy or "how good" they were during the pregnancy. They "ate right" and "lived carefully", not drinking, smoking, or taking drugs.

Some parents are shocked because they have already had healthy children and expected another healthy baby. Some parents are surprised that their baby has a CHD because "there is no family history of heart problems".

Searching and guilt

At first, parents have difficulty believing that their baby has a CHD. As the news starts to sink in, they often ask, "What caused it?" or "Why is this happening to my baby?"

Parents sometimes wonder if they are at fault. One mother believed that her smoking and drinking over Christmas was the cause of her baby's CHD. These suspicions are often untrue, and the feelings of blame, self-doubt, and guilt are not easy to discuss.

Anger

Some parents feel angry. They may be angry with God, or angry with health care professionals who they feel have influence over their child's health. Some are angry that an ultrasound done during pregnancy did not find the heart defect.

Confusion

Parents often say that they feel confused, lost, helpless, "unraveled", or "upside down". These feelings of confusion and worry can make it



*"It felt like we
hit a brick wall."*

PARENT

*"I lived in fear -
fear of what would
happen, fear of the
pain my child may
experience."*

PARENT

*"When our child
was diagnosed I asked,
'why me?' I took it
personally."*

FATHER



Finding answers. For life.

"Sometimes it feels too scary to talk about it."

PARENT

"I was hoping that things would be perfect."

PARENT



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hard to get on with daily life. You may wonder what to do with your feelings, or even ask yourself if your feelings are normal.

TALKING ABOUT YOUR FEELINGS

As you talk about your feelings, you will probably reach a better understanding of how you are behaving. Getting your feelings out in the open may reduce the tension and add to your sense of hope and anticipation.

You and your partner will likely have different feelings at different times and cope with these feelings differently. Sharing your thoughts and feelings helps both of you understand and respect what the other is feeling. Many parents are surprised what they learn about each other during this unexpected event.

Some parents find it hard to talk about their fears, although they are thinking about them all the time.

It may take a lot of effort to express your feelings. Here are some ways that help. Creative activities such as journal writing, art, music, gardening, or other hobbies can be helpful. A healthy lifestyle with physical activity, a nutritious diet, and relaxation activities also help with stress and tension.

CHANGING YOUR EXPECTATIONS

Like most parents, you were probably hoping for a "perfect" baby. Now that you know about your baby's CHD, the way you think about your baby may change. Instead of planning the perfect future, you may spend a lot of time thinking about your child's medical and care needs.

Parents often feel grief as their thoughts of their child change. You can still celebrate your baby's arrival. Grief is normal, but take the

time to cherish how wonderful and special your child is.

TELLING YOUR FAMILY AND FRIENDS

You may not want to share your feelings at first, but may also want the closeness that this sharing brings. Some people know just how to listen and comfort, but not all friends and family are supportive in times of need.

A number of changes happen as you begin to share your news with others.

You may feel:

- supported by your family and friends as they listen and offer comfort,
- frustrated because your well-meaning friends and family members tell you not to worry and don't seem to understand what you are going through,
- anxious about the questions people ask that you do not have answers for or have not even thought to ask,
- alone as some of your family or friends seem to withdraw from you and your family,
- sadness and grief, as sharing with others may make your baby's CHD feel more real to you,
- a sense of relief that others now know your news.

It may be helpful to think about how each family member or friend is likely to respond to what you tell them. You can always tell people later, but you can never "untell" your story. Take your time. This is your choice.

BUILDING YOUR SUPPORT TEAM

Remember that you are not alone. Your friends, family, and work colleagues want to help. Some may not know how to help. Tell your support team exactly what is helpful and what is not. For example, try saying:

- “Just listening to me is helpful. It’s hard when people tell me not to worry.”
- “It’s okay to ask me how I’m doing.”
- “How about taking the kids this weekend so John and I can have some quiet time alone?”
- “I can’t seem to pull the meals and housework together these days—any help would be wonderful.”
- “Come with me to my child’s next appointment.”
- “I need some time off to deal with all of this.”

There may be others you haven’t thought of yet who could offer good support for you and your family. There may be advantages in letting others know about your needs.

Community and Support Groups

Local community organizations such as service clubs, churches, and community centres can offer financial and other forms of help.

Health care professionals in your community such as public health nurses, your family doctor, community social workers, and family counsellors can help you during this difficult time.

Look for support from those who have shared similar life experiences. Talk about your concerns. Parent and family support networks may offer this kind of support (for more information, see *Additional Supports and Resources*, page 12-1).

Questions to ask yourself

You are in charge of building your support team.

Ask yourself:

- What do we need to help us cope right now?
- Who will best be able to support us?
- Is this person stressing us or supporting us?



“I am thrilled to finally be able to e-mail you, to say how excited we are to see Beth looking so much better over the past 24 hours.”

PARENT

* This chapter was adapted from *Knowing But Not Knowing*, 1998.



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REFERENCES

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| <p>■ Rempel, G. (1993), <i>Knowing But Not Knowing: Parent's Experience of Antenatal Diagnosis of CHD</i>. Unpublished Master's thesis, University of British Columbia, Vancouver, BC.</p> | <p>■ Rempel, G., and Cender, L. (1998), <i>Knowing But Not Knowing</i>. Vancouver, BC.</p> | |
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