

# chapter 5:

## the early days

### DIFFERENT FAMILIES – DIFFERENT FEELINGS

You and your family will respond in your own way. You may feel one of these emotions strongly. You may feel none of them. You may feel a whole range of them at different times. Sometimes, you might feel that you're jumping from one feeling to another in the course of a day, or over a longer period of time.

Whatever you are feeling is okay; there's no right way to respond. Your feelings and responses might be influenced by many different things. For example:

- whether your child's hearing loss was completely unexpected or whether you knew it was a possibility
- whether you had been concerned about your child's hearing for a while
- whether other people in your family have a hearing loss
- whether your child's hearing loss was present at birth or developed when your child was a little older
- whether your child has other health difficulties or developmental concerns, and
- how things are going in your life more generally.

Many people say that they experience feelings that seem to contradict each other. Although it can seem quite confusing, there is nothing wrong with having conflicting feelings such as:

- great hopes and dreams for everything your child might experience and achieve in their life; but fear about how a hearing loss might affect these dreams.
- joy at your beautiful child who brings so much fun into your life; but sadness about their hearing loss.

- shock that your child has an unexpected hearing loss, that leaves you wishing it would go away; but love and joy from the life you share with your child just as they are.

Your child is a gift in your life and the joy you experience in having a baby is there regardless of what else happens. Your child having a hearing loss may present challenges, but your child is still your much loved child first and foremost. Hearing loss is a part of who they are, but it's certainly not everything about them.

### SHARING THE NEWS

After you have come to understand a little about your child's hearing loss, there will probably be other people in your life who you will want to tell – your other children, your parents, your brothers and sisters, your friends, and other people close to you.

Some people find they'd like to talk to as many people as possible and gain as much support as they can straight away. Others find this is a private time and would prefer not to talk too much. If you've got strong feelings one way or the other, let people know or ask someone else to tell them. Just as it is okay to say, 'I need to talk,' it's also okay to say, 'I need some space for a while.'

You might notice your own reactions change when telling other people. Sometimes the experience of speaking to others can make the information seem more real and cause strong emotions. At other times, it might be a great relief to share things with people who you know care about you and your family. When deciding to talk to others, you might like to prepare yourself by thinking about some of the following questions.

### QUESTIONS TO THINK ABOUT WHEN SHARING THE NEWS...

- How do you feel about talking to other people about your child's hearing loss?
- Who do you want to tell now? Who would you prefer to wait and tell later?
- Would you prefer to talk to people at your home, meet somewhere else, or talk on the phone?
- What do you think it's most important for them to know? What don't you want to talk about?
- What don't you want other people to say or do? How might you let them know this?
- What would you like from other people at this time? What do you think your friends or family could help with? Do you feel able to ask them about this?
- Would you prefer to ask a close friend or family member you trust to tell some of the other people in your life? If so, who is the best person to do this? What do you want them to say and what would you prefer they didn't talk about?

## SHARING THE JOURNEY

One thing is certain, you are not alone. A wide range of supports is available to help you along your way. Some supports will specifically help you to understand your child's deafness and what it might mean for your family and your child. Other supports will be valuable in more general ways. Support may come from many different people in both formal and informal ways:

- family and friends
- your local community
- community organisations
- other parents who have children with a hearing loss
- other people who have a hearing loss
- services for children with a hearing loss and individual professionals
- Family Support Facilitators

Further information about different support services and websites is provided at the end of this resource.

## PLANNING WITH YOUR PARTNER

Some families find that the unexpected news of finding out that their child has a hearing loss can build strength in their relationship. Other families find it can put a strain on their relationship. Sometimes this can go up and down a bit.

All parents have to make important decisions about their child's wellbeing and future. This involves parents negotiating about many things. When a child has a hearing loss, and both parents are unfamiliar with what this means, this process can be a little more complicated. You'll find that you will agree on some decisions easily, but others will not be so clear and will need you to spend time together thinking about the best way forward.

When your relationship is under strain, remember that you don't need to have all of the decisions sorted out straight away and very few decisions are set in stone forever. Perhaps you could decide which decisions need to be made more quickly, and focus on these and hold off on other issues for a better time.

Try to make opportunities to spend time alone with your partner to discuss how your child's hearing loss has affected you both. Maybe a friend or family member can help by looking after your children. People often have very different reactions to significant events in life and it can sometimes be hard to understand why your partner is responding differently to you. Taking time to talk might help to strengthen your understanding of each other's experiences, and assist you in making better decisions in the short and long term.

Considering the following questions may help you and your partner to build a better understanding of each other:

### QUESTIONS TO THINK ABOUT WHEN PLANNING WITH YOUR PARTNER...

- What are the things that your partner and you agree on and feel the same about?
- What issues do you have different opinions about?
- What would help you to move forward with these issues?
- When are good times for you and your partner to spend time together to discuss your thoughts, feelings and plans?
- What opportunities can you and your partner create to spend some time together to simply enjoy each other's company?
- Could someone help by looking after your children for a couple of hours every now and then?

## BALANCING THE NEEDS OF THE REST OF THE FAMILY

Most families with more than one child will say that balancing everyone's needs can sometimes be a challenge. This might be particularly noticeable in the early days after your child's hearing loss has been diagnosed.

Depending on how old your children are, they may experience a range of different feelings as they come to understand their sibling's hearing loss, and these feelings might be expressed in all sorts of different ways. Here are a few things to think about to help your children understand their brother or sister's hearing loss.

- Make sure your children know that it's okay to ask questions and give them honest answers with the information you have. If you don't know the answers, let them know that you will try to find out.
- Although it's great if your children want to help support their brother or sister's development, it's also important that they don't take on too much. They also need to have the chance just to be children.
- Be aware of children's feelings and support them when they express their emotions.
- Try to find some special time for each child in your family.
- Make sure your children know that nothing they did caused their brother or sister's hearing loss.
- If you know what caused your child's hearing loss, consider explaining this to them.
- If you know that there is no risk of your other children developing the same type of hearing loss, it may be useful to explain this.
- Help your children develop ways to explain their brother or sister's hearing loss to their friends.
- Show your pride in all your children and encourage each of them to be aware of each other's achievements.
- Remind family and friends to consider the needs and achievements of all the children in your family.

## DRAWING ON SUPPORT OF FAMILY AND FRIENDS

Your family and friends can be a great source of emotional and practical support. Examples of support that family and friends can offer include:

- listening to some of your experiences
- looking after your other children while you take your child to an appointment, do something for yourself, or simply have a rest
- making your family a meal on a day that you have a number of appointments
- explaining to others about your child's hearing loss, so you don't have to keep repeating your story, and
- spending time with you socialising and having some fun.

Some people worry about being a burden on others when they accept their generosity, but family and friends are usually delighted to be able to do something practical to help people who are important to them.

If you don't feel like you want or need this sort of support, it's fine to ask friends and family to take a step back. You might suggest that they check in with you again in a few weeks so you can let them know how things are going. This gives you the space that you want without making family and friends feel that you're ignoring them.

In your *Possibilities* kit, you'll find copies of an information sheet for your child's grandparents called 'When your grandchild has a hearing loss' and one for your friends called 'When your friend's child has a hearing loss.' These resources will give your family and friends some extra information as well as some ideas on how they may be able to support you. Pass these on to your family and friends when you feel ready. Extra copies of these resources are available from your Family Support Facilitator as well as online at [www.health.qld.gov.au/hearing](http://www.health.qld.gov.au/hearing).

