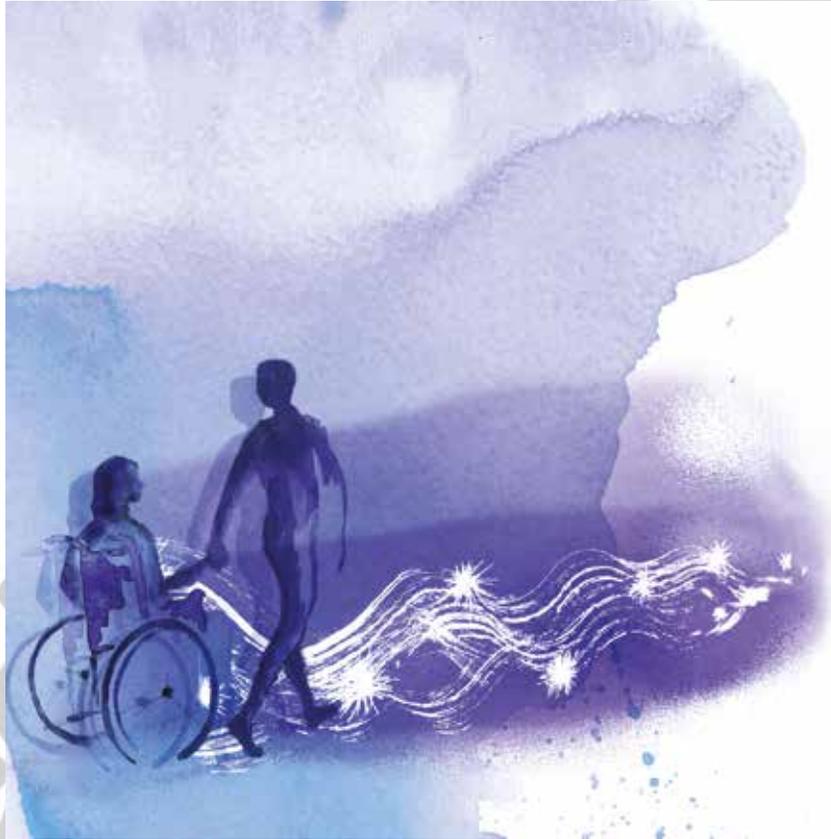


CHAPTER TWO

redemptorist
p u b l i c a t i o n s

REFLECTING THROUGH YOUR OWN STORY: UNEXPECTED PATHWAYS



Parents who receive news of a pre-birth diagnosis of disability have often expressed a common experience. They seem to feel different from all other parents and this leaves them feeling alone. The parents seem to ask similar questions to those

expressed in our imaginative journey with Mary and Joseph. Interwoven into this chapter are some of the words expressed by the parents who have inspired our journey. Below, you will find these reflections in speech marks.

As I have suggested in the introduction and chapter 1, receiving the news that your child has a pre-birth diagnosis is daunting; it is unexpected. The unknown is generally accompanied by fear and a sense of impossibility. As with the Holy Family, you may feel that you have been thrown onto a pathway that you had not planned and that the road seems impossible. Suddenly, the baby you are expecting is surrounded by a series of medical terminologies and information, which build up anxieties more than hope. You may have to undergo blood tests, numerous appointments and feel that you are expected to absorb large amounts of medical information. One of our parents told us that “every time I went to the hospital it seemed the situation was more severe than the previous visit; these were some of the worst moments of my life”. It is most definitely a challenging time. Much of the information you receive may seem to report on how your child should be, on what the child’s (seeming) irregularities might be, whether the child will or will not live inside or outside of the womb. These can often be referred to as “foetal defects”. As with most of the parents I have accompanied, it may already have been suggested to you that termination is the most logical solution to your child’s problem, or at the worst you may feel placed under an unspoken moral obligation to choose not to bring your child to term.¹⁸

Negative language and what seem like urgent expectations surrounding termination are issues that many parents and disabled people, Christian or not, have felt unhelpful in such moments. They have often expressed how “no medical diagnosis can ever discover who your child is or who they can be”. Information about your child’s medical condition is important, it is necessary to know. However, as I have worked with parents, I have always been dismayed by the predictions that seem to devalue the gift of a life and may indeed detach you, somewhat, from your child. It is very important to

know the diagnosis, but I have found that it also helps not to lose sight of the potential of your child's life or need of your love.

As people of faith, our belief in the gift of life is part of who we are. Negative language surrounding life, alongside termination as an ultimate solution, is therefore in direct conflict with all that we believe to be true. Many parents have shared how their faith was acknowledged but not always fully considered as being important in decision making surrounding their baby's life. One of our parents expressed how "it was never really explicitly presented" that they could continue with their pregnancy and that it was "generally presumed that we would choose termination. Often, I felt like I was an illogical religious nut, but I think it helped when I showed I had done my research and that we were making reasonable decisions."

Some parents tell how they felt that "their faith was seen as a negative factor" and "the cause of them making irrational decisions surrounding termination and choice making". Christian parents often have to justify their religious beliefs and overcome feelings of being seen as irrational, when making choices based on biblical and faith-based perspectives of the human person. This is very puzzling as, over the past ten years, considerations surrounding respect for issues of spirituality and religious practice have been written into the equal opportunity and chaplaincy policies of all health providers in the United Kingdom.¹⁹ Knowing what these policies offer you, as well as researching fully into the diagnosis you have been given, can help you find the right language to express your feelings around the life of your child. My advice is to ask that consideration be given to your faith tradition and that it is brought into the conversations surrounding diagnosis.

As you can see, it is very important, to both disabled people and their parents, to speak with honesty and balance surrounding the difficulties and possibilities that you might face as you receive a diagnosis. It is important to note that, as people of faith, you have the right to express feelings and choices that result from your religious conviction. Some of our parents told us

that they often felt “daunted by the numerous visits, medical information and differing opinions” that they received. I believe that your visits to the hospital must include opportunities for you to ask for accurate information about the options that are open to you, including issues of spirituality. This could include information concerning: taking your baby to term; early delivery; and pastoral or palliative care, before or after birth. Having these options as part of their support package made all the difference to one of our *BIA* families, whose daughter was diagnosed with thanatophoric dysplasia: “no chance of survival after birth, as her chest would never develop enough for her to be able to breathe”. Deciding to continue with the pregnancy, this family’s package of support included chaplaincy and palliative care. Our *BIA* parent explains further, “In hospital and from our community midwife, the support was second to none. The midwives who looked after me in hospital, both before and after birth, showed such compassion and care for myself, my husband and daughter. This type of care was incredibly healing in the grieving process. We weren’t treated roughly or without dignity at all.” I believe that planning for such pastoral options and pastoral actions can make all the difference.

You should also receive honest information concerning the psychological and emotional difficulties associated with termination,²⁰ as well as the reality and possibilities of sharing your life with, and enabling the life of, a child with disability. Later in the book we will help you to think of questions that you can ask, and we will look honestly at what you may experience on your own particular path. This could include conversations with a hospital chaplain and support from the chaplaincy team. This might make the road you must travel more manageable.

This has been a lot of information for you to reflect upon. Let us stop now for a moment and share in some of the stories that our parents have expressed about the time of pre-birth diagnosis for their child. Some felt overwhelmed by negativity, some were helped by pastoral workers and some needed time to process. For all the parents having space and time to absorb the situation was vital, as was sharing and speaking to one another.

"We left the hospital that day feeling heartbroken about all the extra challenges that our baby might face. Would they find friends, employers, a partner who could see past their disability?"

"We seemed to move from seeing our child's future to a concept of being different. We decided to stop wondering who our child wouldn't be or what our child couldn't do, it did not seem right somehow to do that. How can anyone really know how or who anyone will be?"

"Going to the scan was exciting; receiving the diagnosis for our child was confusing and worrying. We had to deal with real life all of a sudden with big conversations about who we were as a couple and how we approached life. It was, however, the first time we met our son, we got to know who he was, and we prepared ourselves to welcome him."

"It is natural not to know what to do... to question. It was a hard time for myself and my husband to talk."

"I was praying frequently to God to guide me in my thoughts, in my decision making and to give me strength and courage, to help me support my wife."

"I just needed someone to give me their time, to think with me. It is hard to think alone, I had so many questions: Would my child survive birth? Would I be able to take care of a disabled child? Will we survive this?"

You may be sharing in some of these parents' feelings; you may find it hard to talk to others or express what it is that you are feeling. It is important, I feel, that you stay focused on the fact that everything you are doing, and thinking, is out of love for your child, for each other and for God. The *BIA* journey seeks to give you accurate information concerning a Christian approach to the issue surrounding pre-birth diagnosis, hoping that it will help shift some of the clouds that you may feel are collecting around you. In the following chapter we will continue our journey into God's story as we travel on further with Jesus, Mary and Joseph.

Before moving to chapter 3, take time to breathe with God. I invite you to turn to your *BIA* diary.

The diary will have directions and an activity to help you reflect upon some of the thoughts and stories in chapter 2. It will give you space to record your own story and to notice moments of grace. You could share this time with a partner or alone, with a parish or a family... it is your choice, your time to be.

If you are sharing in a parish setting, you might choose to bring some of the diary thoughts, questions, insights or prayers to the meeting with your priest or with your parish team, but this is entirely your choice.