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- There were many gains from

here's no easy way to tell you, so I'll just tell you straight. Your child has Holoprosencephaly.'1 This may not be the textbook way to deliver bad news but the words from the consultant obstetrician at our 20 week antenatal scan left us in no doubt. There was a problem. Over the next few weeks we would learn more about it, from internet searches and from referrals for confirmatory second opinions.

The medical opinion was fairly overwhelming: '98% of parents in this position terminate the pregnancy', 'Are you sure you want to carry on, you do know what she will look like?"Your daughter is likely to choke to death, and will not recognise you as her mother', 'We can offer you a termination tonight, we can book you a bed to stay the night'.

Just days before, we would not have considered terminating a pregnancy. Now, we were in the difficult position of grieving the loss of our daughter whilst trying to make a decision that would impact

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both our lives and those of our two young boys.

Having grappled with it for a few days we cried out in prayer 'God, what do we do?' and he spoke to us very clearly. Within twelve hours through a chance meeting, Frances was encouraged to read The Shaming of the Strong by Sarah Williams. 2 It is the story of another family from Oxford who had been faced with the same dilemma. The local Christian bookshop happened to have a copy, and in their window Frances' eye was caught by a sticker: 'Books change lives'.

The book spoke to us of our precious daughter who had been given to us by God, not of a medical problem to be faced but a daughter, however imperfect, to be treasured and loved. We should have listened to our three-year-old son, who when first told that his new sister would not be very well, reassured us, 'Don't worry Mummy, I'll give her a hug when she comes out'.

Looking back we're not sure that we could ever have proceeded to a termination. However, we look back at those weeks of agonising and know that God led us through that time. It would have been possible to follow what we knew we should do and battle on through the tough times ahead, but when we cried to him he answered; he called us to receive the gift he had given us. Knowing his calling on our lives we had a great peace from the moment of our decision and throughout Millie's life, and then at the end of her short life were able to hand her back to his care.

I'll lend you for a little time a child of mine,' he said, 'For you to love the while she lives, and mourn for when she's dead.

She may be six or seven years, or only two or three, but will you, till I call her back, take care of her for me?' ³

New parents are advised that having their first child will change their lives. Having Millie (our third child) really changed our lives. It was difficult to prepare for her birth. We did not know if she would make it to full term. Then planning for her life was even more difficult. How long was it likely to be? We had been advised it could be minutes, hours, days or months, but not years.

Everyday life was more of a challenge, NG feeding, multiple medications (antiepileptics, sedatives, antiemetics and antacids to name just a few), frequent vomiting and lack of weight gain, home oxygen and physiotherapy. Frances became very adept at NG tube placement and drug administration. We lived day by day, plans were made and changed.

We decided early on to share Millie with our community. She came to the school gates to pick up her brothers; she went to church and on family outings. We had many sleepless nights, until advised to take the nights in turns, one good night followed by a night with three hours of broken sleep.

Life had its challenges but its great joys as well. We reappraised our priorities. We gained new insights into life. Having lived a successful and relatively sheltered life, through Millie – her life and death – we experienced the depths of sadness and despair that many people in the world are living through, enabling us to come alongside them in a more meaningful way. Living with Millie resulted in a deepening of relationships with those closest to us.

Little did we know when we made that decision that God's gift to us was not just to care for Millie for 22 months. It was also the changes he would work in our lives that would last so much longer. As one friend put it after Millie died, 'Life goes on. You can see this family moving on and thriving, loving life and enjoying life and that's not because Millie's not there anymore, it's because Millie was there.'

Millie's grandfather, Graham Scott-Brown, came twice a week from when Millie was about ten months old to provide respite care overnight. We gained hugely from the love, support and prayers of family and friends and the practical respite support of Helen House and ROSY

- Respite Nursing for Oxfordshire's Sick Youngsters.

At Millie's funeral Graham spoke about Mary Magdalene washing Jesus' feet with precious ointment and that the house was filled with the fragrance of the perfume. Some of those standing near asked 'to what purpose is this waste?' People may look at all the care and love that has been poured out on Millie and question 'to what purpose was all this done?'

Love is the most precious ointment in the world; love is made to be poured out and any love that is poured out is never wasted. Those who pour out love find that they have the capacity to pour more. If you don't pour out love you won't have the capacity to pour more; if you pour it out you will find that God gives you more love to pour out. You become a wider container and you are able to give more.

Millie in a wonderful way called out that sort of loving response from so many people. That love overflowed into the surrounding community. Many of the children and their families from her brothers' school classes attended her funeral, having been impacted by her short life. The fragrance of love filled our house as we loved Millie. We look back and see that it was God's love that was poured out for Millie, from us as parents and all those who came into contact with her.

It is amazing how God could take something that humanly was so tragic and turn it into something so beautiful. Millie has left her lasting impression on us, giving us an entirely new capacity to love, not only our other children, but other people in need, such as many of my patients facing the end of their lives with terminal cancer. We now have a capacity to love that we would never have had if Millie had not been part of our experience.

We are still seeing the impact of Millie's life today. As one friend put it, 'I don't think there was ever a time when I left their house and didn't reflect on life and just see the amount of good that has come out of Millie's life, like a huge ripple, and one day we will see that she has had an impact on people's lives that we didn't even know about.'

After Millie died the sister of a friend was encouraged by Millie's story to continue with a pregnancy that she had been advised to terminate due to the likelihood of severe disability. Their daughter was born completely normal six months later.

God called us to receive his gift of Millie for our lives. Through her life he poured out his love into her life and his love spilled over, and the ripples are spreading far and wide.

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references

- Holoprosencephaly is a condition where the forebrain of an embryo fails to develop into two hemispheres. This leads to insufficient development of facial characteristics such as the nose, lips, and palate.
- Williams S, The Shaming of the Strong. Vancouver: Regent College Publishing, 2007
- Guest EA. A Child Loaned (excerpt), 1930.
 For the full text see All Poetry website bit.ly/NHbGTa (Gender reference changed to fit this story)