

Making Choices



Do you have a family member with Cystic Fibrosis? If so would you consider having yourself and your spouse/partner genetically tested before having a family of your own? And if there's a chance of your child having CF, would you still have a family? Or might you consider IVF to eliminate the prospect of CF?

Perhaps you already have a toddler with Cystic Fibrosis and are considering another baby. You know that there is a 25% chance that the baby will also have this life-shortening condition. So do you play the odds or decide against another baby? If tests reveal CF in a pregnancy, would you have the baby or consider terminating the pregnancy?

These are the gut-wrenching, deeply subjective choices that face some families. Whatever they decide their decisions have far-reaching impacts on them and their wider families.

Here four families with very different circumstances discuss the issues that confronted them, the choices they made and why they made them. For some there was no choice - or they refused to consider choices - their decisions were easily made. For others it was monumentally difficult.

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What would you do?

Never any question

The birth of our son on 26 April 2006 was a deeply distressing experience for me and my family. What should have been a routine birth and joyous occasion became a nightmare when he was obviously very ill from the time he was born.

Within 48 hours we discovered he had Cystic Fibrosis and required major surgery for a bowel blockage. The surgery and intensive post-natal care were traumatic for me, my husband and our families.

When we wanted a sibling for our son it was simply a matter of weighing up the odds. We knew there was a 25% chance of having another CF baby and we were prepared to deal with whatever happened.

Apart from the problems associated with his birth, our firstborn had been a healthy, happy lively little boy, so CF held few fears for us. But we were terrified at the prospect of another blocked bowel and the surgery it would require.

In mid-2009 the amniocentesis test revealed that our second baby, another boy, would also have CF.

Our second son was born on 25 November 2009 - there was no bowel blockage and he appears to have a milder experience of CF. He is healthy, putting on weight and developing exceptionally well.

Would we have considered termination of the pregnancy? Absolutely not! The outlook for CF youngsters continues to improve and we have two beautiful boys who bring us joy. Their future is bright and their healthcare needs are just part of our parenting package.

The opportunity to have a child without CF

When our son was diagnosed with CF at one month old the last thing we were thinking about was having another child. But we knew some day we did want more children, and we wanted our little boy to experience having a sibling.

When the time came we chose to use IVF/ PGD to conceive our second child. Pre implantation genetic diagnosis (PGD) is the process of selecting embryos for transfer that do not have CF.

We were always keen on IVF as we were adamant we didn't want to give CF to any other children. Testing during pregnancy was not recommended due to a problem we have with recurrent miscarriage and the odds of taking our chances were too high.

Advice from various sources on the possible negative implications to Alex's current good health if he had a sibling with CF reinforced our decision. We also wanted the opportunity to have a child without CF and not deal with the day to day issues of CF.

IVF/PGD is considered by some as ethically wrong and we knew that we may be judged but we were comfortable with our decision and telling a child how they were conceived. We felt it was an easier conversation than explaining to a child that we were able to avoid them having CF and didn't.

IVF can be expensive and when you add in PGD with no rebate we had to ensure we could afford it. With no idea how long or how many attempts it would take.

The final consideration was the actual IVF processes and how we would cope, could I actually give myself injections! The emotional and physical toll can be great and there are no guarantees even for a fertile couple. There were a number of times we almost gave up but we kept going.

After three IVF cycles, two miscarriages and a small fortune our beautiful daughter was born without CF on 20 October. When we look at her playing with her big brother we know we made the right decision for our family.

Deciding not to have more children

Rewind 10 years, 11 months and a handful of days, and then focus in on a church office in suburban Canberra. You'd find my husband, me and a rather tolerant priest grinding through that daunting yet legal pre-requisite to the big day - the marriage course. "Yes", we agreed, we would have one child and then "see how it went"...

When it went CF, I resisted my temptation at diagnosis to slap a rather upbeat nurse who cheerfully and excitedly advised us that I could become pregnant again and "simply abort" an "affected foetus". There was nothing simple about the question of a second child.

We weighed the options. We loved parenthood and were emphatic about our child who was doing remarkably well...so far. But what would the impact be of bringing a sibling...yes, a snotty nosed, cold-catching, always in the face of our CF child sibling into our world? Would we have time to actively manage his condition with exercise, nutrition, education and empowerment? Or would we struggle merely to get through daily physio and medications? What would be the impact on him, on his potential sibling, and on us as a family? Our primary desire was for our child to have the best possible life and we felt that enlarging our family would compromise that. Friends had had more than one child with different and significant care requirements... Friends had divorced over less... It was here that our investigations of IVF and adoption halted.

It is incredibly hard to make the choice to have no further children. But we have come to realise that increasing the size of our family is not the only way of having many children in our lives. And that reminds me...I need to phone my nephew...

Being given the option to make choices

One thing about having a child with CF that still makes me angry is the fact that, as parents, we are not given the option of making choices about our potential children. We were not offered prenatal screening, which is as simple as having a mouth swab, to test for carrier status. Nor, once I was pregnant, was an amniocentesis suggested to test if the embryo we were carrying would test positive for CF. If the Government is worried about the cost of these screening options, they should only consider the tremendous cost a CF patient incurs medically and the money they would save if they could dramatically reduce the number of children born with this disease.

If a couple knew they were both carriers they could then make a choice either: take the risk and try naturally to have a child, hoping it doesn't have CF; or explore the IVF option where it is possible to screen for non CF embryos.

Similarly, if an amniocentesis was offered and the embryo was found to be CF positive, the couple could either decide to continue on with the pregnancy or have an abortion. I personally would have had no hesitation in choosing a termination as I think to knowingly bring a child into this world with CF is unfair for both child and parents. This may sound callous but life is hard enough looking after healthy children, let alone ones with a chronic life threatening condition. The constant worry being a major stress for the parents and the affected child having to live with such a terrible disease. To be told, when your child is one month old, that she or he has CF, without any prior warning, is devastating. This need not be the case if we were given the opportunity to make choices as a result of screening.



Cystic Fibrosis Victoria Inc.

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Is there testing available to see if I am a carrier of the CF gene?

Yes! Carriers of a CF gene are healthy and often not aware that they are carriers. If you are planning a pregnancy you can now have testing to clarify your status for cystic fibrosis. Victorian Clinical Genetics Services has produced cystic fibrosis carrier testing packs. Further information about the cystic fibrosis carrier screening program may be found at: www.cfscreening.com.au or ask your general practitioner or obstetrician.

If you would like to speak with someone at CFV, please contact Emma Gibson (CDAMS) on 9686 1811

