

***“My world tilted on its axis”*: Experiencing AFE**

Cara Johnson# experienced an AFE in 2006 at Lyell McEwin Hospital in Adelaide, South Australia. This profile on Cara and comments by her surgeon highlight the impact (long term as well as immediate) that such an event has on family and clinical/maternity staff. Lyell McEwin is a participating site in AMOSS.

I had a natural birth. I remember James being placed on my chest: my husband and I were so in awe of our precious boy! I don't remember what happened next. Apparently I was taken up to theatre to repair a perineal tear, and went into shock on the way. When I woke up in ICU I thought 'What sort of hospital puts you in ICU for having a baby? I've had a baby not a hysterectomy'.

But I had had a hysterectomy. And an amniotic fluid embolism and DIC [disseminated intravascular coagulation]. I was in and out of surgery/ICU and had 125 bags of blood products along the way. Fourteen hours after giving birth the doctors 'ceased active management' and my husband was told to say goodbye. Thank goodness I proved them wrong.

Afterwards, I got tired of hearing about the saga and just wanted to be left to be a mum. They said I'd be in hospital for three months, but I managed to get home three weeks later. And then... James got a twisted and gangrenous bowel with a 20% chance of survival. That's when the reality hit, that's when I went downhill.*

There was an enormous network of support. It seemed that every which way I fell there was someone there to help me. And it wasn't just me: they walked along the path with us all. People just don't understand because they haven't experienced it. The whole thing is surreal. The physical impact was incredible. I was so weak – I couldn't lift a phone. But it was the emotional stuff: knowing I couldn't care for my baby properly, that I couldn't enjoy the new baby moon with my husband and family.

There's the practical aspect too: all the parts that people don't see. Our kids stuck at the hospital for hours on end, them not really understanding what was happening and not coping, the financial strain, all the stress on extended family and friends. Lachlan [Cara's autistic son who was 12 when she had the AFE] still thinks I'll die every time I go back into hospital. It all adds to the anguish. You understand why people go into a shell. The impact on partners and family is profound. You can see why there are relationship breakdowns. For my husband, there was the initial trauma of being told I wouldn't make it – contemplating raising our family alone – and then there's the aftermath.

It's six years on now, and I'm the lucky one. I'm so blessed to spend every day with my beautiful family, especially my husband.

Knowing other women and families who've had an AFE and survived is so important. Talking with others through online media [there is an AFE foundation run through the USA and a Facebook page in Australia] is great but we need to build better networks of support. That's why this [AMOSS AFE research] is so important. It's collating the numbers and getting better information about what works and what can be done... so fewer women experience what I have.

(Note: AMOSS has submitted an NHMRC project grant application for Phase II which will continue AMOSS studies, as well as explore the experiences of women with rare and severe conditions.)

Not her real name

*James has now recovered from his bowel condition.