

My experience

From the other side

My enjoyable and rewarding rural experience was recently interrupted by one of those experiences that one hopes to have only once in a lifetime.

Over the course of a few hours our almost week-old son developed sudden severe cardiac failure with metabolic acidosis. It happened at night while we were at home at St. Apollinaris. We had no idea of what was going on and assumed it was septic shock. We were later to find out this was due to coarctation of the aorta and precipitated by the closure of the ductus arteriosus. He also had a V.S.D.

That night we started a roller-coaster journey which ended with us back home two weeks later after successful surgery.

In the beginning one lives from day to day and hour to hour and there is no time for coming to terms with what happened. Now there are so many emotions one has to come to terms with.

Guilt for ascribing slow feeding to winds and cramps. Maybe we should have noticed earlier that something was wrong?

Feeling incompetent for knowing that if a similar patient had presented to me I would have called it septic shock and would not have thought of a cardiac cause. I never knew that coarctation presented in this way. In the books this is a typical presentation of severe coarctation.

I also remember the emotions during the two hours of travelling in the

ambulance with him to Pietermaritzburg and to have to be prepared to resuscitate him. My wife drove ahead of us, with our daughter, in the dark and mist and she recalls the emotion of not knowing if we were still following and wondering if he still was alive.

The hours spent waiting outside ICU and at the bedside and the support from

emotion of the first week. To try and treat him like a normal baby and not to expect the worst every time he cries. To deal with the fact that we are far away from everywhere should something happen again and that one would rather pitch a tent outside the ICU than be at a rural hospital.

We were also thankful to have access to excellent medical care and high-tech medicine. Something which our patients do not always have.

What have I learned from this? Hopefully by having been a patient I will be able to better attend to the needs of my patients.

Uncommon things also occur sometimes and to look beyond the obvious.

There are no guarantees in life and one has to make the most of the time that is given to us.

The power of faith and prayer and the support of so many people.

Writing this down is part of my way of dealing with it. I hope that it will enable others also to share their emotions.

I also hope that everyone will remember to think about congenital heart disease the next time a neonate presents with shock.

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other parents in the same situation. Experiencing depressive symptoms firsthand.

Now that we are back one has to re-establish a relationship with a baby that spent 2 out of his first 3 weeks in hospital and has almost become a stranger. To try and regain the heady