Austprem Ink

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Life and death decisions in the NICU

Georgia Grace Bendall

Inside this issue:

From the Editor

In this issue of Austprem, we look at the medical decision making process when an extremely preterm baby is born. How can parents who are shocked by the birth and profoundly frightened and stressed by the environment make decisions about continuing or discontinuing medical interventions? What are some of the way that neonatal staff can support them?

Many of the parents in Austprem have had babies in the NICU but for some the NICU period can continue for many many months with numerous setbacks. Our parent story in this issue is by Kate whose daughter was in intensive care for more than 7 months.

This is my last issue as editor. It feels right to end with this complex topic, back where we began 11 years ago when Vincent was born. I have never forgotten those terrifying first weeks of his life, and I'm so glad we have a support network now to help us all get through the days and years. I wish all the families in our group comfort in the dark times and joy in every milestone.

Anne

Life and death decisions in the NICU

There has recently been a number of articles and interviews in the media about the viability of babies born extremely preterm, with a question mark, as always, over whether the cost, both human and financial, of saving these babies is justified given very poor outcomes. These are valid concerns for society but when the experts and bean counters weigh in, parents can feel very threatened. Imagine a tiger or bear with its cubs and you'll get some idea of how parents tend react when it looks like some external force or agency is going to be making life and death decisions about THEIR baby.

Neonatal doctors and nurses are equally concerned about ethical decision making. They deal with the babies every day, and are direct agents of the many painful medical procedures required to sustain life. They also hope for miracles. In the Consensus Workshop held in RPA Hospital in February (and reported in an earlier Austprem Ink), NICU staff repeatedly expressed concern for the capacity of parents to make a fully informed decision about their baby's viability, given the profound stress they are under at the time.

"Even with the most sophisticated technology, predicting the likelihood of impairment in an individual infant is inaccurate. Who should decide whether to initiate/continue intensive care given an almost equal risk of impairment or normal outcome once the infant survives?"

Saroj Saigal, The limits of viability, Pediatric Research, 49 (4) 2001, p. 451

Our medical systems have the skills, experience and technology to sometimes save babies born at the limits of viability (under 25 weeks and/or under 500 g. The babies survive with a lot of help and significant impacts on the lives of their families. While there are more severe disabilities, in the youngest survivors, there are also more normal survivors (including those with very mild disabilities). Even if a baby will almost certainly be significantly impaired, it's often impossible to predict how or how much.

The challenge for both parents and medical caregivers is to work through a process of collaborative decision making, over a period of time that can be both brief and almost unbearably intense as well as drawn out over months and even, occasionally, years.

neonatal staff need to guide and support parents in their decision making

It is the task of parents to be advocates for their baby and to try as best they can to determine the baby's best interests, which may not be the same as their own. In the process, they are relying on information provided by the medical team. As well as caring for the baby, neonatal staff need to guide and support parents in their decision making.

Miracle babies?

For many parents, the birth of their premature baby is unexpected. Unless they are close to another family with a prem, they are likely to know very little about prematurity, especially the implications for an extremely pretem babe.

These families are served a great injustice by the media fascination with "miracle babies" born at the edge of viability and perfect all the same. This popular myth makes it so much harder for parents to adjust to the true precariousness of their baby's situation and the very high chance that there will be long term impacts. It can also mean that family and friends are overly optimistic and not as helpful as they could be.

Barriers to communication

The challenge for neonatal staff is to provide evidence based information about outcomes while parents may still be struggling to accept that the baby is born, that the nightmare is real. Additionally, the situation may be urgent with the parents required to decide whether to continue aggressive treatment or not within hours.

"Concordance between parents and clinicians is poor and anxiety very high. A quarter of parents appear to prefer to relinquish decision making authority, but clinicians cannot accurately identify this subgroup."

Zupancic et al, *Characterising doctor-parent communication in councelling for an impending pre-term delivery*, Archives of disease in childhood, 87 (2), Sept 2002

Despite the best efforts of medical staff to provide counseling about outcomes, in an urgent situation, parents may have difficulty taking in information. It is likely that both parties will remember differently.

...in an urgent situation, parents may have difficulty taking in information

In another study, by Townsville neonatologist Guan Koh, on audio-taping interviews between neonatologists and parents, 85% of the parents who listened to the tape found it contained things they had forgotten. Two mothers could not recall the conversation ever taking place.

"I did not even realize until the second time I listened to the tape that I had been present when you made it."

Koh TH. *Promoting effective communication in neonatal intensive care units by audiotaping doctor-parents conversations*. International Journal of Clinical Practice, 52 (1) 1998, pp 27-29

Stress interferes with short-term memory and enough stress appears to damage memory permanently, something that is now emerging as a problem for extremely low birth weight babies, possibly as a consequence of their early environment.

Life and death decisions in the NICU (cont)

Given these barriers to effective communication, how it is possible for parents to be informed about the complex procedures that may either help their babies recover or be futile or even destructive?

When babies are born in the grey zone of viability, it will help the parents if they can be provided with –

- Basic outcome statistics
- Printed information about immediate and long-term impacts (selected books, and journal articles)
- Practical advice about what it will mean for the family to live with the disabilities,
- Recommendations from the neonatologist

Outcome information

There are many recent articles about outcome but it certainly isn't recommended for parents to attempt to wade through all of them but the primary ones are important. Outcome studies which report on the same cohort over a decade or more are especially useful, e.g. Saroj Siagal, the EpiCURE group or Lex Doyle's Victorian Infant health Study group. These reports help give parents an idea of how their child will grow and develop, with or without disabilities.

Practical advice means providing some context for the disability. For example, it wasn't until Vincent was 3 months old that we even heard the words "cerebral palsy". We were told he would limp and be a "bit stiff" but had no idea what that might mean.

> Parents need time to weigh up the options and to change their minds.

Outcome information alone isn't enough

Parents need time to weigh up the options and to change their minds. They are trying to decide what is best for the baby and to come to terms with the terrible idea that what is best for the baby may be to spare him or her from further painful and probably futile interventions.

Parents need to work out answers to the moral and ethical issues because they will be asked about their decision for years to come. They will also have to live with their own questions.

"Parents may find themselves wishing that someone else could make the decision – someone who knows more … who can foresee the future. But there is no such person…"

"It is a heavy responsibility but your decision is the best one there is."

Davis, Deborah L. and Stein, Mara T. *Parenting your premature baby and child*, Fulcrum, 2004

The best interests of the baby?

Parents will almost inevitably go through a stage or process of fiercely wanting to hold onto the baby, no matter how dire the medical situation is, no matter how well the medical information is communicated. It is therefore imperative that there be joint decision making, combining the knowledge of the physician with the wishes of the parents.

When it's not clear what's in the baby's best interests, the decision is largely subjective and it rightly rests with the parents – it is their hearts, their judgements and their intuition that matters most.

It is parents who are ultimately responsible for the well-being of the child.

Anne Casey

Advice I wish I could have taken home with the baby

When Vincent was born, we became strangers in strange land. Struggling with shock and fear, like all premature parents, we quickly became experts on every known acronym as it applied to our tiny baby.

It was the IVH and PVL that we took home with us, totally besotted with our son but so afraid for his future. We didn't know how severely the brain trauma would affect him and we knew nothing about prematurity except that he needed to gain weight.

One of the healing opportunities that groups like Austprem and Preemie-L give us is the chance to share advice and experience with newer parents. For me, it has at times almost been like the chance to go back in time and comfort my own lost self. Here I am now with Vincent turning 11, and these are some of the things I think I'd like to have been told, 11 years ago.

- Your child needs to be protected from viruses, until he/she is stronger. It's best they not go into a crèche until after their second winter.
- There's a reasonable chance your child will need to be rehospitalized during his/her first year. Hopefully he/she will continue to get stronger and more robust as he/she grows but it may not be a straight progression.
- Your baby will benefit from physiotherapy/other therapies and the contact and advice will probably also be helpful to you. There may be other specialists you'll need to see regularly. That needs to be taken into account if you are planning to return to work.
- Treating your depression is more important than providing breastmilk for your baby, (if these are incompatible). You need to look after yourself so you can look after your baby.
- While mild or moderate cerebral palsy is a lifelong condition, there are effective treatments to help your child reach his/her potential, and Australia has some of the best surgeons/hospitals in the world.
- Your child will benefit from starting school at age 6 rather than age 5.
- You might find it helpful to talk to other parents, when you're ready.
- Extra time with the baby will be of benefit to both of you.
- Your life is unlikely to return to what you considered "normal" up until now, but you will be able to adapt to the changes and in time find ways to be happy again.

Anne

Kate's Story

Our daughter Georgia Grace was born on 1st March 2005. She was born at 24 weeks 3 days, due to chorioamnioitis (an infection of the amniotic fluid). While I was in labour, two doctors came and spoke to us about the chances of survival for our baby. At that time we were very clear that we didn't want her kept alive if she was likely to be profoundly disabled and have no quality of life. Then she was born. She weighed 749g and was sporting a huge infection. For the first month of her life, she had back to back infections and we were told on two occasions she wouldn't survive the night. She managed to beat those infections, including a yeast infection in her blood which took her to her limits. After two months on the ventilator, the doctors spoke to us about Georgia's chances of survival. They said they felt she was unlikely to ever come off the ventilator, and that she would be profoundly disabled. They gave us the option of ending treatment. We said that Georgia would tell us when she didn't want to fight anymore, and opted to try another course of steroids. After a week on steroids, she had made it onto CPAP and the nurses told us not to get too excited – that she would probably end up getting re-ventilated. She is now nearly 6 months old and has been on CPAP for 4 months. The doctors told us last week that we may be faced with another decision to end treatment, as they feel her lungs are not growing. She has continued to deteriorate and require higher doses of steroids.

> We said that Georgia would tell us when she didn't want to fight anymore

When the question of keeping premature babies alive "at the borderlines of viability" was raised in June, Georgia was doing very well. The doctors had stopped talking about "if" she came home and had started talking about "when" she came home. They also said that there was no evidence to suggest she would be profoundly disabled. She was our miracle baby. She was never meant to survive, and had. I was angry that the politicians and ethicists dared to suggest that keeping 23 – 25 weekers alive cost a lot of money and resources, for often poor outcomes. Georgia was an example of why there should not be any cut offs based purely on gestation or weight.

I have been asking myself in the past week whether my position has changed, based on the fact that there is a strong chance that Georgia will not survive. I guess that to the politicians, Georgia would be considered a bad investment. She has cost tax-payers hundreds of thousands of dollars, and taken up a hospital bed for 6 months. To the ethicists, she has gone through a lot of pain and suffering and if she survives may continue to place a burden on services. But for us, she has not been a statistic. We have been blessed to be her parents. She is beautiful, and has loads of personality. She has taught us so much about life, about ourselves, about love and about guts and determination. She has given all her body can give, and more. I regret more than anything else that she has suffered so much, and may never survive to see that there is more to life than the NICU. But she had a chance, and that is what this debate is all about. Without giving these babies a chance, no one would ever know what could happen. Six months down the track the doctors can now look back and say that based on everything they know she may not survive. But at that point, six months ago when the decision would have been made, there were a whole host of possible outcomes. There are plenty of happy and healthy ex 23 - 25 weekers out there who are proof of that.

> She has taught us so much about life, about ourselves, about love and about guts and determination.

Kate

Kate wrote this late in August, sadly Georgia lost her battle early in October.

Georgia and Nikolas together again

Georgia Grace Bendall

1/3/2005 - 8/10/2005

Nikolas Pergaminos

5/5/2005 - 1/9/2005

Journal Articles

Boyle RJ (2004) 'Ethics of refusing parental requests to withhold or withdraw treatment of their premature baby' *Journal of Medical Ethics* 30:402-405

Marlow N et al (2005) 'Neurologic and developmental disability at six years of age after extremely preterm birth' *New England Journal of Medicine* 352(1):9-19

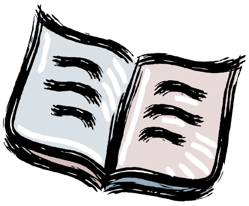
Steiner DL (2001) 'Attitudes of parents and health care professionals toward active treatment of extremely premature infants' *Pediatrics* 108(1):152-157

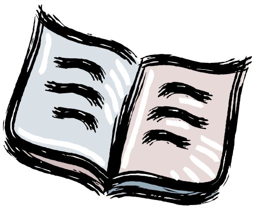
Wood NS et al (2000) 'Neurologic and developmental disability after extremely premature birth' *New England Journal of Medicine* 343(6):378-384

Zupancic et al (2002) 'Characterising doctor-parent communication in counseling for impending preterm delivery'

Archives of Disease in Childhood : Fetal and Neonatal Edition 87:F113-117

If you would like to assistance to access a copy of any of these journal articles, please contact kirsten@austprem.org.au





Books

Davis, Deborah L. ***Loving and letting go : for parents who decide to turn away from aggressive medical intervention for their critically ill newborns***
Centering Corporation, 1993, rev. 1999

There is no other publication that comes anywhere near this book in terms of providing support to parents struggling to make a life and death decision for their extremely premature baby.

This book helps parents to go over the issues and questions, and helps them to find a language to articulate these. In the long term, it will help to answer the doubts and uncertainties that will inevitably arise, even years later.

Davis, Deborah L. ***Empty cradle, broken heart : surviving the death of your baby***
Fulcrum

Davis, Deborah L. and Mara Tessler Stein ***Parenting your premature baby and child : the emotional journey***
Fulcrum 2004

(Austprem has copies of this title available for purchase, see page 9 for more information)

Barsuhn, Rochelle ***Growing Sophia: the story of a premature birth***
A Place to Remember, St Paul, Minnesota, 1996

This is a beautiful book about the birth and long NICU stay of Sophia, born at 24 weeks. It has short chapters that cover the complex range of feelings, fears and hopes of parents watching over their tiny baby's struggle to grow and thrive. This is an easy book to pick up, put down and return to, and the practical advice is comforting and honest. *Growing Sophia* would be a good book to lend to family and friends who'd like a better understanding of what you and your partner might be going through.

Supporting Austprem!

Austprem receives no ongoing funding from any source, and so relies on donations and fundraising to provide revenue so we can continue to offer support and services to families of prems.

For a while now we have been promoting the “You Name It Labels” fundraiser, and we thank you for the many orders which have been placed. Keep them coming!

I am pleased to announce that Austprem has put in place a further fundraiser with Toys and More! Toys and More are an online toy store offering some great deals and fantastic service. Austprem Inc. will receive credits to the value of 20% of any order you make! Just order the toys you would like, and at Step 5 simply type in Austprem, Sunbury, VIC as the fundraising recipient. Anyone can nominate Austprem as a fundraising recipient. The credits we receive will be used to purchase supplies for the Playgroups as they grow, or to purchase items to offer as prizes for future competitions.

Funds raised through Austprem’s sales of *Parenting Your Premature Baby and Child: The Emotional Journey* will also helps to support Austprem’s programmes.

Austprem thanks you for your ongoing support.

Toys and More

Order your toys online, get great products, delivery to your door and support Austprem too!

Simply nominate Austprem, Sunbury, VIC as the fundraising recipient
at Step 5 when you order.

http://www.toysandmore.com.au

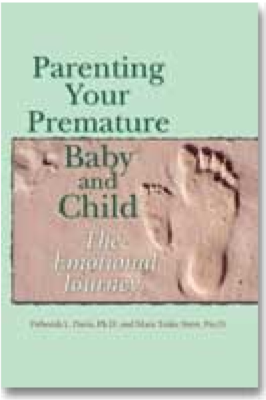
▲

Use Toys and More for
Christmas and Birthday gifts.
Your friends and family may like to
support Austprem this way too!

Great Gift Idea!

Pass the code onto your family and friends - anyone may use it!

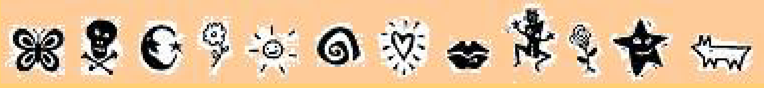
▼



You Name It Labels Fundraiser

- purchase address labels, stick on and iron on name labels for clothing, bottles, snack boxes etc, and heaps of other stuff, and support Austprem too!

Order at http://www.younameitlabels.com
using our code aiv0603 (all lower case, no spaces).
More details from
http://www.austprem.org.au/promotion/you_name_it_fundraising.html



▲We still have some copies available if you are interested! Just $44.95! (Including delivery to your door). For a review of this title, check out the Feb 2005 Austprem Ink. To order your copy, please email austprem@austprem.org.au or visit http;//www.austprem.org.au/promotion/support.html

Prematurity in the Press

This Austprem group is an online forum where summaries/abstracts of articles in journals, print/online media and book reviews etc that feature issues about prematurity will be posted. Where possible links to the full text of the article will also be included, but this depends on the availability of the article and Copyright. This group will be a semi-public group, non-members will be able to read forum, but only members can post articles to the group and join in any subsequent discussions.

For information on joining see http://www.austprem.org.au/pip.html

Chats

Chats are a great way to get to know other members better. They are usually held on Thursday (not in January) and Sunday nights from about 9pm (Eastern Time) and on Friday mornings. A reminder is usually posted to the Austprem Forum the day before a chat, so check there for the exact time. The chats are held in the Austprem Chat Room on the mc2 site, so only Austprem members are able to attend.

> "You can turn up in your pj's and you don't need a babysitter"

Chats are very informal - you can turn up in your pj's (who's going to know?) and you don't need a babysitter. But you can still receive great support and understanding from other parents, or just have a social chat - a bonus if you have been isolated at home all day.

Pregnancy Support Group

http://www.austprem.org.au/psg.html

The Austprem – Pregnancy Support Group has been set up for those who are contemplating or experiencing a pregnancy following a preterm birth, and for those at risk of giving birth prematurely.

Everyone is welcome to join Austprem – Pregnancy Support Group. You might be pregnant again, you might just be thinking about another pregnancy or you might have already completed a subsequent pregnancy and want to support someone else who is just starting on the journey. Sharing your thoughts and experiences might just help another mother, and support is what Austprem is all about.

You can find information about joining Austprem – Pregnancy Support Group at the web address above.

Your Austprem Committee

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Contacting the Committee

If you need to contact any of the Committee, please email them by clicking on their name in the Members list of the mc2 group, or send an email to

austprem@austprem.org.au

and it will be forwarded to the appropriate person.

> Your support helps Austprem Inc. to grow and improve.

Happy Birthday wishes to:

September

2 Malachi (1)
3 Connor (3)
4 April (1)
6 Jack (3)
9 Patrick (6)
10 Olivia (5)
10 Alyssa (3)
11 Tiffany (2)
13 Aiden (2)
15 Nicholas (8)
15 Ashleigh (8)
17 Abby (5)
17 Danica (5)
19 Danielle (15)
19 Hunter (2)
21 Alexandra (6)
21 Cibella (3)
21 Toby (1)
21 Samantha (3)
22 Imogen (3)
23 Casey (6)
23 Connor (3)
23 Hayley (1)
25 Michael (9)
25 Cameron (8)
26 Megan (5)
28 Joshua (4)
29 Jazzmin (10)
30 Renee (6)

October

3 Jessica (14)
4 Em (14)
6 Vincent (11)
6 Liam (5)
7 Samuel (1)
9 Dechlan (1)
10 Jaime (3)
10 Charlie (3)
12 Huon (6)
15 Glenn (14)
15 Samuel (2)
17 Kayla (17)
18 Jesse (1)
18 Caitlin (3)
19 Harrison (2)
19 Micaela (2)
23 Maddison (2)
23 Jaden (4)
24 Liam (3)
24 Stefani (3)
25 Ashley (2)
25 Connor (3)
26 Tahneisha (1)
27 Kaden (3)
28 Emily (8)
28 Callum (2)
31 Caitlyn (2)

November

1 Mia-Louise (2)
2 Oliver (1)
3 David (12)
5 Samuel (3)
6 Phillip (18)
8 Lianna (3)
8 Thomas (2)
8 Isaac (2)
9 Rebecca (7)
9 Tahlor (7)
9 Jack (6)
9 Susan (14)
10 Felicity

11 Caitlin (2)
11 Cassie

12 Lewis (12)
12 Kyle (12)
13 Peter (18)
13 Isabella (2)
13 Zoe (2)
13 Jarred (1)
15 Jordan (13)
15 Amy (3)
15 Eilish (4)
16 Sherie (11)
17 Cody (3)
17 Blake (1)
18 Emmy (1)
19 Adrian (3)
19 Elliot (1)
20 Jay (2)
21 Thomas (4)
21 Jessica

21 Finnian (2)
23 Jessica (16)
24 James (3)
24 Maxwell (3)
25 Bradley (1)
25 Alasdair (3)
28 Madelyn (3)
28 Joshua (13)
30 Lizzie (2)

If you would like your children (full term and prem) added to the Birthdays page at http://www.austprem.org.au/journey/superheroes/birthdays.html
or to be listed in the Newsletter, please email kirsten@austprem.org.au

Donations

Austprem Inc. is a non-profit organisation with no on-going funding.

If you would like to make a donation to Austprem Inc., please send your cheque or money order to:

Austprem Inc.

P.O. Box 2157

Sunbury VIC 3429

Please include you name and address so that a receipt can be posted to you.

Donations $2 and over are tax deductible.

Your support is greatly appreciated.

Joining Austprem

*Austprem is an Internet based support group.
To join Austprem Inc., you will need to go to
http://www.austprem.org.au/join.html
and fill out the online membership form.
To access the online forums and chats
(where most of the Austprem "action" happens),
you will also need to follow the steps at
http://www.austprem.org.au/forums.html
to register with mc2 and subscribe to an
Austprem group.*

Join now - it is a great opportunity to share with others who have "been there" and who can understand your experiences

Membership is FREE!

Any information provided to Austprem is held in confidence and will not be used for any other purpose or given out to any third party without your permission.

Austprem Inc.

ABN 67 731 996 316

Providing friendship, information and support for families of premature babies and children.

Please check with your doctor or health care provider as to what interventions are appropriate for YOUR baby.

Visit the Austprem website :

http://www.austprem.org.au

Contact Us:

austprem@austprem.org.au

Newsletter

Suggestions and Comments?

newsletter@austprem.org.au

Copies of Austprem Ink

may be downloaded from:

http://www.austprem.org.au/newsletters.html

Disclaimer

Please note that Austprem Inc. does not recommend that any interventions are made to any baby or child without the knowledge and assent of the child's doctor or other health care provider.

Austprem Inc. cannot be held liable for the actions of any person based on information that Austprem Inc. has provided.

Please support those that support us!