



Developmental Care

Anne Casey

Developmental Care is a concept first defined by Heideliese Als, PhD, almost 20 years ago. The care protocols she described, known as Neonatal Individualised Developmental Care and Assessment Program (NIDCAP), are designed to respond to the individual baby's needs and capabilities. NIDCAP recognises that even the smallest most immature baby actively struggles to regulate his or her environment. NIDCAP trained staff pay close attention to the baby's behaviour and responses in order to identify the baby's behavioural goals, support their efforts and help diminish their vulnerabilities.

Since the late '80s, there have been many studies designed to prove or disprove the effectiveness of NIDCAP. Some studies have demonstrated increased weight gain, earlier discharge and improved neurological outcome. Others have been less conclusive. Related studies raise the

question of how and to what extent adverse neonatal experiences alter brain development and subsequent behaviour. Most special care nurseries in Australia now make some effort towards reducing stress in the NICU by providing some of the basics of developmental care.

NIDCAP is a strict program of observation and appropriate response. More generally, developmental care attempts to assist the baby's development in a number of ways:

- reducing light and attempting to provide a day/night pattern to the lighting,
- reducing noise from all possible sources, including speaking softly,
- handling and positioning the baby in a way that supports tucked-in posture (i.e. more like the position in the womb than the flat frog posture that is fairly typical of prems)

- providing postural support through swaddling and products or improvisations that help the baby maintain a tucked-in posture and some feeling of safe containment,
- clustering care interventions in order to disturb the baby as little as possible,
- providing a comforting human presence (voice and touch) during painful medical procedures,
- facilitating hand to mouth activity, including providing a dummy to suck during gavage feeding,
- responding to the baby's cues during caregiving, i.e. recognizing stress and allowing time-out

All babies are different. Preterm babies look and behave very differently to full-term babies. They may even appear non-responsive during quite gruelling medical interventions. Understanding their baby's needs and efforts to

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Griffen (23 weeker) starts school for the first time p4



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From the Editor

Welcome to the fourth issue of Austprem Ink. In this issue we focus on developmental care, and developmental activities for toddlers. In the early days there's so much attention on feeding and physiotherapy "homework" that it can be hard to find time to relax with your young child. The suggested exercises are therapeutic while feeling playful. As with developmental care, they will be fun when your child is in the mood and impossible when they aren't. At least there's little chance of mistaking the cues of a toddler!

Anne

Developmental Care (cont)

self-regulate can be difficult for parents, and the lack of recognisable prompts can increase feelings of helplessness and alienation.

Developmental care acknowledges the essential humanity and individuality of the preterm baby. Learning to understand your own baby's signs and responding to them appropriately is as comforting for parents as it is for the baby. Hopefully, the staff in your NICU or Special Care nursery will be able to show you when your baby is looking to be cuddled or massaged and when he or she needs to go to sleep, with or without your soothing touch.

A tired baby will show his or her need to transition to sleep by avoiding eye contact, snuggling or wriggling in an effort to get into a tucked in position, and sucking on lips, tongue or finger.

The "time-out" signals of a baby who is beginning to feel distressed by handling include laboured breathing, pale or flushed skin, eyes closed,

From the President

Hello everyone,

It's hard to believe that the school year has well and truly begun and I now have two big school people. Hannah began school this year and has handled the transition much better than I had even dared imagine. The first day was not one of tears and pleading for me to stay (as I had thought it would be), but instead after only a fleeting look of panic when I announced I'd be leaving, Hannah stayed at school and enjoyed herself...she even "did some writing!!"

That day also brought back memories of James' first day of

school, and the tears that I valiantly held back so that James wouldn't think this school business was a sad thing. How walking out of the school gate that first time reminded me so much of leaving him in the NICU, alone with strangers who had his best interests at heart, but didn't really know him at all. I wondered for a moment if what I felt was that I was abandoning him, or was he abandoning me? Of course it was nothing like the NICU, James came home from school a few hours later and answered that question..."What did you do at school today?" with a very unsatisfactory "I can't remember". In fact I'm still getting that same response 4 years later!!!

I hope you enjoy reading this edition of our newsletter.

Leanne

frowning, yawning, stiff fingers, jerky movements, hiccups, gagging or coughing or straining as if bowels are moving.

In healthy prems, the "quiet alert" state that is ideal for interaction begins at about 32 weeks, sometimes earlier. Sick and medicated babies may take longer to arrive at this developmental stage.

Your baby is ready to interact with you when you can see he or she is awake and bright-eyed, with relaxed body and easy regular breathing. The baby can focus on your face and look away and then back again. One of the most beautiful quiet alert facial expressions looks like the baby is

Developmental care acknowledges the essential humanity and individuality of the preterm baby.

saying "ooh" or blowing a kiss.

Learning to know your baby and to recognise his or her individual cues will help you to adjust the interaction. Sometimes your baby

will need a few minutes to recover and then be ready for more interaction, for example some quiet lying and hand sucking after a nappy change and before anything else. Sometimes you need to settle the baby and try again after a nap.

There are some good products available to assist your baby's posture. You can also improvise with a rolled up towel to provide a secure boundary round your baby's tucked-in body. While your baby is small, it's a good idea to use the smallest possible nappies so the baby's hips and knees are in a natural position rather than forced apart by bulk.

"Handling your premature baby" (see Book Reviews section) has some great suggestions and exercises for helping strengthen your baby's posture.

See photos on the next page...

Developmental Care (cont)



← The frown, tightly held fists and tension in the lower face show this baby is worried but not (yet) distressed.

This baby is showing signs of needing some time out. →



← This baby is calm and alert, holding his mother's gaze. Perhaps he is feeling secure because of the swaddling.



A quiet, alert baby, interested in his mother's face and voice. He almost appears to be mimicking her facial expression →



← A calm alert baby (35 weeks), enjoying kicking without his nappy

Developmental exercises and activities for your growing baby

Hip abduction

Very premature babies miss the end of their time in the womb when their hips and knees are would normally be flexed and slightly compressed. To help encourage that flexion, here are a couple of exercises.

When your baby is "bottomless" after a bath or nappy change, and lying on his back, gently brush his stomach with your fingertips. That stimulus will cause the baby to bring his legs up in a curled up posture. If you do this often (if the baby enjoys it!), it will help the baby's stomach muscles become stronger.

With your baby on your lap, resting against you and facing out, bring the soles of the baby's feet together and draw the feet up towards the chest, flexing the knees out sideways. Hold for a minute and allow the baby to press back, then relax. You can also help your baby hold her feet in that position. Needless to say, don't attempt this just after a feed. Even toddlers seem to enjoy this exercise, if they can stay still long enough.

Developing awareness of the midline

With your baby sitting supported, help him hold a small massage ball between his hands and roll it around. Encourage him to pass it from one hand to the other. The soft spikes of the massage ball seem to stimulate grip. Some babies also enjoy massage balls rolled over the soles of their feet.



Harmonica

Toddlers often enjoy harmonica, and it's a rewarding instrument because it makes a noise both inhaling and exhaling. Bubble blowing is another great activity, although usually needs to be outside or in the bath.

Playdough

Nothing beats warm playdough for a fun time. Toddlers with mild spasticity often find warm playdough relaxing, allowing their hands to feel a bit more supple. Squeezing playdough, and rolling snakes helps to build hand strength.

Sand

Some young prematurely born children are averse to sand but for those who enjoy it, the texture of sand can provide a unique neurosensory stimulus. Again, for young children with spasticity and reduced sensation, warm sand can help them feel more supple.

Your Story - Starting School

We asked Paige to write about her feelings and thoughts as Griffen started school for the first time. She first wrote during the holidays, and then again after the first couple of weeks of school. Griffen had a difficult time initially, so had a rough start to his school life.

Before school started

In 2004, Griffen, now 6 years old, will be starting school for the first time.

Paige is feeling very nervous about letting go, and having someone else take care of Griffen.

Before school started, Paige shared some of her feelings about the big day. "I feel excited after all we have been

We are very proud of him

through together, that now he is starting school like any normal six year old. And that is something that we never expected to be able to celebrate. We are very proud of him."

The first couple of weeks

The last few weeks have been a bit chaotic to say the least.

I would like to share with you the experiences we faced with our preemie starting school.

Although it started off as a horrible mess, it has now sorted itself out.

Where do I begin, Griffen was born at 23 1/2 weeks, 695 grams, 16th December 1997. Monash Clayton. After a stay of 42 weeks in NICU and SCU we began our journey into the real world, as we know NICU and SCU are in a different world.

Each step along the way always had its ups and downs

and we knew that when kinder and school were to face us we would feel a great sense of sadness, happiness, love, relief and complete terror. When we have to let go of our children it is hard, but even harder for preemie parents as we had to let go every day when they were in hospital, when we walked out the door to go home we never knew what the next hour would bring and leaving our babies in the hands of strangers to us, but capable strangers. Well now we face that again walking out and leaving them with a stranger. Someone who has absolutely know idea of what we have had to go through and will probably never understand.

My biggest fear was bullying, and this happened during kinder, by one child, and because we can go on kinder duty, we can control what is happening. But what happens when they go to school, who is going to be there for them? Well my fear came true, same child that had bullied him at kinder was at it again at school. Making Griffen's life hell. Kicking, chasing and teasing. This treatment meant Griffen wasn't eating, so he lost 3 kg in the first week, and we all know that we work so hard for our kids to put on weight. No sleep and crying.

Although the school did their best to sort the situation out, this child was still going to be in Griffen's face day in day out. So we took him out of the school and put him into our local Catholic school.

The difference has been remarkable and we have a much happier boy and school is actually fun now.

It absolutely broke my heart to see what he was going through and my stress levels were really high, I don't think I had been that stressed since the day he was born.

I thought after the fight for life that he had to go through then, that would be it. What more should these children have to go through.

But I am happy to say that after 6 very long years at home by my side he is doing fine. I am a little lost but learning to appreciate the chance we have been given to have our children go to school, where there had been times that we thought that this would just be a dream. When we had learnt to take very minute, and every hour as a blessing when they were in hospital, we now wait 6 hours a day for them to come home from school, its kind of funny really.

I hope the rest of the journey will be filled with laughter, happiness and success.

I wish everyone happiness as you enter the world of education and this time a good feeling of separation.

Paige Barker

See Griffen's "off to school" photo on the front page of this issue.

Book and Website Reviews

Handling your prematurely born baby : a guide for parents : a physiotherapy approach (1993)

Kym Morris

This is a great little book for anyone caring for a premature infant. The advice is specifically for babies up until about three months corrected age but the general guidelines are relevant for the first year and perhaps longer. Topics covered include swaddling, providing postural support to help your premature baby's physical development and getting your baby set up in a way that helps him or her learn about the world and enjoy social interaction.

The baby in the photos is so obviously and endearingly premature. The mighty task of learning to hold his head up is a something we could all relate to.

CopyRight Publishing
G.P.O. Box 2927
Brisbane, QLD, 4001
(07) 3229 6366

\$13.25 including postage.

Baby talk : for parents who are getting to know their Special Care baby

Dale Hatcher and Kathleen Lehman,

This book has recently been updated as ***Baby talk and special beginnings***

US \$4.95

Baby talk is the perfect gift for any family with a premature newborn. With large beautiful photos, it helps explain the facial expressions and gestures typical of preterm babies. *Baby Talk* provides a gentle guide to the psychological and emotional life of the baby and encourages

parents to recognise their baby's signs and to give the appropriate comfort.

At a time when parents are likely to be feeling grief and helplessness, *Baby Talk* is empowering. It emphasises the humanity of the baby and helps us see past the medical situation.

Centering Corporation
1531 North Saddle Creek,
Omaha NE

Can be ordered from bookshops or from <http://www.centering.org/>

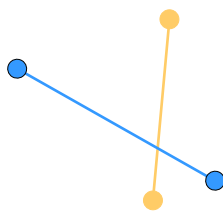
Note - Centering Corporation have a wonderful publication list of books about grief and special needs. You can look through the list on the website.

Learning to love (2000)

Lorraine Rose

Lorraine Rose is one of Australia's pre-eminent experts in infant psychology. This book is not specifically about premature babies but is about the experience of being a baby and of becoming a parent. Sometimes the trauma of premature birth and the consequent medical impacts can completely overshadow what is already a major psychological right of passage. *Learning to love* is designed to help parents to find bearings in the emotional sea that accompanies most births. It is both illuminating and reassuring.

ACER Press
19 Prospect Hill Rd
Camberwell, Victoria
\$19.95



Giving Developmental Care

www.pediatrics.wisc.edu/childrenshosp/parents_of_preemies/understanding4.html

This is part of the For Parents of Preemies : Commonly Asked Questions website maintained by University of Wisconsin and The Center For Perinatal Care at Meriter Hospital Madison, Wisconsin.

For Parents of Preemies is a great website overall and this section provides a helpful clearly written guide to the practical aspects of Developmental Care, including understanding your baby's social and psychological needs.

Developmental Care - Considerations for Touch and Massage in the Neonatal Intensive Care Unit **Joy V. Browne, PhD, RN**

www.preemie-l.org/massage.html

This article is intended primarily for NICU medical staff but the general guidelines of providing the right touch at the right time are always relevant. The bibliography is very good with some of the articles from Neonatal Network available as full-text online.

Early Communications : decoding your premature baby's signals **Amy Tracy**

<http://babiestoday.com/resources/articles/preemisignals.htm>

A basic introduction to some of your baby's signals.

Prematurity in the Press

We are in the process of creating a new Austprem group - 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. To join the group in mc2, just go to <http://mc2.vicnet.net.au/home/premrsch/index.html>

Austprem - Pregnancy Support Group

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

Your Austprem Committee

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Chats

Chats are a great way to get to know other members better. They are usually held on Thursdays and Sunday nights from about 9pm (EST).

A reminder is 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"

We are hoping to hold some special topic chats, so if you have a topic you would like to discuss, or know of anybody who could lead such a discussion, please let us know, either via the Forum or direct to leanne@austprem.org.au

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.

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.



Austprem Membership

Austprem is an internet based support group, providing support to anyone that needs it.

We ask that you consider becoming a Registered Member. Registered Members are eligible to join the Austprem Development Group to help to improve and promote Austprem.

Registered members are also able to vote at the Annual General Meeting, so having a say in how Austprem Inc is run.

Your support helps Austprem Inc. to grow and improve.

Registration is FREE and open to all and everyone is welcome to join. Donations you choose to make are tax deductible and will help us to achieve our goals.

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.

Birthdays

March

2 Jarrod (5)
3 Mikaela (7)
3 Jaiden (2)
3 Hannah (2)
5 Mitchell (4)
11 Dana (4)
14 Antonio (5)
16 Bryce (5)
20 Laine (3)
26 Megan (4)
30 Parker (1)
30 Isabella (1)
31 Zachary (9)

April

7 Breanna (3)
14 Marlee (4)
15 Maddison (2)
17 Bradley (11)
17 Kammryn (6)
20 Bayley (3)
20 Lachlan (3)
25 Logan (1)
28 Caleb (4)
29 Maddison (9)

May

1 Aimee (4)
3 Joshua (3)
5 Sophie (8)
5 Charlie (2)
5 Oscar (2)
11 Ben (4)
13 Jack (4)
19 Samantha (9)
19 Matthew (9)
22 Janarra (8)
23 Jack (1)
23 Jordan (2)
24 Aaron (6)
26 James (6)
29 Jeremiah (2)
30 Sarah (4)
31 Alexander (3)



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



Donations

Austprem Inc. is a non-profit organization 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 your 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/about/membership.html> and fill out the online membership form.

To access the online forums and chats (where most of the Austprem "action" happens), you will need to follow the steps at

<http://www.austprem.org.au/sharing/forum/forums.html> to register with mc2 and subscribe to the 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!



ABN 67 731 996 316

Austprem Inc.

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

Visit our website
www.austprem.org.au

Contact Us:

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kirsten@austprem.org.au

Newsletter

Suggestions and Comments?
newsletter@austprem.org.au



Coming Up in the Next Issue...

Early Intervention, Part I

Copies of **Austprem Ink**
may be downloaded from:

[http://www.austprem.org.au/
newsletters.html](http://www.austprem.org.au/newsletters.html)

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PremiePress is
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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.

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1800 666 550



Please support those that support us.

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