

# NEONATOLOGY TODAY

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## NEONATOLOGY TODAY

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## THERE MAY BE PARTS OF ME THAT YOU DON'T SEE BECAUSE YOU DON'T LOOK!

By Ian Woodroffe, Psychological Support NICU

The concept of a safe and secure assumptive world is one that we normally take for granted. It is difficult to think how we would begin each day if the predominant thoughts were that something serious was going to happen.

The literature on the subject of trauma and related psychological consequences is clear, that if our assumptive world is disrupted or shattered, then there may be serious psychological consequences that may need attention. An example would be the onset of PTSD, Kauffman J (2002).

It is estimated that, in the UK alone, traumatic births may result in 10,000 women a year developing Post Traumatic Stress Disorder (PTSD). Also, as many as 200,000 more women may feel traumatised by childbirth and develop some of the symptoms of PTSD. (Birth Trauma Association).

Although there may be debate about the nature of the treatment, none would doubt that serious symptoms of a disrupted assumptive world are disabling to the person concerned.

Little has yet been written about the psychological disruption of the multiple grief of parents when a baby is admitted to a Neonatal Intensive Care Unit.

*“Little has yet been written about the psychological disruption of the multiple grief of parents when a baby is admitted to a Neonatal Intensive Care Unit.”*

We are more familiar with emotional support that may be given to the parents after a baby has died. Sadly, the whole area of important work on multiple grief may be ignored to the detriment of the parents and the baby.

Multiple grief induces a 'frozen emotional state,' and bereavement overload Kastenbaum (1969) that has consequences on how the individual processes information, makes bonds and works out a strategy of managing the emotional overload. Parents of a baby that is admitted into a NICU will be suffering multiple grief which will compound the terrifying emotional experience.

After videoed interviews with parents, Woodroffe (2006) identified that there is the potential for at least eight major losses for parents after a sudden and unexpected pre-term birth that need to be processed (see Table I).

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**Table I. Losses Around Pre-Term Delivery That Give Rise to Multiple-Grief**

- The lost weeks of the pregnancy
- The dreams of a perfect birth
- Control over the birth process
- Confidence as a Mother
- Normal parenting
- Holding, touching and bonding at the time of birth
- Understanding
- Possible loss of breast feeding

*Table reproduced with permission from the Journal of Neonatal Nursing*

**Table II. Feelings in Multiple Grief**

• Anger	• Isolation	• Devastation
• Helplessness	• Frustration	• Disorientation
• Guilt	• Panic	• Exhaustion
• Resentment	• Despair	• Worry
• Fear	• Confusion	

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**Table III. 3 Potential Behaviours**

- Withdrawal from baby, partner, family and friends and staff on the NICU
- Tearful
- Defensive
- Brave-faced
- Angry
- Numbness
- Apparent obsession with needing to have knowledge
- Aggression
- Shocked

*Table reproduced with permission from the Journal of Neonatal Nursing*

These losses are likely to be experienced before entering the frightening environment of the NICU. Each loss may be accompanied by feelings; some of the feelings reported by parents are in Table 2.

Those who have studied grief theory will recognise these feelings as classic symptoms of grief.

Grief theory and research indicates that present losses may well trigger the unexpressed emotions of previous life losses (which may be deaths, divorce or many other forms of loss) Worden JW ( 2001).

The psycho-biological literature demonstrates that the emotional state of a person will effect the physiological responses in the body. Physical symptoms

may occur as a result of the psychological unease of the individual, Rossi (1993).

With the abundance of literature on these subjects, it is even more surprising that so little coordinated multidisciplinary work is being carried out with families in the NICU. It could be postulated that since there are so few dedicated funded posts for psychological support of this nature, that the work is deemed to be of low priority, or is even seen as an expensive luxury. What is not seen is the health care cost after discharge from NICU, and the cost to the parents and the child of unresolved grief issues. Such unresolved grief issues may lead to depression (that has to be treated incurring cost) and to the destabilisation, or complete breakdown of the parental relationship and even to the difficulty in bonding with the infant.

In the parent interviews (Woodroffe), it becomes clear that losses and the accompanying feelings may give rise to some powerful behaviours that can be seen as disruptive in the NICU. Staff can easily label parents as 'difficult,' and once that label is used, then the whole style of communication is effected and tainted. (See Table III)

Often the documentation in the NICU contains no reference to previous life losses. There is documentation around obstetric history, but it is quite possible that staff may not know that a relative committed suicide a year ago. Certainly, we could predict that such a life event, shattering the assumptive world of the relative, would effect their ability to function if the relative were to end up as a NICU parent twelve months later. Rarely, are genograms used in NICU history taking, and sometimes the information is not known until 'an expression of behaviour' reveals the history.

There are very few dedicated funded posts in the United Kingdom that provide resources to work specifically in the important area of multiple loss support in NICUs. There is little or no evidence of coordinated multidisciplinary work in this field.

A post of 30 hours a week exists at Addnebroke's Hospital Cambridge University NHS Foundation Trust dedicated to providing psychological support for parents in the NICU environment. Much has still to be developed in the delivery of



a psychological support service in the multi-grief environment but the evidence is that such a service is very helpful to parents.

Contact is made with parents as soon as possible after the admission of a baby on the NICU. The concept of psychological support is introduced, and the parents are invited to informally meet with the psychological support worker in a more private environment than the NICU. The NICU environment can be difficult emotionally because of the lack of privacy. The purpose of the early meeting is to discover from the parents story what they have encountered and the associated feelings. A sense of 'normalising' of the feelings that may accompany trauma can be a great comfort to parents. A simple explanation of the effect of multiple grief and naming the losses can allow parents to know that their strong feelings, numbness or behaviour is in line with the evidence of trauma reactions. To be able to explore the 'helplessness' and the 'frightening vulnerability' with another who is aware of these potential powerful disabling feelings is acknowledged as helpful. Such an early meeting provides the opportunity to acknowledge that the Unit places psychological care of parents within the health care provision. The meeting also signals to parents that suppressed emotions can be detrimental to physical health. That very fact can be a revelation to some who have grown up in a family environment where suppression of emotions has been the norm. Parents are invited to meet the psychological support worker and some will not wish to take up the invitation.

After 2 days on the Unit, parents are offered a 'Journey Box' free of charge. The small cardboard box is for parents to store photographs, name tags, the first size nappy (baby diaper) worn by their baby (clean of course!!) and the first size feeding syringe that was used in the baby's first meal. Parents are encouraged to place in the box any significant object that will remind them of the beginning of their baby's journey. Significant objects are an important part of the grief process (Van der Kolk et al 1996). Trauma reactions can cause important memories to be lost. The objects in the Journey Box will provide 'triggers' for the parents that will help them process some of the loss experience and will also provide a continuing bonding moment between parent and child in the future when the box is examined at home. It is hoped that children will use the box in future school projects with a sense of excitement and with a real understanding and acceptance around pre-term birth. The 'Journey Box' project is the first of its kind to incorporate 'significant objects' into the pre-death multiple grief understanding of parents in a NICU.

If the baby should die whilst on NICU, the parents have significant objects for the expression of their baby's death and there is no need to introduce the memory box concept at the time of the death.

(The low cost financing for the Journey Box project is provided by Premrose, a charity that supports the NICU).

At Addenbrooke's, the parents are not invited to join the ward-round, so during the week, coffee is provided for all the parents to meet together and to meet with the psychological support worker. This meeting enables parents to meet and share their 'stories' and thereby confirm the psychological symptoms that are common to parents on a NICU. Parents talk about being comforted hearing that other parents have similar feel-

ings. The process is designed to 'normalise' the fragile nature of the NICU environment where most parents may secretly fear that their baby is going to die. As part of the talking and releasing of emotions, some 'psychological work' around the multiple-grief areas may be facilitated.



*Inside Addenbrooke's NICU.*

The coffee meetings also enable an informal psychological assessment of the parents who attend. This informal assessment creates a priority list for one-to-one invitations for meeting with the psychological worker to discuss the current anxieties. With the parent's consent any major issues that are discussed are written in the parent's notes for the doctors to follow-up.

The process of the meetings is to, first, communicate a message to parents that psychological support is part of the multidisciplinary composition of the NICU, and second, that psychological support is considered to be important for the well-being of parent and baby. More research has still to be done, but the author suspects that anxiety in the parents is transmitted to the baby and that may slow the healing of the baby.

The NICU at Addenbrooke's is a level 3 Regional Unit so transfers to other units are a frequent occurrence. The subject of transfer often causes great stress to parents particularly if the hospital to receive the baby is further away from the parent's home base. The transfers can often take place with as little as twenty-four hours notice for the parents.

As mentioned above, the assumptive, safe world of the parents is shattered by the NICU event. Over a period of time on the NICU some sense of security may be regained, however fragile. The familiarity of the routines of the unit provides a sense of knowledge and in some cases a small restoration of control for the parents. The equipment is understood, and the medical cultural language is picked up by the parents. The staff becomes known and recognised, and there is a sense of support in a fragile and vulnerable environment. The more vulnerable parents may not have left the Neonatal environment for many days, and the outside world is seen as a threat and a source of anxiety. Suddenly, all that sense of control and security is questioned with the prospect that the baby will be transferred to another hospital. There is a real sense of fear and panic in some parents that is reminiscent of the fear

and panic on the first admission to NICU. The challenge for any unit, on the matter of transfer, is to deal with the psychological issues alongside the medical issues. It should be a genuine matter of concern about how the psychological care of parents can be transferred so that the receiving hospital can continue a seamless provision of psychological care. If this is not attended to, then it is likely that the multiple-grief issues will not be processed by the parents. Unexpressed grief can have serious consequences (Worden 2001).

At present there is little provision for such 'psychological handover' within the health care provision in the UK.

If the NICU environment is scary (See Table 1) for parents, then it may be very frightening for siblings who not only need to understand the environment, but may also be competing for attention with the newborn brother or sister. There may be regression of behaviour from the sibling which will complicate the life of the parents. In the Cambridge Unit an excellent leaflet for parents has been designed by one of the neonatal nurses to alert parents on the behavioural symptoms of siblings (Beavis A. 2006).

Parking fees at the hospital, travel and not earning day-by-day, (particularly for the self-employed), are all practical issues that compound the psychological stress for parents on the NICU. Addenbrooke's is fortunate to have 5 parent bedrooms for over night stay on a daily basis so at least some mothers can stay nearby their sick baby day and night.

If the baby dies on the unit, there are opportunities for parents to access post death bereavement support. Currently, a team of bereavement support volunteers are being trained to provide home visits for up to a minimum of one year. The remit of the team will also include psychological support of parents during a subsequent pregnancy which is anticipated to be an anxious time.

There are so many opportunities to provide well-planned coordinated psychological support in a NICU. The question to examine is whether that support is being provided as a planned intervention with a rationale for long term care for families?

The author of this article suggests that if these important psychological issues are attended to, alongside the medical care, then subsequent mental health issues

(which in themselves are costly financially and emotionally) may be less. The well being of the present generation is important, and with all the research at hand, the well being of the next generation must be a priority. Anything that we ignore now may have consequences for the future. Issues such as psychological distress in parents cannot be ignored less we fail in our 'duty of care.'

Such surely are the tenants of good health care.

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## REVIEW OF VIDA DVDS

By Roger E. Sheldon, MD, MPH

Developmentally appropriate care of preterm infants in NICUs, or “developmental care,” has been moving from a theoretically good idea to an evidence-based best practice over the last 10-15 years. Built on the concept that different sorts of care are needed by different individual babies, and by babies of different developmental ages/stages, developmental care holds out the promise that most aspects of neurodevelopment can be preserved even in the face of extreme prematurity. While the evidence has not yet convinced all the meta-analysts, numerous NICUs are adopting all or part of the developmental care model based on steadily accumulating randomized controlled trials suggesting better neurodevelopmental outcomes from shorter hospitalizations for less money[1,2,3,4]. Preliminary data, not yet published, appears poised to add to the underpinnings of the approach.

Among the aspects of developmental care that have had the greatest acceptance to date are:

1. Reductions in sensory inputs (bright light, loud sound, scents and tactile experiences) that would not be encountered at similar gestations in utero
2. Preservation of sleep by clustering care and allowing more extended intervening sleep
3. Avoidance of pain and other noxious sensory experiences to the extent possible
4. Provision of “facilitation”—physical containment and soothing to the child during noxious experiences
5. Exposure to parents’ skin-to-skin holding (“kangaroo mother care”)

The concepts of developmentally appropriate care came out of the work of Heidelise Als, building on concepts of

Blurton Jones, Palay, Werner, Denny-Brown, Gesell, and others. Dr. Als’s extended aspects of behavioral assessment (after T. Barry Brazelton and others) into the world of the extremely premature baby. Perception of the reactions and the approach or avoidance behaviors of the preemie led to an understanding of what experiences a tiny preterm could cope with at various gestational ages. Tailoring care to the individual child, based on his or her specific reactions and capabilities is a central concept of Newborn Individualized Developmental Care and Assessment Program (NIDCAP)[5]. Intuitive human kindness in avoiding or reducing noxious experiences has now found support in controlled trials showing increases in brain connectivity and augmented myelination among infants cared for in this way[6].

Building on neuroscience and the concept that neural circuits develop and synapses are recruited by the repetitive use of those circuits for good or ill (“Neurons that fire together, wire together”), attention is now being paid to the proper augmentation and sequencing of brain tract development, connections, and myelin deposition.

For example, obstruction of one eye in kittens leads to near-absence of the optic visual pathway serving that eye[7], while experimental opening of the eyes of newborn rats and puppies earlier than “intended” can be shown to interfere not with subsequent eyesight, but with the hearing and olfactory pathways that should be developing around the time of birth[8]. Visual inputs in this case are thought to interfere by taking precedence, out of sequence, over the hearing inputs important at that age. While similar effects cannot ethically be shown in human infants, one can argue that out-of-sequence sensations and experiences should be avoided until they are “supposed” to be happening.

Equally important but less well studied is avoiding the enhancement of pathways

(pain, arousal, avoidance, dissociative responses) that should not be fortified at this (or any) gestational age. The normal “pruning,” by apoptosis, of more than half of the neurons initially present at 28 weeks gives shape to each brain over months to years; not eliminating the cells and pathways that should disappear will fashion a brain much different from the one “intended.” Neonatal experiences truly matter.

The subject of this review is a series of video programs on DVD that explains current thinking and evidence regarding developmental care, two for professionals and one for parents and the public. Produced under an NIH grant (from the National Institute of Child Health and Human Development) by VIDA Health Communications, Inc. of Cambridge, Massachusetts ([www.VIDA-health.com](http://www.VIDA-health.com)), these videos provide high-quality, foot-noted discussions presenting experts in the field, showing the behaviors of the newborns, and detailing aspects of care that make up the developmental approach. Parent experiences and reactions are also presented.

The first video, “Focus on the Brain: The Science of Preterm Infant Behavior,” begins with concepts in brain development and describes the scientific underpinnings of developmental care. Chapters include:

1. The Overlooked Organ
2. Fetal and Neonatal Brain Basics
3. How Relationships and Environment Shape the Brain
4. The Sequence of Sensory Development, and
5. The Role of Sleep in Preterm Brain Health

Comments from Stan Graven, George Little, Peter Gorski, Heidelise Als, Petra Hüppi, Frank Duffy, Adre Du Plessis, Bob White and others weave the story of environment in the NICU and the brain changes that can be attributed to devel-



opmental care. Numerical footnotes provide references to the literature for the assertions made in the comments.

The second video, "Focus on the Brain: Clinical Practices for Special Care Nurseries" details clinical methods and approaches in four areas:

1. Observing Infant Behavior,
2. Brain Sensitive Care,
3. Parents As Partners, and
4. Environments for Brain Building.

These demonstrations of practical, bedside approaches can assist a NICU team in adopting developmental practices. Especially useful are the video clips of various behaviors not easily recorded, and the suggestions for developmentally appropriate bedside care.

The third video, "No Matter How Small," describes the concept and methods in lay terms for families. In 39 minutes, it includes 6 chapters:

1. Not What I Expected: NICU Beginnings;
2. Parents Matter: You Make Things Better;
3. Brain Basics: What Shapes Development;
4. Born Amazing: Infant Senses and Strengths;
5. Reading Your Baby: Behavior, Signs and Signals; and
6. Close and Connected: Nurturing in the NICU.

The tone is supportive and reassuring to families that they can play a role in the child's development and parent their child in a supportive and productive way. It encourages fathers to be involved in kangaroo care and other aspects of the child's day—thus supporting involvement by the often-discouraged or excluded fathers. I suspect that it will assist us in involving fathers in their child's life. It supports mothers in kangaroo care and encourages lactation and breast milk supply.

Production values and sound quality are very good, with professional-quality avail-

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***"I feel that these videos are an excellent addition to your teaching and parent-support ...."***

---

able-light video revealing preemie behaviors that are often missed or misinterpreted. A quiet sound track of gentle music gives an impression of the sort of quiet and calm that is being promoted during NICU care.

The script is sophisticated and clear in its descriptions and arguments. The interview clips are to the point and well sequenced to explain the state of the science, and to make the case for brain-sensitive care. The methodology section in video two provides easily understandable advice for moving toward this sort of care.

I feel that these videos are an excellent addition to your teaching and parent-support process—providing as they do, a clear review of the evidence and the steps to take in considering or adopting aspects of developmental care for your patients and families.

Dr. Sheldon is Co-Director of the Sooner NIDCAP Training Center at OU, and a member of the Board of Directors, NIDCAP Federation, International.

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## MEDICAL NEWS, PRODUCTS AND INFORMATION

**Study Recommends Universal Newborn Screening for Cystic Fibrosis**

Newborn screening for cystic fibrosis saves on treatment costs and would offset the actual costs of the screening programme. This new economic evidence suggests that universal newborn screening programmes for cystic fibrosis should be adopted internationally, according to an article in an April issue of *The Lancet*.

The study also showed that newborn cystic fibrosis screening reduced hospital admissions for invasive therapy.

Cystic fibrosis is a life-shortening hereditary lung disease, but treatments are available. In some regions newborn babies have been screened for cystic fibrosis for more than 25 years, and early diagnosis is associated with improvements in some clinical outcomes. Furthermore, the clinical benefit of those screened as newborn babies is associated with a lower treatment burden compared with clinically diagnosed groups. Whether these potential cost savings attributed to reduced therapeutic requirements would offset the cost of a newborn screening programme had not previously been studied.

Cystic fibrosis screening hit the headlines in November 2006, when it was announced that UK Chancellor Gordon Brown's baby son Fraser had been diagnosed. Babies are routinely screened for the condition in Scotland (since 2003), Wales and Northern Ireland, but this is not yet the case for all areas of England including London.

Dr. Erika Sims (University of East Anglia, Norwich, UK) and colleagues from the University of Dundee, UK, used data from the UK cystic fibrosis database for 2002 to compare the treatment costs of 184 children aged 1-9 years who had cystic fibrosis that was identified by newborn screening with those of 950 children in the same age-group, who were identified after clinical presentation of the disease. Patients diagnosed by newborn screening cost significantly less to treat than those who were diagnosed clinically. Patients diagnosed on the basis of clinical presentation alone received therapy costing an estimated 60–400% more than patients diagnosed by newborn screening.

The authors conclude: "Newborn screening is associated with lower estimated treatment costs and reduced hospital admis-

sions for invasive therapy, which suggests that indirect costs and disruption to family life will also be less. Furthermore, the potential cost savings to the yearly treatment budget could offset some, if not all, of the costs of a newborn screening service."

In an accompanying comment, Bridget Wilcken and Kevin Gaskin (both of the Children's Hospital at Westmead, and University of Sydney, NSW, Australia) state: "If clear clinical benefit does not always persuade governments to implement screening, cost benefits might...Some parts of the world - e.g. the Middle East and possibly India—have a high frequency of cystic fibrosis, and screening might have potential in countries with a stable health-care system."

For more information, contact: Dr. Erika Sims at [e.sims@uea.ac.uk](mailto:e.sims@uea.ac.uk).

**Noninvasive Screening in Early Pregnancy Reduces Down's Births by 50%**

Nice, France: Non-invasive screening of pregnant women with ultrasound early in pregnancy, combined with maternal blood analysis, has reduced the number of children born in Denmark with Down Syndrome by 50%, a scientist will tell the annual conference of the European Society of Human Genetics today. Professor Karen Brøndum-Nielsen, of the Kennedy Institute, Glostrup, Denmark, will say that another benefit of the introduction of this procedure in her country was a drop in the number of invasive pre-natal diagnostic procedures from 11% to approx. 6% of pregnancies.

Professor Brøndum-Nielsen told the conference, that the National Board of Health in Denmark recommended new guidelines for prenatal diagnosis. "Previously this was restricted to pregnant women over 35 years of age, but since the implementation of the new guidelines it has been available to any woman who wants it."

The women were offered a measurement of nuchal translucency in the fetus by ultrasound. This test looks at thickness of the black space (fluid) in the neck area of the fetus. If there is more than the normal amount of fluid the risk of Down Syndrome is increased. Likewise, if there is a certain combination

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**kathleen.kyer@hcahealthcare.com**

of serum markers in the maternal blood test, taken at the same time, there is the possibility of an increased risk of a chromosomal abnormality. The combined screening is carried out at 11 to 14 weeks of gestation.

Professor Brøndum-Nielsen and her team looked at the effects of the new guidelines in 2004, 2005, and 2006, in three counties in Denmark with a total population of 1.1 million inhabitants, or about one-fifth of the population of the country. They compared these findings with national figures obtained from the Central Cytogenetic Registry, which confirmed the reduction in invasive procedures and the number of children born with Down Syndrome at national level. "When we looked further at the history of children born with Down Syndrome, we found that their mothers had declined the offer of screening, or had taken it up too late in pregnancy," she says. Another group had risk assessment that did not lead to invasive procedures

Women whose test results showed an elevated risk were offered an invasive procedure (chorionic villus sampling or amniocentesis) to definitely confirm or exclude the diagnosis of Down Syndrome by chromosome analysis. "We found that making non-invasive screening available to all pregnant women meant that the numbers of invasive procedures decreased by 40% between 2004 and 2006," says Professor Brøndum-Nielsen. "Although we have not yet studied the whole of the population, these numbers are significant enough to show that the new guidelines have been accepted by a great majority of Danish parents. However, there is a need for analysis of the psychosocial aspects, both as to the pre-test counselling and the women's attitudes," she says.

For more information, European Society of Human Genetics:  
[www.eshg.org](http://www.eshg.org)

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## THE CRIB

By Tarek Nakhla, MD

Here I am the night before,  
I leave tomorrow, you see me no more.  
It was a pleasure to say the least,  
But going home is my biggest feat.  
I was so tiny, I know I was.  
Less than 2 pounds, with pinpoint toes.  
And now I'm 4, and some ounces more.  
They even say he feeds and grows.

Those early hours scared me big.  
They called a priest just in case I don't  
make it.  
My father cried and asked: "it's that  
bad ??"

The doc said: "a blessing is a blessing,  
Doesn't take, can only add."

This breathing tube was really annoying.  
They gave me Fentanyl, I was out  
enjoying.  
Then came the day, the tube was out ,  
How happy I was!!

I was so happy I forgot to breathe!!  
They said caffeine will wake me up,  
I thought they're bringing some coffee in  
a cup!!

How many times they stuck me with  
needles!!  
Their menu was limited: heel sticks/or  
bleeders.

They came with pain and cries on the side,  
No one to listen no one to defend  
My nurse said: "not to worry,"  
She scores the pain in the beginning and  
the end!!

I felt better, I wanted to drink.  
"Oh no you can't and don't even think."  
They thought I have my "NEC" in my  
tummy!!  
I couldn't believe it, I thought it sounds  
funny.  
The X-ray showed my "neck" in its place.  
That's OK, I think!!  
The big doc said I can now drink.

My whole life I dreamt of being in a crib  
It took a long time, what a long trip!!  
I am now free and happy as I could be.  
This is my last night here in room D.

NT



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