

New Bliss fact sheets – surgical conditions explained

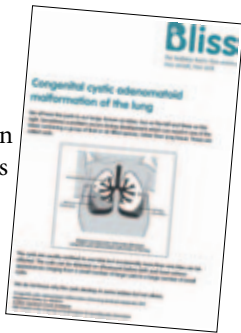
Some babies have serious medical conditions which require surgery. This can be for babies born prematurely or babies born at term.

Bliss has put together a number of factsheets, in partnership with University Hospital Southampton surgical team. These explain certain conditions and the treatment babies will receive and are all available to download from the Bliss website www.bliss.org.uk

They include NEC, congenital cystic adenomatoid malformation of the lung, duodenal atresia, and gastroschisis plus several others.

The factsheets provide a basic understanding of these conditions and cover a number of the more common surgical procedures that may be undertaken. They also encourage parents to ask the team looking after their baby to involve them in the caring process and to explain anything that is unclear.

Bliss is able to provide further information and support. Please contact the Bliss Freephone Helpline on 0500 618140 to talk to one of our advisors or email enquiries@bliss.org.uk



Experts endorse strategies for early nutritional intervention in neonates

At the European Society of Paediatric Research (ESPR) in Newcastle in November 2011, leading international experts explored nutritional strategies in the management of very low birthweight (VLOW) neonates.

They concluded that:

- Evidence supports prophylactic supplementation of probiotics to reduce necrotising enterocolitis (NEC).
- Individualised nutrition is required to ensure optimised postnatal growth and development targets are met.
- Use of low protein formulas in non-breast-fed infants can lead to reduction of chronic disease in adulthood.

Professor Sanjay Patole, University of Western Australia, Perth, argued that today the debate should not be about whether probiotics should be used or not, but how to maximise their effective use, particularly in VLBW.

He highlighted that careful strain selection and addressing the gaps in knowledge (eg potential of single strain versus combination of probiotics) is important to optimise the safety and efficacy of probiotics in reducing the incidence of NEC.

Associate Professor Magnus Domellöf, Department of Clinical Sciences,

Sweden, supported the proposition that being born with VLBW can be regarded as a 'nutritional emergency'. He explained that VLBW infants are a highly heterogeneous group with large variations, due to many factors such as gestational age, birth weight, type of feeding and changes in composition of breast milk etc. Failure to provide optimal parenteral and enteral intakes of different nutrients results in malnutrition and postnatal growth failure, which is associated with poor health outcomes, including deprived cognitive development.

Professor Umberto Simeoni, France, says: "It is clear that breastfeeding is likely to have protective effects on the risk of being overweight or obese later in life. And, of course, breastfeeding is a model of low protein intake. High protein intakes in infants accelerate growth and there is increasing evidence that higher protein intake is also associated with a higher risk of later overweight and obesity."

He concludes: "The low protein/energy ratio of infant formulas should be considered for non-breastfed infants, in order to reduce the incidence of cardiovascular and renal disease at adulthood."

Lucy Air Ambulance for Children Charity

Lucy Air Ambulance for Children is the UK's first dedicated air transfer service ensuring critically ill infants and children are transferred safely and well supported by professional staff, trained specifically for in-flight delivery of care. The charity will work alongside the NHS to deliver the highest standards of service to give the best survival chances to those requiring hospital transfers.

Lucy Patron Zara Phillips says: "Lucy made its first transfer just a few weeks ago and I am pleased to see that already it is making a difference."

Lead Clinician for the London Neonatal Transport Service and Chairman of the National Neonatal Transport Interest Group in England, Dr Nandiran Ratnavel,

says: "The provision of such a service has been long overdue. As the Government sets out its 'Toolkit for Neonatal Services', the creation of Lucy Air Ambulance for Children couldn't come at a better time. We hope that the Government will be able to support such a needed service."

Very ill babies and children require time critical access to specialist life saving support, which is not available to them locally. Road transfer may not be appropriate due to the associated time delays, especially if significant distances are involved.

A co-ordinated road and air ambulance service has been in existence for several years in Scotland. This service is often asked to undertake transfers from England and Wales, demonstrating the need for an independent service south of the border.

Dr C H Skeoch, Consultant Neonatologist and Medical Director of Scotland's Western Regional Neonatal

Transport Service says: "Today, there is no established medical air transport system for babies and children covering the whole of England, Wales or Northern Ireland. It is clear from the figures we have on our national database that there is a vital need for this service to be co-ordinated over the whole of the United Kingdom."

The service will be provided at no cost to those children requiring hospital transfers by air, and will be mobilised at the request of the senior medical staff co-ordinating their care.

Fundraising is already underway and the Lucy Trustees will raise sufficient funds to provide transfers, initially by chartering aircraft and in time, through leasing their own dedicated helicopter equipped for all levels of medical dependency including intensive care.

For more information access www.lucyairambulance.org.uk

Calling all nurses: looking for a new challenge overseas?

Nurses across Britain are being challenged to take up their most demanding but rewarding career move yet as international development charity VSO launches its recruitment drive for 15 much needed skilled and experienced nurses to volunteer in some of the world's poorest countries this year.

VSO is the world's leading independent international development charity that works through volunteers helping to tackle global poverty by sharing their professional skills and changing the lives of the world's poorest and most vulnerable people.

With cut backs and redundancies affecting the UK's health sector workforce, VSO is urging nurses to seriously consider taking a career enhancing and possibly life-changing break for one to two years which will ultimately help save the lives of some of the poorest and most disadvantaged populations in developing countries.

The charity urgently needs to recruit 15 nurses who can start vital volunteering posts throughout 2012 in developing countries like Sierra Leone, Tanzania and Uganda. UK healthcare professionals will work with VSO's partner organisations within national ministries of health and local communities.

Volunteers will be involved in a wide range of work, depending on their experience and skills. This could involve everything from training nurses to developing improved curricula in training schools.

Pam Wilson is a senior charge nurse from Dundee and volunteered with VSO in Malawi as a clinical instructor in a Malawian Government College of Nursing. She says: "It was a fantastic, life

changing experience for me. It was very rewarding being able to share my nursing skills with so many student nurses. It was also comforting to know that I was able to adapt my nursing skills to work in a developing country. My Malawian students and colleagues were also able to teach me a great deal about their culture and healthcare systems.

"The students I taught are now working in Government hospitals looking after Malawian people. They're sharing the skills I taught them with the nursing students and Malawi colleagues working in their wards. I've been back to Malawi twice now and was very pleased to see the improvements in their healthcare system.

"After volunteering for VSO I have a greater understanding of different cultures and global health care systems. I'm also much calmer and can cope better with challenging situations at work. For



any nurses thinking of volunteering, you have a lot to give so do apply now to VSO to share your skills with others in a developing country and make a difference."

VSO's recruitment process normally takes between four and nine months. Those wishing to volunteer are advised to start the process within 12 months of being ready to volunteer.

Volunteers are provided with full training, flights, accommodation and an allowance to cover basic costs. Unlike many UK-based volunteering organisations, VSO does not charge individuals to volunteer and its recruitment policy is based on matching the right professionals with the correct skills and qualities rather than on the ability to pay.

The charity is holding a series of free events which interested healthcare professionals can attend to find out more about volunteering on:

- 17 January, London
- 21 February, London

Full details can be found at www.vso.org.uk/events/.

For further information about healthcare volunteering, please visit www.vso.org.uk/volunteer/

When a baby dies before labour begins

Sands new support booklet, 'When a baby dies before labour begins', has been written specifically for parents who have just been told that their baby has died. It covers all the things that they may want to know during the time between receiving this terrible news to the start of labour.

This booklet is the ideal guide for parents who are waiting for an induction or for labour to start spontaneously.

It covers essential topics such as how the parents are likely to feel, their choices about the labour and its management, information on pain relief during labour and what to expect when their baby is born.

Sands recommends that it is stocked by maternity units, the ultrasound department and in the fetal assessment unit.

Once the baby is born, Sands' well-known booklet, 'Saying goodbye to your baby', which has recently been revised and updated, takes the parents onwards,

through the issues, feelings and reactions that they are likely to have to deal with during the coming days, weeks and months, following their baby's death.

To order copies of Sands new booklet 'When a baby dies before labour begins', or copies of the newly revised booklet 'Saying goodbye to your baby', please contact Sands head office on 0207 436 7940 or visit the Sands shop at www.uk-sands.org/Shop/Shop-Home/Support-leaflets-literature.html

Internet service improves care for newborns

According to researchers at Chalmers University of Technology, Gothenburg, Sweden, premature infants often do better at home than in hospital. The relationships with parents and siblings are more natural, and they run a lower risk of contracting contagious diseases than at the hospital. With the new Internet service developed and tested at Chalmers, patients can be at home and at the same time get better follow-up and maintain a dialogue with staff responsible for their care.

Anna Gund has worked with the new Internet service Care@Distance which includes a website where parents to newborns that require more careful follow-up, regularly fill in measurement values and other data related to their state of health. Care workers thereby receive ongoing information about patients without having to be on site.

“Similar systems have been tested with positive outcomes, but it seems to be hard to make them part of routine care,” says Anna Gund. “We have developed a system based on the technology that is already used in most homes, and we believe that this can facilitate further dissemination.”

The Chalmers researchers designed and tested a simple, inexpensive and adaptable system where parents and care workers only need a computer or a smart phone with Internet capability. Most other systems are based on equipment that is more expensive and more complicated to learn to use. Evaluation of the Care@Distance internet service showed that a key factor is that the caring staff must truly embrace the technology and provide regular feedback on the information submitted by the patient.

Read more about Care@Distance:
www.care-at-distance.se/en/

Opting for a caesarean section

New guidelines were published in November 2011 by the National Institute for Health and Clinical Excellence (NICE) regarding caesarean sections.

Belinda Phipps, Chief Executive of NCT says: “Our services fail women badly at the moment. They are not as safe as they could be and they leave about a third of women reporting their experience as traumatising in some way.

In-utero procedure for CDH significantly improves infant survival

A new study published in the journal *Ultrasound in Obstetrics & Gynecology* reveals that fetal endoscopic tracheal occlusion (FETO) improves infant survival rate in severe cases of congenital diaphragmatic hernia (CDH).

CDH is a birth defect where there exists a severe malformation (hole) of the diaphragm and is a major cause of death in infants due to pulmonary hypoplasia, an incomplete development of the lungs.

Researchers led by Rodrigo Ruano, in Sao Paulo, Brazil, conducted a randomised trial between May 2008 and July 2010 to compare the safety and efficacy of FETO for the treatment of severe isolated CDH.

Twenty patients were assigned randomly to undergo FETO and 21 patients were assigned to no prenatal intervention (control). FETO was performed between 26 and 30 weeks' gestation following a well-established protocol under maternal epidural anesthesia. Delivery occurred at 35.6+2.4 weeks in the FETO group and at 37.4+1.9 weeks in the control group.

In an intention-to-treat analysis, results found that 10 of the 20 (50.0%) infants in the FETO group and one infant out of 21 (4.8%) in the control group survived. The findings demonstrate that FETO improves the chance of surviving after birth from less than 5% without this treatment to about 50% after this treatment.

The FETO procedure appears to improve survival by enhancing pulmonary growth as a consequence of fetal tracheal occlusion.

The present study allows the establishment of this treatment as standard care for severe forms of CDH.

Access the article at: <http://doi.wiley.com/10.1002/uog.10142>

“It is important that women do have the option of caesarean section if they feel, after understanding the risks and benefits, it is in their or their baby's best interests and they are fully informed of the process. It is also important that the vast majority of women who want to have a vaginal birth have confidence that they will be supported properly and are provided with the necessary care.

“Women should not be put in a position where the fear of a poorly

New single voice for children's palliative care



A new organisation, Together for Short Lives, has been launched to provide a powerful voice for life-limited and life-threatened children and young people, their families and those who provide them with support. Together for Short Lives is the new name for ACT & Children's Hospices UK, which merged in October. The Charity's vision is for all children and young people unlikely to reach adulthood and their families to have the best possible care and support in the place of their choice.

Together for Short Lives brings together, for the first time, all those involved in children's palliative care, from the children and families themselves to the professionals and organisations who provide the full range of care and support.

Commenting on the launch of the new organisation Chief Executive Barbara Gelb says: “We are delighted that this new organisation has formed at such a critical time for life-limited children, young people and their families. With so much change taking place in health and social care across the UK, we are ideally placed to provide a strong and consistent voice for children and families and support the very best in care practice across the sector.”

Lizzie Chambers, Deputy Chief Executive, adds: “There are an estimated 23,500 children and young people in the UK who are unlikely to reach adulthood. Together for Short Lives is here to ensure that every single child gets the best possible care and support from the moment of diagnosis, wherever they live and for as long as they need it.”

Together for Short Lives is the beneficiary for this year's X Factor charity single.

For more information, visit
www.togetherforshortlives.org.uk

supported vaginal birth forces them to choose a caesarean section where the medical risks are greater for most women. Much more important than anything is that the NHS runs a service that means – whichever sort of birth you have – your experience is made as positive as possible with a midwife you know and trust by your side throughout your labour. Overall there is a need to reduce the risks of both surgical and vaginal births.”

<http://guidance.nice.org.uk/CG132>