

Parent information following the death of your baby on NICU

Neonatal Intensive Care Unit

INTRODUCTION

All the staff on the Neonatal Unit here at St. Peter's Hospital would like to extend our deepest sympathy to you following the death of your baby.

This leaflet is intended to give you additional information to that received from a nurse or doctor, and is designed to help you at this sad and difficult time, particularly with some of the practical and official matters.

RELIGIOUS AND CULTURAL NEEDS

You may have very specific religious, cultural or other needs and we wish to ensure that these needs are met. Please let us know what your requirements are, and how we can help you.

A BLESSING FOR YOUR BABY

The nurse looking after your baby, with your permission, can contact one of the hospital Chaplains or your own religious leader. Even if you do not have a religious faith, you may find it helpful to talk to one of them, and you may like a blessing for your baby. A Certificate of Blessing will be given to you.

CHAPEL OF REST

Your baby will stay in the Chapel of Rest at St. Peter's Hospital and will be cared for in a sensitive manner at all times. If you wish to see your baby again before the funeral, you may prefer to spend time with him or her in the Chapel of Rest at the Funeral Directors. Once the death has been registered at the Registrar's Office, the Funeral Director can collect your baby as soon as you wish and offer any support you need. However, if you would prefer to see your baby again before this the Bereavement Office can help make this possible. (**01932 722319** or **01932 722516** in office hours). This of course is a very individual matter.

CORONERS POST MORTEM

The Neonatal Consultant reports all the deaths that occur on NICU to the Surrey Coroner. When the Coroner has all the information concerning the circumstances of your child's death he/she may decide that a full post mortem is required. A Coroners Post Mortem does not require your consent.



A POST MORTEM FOR YOUR BABY

If the coroner does not require a full post mortem you or the Neonatal Consultant may feel that it would be helpful to have a post mortem. If so you will be given the verbal and written information to help you to reach a decision. Your written consent is required for this to happen. You may decide to agree to a full post-mortem or to a more limited examination. Your baby's post-mortem will usually take place at St Thomas's Hospital. Although the results may not be ready for up to ten weeks, your baby will be released much earlier than this, usually within 2 – 4 weeks, so that you can make funeral arrangements.

REGISTERING YOUR BABY

You may have already registered the birth of your baby, if not you will need to do this at the same time as registering his/her death. You will usually be given a Medical Cause of Death Certificate by your baby's nurse or doctor, and you will need to take this to the Registrar. It is a legal requirement that the death is registered within 5 working days. The Registrar will issue you with both a Birth Certificate, if this has not yet already been done, and a Death Certificate. You will also be given a green form permitting you to make funeral arrangements for your baby. You will need to take this form to your chosen Funeral Director.

Where?

All deaths are normally registered in the district where the person has died. For St. Peter's Hospital this can be done at the local office. The Registrar of Births, Deaths and Marriages is based in Weybridge:

The Register Office, 81 Oatlands Drive, Weybridge, KT13 9LN, Tel No. **01932 794712**.


Opening Times


They are open Mon-Fri 9.00 - 16.30 except Wednesdays when the office opens at 09.30. You will need to ring the Registrar's Office and make an appointment.

It is also possible to go to any other Register Office in England and Wales. This process is called REGISTERING BY DECLARATION. The birth and death can be registered at the same time and place and although registering by declaration results in a wait of approximately 5 days for the birth and/or death certificate as they will be posted to you, this should not delay the funeral in any way. It is still possible to visit the Funeral Directors and make provisional funeral arrangements.

ARRANGING YOUR BABY'S FUNERAL

You will need to arrange a funeral service for your baby and initial arrangements can begin as soon as you are ready. Unless there are specific religious or cultural reasons for holding a funeral quickly, there is no need to hurry and you can take all the time you need to make sure the funeral is arranged in a way that will be meaningful to you. If you wish to have any type of religious ceremony, the hospital chaplain can advise. It is not necessary to have a religious service and you may like instead, just to plan a service with your family and friends. Your own choice of music or readings can be part of the funeral itself.





The funeral service can only take place once your baby has been registered and, if applicable, once the post-mortem has been completed. The Bereavement Officers are available to help you make contact with a local Funeral Director if you wish. There is often no charge for a Cremation service, although there may be restrictions on the time of day that the service can take place. If you choose to have a burial service you will find that most local cemeteries charge for a baby grave. These charges may vary.

The Funeral Director will need the green form which the Registrar will give you, before final arrangements can be made. The Funeral Director will then contact the hospital and will arrange to bring your baby to their Chapel of Rest.

FOLLOW-UP CARE

If your baby was born in the last 2 weeks, the Community Midwife will be in touch with you to arrange a visit. Your midwife will be able to discuss with you any concerns you may have.

You will also need to make an appointment to see your GP for your post-natal check up at about 6 weeks.

Our care for you continues even after your baby has left the hospital and for as long as you need our support. The NICU Family Support Nurse will telephone you or you can contact her on **07810 756945**.

You will also be offered an appointment with your Neonatal Consultant in approximately 6 weeks, although this may be longer if we are still awaiting post mortem results.

MATERNITY AND PATERNITY LEAVE

For babies born alive and even those who may have only lived for a short time, you are entitled to the full normal maternity leave. You are also entitled to free prescription and dental care for one year after the baby's birth. If your partner is entitled to paternity leave this entitlement also still holds.

BENEFITS


If you are eligible for Statutory Maternity Pay or Maternity Allowance you will still be entitled to these.

If you are on a low income and/or receiving benefits you may be eligible for Sure Start Maternity Grant and/or funeral expenses payment. You will need to complete form SF200 available from your Jobcentre Plus office or Social Security office.

Child benefit is also paid for up to 8 weeks after the date of your baby's death, some parents may find this strange but it is important that parents are aware of this option and that you need to claim within 3 months of your baby's death. You can claim via your Jobcentre Plus office or Social Security office.

CEREMONY OF REMEMBRANCE

The Trust holds an annual Ceremony of Remembrance for children who die at any age, from early pregnancy to adulthood. This ceremony usually takes place on the last Saturday in June and you will be sent an invitation. The Family Support Nurse or the hospital Chaplain can give you more details.



USEFUL TELEPHONE NUMBERS


Weybridge Register Office	01932 794712
Woking Crematorium	01483 472197
Hanworth Crematorium	0208894 9001

HOSPITAL TELEPHONE NUMBERS

Bereavement Office	01932 722319
	or 01932 722516
Chaplain via switchboard	01932 872000
NICU Family Support Nurse	07810 756945
St Peter's Hospital	01932 872000

SUPPORT ORGANISATIONS

BLISS	0500 618140
www.bliss.org.uk	
Child Bereavement Charity	01494 568900
www.childbereavement.org.uk	
Child Death Helpline	0800 282 986
www.childdeathhelpline.org.uk	
Compassionate Friends (for parents who have lost a child)	
www.tcf.org.uk	0345 123 2304
Cruse Bereavement Care	0808 808 1677
www.crusebereavement.org.uk	
The Samaritans (Weybridge)	01932 844444
SANDS (The Stillbirth and Neonatal Death Society)	020 7436 7940
www.uk-sands.org	
SANDS Helpline	0808 164 3332
helpline@sands.org.uk	
TAMBA (Twins and Multiple Births Assoc.) Bereavement Support Group	
www.tambs.org.uk/bereavement	
Winston's Wish	0808 802 0021
www.winstonswish.org.uk (Help for bereaved children who have experienced the death of a family member)	




Below we have listed some books, which might help parents and children who have experienced the death of someone close.

Parents:

- **Empty Arms: Coping with Miscarriage, Stillbirth and Infant Death.** Applebaum A. (ed)(1995) Fairview Press: ISBN 0960945660.
- **Empty Cradle, Broken Heart.** Davis D.L. (1999) Fulcrum Publishing.
- **When a Baby Dies - The Experience of Late Miscarriage, Stillbirth and Neonatal Death.** Kohner N. & Henley A. (2001). Pandora: Sands. *(Includes parents' stories, medical explanations, grieving and future pregnancies).*

Children:

- **A Grief Observed.** Lewis C.S. (1966) Faber and Faber Ltd.
 - **All in the End is Harvest.** Whitaker A. (ed) (1984) Darton Longman & Todd Ltd.
 - **Badgers Parting Gifts.** Varley S. (1992) Picture Lions.
 - **I'll Always Love You.** Wilhelm H. & Knoff A.A. (1985).
 - **Sam's Story.** Chin-Lee F. Obtainable from the Foundation for the Study of Infant Deaths. www.sids.org.uk. Helpline 0870 787 0554. *(A useful book describing a brother's feelings about the death of his baby brother. Designed to be read with an adult).*
 - **Someone Special has Died.** Obtainable from St Christopher's Hospice. www.stchristophers.org.uk. Tel: 020 8768 4671. *(A simple book talking about how we feel when someone special dies).*
 - **The Death of a Child – A Book for Families.** Wilkinson T. & Cape J. (1991).
 - **Waterbugs and Dragonflies.** Sticney D. Continuum International Publishing Group: Academia. ISBN 0-264 67441-3 *(Explaining death to young children).*
 - **When my Little Sister Died.** Cowlishaw S. & Gale C. Merlin Publishing: ISBN 1-870 74216-8.
 - **When Someone Very Special Dies.** Heegaard M. (1991) Fairview Press: ISBN 0-962 05020-2. *(A book to help children understand about death by drawing pictures).*
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Further Information

We endeavour to provide an excellent service at all times, but should you have any concerns please, in the first instance, raise these with the Matron, Senior Nurse or Manager on duty. If they cannot resolve your concern, please contact our Patient Experience Team on 01932 723553 or email asp-tr.patient.advice@nhs.net. If you remain concerned, the team can also advise upon how to make a formal complaint.

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We can provide interpreters for a variety of languages, information in larger print or other formats (e.g. audio) - please call us on 01932 723553.



اگر نیاز به ترجمہ دارید، لطفاً با شماره 01932 723553 تماس بگیرید۔
 ਜੇ ਤੁਹਾਨੂੰ ਤਰਜਮہ ਦੀ ਲੋੜ ہے ਤਾਂ ਕਿਰਪاً ਕਰਕੇ ਇਸ ਨੰਬਰ 'ਤੇ فون کریں: 01932 723553
 اگر آپ اس کا اردو زبان میں ترجمہ چاہتے ہیں، تو براؤزر میں اس فون نمبر 01932 723553 پر رابطہ کریں
 Se precisa de uma tradução por favor contacte: 01932 723553

আপনার অনুবাদের দরকার হলে এখানে যোগাযোগ করুন : 01932 723553
 यदि आपको अनुवाद की ज़रूरत है तो कृपया इस नंबर पर फोन करें: 01932 723553
 Jeżeli chcemy, aby te informacje w innym języku,
 proszę zadzwonić 01932 723553

Ashford Hospital London Road, Ashford, Middlesex, TW15 3AA Tel: **01784 884488**
St. Peter's Hospital Guildford Road, Chertsey, Surrey, KT16 0PZ Tel: **01932 872000**

Website: www.ashfordstpeters.nhs.uk