

ROYAL HOSPITAL FOR WOMEN

LOCAL OPERATING PROCEDURE

CLINICAL POLICIES, PROCEDURES & GUIDELINES

Approved by Quality & Patient Safety Committee 19 December 2013

STILLBIRTHS AND FETAL DEATHS: DIAGNOSIS, DELIVERY, DOCUMENTATION AND TRANSPORT GUIDELINE

1. AIM

- Diagnosis of fetal death and stillbirth
- Sympathetic and appropriate management of the mother and fetus/baby
- Correct documentation completed
- Fetus/Baby transported from site of death to pathology to funeral home/burial site
- Arrangements made for postnatal follow-up

2. PATIENT

- Woman who is of 20 weeks gestation or more, or where the fetus weighs more than 400 grams when the gestation is not known, where the fetus does not have a heartbeat on antenatal ultrasound scan or breathe or show signs of life after birth
- Fetus, stillborn or baby demised within 28 days of birth as defined in educational notes
- Infant death between 29 days and 1 year of age

3. STAFF

- Registered Midwives
- Student midwives
- Registered Nurses
- Porters
- Pathology staff
- Medical staff
- Social Workers
- Secretary to Director of Clinical Services (DCS)

4. EQUIPMENT

- CTG machine
- Ultrasound
- Doppler
- Specimen bucket for placenta
- Pink colour culture medium for cytogenetics
- Sterile container (vellow top)
- Transport containers
- Body bags

5. CLINICAL PRACTICE

Ante and intrapartum

- Suspect fetal death by the absence of a fetal heart beat on auscultation, inform medical officer
- Ensure privacy for woman and family and sensitively discuss findings
- Confirm fetal death on formal ultrasound scan and perform detailed ultrasound scan where possible for fetal anomalies, liquor volume and maternal anatomy
- If muscle biopsies or metabolic studies are needed, the tissues / fluid samples will need to be collected as soon as possible after delivery, preferably within 2 hours of death. This should be discussed with the perinatal pathologists. (Consent from family will be required for this.)

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- Convey the diagnosis to the parents with sympathy, allow time for a grieving reaction before discussing further management
- Recommend amniocentesis for karyotype and infection screen (Microscopy/culture and consider PCR for Toxoplasmosis/ Cytomegalovirus (CMV) / parvovirus) to be performed by fetal medicine dept in working hours or medical imaging
- Discuss options for delivery according to gestation and clinical scenario. Caesarean section/ Hysterotomy should be performed only for compelling maternal risk factors
- Remove all fetal monitoring equipment from room if possible
- Involve Social Work Department as early as possible to provide support, counseling and resources for the family during hospital stay and after discharge
 - o Extension 26670 / pager 44059
 - Weekends/ public holidays on-call roster operates between 08:00 20:00h, page through switchboard
 - o Give parents leaflet: Information for Parents Whose Baby is Stillborn or dies soon after birth (Appendix 5)
- Perform the maternal investigations (if appropriate) as per the checklist (Appendix 1)
- Give parents information leaflet: Information for parents about the post-mortem examination of a stillborn baby or baby who dies soon after birth (Appendix 6)
- Discuss with parents their wishes around the birth including whether or not they wish to see and hold the baby
- Conduct birth with empathy
- Recommend active management of third stage of labour

Postpartum

Mother

- Offer woman, who has with informed consent elected to have her lactation suppressed, a stat dose of Dostinex 1mg as close as practicable to placental delivery
- Arrange social worker review
- Review regarding need for thromboprophylaxis
- Notify all relevant staff including General Practitioner as per Stillbirth/Perinatal/Neonatal/Infant Death Paperwork Checklist (Appendix 4)
- Determine who will perform medical follow up and document. (This may be the □oweling□ loss clinic, or the obstetrician who has cared for the woman antenatally)
- Notify the Perinatal Loss Coordinator to arrange review appointment for mother/parents by phoning Ext. 26047 and leave a message
- Send report of all findings to General Practitioner following postnatal review

Baby

- Arrange further investigations of baby and placenta as below as per stillbirth investigation checklist (Appendix 1 and 2)
- Wrap baby in □oweling/sheet, encourage contact if the parents wish as per discussion
- Allow parents individual time with the baby
- Obtain swabs from baby (Appendix 1)
- Perform clinical examination of baby if autopsy not definitely planned, using Appendix 2. This may be undertaken by an experienced midwife, obstetric registrar, paediatric registrar or genetics team



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- Invite Geneticist to examine the baby/fetus during working hours, particularly if fetus appears structurally abnormal, even if autopsy is planned (phone Ext. 21708)
- Ensure parents have received "Information for parents about the post-mortem examination" and give them information about the NSW Register of Congenital Conditions if applicable
- Discuss and if applicable obtain consent for autopsy from parents. Discuss the option of limited autopsy where the parents are unable to consent to a full autopsy. If parents decline autopsy senior medical staff review is recommended
- Telephone anatomical pathology on extension 29020 during working hours and discuss with □erinatal pathologist regarding autopsy. After hours, send email to □erinatal pathologists with clinical summary. Enclose all relevant information with the request for autopsy form, and □erinatal death certificate, RHW notification of death form and/or fax any relevant clinical information (ultrasound reports, ObstetriX) to anatomical pathology on Fax x29037 or e-mail pathologists
- Obtain verbal consent for babygram and document in the notes (whether or not parents consent to autopsy)
- Obtain consent if parents wish hospital disposal in the case of fetal death (only applicable
 if less than 20 weeks gestation)
- Refer to Stillbirths and fetal deaths post-delivery care LOP for subsequent care of fetus/baby and creation of memorabilia

Placenta

- Examine placenta as per RHW guideline- placental examination and document.
- Take swabs and samples from placenta as per RHW placenta examination guideline and Appendix 1 and Appendix 3
- Send placenta to anatomical pathology with relevant clinical information on request form (at least gestational age and reason for placenta referral should be stated) or attach Obstetrix summary.

Documentation (Appendix 4)

- Report death to Coroner for mandatory post-mortem in the following situations: (Refer to Policy Directive PD2009_083 for guidance and full indications)
 - (a) the person died a violent or unnatural death;
 - (b) the person died a sudden death the cause of which is unknown; e.g. SIDS
 - © the person died under suspicious or unusual circumstances:
 - (d) Death within 24 hours of anesthetic if the death was not "reasonable expected" (Deaths under Anesthesia are to be reported to the Special Committee Investigating deaths Under Anesthesia
- Notify birth defect where appropriate to NSW Register of Congenital Conditions
- Complete confirmation of birth page in Maternity Allowance Bereavement Payment form if applicable and give to parents
- Complete Cremation certificate as appropriate
- Notify the Bed Manager / After Hours Nurse Manager via Pager Number 44020
- Authorisation for cremation and autopsy consent must be reviewed by the hospital's designated officer (Nursing and Medical administration)

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- After Hours Nurse Manager to deliver the following documents and Appendix 4 to DCS secretary:
 - Notification of death
 - Medical Certificate of cause of death
 - Consent for post-mortem examination
 - o Cremation certificate
 - ObstetriX Birth Summary
 - o NSW Register of Congenital Conditions Form
 - Pathology request form

DCS Secretary

- Coordinates the receipt and release of Death Certificates, Cremation Certificates, postmortem consent
- Maintains a log book of documents received, deaths notified
- Becomes a reference point for staff from Anatomical Pathology, funeral directors and other appropriate staff
- Notifies Social Work department when documentation has been collected by funeral director

Transport/Release of Baby

- Release baby to Viewing Room fridge once parents, midwives and social workers have completed viewing, wrapping and obtaining mementoes. Key for viewing room is available in Acute Care Ward
- Enter name of baby in Mortuary Register
- Place the baby in the body bag as per mortuary guidelines
- Transport of baby to pathology department is the responsibility of anatomical pathology in consultation with the social worker. State whether for examination or disposal as per post mortem consent form
- Return baby to Mortuary/Viewing Room Level 4 RHW by Anatomical Pathology staff
- Place the baby in the body bag as per mortuary guidelines
- · Release of baby from hospital can occur by either :
 - Stillbirth/neonatal death baby is released to funeral director or parents as per social work protocol together with medical certificate of cause of death and cremation certificate (if appropriate)
 - <20 weeks gestation directly to parents or their appointed funeral director, in accordance with Social Work LOP and Public Health Act, together with SESLHD Form "Authority to determine suitable arrangements for release of non-viable fetus".

6. DOCUMENTATION

- Integrated Clinical Notes
- ObstetriX
- Perinatal/Neonatal Death Paperwork Checklist
- Pathology Request form
- Post-mortem Consent form
- RHW Notification of Death



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- Mortuary Register
- SESLHD Authority to determine suitable arrangements for release of non-viable fetus
- NSW Register of Congenital Conditions form
- Maternity Allowance Bereavement payment form
- Cremation certificate
- · Medical Certificate of Cause of Death
- · Registration of birth form

7. EDUCATIONAL NOTES

- Unless the baby dies with a known chromosomal/ DNA diagnosis or from a lethal structural anomaly, clinicians should perform all core investigations of perinatal death including ultrasound, amniocentesis, maternal and fetal blood tests, swabs, placental examination and autopsy.
- Unexplained stillbirth remains the largest category of stillbirth
- Common emotional reactions to stillbirth include disbelief, anger, blame, shock, guilt, denial, hope, despair, depression, crying, displacement, fear and anxiety, bargaining, awkward questions, relief, threats and humour. Giving the parents bad news is a challenging task
- Sholder dystocia may be a problem with stillbirth at term, particularly if there is macrosomia
- The autopsy examination remains the gold standard for identification of the cause of perinatal death. An accurate cause of death assists in the parents grieving process by providing an explanation for the death and other information on the circumstances surrounding the death which may alleviate feelings of guilt
- Investigation for thrombophilia should be undertaken 8-12 weeks postnatally where a fetal death is associated with fetal growth restriction, pre-eclampsia, placental vasculopathy/thrombosis, maternal and or family history of thrombosis or where the stillbirth is unexplained. This may include Factor V Leiden and prothrombin gene mutation, Anti Thrombin 3, Protein C, Protein S, fasting homocysteine and MTHFR Gene Mutation, as well as repeating lupus anticoagulant and anticardiolipin antibody if previously positive. MTHFR mutation testing should be performed when the following anomalies are identified-cleft lip/palate, neural tube defects or congenital cardiac defects, or if the fasting homocysteine is positive.
- Anti-phospholipid antibody syndrome and Systemic Lupus Erythematosus (SLE) have been significantly associated with fetal loss. Other thrombophilia mutations are associated with loss, but studies have been too small to show a significant association (Fretts 2005). Therefore caution should be employed with postnatal counseling
- Arrange genetic follow up if fetal karyotype abnormal. Consider parental karyotypes if fetal karyotype abnormal
- Post-mortem needle biopsy, laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected abnormalities.
 MRI has also been used at some centres

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- A retrospective population based study has shown that postpartum, the strongest risk factor for venous thromboembolism was stillbirth (Risk 2,444/100,000 person-years; Incidence risk ratio=6.2)
- Overweight, obesity, and smoking are important modifiable risk factors for stillbirth, and advanced maternal age is also an increasingly prevalent risk factor in high income countries. (1)
- A funeral is not legally necessary if less than 20 weeks gestation unless there are signs of life at time of birth or parents wish it, burial or funeral/cremation are mandatory after this gestation
- Definitions :

FETAL DEATH

- Death of the fetus at less than 20 weeks gestation without a heartbeat or respiratory effort after birth
- Where gestation is unknown a fetus is defined as being less than 400 grams in weight STILLBIRTH
- The fetus is of 20 weeks gestation or more or where gestation is unknown greater than 400 grams in weight
- and does not breathe or have a heartbeat after birth

NEONATAL DEATH

- The baby has breathed and/or had a heartbeat after birth, irrespective of gestation and died within 28 days of birth
- o Infant Death the baby has died after 28 days of birth
- In the case of any stillbirths, neonatal or infant deaths parents can apply for Maternity Allowance Bereavement Payment

8. RELATED POLICIES / PROCEDURES / CLINICAL PRACTICE LOP

- Induction of labour
- Third stage labour management
- Examination of the placenta
- Lactation suppression
- Stillbirths, Neonatal deaths, fetal deaths post-delivery care and creation of memorabilia
- NSW Health: Stillbirth Management and Investigation
- Mifepristone and misoprostol for medical termination of pregnancy or fetal death
- Thromboembolism prophylaxis and treatment
- Circular No2002/52 Hospital Protocol for unexpected Infant Death
- Circular 2003/62 Coroners' Cases and Amendments to Coroners' Act 1980
- Mortuary Procedural Guidelines
- Placenta Removal from Hospital by Parents Guideline
- Cremation or burial for a perinatal loss under 20 weeks gestation (Social Work)
- Placental examination guideline
- Coroners Cases and the Coroners ACT 2009 (PD2009 083))

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9. REFERENCES

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- Fretts RC 2005 Etiology and prevention of stillbirth AJOG;193:1923-35
- Incerpi MH et al 1998 Stillbirth evaluation: What tests are needed? AJOG;178:1121-5
- Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline 2012
- Risk factors for first venous thromboembolism around pregnancy: a population based cohort study from the United Kingdom. Alyshah Abdul Sultan, Laila J. Tata, Joe West, Linda Fiaschi, Kate M. Fleming, Catherine Nelson-Piercy Matthew J. Grainge. Blood 2013;121(19):3953-61.
- NSW Dept of Health Guideline PD2007_025, Stillbirth Management and Investigation
- Flenady V, Middleton P, Smith GC, Duke W, Erwich JJ, Khong TY, et al. Stillbirths: the way forward in high-income countries. The Lancet.377(9778):1703-17.

REVISION & APPROVAL HISTORY

Minor amendment to Appendix 1 February 2014

Endorsed Obstetrics LOPs 3/12/13

Reviewed and combined two documents:

'Stillbirths, Fetal, Neonatal and Infant Deaths: Documentation and Transport Guideline' and 'Stillbirths and Fetal Deaths: Diagnosis and Delivery Guideline'

Following applies to both guidelines:

Reviewed and addition re NCC made following Coronial recommendations Oct 2010

Amended following introduction of SESIAHS form Nov/Dec 2010

Approved Patient Care Committee 8/5/08

Reviewed and endorsed Obstetrics Clinical Guidelines Group March 2008

Previously titled 'Protocol to be followed after Stillbirths, Neonatal Deaths and Fetal Deaths' Approved Quality Council 21/2/05

Endorsed Maternity Services Clinical Committee and Neonatal Clinical Committee 8/7/03

FOR REVIEW: DECEMBER 2018

Appendix 1: STILLBIRTH INVESTIGATION CHECKLIST

Full blood count Kleihauer HbA1c Haemoglobin electrophoresis (if hydrops or clinical suspicion) Lupus anticoagulant Coagulation screen Parvovirus IgM and IgG Toxoplasmosis IgM and IgG CMV IgM and IgG Rubella IgM, IgG, if not done in pregnancy Syphilis serology, if not done in pregnancy Hepatitis B, if not done in pregnancy Thyroid function tests Bile Acids (preferably fasting) Anticardiolipin antibodies Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen PURPLE TUBE X 2 PURPLE TUBE X 2 PURPLE TUBE X 2	Maternal Investigations	Yes	No	
HbA1c PURPLE TUBE X 2 Haemoglobin electrophoresis (if hydrops or clinical suspicion) Lupus anticoagulant Coagulation screen BLUE TUBE X 4 Parvovirus IgM and IgG Toxoplasmosis IgM and IgG CMV IgM and IgG Rubella IgM, IgG, if not done in pregnancy Syphilis serology, if not done in pregnancy Hepatitis B, if not done in pregnancy Thyroid function tests Bile Acids (preferably fasting) Anticardiolipin antibodies Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen	Full blood count			
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Coagulation screen Parvovirus IgM and IgG Toxoplasmosis IgM and IgG CMV IgM and IgG Rubella IgM, IgG, if not done in pregnancy Syphilis serology, if not done in pregnancy Hepatitis B, if not done in pregnancy Thyroid function tests Bile Acids (preferably fasting) Anticardiolipin antibodies Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen BLUE TUBE X 4 BLUE TUBE X 4 BLUE TUBE X 4 GOLD TUBE X 3 FINK TUBE X 1				
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CMV IgM and IgG Rubella IgM, IgG, if not done in pregnancy Syphilis serology, if not done in pregnancy Hepatitis B, if not done in pregnancy Thyroid function tests Bile Acids (preferably fasting) Anticardiolipin antibodies Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen GOLD TUBE X 3 GOLD TUBE X 3 FINK TUBE X 1	Parvovirus IgM and IgG			
Rubella IgM, IgG, if not done in pregnancy Syphilis serology, if not done in pregnancy Hepatitis B, if not done in pregnancy Thyroid function tests Bile Acids (preferably fasting) Anticardiolipin antibodies Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen GOLD TUBE X 3 GOLD TUBE X 3	Toxoplasmosis IgM and IgG			
Syphilis serology, if not done in pregnancy Hepatitis B, if not done in pregnancy Thyroid function tests Bile Acids (preferably fasting) Anticardiolipin antibodies Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen GOLD TUBE X 3 GOLD TUBE X 3 FINK TUBE X 1	CMV IgM and IgG			
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Thyroid function tests Bile Acids (preferably fasting) Anticardiolipin antibodies Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen PINK TUBE X 1	Syphilis serology, if not done in pregnancy			GOLD TUBE X 3
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Liver function tests Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen PINK TUBE X 1	Bile Acids (preferably fasting)			
Urea and electrolytes, uric acid & creatinine Blood group and Antibody screen PINK TUBE X 1	Anticardiolipin antibodies			
Blood group and Antibody screen PINK TUBE X 1	Liver function tests			
Blood group and Antibody Screen	Urea and electrolytes, uric acid & creatinine			
Low yaginal swab MC/S Vaginal swab (Blue)	Blood group and Antibody screen			PINK TUBE X 1
2011 (49)	Low vaginal swab MC/S			Vaginal swab (Blue)

• At 8-12 weeks postpartum: consider Thrombophilia screen if death associated with fetal growth restriction, pre-eclampsia, maternal thrombosis and/or maternal family history of thrombosis, death remains unexplained following the core investigations or where tests for thrombophilia were positive at the time of the intrauterine fetal death (Protein C, Protein S, Antithrombin levels, Prothrombin gene mutation, Factor V Leiden, MTHFR mutation)

Baby Investigations	Yes	No	
Clinical examination			(see Appendix 2)
Cord/cardiac blood for FBC (if possible)			Purple top tube
Fetal blood for chromosomes (if possible)			Green top tube
Fetal blood newborn screening test (if poss)			Newborn Screening Card
Ear swab for M/C/S			Wound swab (Blue)
Throat swab for M/C/S			Wound swab (Blue)
Babygram			Request form
Fetal / neonatal autopsy if consented			Request form

Placenta (see appendix 3)	Yes	No	
Examination of the placenta			
Placental swabs between amnion and chorion			Wound swabs Blue
Umbilical cord in pink culture medium for cytogenetics/ MLPA (if karyotype not already known)			Pink culture medium (Birthing Services Fridge / Pathology)
Whole placenta- for examination and histology			Plastic bag and bucket with sealable lid (attach obstetrix birth summary)

This form completed by:			
Name:	Status:		
Signature:	Date:		

Appendix 2

Other

If other, descri

Posteriorly rotated

1.4 Clinical examination of baby checklist Please fick appropriate box and complete details as required Maternal Sticker (Inc Name, DOB, UR, Address, Telephone Number) Baby measurements 1. Crown - heel (stretched): ome 2. Head circumference...... ems If SSIBSHB Singleton Multiple Baby number (e.g. Twin 1) Estimated date of IUFD:/...... Maceration degree LIMES Fresh; no skin peeling ... П Slight; focal minimal skin slippage...... Normal Short Long Mid; some skin sloughing, moderate Massa П If Short, what segments seem short. skin slippaga.... Moderate; much skin sloughing but Describe: no secondary comprehensive Normal Asymmetric Missing perts changes or decomposition..... If other, describe: CHEST Marked, advanced..... Ī Long & narrow Normal П Short & broad Other HEAD AND FACE If Spine bifide, d. Appearance: Normal Abnormal Relatively normal Collepsed ARDOMEN Hydrocephalic If abnormal, describe: Anencephalic Normal Flattened Abnormal shape Distanded Hemia If abnormally shaped, describe: Omphalocele **Castroschisis** Number present. If not 4 + 4, describe...... BACK Normal Prominent Sunken Straight Far apart Close together Normal Spine bifide П Unusual form of fingers If Spina bifida, descrit Unusual position of fingers Upstanting Downslanting Abnormal webbing or syndactyly Kyphosis Globes normal Absent Scoliosis If abnormal, describe..... П Ī Eyes very small Very large Other If other, describe: Thumbs Comesi opacity Lens opedty Number present ... Eyelids fused Other If not 1+ 1 describe...... GENITALIA If other, describe: Unusual position Normal Imperforate Other Looks like a finger If other, describe: If abnormal, describe. Normal Abnormally small Asymmetric Abnormally large Finger nails Gender Male Female Ambiguous Vostrills -All present. Apparently patent Obstructed If not describe...... 靣 Single nostrii Other Pende Very small Morroal If other, describe: Appearance Normal Chordee Abnormal Hypospadias If abnormal, describe Hypospedies, level of opening Normal size Large Small Scrotum P Number present ... Upper Lip Abnormal Normal Cleft If not 5+ 5 describe.... If abnormal, d If chaff, location Specing Normal Abnormal Tastas If abnormal, describe Undescended Billeteral Ħ Descended Palate Other Toe nails inted If other, describ All present fendible If not describe...... Normal Large Female Small Urathral open Other Absent/unident/fieble Present If other, describe: Revised gestational age ... Veginal intro Based on Absent/unident/fiable Present Ciliaria Normal Presuricular tags Examined by: Unidentifiable Present Lowest Presuricular pits Date: Enlarged Other

If other, describ

Summary of key findings:

Appendix 3 – Placental examination

1.3 Accoucheur placental examination and preparation for pathology Please complete details as required	Maternal Sticker (Inc Name, DOB, UR, Address, Telephone Number)						
Singleton Multiple Baby number (e.g. Twin	1)						
Step 1 Placental cultures Using aseptic technique and being careful not to cross contaminate, swab in between the amnion and chorion.							
Step 2 Accoucheur examination of the place	enta, membranes and cord using sterile gloves						
Cord appearance (Circle) Thin / Thick / Meconium Stained / Other No of cord vessels	tous / Other						
Step 3 Tissue sampling for ch	romosomal analysis						
2	umbilical cord should be collected using aseptic technique as outlined losalicism, then a placental sample may be required as well						
➤ Collect a 1cm³ sample of the middle of the umbili	cal cord, using a sterile surgical knife and dissecting forceps.						
	r a sterile container, with either sterile saline solution or Hank's rnal name, medical record number, date and time of collection and						
Step 4 Send Placenta, Membrane and Cord to the Patho	ology fresh and unfixed for histopathological examination						

Appendix 4 RHW Stillbirth / Perinatal / Neonatal / Infant Death Paperwork Checklist

Addressograph				Consultant Name: Social Worker Name:			
	People to be notified by staf	f (immediately o	or at earliest a	ppropriate ti	<u>me)</u> :		
			Date Comp	<u>oleted</u>	<u> Signature / Name</u>		
	AMO on Call (Neonatologist, Obste	etrician if not					
Α	oresent) After Hours Nurse Manager (Admi	nistration), Pager					
S	.4020 Social Worker (On call) Ext. 26670 Jours Name:	or via switch after					
C	Office of RHW Director of Clinical \$26511	Services, Ext.					
F	Referring GP, Obstetrician and Pac Name(s)	ediatrician					
S	Other Consultants (e.g. geneticist E Surgeon) Names:						
b	Anatomical Pathology if post morte babygram consented, Phone Ext. 2 or email pathologist						
	Perinatal loss coordinator Ext. 2604	47					
	Paperwork to be completed:-	<u>Date</u> Completed	Date Completed	<u>Date</u> Completed	Signature/ Name		
U	completeu	<20weeks	Stillbirth	Neonatal			
		<20Weeks	Stillbirtii	Death			
F	RHW Notification of Death	N/A		Dodin			
	Medical Certificate of Cause of Perinatal Death (≤28 days)	N/A					
n	Consent for Non-Coronial Post- nortem Examination or limited exam	Agreed / Declined	Agreed / Declined	Agreed / Declined			
	Cremation Certificate						
F a	Pathology request form for autopsy: include copies of elevant ultrasounds/ ObstetriX/caryotype if known						
F	Report to Coroner (if applicable)						
	see Circular 2003/62	N1/A					
	Discharge Summary /ObstetriX ISW Register of Congenital	N/A					
	Conditions Form (if applicable)						
	Final checking for accuracy an	nd completeness	of paperwork				
	Signed	_Name (Print):		Date:			
	(Bed Manager)	_					
	Received by DCS Signed:		Date:				

Appendix 5

Information for Parents Whose Baby is Stillborn or dies soon after birth

We understand that this must be a time of great shock and sadness for you. This information sheet is offered as a very basic guide to help you over the next few days.

Support At This Time

Midwives and doctors will provide constant support and answer any questions you may have. They will make a referral to one of the maternity social workers. She will work with you and help with emotional and practical concerns while you are in hospital and after your discharge.

Spending Time With Your Baby

At first you may not be able to say whether you wish to hold your baby after it is born. This must seem an enormous decision. Many parents find it helpful to meet their baby after birth. We will be open to your wishes. There is a calm, comfortable private space on level 4 of the hospital where you and your family can spend time with your baby.

Creating Mementoes

We will offer you the opportunity to make some tangible mementoes of your baby – photographs, foot and hand prints and cot card – kept in a special memento booklet. You can help with creating these if you wish. If you do not wish your baby be disturbed, we will respect your wishes.

Family and Older Children

Your social worker can help you think about the needs of your older children and how to involve them. We can give you written resources and stories.

Spiritual Support

The RHW Chaplains offer support and spiritual comfort. They can hold a naming or blessing ceremony for your baby. We can page them at your request, or you can ask your own priest or clergy to come to the hospital.

Post-Mortem

A post-mortem can help provide some information about why your baby died. Your doctor will talk about the benefits of this, and explain that baby can have a full or partial examination. Your baby will not be examined unless you have given written consent. It is advisable for the post-mortem to be carried out as soon as possible to maximise the information gained. This may mean you have to plan your time with your baby very carefully to allow the post-mortem to take place. You may have to wait several months until the results of the post-mortem are available.

Other Tests

As well as a post mortem, other pathology tests can provide us with valuable information so we may investigate the cause of your baby's death. It can also help to determine the optimal management of your future pregnancies. Your doctor may offer to perform an amniocentesis before your birth. This requires taking a small sample of amniotic fluid from the sac around your baby. This is done from your abdomen. The procedure takes a few minutes. Blood tests taken from you will also be offered. In addition, an x-ray for the baby (babygram) may be recommended. All tests including the amniocentesis will only be done with your consent.

Funeral Arrangements

If you are 20 weeks pregnant or more, or if your baby has died as a newborn infant, you must legally register your baby's birth and arrange a funeral. Please be assured that we can keep baby safely here at the hospital for a few days until you have had time to think about and make these arrangements. Your social worker will help you with these plans.

You may be entitled to receive the Maternity Allowance Payment through Centrelink. The midwives will give you this claim form, including confirmation of baby's birth.

After Your Discharge

The RHW Midwifery Support Program or MGP midwife will visit you at home to provide support and ongoing midwifery care. Before you leave the hospital the doctors will discuss with you any follow-up arrangements. Your social worker will follow up with phone calls and can see you after discharge.

Social Work department

Weekdays: Call 02 9382 6670

Weekends and Public Holidays: 08:00am - 08:00pm, call 02 9382 6111, ask the operator to page

the social worker on call

Follow-Up Appointment –The perinatal loss coordinator will organise your follow up appointments and will be in contact with you. Michele.Simpson@sesiahs.health.nsw.gov.au 02 9382 6007 Tuesday and Thursday mornings

Other Contact Phone Numbers

Delivery Suite - Phone: 02 9382 6100

Midwifery Group Practice and Malabar Midwives – Phone : 02 9382 6111 and ask the operator to phone your midwife

Maternal Fetal Medicine Department – Reception phone number 02 9382 6098

Social Workers – Reception phone number 02 9382 6670

For Women who have been seeing the Maternal Fetal Medicine team your appointments and all support and follow up will be with them. Phone number 02 93826098

Parent Support Networks

- Bears of Hope: http://www.bearsofhope.org.au
- o Pilari: http://www.pilari.org
- o Pillars of Strength: http://www.pillarsofstrength.com.au
- Sids and Kids: http://www.sidsandkids.org

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Appendix 6

INFORMATION FOR PARENTS ABOUT THE POST-MORTEM EXAMINATION OF A STILLBORN BABY OR BABY WHO DIES SOON AFTER BIRTH

When your baby is stillborn, expectations, hopes and dreams are shattered and lives are changed. Any parents have initial feelings of shock and confusion when told that their baby has died. Babies are not supposed to die. When they do, it can be devastating, overwhelming, and painful. It is a great sadness that your baby has died.

You may have a lot of questions and there will be decisions to make over the coming days and weeks. Help is available to you; your caregiver(s) will be able to advise you.

This leaflet has been prepared to help you make a decision about a postmortem examination.

Deciding about a post-mortem can be very difficult. It is important that you make the decision that is right for you and your family. Consider how you and your family will feel in the future. In particular, think about whether a post-mortem would help you and your family to understand why your baby died. Hospital staff will respect and support whatever decision you make about a post-mortem examination. A post mortem examination of a stillborn baby can only be undertaken with the parent/s consent. After reading this information, you may find it helpful to discuss the examination with a doctor or midwife who has cared for you during your pregnancy or a counselor or hospital social worker. You may also ask for more time to think about it and speak with your partner, family, friends or religious leaders.

What is a post-mortem?

The purpose of a post-mortem examination is to find any medical condition which may have contributed to or led to your baby's death. A post-mortem, also known as an autopsy, is a medical examination of a body after death. A doctor undertakes the examination (usually a pathologist or a doctor undertaking specialised training in pathology, under the supervision of a pathologist). Pathologists are doctors who specialise in the study of disease. The post-mortem is carried out with utmost respect and care for the baby's body.

What information can a post-mortem provide?

A post-mortem examination can be a full or a limited post-mortem. These two options will be explained in further detail.

A full post-mortem may:

- Help you to find out more information about medical conditions that may have caused your baby's death.
- Provide information that may confirm or rule out a suspected or unsuspected medical condition. This may be important for you or other members of your family, particularly if the condition is likely to be inherited.
- Provide information to health professionals that may be important in the management of your future pregnancies.
- o Indicate conditions that may affect other children within the family or future pregnancies.
- Contribute to the understanding of those who cared for you and provide knowledge that can be used to help other mothers and babies in the future.

A post-mortem examination does not always provide all the answers about a cause of death.

What is a limited post-mortem?

A limited post-mortem may involve either an external examination only; an external examination and some testing on small samples of tissue or blood; or an external examination with an internal examination limited to one particular area. A limited post-mortem will not provide the same amount of information as a full post-mortem examination and there is always the possibility that something unexpected will be missed. However, a limited post-mortem can provide valuable information.

What happens to your baby at a post-mortem?

A doctor, who is usually a specialist pathologist, performs the post-mortem. The doctor will carefully review the medical record and then undertake a thorough examination of your baby. A full post-mortem examination includes a careful external examination, with measurements, as well as an examination of internal organs. X-rays and photographs may also be taken to further assist in making a diagnosis or to determine the cause/s of death. A full post-mortem examination is undertaken as though the baby was having an operation. The Pathologist will usually make two openings, one across the back of the head, and another on the front of the body. This allows the pathologist to examine all the major organs and look for anything unusual or any clues to the cause of death. Small samples of tissues and fluids will usually be taken for microscopic examination and other tests, such as looking for an infection, or in special cases for genetic testing. Sometimes it is necessary for the pathologist to

retain an entire organ (usually the brain or heart) for further examination in order to test for signs of disease or injury that are not immediately apparent. The importance of retaining a particular organ may not be known until the post-mortem is under way. In some cases, a short delay in the funeral arrangements may be enough to have these organs returned to the body before it is released for burial or cremation. If this is not possible, you can decide whether you would like the baby's organs returned to you or a person nominated by you for separate burial or cremation or disposed of in a lawful manner by the public health organisation (usually by cremation). Your doctor will explain in further detail what these processes are.

What happens after the post-mortem?

Once the examination is complete, the baby is washed and the incisions are closed. In most cases, once the baby has been dressed, the effects of the post mortem are not very noticeable. Normally, after the post-mortem examination you and your family can usually see and hold your baby again. The appearance and colour of your baby's skin will change after death and the body will feel different to touch. These changes occur naturally after death and are not related to the post-mortem.

Will I have to pay for a post-mortem examination?

There are usually no costs associated with the post-mortem examination. However, it is important that you discuss any potential costs with your doctor or hospital representative before you give consent. If you and not the hospital request the post-mortem, these costs may be related to transport of your baby to a hospital that provides post-mortem examinations for babies. Financial assistance with the funeral costs associated with burial of your baby or of the retained organs may be available through the hospital or Area Health Service.

Why is consent needed for a post-mortem?

Written consent is required from you before a post-mortem of your stillborn baby is carried out. This is a legal requirement. You will be approached by a health professional and asked for your consent to the post-mortem examination. You are free to choose whether or not to give your consent for the post-mortem examination. Your consent must be given in writing. Because a post-mortem examination may reveal potential genetic information relating to either biological parent, consent also includes a requirement to find out whether the other parent has no objections. Alternatively, you may prefer someone else to make the decisions on your behalf, regarding consent for the post-mortem and for the use of tissue removed for the purposes of the post-mortem. There is a form you will be asked to complete if you wish to have someone else to make these decisions on your behalf. You must understand that in so doing you are allowing another person to make decisions about your baby in this regard.

What happens after consent is given for a post-mortem?

The post-mortem will be carried out as soon as possible after consent has been given. Occasionally, when certain conditions are suspected, samples need to be taken soon after death to enable the appropriate tests to be done. If this is the case your doctor will discuss this with you. If you wish to see your baby prior to the post-mortem, let your doctor or midwife know and arrangements will be made to delay the post-mortem. The post-mortem can be delayed for a short period, but it is recommended within 48 hours.

When will I know the results of the post-mortem?

A preliminary post-mortem report may be available within a few days of the examination but the results of some tests may not be available for twelve weeks, after which the final report will be prepared. You should consider whether it is best for you to receive the post-mortem report directly from your primary carer, or to receive a copy through your family doctor, or another doctor who can discuss the report with you. It is suggested that you make a time with one of these doctors to discuss the report and any implications it may have for you or your family, as it may contain technical language.

Retaining and using organs and tissue for use for therapeutic, medical and scientific purposes When your health professional approaches you to give consent for a postmortem, you may also be asked to consider allowing the use of your baby's organs or tissue for other purposes (such as research, medical or therapeutic purposes) that are not part of the post-mortem examination. If you consent for your baby's organs and/or tissue being retained for research, medical or therapeutic purposes, the organ or tissue will usually be retained for the period for which it is considered needed if a specific project has been indicated. The period of retention of retained organs or tissue for research may be outlined in the specific information on the research project or you can ask for more information. You do not have to consent to the use of organs or tissue for therapeutic, medical or scientific purposes. A post-mortem can still be carried out, even if you do not consent to the use of tissue for these purposes. If you do give such consent, it applies only to the tissue that was removed for the purposes of the post-mortem examination. It does not mean that any extra organs or tissue will be removed or retained.

Information and bereavement support

If you have any questions, your doctor, midwife, perinatal loss coordinator or social worker will try to answer them for you. Health professionals can provide you with contact details of support groups to help you through this sad time. SIDS and Kids NSW (incorporating SANDS) provide bereavement support services to families who have experienced the death of their baby. For support and information phone 02 9818 8400, toll free 1800 651 186 or information can be accessed via the website http://www.sidsandkids.org

Summary

A post-mortem is an important medical examination to help find answers as to why your baby died and to exclude treatable or inherited conditions for future pregnancies. It may help to talk to your doctor, midwife, social worker or religious leader or other members of your family, if you have more questions about the post-mortem. If you do not want your baby to have a full post-mortem, talk to your doctor about other possible tests, which may give you more information about the cause of the death. A post-mortem cannot take place without your written consent. The hospital post-mortem will be carried out as soon as possible after consent. Usually this is within 48 hours after death. If you wish, you can see and hold your baby again after the post-mortem. Results of the post-mortem are usually sent to the doctor within 6-12 weeks but sometimes it may take longer.

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