

Antenatal Maternal Referral/Transfer: Known Congenital Structural Malformations - Early Surgery

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Summary In accordance with best practice, babies diagnosed antenatally on ultrasound with major structural congenital malformations likely to require surgery soon after birth should be delivered in an appropriate tertiary perinatal centre, adjacent to paediatric surgical services.

Replaces Doc. No. Antenatal Maternal Referral/Transfer: Known Congenital Anomalies Likely to Require Surgery [PD2005_158]

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Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Board Governed Statutory Health Corporations, Affiliated Health Organisations - Non Declared, Affiliated Health Organisations - Declared, Public Health System Support Division, NSW Ambulance Service, Public Health Units, Public Hospitals

Audience Administration, clinical, allied health, nursing, obstetricians, midwives, neonatologists

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Status Active

Director-General

This Policy Directive may be varied, withdrawn or replaced at any time. Compliance with this directive is **mandatory** for NSW Health and is a condition of subsidy for public health organisations.

ANTENATAL MATERNAL REFERRAL/TRANSFER: KNOWN CONGENITAL STRUCTURAL MALFORMATIONS LIKELY TO REQUIRE EARLY SURGERY

PURPOSE

The purpose of this policy statement and attached protocol is to improve neonatal outcomes for babies with major congenital structural malformations diagnosed antenatally on ultrasound and likely to require surgery or other critical therapy soon after birth.

Best practice requires that such babies should be born in an appropriate tertiary perinatal centre located adjacent to paediatric surgical services.

MANDATORY REQUIREMENTS

This policy applies to all health services and facilities where pregnant women and their babies are likely to be managed. It requires development of local protocols/operational procedures for antenatal assessment, consultation and referral/transfer of a pregnant woman whose fetus has a known congenital structural malformation likely to require surgery soon after birth. (Reference: Policy Section 2)

IMPLEMENTATION

Chief Executives are to ensure

- Local protocols/operational procedures are developed for the antenatal maternal referral/transfer of women with known congenital structural malformations likely to require early surgery to a tertiary perinatal unit adjacent to tertiary paediatric surgical services.
- Local protocols/operational procedures are in place in all hospitals and facilities where pregnant women and their babies are likely to be managed.
- All staff treating pregnant women are educated in the use of the local protocols/operational procedures to be used in the hospital or facility.

Directors of Clinical Governance are required to inform relevant clinical staff treating pregnant women of the local protocols/operational procedures based on this Policy Directive

REVISION HISTORY

Version	Approved by	Amendment notes
September 1999 (Circ 99/73)	Director-General	Initial version. Guideline for antenatal maternal referral or transfer: known congenital anomalies likely to require surgery.
January 2005 (PD2005_158)	Director-General	Rescinds Circ 99/73. Guideline reissued as a Mandatory Policy Directive. No change to content.
October 2010 (PD2010_062)	Director-General	Rescinds PD2005_158. Incidence of congenital conditions in NSW and phone numbers updated. Text changed to conform with NSW Register of Congenital Conditions current terminology. Feedback from external stakeholders included.

ATTACHMENTS

1. Antenatal Maternal Referral and/or Transfer for Known Congenital Structural Malformations Likely to Require Early Surgery: Procedures

**Antenatal Maternal Referral/Transfer: Known Congenital
Structural Malformations Likely to Require Early Surgery**

NSW  **HEALTH**
PROCEDURES

Issue date: October 2010

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1 BACKGROUND

1.1 About this document

In NSW in 2007, one or more major congenital conditions were reported in 816 babies during pregnancy or at birth. Many of these babies required admission to a Neonatal Intensive Care Unit (NICU) and some required major surgery soon after birth.¹

Of the 2,296 NSW and ACT infants meeting registration requirements for the Neonatal Intensive Care Units' Data Collection in 2006, 17.8% had a congenital condition. Of these, 359 were major structural malformations. In 2007, congenital conditions as defined in NSW Health [PD2009_069 NSW Register of Congenital Conditions Reporting Requirements](#) were the second most common cause of neonatal death after extreme prematurity, accounting for about one in four deaths.

Many babies with congenital conditions are now diagnosed antenatally on ultrasound. Where a congenital structural malformation requiring surgery is diagnosed, best practice requires referral to a fetal medicine service for confirmation and advice on further management.^{2,3,4,5,6,7,8,9}

The timing, place and mode of birth can be of critical importance for the survival of some babies with major congenital structural malformations and ideally delivery should be in a tertiary perinatal centre co-located with a tertiary paediatric surgical service.

Advantages of antenatal referral include:

1. Improved neonatal outcomes.²
2. The opportunity for parents and families to receive coordinated continuity of care from clinicians experienced in the antenatal and paediatric management of major congenital structural malformations and to discuss the following issues:
 - Options for birth in consultation with appropriate maternal-fetal medicine and paediatric specialists.
 - Anticipated antenatal and longer term care of the baby after birth. In some cases this will include discussion of palliative care only as a possible option.
 - The likely neonatal outcomes.
3. The reassurance of access to the best available obstetric and neonatal care.
4. Parents may also experience less stress and anxiety if birth occurs at an appropriate tertiary perinatal centre, as this avoids emergency separation from their baby after birth owing to the need for an emergency neonatal retrieval to a tertiary paediatric surgical facility.

1.2 Key definitions

In the context of this Policy Directive, major congenital structural malformations are those detected in the fetus during pregnancy or birth that are potentially lethal but also surgically correctable.^{2,10}

Minor congenital conditions occurring in isolation are not included in this Policy Directive. Examples include skin tags, deviated nasal septum, tongue tie, benign heart murmurs,

clicky non-dislocating hips, sacral dimples, positional talipes, abnormal palmar creases, dysmorphic features.^{1,10}

1.3 Legal and legislative framework

Scheduled congenital conditions detected in a fetus during pregnancy, in a stillborn or live born baby at birth, or diagnosed in infants up to one year of age are monitored by the [NSW Register of Congenital Conditions](#)¹⁰, a state wide population-based surveillance system established in 1990 and administered by the NSW Department of Health. Information from the Register is used to monitor the occurrence of congenital conditions for service planning purposes and to identify changes in incidence that may warrant investigation.

Under the *NSW Public Health Act 1991*, doctors, hospitals and laboratories are required to notify scheduled congenital conditions (all structural malformations, chromosomal abnormalities and certain medical conditions) detected during pregnancy or in infants up to one year of age to the NSW Health Register of Congenital Conditions, regardless of whether the pregnancy continues. Examples of structural malformations requiring mandatory reporting include spina bifida, microcephaly, transposition of the great vessels, ventricular septal defects, pulmonary agenesis, polycystic lungs, duodenal atresia, exomphalos, hypospadias, cleft lip/palate, microphthalmia, limb reductions, polydactyly, birthmarks greater than 4 cm diameter, cystic hygroma and multisystem syndromes including at least one structural malformation.

1.4 Related Documents

This Policy Directive should be read in conjunction with the following policy directives:

PD2010_022 Maternity - Australian College of Midwives (ACM)] National Midwifery Guidelines for Consultation and Referral. The ACM Guidelines describe the parameters for identifying low risk pregnancy and support midwives to make appropriate consultation and referral to other clinicians and allied health staff if risk factors arise in pregnancy.
http://www.health.nsw.gov.au/policies/pd/2010/PD2010_022.html

PD2009_069 NSW Register of Congenital Conditions Reporting Requirements. Describes the requirement to report scheduled congenital conditions under the NSW Public Health Act 1991.
http://www.health.nsw.gov.au/policies/pd/2009/PD2009_069.html

PD2005_587 Pregnancy – Framework for Terminations in New South Wales Public Health Organisations. Provides a framework to support the review and development of appropriate local protocols for terminations of pregnancy undertaken in public hospitals.
http://www.health.nsw.gov.au/policies/pd/2005/PD2005_587.html

GL2005_025 Antenatal Card Guideline
http://www.health.nsw.gov.au/policies/GL/2005/GL2005_025.html

2 THE ANTENATAL MATERNAL REFERRAL or TRANSFER GUIDELINE

Each maternity unit in NSW should have a policy on antenatal referral of mothers with babies known to have a congenital structural malformation likely to require surgery soon after birth.

The policy should emphasise:

- antenatal consultation and assessment by maternal-fetal and paediatric specialists at the local fetal medicine unit (section 2.1.1) where available. Subsequent referral can then be made as appropriate to surgical and other consultants (eg genetics, cardiac, renal) in the preferred facility (section 2.1);
- that the decision to make an antenatal maternal referral should take into account patient and clinician preferences;
- include options and processes for antenatal referral for more detailed fetal assessment;
- a plan for the optimal place, mode and timing of birth. This will usually occur mid-pregnancy;
- if surgery or other critical therapy is likely to be required soon after birth, the birth plan should include delivery at a perinatal centre with direct access to appropriate paediatric surgical services;
- include information on the psycho-social aspects of care, such as accommodation and other support available at the tertiary referral centres, especially for indigenous clients;
- the need to document the birth plan and related decision process on the Antenatal Card (or equivalent record) carried by the mother at all times during pregnancy. This will assist with continuity of care.¹¹
- the need for tertiary perinatal and paediatric services to ensure the primary obstetric carers and the fetal medicine units receive feedback on the maternal and neonatal outcome and the baby's subsequent progress.

2.1 TERTIARY PAEDIATRIC SERVICES

Direct access to tertiary paediatric services is currently available at the following tertiary perinatal centres:

- John Hunter Women's and Children's Hospitals, Newcastle NSW
- Royal Hospital for Women/Sydney Children's Hospital, Randwick NSW
- Westmead Hospital/The Children's Hospital at Westmead, Westmead NSW
- The Canberra Hospital, ACT

2.1.1 Referrals and referral services

Advice on referrals and referral services may be obtained from the following NSW and ACT fetal medicine units:

- John Hunter Women's Hospital, Maternal-Fetal Medicine, Telephone: 02 4921 4694
- Liverpool Hospital Feto-Maternal Unit, Telephone: 02 9828 5631
- Nepean Hospital, Feto-Maternal Unit, Telephone: 02 4734 3235
- Royal Hospital for Women Maternal-Fetal Medicine, Telephone: 02 9382 6098
- Royal North Shore Hospital Maternal-Fetal Medicine, Telephone: 02 9926 7099
- Royal Prince Alfred Hospital Fetal Medicine Unit, Telephone: 02 9515 6042
- Westmead Hospital Fetal Medicine Unit, Telephone: 02 9845 6802
- The Canberra Hospital Fetal Medicine Unit, Telephone: 02 6244 3136

2.1.2 Structural cardiac malformations and surgery

Consultative advice for structural cardiac malformations and surgery is available from:

- The Children's Hospital at Westmead, Telephone: 02 9845 0000
- Sydney Children's Hospital Randwick, Telephone: 02 9382 1111
- The John Hunter Children's Hospital, Telephone: 02 4921 4900

3 EMERGENCY NEONATAL RETRIEVAL

The NSW newborn and paediatric Emergency Transport Service (NETS) retrieves neonates to tertiary referral centres for intensive care, diagnostic workup or surgery where antenatal maternal transfer has not been possible. NETS can assist in overcoming any barriers to transferring women antenatally from a hospital without neonatal surgical services.

NETS Clinical Coordination Centre Telephone: 1300 36 2500
(24 Hour Hotline for hospitals and clinicians across NSW and the ACT)

4 OTHER RESOURCES

Following the diagnosis of a major congenital structural malformation, particularly in the case of poor prognosis or an underlying genetic diagnosis, some parents may request additional information. Resources that may assist clinicians include:

- NSW Health Genetics Service: www.health.nsw.gov.au/genetichealth/
- NSW Centre for Genetics Education at www.genetics.com.au

5 REFERENCES

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