

What to do if you have a complaint about how you or your family have been treated

The PMMRC is not the place to make a complaint. If you want to make a complaint about the quality of care you received please contact one of the following:

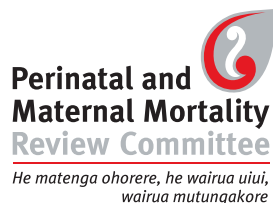
- the manager at the hospital that provided your care
- the Patient Advocate – Phone 0800 555 050
- the Health and Disability Commissioner – Phone 0800 11 22 33.

Support is available

The possibility of living with a child with a disability is very difficult. Having the support of friends, family and whānau will help you cope at this difficult time. You may also find speaking with a professional counsellor helpful.

The following people may also be able to advise you:

- Cerebral Palsy Society of New Zealand
www.cpsoc.org.nz
- a kuia or kaumatua
- your doctor or midwife
- your spiritual or cultural advisor, chaplain, pastor or minister.



How to contact the PMMRC

Perinatal and Maternal Mortality Review Committee PMMRC Secretariat
PO Box 25496
Wellington 6146

Telephone: (04) 901 6040
Fax: (04) 901 6079

Further information on the PMMRC is available on the website: www.hqsc.govt.nz/pmmrc



Information about the Neonatal Encephalopathy Working Group



Te Kāwanatanga o Aotearoa
New Zealand Government



HEALTH QUALITY & SAFETY COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

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What is neonatal encephalopathy?

'A clinically defined syndrome of disturbed neurological function within the first weeks of life in an infant born from 35 weeks gestation, manifesting by difficulty in initiating and maintaining respiration, depression of tone and reflexes, subnormal consciousness and often seizures.'

Neonatal encephalopathy (NE) is a disorder/disease in the brain of the newborn. NE generally affects the term baby and there are a number of possible reasons for why it might happen. NE is associated with brain injury/deficit including cerebral palsy. Of those infants affected by NE, some will die, some will have long-term neurological complications (brain damage) resulting in chronic disability and some will not have ongoing neurological complications.

Who are we?

The Perinatal and Maternal Mortality Review Committee (the PMMRC) is set up under the Pae Ora (Healthy Futures) Act 2022 (the Act). The PMMRC's primary function is to review and report to the Health Quality & Safety Commission (the Commission) on maternal and perinatal death and disability.

Members are appointed by the Commission.

Membership of the PMMRC is listed on the website www.hqsc.govt.nz/pmmrc.

The Neonatal Encephalopathy Working Group was established by the PMMRC in late 2007.

Representation was drawn from a wide range of health professionals involved in care of women and their families. The overall purpose of the group is to review New Zealand data on NE to improve services and outcomes for babies.

What do we do?

The PMMRC aims to reduce the number of preventable perinatal and maternal deaths. The PMMRC also develops strategic plans and methodologies to reduce morbidity (disability).

NE was identified as an area where there may be the potential for improvement of services and outcomes for babies. Despite advances in obstetric and neonatal care, NE remains a cause of brain injury in the term newborn infant.

To establish the true size of the problem, the first priority of the group was to collect data on the number of babies diagnosed with NE in New Zealand.

This information forms a national data set. It is hoped that this data set can be used to assess predictors of NE and to determine the quality of maternity and neonatal care to prevent and appropriately treat NE.

How is the information collected?

Paediatricians who report that they have cared for an infant with NE will be contacted to complete a data collection form. The Lead Maternity Carer(s) will also be contacted by the PMMRC to provide further information.

The data collection forms provide detailed information on both mother and baby. Specific cases are identified for case review. Full sets of clinical notes are requested for both mother and baby in these cases.

This information forms the basis of the NE chapter of the PMMRC Annual Report. The report contains the PMMRC recommendations on how to reduce both the number of deaths and disability from NE.

Papers on the findings of this work will be published in medical journals with the permission of the PMMRC.

Confidentiality of information

All people with access to this data are agents of the PMMRC for the purpose of NE review. As agents of the PMMRC, they are under strict confidentiality obligations under Schedule 5 of the New Zealand Public Health and Disability Act

The information provided is strictly confidential. Data is stored in a secure office and on a secure website.

Information published by the PMMRC is grouped and individuals are not identifiable.

What is the place of families in the system?

One of the purposes of this pamphlet is to make sure that all family and whānau know what information is collected and why. Because all information needs to be kept private, the PMMRC will not write any reports on individual cases.

However if you would like to contribute further information or contact the PMMRC we would welcome your input. Please see contact details on the back of this pamphlet.