

ICPCN INFORMATION ON PALLIATIVE CARE FOR BABIES AND CHILDREN WITH MICROCEPHALY (AND SIMILAR NEUROLOGICAL BIRTH ANOMALIES)

The International Children's Palliative Care Network (ICPCN) is a global network of organisations and individuals working in the field of hospice and palliative care for children. The care of babies, children, adolescents and young adults who face a shortened lifespan should include services, therapies and medications that will reduce pain and suffering and encompass all their physical, social, emotional, spiritual and developmental needs. It includes support to their families into the bereavement period. Palliative care promotes relief of suffering and the best possible quality of life. Palliative care for children represents a special, albeit closely related field to adult palliative care. The World Health Organization (WHO) defines palliative care appropriate for children and their families as follows; the principles apply to other paediatric chronic disorders (WHO 1998a):

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Possible link to Zika Virus

Infection with the Zika Virus itself is not a life-limiting condition, with the illness usually being mild with symptoms lasting from several days to a week. Severe symptoms requiring hospitalisation is uncommon. However, birth defects and other poor pregnancy outcomes have been seen in babies of mothers who were infected with the Zika virus whilst pregnant (CDC 2016a). The most commonly reported defect in babies is microcephaly, and, whilst the possible link between Zika virus infection and microcephaly is still being investigated, the care of affected babies and their parents is paramount and should include palliative care.

What is Microcephaly?



Baby with Microcephaly

Microcephaly is “a birth defect where a baby’s head is smaller than expected when compared to babies of the same sex and age. Babies with microcephaly often have smaller brains that might not have developed properly.” (CDC 2016b). In the womb, the baby’s head grows along with the growth of their brain. If, for some reason, their brain fails to develop as it should, this will result in the baby being born with a head that is smaller than normal. As with many other

conditions, the impact of microcephaly on a child will vary. Some may have normal intelligence and have no particular challenges. However the majority of children with the condition will experience challenges, including:

- Mild to significant learning difficulties
- Impaired motor function
- Difficulty with movement and balance
- Speech delays
- Physical deformities such as short stature, facial deformities, development delays, spasticity
- Feeding, hearing and vision problems
- Seizures

There is no way to reverse microcephaly so any treatment options will be palliative, aiming to improve quality of life, reduce symptoms and prevent complications. Whilst some 10% of children will be able to live a relatively normal life, those with severe microcephaly will need on-going care and treatment and may have a shortened lifespan.

Causes and Risk Factors

The cause of microcephaly in most cases is unknown. Some cases are congenital, occurring in a wide variety of conditions that cause abnormal growth of the brain, or in syndromes associated with chromosomal abnormalities. Other causes of microcephaly can include the following exposures during pregnancy:

- Specific viral infections, such as rubella, toxoplasmosis, or cytomegalovirus. Researchers are currently studying the possible link between Zika virus infection and microcephaly.
- Exposure to harmful substances, such as alcohol, some drugs, toxic chemicals.
- Severe malnutrition.

Diagnosis of microcephaly

Diagnosis can be done by ultrasound during pregnancy from late in the second trimester. Diagnosis may be done after birth with measurement of the baby’s head circumference.

Assessment of babies born with microcephaly – at birth and ongoing

- Developmental assessment to determine the types of services and therapies needed (e.g., physiotherapy, occupational therapy, communication assistance).
- Neurology evaluation.
- Ophthalmology evaluation.
- Swallowing/feeding evaluation.
- Audiology evaluation.
- Echocardiogram and abdominal ultrasound examination to identify concomitant abnormalities.
- Paediatric palliative care consultation and psychosocial support for family.
- Medical genetics consultation.

Provision of palliative care for babies and children with microcephaly

In palliative care for babies, children and young people, the unit of care is the child and family. Families will require support from the time of diagnosis, which may be during the pregnancy, and throughout the baby /child's lifespan. Some babies will be stillborn or die within the neonatal period.

Antenatal palliative care

- With all the fear and uncertainty, it is still so important that the mother receives good antenatal care.
- Families should have the opportunity to discuss their fears, and have these acknowledged before the baby is born.
- If choices to continue the pregnancy or not can be made, mothers and families should be supported through this with due respect and with dignity. Where possible, their choice should be supported by professionals.
- Mothers and families should be helped to plan what they would like to have happen should their baby die in utero or shortly after birth.

After birth

- Support mothers and family members to cuddle baby, place baby on breast, etc.
- Allow time together, making memories such as hand and foot prints and taking photographs.
- Introduce baby to siblings, grandparents and other significant people wherever possible.
- The baby can wear a hat if families find the sight of the baby's head distressing.
- Treat the baby with respect and dignity as for any other baby.
- Religious rituals such as baptism may be required.
- Assess baby for signs of pain and other distressing symptoms and treat where relevant.

- Where possible provide medicines through a non-invasive route e.g. buccal route.

Ongoing palliative care

- Care and treatment focused on coordinating the management of health problems.
- Treatment is symptomatic and supportive to promote the best possible quality of life.
- Co-ordinated developmental services early in life will help such babies maximise their physical and intellectual abilities.
- Mobility aids may be required such as wheelchairs.
- Early intervention includes speech, occupational, and physical therapies.
- Care co-ordination and symptom management are pivotal in the management of microcephaly.
- Appropriate medications as needed to treat seizures or other symptoms.
- Ongoing psychosocial and spiritual support for the family.

Support for emotions of loss and grief

- Feelings of loss and grief can begin at the time of diagnosis when parents learn that their baby may have a life-limiting condition and continue after the death of a baby or child.
- A wide range of emotions may be experienced and may include denial, anger, fear, sadness, and guilt.
- Allow parents to express their feelings and provide counselling to help them cope with their emotions.
- Assure the parents and family members that these feelings are a normal response to loss or potential loss.
- Additional professional support may be required from psychologists, social workers and spiritual counsellors.
- Memory-making should be encouraged.
- Meeting parents with similar experiences and participation in bereavement support groups may be helpful.

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