



Neonatal Palliative Care for New Zealand Neonatal Units

Comfort as a Model of Care

Whakamarietia rite ki te tauira o te tiaki

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A collaborative project
Facilitated by the Neonatal Nurses College of Aotearoa, New Zealand Nurses
Organisation



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Foreword

The Neonatal Nurses College of Aotearoa (NNCA) is a college of the New Zealand Nurses Organisation (NZNO). It has a committee of eight neonatal nurses and a membership of over 580 neonatal nurses. The NNCA objectives include formalising standards and recommendations for neonatal nursing practice.

In early 2014, a member approached the college with a request to develop a document relating to neonatal palliative care. This was based on a personal experience and a lack of supporting information to assist staff, particularly in smaller neonatal units providing palliative care. The passion to create a document that could assist nurses to provide quality and compassionate palliative care to both the neonate and their family was shared by other NNCA members.

I was delighted to facilitate this process with four nominated NNCA members from level two and level three neonatal units who have expertise and interest in palliative care. Lynette, Mandy, Debbie and Maureen have drawn from their own experiences and journeys and have developed '*Comfort as a Model of Care*.'

The document includes a clear set of principles to assist in providing palliative care to babies in partnership with families/whanau. There is also a brief insight into 'caring for the carers,' as it is well recognised that nurses and the clinical team also require support.

It is not to be read as a guideline or pathway and neither is it a neonatal palliative care framework for the neonatal nursing workforce. It is also not intended for the paediatric ward setting, however the principles may well apply to babies less than one month of age admitted to the paediatric ward.

The intended scope of '*Comfort as a Model of Care*' is **primarily for neonatal nurses** caring for families and babies admitted to a neonatal unit requiring palliative care or receiving complex intensive care transitioned to palliative care. It aims to complement other resources that are available in New Zealand and within individual DHB's, such as 'Allow Natural Death' (ADHB 2010). The Paediatric Palliative Care Clinical Network in association with the Paediatric Society of New Zealand and Ministry of Health (August 2015) has also completed national guidelines for end of life care and is available on the Starship clinical guideline website and this will be a valuable evidenced based resource.

Whether in small neonatal settings or a large tertiary neonatal setting, many nurses will be exposed to palliative care for the first time while some nurses will have experience to share. I hope you agree that this resource includes some valuable 'tools' that will help as a practical guidance and equip nurses and potentially the clinical team when introducing compassionate palliative care to provide comfort to families and whanau.

Annie Marshall

NNCA Chairperson
October 2015



Te Tiriti o Waitangi

Whakahaere o Aotearoa me Te Rununga o Aotearoa hoki, i tenei tuhinga Motuhake, a, kawhakanui ka whakapiki hoki tatou kia rite te tunga o te tangata whenua me nga Neehi Whakahaere o Aotearoa.

Neonatal Nurses College of Aotearoa (NNCA), as a college within New Zealand Nurses Organisation (NZNO), is committed to Te Tiriti o Waitangi as the founding document of Aotearoa/New Zealand, and is determined by the partnership relationship with Te Rūnanga o Aotearoa, NZNO (Te Rūnanga).

Te Tiriti o Waitangi acknowledges the rights of all peoples to their place in this land – Māori as Tangata Whenua and others as Iwi kainga (those that have come to make a home for themselves here).

The NNCA would like to acknowledge the place of Te Tiriti o Waitangi in its nursing practice, and incorporates its commitment to Te Tiriti o Waitangi in this document.

“Parents hold their children’s hands for just a little while.. their hearts forever.”

(author unknown)

*“Ahakoa, ka haere tinana te tamariki
ka noho tonu te wairua, me nga whakaaro kia ratou”*

Use of the Document

- Throughout the document, it is important to remember that the best person to make decisions for the baby is the parents, family or whanau as they will know what feels right for their baby
- It is designed to enhance practice and to assist the parents decisions and approach to palliative care for neonatal nurses and potentially the extended neonatal clinical team, within hospital and home settings
- The table of contents refers to sections and appendices, which can be used independantly, therefore some repetition exists between sections
- Templates provided may be adapted to meet individual DHB needs
- The content is designed to be used as an educational tool and may be used to develop individual approaches in consideration to the resources available within each DHB.



Executive summary

The vision for neonatal palliative care in New Zealand is that, when needed, all babies in New Zealand have access to appropriate, high quality, co-ordinated and culturally appropriate palliative care that meets their physical, psychological, social and spiritual needs and their family/whanau are involved in partnership from the time of diagnosis through the course of illness and continue after the death of their baby.

The purpose of this project was to develop a model of care that will assist neonatal nurses and the neonatal clinical team when caring for dying babies and their families. Our model focuses on the importance of providing support and comfort to the baby and their family to maximise the quality of life, minimise suffering and facilitate a peaceful and family centred death for dying newborns.

“Palliative care for neonates with life-limiting and life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the baby’s life, death and beyond. It is a team approach, which embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the baby and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.” (Together for Short Lives, 2013)

Background

The Perinatal Society of Australia and New Zealand (PSANZ) developed a perinatal palliative care special interest group (PPC SIG) in 2013 with the purpose to promote research, education, and improve service delivery in perinatal palliative care in Australia and New Zealand. The role of the PPC SIG includes sharing their expertise, knowledge and experiences and to disseminate any key resources and findings to relevant audiences.

NNCA recognized the opportunity to use these shared resources plus obtain other resources already in New Zealand and develop a neonatal palliative care guidance document specifically for use within New Zealand.

Target audience

NNCA have primarily aimed this document for neonatal nurses. It is hoped it will also prove useful to all the clinical team working in level two and three neonatal units and involved in the management and care of babies, in whom a decision has been made to introduce palliative care in the hospital and home setting. It has been specifically developed for practice in New Zealand however the underpinning principles are relevant globally.



Target population

The target population are all babies within the neonatal setting for whom a decision has been made to introduce palliative care. The term 'baby,' 'neonate' and 'infant' are occasionally used interchangeably to describe the population and refer to preterm babies at or under 24 weeks gestational age to full term babies less than 28 days old. This population can be further classified into five categories defined by the British Association of Perinatal Medicine (2010).

- Category 1: An antenatal or postnatal diagnosis of a condition, which is not compatible with long term survival, e.g. bilateral renal agenesis or anencephaly
- Category 2: An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death
- Category 3: Babies born at the margins of viability, with extremely low birth weights and gestational ages, especially those with gestational ages at or under 24 weeks, or weighing less than 500 grams if no growth retardation exists. Newborns weighing slightly more (<750g) or who are born slightly older (<27 weeks' gestation) may do well but then develop serious complications that become life-limiting as additional time passes
- Category 4: Postnatal conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support e.g. severe neonatal encephalopathy
- Category 5: Postnatal conditions which result in the baby experiencing "unbearable suffering" in the course of their illness or treatment, e.g. severe necrotising enterocolitis, where palliative care is in the baby's best interest.

We hope this document will provide practical guidance for nurses and clinical team members to develop and implement a plan of care with families/whanau whose baby has a life limiting condition.



Photo: Anne Geddes (1993)



1.0 Introduction

Life-limiting or life-shortening conditions in neonates are those for which there is no reasonable hope of cure and which will lead to death, whether hours, days, weeks, months or years away. Professionals working with the family/whanau antenatally and in the neonatal period have a duty to act in the best interests of the family/whanau and baby. Normally the goal of care is to sustain life and restore health. However, there are circumstances in which treatments that sustain life are not considered to be in the baby's best interest.

The decision to introduce palliative care should be a joint decision with the multi-disciplinary team, the parents and their chosen support people. Open clear communication is essential at all times and often includes involving members of the primary care team such as GP/LMC and district nurse.

Neonatal palliative care

Knowing when to introduce neonatal palliative care may be complicated due to rapid changes in condition and prognosis, plus the demand for urgent clinical decisions. Families/whanau should be informed about the palliative care options and support services available to them as early as possible. This will offer them greater control of their care journey and enable them to make choices about which elements of a service they wish to access at different stages. In some cases this discussion may take place before their baby is born or very soon after birth, or as it becomes clear that curative treatments are unlikely to succeed.

Professionals working in neonatal services are used to providing babies and families/whanau with sophisticated expert care using high levels of technical skills and knowledge.

They are increasingly challenged to provide neonatal and sometimes, antenatal palliative care as technology allows more accurate prenatal diagnosis. The environment within neonatal units can foster a dependency on technology and equipment. A baby with palliative care needs may require highly intensive care but not necessarily at the same level of technical care. The focus of this model of care is enabling families/whanau to spend time with their baby, bonding and building memories, in a more home-like environment, and with less dependence on technology.

Purpose

This document and associated templates will be of use to those working to improve the quality and consistency of palliative care and support to babies and families/whanau. It aims to help provide some guidance from diagnosis or recognition of deterioration, through to the baby's end of life and death as well as into bereavement. Babies and their families/whanau will have varied, individual journeys according to their own needs and circumstances. The document focuses on putting babies and families at the centre of a planning process, with the aim of delivering integrated services in response to individual needs.



2.0 Principles of neonatal palliative care

Every baby born in New Zealand regardless of race, religion or culture has the right to benefit from:

- The same respect and dignity as adults
- Decisions affecting their care being made in their best interest
- The same level of specialist care as children and adults
- The same access to specialist palliative care as babies born in similar countries and circumstances
- The information and support needed by parents to help them care for their baby and achieve the best quality of life possible
- The opportunity to have their mother's breast milk when appropriate.

In addition:

- Each baby will have an individualised neonatal palliative care plan developed
- Parents/caregivers shall be acknowledged as the primary carers and involved as partners in all care and decisions involving their baby
- The family home shall remain the centre of caring whenever requested by the family/whanau and whenever possible
- Every family/whanau shall be given the opportunity to have consultations with a paediatric/neonatal specialist who have particular knowledge of their baby's condition
- Every family/whanau shall have timely access to practical support and the following overarching themes should be considered at every stage of palliative care:
 - Communication
 - Psychological support
 - Spiritual support
 - Cultural support
 - Social support

3.0 Planning palliative care with families

Communication

- All communication should be honest, accessible and sensitive to the family's needs. Parents may be shocked, frightened and stressed by the knowledge that their baby has a life-limiting condition or abnormality not compatible with life. They may also be grieving for the loss of a normal pregnancy, birth and a planned for and dreamed of future. Parents of twins and other multiples may have to cope with additional complex and conflicting emotions, for example dealing simultaneously with end of life care for one baby whilst remaining hopeful and optimistic for another. Parents in these situations are likely to be both emotionally and physically exhausted. They may have other children to care for and may be travelling long distances to visit their baby. All of the above make it difficult for parents to understand and take in complex and distressing information



- There should be an honest and open approach to all communication in partnership with parents/caregivers/significant others
- Discussion must be conducted in a quiet and private setting and the family should be offered the opportunity of a support person to be present
- The parents should be given time to assimilate information and time to discuss it with their wider family/whanau if they wish to. Further opportunities for discussion should be offered
- The phrase 'withdrawal of care' should be avoided and 'palliative' or 'comfort care' used instead
- An interpreter should be available when required, as it is essential that the parents have a full understanding of what is being discussed. Family members, friends and siblings should not normally be used unless no alternative is available. If families insist on a relative translating, the difficulties with using family members must be explained and documented in the patient notes
- Be familiar with any interpreter service offered by your DHB

Psychological support

- If parents choose to collect memento's, suggest choices to create and collect memories such as photo's, castings, hand/footprints, items of clothing the baby has worn. These will give some tangible memories of the baby and their time together and can be very important in the months and years to come
- All families should be offered the opportunity to meet with a hospital social worker, Maori liason or other DHB support services such as a psychiatry liason nurse
- Suggest contacting the local Sands NZ who are familiar with supporting parents/families/whanau around the time of the death of their baby
- Where possible, engage a primary nurse or family liason nurse to work with the family.

Spiritual support

- Parents should be offered a choice of who they would like to support them; this may be a member of their church, hospital chaplain, maori chaplain or significant other. Their wishes should be documented in the care plan to avoid the same question being asked multiple times
- Spirituality is not just a person's religious affiliation. To understand spiritual needs better, health care staff should not limit questions to type of religion or to baptism. Include questions about faith, rituals, traditions and needs while caring for the infant and the family
- Ensure the individual spiritual needs is met for all families See appendix five for a list of procedural variances required for specific religious groups.



Cultural support

- New Zealand has its own significant cultural perspective plus a diverse cultural demographic and care should reflect the personal cultural wishes and beliefs of each family
- The principles of Treaty of Waitangi - partnership, participation and protection should be recognised and models of Maori health such as Te Whare Tapa Wha, the four cornerstones (Durie 1982) should be applied as appropriate
- In Maori culture, events surrounding times of illness, dying, death and grieving are among the most sacred and important. They are steeped in Tapu (sanctity), Kawa (protocol) and include Karakia (prayers) and Waiata (chants and oral literature).
- See appendix six for protocols and customs observed around the time of a Maori death.

Social support

- Information should be made available by the social worker for parents informing them of what benefits and support they are entitled to, specific to each DHB.

4.0 Planning care

Pre birth care

- When a diagnosis of a life-limiting condition is made antenatally palliative care planning prior to the birth of the baby should occur
- An obstetrician/neonatologist/paediatrician and neonatal nurse/midwife/LMC should be involved in documenting a palliative care plan for the baby, working in partnership with the family/whanau
- This should include an approach and limitations to resuscitation at birth and location of ongoing care. Include details of what occurs if the baby is stillborn or dies immediately following birth.

Planning care of the baby with parents

- This refers to the period of time before a baby dies. This period of time can typically range from hours or days to weeks but may be longer. Care of the baby needs to be planned and documented, including the approach to resuscitation, nutrition, pain relief and comfort care. The appropriate place for this care should be discussed along with what support the family will need
- Parents will choose how they would like to spend time with their baby and they may need gentle guidance on what they can do
- Ask and document if they wish to be with their baby, some don't but may find this difficult to verbalise. It is important their wishes and needs are respected.

Advance care planning

- Any baby being discharged home for palliative care, may be offered an advance care plan, completed and agreed in partnership with the family/whanau



- This includes resuscitation guidance, what to do in the event of an acute deterioration, wishes of the family and contact details of key members of staff. The parent's decision should be documented and can be printed and disseminated to the appropriate people. Parents should be given a copy
- Discussion around post-mortem examination and organ donation may be included in the advance care plan
- Where possible the team making these decisions with the family should be based where the baby will receive care. The outcome of discussions made in another centre must be communicated as soon as possible to the local team who will be caring for the family
- It is vital to involve or inform members of the Primary Care team /GP/LMC about palliative care planning as soon as possible as they may be part of the team delivering palliative care and will provide ongoing support to the family
- At all times the parents should have the name and contact details of a key member of staff as well direct phone number for NICU/SCBU or specialist paediatric service involved e.g. cardiology, neurology.

Flexible parallel care planning

- Whilst there are many situations where there is a reasonable certainty of death during fetal and neonatal life, there are babies who survive longer than expected
- It is vital that care planning is continuously reviewed in the best interest of the baby. There should be parallel planning for transition periods into and out of active, supportive and end of life care. Any changes should be well documented and communicated on the appropriate care plan.

5.0 Management of an infant when palliative care is agreed

Discussions with parents

- Agree on a time and location for discussion of a palliative care approach with the parents
- All communication with the family/whanau should occur in a quiet room. Give them the option of inviting other family members or a close friend to be with them
- Phrases such as the following may help:
 - "Our aim is to keep your baby as comfortable as possible and minimise any suffering for whatever time they may have with you"
 - "We cannot cure your baby but we will be there to help you"
 - "We want to support you through this difficult time"
- Arrange for an interpreter to be present if needed – avoid interpretation by family members or children
- Enable the nurse caring for the baby to be present during the discussion



- Explain what will physically happen to the infant, what to expect practically and the uncertainty for how long the baby may survive
- If a palliative care approach is more likely to lead to death quickly, then explain symptoms of dying such as gasping respirations, colour changes etc.
- Ask the parents who they wish to be present at time of death.

Attachment, bonding and memories

- Emotional bonding may occur well in advance of birth and parents can bring with them preconceived expectations and dreams about being a parent. It may also be possible for parents to experience a disconnect, following an unexpected diagnosis in pregnancy. This may add to feelings of guilt and grief
- Ask if the parents have any specific preferences for their baby such as having their baby dressed in a special way, bathing or anointing baby etc
- Ask if the parents would like to hold their baby. Holding the baby should be made possible for as long as the parents wish
- Ask if they would like photos to be taken and offer them the opportunity to take handprints and footprints. If parents do not want photos, offer to take some to keep in the medical records in case they decide they would like them at a later date. Ask parent if they wish to keep any items such as blankets, hats or other items that were related to baby's care
- Congenital anomalies- parents may see the good features while the deformities or unusual features may not be important. Many anomalies can be disguised by dressing or wrapping the baby in a blanket.
- In cases where an antenatal diagnosis has been made be gently honest with parents about what they may expect. The baby may be macerated or malformed. Many parents may be aware, following an antenatal diagnosis, that the baby has an abnormality and may have already started grieving
- If the infant is one of a set of twins, or other multiple births, where possible take a photograph of the babies together with the family. This could be in incubators or cots close together if that is the only way to do this if the other baby/s are very sick
- Where possible try to ensure the nurse who is allocated to the infant and family does not have other infants to care for. Ask the parents if they would like the nurse to be present in the room with them or in close proximity and ensure they are aware that the nurse will return after a short time if they do not remain in the room
- Let parents know that it is possible for their baby to remain with them after death if they wish. If a post mortem examination is to be carried out, it is advisable to keep the body in a cooler room. Parents should be informed that it is possible to see their baby after the body has returned from post mortem



- It may be possible for the family to take the baby home after death until the funeral. Please refer to local DHB guidelines and policies or Sands NZ: Transporting Your Baby pamphlet.

Management of pain and comfort care

- Consideration should be given to relief of pain and other distressing symptoms for any baby receiving palliative care. This includes the type of medication, the dose, route of administration and likely duration of need. Consideration should also be given to the use of formal tools to assess pain and other symptoms
- Should the infant have intravenous access in place, this route may be preferable during palliative care
- If an infant is already receiving analgesic medication, this should be continued if required– if opioids are to be initiated, an initial bolus dose should be given before commencing an infusion so that adequate analgesia is achieved promptly. The dose may be increased or reduced depending on ongoing assessment of distress and development of tolerance – parents should be informed that appropriate prescribing of any opioid will relieve pain, distress and dyspnoea but will not cause any suppression of respiration or cause an early death
- If the intravenous route is not available and adequate analgesia cannot be achieved through oral medication, a subcutaneous infusion may be necessary. Intramuscular medication is never appropriate. For rapid symptom management, buccal medication can be considered, usually in addition to longer acting medication via the enteral route or subcutaneous infusion
- Simple analgesia such as paracetamol or oral sucrose may be used for mild pain or in combination with opioid analgesia for moderate to severe pain
- Non pharmacological interventions may be used in conjunction with analgesic medications – these include, but are not restricted to, a calm environment with minimal noise and light stimuli, non-nutritive sucking with a pacifier, music, kangaroo care or positioning with arms and legs flexed close to the trunk using a blanket or rolls and massage
- Parents should be encouraged and facilitated to hold their baby
- Support mother to continue suckling at the breast if achievable.

For appropriate prescribing of analgesic medications and management of other symptoms such as seizures, excess secretions and dyspnoea please refer to national paediatric formulary (National paediatric palliative care clinical guidelines, August 2015)



Physiological monitoring

- Discuss with the family/whanau regarding minimising invasive techniques such as blood pressure monitoring and cardiac and saturation monitors. Consider a weaning process to discontinue monitoring prior to disconnecting mechanical ventilation
- The baby should be monitored for physical signs that suggest discomfort (crying, whimpering, panting, tachycardia, excessive secretions, dry mucous membranes). Please use a validated neonatal infant pain scoring tool.
- Blood tests and blood gas measurements may no longer be required
- Once palliative care has been implemented how the baby is monitored should be established with the parents. This could range from clinical observation through to intermittent physical examination such as auscultation of the heart and assessment of respiratory rate by the nurse or doctor caring for the baby.

Fluids and nutrition

- The goal of care is comfort
- For babies who are able to tolerate milk feeds including suckling at the breast, provision should be determined by parental wishes, baby's clinical condition and the cues that the baby demonstrates
- Oral nutrition could be withheld when the baby is unable to tolerate feeds, is unable to suck and swallow or feeding causes undue pain or discomfort. Intravenous hydration and nutrition need not be started in this situation
- If death does not occur and provision of intravenous hydration and nutrition is the sole intervention maintaining life, then discontinuation is ethically acceptable. The baby can continue to be offered oral nutrition as above. Any such decision should involve discussion with the parents
- Any decision to continue to provide intravenous nutrition and hydration should include a consideration of the benefit/burden ratio for the baby such as pain and discomfort caused by the need for central or peripheral venous access
- If the baby is discharged home for palliative care, then arrangements to continue or discontinue medically assisted hydration and nutrition should be made in advance and the parents supported accordingly
- Gastrostomy, nasogastric and jejunostomy feeding will require parental training and professional community support for babies receiving palliative care at home
- The benefits of surgery to allow feeding either via the intravenous route or via the enteral route must be considered against the burden of the intervention.



Removal of respiratory support

- Explain to the parents exactly what could happen, the sequence of events and who will be present when removal of respiratory support occurs
- Explain that death may not be immediate and that their baby may survive for a prolonged period
- Explain how their baby will be cared for
- Decide in advance who will be responsible for the actual removal of the endotracheal tube and turning the ventilator off
- Follow DHB procedure and policy for removal of respiratory support
- Aspirate the nasogastric tube – consider not feeding the baby just prior to extubation
- Turn off the alarms of the ventilator and monitors prior to disconnecting these
- Suction the endotracheal tube before removal
- Give the parents the choice of being present and holding their baby
- Removal of less invasive forms of respiratory support such as CPAP and nasal cannula oxygen may be appropriate if a baby is dying and continued provision of respiratory support only serves to cause distress or delay death.

Location of care

- The principles of palliative care should be consistently applied regardless of location
- The best available space with privacy and comfort for the parents and family should be used
- Discuss with parents if they prefer to stay in the neonatal unit with a screen for privacy or move to a side room if available
- If the mother is receiving care e.g. after caesarean section, consider providing palliative care on the postnatal ward in a private area that does not compromise her own care and provide nursing support for the baby
- Consider the possibility of transfer home with support from the LMC, homecare nurse and/or paediatric palliative care nurse if available.
- Tailor realistic care to the individual needs of baby and the family
- If a decision for palliative care has been made in the antenatal period ensure that a plan of care is easily available in the clinical notes for all staff to access
- Throughout this process it is important to communicate current information regularly with other specialities that may be community or hospital based. This could include GP's, LMC's and social workers who may be supporting the family.



6.0 Resolving conflicts

Conflicts between parents and healthcare team

- Allow parents time to consider the decision and arrange for a senior clinician with the best relationship with the family to see them again to hear their concerns
- Discuss with parents the aim of palliative care with focus on support and comfort. Staff should not be judgemental should a parent indicate a wish to continue life-sustaining support
- If relevant, explain that life sustaining support is not curative and does not alter the baby's underlying condition or ability to survive
- Explore the reasons behind the parents' views
- Ascertain if parents would find it helpful to discuss their views with family, friends or spiritual/religious figures – offer access to hospital service representative if appropriate
- Consider approaching a clinical ethics committee (if access to one exists) or medical mediation service if appropriate
- While awaiting the outcome of any actions, inform parents that the care of their baby will continue unchanged.

Conflicts among members of the healthcare team

- All members of the healthcare team whatever their level of seniority should be included in discussions about the ongoing care of the baby and decisions about appropriateness of continuing life-sustaining support – the opinion of each member of the clinical team will depend on their experience but the ultimate decision rests with the senior clinician in charge
- Regular, scheduled and well attended unit meetings, psychosocial meetings and multidisciplinary case discussions promote team cohesiveness and healthy team functioning. This can be a key means of reducing conflict between team members and reduce the potential for escalation
- An external facilitator may be helpful where there is significant conflict
- Neonatal units and team members should be aware of other sources of support. Refer to your individual DHB resources
- Reflective practice, facilitated by a trained team member can be helpful both before and after a decision to introduce palliative care. Team members should be offered debriefing after the death of a baby
- Chaplaincy/multi-faith chaplaincy/spiritual care team members can provide support for staff.



7.0 Bereavement support

Religious and spiritual support

- The family's religion/spiritual belief's should be documented when taking the admission history
- Assess the spiritual and religious needs of the family/whanau and if appropriate, refer to the chaplaincy or equivalent. Ask if the family/whanau would like to have their own religious or spiritual representative contacted
- Be respectful of each family/whanau as being individual with different beliefs and rituals. Even with a known religious framework, ask the family/whanau about their spiritual and religious needs including important rituals and procedures
- The parents' spirituality/faith may influence their emotional, psychological and physical responses to bereavement
- Be mindful that the mother and the father may have different religious, spiritual or cultural beliefs
- **In Maori culture**, losing a baby is viewed as a loss not only to the parents but also to the whanau, hapu and iwi. When it occurs the immediate family will assume the mantle of mourning. The baby may be named and baptised. Members of the whanau piri/pani (grieving next-of-kin) are left to mourn whilst other members take over the responsibility of making practical arrangements such as notifying the funeral director, informing the Marae and contacting other relatives and friends. The deceased baby is never left alone.

Psychosocial and emotional support

- The primary providers of emotional and psychosocial support to families/whanau on the neonatal unit are nursing and medical staff – they should be empowered to offer appropriate choices to families/whanau
- Parents should be informed of what support is available but it is their decision as to whether they take up the offer
- Be aware that families/whanau may show distress in different ways, i.e. tearful, withdrawn, short-tempered or angry
- The need for support by families/whanau varies. Some may wish to have frequent appointments following the death of their baby; others may wish for no support or shorter, more specific support, i.e. how best to support a sibling
- Parents with a surviving twin/triplet may require specific bereavement support as they may be caring for another sick baby on the unit or a healthy child at home
- Support can be provided by a range of professionals, such as a clinical psychologist, child psychotherapist, counsellor or social worker
- Sands NZ is familiar with supporting parents/families, see appendix seven: The Sands NZ Three Point Model of Care



- Provide information on the financial support available to assist with funeral costs and time taken off work
- Inform families/whanau that a team member will contact them (*preferably a named person*) provide details of when this will occur supported by written information including how to access ongoing bereavement support
- Support to be offered by the neonatal team with referral to other services as appropriate
- Inform mothers of the options available for lactation suppression and involve a lactation consultant when required. It is often better to gradually reduce milk supply rather than effect a sudden suppression
- Offer suggestions of what to do with stored expressed breast milk. Some mothers may wish to donate breast milk to a NZ milk bank and there is some literature that this may help the grieving process.

Care after death

- Do not rush this-The parents may wish to spend time with their baby, bathe and dress their baby and continue to collect mementos/memories
- Contact the funeral director to assist planning a funeral or taking the baby home if they wish.
- Some parents may choose to take their baby home. It is important to have the relevant documentation and to keep the documents with baby when travelling. The baby is able to be transported in a Moses basket, or a little casket but must be secured in the car (the funeral director often has an appropriate casket) or the parent may decide to carry the baby wrapped in a shawl (refer Sands NZ pamphlet: Transporting your baby)
- If it is necessary to transport the baby by plane, it may be easier and less distressing for the arrangements to be carried out in consultation with the funeral director. It requires the baby to travel in a casket or coffin in the hold of the plane, not the cabin, which can be upsetting for parents and families
- If the parents take the baby home, it is important to keep the baby in a cool environment and cool packs may be used in the bedding. Suggest using a warm blanket if a family member wants to hold the baby. (see appendix seven)



8.0 Post-mortem examination and organ donation discussions

- Parents may have discussed the issue of post-mortem examination in an advance care plan. Be aware of post-mortem examination requirements before discussing this with the parents
- A post-mortem examination should be offered to all parents of babies that die even if the cause of death appears obvious. This may identify unsuspected problems, provide additional information as to the cause of death and may inform future pregnancies
- Explain to parents, if the DHB requires the baby to be transferred to a tertiary centre for the post-mortem. Follow local DHB policy and processes.
- The person obtaining consent for post-mortem should be trained to do this and the parents provided with written information
- Consider the PMMRC resource:
<http://www.hqsc.govt.nz/assets/PMMRC/Resources/Panui-for-Postmortum-jul09.pdf>
- If the cause of death is unclear discuss the need for a post-mortem examination with the relevant authority e.g. coroner
- Some parents may wish to donate their infant's organs – it is important to establish if this is possible then explain the situation
- Contact and involve the local DHB pathologist.

9.0 Caring for the carers

- Neonatal team members should have access to Employee Assistance Programme (EAP) and providers of spiritual support
- To feel confident and competent in discussing palliative care with parents and families, the neonatal team members should receive training in the principles of palliative care and sensitive communication with parents
- All members of the team whatever their level of seniority should be included in discussions about the ongoing care of the baby, and in decisions about the appropriateness of continuing intensive support
- Team members should be offered debriefing after a death. This might take the form an informal discussion through to a focused reflective practice session(s) facilitated by a trained member of the team or external facilitator. This is distinct from the more traditional medical debrief as it allows space for team members to develop a shared narrative of events, appreciate practice that has gone well, and consider alternative ways to support families/whanau
- All team members should be allowed and supported to care for families/whanau who have a baby receiving palliative care. This ensures expertise is not concentrated to a small group and allows all of the team to appreciate the experience of families/whanau in this situation, as well as the needs and experience of the carers



- Some team members may feel unable to care for baby's and their family/whanau requiring palliative and end of life care and, if possible, should be assigned to other duties
- Members of the team who express their reluctance to care for baby's and their family/whanau requiring palliative and end-of- life care should be offered support and training to enable them to fulfil this role in the future.



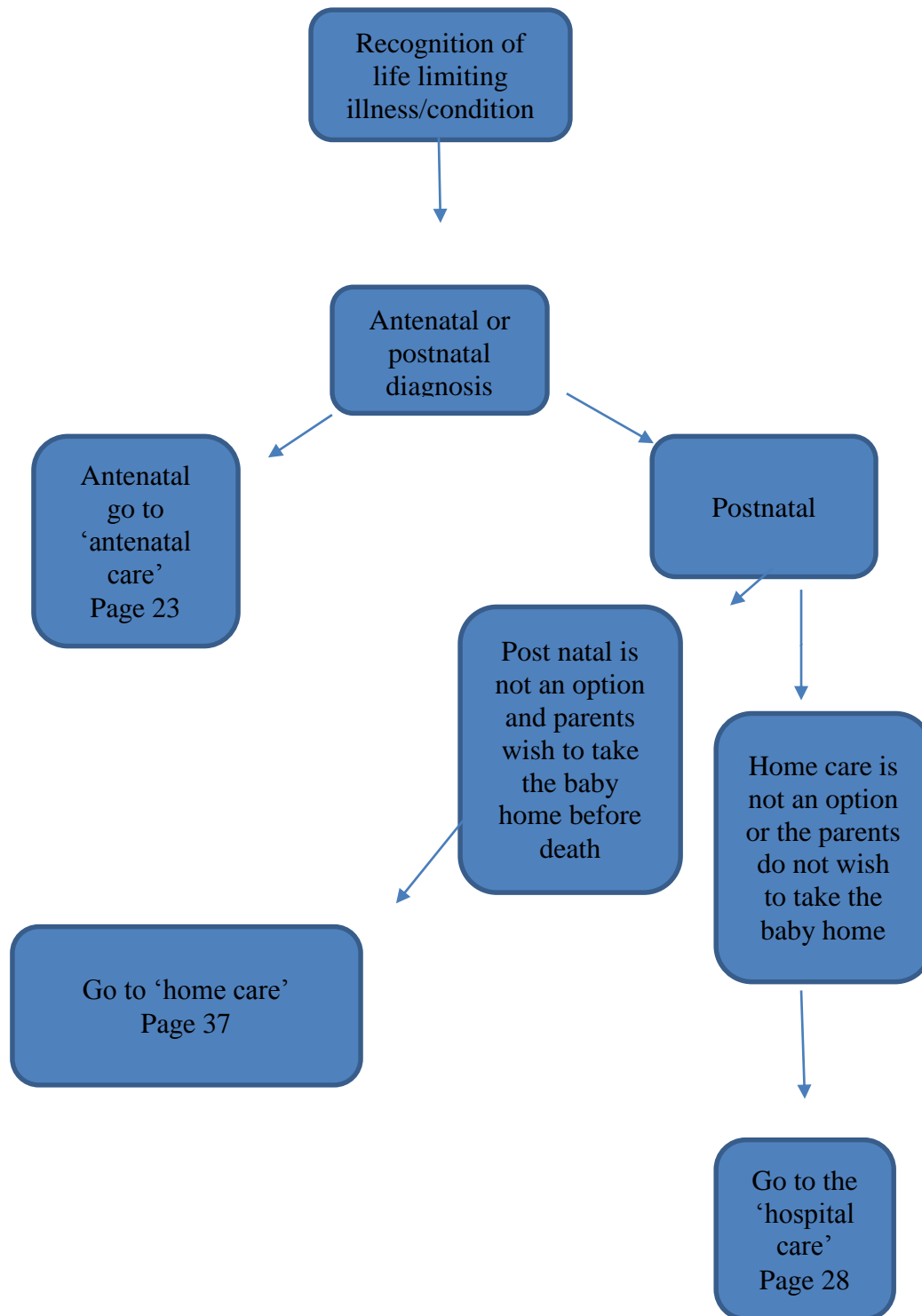
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Appendix one: Which section suits best?

Palliative care – which section suits best?

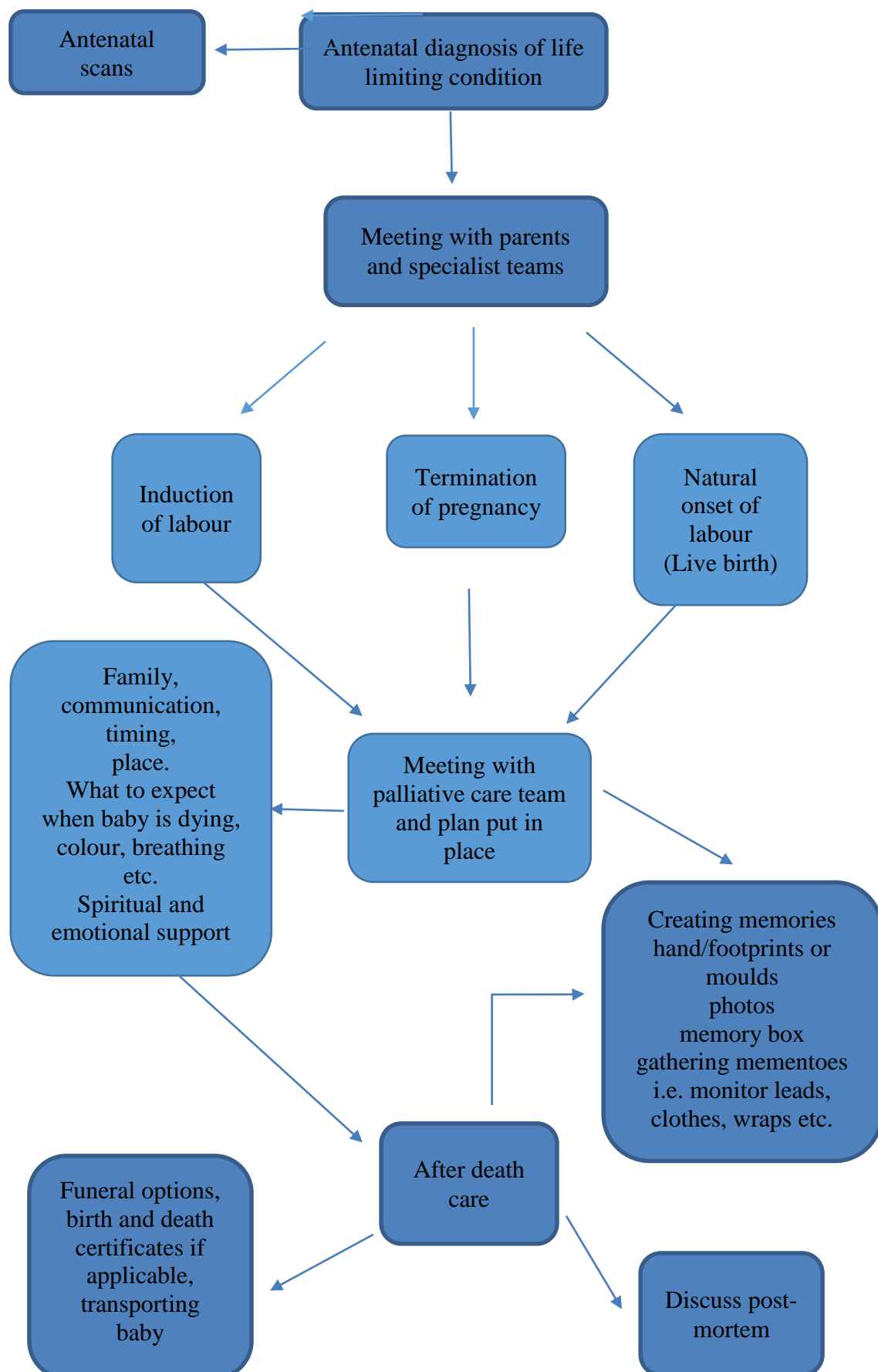




Antenatal Care



Appendix two: Antenatal care





Palliative Care – Antenatal

This pathway should be commenced when:

A confirmed diagnosis of a life limiting condition is made antenatally

Confirmation made by:

- Ultrasound scan
- Amniocentesis/chorionic villus sampling
- Consultation with specialist teams e.g. cardiologist, surgeon, geneticist

Where possible, it is important to develop a trusting relationship early on. As much as possible parents need to be seen by a core team. Communication must be clear and concise. Information in writing needs to be available.

It may be appropriate to have a genetic counsellor involved.

Discussion to have with parents:

Options:

- Termination of pregnancy
- Early induction of labour
- Live birth

Supportive palliative care needs to be available/provided no matter which decision. A discussion needs to take place with the parents re the chance their baby may die at any time.

People involved in Care Plan:

- Parents/support people/family/whanau
- Senior Clinician
 - neonatal
 - cardiologist
 - surgeon
- NZ Maternal Fetal Medicine
- Midwife/LMC
- Obstetrician
- It may be appropriate to have a genetic counselor involved

Post Delivery

If baby does not deliver stillborn or die at birth a plan needs to be in place.

This plan will include:

- Place of care
- Pain relief if required
- After hours contacts

At this time it may be appropriate to move to further plan of care.



Post delivery following death

It is important to follow the wishes of family/whanau and include the extended family.

Do not rush; give the parents and family time.

MDT involvement:

- Chaplain
- Social worker
- Bereavement support
- Neonatal involvement –paediatrician, nurse, midwife/LMC

If pre-delivery legal requirements of cremation/burial have not been discussed this needs to happen and consultation with a funeral director can assist parents and families

Discussion re post-mortem needs to have happened. This may have been discussed pre delivery.

Memories

It is very important to assist the family in creating memories, for example:

- Memory box – to hold items like ID bracelet
- Photo's: 'Now I Lay me Down to Sleep', professional photographers who donate their time: see website to see if there is a photographer in your area
- Footprints / handprints / castings
- Creation of memory book
- Refer to Sands NZ pamphlets - contact: www.sands.org.nz

On-going support

- GP, well child provider, social worker informed
- Follow-up appointment with selected team
- Is an appointment with genetics needed?
- Bereavement follow-up
- Sands NZ support pack: This has practical information and support for parents who experience the death of their baby - contact local sands group: www.sands.org.nz



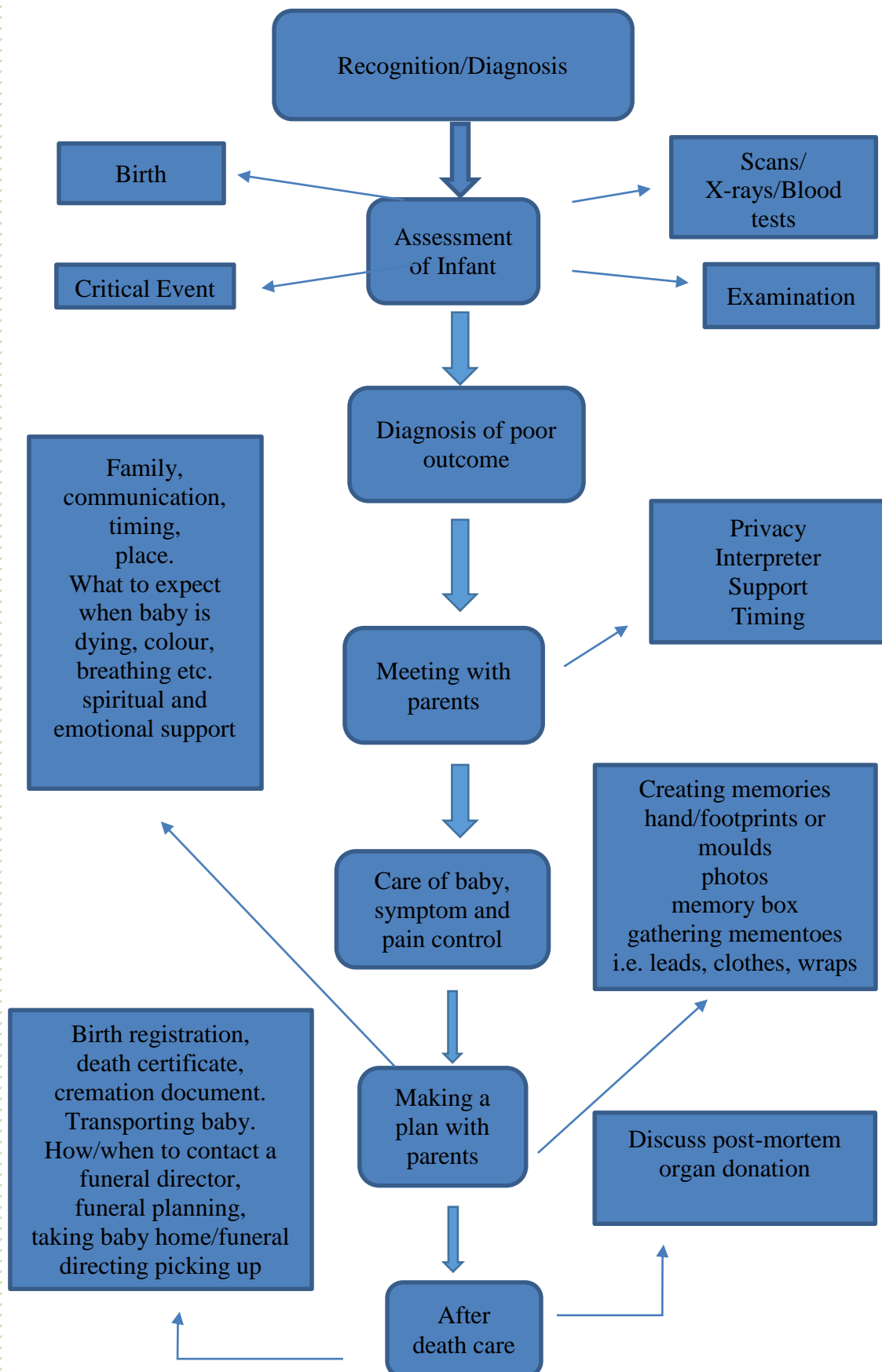
Care plan for ante-natal diagnosis of life limiting condition	
Baby's Name:	EDD:
NHI:	
Diagnosis:	
Mother: Contact No:	Father: Contact No:
Other Contacts:	
Family Address:	
Midwife/LMC Neonatal nurse Obstetrician: Lead Consultant: Palliative Care Team Contact: GP details:	
Preferred place for delivery:	
Interpreter needed: Yes / No	
Birth Plan:	
Cultural considerations:	
Those to be present at delivery:	



Hospital Care



Appendix three: Hospital care





Palliative Care – in hospital

This pathway should be commenced when:

A confirmed diagnosis of a life limiting condition

Confirmation made by:

- Ultrasound scans, x-rays, MRI,
- Overall clinical picture
- Consultation with specialist teams e.g. geneticist, surgeon, cardiologist

Aspects of Palliative care to consider:

- Eligibility of infant for palliative care
- Family/whanau care
- Communication and documentation
- Transition from intensive care to palliative care
- End of life care
- Post end of life care

Establishing eligibility of infant for palliative care:

- Antenatal or postnatal diagnosis of a condition that is not compatible with long term survival, e.g. anencephaly
- Antenatal or post natal diagnosis of a condition which carries a high risk of significant morbidity or death
- Infants born at the margins of viability where continuing intensive care has been deemed inappropriate
- Postnatal conditions that have a high likelihood of severe impairment of quality of life, e.g. severe neonatal encephalopathy
- Postnatal conditions which result in the infant experiencing unbearable suffering, e.g. severe necrotising enterocolitis where palliative care is deemed by the MDT as being in the baby's best interests

The decision for introducing palliative care should be a joint decision with the multi-disciplinary team and the parents and their chosen support people. Gentle and open clear communication is essential at all times.

It is important to develop a trusting relationship early on. As much as possible parents need to be seen by a core team. Communication must be clear and concise. Information in writing needs to be available.

Discussion to have with parents:

Options:

- Introduce a palliative care approach
- Private area with full nursing and medical support
- Feeding, pain relief, back up support

Supportive palliative care needs to be available/provided no matter which decision. Gently discuss with the parents the possibility that their baby may die at any time.



People involved

- Parents/support people
- Senior Clinicians: e.g. neonatologist/paediatrician, cardiologist, surgeon
- NICU nurses
- LMC/Core Midwife
- Social workers/Cultural/Spiritual/Psychosocial

Communication

Parent's need:

- Clear concise information in a simple language of what is wrong with their baby and reasons why they are not expected to survive
- How long their baby is expected to survive and the pros and cons of available treatments
- The likely outcome if treatment is continued and how this will impact on the their baby both now and long term
- To be part of the decision making process
- To be given time to process the information and to seek support and guidance if they wish and to have further discussions with the team anytime they wish.

Once a decision has been made to introduce palliative care then discussions with parents should include:

- How the infant may die, though it should be stressed that it is difficult to predict how long it will take for an infant to die.
- Descriptions of what the baby will look like, and what changes are expected as the baby deteriorates e.g. colour changes, breathing changes.
- Where the death will occur e.g. self-care room, or side room in the unit
- Knowledge that they will not be alone, that they will have an allocated nurse looking after them who will work with them through the process. Offering social work, chaplaincy, and Maori liaison support as appropriate
- Who will be present and the timing of the removal of a ventilator
- Any rituals or spiritual aspects that are important to them
- Making memories including the taking of foot/handprints, photos, mementoes

Documentation

- All discussions with the family should be documented including any plans or decisions made.
- Be familiar with the legal documentation and forms to complete following death of the baby.
- The documentation required for a stillborn baby or a baby who has died after birth is the 'Transfer of Charge of Body' form (BDM 39) and the Medical Certificate of Causes of Fetal and Neonatal Death (HP4721),

Transition from intensive to palliative care

When a baby transitions from extensive to palliative care the parents may be at their most vulnerable. They may feel isolated as other parents in the unit begin to realise or are informed of what is happening.

Other parents may keep away to allow the family time and space to deal with what they are going through but this can be seen as a lack of support.

There can be a drop off in the number of people that they see each day as the team changes from intensive care with many tests and procedures to palliative care with comfort being at the forefront. This adds to the difficulties the family faces and it is important that all members of the team caring for the infant make contact as appropriate.



Care plan for in hospital diagnosis of life limiting condition

Date Care Plan Initiated:	
Baby's Name:	Date of Birth:
NHI	
Mother:	Father:
Contact Number	Contact Number
Siblings:	Other Contacts
Address	
Consultant:	Primary Nurses:
LMC:	GP:
Post mortem	Organ Donation



Discussion with Parents	Yes/No
What baby will look/feel like	
Breathing /gaspings	
Colour	
Process around extubation	
Spiritual support, Chaplin/Priest/Maori Liaison worker, Baptism, blessing, christening	
Cultural support	
Social Worker	
Funeral Director	
Memories Keepsakes	
Hand and Footprints	
Journal	
Photos	
Lock of Hair	
Memory box	
Mementoes hand and foot mouldings	
Blankets, wraps, equipment that has been used	



Plan for change of direction of care

Family/Whanau hopes and wishes: (Visitors, skin to skin, extended family cuddles photos etc.)

Spiritual Plans: Baptism etc.

Cultural Support

Around the time of death



Family wishes: (people present, timing of removal of ventilation, place)

Pain Relief

Photos

Hand and Foot moulds, (some neonatal trusts will pay for this)



After Death:

Hand and Footprints

Bathing Baby

Death Certificate

Cremation Certificate

If taking baby home: transfer care of body forms:

Contacting People:

Funeral Director

Coroner

GP

LMC

Social Worker

National Immunization Register

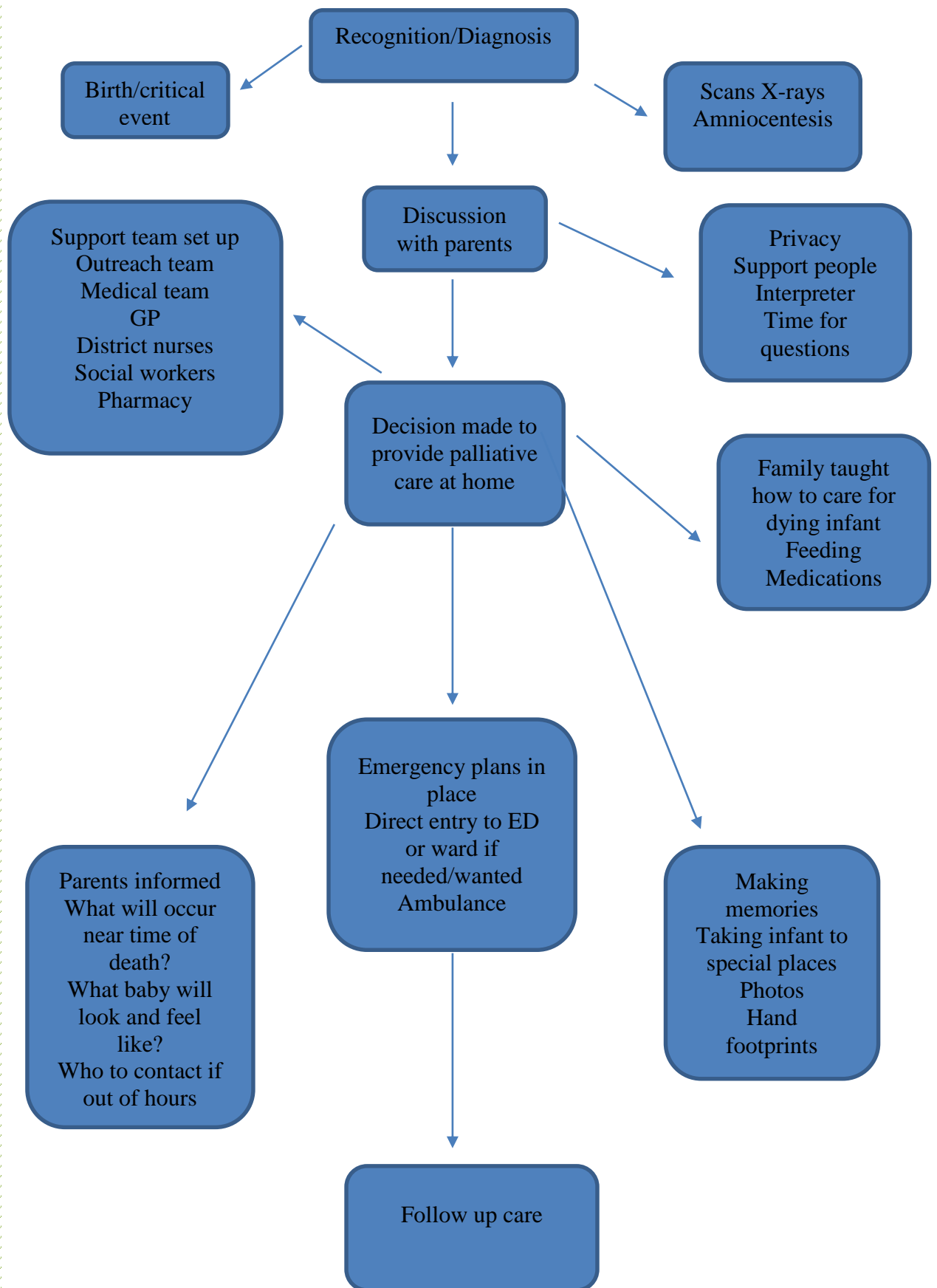
Outpatient follow up appointment:



Home Care



Appendix four: Home care





Palliative Care – At Home

This care plan should be commenced when:

A confirmed diagnosis of a life limiting condition

Confirmation made by

- Ultrasound scans, x-rays, MRI,
- Overall clinical picture
- Consultation with specialist teams: e.g. geneticist, cardiologist, surgeon

Aspects of Palliative care to consider:

- Eligibility of infant for palliative care
- Family/whanau care
- Communication and documentation
- Transition from intensive care to palliative care
- End of life care
- Post end of life care

Establishing eligibility of infant for palliative care:

- Antenatal or postnatal diagnosis of a condition that is not compatible with long term survival, e.g. anencephaly
- Antenatal or post natal diagnosis of a condition which carries a high risk of significant morbidity or death
- Infants born at the margins of viability where continuing intensive care has been deemed inappropriate
- Postnatal conditions that have a high likelihood of severe impairment of quality of life e.g. severe neonatal encephalopathy
- Postnatal conditions which result in the infant experiencing unbearable suffering, e.g. severe necrotising enterocolitis where palliative care is deemed by the MDT as being in the infants best interests

The decision for introducing palliative care should be a joint decision with the multi-disciplinary team and the parents and their chosen support people. Gentle and open clear

It is important to develop a trusting relationship early on. As much as possible parents need to be seen by a core team. Communication must be clear and concise. Information in writing needs to be available.

Discussion to have with parents:

Options:

- Introducing a palliative care approach
- Taking baby home
- Ongoing support
- Feeding, pain relief, back up support

Supportive palliative care needs to be available/provided no matter which decision. Gently discuss with the parents the possibility that their baby may die at any time.

People involved

Neonatal Palliative Care: Comfort as a Model of Care. NNCA Nov 2015. ©



- Parents/support people
- Senior Clinicians: neonatologist/paediatrician
- District nurses
- NICU/Pediatric outreach team
- Midwife/LMC/GP
- Pharmacist
- Social workers
- Pastoral/Church representatives
- Local ambulance service

Communication

Parent's need:

- Clear concise information in a simple language of what is wrong with their baby and reasons why they are not expected to survive
- How long their baby is expected to survive and the pros and cons of available treatments
- The likely outcome if treatment is continued and how this will impact on their baby both now and long term
- To be part of the decision making process
- To be given time to process the information and to seek support and guidance if they wish and to have further discussions with the team anytime they wish.

Once a decision has been made to introduce palliative care at home then discussions with parents should include:

- How the infant may die, though it should be stressed that it is difficult to predict how long it will take for an infant to die
- Descriptions of what the baby will look like, and what changes are expected as the baby deteriorates e.g. colour changes, breathing changes
- Where the death will occur e.g. at home, in hospital
- Making memories including the taking of foot/hand prints, photos, mementoes, taking the baby to any place that is special to them e.g. beach or park
- What will happen around the time of death, who will be there, who to contact etc.
- After death care, including contacting the funeral director, planning a funeral, registering the birth, cremation paperwork and death certificates.

Documentation

All discussions with the family should be documented including any plans or decisions made. Be familiar with the legal documentation and forms to complete following death of the baby.

The documentation required for a stillborn baby or a baby less than 28 days of age who has died after birth is the 'Transfer of Charge of Body' form (BDM 39) and the Medical Certificate of Causes of Fetal and Neonatal Death (HP4721),

When a baby transitions from extensive to palliative care the parents may be at their most vulnerable. They may feel isolated and alone, and the fear of being isolated at home may be overwhelming. It is essential that plans are in place to ensure that parents have access to all the support they need, and that they are aware of who they can contact for support and help. It is essential that all the people who will be involved in the care of this family at home are informed of all the plans in place, and the documentation is complete.

Section one: Key personnel and information sharing



Service	Name and contact details / comments	Date contacted
Lead Paediatrician		
LMC		
Home Care Nurse		
GP		
Social worker		
Cultural support person		
Spiritual support person e.g. Chaplaincy		
On call paediatrician for deterioration in condition or sudden death		
Emergency Dept.		
Ambulance		
Local Pharmacist		
Hospice		
Transition of care to paediatric outreach		
Direct admission via ED		

Organ donation-
Post-mortem – Has this been discussed with parents Yes/No

Memories / keepsakes
Foot and handprints
Journal
Lock of hair
Photo's
Blankets, clothes, equipment that may have been used.



Section two: Planning for going home

Topics discussed <ul style="list-style-type: none"> Diagnosis Likely course of events Level of intervention What to expect near end of life Follow up 	
Potential training needs of parents/family/carers: <ul style="list-style-type: none"> How often to feed their baby How much to feed their baby Plan if baby unsettled, not tolerating feeds Bathing Feeding tube changes Care of baby, handling 	
Medication – Script required/written Yes/No <div style="text-align: center;">Any medication instructions</div>	
Family/whanau needs assessment completed – what are the family's expectations/concerns? <div style="height: 40px;"></div>	
Written information given <ul style="list-style-type: none"> Family/whanau information handbook Information on particular illness/syndrome 	Yes/No Yes/No
LMC aware of discharge What will their involvement be?	Yes/No
Home care nurse to accompany home? Yes/No	
Multi disciplinary meeting with parents/family/whanau: actions resulting. <div style="height: 150px;"></div>	



Section three: Resource needs

[illegible]



Section four: Hopes and wishes during life

Family / whanau (including sibling/s), hopes and wishes

Spiritual wishes

Cultural support

Plans for respite care.



Section five: Plans for when the baby's condition deteriorates

What may happen?

<p>Preferred place for care: Hospital or home</p>
--

Preferred treatment options:

Analgesia/medication

Feeding

Antibiotics

Fluid Management

Respiratory support, oxygen, airway management
--

Seizure management

If baby deteriorates further, preference(s) for place of death and persons present.

No intervention – GP, ED, LMC, Ambulance informed (Circle)



Section six: Around the time of death

Family wishes:

Information needs:

What is the preferred place of care for end of life care?

Where would the family/whanau like the body to be cared for after death?

Practical support on day of death:

During end of life care. e.g. LMC, Homecare Nurse, GP, ?Hospice, Chaplaincy service

Support for the family/whanau on the day of death. e.g. Paediatrician, LMC, Homecare, Chaplaincy, S/W, Iwi and Hapu

Who to contact and when.

Support needs up to the funeral. e.g. Chaplaincy, Funeral director

Notification of death to: Lead Paediatrician or on call Paediatrician through the neonatal unit or LMC, GP, St John and ED
Who will certify death?

Follow up:

Paediatrician out- patient appointment

S/W involvement

Referral to counsellor

Genetic counselling

Is a debrief with obstetrician, paediatrician, neonatal unit team required?

Paediatric outreach nurse has attended MDT meetings and is aware of this case?

Outcome of visit and further plans.

[illegible]



Appendix five: Alternative religious beliefs

Jewish families: Traditionally, the body is not to be touched for 10 minutes after breathing has stopped. After 10 minutes, a feather is then placed over the mouth and nose to ensure that breathing has stopped. Cleansing of the body is performed by specially trained members of the community of the same sex as the child.

Christian families: Many Christians will want their child to be baptised if death is imminent. If this is not possible before death, a priest, chaplain or minister may conduct a naming and blessing ceremony after death.

Muslim families: Muslims believe that all children are innocent and that after death their souls will ascend directly to paradise. This is also the case for stillbirths and miscarriages, in which case these babies are given names, bathed, and shrouded.

When someone dies within the Muslim culture, males always bathe males and females bathe females. The body must not be touched by a non-Muslim, but if it is unavoidable, a non-Muslim should wear disposable gloves. The body is then wrapped in plain white cotton, with the face facing towards Mecca.

Hospitals' common practice of gathering memories, such as handprints or footprints as well as photographs of the baby, may cause distress to a Muslim family. This may be considered a desecration of the body.

Hindu families: The death of a child within the Hindu faith is viewed as Gods' will. Hindus believe that things happen because they are predestined and that actions in the present life are the result of sins in a past life.

A Hindu family is likely to prefer that their child dies at home and may wish a priest to be present at the child's bedside to perform holy rites. A relative then bathes and anoints the body, males washing males and females washing females. A Holy thread is placed around the child's limbs or body, the skin may be marked with paste or a sacred leaf placed in the mouth. The body is dressed in white cloth and is face north with the feet facing south in preparation for rebirth.

Sikh families: It may be inappropriate to remove underclothing as this may have religious significance. The face may be cleansed if it is dirty. The body of a Sikh child is cared for by family members of the same sex as the child.

Any religious emblems (bracelets or necklets made from Holy thread) and jewellery on the body of a Hindu or Sikh child must be left in place on the body.

Chinese families: There is no monolithic Chinese culture. Rituals will depend upon religion (Buddhism, Confucianism, Taoism, and Christianity). Illness and death often viewed as a natural part of life. Health is the result of balancing competing energies: hot and cold, light and dark. May be reluctant to say "no" to a doctor or healthcare provider because it is considered disrespectful or cause disharmony.

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Appendix six: Protocols and customs observed at the time of a Maori death

Depending on the tribal group there may be slightly different customs followed when someone dies.

Tangihanga –is the traditional Maori mourning process where whanau, hapu and iwi come together under the mantle of whanaungatanga (family relationships) in love, respect and sorrow to grieve over the loss of a loved one.

Ohaki – Final words- Where a person has been unwell for a period of time and their death is anticipated there will generally be a gathering of whanau. This is a special time when the person dying has access and is accessible to two worlds – the spiritual and the physical.

Tuku Wairua – Spirit Leaving- One or more people will be identified as spiritual shepherds to the dying person and their whanau. One of these will usually conduct the Tuku Wairua (Spirit Leaving) ceremony. This process is performed to help the spirit depart from the body lest the wairua become restless and wander aimlessly instead of following which will take it to its proper place in Te Ao Wairua (the spirit world).

Ko Mate – Death- For Maori, death is a pivotal experience, which brings about a number of changes, both spiritual and physical.

The Spirit –At the moment of death, many Maori believe the wairua (spirit) leaves the body and travels to its old haunts before entering on Te Ara Wairua (the spiritual pathway) leading to Te Rerenga Wairua (at the top of the North Island) where they depart from this earth.

The Body – Always considered **tapu** (sacred) in a positive sense while alive, death invests the body with a broader tapu which includes some of its more sensitive and restrictive aspects: e.g certain activities like eating are no longer permitted near this body, the hands of the living are to be washed after they have touched it. For Maori the removal of their loved one's body from their management e.g. post-mortem, leaves it exposed and defenceless to practices which may violate its tapu by people who lack understanding of what that means. In cases where no post-mortem is required the tupapaku is washed and dressed by the family and unless a funeral director is engaged, the family may conduct full preparations of the body before taking it straight to the marae where the rest of the tangihanga process is carried out over a period of days.

The Family – The bereaved family undergo a change in their status. They will now be accorded an extra respect which they may never before have experienced and concern for their care will probably never be so high.

The Place of Death – Death often means that a tapu is also imposed over the building or the place where it occurred. Blessing of a hospital room is respectful and should be conducted before the room and any equipment is physically cleaned and reused.

Reference

Herbert A. (2001) Protocols and Custom at the time of a Maori death. Available at: <http://www.whakawhetu.co.nz/sites/default/files/Protocols%20%26%20Customs%20at%20the%20Time%20of%20a%20Maori%20Death.pdf> accessed 7/10/15



Appendix seven: The Sands NZ Three Point Model of Care

1 Slow Down

There is no need to rush. In the case of stillbirth, once baby is born things can slow down, the post-mortem does not have to happen immediately and the family can spend some time with their baby. Many parents have reported feeling a sense of urgency once their baby was born and a need to make decisions quickly. As a result, parents, families and whanau make decisions that have a lifelong impact - they don't want to see their baby, they don't want to bath their baby, they don't want a lock of hair, they don't want their other children to see this baby. This can also be the case with a neonatal death, again we emphasis the need to take things slowly.

We encourage the health professionals that are supporting and working with a bereaved family to gently ask again, to gently provide as much information as possible in order for the family to make an informed decision. The family now has a limited time with their baby physically (whether it is hours or days). Slowing down means the next two points are able to happen more easily.

2 Assist in Active Parenting

Even though their baby has died, the parents, family and whanau are still caring for and parenting this precious member of their family. Making decisions, showing love in physical, emotional, spiritual and social ways, caring for our child – these are the ways we parent our children.

Because things have slowed down, the opportunity to parent their deceased baby is enhanced. Parents, families and whanau have the time to think about their decisions – the name of their baby, whether they will have a funeral, who they will invite to see their child, what they will dress their baby in...what will happen next. The more we can encourage the families to actively parent their baby, the better the opportunity to create memories.

3 Help to Create Memories

In actively parenting their baby, memories are created. The time available for parents, families and whanau to physically spend with their baby is now finite. At this point families are encouraged to do as much as possible (under the circumstances) – to take photos and videos, to have handprints and footprints done, to dress baby in special clothes, to bath baby, to cut a lock of hair. There is also the chance to take baby to a significant or special place. These memories can sustain a family when things seem very bleak. Do not underestimate their importance.

Practicalities

As a health professional it is helpful to know about the practicalities of perinatal death. Most bereaved parents are often in shock and their baby's/babies' death is the first time they have had such an experience. Therefore they will look to you to know these things.

- Knowing what baby might look like – at 20 weeks, at 30 weeks, full-term, a neonatal death, being able to tell parents what to expect (the colour or state of the skin, the appearance of a baby with a certain condition)
- Taking baby home – have a Sands 'Transportation of a Deceased Baby' pamphlet available.
- Organising a funeral/service – giving parents as much information as possible, a list



of funeral directors, costs, funeral grants, knowing they don't have to use a funeral director

- Keeping baby cool/cold – the logistics in doing this (using ice, a refrigerator of some sort), fridge temperature, warming a blanket when people want to hold baby
- Knowing about the physiological changes – seepage from baby's body, the natural process of deterioration, that a deceased baby can still be held and cuddled.
- Having some idea about grief – that grief is individual, there is no pattern that 'should' be followed, that just because a baby is small physically, the grief will not be little or minimal as well.
- The postnatal experience - six week check, midwife visits, the appointment with the hospital to receive the post-mortem results.
- Resources – having information available for bereaved parents, families and whanau on books, DVDs, groups, agencies. Look for your nearest Sands group under the 'Support & Information' tab, then 'Sands Support Groups' on our website www.sands.org.nz, or send your correspondence to contact@sands.org.nz.

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