Guidance on Supportive and Comfort Care in Vulnerable Babies 2018





Endorsed by:



Chapter of Neonatologists



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Foreword

On behalf of our team at the Lien Centre for Palliative Care, I am pleased to write the foreword for this important document. As a parent of three children, I have always felt that the worst event that could possibly happen is the loss of a child. However, after hearing the stories of parents who have gone through this horrible experience, I now know that what is even worse is losing a child and feeling that the care received was inadequate and may have resulted in needless suffering.

Unfortunately not every baby can be saved, and ironically, advances in medical technology mean that the number of babies born with life limiting illnesses is likely to increase as we push the bounds of medical technology for neonates. Other unforeseen circumstances, as was seen with the Zika virus, will also influence the number of babies who will need both life extending and comfort care. Whereas Singapore excels in the delivery of life extending treatment for vulnerable babies, we are less skilled in the delivery of neonatal supportive care.

Therefore, when Assoc. Prof. Roy Joseph and his team asked for support for this effort, I was happy to oblige. This document represents the culmination of a long process that began with a symposium in 2016 of international and local experts in neonatology, medical ethics and palliative care alongside testimonials from parents of babies with life limiting illnesses and who felt that the health system provided suboptimal support. The symposium led to a momentum to develop guidelines to improve supportive and comfort care delivery for vulnerable babies.

Assoc. Prof. Roy Joseph from National University Hospital and representatives from KK Women's and Children's Hospital, Singapore General Hospital and HCA Hospice Care subsequently formed a taskforce and worked tirelessly over the next year to develop the guidelines, with input from Prof. Brian Carter and Senior Nurse Alexandra Mancini. Lien Centre for Palliative Care provided the funding and secretarial support. I congratulate the taskforce on this effort but also recognize that this is not the end. We will continue to educate and engage stakeholders to further improve our practices.

Although we cannot save every baby, our hope is that this document can minimize needless suffering and help families cope with the heart breaking loss of a child.

Prof. Eric Finkelstein Executive Director

Lien Centre for Palliative Care, Duke-NUS Medical School

17 July 2018

Preface

In August 2016, the Lien Centre for Palliative Care organized in Singapore a symposium titled "When Caring Never Stops — Meeting the Needs of Vulnerable Babies", led by experts in Neonatal Palliative Care, Neonatology and Medical Law and Ethics and attended by 163 healthcare professionals. The discussions there in concluded with an informal and unanimous declaration of the value of a comprehensive resource for healthcare professionals in the form of a practice guideline on Neonatal Palliative Care.

With financial and administrative support from the Lien Centre for Palliative Care, a taskforce comprising physicians with experience in the care of babies and in palliative care was formed in April 2017 with the goal of developing the guidelines within a year. We studied what was being practiced locally and reported as baby and parental needs, compared these with guidelines from around the world and identified the following objectives:

The guidelines are to be for both professional caregivers and parents and it will enable education on the varied physical, emotional and social needs of a baby who is expected to either die or go through a prolonged period of physical suffering and how these could be met in a systematic manner. The next is for it to achieve an understanding that care needed to be customized to the unique circumstance that each baby and parents presented. It followed that guidance rather than directions is the need and that it should be presented in a tone and language that is reader-friendly and empowering. The need for interventions to come in early was to be achieved by replacing the often-misunderstood phrase, palliative care with the phrase - supportive and comfort care.

We are indebted to our professional colleagues for their individual reviews and suggestions, and to our advisors, Prof. Brian Carter and Senior Nurse Alexandra Mancini for formally reviewing the draft and their helpful inputs. The endorsements by our College of Paediatrics and Child Health, Singapore, the Chapter of Neonatology and the Perinatal Society of Singapore, we believe, reassures readers of the validity and applicability of the Guidance in any care setting.

We are grateful to the organizing committee of the Singapore Paediatric and Perinatal Annual Congress 2018, for providing the unique opportunity of a regional platform for the release of the Guidance.

Assoc. Prof. Roy Joseph

Taskforce Chairman

Guidance on Supportive and Comfort Care in Vulnerable Babies

17 July 2018

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- **Prof. Brian Carter,** Professor, School of Medicine, University of Missouri-Kansas City, Children's Mercy Hospital

GUIDANCE ON SUPPORTIVE AND COMFORT CARE IN VULNERABLE BABIES

This guidance is formulated on the following ethical principles:

- 1. Respect of the experience of living and support of the process of dying
- 2. Acknowledgement of differences in social, cultural and spiritual values and practices
- 3. Observance of the right to information and choice
- 4. Promotion of equity
- 5. Preservation of professional & ethical integrity
- 6. Deliverance of appropriate care and ethical practices

The guidance is divided into 2 sections:

Section I describes the complex needs of vulnerable babies and the scope which supportive and comfort care covers.

Section II is targeted at healthcare professionals managing vulnerable babies, with the goal of equipping them the knowledge and skills required to provide supportive and comfort care.

SECTION I

Introduction

When medical interventions are no longer able to cure or prevent death, the baby and/or the parents will enter a phase which is invariably associated with varying degrees of physical, emotional, psychological and spiritual suffering. The suffering may often have at its root, pain and/or distressing symptoms, the addressing of which is the goal of supportive and comfort care.

Comfort care is usually meant to describe the specific care plan or processes offered when death is imminent or inevitable. This period may have a variable duration ranging from minutes to months. Babies who are physiologically unstable or have been unwell for prolonged periods, together with their families can experience similar suffering. Hence an extension of support to these babies and their families based on needs, rather than wholly on individual estimated prognoses, is required. These babies, given their age and needs for special care and support, are considered to be **vulnerable** as their suffering is often overlooked or inadequately addressed.

Palliative care appropriate for children and their families is defined by the World Health Organisation (WHO) as the active total care of the child's body, mind and spirit that also involves giving support to the family. It begins when the illness is first 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 as a package.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources and 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 (WHO, 1998).

This document highlights the needs of vulnerable babies, and provides guidance on how these needs can be addressed. One group of vulnerable babies consist of those who are at the limits of viability; babies who are critically unwell with life-threatening conditions; or those who are faced with uncertain and life-limiting futures. Another group of vulnerable babies include those in whom curative interventions are no longer indicated, examples of which are found in Appendix 3.

Domains of needs are broadly classified into three categories - physical comfort, practical care and emotional, psychological and spiritual needs.

(a) Physical comfort

Babies who are critically unwell can experience distressing symptoms like pain, vomiting and increased respiratory tract secretions. These need to be assessed and managed effectively. Usually, most symptoms can be minimised through effective nursing measures that restore comfort, and if necessary by pharmacological means and use of medications.

For specific guidance on the management of these symptoms, please refer to Section II, Part 1.

(b) Practical care

- 1. When it is highly likely that ongoing interventions will not benefit the baby and demise is inevitable, discussion pertaining to change in the goals of care, place of care and impending demise should be broached with parents in a sensitive manner by the attending Neonatologist or Paediatrician.
- 2. Some families may wish for the baby's last days to be spent at home with the family and loved ones. Others may wish for their baby to remain in a hospital setting with nurses and doctors readily available as the baby's condition deteriorates.

3. Locally, services are available for the baby to be cared for both at home or in the hospice setting and these may be explored with the baby's parents.

For specific guidance to the decision-making process and transition of care, please refer to Section II, Parts 2 & 3.

(c) Emotional, psychological, spiritual needs

- 1. Families go through enormous emotional, psychological and spiritual stress when a baby is diagnosed with serious illness. The illness journey is often unpredictable and emotionally stressful. Families often experience various stages of grief fraught with a mix of denial, anger and sadness to eventual acceptance of the outcome. Hence parents require support that is tailored to meet the needs of individual family and the specific situation. Primary care teams should receive training on how to recognise early, the anticipated distress likely to be faced by the family and relevant professionals could be introduced to render appropriate support.
- As death approaches and eventually occurs, families may feel isolated and have difficulty coping emotionally. This will require the compassionate presence of the nursing and medical team and/or a trained psychosocial professional as necessary.
- 3. With time, parents may eventually come to accept their loss and move forward. However, for some, the feeling of loss continues and becomes debilitating, leading to adverse impacts on day to day living (Hendrickson, 2009; van der Geest et al., 2014). The role of a dedicated bereavement team with involvement from a Medical Social Worker is vital for ongoing support of the parents during this phase.

For specific guidance to rendering psychosocial support, please refer to Section II, Parts 3 & 4.

SECTION II: PART 1

Physical comfort and needs

(a) Pain control

All babies should be assessed for pain using relevant pain assessment tools including elucidating the cause of pain.

For specific guidance regarding pain assessment tools, please refer to Appendix 1.

Appropriate pain treatment should be initiated accordingly and escalated as appropriate using a stepwise approach (choose the least painful and invasive options first e.g. Sucrose).

- Non-pharmacological pain treatment should be considered initially to minimise pain and discomfort. The use of pacifier, latching, swaddling and changes to the environment such as dimming of room, reduction of noise level and music may be considered.
- 2. Minimise interventions (such as suctioning and OG tube insertion) unless the omission of these results in increased discomfort to the baby.
- 3. Consider pharmacological measures if there are increasing pain and distress not alleviated by the above measures. Oral sucrose, buccal, subcutaneous or intravenous analgesia may be considered. Advice from other specialists experienced in this aspect of care (e.g. palliative care team) may be sought if needed.

(b) Symptom control - Recommendations

Common symptoms that may be encountered in the care of vulnerable babies and the management thereof are described below:

1. Seizures

 Assess and address underlying causes with aim of facilitating symptom control

- ii. Continue seizure control medications even after curative treatment is no longer indicated
- iii. Consider the least invasive and distressing route of administration

2. Respiratory tract secretions

- i. Gentle suctioning
- ii. Medications may be considered (e.g. Hyoscine Hydrobromide patch) to control excessive secretion

3. Constipation

- i. Opiates may cause constipation
- ii. Consider use of lactulose or glycerine suppositories

4. Vomiting

- i. Assess cause of vomiting
- ii. Reduce feed volumes to an amount that the baby can tolerate
- iii. Consider comfort feeding e.g., breast feeding, non-nutritive sucking
- iv. Consider anti-emetic or anti-reflux medication

5. Urinary retention

- i. Assess the cause of urinary retention
- ii. Review medications that may contribute to its occurrence
- iii. Consider bladder compression
- iv. Consider urinary catheterisation if needed (e.g. concomitant use of Opioids)

6. Skincare

- i. The skin of vulnerable babies is fragile and needs to be handled with care.
- ii. Bathe with gentle, non-soap based shower lotions.
- iii. Careful inspection of the baby's skin needs to be carried out; barrier creams may be considered.
- iv. Care should be taken to ensure pressure sores do not develop by regular repositioning. The use of foam wedges may be considered.

For guidelines on medication dose and route of administration, please refer to Appendix 2.

(c) Nutrition and hydration – Recommendations

The aim of feeding at the end of life is not to optimise delivery of calories but to alleviate symptoms of hunger and thirst.

- 1. Oral feeding should only be withheld if it causes pain or distress e.g. little functioning bowel or if death is imminent.
- 2. Feeds given by invasive intervention (e.g. OGT/NGT, gastrostomy, parenteral nutrition) are considered medical treatment and may at times be viewed as an extraordinary measure (Larcher et al., 2015).
- 3. Decision to commence or continue artificial hydration and nutrition must be considered carefully to establish whether it will bring overall benefit to the baby.
- 4. The consequences of artificial nutrition and hydration on care must be clearly explained to parents.

At the time of imminent demise, artificial hydration and nutrition may not be in the best interest of the baby and merely prolong suffering and death.

SECTION II: PART 2

Decision-making in the care of vulnerable babies

(a) Recommendations for decision-making

1. Comprehensive and objective assessment of the patient's medical diagnosis and prognosis should be attained.

The prognosis should be agreed upon by at least two specialists (e.g. Neonatologist, Paediatrician, Paediatric Palliative Care Consultant or equivalent). In the presence of an irreversible life-threatening medical condition, ascertain if forgoing invasive and or intensive interventions is indicated.

For medical conditions in which forgoing intensive interventions may be considered, please refer to Appendix 3.

2. The role of parents in the decision-making process is central.

Parents need to be provided with sufficient information regarding diagnosis, prognosis and treatment options, including the physician's recommendation for their consideration. This information should be communicated in plain language which the parents are able to understand and in a sensitive and constructive way, so that they can participate in making decisions in the best interests of the baby. If necessary, a translator who can communicate in the language they prefer may be arranged. These conversations are best witnessed by another team member and must be clearly documented in the case notes. Consider also the provision of support from parents with children who have similar experiences and who are willing to share these with the family.

3. Decision-making should be collaborative, and all members of the multidisciplinary team are given the opportunity to share their insights on values and preferences of the parents, which they may have become aware of while caring for the baby.

The physician in-charge will take the lead in coordinating care plans and serve as the point of contact for the team and the family when the need arises.

4. Consensus in decision-making should be pursued and/or arrived at through facilitated discussions between the healthcare team and family.

Time should be given for shared decision-making if the clinical situation allows. The consensus that is reached and the agreed-upon care plans must be documented, including changes made if any. A complete handover is essential if care is transferred to another team receiving the baby (e.g. community palliative care team or children's ward).

(b) <u>Differences in opinion</u>

Differences in opinion may arise when the parents and family are at different stages of the grieving process or have distinct and deeply held beliefs on direction of care for their baby and hence may not be accepting of outcomes and care plans proposed. Every attempt must be made to enable the parents to reach the stage of mutual understanding and agreement before commencing decision-making related to end of life care. Similarly, there could be genuine differences outside personal grief that are related to real uncertainties in outcomes or alternative professional opinions. The same may also hold true when there are differences in opinion within the multi-professional team caring for the baby.

1. Within the treating team

Differences in opinion within the healthcare team may be resolved with inclusive discussions in order to arrive at a consensus regarding decision for care with palliative intent. In the event of persistent differences in opinion, the views of a Senior Clinician, Ethics Consultant, and experts trained in conflict resolution, or the opinion of an external physician from another institution may be sought.

2. Within the family

If the clinical situation allows, family members should be given time to consider and discuss the contentious issues in an attempt to arrive at a consensus or a negotiated compromise.

3. Between family and the team caring for the baby

Consider seeking second opinion from in-house clinicians outside the treating team or external to the present neonatal unit who are not directly involved in the care of the baby. A referral to the hospital clinical ethics committee or involvement of dedicated staff trained in conflict resolution might be considered. Legal advice may be sought if all these avenues have been explored and differences cannot be resolved in spite of intensive dialogue between the team and family.

(c) Change in the focus of care

- 1. Acute and palliative care can be provided in parallel (Larcher et al., 2015; Uthaya et al., 2014), even when focus of care has changed.
- 2. If the focus of care shifts towards palliation, consider ceasing the following interventions once decision for palliation is agreed upon.
 - i. Endotracheal ventilation and other respiratory support (e.g. CPAP)
 - ii. Intravenous antibiotics, inotropes, dialysis
 - iii. Continuous and/or frequent monitoring of vital signs, cerebral, cardiac, respiratory and other organ functions, especially if invasive (e.g. indwelling intravascular arterial catheters, cerebral function monitoring CFAM)
 - iv. Blood tests, X-rays, Ultrasounds
- 3. Prepare parents for what to expect during and after withdrawal of interventions.
 - i. Explore preferences e.g. the presence of other family members, parents' desire to hold the baby or participate in any rituals or preparing memory boxes prior to/during removal of interventions.

- ii. Prepare parents through parallel planning the possibility that the baby may continue breathing unaided for some time, and that death may not occur immediately after withdrawal of interventions.
- 4. Have a plan for management of existing symptoms prior to withdrawal of interventions e.g. gasping respirations, pain and seizure control.
- 5. Neuromuscular blocking agents should be discontinued prior to extubation.
- 6. Supplemental oxygen and gentle suctioning may be performed if it provides comfort to the baby.
- 7. Maintenance of nutrition and hydration.
- 8. Provide comfort through breast-feeding or non-nutritive sucking.
- 9. Avoid intravenous nutrition as it involves cannulation and the risk of extravasation, infection and continuing discomfort.
- 10. Tube feeding requires insertion of an oro-gastric or nasogastric tube, a procedure that is uncomfortable and can predispose the baby to risk of aspiration.
- 11. Alternative modes of feeding, including bottle-feeding, spoon-feeding, cupfeeding and dropper-feeding may be an option if the baby shows a desire for feeds.

(d) Withdrawing life-sustaining respiratory support - Recommendations

- 1. Sequence of events should be planned and briefed to the medical team and parents prior to extubation.
 - Plan in advance the named staff who would be removing the endotracheal tube, doing suctioning and disconnecting the ventilator (Mancini et al., 2014). For more specific guidance on terminal extubation, please refer to Appendix 4.
- 2. Staff rendering psychosocial and spiritual support (e.g. social worker, pastoral care worker) should be made accessible upon request by team or parents.
- 3. Medications that might need to be given for the baby's comfort should be readily available for use prior to extubation.
- 4. Ensure feeds have been withheld for a safe duration prior to extubation to minimise the risks of aspiration.

- 5. Consider administration of corticosteroids in babies who have been intubated for a prolonged period of time to reduce post extubation stridor and the distress associated with it.
- 6. Provide family with a quiet, private and nurturing environment after intervention is withdrawn whenever possible, but bearing in mind that some families may choose to remain within the confines of a busy Intensive care environment.
- 7. Parents could be encouraged to do kangaroo care and hold the baby after withdrawal of interventions.
- 8. Ensure priority for the baby's comfort and privacy for family during and after withdrawal of interventions.

SECTION II: PART 3

Planning for End of Life care

(a) Flexible parallel planning

Not every baby dies immediately after withdrawal of interventions and parents must be alerted to this possibility. Alternative plans prior to withdrawal of intensive treatment should be explored (e.g. continuation of care in a home or hospice). Palliative care teams may help in the coordination of care between the Community and Hospital, and follow up arrangements should be put in place as necessary with the baby's attending Neonatologist. Effective communication between teams must be ensured with good handovers and all information must be documented.

(b) End of life care

Advance care planning should be carried out at the earliest appropriate time in advance of the terminal. The discussions between family and the multidisciplinary team should focus around the family's needs and preferences for care at end of life.

- 1. Possible aspects to be considered in the discussion include:
 - Anticipatory counselling on symptoms that may arise as the baby's demise is near, and the management thereof
 - ii. Memory making and psychosocial support for the whole family, including siblings, grandparents, other important family and friends
 - iii. Staff/team leading end of life care
 - iv. Post-mortem
 - v. Organ donation
- 2. Parents should be allowed to voice their preference as to where end of life care should occur, taking into account the estimated rate of deterioration (e.g. hours vs days vs weeks). Acknowledge that it is difficult to predict how long the baby may continue to breathe unaided, which is an essential component of Advance Care Planning and Parallel Planning.

- 3. Prior to formalising the preferred place of care or demise, a discussion of palliative community services may be arranged. This may include site visits by parents, or meetings with community care providers (facilitated by the Neonatologist and/or care team).
- 4. Commence early with a clear plan for transfer as agreed jointly by the family, primary care team and community palliative care team. If the preference is to remain in hospital for care, ascertain the wishes for rapid transfer (terminal discharge) for the baby to spend the last hours/days at home.
- 5. Due consideration to the mode of transfer is to be raised in the discussion among the neonatologist, parents, and community palliative care teams.

 For services available locally, please refer to Appendix 6.
 - i. Community hospice teams may elect to visit the baby and family prior to discharge to familiarise with the care needs of the child and the family's expectations. Parents who are considering inpatient hospice care may be offered the opportunity to visit a hospice.
 - ii. A detailed handover, supplemented by written documentation, should be given by a senior member of the team looking after the baby in Hospital (registrar and above) to the community palliative team taking over the care.
 - iii. For home care, transport arrangements and necessary equipment and supplies should be arranged prior to discharge, including appropriate training of caregivers.
 - iv. If transfer of care to the family home or hospice is not possible or not preferred, measures should be taken to optimize comfort and privacy of the family in the hospital.

(c) Post end of life care

1. Post-mortem examination remains the gold standard in evaluating the cause of death and is mandatory when it is believed to be unnatural. It may be offered when additional information may be helpful in planning of future pregnancies or aid the grieving process by enhancing parental understanding of the cause of death. The topic may be brought up for discussion before demise if parents

raise the discussion themselves; otherwise the best time to broach the issue is soon after the baby's death. Parents and families are to be provided details on:

- Extent of post-mortem and the likely appearance of the baby following the procedure
- ii. Duration of the post-mortem itself and possible time of release of the body
- iii. How and when the baby may be collected for burial or cremation
- iv. Duration taken to arrive at the findings and issuance of a formal report by the Pathologist. The parents must be made aware that some samples (e.g. neuropathology) can take a considerable period of time to be prepared, examined and reported.
- v. How the findings from the post-mortem may be conveyed to the families
- vi. Charges for the procedure

It is good practice to make available parent information sheets outlining the above procedures.

- 2. It is best that a member of the team be identified to obtain consent and arrange a follow up meeting with parents to convey the results of the post-mortem. Be aware of possible delays in releasing the body to a funeral home and stay sensitive to cultural practices in the handling of the deceased.
- 3. Bereavement Support This is to be provided by the respective neonatal unit or community service providers. All deaths deserve adequate attention to closure, for both parents and staff involved in the care of the baby.

 Please refer to Section II, Part 4.
- 4. Organ or tissue donation is now recognised as an effective treatment option of end-stage organ failure and further interdisciplinary collaboration can be explored when surgical colleagues are ready to embark on this initiative for babies.

SECTION II: PART 4

Emotional, psychological and spiritual support

- 1. When a baby is critically ill, families may experience intense grief and struggle with a sense of loss.
- Careful consideration should be taken to assess and manage the emotional, social and spiritual needs of each family and their specific preferences, including accommodating cultural and religious practices. It is important to acknowledge that there may be differing beliefs amongst the parents themselves.
- 3. It is desirable that medical social workers, counsellors and pastoral care staff are available to render support to families depending on their needs, and a referral should be made when appropriate.
- 4. Ongoing trauma, grief and moral distress may persist in staff members that have cared for vulnerable and dying babies and their families. Debriefing or reflective practice following the death of a baby is recommended to be standard procedure in all units. Access to counselling or other forms of professional support should be made readily available for staff members.
- 5. Child bereavement is a risk factor in itself for complicated grief and its adverse outcomes (Sanders, 1988). Emotional, psychological and spiritual support should continue even after the baby has died or is discharged from the hospital setting.
- 6. Wider members of the healthcare team may also benefit from training in communication and palliative care principles, to equip them with the skill in supporting grieving families.

References

- Hendrickson, K. C. (2009). Morbidity, mortality, and parental grief: a review of the literature on the relationship between the death of a child and the subsequent health of parents. *Palliat Support Care*, 7(1), 109-119. doi:10.1017/S1478951509000133
- Larcher, V., Craig, F., Bhogal, K., Wilkinson, D., Brierley, J., Royal College of, P., & Child, H. (2015). Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Arch Dis Child*, 100 Suppl 2, s3-23. doi:10.1136/archdischild-2014-306666
- 3. Sanders CM. Risk Factors in Bereavement Outcome. *Journal of Social Issues*. 1988 44(3):97–111.
- 4. Uthaya, S., Mancini, A., Beardsley, C., Wood, D., Ranmal, R., & Modi, N. (2014). Managing palliation in the neonatal unit. *Arch Dis Child Fetal Neonatal Ed, 99*(5), F349-352. doi:10.1136/archdischild-2013-305845
- 5. van der Geest, I. M., Darlington, A. S., Streng, I. C., Michiels, E. M., Pieters, R., & van den Heuvel Eibrink, M. M. (2014). Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *J Pain Symptom Management, 47*(6), 1043-1053. doi:10.1016/j.jpainsymman.2013.07.007
- 6. World health statistics annual, 1996. Geneva, World Health Organization, 1998.

Appendices

Appendix 1: Pain management in neonatal palliative care

1. General principles in the management of pain in children

Pain is one of the most prevalent symptoms in children requiring palliative care (APPM, 2017) and one that concerns parents most. The baby in pain can be a very distressing experience for everyone: baby, parent and professionals alike.

Babies can suffer pain due to disease, trauma and psychological factors. Failure to alleviate pain from any cause has adverse physiological consequences and causes needless suffering.

Meticulous assessment, individualised treatment and regular reviews using the varied skills of the multi-disciplinary team and good communication between healthcare professionals and parents are essential for adequate symptom control and pain relief.

2. Specific issues relevant to the neonatal setting

Due consideration should be given to the relief of pain and discomfort for babies receiving palliative care. It includes planning the type of medication, the dose, the route of administration and the likely duration of treatment. Use of validated tools (e.g. FLACC scoring) to assess pain in this group of patients and their limitations should be recognised by users. Accurate assessment involves a comprehensive evaluation, obtaining physiological markers of distress like heart rate and observations of parents and nurses on the NICU.

For acute pain that is not persistent, oral or buccal routes of medicine administration are preferred to the subcutaneous or intramuscular routes as the latter are unreliable and painful. Should the baby have intravenous access in place, this route is preferable for immediate pain relief particularly after discontinuation of life sustaining treatments.

If a baby is already receiving analgesic medication, this should not be discontinued. In moderate to severe pain, or when the trial of first line medication fails and an opioid needs to be initiated, an initial or loading dose should be given before commencing on a continuous infusion so as to achieve prompt and adequate analgesia.

The dose can then be adjusted, depending on ongoing assessment of pain, or development of tolerance. About 30 minutes after starting analgesia, it is a good practice to obtain feedback from parents and nurses to ascertain whether a desired level of comfort has been achieved. If pain relief is suboptimal at current doses, medication must be escalated in a stepwise manner. Parents may have to be alerted to the possibilities that the medication may suppress respiratory drive, and in rare circumstances even hasten death. The 'doctrine of double effect' is used to justify the prescription of a certain treatment aimed at relieving distressing symptoms even though this might unintentionally shorten a patient's life or hasten death. This is in contrast to Euthanasia where a prescription is deliberately intended to cause death (McIntyre, 2006).

If the intravenous route is not accessible and adequate analgesia cannot be achieved using oral medications, a subcutaneous infusion may become necessary in preference to intramuscular medication which is never appropriate.

Non-narcotic analgesia such as paracetamol and oral sucrose may be continued in combination with opioids (Uthaya et al., 2014).

Non-pharmacological interventions should always be encouraged, no matter which pharmacological options have been chosen. These include maintaining a calm environment with minimal noise and light stimuli, continued suckling at the breast or non-nutritive sucking with a pacifier, music, gentle rocking, gentle massage and positioning with arms and legs flexed close to the trunk using a blanket (swaddling).

3. Physiological monitoring after termination of life-sustaining treatments

Procedures such as invasive blood pressure monitoring should be discontinued and pulse oximetry and cardiac monitoring should also be disconnected, prior to withdrawal of mechanical ventilation. All blood tests and blood gas measurements,

while at the discretion of the attending team should no longer be 'routinely' performed if they do not serve the purpose of optimising goals for comfort.

The babies should be monitored for physical signs that suggest discomfort (crying, whimpering, panting, tachycardia, excessive secretions and dry mucous membranes).

Once life-sustaining support has been withdrawn, physical examination and auscultation for the heart rate should be periodically performed by the doctor or nurse to determine continuing heart rate or death.

References

- 1. Satbir Singh Jassal et al. The Association of Paediatric Palliative Medicine Master Formulary.4th edition 2017.
 - http://www.appm.org.uk/resources/APPM+Master+Formulary+2017+-+4th+edition.pdf
- 2. Paediatric Formulary Committee. BNF for Children 2016 -2017 ed. London, UK. Pharmaceutical Press. 2016.
- 3. Uthaya, S., Mancini, A., Beardsley, C., Wood, D., Ranmal, R., & Modi, N. (2014). Managing palliation in the neonatal unit. *Arch Dis Child Fetal Neonatal Ed, 99*(5).
- 4. McIntyre, Alison. "Doctrine of Double Effect". In Edward N. Zalta. *Stanford Encyclopedia of Philosophy* (Summer 2006 Ed.).

Tools for the assessment of pain

Assessment of pain in babies can be quite challenging and subjective but several scoring systems have been validated in children and use similar behavioural (e.g. facial expression), physiological (e.g. heart rate) and contextual parameters (e.g. gestational age). Choice of the pain assessment tool is based on individual institution preferences but some of these include:

- The Face, Legs, Activity, Cry, Consolability scale (FLACC) ^{1,2,6}
- The Premature Infant Pain Profile (PIPP) 2,3,6
- Neonatal Infant Pain Scale (NIPP)^{4,6}
- Pain Assessment Tool (PAT) 5,6

For a more detailed description of the individual pain assessment tools, please refer to the references on the following page.

References

- 1. S Merkel et al. The FLACC: A behavioural scale for scoring postoperative pain in young children. *Pediatr Nurs.* 23(3), 1997, p. 293–297.
- Heng RM, Poon WB, Ho SKY. FLACC is a valid And Reliable Tool As Compared To the PIPP for Assessment of Neonatal Pain. http://dx.doi.org/10.1136/archdischild-2014-307384.1362
- 3. Stevens B, Johnston C, Taddio A et al. Premature Infant Pain Profile: Development and Initial Validation. *The Clin J Pain* Volume 12(1), March 1996, pp 13-22.
- 4. Hudson-Barr D, Capper-Michel B, Lombardo S et al. Validation of the Pain Assessment in Neonates (PAIN) scale with the Neonatal Infant Pain Scale (NIPS). *Neonatal Netw.* 2002 Sep-Oct;21(6):15-21.
- 5. Spence K1, Gillies D, Harrison D, Johnston L, Nagy S. A reliable pain assessment tool for clinical assessment in the neonatal intensive care unit. *J Obstet Gynecol Neonatal Nurs*. 2005 Jan-Feb; 34(1):80-6.
- 6. The recognition and assessment of acute pain in children. Royal College of Nursing UK.
 - https://www.rcn.org.uk/professional-development/publications/pub-003542

Appendix 2: List of Medications, Dosages and Indications

Medication	Indications	Dosages	Route	Comments
Chloral Hydrate	Sedation/Analgesia	Sedation: PO 10 mg/kg/dose every 6 - 8 hourly. Painful procedures: PO 25 - 50mg/kg/dose (start with maintenance 10 mg/kg/dose every 8 hourly).	Oral/rectal	Review on a daily basis Administer with feeds
Diazepam	Seizures	1.25 - 2.5mg	Rectal	Repeat after 10 minutes if necessary
Domperidone	Gastro-oesophageal reflux	PO 0.2 - 0.4mg/kg/dose 8 hourly	Oral	Before feeds
Fentanyl	Sedation/Analgesia	0.5 - 4 mcg/kg/dose. Repeat as required every 2 - 4 hourly. Continuous infusion at 1 - 5 mcg/kg/hour.	Intravenous	Intravenous injection over at least 30 seconds
Glycerin suppository	Constipation	Child < 1month: Tip of a glycerol suppository Child > 1 month: 1g suppository as required	Rectal	1g suppository
Hyoscine Hydrobromide	Excessive airway secretion Hyper salivation	250mcg (equals one quarter of a patch) every 72 hours	Transdermal patch applied to hairless area of skin behind ear	1 patch releases 1mg/72 hours when in contact with the skin

Medication	Indications	Dosages	Route	Comments
Ibuprofen	Pain/Symptom	5 mg/kg/dose 3 times daily	Oral	Not licensed for
	relief			children < 5 kg
Lactulose	Constipation	2.5 ml/dose twice a day	Oral	Contraindicated in
				galactosaemia or
				intestinal obstruction
Levetiracetam	Seizures	Loading dose:	Intravenous	Not necessary to
		40mg/kg followed by		perform routine drug
		10mg/kg 8 hourly(< 7 d old)		levels
		Or		
		20mg/kg 12 hourly (> 7 d old)		
Midazolam	Sedation/Seizures	Sedation: 50 - 150 mcg/kg/dose. Repeat as	Intravenous	Slow IV push over 5
		required every 2 - 4 hourly.		minutes. Give a lower
		IV Infusion: 60mcg/kg/hr		dose if opiates being
		(if < 32 weeks postmenstrual age, reduce to		administered
		30mcg/kg/hr according to response)		concurrently.
		Anticonvulsant: Loading dose: 150 mcg/kg	Intravenous	
		IV, followed by IV maintenance infusion: 1	infusion	
		to 7 mcg/kg/minute		
		Buccal: 200 - 300 micrograms/kg	Buccal	Repeat once after 10
			administration	minutes if necessary in
				status epilepticus

Medication	Indications	Dosages	Route	Comments
Morphine	Pain/Symptom	IV / IM / SC: 50 - 200 mcg/kg/dose over 5	Subcutaneous	
	relief	minutes. Repeat as required every 4 hourly.	Intravenous	Over 5 minutes
		Continuous infusion: Loading dose of 100 -		Adjust as per response
		150 mcg/kg/dose over 1 hour, followed by	Intravenous	
		maintenance infusion at 10 - 20	infusion	
		mcg/kg/hour		
Nystatin	Oral & perioral	Oral thrush: PO 1 ml (for preterm babies) or	Oral	
	fungal infection	2 ml (for term babies) every 6 hourly in 2		
		divided doses to each side of mouth with		
		dropper or swab		
Omeprazole	Gastro-oesophageal	0.5 - 1.5 mg/kg/dose once a day	Oral/IV	Administer with care if
	reflux	(start at a lower dose and increase after 7 -		administrating via
		14 d if necessary)		gastrostomy feeding
	Acid related			tubes to minimise risk
	dyspepsia			of blockage
Paracetamol	Pain/Symptom	Neonate 28 - 32 weeks corrected	Oral	
	relief	gestational age: 20 mg/kg as a single dose		
		then		
		10 - 15 mg/kg every 8 - 12 hours as		
		necessary (maximum 30 mg/kg/day in		
		divided doses),		

Medication	Indications	Dosages	Route	Comments
		Neonates over 32 weeks corrected gestational age: 20 mg/kg as a single dose then 10 - 15 mg/kg every 6 - 8 hours as necessary (maximum 60 mg/kg/day in divided doses),		
		Child 1 month onwards: 20 - 30 mg/kg as a single dose then 15 - 20 mg/kg		
Paracetamol	Pain/Symptom relief	Neonate 28 - 32 weeks postmenstrual age (PMA) 20mg/kg as a single dose then 15 mg/kg every 12 hours as necessary (max 30mg/kg daily) Neonate > 32 weeks PMA 30mg/kg as a single dose then 20mg/kg every 8 hrs as necessary (max 60mg/kg daily in divided doses) Child 1 - 3 months: 30 - 60mg every 8 hrs as necessary Child 3 - 12 months: 60 - 125 mg every 4 - 6 hours as necessary (max 4 doses in 24 hours)	Rectal suppositories	

Medication	Indications	Dosages	Route	Comments
Paracetamol	Pain/Symptom	Preterm neonate over 32 weeks corrected	Intravenous	Over 15 minutes
	relief	gestational age: 7.5 mg/kg every 8 hours,	infusion	In moderate renal
		maximum 25 mg/kg/day,		impairment use
		Neonate: 10 mg/kg every 4 - 6 hours		maximum frequency of
		(maximum 30 mg/kg/day),		6 hourly; in severe
		Baby bodyweight <10kg: 10 mg/kg every		renal impairment
		4 - 6 hours (maximum 30 mg/kg/day),		maximum frequency 8
		Baby bodyweight > 10 kg: 15 mg/kg every		hourly.
		4 - 6 hours (maximum 60 mg/kg/day)		
Phenobarbitone	Seizures	Loading: IV 20 mg/kg over 10 - 15 minutes.	Oral, intravenous	Dilute to a
		Repeat with additional doses of 5 - 10	injection	concentration of
		mg/kg/dose every 15 - 30 minutes until		20mg/ml with water
		seizures are controlled to a maximum total		for injection &
		dose of 40 mg/kg.		administer over 20
		Maintenance dose: PO / IV 2.5 - 5		minutes if given
		mg/kg/day given once daily; maintenance		intravenously
		dose usually starts 12 hours after loading		
		dose.		
Phenytoin	Seizures	Loading: IV 15 - 20 mg/kg over 30 minutes	Slow IV injection	May cause respiratory
		Maintenance: IV / PO 4-8 mg/kg every 24	or infusion	depression,
		hourly. Start after 12 hours of loading dose.		arrhythmias and
				hypotension

Medication	Indications	Dosages	Route	Comments
		After 1 week of age, can be given up to 8		
		mg/kg/dose every 8-12 hourly.		
Ranitidine	Reflux oesophagitis,	For term babies: IV 1.5 mg/kg/dose every 8	Intravenous/oral	
	gastric & duodenal	hourly		
	ulcers, prophylaxis	For preterm babies: IV 0.5 mg/kg/dose		
	of stress ulcers	every 12 hourly		
		PO 2 mg/kg/dose every 8 hourly		

References

- 1. BNF for children 2016-17. Joint publication of the BMJ Group, RPSGB, RCPCH & NPPG. www.bnfc.org
- 2. Neofax online https://neofax.micromedexsolutions.com/neofax/neofax.php
- 3. Lexicomp online http://online.lexi.com/action/home
- 4. A Mancini, S Uthaya, C Beardsley Wood and N Modi. Practical guidance for the management of palliative care on neonatal units. RCPCH Publication Feb 2014. http://www.togetherforshortlives.org.uk/assets/0000/6890/NICU-Palliative-Care-Feb-2014.pdf
- 5. Satbir Singh Jassal et al. The Association of Paediatric Palliative Medicine Master Formulary.4th edition 2017. http://www.appm.org.uk/resources/APPM+Master+Formulary+2017+-+4th+edition.pdf
- 6. Jassal SS. Basic symptom control in Paediatric palliative care. Bristol, England: ACT, the Rainbow Children's Hospice Guidelines. 2011.
- 7. World Health Organization. WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. World Health Organization; 2012.
- 8. West Midlands Paediatric Palliative Care Network https://wmppcn.wordpress.com/wm-toolkit/

Appendix 3: Categories of conditions for which palliative care may be considered

(a) Conditions where premature death is highly likely

- 1. Deliveries at a confirmed gestational age of < 23 weeks' gestation
- 2. Known congenital anomalies such as Anencephaly, Bart's hydrops etc.

(b) <u>Antenatally identified congenital anomalies associated with an almost certain</u> <u>early death and unacceptably high morbidity among the rare survivors</u>

- 1. Trisomy 13, Trisomy 18
- 2. Thanatophoric dwarfism or lethal forms of osteogenesis imperfecta
- 3. Potter's syndrome/renal agenesis/severe oligohydramnios sequence
- 4. Severe lung hypoplasia, severe congenital diaphragmatic hernia
- 5. Holoprosencephaly, complex or severe cases of meningomyelocele or large encephalocele, hydranencephaly, congenital severe hydrocephalus with absent or minimal brain growth
- 6. Neurodegenerative diseases requiring ventilation (e.g. spinal muscular atrophy)
- 7. Univentricular congenital heart disease requiring surgical palliation

(c) <u>Babies not responding to intensive treatment despite all appropriate efforts,</u> or in combination with a life-threatening acute event

- 1. Recipients of repeated cardiopulmonary resuscitations
- 2. Severe cases of perinatal brain injury, such as haemorrhages or leukomalacia, severe hypoxic–ischemic encephalopathy
- 3. Irreversible multiple end-organ disease/failure
- 4. Ventilator dependent chronic lung disease (non-responsive to maximal medical therapy)

- 5. Necrotising Enterocolitis or mid-gut volvulus without viable intestines, or for whom an extremely short gut makes feeding/growth impossible
- 6. Newborns unable to be weaned off ECMO

Appendix 4: Practical management of extubation in a dying baby

- 1. A **Family Conference** must be held for the parents to meet with the Clinical Care Team (primary physician, nurse, therapists or medical social worker) to discuss and agree on the sequence of events prior to elective extubation in the critically unwell baby. The clinical care team must assure parents that every attempt will be taken to minimise pain and discomfort and the baby is treated with the utmost dignity. The family conference is best held in a private room.
 - i. Junior doctors in the clinical care team (e.g. residents) should be encouraged to attend as part of the learning and reflective process.
 - ii. The family may wish to include persons to render psychosocial or spiritual support. Spiritual support in the form of prayers, blessings or a short service at the bedside are encouraged.
- 2. **Clear documentation** of the Family Conference must be made, including the family's agreement regarding plans to cease mechanical ventilation, forego cardio-pulmonary resuscitation, reduce invasive monitoring devices and cease blood sampling, with appropriate signatures.
 - i. Doctors are expected to document and sign an "Extent of Care Status Plan" or equivalent paperwork as required in their respective Hospitals.
 - ii. Discussion with the family regarding post-mortem (if anticipated) and undertaker services may be useful.

3. **Before performing extubation**, the staff should:

- i. Withhold enteral feeding for several hours and/or empty the stomach in order to reduce the risk of aspiration.
- ii. Ensure that intravenous access remains in place to administer medication for symptom relief, including relief of pain, laboured breathing and seizures. Consultation with the Pharmacist aids in optimal delivery of medication required to relieve symptoms.
- iii. Ensure that any neuro-muscular blocking agents (paralytics) are weaned off prior to extubation.

- iv. Consider the usefulness of corticosteroids in babies who have been intubated for a prolonged period of time to reduce post extubation stridor and the distress associated with it.
- v. Decide beforehand who will remove the endotracheal tube (doctor or nurse, and in certain circumstances parents may wish to do this themselves).

4. At the pre-determined time of extubation, the staff:

- Removes invasive monitoring (e.g. in-dwelling intra-arterial catheter).
 Non-invasive monitoring of vital signs (e.g. Auscultation of heart rate) is preferable to invasive devices.
- ii. Removes any tape on the face.
- iii. Turns off ventilator alarms.
- iv. Gently suctions the endo-tracheal tube just prior to its removal, followed by gentle suctioning of the mouth to remove secretions.

5. **Just after extubation** and withdrawal of intervention, the staff:

- i. Ensures that the family has a private environment to grieve. Parents may be encouraged to provide kangaroo care or carry the baby for as long as they wish. Good environmental support includes dimmed lights, minimise noise by reducing conversations around the baby's bed space and limit movement in and out of the room.
- ii. Ensure that the baby is dressed and wrapped in accordance to parents' wishes.
- iii. Collect mementoes for memory-keeping, such as a lock of hair, handprints, footprints or family portraits.
- iv. Provide information regarding collection from the mortuary for burial or cremation, and availability of 'angel clothes', where required when death is imminent.

Appendix 5: Neonatal bereavement support

Useful links and contacts for bereavement care practices can be found at the following:

- KK Women's and Children's Hospital Medical Social Work Department
 https://www.kkh.com.sg/Services/AlliedHealthSpecialties/ourspecialties/medicalsocialwork/Pages/Home.aspx
- 2. Khoo Teck Puat National University Children's Medical Institute
 https://www.nuh.com.sg/ktp-nucmi/patients-and-visitors/neonatology.html
- 3. Singapore General Hospital Medical Social Services Department https://www.sgh.com.sg/Clinical-Departments-Centers/Medical-Social-Services/Pages/medical-social-services-department.aspx

Neonatal & Developmental Medicine Overview

https://www.sgh.com.sg/clinical-departments-centers/neonatal-developmental-medicine/pages/overview.aspx

- Star PALS for Children https://www.hca.org.sg/Star-PALS
- Child Bereavement Support (Singapore)http://www.cbss.sg

Appendix 6: Local paediatric palliative care services

This section provides an overview of the various palliative care services provided by the different institutions across Singapore.

Please refer to the respective websites by the relevant service providers for the most updated information.

1. Hospital palliative care services

These comprise multi-disciplinary teams of doctors, nurses, medical social workers and therapists in the hospital providing palliative care.

<u>Services</u>

- Pain and symptom control
- Psychosocial and spiritual support
- End of life care

Facilities

- National University Hospital
- KK Women's and Children's Hospital

Eligibility criteria

• Patients with life-limiting illnesses with palliative care needs. Not prognosis limited as long as hospital's palliative team can value add.

How to refer

• Via referral system within each hospital

2. Inpatient hospice services

These cater to patients with life-limiting illnesses, with prognosis of less than 3 months. When care at home becomes difficult, option of inpatient hospice can be considered.

Services

- Pain and symptom control
- Psychosocial and spiritual support
- Respite Care
- End of life care

Facilities

Assisi Hospice

Eligibility criteria

For respite services: Patients below 21 years of age who have life-threatening or life-limiting illness

For end of life care: Patients below 21 years of age who have a prognosis of 3 months or less

How to refer

- Made by the doctor-in-charge via Agency for Integrated Care website, or
- Fax common referral form to Agency for Integrated Care
- An email or phone call to discuss the case being referred with Assisi hospice doctors

Charges

- To contact Assisi Hospice regarding charges
- Follows means testing

3. Palliative home care services

Home visits are conducted by doctors, nurses, counsellors/medical social workers and therapists. Frequency of visits depends on clinical needs. Respite services and allied health specialist inputs at home are available.

Services

- Pain and symptom control
- Psychosocial and spiritual support
- End of life care
- Caregiver training
- Equipment loan
- 24-hour coverage with hotline and after office hours visits as needed

Facilities

• Star PALS paediatric palliative care team, HCA Hospice Care

Eligibility criteria

• Patients less than 19 years of age suffering from life-limiting illnesses

How to refer

- Made by the doctor-in-charge via Agency for Integrated Care website, or
- Fax common referral form directly to HCA Hospice Care

Charges

• The service is complimentary

Community paediatric palliative care services

Assisi Hospice

832 Thomson Road, Singapore 574627

1 http://www.assisihospice.org.sg/

6832 2650

☐ assisi@assisihospice.org.sg

StarPALS by HCA Hospice Care

12 Jalan Tan Tock Seng, Singapore 308437

http://www.hca.org.sg

2 6251 2561

⊠ starpals@hcahospicecare.org.sg

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