PALLIATIVE CARE AT HOME-SUPPORTED BY SPECIALIST PAEDIATRIC PALLIATIVE CARE SERVICES

PRACTICE GUIDELINE ©

DOCUMENT SUMMARY/KEY POINTS

- The content of this practice guideline is aimed at services provided by Level 3 Specialist Paediatric Palliative Care services for patients in the home or community.
- Palliative care encompasses the physical, emotional, psychosocial and spiritual care of the child in the context of his or her family.
- Palliative care is not only end of life care, but also encompasses the care provided to children with a life limiting illness, starting from diagnosis, and can be provided at the same time as curative treatments are being pursued.
- Families are supported in their decisions about the location for palliative care and end of life care.
- Palliative care provided at home requires good communication and co-ordination between all service providers, appropriate symptom management, equipment, support and care planning.
- Arrangements for palliative care at home must be flexible, individually planned and parents must have access to the supports they require to continue caring for their child.
- Bereavement support services should be offered to all families following the death of a child.

Approved by:	SCHN Policy, Procedure & Guideline Committee	
Date Effective:	1st September 2019	**Review Period:** 3 years
Team Leader:	Quality Manager	**Area/Dept:** CHW Pain Management Unit

CHANGE SUMMARY

The changes include:

- Updated links to appropriate policies, procedures and guidelines
- Information about the Paediatric Palliative Care Programme After Hours Medical On-call Service
- Updated information about the introduction of the NSW Resuscitation Plan-Paediatric

READ ACKNOWLEDGEMENT

- Palliative Care staff working in the various areas of SCHN Services is to read and acknowledge this document.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

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This Guideline may be varied, withdrawn or replaced at any time.

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This policy is a standard of practice as outlined by the specialist Paediatric Palliative Care Services (SPPC) to support all patients and families in the home setting**.**

1 Definitions

The SCHN Department of Palliative Care

Is represented by the specialist multidisciplinary paediatric palliative care (SPPC) services at CHW, SCH and Bear Cottage. The specialist hospital based teams are consultative and offer support and guidance in the provision of palliative care to a child, their family, the primary care team and community health services. SPPC services are offered across the spectrum of hospital, home and hospice. This policy is specifically for patients and families who are cared for at home.

The following definitions will be used for the purposes of this document.

Palliative Care

Palliative care is a philosophy of care that is characterised by flexible, family-centred care and support throughout the course of an incurable illness and continues after the infant, child or young person's death. Palliative care is holistic care that encompasses physical, psychosocial and spiritual care of the child in the context of his or her family.

Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders[1]:

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

Level 3 Specialist Paediatric Palliative Care Service

SPPC services are defined by the qualifications of staff consisting of the following disciplines:

- A Medical Practitioner (who is a Fellow of the Chapter of Palliative Medicine-FAChPM),
- A Clinical Nurse Consultant (CNC)/ Nurse Practitioner (NP) and
- An Allied Health staff member
- It may also include other clinical and administrative staff members.

Level 3 refers to those specialist services which are accredited by the Chapter of Palliative Medicine

Primary Team

The primary team is the child's main treating team and the SPPC provide consultation for the palliative management of the child.

Neonate

The term "neonate" refers to a baby who is less the 28 days old

Child/Children

The term "Child" or "Children" refers to infants, children and young people up to the age of 18.

Home Care

The term "Home Care" refers to the care provided to the child and their family in their home or other residence of the family's choice by staff of the SPPC

2 Ethical Standards Statement

The principles contained in the document "Decision Making at the End of Life in Infants, Children & Adolescents - a policy of the Paediatric & Child Health Division of the Royal Australasian College of Physicians"[2] are supported by SPPC. This document can be found on the Royal Australasian College of Physicians website https://www.racp.edu.au/docs/default-source/advocacy-library/decision-making-at-the-end-of-life-in-infants-children-and-adolescents.pdf

3 Criteria for Receiving Specialist Paediatric Palliative Care Services

Criteria for inclusion in the SPPC Service are:

- Children with life limiting illnesses
- Children for whom a decision has been made to forego life-sustaining treatment
- Children who have an illness that is not primarily life threatening, but may have concurrent factors that increase their risk of dying before the age of 18. These children should be considered on an individual basis.

If a child is over 16 years of age, SPPC will follow the admission criteria of SCHN. If further information is needed, please contact the SPPC service for further advice.

See SCHN Transition and Trapeze Practice Guideline

4 Referral to SPPC

It is often difficult to predict the progression of many childhood conditions even when medical treatment is provided as life prolonging or in the hope of cure. An early referral to the palliative care service provides the team with more time to plan care and work with families to identify their goals of care that may change throughout the illness trajectory of the child.

A referral to the SPPC should be made by the consultant or medical officer from the primary team

The Palliative Care consultation request should be made in Powerchart and the team must be notified by telephone or in person for all new patient referrals.

Outside the SCHN, patient referrals can be made by accessing the following SPPC Referral Form

Urgent referrals will be seen within 24 hours, non-urgent will be seen in liaison with the primary team.

5 Palliative Care at Home

When a family chooses to care for their child at home, appropriate advice, care and support is needed. The SPPC service act as a liaison between the hospital, hospice and with community based care providers to coordinate home visiting, the provision of medical supplies and equipment that will be needed to support care in the home setting.

The provision of palliative care at home requires:

- Careful preparation and planning
- Care arrangements that are flexible
- Clinical assessment to identify the support needs of the family including access to relevant community services
- Access to Specialist Paediatric Palliative Care.

5.1 Role of the Clinicians in Specialist Paediatric Palliative Care

Once the family has made a decision to care for a child at home, the clinicians need to ascertain the goals of the family and child, and develop a comprehensive management plan to endeavour to meet these goals. Discussions with the family may include:

- Introduction to the team and explanation of the teams' role
- Explanation to the family of the meaning of palliative care in the context of their child's illness
- Identification of the family's needs
- Provision of contact details
- Discussion of current symptoms and proposed management
- Identifying location of care options
- Discussion of other needs eg medical supplies/equipment

- Coordination of local services including community, medical and/or nursing teams and an assessment of respite options
- Development of a Comprehensive Management Plan

Based on individual child/family needs or wishes, the following should be considered:

- Preparation of an “Allow a Natural Death” Form (CHW) and/or NSW Resuscitation Plan-Paediatric
- Preparation of a NSW Ambulance Authorised Care Plan to guide Paramedics and Advanced Care Planning
- ‘Notifying relevant Emergency Departments when possible
- Identification of preferred location for end of life care (may change regularly)
- Identification of appropriate medical practitioner to provide Death Certification eg GP
- Consideration of any specific spiritual, religious or cultural requirements

6 Discharge from Hospital to Home

Discharge planning needs to be done so the transition from hospital to home is smooth and all aspects of care are considered. Support given by staff will vary based on the assessed need of each child and family. The discharge planning processes requires a high level of communication across all involved hospital and community teams to ensure there is ~~is~~ well coordinated care and a developed Comprehensive Management Plan in place

Refer to Care Coordination: Planning from Admission to Transfer of Care [SCHN policy]

6.1 Palliative Care Management Plan

When a child is receiving palliative care at home, it is essential that a management plan is developed. This is particularly important when there are multiple service providers, to establish clear goals and lines of communication. The SPPC will develop the management plan in consultation with service providers and families. The management plan should include goals of care as well as the following:

- Symptom Management. See section 12
- Equipment Supply. See section 11
- Nutritional Needs. See section 10
- Psychosocial Family Support. See section 7.3
- Spiritual Support. See Section 7.4
- Respite Needs. See section 8
- Contact details and emergency contact details

6.2 General Practitioner (GP)

It is important to engage the GP in the care of the child and family to ensure the following:

- Continuity of medical follow up close to home including at end of life
- Support for community palliative care teams
- Managing intercurrent problems
- Psychosocial support for the family (including siblings)
- Signing of a death certificate
- Linking families with appropriate bereavement services if needed

It is standard practise for the SPPC to provide the GP with a Palliative Care Management Plan that provides information regarding:

- The child's illness
- A Current medication list
- Estimated prognosis
- End of life symptom management plan if appropriate
- SCHN Palliative Care contact details including after-hours support
- Primary team clinician contact details at SCHN
- Copy of the NSW Resuscitation Plan-Paediatric, if appropriate.

6.3 After Hours Medical ON-Call Service

The After Hours Medical On-Call Service is available to all NSW and ACT health professionals who require specialist advice relating to paediatric palliative care issues outside of standard business hours. Specialist advice is available for any child that is:

- Known to one of the paediatric palliative care service providers
- Unknown to paediatric palliative care services at the time of contact

An inpatient in any NSW hospital facility or being cared for in the community.

Health professionals requiring specialist PPC advice after hours about a child with a life limiting illness can be known or unknown to any of the NSW specialist paediatric palliative care services

The After Hours Medical On-Call Service can be contacted through the hospital switchboards for CHW, SCH and John Hunter Children's Hospital, Newcastle.

6.4 Community Nursing/Community Palliative Care Referral

Dependant on need, children receiving palliative care who are discharged home may be referred to community nursing. As the child approaches the terminal phase of their illness, the community nursing team and community palliative care team may be involved. The support that is available from community nursing and community palliative care services can vary depending on their location. The SCHN palliative care clinicians will identify and refer appropriate supports with community nursing/community palliative care to ensure a family has access to local services.

The SPPC, or CNC from the child's primary team, will coordinate the referral to the local community nursing/palliative care service and an initial joint visit will be made to the family home where possible. For families living in rural/regional locations, telehealth will be available to facilitate a joint consultation.

Important aspects for optimal care at home include:

- Family understanding of role and capacity of the community nursing/palliative care services, including realistic expectations of support available, including after hours
- Availability of GP for home visiting (and details of after-hours processes) – particularly if terminal care at home is a goal
- Active engagement by family/carers with the community team and GP (enabling appropriate clinical reviews and telephone contact)
- Cleary identified options for hospital admission (and admitting clinician/team) if required
- Periodic review of appropriateness of the linkage with community palliative care and communication of any changes back to the primary team

Community nursing/palliative care supports the provision of:

- Symptom management in liaison with SPPC The provision of medical supplies/equipment
- Home support including regular visits and telephone follow up
- SPPC After-hours Medical support if needed
- Coordination with other involved community services eg palliative care, schools, counsellors
- Discharge planning with the SPPC service

6.5 Allied Health

Allied Health plays an important role in providing support to patients, families and other community allied health staff involved in care. If Allied Health support is required appropriate referrals should be made.

6.6 Hospital follow up post discharge

Discharge support needs will vary for individual families and appropriate information will be provided to the family prior to leaving hospital. A home visit or telehealth consult will be arranged as needed by the SPC team following hospital discharge. All hospital teams involved in the care of the child will need to coordinate family follow up to ensure they are not contacted inappropriately.

6.7 Staff Safety

Staff who are providing clinical support services to children and their families in the community setting must be aware and comply with certain practices and approaches that will reduce risks to their personal safety. Community visiting includes the home residence, schools, childcare centres, community centres and hospitals.

See SCHN Home and Community Visiting: Risk Management Procedure

6.8 Transport from hospital to home

The primary team or ward that the child has been admitted to will organise appropriate transportation for children who are discharged from hospital. The SPPC service will liaise with these staff if a child is going home for end of life care.

One of the following modes of transport will be selected:

6.8.1 Self-transportation

This mode and time of transport is usually arranged by the family and an assessment needs to be done to ensure a safe environment for transport home. If child's condition has changed an assessment by an OT should be arranged prior to discharge to ensure that the family have the necessary equipment/devices for transfer.

6.8.2 Hospital transport

If hospital transport is required to the home, the transport department must be informed and a transport form needs to be completed by 1300 hours on the day the transport is required. Hospital transport is only available from Monday to Friday. The type of transportation needs to be specified i.e. car, station wagon, ambulance. All transfers require an escort. This may be a parent or health care professional.

- For information about transport see Transport Dept Page [CHW]: http://chw.schn.health.nsw.gov.au/ou/transport/

For information about safety issues for transport see Transporting Children under 16 years including Exemptions for Child Restraints and Booster Seats

6.8.3 NSW Ambulance Authorised Paediatric Palliative Care Plan

The Authorised Paediatric Palliative Care Plan is a NSW Ambulance form to guide paramedics when they are called to a patient who has deteriorated at home. The information documented is consistent with advanced care planning and end of life care decisions made by families with the support of their palliative care team and/or the primary medical team.

6.8.4 Other Transport Options

- Community Ambulance can be organised by phoning them directly on 131 233; please note that emergency situations will be given priority. Generally, transport times are nominated as morning or afternoon/evening blocks. Check if the family have information regarding costs of transfer by ambulance.
- Angel Flight is a free service for qualifying rural families provided by volunteer pilots
- CareFlight is usually arranged by the Primary Team
- Little Wings Children's Charity provides flight and ground transport for children returning from hospital to home in rural and remote locations

7 Providing Care At Home

7.1 Palliative Care

When a child's illness is life limiting but it is anticipated survival will be a number of years, clinicians will endeavour to ensure that support options in the community are known to the family. The SPPC will continue to make regular contact with the family and assist by providing guidance. Symptom management will predominately be managed by treating team with palliative care taking an advisory role. Should the child's condition change, the support offered will be reviewed and changes to their plan of care made. The child's care will be discussed on a regular basis with the child's primary care team and community support services.

7.2 End of Life Care

When a child at home is deteriorating or has reached the end of life stage of illness, increased support will be offered. . SPPC will complete a palliative care management plan that will contain detailed information about symptom management (including symptom escalation and pre-emptive medication administration), and emergency contact details families are able to access. Health professionals involved in supporting the family at home will have access to SPPC advice during business and after hours when needed.

7.3 Psychosocial Family Support

In most circumstances, a psychosocial assessment will be done for families by their primary team and/or the palliative care team. Palliative care will provide continual psychosocial support to families at home.

7.4 Spiritual Support

Spirituality is an important aspect of palliative care and should always be explored with each family. Spiritual beliefs and practices will differ for each family; these will often influence care planning and decision making for their child.

7.5 Medical Record documentation

All communication (home visits/telehealth interventions) to a family must be documented in the patient's electronic medical record.

8 Respite Care

The need for respite support should be discussed with families. 'In home' respite options will vary and may be accessible through NDIS depending on the child's illness and/or other individual family circumstances. Out of home respite care is offered at Bear Cottage (hospice) and at some other institutions. The Palliative Care Social Worker has access to further information about respite options when needed.

9 Palliative Procedures at Home

SPPC does not provide blood product support or IV Fluids in the home. The following guidelines may be utilised in the home:

9.1.1 Administration of IV Medications

- Home Intravenous Medication: Parent/Carer Administration Parent/Carer Guideline [CHW]:

  or

- Home Intravenous Antibiotic Administration for Hospital in the Home Practice Guideline SCHN
- Insertion and Care of a Feeding Tube at Home Guideline

9.1.2 Central Venous Access Devices

- See SCHN Central Venous Access Devices (CVAD) Practice Guideline

9.1.3 Gastrostomy Home Care

- SCHN Gastrostomy Homecare Guideline
- SCHN Indwelling Urinary Catheter at Home Guideline

10 Nutritional Support

As a child approaches the end of their life, loss of appetite and feeding issues (e.g. feeding intolerance), may be a major source of distress for families. Feeding goals of care change to focus on the child's comfort. The palliative care team will work with the primary team/ paediatrician and the parents/carer to optimise the child's comfort during this time. Please see:

- SCHN Gastrostomy Homecare Guideline
- SCHN Parental Nutrition Practice Guideline

11 Equipment Supply

Supply of equipment for children receiving palliative care follows the same process as any child receiving care at home.

11.1 Oxygen

Supply and administration of oxygen for children receiving palliative care is provided by a referral to the Respiratory Support Service (CHW). The Primary Team (SCH) will organise oxygen prior to patient discharge with the Care Continuum Coordinator

If a child is dying the parameters for supply may be different than described within the procedure. This should be discussed with the palliative care service.

See SCHN Oxygen Therapy and Delivery Devices Policy.

11.2 Suction Units/Feeding Pumps

There may be certain costs involved for equipment and medical supplies that are needed to care for a child at home; these need to be discussed with families by relevant hospital staff prior to dischargef. Please refer to:

SCHN Equipment Hire from the Equipment Loan Pools Procedure

11.3 Beds/Chairs/Bathing Equipment

It is recommended that Allied Health staff review a child prior to discharge to assess equipment needs or advise on home modifications that are needed to ensure that care can be provided safely in the home setting.

11.4 Consumables

Supplies (e.g. NG tubes, syringes, suction catheters) can be provided on discharge through either The Appliance Centre (CHW) or HELP (SCH). Appropriate forms need to be completed. There may be a fee attached.

11.5 Costs

This will vary depending on the equipment needed and the circumstances of each family. If the family requires financial assistance a financial assessment may need to be completed by the social worker. There may also be charitable organisations who can help with short term equipment needs. The Social Work Department can provide advice on this.

Patients who have a disability may be entitled to obtain equipment under the ENABLE Program or coordinated through their NDIS package.

Medications

11.6 Medications at home

Children may experience pain at end of life and will require analgesia to manage this. Most general practitioners are not used to prescribing opioids for children and therefore these are dispensedvia the hospital pharmacy. Arrangements are made for the family to collect these medications from the hospital or for them to be delivered to home. See Section 13 Symptom Management for further information.

11.7 Dosing Information

For information relating to doses, refer Meds 4 Kids Dosing Guideline (CHW) or SCH Drug Formulary

11.8 Subcutaneous/IV Medications

Subcutaneous or IV medications are useful when administration of medications by the oral route is not possible. This will ensure effective symptom control is maintained. Circumstances requiring change to alternative routes include:

- Swallowing difficulties
- Inability to tolerate oral medications e.g. nausea, vomiting
- Rapid dose titration
- Intestinal obstruction
- Comatose patients or those with decreased level of consciousness, due to disease progression or sedation
- Terminal stage of illness – during the final 48 hours of life many patients are unable to continue oral medications.

Children may have Central Venous Access Devices (CVAD) (e.g. port or central line) during their period of active treatment. Consideration may be given to insertion of a CVAD for pain and symptom management in children who do not already have a CVAD on an individual basis. The subcutaneous route is an alternative which alleviates the need for a CVAD.

Some children may be cared for by community and palliative care services which may prefer to use a continuous infusion via a syringe driver. In this case breakthrough doses can be given to children either orally or subcutaneously.

11.9 Disposal of Unused Drugs

The palliative care team should discuss options for safe disposal of medications with the family or the community supporting team. See Medication Handling in NSW Public Health Facilities Policy

12 Symptom Management

A symptom management plan will be developed for each child where required.

The adequate, proficient and timely management of symptoms is of critical importance. Not only is it important from a humanitarian viewpoint, but also it is apparent that the memory of unrelieved symptoms in dying children may be retained by parents many years after their child has died[3]. When physical symptomatology has been adequately treated, children and their families are better supported to negotiate the domains of psychological and spiritual care.

Medications should be reviewed regularly to ensure that unnecessary treatments are ceased (as they may add extra burden to care, and contribute to other symptoms such as nausea and lethargy). Parents/carers should be educated in the administration of medications where possible. Adolescents will sometimes share responsibility for administration of their medications with their parents/carers.

12.1 Pain

Pain is one of the most feared and distressing symptoms that children and parents/carers' experience. It is a symptom recognised by and given high priority by the World Health Organisation[4].

When assessing pain in neonates and children, staff should use recognised pain tools

For older children, where possible, a pain assessment using a validated pain assessment tool should be done before adjusting analgesic doses of children at home.

Non pharmacological methods of pain control should be considered in every child with pain management issues.

The oral route of administration should be used where possible. Regular doses of analgesia should be given around the clock for children with constant pain. PRN "as needed" dosing is the basis for the management of incident and breakthrough pain. Parents / carers should be encouraged to record the number, time and circumstance of breakthrough doses to assist analgesia management.

- Pain Management Guidelines [CHW]
- Opioid Management - SCH

12.1.1 Pain Crisis

A pain crisis in palliative care is an emergency. A documented plan needs to be in place should this be anticipated.

12.1.2 Interventional Methods of Analgesia

Interventional methods of analgesia may be considered in patients where pain is not controlled by analgesics prescribed by the palliative care team. A hospital admission is required for these rare interventions.

12.1.3 Sedation as a Therapeutic Modality for Intractable Pain

The use of sedation in the setting of refractory pain generally assumes that therapies beyond the conventional have been utilised and that there is no acceptable means of providing analgesia without compromising consciousness. This trade-off between sedation and inadequate pain relief requires the consideration of the wishes of the child and his or her family. The ethical issues surrounding prolonged sedation in paediatrics, including the principle of double effect have been reviewed previously[5]. The continuation of high-dose opioid infusions in these circumstances is recommended to avoid situations in which a patient may have unrelieved pain but inadequate clarity to express pain perception. A variety of drugs have been used in this setting, including barbiturates, benzodiazepines, and phenothiazines.

12.2 Dyspnoea

Dyspnoea, which has been defined as "an uncomfortable awareness of breathing"[6], is more common and often more severe in the last few weeks before death[7]. It is often distressing to the patient and difficult for the family to watch. Additional support may be needed.

Terminal dyspnoea may be due to a variety, and perhaps combination, of causes. These include pulmonary metastases, intrinsic lung disease or infection, cardiac failure, acidosis, muscle weakness etc. Diagnosis is important as this may influence choice of therapies. Noninvasive ventilation may be a viable choice for symptom management of dyspnoea related to muscle weakness, for example, and bronchospasm could be easily reversed with bronchodilators.

The goal of palliative therapies for dyspnoea is to improve the patient's subjective sensation. Systemic opioid therapy and cognitive-behavioural strategies and simple measures such as the use of a fan[8] have been shown to be of benefit to patients with dyspnoea. As anxiety is often a component of dyspnoea, judicious prescription of a benzodiazepine may be warranted.

12.3 Constipation

Constipation is a relatively common symptom in children receiving palliative care. The aetiology of constipation is often multi-factorial and may include reduced physical activity, mechanical obstruction, metabolic derangement, poor diet and low fluid intake, bowel atony due to opioids. Bowel obstruction and faecal impaction, though unusual must be excluded and treated urgently in any child presenting with constipation. Constipation may also cause faecal overflow, urinary retention and pain.

Management of constipation may include:

- Dietary changes
- Appropriate hydration
- Increased mobility where feasible
- Introduction or review of laxatives
- Appropriate facilitation of activities of daily living and toileting facilities

12.4 Seizures

Seizures in palliative care patients may be either recent in onset or part of a long-standing underlying seizure disorder. Where possible it is important to identify the cause and implement appropriate anti convulsant therapy. Where they are part of a long-standing disorder, an increase in seizure activity may indicate either disease progression or factors related to anti-convulsant dosage, class, or administration which should be reviewed.

- Buccal/Intranasal Midazolam is a good first line agent for breakthrough seizure management[9] where seizures are not controlled by prescribed anticonvulsants. Management of these See SCHN Seizures Acute Management In Infants and Children Practice Guideline

12.5 Nausea and Vomiting

Nausea and vomiting are common in children receiving palliative care. They occur when the vomiting centre in the brain is activated by any of the following:

- Cerebral cortex (e.g. anxiety)
- Vestibular apparatus
- Chemoreceptor trigger zone (CTZ)
- Vagus nerve, or

- By direct action on the vomiting centre

Determining the aetiology will help direct therapy as the list of potential causes is great and therapies differ, depending on the putative mechanism.

Commonly used anti-emetics include ondansetron (wafer, tablet and syrup), metoclopramide (syrup and tablets) and cyclizine. Extra-pyramidal side effects should be observed for when a child is commenced on metoclopramide. These effects can be reversed with benztropine.

Cyclizine is an effective 2nd line anti-emetic particularly in children with central nervous system pathology.

Other 2nd and 3rd line options for anti-emetics include haloperidol, levomepromazine and lorazepam. Consultation with the Palliative Care Service is advised before commencing these medications.

A Special Access Scheme Form needs to be completed to access some of these medications (e.g. cyclizine, and levomepromazine).

Ondansetron, metoclopramide, cyclizine, haloperidol and levomepromazine can all be administered by the subcutaneous or intravenous route. They can be given as a bolus or as part of an infusion.

12.6 Secretions

Secretions can be a significant symptom in some children which may or may not require intervention. Individual assessment is required and management may include positioning, suctioning and possibly anticholinergics. In the terminal phase, noisy secretions should be discussed with the family because of the potential for family distress. Hyoscine hydrobromide and glycopyrrolate are the most commonly used anticholinergics.

12.7 Bleeding

Families and carers of children dying of either haematological malignancy or liver failure may fear external bleeding. This mode of death in childhood is rare. Where significant bleeding is a potential issue, an appropriate documented management plan needs to be in place e.g. crisis medication and use of dark towels.

12.8 Mouth Care

Routine mouth care promotes patient comfort and ability to eat and drink, prevents halitosis and helps identify problems such as dry mouth, candidiasis and ulceration[10]. Lip emollients and mouthwashes are important therapies for mouth care. The sensation of a dry mouth may be due to local causes (e.g. mouth breathing, candidiasis, radiotherapy to salivary glands etc.) or systemic causes (e.g. dehydration, anticholinergic drugs uraemia etc.).

12.9 Hydration

The issue of hydration in palliative care patients is complex. As with all therapies, the benefits and deficits of any intervention must be discussed with the patient and family before any therapeutic intervention is implemented[11].

IV fluids are not given at home to children receiving palliative care.

12.10 Pressure Area and Skin Care

Appropriate maintenance of skin integrity includes education regarding the monitoring of skin integrity and the provision of a skin care regime. This may include assessment for the use of equipment e.g. pressure care mattress and hoists.

12.11 Terminal Delirium

Delirium during the final phase of dying is very rare in children. Management will be determined by aetiology. Use of non-pharmacological approaches and optimising pain relief is often beneficial in this setting. These may include the use of imagery, relaxation, massage, being present and comforting the child.

12.12 Anxiety

Children often experience grief, depression and a sense of loss and hope at their time of death. Allowing a child to talk openly about their feelings with people they trust can help alleviate anxiety and misconceptions. Additionally, fears that the child may have include pain and being alone. Reassurance and including them in the planning process of pain management may assist them to feel less powerless and helpless and more in control[12].

12.13 Insomnia

The aetiology of insomnia is multi-factorial and is often a combination of physical, psychological and perhaps environmental factors. When depression is a factor, consideration should be given to psychotherapy and pharmacologic treatment. Lifestyle changes, including improved sleep hygiene and activity may be helpful to improve sleep. Low doses of melatonin are often helpful pharmacologic agents for the management of insomnia in terminally ill children.

12.14 Fatigue

The aetiology of fatigue in children may be due to a combination of factors including: anaemia, poor nutrition, insomnia, metabolic derangement, the increased work of breathing in children with dyspnoea, side-effects of medication, and psychological factors[13].

In the assessment of fatigue in a child, and the matrix of its potential causes, it is important to establish if this symptom is distressing to the child and/or his family. If so, the potential remediable causes should be considered. Therapies directed at the primary cause should be instituted only if these therapies are not of substantial burden to the patient and/or his family.

13 Special Issues

13.1 Palliative Care of the Neonate

Home care is an option for delivery of palliative care services for newborns. Specific considerations are required for neonatal management at home. These are coordinated prior to discharge. It is important that neonates have a paediatrician identified and a plan for readmission in case required.

13.2 Adolescent and Teenage Issues

Palliative Care of an adolescent or teenager follows the same process as any other palliative patient. Issues for particular consideration include:

- Consent
- Transition to adult services
- Need for increased independence in decision making
- Fertility and sex issues
- Transition to Adult Services (see SCHN Transition and Trapeze Practice Guideline)

13.2.1 Consent

See the following guideline:

- SCHN Consent to Medical Treatment: Patient Information Policy

13.2.2 Giving of Information

Before giving information to an adolescent, the maintenance of family integrity should be considered. It is prudent to attain family agreement regarding disclosure of information that is consistent with that particular family's usual way of communication and will not cause the adolescent or caregiver undue distress. However, a child over 14 has the legal right to be given information regarding their condition. This needs to be considered if the child is asking for information, even if it is in conflict with the wishes of the parents/caregivers.

13.3 School support

Support or advice for schools can be arranged through the PPC team and contact will require permission from the parent/ carer. The NSW Department of Education has specific policies for the management of health related issues of students. The SPPC team will work with schools within their existing guidelines and in conjunction with parents/carers to support children and siblings in the educational setting.

- School visiting or telehealth support may be needed to offer advice about:
    - Speaking with classmates about the child's illness
    - Symptom management
    - Supporting school attendance (as this can be an important goal of care for the child and family)
    - The school staff will also be given advice and information regarding death and bereavement support

13.4 Families located in regional and rural locations

Comprehensive community connections are vital for the care of families who are located in regional and rural locations. Preferably a designated local care coordinator is identified, usually a nurse. Initially a case meeting (either face to face or via telehealth) is recommended to support the continuity of care and to ensure there is a clear plan for how the team will work together for the child and family's wellbeing. Key people in the care of these children and families could include:

- GP - the GP is primarily responsible for prescriptions, ongoing physical assessment, family support and death certificates
- Paediatrician – supports the family in ongoing assessment of the child's physical status and works with the GP to provide that support.
- Community Nursing/Palliative Nursing - Community nursing (CN) will be the first contact and when appropriate they will refer to the Community palliative services. The CN will contact either the primary team or paediatric palliative team CNC's regularly to obtain support and guidance and provide updates to SCHN on the child's condition.
- Local Hospital – If the child is approaching end of life it is possible the family may access the service of the local hospital. These hospitals are often not use to caring for children who are dying and regular SCHN clinical support will be maintained via regular telehealth consultations
- Allied Health Services – Local allied health services are usually available.

13.4.1 Family Support in Rural Locations

The child's primary team and appropriate palliative care services will continue to contact the family to offer ongoing telehealth support. After the initial visit, home visits can be arranged intermittently if required by the family or the community team.

The local community team will be the main providers of care and symptom support. Any contact between SCHN and the family should be relayed to the community team to foster strong networks of care around the child and family

13.4.2 Specific Cultural Issues

The health care professional should be assess and have a strong understanding of each family's cultural and other beliefs and respond to them accordingly.

13.4.3 Patients who identify as Aboriginal or Torres Strait Islander

The needs of patients and their families who identify as Aboriginal or Torres Strait Islander need to be carefully considered. An Aboriginal Health Worker should be engaged in the care of these families, to ensure appropriate links are made to community based services.

13.4.4 Families for whom English is not their first language

If there is any doubt about the family's ability to communicate in or understand English, an interpreter should be engaged. The interpreter services will provide interpreters for home visits as well as telephone interpreting services.

14 Management of Emergencies

14.1 Care in Emergency Department (ED)

A child receiving palliative care who presents to ED should be assessed and treated the same as usual ED protocol, even during end of life care. In order to determine cause of symptoms, a thorough history and physical examination should be undertaken. Laboratory investigations and medical imaging should be undertaken, unless the child's physician (or PCS) in consultation with the family has requested otherwise. These children should have been previously "flagged" for ED staff to identify that they are receiving palliative care (see Section 14.2). Goals of care should be checked with the parent or carer to ensure they are still current.

Children who are receiving palliative care at home may have many clinical issues which require intervention and necessitate presentation to the ED. Unanticipated problems require assessment and possible intervention. In an emergency situation, all relevant family members or significant people may not be present to discuss the management of these symptoms. This should be considered when making a decision regarding the implementation or withholding of potentially lifesaving measures.

Many measures taken to relieve suffering, although resembling 'treatment' can primarily alleviate physical symptoms and psychological distress that the child and/or family may be experiencing.

Unanticipated problems may include sepsis, bleeding, uncontrolled pain, seizures, dyspnoea, uncontrolled vomiting and unconsciousness (see Section 12).

14.2 Hospital Admission

The child or their family/carers may decide at any time that they no longer wish to be at home and their preferred location is hospital. Reasons may include:

- Unanticipated and uncontrolled symptom e.g. sepsis, respiratory infection, normal childhood illnesses
- Fear of being alone when the child dies
- Fatigue from lack of sleep
- A wish not to have a dead body in the house

Every effort will be made to expedite these admissions by:

- Requesting the family to notify their palliative care clinician of intention to come to hospital
- 'Fast tracking' a child through the Emergency Department by 'flagging' them in the ED records (CHW)
- Admission to PICU/NICU

If a child receiving palliative care arrives to the ED in cardiac or respiratory arrest, the goals of care should be identified in discussion with the family and primary team. Decisions to admit to PICU will be made by the ED admitting officer & PICU consultant on call in conjunction with the family and the child's physician or SPPC.

15 End of Life Care

End of life care is supported around the goals of care that have been identified by the family. Location of care can be supported at home, in hospital or at Bear Cottage.

If families have been provided with information about end of life symptoms, it will help to reduce some of their anxiety and distress experienced during this time. Even though the child may be prescribed analgesia-sedation, irregular and/or noisy breathing, prolonged periods of apnoea and colour change are common pathophysiologic accompaniments of dying over hours or even days.

15.1 End of Life Care Planning

Many families have the opportunity to enter into discussion with their primary physician or SPPC service about end of life care decisions and plans for how care will be managed in the event of an acute and/or life threatening event. These decisions are documented in the "Allow a Natural Death" or AND Form (CHW) or The NSW Resuscitation Plan-Paediatric (SCH) The information on these Plans aim to guide health professionals providing end of life care and additionally provide families with opportunity to discuss changes in their decisions which may have been previously made.

The information documented on the AND/Resuscitation Plan will provide an outline of the supportive care measures which will be initiated and maintained whilst the child is in SCHN care. These documented advanced care planning goals need to be reviewed with each new hospital admission

In the event of a cardiac or respiratory arrest, bag and mask and CPR must be implemented if this is consistent with the wishes of the family until reviewed by the appropriate medical team.

See Allow a Natural Death by Limiting the use of Life-Sustaining Treatment - CHW and Resuscitation Plans - End of Life Decisions

15.2 Symptom Management during End of Life

See section 12.

15.3 Contacts

The family of a child who is at home during the terminal phase of the child's illness will be given the contact details of the appropriate staff.

16 Organ Donations

Families expressing an interest in organ donation should be encouraged to discuss the process with their primary care team.

17 Death Of A Child

17.1 Information for Parents Following the Death of a Child

It is vital that families are provided with information to guide them about what needs to happen when their child dies outside hospital. The following information must be given:

- In special circumstances the timeframe may vary. They need to call the specified doctor for a death certificate, but this does not need to be done immediately. If, for example, the child dies during the night the family should be informed that it is alright, if they wish, to wait until the morning and spend time with their child before calling anyone.
- The family may find it helpful to make contact with the local palliative care/community team for support and guidance in these circumstances. It is helpful, but not imperative, for the family to have decided upon a funeral director before the child's death and nominate someone to be responsible for contacting them (preferably not the parents due to their distress). If necessary a list of funeral directors can be obtained from the Social Work Department. When the family are ready they will need to contact the funeral directors. Once the family have contacted the funeral directors, the funeral directors are obliged to go to the family home to collect the body. The majority of funeral directors will collect the body within a few hours. The parents should know that the funeral director is required by law to place the child's body in a bag or other culturally appropriate coverings for transport to the funeral home.
- It is helpful to inform parents that body movements and sounds may be present in the first few hours after death.

17.2 Care of the Body

The SPPC service or other staff should ensure that the family are offered the opportunity to discuss care of the body after death. Discussion points are:

- Infectious diseases/medical issues
- Washing and dressing the body
- Any cultural issues that staff need to be aware of
- Memoirs such as photos of their child, taking hand and footprints, taking a lock of their child's hair or recording their child's height and weight.

17.3 Death Certificates

When a child dies at home a medical officer, usually the child's local GP, will need to sign a Death Certificate and can issue a Cremation Certificate for the family.

In the case of neonates, a medical practitioner is responsible for completing a Medical Certificate of Cause of Perinatal Death if death occurs within 28 completed days from birth or a Medical Certificate of Cause of Death if death occurs later.

17.4 Transfer to/from home or private location after death

If the family wish to take the body to a private location they must have the Death Certificate with them.

See: NSW Policy Directive: Burials - Exemptions from Public Health Regulation 2012 for Community and Religious Reasons

17.5 Notifying the Coroner - Children who have Family and Communnity Services (FACS) Involvement

- A medical practitioner should report the child's death to the Coroner if: -
    - Any contact has been made to FACS about the child within 3 years immediately preceding the child's death

OR

-
    - Any contact has been made to FACS about any of the child's siblings within 3 years immediately preceding the child's death.
- Ministry of Health Coroners Cases and the Coroners Act 2009

AND

- SCHN Death of a Child Procedure

17.6 Post Mortem

The need for post mortem tissue sampling (skin, liver and muscle) for the purpose of disease diagnosis and genetic counselling should have been anticipated and these procedures must be performed within two hours of death.

- Primary teams should be guided by SCHN Death of a Child Procedure

After Hours Plan

Ensure the family understands the after-hours plan if a post mortem is to be carried out.

18 Bereavement Follow Up

A bereavement support person should be identified for each family in order to ensure there is a comprehensive, appropriate bereavement support plan of care in place. This may include:

- Home visits following the death of the child
- Individual bereavement counselling sessions
- Parent support group
- Sibling support groups
- Information in the form of literature or books

- Referral to outside bereavement agencies
- Memorial Day at CHW and SCH annually
- Phone calls and cards to the family

19 Service Evaluation and Quality Improvement

The provision of palliative care and support at home will be evaluated on a regular basis. This will involve consultation with parents/carers and other health professionals (hospital and community based) also involved in care. Feedback provided by consumers will be utilised to guide continual service improvement.

20 Incident and Complaints Management

20.1 Incidents

All clinical incidents will be recorded in the Incident Information Management System (IIMS) as outlined in SCHN Incident Management Policy

20.2 Complaints

The following policies and procedures will be utilised to manage complaints for patients and families receiving specialist level 3 palliative care services at home

- SCHN Patient Complaints Management Policy
- SCHN Patient Complaints Management Procedure
- SCHN Managing Complains and Concerns about Clinicians

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