

PALLIATIVE CARE FOR INPATIENTS

PRACTICE GUIDELINE[®]

DOCUMENT SUMMARY/KEY POINTS

- The purpose of this document is to provide information for:
 - SCHN Palliative Care staff to guide care for inpatients at Westmead, Randwick Campuses or Bear Cottage.
 - Other SCHN staff who are involved in the provision of inpatient care to paediatric palliative care patients and families.
- Palliative care encompasses the physical, emotional, psychosocial and spiritual care of a child with a life limiting illness within the context of his or her family.
- Palliative care services are flexible and can be provided to children at home, in hospital and at Bear Cottage (hospice) by the Sydney Children's Hospitals Network (SCHN). This practice guideline should be read in conjunction with the [SCHN Palliative Care at Home Practice Guideline](#).
- Palliative Care includes the provision of competent symptom management for the duration of palliative care including end of life care.
- Palliative care is a consultative service that works in conjunction with the primary team and other community support services throughout the child's illness.
- Medical after hours telephone support is available for clinicians (only) caring for a child receiving palliative care via NSW PPC Programme Medical On-Call Service. This service is accessed via the hospital switchboards at CHW, SCH or JHCH.
- After hours nursing telephone support is available to families of children receiving palliative care who have an unforeseen issue via Bear Cottage on 0429 896 586
- Bereavement support services are offered to all families following the death of a child.

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.

Approved by:	SCHN Policy, Procedure and Guideline Committee	
Date Effective:	1 st August 2021	Review Period: 3 years
Team Leader:	Quality Manager	Area/Dept: Pain & Palliative Care Services

CHANGE SUMMARY

- Staffing updates including Palliative Care, Chronic and Complex Aboriginal Health Worker role information
- NSW Ambulance transport information has been included in the document
- SCHN opioid preparation table has been removed and reference guidance links provided to Meds4Kids (CHW) & SCH Formulary/CIAP online
- Inclusion of Bear Cottage Nursing After Hours Support for families
- The National Consensus Statement: Essential Elements for Safe and High Quality End of Life Care link has been included in the document
- NSW Health End of Life and Palliative Care Framework 2019-2024 link has been included in this document
- Updated links

READ ACKNOWLEDGEMENT

- All staff working in Specialist Paediatric Palliative Care Services (SPPC) are to read and acknowledge they understand the contents of this document.
- Other clinical staff should be aware of 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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1 Definitions

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 a life limiting 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 and in the context of his or her family. It may be provided for a few hours or over many years. Although death is the expected and usual outcome, death is not always inevitable. Some children will be discharged or transition into adult services and others unexpectedly recover as prognostication in children is often difficult.

The WHO definition and principles of palliative care appropriate for children and their families are as follows; (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 includes supporting families and carers.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- The goal for health professionals is to assess 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 with limited resources.

This document refers to palliative care for inpatients however, the SPPC service also supports patient and family care in the community setting (including metropolitan/regional and rural locations) to ensure care can be provided at home or as close to home as possible.

SPPC are consultative, available on both campuses and offers support and guidance to a child's primary care team in the provision of palliative care. It may also provide direct support to the child and family.

Supportive Care

In cases when a decision to refer to palliative care has not yet been reached, the team can provide guidance on symptoms and other support to staff.

Child/Children

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

SPPC Service (SPPC)

Level 3 tertiary services specialising in paediatric palliative care.

2 Palliative Care Guidance Documents

The principles contained in the RACP's "[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](#)" are supported by the Specialist Paediatric Palliative Care Services at SCHN.

The [National Consensus Statement: Essential Elements for Safe and High Quality Paediatric End of Life Care](#) document outlines the key principles to ensure an optimal standard of care is available to children with a life limiting illness receiving end of life care and their families. [NSW Health End of Life and Palliative Care Framework 2019-2024](#) outlines the key priority areas to improve the delivery of accessible, high quality, end of life and palliative care.

3 SCHN Palliative Care

The SPPC Services are consultative services that offer support and guidance to a child's primary care team in the provision of palliative care, as well as providing direct support to the child and family. Palliative care services are offered across the spectrum of hospital, community and hospice care.

This document provides guidelines for the management of children receiving support from the SPPC Service as an inpatient of SCHN Randwick or Westmead campuses. Hospice care (respite and/or end of life care) can be provided at Bear Cottage, Manly. See [Section 11](#) for details about Bear Cottage.

For services provided at home, see [SCHN Palliative Care at Home Practice Guideline](#).

4 Criteria for Receiving Palliative Care Services

Criteria for inclusion:

- Children with life limiting illnesses.
- Children for whom a decision has been made to forgo life sustaining treatment.
- Children for whom the primary team require symptomatic advice only (child may be referred to Palliative Care at a later date).
- Children who have an illness that is not primarily life threatening, e.g. cerebral palsy, but may have concurrent factors that increase their risk of dying. These could include, for example, chronic and life threatening respiratory infections, sepsis or uncontrolled seizures which decrease life expectancy. These children would be considered on an individual basis for access to SPPC services.
- Children who have a high risk of dying but have a potentially curative therapy available (e.g. liver transplant).
- If a child is over 16 years of age and up to age of 18 years, but remains under the care of a physician within the SCHN, they will continue to have access to SPPC.

Refer to [Transition and Trapeze Policy](#) for information related to patient transition process.

5 SCHN Palliative Care Staffing Roles

The SPPC Service is provided by teams which include:

- Head of Department
- Palliative Care Co-Lead Manager
- Staff Specialist
- Fellow
- Nurse Practitioner/Transitional Nurse Practitioner
- Clinical Nurse Consultant
- Social Worker
- Bereavement Coordinator/Counsellor
- Physiotherapist
- Occupational Therapist
- Music Therapist
- Child Life Therapist

Non-clinical services:

- Volunteer Coordinator
- Aboriginal Health Worker
- Administrative officer

As a minimum, families receiving support from the SPPC Service can expect:

- Comprehensive medical assessment and symptom management
- Care co-ordination, planning and support regarding treatment goals and plans
- Psychosocial and financial assessment and support, including links to appropriate services (such as NDIS)
- Ongoing home visiting support where possible following discharge from hospital and ongoing email and telehealth contact with the family
- Coordinated referrals to appropriate community services
- Identification and provision of appropriate emotional, psychosocial and spiritual support
- End of life discussions, if and when appropriate, in discussion with primary care providers
- Bereavement follow up after the death of their child. This may be provided by telehealth support, home visiting or by coordinating links to appropriate bereavement support services

6 Providing Palliative Care

The provision of SPPC Service aims to support a child and their family in the location of the family's choice. The provision of palliative care requires:

- Family centred preparation and planning.
- Flexible care arrangements which provide families with the specific support they require to manage a difficult and stressful life experience.

For full details see the [SCHN Palliative Care at Home Practice Guideline](#)

6.1 SPPC Contact Details (Including After-hours)

Staff requiring further information about the SPPC Service can contact:

Business Hours

- **At CHW:** Page 6794/6322 - Palliative Care Nursing, Mon-Fri 8am-4.30pm
- **At SCH:** Page 44640 Palliative Care Nursing Mon-Fri 08:30-5:00pm

After Hours PPC Medical On-Call

Provides a state-wide telephone advice service to all health professionals in NSW & ACT for palliative care issues that occur outside of standard business hours. Patients can be known or unknown to one of the specialist PPC services at SCHN or John Hunter Children's Hospital, Newcastle.

If the patient is admitted and requires After Hours Medical On-Call advice:

- Approval from the managing consultant is required before contacting the After Hours Medical PPC On-Call
- Contact should be made by a medical officer
- For complex symptom issues, the medical officer should consider including the bedside RN when discussing patient care with the on-call paediatric palliative care doctor

(Please note that for COMMUNITY patients, any health professional can contact the After Hours PPC Medical On-Call.

6.2 Referral to the SPPCS

A palliative care referral is made via a medical consult order on Powerchart. The referral must be approved by the child's primary team AMO and the palliative care service must be notified by phone that a referral has been made.

Any member of the palliative care service can be notified of the referral.

- Urgent referrals should be discussed with the Palliative Care Consultant/Fellow and will be seen within 24 hours; non-urgent referrals will be seen in liaison with the primary team.

Reasons for referral may include:

- Palliative care assessment
- Advanced care planning
- Community care planning
- Social support
- End of life care
- Support for grief and loss

6.3 Role of Specialist Palliative Care Clinicians in Palliative Care and Family Support

Following a referral to palliative care, the SPCC clinicians will work with the child and family to identify areas of need and develop a management plan when appropriate to ensure that those needs are met

At SCH, the first meeting is usually with the team member whose expertise the child and family most requires.

At CHW the first meeting is usually with as many members of the palliative care multi-disciplinary team as possible.

- The initial meeting with the family will serve to:
 - introduce the team
 - explain the meaning of palliative care in the context of their child's illness
 - identify the family's needs and expectations of the team
 - provide the family with contact details and service information resources
 - discuss current symptoms and proposed management
 - explore ways to provide psychosocial /spiritual support
 - determine the need for social work involvement to provide a comprehensive social assessment and support of the family.
 - liaise with family about engaging community services including community medical/nursing/allied health services
 - determine need for respite services including Bear Cottage
 - assess the need for a Palliative Care Family Support Volunteer
- The following issues around end of life care documentation also need to be considered and based on individual child /family needs or wishes:
 - **CHW:** Completion of an "Allow a Natural Death" (AND) Plan in conjunction with their primary team. If the child is going to receive care at another hospital, a statewide Resuscitation Plan-Paediatric should also be completed
 - **SCH:** Completion of the Statewide Resuscitation Plan-Paediatric/Adult
 - If there have been no discussions/decisions about resuscitation or end of life care then a 'NSW Ambulance Authorised Paediatric General Care Plan (P6)' can be completed ensuring the child is taken to the most appropriate hospital/facility
- Ongoing provision of care when the child is discharged from hospital may include:

- planning for monitoring and managing symptoms
- identifying community groups/support
- establishing and supporting, where possible, the hopes and wishes of the child and family
- actively promoting ongoing contact with the primary team
- flagging patient for Emergency Department presentations, where appropriate
- identifying spiritual or cultural requirements/supports especially for end of life care e.g. transporting a body after death

6.4 Nutritional Needs

Children are encouraged to continue with normal nutrition as tolerated and a SCHN dietician may liaise with the family to help optimise the child's nutrition. During end of life, loss of appetite is a normal part of the dying process and this may create distress for families. The child's comfort and prognosis (hours, weeks, months or years) is a consideration when discussing options for nutritional support of the child.

In most circumstances, SPPC will support the continuation of nasogastric/PEG feeds. A PEG tube procedure will sometimes be carried out to provide the needed nutrition throughout the illness of the child.

6.5 Psychosocial Family Support

The SPPC clinicians will ask families about their existing support networks. A social worker will be available for the family either through the primary team or SPPC service. Referrals for psychological support can be made through the Psychology Department (SCH), or Department of Psychological Medicine (CHW). If families request or require further support the SPPC Service will make every effort to ensure they are connected with an appropriate provider. In most circumstances, a psychosocial assessment will be completed with families caring for a child with a life limiting illness.

6.6 Spiritual Care

Spirituality is a universal human expression. It is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. It is different from religion, though this provides a spiritual expression and spiritual community for some people. Spirituality can help people make sense of their lives.

The SPPC clinicians will explore the meaning of spirituality and the role of religious and/or spiritual care networks with each family. If the family has religious connections they will often have pre-established connections to these groups. The SPPC Service or clinicians involved can help liaise with these groups if required. Spiritual communities can, in some cases, have a major role in the family's decision-making process and this should be assessed on an individual basis with each family and if necessary a meeting with them arranged.

6.7 Allied Health

Palliative care allied health staff liaise with primary teams and therapists who may already be involved with the child and family to facilitate continuity of care and provide appropriate support.

Physiotherapy, Occupational Therapy, Child Life Therapy, Music Therapy and Social Work are part of the SPPC multidisciplinary services and are available to consult and provide services to children referred to the team. Referrals to speech therapy, dietetics and orthotics may also be required and this would be done in consultation with the primary team.

6.8 End of Life Care

The role of the SPPC Service in end of life care will depend on the length of involvement with child and family. This may range from helping to coordinate a ward admission (to a ward known to and pre-arranged with the family) to avoid unnecessary distress through to advice / providing symptom management in a terminal care phase.

6.9 Medical Record Keeping

All palliative care interventions with the child and family should be documented in the child's electronic medical record. For documentation after the death of child please refer to [SCHN Death of a Child Policy](#).

7 Medications

7.1 Dosing Information

For information relating to doses, refer to:

- **At CHW:** [CHW Meds 4 Kids](#)
- **At SCH:** [Australian Medicines Handbook –Children's Dosing Companion](#) on the Clinical Information Access Portal (CIAP). For specific information on medications for symptom management see [Section 8](#).

7.2 Subcutaneous/IV Medications

When administration of medications by the oral route is not possible, it is necessary to change the route of administration to maintain effective symptom control. Circumstances requiring change to alternative routes include:

- swallowing difficulties
- inability to tolerate oral medications e.g. nausea, vomiting, malabsorption
- 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

Some children have Central Venous Access Devices (CVAD) (e.g. infusaport or central venous catheters) during their period of active treatment. Careful consideration in conjunction with the primary team should be given to insertion of a CVAD for pain and symptom management in children who do not already have a CVAD- particularly those with significant escalations in pain. This will occur on an individual basis. The subcutaneous route is an alternative which removes the need for a CVAD. If the child is to be discharged home, consideration to the local policy of community nursing services is given to determine parental routes of medical administration

8 Symptom Management

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 in the memory of parents many years after their child has died². It will be impossible for children and their families to negotiate the domains of psychological and spiritual care if physical symptomatology has not been adequately treated. Consult with the Pharmacy Department at either site for support to provide appropriate medicines and formulations for the child. Upon discharge for children with complex medication regimens ask Pharmacy to prepare a medication list for the carers

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. To obtain symptom control unusual doses of medications can be required. Please consult with the Palliative Care team if doses outside of the reference range are prescribed.

8.1 Pain

Pain that cannot be relieved using conventional treatment is intractable. Intractable pain that does not respond to therapies beyond conventional practice is refractory. The relief of refractory pain may require a therapy that compromises consciousness. The modalities of pain control for the management of intractable pain in paediatric patients include opioid dose titration, adjuvant analgesics, regional anaesthesia, and sedation. Non-pharmacologic methods of pain control have a secondary role in the setting of intractable pain.

When assessing pain, staff should use recognised pain assessment tools. For information about pain assessment tools see:

- [Pain Management Guideline-CHW](#).

Where possible, the oral route of administration is used. Regular doses of analgesia should be given by the clock for patients who have constant pain (e.g. BD, 4 hourly, every 12 hours) irrespective of whether the patient has pain. PRN or breakthrough dosing is to be used on an “as needed” basis for the management of incident and breakthrough pain.

8.1.1 Oral Analgesia

For mild pain, paracetamol or a non-steroidal anti-inflammatory drug (NSAID) can be used. Ibuprofen is often the NSAID of choice in children. Caution should be exercised when prescribing paracetamol to children with liver dysfunction or for extended periods of time. Care should also be exercised when prescribing NSAIDs to children with renal impairment, dehydration, poor oral intake, heart failure, severe asthma and peptic ulceration. NSAIDs should also be avoided in children with cancer who are thrombocytopenic.

For moderate to severe pain, an opioid analgesic is used. Morphine mixture or oxycodone are the first line agents. Oxycodone is available as tablets (Endone[®]) or capsules/liquid formulation (OxyNorm[®]). The medication can be given on an as required basis or regularly. The dosing interval is generally 4 – 6 hours. However if a child has persistent severe pain the dosing frequency can be increased to 1 – 2 hourly.

If a child is requiring a short acting opioid regularly and their analgesic requirements have stabilised they can be converted to a long acting preparation. Oxycodone preparations (Oxycontin[®] and Targin[®]) are only available in tablet form. Consult the Pharmacy Department for use of other alternate opioid sustained release options. The total daily dose of short acting opioid is halved to give the morning and evening dose of a long acting preparation. In addition to the long acting dose a break through dose of a short acting drug can still be given every 1 – 2 hours for breakthrough or incidental pain. This dose is generally 1/6 to 1/10 of the total daily dose of regular opioid.

Other opioid preparations are available at the hospital including hydromorphone and fentanyl patches and sublingual sprays. Methadone is another agent which can be particularly effective when other agents have failed. Consultation with the SPPC Service should occur before these are prescribed by treating teams.

Particular consideration should also be given to using adjuvant agents when there is evidence of neuropathic pain. Agents that may be considered include amitriptyline, pregabalin and gabapentin.

For SCHN opioid preparations please refer to:

CHW: [Meds 4 Kids - Dosing Guide](#)

SCH: http://seslhnweb/Pharmacy/Online_Formulary/ & CIAP Online (including Up to date, BNF-C and AMH-C, Micromedex)

8.1.2 Intravenous/Subcutaneous Analgesia

Opioids

Children will often require a background infusion to provide a consistent dose of drug over a 24 hour period. In addition to the background infusion, additional doses for “breakthrough” and “incident” pain (e.g. pain on moving and coughing) need to be available. Where possible, patient controlled analgesia (PCA) is used. This refers to an infusion device, which can be activated by the patient to self-administer a pre-set bolus of the drug. In younger and cognitively impaired children, nurses will activate the infusion device (NCA). The PCA allows some control over the wide and often unexpected analgesic requirements of individual children by allowing for additional analgesia as required.

The daily dose of parenteral morphine for children who are already on morphine is 1/3 of their total daily dose of oral morphine. Breakthrough doses of opioid may be calculated as approximately 5% to 10% of the total daily opioid requirement. The PCA device must be programmed to deliver an opioid dose at a predetermined frequency, with a maximum total dose over a set time period. PCA use should be determined on an individual basis with age 7 being a common age of effective use.

Guidelines for the initial prescription of opioids can be found:

- **At CHW:** [Pain Management - CHW Practice Guideline](#).
- **At SCH:** [Opioid Management](#)

8.1.3 Opioid Dose Escalation

If pain cannot be controlled by the opioid loading technique (above), then the subsequent opioid dose escalation may be calculated as follows:

- If greater than approximately six rescue doses of opioid are required in a 24 hour period, then the hourly average of this total daily rescue opioid should be added to the baseline opioid infusion. An alternative would be to increase the baseline infusion by 50%³.
- Rescue doses are kept as a proportion of the baseline opioid infusion rate and are re-calculated as between 50% and 200% of the hourly basal infusion rate³.

8.1.4 Opioid Switching (fentanyl, hydromorphone)

The usual indications for switching to an alternative opioid are dose-limiting opioid toxicity, insufficient analgesia or intolerable side effects (e.g. itch, nausea, neuro-toxicity). In these cases, an alternative opioid can be trialed. Options include fentanyl, hydromorphone and sometimes methadone. A switch from one opioid to another is often accompanied by change in the balance between analgesia and side-effects⁴.

Both background and bolus doses should be taken into account when switching opioids. Switching to methadone is more complex and should be discussed with the SPPC Service.

In order to limit the risk of error, prescriptions for hydromorphone must include the trade name of the preparation intended for use.

Generally, equianalgesic dosing should be halved when switching to a different opioid and retitrated upwards to meet the needs of the patient. Additional breakthrough doses may be required during this period.

Please refer to:

CHW: [Pain Management Practice Guideline](#) -Section 5.5

SCH: [Opioid Management Practice Guideline](#) -Section 7

Opioid comparative information

(Adapted from The Australian Medicine Handbook, July 2020:

<https://amhonline.amh.net.au.acs.hcn.com.au/chapters/analgesics/drugs-pain-relief/opioid-analgesics#opioids-table>)

8.1.5 Transdermal Analgesia

The transdermal route should also be considered in the case of fentanyl. A child would need to be receiving approximately 15 mg of parenteral morphine (or 45 mg of oral morphine) a day before consideration could be given to starting a 12 micrograms/hour fentanyl patch. Analgesic requirements should also be stabilised at the time of commencing a patch. Full effect of the patch takes 12 – 18 hrs after commencement of the first patch. Assistance with reducing previous opioid and when patches can be started after the last dose of the previous opioid can be obtained from the SPPC Service.

8.1.6 A Paediatric Pain Crisis

A pain crisis in a child is an emergency. A specific diagnosis must be made, as therapies directed at the primary cause may be more effective in the longer term. The management of intractable pain requires the clinician to be at the child's bedside to titrate incremental intravenous or subcutaneous doses every 10-15 minutes until effective analgesia has been achieved. The analgesic effects of opioids increase in a log-linear function, with incremental opioid dosing required until either analgesia is achieved or somnolence occurs³. The total amount of opioid administered to achieve this reduction in pain intensity is considered the opioid loading dose. A continuous infusion of opioid may need to be commenced to maintain this level of analgesia, and the infusion rate is often based on the opioid administered as a loading dose⁵. An alternative to a continuous infusion of opioid is intermittent parenteral opioid, especially in the setting of an unpredictable pain syndrome.

8.1.7 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/her family. A variety of drugs have been used in this setting, including barbiturates, benzodiazepines and phenothiazines⁶.

The ethical issues surrounding prolonged sedation in paediatrics, including the principle of double effect have been reviewed previously⁵⁻⁷. 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.

8.2 Dyspnoea

Dyspnoea, which has been defined as “an uncomfortable awareness of breathing”⁸, is more common and often more severe in the last few weeks before death. It is often not distressing to the patient however 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. Non-invasive ventilation may be a viable choice for symptom management of dyspnoea related to

muscle weakness, for example, and bronchospasm could potentially be reversed with bronchodilators.

The goal of palliative therapies for dyspnoea is to improve the patient's subjective sensation. Systemic opioid therapy^{8,9} and cognitive-behavioural strategies¹⁰ and simple measures such as use of a fan¹¹ 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.

8.3 Constipation

Constipation is a relatively common symptom in children receiving palliative care. The aetiology of constipation is often multi-factorial and may be a side effect of some medications. It can also occur due to 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

Laxatives

Movicol[®] is the most effective laxative (macrogol 3350 with electrolytes). Children will often be started on Movicol Junior[®] formulations.

Other options for managing constipation include paraffin oil emulsion (Parachoc[®] is chocolate flavoured), lactulose and Coloxyl with senna[®]. Coloxyl with senna[®] can be effective in adolescents who may not want to take liquid formulation. Microlax[®] enemas or glycerine suppositories can be considered in children unable to take medications by the oral route (caution should be exercised in children with low platelets or neutropaenia).

8.4 Seizures

Seizures in palliative care patients may be either recent in onset or part of a long-standing underlying seizure disorder. If recent in onset, it can be especially upsetting to patients and families. Seizures may be due to many possible causes (e.g. cerebral metastases, infection, metabolic disorder, hypoxia etc.) which must be excluded as treatment directed at the primary causes may be appropriate whilst anti-convulsant therapy is implemented. Where they are part of a long-standing disorder, worsening seizure control may indicate either disease progression or factors related to anti-convulsant dose, class, or administration which should be reviewed.

Seizure Management

Buccal/intranasal midazolam is the first line agent for breakthrough seizure management where seizures are not controlled by prescribed anticonvulsants. It has been shown to be as effective as rectal diazepam in the acute treatment of seizures¹².

Buccal/intranasal midazolam: 0.2 – 0.3 mg/kg (maximum 10 mg) as a single dose only, may be repeated once after 5 – 10 minutes. Maintenance drugs are usually required for seizure management (e.g. phenytoin, phenobarbital, valproate, clobazam). If frequent buccal/intranasal doses of midazolam are required, a midazolam bolus can be administered intravenously or subcutaneously. Consideration should be given to commencing a midazolam infusion at this time.

For initial treatment of status epilepticus, please refer to: [SCHN Seizures and Status Epilepticus – Management Practice Guideline](#).

The Neurological Service can advise on seizure management (contact on call Neurologist via hospital switch 9382 1111 (SCH) or 9845 0000 (CHW)).

8.5 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
- 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.

Table 3 – Nausea and Vomiting Causes and Treatments

Cause	Putative Mechanism ¹⁴	Treatment
Gastrointestinal causes: Poor mouth care Gastric irritation Intestinal obstruction Constipation Hepatic distension	Cerebral cortex, vagus Vagus Vagus Vagus Vagus	Regular mouth care Exclude drug related causes, consider prescription of H1 antagonists May require surgical opinion Laxatives (see below) Depends on aetiology (e.g. furosemide (frusemide) for cardiac failure, dexamethasone for tumour related causes)
Metabolic causes: Renal failure Hypercalcaemia	Chemoreceptor trigger zone (CTZ) CTZ	Consider anti-emetics if more invasive therapies not appropriate If appropriate, consider hydration, diuretic (osteoclast inhibitors may also be appropriate)
CNS causes: Raised intracranial pressure Vestibulitis	Vomiting centre Vestibular apparatus	Dexamethasone Antihistamine
Treatment related causes: Medications (chemotherapy, opioids etc)	Chemoreceptor trigger zone Vagus	Consider an opioid switch for dose limiting side-effects
Psychological trigger: Anxiety Emotional distress	Cerebral cortex Cerebral cortex	Consider cognitive –behavioural therapy alongside medication
Other causes: Pain Infection Migraine headache Situational triggers (unpalatable food etc)	Vagus Chemoreceptor trigger zone, Vomiting centre Vagus Cerebral cortex	Treat the primary cause Treat the primary cause Anti-migraine therapies Alter situation

8.5.1 Anti-emetics

Common anti-emetics that are used include ondansetron (wafer, tablet and syrup), metoclopramide (tablets) and cyclizine. A child should be monitored for extra-pyramidal side effects when commenced on metoclopramide. These effects can be reversed with benztropine.

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

Other options for anti-emetics include haloperidol, levomepromazine (SAS- extremely sedating) and lorazepam. Consultation with the Palliative Care Service is advised before commencing these medications.

A [TGA Special Access Scheme \(SAS\) form](#), either Category A or Category B, needs to be completed to access medications that are not registered in Australia by the TGA (e.g. 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. **Please check dosages if you are unfamiliar with these drugs.**

Compatibility with other drugs in the infusion should be checked. Access to ondansetron varies between hospitals – if you have any queries, please contact the Specialist Palliative Care team.

8.6 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, the noise created by secretions should be discussed with the family. The noise is usually not distressing to the child but may be to the family. Hyoscine hydrobromide and glycopyrrolate are the most commonly used anticholinergics¹⁵.

Hyoscine hydrobromide or glycopyrrolate are initially given as bolus doses and administered via the enteral, subcutaneous or intravenous route. Dosing is also possible by oral and transdermal routes. For information on dosing:

- **At CHW:** see [CHW Meds 4 Kids Dosage Guideline](#)
- **At SCH:** see [Australian Medicines Handbook –Children's Dosing Companion](#)

8.7 Bleeding

Families and carers of children dying from 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 management plan needs to be in place e.g. crisis medication and availability of dark towels.

8.8 Mouth Care

Routine mouth care promotes patient comfort and ability to eat and drink, prevents halitosis and helps to identify problems such as dry mouth, candidiasis and ulceration¹⁴. Lip emollients and mouthwashes are important therapies for mouth care. The sensation of a dry mouth may be due to local (e.g. mouth breathing, candidiasis, radiotherapy to salivary glands etc.) and systemic causes (e.g. dehydration, anticholinergic drugs uraemia etc.) and is often distressing.

8.9 Hydration

The issue of hydration in dying patients may be a complex issue. 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. Small but frequent volumes of fluid to maintain insensible losses may be appropriate via the oral route. However, this may be impossible in some instances unless other routes of administration are available.

8.10 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.

- See [Pressure Injury Preventions and Management Policy](#)

8.11 Terminal Delirium

Delirium during the final phase of dying is one of the most distressing symptoms for caregivers to watch, especially if the delirium is manifested as agitation. The aetiology of delirium in the setting of an actively dying patient is usually multifactorial with a physical rather than psychological basis (e.g. hypoxia, metabolic derangement, central nervous system disease, infection, fever etc.). As terminal delirium cannot be predicted, a therapeutic plan for its management should be considered in every dying child.

The usual therapies consist of haloperidol for delirium per se with consideration of adding a benzodiazepine if there is agitation as well. Use of non-pharmacological approaches and optimising pain relief is often beneficial in this setting. These may include imagery, relaxation, massage or simply being with the child allowing them to talk about their feelings.

8.12 Anxiety

Some children feel grief, depression and a sense of lost hope at their time of death. These are normal feelings, however allowing the child to talk openly about their feelings with people they trust, when appropriate, can help alleviate anxiety and misconceptions. Additionally, assumptions should not be made that all fears the child may have are about dying; instead they may be about things like pain or being alone. Reassurance, asking what they're worried about and including them in the planning process of pain management may assist them to feel less powerless or helpless and more in control¹⁶.

Anxiety, particularly at night, can be a significant symptom for children receiving palliative care. An attempt should always be made to address the underlying cause and use non-pharmacological approaches to managing this symptom. Social work and/or psychology can support families with exploring non pharmacological approaches. These may include counselling, relaxation techniques, distraction, massage, music and meditation.

Diazepam or clonazepam can be used. Clonazepam has the advantage of a longer half-life and can be administered sublingually in droplet form. Midazolam can also be administered via the buccal/ intranasal route for anxiety or agitation. These medications can also be effective in relieving dyspnoea related to anxiety.

Midazolam can also be used to treat agitation. Other alternatives for treating agitation include promethazine, haloperidol and levomepromazine (See [CHW Meds 4 Kids Dosage Guide/ SCH CIAP Online](#) including Up to date, BNF-C and AMH-C, Micromedex)

8.13 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 exercise may be helpful to improved sleep. Low doses of amitriptyline or melatonin are often helpful pharmacologic agents for the management of insomnia in terminally ill children. Amitriptyline may be helpful particularly if pain is a symptom management issue.

Note: Melatonin is available as 3 mg lozenges (immediate release) which are SAS and 2 mg SR (slow release) tablets which are registered in Australia.

Melatonin is non-formulary at SCH and approval is available for inpatient use only.

8.14 Fatigue

Fatigue is a common symptom of children with cancer¹⁷⁻²⁰ and one that is often highly distressing. The aetiology of fatigue in children may be due to a combination of factors including anaemia, poor nutrition, insomnia, metabolic derangement, increased work of breathing in children with dyspnoea, side-effects of medication, and psychological factors.

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. There are limited paediatric data on the use of stimulant medication for the treatment of opioid induced somnolence^{4, 21-23}. In children it has become more common practice to switch opioids (see above) for somnolence as a dose-limiting side-effect of opioid therapy.

9 Discharge from hospital to home

It is recommended that a referral is made as early as possible to SPPC to assist wards with discharge planning and ensure links are made to appropriate community services.

9.1 General Practitioner (GP)

Families should be encouraged to engage with their GP before, or as soon as possible after discharge. In some instances, a paediatrician will provide the support usually provided by a GP, in which case, the following also applies to the Paediatrician. In the absence of a known GP, SPPC or community nursing will usually help with locating a GP and determine if they are able to do home visits.

- GP involvement is necessary for:
 - continuity of medical follow up close to home
 - managing intercurrent problems
 - family support
 - signing of a death certificate
- Refer to:
 - [SCHN Death of a Child Procedure](#) (Coroners and Non-Coronial)
 - **or** NSW Health Policy [PD2010_054 Coroners Cases and the Coroners Act 2009](#)
- The GP must be provided with a Paediatric Palliative Care Symptom Management Plan including:
 - child's condition
 - current medications
 - estimated prognosis
 - end of life symptom management plan if appropriate

- contact details of all clinicians involved
- An authorised copy of the NSW Ambulance Plan (from SPPC) can be also provided. Families will have an authorised copy and these are sent directly to them from NSW Ambulance.
- A copy of The NSW Resuscitation Plan-Paediatric/ Adult, if appropriate (from SPPC)

9.2 Community Nursing/Community Palliative Care Referral

Most children receiving palliative care, who are discharged home, will be referred to community nursing or community palliative care. If the child is approaching the terminal phase, direct referral to the appropriate community palliative care team will be made. Referrals are made by the SPPC. Community palliative care service providers vary and are dependent on the local health district that the family reside. The SCHN palliative care clinicians will liaise regularly with community teams to offer support and provide an integrated service to the family. Unless the family are already linked to community services via their primary team, the SPPC will refer to community nursing and an initial joint visit will be made by all parties to the family home where possible.

Role of these teams:

- assist with symptom management in liaison with SPPC (SPPC will continue to prescribe medications for the child)
- equipment provisions where appropriate
- provide support via telehealth and home visiting
- provide after-hours/weekend home visiting support
- link to other community services e.g. palliative care, schools, counsellors
- When possible attend case meetings before discharge.

For more information, see [SCHN Palliative Care at Home Practice Guideline](#).

9.3 Care and management planning

When a patient is being discharged from hospital, it is essential that the relevant hospital teams ensure there is an ongoing care and management plan to support the child and family at home. Care and management planning aims to establish clear goals and lines of communication between the multiple of health teams providing care. This plan is usually in the form of a community nursing 'referral form' detailing basic information about the family and the child's history. A discharge summary may also be included when appropriate to incorporate the child's ongoing management information. The following relevant details should be included:

- Contact details of all treating health care teams
- Symptom management
- Equipment supply
- Nutritional needs

- Psychosocial family support
- Spiritual/religious support
- Palliative Care after hours support

9.4 Contact details of staff

A contact list of clinicians involved in the child's care should be included in the home management plan. This should include name, designation, phone number and when they can be contacted. There must be clear directions about who to contact in an emergency.

9.5 Contact by hospital staff

Support given by staff will vary from family to family and will also be dependent on the child's condition. Information must be given to the family advising them who will be contacting them, who will be visiting their home and when that will be. All hospital teams involved in the care of the child need to co-ordinate their contact to ensure families are not contacted inappropriately.

9.6 Transport from hospital to home

If a decision is made to transport the patient from hospital to home, one of the following modes of transport will be selected:

9.6.1 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. Also ensure that the family have the necessary equipment/devices for transfer.

9.6.2 Hospital Transport

If hospital transport is required to the home, the transport department must be informed and Patient Transport Request online form completed by 1300 hours on the day of transport (available from Monday to Friday). Specify the type of transportation needed (i.e. car, station wagon, ambulance).

- For **transfers to** Bear Cottage refer to [Information on Transfer to Bear Cottage](#) (From Death of a Child policy under the staff information tab). Alternatively please call Bear Cottage and speak to the nurse in charge.
- For information on transferring patients, see [SCHN Transfer and Transport of Patients within SCHN Hospitals](#) Procedure
- For **transfers from CHW**: See [CHW Intranet - Transport](#) or see CHW online booking form [Patient Transport Request Form](#)
- For **transfers from SCH**: See SCH online booking form [Patient Transport Booking Request Form](#).

9.6.3 Emergency Transport: NSW Ambulance Authorised Paediatric Palliative Care Plan

In the event of an emergency, an ambulance will be organised via emergency services following 000 procedures. Children receiving palliative care may have a NSW Ambulance Authorised Paediatric Palliative Care Plan, which documents their end of life care choices. This outlines the support to be provided by the paramedics, and may include information about transport to hospital.

9.6.4 Other Transport Options

- Community Transport Ambulance can be organised by phoning them directly on 131 233 (Note: 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. Possession of a health care card precludes costs.
- 'Angel Flight Australia' is a charity organisation which co-ordinates non-emergency flights for eligible rural families, operated by volunteer pilots.'
- CareFlight or Wing Away is usually arranged by the Primary Team
- NETS is arranged by the child's primary physician

9.7 Equipment Supply

Supply of equipment for children receiving palliative care follows the same process as any child being discharged from hospital. If the child is approaching end of life, occupational therapy/physiotherapy should be consulted as soon as possible so that support can be provided as early as possible. At CHW, families whose child is approaching end of life will not be charged for equipment if the Appliance Centre is notified.

See [SCHN Equipment Hire from the Equipment Loan Pools Procedure](#)

10 Special Issues

10.1 Adolescent and Young Adult Issues

Palliative Care of an adolescent or young adult 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 sexual health issues

10.1.1 Consent

- Refer to SCHN [Consent To Medical and Healthcare Treatment Manual](#)

10.1.2 Giving of Information

Before giving information to an adolescent/young adult, 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/young adult or care-givers undue distress. However, a child over 14 years of age 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.

10.2 Specific Cultural Issues

The complex interweaving of an individual's personality, family, society, culture and religion makes generalisations about culturally sensitive care inappropriate. The health care professional should ask parents about their cultural and other beliefs and respond to them accordingly.

10.2.1 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.

The SPPC Service recognise the diversity of beliefs and culture around death and dying for patients and their families who identify as Aboriginal or Torres Strait Islanders and should respond to their needs accordingly.

The SCHN Palliative Care, Chronic and Complex Aboriginal Health Worker is available to provide cultural support to children and families receiving palliative care and can be contacted via the Aboriginal Health Unit (Telephone 9845 3021/pager 6016).

10.2.2 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.

At CHW: Please contact Health Care Interpreter Service (HCIS) 9912 3800 or Telephone Interpreter Service (TIS) 131450.

At SCH: Please contact Health Care Interpreter Service (HCIS) 9515 0030 or Telephone Interpreter Service (TIS) 131 150.

11 Palliative and Respite Care at Bear Cottage

Bear Cottage provides palliative respite and end of life care for children with life limiting illnesses and their families in a friendly home-like environment. The care team comprises nursing and medical staff, play, music and art therapists and social workers.

The admission criteria to Bear Cottage includes children with a life limiting illness from which death is expected before adulthood.

Bear Cottage provides regular booked respite, emergency respite, step down from hospital to home, symptom management, end of life care and bereavement care.

Priority for Admission

- Children and young people requiring end of life care where Bear Cottage is the preferred location of care
- Emergency admission for symptom management
- Emergency respite admission
- Booked respite admissions

Family Accommodation

Bear Cottage has capacity to accommodate the family as a whole. Parents and siblings are welcome to stay with their child in this home like environment. Care is family centred ensuring that each families individual needs are met.

11.1 Planned Respite Care

11.1.1 Referral Process

Referrals can be made to Bear Cottage by health care professionals, families or carers/ friends in conjunction with the parents' approval.

If the referral is made by a health care professional it can only be treated as a preliminary inquiry until the parents have been spoken to and given consent for the referral.

A Bear Cottage medical form will need to be completed by the medical officer most involved in the child's care. A separate Bear Cottage Child/Family information form will need to be completed by the family. These will need to be completed prior to a decision being made as to the child's eligibility. If there are any questions regarding the child's eligibility we strongly advise ringing Bear Cottage prior to giving the form to the family to fill complete. The Medical Officer and Child/Family Information Forms will be posted to either the person making the call or the parents. They are also available on the Intranet. Please refer to:

- [Bear Cottage Child/Family Information Form](#)
- [Bear Cottage/Medical Referral Form](#)

For routine referrals no decision will be made prior to receiving the completed referral forms and relevant information. Once a decision is made the family and / or the referring person will be contacted to discuss the outcome and potential booking if the child is eligible.

11.1.2 Bookings

Bookings for planned respite are made with the Nursing Unit Manager (9976-8324). Three weeks prior, the family will be sent confirmation of dates, a medical update form and medication charts to be completed by their medical officer. This paper work can be returned by mail to Bear Cottage or brought in with the child on admission. The admission can only proceed if the relevant paperwork is completed.

Emergency Admission to Bear Cottage

Bear Cottage provides emergency palliative and respite care for children with life limiting illnesses and families. Emergency care includes:

- end-of-life care
- admission for symptom management
- emergency respite admissions

Referrals for emergency admission can be taken by the Nursing Unit Manager during business hours or the Registered Nurse in charge of the shift after hours. Appropriate paperwork is to be faxed/ emailed to the relevant medical officer for completion and the Bear Cottage GP is to be notified of the pending admission once the decision to accept is made.

11.1.3 Bear Cottage Nursing After Hours Telephone Support

Bear Cottage Nursing After Hours Telephone Support is available for parents/carers receiving palliative care via 0429 896586. The child's palliative care team at CHW or SCH and/or the child's primary medical team will be notified the following working day to provide family follow up during normal business hours.

11.1.4 After Death care

Children who die at Bear Cottage have the opportunity to stay at Bear Cottage, with their family, for an extended period of time following their death. This allows families to say their goodbyes and receive support.

Following the death, the GP on call will be notified and attend Bear Cottage. Medical staff from CHW/SCH are notified directly by Bear Cottage staff.

The online Death Notification Form is completed by the NUM/NM, who also contacts all the relevant health professionals to advise them of the child's death.

Family and friends are able to spend as much time with their child up to 3 days after the death of a child. Staff will consider and accommodate the cultural needs of the family.

Families whose children die in hospital or at home can be transferred to Bear Cottage to allow family members to have extra time with their deceased child and 24 hour support from staff. The child can be transported with Bear Cottage staff in Bear Cottage transport if available, via the funeral director or in the parents' vehicle with appropriate restraints and the appropriate documentation (MCCD and letter of explanation). To organise please contact Bear Cottage NUM 9976 8324 in working hours or the Team Leader after hours- 9976 8309/0429 896 586 and see Criteria for Transfer to Bear Cottage on SCHN Intranet.

11.1.5 Duration of Admission

Duration of admission for children needing end of life care will be open-ended.

Up to four weeks of respite, dependant on availability will be offered to families per year dependant on the family's needs. Only one week can be booked in NSW school holiday periods and only every second school holidays. Respite admissions are reliant on demand and maybe cancelled in the event of an emergency admission.

11.2 Presentation to the 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 SPCC) in consultation with the family has requested otherwise.

Children receiving palliative care may have been previously "flagged" for ED staff to identify that they are receiving palliative care. Goals of care, especially during end of life **should be checked with the parent or carer** to ensure they are still current.

- **At CHW** an 'Allow Natural Death' (AND) Form will be located in PowerChart under the Acute Management Plan menu. This will need to be reviewed and updated if necessary by the attending ED physician.
- **At SCH**, There will be an eMR Clinical Alert in place if a child has a Resuscitation Plan-Paediatric/Adult. A scanned copy of the Resuscitation Plan-Paediatric/Adult can be accessed from Powerchart. Please see Quickstart instructions to access scanned records
([http://sch.sesahs.nsw.gov.au/departments/hiu/resources/QuickStart for Scanned Health Records.pdf](http://sch.sesahs.nsw.gov.au/departments/hiu/resources/QuickStart%20for%20Scanned%20Health%20Records.pdf))

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 and improve a child's comfort, 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 8](#).

11.3 End of Life Decision Making in ED

Where possible, documentation for end of life care planning should be filled out and families given ample opportunity for discussion. Pre-existing documentation should be provided to the ED. If there is no record on Powerchart of an Allow a Natural Death form [CHW] or Resuscitation Plan- Paediatric/ Adult [SCH], treatment will be given according to regular protocols for any child presenting to the Emergency Dept.

- **At CHW**, an Allow Natural Death Form (AND) is available on PowerChart for end of life discussions. This form will document the supportive care measures, which will be initiated and maintained whilst the child is in CHW care and provision is made for a 'standing order' when relevant. Some families, despite the knowledge that the child has

a terminal illness, are unable to agree to an order to 'allow a natural death' for their child.

- [CHW Allow a Natural Death By Limiting the Use of Life Sustaining Treatment Policy](#)
- **At SCH**, the Resuscitation Plan-Paediatric/Adult is available and should be ordered by each hospital ward ([Ordering these forms](#)). Please contact the paediatric palliative care service if further information is required when completing the Resuscitation Plan-Paediatric/Adult.
 - [Resuscitation Plans-End of Life Decisions Policy](#)
- For more information, see Section 13 (below)

11.4 Admission to Intensive Care Units (PICU, CICU or GCNC)

If a child receiving palliative care deteriorates while in SCHN, decisions to intubate/admit to CICU/PICU/GCNC will be made by the Resuscitation Team & CICU/PICU/GCNC consultant on-call in conjunction with the child's physician and family, unless AND order/Resuscitation Plan-Paediatric/Adult have been discussed and agreed upon.

12 End of Life

12.1 Care

End of life care is based on individual patient and family needs and the family can be supported at home, in hospital or at Bear Cottage.

Irregular and/or noisy breathing, prolonged periods of apnoea and colour change are common pathophysiological accompaniments of dying over hours or even days. If parents/carers are forewarned about these manifestations of dying, the inevitable shock and fear associated with this process may be lessened.

See [Section 8](#) for Symptom Management.

12.2 Documentation

Where possible, documentation for end of life care planning should be filled out and families given ample opportunity for discussion.

Families may have already had discussions with their primary physician or SPPC team in terms of 'end of life decisions' and plans for how care will be managed in the event of an acute and/or life threatening event.

- **At CHW**, an Allow Natural Death Form (AND) is available on PowerChart for end of life discussions. A 'standing order' can be nominated by the carers for the duration of a single admission. See [CHW Allow a Natural Death By Limiting the Use of Life Sustaining Treatment Policy](#).
- **At SCH**, Resuscitation Plan- Paediatric/Adult can be ordered by each hospital ward

For further information please see guideline below. These forms will document the supportive care measures which will be initiated and maintained whilst the child is in hospital.

Some families, despite the knowledge that the child has a terminal illness, are unable to agree to any limitation of resuscitation. These wishes should be respected. If there are no AND or Resuscitation Plan -Paediatric/Adult usual protocols for the care of the deteriorating child should apply.

13 Following the Death of a Child

This section should be read in conjunction with [SCHN Death of a Child Procedure](#).

13.1 Information for parents

It is vital that the family are informed about procedures after their child dies. The following information must be covered:

13.1.1 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 (special considerations for Coroners case

Discussion points may include:

- Washing and dressing the body
- Any cultural issues that staff need to be aware of
- Transfer to mortuary and / or other requested place
- Mementos 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.

13.1.2 Certifying Death

When a child dies at SCHN, appropriate documentation should be completed. Please refer to [SCHN Death of a Child Procedure](#)

Notifying the Coroner - child palliative care deaths who have Department of Communities and Justice (DCJ) Involvement: Please refer to: [SCHN Death of a Child Procedure](#)

Additionally please see: [2020 Coroners Paediatric Palliative Care Death Case Notes Section 24](#) (from Death of a Child Policy under the Staff Information Tab)

13.1.3 Transfer to home or private location (e.g. mosque) after death in hospital

If the family wish to take the body to a private location e.g. mosque they must have documentation with them (Medical Certificate of Cause of Death).

In addition, it is recommended that staff provide a signed letter detailing the transport arrangements, and ensure this letter accompanies the child. A draft Transportation of Deceased Patient form is available online.

See also NSW Health PD2013_048 [Burials - Exemptions from Public Health Regulation 2012 for Community and Religious Reasons](#).

13.1.4 Funeral arrangements

The parents or their proxy should telephone a funeral director at a convenient time and inform them of the child's death and make arrangements for the child's body to be transferred to the funeral director or arrange for them to collect the child's body. The parents should also be informed that they can arrange to see their child's body again at the hospital or at the funeral directors before the funeral.

14 Bereavement Follow Up

Bereavement follow up to family members who have been supported by the SCHN Palliative Care services and significant others has become recognised as an integral part of the provision of palliative care²⁴. Social workers routinely undertake a risk assessment of all families to identify the possibility of complicated grief reactions.

The following services may be available for bereavement support:

- Individual bereavement counselling sessions (in person or via telehealth)
- Bereavement support groups (including siblings)
- Information in the form of literature or books
- Referral to external bereavement agencies
- Phone call or card at time of first anniversary of child's death
- A follow up visit by the PC team, to the family, within 4 weeks of a child's death to review circumstances of death and offer support to the family (CHW)
- Service of Remembrance
- Sympathy and anniversary cards
- Debriefing sessions to ward staff and other involved medical teams.

For more information see [SCHN Palliative Care Bereavement Support Practice Guideline](#).

15 Transition to Adult Services

Refer to [SCHN Transition and Trapeze Practice Guideline](#).

16 Organ Donation

Families expressing an interest in organ donation should be encouraged to discuss the process with their primary care team or the Organ & Tissue Donor Co-ordinator. [Refer to relevant SCHN policies.](#)

17 Post Mortem

Please refer to [SCHN Death of a Child Policy.](#)

18 Service Evaluation and Quality Improvement

The provision of palliative care by the SPPC Service may be evaluated by the following methods:

- Consumer satisfaction surveys – this may include surveying patients/family members, or members of the health care teams that were involved in care during the illness of the child
- Monitoring of complaints
- Collection, collation and analysis of Palliative Care Clinical Indicators
- Palliative Care Death Review
- Review of each death in relation to the Palliative Care Standards
- National standards and Quality Health Service

19 Incident and Complaints Management

19.1 Incidents

All clinical incidents at Westmead and Randwick campuses will be recorded in the Incident Management System (IMS +) and managed in accordance with [NSW Health Incident Management Policy Directive.](#)

Please refer to [SCHN Incident Management Procedure](#) for further information.

19.2 Complaints

Refer to the NSW Health Policy Directive [Complaint Management](#), where links to the NSW Health Complaint Management Guidelines is also available. In addition:

Please refer to [SCHN Patient Complaints Management Procedure](#)

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