

# PALLIATIVE CARE AT HOME - LEVEL 3 SPECIALIST PAEDIATRIC PALLIATIVE CARE SERVICES PRACTICE GUIDELINE<sup>®</sup>

## 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.

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.

<b>Approved by:</b>	SCHN Policy, Procedure & Guideline Committee	Original endorsed by SCHN HCQC
<b>Date Effective:</b>	1 <sup>st</sup> October 2012	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Department Head	<b>Area/Dept:</b> CHW Pain Management Unit

## CHANGE SUMMARY

- This policy has been updated from a CHW policy to a SCHN policy. It is now applicable to both Westmead and Randwick Campuses.
- The changes include:
  - Extensive re-write of entire document to reflect current practices at both hospitals
  - Removal of drug dosage table (Intranet/Internet links to WHO Guidelines have been inserted)
  - Insertion of a range of current campus and external document links
  - Addition of information about campus specific services eg equipment loan pools
  - Additional information about Allow a Natural Death Policy [CHW] and NSW Ambulance Program Care Plan.

## 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.

<b>Approved by:</b>	SCHN Policy, Procedure & Guideline Committee	Original endorsed by SCHN HCQC
<b>Date Effective:</b>	1 <sup>st</sup> October 2012	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Department Head	<b>Area/Dept:</b> CHW Pain Management Unit

# TABLE OF CONTENTS

<b>1</b>	<b>Definitions</b> .....	<b>5</b>
<b>2</b>	<b>Ethical Standards Statement</b> .....	<b>6</b>
<b>3</b>	<b>Criteria for Receiving Specialist Paediatric Palliative Care Services</b> .....	<b>6</b>
<b>4</b>	<b>Palliative Care at Home</b> .....	<b>7</b>
4.1	Referral for Palliative Home Care .....	7
4.2	Role of the Clinicians in Specialist Paediatric Palliative Care and Family Support .....	7
<b>5</b>	<b>Discharge from Hospital to Home</b> .....	<b>8</b>
5.1	Home Care Plan .....	8
5.2	General Practitioner (GP) .....	9
5.3	Community Nursing/Community Palliative Care Referral .....	9
5.4	Allied Health .....	9
5.5	Contact by Hospital Staff .....	10
5.6	Transport from Hospital to Home .....	10
5.6.1	<i>Self-Transportation</i> .....	10
5.6.2	<i>Hospital Transport</i> .....	10
5.6.3	<i>Emergency Transport</i> .....	10
5.6.4	<i>Other Transport Options</i> .....	10
<b>6</b>	<b>Providing Care At Home</b> .....	<b>11</b>
6.1	Nutritional Needs .....	11
6.2	Psychosocial Family Support .....	11
6.3	Spiritual Support .....	11
6.4	Long Term Palliative Care .....	11
6.5	Short Term Palliative Care/End of Life Care .....	12
6.6	Palliative Procedures at Home .....	12
6.6.1	<i>Administration of IV Medications</i> .....	12
6.6.2	<i>Insertion of NG Tube</i> .....	12
6.6.3	<i>Central Venous Access Devices</i> .....	12
6.6.4	<i>Gastrostomy Home Care</i> .....	12
6.6.5	<i>Indwelling Catheter</i> .....	12
6.7	Respite Care .....	12
6.8	Medical Record Keeping .....	12
<b>7</b>	<b>Equipment Supply</b> .....	<b>13</b>
7.1	Oxygen .....	13
7.2	Suction Units/Feeding Pumps .....	13
7.3	Beds/Chairs/Bathing Equipment .....	13
7.4	Consumables .....	13
7.5	Costs .....	13
<b>8</b>	<b>Medications</b> .....	<b>14</b>
8.1	Medications at home .....	14
8.2	Dosing Information .....	14
8.3	Subcutaneous/IV Medications .....	14
8.4	Disposal of Unused Drugs .....	14
<b>9</b>	<b>Symptom Management</b> .....	<b>15</b>
9.1	Pain .....	15
9.1.1	<i>Pain Crisis</i> .....	15

9.1.2	<i>Interventional Methods of Analgesia</i>	15
9.1.3	<i>Sedation as a Therapeutic Modality for Intractable Pain</i>	16
9.2	Dyspnoea	16
9.3	Constipation	16
9.4	Seizures	17
9.5	Nausea and Vomiting	17
9.6	Secretions	18
9.7	Bleeding	18
9.8	Mouth Care	18
9.9	Hydration	18
9.10	Pressure Area and Skin Care	18
9.11	Terminal Delirium	18
9.12	Anxiety	18
9.13	Insomnia	19
9.14	Fatigue	19
<b>10</b>	<b>Special Issues</b>	<b>19</b>
10.1	Palliative Care of the Neonate	19
10.2	Adolescent and Teenage Issues	19
10.2.1	<i>Consent</i>	19
10.2.2	<i>Giving of Information</i>	20
10.3	Transition to Adult Services	20
10.4	Rural Families	20
10.4.1	<i>Family Support in Rural Locations</i>	21
10.4.2	<i>Specific Cultural Issues</i>	21
10.4.3	<i>Patients who identify as Aboriginal or Torres Strait Islander</i>	21
10.4.4	<i>Families for whom English is not their first language</i>	21
<b>11</b>	<b>Management of Emergencies</b>	<b>21</b>
11.1	Care in Emergency Department (ED)	21
11.2	Hospital Admission	22
<b>12</b>	<b>End of Life Care</b>	<b>22</b>
12.1	End of Life Care Planning	22
12.2	Symptom Management during End of Life	23
12.3	Contacts	23
<b>13</b>	<b>Organ Donations</b>	<b>23</b>
<b>14</b>	<b>Death Of A Child</b>	<b>23</b>
14.1	Information for Parents Following the Death of a Child	23
14.2	Care of the Body	24
14.3	Death Certificates	24
14.4	Transfer to/from home or private location after death	24
14.5	Notifying the Coroner - Children who have Dept Of Community Service (DoCS) Involvement	24
14.6	Post Mortem	25
<b>15</b>	<b>Bereavement Follow Up</b>	<b>25</b>
<b>16</b>	<b>Staff Safety</b>	<b>26</b>
<b>17</b>	<b>Service Evaluation and Quality Improvement</b>	<b>26</b>
<b>18</b>	<b>Incident and Complaints Management</b>	<b>26</b>
18.1	Incidents	26
18.2	Complaints	27
<b>19</b>	<b>References</b>	<b>28</b>

# 1 Definitions

## **Palliative Care for SCHN Patients**

Palliative care is provided by a number of different services in the Sydney Children's Hospitals Network (SCHN), including the Palliative Care Services, Oncology, Neurology, Neonatal Intensive Care (NICU), Paediatric Intensive Care Unit (PICU) and Bear Cottage, (an in-patient hospice unit for children located at Manly, Sydney). Specialist Paediatric Palliative Care (SPPC) services are offered across the spectrum of hospital, home and hospice.

Specialist Paediatric Palliative Care (SPPC) is 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.

*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<sup>1</sup>:

- 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 even in children's homes.

## **Level 3 Specialist Paediatric Palliative Care Service**

SPPC services are defined by the qualifications of staff consisting of, but not limited to, a medical practitioner who is a Fellow of the Chapter of Palliative Medicine (FACHPM), a Clinical Nurse Consultant (CNC) and an Allied Health staff member. Level 3 refers to those specialist services which are accredited for training at the faculty of Pain Medicine, Australia and New Zealand College of Anaesthetists (ANZCA).

## **Primary Team**

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

## **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 the family home or other residence of the family's choice by staff of the SPPC of The Sydney Children's Hospitals Network (SCHN). It may include all members of the multidisciplinary paediatric palliative care team.

## **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"<sup>2</sup> are supported by SPPC. This document can be found on the Royal Australasian College of Physicians website

<http://www.racp.edu.au/index.cfm?objectid=39396AC9-E30B-7941-0FD53740FF78DBC8>

## **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.

- For transitional care see Transitional Care Policy [CHW]  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2006-8157.pdf> or
- Transition Guidelines for Adolescents & Young People at SCH [SCH]  
<http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/4.T.2%20Transition%20of%20Care%20Guidelines.pdf> )

## 4 Palliative Care at Home

When the family chooses to care for their child at home, appropriate care, support, equipment and advice will be sourced and clinicians can act as a liaison between the hospital, hospice and community based care providers.

The provision of palliative care at home requires:

- Careful preparation and planning
- Care arrangements that are flexible
- Health care professionals who are able to assess the needs and support the families' access to relevant community health care services
- Access to Specialist Paediatric Palliative Care.

Staff requiring further information about the Palliative Care Service at any stage can contact the Westmead Campus Palliative Care CNC, 9845 0000 pager 6794 or the Randwick Campus Palliative Care CNC, 9382 2095. Family enquiries for Randwick Campus can be directed to 9382 0035. Families from Westmead can call via the hospital switchboard. To provide care at home safely, staff should comply with the appropriate policies for providing services at home.

- See Home and Community Visiting: Risk Management Policy[CHW] <http://chw.schn.health.nsw.gov.au/o/documents/policies/procedures/2006-8146.pdf>) or
- OHS – Staff Working Offsite [SCH] [http://www.sesiahs.health.nsw.gov.au/Policies\\_Procedures\\_Guidelines/Workforce/WSIMS/documents/OHS-%20Staffworkingoffsite-riskmanagementprocedureSESLHNPDP76.pdf](http://www.sesiahs.health.nsw.gov.au/Policies_Procedures_Guidelines/Workforce/WSIMS/documents/OHS-%20Staffworkingoffsite-riskmanagementprocedureSESLHNPDP76.pdf)

### 4.1 Referral for Palliative Home Care

Once a formal Referral has been received from the child's primary consultant, relevant SPPC staff will make every attempt to visit the family within 24 hours. For Westmead patients, the referral form is on PowerChart.

### 4.2 Role of the Clinicians in Specialist Paediatric Palliative Care and Family Support

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 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

- Discussion of other needs eg equipment
- Engaging community services including community, medical and/or nursing teams and respite services
- Development of a Care Plan

**Reasons for ongoing contact may include:**

- Provision of support to community based and other services
- Provision of direct care and support to the child and family in the home where appropriate.

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

- Preparation of an “Allow a Natural Death” form (CHW Primary Team) or “End of Life Care Plan” (SCH Primary Team)
- Preparation of an Ambulance Service of NSW Pre-Authorised Care Plan P1 Form (Ambulance Form) for support by paramedics at home during end of life care
- ‘Flagging’ in Emergency Department
- Identification of preferred place of death (may change regularly)
- Identification of appropriate medical practitioner to provide Death Certificate eg GP
- Consideration of any spiritual or cultural requirements

## 5 Discharge from Hospital to Home

Thorough discharge planning needs to be done so the transition from hospital to home is smooth and all aspects of care are considered.

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

<http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2012-9008.pdf>

### 5.1 Home Care Plan

When a child is receiving palliative care at home, it is essential that a care 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 care plan in consultation with service providers and families. The care plan should include goals of care as well as the following:

- Symptom Management. See [Section 9](#)
- Equipment Supply. See [Section 7](#)
- Nutritional Needs. See [Section 6.1](#)
- Psychosocial Family Support. See [Section 6.2](#)
- Spiritual Support. See [Section 6.3](#)
- Respite Needs. See [Section 6.7](#)
- Contact details and emergency contact details



## 5.2 General Practitioner (GP)

GP involvement is necessary for:

- Continuity of medical follow up close to home
- Managing intercurrent problems
- Signing of a death certificate

See NSW Health Policy Coroners Cases and the Coroners Act 2009 at [http://www0.health.nsw.gov.au/policies/pd/2010/pdf/PD2010\\_054.pdf](http://www0.health.nsw.gov.au/policies/pd/2010/pdf/PD2010_054.pdf)

The GP must be provided with the home care plan as well as:

- Child's condition
- Current medications
- Estimated prognosis
- End of life symptom management plan if appropriate
- Palliative care clinician contact details at SCHN
- Primary team clinician contact details at SCHN
- Copy of Allow a Natural Death form [CHW], End of Life Care Plan [SCH] and Ambulance Form, if appropriate.

## 5.3 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, the community nursing team and community palliative care team may be involved. The SCHN palliative care clinicians will liaise regularly with community nursing to offer support and provide an integrated service to the family. The SPPC, or primary team CNC, 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 care
- Provide equipment on occasions
- Provide support in form of phone calls and visitations
- Provide after-hours/weekend visiting and trouble shooting
- Act as a link to other community services eg palliative care, schools, counsellors
- When possible attend case meetings before discharge

## 5.4 Allied Health

Allied Health staff may be a part of the existing Community Teams, however if Allied Health staff are required and not already established in the child's care, then appropriate referrals should be made. Allied Health sources include ADHC, SCHN and local Community Health Centres.

## 5.5 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 family contacts so that families are not contacted inappropriately.

## 5.6 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:

### 5.6.1 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.

### 5.6.2 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/>

SCH will provide transport for patients between CHW and SCH.

- Please click here for the:
  - Transport Form [CHW]: [CHW Intranet - Transport](#) or
  - Patient Transport Form [SCH] :  
<http://sch.sesahs.nsw.gov.au/clinical/transport/tb.asp>

For information about safety issues for transport see Transporting Children Under 16 Years Old Including Exemptions for child Restraints and Booster Seats. [SCH/CHW]:  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2011-9002.pdf>

### 5.6.3 Emergency Transport

Emergency ambulance will be organised via emergency services following 000 procedures.

All children receiving palliative care can have an Ambulance Form, which documents the end of life care choices. This outlines the support to be provided by the paramedics, and may include information about transport to hospital.

### 5.6.4 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
- NETS is arranged by the child's physician.

## 6 Providing Care At Home

### 6.1 Nutritional Needs

Children are encouraged to continue with normal nutrition as long as possible and a dietician may liaise with the family to maintain optimal nutrition. Loss of appetite and feeding issues may be a major source of distress for families and consideration is given to this when discussing options for nutritional support of the child.

Support can be provided at home with nasogastric/PEG feeds. The Stomal Therapist (for CHW) provides telephone home enteral support for families –

- See Gastrostomy Home Care Guideline [CHW]:  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/homecare/2006-8314.pdf>
- For a child on home TPN see Parenteral Nutrition Guidelines (PN) [CHW]  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/guidelines/2006-8145.pdf> or
- Administration of Parenteral Nutrition Guideline [SCH]:  
<http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/11.06%20Guidelines%20for%20Administration%20of%20Parenteral%20Nutrition.pdf>

### 6.2 Psychosocial Family Support

In most circumstances, a social assessment will be done on families caring for a child with a life limiting illness and appropriate support will be arranged by the SPPC Service. An after-hours social work advisory service is available 24 hours per day for emergencies via hospital switchboards.

### 6.3 Spiritual Support

The palliative care clinicians will discuss with families what religious and/or spiritual support they need. Spiritual support groups can, in some cases, have a major role in the family's decision making process and if this is the case a meeting with them should be arranged.

### 6.4 Long Term Palliative Care

When a child's illness is life limiting but it is anticipated survival will be a number of years with appropriate support, the clinicians involved will endeavour to ensure that every possible support available in the community is known to the family. The SPPC will continue to make regular contact with the family to ensure that no major issues or symptoms are unresolved. Should the child's condition change, the support offered will be reviewed and changes made. The child's care will be discussed on a regular basis with relevant clinicians.

## 6.5 Short Term Palliative Care/End of Life Care

When a child at home is deteriorating or has reached the end of life stage of illness, appropriate support will increase. SPPC will arrange emergency contact details for support for individual families after hours.

## 6.6 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:

### 6.6.1 Administration of IV Medications

- See Home Intravenous Medication: Parent/Carer Administration guideline [CHW]: <http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2006-8301.pdf> or
- Home Intravenous Antibiotic Administration for CAPAC Practice Guideline [SCH]: <http://chw.schn.health.nsw.gov.au/o/documents/policies/guidelines/2010-0005.pdf>

### 6.6.2 Insertion of NG Tube

See Insertion and Care of a Feeding Tube at Home guideline [CHW]:

<http://chw.schn.health.nsw.gov.au/o/documents/policies/homecare/2006-8247.pdf>

### 6.6.3 Central Venous Access Devices

- See Central Venous Access Devices Guideline [CHW]: <http://chw.schn.health.nsw.gov.au/o/documents/policies/guidelines/2006-8175.pdf> or
- Management of Central Venous Access Devices Business Rule [SCH]: <http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/6.C.1%20management%20of%20Central%20Venous%20Access.pdf>

### 6.6.4 Gastrostomy Home Care

- See Gastrostomy Home Care Guideline [CHW]: <http://chw.schn.health.nsw.gov.au/o/documents/policies/homecare/2006-8314.pdf>

### 6.6.5 Indwelling Catheter

- See Indwelling Urinary Catheter Care at Home [CHW]: <http://chw.schn.health.nsw.gov.au/o/documents/policies/homecare/2006-8115.pdf>

## 6.7 Respite Care

The need for respite care should be discussed with families. Options for in home respite care vary depending on the geographical location of the family home. 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 options for respite care.

## 6.8 Medical Record Keeping

All phone calls, contacts to family and home visits must be documented in:

- PowerChart (CHW)
- PCS database and eMR Scheduling (SCH)

## 7 Equipment Supply

Supply of equipment for children receiving palliative care follows the same process as any child being discharged from hospital.

### 7.1 Oxygen

Supply and administration of oxygen for children receiving palliative care is provided by a referral to the Respiratory Support Service (CHW). 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 Oxygen Therapy and Delivery Devices Policy [CHW]:

<http://chw.schn.health.nsw.gov.au/o/documents/policies/procedures/2006-8051.pdf> or

Guideline for Oxygen Therapy and Delivery Devices [SCH]:

<http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/10.07%20oxygen%20therapy.pdf>

### 7.2 Suction Units/Feeding Pumps

Equipment supplies and payments can be arranged by staff. At CHW this is arranged via Biomedical personnel and The Appliance Centre on Level 2. See

[http://chw.schn.health.nsw.gov.au/ou/appliance\\_centre/](http://chw.schn.health.nsw.gov.au/ou/appliance_centre/) [CHW]

At SCH see HELP Centre on Level 0 or intranet page to obtain relevant forms:

<http://sch.sesahs.nsw.gov.au/policy/forms/HE.00.1%20Process%20for%20Hire%20of%20Equipment%20from%20the%20HELP%20Centre.pdf>

Long term support is available through ENABLE.

### 7.3 Beds/Chairs/Bathing Equipment

The Allied Health staff should be consulted re: home/bathroom modification/seating and other requirements that may be needed for care at home and if assistance is required for activities of daily living (ADL).

### 7.4 Consumables

Supplies (e.g. NG tubes, syringes, suction catheters) can be provided on discharge through either The Appliance Centre (CHW) or HELP (SCH). (See links in 7.2 above) Appropriate forms need to be completed. There may be a fee attached.

### 7.5 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. A letter of referral must come from a primary team specialist. There is an annual co-payment. Nominated specialist CNC's may also be available to assist with this process (e.g. stomal therapist).

## 8 Medications

### 8.1 Medications at home

Many children receiving end of life care are receiving high doses of analgesia and medications that most general practitioners are not used to providing for children and many of the medications are provided via the hospital pharmacy. Arrangements are made for the family to collect these medications from the hospital or for them to be delivered to home during a regular visit. See Section 9 Symptom Management for further information.

### 8.2 Dosing Information

For information relating to doses, refer to Drug Doses Guidelines [CHW]  
[http://chw.schn.health.nsw.gov.au/o/apps/picu/drug\\_doses/](http://chw.schn.health.nsw.gov.au/o/apps/picu/drug_doses/)

### 8.3 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.

### 8.4 Disposal of Unused Drugs

The palliative care team should discuss options for safe disposal of medications with the family or the community supporting team. Advice may also be sought from the NSW Ministry of Health Duty Pharmaceutical Officer, Pharmaceutical Services Unit on (02) 9879 3214.

## 9 Symptom Management

A detailed 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 an 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 died<sup>3</sup>. 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 carers.

### 9.1 Pain

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

When assessing pain in neonates and children, staff should use recognised [pain tools \[CHW\]](#). 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.

- See Pain Management Guidelines [CHW] <http://chw.schn.health.nsw.gov.au/o/documents/policies/guidelines/2006-8215.pdf> or
- WHO Guidelines on the pharmacological treatment of persisting pain in children with medical illnesses: [http://whqlibdoc.who.int/publications/2012/9789241548120\\_Guidelines.pdf](http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf)

#### 9.1.1 Pain Crisis

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

#### 9.1.2 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.

### 9.1.3 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<sup>5</sup>. 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.

## 9.2 Dyspnoea

Dyspnoea, which has been defined as “an uncomfortable awareness of breathing”<sup>6</sup>, is more common and often more severe in the last few weeks before death<sup>7</sup>. 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. Non-invasive 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 use of a fan<sup>8</sup> 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.

## 9.3 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



## 9.4 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<sup>9</sup> where seizures are not controlled by prescribed anticonvulsants. Management of these seizures would be in conjunction with the primary team and/or neurology team.

- For intractable seizures, see Midazolam Practice Guideline [CHW]:  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/guidelines/2006-8037.pdf> or
- Buccal Midazolam For Seizures [SCH]:  
[http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/20.16\\_buccal\\_midazolam\\_for\\_seizures.pdf](http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/20.16_buccal_midazolam_for_seizures.pdf)

## 9.5 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 2<sup>nd</sup> line anti-emetic particularly in children with central nervous system pathology. .

Other 2<sup>nd</sup> and 3<sup>rd</sup> line options for anti-emetics include haloperidol, levomepromazine and lorazepam. Consultation with the Pain and 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.

## 9.6 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.

## 9.7 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 management plan needs to be in place e.g. crisis medication and use of dark towels.

## 9.8 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<sup>10</sup>. 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.).

## 9.9 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<sup>11</sup>.

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

## 9.10 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.

## 9.11 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.

## 9.12 Anxiety

Children often feel grief, depression and a sense of lost hope at their time of death. Allowing the 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<sup>12</sup>.

## 9.13 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.

## 9.14 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<sup>13</sup>.

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.

# 10 Special Issues

## 10.1 Palliative Care of the Neonate

Home care is an option for delivery of palliative care services for newborns. The management process is the same as for any paediatric palliative care patient prior to discharge home. It is important that these children have a paediatrician identified and a plan for readmission in case required.

## 10.2 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

### 10.2.1 Consent

See the following guidelines

- Consent to Medical Treatment – Patient Information [CHW]  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2006-8325.pdf>
- Consent to Medical Treatment – Patient Information [SCH]  
[http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/2.01.1%20patient%20information%20and%20consent%20to%20medical%20treatment%20\(link%20to%20nswhealth%20pd2005\\_406\).html](http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/2.01.1%20patient%20information%20and%20consent%20to%20medical%20treatment%20(link%20to%20nswhealth%20pd2005_406).html)

### 10.2.2 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 caregivers 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.

## 10.3 Transition to Adult Services

- See Transitional Care [CHW]  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2006-8157.pdf>
- See Transition Guidelines for Adolescents & Young People at SCH [SCH]  
<http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/4.T.2%20Transition%20of%20Care%20Guidelines.pdf>

## 10.4 Rural Families

Comprehensive community connections are vital for the care of rural families. Preferably a designated local 'link' person is identified, usually a nurse. Initially a case meeting (either face to face or teleconference) is recommended to ensure continuity of care and ensure the team works together for the child and family's wellbeing. Key people in the care of these children 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 bring in the Community palliative services. The CN will contact either the primary team or 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 may be unused to caring for children who are dying and support from SCHN staff will be maintained via regular phone-calls.
- School – A single visit or phone call to the school to offer advice about speaking with classmates, symptom management and ways to assist (if possible) the child attending school should be made. The school staff will also be given advice and information regarding death and bereavement responsibilities or school activities.
- Allied Health Services – Local allied health services are usually available.

### **10.4.1 Family Support in Rural Locations**

The child's primary team and appropriate palliative care services will continue to contact the family to offer ongoing telephone 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 harmonious relationships in providing care and to ensure optimal care to the child.

### **10.4.2 Specific Cultural Issues**

The health care professional should be aware of the each family's cultural and other beliefs and respond to them accordingly.

### **10.4.3 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. Of particular importance is planning to allow enough time for families to travel to country before death if this is important.

### **10.4.4 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.

## **11 Management of Emergencies**

### **11.1 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 11.2](#)). 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 9](#)).

## 11.2 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:

- An 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 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 in ED in cardiac or respiratory arrest, bag and mask and CPR must be implemented unless they have an AND order. Decisions to intubate / admit to PICU will be made by the Resuscitation Team & PICU consultant on call in conjunction with the family and the child's physician or SPPC.

## 12 End of Life 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.

If families are forewarned about the manifestations of dying, they are not so shocked and frightened when they occur, though some distress is perhaps inevitable. 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.

### 12.1 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 are described as an "Allow a Natural Death" or AND order (CHW) or End of Life Care Plan (SCH) The orders should be clearly documented on the appropriate forms, and families given ample opportunity to discuss changes in their decisions which may have been previously negotiated.

AND orders will document the supportive care measures which will be initiated and maintained whilst the child is in SCHN care. These orders need to be reviewed weekly, unless the family choose for them to become standing orders.

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 Policy and Procedure [CHW]: <http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2006-8331.pdf>

## 12.2 Symptom Management during End of Life

See [Section 9](#) Symptom Management

## 12.3 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.

In consultation with the child's primary team it is possible for a child to be extubated outside of hospital.

# 13 Organ Donations

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

# 14 Death Of A Child

## 14.1 Information for Parents Following the Death of a Child

There are many factors to be considered before bodies may be moved; please refer to:

NSW Public Health (Disposal of Bodies) Regulation 2002:

[http://www.austlii.edu.au/au/legis/nsw/consol\\_reg/phobr2002371/](http://www.austlii.edu.au/au/legis/nsw/consol_reg/phobr2002371/)

It is vital that the family are informed about procedures to follow 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 spend a few hours 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.

## 14.2 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.

## 14.3 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.

## 14.4 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 Ministry of Health Policy Directive

Burials – exempt for community religious and cultural reasons:

[http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007\\_004.pdf](http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_004.pdf)

## 14.5 Notifying the Coroner - Children who have Dept Of Community Service (DoCS) Involvement

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

### **OR**

- Any contact has been made to DoCS about any of the child's siblings within 3 years immediately preceding the child's death.
- See Ministry of Health Coroners Cases and the Coroners Act 2009:  
[http://www.health.nsw.gov.au/policies/pd/2010/PD2010\\_054.html](http://www.health.nsw.gov.au/policies/pd/2010/PD2010_054.html) and



- Death of a Child Procedure [CHW]:  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/procedures/2006-8059.pdf> or
- Death of an Infant or Child [SCH]:  
<http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/3.D.1%20Death%20of%20an%20Infant%20or%20Child.pdf>

## 14.6 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 Death of a Child procedure [CHW]  
<http://chw.schn.health.nsw.gov.au/o/documents/policies/procedures/2006-8059.pdf> or
- Death of an Infant or Child [SCH]:  
<http://sch.sesahs.nsw.gov.au/policy/manuals/clinical/3.D.1%20Death%20of%20an%20Infant%20or%20Child.pdf>

### After Hours Plan

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

## 15 Bereavement Follow Up

A bereavement support person should be identified for each family in order to provide a comprehensive, appropriate bereavement support program. Elements of this program are:

- 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 annually
- Phone calls or cards to the family

For further information on bereavement support, see Bereavement Support Practice Guideline [CHW] <http://chw.schn.health.nsw.gov.au/o/documents/policies/guidelines/2008-0023.pdf>.

## 16 Staff Safety

Staff who are providing clinical services to children and their families at home must comply with the Risk Management Policies.

See Home and Community Visiting: Risk Management Policy [CHW]:

<http://chw.schn.health.nsw.gov.au/o/documents/policies/procedures/2006-8146.pdf> or

OHS – Staff Working Offsite [SCH]:

[http://www.sesiahhs.health.nsw.gov.au/Policies\\_Procedures\\_Guidelines/Workforce/WSIMS/documents/OHS-%20Staffworkingoffsite-riskmanagementprocedureSESLHNP76.pdf](http://www.sesiahhs.health.nsw.gov.au/Policies_Procedures_Guidelines/Workforce/WSIMS/documents/OHS-%20Staffworkingoffsite-riskmanagementprocedureSESLHNP76.pdf)

## 17 Service Evaluation and Quality Improvement

The provision of palliative care and support at home will be evaluated by the following methods:

Consumer satisfaction surveys are a valuable source of information for continuous improvement and are required for accreditation. Survey formats may include patients/family/primary health care team members' questionnaires conversational feedback, thank you cards, follow up or complaints. Consumer satisfaction can be monitored through some of the following pathways:

- Monitoring of complaints
- Collection, collation and analysis of Palliative Care Clinical Indicators
- Review of each death in relation to the Palliative Care Standards
- Participation in the National Standards Assessment Program (NSAP)
- Benchmarking clinical indicators via CareSearch

Information gathered via these methods will form the basis of quality improvement projects to enhance the provision of palliative care services.

## 18 Incident and Complaints Management

### 18.1 Incidents

All clinical incidents at Westmead and Randwick campuses will be recorded in the Incident Information Management System (IIMS) to be read in conjunction with NSW Health Incident Management Policy Directive [http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007\\_061.pdf](http://www.health.nsw.gov.au/policies/pd/2007/pdf/PD2007_061.pdf) and managed in accordance with the Incident Management Policy for patient incidents [CHW] <http://chw.schn.health.nsw.gov.au/o/documents/policies/policies/2006-8324.pdf>

Staff and visitor incidents will be managed in accordance with the

- Incident Management: Staff, Visitors, Volunteers, Contractors and Others Procedure [CHW]: <http://chw.schn.health.nsw.gov.au/o/documents/policies/procedures/2007-8026.pdf>

## 18.2 Complaints

The NSW Health Policy Directive “Complaint Management Policy” is available at [http://www.health.nsw.gov.au/policies/pd/2006/pdf/PD2006\\_073.pdf](http://www.health.nsw.gov.au/policies/pd/2006/pdf/PD2006_073.pdf)

NSW Health has also developed Guidelines providing detailed information for dealing with a complaint. The guidelines can be accessed at:

[http://www.health.nsw.gov.au/policies/gl/2006/pdf/GL2006\\_023.pdf](http://www.health.nsw.gov.au/policies/gl/2006/pdf/GL2006_023.pdf)

At CHW Patient complaints are not recorded on IIMS and are managed in accordance with the Patient Complaints Management Procedure [CHW]:

<http://chw.schn.health.nsw.gov.au/o/documents/policies/procedures/2012-8016.pdf>

## 19 References

1. World Health Organization, 2012, 11.7.2012, [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)
2. Royal Australasian College of Physicians. Decision Making at the End of Life in Infants, Children & Adolescents - a policy of the Paediatric & Child Health Division. Royal Australasian College of Physicians, 2008.
3. Berde CB, Lehn BM, Yee JD, et al. Patient controlled analgesia in children and adolescents: a randomized, prospective comparison with intramuscular morphine for post-operative analgesia. *Journal of Pediatrics* 1991; 118:460-466.
4. World Health Organisation, WHO Guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. 2012.
5. Kenny NP, Frager G. Refractory symptoms and terminal sedation in children: ethical issues and practical management. *J Palliat Care* 1996; 12:40-45.
6. Boyd KJ, Kelly M. Orla morphine as symptomatic treatment of dyspnoea in patients with advanced cancer. *Palliative Medicine* 1997; 11:277-281.
7. World Health Organisation. Symptom Relief in Terminal Illness. 1998; 55-56
8. Galbraith S, Fagan P, Perkins P, Lynch A, Booth S. Does the use of a handheld fan improve chronic dyspnea? A randomized, controlled, crossover trial. *J Pain Symptom Management* 2010 May 39(5):831-8.
9. Pellock JM. Use of midazolam for refractory status epilepticus in pediatric patients. *Journal of Child Neurology* 1998; 13(12):581-587.
10. Wolfe J, Grier H.E., Klar N. et al. Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine* 2000; 342(5):326-333.
11. Diekema, D & Botkin, J et al, Forgoing Medically Provided Nutrition and Hydration in Children. *Pediatrics*, April 2011, pp 813-822
12. Rollins, J., Bolig R., Mahan, C., 2005. Meeting Children's Psychosocial Needs, Across The Health Care Continuum, Pro-ED, USA
13. Collins JJ, Byrnes ME, Dunkel I, Foley KM, Lapin J, Rapkin B et al. The Memorial Symptom Assessment Scale (MSAS): Validation Study in Children Aged 10-18. *Journal of Pain and Symptom Management*. *Journal of Pain and Symptom Management* 2000; 19(5):363-367.

### **Copyright notice and disclaimer:**

The use of this document outside Sydney Children's Hospitals Network (SCHN), or its reproduction in whole or in part, is subject to acknowledgement that it is the property of SCHN. SCHN has done everything practicable to make this document accurate, up-to-date and in accordance with accepted legislation and standards at the date of publication. SCHN is not responsible for consequences arising from the use of this document outside SCHN. A current version of this document is only available electronically from the Hospitals. If this document is printed, it is only valid to the date of printing.