

Women's and Children's Hospital

Home care companion



A nursing resource
for paediatric palliative care



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This publication was produced by the Paediatric Palliative Care Service at the Women's and Children's Hospital, as a resource for community-based nurses who are caring for children and their families on a palliative care journey.

Contents

- 1 Section 1: Paediatric Palliative Care
- 7 Section 2: Differences between adults and children
- 11 Section 3: Communication
- 21 Section 4: Family centred care
- 23 Section 5: Medications
- 27 Section 6: Comfort focussed care
- 35 Section 7: Dying process
- 41 Section 8: Spiritual issues
- 45 Section 9: Ethical and legal issues
- 47 Section 10: Appendices and references



Section 1:

Paediatric Palliative Care

- 2 Where should I go for any problems?
- 3 Definition
- 3 Paediatric age range
- 3 Conditions involved
- 4 Place of care
- 5 Parental expectations
- 5 Duty of care
- 5 Paediatric palliative care service expectations
- 6 Checklist

The Paediatric Palliative Care Service at the Women's and Children's Hospital (WCH) is a state-wide multidisciplinary service that offers clinical expertise and hands on comprehensive case management and care coordination.

The Paediatric Palliative Care Service (WCH) is free and focuses on preventative health, treating symptoms, counselling, giving of information and linking services. Children are cared for either in the hospital or the home and the team works in collaboration with other health care teams in the community.

Because the service is state-wide the team will travel to rural areas if required. The service provides 24 hour telephone support and home visits during office hours. Office hours are Monday to Friday from 8.00am–4.30pm.

The Paediatric Palliative Care Service is about living life to the 'max'. Our mission is 'to serve all children who have life limiting illnesses and their families' and our approach is about embracing the different journeys of each family and promoting choice and flexibility. We look forward to working in partnership with you and to do this we ask that you contact us whenever you need to. We look after patients who have varying levels of care requirements and are triaged into the categories of critical, complex and stable. We will provide you with comprehensive details about the child's situation, clinical condition and provide detailed care plans to manage the child's condition and possible changing status. We do not expect you to manage the child alone on a shift and encourage you to contact us for any reason you may need support.

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Where should I go for any problems?

Paediatric Palliative Care Service

Phone (08) 8161 7000, ask for palliative care

- > After hour's pager 5719
- > Administration (08) 8161 7994

Please contact Paediatric Palliative Care Service about any of the following:

- > Family distress and/or not coping with caring for the child at home.
- > Personal support.
- > Unexpected events.
- > Death.
- > Trouble shooting.
- > Paper work missing or incomplete.
- > Pain management.
- > Escalating symptoms.
- > Disease (progress).
- > Low drug supply.
- > Equipment.
- > Any other problems/needs.



Definition

Paediatric palliative care is the specialist care of children who are living with a life limiting condition¹. This includes the social, emotional, psychological and spiritual support of the child and their family from diagnosis to death and through to bereavement support¹.

Palliative care services can be provided alongside active treatment with the main aim of care being to achieve the best quality of life possible¹. The intensity and amount of support required during a child's palliative journey varies greatly and is often uncertain due to the types of conditions involved¹.

Paediatric age range

The age range of children referred and treated at the WCH is 0–18 years.

Conditions involved

- > Life limiting conditions of childhood vary greatly and are often rare.
- > The Goldman classification model describes four possible illness pathways that a family may experience depending on their child's diagnosis^{2b}:
 - Diseases for which curative treatment may be possible but may fail (e.g. cancer)
 - Diseases in which premature death is anticipated but intensive treatment may prolong good quality of life (e.g. cystic fibrosis).
 - Progressive diseases for which treatment is exclusively palliative and may extend over many years (e.g. neurodegenerative disorders).
 - Conditions with severe neurological disability that, although not progressive, lead to vulnerability and complication likely to cause premature death (e.g. severe cerebral palsy).
- > The variation of childhood conditions influences the illness journey the child and family will travel. Therefore, the length and experience of each child and family's journey is individual and unique and cannot be generalised.¹

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Place of care

- > Parents and children primarily choose to be at home because¹:
 - It is a familiar environment.
 - The family can engage in normal home routines.
 - There are no hospital routines to interrupt family life.
 - There is greater privacy.
 - Siblings and the extended family can be included.
 - Parents feel more in control.
 - Children like to be amongst their own toys, pets, family and friends.
- > Home care involves careful planning, coordination and communication amongst multidisciplinary health professionals, this includes you.
- > There may be episodes of care that require hospitalisation depending on the child's condition and family's needs and choices.
- > You have been asked to nurse a sick child in their home for significant reasons. Be aware of the reason home nursing care is required for this family and ensure the underlying need is supported. For example if the family require respite care, ensure that the parents get rest or take a break while you are present.
- > Some parents find it difficult to hand over the care of their child to a health professional they don't know even if they are exhausted. It is helpful if you demonstrate to the family that you are competent and confident to care for their child during their absence. For example:
 - Understand the child's condition and status before you enter the home.
 - Be proactive in seeking out the resuscitation plan, care plan and terminal care plan (if appropriate).
 - Keep your skills up to date with equipment that is used in the home to support palliative patients.
 - Look up any drugs you are unfamiliar with including how and when they are administered.
 - Demonstrate concern and empathy towards the child and family.
 - Talk to the family about any issues or concerns they are experiencing and be active in supporting them. If you are unsure how to support the family or need more information, ring the Paediatric Palliative Care Service.

Parental expectations

- > Know the name of the child you are visiting and use their preferred name during your visit.
- > Use the correct name of the parents or guardians of the child.
- > It is not necessary to know all the names of the siblings before entering the home but it is important to make the effort to introduce your self to any siblings that may be present and learn their names also. Your introductions and knowledge of family members indicates that you value and care for them as well as their child.
- > Acknowledge the child upon entering the home and before you read any paperwork provided. Engage with the child in a meaningful and developmentally appropriate way.
- > Ask permission to touch the child if you need to and how to touch the child before you do.
- > Explore with the parents aspects of their child that will help you care for them. For example:
 - What do they like and dislike?
 - How do the parents distract them (during interventions, separations or when needed)?
 - What games do they like to play or how do they like to be amused?

Duty of care

- > Orientate yourself to the equipment used in the home to support the child. It is ok to ask parents questions about the equipment used as they are the experts and will be best placed to answer your questions.
- > Check that the medications charts are correct.
- > Ask the parents what their expectations are for using pro re nata (PRN) medication and other comfort measures.

Paediatric Palliative Care Service expectations

- > Read the palliative care profile and Care Plan provided by the Paediatric Palliative Care Service.
- > If the child's death is imminent, make an effort to understand what the terminal care plan is for the child and follow any written resuscitation orders.

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Checklist

Patient details

- Child and parent's name
 - Resuscitation plan
 - Terminal care plan
 - Locate Paediatric Palliative Care number
 - Patient profile
 - Care plan
-

Equipment – locate and read instructions

- Syringe pump
 - Enteral feeding pump
 - Suction unit
 - Bi-pap machine
 - Oximeter
-

Drugs

- Drug prescription
 - Drug safety (storage/location/equipment locked)
 - Drug stocks
-

Home safety

- Physical environment
- Smoke free
- Pet restraint
- Suitable workspace

A bright sun with a starburst effect is positioned in the upper left quadrant of a light blue sky. The sky is filled with soft, white, fluffy clouds. The overall scene is bright and clear.

Section 2:

Differences between adults and children

- 7 Development – General
- 7 Physiological/metabolic
- 8 Cognitive
- 8 Physical
- 9 Emotional and psychological
- 10 Clinical implications
- 10 Play

Development – General

'Think developmental stage rather than chronological age, particularly for children with disabilities.'

- > Children are NOT small adults. They are competent individuals on a journey of growth and maturation towards adulthood.
- > Children are experiencing significant growth and development in cumulative short bursts over a long period of time (birth to adulthood) which impacts on how they communicate, behave, metabolise, sleep, eat, play, feel about themselves and think².
- > Children's expression of language and behaviour in relation to how they feel and what they want or need will vary depending on their age and stage of development.
- > Illness will impact on a child's developmental progress and potential and the stage of a child's development will affect how they experience and understand their illness¹.
- > All of the above impacts on how parents will 'parent' and how nurses will 'nurse' the child.

Physiological/metabolic

- > The ability of neonates and infants (younger than 12 months of age) to clear drugs from their system is reduced compared to adults due to immature liver enzyme systems and lower renal excretion. This can result in the half life of drugs being prolonged³.
- > The risk of respiratory depression is significant in infants due to their sensitivity to opioids³.
- > Children aged between 2–6 years may need higher doses of morphine per kilogram body weight than adults because they have a large liver in comparison to their body size and clearance of the drugs is increased³.

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Cognitive

- > Very young children are unable to articulate symptoms or pain except through behavioural cues.
- > Children's ability to be autonomous depends on their level of cognitive development. Children can be considered autonomous if they can understand their situation and communicate their understanding³.
- > For all of these reasons parents are generally much more involved as care givers and decision makers.

Physical

- > Physical development involves a highly complex series of changes in body size, proportion and composition⁴.
- > The fastest growth periods in childhood are from birth to age two and adolescence. Preschool and middle childhood years have a slow and steady growth rate⁴.
- > Physical development is crucial to cognitive development and vice versa.



Emotional and psychological

- > Emotional development relates to how children express, recognise and interpret emotional signals⁴.
- > Children's emotional and psychological development is closely intertwined and is influenced by the quality of the child's relationship with significant carers and the child's temperament type⁴.
 - A quiet child may need more time to adapt to situations and people.
 - An easy going child may be easier to get to know and work with but be aware that they will still have fears and anxieties regarding their situation.
 - A child who doesn't cope with any type of change will need increased preparation time for nursing care, new people, and new routines.
- > Children can recognise expressions of emotion by looking at facial and body positions from a very young age including expressions of being happy, sad, and angry or fearful⁴.
- > As children develop a sense of self they begin to feel and recognise complex emotions such as shame, guilt and embarrassment⁴.
- > Very young children look to their parents for cues on social situations. Depending on what emotion the parent(s) are expressing towards a situation or person(s) will influence how the child behaves towards the same situation and people⁴.
- > Children's emotional development occurs in the social context of their family⁴.

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Clinical implications

- > Support expression of emotion so children know they can express their feelings without upsetting those around them³.

Play

- > Play is children's work. It allows them the opportunity to express their feelings, experiences and observations of their world.
- > Expression through play helps children to cope with the complexities of their world and teaches them how to act and be in their world.
- > Encourage play for distraction during nursing care, separation from primary care givers or any unpleasant event.
- > Ask parents what their child likes to play and how they like to play so you can initiate and support play episodes.
- > Kindergarten and school are very important in the child's day to day life and should be encouraged wherever possible. Friends can be a great support to the child during their illness¹.





Section 3:
Communication

- 11 General
- 12 Communicating with children – A list of do's and don'ts!
- 14 Considerations
- 20 Cultural awareness

'A child can live through anything so long as he or she is told the truth and is allowed to share with loved ones the natural feelings people have when they are suffering.' Herbert 1997

General

Although parents are encouraged to tell their children the truth about their illness and palliation, many parents do not want their child to know that they are dying. All health professionals need to know what the parents have chosen to tell their child and respect this decision!

'It is important to realise it is impossible NOT to communicate to children. Every contact with them communicates something and every exclusion from contact communicates something'.

(A practical guide to palliative care in paediatric oncology, 2009, page 22).

- > When communicating with parents and children consider the following⁵.
 - Environment – is it conducive to conversation?
 - Who is present – Are there too many people or are the key people present?
 - What is happening at the time? (i.e. procedures, rest time etc)
 - The age of the child – how am I going to understand the child or let the child know what I am going to do.
 - Non verbal communication including tone, modulation and body language. Am I shouting? Whispering? Do I sound stern or compassionate? Am I facing the child or parents? Am I excluding anyone?
- > Ask parents what words they use when talking with their child about their illness and treatments and try to use these same words when you are communicating with the child.
- > Where possible use the correct medical terminology for any nursing care required.
- > Listening is the key to any communication with children and will demonstrate that you⁵;
 - Respect the child.
 - Regard them as important.
 - Are trying to understand their world and.
 - Support them.



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- > Parents are the best people to support their child. They understand what their child needs and how to provide support⁶.
- > Children won't necessarily have a negative reaction to their situation and won't necessarily need to talk about it. Therefore, be emotionally available to support the child but don't force support on them if there is no need.

Communicating with children – A list of do's and don'ts!

Not all children can communicate verbally because of their age, disease or disability. It is just as important to find out how you can communicate with these children as with children who are verbal. Parents communicate with their non-verbal child every day because it is impossible not to care for someone and communicate either directly or indirectly. Ask parents how, so you can communicate with their child successfully. (Refer to table on page 13 for list of do's and don'ts.)

Do's

- > Take the time to get to know the child.
- > Be gentle in all your actions and words.
- > Smile gently when approaching the child and make eye contact briefly.
- > Talk to the parents to get to know them and show the child that you are trustworthy.
- > Talk to a child through their favourite toy.
- > Speak to children confidently and use short sentences and words they can understand.
- > Get down to the child's eye level when communicating.
- > Be honest and where possible give children some control over the situation.
- > Let children have the opportunity to express themselves.
- > Ask the child if you can touch them before you do.
- > Play with the child as much as they would like you to.
- > Ask parents how their child communicates if they are non-verbal because of age or disease and disability. Consider the following;
 - Cries.
 - Vocalisations.
 - Eye movements.
 - Head/body/limb movements.
 - Signing.
 - Communication boards.

Don'ts

- > Overload the child with information; tell them only what they want to know^{3, 5}.
- > Stand over them as this can be intimidating for the child.
- > Rush a child through any aspect of their day or procedures.
- > Tell children to stop crying or to 'be brave'. Let them know that feeling sad, scared and angry is normal for their situation.
- > Don't leave a crying child alone, they are trying to tell you something about how they are feeling and need reassurance.

Considerations

Infants⁶ (0–1 years)

- > The most important aspect of communication for a baby is attachment to a key caregiver and normal routine.
- > If an infant experiences separation for any reason then it may become distressed.
- > Infants are sensitive to non-verbal cues and will pick up on the emotional atmosphere around them⁷.
- > An infant may express distress through increased crying, difficulty settling, unable to sleep for long periods or being fussy when fed.

Clinical implications

- > Assist in maintaining normal home routine.
- > Promote and support the key attachments the infant has formed.
- > Use simple language in a soft voice when talking to an infant.
- > Look at the infants face and use eye contact when talking.
- > Comfort and hold the infant if they are distressed.

Toddlers⁶ (1–2 years)

- > Are similar to infants in as much as they depend on routine and key caregivers to feel safe and secure in their world.
- > If a caregiver is stressed or upset the toddler may feel insecure and anxious.
- > Anxiety in a toddler may be expressed by being more clingy, not wanting to be far from the main caregiver or other behaviour that allows the child to seek comfort and be comforted.

Clinical implications

- > Assist in maintaining normal home routine.
- > Ask the parents what words the toddler understands for routines and treatments and use these words consistently.
- > Use simple sentences when talking to the toddler.
- > Ensure a key comfort object is with the toddler such as a dummy, toy or blanket.
- > Play with toys of interest to the child while the care giver is away to distract them from the separation.
- > Comfort and hold the child if they are distressed. Ask the parents what the best way to comfort their toddler is.

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Pre-schooler (3–6 years)

- > This age group is developing language skills and some understanding of concepts such as illness and death by what they see, hear and experience⁶.
- > Pre-schoolers are very ego-centric.
- > Pre-schoolers have magical thinking and believe they have the power to make things happen by thinking about it⁶.
- > This age group is frightened of being separated from their main caregivers especially their mother and will become very distressed if they think they are going to be left alone⁶.

Clinical implications

- > Be honest in your communication.
- > Ask questions in response to a pre-schoolers question to find out why they are asking.
- > Play can help you communicate with children because it is central to their daily activities and is a forum to express their feelings, emotions and understanding of their world.
- > Some young children may be fearful and anxious about being separated from their mother or caregivers⁶. They may not be able to articulate this but could express their fears as;
 - Not wanting to go to sleep.
 - Being clingy to their caregivers.
 - Regression of achieved developmental milestones.
 - Crying.
- > Stick to routines as much as possible.
- > Encourage kindergarten if possible.
- > Encourage the care givers to talk to the child about what is happening to them and reassure their presence⁶.

Early childhood (6–9 years)

- > Children in this age group begin to understand that 'bad' things can happen to people but don't think it will happen to them⁶.
- > They will be aware of everything that is happening within the family and to them⁶.
- > Children in this age group want to be with their friends as much as possible and school life is important⁶.

Clinical implications

- > Be honest in your communication.
- > The parents are more likely to be the best source of information and support for the child⁶.
- > Siblings in this age group may be fearful that they can 'catch' the condition or it will also happen to them⁶.
- > Talking about friends and interests can be a good starting point for getting to know the child and building a rapport.



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Middle childhood (9–12 years)

- > This is the in between stage of childhood and adolescence⁶.
- > Children are beginning to think abstractly and can start to reason⁶.
- > Beginning to seek independence⁶.
- > The child in this stage will swing between seeking comfort as a child and being treated as a more independent person⁶.
- > They may experience feelings that are too overwhelming to deal with or articulate so they don't⁶.

Clinical implications

- > Be sensitive to how the child is feeling and respond appropriately.
- > Be prepared to listen to any questions the child has about death and dying as they explore their experience and seek information.
- > Children in this age group can understand abstract concepts and can engage in more mature conversations.
- > If you are not sure how to respond to a question they ask about death or dying, be honest and tell them you are not sure but explore with them who they could ask and help facilitate this interaction.
- > Remember the range of maturity will fluctuate greatly in this age group depending on life experience, family functioning and personality. Look for cues in the child and family that indicate where the child might be in their thinking and exploration of their illness and situation.

Adolescence

- > Starts around the age of 12 years until the age of 20⁶.
- > There are three phases of adolescence, early, middle and late⁶.
- > Adolescents are more aware of influences that affect the family unit⁶.
- > They understand how the family unit functions and how it manages during a crisis⁶.
- > Friendships can be more important than family relationships⁶.
- > Self image is developing and is at risk of being altered¹.
- > The adolescent is progressively seeking independence.
- > The adolescent will either withdraw or fight depending on their personality when they are faced with a crisis or conflict⁶.
- > Late adolescence brings reflection on life and death and exploration of their spirituality⁶.

Clinical implications

Support adolescent's quest for independence:

- > Give them privacy during nursing care.
- > Talk to them directly and refer to parents when the adolescent indicates it is ok to.
- > Understand how the adolescent is coping with their illness.
- > Listen when they are talking to you and answer any questions honestly.
- > Show interest in their friends, activities and hobbies as these conversations may lead to thoughtful supportive discussions.
- > Collaborate with the parents and the adolescent at all times.

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Parents and family

Clinical implications

- > At all times respect the beliefs and knowledge unique to the family you are supporting⁵.
- > Listen to what parents are trying to tell you⁵.
- > Try not to placate parents by superficial answers, instead explore what they are saying so you can understand what is worrying them⁵.
- > Always be honest in your communication⁵.
- > Include extended family members in communication as indicated by the parents and based on normal family dynamics.
- > Use language similar to the family when communicating with them.
- > Show them you understand what they are saying by reflecting what they are saying to you.
- > Check with them that they understand what you are saying by asking them to repeat in their words what information you are trying to give them⁵.

Cultural awareness

Families from a culturally diverse background may have customs and beliefs that will influence how you communicate with them and their child. Ask the parents if there are any considerations that you should know regarding their culture and communication so you can be sensitive to their needs.



Section 4:
Family
centred care

- 21 General practice points
- 21 If in doubt, parents know their child best
- 22 Siblings
- 22 Cultural issues

General practice points

- > Parents are legally responsible for all decision making regarding their child's medical treatment until their child is 16. However if the child is cognitively impaired the parents legal responsibility is ongoing.
- > Children are a part of a family unit and it is therefore necessary to care for the family unit in order to care for the child².
- > Find out what parents have told their child and the child's siblings about their condition and palliation. It is important that you work within the parents wishes and do not breach their trust.
- > Respect diversity².
- > Families have different ways of coping and receiving support.
- > Look for the strengths within the family and use these to empower them to care for their child².
- > Make sure your communication with parents, children, the Paediatric Palliative Care Service and other relevant health professionals is up to date, complete and non judgemental².
- > No two families will ever function in the same way².
- > The Paediatric Palliative Care Service relies on your information about the child's condition and feedback on equipment available to assist them in coordinating appropriate care to effectively support the family in the home.

If in doubt, parents know their child best

- > Parents know their children best so LISTEN to them when they are telling you what works best for their child.
- > Work with the parents to find the best solutions to any care concerns based on the individual child's needs and development – remember to think developmental stage rather than chronological age.

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Siblings

'Children experience things just the same as adults – the only difference may be that they do not have the language or maturity or experiences to let us know how they feel or what they feel about it.' (Crowe, 2003, page 28)

Siblings are an important part of the family and can sometimes feel invisible. Make an effort to greet and talk to siblings about their day as well as what is happening with the sick child.

Siblings may feel good about being able to help with their sick brother or sister by⁷:

- > Playing with them.
- > Talking to them.
- > Cuddling them.
- > Holding equipment to help you.
- > Giving them food or drink.
- > Changing nappies.

Communicate with siblings using the guidelines for their age groups as suggested in the section under communication.

Cultural issues

Some issues to consider that might vary from culture to culture include⁷:

- > Thoughts about illness, pain and disease.
- > Attitudes to medicine and nutrition.
- > Understanding of death and dying.
- > Customs surrounding death, burial, cremation and bereavement.
- > Spiritual matters, religious issues including rituals.
- > Family or social network.



Section 5:
Medications

- 23 Doses
- 23 Frequency
- 23 Routes
- 24 Indications
- 24 PRN orders – ‘As required’ PRN medications
- 25 Prescribed medication
- 25 Syringe drivers

Doses

- > The majority of children's medications are calculated on mg/kg.
- > Some drug doses will require higher doses per kg of weight than adults because of the rate of children's metabolism.
- > Neonate doses will be lower per kg.

Frequency

Some drugs will be given more frequently than in the adult population because of how quickly the drug is cleared in children. Slow release preparations are often used to reduce the pressure of getting a child to take medicine.

Routes

The route of medication administration will depend on the child's underlying disease and stage of palliation, bioavailability of the drug and patient preference. Possibilities include³;

- > Oral (nasogastric, PEG).
- > Sublingual.
- > Buccal.
- > Nasal.
- > Intravenous (CVC's, Ports, PICCS will be used over subcutaneous).
- > Subcutaneous.
- > Transdermal.
- > Rectal.
- > Epidural.

Oral medication is the preferred route if tolerated.

There is rarely a reason to give a child an intramuscular injection.

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Indications

There is a wide range of drugs that are commonly used in paediatric palliative care for the following reasons³:

- > Agitation/delirium.
- > Bleeding.
- > Constipation.
- > Cough.
- > Hiccup.
- > Mouth care.
- > Nausea and vomiting.
- > Pain.
- > Psychological issues.
- > Skin.
- > Terminal restlessness.
- > Anorexia.
- > Breathlessness.
- > Convulsions.
- > Gastro-oesophageal reflux.
- > Infection.
- > Muscle spasm.
- > Noisy breathing.
- > Other pain syndromes.
- > Raised intracranial pressure.
- > Sweating.
- > Emergency drugs.

Please see appendix 6 for the table of commonly used drugs, dosages and rationales.

PRN orders

– ‘As required’ PRN medications

- > Discuss with parents at the beginning of your shift when they give any PRN medications and how they assess this need.
- > Collaborating with the child’s parents will ensure consistency of care and alleviation of symptoms as well as building a trusting and respectful relationship.
- > Check the medication orders and notify the Paediatric Palliative Care Service if anything is unclear or unexpected.

Prescribed medication

At the beginning and end of your shift in the home, assess how much medication is available for regular and PRN medications. Consider if there are enough doses for the next 24 hours? For the weekend? Long weekend? If the supply is running low contact the Paediatric Palliative Care Service as soon as possible to ensure supplies can be organised in day time hours.

If there is an error on a medical prescription or a discrepancy between the prescription and drugs dispensed, contact the Paediatric Palliative Care Service.

Please check that the family have safely and appropriately stored the medication i.e. refrigeration, locked cupboard etc.

Syringe drivers

- > A syringe driver is a small portable battery driven infusion pump used to give continuous medication over a 24 hour period³.
- > A syringe driver can be used either subcutaneously or intravenously.
- > Subcutaneous syringe drivers are an effective alternative to medication administration if children⁸;
 - can no longer tolerate oral medication.
 - have nausea and vomiting.
 - can no longer absorb enteral forms of medication.
 - refuse to take oral medication or are unconscious.
- > The advantages of subcutaneous or intravenous continuous medication administration include⁸;
 - a reduced need for repeated injections.
 - up to 3 or 4 drugs can be combined in a syringe to alleviate several symptoms at once.
 - plasma levels remain steady.
 - mobility is still possible due to the small size of the syringe and equipment.
- > Not all drugs can be given subcutaneously.
- > Not all medications can be mixed due to incompatibilities⁸.

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Clinical implications for children using syringe drivers

- > Preferred subcutaneous sites for children include the abdomen and thighs but assess the location based on the child's general condition and mobility and likelihood to pick at site.
- > Keep infusion volumes and bolus doses as small as possible to reduce swelling and extend the life of the infusion site.
- > Firmness and swelling at the injection site is not an indication for cannula change. Pain and obvious inflammation are indications for change⁸.
- > Use a carry pouch to hold the syringe driver to encourage mobility and play.
- > Administer any required bolus doses of medication as a subcutaneous injection, through the 'y' junction not via the syringe driver.

Safety tips

- > Ensure the syringe driver is encased correctly so the child and/or sibling cannot touch the syringe or driver.
- > If using pre-drawn medications make sure they are out of reach of any children in the house.



Section 6:

Comfort focussed care

- 27 Symptom management
- 28 Observations
- 28 Considerations in the paediatric population
- 28 Pain management
- 30 Respiratory
- 30 Nutritional needs
- 31 Constipation
- 31 Seizures
- 31 Nausea/vomiting
- 32 Disabilities
- 32 Resuscitation issues/plan
- 33 Complementary therapies

Symptom management – hope for the best, prepare for the worst!

Symptoms in children vary widely depending on the child's illness or condition and it is not possible to list them all here. Primarily symptoms will relate to pain, the respiratory system, the gut, the central nervous system and physical and/or intellectual disability that may or may not be progressive. The key for community nurses managing children's symptoms at home during their palliation are listed below:

1. Locate and read the management care plan for the child you are caring for. The management care plan will include 'goals of care' and the management of any 'anticipatory' symptoms.

NOTE: Children whose clinical condition is triaged to level 2 will be receiving weekly contact from the Paediatric Palliative Care Service. Children whose condition is triaged to level 1 will be receiving daily contact from the Paediatric Palliative Care Service. Management care plans will be updated accordingly based on the child's condition.

2. Manage all symptoms in a calm and logical manner.
3. Collect a good recent history of the symptoms over the last 24–48 hours from the parents/caregivers and the Paediatric Palliative Care Service.
4. If the child's symptoms are progressing rapidly or new symptoms are presenting contact the Paediatric Palliative Care Service.
5. Check with the parents how they feel about their child's condition. Do they understand what is happening from a palliative perspective? Are they distressed? What are the goals of care for their child? Do the parents have any criteria regarding their child's symptoms for when they would readmit their child to hospital? If you have an understanding of what the parent's are expecting you will be better equipped to support them.
6. Match symptom management to the personality of the child and family, the environment you are in and what is available for you to achieve the goals of care. Symptom management in children may require creativity and flexibility so they can engage in their normal life routine.

NOTE: If the parents are getting distressed due to any progressive symptoms that are challenging to manage and they want to call an ambulance, support them and ring the Paediatric Palliative Care Service as soon as possible.

7. Remember that children are children first and patients second, so use play, stories and activities to help with distraction through symptoms or nursing procedures.

Home care companion

Observations

- > Do not take children's observations unless under the direction of the Paediatric Palliative Care Service.
- > If the child's condition is deteriorating this will be visually observed by changing clinical signs such as rate, depth, and noise of breathing, level of consciousness, possible worsening of symptoms, temperature of the skin and amount of urine being produced.

Considerations in the paediatric population

The Paediatric Palliative Care Service will have up to date information available on the illness or chronic condition of the child you are caring for. Ask for this information if it is not available.

Pain management

- > A big fear for parents is that their child will experience pain.
- > Children experience pain just like adults but may not have the ability to express what their pain is like.
- > Poorly managed pain is considered a palliative emergency⁹. If the child you are caring for has severe pain, contact the Paediatric Palliative Care Service immediately for advice.
- > There are several pain scales available that you can use to assess the level of a child's pain and your choice of scale will depend on the age or stage of development of the child.
- > Parents are your best resource for assessing if their child is in pain. The following is a guide for choosing the most appropriate pain scale based on developmental stage:
 - Infants and toddlers – FLACC pain scale (appendix 6)
 - Pre-schoolers and early childhood – Wong Baker Faces Pain Rating Scale (appendix 7)
 - Middle childhood and adolescence – Numerical visual analogue scale (appendix 7).

- > The Paediatric Palliative Care Service will have a good knowledge of the reasons why pain is occurring or why pain may occur.
- > Possible causes of pain in palliation include⁹;
 - Direct organ involvement.
 - Bone involvement.
 - Soft tissue infiltration.
 - Nerve compression.
 - Nerve destruction.
 - Raised intracranial pressure.
 - Muscle spasm.
 - Colic/constipation.
 - Gastritis.
 - Retention of urine.
 - Psychological.
- > Follow the treatment plan for pain management as documented, even if the child looks comfortable. It is important that the child has steady pain relief so they can function to their best potential rather than experience peaks and troughs which will interrupt their daily routine and quality of life.
- > Children will not get addicted to opioids during palliative pain management so use opioids as often as needed to relieve pain.

Home care companion

Respiratory

Secretion management, oxygen therapy, oximetry, Bi-pap machines, pneumonia

- > Respiratory symptoms in a child are distressing for the child and the family.
- > Wherever possible, nurse the child in an upright position to maximise lung function and use a fan or open a window to circulate fresh air around the room^{5,9}.
- > Use anti-anxiety medications to calm the child which can assist with breathing difficulties, hypoxia or mental confusion^{5,9}. Opioids are sometimes used to relieve respiratory distress.
- > If the child has a respiratory infection anti-biotics may be prescribed to relieve symptoms and provide comfort to the child.
- > Excessive secretions can be managed by a drying agent^{5,9} and if necessary a suction unit will be available.
- > A child with respiratory distress will have signs of rapid and irregular breathing, tracheal tug and abdominal heaving, nasal flaring – this may not necessarily be uncomfortable for the child.
- > Children with a neurodegenerative condition may require a bi-pap machine for use at night.

Nutritional needs

- > Feeding a child is a basic parental role and any difficulties to meet this need can be distressing to parents.
- > Food and fluid should always be offered if the child is able to take it by mouth³.
- > Supplemental feeding in paediatric palliative care is a common practice.
- > Many children with chronic progressive conditions are fed via gastrostomy or nasogastric tube.
- > As the child nears death the feeds may be slowed or stopped completely depending on how well the child is tolerating their supplemental feeds.

Constipation

- > If a child is receiving opioids then constipation should be expected and prevented with laxatives^{5,9}.
- > Treatment for constipation in children may be dependent on finding the most palatable drug the child will take to manage the problem rather than the most effective.

Seizures

- > Commonly seen in children with neurodegenerative conditions or brain tumours.
- > Seizures may become more frequent, severe and difficult to control in children with terminal neurodegenerative conditions.
- > Parents are often the most knowledgeable in recognising and treating seizures.
- > If children develop seizures it can be a frightening new symptom for the parents to learn to manage. Things to consider:
 - The Paediatric Palliative Care Service will inform and educate parents whose child is at risk of developing seizures due to their disease.
 - Usually intranasal midazolam will be used to manage seizures and can be found in the medical kit given to the family – know where this is located.
 - Assist parents with the management of seizures in a calm and logical approach.

Nausea/vomiting

There are many reasons why nausea and vomiting can occur;

- > Treatment of nausea and vomiting depends on the vomiting site stimulated. When the reason for the child's nausea and vomiting is correctly identified then the appropriate anti-emetic can be administered based on the mode.
- > There may be more than one anti-emetic used and these drugs should work in different ways for maximum effectiveness.

Home care companion

Disabilities

- > The Paediatric Palliative Care Service will ensure appropriate equipment is available in the home for the parents and community nurses to meet the daily needs of the child.
- > Contact the Paediatric Palliative Care Service if any of the following occurs:
 - Any equipment in the home does not match the size of the child.
 - The equipment available is not appropriate to assist with the nursing care needed.
 - The child's condition has deteriorated and the equipment is no longer suitable.

Resuscitation issues/plan

- > The children who are receiving community nursing care for palliation should have a resuscitation plan identifying levels of life support expected by their parents.
- > Talk to the parents and assess their understanding of the plan.
- > Resuscitation is a complex and emotive issue for parents and their decision can be reviewed and changed by them at any time.
- > If an ambulance is called to the home and the child is dying then attempts may be made to resuscitate the child or if the child has died there is a strong chance the police and coroner will be called by the paramedics. If an ambulance is called for any reason contact the Paediatric Palliative Care Service immediately.



Complementary therapies

- > Complementary therapies are often used in paediatric palliative care. There are many therapies available in the community¹⁰. Such as;
 - Aromatherapy.
 - Music therapy.
 - Massage therapy.
 - Art therapy.
- > Do not suggest use of complementary therapies except those listed above.
- > There are also complementary therapies that are less well known and are not regulated by any professional body and which the use of may not be in the best interest of the patient.
- > Be non-judgemental of the family's decision to use complementary therapies.
- > The use of a range of therapies is generally supported by the Paediatric Palliative Care Service as long as;
 - The therapy doesn't result in any pain or suffering for the child.
 - The therapy can be tolerated by the child.
 - The child assents to the therapy if age appropriate.
- > Do not participate in any complementary therapy practice that makes you feel uncomfortable, is outside the scope of your practice or you do not know anything about or you feel it is detrimental to the comfort of the patient. You are not obliged to deliver care outside of that which is documented by the Paediatric Palliative Care Service.



Section 7:
Dying process

- 35 What to expect
- 36 Decision making
- 37 Terminal care plan
- 39 Care of child's body after death
- 39 Cultural awareness

What to expect

- > Parents often ask what the signs of the dying process are. The following is a list that can help you recognise the terminal phase of care⁷:
 - As breathing and circulation slow so does brain function and the function of internal organs.
 - The child's body colour may change, their hands, feet and lips may be pale or bluish in colour and their legs and arms may look mottled.
 - Their hands and feet will be cool to touch.
 - They may be very sweaty and damp to touch.
 - Their breathing will be irregular (cheyne-stokes breathing).
 - They may be restless or unsettled.
 - They may be sleeping more but are rousable or they may be semi-conscious or unconscious.
 - They will have less interest in eating and drinking and may not tolerate their supplemental feeds.
 - Their breathing may be noisy due to increased secretions.
 - They may become incontinent of urine and faeces.
 - Their eyes may look sunken or glazed.
- > These signs of dying may be unpleasant for family generally. Parents may need reassurance that it is normal for any of the above symptoms to occur without causing pain or suffering to the child.



Home care companion

- > Reassure parents that the child can still hear and feel, and assist them to be positioned as closely and as comfortably as they can to their child so the parent can touch their face and talk to them or read them stories if they want to. All nursing staff should ensure that they do not position themselves between the child and parent when delivering nursing care.
- > If the child has increased secretions, consider nursing them on their side with their head tilted slightly upwards and using anticholinergic agents if needed.
- > If the child is very sweaty try using absorbent pads underneath them to avoid having to change their bedding too often.
- > Consider the comfort of the physical environment for the child and parents and attempt to control the following where possible;
 - The temperature (not too hot or too cold).
 - Smells (use aromatherapy if there are unpleasant odours).
 - Noise (keep noise to a minimum and suggest any music to be played softly).
 - Make sure tissues are available.
 - Avoid bright lights.
- > If the child's is experiencing any particular symptom that is distressing then contact the Paediatric Palliative Care Service.
- > If the parents are very distressed, contact the Paediatric Palliative Care Service for support.

Decision making

- > The Paediatric Palliative Care Service will have already discussed with the family the anticipated terminal event of their child and this will be documented in the resuscitation plan and the terminal care plan.
- > The family may have already chosen a funeral director and started planning the child's funeral (with the child if age appropriate).
- > If the parents change their mind about any aspect of their child's terminal plan or resuscitation plan contact the Paediatric Palliative Care Service.

Terminal care plan

- > If there is no clear resuscitation or terminal care plan then ring the Paediatric Palliative Care Service or an ambulance if the parents want you to.
- > No matter how prepared parents are they will never be completely ready for their child's death.
- > Try to ensure the room where the child is dying has low lighting, soft music and/or sounds and is not overly stimulating. Intense grief can make people sensitive to light and noise and therefore needs to be kept to a minimum.
- > Follow the terminal care plan in collaboration with the parents at all times.
- > If you are caring for the child during the night (so the parents can sleep), ensure that you understand when and if the parents want you to wake them (such as any changes in condition that indicates death is near).
- > It is important that parents are able to experience their child's death with minimal regrets so allow the family the space and respect to take as much time as they need to say goodbye to their child.
 - Ask the parents if they want to take photos, cut a lock of hair, take hand and foot prints, video, journaling or any other memory making act that is meaningful to them before their child is removed from the home.
- > There is no time limit for how long the child's body can be in the home. Some parents will choose to have their child's body in the home for several days so family members can say goodbye (this is done in collaboration with the funeral directors).
 - The parents may require assistance with washing and dressing the child. Ask them how they want you to be involved.
 - You may be required to remove any tubes, drains or other external devices used to support the child through death. This may include any intravenous tubing attached to central venous access devices, subcutaneous lines, peripherally inserted central catheters (PICC), jelcoes and nasogastric tubes. **DO NOT CUT OFF or PULL OUT** any external lumen central venous lines or gastrostomy tubes, just seal them off.
 - Help create a comfortable touching space for the parents and family members to say goodbye. Do the parents want to be able to lie with the child or sit next to the child?
 - Make the environment as pleasant as possible for the parents to be with their child.

Home care companion



- > Prior to your shift ending, liaise with the parents and the Paediatric Palliative Care Service as to whether further community nursing support is required for the family.
 - The parents may need the support of a health professional until the child's body is picked up by the funeral director.
- > The terminal care plan will inform you of who to contact upon the child's death (usually the Paediatric Palliative Care Service).
- > Supporting parents during the death of a child is an intimate and emotional event. Sometimes knowing what to say or what not to say can be challenging.
 - Just listen, the parents may not be looking for a conversation but are expressing and relieving their distress.
 - Be as open and honest as you feel comfortable with.
 - Follow your intuition with the situation and if you are uncomfortable contact the Paediatric Palliative Care Service for support.

Care of child's body after death

When a person is grieving their senses are heightened so a soothing environment is essential.

- > Make sure the room where the child's body is placed continues to have low lighting and low level noise.
- > If the body is going to stay in the home for a period of time the room needs to be kept as cool as possible – this may involve additional portable air conditioning.
- > Warn the parents of the post-mortem changes in the child's body.
- > The child's body may leak urine and faeces for several hours after death. Change the child as regularly as required to keep odours away.
- > Secretions may also leak from the nose or the mouth; soft gauze padding placed inside the cheeks can be used to reduce leakage.
- > Tegaderm® can be applied to any leaking wounds.
- > Following the death of a child, it is not uncommon for an unpleasant odour to be present. This can be managed by burning aromatherapy in the child's room, cleaning their mouth out with peppermint mouth wash and changing and removing any soiled materials regularly.
- > Blood will pool within the lowest points of the body because of gravity and it may look like a bruise or purple discolouration.
- > Empower parents to spend the time following their child's death alone with their child and/or siblings without extended family or other visitors being present. Reassure them that it is ok to be selfish about how much they do or don't want to share this moment, it is a personal choice.

Cultural awareness

- > The cultural requirements for each child following death will be documented in the terminal care plan.
- > If cultural or religious requirements following death are not clear please talk directly to the parents.



Section 8:
Spiritual issues

- 41 Child
- 41 Family
- 42 Cultural issues – respect rituals
- 42 Do and don'ts when supporting parents
- 43 Self care
- 44 Bereavement support

Child

- > Spirituality is about how people find meaning in their world based on what they are experiencing⁷.
- > Children have spiritual needs just as adults do but will express these needs based on their age, developmental stage and capabilities.
- > Ensure the child is as comfortable as possible so there is space for them and their parents to explore their spiritual journey^{7,9}.
- > Parents are the best people to assist their child in exploring their spiritual needs but they may seek support from you or the child may engage with you directly³.
- > If children ask you a direct question about dying respond with a question such as 'what makes you ask me that' and their response may help you understand their perspective and answer their question in an age appropriate way³. Remember to follow the parent's wishes.
- > Allow the child opportunity to express their spiritual needs in an age appropriate way.
- > Support any rituals the child has that promote spiritual wellbeing⁷.

Family

- > Parents will have their own spiritual needs and will be seeking meaning to their life situation.
- > All parents will express the pain and distress of their child's situation differently; some parents may be peaceful and accepting, others may be distressed and some may be angry and hostile.
- > Remember these are expressions of the parent's pain and are not about you or your nursing care.
- > Parents also need opportunities to express their spiritual needs and they may seek to do this in several ways such as^{5,7};
 - Talking to you and other health professionals.
 - Talking with religious leaders or support people.
 - Reading books, watching DVD's or listening to music.
 - Engaging in rituals with their child that promotes spiritual wellbeing.
- > Often the conversations with health professionals will be spontaneous and based on opportunity^{3,10}.

Home care companion

Cultural issues – respect rituals

- > Spirituality is different from cultural or religious needs however children and families may express their spirituality through aspects of their cultural understandings and beliefs¹⁰.
- > The patient profile will indicate which culture or religion the child and family practice within. If there is no clear information about what death and dying means to this family or their culture/religion please ask the parents directly.
- > Treat each child and family member as a group of individuals and try to understand their needs as their own instead of expectations based on a culture¹⁰.
- > Make sure you can put aside your own beliefs and values to be able to truly understand and help meet the needs of the child and family.

Do and don'ts when supporting parents

DO's

- > Tell the family how sorry you are about the child's death and about the pain they must be feeling – 'I am so sorry for your loss'.
- > Support them in spending their final moments together with their child and other family members as they wish.
- > Support them in making memories with their child.
- > Use photos, toys, treasured objects and any other mementos to give opportunity for communication with the parents about their child and their palliation¹⁰.

DON'TS

- > Rush them through any aspect of their experience.
- > Tell them what they should feel or do⁷.
- > Make any comments which in any way suggest that their loss was their fault⁷.
- > Point out that at least they have their other children⁷.
- > Say you know how they feel⁷.
- > Try to find something positive about their loss⁷.

Self care

- > It is important that you can identify and manage the additional stress brought by caring for dying children and their families¹⁰.
- > You can minimise the stress in your life by having a healthy work/life balance that enables you to express your feelings and grief, have set timeout from work and ensure you have available supports in place. Some examples could be¹⁰;
 - Taking regular breaks and holidays.
 - Talking to colleagues about your experiences and expressing feelings associated with these.
 - Having fun with family and friends.
 - Getting regular exercise.
 - Attend funerals (if appropriate for you) or work out a ritual for you to say goodbye to patients.
 - Giving yourself permission to grieve.
- > Identifying stresses related to caring for sick and dying children is important so you can recognise when you need to implement strategies for support or seek help¹⁰.
- > A particular challenge can be spirituality or meaning-making that arises within you. It is important to address these issues and the questions below may help you explore how¹⁰:
 - How do I relate to this situation?
 - Am I close to the age or circumstances of the parents?
 - How does this fit in with my own thoughts and experiences?
- > There are no right or wrong answers, it is just important to recognise that these issues are arising within you and to adjust to them through personal reflection and talking to colleagues¹⁰.
- > The Paediatric Palliative Care Service is here to support you in coping with this challenging work – feel free to call the service for your own needs.



Bereavement support

- > Bereaved families will be followed up by the Paediatric Palliative Care Service or other appropriate home team.
- > It is appropriate for nurses to attend the child's funeral to support the family and say goodbye if desired.
- > If you would like to contact the family of a child you cared for following their death, please contact the Paediatric Palliative Care Service to discuss this sensitive issue.



Section 9:

Ethical and legal issues

- 45 Informed consent
- 45 Nursing documentation
- 45 Palliative Care Act
- 46 Giving advice

Informed consent

- > As described elsewhere, children can only engage in informed decision making if they are at a developmentally appropriate age or stage of development. To act autonomously a person must act with intention and understanding of both the situation and the implications of decisions made and are able to communicate these decisions³.
- > Therefore, parents will primarily make decisions about their child's care and give consent to any procedures or treatments, if the child is under the age of 16 years.
- > However, even young children can be asked what they think or feel about what is happening to them and this understanding may influence decision making by others.
- > Where possible and appropriate, include children in the decision making of their care and seek their assent to procedures, interventions and decision making.
- > It could be as simple as giving the child control over how procedures are going to be performed rather than whether or not they are performed.

Nursing documentation

- > All care must be documented as per community nursing procedures.

Palliative Care Act

- > The Palliative Care Act allows health professionals to consider the intent of treatments at the end of life.
- > At the terminal phase of care significant amounts of analgesia may be given to relieve pain. There is a risk with large doses of analgesia that respiratory function may be depressed resulting in death. This is called the double effect of analgesia⁵. If the primary intent is to use analgesia to relieve pain then this is acceptable ethical and legal practice and is not euthanasia (where the primary intent is to cause death)⁵.
- > It is important to remember if you are administering regular or large doses of analgesia for pain relief that you need to explain to parents the risk of the double effect of analgesia before administration. This prepares parents for the possibility that their child's death may occur because of the drugs needed to control symptoms and they can decide if this is acceptable to them.

Home care companion

- > Nurses are also under no obligation under the palliative care act to 'use measures which are useless because death is imminent and inevitable or measures which are so burdensome that they are out of proportion to any benefit'¹⁰. Therefore if there is any care you are expected to give that you consider 'burdensome' to the child and are uncomfortable with, contact the Paediatric Palliative Care Service.
- > A child's death in the home is not an automatic coroners case nor for police notification. There is a coroners check list available that indicates whether the coroner needs to be involved. It will also be indicated on the Terminal Care Plan. If you are unsure please contact the Paediatric Palliative Care Service.

Giving advice

Refer to service

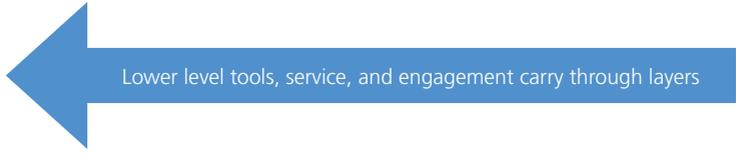
- > Please work within the care guidelines and management plans that have been individually detailed for each child collaboratively with the family and other key health professionals.
- > If care plans do need to change, document the date, time and name of the Paediatric Palliative Care Service on call health professional that you spoke to.
- > It is important that consistent information is being given to each family. To achieve this you will need to read all detailed information available for the child, speak to the Paediatric Palliative Care Service if required and collaborate with the family in the planning and delivery of care.



Section 10:

Appendices and references

47	Appendix 1 – Paediatric Palliative Care Service triage assessment
48	Appendix 2 – Resuscitation plan
50	Appendix 3 – Terminal care plan
51	Appendix 4 – Goals of care plan
52	Appendix 5 – Common drugs and doses used for symptom management in paediatric palliative care settings
65	Appendix 6 – FLACC Pain Scale
66	Appendix 7 – Wong faces score and numerical visual analogue scale
67	Appendix 8 – A child’s developmental understanding of death and the consequences of incomplete understanding
68	References
69	Reference links



Appendix 1

Paediatric Palliative Care Service triage assessment

Level	Criteria	Engagement	Service	Tools
1. Critical	<ul style="list-style-type: none"> Terminal Care, <2 weeks Admitted Rapid escalation of symptoms New referral workup Multi-aspect family needs High level home resource management 	<ul style="list-style-type: none"> Daily Document in Unit Record 	<ul style="list-style-type: none"> Medical ± Arts Therapist 	<ul style="list-style-type: none"> Death Plan Bereavement Plan Memorial Activities Clinical Review Meeting Drug list in Outlook Contacts file
2. Complex	<ul style="list-style-type: none"> Unstable symptoms High risk of rapid deterioration Multiple agency communication Fragile family Recent discharge from hospital Intercurrent illness 	<ul style="list-style-type: none"> Weekly Monthly Summary 	<ul style="list-style-type: none"> Counsellor ± Medical ± Arts Therapist 	<ul style="list-style-type: none"> Bereavement Risk Assessment Resuscitation Plan Home Nursing Care Plan Medication Chart Home Handy Hints book High Resource Package Symptom Management Evaluation Case Meetings
3. Stable	<ul style="list-style-type: none"> Plateau in disease process Symptoms well managed Early in disease trajectory Community agencies engaged Family coping well, receiving supports 	<ul style="list-style-type: none"> Monthly 	<ul style="list-style-type: none"> Primary Nurse 	<ul style="list-style-type: none"> Make a Wish/ Starlight Foundation Photography Project Demographics and Assessment Docs Service Information pamphlet and magnet Goals of care determined

Home care companion

Appendix 2

Resuscitation plan

 <p>Government of South Australia Children, Youth and Women's Health Service</p> <p style="text-align: center;">RESUSCITATION PLAN</p>	<p style="text-align: center;">PATIENT LABEL</p> <p>UR Number:</p> <p>Surname:</p> <p>Given Names:</p> <p>D.O.B. Sex:</p>																												
To be completed by the responsible Clinical Consultant																													
<p>The patient's primary diagnosis is</p> <p>The patient's current clinical condition is</p> <p>.....</p> <p>It has been agreed that in the event of deterioration in the patient's condition:</p> <p style="margin-left: 20px;">Full cardio-pulmonary resuscitation with total body support, as required, will be undertaken Yes/No</p> <p style="text-align: center;">OR</p> <p style="margin-left: 20px;">Intensive medical support will be undertaken with initiation of:</p> <table style="width: 100%; margin-left: 20px;"> <tr> <td style="width: 80%;">Airway suction</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>Bag mask ventilation</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>Intubation and mechanical ventilation</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>External chest compressions</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>Vasoactive drugs</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>Dialysis</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>Intravenous rehydration</td> <td style="text-align: right;">Yes/No</td> </tr> </table> <p style="text-align: center;">OR</p> <p style="margin-left: 20px;">Management will focus on the relief of discomfort: Yes/No</p> <p style="margin-left: 20px;">Other considerations: eg: antibiotics, enteric feeds,</p> <p>.....</p> <p>The following were present at the discussion of this Resuscitation Plan</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>Other Key Clinicians:</p> <table style="width: 100%; margin-left: 20px;"> <tr> <td style="width: 50%;">Name of Clinical Consultant <i>(on behalf of clinical team)</i></td> <td style="width: 50%;">Name of Legal Guardian/s <i>and/or consenting adolescent.</i></td> </tr> <tr> <td>.....</td> <td>.....</td> </tr> </table> <table style="width: 100%; margin-left: 20px;"> <tr> <td style="width: 50%;">Signature</td> <td style="width: 50%;">Signature/s</td> </tr> <tr> <td>Date</td> <td>Date</td> </tr> </table> <p>This order will be reviewed on / / (recommend a minimum of Annual Review)</p> <p>Copies of this order are held by (list);</p> <table style="width: 100%; margin-left: 20px;"> <tr> <td style="width: 80%;">Emergency Department <i>(specify which hospital(s))</i>:</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>Parents/Guardian/Patient:</td> <td style="text-align: right;">Yes/No</td> </tr> <tr> <td>Other clinical units/services:</td> <td style="text-align: right;">Yes/No</td> </tr> </table> <p style="margin-left: 20px;">eg: case note files, other hospitals, GP, Novita, RDNS</p>		Airway suction	Yes/No	Bag mask ventilation	Yes/No	Intubation and mechanical ventilation	Yes/No	External chest compressions	Yes/No	Vasoactive drugs	Yes/No	Dialysis	Yes/No	Intravenous rehydration	Yes/No	Name of Clinical Consultant <i>(on behalf of clinical team)</i>	Name of Legal Guardian/s <i>and/or consenting adolescent.</i>	Signature	Signature/s	Date	Date	Emergency Department <i>(specify which hospital(s))</i> :	Yes/No	Parents/Guardian/Patient:	Yes/No	Other clinical units/services:	Yes/No
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Other clinical units/services:	Yes/No																												

 <p>Government of South Australia Children, Youth and Women's Health Service</p> <p>RESUSCITATION PLAN</p>	<p style="text-align: center;"><i>PATIENT LABEL</i></p> <p>UR Number:</p> <p>Surname:</p> <p>Given Names:</p> <p>D.O.B. Sex:</p>
<p>The aims of these orders are to:</p> <ul style="list-style-type: none"> • encourage and facilitate clear and timely discussion regarding resuscitation of children who have life limiting diseases, including a plan for management in the event of a clinical deterioration. • provide specific details regarding different levels of resuscitation for each patient in this situation. • ensure readily accessible documentation about resuscitation at the front of the Unit Record, and appropriate dissemination of the documentation to all health care providers. • promote regular review of Resuscitation Orders. <p>The intended process for use of this document is that there will be a meeting between the members of the clinical team, the patient's parents and/or carers/legal guardians and family, and patient (if appropriate).</p> <p>Note that it is prudent to include both parents if involved with the child. Adolescents should be assessed for cognitive capacity to consent for themselves once > 16yrs. If not capable, their assent should be sought and documented.</p> <p>Following discussion of the patient's clinical status and possible events of deterioration and their sequelae, the levels of resuscitation would then be reviewed. Clear, legible documentation on the form will then inform others of the plan in place.</p> <p>The "clinical condition" documentation should include for example respiratory status, nutritional support, significant disease progression.</p> <p>The parents/carers may be invited to sign the form to confirm that the discussion has taken place</p> <p>Original to be filed in Patient Summary Section PS - 6</p> <p>Copies of the form must be sent/given to:</p> <ul style="list-style-type: none"> • the special needs file of the Emergency Department, WCH + entry on the Patients Expect screen in HAS-ED. • any other hospital where the child is routinely taken to, including the closest to their home and school. • with the family. • to all community health care providers. <p>If you have any questions or comments regarding this Resuscitation Plan please direct them to the Palliative Care Service, CYWHS. Phone: 81617994, page 81617000 #5719.</p>	

Home care companion

Appendix 3

Terminal care plan

Patient information	
Name:	Parents/Carers:
Address:	
Telephone numbers:	
Diagnosis:	
Primary Nurse, Clinicians:	
CHECKLIST	
<input type="checkbox"/> Place of death:	
<input type="checkbox"/> Funeral Director: Name: _____	Precontacted?: <input type="checkbox"/> YES <input type="checkbox"/> NO
<input type="checkbox"/> Phone: _____	
<input type="checkbox"/> Privacy Needs, choices of family/friends present	
<input type="checkbox"/> Resuscitation Plan	For Resus?: <input type="checkbox"/> YES <input type="checkbox"/> NO
<input type="checkbox"/> Pronunciation of Life Extinct	In Hours: After Hours:
<input type="checkbox"/> Death Certificate	In Hours:
<input type="checkbox"/> Cremation? <input type="checkbox"/> Burial?	After Hours:
For Coroner's notification <input type="checkbox"/> YES <input type="checkbox"/> NO	
<input type="checkbox"/> Spiritual Support needs	Contact person:
<input type="checkbox"/> Family wishes for time with child's body?	
<input type="checkbox"/> Home Nursing Support? <input type="checkbox"/> YES <input type="checkbox"/> NO	
<input type="checkbox"/> Post Mortem Autopsies/ Biopsies? <input type="checkbox"/> YES <input type="checkbox"/> NO	
<input type="checkbox"/> Immediate persons to notify of death (after hours)	

Plan Developed by _____

Date _____

Appendix 4

Goals of care plan

Name		Weight
Carers/Family Names		
Address		Triage Code
ID Numbers		Date of Birth Age
Allergies/ Sensitivities		
Diagnosis/Conditions		
Case Manager/Team		Contact Details
Changes in Care	Problem/Event	Instructions

Daily Living Activities

Problem/Need Rationale	Care Goal	Actions/Interventions
Nutrition		
Skin Care Positioning		
Bathing		
Elimination		
Sleep		
Pain		
Nausea/Vomiting		
Fitting		
Muscle Spasm		

Plan Developed by _____

Contact Number _____

Date _____

Appendix 5

Common drugs and doses used for symptom management in paediatric palliative care settings

(adapted with permission from 'a practical guide to palliative care in paediatric oncology', 2nd edition, 2009)

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Amitriptyline 'Endep®' <ul style="list-style-type: none"> • Tablets: 10mg, 25mg, 50mg 	<ul style="list-style-type: none"> • Neuropathic pain • May assist sleep 	PO	0.2–1 mg/kg/dose nocte	50 mg/day
Benzotropine 'Cogentin®' <ul style="list-style-type: none"> • Amp: 1mg/ml • Tablets: 0.5, 2 mg 	<ul style="list-style-type: none"> • Extrapyramidal side effects • Dystonia 	IV/IM	<ul style="list-style-type: none"> • <12 years • 0.02mg/kg/dose stat. • >12 years • 1–2 mg/dose stat. • Repeat after 15 min if required 	2 mg/dose
Carbamazepine 'Tegreto®' <ul style="list-style-type: none"> • Tablets: 100mg, 200mg • Tablets CR: 200mg, 400 mg <p>Controlled release tablets should be given every 12 hours</p> <ul style="list-style-type: none"> • Liquid: 20mg/ml 	<ul style="list-style-type: none"> • Seizures • Neuropathic pain 	PO/PR	<ul style="list-style-type: none"> • 2mg/kg/dose increase over 2 weeks to 5–10 mg/kg/dose • q8–12 hours 	2 g/day
Chloral Hydrate Liquid: Concentration varies	<ul style="list-style-type: none"> • Sedation 	PO/PR	<ul style="list-style-type: none"> • 10–20 mg/kg/dose, • q6 h prn, • Can use higher doses (up to 50 mg/kg) with care 	1 g/dose
Chlorpromazine 'Largactil®' Tablets: 10mg, 25mg, 100mg, Liquid: 5mg/1ml, 10mg/1 ml Amp: 25mg/ml	<ul style="list-style-type: none"> • Agitation • Nausea 	PO/IV	<ul style="list-style-type: none"> • 0.1–1 mg/kg/dose • q6–8h 	75 mg/day

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Clonazepam 'Rivotril®' <ul style="list-style-type: none"> • Tablets: 0.5mg, 2mg • Liquid: 2.5mg/ml • Amp: 1mg/ml & diluent 1 drop = 100mcg 25 drops = 1 ml	<ul style="list-style-type: none"> • Agitation/Anxiety • Seizures • Dyspnoea 	PO/ Sublingual	≤12yr <ul style="list-style-type: none"> • 0.01mg–0.05mg/kg/dose • q8–12h ≥12yr <ul style="list-style-type: none"> • Initially 0.5mg/dose • q 8–12h 	20mg/day 1mg/dose (IV)
Codeine (S8) <ul style="list-style-type: none"> • Tablets 30 mg 	<ul style="list-style-type: none"> • Analgesic 	IV/SC PO/PR	<ul style="list-style-type: none"> • 0.125–50mcg/kg stat (slow). • Repeat if required • 0.5–1mg/kg/dose • q4–6h 	60mg/dose
Cyclizine (SAS) <ul style="list-style-type: none"> • Tablets: 50mg • Amp: 50mg/ml 	<ul style="list-style-type: none"> • Nausea 	PO/IV/SC	<ul style="list-style-type: none"> • 0.5–1mg/kg/dose • q6–8h • Can be administered as continuous infusion 	50mg/dose
Dexamethasone <ul style="list-style-type: none"> • Tablets: 0.5mg, 4 mg • Amp: 4 mg/ml Consider prophylaxis with antacid medication such as ranitidine or omeprazole	<ul style="list-style-type: none"> • Cerebral Oedema • Spinal Cord Compression 	PO/IV/SC	<ul style="list-style-type: none"> • 0.25–0.5 mg/kg/dose • q6–12h • Seek specialist advice: A bolus dose of 1–2 mg/kg can be given initially prior to urgent imaging if available/appropriate 	8mg/dose
	<ul style="list-style-type: none"> • Anti-inflammatory (peripheral nerve compression, pain, bowel obstruction) 	PO/IV/SC	<ul style="list-style-type: none"> • 0.1–0.25mg/kg/dose • q6–12h 	8mg/dose
	<ul style="list-style-type: none"> • Nausea 	PO/IV	<ul style="list-style-type: none"> • 0.1–0.25mg/kg/dose • q6h, daily 	8mg/dose

Home care companion

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Diazepam 'Valium' <ul style="list-style-type: none"> • Tablets: 2mg, 5mg • Liquid: 1mg/ml • Amp: 5mg/ml • Enema: 5mg 	<ul style="list-style-type: none"> • Anxiety • Muscle Spasm 	PO	<ul style="list-style-type: none"> • 0.05–0.3mg/kg/dose • q6–12h 	40mg/day
		IV 0.1	<ul style="list-style-type: none"> • 0.3mg/kg • q 4–12h 	
	<ul style="list-style-type: none"> • Seizures 	IV	<ul style="list-style-type: none"> • 0.1–0.3mg/kg/dose stat. 	10mg/dose
		PR	<ul style="list-style-type: none"> • 0.5mg/kg/dose • Repeat at 15–30 minute intervals if required 	
Diclofenac 'Voltaren®' <ul style="list-style-type: none"> • Tablets: 12.5, 25mg, 50mg • Tablets (EC): 25mg, 50mg • Suppositories: 12.5mg, 25mg, 50mg, 100mg 	<ul style="list-style-type: none"> • Anti-inflammatory 	PO/Rectal	<ul style="list-style-type: none"> • 1mg/kg/dose • q8–12h with food 	50mg/dose
		PO	<ul style="list-style-type: none"> • ≤3 yrs • consider poloxamer drops • 3–6yrs • 50mg • q8h, daily • 6–12yrs • 50–120mg • q8h, daily • ≥12yrs • 100–150mg • q8h, daily 	
Docosate Sodium 'Coloxyl®' <ul style="list-style-type: none"> • Tablets: 50mg, 120mg 	<ul style="list-style-type: none"> • Constipation 	PO	<ul style="list-style-type: none"> • 1–2 tablets/dose • q8h–daily 	6 tablets/day
		PO	<ul style="list-style-type: none"> • 1–2 tablets/dose • q8h–daily 	

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
<p>Domperidone 'Motilium®'</p> <ul style="list-style-type: none"> • Tablet: 10mg 	<ul style="list-style-type: none"> • Nausea • Gastrointestinal stasis 	PO	<ul style="list-style-type: none"> • 0.2 – 0.4mg/kg/dose • q6–8h 	20mg/dose
<p>Fentanyl</p> <ul style="list-style-type: none"> • Lozenge: 200mcg; 400mcg; 600mcg; 800mcg; 1200mcg; 1600mcg; • Amp: 50mcg/ml • Patch: 12mcg/hr; 25mcg/hr; 50mcg/hr; 75mcg/hr; 100mcg/hr 	<ul style="list-style-type: none"> • Acute pain • Chronic pain • Break through pain 	SC	<ul style="list-style-type: none"> • 0.3 mcg/kg/hr continuous infusion 	
		Transdermal	<ul style="list-style-type: none"> • Base on 24 hour opioid requirements. Change patch every 3 days. 	
		Lozenge	<ul style="list-style-type: none"> • (For breakthrough pain) Initially 200mcg q4h, titrate to effect 	
		Intranasal	<p>1–3 yrs (10–14kg)</p> <ul style="list-style-type: none"> • 20mcg (0.4ml) <p>3 – 7 yrs (15–24kg)</p> <ul style="list-style-type: none"> • 25mcg (0.5ml) <p>8 – 12 yrs 925 – 36 kg)</p> <ul style="list-style-type: none"> • 50 mcg (1ml) <p>Repeat at 10 minutes if no effect. 2nd dose at 30 minutes if required.</p>	
<p>Gabapentin</p> <ul style="list-style-type: none"> • Tablets: 600mg; 800mg • Capsules: 100mg; 300mg; 400mg (Capsules may be opened and dissolved in water.) 	<ul style="list-style-type: none"> • Neuropathic pain • Itch 	PO	<ul style="list-style-type: none"> • 5mg/kg/dose Daily • q8h <p>Increase dose over days–weeks</p> <ul style="list-style-type: none"> • Day 1: Daily • Day 2: q12h • Day 3: q8h 	20mg/kg/dose

Home care companion

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Glycopyrrolate 'Robinul®' <ul style="list-style-type: none"> • Tablets: 1mg (SAS) • Amp: 0.2mg/ml (can be given orally) 	<ul style="list-style-type: none"> • Reduce secretions 	PO IV/SC	<ul style="list-style-type: none"> • 40–100mcg/kg/dose • q6–8h • 4–10 mcg/kg/dose • q6–8h • Can be administered as continuous infusion 	400mcg/dose
Haloperidol 'Serenace®' <ul style="list-style-type: none"> • Liquid: 2mg/ml • Tablets: 0.5, 1.5mg, 5mg • Amp: 5mg & 10 mg/ml 	<ul style="list-style-type: none"> • Agitation/Delirium • Nausea/Vomiting 	PO/IV/SC	<ul style="list-style-type: none"> • ≤12 years • 0.01–0.1 mg/kg/dose • q8–12h • ≥12 years • 500mcg–2.5mg • q8–12h • Can be administered as continuous infusion 	7.5mg/day
Hyoscine N-Butylbromide 'Buscopan®' <ul style="list-style-type: none"> • Tablet: 10mg • Amp: 20mg/ml 	<ul style="list-style-type: none"> • Antispasmodic (renal, gastrointestinal) 	PO/IV/SC	<ul style="list-style-type: none"> • 0.5mg/kg/dose • q6h 	20mg/dose
Hyoscine Hydrobromide <ul style="list-style-type: none"> • Tablets: 0.3mg (Kwells®) • Amp: 400mcg/ml • Patch: 1.5mg (Scopoderm®) (SAS) 	<ul style="list-style-type: none"> • Reduce secretions 	PO IV/SC	<ul style="list-style-type: none"> • 2–7 years • 1/4 tablet/dose • q6h • ≥7 years • 1/2–1 tablet/dose • q6h • 6–10 mcg/kg/dose • q6h • Can be administered as a continuous infusion 	400mcg/dose

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
CONTINUED... Hyoscine Hydrobromide <ul style="list-style-type: none"> • Tablets: 0.3mg (Kwells®) • Amp: 400mcg/ml • Patch: 1.5mg (Scopoderm®) (SAS) 		Transdermal	<ul style="list-style-type: none"> • ≤ 3 years • ¼ patch q72h • 3–9 years • ½ patch • q72h • ≥ 9 years • 1 patch • q72 	
ibuprofen 'Nurofen®' <ul style="list-style-type: none"> • Liquid: 20mg/ml • Tablet: 200mg, 400mg 	<ul style="list-style-type: none"> • Anti-inflammatory 	PO	<ul style="list-style-type: none"> • 5–10 mg/kg/dose • q6–8h with food 	400mg/dose
Lactulose 'Duphalac®' <ul style="list-style-type: none"> • Liquid: 0.67g/ml liquid 70% 	<ul style="list-style-type: none"> • Constipation 	PO	<ul style="list-style-type: none"> • 1ml/kg/dose • q12h-daily 	45ml/dose
Levomepromazine (SAS) <ul style="list-style-type: none"> • Tablet: 25mg • Amp: 25mg/ml 	<ul style="list-style-type: none"> • Nausea and vomiting 	PO/IV/SC	<ul style="list-style-type: none"> • ≤ 12yrs • 0.1mg–1mg/kg/dose • q12h-daily 	25mg/day
			<ul style="list-style-type: none"> • ≥ 12 yrs • 6.25–25mg • q12h-daily • Can be administered as continuous infusion 	50mg/day
Loperamide 'Imodium®' <ul style="list-style-type: none"> • Capsule/tablet/melts: 2mg 	<ul style="list-style-type: none"> • Terminal restlessness • Diarrhoea 	IV/SC	<ul style="list-style-type: none"> • 0.3–3mg/kg/day as an infusion 	
		PO	<ul style="list-style-type: none"> • 0.05–0.1mg/kg/dose • 8–12h 	2mg/dose

Home care companion

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Lorazepam 'Ativan®' <ul style="list-style-type: none"> • <i>Tablets: 1mg, 2.5mg</i> 	<ul style="list-style-type: none"> • Anxiety • Anticipatory nausea and vomiting • Dyspnoea 	PO	<ul style="list-style-type: none"> • 0.02–0.05mg/kg/dose • q8–24h • Can be administered sublingually 	2.5mg/dose
Macrogol 3350 and electrolytes 'Movicol®'	<ul style="list-style-type: none"> • Constipation 	PO	<ul style="list-style-type: none"> • <u>2–5 yrs</u> <ul style="list-style-type: none"> • 1 X Movicol-half sachet daily • <u>6–11 yrs</u> <ul style="list-style-type: none"> • 1 X Movicol sachet/dose daily • <u>>12 yrs</u> <ul style="list-style-type: none"> • 1–2 X Movicol sachet/dose daily • May need to increase to q8h 	6 sachets/day
Methadone <ul style="list-style-type: none"> • <i>Tablet: 10mg</i> • <i>Liquid: 5mg/ml</i> • <i>Injection: 10mg/ml</i> 	<ul style="list-style-type: none"> • Severe chronic pain 	PO/IV/ Buccal	<ul style="list-style-type: none"> • Difficult to predict and conversion complex from other opioids. • Dose titration only with consultation with specialist. 	
Metoclopramide 'Maxalon®' <ul style="list-style-type: none"> • <i>Tablet: 10mg</i> • <i>Syrup discontinued</i> • <i>Amp: 10mg/2ml</i> 	<ul style="list-style-type: none"> • Nausea and vomiting 	PO/IV/SC	<ul style="list-style-type: none"> • 0.1–0.2mg/kg/dose • q6h • Can be administered as continuous infusion 	10mg/dose

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Midazolam 'Hypnovel®' <ul style="list-style-type: none"> • Amp: 5mg/ml, 15mg/3ml, 50mg/10ml • Plastic 5mg/ml amps can be used nasally or buccally 	<ul style="list-style-type: none"> • Agitation • Seizures • Dyspnoea • Premedication 	Buccal/PO/ Intranasal	<ul style="list-style-type: none"> • <20kg <ul style="list-style-type: none"> • 0.3 – 0.5mg/kg/dose • >20kg <ul style="list-style-type: none"> • 5–10mg/dose • Dose can be repeated IV/SC <ul style="list-style-type: none"> • 0.1– 0.4 mg/kg/dose • q4h Can be administered as continuous infusion <ul style="list-style-type: none"> • 1–5mcg/kg/min • (1–5ml/hr of 3x body weight in 50 ml) or 0.2 – 1mg/kg/day 	10–15mg/dose – higher in refractory cases
Morphine Sulphate (S8) Immediate release <ul style="list-style-type: none"> • Tablet: 'Sevredol®' 10mg, 20mg 'Anamorph®' 30mg • Liquid: 'Ordine®' 1mg/ml, 2mg/ml, 5mg/ml, 10mg/ml 	<ul style="list-style-type: none"> • Analgesic for moderate-severe pain 	PO	1mo–6mo <ul style="list-style-type: none"> • 0.1 mg/kg/dose • q4–6h >6mo <ul style="list-style-type: none"> • 0.2 – 0.5mg/kg/dose • q4–6h SC/IV <ul style="list-style-type: none"> • 0.1–0.2mg/kg/dose • q4–6h • Dose can be given more frequently if required with frequent re-assessment of the child's pain. 	Increase dose as required, no maximum dose
<ul style="list-style-type: none"> • Amp: Morphine sulphate 5mg/ml, 10mg/ml, 15mg/ml, 30mg/ml • Morphine tartrate 120mg/1.5ml, 400mg/5ml 	<ul style="list-style-type: none"> • Dyspnoea 	PO	<ul style="list-style-type: none"> • 0.05–0.1 mg/kg • q4–6h 	Increase dose as required, no maximum dose

Home care companion

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
<p>CONT... Morphine Sulphate (S8)</p> <p>Controlled release</p> <ul style="list-style-type: none"> MS Contin® tablet: 5, 10, 30, 60, 100, 200 mg Suspension – 20, 30, 60, 100, 200mg Kapanol® capsule: 10, 20, 50, 100 mg 	<ul style="list-style-type: none"> Dyspnoea 	<ul style="list-style-type: none"> SC/IV 	<ul style="list-style-type: none"> 0.025–0.5mg/kg q4–6 h 	<p>Increase dose as required, no maximum dose</p>
<p>Naloxone 'Narcan'</p> <ul style="list-style-type: none"> Amp: 400mcg/ml 	<ul style="list-style-type: none"> Acute respiratory depression related to opioids Itch 	<ul style="list-style-type: none"> IV 	<ul style="list-style-type: none"> 5mcg/kg. Repeat every 2–3 minutes until adequate respirations are established. Caution in children receiving chronic opioid therapy. 	<p>100mcg/dose</p>
		<ul style="list-style-type: none"> IV 	<ul style="list-style-type: none"> 0.5mcg/kg may assist itch. Consider low dose infusion (0.5mcg/kg/hr) 	
<p>Omeprazole 'Losec®'</p> <ul style="list-style-type: none"> Tablets: 10mg, 20mg Capsule: 20mg <p>Some hospitals prepare a mixture for small doses and nasogastric tubes</p>	<ul style="list-style-type: none"> Antacid Reflux Oesophagitis/gastritis 	<ul style="list-style-type: none"> PO 	<ul style="list-style-type: none"> 0.5–1 mg/kg/dose q12h–daily 	<p>30mg/dose</p>
<p>Ondansetron 'Zofran®'</p> <ul style="list-style-type: none"> Tablets/waters: 4mg, 8mg Liquid: 4mg/5ml Amp: 4mg & 8 mg/2ml Suppository: 16mg 	<ul style="list-style-type: none"> Nausea and vomiting 	<ul style="list-style-type: none"> PO/IV/SC 	<ul style="list-style-type: none"> 0.15mg/kg/dose q8h 	<p>8mg/dose</p>
		<ul style="list-style-type: none"> PR 	<ul style="list-style-type: none"> ≥12 years 16 mg/dose daily 	

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Oxycodone (58) Immediate release <ul style="list-style-type: none"> • <i>Tablet: 5mg (Endone®)</i> • <i>Capsule: 5mg, 10mg, 20mg (Oxynorm®)</i> • <i>Liquid: 1mg/ml</i> • <i>Amp: 10mg/ml, 20mg/2ml</i> • <i>Suppository: 30mg(Proladone®)</i> Controlled Release <ul style="list-style-type: none"> • <i>Oxycontin® 5mg, 10mg, 20mg, 40mg, 80mg</i> 	<ul style="list-style-type: none"> • Analgesic for moderate – severe pain 	<ul style="list-style-type: none"> • PO 	<ul style="list-style-type: none"> • 0.1–0.25mg/kg/dose • q4–6h 	Increase dose as required – no max dose
Paracetamol 'Panadol®' <ul style="list-style-type: none"> • <i>Liquid: 24mg/ml, 48mg/ml, 50mg/ml, 100mg/ml</i> • <i>Tablet/capsule: 500mg</i> • <i>Amp: 500mg; 1g (Perfalgan®)</i> • <i>Suppositories: 125mg, 250mg, 500mg</i> 	<ul style="list-style-type: none"> • Analgesic • Antipyretic 	<ul style="list-style-type: none"> • PO/PR/IV 	<ul style="list-style-type: none"> • 15mg/kg/dose • q 4–6h 	< 6mo: 60mg/kg/day > 6mo: 90mg/kg/day
Paraffin Liquid <ul style="list-style-type: none"> • <i>Liquid: 50%</i> 	<ul style="list-style-type: none"> • Constipation 	<ul style="list-style-type: none"> • PO 	<ul style="list-style-type: none"> • 1–3 ml/kg/dose daily 	50ml/day
Phenobarbitone <ul style="list-style-type: none"> • <i>Tablet: 30mg</i> • <i>Liquid: 3mg/ml, 10mg/ml</i> • <i>Amp: 200mg/ml</i> 	<ul style="list-style-type: none"> • Seizures 	<ul style="list-style-type: none"> • PO/IV/SC 	<ul style="list-style-type: none"> • 2.5–3mg/kg/dose • q12–daily (Maintenance) 	600mg/day – higher in refractory cases 1g/dose
		<ul style="list-style-type: none"> • IV (slow) or IM 	Loading dose: <ul style="list-style-type: none"> • 20–30mg • Can be administered as continuous infusion 	

Home care companion

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Phenytoin 'Dilantin®' <ul style="list-style-type: none"> • <i>Infatab: 50mg chewable</i> • <i>Capsules: 30mg, 100mg</i> • <i>Liquid: 6mg/ml</i> • <i>Amp: 50mg/ml</i> 	<ul style="list-style-type: none"> • Seizures 	<ul style="list-style-type: none"> • PO/IV 	<ul style="list-style-type: none"> • 2mg/kg/dose • q8–12h (maintenance) 	<ul style="list-style-type: none"> • 100mg/dose –higher in refractory cases
		<ul style="list-style-type: none"> • IV 	Loading dose: <ul style="list-style-type: none"> • 15–20mg over 20 minutes (can be given in 3 parts over 6 hours orally) 	<ul style="list-style-type: none"> • 1.5g
Poloxamer 'Coloxyl drops®' <ul style="list-style-type: none"> • <i>Liquid 10%</i> 	<ul style="list-style-type: none"> • Laxative 	<ul style="list-style-type: none"> • PO 	<ul style="list-style-type: none"> • <math>\leq 6\text{mo}</math> • 10 drops/dose • q8h <hr/> <ul style="list-style-type: none"> • 6–18mo • 15 drops/dose • q8h <hr/> <ul style="list-style-type: none"> • 18mo–3yrs • 25 drops/dose q8h 	
Prochlorperazine 'Stemetil®' <ul style="list-style-type: none"> • <i>Tablets: 5mg</i> • <i>Amp: 12.5mg/ml</i> • <i>Suppository: 5.25mg</i> 	<ul style="list-style-type: none"> • Nausea and vomiting 	<ul style="list-style-type: none"> • PO/IV/IMPR 	<ul style="list-style-type: none"> • 0.1–0.2mg/kg/dose • q6–12h 	<ul style="list-style-type: none"> • Oral 10mg/dose
Promethazine 'Phenergan®' <ul style="list-style-type: none"> • <i>Tablets: 10mg, 25mg</i> • <i>Liquid: 1mg/ml</i> • <i>Amp: 25mg/ml</i> 	<ul style="list-style-type: none"> • Nausea and vomiting • Anti-histamine • Itch • Sedation 	<ul style="list-style-type: none"> • PO/IV/SC 	<ul style="list-style-type: none"> • 0.125–0.5mg/kg/dose • q6–8h 	<ul style="list-style-type: none"> • 150mg/day

Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
<p>Ranitidine 'Zantac®'</p> <ul style="list-style-type: none"> • Tablets: 150mg, 300mg (effervescent tabs 150mg) • Liquid 15mg/ml • Amp: 10mg/ml, 25mg/ml 	<ul style="list-style-type: none"> • Antacid • Reflux • Oesophagitis/Gastritis 	<ul style="list-style-type: none"> • PO • IV 	<ul style="list-style-type: none"> • 2–4mg/kg/dose • q8–12h • 1mg/kg/dose • q8h 	<p>300mg/day</p>
<p>Sennosides 'Senokot®'</p> <ul style="list-style-type: none"> • Tablets/chocolate squares: 7.5mg • Granules: 5.5mg/g (1x5ml teaspoon of granules contains approximately 15mg of senna) 	<ul style="list-style-type: none"> • Constipation • (stimulant laxative) 	<ul style="list-style-type: none"> • PO 	<p><u>2–6yr</u></p> <ul style="list-style-type: none"> • ½–1 tablet/dose nocte <p><u>6–12yrs</u></p> <ul style="list-style-type: none"> • 1–2 tablet/dose nocte <p><u>>12yrs</u></p> <ul style="list-style-type: none"> • 1–4 tablet/dose nocte <p><u><3yrs</u></p> <ul style="list-style-type: none"> • ½–1 tsp granules • q12 h–daily <p><u>3–yrs</u></p> <ul style="list-style-type: none"> • 1–2 tsp granules • q12 h–daily • Can give 1 teaspoon per 5 kg body weight for severe constipation 	<p>30mg/day 4 teaspoons</p>
<p>Sucralfate</p> <ul style="list-style-type: none"> • Tablet: 1g • Some pharmacies make cream 	<ul style="list-style-type: none"> • Mucosal bleeding/oozing 		<ul style="list-style-type: none"> • ½–1 tablet dispersed in water and applied topically as required 	

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Drug and Formulation	Indication	Route	Dose and frequency	Ceiling dose
Tramadol 'Tramal®' <ul style="list-style-type: none"> • Caps: 50mg • Liquid: 100mg/ml • Tabs CR 12h: 50mg; 100mg; 150mg; 200mg • Tabs CR 24h: 100mg; 200mg; 300mg 	<ul style="list-style-type: none"> • Moderate – severe acute/chronic pain • Neuropathic pain 	<ul style="list-style-type: none"> • PO 	<ul style="list-style-type: none"> • (Conventional product) 1–2 mg/kg q6h • Can convert to controlled release once stabilised 	400mg
Tranexamic Acid 'Cyclokapron®' <ul style="list-style-type: none"> • Tablet: 500mg • IV formulation available (SAS) 	<ul style="list-style-type: none"> • Antifibrinolytic for bleeding • Also used for mouthwash 	<ul style="list-style-type: none"> • PO 	<ul style="list-style-type: none"> • 15–25mg/kg/dose • q8–12h • 500mg tablet dissolved in 5–10 ml water (or 5% mouth wash) 	1.5g/dose

Appendix 6

FLACC Pain Scale

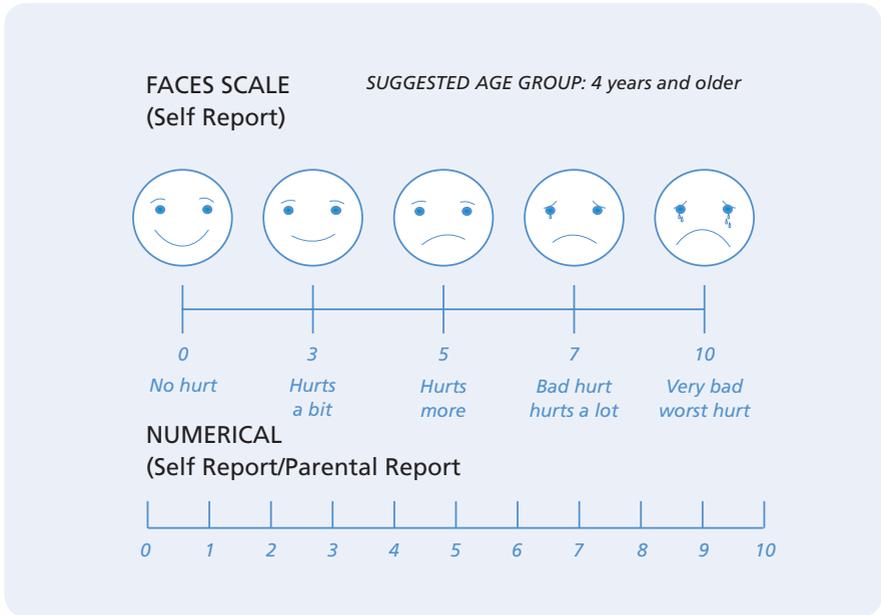
Category	Scoring		
	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to distractable	Difficult to console

Each of the five categories (F) face, (L) legs, (A) activity, (C) cry, (C) consolability is scored from 0–2, resulting in total range of 0–10.

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Appendix 7

Wong faces score and numerical visual analogue scale



WCH Children's Acute Pain Service

Appendix 8

A child's developmental understanding of death and the consequences of incomplete understanding.

(Adapted with permission from Palliative Care Expert Group. Children's concepts of death [table]. In: Therapeutic Guidelines: palliative care. Version 2. Melbourne: Therapeutic Guidelines Ltd. P136.)

Component to be understood	Average age of understanding	Incomplete understanding	Consequences
Separation <i>The deceased are located separately to the living</i>	5	–	–
Causality <i>Death is caused by illness, age, trauma</i>	6	Child may believe they have caused death through bad behaviour or thoughts	Excessive guilt
Irreversibility <i>The dead do not physically return</i>	6	Child expects deceased to return as if from a trip	Child may not detach personal ties to deceased, which is a necessary first step in mourning
Cessation of bodily functions <i>The dead cannot move, breathe</i>	6	Child worries about buried relative being cold, hungry or in pain	Preoccupation with physical suffering of deceased
Universality <i>All living things ultimately die</i>	7	Child may see self and significant others as immortal	Death may be viewed as punishment or the result of bad behaviour or thoughts
Insensitivity <i>The dead cannot feel pain, fear</i>	8	–	–

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References

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- 2a. Wong D (1999) Whaley & Wong's Nursing Care of Infants and Children. 6th Edn, Mosby, St Louis, Missouri.
- 2b. Goldman A (1998) ABC of Palliative Care; special problems of children. BMJ 316 (7124), 3rd January pp 49 – 52.
3. (2009), Oxford Handbook of Palliative Medicine, Version 2, Oxford University Press
4. Berk L, (2009) Child Development 7th Edition, Allyn and Bacon
5. Queensland Government (2009) A practical guide to palliative care in paediatric oncology, 2nd Edn, Children's Health Services District Queensland.
6. Crowe L (2003) When children have a life limiting illness. Questions and answers around grief and loss.
www.health.qld.gov.au/cpcrc/pdf/when_child_dies.pdf
7. Fleming S (2010) Journeys version 2, Palliative Care Australia
www.pallcare.org.au
8. Jassal S (2008) Basic Symptom Control in Paediatric Palliative Care, The rainbows children's hospice guidelines. 7th Edn
9. Taylor A (2001) Palliative nursing care a community perspective, 2nd Edn, Palliative Care Council, South Australia.

Reference links

Paediatric Palliative Care

Definition

- > WHO Definition of Paediatric Palliative Care
www.who.int/cancer/palliative/definition/en/
- > Royal Children's Hospital Melbourne – Palliative Care
www.rch.org.au/rch_palliative/families/index.cfm?doc_id=1651
- > There is an online course available through www.cancernursing.org titled – Introduction to palliative care nursing www.cancernursing.org/
- > Palliative Care Australia
www.palliativecare.org.au/Default.aspx?tabid=1779
- > Care Search is an online resource for palliative care information
www.caresearch.com.au/caresearch/Default.aspx
- > Paediatric Palliative Care Service web page
www.wch.sa.gov/services/az/divisions/paedm/pallcare/index.html
- > Queensland Government Royal Children's Hospital Palliative Care
www.health.qld.gov.au/cpcrc/rchpallcare.asp
- > National Council for Palliative Care
www.ncpc.org.uk
- > PEPA – Program of Experience in the Palliative Approach
www.pepaeducation.com
- > Mapcare – Caring for a patient with a life limiting condition in South Australia
www.mapcare.org.au
- > Palliative Care Council of South Australia
www.pallcare.asn.au
- > Virtual Hospice (Canada)
www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx

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Conditions involved

- > National Institute of Neurological Disorders and Stroke (National Institute of Health)
www.ninds.nih.gov/
- > CureSearch – Information on cancers in children
www.curesearch.org/
- > Royal Children’s Hospital Melbourne – Information for Health Professionals
www.rch.org.au/rch/index.cfm?doc_id=1495
- > EdCan Learning Resource
www.cancerlearning.gov.au/edcan_resources/#/xml/module_3/casestudies/osteosarcoma
- > Children with life limiting conditions
www.health.qld.gov.au/cpcrc/pdf/chldrnlifelim.pdf
- > CanNet
www.canceraustralia.gov.au

Communication

Communicating with children – A list of do’s and don’ts!

- > www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
– Click on ‘talking with children’ article

Medications

Types

- > e-Therapeutic guidelines for palliative care etg.tg.com.au/ref/
- > Health Insite has a section on medications in palliative care
www.healthinsite.gov.au/topics/palliative_care

Syringe drivers

- > There is a syringe driver compatibility database available on the Palliative Care Matters web site, contact the Paediatric Palliative Care Service if unsure
www.pallcare.info/mod.php?mod=sdrivers&menu=14
- > This link is a Guidelines Summary for syringe driver management in palliative care developed by the Centre for Palliative Care Research and Education (CPCRE) (Date Unknown, accessed on internet 14/4/2010
www.health.qld.gov.au/cpcrc/pdf/cpcrc_sd_gdlne.pdf).
- > Online course available through cancernursing.org titled – Graseby syringe drivers in palliative care

Comfort focussed care

Considerations in the paediatric population

- > Basic symptom control in paediatric palliative care
cnppc.ca/documents/2008rainbowhospicesymptomcontrolmanual.pdf

Pain management

- > International Association for the Study of Pain. Pain assessment in children
www.iasppain.org/PCU95b.html
- > Cancer page. Pain relief for children
www.cancerpage.com/centers/pain/pediatrics_p.asp
- > Paediatric pain profile, a behaviour rating scale for children with severe to profound neurological impairments
www.ppprofile.org.uk
- > Online courses available through cancernursing.org titled – Pain 1, Pain 2 and Pain 3
cancernursing.org/
- > Health Insite has a section on pain in palliative care
www.healthinsite.gov.au/topics/palliative_care

Complementary therapies

- > Health Insite has a section on complementary therapies in palliative care
www.healthinsite.gov.au/topics/palliative_care

Dying process

What to expect

- > End of life: The facts
www.mariecurie.org.uk/aboutus/publications_and_resources/end_of_life_home.htm
- > When a child dies
www.health.qld.gov.au/cpcrc/pdf/when_child_dies.pdf

For more information

**Paediatric Palliative Care Service
Women's and Children's Hospital**
Telephone: (08) 8161 7000
www.wch.sa.gov.au

*After hours pager 5719
Administration (80) 8161 7994*

If you require this information in an alternative language or format please contact SA Health on the details provided above and they will make every effort to assist you.



<http://www.gjlf.gov.au/>

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