

Care Plan for the Dying Child (CPDC) Ongoing Assessment

Supporting care in the last hours and days of life

(Affix identification label here)

URN:
Family name:
Given name(s):
Address:
Date of birth: Sex: M F I

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Instructions for Ongoing Assessment, Symptom Management and End-of-life Care

Overarching Principles

- Daily medical assessment
- Cease vital sign monitoring (or as negotiated with family and treating team), check infusions and devices and nursing observations/care hourly or as per HHS policy
- Consider causes of escalated distress (e.g. fever) and action to address
- Negotiate provision of care with the family at the start of each shift and discuss all changes of care with child/young person and family
- Be inclusive of family goals; support the family to manage visitors and how their child/young person is cared for
- Empower the family to participate in care provision and facilitate parenting opportunities (e.g. non-pharmacological symptom management). This can have a direct positive impact on the family's long term bereavement health
- Maintain the family-child/young person connection; avoid separating the family from their child/young person
- Be aware of "abandonment by staff perception" in the context of the changed goals of care; maintain active symptom and comfort care observations and management
- Balance the parental desire to "nurture" with the burden on the child/young person's symptoms. When negotiating the need to "cease" a specific caring task, ensure you provide alternate options/suggestions for the parents to continue with (e.g. if they are no longer able to eat/drink, support the family to replace this nurturing task with mouth cares)

Instructions for Response to Symptom Rating

- Use standardised medication management guidelines to respond to symptoms. Refer to Appendix in *Health Professional Guideline*
- Chart required PRN medication
- Reassess symptoms following any treatment intervention
- Document actions and outcomes as per HHS policy
- Refer to HHS policies for instructions on how to escalate care

Symptom Rating – Absent

- Problem/Symptom distress absent
- Continue with current care

Symptom Rating – Mild

- Problem/Symptom distress present but managed by existing plan of care

IF THE CHILD/YOUNG PERSON HAS ANY YELLOW ZONE OBSERVATIONS YOU MUST:

1. Treat problem/symptom according to service protocols
2. Increase the frequency of symptom assessment and comfort observations

Symptom Rating – Moderate

- The child/young person has more than one 'Mild Symptom Rating'
- The child/young person has not responded to treatment as expected and symptoms are persisting
- Problem/Symptom distress requires a change in plan of care

IF THE CHILD/YOUNG PERSON HAS ANY ORANGE ZONE OBSERVATIONS YOU MUST:

1. Consult promptly with the NURSE-IN-CHARGE to:
 - a. Discuss the problem/symptom and agree on a plan of care
 - b. Discuss whether a MEDICAL/PALLIATIVE CARE REVIEW is required
2. Increase the frequency of symptom assessment and comfort observations

Symptom Rating – Severe

- Problem/Symptom distress requires urgent intervention and escalation
- Plan of care is ineffective, and change is required

IF THE CHILD/YOUNG PERSON HAS ANY RED ZONE OBSERVATIONS YOU MUST:

1. Initiate appropriate clinical care
2. Initiate a MEDICAL/PALLIATIVE CARE REVIEW
3. Increase the frequency of symptom assessment and comfort observations

Strategies

The following strategies are intended to provide basic information/advice only. For additional information, please refer to CPDC section 4.0 and the *Care Plan for the Dying Child: Health Professional Guidelines, June 2019*.

Symptom management

Medication:

- Review PRN medication orders to optimise pharmacological symptom management

Pain/distress/fever:

- Consider PRN analgesia for breakthrough pain
- Consider antipyretics PO or PR only if fever is contributing to discomfort. If fever is related to infection consider PO antibiotics
- Consider position change, cool sponges and use of fans
- Consider referral to Allied Health (e.g. Music Therapy, Occupational Therapy, Psychology etc.)

Restlessness and/or agitation:

- Assess the child/young person for reversible causes, including pain, incontinence, fever, breathlessness, urinary retention, constipation
- Consider position change

Sleep/reduced arousal:

- Anticipate decreasing level of arousal towards the end-of-life
- Consider normalising this for the family if they find this distressing

Nausea and/or vomiting:

- Consider anti-emetics
- Consider ceasing or slowing rate of artificial nutrition/hydration if not being tolerated

Breathlessness and/or respiratory tract secretions:

- Consider introducing opioids/anxiolytic for dyspnoea
- Consider anticholinergic medication (more effective if given as soon as symptom occurs)
- Consider semi-prone position, use of fan/access to breeze or gentle suctioning
- Consider referral to Physiotherapy

Family distress:

- Consider the severity of the problem the family is experiencing (e.g. anger, family conflict etc.)
- Staff simply being at the bedside can be supportive and caring. Use respectful verbal and nonverbal communication and active listening skills
- Encouraging parent-child connection through use of touch if appropriate
- Consider referral to Social Work/other appropriate services

Comfort management

Environment:

- Single room; curtains/screens; clean environment; sufficient space at the bedside; silence; music; lighting; pictures; photographs
- Familiar blanket/pillows/special soft toys
- Nurse call bell accessible

Mouth care:

- Aim to keep the child/young person's mouth clean and moist. Mouth care second hourly and PRN is recommended
- Wet swabs or ice chips to the lips and inside the mouth
- Suction toothbrush may be helpful for oral secretions

Eye care:

- Ensure eyes are clean and moist
- Swab with normal saline or apply lubricant drops PRN

Bladder and bowel care:

- Monitor for constipation and diarrhoea
- Bowel movements documented/bowel monitoring chart
- Use of pads, urinary catheter or urodome as required

Skin care:

- The frequency of assessment, repositioning and special aids (e.g. pressure relieving mattress) should be determined by skin inspection and the child/young person's individual needs
- Consider frequency of dressing changes
- Consider referral to Occupational Therapy

Religious/spiritual/cultural needs:

- Belief systems are supported as per Initial Assessment
- Consider referral to Religious/Spiritual/Cultural Advisor

Food and fluids:

- The child/young person should be supported to eat and drink as long as tolerated and/or it remains a positive experience for them. Aspiration events (resulting in coughing episodes) or instances of choking can be distressing for the child/young person and their family

Food and fluids: (continued)

- Support family to understand that a loss of interest in, and reduced need for food/drink is a normal part of the dying process:
 - calorie and fluid requirements will be very low
 - the child/young person is unlikely to experience "hunger" or "thirst"
 - this can be difficult for families to accept, and is often viewed by families as a key nurturing role
 - gently redirect families to focus on providing good mouth cares. Redirect emotive or negative language (e.g. starving, dehydration)
- Consider whether the child/young person and/or family would benefit from:
 - referral to dietitian to support nutrition and hydration management plan.
 - Referral to speech pathology to support comfort feeding/fluids.
 - Use of thickened fluids and soft/smooth diet
 - if appropriate, consider clinically assisted (artificial) hydration
- **Support for family:**
 - Offer food/drink/rest
 - Check understanding of all visitors
 - Listen and respond to worries and fears; provide age appropriate information
 - Use clear language; avoid euphemisms or jargon
 - Offer family respite to allow them to eat/drink/toilet/shower
 - Allow the opportunity to reminisce
 - Assess bereavement risk and refer to support services as needed



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DO NOT WRITE IN THIS BINDING MARGIN

CPDC Ongoing Assessment

Table with columns for Symptom Assessment and Comfort Assessment, including categories like Pain, Distress, Nausea, and Other symptoms, with a grid for recording observations and actions.

Instructions for Symptom Assessment and Management
• Observations must be performed routinely at a minimum of (1) hourly in consultation with IPT and parent/carer(s)
• When graphing observations, place a dot (•) in the appropriate box and join the preceding dot (e.g. →)

Symptom Rating Scale
Severe: Escalate to medical/palliative care team
Moderate: Escalate to nurse-in-charge
Mild: Routine symptom management
Absent: No symptom/problem

Instructions for Comfort Assessment and Management
• Assess and manage comfort at a minimum of (1) hourly. Refer to comfort assessment and management prompts (over page) for further details
• Assess each care need and document with:
• for Yes
• X for No
No should always prompt an action. Document problem, action and outcome of action in medical record or CPDC Record of Actions (SW969).

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Pain Assessment Tools section including FLACC Pain Scale, The Faces Pain Scale - Revised (FPS-R), Numerical Pain Scale, and Baxter Animated Retching Faces (BARF) Nausea Assessment Scale.

References: FPS-R: Hicks et al., (2001). The Faces Pain Scale-Revised. Pain 93:173. ©2001 International Association for the Study of Pain... BARF: Baxter et al., (2011). Development and Validation of a Pictorial Nausea Rating Scale for Children. Pediatrics 127(6), 1542-9. Copyright © 2011, The American Academy of Pediatrics, reproduced with permission.