



(Affix identification label here)

URN:

Family name:

Given name(s):

Address:

Date of birth:

Sex: M F I

Comfort, Observation and Symptom Assessment (COSA)



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Comfort, Observation and Symptom Assessment (COSA)

Overarching Principles

- Daily medical assessment.
- Cease vital sign monitoring (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, recent events, medication changes, positioning, disease related process) and action to address.
- Negotiate care with the family at the start of each shift; discuss 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.
- For First Nations families, explore cultural preferences around location of care (e.g. outside, balcony), smoking ceremony leading up to and after death, and other rituals; collaborate with Indigenous Health Liaison Officer/Aboriginal Health Worker.
- Empower the family to participate in care provision and facilitate parenting opportunities (e.g. non-pharmacological symptom management, bathing etc). 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 the perception of 'abandonment by staff' in the context of the changed goals of care; maintain active comfort and symptom assessment and management; talk to and about the child/young person.
- 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, try to 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 the [Health Professional Guideline](#) or the [Green Book](#).
- Chart required PRN medication
- Reassess symptoms following any treatment intervention or more frequently if indicated
- 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

COSA Management Strategies

The following strategies are intended to provide basic information/advice only. For additional information, please refer to Appendix in the [Health Professional Guideline](#) or the [Green Book](#).

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 end-of-life
- Normalise this for the family if they find this distressing

Nausea and/or vomiting:

- Consider anti-emetics

Nausea and/or vomiting: (continued)

- 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.
- Encourage parent-child connection through use of touch
- Consider referral to Social Work or Psychology
- Consider if siblings need additional support
- Consider referral to Indigenous Health Liaison Officer/Aboriginal Health Worker if appropriate

Comfort management

Environment:

- Single room; curtains/screens; clean home-like environment; sufficient space at the bedside; silence; music; lighting; pictures; photographs
- Familiar blanket/pillows/special soft toys
- Nurse call bell accessible
- Consider removing unnecessary equipment e.g. monitors

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 for pressure care support
- Include family in cares e.g. massage of limbs, applying lotion

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
- Support family to understand that a loss of interest in, and reduced need for food/drink, is a normal part of the dying process:

Food and fluids: (continued)

- 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

Religious/spiritual/cultural needs:

- Support belief systems
- Consider referral to Religious/Spiritual/Cultural Advisor
- Consider referral to Indigenous Health Liaison Officer/Aboriginal Health Worker if appropriate

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; ask family about their child/young person; talk about their child/young person if you have known them prior
- Assess bereavement risk and refer to support services as needed



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DO NOT WRITE IN THIS BINDING MARGIN

Comfort Observation and Symptom Assessment (COSA)

Table with columns for Date, Time (24hr), and rows for Pain, Distress related to breathlessness, Distress related to respiratory secretions, Restlessness and agitation (delirium), Nausea and/or vomiting, Other symptoms (specify), and Comfort Observation.

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 Observation 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 Select (with tick) appropriate pain assessment tool (refer to HP Guidelines for other paediatric pain assessments)

FLACC Pain Scale 15 days to 3 years (or as required)
Each category is scored 0 to 2 resulting in a total score of 0 to 10
Categories: Face, Legs, Activity, Cry, Consolability
Score 0, Score 1, Score 2
The Faces Pain Scale - Revised (FPS-R) 4+ years
Numerical Pain Scale 7+ years
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, reproduced with permission. www.lasp-pain.org/FPSR. FLACC: Merkel et al., (1997). The FLACC: A behavioural scale for scoring postoperative pain in young children. Pediatric Nursing 23(3), 293-297. © 2002, The Regents of the University of Michigan. All rights reserved. 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.

COSA Management Strategies and Considerations *(continued)*

Talking to families about their child/young person who is dying

Principles	Practical ideas
<ul style="list-style-type: none"> Active listening to hear the family's perception of the situation, especially their views on what they think their child/young person knows about dying and what is important for them. Reflective listening – rephrasing your understanding of the conversation – demonstrates you are listening to their concerns. Some families will be very open and honest with their child/young person about dying, whilst others may not; there is no right or wrong way. The family knows their child/young person best and we must be guided by them. Be aware of how our nonverbal communication can be interpreted by a child/young person. Even exclusion from contact communicates something. Be aware of issues, such as blame and guilt felt by either the parents or the child/young person and sibling(s). Acknowledge/validate feelings and experiences. It is generally accepted that a typically developing child/young person, will have a reasonably full understanding of death from approximately 7 years of age. 	<ul style="list-style-type: none"> Provide reassurance so that they understand we are here to guide them. Encourage family members to answer questions as openly and honestly as possible, and that they do not need to have all the answers right now. When parents are separated and share parental responsibility, ensure parents are given the same information. Use open ended questions 'what do you think your child/young person understands about what is happening to them?' Encourage the family to reflect on previous experiences with death (e.g. the death of a family pet, grandparents, significant other). 'Have you experienced loss before? What was that like?' Has the family/child/young person been exposed to books that talk about the life cycle/dying (e.g. <i>The Invisible String</i> by Patricia Karst)? Refer to Health Professional Guideline for further resources. Ask the family what words or phrases they use to explain what is happening to the child/young person.

Talking to the child/young person and/or their siblings about death and dying

Principles	Practical ideas
<ul style="list-style-type: none"> Listen to the child/young person. Gain an understanding of their world (their understanding and perceptions about their life and the lives of their family). Children strive to make sense of their world to gain a sense of mastery over it, and to understand how they fit into it. Children gather information from multiple sources including their own experiences, and observations of both subtle and unsubtle cues (e.g. parent returning from meeting crying/having been crying). Ask them about it. If the family have requested support to talk about death and dying with their child/young person, it is important to clarify what they think their child/young person knows, what words/phases they have used in the past, and what words/phrases they would prefer you to use with their child/young person. Ask if there are any specific words/phases that they don't want to be used when talking to their child/young person. A health professional's role is to help families talk with their child/young person and spend quality time with them. Answer the questions the child/young person has asked but do not overwhelm them with extra details. 	<ul style="list-style-type: none"> Observe their behaviour and nonverbal responses, as cues to what may be worrying them. Reassure the child/young person that the situation is not their fault. Use a range of activities, such as reading, drawing or writing to answer/communicate. Consider using specific books or videos to answer the child/young person's questions, with the family's consent. Give information gradually rather than giving it all in one large session; repetition of information may be required. Use developmentally appropriate language. In cases where the family do not wish to tell their child/young person that they are dying, and the child/young person has asked this directly of a health professional, consider the following responses: <ul style="list-style-type: none"> 'What do you think is happening?' 'What have you heard?' 'What has mum/dad told you?' 'What do you think?' 'How do you feel about these meetings?' 'Is this something we can talk to mum/dad about?' <i>(delivered sensitively)</i>

Memory making/rituals *(refer to the [QCH Memory Making guideline](#) for further information)*

- Memory making can be provided by any health professional. Provide information on the benefits and gently encourage. Consider referral to Social Worker to facilitate memory making opportunities as required.
- Ensure suggestions are culturally appropriate.
- Explore with the family if there is anything they would like to be able to do:
 - 'What's important for you to remember from today?'
 - 'Are their cultural or religious traditions we can help you to arrange?'
 - 'Tell me about some of the things that were special for you and your sister/brother?'
 - 'In the past families we have worked with have appreciated the opportunity to have photos taken with their child/young person, is this something you would also like?'
 - 'Some parents like to rest/or cuddle with their child/young person in bed, is this something you would like?'
- Encourage siblings, grandparents and other significant family members to be involved in memory making.
- Some siblings like to be given special jobs that they can do so they feel involved and helpful (e.g. looking at books together, watching video/movies, or sharing stories and memories).
- Heartfelt Photography (a specialist company) may be available in the hospital, where professional photographers can attend to take photos of the child/young person and the family either before or after death.
- Bereavement boxes may be available in your hospital (e.g. Precious Wings).
- Hand and foot prints (inkless is preferable).

COSA Management Strategies and Considerations *(continued)*

Memory making/rituals *(continued)*

- Hand and foot molds, and toe and finger print jewelry may be organised at the hospital. This can also be supported by the Social Worker or funeral home.
- Taking a lock of hair; toy/jewelry exchange.
- Drawing/writing letters to their family/loved ones.
- Support families to comfort and hold their child/young person. This includes enabling the parent(s) to lie in the bed with their child/young person, hold in their arms, stroking, brushing their hair. Consider placing mattresses on floor or another bed beside the child's/young person's bed (if room allows).
- Bathing their child/young person. This can be done either using a baby bath, sponge bathing or using a special bathing bowl if available in the hospital.
- Dressing their child/young person; reassure families that they do not need to choose 'forever clothes' at this time.
- Family singing to the child/young person or playing music. Consider contacting Music Therapy to provide music options (e.g. sessions, recordings, CD players).

Understanding the process of dying

- Families may wish to know the physical changes that are an expected part of the dying process.
- These changes may be distressing to witness. Health professionals should normalise these physical changes and provide management strategies.

Physical changes	Principles	Practical ideas
Respiration changes	<ul style="list-style-type: none"> Breathing may be rapid, shallow and irregular. Breathing may also slow with periods of apnoea, known as Cheyne-Stokes breathing. These symptoms may be present for a significant period of time. 	<ul style="list-style-type: none"> This may be distressing to witness. Family will require reassurance that this is expected and is not distressing for their child/young person.
Noisy/rattly breathing	<ul style="list-style-type: none"> Caused by excessive secretions or difficulty clearing pharyngeal secretions. 	<ul style="list-style-type: none"> This may be distressing to witness. Family will require reassurance that this is expected and is not distressing for their child/young person. Consider postural changes or medications. Consider some gentle background music to diffuse sound if noisy/rattly breathing is distressing to the family.
Incontinence	<ul style="list-style-type: none"> Caused by relaxation of the gastrointestinal and urinary tracts. 	<ul style="list-style-type: none"> It is important for the family that their child/young person's dignity is respected. Consider a catheter, nappy/pad or disposable waterproof pad/sheet.
Loss of circulation to the extremities	<ul style="list-style-type: none"> Hands, feet and face may become cold, pale and cyanotic. Skin may change colour and start to look white, blue or greyish. Caused by slow and irregular heartbeat as circulation of blood is decreased to the extremities. May also sweat profusely and be damp to touch. 	<ul style="list-style-type: none"> Parents may wish to change the child/young person's clothes and keep them warm with a blanket.
Eye changes	<ul style="list-style-type: none"> Pupils may become fixed and dilated; eyes may become sunken or bulging and glazed. 	<ul style="list-style-type: none"> If eyes are bulging, a small damp bandage may be placed upon the eye. Eye secretions can be removed with a warm damp cloth. Eye drops/lubricants or ointments (e.g. POLY VISC® Lubricating Eye Ointment or Celluvisc®) may be applied. Eye ointment may also be used to close the child/young person's eye lids at the time of death.
Bodily fluids	<ul style="list-style-type: none"> There may be bodily fluids leaking from the mouth and nose, bladder, bowel and any drainage sites or openings. Blood may pool causing the appearance of bruising, especially on the underside of the child/young person. 	<ul style="list-style-type: none"> Family may find this very distressing if they are not prepared/aware of this possibility. Normalise this for the family and provide a management strategy. Anticipate bodily fluids by placing dark coloured sheets on the bed (where available). Ensure towels are easily accessible. Place a waterproof pad/sheet on the parent's shoulder/lap/ chest to allow cuddling. Place a waterproof pad/sheet on the bed surface when repositioning/rolling the child/young person. Apply a nappy or pad. Health Professionals should don Personal Protective Equipment when moving or handling the child/young person.