PalliativeCare
AUSTRALIA

Planning Care at Home for a Child Requiring Palliative Care

Paediatric Palliative Care

'Cupcake World' by Reuban, 5 years old

Planning Care at Home for a Child Requiring Palliative Care

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This prompt sheet outlines a process for health professionals to plan care at home for a child receiving palliative care. This is to ensure appropriate planning to prepare, empower and support the child, family and to support other health care professionals. This information can complement your organisation's policies and procedures and may be helpful for health professionals to consider additional requirements.

Checklist

Many families wish to be at home when their child is dying. Palliative care services can work with the child's primary teams (e.g. general paediatrics, oncology) to support the child at home.

Referral

1. A referral from the primary medical team to a consultative paediatric palliative care service will ensure appropriate supports are available to the family and health care professionals, particularly at the time end of life care is required.
2. Consider a referral to the children's hospice, if available.
   a. Depending on the jurisdiction, referrals may need to be made by medical professionals.

Multidisciplinary or Interdisciplinary Meetings

1. It is helpful for health professionals to meet together before meeting with the family to discuss and plan the child's care.
2. It is important to have agreement regarding prognosis of the child's condition and transition to palliative or end-of-life care.
3. Evaluate the appropriateness and practicalities of alternate locations for care (e.g. home or hospic or a hospital closest to home).
4. If there is disagreement between treating teams or moral distress around decisions relating to treatment then it may be useful to consider a clinical ethics consultation.

Family Meetings with Care Teams

1. The key care teams and a social worker should be present, if possible. Identify a primary lead for discussion prior to commencing meeting. Identify cultural requirements and whether an interpreter will be needed.
2. Clarify the family's understanding of the child's current condition with a parent summary.
3. The care team should provide an update on the child's current condition with a medical summary in a way the family can understand. This may include discussion of prognosis.
   a. Allow time for the family to talk and ask questions. Also allow for pauses and recognise emotions that are expressed during the meeting.
4. Introduce the concept of end-of-life care, if appropriate.
5. Explore the child and family's goals and wishes, acknowledging these may change over time.
6. Address any fears the family may have.

7. Discuss the options available to the child and family based on their current condition and family's goals and wishes (e.g. home, hospital closes to home, children's hospice).
8. 'Pop-up' educationalmodels of care and telehealth can be considered to support community teams.
9. There should be clear documentation recording the meeting, this may include: who attended, their relationship, the issues discussed, the outcomes, who is responsible for following up, and any plan for future meeting/s.

Discussions around possible scenarios

1. Discuss the child's prognosis. This can be framed in hours to days, days to weeks, weeks to months, or months to years, and you should explain any uncertainty around this timeframe.
2. Explain the possibility of the child living longer than expected and what this may entail (i.e. parallel planning).
3. Discuss current and anticipated symptoms and their clinical management.

Subsequent family meetings

1. Where possible it is helpful to have subsequent family meetings.
   a. This could be on a weekly basis for a child who is having a prolonged hospitalisation, or on a daily basis for a child who is deteriorating rapidly.
   b. Family meetings then become a series of meetings, rather than a single event and their content can evolve, and style of communication be tailored to suit the family's needs. Some families prefer smaller meetings in terms of number of participants.
2. Explore the family's goals and wishes. This may include tissue donation and funeral wishes.
3. Clarify the family's understanding of their child's condition and what information requirements they may have.
4. Discuss end of life care as requested by the family or as appropriate.
5. Discuss current and anticipated symptoms at end of life and symptom management.
6. Respond to the family's questions and concerns.

Please refer to *An Overview to Family Meetings and Difficult Conservations* prompt sheet for more information.

Organising Community Supports and Appropriate Referrals

Consider referrals to the following agencies depending on the child's needs:

- General Practitioner
- Local teams and supports (e.g. paediatrician, local hospital, allied health and multi-disciplinary support)
  - How will the family access physiotherapy, occupational therapy, music therapy, social work, dietician and bereavement support, if required.
- Non-government organisation community supports including disease specific organisations
- Community nursing and allied health services
- Hospital in the home
- Complex or connected care services, if appropriate
- Respite centres
- A children's hospice, if available
- Child safety or equivalent, if involved
- Any other additional teams
- Consider support for childcare or school

It can be helpful to do a combined visit when a community nursing service first meets a family receiving palliative care. Consider a "pop-up" educational visit if the family live in an outer metropolitan area or outside of the capital city.

Telehealth can be used to support families who live outside of the capital city, or those who are unable to attend hospital for various reasons (e.g. immobility due to the child's condition, or family preference to stay away from the hospital).

Documentation

- Resuscitation Plans (or equivalent) — this is a clinical record of the family's wishes for clinical treatments in the event of an emergency.
  - Completed by the child's primary paediatrician in consultation with the family, based on an assessment of the child.
  - A copy of the resuscitation plan can be given to the family, supporting healthcare teams, the general practitioner and ambulance services.
- Ambulance Letter (only available in some states)
  - This can include the resuscitation plan.
  - It can be used to notify the local ambulance service that the child is at home and in case of an emergency an ambulance may be called.
  - It would briefly described the child's condition, recommended treatment, preference of hospital to be taken to and contact details of key persons in the child's care team.
  - Copies should be given to the family and lodged with their state ambulance service if available.
- Child Safety Plans
  - This is important if the child is under the care of Child Safety Services, or equivalent.
- Symptom Management Plan
  - Includes management for current and anticipated symptoms.
  - A copy is given to the family, supporting healthcare teams and primary teams.
- Care Assessment and Planning Document
  - Such a document provides a holistic summary of the child's needs and care plans.
  - This can be a useful communication tool for childs between health care teams.
  - Copies should be sent to the relevant health professionals involved in providing care in the home (e.g. general practitioner, local community nursing team).
- Additional Considerations
  - A clearly documented plan in the event the child lives longer than expected after transfer home. Parallel planning should commence and include nutrition, medications, equipment, consumable, ongoing nursing and community support.
  - Documentation of preferred location of death, if applicable.
  - Communication to all relevant parties.

Equipment

Home equipment will be individualised to the child's current clinical needs and should take into consideration both short and long term needs. Below are some things to consider:

Home Oxygen

- Assess oxygen need and requirement (e.g. intermittent, continuous, symptom relief, underlying condition, short term, long term).
- Short term or interim oxygen can sometimes be scripted through palliative care pathways.
- Long term oxygen scripted by the primary treating team or respiratory service to the government provider for home oxygen.
- Ensure home has appropriate access to power sources for oxygen concentrator.
- Consider risk factors such as parental smoking.

Suction unit and consumables

- Primary teams are ideally responsible for organising suction and consumables. Palliative care services can assist in the process in an attempt to streamline and co-ordinate care processes for the family.
- Consider any additional ventilatory support and consumables required for trouble-shooting.
- Consider the geography of discharge location. Additional paediatric specific consumables and resources may be required. The local paediatric service may be able to assist, if available.

Mobility, pressure injury management and other equipment

- Assessed by the multi-disciplinary team to consider needs for home prior discharge (including occupational therapy (OT) and physiotherapy assessments).
- Referral to appropriate OT, which could include but is not limited to, hospital OT (specialist or ward based), local/community OT or primary ward OT.
- Consider pressure area care requirements.

Continence aids

- Assessment and recommendation by OT or community nurses.

Nutrition

- Enteral feeds and discharge planning are generally organised through the dietician.
- Provision of the feeding pump, stand for the pump and consumables.
- Some families may be entitled to a financial subsidy for feeds.

Medications

- Medications for current and anticipated symptoms should be prescribed as per a written Symptom Management Plan with relevant Community Agency Authorities.
- Medications can be supplied by the tertiary children's hospital pharmacy, another hospital pharmacy, or a community pharmacy. It is important to remember that medications that are not on the PBS (e.g. midazolam) will be expensive at a private pharmacy.
- If a care team from the hospital is visiting the family home, they may be able to deliver medications. Alternatively, another family member may be able to assist the parents by collecting medications.
- A "Palliative Medicine Kit" may be considered, which would include key medications to manage pain, dyspnoea, delirium, nausea and noisy breathing. This would also include key consumables and an infusion pump (or equivalent). This would allow health professionals to access medication and equipment for timely symptom management and end of life care.
- Key medications to consider for end of life symptom management include morphine, midazolam, metoclopramide and an anti-secretory agent (glycopyrrolate or hyoscine hydrobromide).
- Some risk assessment should be made in relation to storing medications in the home (e.g. substance use by other family members, mental health risk factors of parents).

Transport

Transport from hospital to home is usually coordinated by the child's primary team in collaboration with the palliative care service.

Transport can be dependent on geographical location of choice, availability of transport, stability and complexity of the child's condition and urgency of transfer.

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The following services may be of assistance:

- Hospital Based Transport Coordination Hub or similar — such a hub has a role in coordinating inter-hospital transfers, and transfer of childs home by ambulance services.
- Retrieval Services or equivalent — may become involved if the child is requiring medical transfer from intensive care to the home or another health facility. They will also help coordinate aeromedical transfers of the child if required.
- Telehealth can assist in acute transfer of children at times.
- Child Travel Subsidy Scheme or equivalent — this can assist in assistance with funding of commercial flights were appropriate, or long distance car travel. Overnight accommodation may also be funded.
- The family may be able to travel in a private vehicle — consider aspects such as whether a car seat will be used.

It is often very important for at least one family member to travel with the child. Transport home of parents, family members and siblings will also need to be considered.

After Hours Support

The family should be given a list of contact numbers, including someone who they can contact after hours.

Family Education

The family should receive education on the following topics, as well as additional ones, as required:

- Symptom management
- Medication safety
- Oxygen safety
- After hours support — option to call emergency services if required
- Discussing death and dying at home. Follow the family's lead in how to progress with this.
- Information should also be provided in written form.

For more information

- Standards for Providing Quality Palliative Care for all Australians
- A Practical Guide to Palliative Care in Paediatrics (the 'Green Book')

This checklist is based on the Children's Health Queensland Hospital and Health Service's "Work Instruction – PPCS: home care planning for the palliative child (end of life)".

'A big red and green snail' by Alessandro, 4 years old