



Paediatric
Palliative Care

Transferring a Child Requiring Palliative Care Home



PalliativeCare
AUSTRALIA

Transferring a Child Requiring Palliative Care Home

This prompt sheet outlines a process for health professionals to transfer a child receiving palliative care to their home. This is to ensure appropriate planning is undertaken to prepare, empower and support the child, family and health care professionals. It is specifically written for a child who is near death and may need intensive, supported care to meet their wish to be at home. This information can complement your organisation's policies and procedures and may be helpful for health professionals to consider additional requirements.

Process

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 or oncology) to support them to be at home. Home care planning should begin early, ideally at the time of admission, and a minimum of 1–5 days prior to discharge. Sometimes this isn't possible so this information may help to develop a faster pathway.

Within 24 hours of the child going home

1. Review any advance care planning documents, including whether the child has a resuscitation plan. This may need to be reviewed particularly if the ambulance service is taking the family home.
2. Consider any risk factors for home visiting of health care teams (e.g. pets at home).
3. Ensure sufficient staff are available on the day of transfer home.
4. Meet with other key members of the team involved in transferring the child home. This is likely to include more than one team (e.g. general paediatrics, paediatric intensive care) and more than one discipline — e.g. medical, nursing, allied health.
5. A quilt or blanket for the child may be helpful. The child could be wrapped in this for transport.
6. Ensure staff goodbyes to child and family take place before the transfer.
7. For children on life sustaining therapies (this is a carefully negotiated, limited option only)
 - a. The responsible care team will need to develop a plan on the withdrawal or weaning of life sustaining therapies (e.g. mechanical ventilation, or inotropes).
 - i. This may be done slowly, or alternatively some withdrawal of therapy could be done at the home.
 - ii. This would include consideration of when to remove central venous lines and what feeding tubes the child will have at home.
8. Symptom management:
 - a. Management within the hospital should reflect what management at home might be like before discharge (e.g. use of the subcutaneous route rather than intravenous, and use of infusion pumps appropriate for home care).
 - b. A written plan should be developed for current and anticipated symptoms during transfer and also at end of life. Key symptoms to consider include pain, nausea, vomiting, agitation, secretions and seizures.

9. Transport:

- a. The child's ward will need to confirm transfer details including method, date and time. This needs to be communicated with the family and all relevant teams.
- i. One parent (or family member) may be able to travel with the child. Other family members will need to consider timing of when they leave the hospital so they can meet their child when they arrive home.

10. Memory Making:

- a. Ward staff should offer memory making within the hospital, for example:
 - i. a memory box to capture mementos from hospital admission.
 - ii. professional photography available through a volunteer services.

11. Tissue Donation:

- a. The family may like to consider donating tissues (e.g. cornea, heart valves, bone, skin). Age and size of the child, as well as their underlying condition, will impact on whether this is possible.
- b. Discuss with your hospital's organ donation coordinator or DonateLife.
- c. The family may also wish to consider organ or tumour donation for research purposes.

12. Family Care:

- a. Encourage family members to continue adequate self-care to ensure they have adequate nutrients, sleep and medications.
- b. Ensure their general practitioner is updated.
- c. Consider respite choices for the family.

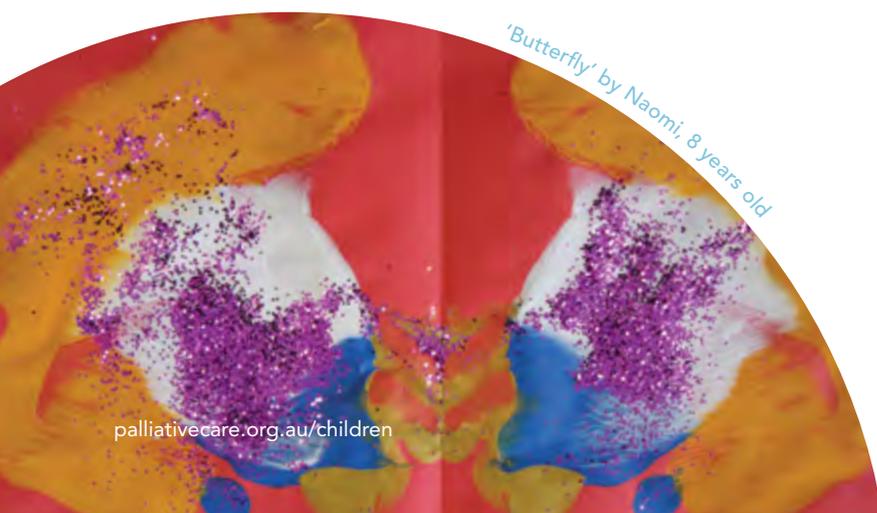
13. Team Care:

- a. Consider a debrief after the transfer occurs, either later that day or the following morning.

Day of the transfer

The team involved in the transfer should meet. This can be helpful as team members involved in transferring the child home may not have been heavily involved in planning discharge in previous days due to rostering or availability. Health professionals from different services may also be working together for the first time (e.g. intensive care, palliative care, retrieval or transport services, general paediatrics).

1. Discuss roles and anticipated issues.
2. Review the child's current symptoms and management required. Also consider anticipated symptoms during the transfer and after arrival at destination.
3. Confirm travel plans of any returning teams and expected time for return from destination.
4. Confirm the plan for transfer of care at the home.
5. It can be helpful to have a staff member who is able to visit the home and a second staff member who can provide support from the hospital.
 - a. The staff member at the hospital can:
 - i. Ensure medications for symptom management are available.
 - ii. Collect additional equipment, resources or support required.
 - iii. Identify and complete tasks as they arise during transfer.
 - b. The staff member at the home can:
 - i. Ensure they have sufficient resources at home (e.g. equipment to examine the child or provide ongoing cares).
 - ii. Ensure they arrive at the home in a timely way so they can receive handover of the child.
 - iii. Ensure all equipment is working and ensure family know how to operate it (e.g. oxygen, suction).
 - iv. Ensure the family have an understanding of the symptom management and medications for breakthrough doses (e.g. for pain or shortness of breath) are available. Syringes may be drawn up and labelled for the family to use when required.
 - v. Further tasks or requests from the family may be identified during the transfer.



6. Consider stopping enteral feeds approximately 2 hours before pick up. Consider alternative therapy for transfer if the child is at risk of hypoglycaemia (e.g. IV dextrose).
7. If relevant, ensure that there is a clear plan for tissue or tumour donation.
8. Consider the documentation required at home. This may include:
 - a. Summary of contact details for family
 - b. Resuscitation plan (or similar)
 - c. Written symptom management plan and medication authorities
 - d. Discharge documentation
 - e. Home Visit Risk assessment plan
 - f. Transport specific paperwork

At time of transfer

1. Ensure good communication between team members.
 - a. Notify all teams that the child is leaving the hospital
 - b. Notify other key managers within hospital as appropriate.
2. Have a plan in place in the event of deterioration or death during transfer. Transfer to the planned location of care could continue in this situation, or alternatively the family may prefer to return to hospital.
3. Reduce monitoring where possible. On arrival at home, limit use of lines and alarms.
4. Consider how the child will be taken into the home on a stretcher or carried by their parents.
5. Settle the child into their home and make them comfortable.
6. Ensure privacy and dignity for the child and family.
7. Monitor symptoms and administer medications, if required.
8. Handover any information to other health professionals, as required and document as appropriate.
9. Assist family in receiving the cultural and spiritual support they require.

After transfer home

1. Ensure privacy of the child and family.
2. Monitor symptoms and administer breakthrough medications as required.
3. Ensure equipment is available and set up environment (e.g. oxygen and suction).
2. Disengagement after transfer:
 - a. Supporting teams will need to leave the home at a designated time and should do this in consultation with other staff and the family.
 - b. Some team members (e.g. palliative care) may provide ongoing care and support in the home for the child and family.
3. Ongoing care at home:
 - a. Assess symptoms and modify medication management, as required.
 - b. Encourage memory making where possible.
 - c. Encourage family members to look after themselves. Encourage them to have short breaks where possible, and utilise trusted family members and friends to help as able.
 - d. A general practitioner may have a key role in caring for the child by visiting them at home as well as other family members including siblings.
 - e. Consider spiritual and cultural supports that the family may need.
4. When the child dies:
 - a. The family should understand the process of what happens if their child dies and who to call. In particular, there is no need for them to rush or to call emergency services.
 - b. Relevant paperwork should be at the home to facilitate documentation required for after the child dies, so the funeral home can take over care of the child at a time when the family choose.
5. Documentation
 - a. Document all clinical care and communication in the medical record.

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