Clinical Standard Operating Procedure (SOP)

TRANSFER OF A CHILD TO A HOSPICE FOR WITHDRAWAL OF LIFE-SUSTAINING TREATMENT

SETTING	Paediatric Intensive Care Unit (PICU) and High Dependency Unit (HDU) at Bristol Royal Hospital for Children (BRHC)
FOR STAFF	Any staff arranging transfer to a children's hospice for withdrawal of life-sustaining treatment
PATIENTS	Child who has been accepted by a children's hospice for withdrawal of life-sustaining treatment and ongoing care

STANDARD OPERATING PROCEDURE

Each year a number of children are transferred from BRHC to a hospice facility. The hospices offer respite and end of life care. This SOP guides clinical teams planning the transfer of children from BRHC to a hospice for withdrawal of life-sustaining treatment (LST) and end of life care, although plans should be made for the possibility of the child surviving following withdrawal of LST. Reasons to consider withdrawal of LST at a hospice might include:

- For a child and family to be closer to home, to better enable support from local friends, family and known teams (those based in the hospice and local to the hospice);
- Provision of end of life care in a less medical environment;
- To enable time to be spent with wider family and friends and for those people to be supported (particularly siblings);
- Some families will be more familiar with the hospice and team than the hospital;
- In some situations the hospice teams may be better placed to meet the spiritual and psychosocial needs of the family.

1. DEFINITIONS

Life-sustaining treatment (LST) – treatment, usually provided in a critical care environment, without which a child would be expected to die. Most commonly this would be breathing support (ventilation via mask, endotracheal tube or tracheostomy) but also other support such as inotropic support).

Family – the adults with parental responsibility for the patient.

Child – the patient, may be an infant, child or young person

Team – unless otherwise specified the term 'team' in this document refers to the multi-disciplinary team of professionals working in the hospital, hospice and transport teams planning delivery of this care.

2. OVERVIEW OF STEPS FOR PLANNING CARE

- Introducing withdrawal of LST outside the intensive care setting.
- Preparation prior to transfer.
- Extubation and/or withdrawal of other LST.
- Care of the child and family following withdrawal of LST.
- Care of the child and family after the child dies.

3. INTRODUCING WITHDRAWAL OF LST OUTSIDE THE INTENSIVE CARE SETTING

Consideration of the following should inform the team's decision to offer transfer to a hospice for withdrawal of LST. Only once the team have established that transfer might be possible should this be offered to the family.

Reasons why transfer might not be preferable:

- **The child is too unstable to transfer**. If there is a significant risk that transfer to another care setting might cause them to suffer or they might die *en route,* then transfer is not recommended.
- **The child's clinical course is too unpredictable following withdrawal of LST**. In order for transfer to take place the team must be sure that the child's predicted clinical needs will be met in the chosen place of care. Possible symptoms should be considered and their management planned for. If it is felt by the team that it would be too difficult for symptoms to be managed outside the critical care setting then transfer may not be appropriate. How sure are the team that the child will die following withdrawal of LST and within what timeframe? In all cases, parallel planning must take place. Even when a child is expected to die, plans must be made for the delivery of their ongoing care in the event that they do not (see 8.1 – Parallel planning). Some hospices will be looking to make plans to discharge a child if they are stable 2 weeks following transfer. Transfer back to hospital may be necessary at this point.
- **The family's care needs cannot be met in a hospice setting.** What are the expected care needs of the family during the child's end of life care and after the child dies? If these cannot be met in a hospice setting then transfer should not be offered (e.g. postpartum mother still requiring hospital care).
- **The time required to plan transfer does not fit with the needs of the child and family**. The hospices provide a first-class environment for children and their families at the end of life. They are not, however, hospitals and have limited medical facilities. They will not have access to piped oxygen, to drugs or to doctors unless this has been arranged beforehand. Hospice teams will work to enable transfer to happen in a timely way but this may take a few days.
- **The family do not have an established relationship with a hospice team.** Some children may already be known to a hospice team but others will not. For the latter group, transfer will require the child and family to meet a new group of professionals. The choice as to whether transferring to a hospice warrants building new relationships at this point should lie with the family but this issue must be considered. Some families will prioritise being cared for by a familiar team over being out of hospital.
- **Legal or other investigative processes expected to need to take place following death are not deliverable outside of hospital.** If it is expected that the child's death will be subject to a Coroner's investigation or hospital post mortem examination then transfer, although not impossible in such circumstances might not be advisable (see 10.2 – Legal/procedural requirements).

Once the hospital and hospice teams have agreed that transfer might be possible, this option can be offered to the family. Conversations with the family should be led by a team member who can provide a detailed explanation of the care that will be delivered around the time of withdrawal of LST. A member of the Paediatric Palliative Care & Bereavement Support Team (PPCBST) or hospice team may support the PICU team and family in this discussion.

4. WORKING WITH THE HOSPICE TEAM

Children's Hospice Southwest (CHSW) runs 3 hospices in the Southwest of England. Charlton Farm (near Bristol), Little Bridge House (Barnstaple) and Little Harbour (near St Austell). There are a number of hospices in neighbouring regions to which we also transfer children occasionally, i.e. Ty Hafan (South Wales), Acorns (Worcester) and Naomi House (Wiltshire). The principles apply equally to these.

If the child is not already known to one of the hospice teams, first contact should be made with the hospice that serves the geographical area where the child lives.

When making a referral, the hospice team will request demographic information about the child but will require the family to give consent for the hospital team to share medical information with the hospice team (as non-NHS organisations). This does not stop a theoretical (anonymised if necessary) discussion between teams to establish that transfer might be possible before going to seek consent from the family.

Once in receipt of information about the child and family the hospice team will confirm whether or not they are able to accept the referral and accept transfer for withdrawal of LST.

Members of the hospice team should then join care planning discussions.

If the family are not already familiar with the hospice and if time and circumstances allow, the family should be given the opportunity to visit the hospice. If not possible, member(s) of the hospice team may try to visit the family at BRHC.

5. TRANSFER PLANNING MEETING

5.1 Aim of the transfer planning meeting

The meeting plans to seek clarity on the delivery of care during transfer, at the point of withdrawal of LST and following withdrawal of LST.

The WATCh call handler will facilitate the setting up of this meeting via teleconference when requested by telephoning 0300 0300 789.

5.2 Core attendance

- Core PICU consultant;
- Named PICU nurse;
- Nurse and doctor from the WATCh transport team (WATCh will coordinate a teleconference for this meeting);
- Member of the UH Bristol PPCBST;
- Care team member and doctor from receiving hospice;
- Child's lead specialty consultant +/- other members of the specialty team (particularly important if the clinical course following withdrawal of LST is uncertain and therefore planning discharge from the hospice needed).

Engagement with a wider number of professionals, including the family's GP, community nursing teams, and Coroner's office may be required on a case by case basis. Family members should be invited to the planning meeting at the discretion of the team. As a minimum they should be aware that the meeting is taking place and have an opportunity to ask questions of the group via one of the team and be fully updated as to what plans are made. (See 11 – Information for the family).

6. TRANSFER PLANNING – CARE DURING TRANSFER AND PRIOR TO WITHDRAWAL OF LST

6.1 Transport

WATCh transport team will assist with transfer to any of the hospices with adequate notice and should be core members of the transfer planning team.

6.2 Equipment and drugs

The hospices will have a limited amount of oxygen available for emergency situations only. If the child is oxygen dependent, the team will need to estimate the volume of oxygen needed per hour and ensure an adequate supply is available at the hospice to meet the expected care needs. Additional oxygen can be made available but needs to be ordered in advance.

A symptom management plan should be written and agreed prior to transfer; the plan should take into account the possible need to change routes of medicines administration in time:

- 14 days' supply of medication (child's own and any listed in the symptom management plan) should be supplied by BRHC as TTOs. A member of the PPCBST or hospice team should take responsibility for working with the PICU team to ensure all required medication is prescribed.
- 14 days' supply of feeds should be provided if applicable.
- The team should establish what other equipment might be required, (e.g. suction machine or feed administration pump, feeding tubes, urinary catheters) and ensure it is available.

6.3 Access for drug administration

Routes of drug administration should be decided prior to transfer. Sustainable access must be obtained before leaving hospital. Drug delivery at the hospices may not be possible via peripheral IV cannulae. Subcutaneous, central IV and enteral routes may all be possible but should be discussed before transfer.

6.4 Personnel

Support for ongoing ventilation (except established long term home ventilation) is not available at any of the CHSW hospices. If transferring a child for withdrawal of ventilation then the WATCh team must be able to remain with and support the child until ventilation is withdrawn and their care has been taken over by the hospice team. The WATCh team needs to allow enough time to travel to PICU; prepare and package the child for transfer; travel to the receiving hospice; transfer the child to the hospice bed; wait until the child has settled into the hospice environment (1 – 2 hours); withdraw life-sustaining treatment (extubate, discontinue infusions etc), and wait until it is clear whether the child's death is imminent (another 1 – 2 hours).

The team should establish who will be travelling with the child in the ambulance and which other family members will be travelling to the hospice. In all circumstances the WATCh team should consist of a senior member of the medical team and a nurse with experience in end of life care.

The team accepting care at the hospice must be established in advance.

6.5 Plan for the care of the patient in the event of deterioration during transfer

What is the plan for care if the child deteriorates or dies during the transfer? Plans for care in the event of cardiorespiratory arrest should be discussed with the family and documented prior to transfer (on a personal resuscitation plan or wishes record as appropriate).

If the family do not plan to travel in the ambulance with the child the team should be clear of the family's wishes in the event of the child dying during transfer. Would they want the team to stop the transfer and inform the family *en route*? Would they want the team to return to BRHC with the child? Or would they want the team to continue to the hospice with the child?

7. TRANSFER PLANNING – CARE AT THE POINT OF WITHDRAWAL OF LST

The team should plan the timing of withdrawal, so that the hospice and transport teams can plan the delivery of care appropriately. The family needs to be provided with an approximate timeframe. It is usual to plan to start withdrawal after an hour or so of arriving at the hospice but this will need to be negotiated according to the needs of the child and family and other demands on the teams.

The step down from intensive care to a hospice environment can be dramatic and stark. By pushing the boundary of the PICU out by providing a full intensive care team, the change from PIC care to hospice care happens abruptly in the child's bedroom. The WATCh team needs to have thought through what aspects of care are essential for a safe transfer at the time of the planning meeting.

Withdrawal of an endotracheal tube may be taken by either member of the WATCh transport team if they feel supported and comfortable in doing so. It may be appropriate to administer a bolus of sedation and/or analgesia immediately before extubation if infusions are running and respiratory distress is anticipated.

8. TRANSFER PLANNING – CARE OF THE CHILD & FAMILY AFTER WITHDRAWAL OF LST

8.1 Parallel planning

Although survival following the withdrawal of LST may be thought unlikely, it is not uncommon. This should be discussed, both within the professional team and with the family, and plans should be put in place.

Plans should be made with the receiving team for the delivery of care if the child survives withdrawal of LST and where possible there should be an understanding of what to expect in the first 6, 12 and 24+ hours following withdrawal. Plans should be made for the management of symptoms that may occur following withdrawal.

The team must be clear who will continue to take medical leadership responsibility for the child if they survive withdrawal of LST. It should also be understood that most hospices will be looking to plan for a child's discharge to another care setting if they are still alive 2 weeks following withdrawal.

If the team feel there is a strong possibility that the child may survive withdrawal of LST it may be appropriate to begin planning for the delivery of that care (medical, nursing, social) prior to transfer from BRHC and invite the wider team to the transfer planning meeting.

9. TRANSFER PLANNING – CARE OF THE CHILD & FAMILY AFTER DEATH

9.1 Understanding the family's wishes about place of care after death

In many cases, the family will choose for their child to be cared for in the special bedroom at the hospice after death but this should not be assumed. Other options for families might include taking their child home or to a local funeral director. If possible, it is helpful to understand what the family might wish for in advance of transfer. As a minimum they should be given the opportunity to hear what options might be available to them.

9.2 Legal/procedural requirements

It is the responsibility of the hospital team to ensure that before transfer:

- **If there is any expectation to need to discuss the child's death with the Coroner, such a discussion should take place before transfer**. NB. The case should be discussed with the Coroner with jurisdiction for the place where the child is expected to die, i.e. where the hospice is located.
- **The potential value of post mortem examination should be considered by the hospital team and discussed with the family**. If there is a decision to proceed with a post mortem examination, it may still be possible to facilitate withdrawal of LST out of hospital but a detailed understanding of how such an examination might take place must be fully explored and discussed with the pathology team prior to transfer taking place. The post mortem examination consent process will remain the responsibility of the UH Bristol team.
- **The family's wishes about organ and tissue donation should be known.** They should understand that withdrawal of LST at a hospice will preclude the child from becoming an organ donor. Donation of tissues (heart valves and eyes) has taken place from a hospice setting. If the family wish to consider this the team should establish if it might be possible by contacting NHS Blood & Transplant and plan for this before transfer.
- **The team should discuss and document the likely cause of death to inform completion of the Medical Certificate of Cause of Death (MCCD).** A plan should be made as to who will be able to complete the MCCD. It is a legal requirement that the doctor completing the MCCD cared for the child during their final illness and has seen the child alive in the 14 days leading up to their death (UH Bristol guideline: How to Complete a Medical Certificate of Cause of Death (MCCD)). The team may need to plan for this responsibility falling to a number of different doctors depending on when the child dies. If the child dies immediately following the withdrawal of life sustaining treatment, the WATCh team should discuss with the hospice medical staff who is best placed to complete the MCCD.
- **The team caring for the child at the point of death will report the death to the CDOP office through completion of form A.**
- **Responsibility for the Child death review (CDR) meeting.** Responsibility for arranging the CDR meeting will default to the BRHC CDR team. The exception to this would be when children survive for a prolonged period of time (CDR meeting to be organised by the hospice team) or should the child survive to discharge (CDR meeting to be organised by the responsible paediatric team at the time of death).

9.3 Meeting the ongoing needs of family members

The expected care needs for the family who will be present at the hospice should be understood by the receiving team prior to transfer, including:

- Which family members will accompany the child (or meet them at the hospice).
- Ages and anticipated needs of any accompanying siblings (including an overview of what involvement they have had in discussions and what their understanding of their sibling's situation is felt to be).
- Mental health needs, and if already identified, which professionals are providing support. Details of any crisis plans must be communicated.
- Any expected physical healthcare needs (e.g. in the case of a postpartum mother still under community midwifery follow up, plans should be made for a team local to the hospice to provide this).

9.4 Ongoing family follow up in bereavement

Follow up of parents in bereavement whose child has died following withdrawal of LST by the Bristol PICU team should follow the UH Bristol SOP – Support to families following the death of a child in hospital; 'the core offer' even if the child dies at a hospice. Prior to transfer the team should identify which professionals will take on the bereavement medical lead and the bereavement care coordinator roles for UH Bristol.

When the UH Bristol bereavement care co-ordinator is informed of the child's death by the hospice team it is their responsibility to:

a. Inform teams within UH Bristol previously involved in the child's care of their death.
b. Ensure information on Medway pertaining to the child is updated.
c. Document all activity related to support offered to the family following their child's death on a Medway Paediatric Bereavement Proforma.
d. Report to the weekly bereavement tracking meeting on PICU.

The UH Bristol bereavement care coordinator should work closely with the hospice team and other involved professionals to ensure that the roles of the team around the family in bereavement are identified so that care is joined up and work not duplicated.

10. INFORMATION FOR THE FAMILY

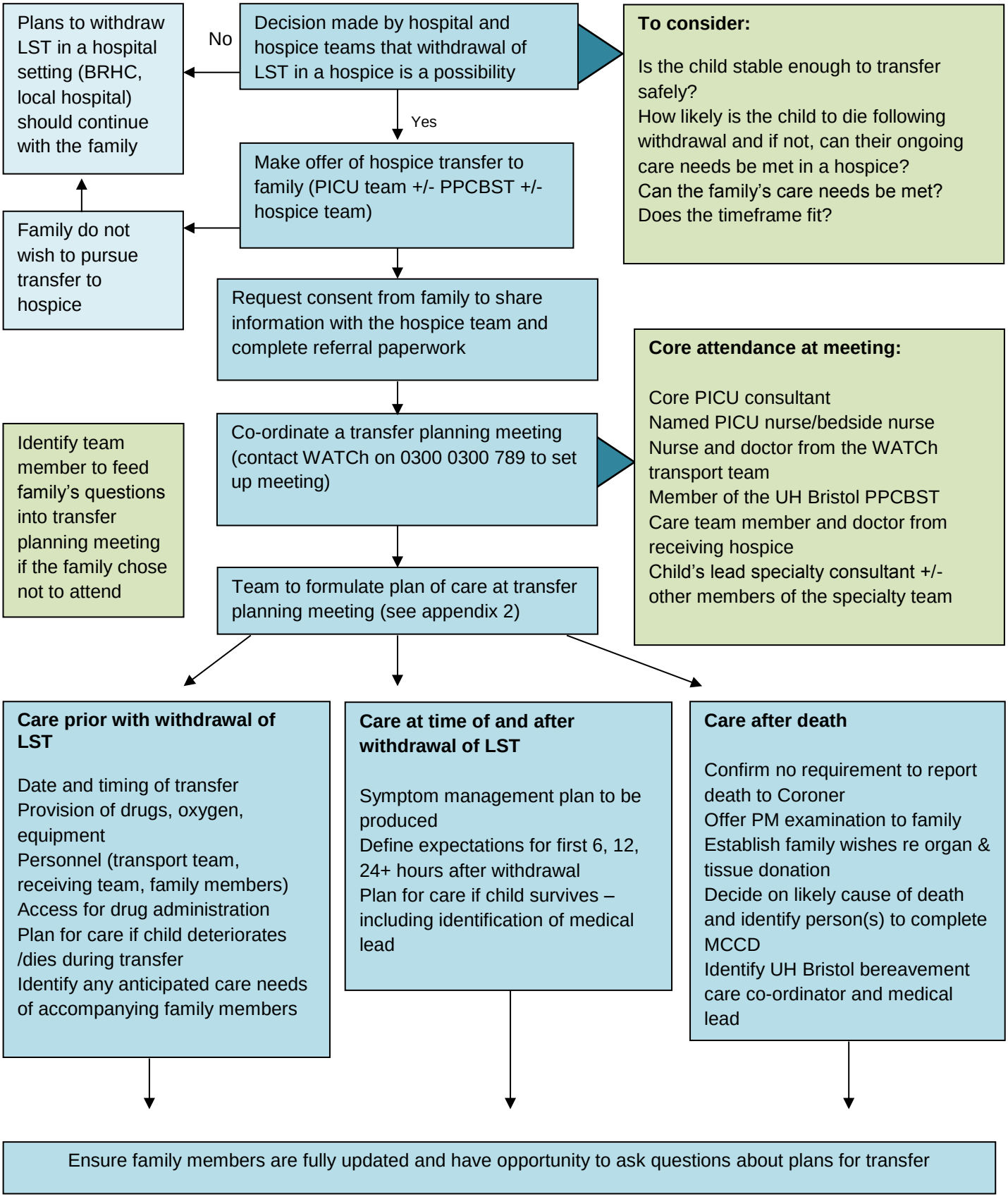
The family should be fully updated as to what to expect on the day of transfer, at the time of withdrawal of LST and in the period following this. They should be given opportunities to ask questions as required. The team should ensure that the family understand:

- The plan for the timings for the day of transfer, including an estimate of how long they will be at the hospice before LST is withdrawn.
- What the team expect to happen after LST is withdrawn, including possible symptoms and how they will be managed. Families may wish to know how long the team expect the child to live for following withdrawal of LST. If the team are not sure about this (and even if they think they *are* sure) then they must share this uncertainty with the family so they know what to expect and can be effectively supported during end of life care and beyond.

11. CONTACT INFORMATION

WATCh transport service	http://www.watch.nhs.uk	0300 0300 789
UH Bristol Paediatric Palliative Care & Bereavement Support Team	http://www.UHbristol.nhs.uk/ppcbss	0117 3427293 or bleep 1061
Charlton Farm Hospice	https://www.chsw.org.uk/	01275 866 611
Little Bridge House Hospice	https://www.chsw.org.uk/	01271 321 999
Little Harbour Hospice	https://www.chsw.org.uk/	01726 65 555
NHS Blood & Transplant (to discuss tissue donation)		0800 432 0559

Appendix 1. Flowchart: Planning the transfer



Appendix 2. Planning meeting – template for discussion

Contact WATCh team on tel. 0300 0300 789 to arrange the teleconference meeting

Core attendance for meeting	
• Core PICU consultant • Named PICU nurse • Nurse and doctor from the WATCh transport team • Member of the UH BRISTOL PPCBST • Care team member and doctor from receiving hospice • Child's lead specialty consultant +/- other members of the specialty team	
Personnel	
Which team members (WATCh +/- PICU team +/- others) will transfer the child and family?	
Which hospice team members will receive child?	
Which family members will accompany child in the ambulance or meet them at the hospice?	
Dates & times	
Date/time of expected arrival of WATCh team on PICU	
Date/time of expected arrival of WATCh team and child at hospice	
Equipment	
Oxygen. Calculate amount likely to require and double	
Is there adequate oxygen available at the location?	
Is a suction machine and appropriate sized catheters available?	
Is any other equipment required?	
Drugs	
Management plan for anticipated symptoms completed prior to transfer	
14 days' supply of current medications and those listed on the symptom management plan to be supplied. Feeds should also be supplied if required.	

Access	
Route(s) of drug administration to be agreed	
- During transfer	
- When at the hospice	
Plan for care of patient in event of deterioration/death during transfer	
What is the plan for care if the child deteriorates or dies during the transfer? Plans for care (incl. DNACPR) should be discussed with the family and documented prior to transfer	
If the family do not plan to travel in the ambulance what are their wishes should the child die during transfer?	
Plan for care at the point of withdrawal of LST	
Parallel planning	
What are the expectations for the 6, 12, 24+ hours following withdrawal of LST?	
Who will be the child's named medical lead whilst at the hospice and then if they survive to discharge?	
If there is an expectation the child might survive withdrawal of LST have appropriate local team members been involved in planning?	
Planning for care of the child and family after death	
Is it agreed that there is no expected need to discuss this case with the Coroner?	
Are the family's wishes about organ & tissue donation known and planned for?	
Has a hospital post mortem examination been offered to the family?	
Has the likely cause of death been considered and documented? Has it been agreed who will complete the	

medical certificate of cause of death?	
UH Bristol bereavement medical lead identified	
UH Bristol bereavement care co-ordinator identified	

Appendix 3. Pre-departure checklist

		tick	Comments
Documentation	Discharge summary		
	Symptom management plan		
	Advance Care Plan		
Medication	14 days' supply (child's own and those listed on symptom management plan)		
Feeds	14 days' supply		
Oxygen	Sufficient for transfer and for ongoing care at hospice		
Equipment	Suction machine		
	Other		
Local team	Lead specialty or community paediatrician updated re transfer		
	GP updated re transfer		
Family	Updated		

Helpful guidelines on symptom control, formulary and use of syringe drivers are available on DMS under Paediatric palliative care.
http://nww.avon.nhs.uk/dms/download.aspx?did=18815
http://nww.avon.nhs.uk/dms/download.aspx?did=18377
http://nww.avon.nhs.uk/dms/download.aspx?did=19415
http://nww.avon.nhs.uk/dms/download.aspx?did=17572
http://nww.avon.nhs.uk/dms/download.aspx?did=18658

AUTHORISING BODY

SAFETY Inadequate preparation can lead to an unsafe situation and poor experience at the hospice

QUERIES Paediatric Palliative Care & Bereavement Support Team