

Clinical Guideline

PLANNING END-OF-LIFE CARE IN BRCH AND FOR CHILDREN WHO MAY HAVE A CHANGE IN CARE LOCATION AT THE END OF LIFE

SETTING	BRCH
FOR STAFF	All Consultants, junior doctors, and nursing staff
PATIENTS	All palliative care patients

This document offers practical guidance to professionals who are caring for a child or young person who has been identified as requiring 'palliative care' or who may be approaching the end of their life and so likely to require end of life (EOL) care in the near future. EOL care may follow a period of palliative care or an acute illness. This guidance is not a clinical decision making tool, but an aid to planning timely care.

What is paediatric palliative care (PPC)?

Palliative care aims to optimise quality of life in the face of an ultimately terminal condition. Paediatric palliative care is an active and total approach to the care of children and young people with life-limiting conditions that embraces physical, emotional, social and spiritual elements through death and beyond. Palliative care is not a single intervention; it is a philosophy of care. It can be seen as a thread that weaves through the lives of all children with a life limiting illness, often alongside active interventions and treatment.

What is end of life care?

End of life care is the care a child and family receive in the last few days or weeks leading up to the child's death. Medication and interventions are reviewed in relation to their appropriateness throughout this time.

When should PPC be introduced?

Evidence has shown that families with a child with a life-limiting or life-threatening condition value the on-going support from palliative care professionals, including psychological and spiritual support along with symptom management, from the point of diagnosis. However, palliative care is often only considered right at the end of child's life. There are often times during the child's illness that families need to be supported to make difficult decisions, for example about reassignment of treatment goals. Palliative care professionals may be better able to support this process if they have already had the opportunity to build a relationship with the child and family. A referral to palliative care services can be made at any point from the diagnosis of a life-limiting or life-threatening illness.

The surprise questions: These have been designed to help health professionals think about the potential need for palliative care in a timely manner thus avoiding complex and important decisions being made out of hours by professionals who do not know the child and family well. Some clinicians find it helpful to ask themselves "Would you be surprised if this patient were still alive in 6-12 months?" If you **would not be surprised** it is important to establish what measures might be taken to improve the child's quality of life and what advance preparations will be

needed to provide best care for them in the future as death approaches.

The aim is to enable the right thing to happen at the right time, e.g. if days, then begin an 'Anticipatory Care Plan' immediately. In paediatric palliative care the surprise questions are:

The surprise questions....

Diagnosis or recognition

- ❖ Would you be surprised if this baby / child died as a result of this condition or problem?

Death before adulthood

Would you be surprised if this baby/ child died before adulthood (18th birthday)?

Increasing instability

- ❖ Would you be surprised if this baby / child died in the next few months to years?
- ❖ Would you be surprised if this child died in the next five years?

Critical illness or end of life

- ❖ Would you be surprised if this baby / child dies in the next few days / weeks?

If your answer is '**NO I would not be surprised**' to any of these questions you should be thinking about palliative care for this child or young person.

'Parallel Planning': A key concept in PPC

It is often hard to predict what the future holds for children requiring palliative care. Some are at risk of an unpredictable and potentially terminal event during periods of relatively good health. Others may be very vulnerable and living with significant health needs, yet the child may have a considerable time to live. During this time their quality of life should be maximised. Parents experience the uncertainty that living with a child requiring palliative care brings, and with support, value a 'parallel planning' approach. Discussions with the child (where appropriate) and the family enable various options for care in response to a range of potential outcomes to be considered and for their preferences for care to be written down in advance (e.g. using the Wishes document). Some children assessed as deteriorating or approaching the end of their life sometimes survive these episodes. Planning for life while also planning for deterioration or death allows a child's full potential to be achieved and initiates the mobilisation of services and professionals where necessary (See 'High level end of life care pathway' below for how this should be approached locally). Planning for the future at times of great uncertainty can also be comforting for children and parents. These plans often include the development of an 'Advance Care Plan' (Wishes document).

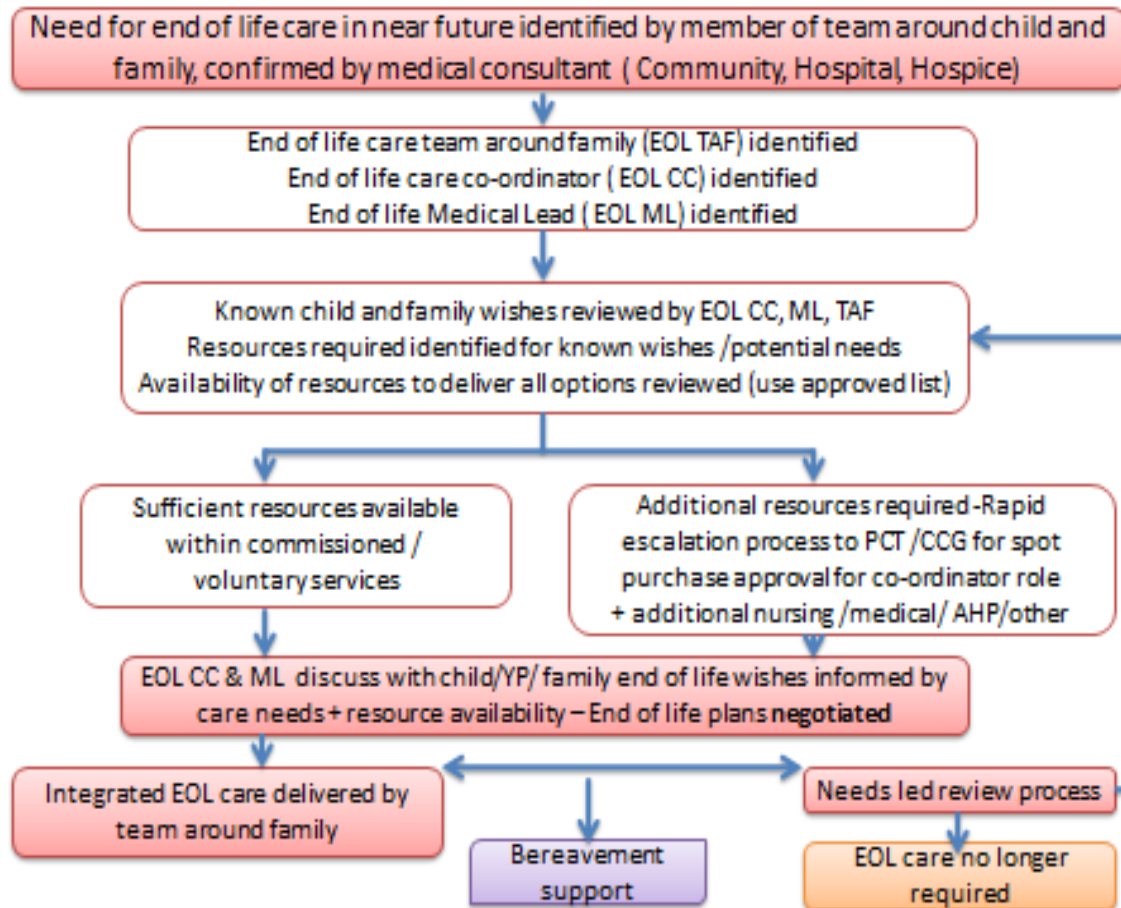
A process should be in place to prepare parents for their child's potential readmission to hospital. This may be to a unit or ward the family are familiar with or may involve a new ward, consultant and care team in the same or a different hospital. Therefore, it is important to communicate, document and share the outcomes of key parallel planning discussions with relevant colleagues in a timely manner.

High level end of life care pathway:

To aid the planning process locally this high level map has been agreed as the approach that

should be taken when starting to think about and plan a child's end of life care. It sets out the steps that should be taken from the point of recognition of 'need' by the professionals. It is important that these steps are taken *before* approaching the family and asking them where their preferred place of care would be at the end of life.

High level end of life care delivery pathway



The first step: The likely need for end of life care in the near future is identified by a member of the team around the child and family and confirmed by the lead consultant.

Identify the team around the child and family (TAF). This should include the child's lead consultant (ML), lead nurse and an end of life care co-ordinator who should liaise with professionals to collect information required to plan care. The EOL care co-ordinator (EOL CC) could be any professional working with the family. The team should meet with the child and family to discuss their EOL choices.

Known child and family wishes reviewed by EOL CC, ML & TAF: The team should review what they know about the child and family wishes, asking the question 'does this child have a Wishes Document and do we know where their preferred place of care and death are'? If not should we offer the family the chance to complete a Wishes Document or have conversation? Knowing what we know about the family, what resources are required to deliver their known wishes / potential needs? **Do we need to escalate anything to the local Clinical Commissioning Group (CCG) to seek funding at this stage?** If yes speak with the palliative care support team.

MDT Meeting: It is good practice to convene an MDT to plan a co-ordinated approach to care and to ensure that all necessary resources are in place. This may be particularly important if there is to be a change in location of care. The involvement of the child's GP and community

staff are essential to the provision of safe palliative care in the home setting. The primary outcome of the meeting should be a **clear end of life care plan** along with a list of **'Who is who'** in the team around the family and a list of contact numbers for the family and team. It is important that the outcomes of this meeting are clearly documented in the clinical notes

When discussing EOL care choices it is important to establish the child and family's preferred place of care; as this will affect how care is planned. Options might include:

1. Ward at BRCH ([see appendix 1](#))
2. Home ([See appendix 2](#))
3. Hospice ([See appendix 3](#))
4. Extubation in a different location ([See appendix 4](#))
5. Symptom Control ([See appendix 5](#))
6. Discharge Checklist ([See appendix 7](#))

Please do consider the potential challenges in symptom management in these different settings and how they might be addressed. You may like to have a 'symptom management plan' documented that can be shared with the different health care professionals. It is always best to have a 'back-up' plan (**Parallel plan**) in case the child is re-admitted to hospital or a change in location becomes necessary.

A simple framework: It may be useful to think about:

1. What do I need to have in place before the child dies (This will vary depending on preferred location?)
2. What do I need to have in place for the time of death?
3. What do I need to have in place for after the death?

In [appendix 6](#) to this document you will find some 'End of Life Prompts' These should help you answer these questions.

Who can help me? BRCH Palliative Care Support (PCS) – Who we are:

Dr Charlotte Mellor – Charlotte is a palliative care paediatrician, based at Charlton Farm Children's Hospice.

Francis Edwards – Francis is the Palliative Care Liaison Nurse, based at BRCH.

Dr James Fraser – Consultant in Paediatric Intensive Care.

What we can offer:

- Support in having difficult conversations with families
- Help with thinking about palliative care and end-of-life care in different settings (Ward, Home or Hospice)
- Support in completing 'Wishes' or 'DNACPR' documentation
- Support in discharging a child for end of life care at home or in another setting
- Clinical review and support with symptom management

- Attendance at 'Team around the child' meetings
- Help with the local Child Death Review meeting
- Teaching on palliative care issues
- Staff support and 'times of reflection' following the death of a child
- Support with Parallel Planning (Planning for life whilst also planning for death allows a child's full potential to be achieved)

When we will be here: The PCS team will review children and referrals normally on a Tuesday and attend 'Team around the child' / young person's meetings on a Tuesday.

How to make a referral: You can make a referral in the following ways:

- Contact Charlotte or Francis to have a discussion / consult leading to a managed referral: by phone 0778533014 (Calls to this number will be monitored throughout the week) or via email: charlotte.mellor@nhs.net or Francis.edwards@UH Bristol.nhs.uk
- Complete a [palliative care referral form](#). Teams will need to complete a referral form for a formal patient review. This form should be signed by the Lead Consultant and the family should be aware of the formal referral. (Please note that it may be a few days before an email is seen so always best to phone). Please leave completed referral forms on PICU FAO PCS Team or email to above email address. For an urgent review please contact 07785333014

SYMPTOM MANAGEMENT TOOLS:

Basic Symptom Control in Paediatric Palliative Care, 2011.

http://www.togetherforshortlives.org.uk/professionals/external_resources

The Association of Paediatric Palliative Medicine Master Formulary 2012.

http://www.togetherforshortlives.org.uk/professionals/external_resources

REFERENCES:

A Core Care Pathway for Children with Life-Limiting and Life-threatening Conditions – 3rd edition, 2013. <http://www.togetherforshortlives.org.uk/professionals/resources>

A Care Pathway to Support Extubation within a Children's Palliative Care Framework, 2011.

<http://www.togetherforshortlives.org.uk/professionals/resources>

The verification of expected death in childhood – guidance for children's palliative care services

2012. <http://www.togetherforshortlives.org.uk/professionals/resources>

End of life planning prompt sheets (2012).

<http://www.togetherforshortlives.org.uk/professionals/resources>

All these resources can be found on the resources page in help for professionals on the Together for Short Lives website. You will also find support on the Children's Palliative Care Workspace on Connect under symptom management:

<http://workspaces/sites/Teams/ChildrensPalliativeCare/default.aspx>

RELATED DOCUMENTS

SAFETY

QUERIES

Palliative care team 07785333014

APPENDIX 1

End of Life Care in Hospital

To be considered before the child dies:

- Lead clinician, nurse, child, young person and family discuss and agree end of life care plan & wishes (You may like to involve the palliative care team)
- Complete a Wishes document or DNACRP form – which ever seems more appropriate
- Establish preference for place of care within hospital. The environment should be prepared to meet child, young person and family's palliative care needs and wishes.
- Review non-essential interventions and consider stopping them if they are not contributing to improving quality of life. This might include some medication and monitoring.
- Formulate a symptom management plan and document this clearly in the medical notes. This should address current symptoms and those which commonly occur at the end of life. (See symptom control' for further information).
- Pre-emptive prescribing should be done according to symptom management plan. This is particularly important to ensure that good symptom control can take place out of hours when advice might not be easily available.
- Palliative care should be an active and responsive process and so frequent review of the child and family is imperative. In addition to reviewing the patient frequently the end of life care plan should be reviewed by the team around the child.
- Ensure that an inclusive handover takes place. Key individuals include the nursing team, Clinical Site Team and medical team on call, ensuring the middle grade and consultants are informed of plans for the child and family.
- Establish the child and family's views on organ and tissue donation and post mortem examination if appropriate.
- The family should be informed of other support services available within the hospital such as Chaplaincy and the LIAISE Support Officer. Also inform them of external sources of support for the family (See Children's palliative care WorkSpace
- Ensure GP and relevant community staff are informed and updated as appropriate.
- Useful resources available to you: The Children Palliative Care WorkSpace.
<http://workspaces/sites/Teams/ChildrensPalliativeCare/default.aspx>

Planning for the child's death:

- Decide who is going to verify the death, in and out of hours?
- Decide who is going to complete the death certificate, in and out of hours? It is sometimes helpful to have a conversation with the child's speciality Consultant in advance of the death to agree the precise form of wording on the MCCD. You may also like to clarify if you need to speak with the Coroner's office to prevent delays

- Establish the family's wishes for caring for their child after death, e.g. do they want to be involved in washing their child?
- Establish where the family want their child to be after death. Options include The Rainbow room, their home, at the undertakers,' or, if the family is already known to the hospice team, the 'Starborn' room at Charlton Farm children's hospice. Please inform the Clinical Site Team of any plans that have been made
- Start to compile a list of professionals to be informed of the child's death. It may be helpful to involve the family in this process. Key professionals may include hospital based doctors, GP, community paediatrician, Lifetime, Jessie May, Midwife, Health visitor, allied health professionals.
- Establish who will provide bereavement support for the family.

What needs to happen after the child has died?

- Start and complete the check list in the Rainbow pack – This can be found on PICU (Medical & Nursing)
- Complete the medical certificate of death and give to family. You may wish to agree the precise wording of this with the child's speciality Consultant.
- Inform the Child Death Overview Panel office of the child's death (0117) 342 5151 and start the Child Death Review (CDR) paper work and arrange the 'local' CDR meeting
- Inform involved professionals of the child's death
- Ensure that support continues for the family – See hospital bereavement pathway.

APPENDIX 2

End of Life Care at Home

It is often the wish of families and children to receive end of life care at home. Whilst professionals should endeavour to meet this wish it should be recognised that this may not be possible due to the lack of 24/7 support available in the community. Professionals have a responsibility to formulate a robust plan for care and to ensure that children and families will be adequately supported and cared for in a safe environment. It may be helpful to put in place a plan B for care outside of the home, e.g. at the hospice or in hospital, should this become necessary (parallel planning).

- Lead clinician and End of life care co-ordinator, child and family should discuss the options available for end of life care at home and plan for a package of care that can be delivered at home with the right resources 24/7
- Lead clinician and end of life care co-ordinator should identify lead persons in the community to be involved in the delivery of care. They should liaise with the GP and also with professionals from other services as appropriate. These might include Lifetime, Jessie May, Children's Community Nursing team, District Nursing team and Social work team.
- If the child has a Wishes document an alert should be sent to their local Ambulance service and the GP – The GP may want to send this to their 'Out of Hours' service
- Arrange a discharge planning meeting with community services (including the GP) to plan the care required by child & family at home. It is important that we understand what support the GP is able to offer the family. Consider inviting the hospital palliative care support team to this meeting as part of a parallel planning process.
- Identify who is going to be the child's medical lead and Key Worker in the community
- Review non-essential interventions and consider stopping them if they are not contributing to improving quality of life. This might include some medication.
- Formulate a symptom management plan and document this clearly. This should address current symptoms and those, which commonly occur at the end of life. (See 'symptom control' (appendix 5) for further information). Pre-emptive prescribing should be done according to symptom management plan.
- Palliative care should be an active and responsive process and so frequent review of the child and family is imperative. A plan should be made identify which professionals will visit the child at home and how frequently this should happen. This will be dictated by clinical need.
- Ensure that a 'parallel plan' is in place for the child, in case the child continues to live?
- Is there an emergency plan and escalation of treatment guidelines in place?
- The team around the family should identify additional resources required to meet child & family's needs and escalate to PCT / CCG for 'spot purchase.'

- Lead clinician & EOL CC identify and source all equipment and medication required to take home for the first seven days. This may also include a 'Just in case box' with a clear prescription for medications.
- If needed clear guidelines should be in place for the administration of blood products and who to contact if this is needed.
- Ensure they have an end of life care plan in place
- Ensure they have an up to date drug chart to take home along with a seven day supply of medication.
- Ensure they have a prescription for oxygen if they are requiring oxygen .
- Refer to the Dietetic Department if patient requires enteral feeding. The appropriate feed and equipment can then be organised. Make sure this is then prescribed.
- A discharge summary should be given to the family to take home along with a copy of the Wishes document. The EOL CC should make sure this is sent to all other agencies involved with the family.
- Arrange transport to preferred place of care, with escort if required
- Inform the family of other Support Services available to them in the community
- Ensure the family know who to call for advice in the event of the child becoming more unwell or dying whilst recognising that this may occur out of hours. They should have a clear list of contact numbers and advice on when to call them.
- Plan who is going to verify the death and who is going to certify the death – in and out of hours.
- Ensure the family understand that, after the child has died, there is no immediate need to contact any professional. However, they will need to call their pre-designated doctor (GP, Community Paediatrician, and Hospice Doctor) for verification and certification of death to allow registration of the death to proceed.
- EOL CC to inform GP and community staff of proposed discharge prior to discharge from hospital.
- Make sure all the key multi-agency team have an NHS.Net email address so that information can be safely shared with each other.
- Where specialist palliative care advice and support is required (for complex symptom management and difficult end of life cases) each service /organisation should be aware of their local specialist team and resources.
- Does the family home address have a current risk assessment attached to it?
- Check that all the necessary medical supplies and equipment has been delivered and are working.

What is needed if a child is being discharged from Bristol Children's Hospital for End of Life Care in the Community involving Jessie May

- A clear referral to Jessie May – however Jessie May is happy to work in partnership with Lifetime and Charlton Farm for one joint end of life referral
- Invitation to regular multi-disciplinary meetings – throughout the discharge planning process
- A verbal handover along with a discharge letter with information about the last hospital admission and prognosis
- A copy of all the paperwork/written instructions that have been given to the parent /carers for example information on how to give the medication and what changes can be made by the parent/carer
- Written instructions for the parent/carers in their own language if possible
- A list of all the other agencies involved with up to date contact details
- An identified key worker for Medical input and Nursing input for both the acute and community service
- A direct hand over from the medical lead in the acute care to the medical lead in the community.
- Clear information about treatment and the changes that are appropriate for example with feeds and medication should be documented in a format that the family and all the professionals involved are able to understand
- A copy of an up to date wishes document
- Information of what equipment may be needed should be ordered and in place for home visits to commence
- We need a list of all the NHS net email addresses of all the key multi-agency teams involved with the family so that information can be safely shared with each other

APPENDIX 3

End of Life Care in Hospice

- Lead clinician makes urgent referral to hospice, shares care & management plan and agrees suitable time for an MDT and date for transfer
- Lead clinician and team around the child discuss and agree end of life care and symptom management plan with child, young person, family and Hospice staff.
- Ensure end of life care plan, drug chart, discharge summary, medicines for 7 days, medical supplies and equipment and are also taken to hospice with child or young person
- Transport and escort arranged if required
- Inform GP, relevant community staff and Site Team of transfer

Information required before discharge from Bristol Children's Hospital to Charlton Farm Children's Hospice for end of life care.

Charlton Farm provides respite and end of life and bereavement care for children with life-limiting illnesses and their families. Emergency admissions for end of life care will be prioritised but will likely require cancellation of another family's respite visit. For this reason and due to there not being a doctor on site around the clock, planning a safe transfer may take some time. The hospice aims to provide care in a home from home environment. It should therefore be recognised that, whilst many nursing and medical interventions are possible, these are likely to require some forward planning and should be discussed with the head of care or medical director when arranging the transfer of a child or young person.

Referral process

Contact the head of care, medical director or their deputies to discuss transfer of a patient for end of life care on (01275 866611). Such referrals can be processed urgently. If possible the child and family are encouraged to visit the hospice prior to transfer. Once the referral has been accepted, two contacts (hospice care team members) will be assigned to support the family. They will aim to meet with the child and family, either in hospital or during their visit to the hospice.

The following information will be required to support the child and family's transfer:

Clinical

1. A full medical summary, including:
 - a. Background medical history
 - b. An estimation of life expectancy where possible
 - c. Clinician's predictions for possible modes of death
 - d. Symptoms which are currently (or expected to be) an issue
2. List of current medication, including:
 - a. Information about recent changes (e.g. opioid titration)
 - b. Medication tried and not worked/not tolerated
 - c. A copy of the child's current drug chart
3. Plans for administration of blood products if appropriate – please note that blood products which could be administered in the home setting, e.g. platelets, could also be

administered at Charlton Farm by hospital outreach teams following discussion but blood transfusions are not possible on site and will require transfer back to hospital.

4. Current situation and future plans re feeding – including route of nutrition and the child and family's expectations.
5. Information re current intravenous/subcutaneous access – e.g. portacath, Hickman, PICC lines; including when they were last accessed and flushed. Peripheral intravenous lines cannot be resited at the hospice; replacement of subcutaneous lines is possible.
6. Information about any infection control issues
7. Outcome of tissue viability assessments, e.g. need for special mattress
8. Care plans for additional nursing needs – e.g. ventilator usage, TPN, peritoneal dialysis, oxygen administration, external ventricular drains, urinary catheterisation. Please discuss requirements for specialist equipment (e.g. infusion pumps) prior to transfer.
9. Level of nursing dependency, e.g. 1 to 1 or 2 to 1.
10. TTAs should be dispensed prior to transfer – please arrange for 7 days' worth of medication to come with the child.

Transfer

1. Requirements for transport, including the need for a stretcher or wheelchair.
2. Consider the need for a nursing or medical escort if the child is likely to require analgesia or sedation en route to the hospice.
3. Telephone contact should be made with the hospice prior to the child and family leaving the hospital.

Plans for future care in life

1. Plans for on-going treatment and hospital reviews if appropriate.
2. Completion of a Wishes document is strongly recommended. As a minimum, the child should have a resuscitation plan that has been discussed with the family. If the child is for resuscitation in the event of collapse, the family should be aware of the potential limitations of this in the hospice setting. Basic life support would be instituted and a 999 ambulance called.
3. In some situations, children who are transferred to the hospice for end of life care stabilise and improve to the point that they are able to be discharged. Consideration of this possibility should be made before transfer and plans made as appropriate on a case by case basis.

Child & family

1. Information about the family:
 - a. Names of key family members (including parents, step parents, siblings and others)
 - b. List of those planning to stay at the hospice
 - c. Health needs (including psychological)
 - d. Cultural requirements
 - e. Language spoken
 - f. Particular needs of siblings (to inform work done by the hospice sibling team)
2. Who has parental responsibility?
3. Information about additional social needs – Do the family have a social worker? Have there been any safeguarding concerns?
4. Details of conversations held with the family, particularly about EOL care planning/wishes but also any other significant events
5. Information about what the child's awareness is of their situation; how involved they have been in decision making and how we should be approaching such discussions once they

are discharged from hospital (e.g. Do we have decision-making discussions with parents first?)

6. The family's wishes re place of care - for palliative care/EOL care/bereavement care
7. Religious or spiritual needs

Professionals

1. A list of all of those involved in the child's care (might include but not limited to):
 - a. Lead doctor
 - b. Lead nurse
 - c. End of life care co-ordinator
 - d. Other members of the end of life team around the family
 - e. Other doctors (including GP, community paediatrician, other hospital doctors – at Bristol Children's Hospital and regional hospitals)
 - f. Community nursing team - Lifetime and/or Jessie May/other
 - g. Other health professionals – Physiotherapist, dietician, psychologist etc

Plans for care after death

1. Have the child & family been asked about their views on tissue and organ donation – if so, what are they?
2. Is a post mortem examination required? Has this been discussed with the family and what is the outcome of this discussion? It is the responsibility of the child's lead clinician to obtain the family's consent for the post mortem examination, if required, before transfer to Charlton Farm.
3. Outcome of any discussions about care of the child around the time of death, these may or may not be according to religious or cultural rituals.
4. Where does the family want their child to be cared for after death? (E.g. in Starborn at Charlton Farm, at home or at the funeral director's).

Clinical information can be provided by letter, to be faxed to (01275) 866621 or can be emailed securely from an nhs.net email account to Charlton.farm@nhs.net

APPENDIX 4

Support for extubation in different locations: Hospital, Hospice & Home

If you are thinking about 'extubating' a child there are many issues to consider, such as location and how sure are you of the outcome? It is worth considering what are you going to do if the child does not die straight away? – Who else have you involved in the process? What support has been put in place for the family? **Please think about parallel planning.** There are many sources of published guidance on [end-of-life care and extubation](#) which you may find helpful to review at this stage.

It should be made clear that sometimes invasive treatment options such as ventilation are withdrawn, but care is never withdrawn. The Royal College of Paediatrics and Child Health have published guidance on withdrawing treatment in children (RCPCH 1997); the British Medical Association has published guidance and extensive discussion of the ethics around end of life care. (BMA 1999); and the GMC has also published guidance on treatment and care towards the end of life – Good Practice in Decision Making (2010). There is also a parent's guide: ['Making critical care choices for your child'](#) which may be helpful to give to parents.

If you are thinking about extubating this child outside of the hospital – who have you involved in the process? What support has been put in place for when you leave the location, if the child has not died? In all these instances **Parallel Planning** is key. Although survival following the withdrawal of life-sustaining treatment may be thought unlikely, it is possible in some cases. This should be discussed, both within the professional team and with the family, and plans should be put in place. Planning for further assessment or support from health, social care and education services may seem unnecessary and may be discontinued, or never started. It is important that proactive parallel planning is in place. Planning for the delivery of good end of life care and care after the death, whilst also continuing to plan and make available the full range of local children's services in case of the child's on-going survival (whilst acknowledging realistically the relative doubtfulness of this).

Such **Parallel Planning** for life whilst also planning for death allows a child's full potential to be achieved. Families can often draw comfort from planning for the future at times of great uncertainty. A process should be in place to prepare parents if their child requires subsequent readmission to hospital.

Please see the [hospital policy on the use of medication](#).

APPENDIX 5

Symptom Control

As the end of life approaches treatment goals should be reassigned to focus on maximising quality, rather than duration of life. This may involve the withdrawal of non-essential medications, feeding & hydration or other invasive interventions. Such decisions should take place as part of End-of-Life planning discussions and the family should be involved in the decision making process. It should be clear that the aim of these decisions is to ensure optimum quality of life for the child and family and not to alter the duration of the child's life is the goal.

All discussions and planning should take place in the context of a Multi-professional approach and involving those experienced in end of life planning, symptom management in the context of the child's disease profiles. It is worth noting that not all symptoms will be solely physical. They may well be social, psychological or spiritual and it is important that these are address as well. (The concept of 'Total Pain')

All decisions should be child centred and care should be delivered in partnership with the child and family. This involves skilled and sensitive communication, which empowers the child and families. Anticipatory prescribing, planning and being prepared for the unexpected are key as is having 'just in case' medication prescribed and available. A symptom management flowchart can sometimes be helpful to guide professionals and parents regarding likely symptoms and provide clear advice on the management of such symptoms. (What is this?)

The principles of symptom management at the end of life are exactly the same as for symptom control in other situations, but the tolerance of side effects may be different. The most common symptoms encountered are:

- Pain
- Nausea and vomiting
- Breathlessness
- Drooling and problems managing secretions
- Seizures
- Constipation

Guidance for management of most symptoms can be found in the most used resource in paediatric palliative care – Basic Symptom Control in Paediatric Palliative Care, 2011.

http://www.togetherforshortlives.org.uk/professionals/external_resources

The Association for Paediatric Palliative Medicine (APPM) formulary can be found here:

http://www.togetherforshortlives.org.uk/assets/0000/1492/APPM_Master_Formulary_2012.pdf

For oncology children you may like to see: [CCLG booklet: Managing Symptoms at Home: Palliative Care Information for Families](#).

Both of these resources can also be found on the [Children Palliative Care Workspace](#) in the symptom management section.

You can find more information in the ['End of life planning series'](#), Section 2 - Care before death (2.7 Symptom management planning) page 21.

For helpful information and algorithms on symptom management see '[Approaching Symptom Management in Palliative Care](#)'. This can be found within the West Midlands Children and Young People's Palliative Care Toolkit, Part three.

Where specialist palliative care advice and support is required (for complex symptom management and difficult end of life cases) each service /organisation should be aware of their local specialist team or where they can get support.

APPENDIX 6

End-of-Life Prompts

This appendix gives you an overview of the main things to think about when working with a child in the immediate period before their death.

The following prompts should help trigger any considerations you need to make at this stage of caring for a child (Care before death**)**

- The child's needs should be assessed, and a plan of care should be discussed and developed with the child and their family. The child and family's beliefs and choices should be incorporated into the end of life care plan.
- Families and carers should be given appropriate written information to back up discussions and plans. Information should be provided for the child, siblings and parents in a way that is appropriate for their age and understanding.
- The child's current medication should be re-assessed. If appropriate, you might want to discontinue any medication which is 'non-essential'. Consider whether to discontinue inappropriate interventions at this stage such as blood tests, intravenous fluids and routine observation of vital signs.
- It is important to anticipate and prescribe for a range of possible symptoms such as pain, agitation, nausea and vomiting and respiratory tract secretion and ensure that 'as required' subcutaneous and other medication is prescribed according to an agreed protocol to manage symptoms.
- Ensure that the family has up to date emergency contact details for relevant staff and agencies. The GP practice, care team (e.g. community children's nursing services, consultants) and others (e.g. ambulance trust) including out of hours services, should be made aware that the child is now at their end of life phase.
- The family should be given the opportunity to discuss their plans for after death care including information about who to call, what needs to be done immediately and what can wait. Help the family to think in advance about support systems available after their child has died.
- Family members, including parents or carers, siblings, grandparents and others should have their needs considered at this stage.

This sheet gives you an overview of the main things to think about when caring for a child at the **time of their death.**

At such a significant time, it is essential to provide sensitive and meaningful support that meets the needs of each individual family. The following prompts should help trigger any considerations you need to make at this stage of caring for a child.

- Joint planning should take place with the family, which includes discussion about the preferred place of care and death for their child.
- Always refer to the child's end of life plan at the time of death, where one exists.
- You need to think about whether all the professionals involved are aware of the family's wishes for care at the time of death – if not, try and have a conversation as soon as possible to discuss this.
- The family's religious and cultural wishes should be considered at all times, and nothing should be assumed.
- Any wishes regarding organ donation or post-mortems need to be considered at this time.

- Think about whether there are any investigations, post-mortems or organ retrieval that need to be carried out after death.
- Plans should be in place regarding who will verify and certify the death.
- Ensure you are aware of all the relevant legal and regulatory issues around death when a child in your care dies. If you're not sure, consult a colleague or talk to the coroner beforehand.
- Families' wishes for the moments before and after death should be respected, and you should try to facilitate the presence of the people they want around them at these times.
- It is important that families know who to contact after the death of their child, and when they need to do it. You can help advise them of this, and maybe write a list so they don't forget.
- Make sure you know what support is available for the family following the death of their child and through their bereavement, so you can let them know at appropriate times.

Care after death:

Care of the child and family after death includes the consideration of many areas of care, support and regulatory requirements. The following prompts should help trigger any considerations you need to make at this stage of caring for a child.

- You should be aware of the policy and procedures locally and within your organisation when caring for a child after death.
- You should ensure the family are given appropriate information, resources and advice
- Families may require guidance and information around registration of their child's death and you should check that they have appropriate support with funeral planning.
- Sensitive and thoughtful communication is essential at all times when supporting families after their child has died.
- Consider all of the child and family's needs including their spiritual and cultural needs.
- Ensure that siblings are included and involved, and that grandparents are cared for and supported along with other family members, as well as friends that are important to the child and family.
- The bereavement needs of the whole family should be assessed and support provided to meet these needs.

Alongside the emotional and spiritual care of the family at the time of death, there are a number of practical aspects of care that need to be considered. The choice of where to provide care after death may include a combination of options including the hospital mortuary, the funeral directors, a cool room at home or a children's hospice. The following prompts should help you think about the various aspects of caring for a child's body after their death.

- You need to be aware of organisational and local policies in caring for a child after death.
- You should ask the family what their needs and wishes are and work with them at an appropriate pace – it is essential for parents to retain control and choice in the care of their child. Parents may wish to wash and dress their child. Siblings may also wish to be involved in any aspect of caring for their brother or sister.
- Families will need to be informed of any changes to their child's body and you should make them aware of likely changes.
- You should be aware of the correct policy and procedures for discontinuing controlled drugs, any IV or SC infusions and medication.
- Following verification of expected death it is acceptable, if parents agree to remove other medical equipment, cannulas, nasogastric tubes, gastrostomies and tracheostomies. You

should be prepared for any leakage and if in any doubt about these or other equipment, seek advice.

- You should be knowledgeable and informed about changes to the child's body and the best way to deal with this and to be up to date with new technologies in caring for a child after death.
- You should ensure continued care of the body, the eyes, mouth, skin and attend to any leakage or bleeding.
- Moving the child into the coffin can be a poignant moment – it needs careful planning and support from the funeral director. You should be aware of the needs and wishes of the family and whether they wish to be present at this time.
- It is essential that the importance of cooling the body whether this is at home, a hospice or at the funeral directors is recognised.
- You should seek continued support and regular supervision when caring for child at the end of life and after death.

Bereavement support

No one can anticipate quite how they will feel or react after the death of their child; most people describe a 'rollercoaster' of emotions, ranging from numbness to furious anger, profound sadness to sometimes a certain relief. Seemingly irrational behaviour and reactions are also very common, as well as overwhelming physical exhaustion or 'manic' energy and compulsive activity. Families, communities and cultures may grieve and mourn differently, and rituals can often help to bring healing and closure. It's worth keeping in mind that while there are similarities, children do not grieve in the same way as adults. The following prompts should help you when thinking about how you will support a family after the death of their child.

- Parents should feel in control of events before and after death and should be able to follow their own choices and wishes. Help them to avoid being rushed into decisions or activities that they don't feel ready for.
- Reassure family members that whatever they feel or do will probably be 'normal', and it is important to try and respect their own instincts and those of others also grieving, about what is right for them as individuals.
- Recognise that every child and family's experience is different and they will need different levels and aspects of care during their bereavement e.g. some will need immediate support, whereas others may need support years later.
- Find out about the many sources of help and support available, both locally and nationally so that you can help to signpost families to the services that are most appropriate for them.
- Bereavement support should be offered based on assessed need.
- The bereavement needs of siblings, grandparents and the extended family should be recognised and support offered.
- Staff support is essential. Debriefing, on-going staff support and supervision should be readily available. You may like to speak with the PC support team?

APPENDIX 7

DISCHARGE CHECKLIST FOR SERVICE DELIVERY WHERE END OF LIFE CARE IS INDICATED IN THE COMMUNITY

Hospital no:.....
 NHS no:.....
 Surname:.....
 Forename(s):.....
 Gender (M/F):.....
 D.O.B:.....

ACTIONS	COMMENTS (if needed)	PRINT NAME & DESIGNATION	DATE & SIGNATURE
<p>Identify team around the child & family following an MDT meeting with all key professionals</p> <p>Hospital Medical Lead: Hospital care Coordinator Community Medical Lead Community Care Coordinator TYA Input / Referral Core Team / services within the community</p>			
<p>Identify Place of care</p> <p>Hospital / Home / Hospice / Other / Combination</p>			
<p>Identify level of care needed if discharge home to be facilitated</p> <p>Mon – Fri within hours 7 Day week (Daily visits) 24/7 - (round the clock provision) Out of Hours Arrangements: If at Home medical review provided by: Other</p>			
<p>Identify if this is feasible, appropriate, safe and sustainable</p> <p>Yes No</p>			
<p>Consider Referral to Additional agencies:</p> <p>CHSW or other hospice closer to home: Jessie May Trust:</p> <p>Lifetime: Rainbows:</p>			

<p>For TYA consider: Adult palliative care teams: St Peter's Hospice: District Nurses:</p>			
<p>Identify if Specialist commissioned Package required</p> <p>If Yes - Discuss with Senior nursing staff at BRHC who can take action forward with the palliative care support team</p>			
<p>Identify local Commissioning responsibility</p> <p>BNSSG / Regional</p>			
<p>Identify presence of core documentation</p> <p>Does they child have a Wishes document (ACP)? Date last updated Does they child have an Emergency Care plan? Date last updated Does they child have a DNACPR? Review date Does the child have a symptom management plan and medication prescribed? Does the family have a 'Contact sheet'</p>			
<p>Identify Support needed, current plans in place</p> <p>Medical Nursing Dietetic Department Occupational Therapist Physiotherapy Assessments Family Support Spiritual Support Social Work</p>			
<p>Identify level of support GP is able to offer and how this will be delivered</p> <p>GP Informed of discharge</p>			
<p>Identify how core professional team will communicate</p> <p>Email – (will need nhs.net email address) Face to Face Out of Hours contact arrangements Communication with family led by</p>			

<p>Identify Equipment needed and provider</p> <p>Bed Hoist Commode Urine Bottles Bed pans Disposables Oxygen Other</p>			
<p>Identify and consider complex medical factors</p> <p>Blood product administration and requirement: Hospital / Hospice / Home</p> <p>If platelet dependent, Challenge clinical requirement before discharge - if daily, test if every other day is achievable</p> <p>TPN</p> <p>Other</p>			
<p>Identify Medication and administration practicalities</p> <p>Medication Lead Prescriber within BRCH:</p> <p>Primary Care & Tertiary Centre</p> <p>Medication source- Community Pharmacy Hospital Pharmacy</p> <p>Lead time / Availability of Medication</p> <p>Syringe Driver and ancillary equipment sourced from:</p> <p>Escalation Plan in place re Medication</p> <p>Consider Lead Times for arranging equipment, complex medication, TPN (can take up to 2 weeks)</p>			
<p>Identify how the child will get home or to place of care</p> <p>Transport: Ambulance Transfer Car</p>			

Identify Post Death Considerations

Verification of death by

Certification of Death by

Will there be a PM?

Place of Care of the body

Name of Undertaker

CDR paper work by whom?

On-going Support for:

Family

School

Other service providers in community