

Clinical Guideline

PLANNING PALLIATIVE & END-OF-LIFE CARE FOR CARDIAC PATIENTS ACROSS THE CARDIAC NETWORK TOOLKIT

SETTING	Congenital Heart Disease Network for South Wales and South West
FOR STAFF	All cardiologists, surgeons, junior doctors, nursing staff and allied health care professionals
PATIENTS	All Congenital Heart Disease patients within the CHD Network regardless of location of care

Guidance

EXECUTIVE SUMMARY:

Introduction

This toolkit has been written in response to the Congenital Heart Disease (CHD) Standards and Specifications, published by NHS England in 2016. The standards consider the lifespan care of patients born with CHD and seek to ensure high quality, equitable and consistent care for all patients across the Network in South Wales and the South West. The standards are divided into several sections and section L covers palliative care. The standards cover the Level 1 specialist surgical centre (Bristol), Level 2 specialist cardiology centre (Cardiff) and the many level 3 centres across the network.

Background

This toolkit is a guide to principles of symptom support or palliative care.

The CHD standards state (page 14) that the appropriate cardiac service will:

- provide symptom support and control where appropriate for patients with untreatable or degenerative conditions
- monitor patient response on a regular basis
- use nationally approved palliative medicine pathways to plan care
- agree a named lead doctor and nurse for any patient entering a symptom support or palliative care pathway who will ensure the patient and their partner/family/carers are supported up to and beyond death
- produce a written, agreed, individual, end-of-life care plan
- discuss the potential for tissues and organ donation
- liaise actively with NHS and non-NHS professionals to ensure access to appropriate palliative or end-of-life services and make the patient and their partner/family/carers aware of these
- ensure that when a death occurs in hospital, the processes that follow a death including legal aspects are explained verbally, at the family's pace and backed up with written information
- maintain, where possible, continuity of care, the clinical team working closely with the bereavement team
- offer help with the registration of the death, transport of the body and signposting of funeral services
- generate and publish evidence of effective symptom support, palliative or end-of-life care for patients/carers

The Key Messages

There are a number of key messages which are important in the care of the patient with congenital heart disease, whatever their age, and also to their families. These are:

- Palliative care should start at diagnosis of a life-limiting condition and not be confined to the very end of life
- Early palliative care improves quality of life by focusing on living well with deteriorating health
- All health professionals need to incorporate holistic palliative care into their practice
- An understanding of typical, multidimensional illness trajectories can help health professionals know what to offer
- Palliative care is about a philosophy of care and not a location of care
- Early palliative care improves quality of life by focusing on living well with deteriorating health
- All health professionals need to incorporate holistic palliative care into their practice

Contents

The network palliative care toolkit contains advice and guidelines for introducing palliative care, considering parallel planning and planning for the end of life.

The check list and ten appendices are a guide to setting up care before, during and after the end of life which should be as near to the patients home as possible.

The toolkit has been created as an over-arching guide for all centres in the network: each centre is advised to map local palliative and end of life care services accessible to patients in their local area.

Resources

'Help the Hospice UK' has a list of all hospices and community services, and it is a good place to start searching for local services. The details are at the end of the toolkit. There are number of helpful websites and resources throughout the document.

Contents of the detailed Palliative Care Toolkit:

Key Messages and overview to the pathway

Introduction to what is palliative care	4
Strategies for introducing palliative care	5
The surprise questions	9
'Parallel Planning': A key concept in PPC	10
High level end of life care pathway	13
A simple framework	14

Appendix:

Appendix 1	16
Overarching Principles of the Care Pathway or Principles of good practice within the pathway?	
Appendix 2 Parallel Planning checklist	20

Family's preferred place of care:

Appendix 3 End of life care in hospital	21
Appendix 4 End of life care at home	23
Appendix 5 End of life care in local hospice	26
Appendix 6 Support for extubation in different locations: Hospital, Hospice & Home	29
Appendix 7 Symptom Control	30
Appendix 8 End-of-Life Prompts	32
Appendix 9 Discharge planning Checklist	35
Appendix 10 Local hospice directory South West and South Wales	39

Introduction:

Key Messages

Palliative care should **start at diagnosis** and not be confined to the very end of life.

Early palliative care improves quality of life by **focusing on living well** with deteriorating health.

All health professionals need to **incorporate holistic palliative** care into their practice.

An **understanding of typical, multidimensional illness trajectories** can help health professionals know what to offer and when.¹

Palliative care is about a **philosophy of care** and not a location of care.

Palliative care is **everyone's business** working with patients and families.

This 'toolkit' offers practical guidance to professionals caring for a patient with congenital heart disease who has been identified as requiring symptom support or 'palliative care', or who may be approaching the end of their life and likely to require palliative or end of life (EOL) care in the near future. EOL care may follow a period of palliative care or an acute illness.

As congenital heart disease is a long-term condition, reference to the patient will reflect this lifespan service. It will refer to a new born baby, child, young adult and adult as, the patient throughout the document.

This guidance is not a clinical decision-making tool, but an aid to planning timely care and to address the CHD (Congenital Heart Disease) Standards, for Palliative Care & Bereavement²

It is based on the 'framework document' written by Together for Short Lives (TfSL) 'A Core Care pathway for patients with life-limiting and life-threatening Conditions'³, and the NICE guidance and standards published in September 2017⁴. Regardless of age the good principles of palliative care cross the life span.

What is palliative care (PC)

Palliative care aims to optimise quality of life in the face of uncertainty. Palliative care is an active and total approach to the care of patients with life-limiting or life-threatening conditions that embraces the physical, emotional, social and spiritual elements through death and beyond (TfSL's 2013). 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 patients' with a life-limiting or life-threatening illness, often alongside active interventions and treatment. It is a philosophy of care that can be offered at home, in hospital or in a hospice setting.

¹ Murray et al BMJ March 2007 page 248

² <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf>

³ http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway_ONLINE_.pdf

⁴ <https://www.nice.org.uk/guidance/qs13/2017>

What is end of life care?

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

When should PC be introduced?

Evidence has shown that families with a relative with a life-limiting or life-threatening condition value on-going support from symptom support and palliative care professionals, including psychological and spiritual support along with symptom management, from the point of diagnosis. However, palliative care is often only considered by professional's right at the end of a patient's life. There are times during the patient's illness when 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 patient and family. A referral to symptom support and palliative care services can be made at any time from the diagnosis of a life-limiting or life-threatening illness.

Strategies for introducing early palliative care:

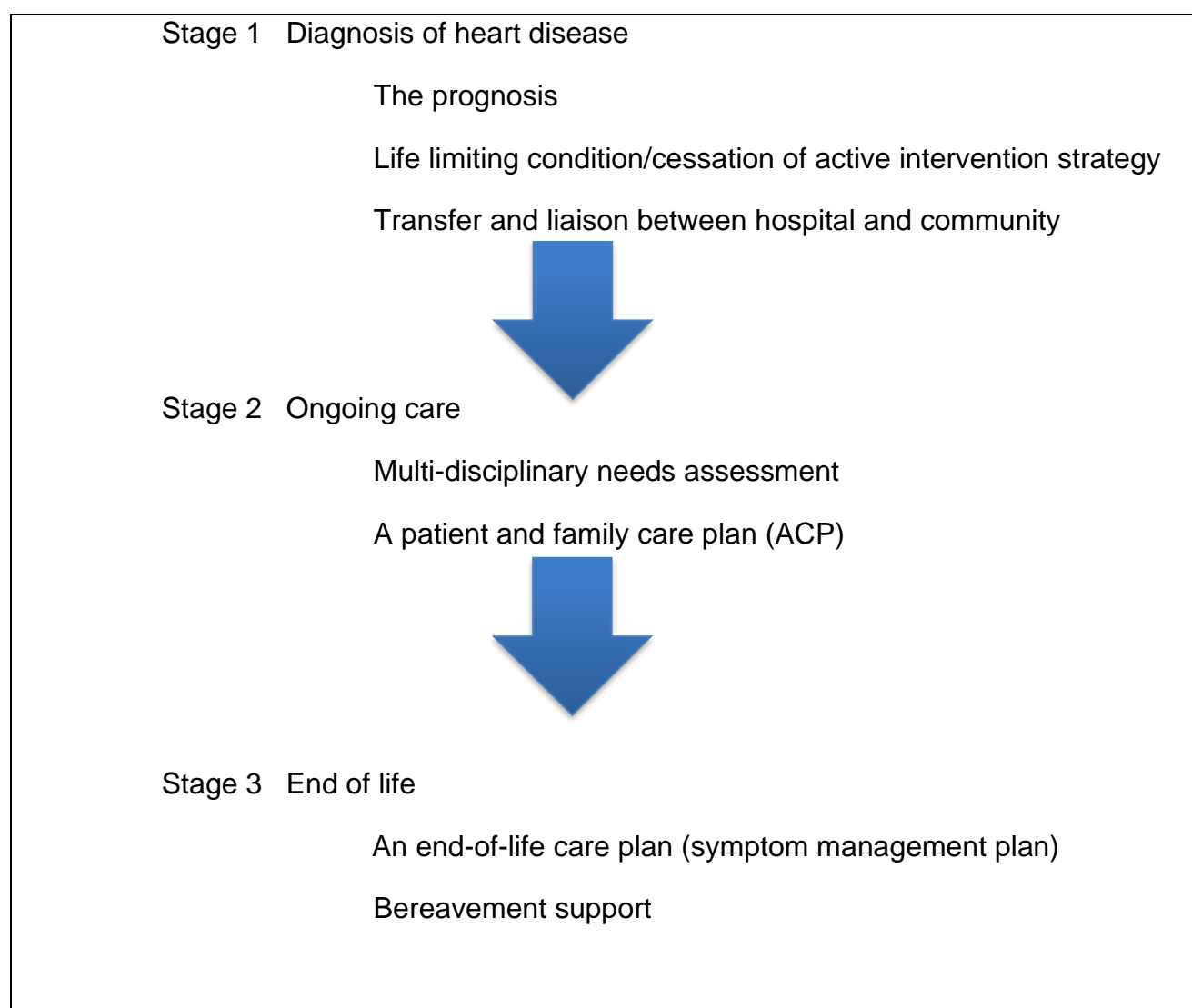
- Talk about why starting a conversation about what is happening is important:
 - *"When someone has this sort of health problem, we usually plan to have a talk together about what is happening and what help they might like to have now or in the future"*
 - *"The treatment has helped this time and I am glad you feel better, but I am worried you may get unwell again so can we talk about how we might plan for that?"*
- Ask who should be involved:
 - *"What would be the best way for us to talk about this? People often like us to involve a family member or close friend"*
- Talk about the main aims of the conversation:
 - *"We want to find out about the things that are important for you like what you'd like to be able to do now and in the future."*
 - *"We can talk about your current situation and what you want to know about your health problems. How have you been doing recently?"*
 - *"This is a good time for us to talk about any thoughts or worries you might have about the future".*
- Ask what the person knows, has been told, and thinks could happen to them
- Talk about what might happen linked to this understanding and awareness using short "chunks" with pauses and time for questions or reactions
- Ask what matters most so that good plans can be made
- Talk about getting advice from a colleague who can help you look after the patient well if the situation is more complicated or unstable. Explain that palliative care is all about what we can do to help people stay as well as possible¹ (Murray et al, 2007 p249)

A simple framework:

1. What do I need to have in place **before the patient dies** (This will vary depending on preferred location e.g., Ward, hospice, or home?)
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.

This **Pathway** sets out three key stages and considers what needs to be thought about at each stage. This is not prescriptive approach, but more 'have you thought about...?'



This translates into:

Stage 1 Diagnosis

- Diagnosis should be shared in face-to-face discussion in a quiet room by CHD team and palliative care team
- Written information must be used to support verbal communications

- Offer of emotional support
- Information conveyed should be easy to understand for the individual, including the presence of interpreters if needed. A written summary of information given may be helpful
- Patients and families should be treated together with openness and honesty at all times
- This is the time to introduce the concept of parallel planning – we hope for this but if this happens we may need to speak again

Liaison between hospital and community should include:

- Community notification as soon as possible i.e. Community nursing services and GP
- Community 'in reach' to the hospital, this may include Hospice services
- Lead community nurse identified as soon as possible
- Equipment and services supplied before discharge
- Transport needs arranged
- Training for hospital and community staff for family and carers may be required from the palliative care team
- Clear lines of communication established
- Home visit arranged by the community team within 3 days of transfer
- 24-hour contact number for the family to ring if necessary i.e. community team or local ward

Stage 2 Ongoing care

Multi-disciplinary needs assessment of the patient and family care plan by palliative care team and CHD team

- Family
 - Information and training needs
 - Financial review and access to benefits
 - Emotional needs
 - Physical needs, medical supplies
 - Sibling wellbeing, groups and short breaks
 - Quality of life, emotional and spiritual support
 - Interpreter if relevant
- Patient
 - Personal care needs and nursing support
 - Therapies
 - Focus on quality of life and emotional support
 - Information, education
 - Short breaks, social and leisure
 - Psychological support
 - Transition plan to adult services
 - Environment
 - Home needs (e.g., oxygen)
 - Equipment needs (e.g., monitors)
 - Transport needs
 - Education / employment

The multi-agency and multi-disciplinary care plan should include:

- Details of the professionals involved and identified lead professional duties
- Identified multi-agency and multi-disciplinary team
- Personal care including a privacy and dignity plan
- Dietary plan
- Emotional, spiritual, and psychological care plan for the patient and family
- An outline of what will be provided by each service

- Details of how to access services in and out of hours, hospital, and community
- Advance care plan including symptom management plan
- Emergency escalation plan
- Risk assessments, including moving and handling
- Agreement of care including parent, family, and staff responsibilities
- Information pertinent to the patient's needs
- Equipment information ~ Occupational Therapies and Physiotherapist may be able to help with this
- Local competency-based education plan for patient & family, and staff
- Play and education or employment plans
- Communication diary
- Local policies where appropriate, for example on washing hands
- Checklists for daily routine
- Understanding roles within the family and how they interact, and build on strengths identified
- The plan should address both acute and chronic changes in the patient's condition
- For some patients, it could be helpful to introduce specific local documentation around advance or emergency care planning during this stage of the pathway

Stage 3 End of Life

Care before death – recognition that end of life is approaching

This is often not easy, and it is common for a patient to have a period of stability after a period of decline. At this stage we can go back to the family and say 'do you remember we had this conversation about paralleling planning – may be now is the time to revisit that conversation and review what you wanted at the end of life?'

Parallel planning can help families prepare for the future and can make it feel acceptable to hope for the best but plan for the worst.

Transition to the end-of-life phase is clearer when there has been a decision to stop all life-prolonging treatment. In these situations, the family will be aware that their relative's death is inevitable, and ideally, they will receive care and support from professionals. They still need reassurance that pain and symptoms will be appropriately treated. Predicting prognosis in adult patients is particularly difficult.

Emotional support is vital at this time and is best provided by someone the family already knows and trusts. Planning together with the patient and family may be a positive experience. Although parents often want to shield the patient from the future, often the patient knows already and will introduce this into conversation.

The person who is working with the family needs to be compassionate, have a good relationship with the family, understand the issues they will face and be able to stay alongside them throughout.

Bereavement offer / support to families

Physical and psychological space need to be given to the family, siblings, children, and others directly involved. This needs to be both immediate and for the future months, sometimes even years.

The 'local bereavement pathway' and policy needs to be followed at this stage, in the Level 1, 2 or 3 centre. This should include a bereavement letter with an offer of a follow-up meeting in a place of the family's choice needs to be sent to them, often about 3 - 6 weeks after the patient's death. This meeting might be to answer any questions the family may have, provide support or

to update the family.

The CHD standards state the family will receive a call from the cardiac CNS as soon as the CNS has been informed of the death. The Cardiologist will write to the family and offer a visit to the hospital to discuss the death with the team. The CNS team may also follow up with a letter.

In paediatrics in England, they have the Child Death Review Process (CDR). This family meeting can be used to update the family on the CDR process or any other process that may have or taking place i.e., root cause analysis. Clear expectations need to be managed in terms of further information concerning review processes.

The surprise questions:

These have been designed to help health professionals think about the potential need for symptom support or palliative care in a timely manner thus avoiding complex and important decisions being made out of hours by professionals who do not know the patient 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 the answer is yes, this is an indication for advance care planning +/- referral to palliative care. As part of this it is important to establish what measures might be taken to improve the patient’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 palliative care there are four ‘surprise’ or ‘trigger’ questions:

The surprise questions....

1. Would you be surprised if this patient died as a result of this condition or problem?
2. Would you be surprised if this patient died in the next few months to years?
3. Would you be surprised if this patient died in the next five years?
4. Would you be surprised if this patient died in the next few days / weeks?

If your answer is **‘No I would not be surprised’** to any of these questions you should think about palliative care for this patient, young person, or adult.

Things that may help:

1. General indicators of decline - deterioration, increasing needs or choice for no further active care
2. Specific clinical indicators related to certain cardiac conditions - see tables below
3. **Gold Standard Framework** – this has a great deal of useful information that can be applied to cardiac patients. (The GSF is a practical systematic, evidence-based approach to optimizing care for all people nearing the end of life, given by generalist front-line care providers. GSF is all about quality care and quality improvement.)

4. Outcomes from this framework include:

- Earlier identification of patients declining or in the final year of life, leading to more proactive care for those with life limiting conditions
- More advance care planning discussions, more dying where they would choose, better listening to patients
- Providing care to meet their needs
- More dying in their preferred place of care
- Halving hospital admissions and hospital deaths
- Greater staff confidence, job satisfaction, boosted morale, staff retention 'culture change' more compassionate care
- Better carer and relative satisfaction with care

Parallel Planning: A key concept in PC

It is often hard to predict what the future holds for patients 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 patient may have a considerable time to live. During this time their quality of life should be maximised.

Parents and families experience the uncertainty that living with a patient requiring palliative care brings, and with support, value a 'parallel planning' approach. Discussions with the patient (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, Planning for your future care, or Preferred priorities of care). Some patients 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 patient'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 patients and family. These plans often include the development of an 'Advance Care Plan' (ACP) (Wishes document) (**See appendix 2 for a Parallel Planning Checklist**)

A process should be in place to prepare parents, partner and families for the patient's potential readmission to hospital or hospice. 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.

It is clear that not every patient will require a parallel pathway. However, it is also recognised that those who need it most, are those where death is least expected. Bereaved families often feel that opportunities to support the patient and the family were missed, "if only we had known..." Hence it is recommended that at the time of diagnosis of any **congenital heart disease**, thought is given as to whether a parallel planning pathway is required. It is not likely that this would be entertained when a 4-year-old patient is being admitted for uncomplicated balloon dilation of a pulmonary valve, for example. It would, however, be much more appropriate if a patient with Noonan syndrome with severe pulmonary stenosis and hypertrophic cardiomyopathy was undergoing an open heart pulmonary valvotomy and pulmonary artery patch insertion, for severe pulmonary stenosis or surgery to alleviate obstruction due to hypertrophic cardiomyopathy.

The concept of excess mortality/ high risk needs to be considered in both paediatric and adult patient groups. These discussions can be re-visited and updated during discussions around the time of transfer to adult services.

Any child has a small risk of sudden infant death syndrome, or death from sepsis. What is important for the pathway is to consider the excess mortality from the cardiac disease.

In Children

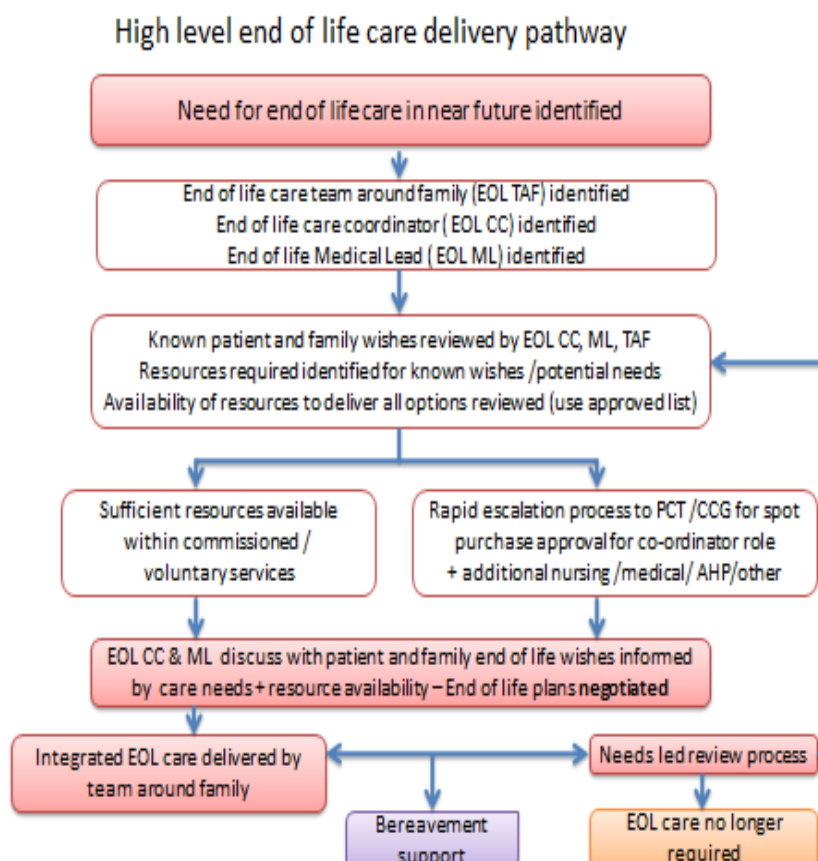
Category 1.	Uncomplicated disease, with expected excess mortality <1%.	<ul style="list-style-type: none"> • Diagnostic cardiac catheterisation • Interventional cardiac catheterisation ASD, PDA closure Balloon dilation pulmonary valve • Electrophysiology intervention for SVT • Pacemaker insertion • Medical Treatment of arrhythmia
Category 2.	Uncomplicated disease but undergoing surgical or catheter intervention. Mortality 1-5% in 5 years You would be surprised if they died	<ul style="list-style-type: none"> • Interventional cardiac catheterisation Balloon dilation of aortic valve Stent insertion aorta, branch pulmonary artery Electrophysiological intervention in infancy • Cardiac surgery after 1 year old
Category 3.	Complex heart disease or co-morbidities such that mortality is a real but unlikely possibility. Mortality 5-20% in 5 years A few patients will die of this each year.	<ul style="list-style-type: none"> • Complex Catheter intervention Stent insertion to Fallot outflow tract Radiofrequency perforation Pulmonary Valve Hybrid intervention • Cardiac surgery - Neonatal Arterial switch, TAPVC
Category 4.	Complex heart disease or co-morbidities. A high chance of mortality or serious complication. Mortality >50% in 5 years. You would not be surprised if they died.	<ul style="list-style-type: none"> • Cardiac surgery: Neonatal complex intervention Atrial isomerism Common arterial trunk Hypoplastic left heart Norwood

In adults

Category 1.	Uncomplicated disease, with expected excess mortality <1%.	<ul style="list-style-type: none"> • Diagnostic cardiac catheterisation • Interventional cardiac catheterisation ASD, PDA closure Balloon dilation pulmonary valve • Electrophysiology intervention for SVT • Pacemaker insertion
Category 2.	<p>Uncomplicated disease but undergoing elective surgical or catheter intervention.</p> <p>Mortality 1-5% in 5 years</p> <p>You would be surprised if they died.</p>	<ul style="list-style-type: none"> • Interventional cardiac catheterisation Stent insertion aorta, branch pulmonary artery stenting, balloon dilation of aortic valve • Redo cardiac surgery
Category 3.	<p>Complex heart disease or co-morbidities such that mortality is a real but unlikely possibility. Mortality 5-20% in 5 years</p> <p>A few patients will die of this each year.</p>	<ul style="list-style-type: none"> • Complex catheter intervention multiple redo or high risk cardiac surgery <p>High risk pregnancy (WHO Class III)</p> <p>Poor sub pulmonary ventricular function</p>
Category 4.	<p>Complex heart disease or co-morbidities.</p> <p>A high chance of mortality or serious complication.</p> <p>Mortality >50% in 5 years.</p> <p>You would not be surprised if they died.</p>	<p>Emergency high risk cardiac surgery</p> <ul style="list-style-type: none"> • Any intervention in pulmonary hypertension • High risk pregnancy (WHO Class IV) • Poor systemic ventricular function

High level end of life care pathway:

To aid the planning process locally for good EOL care this high-level map has been agreed as the approach that should be taken when starting to think about and plan a patient'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.



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 patient and family and confirmed by the lead consultant.

Identify the team around the patient and family (TAF). This should include the patient's lead CHD 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 patient and family to discuss their EOL choices.

Known patient and family wishes reviewed by EOL CC, ML & TAF: The team should review what they know about the patient and family wishes, asking the question 'does this patient have a Wishes Document/Advanced Care plan or patient Directive 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 patient'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 patient and family's preferred place of care as this will affect how care is planned. Options might include:

1. Ward ([see appendix](#))
2. Home ([see appendix](#))
3. Hospice ([see appendix](#))
4. Extubation in a different location ([see appendix](#))
5. Symptom control ([see appendix](#))
6. Discharge checklist ([see appendix](#))
7. Local developed Information Directory ([see appendix](#))

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 patient is re-admitted to hospital or a change in location becomes necessary out of hours.

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

- What do I need to have in place **before the patient dies** (This will vary depending on preferred location?)
- What do I need to have in place for **the time of death?**
- 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.

REFERENCES:

For adults with Learning Disabilities guidance on capacity can be found here: <http://www.gmc-uk.org/learningdisabilities/336.aspx>

Mental Capacity Act: making decisions: <https://www.gov.uk/government/collections/mental-capacity-act-making-decisions>

Murray et al, 'Palliative care from diagnosis to death', BMJ, 2017; 356:j878 doi: 10.1136/bmj.j878 (Published 27 February 2017)

The Gold Standards Framework: <http://www.goldstandardsframework.org.uk/home>

A Core Care Pathway for Patient's 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 Patient's Palliative Care Framework, 2011.

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

The verification of expected death in patienthood – guidance for patient'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/2779_end_of_life_planning_prompt_sheets_2012

Most of 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 Patient's Palliative Care WorkSpace on Connect under symptom management if you work within Bristol Royal Children's Hospital:

<http://workspaces/sites/teams8/ChildrensPalliativeCare/default.aspx>

The Wessex Palliative Care Handbook: a good practice guide | Health Education England

<https://www.hee.nhs.uk/sites/default/files/documents/Wessex%20palliative%20care%20handbook.pdf>

Perinatal Pathway for Babies with Palliative Care Needs: [Perinatal pathway for babies with palliative care needs](#)

APPENDIX 1

An A-Z of the overarching principles of the care pathway or principles of good practice within the pathway

There are a number of overarching themes which should be considered at every stage of the care pathway – from recognition that the patient may have a life-limiting condition, to the patient's death and ongoing bereavement support to the family including children.

A unique bereavement journey for every patient and family: Family life for everyone is affected when a patient is diagnosed with a life-limiting illness, and of course, when they die. Grief is individual to each person, experienced very differently. Choice is therefore vital. It is important to ask the family what they want to ensure the whole family focus is retained while ensuring a professional approach, underpinned by theory. All types of support should be available throughout the family's journey. Sometimes a professional approach, over-reliant on theories and ideas, can lead to inappropriate support for families. For example, support groups suit some, but not all. Couple support can be helpful because of the strain the parent's relationship is under when caring for a seriously ill or dying patient. If there are children, they may also require specialist support.

Ability to respond quickly and flexibly: Some patients will have a very short life expectancy and the normal planning meetings may not happen.

Advance Care Plan: Advance Care Planning (ACP) is a process of discussion between an individual and their care provider and often those close to them. The End-of-Life Care Strategy (Department of Health, 2008) clearly states that ACP and clarity about ceilings of treatment and resuscitation decisions are essential to quality care. This is important for all patients and families receiving end of life care. ACP may lead to patients and families making advance statements about wishes and preferences, preferred place of care, withdrawal of treatment and resuscitation status. For patients and families this will include decisions relating to care in the case of acute deterioration and may also address preferences for organ and tissue donation.

Bereavement medical lead or lead Consultant: this is the most appropriate consultant to continue to support the family following the death of a patient. The bereavement medical lead will offer follow up sessions to discuss any clinical issues with the family and ensure transition to local care, GPs/local clinicians, as appropriate.

This role might be undertaken by the person that the family have had the most involvement with whilst the patient was alive, or it might be the consultant who was closest to the family at the time of death. Those involved in the patient's care should agree who this will be as early as possible.







Bereavement key worker: this will be the professional most suitable to support the family of a patient after death. The bereavement key worker will be the key contact for the family and for staff who are part of the "team around the family" (see below). They will have experience in managing and supporting the processes surrounding the death of a patient and be able to coordinate support for the family. They may be the key person offering emotional support and informational counselling unless this is to be provided by another member of the team around the family.

This approach will need to be different for adult bereavement care and a local offer should be described by the local team.

Best Interests: The overriding legal and ethical principle is that all treatment decisions must be taken in the patient's best interest. Best interest decision making is designed to determine the patient's best interests for particularly important decisions affecting them if they are unable to make decisions themselves. It should involve decision-makers with relevant areas of expertise and balance all relevant factors in order to assess the best option for the individual. It is a fundamental principle of the United Nations Convention on the Rights of the Patient.

Care for the team around the patient: Everyone who is called upon to support the patient and their wider family throughout this care pathway journey will at times, find this journey emotionally challenging. Every member of the team around the patient and family should receive support and an opportunity to feedback/ discuss what is happening. Professionals should also have access to ongoing support and supervision.

Categories of life-limiting and life-threatening conditions: We recognise that there are four broad groups of life-threatening and life-limiting conditions. Categorisation is not easy, and the examples used are not exclusive. Diagnosis is only part of the process; the spectrum of disease, severity of disease and subsequent complications as well as the needs of, and impact on the patient and family need to be considered. These **four categories** outline the four types of illness trajectory which will require patients' palliative care provision. The categorisation is important for the purpose of planning and needs assessment. The categories demonstrate the range of conditions patients have and show how patients may benefit from palliative care, or elements of palliative care during their journey. The need for palliative care should always be assessed on an individual basis. Patients from all four of these categories would benefit from some, if not all, elements of this pathway. Together for Short Lives has also developed this illustration which shows the various patterns of relationship between palliative care and treatments aimed at cure:

Relationship between palliative care and treatments aimed at cure or prolonging life	
	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.
	Highly technical invasive treatments may be used both to prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	No cure is possible and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.
Key:  curative  palliative	

Consent, confidentiality and capacity: Confidentiality, consent and capacity issues must be addressed throughout the care pathway. A number of resources are available to support professionals, including the Mental Capacity Act Tool Kit (BMA, 2008).

Communication: There should be an honest, open, and timely approach to all communication with parents, family and carers, who should be treated as equal partners in any discussions with the care team. It is crucial to remember the importance of talking to patients where possible, parents and the family, giving them choices and maintaining a flexible, 'can-do' attitude to support their choice. If they choose to allow their patient to die at home or at a local hospice, then the pathway below should be followed to support the patient's rapid discharge from hospital. At such times, it is vital that one practitioner is identified to take the lead, so they can act as the family's first point of contact for communication, and to ensure that information flows to all services.

Co-ordinated care: Patients and their families should receive coordinated care, where services work together to deliver integrated, patient-centred, life-long care to improve quality of life.

Decision-making about treatment options: We can all give patients the opportunity to plan for their future. There is much evidence that engaging patients in treatment decisions and supporting their efforts at self-care can lead to beneficial outcomes. Patients who are active participants in a shared decision-making process have a better knowledge of treatment options and more realistic perceptions of likely treatment effects. Patients with life-threatening conditions face frequent decisions about diagnostic tests and treatment. In any setting, treatment decisions should be driven by the patient goals for care. With the

patient's permission, families are often included in the discussions about goals for care and treatment options.

Diversity and cultural issues: Culturally appropriate care which respects diversity helps maintain the quality of family centred care for all. An understanding of specific cultural and religious practices around death, dying and bereavement assists in providing culturally appropriate palliative care, identifying, and supporting individual family needs and preferences and preventing assumptions that all people from the same culture or religion practice the same rituals or share the same beliefs.

Emotional and psychological support: This is needed throughout the patient and family's experience, from diagnosis, through end-of-life care and following the death of the patient. Families should be enabled to access support when they want to, rather than having their needs assessed at pre-set intervals. The specific needs of partners, siblings and children should be considered throughout this care pathway.

Key point of contact: Every family should have a named medical specialist who leads on and co-ordinates their care. (NICE 2016). If the patient leaves hospital, there are likely to be several agencies involved in their care. A key working principles approach should be in place where one agency takes a lead role. This lead would be a person that the family would get to know well and who would have local knowledge and expertise. Sometimes the key professionals will be a small group and the individuals involved may change depending on the patient's location, condition, progress, or care setting.

Mental Capacity Act: 'Mental capacity' means a person's ability to make their own choices and **decisions**. Under UK law, someone's capacity is judged according to the specific decision to be made, so a person may have sufficient capacity to make simple **decisions** but not more complicated ones. See ALSO Best Interest section, above. Disabilities guidance on capacity can be found in the Mental Capacity Act. 2005 see link in references below

Multiple admissions: Patient's with life-limiting or life-threatening conditions often experience multiple admissions to hospital. Professionals should prepare the family for this possibility and the potential for their patient being cared for in different environments, possibly in different hospitals under different care teams.

Parallel planning: A key principle in providing good palliative care is parallel planning. This is the process of planning for ongoing care alongside planning for end-of-life care. It takes account of the often-unpredictable course of life-limiting conditions and involves making multiple plans for care, and using the one that best fits the patient and family's circumstances at the time (NICE, 2016).

It is often hard to predict what the future holds for patient's requiring palliative care. For some, periods of relatively good health are associated with the potential for an unpredictable deterioration, which may lead to the patient's death. For others, a period of deterioration may be observed, yet the patient may have considerable time to live when the quality of their life should be maximised. Parents and family quickly experience the uncertainty that living with a patient requiring palliative care brings, and with support, value a 'parallel planning' approach. Discussions with the patient (where appropriate) and the family enable various options for care in response to a range of potential outcomes to be considered and written down in advance. Although patients may be assessed as deteriorating or approaching the end of

their life, it is sometimes the case that patients survive these episodes. Assessing prognosis in adults with congenital heart disease is difficult. Parallel planning for life while also planning for deterioration or death allows a patient's full potential to be achieved and primes the mobilisation of services and professionals where necessary. Planning for the future at times of great uncertainty can also be comforting for patients and families. These plans often include the development of an Advance Care Plan.

Siblings, children, and extended family: The specific needs of siblings should be considered throughout the care pathway. Dedicated support for siblings is essential for their emotional well-being. Siblings, grandparents and other relatives/carers, where appropriate, should be included in discussions about choices regarding quality-of-life issues.

It may be appropriate to refer to services which provide sibling or children's groups and activities. Schools are often in a position to support siblings and children through the use of dedicated and specialised

counsellors based within the school setting. Hospices may also be a source of support for children whose parents have died.

Social Care Support: Specific needs for social support should be discussed at each stage of the family journey, for example, parents and families should be signposted to information about benefits and in some cases maternity and paternity rights.

Spiritual support: Every patient and family should receive spiritual support to meet their individual needs. This should begin at diagnosis and continue throughout the patient's lifetime, death and during bereavement.

Support for families: Providing details of sources of support at the earliest possible stage is beneficial to families who often feel a sense of isolation in these early days following the starkness of a diagnosis. Each unit should have information about national & local support groups for parents.

It is important to remember that families are all different in the way that they find support. Mutual help such as support groups suit some, but not all. For some families, couple support can help them to discuss the strain on their relationship that can come from caring for patient who may die. Other families, such as those where the parents are very young or where there is a lone parent may need extra support. There should be an individual assessment of what will be beneficial to individual families and signposting to what is appropriate.

Team around the patient and family (TAF): This should include the patient's lead CHD consultant (Medical Lead), lead nurse (Key Worker) 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 patient and family to discuss their EOL choices.

Uncertainty and losses: Families often experience repeated uncertainty and losses: first the loss of the 'normal' patient, followed by the anticipated loss of a patient for whom death is expected. At times, the patient may defy medical expectations and survive episodes of life-threatening deterioration, only for the family to face their death in the future. Some families may also face multiple losses with more than one patient having the same medical condition. Often the only honest answer to a family's questions about how long the patient will live is simply that you don't know.

24-hour support at home: If a patient is discharged home they should have access to flexible support, and be in the care of their GP or a community clinician who should have access to 24-hour telephone support from a multi-disciplinary patient's cardiac & palliative care teams. They may also need access to care from community patient's nurses at any time (day and night). In the case of adults, the GP, district nurses and community palliative care must be involved in the patients, treatment plan and prognosis.

APPENDIX 2

Parallel planning CHECKLIST

Item	Answer	Name and Date
Has parallel planning been discussed (Yes/No)		
Category of life threatened status (1,2,3,4)		
Stage 1 of pathway		
<ul style="list-style-type: none"> • Diagnosis given? 		
<ul style="list-style-type: none"> • Prognosis given? 		
<ul style="list-style-type: none"> • Liaison with community teams i.e., Nursing & GP? 		
Stage 2 of pathway		
<ul style="list-style-type: none"> • Multidisciplinary needs assessment performed? 		
<ul style="list-style-type: none"> • Multidisciplinary Advanced Care Plan constructed and filed in notes? 		
Stage 3 of pathway		
<ul style="list-style-type: none"> • End of life discussed? 		
<ul style="list-style-type: none"> • Symptom management plan constructed and filed in notes? 		
<ul style="list-style-type: none"> • Care after death discussed and document? 		
<ul style="list-style-type: none"> • Bereavement support plan in place? Who are the link Medical and Nursing leads? 		

APPENDIX 3

End of Life Care in Hospital

To be considered before the patient dies:

- Lead clinician, nurse, patient and family discuss and agree end of life care plan & wishes (You may like to involve the local palliative care team in these discussions).
- Review or update the Advanced Care Plan or Personal Resuscitation Plan – whichever seems more appropriate.
- Establish preference for place of care within hospital. The environment should be prepared to meet patients 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 patient 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 patient.
- 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 patient and family.
- Establish the patient and family's views on organ and tissue donation and post mortem examination if appropriate. (**See note at the end of this section**)
- The family should be informed of other support services available within the hospital. For example, this may include Chaplaincy service or a patient support service.
- Ensure GP and relevant community staff are informed and updated as appropriate

Planning for the patient'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 patient's speciality Consultant in advance of the death to agree the precise form of wording on the medical certificate cause of death (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 patient after death, e.g., do they want to be involved in washing the patient?

- Establish where the family want their family member to be after death. (For example, in Bristol the options for children include The Rainbow room at BRCH and in some cases the local hospice may take a child if they are known to the hospice, their home or the undertakers,' or, if the family is already known to the hospice team, the 'Starborn' room at Charlton Farm patient's' hospice or Ty Hafan). Please follow local policy and inform your local Clinical Site Team of any plans that have been made.
- Adults may be cared for in a side room and the family able to spend time with them there.
- Start to compile a list of professionals to be informed of the patient's death. It may be helpful to involve the family in this process. Key professionals may include hospital-based doctors, GP, community paediatrician/clinician, local nursing teams who have known the patient, midwife, health visitor, allied health professionals.
- Establish who will provide bereavement support for the family?

What needs to happen after the patient has died?

- Start and complete the local post death check list (Medical & Nursing)
- Complete the Medical Certificate of Cause of Death and give to family. You may wish to agree the precise wording of this with the patient's speciality Consultant.
- If the patient is a child and died in England inform the local Child Death Overview Panel office of the patient's death (In Bristol it is 0117 342 5151 and start the Child Death Review (CDR) paperwork and arrange the 'local' CDR meeting In Wales follow the PRUDIC process.
- Inform involved professionals of the patient's death in community and hospital.
- Ensure that support continues for the family into Bereavement and that they are allocated a Key Worker and Medical Lead for their bereavement care.

The cardiac clinical nurse specialist team will also contact and support the family as soon as they have been informed of the death i.e. on Monday morning if the death was over a weekend. A letter to the family of an adult patient may be sent by the adult CNS team.

Discussing the post - mortem with the family: The way in which a post-mortem examination is discussed with the family is extremely important and should be documented clearly in the clinical notes by the medical team. They should be given:

1. Honest, clear, objective information
2. The opportunity to talk to someone of whom they feel able to ask questions
3. Reasonable time to reach decisions (for example about the retention or donation of tissue)
4. Privacy for discussion between family members, if applicable; and
5. Emotional or psychological support if they need and want it
6. For hospital (post-mortem) examinations, relatives should have the opportunity to change their minds, within an agreed time limit

The Human Tissue Authority (HTA) code of practice 3 – Post-mortem examination (September 2009)

APPENDIX 4

End of Life Care at Home

It is often the wish of families and patients 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 patients 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, end of life care co-ordinator, patient 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 local services as appropriate.
- If the patient 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 (this may include the GP if they can attend) to plan the care required by patient and 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 patient’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, so frequent review of the patient and family is imperative. A plan should be made that identifies which professionals will visit the patient 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 patient in case the patient 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 the patient and family’s needs and escalate to Clinical Commissioning Groups locally for ‘spot purchase.’
- Lead clinician & EOL Care Coordinator 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 it.
- 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 Care Coordinator 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 patient 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 patient 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 Care Coordinator to inform GP and community staff of proposed discharge prior to discharge from hospital.
- Make sure all the key multi-agency teams 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 patient is being discharged from Hospital to Patient's home for End-of-Life Care in the Community?

- A clear referral to community
- Invitation to regular multi-disciplinary / discharge 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
- Any equipment that may be needed should be identified and ordered, ready to be in place for home visits to commence by the local nursing team
- 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 5

End of Life Care in your Local Hospice

- Lead clinician makes referral to hospice, shares care and management plan, and agrees suitable time for an MDT and date for transfer.
- Lead clinician and team around the patient discuss and agree end of life care and symptom management plan with patient, 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 patient.
- Transport and escort arranged if required.
- Inform GP, relevant community staff and Site Team of transfer.

Information required before discharge from hospital to local hospice for end-of-life care

Hospices provide respite and end of life and bereavement care for patients 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 relevant head of care or medical director when arranging the transfer of a patient.

The following information will be required to support the patient 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 patient's current drug chart
3. Plans for administration of blood products if appropriate.
4. Current situation and future plans re feeding – including route of nutrition and the patient 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 re-sited 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, and 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 patient.

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 patient is likely to require analgesia or sedation en route to the hospice.
3. Telephone contact should be made with the hospice prior to the patient 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 patient should have a resuscitation plan that has been discussed with the family. If the patient is for resuscitation in the event of collapse, the family should be aware of the potential limitations of this in the hospice setting. (e.g., Basic life support would be instituted and a 999-ambulance called.)
3. In some situations, patients 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.

Patient & family

1. Information about the family:
 - a. Names of key family members (including parents, step parents, siblings, children, partner 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 of paediatric patients?
3. Information about additional social needs – does the family have a social worker? Have there been any safeguarding concerns? Learning disability team support?

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 patient'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 patient'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 regional hospitals)
 - f. Local Community nursing teams
 - g. Other health professionals – Physiotherapist, dietician, psychologist etc. Learning disability team member.

Plans for care after death

1. Have the patient and 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 patient's lead clinician to obtain the family's consent for the post mortem examination, if required, before transfer to Hospice.
3. Outcome of any discussions about care of the patient around the time of death, these may or may not be according to religious or cultural rituals.
4. Where does the family want their patient to be cared for after death? (E.g., at the hospice, at home or at the funeral directors?)

APPENDIX 6

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

If you are thinking about 'extubating' a patient 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 patient 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 The extubation care pathway 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 Patient Health have published guidance on withdrawing treatment in patient's (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 patient' which may be helpful to give to parents.

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 patient's services in case of the patient's on-going survival (whilst acknowledging realistically the relative doubtfulness of this).

Such **Parallel Planning** for life whilst also planning for death allows a patient'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 patient requires subsequent readmission to hospital.

APPENDIX 7

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 patient and family and not to alter the duration of the patient'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, and symptom management in the context of the patient'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 addressed as well.

All decisions should be patient-centred, and care should be delivered in partnership with the patient and family. This involves skilled and sensitive communication, which empowers the patient 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 plan or flowchart can sometimes be helpful to guide professionals and families regarding likely symptoms and provide clear advice on the management of such symptoms.

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
- Oedema, poor peripheral circulation, hypoxia
- 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, 2017.
<https://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/>

The Association for Paediatric Palliative Medicine (APPM) formulary can be found here: [APPM Master Formulary 4th Edition 2020](#)

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

The Wessex Palliative Care Handbook | Health Education England
[The 'Wessex Palliative Care Handbook: a good practice guide'](#)

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

(2.7 Symptom management planning) page 21.

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.

SYMPTOM MANAGEMENT TOOLS:

Dr Back Palliative Medicine Handbook

<http://book.pallcare.info>

The Wessex Palliative Care Handbook | Health Education England

The '**Wessex Palliative Care** Handbook: a good practice guide'

Basic Symptom Control in Paediatric Palliative Care, Edition 9.5, 2016

http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download

The Association of Paediatric Palliative Medicine Master Formulary 2020

<https://www.togetherforshortlives.org.uk/resource/appm-master-formulary-2020-5th-edition/>

Paediatric guidance:

<http://paed.pallcare.info/>

APPENDIX 8

End-of-Life Prompts

This appendix gives you an overview of the main things to think about when working with a patient 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 patient (Care before death)

- The patient's needs should be assessed, and a plan of care should be discussed and developed with the patient and their family. The patient 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 patient, siblings and parents or partner and children, in a way that is appropriate for their age and understanding.
- The patient'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 are prescribed according to an agreed local 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 patient's nursing services, consultants) and others (e.g. ambulance trust) including out of hours services, should be made aware that the patient 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 the patient 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 patient 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 patient.

- Joint planning should take place with the family, which includes discussion about the preferred place of care and death for their relative.
- Always refer to the patient'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. Be aware of the opt out organ donation policy.

- 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 patient 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 patient, 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 relative and through their bereavement, so you can let them know at appropriate times.

Care after death:

Care of the patient 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 patient.

- You should be aware of the policy and procedures locally and within your organisation when caring for a patient after death.
- You should ensure the family are given appropriate information, resources and advice
- Families may require guidance and information around registration of their patient'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 relative has died.
- Consider all of the patient and family's needs including their spiritual and cultural needs.
- In the case of children ensure that parents and 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 patient and family.
- In the case of the death of an adult patient ensure the partner, children, parents and close friends are involved.
- 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 patient's hospice. The following prompts should help you think about the various aspects of caring for a patient's body after their death.

- You need to be aware of organisational and local policies in caring for a patient 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 patient. 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.
- A partner of the patient or their children may wish to help wash their parent.
- Families will need to be informed of any changes to their patient'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 relatives 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 patient's body and the best way to deal with this and to be up to date with new technologies in caring for a patient after death.
- You should ensure continued care of the body, the eyes, mouth, skin and attend to any leakage or bleeding.
- Moving the patient 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 patient 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 patient; 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 patient.

- 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 patient 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 parents, siblings, grandparents or children, 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 your local palliative care team or contact a Psychologist at the Level 1 or 2 Centre

APPENDIX 9

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

Child/ Young person/ Adult

Hospital no:.....

NHS no:.....

Surname:.....

Forename(s):.....

ACTIONS	COMMENTS (if needed)	PRINT NAME & DESIGNATION	DATE & SIGNATURE
Identify team around the patient & family following an MDT meeting with all key professionals Hospital Medical Lead Hospital care Coordinator Community Medical Lead Community Care Coordinator TYA Input / Referral Core Team / services within the community			
Identify Place of care Hospital / Home / Hospice / Other / Combination			
Identify level of care needed if discharge home to be facilitated 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			
Identify if this is feasible, appropriate, safe and sustainable Yes No			
Consider Referral to Additional agencies: CHSW or other hospice closer to home: Jessie May Trust: Lifetime:			

Rainbows: Adult palliative care teams: St Peter's Hospice: District Nurses:			
Identify if Specialist commissioned Package required If Yes - Discuss with Senior nursing staff at Level 1 or 2 centre who can take action forward with the palliative care support team			
Identify local Commissioning responsibility			
Identify presence of core documentation Does the patient have an ACP or a Wishes document? Review date last updated? Does the patient have an Emergency Care plan? Review date last updated? Does the patient have a symptom management plan and medication prescribed? Does the family have a local 'Contact sheet' for in and out of hours?			
Identify Support needed, current plans in place Medical Nursing Dietetic Department Occupational Therapist Physiotherapy Assessments Learning disability team Family Support Spiritual Support Social Work			
Identify level of support GP is able to offer and how this will be delivered GP Informed of discharge			

Identify how core professional team will communicate Email – (will need nhs.net email address) Face to Face Out of Hours contact arrangements Communication with family led by			
Identify equipment needed and provider Bed Hoist Commode Urine Bottles Bed pans Disposables Oxygen Other			
Identify and consider complex medical factors Blood product administration and requirement: Hospital / Hospice / Home If platelet dependent, Challenge clinical requirement before discharge - if daily, test if every other day is achievable TPN Other			
Identify Medication and administration practicalities Medication Lead Prescriber within Hospital: Primary Care & Tertiary Centre Medication source- Community Pharmacy Hospital Pharmacy Lead time / Availability of Medication Syringe Driver and ancillary equipment sourced from: Escalation Plan in place re Medication Consider Lead Times for arranging equipment, complex medication,			

TPN (can take up to 2 weeks)			
Identify how the patient will get home or to place of care Transport: Ambulance Transfer Car Other			
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			

APPENDIX 10

LOCAL SERVICE DIRECTORY

Please use this space to develop your own local services directory i.e., community nursing teams; local hospices; local palliative care support....

If you are looking for your local hospice you can look here: Help the Hospice UK has a list of all hospices and community services, and it is a good place to start. It is good practice to understand local referral routes. Here is a link to help their website:

<http://www.hospiceuk.org/about-hospice-care/find-a-hospice>

Wales: Please see this site for information on services in Wales:

<http://wales.pallcare.info/index.php>

REFERENCES	If you have referenced any <u>external</u> papers or websites, enter them here.
RELATED DOCUMENTS AND PAGES	Any <u>internal</u> documents or team pages that relate to this guidance from Connect or from the DMS should be included here, along with their links (either as hyperlinks or as links next to the title).
AUTHORISING BODY	Name of committee or group that authorised this document. THIS MUST BE COMPLETED IN ORDER FOR YOUR DOCUMENT TO BE ACCEPTED AND PLACED ON THE DMS.
SAFETY	If there are unusual or unexpected safety concerns (to staff or patients) which you would wish to draw users' attention to, add them here.
QUERIES AND CONTACT	This is for whomever might be best placed to answer a query, not necessarily the author of the document. A department telephone or bleep can be placed here.

Appendix 1 – Sign off process

Once your document has been written, it should go to the relevant group for approval. This might include the Steering Group for the relevant speciality, or the Governance Group for the relevant division, especially if the document covers many different specialities/departments.

If you are unsure of who your document should be signed off by, please contact Clinical.guidelines@uhbristol.nhs.uk where the team can advise you.

Once your document has been signed off, include the name of the authorising group in **Table A** above and send the document to Clinical.guidelines@uhbristol.nhs.uk for uploading. Please note: this can take up to **two weeks** to be completed.