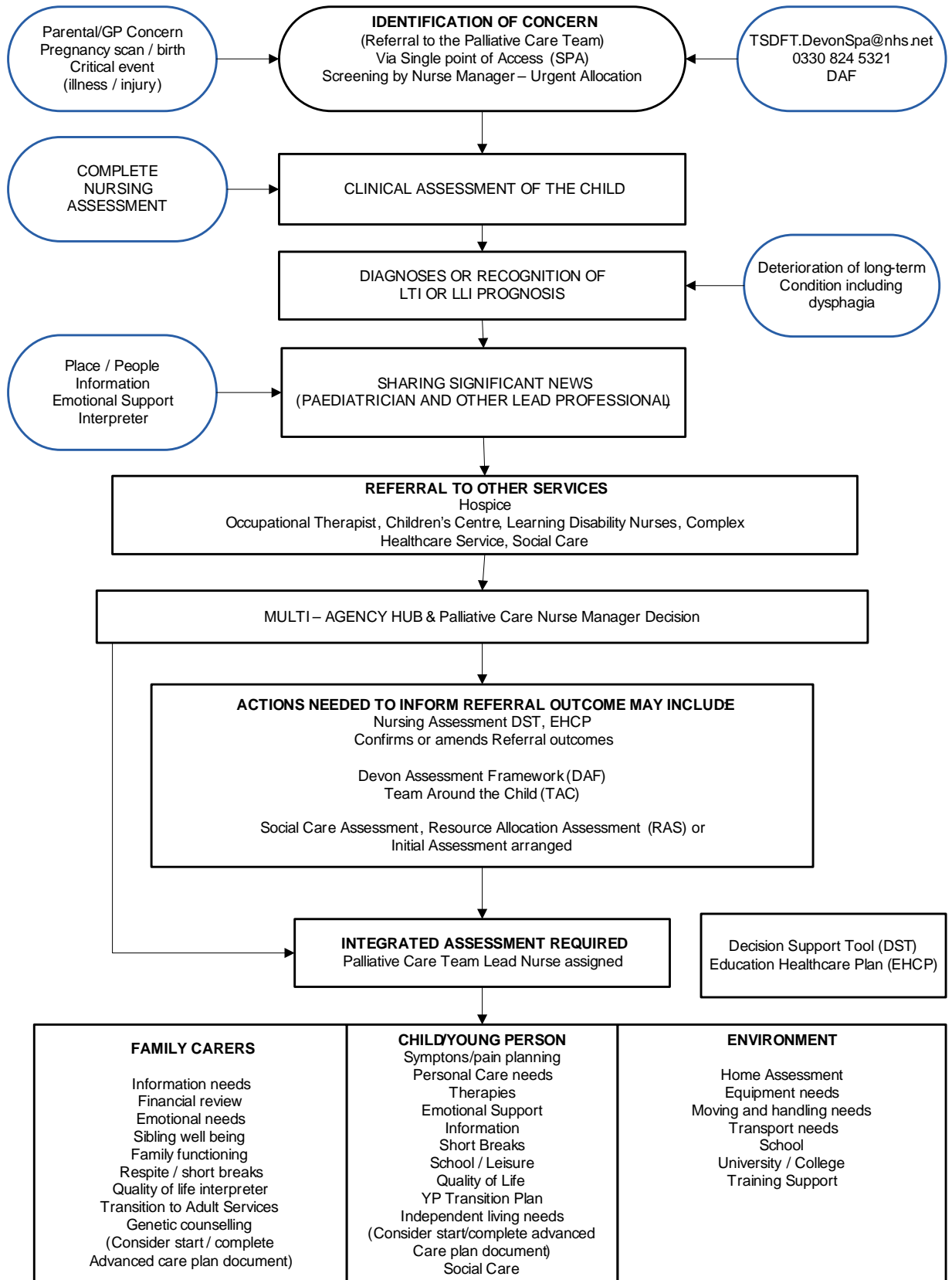


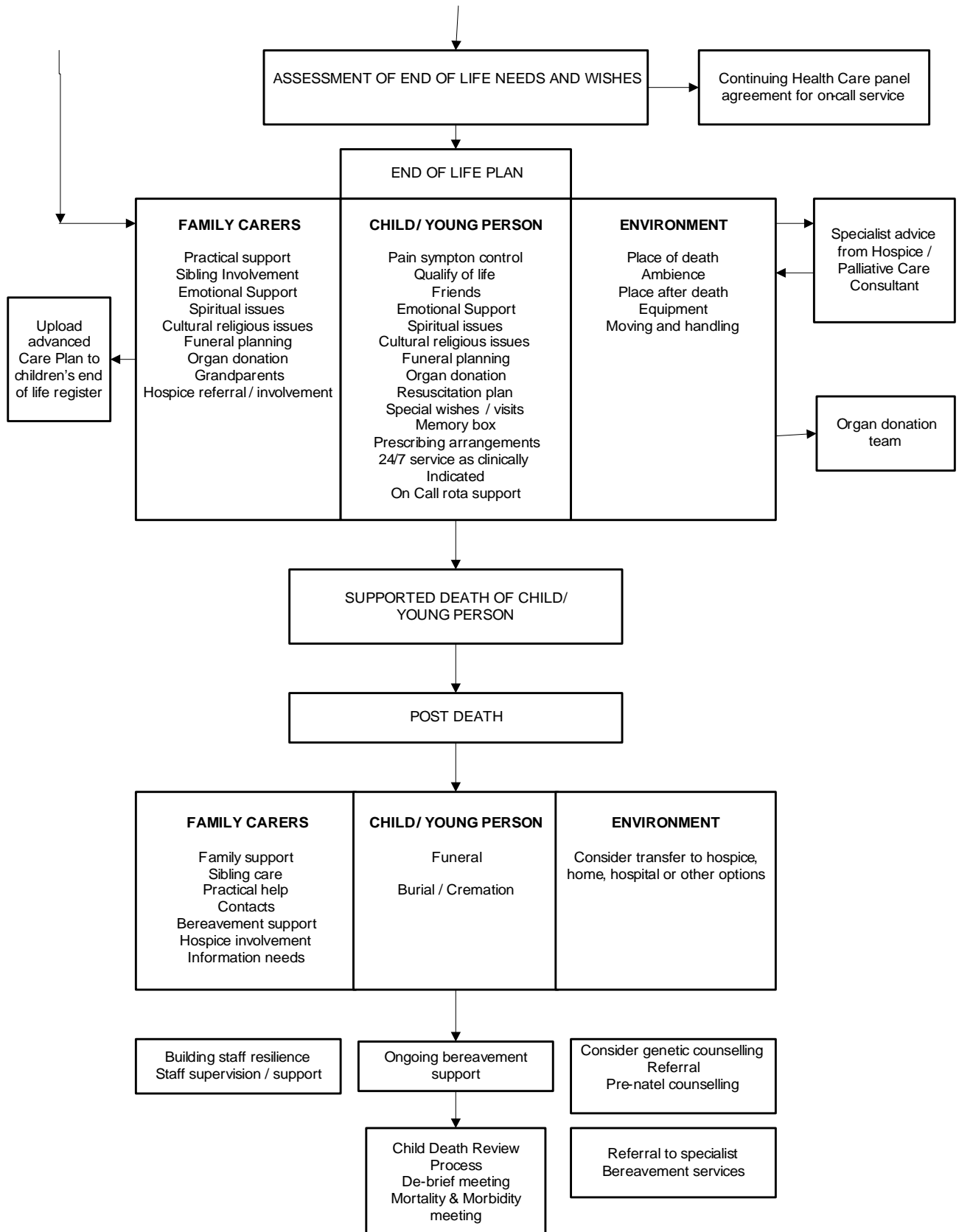
Document Type:		Standard Operating Procedure	
Reference Number : 2451	Version Number: 2	Next Review Date: 21 February 2023	
Title:	Devon Palliative Care Pathway		
Document Author:	Service Lead		
Applicability:	For Children And Family Health Devon Specialist Community Nurses And For Healthcare Professionals Employed By Children And Family Health Devon		

Please see flowchart(s) on Pages 2 and 3

Appendix 1 – [Treatment Escalation Plan \(TEP\) & Resuscitation Decision Record \(0-19th Birthday\)](#)

Appendix 2 – [Child and Family Wishes Advance Care Plan](#)





Appendix 1

Children and Young Peoples' Treatment

Treatment Escalation Plan (TEP) & Resuscitation Decision Record (0-19th Birthday)

[Documentation – Pages 5 - 7](#)

[Instructions for use – Page 8](#)

NHS	Space for bar code, if required
-----	---------------------------------

Children's and Young People Treatment Escalation Plan (TEP) & Resuscitation Decision Record (0-19th Birthday)

Surname:
First Name:
Hospital Number:
NHS Number
DOB:
GP:

Affix patient label here or write patient details

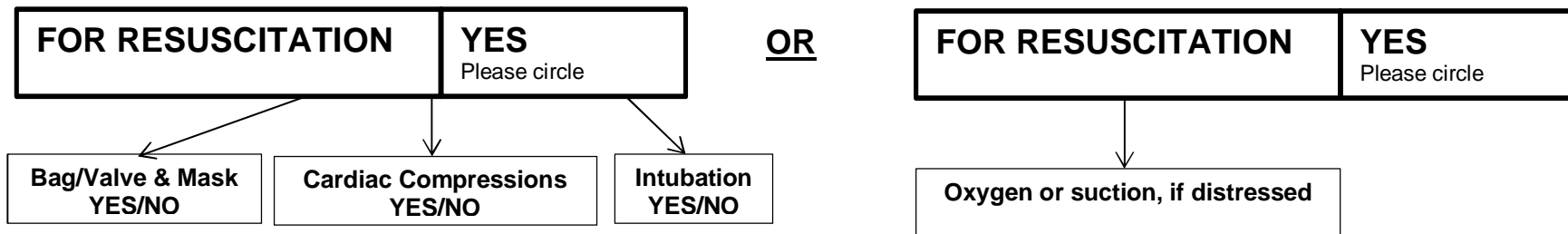
PART A: Advanced Care Planning

Life Expectancy
Would it be reasonable to expect that limiting event in the next 12 months this child/young person may have a life limiting event in the next 12 months

1. Discuss preferred priorities of care (Care Planning tool)
2. Update the Children and Young Peoples Palliative Care register If Yes
3. Consider treatment options & resuscitation status
4. Consider child/young person's/parent's wishes
5. Is referral to the Children's Hospice appropriate?

PART A: If the patient is currently very unwell or their condition deteriorates: <i>(please circle)</i>					
Is hospital admission appropriate	Yes	No	Are Intravenous fluids appropriate?	Yes	No
Is community care appropriate Yes No	Yes	No	Is artificial feeding appropriate?	Yes	No
Is children's Hospice admission appropriate Yes No	Yes	No	Is a critical care admission appropriate (HDU/PICU/ITU)	Yes	No
	Yes	No	Is non-invasive ventilation, on the ward, appropriate	Yes	No
Are oral antibiotics appropriate?	Yes	No	Are inotropes and vasopressors appropriate?	Yes	No

PART B: In the event of a cardiorespiratory arrest this patient is either:



(Continued overleaf)

Record reason why resuscitation would be appropriate/inappropriate, or not in the patient's best interest (be as specific as possible).
Include child/young person/parent's wishes specific Include child/young person/parent's wishes

Signature of consultant:.....

GMC NO:.....

Name(print) Date:.....Time:.....

Have the treatment decisions in Part A and/or Part B been discussed with:

1. Child/YP : Yes / No (*please circle*)

If no, please state reason:.....

2. Parent /Carer (holding Parental Responsibility and/or Legal Guardianship: Yes / No(*please circle*).

SignatureYoung Person/Parent/Guardian (*please circle*)Date:

All treatment decisions above should be reviewed as child/YP's clinical condition changes or as per child's/parent wishes

NEXT REVIEW DATE (must be completed):(minimum 12 monthly)

Who has been informed and hold copies of TEP decision (optional): *please tick*

Family	<input type="checkbox"/>	GP	<input type="checkbox"/>	Out of Hours GP	Emergency Dept.	<input type="checkbox"/>	Ambulance Service	<input type="checkbox"/>
Paediatrician	<input type="checkbox"/>	Community Nursing Team	<input type="checkbox"/>	Public Health Nurse (PHN,HV,SNS)	<input type="checkbox"/>			
Lead professional	<input type="checkbox"/>	Parent/Guardian	<input type="checkbox"/>	Child's Social Worker	<input type="checkbox"/>	Other (please state)	<input type="checkbox"/>	

PART C: Child/Young Persons/Carer wishes regarding organ donation have been discussed.

Yes/No (please circle)

(Discussion to be documented in child's medical notes)

If child/young person is being transferred to another healthcare setting the original of this document should travel with them with a photocopy filed in medical and community notes of the current provider

Instructions for use: This form should be completed legibly in black ball point ink

- Complete patient details or affix the patient's identification label to the top right hand corner
- Ensure all boxes are considered
- The date and time of writing the order should be entered
- This order will be regarded as '**INDEFINITE**' unless it is clearly cancelled
- The order should be reviewed whenever clinically appropriate or whenever the child/young person is transferred from one healthcare institution to another, admitted from home or discharged home

Life Expectancy

The challenge of identifying when a child or young person's life may be limited or when they are reaching the end of their lives, is clearly recognised. However it is acknowledged that we need to do more to improve the present situation for planning and supporting children, young people and their families, during this difficult period. The use of a "surprise question", where the health professional asks themselves "Would it be reasonable to expect that this child/YP may have a life limiting event in the next 12 months?" was felt by professionals to be the correct approach to elicit information that could usefully inform planning and so increase the quality of care offered.

When completing this form it is important that the healthcare professional has knowledge of:-

- any child/young person's advanced care planning (may be contained within "**Wishes document**", if used)
- their Trust's end of life procedures
- the children/young person's palliative care register (separate & distinct pages within the Adult End of Life register)

Part A & B Advanced Care Planning

Healthcare professional making the Treatment Escalation Plan (TEP) and resuscitation decision

The TEP and resuscitation decision should be made by the **most senior medical clinician** looking after the patient. If a more junior member of staff is completing the form it must be in consultation with their Registrar or Consultant and be countersigned by one of them.

TEP and resuscitation decision review

A fixed review date is not recommended. These decisions should be made and reviewed at every senior medical review or whenever clinical circumstances change, which may vary according to the child/young person's condition. However it **must** be subject to an annual review, where a child/YP has an on-going life limiting condition.

Summary of communication with child/young person/parents/carers

State clearly what was discussed and agreed and with whom (Child/young person/parent/carer). If this decision was not discussed with the child/young person state the reason

NOTE: It is good and recommended practice to discuss treatment decisions with both the parents/carer and child /young person but if their capacity to understand is limited due to their age or intellectual ability, this should be recorded.

If the young person is assessed as having the competency & capacity, they have the right take the responsibility for their own decision and sign the form themselves. It is important their right to confidentiality is respected. If the decision of the young person and their parents/guardian is different, the responsible medical practitioner should record in notes, and if necessary refer to local Trust policy and/or discuss with legal department.

State the names and relationships of parents/carers or other legal guardians with whom this decision has been discussed. More detailed description of such discussion should be recorded in the clinical notes where appropriate.

Members of multidisciplinary team

Ensure that the TEP decisions have been communicated to all relevant members of the healthcare team.

Communication across other healthcare settings

This form should accompany the patient on transfer. This document remains valid until reviewed/endorsed by the receiving healthcare professional. As part of the patient's discharge letter, the patient's GP should be informed of all Treatment Escalation Plan's/ resuscitation decisions.

If, following clinical review treatment decisions are changed:

- Clearly score through this form, then sign & date the change
- File copy at the back of the patient's notes
- Document the change of decision in the patient's notes

-
- Complete a new form and insert in the patient's notes

NOTE: Individual Trust's must have a clear process for version control of TEP and for informing other settings when changes occur.

Part C: Organ donation

Patient and family wishes regarding organ / tissue donation after death should be ascertained and documented. It is essential for staff to establish if the patient has previously expressed the wish to be a donor; and if the patients on the NHS Organ Donor register or carries a Donor Card. Please refer to your organisation's guidelines relating to organ donation.

Appendix 2

Child and Family Wishes Advance Care Plan

Advance care planning with families of children with life-limiting conditions is possible months or years before the end of life. Advance decisions evolve over time through the development of a trusting relationship and an ethos of shared decision making.*

This advance care plan can be used by **any member of the Healthcare Team** in co-ordination with colleagues, to record a family's preferences and requests.

These are difficult but necessary discussions and guidance is offered in the accompanying 'Child & family Wishes - Information for Health Professionals' and 'Child & Family Wishes – Information for Families' leaflet.

Name of child:

Date of birth:

NHS/patient ID number:

Date(s) plan discussed:

After discussion with the family, please ensure that a copy of the plan is included in all medical notes and a copy is given to the family, the child's GP & all other relevant services.

*Ref: Fraser J, Harris N, Beringer AJ, Prescott H & Finlay F (2010) Advanced care planning in children with life-limiting conditions – the Wishes document. Archives of Disease in Childhood 95:79-82

CHILD AND FAMILY WISHES

COORDINATION INFORMATION

Name of child:

Date of birth:

Name of parent(s):

Name and age of sibling(s):

Address:

Telephone No:

Diagnosis & background summary:

Lead Consultant:

Name:	
Post:	
Organisation:	
Tel No:	Email

Other professionals in the Team around the child: (this should include the care coordinator - the person who works closely with the family to plan, coordinate and communicate between different members of the team)

Name:	
Post:	
Organisation:	
Tel No:	Email

Name:	
Post:	
Organisation:	
Tel No:	Email

Name:	
Post:	
Organisation:	
Tel No:	Email

CHILD AND FAMILY WISHES

WISHES DURING LIFE

Child's wishes during life

Family's wishes during life

Other's wishes during life (e.g. school friends, siblings)

This page discussed by:

Child / Parent / Carer	
Professional (Name & Job Title)	
Date	
Updated on (new date)	

CHILD AND FAMILY WISHES

PLANS FOR WHEN CHILD BECOMES MORE UNWELL

Name:	Date of Birth

What may happen?

E.g. deteriorating mobility, feeding, cognitive function, worsening seizures.

Preferred place of care:

Preferred treatment options: (Indicate if not applicable or inappropriate)

Antibiotics - e.g. Oral / IV / 'Portacath'

Feeding - e.g. NG tube / gastrostomy

Respiratory Support - e.g. mask ventilation

Seizure Management Plan

If child deteriorates further and end of life phase is recognised, identify from within the team an 'end-of-life care coordinator' and medical lead to facilitate and implement end of life care pathway (refer to 'Information for Health Professionals' leaflet regarding these roles)

Inform Ambulance Service if DNA CPR has been agreed and child is going/at home.

This page discussed by:	
Child / Parent / Carer	
Professional (Name & Job Title)	
Date	
Updated on (new date)	

CHILD AND FAMILY WISHES

PLANS FOR CARE DURING AN ACUTE LIFE THREATENING EVENT

	YES	NO
Oxygen via face mask/nasal cannulae	<input type="checkbox"/>	<input type="checkbox"/>
Airway management using oral/ nasopharyngeal airway	<input type="checkbox"/>	<input type="checkbox"/>
Bag & mask ventilation	<input type="checkbox"/>	<input type="checkbox"/>
Endotracheal tube & ventilation	<input type="checkbox"/>	<input type="checkbox"/>
External cardiac compressions	<input type="checkbox"/>	<input type="checkbox"/>
Defibrillation & adrenaline	<input type="checkbox"/>	<input type="checkbox"/>
Advanced life support requiring PICU admission (Including inotropic drugs and advanced renal replacement therapy)	<input type="checkbox"/>	<input type="checkbox"/>

Please give further details, if required:

Other issues discussed:

If child deteriorates further and end of life phase is recognised, identify from within the team an 'end-of-life care coordinator' and medical lead to facilitate and implement end of life care pathway

Inform Ambulance Service if DNA CPR has been agreed and child is going/at home.

This page discussed by:	
Child / Parent / Carer	
Professional (Name & Job Title)	
Date	
Updated on (new date)	

CHILD AND FAMILY WISHES

WISHES FOR AFTER DEATH

Preferred place of care of child's body:

Funeral preferences

Spiritual & cultural wishes:

Other child & family wishes: e.g. what happens to possessions?

Organ & tissue donation:

This page discussed by:

Child / Parent / Carer

Professional (Name & Job Title)

Date

Updated on (new date)

CHILD AND FAMILY WISHES

Information for Health Professionals’ and **‘Information for Families**’ leaflets have been designed to support the use of the ‘Child & family Wishes: advance care plan’. These are available on request from;

Francis Edwards, Paediatric Palliative
Care Liaison Nurse,
07785 333014
francis.edwards@UH Bristol.nhs.uk

Antonia Beringer,
Senior Research Fellow, UWE Bristol
0117 328 8209
antonia.beringer@uwe.ac.uk

or for free download at the Together for Short Lives website

End of life care planning - useful resources:

1. Together for Short Lives (The Association for Children’s Palliative Care and Children’s Hospices UK www.togetherforshortlives.org.uk)
2. Child Bereavement Trust www.childbereavement.org.uk
3. Department of Health guidance relating to child death:
www.everychildmatters.gov.uk/socialcare/safeguarding/childdeathreview
Since April 1st 2008, there has been a statutory requirement to investigate **unexpected and unexplained** deaths of children. The website summarises these processes.
4. Child Bereavement Network www.childhoodbereavementnetwork.org.uk
5. CLIC-Sargent (Cancer and leukaemia in childhood) leaflets/booklets, including; ‘When there is no Longer a Cure’, ‘When our Child Has Died’, ‘Living Without your Child’, available at www.clicsargent.org.uk
6. Children’s cancer and leukaemia group (CCLG) leaflets, including; ‘Choices: When it seems there are none’, ‘Facing the Death of Your Child’, ‘Bereavement: Where to go for help’, available at www.cclg.org.uk

The Child & Family Wishes: advance care plan was developed by members of the Avon

Children’s Palliative Care Partnership Group and is freely available to support, and promote,

End of Life planning for children with life-limiting conditions.

We update the plan regularly and are always pleased to receive suggestions about how it can be improved. Please email these to antonia.beringer@uwe.ac.uk

Document Control Information

This is a controlled document and should not be altered in any way without the express permission of the author or their representative.

Please note this document is only valid from the date approved below, and checks should be made that it is the most up to date version available.

If printed, this document is only valid for the day of printing.

This guidance has been registered with the Trust. The interpretation and application of guidance will remain the responsibility of the individual clinician. If in doubt contact a senior colleague or expert. Caution is advised when using clinical guidance after the review date, or outside of the Trust.

Ref No:	2451		
Document title:	Devon Palliative Care Pathway		
Purpose of document:			
Date of issue:	21 February 2020	Next review date:	21 February 2023
Version:	2	Last review date:	November 2019
Author:	Service Lead		
Directorate:	Child Health		
Equality Impact:	The guidance contained in this document is intended to be inclusive for all patients within the clinical group specified, regardless of age, disability, gender, gender identity, sexual orientation, race and ethnicity & religion or belief		
Committee(s) approving the document:	Head of Service, Children with Additional Needs		
Date approved:	19 February 2020		
Links or overlaps with other policies:			

Have you identified any issues on the Rapid (E)quality Impact Assessment. If so please detail on Rapid (E)QIA form.	Yes <input type="checkbox"/>	
	Please select Yes No	
Does this document have implications regarding the Care Act? If yes please state:	<input type="checkbox"/>	<input type="checkbox"/>
Does this document have training implications? If yes please state:	<input type="checkbox"/>	<input type="checkbox"/>

Does this document have financial implications? <i>If yes please state:</i>	<input type="checkbox"/>	<input type="checkbox"/>
Is this document a direct replacement for another? <i>If yes please state which documents are being replaced:</i>	<input type="checkbox"/>	<input type="checkbox"/>

Document Amendment History

Date	Version no.	Amendment summary	Ratified by:
9 December 2019	1	New	Head of Services, Children with Additional Needs
21 February 2020	2	Revised (Appendices 1 and 2 added)	Head of Services, Children with Additional Needs

The Mental Capacity Act 2005

The Mental Capacity Act provides a statutory framework for people who lack capacity to make decisions for themselves, or who have capacity and want to make preparations for a time when they lack capacity in the future. It sets out who can take decisions, in which situations, and how they should go about this. It covers a wide range of decision making from health and welfare decisions to finance and property decisions

Enshrined in the Mental Capacity Act is the principle that people must be assumed to have capacity unless it is established that they do not. This is an important aspect of law that all health and social care practitioners must implement when proposing to undertake any act in connection with care and treatment that requires consent. In circumstances where there is an element of doubt about a person's ability to make a decision due to 'an impairment of or disturbance in the functioning of the mind or brain' the practitioner must implement the Mental Capacity Act.

The legal framework provided by the Mental Capacity Act 2005 is supported by a Code of Practice, which provides guidance and information about how the Act works in practice. The Code of Practice has statutory force which means that health and social care practitioners have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves.

“The Act is intended to assist and support people who may lack capacity and to discourage anyone who is involved in caring for someone who lacks capacity from being overly restrictive or controlling. It aims to balance an individual's right to make decisions for themselves with their right to be protected from harm if they lack the capacity to make decisions to protect themselves”. (3)

All Trust workers can access the Code of Practice, Mental Capacity Act 2005 Policy, Mental Capacity Act 2005 Practice Guidance, information booklets and all assessment, checklists and Independent Mental Capacity Advocate referral forms on iCare

http://icare/Operations/mental_capacity_act/Pages/default.aspx

Infection Control

All staff will have access to Infection Control Policies and comply with the standards within them in the work place. All staff will attend Infection Control Training annually as part of their mandatory training programme.

Rapid (E)quality Impact Assessment (EqIA) *(for use when writing policies)*

Policy Title (and number)		Version and Date	
Policy Author			
An (e)quality impact assessment is a process designed to ensure that policies do not discriminate or disadvantage people whilst advancing equality. Consider the nature and extent of the impact, not the number of people affected.			
Who may be affected by this document?			
Patients/ Service Users <input type="checkbox"/>		Staff <input type="checkbox"/>	Other, please state... <input type="checkbox"/>
Could the policy treat people from protected groups less favourably than the general population? PLEASE NOTE: Any 'Yes' answers may trigger a full EIA and must be referred to the equality leads below			
Age	Yes <input type="checkbox"/> No <input type="checkbox"/>	Gender Reassignment	Yes <input type="checkbox"/> No <input type="checkbox"/>
Race	Yes <input type="checkbox"/> No <input type="checkbox"/>	Disability	Yes <input type="checkbox"/> No <input type="checkbox"/>
Gender	Yes <input type="checkbox"/> No <input type="checkbox"/>	Pregnancy/Maternity	Yes <input type="checkbox"/> No <input type="checkbox"/>
Sexual Orientation			Yes <input type="checkbox"/> No <input type="checkbox"/>
Religion/Belief (non)			Yes <input type="checkbox"/> No <input type="checkbox"/>
Marriage/ Civil Partnership			Yes <input type="checkbox"/> No <input type="checkbox"/>
Is it likely that the policy could affect particular 'Inclusion Health' groups less favourably than the general population? (substance misuse; teenage mums; carers ¹ ; travellers ² ; homeless ³ ; convictions; social isolation ⁴ ; refugees)			Yes <input type="checkbox"/> No <input type="checkbox"/>
Please provide details for each protected group where you have indicated 'Yes'.			
VISION AND VALUES: Policies must aim to remove unintentional barriers and promote inclusion			
Is inclusive language ⁵ used throughout?			Yes <input type="checkbox"/> No <input type="checkbox"/> NA <input type="checkbox"/>
Are the services outlined in the policy fully accessible ⁶ ?			Yes <input type="checkbox"/> No <input type="checkbox"/> NA <input type="checkbox"/>
Does the policy encourage individualised and person-centred care?			Yes <input type="checkbox"/> No <input type="checkbox"/> NA <input type="checkbox"/>
Could there be an adverse impact on an individual's independence or autonomy ⁷ ?			Yes <input type="checkbox"/> No <input type="checkbox"/> NA <input type="checkbox"/>
EXTERNAL FACTORS			
Is the policy a result of national legislation which cannot be modified in any way?			Yes <input type="checkbox"/> No <input type="checkbox"/>
What is the reason for writing this policy? (Is it a result in a change of legislation/ national research?)			
Who was consulted when drafting this policy?			
Patients/ Service Users <input type="checkbox"/>		Trade Unions <input type="checkbox"/>	Protected Groups (including Trust Equality Groups) <input type="checkbox"/>
Staff <input type="checkbox"/>		General Public <input type="checkbox"/>	Other, please state... <input type="checkbox"/>
What were the recommendations/suggestions?			
Does this document require a service redesign or substantial amendments to an existing process? PLEASE NOTE: 'Yes' may trigger a full EIA, please refer to the equality leads below			Yes <input type="checkbox"/> No <input type="checkbox"/>
ACTION PLAN: Please list all actions identified to address any impacts			
Action	Person responsible	Completion date	
AUTHORISATION:			
By signing below, I confirm that the named person responsible above is aware of the actions assigned to them			
Name of person completing the form		Signature	
Validated by (line manager)		Signature	

Please contact the Equalities team for guidance:

For South Devon & Torbay CCG, please call 01803 652476 or email marisa.cockfield@nhs.net

For Torbay and South Devon NHS Trusts, please call 01803 656676 or email pf.d.sdhct@nhs.net

This form should be published with the policy and a signed copy sent to your relevant organisation

Consider any additional needs of carers/ parents/ advocates etc, in addition to the service user

² Travelers may not be registered with a GP - consider how they may access/ be aware of services available to them

³ Consider any provisions for those with no fixed abode, particularly relating to impact on discharge

⁴ Consider how someone will be aware of (or access) a service if socially or geographically isolated

⁵ Language must be relevant and appropriate, for example referring to partners, not husbands or wives

⁶ Consider both physical access to services and how information/ communication is available in an accessible format

⁷ Example: a telephone-based service may discriminate against people who are d/Deaf. Whilst someone may be able to act on their behalf, this does not promote independence or autonomy

Clinical and Non-Clinical Policies – Data Protection

Torbay and South Devon NHS Foundation Trust (TSDFT) has a commitment to ensure that all policies and procedures developed act in accordance with all relevant data protection regulations and guidance. This policy has been designed with the EU General Data Protection Regulation (GDPR) and Data Protection Act 2018 (DPA 18) in mind, and therefore provides the reader with assurance of effective information governance practice.

The UK data protection regime intends to strengthen and unify data protection for all persons; consequently, the rights of individuals have changed. It is assured that these rights have been considered throughout the development of this policy. Furthermore, data protection legislation requires that the Trust is open and transparent with its personal identifiable processing activities and this has a considerable effect on the way TSDFT holds, uses, and shares personal identifiable data.

Does this policy impact on how personal data is used, stored, shared or processed in your department? Yes No

If yes has been ticked above it is assured that you must complete a data mapping exercise and possibly a Data Protection Impact Assessment (DPIA). You can find more information on our [GDPR](#) page on ICON (intranet)

For more information:

- Contact the Data Access and Disclosure Office on dataprotection.tsdf@nhs.net,
- See TSDFT's [Data Protection & Access Policy](#),
- Visit our [Data Protection](#) site on the public internet.