Alder Hey Children's NHS
NHS Foundation Trust

C26 – CHILDREN'S ADVANCE CARE PLAN POLICY

Version:	2
Name of ratifying committee:	Clinical Quality Steering Group
Date ratified:	10/05/2016
Name of originator/author:	Lynda Brook, Palliative Care Consultant
Name of approval committee:	Resuscitation Committee
Date approved:	01/12/2014
Name of Executive Sponsor:	Medical Director
Key search words:	Advance Care Plan, Do not resuscitate, End of Life Care, Cardio Pulmonary Resuscitation, DNA-CPR, EOLC, Palliative
Date issued:	May 2016
Review date:	May 2019

Quick Reference Guide – Advance Care Plan Policy

This policy applies to all staff involved in the care of babies, children and young people with complex chronic, life threatening or life limiting (life shortening) conditions. The policy applies to all care settings including: home, hospital, school, hospice, respite care, and ambulance service.

Throughout this document the term 'child' will be used to refer to any baby, child or young person up to the age of 18, unless otherwise specified.

What is the Children's Advance Care Plan (ACP)?

- The Children's Advance Care Plan is a tool for discussing and communicating the wishes of a child and their parents or carers.
- It contains detailed information about the child and their health needs.
- The Advance Care Plan helps ensure that the child receives the most appropriate care particularly in an emergency.
- It should also reduce the number of times a family have to tell and re-tell their story.

The new standard format Advance Care Plan is being introduced across the Northwest of England (Merseyside and Cheshire, Greater Manchester, Lancashire and South Cumbria).

What are the important features of the Children's Advance Care Plan?

- The Children's Advance Care Plan has a review date but does not have an expiry date. This means that the plan will remain valid after the review date has passed, but the review date will still prompt professionals to update the plan
- The page about "me and my family" is at the beginning of the document. This is because children and families have told us that it is important to think of them as people first and foremost not just as a "diagnosis"
- There is an optional section for documenting the child's and family's wishes during their child's life.
- There is a detailed section on management of a life threatening event which provides space to document preferences such as transfer to hospital, breathing support and attempted venous access.
- There is a space for documenting the child's and family's wishes for care around the end of life. This is an optional section.
- The management of a cardio-pulmonary arrest (DNA-CPR) page is at the back. Professionals will <u>always</u> attempt full cardiopulmonary resuscitation unless this page has been completed.

Where is the most up to date version stored?

Each time the Advance Care Plan is reviewed the updated version is uploaded on to MEDISEC. A Critical Patient Management Letter alert (CPML) is set up on MEDITECH 6 and the new Advance Care Plan is uploaded into the Critical Patient Management Letters folder on Image Now and any previous Advance Care Plans are archived. . The Northwest Ambulance Service is also notified via Northwest Ambulance Electronic Referral and Information Sharing System (ERISS). The updated Advance Care Plan is distributed to the family and involved professionals. . Paper copies of the Advance Care Plan are printed on lilac paper. Parents are advised to ensure a copy of the child's plan stays with the child at all times.

How can I set up an Advance Care Plan for my patient?

Any child who may benefit can have an Advance Care Plan. Discussions can be initiated by any professional, but the final plan will need an identified Plan Co-ordinator and to be signed off by the child's Lead Consultant and other professionals as appropriate. The Alder Hey Specialist Palliative Care team is also happy to provide advice and take referrals for advance care planning for children with life threatening and life limiting conditions.

Version Control, Review and Amendment Logs

Version Control Table				
Version	**Date**	**Author**	**Status**	**Comment**
2	May 2016	Lynda Brook	Current	
1	March 2015	Lynda Brook	Archived	

Record of changes made to Advance Care Plan Policy – Version 1			
Section Number	**Page Number**	**Change/s made**	**Reason for change**
Quick reference	2	Update to reflect new procedures with Meditech 6 and ERISS	Introduction of Meditech 6 and ERISS
6.2.3	8	Update to reflect new RCPCH guidance	Introduction of new RCPCH guidance

Contents

1 Introduction

1.1 The Alder Hey Advance Care Plan Policy is derived from the Northwest Children's Unified Advance Care Plan Policy, developed by the Northwest Children's Palliative Care Network, in partnership with the Northwest Ambulance Service.

1.2 The overarching Northwest Unified Advance Care Plan Policy was adapted from the Child and Young Person's South Central Advance Care Plan Policy produced by a subgroup of the NHS South Central End of Life Care Programme Board. It provides a framework for a unified Advance Care Plan format which can be used to support care of babies, children and young people with complex chronic, life threatening or life limiting conditions across all care settings. A separate Northwest Unified Advance Care Plan Policy is available for adults.

1.3 The Northwest Unified Advance Care Plan Policy is designed for use across the Northwest area comprising Merseyside and Cheshire, Greater Manchester, Lancashire and South Cumbria. It details responsibilities for all organisations working in partnership to support children with Advance Care Plans across the Northwest including Alder Hey Children's NHS Foundation Trust. This is part of a consistent approach to advance care planning is being implemented across the Northwest Children's Palliative Care Network through local policies and procedures.

This policy links to the Trust Resuscitation Policy – C23.

This policy is supported by a package which consists of:

- A comprehensive three level awareness raising and training programme
- An Advance Care Plan Proforma
- A Guide to using the Children and Young Person's Advance Care Plan
- An Information leaflet for parents and carers about Advance Care Plans
- An Information leaflet for young people about Advance Care Plans

See Palliative Care intranet pages.

1.4 A Children's Advance Care Plan (ACP) is designed to communicate the health-care wishes of children or young people who have complex chronic, life threatening or life-limiting conditions and their families. A different format Advance Care Plan is available for use by adults.

1.5 The Children's Advance Care Plan sets out an agreed plan of care to be followed when a child's condition deteriorates. It provides a framework for both discussing and documenting the agreed wishes of a child or young person and his or her parents, when the child or young person develops potentially life-threatening complications of his or her condition. It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service. The Children's

Advance Care Plan includes guidance for management of a life threatening deterioration, management of a cardio-pulmonary arrest and end of life care as appropriate. It remains valid when parent(s) or next of kin cannot be contacted.

2 Definitions

Throughout this document the term 'child' will be used to refer to any baby, child or young person up to the age of 18, unless otherwise specified.

2.1 **A Children's Advance Care Plan (ACP)** is a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different ACP can be used in adults. An ACP will include whether the child's resuscitation status has been discussed, and the outcome of that discussion.

2.2 **Cardiopulmonary Arrest** is the cessation of breathing and loss of cardiac output.

2.3 **Cardiopulmonary Resuscitation (CPR):** Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and ventilations and may include attempted defibrillation and the administration of drugs.

2.4 **Do Not Attempt Cardio Pulmonary Resuscitation (DNA-CPR)** refers to not making efforts to restart breathing and/or the heart following a cardiopulmonary arrest.

2.5 **Valid DNA-CPR:** A DNA-CPR is only valid if it is signed and dated.

2.6 **Lead Clinician for Advance Care Planning:** Acts as the primary link between Alder Hey and the North West Children's Palliative Care Network

2.7 The **Advance Care Plan Co-ordinator** is a named professional, identified, through their role with an individual child and family, to take overall responsibility for co-ordinating the child's Advance Care Plan. The name of the child's Advance Care Plan Co-ordinator is documented on the front of the Advance Care Plan. This may be the child's Lead Consultant, Key-worker or another professional who is appropriately placed to take on this role.

2.8 **Child Death Overview Panel (CDOP):** This group monitors and reviews the deaths of all children, and a rapid response team is activated to initiate a review within a designated time frame each time a death occurs.

2.9 **Adult:** A person aged 18 years or over **Young Person:** A person aged 16 or 17. Anyone under this age is regarded as a child.

3 Policy Statement

The Children's Advance Care Plan Policy will ensure that:

3.1 All children are presumed to be “For attempted CPR” unless a valid DNA-CPR decision has been made.

3.2 All DNA-CPR decisions are based on current legislation and guidance.

3.3 Standardised documentation for the Children’s Advance Care Plan will be used.

3.4 The existence of an Advance Care Plan for a child will be communicated to all affected members of the child’s multidisciplinary team and to all relevant settings.

3.5 The Children’s Advance Care Planning process is measured, monitored and evaluated to ensure a robust governance framework.

3.6 Training will be available to enable staff to meet the requirements of this policy.

4 Purpose

4.1 This policy will provide guidance for staff responsible for providing or organising health care for children. This will be consistent with guidance across the geographical area covered by the Northwest Children’s Palliative Care Network: Merseyside and Cheshire, Greater Manchester, Lancashire and South Cumbria.

5 Scope

5.1 This policy applies to all the multidisciplinary healthcare team involved in children’s care. It is consistent with policies across the range of care settings within the geographical area covered by the Northwest Children’s Palliative Care Network.

5.2 This policy is appropriate for all children up to 18 years of age. Once initiated the Children’s Advance Care Plan may be extended beyond the 18th birthday, with discretion, for young adults within the special education or hospice environment.

6 Legislation and Guidance

6.1 Legislation www.opsi.gov.uk/acts

6.1.1 Under the Children Act (1989 & 2004) clinicians are expected to understand how the Act works in practice. The key consideration is to make decisions consistent in the Best Interests of the child.

6.1.2 Adoption and Children Act 2002: Clinician’s are expected to understand who has parental responsibility to consent to treatment in a child.

6.1.3 Mental Capacity Act- 2005. Particularly pertaining to 16 and 17 year olds (see point 7.2).The Mental Capacity Act (MCA) 2005 is specific to a particular decision being considered: so a person may lack capacity for a DNA-CPR decision but have capacity for another e.g. preferred place of care.

6.1.4 Working Together to Safeguard Children 2006 as this pertains to responsibilities to report child deaths to the Child Death Overview Panel (CDOP) and the role of the local Rapid Response Team.

6.1.5 The following sections of the Human Rights Act (1998) are relevant to this policy:

The individual's right to life (article 2)

- To be free from inhuman or degrading treatment (article 3)
- Respect for privacy and family life (article 8)
- Freedom of expression, which includes the right to hold opinions and receive information (article 10)
- To be free from discriminatory practices in respect to those rights (article 14).

6.1.6 Coroners Act 1988: Clinicians are expected to know the circumstances when a death must be discussed with the District Coroner.

6.2 Guidance

6.2.1 European Resuscitation Guidelines.
www.resus.org.uk/siteindx.htm

6.2.2 Advanced Paediatric Life Support Group Guidelines.
www.alsg.org/en/?q=en/apls

6.2.3 Royal College of Paediatrics and Child Health (2015) Making Decisions to limit treatment in children with life limiting conditions
Larcher V, et al. Arch Dis Child 2015;100(Suppl 2):s1–s26.
doi:10.1136/archdischild-2014-306666.

6.2.4 Resuscitation Council (UK) Recommended standards for recording "Do not attempt resuscitation" (DNAR) decisions (2009).
www.resus.org.uk/siteindx.htm

6.2.5 Decisions relating to Cardiopulmonary Resuscitation, A Joint Statement from the British Medical Association(BMA), the Resuscitation Council (UK), and the Royal College of Nursing. (October 2007, updated November 2007).
www.bma.org.uk/ethics/cardiopulmonary_resuscitation/CPRDecisions07.jsp

6.2.6 BMA (2006) Parental Responsibility: Guidance from the BMA
www.bma.org.uk/ethics/consent_and_capacity/Parental.jsp

6.2.7 General Medical Council (2007) 0-18 years: guidance for all doctors.
www.gmc-uk.org/publications/standards_guidance_for_doctors.asp#0-18

6.2.8 General Medical Council (2010) Treatment and Care Towards the End of Life www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

6.2.9 DNAR decisions in the Perioperative Period; Association of Anaesthetists of Great Britain and Ireland May 2009 www.aagbi.org/publications/guidelines/docs/dnar-09.pdf

6.2.10 Withholding and withdrawing life-prolonging medical treatment 3rd Ed BMA 2007 www.bma.org.uk/ethics/end_life_issues/Withholdingwithdrawing.jsp

7 Ethical and legal background

7.1 18 year olds and older (terminology for this age group is adult)

7.1.1 The legal definition of an adult is anyone of 18 years or over. Anyone of 18 years of age or above can make his or her own decisions about consenting to, or refusing treatment. He or she can also make a legally binding 'Advance Decision' about these issues. An Adult Advance Care Plan should not be used for this purpose.

7.1.2 In the majority of circumstances the Children's Advance Care should not be initiated after the 18th birthday and the adult form should be used. However if the form is already being used it may be better for the individual and their family to continue with the Children's Advance Care Plan beyond the 18th birthday. There may also be occasions where it is appropriate to use this form for adults still under paediatric services or within the hospice environment.

7.1.3 The Mental Capacity Act provides a test for capacity. A person lacks capacity if they have an impairment or disturbance that affects the way their mind or brain works and the impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made. This two-stage test should therefore be used if a clinician has cause to believe that the person lacks capacity. A person is deemed to be 'unable to make a decision' if they cannot:

- Understand information relating to the decision that has to be made
- Retain that information in their mind
- Use or weigh that information as part of the decision-making process, or
- Communicate their decision.

7.1.4 If an adult is found to lack capacity then the decision is made on the grounds of Best Interests. The only person who determines Best Interests (i.e. decides what the Best Interests of the person are) is the decision maker. The decision maker is usually the clinician in charge, otherwise the Court of Protection, its deputy, or someone with Lasting Power of Attorney. Everyone else including parents or Independent Mental Capacity Advocates, are not legally able to determine Best Interests; they merely support the decision maker by, amongst other means, providing the information to allow the decision to be made.

7.1.6 Adult DNA-CPR documentation and the Mental Capacity Act provide clarification on decision making in adults.

7.2 16 and 17 year olds (terminology for this age group is young person)

7.2.1 Although applicable to young people in many respects, the Mental Capacity Act does not permit 16 & 17 year olds to make arrangements to enable them, once incapacitated, to refuse lifesaving treatment. Thus there is no provision for them to appoint Lasting Powers of Attorney, or to make an Advance Decision to Refuse Treatment (ADRT).

7.2.2 There is a presumption that 16 and 17 year olds have the capacity to make decisions for themselves. Young people of this age can consent to treatment and may be able to refuse treatment in some circumstances. Legal advice may be required in this situation.

8 Roles and Responsibilities

8.1 Chief Executive of Alder Hey Children's NHS Foundation Trust is responsible for:

- Ensuring that this policy adheres to statutory requirements and professional guidance
- Supporting policy development and implementation consistent with other organisations across the north west network
- Ensuring that the policy is monitored and reviewed
- Review of policy.

8.2 National Health Service (NHS) Commissioners should:

- Ensure that commissioned services implement and adhere to the Northwest Children's Palliative Care Network Advance Care Plan policy and procedures and provide funding to ensure staff training.
- Be aware of the Northwest Children's Palliative Care Network Advance Care Plan policy and consider its implications when commissioning or providing services.

8.3 Chief Executives of all provider organisations should ensure that provider services:

- Implement and adhere to the Northwest Children's Palliative Care Network policy and procedures
- Procure and/or provide legal support when required
- Ensure adequate resources, funding and administrative support so that professionals are able Set up, Co-ordinate and update Advance Care Plans for all children under the care who may benefit
- Resource / enable training for staff

8.4 Directors or Managers who are responsible for the delivery of care must ensure that the policy is implemented and that:

- Staff are aware of the policy and how to access it

- Staff understand the importance of issues regarding DNA-CPR/ ACPs
- Staff are trained and updated in managing DNA-CPR/ ACPs
- Sufficient supporting materials are available for staff and for families
- The policy is audited and the audit details fed back to nominated Director.

8.5 Lead Clinician for Advance Care Plan Policy, liaising with the North West Network, is responsible for:

- Disseminating information about the Advance Care Plan package to all staff in their area who are affected by it
- Feeding back queries about the contents and application of the package to the network on behalf of the Trust
- Acting as a resource and support for clinicians.

8.6 Senior clinicians take ultimate responsibility for the completion of an Advance Care Plan for a child in their care. They will ensure that:

- All 'interested parties' are involved in the initial discussions about the possibility of an ACP for a particular child
- Information about all possible treatment options for the child, and their implications, are available while discussing Advance Care Planning
- The group of 'interested parties' discuss whether it would be appropriate to raise the issue of DNA-CPR with the child and his or her family
- Decisions are appropriately documented, disseminated and reviewed.

8.7 The child's Advance Care Plan Co-ordinator is responsible for

- Setting up the child's Advance Care Plan and ensuring the documentation is appropriately completed.
- Ensuring that the Advance Care Plan is reviewed regularly including when the child's condition has changed.
- Ensuring the safe storage of the master copy of the individual child's Advance Care Plan on their employing organisations' electronic Patient Administration System.
- Ensuring that the Advance Care Plan is shared with the family and other professionals who require a copy.

8.8 The Alder Hey Specialist Palliative Care Team Co-ordinator has a pivotal role in identifying when Advance Care Plans are due for renewal and providing administrative support for the updating and distribution of Advance Care Plans. In order to facilitate this, the Alder Hey Specialist Palliative Care team database includes a record of children with Advance Care Plans known to Alder Hey Children's NHS Foundation Trust. This is used to identify when Advance Care Plans co-ordinated by the Alder Hey Specialist Palliative Care team are review are due for renewal. It can also be used to identify when plans co-ordinated by other professionals are due for updating.

8.8 Clinical staff delivering care must:

- Adhere to the policy and procedures

- Notify line manager of any training needs
- Check the validity of any decision – that it is in date and signed
- Notify other services of the DNA-CPR / ACP on the transfer of a child
- Participate in the audit process
- Be aware of local procedures for storing and accessing ACP information.

8.9. The North West Ambulance Service (NWAS) will:

- Adhere to the Northwest Children's Palliative Care Network Advance Care Plan policy and procedures
- Notify line managers of any training needs
- Ensure they are aware of the existence of a DNA-CPR/ ACP via the individual / relatives or the health care professional requesting assistance
- Check the validity of any decision – that it is in date and signed
- Participate in the audit process
- Be aware of local procedures for storing and accessing ACP information.

8.10 Children's hospices will adhere to the Northwest Children's Palliative Care Network Advance Care Plan policy and procedures, and will ensure that:

- Information regarding a DNA-CPR/Children's Advance Care Plan is included in pre-admission documentation
- All DNA-CPR/ Advance Care Plans are effectively cascaded to staff

Individual staff will:

- Notify line manager of any training needs
- Ensure they are aware of the existence of any DNA-CPR/ ACPs
- Check the validity of any decision– that it is in date and signed
- Participate in the audit process
- Be aware of local procedures for storing and accessing ACP information.

8.11 Schools have a responsibility to ensure that:

- The Advance Care Plan is available and followed
- In an acute event, an ambulance is called and the presence of the ACP highlighted to ambulance staff (follow protocol including giving home postcode)
- Parents are immediately contacted by phone.

9 Process

9.1 The guide to using the Children's Advance Care Plan should be used when initiating an ACP. It provides guidance on the overall process as well as page-by page instruction on completing the documentation.

10 Do Not Attempt Cardiopulmonary Resuscitation (DNA-CPR)

10.1 A child with a valid DNA-CPR decision in place should not be resuscitated in the event of a life threatening change in his or her clinical condition, unless this is due to a rapidly reversible cause such as choking or anaphylaxis, or causes specific to the individual child specified in the Advance Care Plan.

10.2 In hospital, a clinical emergency call (2222) may still be made, if specific interventions are agreed in the Advance Care Plan. Active interventions to assist the child's failing respiratory or circulatory function, such as chest compressions and ventilation will not usually be undertaken.

10.3 If an ambulance is called then Ambulance Control must be told about the existence of an ACP.

10.4 If the death is anticipated, the GP should be called.

10.5 A DNA-CPR decision does not mean withdrawal of care.
Every attempt will continue to be made to make the child as comfortable as possible, and to fulfil his or her and the families' wishes.

10.6 All children are for attempted resuscitation unless there is a valid DNA-CPR decision in place. If there is any doubt about the validity of a DNA-CPR decision then resuscitation should be initiated.

10.7 A valid DNA-CPR decision:

- Reflects the agreed wishes of the child (where appropriate), those with parental responsibility for the child, and the health care professionals caring for the child
- Is clearly recorded in the DNA-CPR section of the ACP
- Is dated and signed by the child's Lead Clinician.

10.8 The ACP will only apply to situations described within the care plan and only when it is current, dated and signed by the child's parent or legal guardian (see section 7 on ethical and legal background). If the young person has capacity for the decision, his or her signature may also appear on the form, although this is optional.

10.9 The Child and Young Person's ACP should not usually be used for the first time in an adult of 18 years or over. There may be some young adults in which this form was initiated before their 18th birthday. If the young adult is deemed competent and has signed the form, it will remain valid, and a parental signature is no longer required.

10.10 In all circumstances not covered by the ACP it must be assumed that the child should have full resuscitation measures in the event of deterioration or collapse. Clinicians retain the right to not resuscitate or to stop resuscitation if they believe it is futile.

10.11 A valid ACP should be followed even when the parent or legal guardian is NOT present at the time of the child's acute deterioration or collapse.

10.12 If a parent or legal guardian is present at the time of his or her child's collapse, and they wish to deviate from the previously agreed ACP, then their wishes should be respected provided they are thought to be in the Best Interests of the child.

Note: For further guidance on how to complete the Children's Advance Care Plan, please see Staff Guidance leaflet.

11 Review of Advance Care Plan

11.1 The ACP should be reviewed regularly, and in good time to ensure there is always a current valid plan. The ACP co-ordinator is responsible for ensuring that the latest version of the Advance Care Plan is distributed and previous copies are marked as "date expired".

12 Situations where there is lack of agreement

12.1 Where the clinical decision is seriously challenged and agreement cannot be reached, legal advice must be sought.

13 Cancellation of a DNA-CPR Decision

13.1 In rare circumstances a decision may be made to cancel or revoke the Advance Care Plan or DNA-CPR decision. In this situation the paper copies of the Advance Care Plan should be crossed through with 2 diagonal lines in black ball-point ink and the word **'CANCELLED'** written clearly between them, dated and signed by the senior clinician, and the reasons clearly documented. The equivalent procedure must be applied to electronic copies on the employing organisations' electronic Patient Administration System.
It is the responsibility of the child's ACP Co-ordinator to ensure that all parties are informed and to organise an urgent review so that a new ACP can be completed.

14 Exclusions from and suspension of DNA-CPR Decision

14.1 A DNA-CPR decision does not include immediately remediable and acutely life-threatening clinical emergencies such as choking or anaphylaxis. Appropriate emergency interventions, including CPR should be attempted if it is in the child's Best Interests to do so.

14.2 A valid DNA-CPR decision may be temporarily suspended, for example around the time of specific interventions such as anaesthesia or surgery that have an associated increased risk of cardiopulmonary arrest. If such procedures are planned then the ACP should be reviewed and whatever decision is made should be documented and communicated accordingly. This documentation should clearly specify the beginning and end date of the suspension.

15 Training

15.1 Three levels of training will be available to staff to support the implementation of this policy.

Level	Applicable to	Format
1 Basic awareness raising	All professionals caring for children	Online learning to be incorporated into induction and mandatory training
2 Core competencies	Professionals caring for children with life threatening or life limiting conditions	One day experiential learning course.
3 Advanced communication skills as applied to Advance Care Planning and End of Life Care	Senior doctors and nurses who are likely to be actively involved in advance care planning discussions and discussions on with-holding or withdrawing life sustaining treatment	One day advance communication skills course with materials and scenarios focussed on advance care planning, with-holding and withdrawing. This course to be taken after level 2.

15.2 Core competencies to be achieved through the final programme

Universal competencies – level 1

- To be aware of Children's Advance Care Plans, who may have them, how to access them, when they are valid and when to seek further advice
- To be aware of local (Trust) do not attempt resuscitation policy
- To be aware of legal requirements when to report to the coroner, safeguarding etc
- To be aware of internal organisational sources of support – palliative care services, bereavement team

Core competencies – level 2 (in addition to the above)

- To be able to recognise the child who is likely to be in the last few hours and days of life and understand the degree of uncertainty inherent within this
- To be able to interpret core guidance from an Advance Care plan particularly with reference to personalised resuscitation plans
- To be aware of Rapid Discharge Pathway, how to access advice and support to use pathway
- Know basic ethical principles, when ethical guidance may be needed and how to access
- To be able to support advance care planning discussions with child and family
- To be able to recognise when a child may benefit from advance care planning

- Diagnostic/ prognostic indicators – using Spectrum of Palliative Care Needs
- Recognising cues from child and/ or parent
- To be aware of external sources of support – palliative care services, hospices etc

Specialist competencies – level 3 (in addition to the above)

- To discuss the fact that a child may be in their last few hours and days of life with the parents and where applicable the child
- To be able to use rapid discharge pathway and to support and empower others to do so
- To be able to lead advance care planning discussions with child and family
- To be able to document advance care planning outcomes clearly and accurately
- To be familiar with GMC guidance and local clinical ethics committees; to know when legal advice is indicated and how to access
- To understand the legal difference between consent assent and refusal of treatment with regard to a young person who may have capacity

16 Monitoring

16.1 The Palliative Care Team will monitor use of the Advance Care Planning documentation, the frequency of review, adherence to ACPs in the event of an acute life-threatening event and deaths taking place without an ACP in place. The team will also monitor training of staff.

16.2 Information will be used for future planning, identification of training needs and for policy review.

16.3 Information will be reported to the Clinical Quality Steering Group and the Northwest Children's Palliative Care Network and Northwest Ambulance Service Advance Care Planning Implementation Group.

17 Further Information

Equality Analysis (hyperlink)

Associated Documentation

C28 – Resuscitation Policy

- Advance Care Plan Proforma
- Alder Hey local Guide for disseminating Children's Advance Care Plans
- Guide to using the Children's Advance Care Plan
- Information leaflet for parents and carers about Advance Care Plans
- Information leaflet for young people about Advance Care Plans
- Children's Advance Care Plan Audit Tool

See Palliative Care intranet pages

Appendix A – Quick Reference Guide to Advance Care Plans

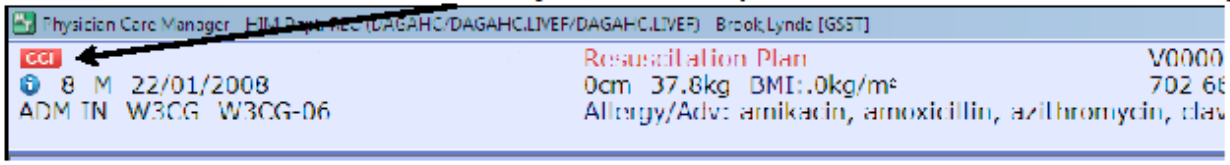
Alder Hey Children's NHS
NHS Foundation Trust

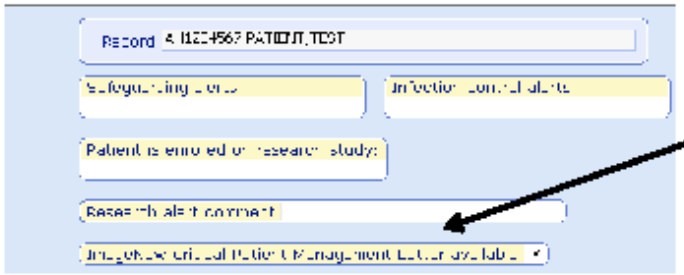
Advance Care Plans

- **Advance Care Plans** contain important information including diagnosis, contact details of key professionals and emergency treatment plans.
- Some Advance Care Plans include a **Personal Resuscitation Plan**
- Paper Advance Care Plans are printed on **purple paper** or with purple borders

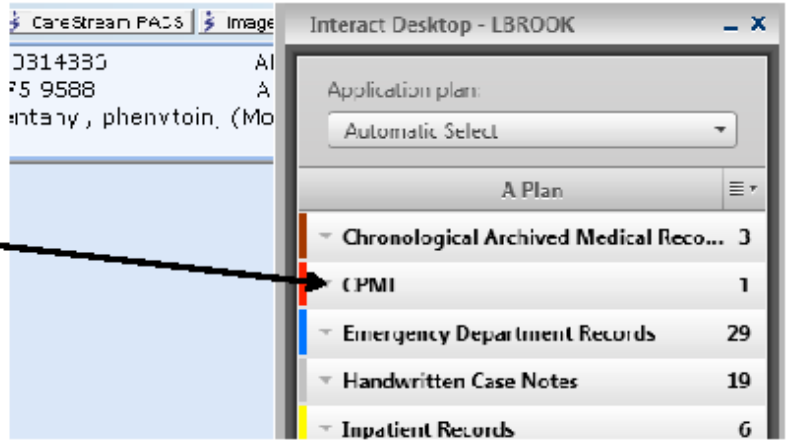
Viewing Advance Care Plans on MEDITECH

1. Click on Critical Care Indicator CCI symbol in the top left-hand corner of the electronic patient record





2. Record indicates there is a Critical Patient Management letter on Image Now



3. Open Image now Critical Patient Management Letters folder to view Advance Care Plan

4. Alternatively find most recent Advance Care Plan in Medisec Letters

Appendix B – Quick Reference Guide to Personal Resuscitation Plans

Alder Hey Children's NHS
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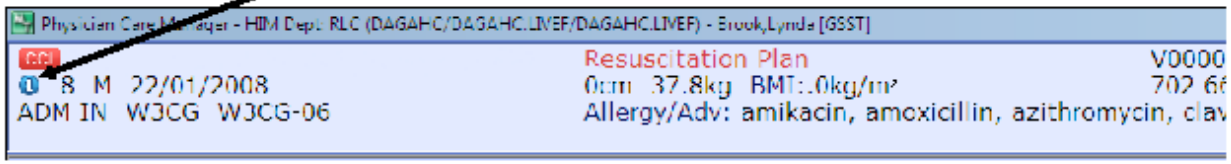
Personal Resuscitation Plans (may include DNA-CPR)

- Community/ long term Personal Resuscitation Plans are documented in the child's **Advance Care Plan**
- **All inpatients with Personal Resuscitation Plans** (i.e. short term during critical illness on PICU, or long term) must have this documented on MEDITECH

Viewing Inpatient Personal Resuscitation Plans on MEDITECH

- Resuscitation Plan is displayed across the top of the electronic patient record
- Click on the blue ⓘ button to view the Personal Resuscitation Plan



Documenting Inpatient Personal Resuscitation Plans

- Initial documentation in medical case notes must include details of discussions leading to the development of the Personal Resuscitation Plan including
  - Rationale for the Personal Resuscitation Plan
  - Date and time of discussions
  - Who was present during discussions
  - Who else has been consulted (e.g. the child's GP or DGH consultant)
- Inpatient Personal Resuscitation Plans must be documented on
  - Meditech Order Entry - Resuscitation Status [RS]
- The Personal Resuscitation Plan must be handed over at each nursing and medical handover

Need help? Contact the Palliative Care Nurse Specialist On-Call via switchboard