



ADVANCE AND EMERGENCY CARE PATHWAY (AECp) POLICY FOR CHILDREN/YOUNG PEOPLE (IE. THOSE UNDER 18 YEARS OF AGE) WITH LIFE THREATENING OR LIFE LIMITING ILLNESS

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Documents to read alongside this Policy	<ul style="list-style-type: none"> • Cardiff and Vale UHB Adult DNAR Policy • Cardiff and Vale UHB Advance and Emergency Care Pathway document for children with life threatening or life limiting illness • Parent AECp information leaflet
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CONTENTS	PAGE
1.0 Executive Summary	5
1.1 Purpose of Policy	5
2.0 Introduction	5
3.0 Policy Statement	6
4.0 Aims of the Policy	6
5.0 Scope	6
6.0 Definition of Terms	7
6.1 Child, Young Person, Capacity and Consent	7
6.2 DNACPR	8
6.3 Life Limiting Conditions	8
6.4 Life Threatening Conditions	8
6.5 End of Life	8
6.6 Advance and Emergency Care Pathway	9
6.7 CPR	9
7.0 Roles and Responsibilities	9
7.1 Health Board	9
7.2 Resuscitation Committee	9
7.3 Resuscitation Service	10
7.4 Child Health Advance and Emergency Care Pathway Focus Group	10
7.5 Divisional Directors and Line Managers	10
7.6 Individual Staff Members	10
8.0 Advance and Emergency Care Pathway Decision Making	11
8.1 Advance and Emergency Care Pathway for Children/Young People with Life threatening/Life limiting Conditions – A New Standard of Care	11
8.2 Timing of Initiating the Advance and Emergency Care Planning Process	11
8.3 Ethical Issues in Advance and Emergency Care Planning	12
8.4 When to Attempt CPR	13
8.5 Refusal of Treatment	13
9.0 Temporary Suspension of a DNAR Order Recorded in an AECP	14
10.0 Responsibility for DNAR Decision Making and Advance and Emergency Care Planning	14
11.0 Communicating Advance and Emergency Care Pathway Decisions within Health	15
12.0 Recording Advance and Emergency Care Pathway (DNAR) Decisions	16
13.0 Communicating Advance and Emergency Care Pathway Decisions to Multiagency Team	16
13.1 Ambulance Service	16
13.2 General Practitioner	17
13.3 Education	17
13.4 Child Health & Disability (CHAD) Social Services	17
13.5 The Coroner	18
13.6 Police	18
13.7 Ty Hafan Children’s Hospice	19
14.0 Reviewing the Advance and Emergency Care Pathway (DNAR) Decision	19
15.0 Raising Awareness of the Advance and Emergency Care Pathway Policy	20

Cardiff and Vale University Health Board

16.0	Review of the Advance and Emergency Care Pathway Policy	20
17.0	Implementation	20
18.0	Resources and Funding	21
19.0	Audit	21
20.0	Equality	21
21.0	Contributors	21
22.0	References	22

1. EXECUTIVE SUMMARY

1.1. Purpose of Policy

For every person there comes a time when death is inevitable. For a child/young person under 18 years of age with life threatening or life limiting illness this may be during childhood or adulthood.

The purpose of the Advance and Emergency Care Pathway (AECP) Policy is to outline the legal and ethical standards for planning patient care and decision making in relation to the terminal phase of a child's life and cardiopulmonary resuscitation.

2.0 INTRODUCTION

“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms; provision of short breaks, and care through death and bereavement.”¹

The palliative phase for children is often longer than for adults with specialist support needed over years rather than months.¹

Paediatric palliative care services must meet the needs of children and young people with a wide range of differing conditions including neurodisability, neurodegenerative conditions and chronic conditions such as cystic fibrosis, cardiac disease and cancers.

Decisions regarding Cardiopulmonary Resuscitation (CPR) should form part of a holistic end of life, or Advance and Emergency Care Pathway for a child or young person with a life threatening or life limiting illness.

Consideration for the need for an Advance and Emergency Care Pathway (AECP) which includes options regarding Cardiopulmonary Resuscitation should alert the beginning of a process of discussion and care for that child and family.

It is vital to involve the patient, their family, the health care team and people close to the patient in decision making (subject to consent being obtained), and to ensure the communication of decisions to all relevant health and multiagency professionals (GP, Community Nursing service, Respite, Education, Social Services, Ambulance, Police, Coroner, Bereavement Services²) subject to consent being obtained.

3.0 POLICY STATEMENT

Cardiff and Vale University Local Health Board (UHB) is committed to implementing the guidance for Advance and Emergency Care Pathway for children and young people with life threatening or life limiting illness as supported by the reference list. This policy should be read in conjunction with guidance from the BMA, RC (UK), RCN.³ and with the UHB's Do Not attempt Cardiopulmonary Resuscitation (DNACPR) Policy⁴.

The purpose of the Advance and Emergency Care Pathway Policy is to outline the legal and ethical standards for planning patient care related to the terminal phase of a child or young person's life; it should include plans about cardiopulmonary resuscitation.

4.0 AIMS OF POLICY

- To implement a consistent approach to Advance and Emergency Care Pathways
- To ensure patients receive appropriate and effective resuscitation when necessary and without delay
- To ensure patients are treated with dignity and their human rights and the law are respected and upheld⁵
- To ensure appropriate, correct and respected application of United Nations Convention on Rights of the Child⁶
- To promote current best practice in children/young people's palliative care and specifically in the area of advance care planning based on current national guidance from Association for Children's Palliative Care (ACT)¹, Royal College of Paediatrics and Child Health⁷, Royal College of Physicians⁸, IMPaCCT group (the steering committee of the European Association of Palliative Care task force on palliative care for children and adolescents)⁹, Department of Health¹⁰, General Medical Council¹¹, Welsh Assembly Government¹², National Service Framework for Children¹³.
- To comply with Welsh Assembly Government requirements
- To provide support for clinical staff
- To provide written information for patients and relatives
- To satisfy legal and professional requirements
- To minimise clinical risk, litigation and material loss
- To comply with UHB requirements for formal organisation-wide policies
- To ensure the AECP procedures are monitored and audited
- To facilitate improving end of life care as a key performance indicator of all NHS Health Boards and Trusts in Wales

5.0 SCOPE

This policy is applicable to all circumstances where children or young people (ie. those under 18 years of age) are suffering from life threatening or life limiting illness requiring an advance and emergency care pathway with

regards to active treatment and/or symptom control and cardiopulmonary resuscitation. All members of staff who are involved in planning of patient care, review and decision making in relation to such children or young people must be aware of and abide by the contents of this policy.

6.0 DEFINITION OF TERMS

6.1 Child, young person, capacity and consent

Under Article 1 of the United Nations Convention on the Rights of the Child (UNCRC): 'A child is recognized as a person under 18'.

Children aged under 16 years

Children under 16 years of age are presumed not to be capable of taking their own decisions. However, such children may be Gillick¹¹ competent and if so, then they are the person who will either consent to or refuse treatment and care. If the child is not Gillick competent, then a person with parental responsibility will consent to or refuse treatment and care on the child's behalf.

Parental responsibility

A person with parental responsibility is

- the child's mother
- the child's father if he was married to the mother at the time of the birth

Where the father is not married to the mother at the time of the birth he can acquire parental responsibility:

- in the case of a child born before 1 December 2003 if he marries the mother of their child or has a parental responsibility order
- in the case of a child born after 1 December 2003 he is registered on the birth certificate as the child's father, he marries the mother or has a parental responsibility order from the court.

Persons other than the mother and father who may have parental responsibility are:

- the child's legally appointed guardian
- a person in whose favour the court has made a residence order concerning the child
- a Local Authority designated in a care order in respect of the child
- a Local Authority or other authorised person who holds an emergency protection order in respect of the child.

Young people aged 16-17 years

Young people aged 16 years and over are presumed to have capacity to consent to or refuse treatment and care. However,

if there is reason to believe that the young person lacks mental capacity, then the Mental Capacity Act 2005¹⁴ and its *Code of Practice*¹⁵ must be followed when making arrangements for the child's treatment and care.

Adults aged 18 years and over

Recording of the child/young person/family's preferences for care remain valid once that young person becomes an adult (18 years old). However, professionals must be aware that once a person attains 18 years of age additional provisions of the Mental Capacity Act 2005¹⁴ come into effect (e.g. advance decisions and Lasting Powers of Attorney) where appropriate, professionals should seek appropriate advice regarding this matter.

6.2 “Do not attempt cardiopulmonary resuscitation (DNACPR)”

'DNACPR' is a term that is historically used for 'Do Not Attempt Cardiopulmonary Resuscitation' orders and applies only to cardiopulmonary resuscitation. It does not imply 'non-treatment;' all other treatment and care appropriate for the patient should be offered.⁴

However, writing 'DNACPR' on its own in the notes lacks an information prescription which is more appropriate in context of a child/young person with life threatening or life limiting illness where there are multiple family members, carers and child health professionals and non health agency staff involved in their care. Effective communication is key to the success of an Advance and Emergency Care Pathway.

6.3 Life-limiting Conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child/young person increasingly dependent on parents and carers¹.

6.4 Life-threatening Conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer.¹ Children or young people in long-term remission or following successful curative treatment are not included.

6.5 End of Life

The 'end of life' phase ends in death. Definition of its beginning is variable according to individual child/young person/family and professional perspectives. In some cases it may be the child/young person or family who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient.

6.6 Advance and Emergency Care Pathway

An Advance and Emergency Care Pathway is developed when a child/young person is at risk of life threatening deterioration, whether following an acute event or a more gradual decline. It includes discussing life-sustaining (active) treatments and establishing long-term care goals. The capable child/young person, their parent/carers (with the child/young person's agreement) and the child's paediatrician should agree on the most appropriate care in an emergency or slow deterioration and sign a [pathway form](#). An Advance and Emergency Care Pathway may communicate any of the following to be in the child/young person's best interests and in line with the current wishes of the child/young person/family:

- Full resuscitation including invasive ventilation and CPR
- Active treatment, which might be life-prolonging (e.g. treatment of a chest infection with IV antibiotics) but stop short of invasive ventilation support or CPR.
- Symptom control, care and comfort measures only, where the aim of treatment is to relieve symptoms but not necessarily prolong life

6.7 Cardiopulmonary Resuscitation (CPR)

Cardiopulmonary Resuscitation: may include artificial respiration chest compressions and defibrillation in an attempt to restart the heart.⁴

7. ROLES AND RESPONSIBILITIES

Cardiff and Vale UHB aims to comply with national guidance to healthcare professionals both through the development of this policy and the production of an information leaflet for patients and relatives.

7.1 UHB Board

The UHB Board carries overall responsibility for Cardiff and Vale UHB. It has delegated powers from the Welsh Assembly Government in respect of the ownership and management of hospitals and other health facilities; it is responsible for the performance of the UHB. The Chief Executive must ensure the UHB has an agreed Resuscitation Policy that respects Children' Rights and that any decisions made by staff are informed via the Advance and Emergency Care Pathway Policy and relevant child/young person/family information.

7.2 Resuscitation Group

The UHB Resuscitation Group, led by its chairperson, meets on a regular basis. Its role is to ensure that UK Resuscitation Council guidelines for the resuscitation of victims of cardiopulmonary arrest are implemented effectively. Group members should be conversant with contemporary issues related to new developmental knowledge. The UHB Resuscitation Group is a sub-group of the UHB Quality and Safety Committee

7.3 Resuscitation Service

The Resuscitation Service is answerable to the Resuscitation Group in terms of its clinical lead. It is responsible for implementing decisions made by the Resuscitation Group and promoting good practice primarily through training and audit. The Resuscitation Service is responsible for assessing those it teaches and ensuring that they meet standards that reflect UK Resuscitation Council guidelines. The Resuscitation Service develops policies and procedures using guidance to ensure full multidisciplinary representation. It monitors cardiac arrest outcome and team response as well as adherence to resuscitation policies (including AECP policy). The Senior Resuscitation Practitioner will maintain, manage and develop the service, within available resources, to meet the needs of the Health Board.

7.4 Child Health Advance and Emergency Care Pathway Focus Group

The AECP focus group meets on a regular basis. Focus group members should be conversant with contemporary issues related to new developmental knowledge. The Chair's role is to coordinate audit feedback and review and update this policy every two years through regular clinical governance procedures.

7.5 Divisional Directors and Line Managers

While the UHB has the responsibility to ensure that resuscitation policies and relevant patient information are developed through the UHB Resuscitation Service, those who manage staff, particularly clinical staff, have a responsibility to ensure that staff and, where relevant, patients and their relatives have access to and understand resuscitation policies, including the AECP policy.

7.6 Individual Staff Members

While the UHB has a responsibility to provide a Resuscitation Service and its managers are responsible for ensuring staff have access to and understand resuscitation policies and relevant patient information leaflets, each individual is responsible for their own actions and professional practice. Paediatric health care practitioners have an obligation to educate themselves about this aspect of medical care. Individual staff members should familiarise themselves with UHB resuscitation policies and, with respect to the AECP policy, ensure that patients and their families have access to and understand it. Staff must respect patient rights to confidentiality whilst ensuring that decisions relating to AECP are communicated to appropriate colleagues with informed consent.¹⁶

8. ADVANCE AND EMERGENCY CARE PATHWAY DECISION MAKING

Advance and Emergency Care Pathways are an extension of usual discussions about plans for treatment, which conventionally focus on curative measures and on what will be provided rather than what will not. An Advance and Emergency Care Pathway broadly encompasses both short-term and long-term health care goals and treatments. It may include the drafting of advance options, which specify what treatments will or will not be provided for the child/young person. The benefits of Advance and Emergency Care Pathways are both procedural, in that two-way communication is improved, as well as substantive, in that the actual details of the plans for care are clarified. When an Advance and Emergency Care Pathway is executed well it ensures that shared goals of care, be they curative or palliative, are aligned with the planned course of treatment.

8.1 Advance and Emergency Care Pathways for Children/Young People with Life Threatening or Life Limiting Conditions –a New Standard of Care

Advance care planning in paediatrics is most frequently carried out in intensive care settings and in specific disease populations. The stimulus for discussion is usually the recognition of impending death by family or health professionals. Such discussions may lead to an abrupt transition from a curative to a palliative focus of care. However, health care providers should be aware that palliative care is appropriate at any point following diagnosis of a life-limiting or life threatening condition and can exist in partnership with other treatments which may have a different intent, such as cure.

8.2 Timing of Initiating the Advance Care and Emergency Pathway Process

If the child/young person and family do not appear to be ready to address an advance and emergency care pathway, particularly when death is not imminent, respect for the child/young person's autonomy or parental authority must allow them to refuse information and defer decision-making.

- Multiple discussions are often required. Even in the paediatric intensive care setting, in which decision-making often occurs on a compressed timeline, one Canadian study¹⁷ found that two or more meetings were required to achieve consensus in 46% of cases involving decisions to forego life-sustaining therapy.
- Effective communication includes being open and available for feedback, having ongoing discussions and re-evaluating treatment goals.
- Emotional and psychological needs of child/young person/family must be considered at all times. Available counselling and psychological support services should be accessed when appropriate e.g. parent counselling service.

8.3 Ethical issues in Advance and Emergency Care Planning

The ethical principles that underlie advance and emergency care planning are the same as in other health care encounters; respect for autonomy, beneficence, non-maleficence and justice. Any course of action should only be undertaken when the benefit to the child/young person proportionately outweigh the burden¹⁸ and with the appropriate consent. Herein lays the challenge – to predict benefits and burdens within the context of uncertainty. Potential outcomes must be evaluated based on facts and values, which may be very subjective.

Health care professionals should be aware of differences in how burden is perceived, looking from the perspective of the child/young person in isolation versus being embedded in a family unit. It may be difficult to separate the best interests of the child from those of their caregivers and extended family members. The best interests of the child should be of paramount consideration¹⁹.

8.3.1 Assessment of Best Interest.

- (1) Guidance is set out by the GMC¹¹ (0-18 years: guidance for all doctors. General Medical Council 2007, paragraphs 12-13)
An assessment of best interests will include what is clinically indicated in a particular case. You should also consider:
 - a) The views of the child or young person, so far as they can express them, including any previously expressed preferences
 - b) The views of parents
 - c) The views of others close to the child or young person
 - d) The cultural, religious or other beliefs and values of the child or parents
 - e) The views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
 - f) Where there are a number of options, that which will least restrict the child or young person's future options should be selected.

This list is not exhaustive. The weight attached to each point will depend on the circumstances, and all other relevant information should be considered. One should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability.

Guiding principles are set out by the General Medical Council (GMC) 'Respect for human life and best interests', (see paragraphs 9-11).

In cases of acute critical illness where the outcome of treatment is unclear, as for some patients who require intensive care, survival from

the acute crisis would be regarded as being in the patient's best interests.²⁰

In the case of a 16 or 17 year old who lacks capacity to consent to treatment and care, the Mental Capacity Act 2005 and its *Code of Practice* must be adhered to.

8.4 When to Attempt CPR

Where no explicit decision has been made about the appropriateness or otherwise of attempting resuscitation prior to a patient suffering cardiac or respiratory arrest, and the express wishes of the child and/or family are unknown and cannot be ascertained, health professionals should make all reasonable efforts to attempt to revive the patient.

Ideally, decisions about whether to attempt to resuscitate an individual are made in advance as part of overall care planning for that patient and, as such, are discussed with the patient along with other aspects of future care. Neither patients, nor those close to them, can demand treatment that is clinically inappropriate.

In an emergency situation and in the absence of the patient's consultant/GP, the doctor on duty should attempt CPR unless:

- The Advance and Emergency Care Pathway suggests alternative management
- The patient is clearly in the terminal phase of illness
- Sufficient information is available to make a judgement that CPR would not be in the child/young person's best interest.

Where CPR may restart the heart and breathing for a sustained period but there are doubts about whether this is in a child's best interest, the views of the family, child or young person should be taken into consideration in deciding whether it should be attempted.³

8.5 Refusal of Treatment

- Parents or carers with parental responsibility are the usual proxy decision makers for children under 16 years of age who are unable to decide for themselves.
- Gillick competent children or 16-17 year olds with mental capacity to decide must be fully involved in all decisions affecting them and give consent to proposed treatment and care.¹¹
- The views of children and young people must be taken into consideration when making decisions about attempting CPR.
- Gillick competent children and 16-17 year olds with capacity can consent to treatment in England and Wales^{20,21}.

- Where either a young person of 16 or 17 with capacity or a Gillick competent child under 16, refuses treatment, case law has stated that such a refusal can be over-ruled by a person with parental responsibility for the child. However this case pre-dates the Human Rights Act 1998⁵ and the Mental Capacity Act 2005¹⁵ and any health professional faced with these circumstances should exercise extreme caution. It is the Welsh Assembly Government's view that a Gillick competent child/young person or a young person aged 16-17years should be treated in the same way as an adult and treatment should not be given on the basis of parental consent.^{20,21}
- Patients/parents cannot require doctors to provide treatment contrary to their professional judgement, but doctors will try to accommodate patient/parental wishes as far as they are compatible with the child/young person's best interests.
- If there is disagreement between the child/young person/those with parental responsibility and the health care team which cannot be resolved by any other measures such as independent advice, then legal advice must be sought^{11,19,20}.

9. TEMPORARY SUSPENSION OF A DNAR ORDER RECORDED IN THE ADVANCE AND EMERGENCY CARE PATHWAY

- Some patients for whom a DNAR decision has been established may develop cardiac or respiratory arrest from a readily reversible cause such as choking, induction of anaesthesia, anaphylaxis or blocked tracheostomy tube. In such situations CPR may be appropriate while the reversible cause is addressed, unless the child/young person/parents have specifically refused intervention in these circumstances.
- In addition to readily reversible causes, it may be appropriate to temporarily suspend a decision not to attempt CPR during some procedures if the procedure itself could precipitate a cardiopulmonary arrest – for example surgical operations. General or regional anaesthesia may cause cardiovascular or respiratory instability that requires supportive treatment. Many routine interventions used during anaesthesia may be regarded as resuscitative measures. DNAR decisions should be reviewed in advance of the procedure. Ideally this should be discussed with the child/young person, family and health care team, as part of the consent process. The time at which the DNAR decision is reinstated should also be discussed, agreed and documented.

10. RESPONSIBILITY FOR ADVANCE AND EMERGENCY CARE PATHWAY DECISION MAKING

- Overall responsibility for ensuring that decisions about CPR and DNAR orders are made and are clear rests with the consultant or GP in charge of the patient's care. It may be a health care

professional with primary responsibility for the most significant illness at the time (e.g. oncologist for a child/young person with cancer). He/she should discuss the Advance and Emergency care pathway for a patient with other health care professionals involved in the individual's care, always providing the appropriate consent has been given for this.

- Advance and Emergency care pathways should involve other members of the team to address physical, psychological and spiritual needs of the child and their family²². Input from a respected spiritual leader may be invaluable. The language needs of patients and their families must be met; interpreters must be used when necessary.
- Where responsibility for a child/young person's care is shared (e.g. between a consultant and a GP or between more than one consultant) decisions should be made together.
- Following initial discussions, one individual should take charge of ensuring that the decision is properly recorded and communicated to those who need to be aware of it.
- Decisions about AECPs/DNAR should be undertaken in compliance with the organisations Policy on Consent for Imaging, Examination and Treatment.²³
- Any AECPs/DNAR decisions must be made based on the current clinical condition of the patient. AECP decisions must be based on reliable, up-to-date clinical guidelines. An AECP decision must be made on an individual basis. Standard rules or blanket policies are unlawful and cannot apply.

11. COMMUNICATING ADVANCE AND EMERGENCY CARE PATHWAY DECISIONS

- Decisions regarding AECPs in children need to be clearly communicated to all involved with their care, for example; schools, hospice, respite carers etc. Consent from either the child/young person or the person with parental responsibility (whichever is relevant) must be obtained.
- A leaflet should be made available to patients and people close to them explaining AECPs, how decisions are made and what their involvement would be in the process.
- Any decisions about CPR should be communicated between health professionals whenever a patient is transferred between establishments, between different areas or departments of the same establishment, or is discharged home.
- Transfer of patients between facilities: it is the responsibility of the clinical team caring for the patient to review the patient's resuscitation status at the earliest opportunity following transfer between healthcare settings or out into the community. This may mean review after transfer by the transferring lead clinician or handover to and review by receiving team (e.g. other speciality team neurology, respiratory, renal, cardiac, community consultant).

12. RECORDING ADVANCE AND EMERGENCY CARE PATHWAY (DNAR) DECISIONS

- All decisions relating to resuscitation should be clearly documented with the date of the decision and the reason for it.
- Any DNAR decision and the reasons for it must be recorded in the medical notes*. The documentation must be dated and signed by the most senior member of the team.
- *The use of the dedicated [AECP form](#) is recommended; this form should be completed and filed in the front of the medical notes.
- Any decision relating to attempting CPR should be clearly recorded in the nursing notes by the primary nurse or the most senior member of the nursing team whose responsibility it is to inform other members of the nursing team.
- Any decision about the provision of attempted CPR must be readily accessible to all relevant health care professionals.
- In acute hospitals the consultant making the decision may delegate the communication of this decision to his/her colleagues.
- Where GPs make this decision, they are responsible for its appropriate dissemination.

13. COMMUNICATING ADVANCE AND EMERGENCY CARE PATHWAY DECISIONS TO THE MULTIAGENCY TEAM

13.1. Ambulance

- Clinical guidelines issued by the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) advise ambulance staff that they should always initiate CPR unless: there is a formal AECP decision, which has been seen by the ambulance crew, and the circumstances in which CPR may be attempted are consistent with the wording of the AECP decision; or the child/young person is known to be terminally ill and is being transferred to a palliative or terminal care facility (unless specific instructions have been received that CPR should be attempted).
- To enable the ambulance staff to comply with these guidelines, procedures must be in place to notify the ambulance staff of the child/young person's CPR status, and provide them with the necessary documentation before the transfer commences.
- If a child/young person is being transferred from hospital to a palliative care facility for terminal care then it is the responsibility of the transferring clinician to ensure that the ambulance crew have viewed a copy of the child/young person's AECP prior to transfer.

- If an ambulance crew is called to attend a child/young person with an AECp in the community – e.g. at home, the ambulance control system will alert the crew that an AECp exists. The crew will receive no information about the contents of the AECp; it will be the responsibility of the child/young person's carer to show the crew the most up to date copy of the child/young person's AECp.
- The ambulance control system will only communicate information to the ambulance crew about the existence of an AECp if the 999 call is made from the child/young person's home address. If an ambulance is called from an address other than the home – e.g. school; it will be the responsibility of the child/young person's attending carer to show the crew the most up to date copy of the child/young person's AECp.
- When attending the child, professionals must be aware that where the AECp has been drawn up on the basis of consent by a person with parental responsibility, that person may change their mind and request resuscitation for their child.

13.2 General Practitioner (GP)

- The child/young person's GP will be invited to contribute to the AECp planning process.
- It will be the child/young person's GP's responsibility to ensure that details of the individual's AECp are communicated to the Out of Hours GP service with the appropriate consent.
- It remains the GP's responsibility to ensure that the information that the Out of Hours GP service holds is up to date and that they are in receipt of the child/young person's current AECp.

13.3. Education

- Timely and sensitive use of the AECp should also facilitate discussion around the limitations of its use, for example in the school setting where education staff have a duty to call an ambulance and initiate resuscitation.

13.4. Child Health and Disability (CHAD) Social Services

- Any child/young person with a AECp is likely to have an appointed Special Needs Health Visitor (SNHV) or CHAD Social worker (SW).
- Some children/young people requiring an AECp would benefit from accessing Cardiff Child Advocacy Team (tel. 02920668956) as provided by Cardiff Children's Services to ensure their participation in decision-making is optimised. Current work in development is an equivalent Advocacy Service in the Vale of Glamorgan though in the interim an assigned key worker may facilitate this role on an individual case basis.

- Advocacy needs may be discussed with the child/young person/family and their respective Special Needs Health Visitor or CHAD social worker.
- It will be the responsibility of the named SW/SNHV to disseminate information about an AECP to respite carers other than Community Children's Nurses with the appropriate consent.

13.5. The Coroner

- The Coroner investigates all deaths the cause of which is unknown or unnatural. A child/young person with an AECP may die unexpectedly or the cause of their death may not be known. If a child/young person has an AECP this does not negate the need to involve the Coroner.
- Families should be made aware that if an ambulance is called to attend a child/young person's death the police and therefore also the Coroner will automatically be informed of the child/young person's death. The Coroner then has a duty to investigate the death.
- The aim of the Coroner's investigation is to establish the cause of a child/young person's death. This may only involve seeking this information from a doctor who knows this child. For deaths that occur out of hours this may not be possible until the next working day. If the cause of death is unclear from discussions with health professionals the Coroner may proceed to further investigations which may include a post mortem examination of the child/young person.
- If a death is being investigated by the Coroner the child/young person's body must reside in the local mortuary. The child/young person should not be washed or changed and equipment, such as indwelling tubes or lines must not be removed without the Coroner's permission.
- Creating an AECP should provide an opportunity to prepare parents and carers for possible Coroner involvement when their child dies. It does not negate the need for a Coroner's investigation of an unexplained death.

13.6 Police

- When a child dies at home (or elsewhere in the community) the police may have a duty to investigate the circumstances of the death.
- The existence of an AECP cannot remove the obligations that the police have or limit their investigative responsibility. The police should be made aware at the earliest opportunity of the existence of such an AECP as this will assist information sharing between professionals and support the decision making process.

- Creating an AECP should provide an opportunity to prepare parents and carers for possible police involvement when their child dies.

13.7 Tÿ Hafan Children's Hospice

- The team at Tÿ Hafan Children's Hospice have a wealth of experience of caring for children/young people with life-limiting illnesses and their families; throughout life, through death and into bereavement. The team are able to share this expertise with families and professionals.
- Tÿ Hafan uses its own advance care planning documentation with its children and young people when felt to be appropriate. The documentation includes planning for spiritual care and pre and post bereavement support. Such care should complement the Cardiff and Vale AECP.
- The Family Support team at Tÿ Hafan offer a 24-hour on call service to families. Tÿ Hafan could act as 1st contact for families in the event of their child dying outside of normal working hours when other professionals may not be contactable. This might involve the Tÿ Hafan family support worker supporting the family at home if needed and liaising with professionals from other agencies.
- In order for Tÿ Hafan to offer this service the child/young person does not need to be accessing the hospice already but Tÿ Hafan must hold an up to date copy of the child/young person's AECP.
- All AECPs drawn up for children/young people in Cardiff and The Vale of Glamorgan must be copied to The Assistant Director of Care at Tÿ Hafan, providing consent has been obtained for this. The family support team will then hold up to date information in order to support families and will monitor the need for annual review of AECPs.
- If professionals need to access information from a child/young person's AECP outside of normal working hours and in the absence of being able to access any other copy of the AECP such as the parent-held copy, they could contact the family support team at Tÿ Hafan to access Tÿ Hafan's copy.
- The Tÿ Hafan family support team are contactable on Tel. (029) 20532200

14. REVIEWING THE ADVANCE AND EMERGENCY CARE PATHWAY/DNAR DECISION

- AECP/DNAR decisions must be reviewed regularly. The frequency of the review will be determined by the child/young person's health care needs and professional in charge and may be influenced by:
 - Changes in the child/young person's condition
 - Changes in patient or family wishes
 - Transfer from one facility to another

- Changes in the consultant or GP in charge
- When a DNAR decision is documented in the patient's medical notes a review date should be written at the same time. The AEC Pathway form (Appendix 1) should be completed to document the AEC/DNAR decision.
- These discussions should occur early and regularly throughout the course of treatment, ideally before crises arise, and as the goals of care are clarified or change over time. Decisions should be reviewed on a regular basis and revised as necessary as the medical condition and knowledge of treatment and prognosis evolve.
- Paediatric palliative care professionals should be involved early in discussions of treatment goals. Discussions about palliative care should ideally take place well before the child is at imminent risk of dying.

15. RAISING AWARENESS OF THE ADVANCE AND EMERGENCY CARE PATHWAY POLICY

All newly employed health professionals will be made aware of the Cardiff and Vale UHB policy on DNAR and their responsibilities according to the policy at Health Board induction. Staff must have access to this document. The Resuscitation Service will provide this information. Existing staff will be made aware of the Cardiff and Vale Child and Young person AEC or Adult DNAR policy through the Resuscitation Service and attending regular health professional scheduled meetings.

16. REVIEW OF THE ADVANCE AND EMERGENCY CARE PATHWAY POLICY

It is the responsibility of the Child Health Advance and Emergency Care Pathway Focus Group in liaison with the Resuscitation Group of Cardiff and Vale UHB to review and update the AEC policy, taking into account new guidelines, changes in the law, and/or recommendations arising from audit following the implementation of the policy. Review of the policy will occur routinely once every two years and more frequently if required. These amendments will be presented to The Children & Women's Division Safety and Quality Group.

17. IMPLEMENTATION

All newly employed health professionals will be made aware of the Cardiff and Vale UHB policy on AEC and their responsibilities according to the policy at their local induction. Existing staff will be made aware of the policy through training and dissemination of this information to all appropriate divisions and managers in accordance with the management of policies and procedures for Cardiff and Vale UHB.

It will also be available to the public via the UHB website.

18. RESOURCES AND FUNDING

The policy will be distributed electronically and introduced to doctors as part of the in-house training programme when being appointed to work for Cardiff and Vale UHB. Full printed forms will be available on specific request.

The implementation of this policy does not require any additional resources.

19. AUDIT

Compliance with this policy and the completion of AECP forms will be assessed through a process of spot-check audit. Professionals using the AECP will be required to complete an audit form and return this to St David's Children's Centre. Audit data will be examined by the Child Health Advance and Emergency Care Pathway Focus Group and presented to the Child Health and Women Division at a Clinical Governance Meeting 12 months after the introduction of the AECP and then at regular intervals thereafter.

20. EQUALITY

The UHB is committed to ensuring that, as far as is reasonably practicable, the way it provides services to the public and the way it treat its staff reflects their individual needs and does not discriminate against individuals or groups.

The UHB has undertaken an Equality Impact Assessment and received feedback on this policy and the way it operates. The UHB wanted to know of any possible or actual impact that this policy may have on any groups in respect of gender (including maternity and pregnancy as well as marriage or civil partnership issues), race, disability, sexual orientation, Welsh language, religion or belief, transgender, age or other protected characteristics. The assessment found that there was no impact to the equality groups mentioned.

Where appropriate the UHB will make plans for the necessary actions required to minimise any stated impact to ensure that it meets its responsibilities under the equalities²⁴ and human rights legislation⁵.

21. CONTRIBUTORS

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We would like to acknowledge the work of Neath Port Talbot Safeguarding Children's Board Management Group. The Cardiff and Vale AECP and Neath Port Talbot ACP have been developed as comparable documents with the ultimate aim of developing an all Wales document and policy.

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