

**ALL WALES PAEDIATRIC ADVANCE CARE PLAN (PAC-PLAN) POLICY FOR PATIENTS UNDER 18 YEARS OF AGE WITH LIFE THREATENING OR LIFE LIMITING ILLNESS**

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**Author Name and Job Title:** PAC-Plan Development sub-group of All-Wales Network in Paediatric Palliative Care

**Responsible Officer:** Richard Hain  
**Name and Job Title:** Clinical Lead, Paediatric Palliative Care

**Details of lead/responsible:** Chair  
**Group/Committee:** All-Wales Network in Paediatric Palliative Care

**Consulted Via:** All-Wales Medical Directors' Group  
 Clinical Ethics Committee  
 Cardiff and Vale of Glamorgan Local Safeguarding Children Board (formerly UHB Safeguarding Children's Board)  
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## 1. EXECUTIVE SUMMARY

### 1.1. Purpose of Policy

For every person there comes a time when death is inevitable. For a child with life threatening or life limiting illness that time is expected to arrive during childhood.

The purpose of the Paediatric Advance Care Plan (PAC-Plan) policy is to outline the legal and ethical standards for planning patient care and decision making at the end of a child's life, particularly in relation to interventions that might delay death at the cost of pain or discomfort to the child.

## 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.”<sup>1</sup>

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

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 interventions at the end of life should form part of a holistic end of life planning for a child or young person with a life threatening or life limiting illness.

Use of a Paediatric Advance Care Plan (PAC-Plan) includes options regarding resuscitation should alert the beginning of a process of discussion and individualised care for that particular child and family with the condition.<sup>2</sup>

It is vital to encourage the involvement of the patient, their family, the health care team and people close to the patient in decision making, and to ensure the communication of decisions to all relevant health and multiagency

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professionals. (GP, Community Nursing service, Respite, Education, Social Services, Ambulance, Police, Coroner, Bereavement Services) <sup>3</sup>

### 3.0 POLICY STATEMENT

Cardiff and Vale University Health Board is committed to implementing the guidance for Paediatric Advance Care Planning 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 the Cardiff and Vale University Local Health Board Policy on DNAR in adults<sup>4</sup>, and Guidance from RCPCH <sup>2,8</sup>, NICE, the GMC, BMA, RC (UK), RCN.<sup>3</sup>

The purpose of the Paediatric Advance Care Planning 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 and admission to intensive care for mechanical ventilation.

### 4.0 AIMS OF POLICY

- To implement a consistent approach to Advance Care Planning in children.
- To ensure children receive appropriate and effective resuscitation when necessary and without delay
- To ensure children are treated with dignity and their human rights are respected<sup>5</sup>
- To ensure appropriate, correct and respected application of United Nations Convention on Rights of the Child<sup>6</sup>
- **To promote current best practice in children's palliative care and specifically in the area of advance care planning based on current national guidance from ACT <sup>1</sup>, Royal College of Paediatrics and Child Health <sup>7</sup>, Royal College of Physicians <sup>2,8</sup>, IMPaCCT group<sup>9</sup>, Department of Health<sup>10</sup>, General Medical Council<sup>11</sup>, Welsh Assembly Government <sup>12</sup>, National Service Framework for Children<sup>13</sup>.**
- **To comply with Department of Health requirements**
  - To provide support for clinical staff
  - To provide written information for children and relatives
  - To satisfy legal and professional requirements
  - To minimise clinical risk, litigation and material loss

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- To comply with UHB requirements for formal organisation-wide policies.
- To ensure the PAC-Plan 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

All members of staff who are involved in planning of patient care, review and decision making in relation to children or young people with life threatening or life limiting illness requiring paediatric advance care planning with regards to active treatment and/or symptom control and cardiopulmonary resuscitation.

## 6.0 DEFINITION OF TERMS

**6.1** 'DNAR' ('Do Not Attempt to Resuscitate') was a term historically used to record a decision that in the event of a sudden deterioration resulting in cardiorespiratory failure, no resuscitation would be carried out.<sup>4</sup> Developed in adults, 'DNAR' is not appropriate in the context of a child/young person with life threatening or life limiting illness, for three main reasons:

- DNAR is often seen to represent a unilateral decision on the part of the doctor or healthcare team. Where there are multiple family members and carers involved, as is usual in the care of a child with a life-limiting condition, other views (especially those of parents) must be solicited before such a decision is made.
- DNAR offers only binary options ("do everything/do nothing") and its scope is limited to cardiopulmonary resuscitation, rather than to life-saving or life-sustaining treatments more generally. In children, it is more important to set out the range of options that have been discussed and an indication that consensus has been reached. Effective communication is key to the success of paediatric advance care planning.
- Parents do not have the same right to refuse treatment on behalf of their child as an adult patient would have to refuse her own treatment. Conclusions about end of life care in children represent preferences on the part of a child, young person and/or their family. that are agreed by healthcare professionals to be reasonable.

## 6.2 Life-limiting Conditions

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people are expected to die before reaching adulthood. They typically cause progressive deterioration, rendering the child increasingly dependent on parents and carers as adulthood approaches<sup>1</sup>.

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### 6.3 Life-threatening Conditions

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

### 6.4 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. Since it is rarely clear at the outset of an acute deterioration whether or not it will result in death, it is usual for children with complex chronic conditions to have several 'end of life' episodes.

### 6.5 Paediatric Advance Care Planning

Paediatric advance care planning begins when a child or fetus 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 child/young person, their parent/carers and the child's paediatrician should agree on the most appropriate care in an emergency or slow deterioration and sign a pathway form (see Appendix 1). Paediatric advance care planning may conclude that any of a range of options be in the child/young person's best interests, from full resuscitation including invasive ventilation through active treatment which might be life-prolonging (e.g. IV antibiotics) but stops short of invasive ventilation support or CPR, to measures where the aim of treatment is to relieve symptoms without prolonging life.

### 6.6 Child

There is a clear legal distinction, in terms of treatment decision-making between those who are 16 years of age and over and those who are under 16. In this Policy, reference to a child means a patient who is under 16 years of age. Patients who are 16 and 17 years old are referred to as young people. Children are presumed not to be competent to make their own treatment decisions, unless they have been assessed to be *Gillick* competent. In contrast, patients aged 16 years and over are presumed to have capacity to make their own decisions.

A child or young person may have a PAC-Plan or begin the discussions about completing a PAC-Plan at any point in time while they remain under the primary care of a lead child health professional.



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Work is under way to develop a PAC-Plan for young adults with life-limiting conditions who lack capacity. Professionals should be aware that the legal framework and systems for assessing capacity are different for adults. Professionals should seek appropriate advice regarding this matter.

### **6.7 Cardiopulmonary Resuscitation (CPR)**

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

## **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 children and relatives.

### **7.1 Health Board**

The UHB Board carries overall responsibility for Cardiff and Vale UHB. It has delegated powers from the National Assembly for Wales 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's Rights and that any decisions made by staff are informed via the Paediatric Advance Care Planning 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, and be aware of the need to specify them appropriately for the particular issues of children through discussion with specialists in paediatric end of life and intensive care.

### **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 using guidance to ensure full multidisciplinary representation. It monitors cardiac arrest outcome and team response as well as adherence to resuscitation policies (including PAC-Plan policy). The Senior Resuscitation Practitioner will maintain, manage and develop the service, within available resources, to meet the needs of the Health Board.

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#### **7.4 All-Wales Network in Paediatric Palliative Care**

The PAC-Plan subgroup is convened under the All-Wales Network in Paediatric Palliative Care. The Network meets on a regular basis. Members should be conversant with contemporary issues related to new developmental knowledge and review and update this policy annually through regular clinical governance procedures.

#### **7.5 Clinical Board 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, children and their relatives have access to and understand resuscitation policies, especially the PAC-Plan 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 PAC-Plan policy ensure that children and their families have access to and understand it. Staff must respect patient rights to confidentiality whilst ensuring that decisions relating to PAC-Plan are communicated to appropriate colleagues with informed consent.<sup>14</sup>

### **8. PAEDIATRIC ADVANCE CARE PLANNING DECISION MAKING**

Advance Care Planning is an extension of usual discussions about plans for treatment, which have conventionally focused on curative measures and on what will be provided rather than what will not. Paediatric advance care planning broadly encompasses both short-term and long-term health care goals and treatments. It may include the drafting of formal advance options, which specify what treatments will or will not be provided for the child/young person. The benefits of Advance Care Planning **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 paediatric advance care planning 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 Care Planning for Children/Young People with Life Threatening or Life Limiting Conditions – a New Standard of Care**

Advance care planning in paediatrics is most important among children with

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life-limiting or life-threatening conditions. Among such children, the expected mode of death is often an acute deterioration in respiratory, brain or bowel function. The stimulus for discussion is usually recognition that some interventions, especially those associated with intensive care, will do harm to the child that cannot be justified because the chance that they will prolong the child's life is too small. Such discussions represent a transition from a curative to a palliative focus of care that can be abrupt if the discussions are left too late. 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 proceed alongside treatments which may have cure as their goal.

## 8.2 Timing of Initiating the Advance Care and Emergency Pathway Process

- As a general rule, the earlier PAC-Planning begins in the trajectory of an individual child's illness, the better prepared the family and healthcare team can be at the time of the child's death.
- Each family is different, however, and the most appropriate timing will depend on the readiness of the family to engage with the process. A significant minority of families will never be willing to do so, while others will feel comfortable with having the discussions but will never sign the form.
- PAC-Plan discussions take place over many weeks and months. Even in the paediatric intensive care setting, in which decision-making often occurs on a compressed timeline, one Canadian study<sup>15</sup> 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 Care Planning

The ethical principles that underlie Advance Care Planning include 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 burden<sup>16</sup>. Since it is not possible precisely to predict benefits and burdens, the PAC-Plan is designed to encourage 'parallel planning'; that is, an exploration of different scenarios that might occur at the end of life, and a record of preferences in each. Those preferences result from values as well as medical facts, and the PAC-Plan accommodates views that are subjective. Health care professionals should be aware of differences in how burden is perceived, looking from the perspective of the child/young

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person in isolation versus being embedded in a family unit. It may even be difficult to separate the interests of the child from those of their caregivers and extended family members. The best interests of the child, however, should be of paramount consideration<sup>17</sup>.

### **8.3.1 Assessment of Best Interest.**

- (1) General guiding principles are set out by the General Medical Council (GMC) 'Respect for human life and best interests, (see paragraphs 9-11). There is specific guidance in children<sup>11</sup> (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.

In cases of acute critical illness where the outcome of treatment is unclear, as for some children who require intensive care, survival from the acute crisis would be regarded as being in the patient's best interests<sup>18</sup>

### **8.3.2 Capacity to Consent**

Guidance is set out by the GMC re decisions on capacity to consent (see paragraphs 24-29)<sup>11</sup> (see Paragraph 68-72)<sup>18</sup> See also the UHB's Consent to Examination or Treatment Policy.

The capacity of paediatric patients to consent ranges from those who lack capacity altogether to those who are fully capable of consent. The

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latter defines the mature or ‘Gillick Competent’ minor, who is legally not an adult according to chronological age criteria, but has the cognitive ability to consider treatment choices and alternatives and weigh the consequences and, other than by age, would be considered to have capacity as defined by the Mental Capacity Act 2005.

The authority of the expressed preferences of a Gillick competent minor are essentially those of an adult and cannot usually be overridden, even if they are seen to be perverse or irrational, without express permission from the Court.

Where minors lack ‘Gillick Competence’ but are capable of expressing a preference, that preference is important and should be given weight in end of life decision-making, even if it is ultimately necessary to override it on the grounds of the child’s interests.

A Scandinavian study<sup>19</sup> found that a quarter of parents regretted not talking about death with their child who was dying of cancer, suggesting that one of our responsibilities is to help parents address this issue. Providing information is consistent with the duty to be honest with our children. We respect their dignity by only administering treatments that they have freely chosen and desire.

#### **8.4 When to Attempt CPR**

Where no explicit advance 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 children, 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 Paediatric Advance Care Planning 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.

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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.<sup>3</sup>

### 8.5. Refusal of Treatment

- Adults with parental responsibility are the usual proxy decision makers for children who are unable to decide for themselves.
- Whenever possible, children or young people should be fully involved in all decisions affecting them, even if they are not Gillick competent or lack capacity.<sup>11</sup>
- The views of children and young people must be taken into consideration when making decisions about end of life interventions, even when they are not able to make the decisions for themselves.
- Competent children can consent to treatment in England and Wales<sup>9</sup>.
- Refusal of treatment by a Gillick-competent minor cannot usually be overturned without express permission from the Courts<sup>11</sup>. In the past, the Courts typically supported the treatment preferences of parents over those of the child, but that is becoming increasingly uncommon and should not be assumed.
- Parents cannot require doctors to provide treatment contrary to their professional judgement, but doctors must try to accommodate parental wishes as far as they are compatible with the child's best interests.
- If there is disagreement between those with parental responsibility and the health care team, advice from the Clinical Ethics Committee and/or legal advice must be sought in a timely fashion<sup>11</sup>.

## 9. TEMPORARY SUSPENSION OF A PAC-PLAN ORDER RECORDED IN AN ADVANCE & EMERGENCY CARE PATHWAY

- The PAC-Plan discussions include exploration of the possibility that cardiac or respiratory arrest will occur in a child with a life-limiting condition, but from a readily reversible cause such as choking, induction of anaesthesia, anaphylaxis or blocked tracheostomy tube. In such situations CPR will usually be appropriate while the reversible cause is addressed. A specific example is where an intervention carries the risk of cardiopulmonary arrest. General or regional anaesthesia, for example, may cause cardiovascular or respiratory instability that

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should usually be treated, irrespective of the conclusions recorded in a PAC-Plan.

- It is good practice to review the PAC-Plan as part of the clinical preparation for surgery, and again once the child has returned to base-line health afterwards.

## 10. RESPONSIBILITY FOR PAEDIATRIC ADVANCE CARE PLANNING DECISION MAKING

- The conclusions recorded on a PAC-Plan are to guide clinicians making decisions about the appropriateness or otherwise of certain interventions at the end of a child's life. They are not legally binding, and do not replace discussions with patients/families at the actual time of an acute deterioration.
- They do not obviate the need to make a decision in the interests of the child at the point of an acute deterioration. 'Standard rules' or 'blanket policies' that restrict interventions for reasons other than the interests of the child at the time are unlawful and cannot apply.
- Overall responsibility for decisions about what interventions are appropriate rests with the physician in charge of the patient's care, who may be the specialist with primary responsibility for the most significant illness at the time (e.g. oncologist for a child/young person with cancer).
- Where responsibility for a child/young person's care is shared (e.g. between general paediatrics and paediatric palliative care) decisions should be made together. However, one individual should take the lead in the PAC-Plan process, ensuring discussions are properly recorded and communicated to those who need to be aware of them.
- If it becomes clear that there is important disagreement within the team (or between the team and parents, for example), legal advice should be sought from the Clinical Ethics Committee and/or a legal representative. This should be timely enough to allow the possibility of resolution before a life-threatening episode.
- PAC-Plan conclusions must be based on reliable, up-to-date clinical guidelines.
- The language needs of children and their families must be met; interpreters should be used when necessary.
- Decisions about what interventions are appropriate should be undertaken in compliance with the Cardiff and Vale UHB's Policy Consent to Examination or Treatment Policy.<sup>21</sup>

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## 11. COMMUNICATING PAEDIATRIC ADVANCE CARE PLANNING DECISIONS

- Decisions regarding PAC-Plans in children need to be clearly communicated to all involved with their care, for example; schools, hospice, respite carers, etc. Consent to share this information must be sought from the patient/ someone with parental responsibility for them/ in their best interests.
- A leaflet should be made available to children and people close to them explaining PAC-Plans, 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 children 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 PAEDIATRIC ADVANCE CARE PLANNING (PAC-PLAN) DECISIONS

- All decisions relating to resuscitation should be clearly documented with the date of the decision and the reason for it.
- Any PAC-PLAN 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 PAC-Plan 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.



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- Where GPs make this decision, they are responsible for its appropriate dissemination.

### **13. COMMUNICATING PAEDIATRIC ADVANCE CARE PLANNING 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 PAC-Plan conclusion, which has been seen by the ambulance crew, and the circumstances in which CPR may be attempted are consistent with the wording of the PAC-Plan conclusion; 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 PAC-Plan prior to transfer.
- If an ambulance crew is called to attend a child/young person with a PAC-Plan in the community – e.g. at home the ambulance control system will alert the crew that a PAC-Plan exists. The crew will receive no information about the contents of the PAC-PLAN; 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 PAC-Plan.
- The ambulance control system will only communicate information to the ambulance crew about the existence of a PAC-Plan 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 PAC-Plan
- When attending the child/young person professionals must be aware that the patient, parents/carers of a child or young person with a PAC-Plan may change their mind and request resuscitation for their child.

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### 13.2 General Practitioner (GP)

- The child/young person's GP will be invited to contribute to the PAC-Plan planning process.
- It will be the child/young person's GP's responsibility to ensure that details of the individual's PAC-Plan are communicated to the Out of Hours GP service.
- It remains the GP's responsibility to ensure that the child is on the practice palliative care register information, so that the information available to the Out of Hours GP service is up to date and that they are in receipt of the child/young person's current PAC-Plan.

### 13.3. Education

- Timely and sensitive use of the PAC-Plan 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 PAC-Plan is likely to have an appointed Special Needs Health Visitor (SNHV) or CHAD Social worker (SW)
- Some children/young people requiring a PAC-Plan would benefit from accessing the services of the National Youth Advocacy Service (tel. 029 2066 8956) to ensure their participation in decision-making is optimised.
- 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 a PAC-Plan to respite carers other than Community Children's Nurses.

### 13.5. The Coroner

- The Coroner investigates all deaths the cause of which is unknown or unnatural. A child/young person with a PAC-Plan may die unexpectedly or the cause of their death may not be known. If a child/young person has a PAC-Plan 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.

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- 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 her permission.
- Creating a PAC-Plan 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 a PAC-Plan 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 a PAC-Plan as this will assist information sharing between professionals and support the decision making process.
- Creating a PAC-Plan should provide an opportunity to prepare parents and carers for possible police involvement when their child dies.

### 13.7 Ty Hafan Children's Hospice

- The team at Ty 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.
- Ty 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 PAC-Plan.
- The Family Support team at Ty Hafan offer a 24-hour on call service to families. Ty Hafan could act as 1<sup>st</sup> contact for families

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in the event of their child dying outside of normal working hours when other professionals may not be contactable. This might involve the Ty Hafan family support worker supporting the family at home if needed and liaising with professionals from other agencies.

- In order for Ty Hafan to offer this service the child/young person does not need to be accessing the hospice already but Ty Hafan must hold an up to date copy of the child/young person's PAC-PLAN.
- **All** PAC-Plans drawn up for children/young people in Cardiff and The Vale of Glamorgan must be copied to The Assistant Director of Care at Ty Hafan, providing consent has been given 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 PAC-Plans.
- If professionals need to access information from a child/young person's PAC-Plan outside of normal working hours and in the absence of being able to access any other copy of the PAC-Plan such as the parent-held copy, they could contact the family support team at Ty Hafan to access Ty Hafan's copy.
- The Ty Hafan family support team are contactable on Tel. (029) 20532200

#### **14. REVIEWING THE PAEDIATRIC ADVANCE CARE PLANNING DECISION**

- PAC-Plan documentation 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
- Every PAC-Plan document should include a review date.
- PAC-Plan 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

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care should ideally take place well before the child is at imminent risk of dying.

## **15. RAISING AWARENESS OF THE PAEDIATRIC ADVANCE CARE PLANNING POLICY**

At Health Board induction, all newly employed health professionals will be made aware of the Cardiff and Vale UHB paediatric advance care planning policy and their responsibilities according to the policy. 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 advance care planning policy for children through the Resuscitation Service and attending regular health professional scheduled meetings.

## **16. REVIEW OF THE PAEDIATRIC ADVANCE CARE PLANNING POLICY**

It is the responsibility of the Child Health Paediatric Advance Care Planning Focus Group in liaison with the Resuscitation Group of Cardiff and Vale UHB to review and update the PAC-Plan 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 three years and more frequently if required. These amendments will be presented to The Quality, Safety and Experience Committee

## **17. IMPLEMENTATION**

All newly employed health professionals will be made aware of the Cardiff and Vale UHB policy on PAC-Plan 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 Clinical Boards and managers in accordance with the management of policies and procedures for Cardiff and Vale UHB.

## **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 as a download from the Intranet.

## **19. AUDIT**

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Compliance with this policy and the completion of PAC-Plan forms will be assessed through a process of spot-check audit. Professionals using the PAC-Plan 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 Paediatric Advance Care Planning Focus Group and presented to the Children and Women Clinical Board at a Quality, Safety and Experience Meeting 12 months after the introduction of the PAC-Plan and then at regular intervals thereafter.

## 20. EQUALITY

An equality impact assessment has been undertaken to assess the relevance of this policy to equality and potential impact on different groups, specifically in relation to the General Duty of the Race Relations (Amendment) Act 2000 and the Disability Discrimination Act 2005, Equality Act 2010 and including other equality legislation. The assessment identified that the policy presented a low risk to the UHB.

## 21. CONTRIBUTORS

These have contributed to the original policy, or to the updated policy, or to both. Some have moved on to other roles since making their contribution.

Dr Richard Hain	Consultant Paediatric Palliative Medicine (CVUHB)
Dr Jo Griffiths	Consultant Paediatric Palliative Medicine (ABMU)
Dr Sian Moynihan	Consultant Community Child Health
Dr Charlotte Mellor	Paediatric Palliative Medicine SpR
Dr Michelle Jardine	Consultant Paediatric Intensive Care
Dr Helen Fardy	Consultant Paediatric Intensive Care
Dr Cath Norton	Associate Clinical Director Consultant Community Child Health
Dr Louise Hartley	Consultant Paediatric Neurologist
Dr Graham Shortland	Consultant Paediatrician
Cath Thompson	Assistant Director of Care , Ty Hafan
Liz Pendleton	Lead Nurse Community Children's Nursing Cardiff
Mary Glover	Senior Nurse Neonatal Unit
Dr J Calvert	Consultant Neonatologist
Carys Davies	Special Needs Health Visitor
Wendy Herbert	Head of Health Visiting
Diane Rogers	Head of Paediatric Physiotherapy Services
Nuala Mahon	Lead Nurse School Health
Dr Rhodri Lewis	General Practitioner
Chris Horrocks	Service Manager Child Health and Disability

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Ms ME Hassell	HM Coroner for Cardiff and The Vale of Glamorgan
Mrs Hillary Valle	Parent representative

We would like to acknowledge the work of Neath Port Talbot Safeguarding Children's Board Management Group. The Cardiff and Vale PAC-Plan 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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