



All-Wales

Paediatric Palliative Care Network

Guide to using the Paediatric Advance Care Plan (PAC Plan) 2021



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*A Guide for professionals supporting families in developing personalised Advance Care Plans for
Babies, Children or Young people in their care.*

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Definitions and Terminology

Paediatric Advance Care Plan (PAC Plan): is a document that records the advance wishes of a child or young person and/or those with parental responsibility for them. A different Advance Care Plan should normally be used in adults. **For the purposes of this document, where “Advance Care Plan” or ACP is written, it should be read as referring to the “Paediatric Advance Care Plan (PAC Plan)”**. A PAC PLAN will include whether the cardiopulmonary resuscitation status has been discussed, and the outcome of that discussion should a cardiorespiratory arrest occur.

Cardiorespiratory Arrest: is specifically the cessation of breathing and loss of cardiac output. This definition is strict and should not be extrapolated to include any other circumstances. The terminology Cardiopulmonary Arrest is also used in some documents. In children a particular arrest is sometimes documented as a respiratory arrest where there is still cardiac output but cessation of breathing or as a cardiac arrest where there is cessation of breathing and loss of cardiac output. A respiratory arrest is much more common in children than in adults.

Cardiopulmonary Resuscitation (CPR): Interventions delivered with the intention of restarting the heart and breathing. These will include chest compressions and manual ventilation via mouth, bag and mask or endotracheal tube, and may include attempted defibrillation and the administration of drugs.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): refers to a specific, agreed decision to refrain from making efforts to restart breathing and/or the heart following a cardiorespiratory arrest.

Local Lead Clinician for Advance Care Planning: Acts as the primary link between members of his or her organisation and the PAC Plan Co-ordinator.

PAC PLAN Co-ordinator: is responsible for ensuring that all PAC Plans in his or her area (either North or South Wales) are appropriately completed, regularly reviewed and that all relevant parties have the most recent copy of the PAC PLAN.

This role is usually undertaken by a senior clinician, a clinical nurse specialist or member of the All Wales Palliative care network. If an area does not have such a post, an individual nurse or key worker can act as a PAC PLAN co-ordinator for individual children on their caseload.

Child Death Review Panel (CDRP): This group monitors and reviews all deaths of children.

Procedural response for unexpected death in childhood (PRUDiC): When there is a sudden and unexpected death in childhood a PRUDiC occurs. Police and Health work together to understand why the death occurred at that time. If the death of a child with a PAC PLAN occurs at an unexpected time, a PRUDiC response may be triggered.

Adult: A person aged 18 years or over

Young Person: A person aged 16 or 17. Anyone under this age is legally regarded as a baby, infant or child.

For the purposes of this document, when the word “child” is used it can be read as “baby, infant, child or young person”.

Introduction

This guide has been developed by the Paediatric Advance Care Plan working group of the All Wales managed clinical network for paediatric palliative care. It draws heavily on information previously designed for a series of workshops run across Wales on difficult conversations and PAC plans. The working group comprises both NHS and non-NHS healthcare organisations who have come together to adopt a uniform approach to care planning for children with conditions that are likely to foreshorten their lives. It is designed for health care professionals who are considering an Advance Care Plan for a child in their care.

This guide is part of a complete package of documentation that consists of:

- A PAC Plan pro-forma
- A policy on the PAC Plan
- A guide to using the Advance Care Plan
- An information leaflet for parents
- A webpage for professionals [PAC planning \(paedpallcarewales.com\)](http://paedpallcarewales.com)
- A Learning bundle for local teaching events

1. What is a Paediatric advance care plan (PAC Plan) ?

A PAC plan is designed to communicate the health-care wishes of children who have chronic and life-limiting conditions. It sets out an agreed plan of care to be followed when a child or young person's condition deteriorates.

The purpose of the PAC-Plan is to support timely and sensitively paced conversations that resolve the conflict between the family's need for time and the clinicians' need for information. The PAC-Plan provides three things:

1. A 'script' that offers clinicians a structure for difficult discussions about end of life care.
2. A record of what has been discussed.
3. A means of disseminating the results of those discussions.

Where a child/young person is considered to have capacity, their views should be considered in the decision-making. Capacity is related to specific decisions so a child/young person may have capacity for one decision and not another.

It is designed so that it could be used in all environments that the child encounters: home, hospital, school, hospice and respite care. It is also appropriate for use by the ambulance service.

2. Who should initiate and complete a PAC Plan?

Any professional working with the family can complete or contribute to the PAC planning process – It does not have to be the Palliative care team (although they are always happy to help and advice with and support the process). It is best done by a professional who knows the child and family well and is available to support them through the process. This is usually a senior clinician or clinical nurse specialist who knows the child and his or her family well. It is important that all possible treatment options for the child's condition are considered in terms of benefit to the child

It is good practice to involve all key members of the multidisciplinary team in the process, including the general practitioner. If not leading on the process, at least one of the child's consultants should be involved. The process may involve several different discussions over a period of time as it is essential that all concerned in the decision-making process are allowed enough time for information to be given and understood, to consider, to ask questions and to express their opinion.

Step	Action	By
1	Make an assessment of the child's clinical situation: Has there been a new diagnosis or recent change in the prognosis or clinical condition that should prompt the formulation (or revision) of a PAC Plan?	Any professional involved with the child's care
2	Facilitate discussion/s with all health care professionals involved in the child's care and secure their opinions regarding the appropriateness of preparing a PAC Plan.	Senior clinician or CNS in PPC
3	Discuss the child's status with the child's parents/guardians and child (if appropriate). Also include other significant family members where appropriate or social services if Parental responsibility is shared. Establish their feelings regarding the need for a PAC plan. Consider leaving a copy of a PAC plan and information about PAC Plans with the family but stress that they are not expected to complete it themselves. Consider involving an interpreter if they are not fluent in English.	Senior clinician
4	Allow plenty of time to discuss and complete the document with the parents/guardians (and child as appropriate). Allow a minimum of 1–2 hours. Consider the best setting for this conversation or conversations (home, hospital or elsewhere). Completion of the plan may require several consultations/discussions, which may take place over several days or weeks. The amount of input into this process by the child depends on their capacity for this decision	Palliative care nurse specialist, senior clinician or Senior children's community nurse (CCN)
5.	The document should be signed by the person leading discussions (PAC plan lead) to ensure it reflects the discussions. A senior clinician (who may or may not be the same person as the PAC plan lead), should sign to say they are in agreement with the plan. This is usually the child's lead consultant.	As per part 4 Senior clinician
6	Once the PAC plan is completed it is important to discuss who it will be shared with and why. Gain parental consent to share information and obtain signature for the same – steps 9 onwards depend on parental consent to share information.	Senior specialist nurse and/or senior clinician

7	<p>Set review date for PAC plan.</p> <p>There is no standard maximum time before review: this depends on the child's individual circumstances and is at the discretion of the lead clinician. An earlier review should be triggered should the child's condition change significantly.</p>	Senior specialist nurse or senior clinician
8	<p>Ensure that all care settings that the child attends have copies of the plan, (or know how to access it), and receive updated copies as appropriate. Template cover letters explaining what a PAC plan is are available.</p> <p>The responsibility for this lies with the completing professional unless specifically designated to the local Palliative care team.</p>	Completing professional
9	<p>Send a copy to the central email PAC.plans.cav@wales.nhs.uk for action by the AWMCN data manager for audit purposes</p>	Completing professional
10	<p>Send a copy to Welsh ambulance service at amb_PacPlans@wales.nhs.uk (there is an underscore between amb and Pac)</p>	Completing professional
11	<p>The Pac plan is added to the central databases in Ty Hafan and the palliative medicine service to ensure out of hours access.</p>	PPC Data manager

For further information and advice about the process of PAC planning, link with your local palliative care leads or email PAC.plans.cav@wales.nhs.uk

There are information leaflets for families and for professionals about advance care planning available from www.paedpallcarewales.com.

3. When to complete a PAC Plan?

If you would not be surprised if a child were to die prematurely, during this episode of care or within the next year it is probably a good idea to start thinking about a PAC plan.

Often families will have heard about PAC planning from other families or professionals or it might come up naturally in conversation whilst discussing other things with the family. Sometimes especially if you know the family well you will already have some idea of what their wishes may be and what their fears are.

The best time to complete a PAC plan (although not always practical) is when a child is well and the family can consider things objectively knowing that they have time to think about things. Often you find a PAC plan will be discussed after a period of acute illness if the child has been very unwell and especially if they have been in intensive care.

4. What a PAC Plan is not.

The PAC-Plan provides a script for discussing end of life scenarios that are reversible, those that are irreversible, and those that are intolerable. It provides a record of the fact of the

discussions, the place of care and/or death that the family would prefer, and the interventions they would ideally like to happen at the time of acute deterioration. Finally, it offers a way of disseminating the results of those discussions to the medical notes, the ambulance service and the police.

There are some important things that the PAC-Plan is not:

- It is not a new version of the DNACPR. It is no longer ever appropriate for the healthcare team unilaterally to decide that a child should not receive certain interventions on the basis of their illness.
- It is not parental permission to withhold some treatments. The medical team does not require such permission and parents on their own would not be in a position to give it.
- It is not a legally binding instruction by parents as to what the healthcare team should or should not do in the event of an acute deterioration. Parents do not have a moral or legal right to harm their child, and they do not acquire such a right simply by asking the doctor to do the harm for them. Parents should expect to be able to choose from among several reasonable treatment options to their child, but that does not extend to the right to choose an intervention that is not reasonable because it will, on balance, harm the child.
- It is not a pass that means the child should automatically be excluded from the intensive care unit. The presence of the PAC-Plan represents an acknowledgement by parents and health care team that the child's lifespan is likely to be limited. That is relevant to the discussion about whether intensive care is appropriate, but it does not render that discussion superfluous. Intubation and ventilation will certainly be justified in many children with life-limiting conditions who have a PAC-Plan in place. There still need to be discussions with the intensive care team at the time they are considered.

A PAC plan which documents intensive treatments are not appropriate does NOT mean a withdrawal of care. Every attempt should always be made to make the child as comfortable as possible, and to fulfil the child's and the family's wishes.

All children must be assumed to be for attempted resuscitation unless there is a valid, documented PAC plan limitation (section 5.2) decision in place. If there is any doubt about the validity or applicability of a PAC Plan decision, then resuscitation should usually be initiated.

5. How to complete (and utilise) the PAC Plan form

When completing, remember the PAC PLAN should be given to families and should be kept with the child. It needs to be family friendly but contain appropriate information for professionals. Section 5 should be printed on coloured paper if available for ease of access.

Writing must be legible and completed using dark ink or preferably typed. The name of the child should appear on every page. Once the document is completed it must be signed by professionals on page 9 and by families consenting to share information on page 11.

Clinicians should include their professional registration number. This is compulsory for doctors but optional at present for nurses. Guidance should be taken from the Nursing and Midwifery Council (NMC) <http://www.nmc-uk.org/>.

The original copy of the PAC PLAN must stay with the child.

Where electronic circulation is not possible, photocopies of the original should be made for distribution.

Additional modules may be kept with the master copy of the PAC PLAN.

Page 1: Basic demographic information and Dates

- **Home address:** This is essential information used by ambulance control in many areas to identify whether a PAC Plan is in place. The **home post code must be included** in the address as this is the key piece of information against which many ambulance control systems log the PAC PLAN as well as being useful for navigation should collapse happen at home.
- **Dates:** The date of finalising the plan should be recorded, and a date for review must be set and documented at the same time by the supervising clinician. If, at the time of looking to use a plan, the review date has passed, the validity of the contents must be confirmed by either the child's parents or the lead clinician, ideally both

Section 1: Completing the background information in this section is useful, particularly for clinical encounters where the child is not known to the clinician. It provides useful context and goes some way to ensuring that parents do not need to tell their story repeatedly.

Brief detail of medical condition

- Include key information needed in an emergency. Primary diagnosis should be entered but also details useful for paramedics to know e.g
 - Normal ventilator settings if on home ventilation
 - Which route can be safely used for emergency medication: if swallow is unsafe, include this. If the child has venous access or challenging venous access note it here.
 - Normal observations for this child e.g " Saturations above 82 in air" would be useful for a 999 team to know.
- Please include any safeguarding issues including if the child is subject to a Plan or is a "looked after child".

Section 1.1: Background to this review

It is important to tick the appropriate box for each specific module the child has. These include

- Epilepsy plan
- Symptom control plan
- Ventilation support plan
- Organ donation
- Wishes Plan

For support in accessing any of these please contact the specialist teams involved or Paediatric palliative care nurse specialist.

at the bottom of this page. This flags clearly the methodology used to arrive at the position documented in the PAC PLAN.

Section 1.2: The plan was discussed with:

It is important to tick the appropriate decision making boxes in this section. This flags clearly the methodology used to arrive at the position documented in the PAC PLAN.

If the Local authority has overriding parental responsibility, emergency contact details for a decision maker must be clearly documented.

Section 1.3: Additional support and information

This should detail contact information for clinicians. This is particularly important for first line responders and medical teams who do not know the child well to be able to access advice and support in a timely fashion.

Section 1.4 : Background information

This section will be completed differently according to need. Ensure that between section 1.0 and 1.4 all important factors are included

- Where children or young adults wish to be involved in writing their own plan, this section can be used to share their own words.
- Include information about the child's normal level of well being and functioning
- Include key information for emergency care – e.g changes in ventilator settings when unwell
- Outline why the PAC plan is being completed at this time.

Section 1.5 : Social considerations

- In the case of a Looked after child please ensure details of the social worker are included, along with details of those to be contacted in an emergency.
- Families may want to include details that impact on care givers needs in an emergency –e.g transportation challenges in this section

Section 2: Contacts and consent

Section 2.1 Whom to call

The purpose of this section section is for families to clearly record who they can contact in the event of a sudden and severe deterioration or death at home.

- If a child is expected to die at home, this might be a close family member, the childrens hospice, local ward or a member of the paediatric palliative care team.
- Consider if this contact is available 24/7
- It can be helpful to highlight this on the families copy.

Section 2.2 Parents / main carers:

This should detail contact information for the child's parents/guardians. The family may nominate additional emergency contacts (such as grandparents, other relatives or close friends) as a back up in case it is not possible to contact the parents.

Section 2.3: Who can give consent?

Clearly tick the appropriate box dependant consent and capacity at the time of discussing the PAC plan.

Section 3: Preferences (*optional*)

- It is good practice to allow children and families space to discuss their wishes around place of care, community involvement and goals that are important to them.
- Completion of this page is optional and is largely self-explanatory.
- Any information that the parties involved in the decision making process wish to share with the professionals involved in their care should be recorded on this page.
- No information is deemed too small or trivial to include.
- When discussed in detail the wishes module should be used with important elements that the family want shared included on this section of the pac plan. Not all families will want to document these on the main plan. If this is the case, signpost the reader to a key professional who has knowledge of the families wishes or add the words “not included at request of family”
- Whether or not organ donation is discussed is up to the individual clinician's discretion. Evidence tells us that families value having the discussion even if this is unlikely to be possible as it values their child. You may wish to have a discussion with the organ donation co-ordinator prior to your meeting to understand possibilities, although full counselling should be left to the specialist team if the family wish to proceed.
- There are 2 types of organ donation; beating heart and no-beating heart.

Beating heart donation is only considered in a child who has confirmed brain stem death but whose heart is still beating.

Non-beating heart donation is usually only considered for children who have a death that is expected within a specific time period, e.g withdrawal of advanced support. For most organs the child must be taken to theatre within 10 minutes of death for organ harvesting. Corneas and heart valves can be harvested up to 48 hours after death.

Tissue donation may be possible even when organ donation is not feasible. For more information please contact your local transplant co-ordinator. You may also wish to give families written local information about tissue and organ donation.

Section 4: Management of anticipated complications

- Specific plans (epilepsy, symptom control, ventilation) as highlighted on page 2 should be flagged. In the absence of instructions to the contrary standard APLS guidelines should be followed for seizure control and local medical policy used to inform the treatment of suspected infection. It is good practice to record the above, standard actions, in this section even in the absence of an agreed alternative plan.

- Where the child's condition may manifest with other presentations for which a specific response has been agreed (for example the management of metabolic emergencies), the details should be added here.

Section 5: Managing acute significant deterioration.

Prior to discussion with the family it is useful as a professional to think about the possible ways that the child may deteriorate or die – for example it might be because of deterioration in their disease or because of recurrent chest infections or gut failure. Many families will want to explore this and helping them to understand how this might happen will help them to make appropriate choices and decisions. Some families will have had experience of resuscitation and the paediatric intensive care unit and will probably need less explanation around these situations than a family who has not, but it is always good to discuss this – for example commonly parents who have seen an intraosseous needle inserted may not want their child to go through this experience again – but it would be important for them to understand the consequences of this.

- During the process it might be necessary to involve other professionals such specialist teams including critical care colleagues – this might simply be a phone call to them to obtain information or it might mean them talking with the family.
- All reversible causes of acute deterioration should be treated in the absence of instructions to the contrary. This position should be made clear to all parties involved in the decision making process.
- If other possible problems e.g bleeding should be managed actively, please state clearly and signpost to other management plans (e.g symptom control plans).
- Clearly tick all appropriate interventions. All actions not requested/ required should be clearly crossed through.
- After discussion it may be agreed that it is appropriate to attempt resuscitation, as per current Resuscitation Council (UK) guidelines. This must be documented by ticking all boxes.

When considering levels of appropriate resuscitation The Royal College of Paediatrics and Child Health (RCPCH) guidance on 'Making a decision to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice' (2015) can be a useful resource

http://adc.bmj.com/content/100/Suppl_2/s1.full.pdf+html

The 2015 guidance from the RCPCH describes three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit:

- I. **When life is limited in quantity** If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:
 - a. Brain stem death, as determined by agreed professional criteria appropriately applied
 - b. Imminent death, where physiological deterioration is occurring irrespective of treatment

c. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by life-sustaining treatment confers no overall benefit.

II. When life is limited in quality This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- a. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
- b. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
- c. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.

III. Informed competent refusal of treatment Adults, who have the capacity to make their own decisions, have the right to refuse life-sustaining treatment and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of life-sustaining treatment. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide life-sustaining treatment.

Section 6 : Agreement with discussion.

- The professional who led on discussions with the family and a senior clinician's agreement must be obtained with appropriate signatures and GMC number for the latter.
- Where an interpreter has been used, section 6.3 must be completed. Ensure that the need for an interpreter is flagged earlier in the PAC plan. This is very important for any family where English is not their first language even if they speak English well.
- Document others who have been involved in decision making. It is not necessary for all to be signatories but contributions and involvement should be recorded.
- The health care team should ideally be in agreement about the proposed plan. Although unanimity for the final decision is not required, it is clearly beneficial for all if consensus is obtained. The consultant/senior clinician in charge of the child's care has final responsibility for the decision.

The parents and child should no longer be asked to sign the PAC Plan. This is felt to place an unnecessary burden on families. It is sufficient for the lead clinician to document and endorse the PAC plan to confirm that this has been discussed and agreed.

If parents or child request adding their own signature, this can be added to the box at the bottom of the page.

A PAC plan should only be made in partnership with the parents/ carers, and the child/ young person where appropriate. If the family do not agree with the plan proposed by senior clinicians, then a second opinion should be offered. If agreement cannot be reached the PAC plan should not be circulated and in some circumstances it may be appropriate to seek legal advice. The nature of all discussions, concerns and referrals should be comprehensively documented in the patient notes.

SECTION 7: Sharing information

The purpose of page 9 is to document who holds a copy of the PAC PLAN. This is particularly important in order to ensure that everyone has the most up to date version. .

Consent to sharing information (page 10) is required before circulation

- The list should include all key professionals: most of these will be obvious. It is especially important to include all of those with on-going care commitments who might make routine contact with the family.
- In most cases the responsibility for distribution of the plan lies with the completing professional unless specifically designated to the local Palliative care team. Clearly document the name, role and contact details of this professional at the top of the page.
- Please ask the child / young person (where appropriate) and his or her family as to whom should be sent copies of the PAC plan , or made aware of its existence.
- Discuss the following and ensure understanding of why sharing is suggested:
 1. Welsh Ambulance Service (WAST)
 2. Police
 3. Coroner (where appropriate)
 4. All Wales network for children's palliative care including Ty Hafan.

Education:

Parental (and child's) consent should be obtained to notify the head teacher. Whilst many schools will advise that they are required to call 999 irrespective of PAC plan documentation, implications for this should be discussed and explored with families. Local authorities should be encouraged to work with teams to develop policies regarding the use of PAC plans in schools.

Ty Hafan Children's Hospice acts as a central repository for PAC plans currently. We recommend that all the PAC plans are collated here for out of hours access, irrespective of whether families use hospice services in North or South Wales.

Ty Gobaith/Hope House: PAC plans are stored within individual child's notes. There is also a copy available for quick access in the nurse's station. Visiting clinicians also have access to the Welsh Clinical portal at Ty Gobaith.

Welsh Ambulance Service (WAST)

WAST collate information on children with PAC plans in order that crews can provide appropriate and timely support when called. Once received, a marker is placed on the home address to alert crews that someone at that address has a PAC plan. Senior WAST clinicians are able to access the PAC plan and advise crews en-route of it's content through access to the All Wales Paediatric Palliative care PAC plan repository, As a back up to this a summary is prepared and placed on the WAST system.

Police:

When shared with police, a marker is placed on the system against the family's home to alert officers of a child's fragility. The full PAC plan is shared and key information is taken from the form to support officers in decision making. By sharing information the likelihood of police needing to attend the family home after the death of a child is reduced but it is important to know that they may sometimes still be required to attend (particularly if alerted by WAST). In

these cases it is more likely to be a non-uniformed senior officer who can liaise with the child's clinical team if a PAC plan is in place.

In many areas of Wales a separate information sheet is required including personal details of parents and carers. This allows an occurrence to be created so that if a call is made to the family home, it will link with the PAC plan. Parents should be aware that their own details will be shared when consenting to sharing a PAC plan with police.

This sharing of information in advance can help reduce the chance of a disproportionate or incompletely informed "PRUDiC response" should the child die suddenly. Where death is expected and a PAC plan is in place, a PRUDiC will not occur. Some children will die unexpectedly, but in the context of their illness, this will not be surprising. The PRUDiC response team will need to consider these deaths, but will not need to investigate the circumstances. Where a death is unexpected, but not surprising, a home visit will usually not be necessary.

Local police information can be found in appendix 1.

Coroner:

Whether the coroner routinely knows about PAC plans varies across Wales. In circumstances where the child is likely to be referred to the coroner after death it is good practice to speak with a coroners officer in advance and if the family consent, to share the PAC Plan.

The responsible team will inform the coroner about the death according to local policy: in some areas all child deaths need to be reported. In all areas either the GP, attending health care professional, ambulance service or the police will need to contact PRUDiC team if the child dies unexpectedly.

An unexpected death is defined as the death of an infant or child (less than 18 years old) which was not anticipated as a significant possibility for example 24 hours before the death or where there was a similarly unexpected collapse or incident leading to or precipitating the events which lead to the death (Working Together to Safeguard Children, 2013: Chapter 5;12)

The coroner will also need to be contacted (as an emergency or electively as appropriate) if

- The cause of death appears to be related to a medical procedure, medical treatment or equipment failure
- The cause of death appears to be related to drug use, overdose, alcohol or neglect
- There are any suspicious circumstances or a history of violence
- The cause of death appears to be suicide
- The death is linked to an unnatural event or accident (Coroners Act 1988)
- The death has occurred while the patient was in police custody or any state detention

Following the death certification reforms in England and Wales (Update for Coroners Department of Health 2012 *cross reference Policy 6.16 page 6*) deaths may be reported to the coroner by the medical practitioner, by the police or after advice from the medical examiner. If there is doubt as to whether the death should be reported to the coroner, advice can be sought from the coroner's officer or the medical examiner.

All Wales Network for Children's Palliative Care (AWMCN)

- The network hosts current PAC plans in an accessible format for those paediatricians who cover the 24/7 rota allowing up to date advice and support to be provided to clinical teams.
- The data co-ordinator will support local teams in ensuring reviews happen in a timely fashion and that plans are circulated appropriately.

- Anonymised Information will also be used for audit purposes, quality improvement and reporting to welsh government.

6. Key points

5.1 The PAC PLAN will only apply to situations described within the document and is a documentation of wishes and previous discussions. It is valid when it is current (before the review date), dated and signed by the child's lead clinician. The parents and the child's signature are not required.

5.2 The PAC PLAN should not usually be used for the first time in an adult. There may be some young adults for whom this form was initiated before their 18th birthday and it is deemed appropriate to continue to use the same format for reviews

5.3 A valid PAC PLAN may be followed even when the parent or legal guardian is NOT present at the time of the child's acute deterioration or collapse. Phone contact should be made immediately with the parent or legal guardian to inform them of their child's deterioration and that the PAC PLAN will be followed.

5.4 If a parent or legal guardian is present at the time of their child's collapse, they may wish to deviate from the previously agreed PAC PLAN and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child. This should be made clear to families at the time of writing the PAC PLAN.

5.5 It is assumed that the completing health care professional is responsible for keeping the plan up-to-date or delegating appropriately. Where agreed, the AWMCN data manager will be listed on page 9 of the PAC PLAN. They will hold a list of relevant organisations and named responsible persons in each setting where a copy is held e.g. school, emergency department, paediatric ward, GP surgery, hospice and ambulance department. There should ideally be a designated alternative contact in each setting, to avoid problems of who to contact when a member of staff is on leave.

7. Review Process

The PAC PLAN should be reviewed regularly. Review meetings need to be organised well ahead of time to ensure that there is always a current valid plan. The completing professional is responsible for distributing the latest version of the PAC plan or delegating accordingly, this task may fall to the paediatric palliative care clinical nurse specialist in each area.

- The timing of reviews is at the discretion of the lead clinician. This is often annually but those with a changing clinical status will require a more regular review. There may also be some children, with stable conditions where the frequency between reviews is longer than annually.
- When setting the **Review date** the following should be considered
 - The nature of the child's condition or disability, and the likelihood of changes in prognosis or treatment options.
 - The child's developing maturity (competence) and need for involvement in the discussion (if not already complete)
 - Whether there are any planned procedures or interventions that have the potential to precipitate a collapse, such as major surgery. In such

circumstances the potential complications should be discussed, and an appropriate level of intervention (or non-intervention) agreed and documented. This may involve a temporary suspension of a PAC plan. The surgeon and anaesthetist must be consulted and kept informed of any decisions. Families should be invited to take part in any such review process.

Once the initial PAC PLAN has been completed, any senior clinician in the child's team can undertake the review process with the child and family (where appropriate). Usually the child's lead clinician should be consulted and at the very least they and the PPC Data manager, must always be informed of any changes made to the initial plan.

NB Any significant change in the child's condition or anticipated prognosis should prompt consideration of an early review of the plan.

It is vital that every contact documented on page 9 of the PAC PLAN receives the updated version.

When a plan is revised, old plans should be crossed through and filed.

If you do not have a current valid PAC PLAN for a child you should contact the local paediatric palliative care team or the child's lead clinician as appropriate.

8. Cancellation of a PAC plan

In some circumstances a decision may be made to cancel or revoke the PAC. Should this occur, the PAC PLAN should be crossed through on printed copies, on every page, with 2 diagonal lines in dark ball-point ink and the word "**CANCELLED**" written clearly between them, dated and signed.. The reasons for the change should also be clearly documented.

It is the responsibility of the lead clinician or allocated colleague to inform all parties and to arrange an urgent review so that a new PAC PLAN can be completed.

Following the death of a child, the lead clinician or allocated deputy should contact all current holders of the PAC plan to inform them of the child's death. The data management team can assist with this if alerted by the primary clinical team.

9. Transition to adult services

The adult version of ACP documents are available at (www.wales.nhs.uk/AFCP). Documentation can be changed as part of the transition process when young people are 18 years of age. In some cases, attaching the existing PAC plan, to the adult ACP form may provide additional information and remains a valid record of discussions.

Child and Young Person's PAC Plan Working group (2021)

Working Group

Lead

Jo Griffiths Consultant in Paediatric Palliative medicine, All Wales managed clinical network. Swansea Bay University Health board.

Members

Megumi Baba Consultant in Paediatric Palliative medicine and Transition. All Wales managed clinical network / Ty Hafan Childrens hospice

Vera Clement Clinical nurse specialist Paediatric palliative care, Cwm Taff Morganwg Health board

Richard Hain Consultant in Paediatric Palliative medicine, Clinical lead All Wales managed clinical network. Cardiff & Vale University Health board

Leigh Holborn Detective chief inspector, Gwent Police force.

Tracy Jones Head of community services and partnership, Ty Hafan Childrens hospice, South Wales.

Madalitso Kubwalo Consultant Paediatrician, Betsi Cadwalader University health board

Rebecca McDonald Clinical nurse specialist Paediatric palliative care, Hywel Dda health board.

Kathryn McSorley Paediatric palliative care nurse specialist, Cardiff & Vale University Health board

Edward O'Brien Macmillan Paramedic, End of Life Care Lead Welsh Ambulance Services NHS Trust

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PAC PLAN CIRCULATION



1

Leave the original copy with the family. If handwritten photocopy first.

2

Completing professional should advise all teams who need to know of PAC plan imminently – in most cases this includes GP WAST and police.

3

Email to Ambulance at amb_PacPlans@wales.nhs.uk & local police force.

4

Circulate to all teams as agreed with family within 1 working week.

5

Email to PAC.plans.cav@wales.nhs.uk for action by the AWMCN data manager.

- i) Uploads to WCP and ensures searchable text box is added.
- ii) Upload to shared MS teams channel for out of hours access by PPC & WAST senior clinicians on call.
- iii) Logs for audit purposes.
- iv) Forwards to Ty Hafan team.
- v) Ensures Police / ambulance are updated.
- v) Flags review date at PPC ward rounds.





FOR SUPPORT CONTACT YOUR LOCAL CHILDRENS PALLIATIVE CARE TEAM OR EMAIL PAC.PLANS@WALES.NHS.UK

ALL WALES MANAGED CLINICAL NETWORK FOR PAEDIATRIC PALLIATIVE CARE



Police Processes

Police processes for supporting and utilising PAC plans vary across Wales. The following is correct at the time of writing (June 2021)

	South Wales Police	Gwent Police	Dyfed Powys	North Wales
Principal areas	Bridgend , Cardiff , Merthyr Tydfil , Neath Port Talbot , Rhondda Cynon Taf , Swansea , and the Vale of Glamorgan	Blaenau Gwent , Caerphilly , Monmouthshire , Newport , and Torfaen	Principal areas of Carmarthenshire , Ceredigion , Pembrokeshire , and Powys	North Wales
Police lead for PAC plan discussions	Deborah Farrah	Leigh Holborn		
First contact	PPDBusinessUnit@south-wales.police.uk Tel PPD HQ 01656- 305944	Leigh.Holborn@gwent.pnn.police.uk Tel 01633 838 111	centralreferralunit@dyfed-powys.pnn.police.uk Tel 01267 226370 to	publicprotectionreferralunit@nthwales.pnn.police.uk
Documents to send	Full PAC plan & short document  PAC PLAN BLANK FOR HEALTH V2.doc	Full PAC plan and short document  Blank police info.doc	Full PAC plan	Full PAC plan
Police response	Occurrence record created (on NICHE*) and referrer emailed once done .Marker placed on home address	Occurrence record created (on NICHE) and referrer emailed once done .Marker placed on home address	Delivery / read receipt and acknowledgment that the plan has been received.	Police will provide a receipt number to note
Out of hours	ring 101 and speak to the Bronze or Silver Inspector for the Public Protection Unit			

*Niche system is use by Gwent and South Wales police, Data entered will be accessible in either area.

