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implementation board

# Paediatric Advance Care Plan (PAC-Plan)



All-Wales

## Paediatric Palliative Care Network

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

*Arch Dis Child 2010;95:79-82 doi:10.1136/adc.2009.160051*

Name: .....

Date of Birth: .....

NHS number: .....

Date of this review: .....

**PLEASE NOTE:**

- This document is not legally binding. It is a record of discussions about preferences for what happens in the event of a child becoming seriously unwell.
- For it be effective, relevant portions must be easily identifiable by ambulance staff in an emergency. The edges of Section 5 printed in grey. Please also print a second copy of those pages on coloured paper and save it at the back of this document for ease of access.

## Section 1: Frequently asked questions

### 1.1. What is this document for ?

PAC-Plan is a tool for discussing and communicating the wishes of a child, young person and/or their family. Its main aim is to explore the various things that might happen as a child's illness progresses (particularly towards the end of life), but at a point when there is plenty of time to discuss them. The PAC-Plan has three functions:

- i. It offers the child or family an opportunity to explore what might happen in the event of a sudden serious event. Some of those can be reversed, but others cannot, or could only be reversed by treatments that would be too unpleasant to bear.
- ii. It records that those discussions have taken place.
- iii. It documents what the child and/or family has expressed about each of those three potential scenarios, in a way that is easily accessible to the medical team at the time discussions about treatments need to take place (usually in a hospital ward, casualty or intensive care unit) because a sudden serious event has occurred.

PAC-Plan can include specific plans for managing (eg) pain, seizures or other symptoms, or 'Wishes' documents. Those plans are referred to in the PAC-Plan as modules.

### 1.2. When should these discussions take place ?

As a general rule, as early in the course of an illness as possible, because it offers the greatest opportunity to explore what might happen as the child's illness progresses. The right time to introduce the PAC-Plan process depends on the needs of the individual child and family.

### 1.3. Who can use the PAC-Plan ?

Any member of the Healthcare Team can take the lead in the PAC-Plan process, working in collaboration with colleagues. The child's main consultant should usually be involved in the discussions but does not have to take the lead at all times.

### 1.4. Is it legally binding ?

No. The document records your discussions, **but it does NOT AT ALL mean you cannot discuss those issues again, or change your mind at some point in the future.** Only the section relating to permission to disseminate the information represents a form of consent. We do suggest the document is signed by both consultant and patient or family. That makes it more likely the document will be acted on, but it is not strictly necessary, and some families never feel able to sign it. There is still considerable value in the PAC-Plan discussions, and in completing the rest of the document as a record.

### 1.5. Will I have a chance to discuss these issues again ?

Yes. You can ask to have these discussions again at any time. Ideally they should be discussed every 6 – 12 months anyway, even if there have been no changes.

**Section 2: Background to this review**

2.1. Date first completed: ..... by .....

Date last amended: ..... by .....

Date to be reviewed: ..... by .....  
(usually < 12 months)

**2.2 Additional modules**

This PAC-Plan includes the following specific modules (please circle):

Epilepsy plan	Wishes document	Ventilation support plan	Other (2) .....
Symptom control plan	Organ donation	Other (1) .....	Other (3) .....

**2.3 The Plan was discussed with:**

- Patient
- Mother/ Father
- Other family, especially grandparents
- Other e.g. nurse/respice/key worker
- Local authority       Local authority has overriding parental responsibility.

**2.4. Background information (including diagnosis, significant problems, usual level of health and well-being and reason for completing PAC-Plan at this particular time).**

### Section 3: About other people in the family

#### 3.1 Whom to call.

This should be the name of the professional the child or family would want to be contacted first if there were a sudden and severe deterioration.

Name of person to call	Contact number

#### 3.2. Parents/ Main Carers (these should be the people who usually care for the patient).

Name	Relationship to child	Parental responsibility? Y/N	Contact telephone number

#### 3.6 Who can give consent.

The patient to whom this PAC-Plan refers is:

- A child who is 'Gillick competent' and can give consent on his/her own behalf.
- A child whose parents or guardian have parental responsibility and can give consent on his/her behalf.
- Someone with capacity under the 2005 Mental Capacity Act (MCA), who can give consent on his/her own behalf.
- Someone who lacks capacity under the MCA in whom best interests must be decided according to the MCA.
- Subject to other legal protection e.g. care order, court decision.

## Section 4: Planning ahead

Life-limiting conditions in childhood often cause a slow deterioration over many months or even years. Sometimes, however, there can be sudden illnesses that are serious enough to pose an immediate threat to life. Often these involve the breathing. Some can be reversed with the help of medical interventions. Others can't, or else can only be reversed by treatments that would be too unpleasant to bear. The purpose of this section is to explore the most appropriate treatment for each of those possibilities.

**BRIEF detail of medical condition (please note that Section 5 of the PAC-Plan is all that is seen by police and ambulance crew. Information in this box should summarise box 2.4)**

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### 4.1: Management of a sudden, severe deterioration caused by something that can be reversed:

This might include a problem during anaesthesia or an episode of choking in which there are medical interventions that can resolve the problem without being unbearable for the patient.

- Under these circumstances, all appropriate measures should be taken to reverse the problem.

### 4.2: Management of slow, life-threatening deterioration:

NB Comfort and support of child and family, and attention to management of symptoms (see symptom control module where appropriate) are part of routine care in all patients.

- Transfer to .....(preferred place of care).
- Transfer to high dependency unit.
- Use of non-invasive ventilation.
- Use of invasive intubation and ventilation (ie transfer to intensive care unit environment).

**4.3: Management of a sudden, severe deterioration that cannot be reversed, or could only be reversed by treatments that are unpleasant for the patient:**

NB Comfort and support of child and family, and attention to management of symptoms (see symptom control module where appropriate) are part of routine care in all patients.

- Comfort measures only; no medical attempt to reverse the problem.
- Suction upper airway, and other airway clearance techniques.
- Oxygen via face mask or nasal cannulae if it helps symptoms.
- Airway management including oral / nasopharyngeal airway if it helps symptoms.
- Mouth to mouth (or bag-and-mask) for five inflation breaths.
- Call 999 and transfer to .....Hospital
- Give fluids and drugs intravenously.
- If that is not possible, give fluids and drugs via an intraosseous needle (ie one that goes into the bone).
- Consider transferring to high-dependency or intensive care environment.
- Consider putting a tube into airway and attaching it to a ventilator. That would mean transferring to intensive care.
- If the heart stops, consider attempts to get it started again using chest compressions or an electric defibrillator. That would also mean endotracheal tube and intensive care as above.

The PAC-Plan document provides a guide in providing care for this child in the event of a deterioration at the end of life. It is compiled in detailed discussions with the family and, where possible, the child. But those discussions cannot predict all eventualities. Notwithstanding the preferences recorded in this document, individual professionals are obliged to use their professional judgment to act in the best interests of the child, and to instigate further discussions regarding treatment if situations change.

**4.4: Organ donation**

Although organ donation is not always possible for children who have life-limiting conditions, all families should be offered the opportunity to discuss it with the local organ donation lead nurse.

- We have discussed this, and are not planning to take it any further.
- We have discussed this, and will contact the lead nurse on .....(contact number). Please see organ donation module.

**Section 5: Agreement with discussions**

**5.1 PAC-Plan lead (person leading on discussions eg specialist nurse)**

Signature:.....Designation:.....

Name (PRINT): .....Date: .....

**5.2 Senior Clinician’s agreement (“I support this Paediatric Advance Care Plan”):**

Signature:.....

Designation:.....GMC No:.....

Name (PRINT): .....Date: .....

*A consentor’s signature supports that this document is an accurate representation of discussions held with named professionals to date. It is not binding. Discussions within the PAC-Plan can be revisited at any time and should be reviewed regularly.*

**5.3 Child or young person’s agreement**

I have discussed the treatment and care outlined in this PAC-Plan with the appropriate professionals. I confirm that the Plan accurately represents the wishes I have for care and treatment for me..... ( name of child/young person)  
I understand that before any of the treatment commences I will be asked (wherever possible) whether I still consent to it.

Child/ young person signature:.....Date: .....

**5.4. Parent or Guardian’s agreement**

I/We have discussed the treatment and care outlined in this PAC-Plan with the appropriate professionals . I/We confirm that the Plan accurately represent the wishes I /we have for care and treatment for .....(name of child/ young person)  
I/we understand that before any of the treatment commences I / we will be asked whether I /we still consent (s) to it.

Name & signature: .....Date: .....

**5.5. Statement of interpreter (where appropriate)**

I have interpreted the information above to the child/young person/parent to the best of my ability and in a way in which I believe the child/young person/parent can understand.

Name & signature: ..... Date: .....

**Section 6: Permission to share information with others**

**6.1 We will send copies of this Plan to:**

	Yes/No and initial added by Consentee	
Local PAC-Plan coordinator (responsible for dissemination)		
Parents/Guardians		
Hospital notes		
Local Hospital paediatrician(s)		
Community paediatrician		
GP		
GP out of hours service		
Other Hospital departments Children's Assessment Unit		
Community Nurses including Clinical nurse specialists		
(Audit file) (With child/young person/ parental consent)		
School health nursing team		
Social Worker or Special Needs Health Visitor		
Paediatric Oncology Outreach Nurse Specialist		
Children's Hospice		
School/ College Head teacher (with consent to share with school staff)		
Other e.g Social Care, short break care provider		
Adult services / transition team		
Welsh Ambulance NHS Trust Directed to Deputy Director of Medical and Clinical Services / Consultant Paramedic and the Named Professional Safeguarding Children.		Plan will be sent via post, secure email or via a safe haven fax. In the first instance phone 01792 315884 to inform the Safeguarding Team that Plan is being sent and by what method
Police		Police: North Wales 01407 724469 South Wales 01656 305944 Dyfed Powys 01267 226370 Gwent 01495 745590 Out of hours: Local Public Protection Unit Tel 101 <i>The Police will be informed of Plan's existence,</i>

		<i>but they will not usually receive a copy of it.</i>
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**6.2 Consent to Information Sharing**

I agree to the sharing of information contained within this advance and emergency care pathway with the agencies listed above (agreement confirmed by 'yes' and initial). I understand that withholding consent to sharing of information may limit the utility of the ECP. All the information that will be shared and the reasons why have been explained to me. I have had the opportunity to discuss any issues arising from this matter.

Signature:..... (Child/young person/Parent /Guardian)\*

Name (PRINT): ..... Date: .....

Second signature where needed:..... (Parent /Guardian)\*  
(eg if consentee above is a child):

Name (PRINT): ..... Date: .....

\*Delete as appropriate

(Or, if patient is over sixteen years of age:

This patient has been assessed under the MCA and is considered to lack capacity. In accordance with MCA, the Lead Consultant has considered the best interests of the patient and, after appropriate consultation set out that Act considers it to be in the patient's best interests for the information to be shared with the people/organisations set out above.

Signature:.....(Lead consultant)

Name (PRINT): ..... Date: .....