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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

Date plan initiated	<i>dd/mm/yyyy</i>	Date review due (if appropriate)	<i>dd/mm/yyyy</i>
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Name	Name	DOB	DOB
Address			
		Post code	
NHS No.	NHS number	Hospital No.	

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.

This plan could begin antenatally or extend to include young adults

Section 1: Background to this review

BRIEF detail of medical condition (Key information needed in an emergency)

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1.1 Additional modules

This PAC-Plan should be read alongside the following specific modules (please tick):

Epilepsy plan	Symptom control plan	Ventilation support plan	Organ donation	Wishes Plan
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1.2 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.

1.3 Additional support and information is available from

Children’s clinical nurse specialist in hours	
Children’s palliative care clinician in hours	
Children’s palliative care clinician out of hours	02920 747747 (UHW Switchboard. Ask for on-call paediatric palliative medicine consultant)
Lead consultant	
GP (..... Surgery)	

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

1.5 Social considerations (include if looked-after child)

Section 2: About other people in the family

2.1 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

2.2. 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

2.3 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 3: Preferences

This section is a short summary of wider discussions – please use the Wishes module.

CHILD & FAMILY PREFERENCES DURING LIFE

Child's / Young Person's Preferences e.g. Place of care, symptom management, people to be involved (professional/ non-professional), activities to be continued (including spiritual and cultural) and goal-directed outcomes.

Family preferences e.g. Where you want to be as a family, who you would like to be involved, sibling needs (e.g medical, spiritual or cultural backgrounds).

Others' preferences (e.g. siblings, school friends)

Preferences around End of Life (Optional)

PREFERENCES AROUND THE END OF LIFE
<p>Organ & tissue donation (see separate guidance on web link http://www.organdonation.nhs.uk) National contact numbers. 0300 123 2323 Regional contact numbers.</p>
<p>Priorities for care, including preferred place of care of child /young person</p>
<p>Spiritual and cultural wishes</p>

Section 4: Management of Anticipated Complications

Date of Weight	Weight (Kg)	This section should be used to record plans for specific circumstances which might be encountered e.g. management of chest infections. Where a management plan already exists (e.g. seizure management plan) it should be signposted
<i>dd/mm/yyyy</i>	<i>weight</i>	

Instructions for specific circumstances

Link to additional modules or symptom control plans here
Include below as to if, or when, to call 999 and transfer to hospital.

Section 5: Managing acute significant deterioration.

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.

5.1: In the event of a likely *reversible* cause for acute life-threatening deterioration such as **choking, tracheostomy blockage or anaphylaxis please intervene and treat actively.**

Please also treat the following possible problems actively e.g. bleeding (**please state**):

5.2: 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 (to support airways, without CPR)
- Call 999 and transfer toHospital
- 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 a child, young person and/or their family. 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.

Section 6: Agreement with discussions

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

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

Name (PRINT): Date:

6.2 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.

6.3. 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:

Others involved in decision-making, for example Multi-Disciplinary Team (MDT)

The young person or parents /carer can change their mind about any of the preferences on the care plan at any time. If a parent /person with parental responsibility is present at the time of their child’s collapse, they may wish to deviate from the previously agreed plan and under these circumstances their wishes should be respected, provided they are thought to be in the best interests of the child/ young person.

Section 7: Permission to share information with others

7.1 We will send copies of this Plan to:

Who is responsible for the distribution of the PAC Plan, bringing it to the attention of professionals, and circulating any updates to it?	
Name and/or Role	Contact Details
<i>Name & Role</i>	<i>Contact detail</i>

NB: The child and family will hold a full copy of their plan
A full photocopy of the plan also to: (include date sent and by whom)

	Full copy= Aware of plan=	FC/ A	Name and contact details	Date sent and by whom
<input type="checkbox"/>	Local Emergency Department	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Children's Community Nursing Team	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Hospice	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Lead Paediatrician	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	GP	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Hospital (ward or assessment unit)	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Respite / Short Break Care provider	FC/A	<i>Name and contact details</i>	<i>By dd/mm/yyyy</i> By
<input type="checkbox"/>	GP Out of Hours	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Welsh Ambulance Service	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	School Nurse / Head Teacher	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Social Services	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Other (e.g. Hospital Specialists)	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	All wales network for children's palliative care co-ordinator for audit and OOH advice.	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Police	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Other	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By
<input type="checkbox"/>	Other	FC/A	<i>Name and contact details</i>	<i>dd/mm/yyyy</i> By

Comments

7.2 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 PAC plan. 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: