

# Our ACP Journey

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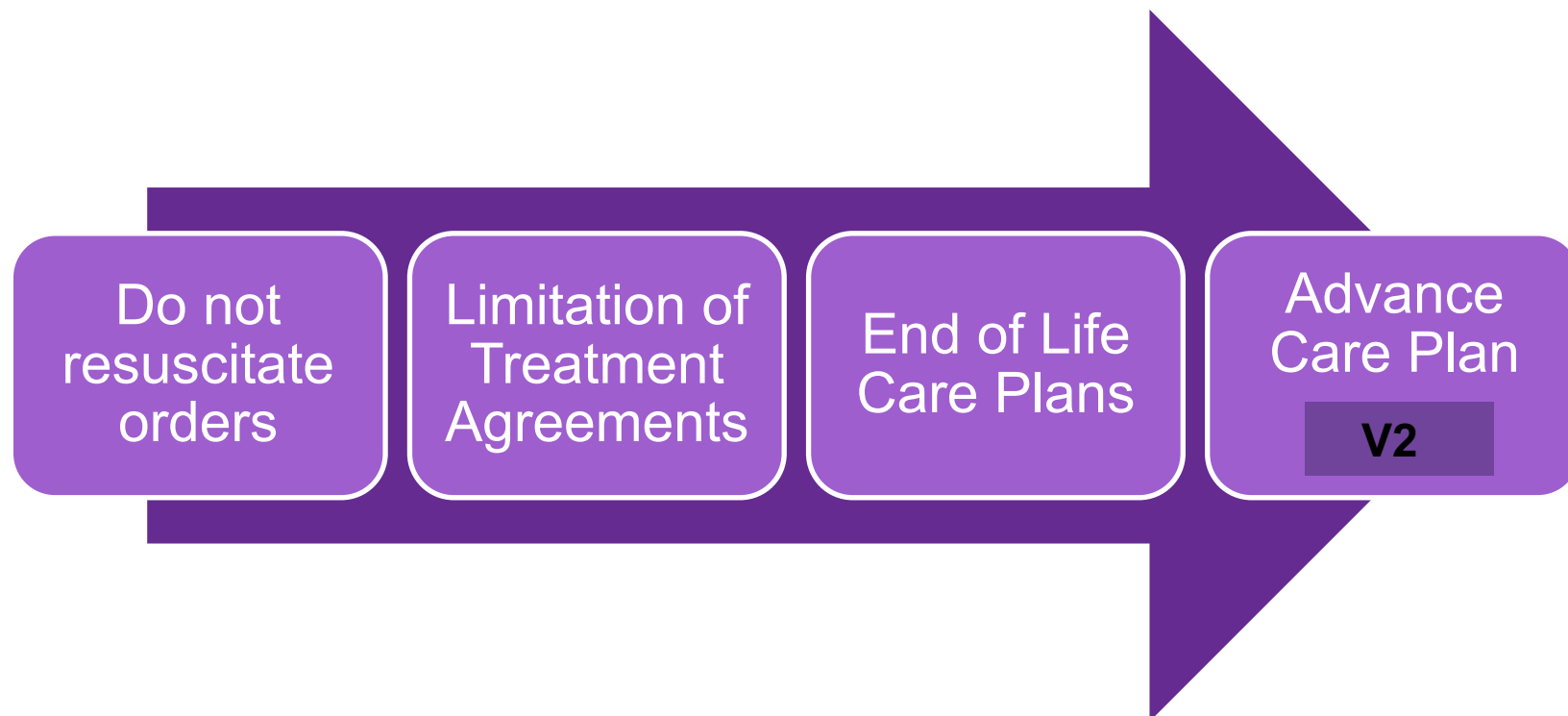
**ACP Lead West Midlands Network**



**West Midlands Paediatric Palliative Care Network**



# Building on Approaches Gone Before.....



...over time, embedding locally



# Building on the Work of Others

West Midlands

South Central

EACH

Avon

Liverpool



West Midlands Paediatric Palliative Care Network



Department of  
Health Funded  
Project  
Oct 2010 –  
March 2011



## West Midlands Children and Young People's Palliative Care Toolkit

West Midlands Paediatric  
Palliative Care Network



West Midlands Paediatric Palliative Care Network

# Advanced Care Planning The Advanced Care Plan Tool

.....  
West Midlands  
Children & Young  
People's Palliative  
Care Toolkit

Section 6



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# The ACP Vision – Taken to the W.Midlands

To Improve End of Life Care by:

1. Standardising guidance
2. Standardising paperwork for the region
3. Developing a tool that is recognised and used
4. Empowering clinicians to discuss Advance Care Plans
5. Create a joined up care pathway:

Home, school, ambulance, community, hospital

Led by Fiona Reynolds, PICU BCH

Taking the teams forwards with us as benefits seen



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NHS

*Facilitating conversations to remove ambiguity, to be as clear and transparent as possible, planning together as a team, with the family central within the discussions, reaching common, communicated, agreement.*



*The 'purple pages' branding*



West Midlands Paediatric Palliative Care Network





NHS

## Advance Care Plan for a Child or Young Person

West Midlands Paediatric  
Palliative Care Network



NHS

## Child and Young Person's Advance Care Plan Policy

West Midlands Paediatric  
Palliative Care Network



NHS

## Guide to using the Child and Young Person's Advance Care Plan

This guide is for professionals who may be  
involved in developing an Advance Care Plan  
for a child or young person in their care.



NHS

## What Happens If...?

Advance Care Plans: Planning ahead for  
needs of children and young people with  
life-limiting or life-threatening conditions



NHS

## What Is An Advance Care Plan

Planning ahead for the needs of  
young people with life-limiting or  
life-threatening conditions.





# Advance Care Plan for a Child or Young Person

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Palliative Care Network

Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_

NHS Number: \_\_\_\_\_



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## Advance Care Plan for a Child or Young Person

This document is a tool for discussing and communicating the wishes of a child / parent(s) or young person. It is particularly useful in an emergency, when the individual cannot give informed consent for themselves and / or next of kin / parent(s) cannot be contacted.

Name:	Date of Birth:
Known As:	Hospital No.
First Language:	NHS Number:
Home Address:	
Postcode:	
Telephone Number:	

**NB: If the child or young person becomes unwell and needs an ambulance, inform ambulance control that the child has an Advance Care Plan. Ambulance Control will have an electronic copy of the ACP flagged under the child's home address and postcode. Don't forget to give ambulance control the child or young person's current location as well, if they are away from home.**

Name of person/people with parental responsibility (and address if different from above):

Emergency contact number for person with parental responsibility: \_\_\_\_\_

Other emergency contact numbers: \_\_\_\_\_

Other key people (e.g. family and friends): \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_ Tel: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_ Tel: \_\_\_\_\_

Primary diagnosis and background summary:

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Advance Care Plan for Use In:

☐ Home ☐ School ☐ Hospital ☐ Hospice ☐ Other: \_\_\_\_\_

Date Plan Initiated \_\_\_\_\_ Date Review is due \_\_\_\_\_

Date reviewed/amended:	Name & Title of Lead Reviewer	Next Review Date

In certain circumstances it may be appropriate for the advance care plan not to have a review date but to run indefinitely. This should be indicated by writing the word "indefinite" under review date.



**Advance Care Plan: Intercurrent illness/acute deterioration** *continued*

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ NHS No. \_\_\_\_\_

Address: \_\_\_\_\_

**Specific treatment plans if indicated**

**Management of seizures**

Description of usual seizure pattern / types: \_\_\_\_\_

*What do we know about this child, from their past episodes of care, that an ambulance crew or junior doctor need to know when managing an acute situation?*

*What do we need to know about their ongoing care – antibiotic choice and route?  
What action in the event of a metabolic crisis?*

**Management of infection** (check for known allergies)

Preferred antibiotic or regime for recurrent infections – drug dose, route, duration:

Intravenous antibiotics will normally require transfer to hospital for investigation and initiation of treatment.

Other instructions/comments regarding infection-related symptoms e.g. nebulisers, steroids.

**Instructions for emergency care in other specific circumstances:**

(Document here regimes specific to this child/young person, for example for management of metabolic disturbance etc).



## Advance Care Plan: Management of cardio-respiratory arrest

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ NHS No. \_\_\_\_\_

Address: \_\_\_\_\_

Regardless of the patient's resuscitation status, the following immediately reversible causes should be treated: choking, anaphylaxis, blocked tracheostomy tube, other:

### RESUSCITATION STATUS

- ☐ Resuscitation status has not been discussed – attempt full resuscitation
- ☐ Resuscitation status has been discussed and the following has been agreed:

Clearly DELETE actions NOT required

For full resuscitation	OR	Attempt resuscitation with modifications below:	OR	Do not attempt cardiopulmonary resuscitation DNACPR
Resuscitation as per standard RC(UK) guidelines		<b>Patient-specific modifications to standard resuscitation guidelines</b>  Airway: Breathing: Circulation: Drugs: Other: PICU/HDU:		Patient-specific supportive care is documented on pages 2 and 3  In the event of sudden death 24 hour emergency number for doctor who knows the child:  Phone Number:

Ambulance directive: (eg Transfer to Home/Ward/Emergency Department /Hospice)

Reason(s) for decision

Senior Clinician Name: \_\_\_\_\_ Signature: \_\_\_\_\_

GMC No: \_\_\_\_\_

Name: \_\_\_\_\_ Relationship: \_\_\_\_\_

Parent/Guardian/Child/Witness Signature: \_\_\_\_\_

Date Initiated: \_\_\_\_\_ Review Date (see page 1): \_\_\_\_\_

Photocopies may be made of this page but must have the word "PHOTOCOPY" written clearly at the top. The original copy of the document must be signed in black ink by a senior clinician and a second person and given to the family. The second person can be the person with parental responsibility or a witness e.g patient's nurse if a family member agrees with the plan but feels unable to sign the document

Fax copy of form to Special Patient Notes Team: Ambulance Control - Fax 01926 832 898  
Send a copy to the Resuscitation Department for hospital in-patients.



## Advance Care Plan: Decision making

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address \_\_\_\_\_

Basis of discussion / decision-making? (Tick as appropriate)

- ☐ Wishes of child/young person with capacity
- ☐ Wishes of parent(s) for child on "best interests" basis
- ☐ Best interests basis (as in Mental Capacity Act 2005)

*Following consultation with the child's wider clinical team including.....*

Consider the following questions. For detailed responses use free text below

- What do you/the child/ young person know about this condition, any recent changes, and anticipated prognosis?
- What do siblings understand about the condition and anticipated prognosis?
- What involvement is appropriate / possible for the child/young person in decision-making?
- To what extent has the child/young person been involved in decision-making in this area?
- What does the child/young person know about what decisions have been taken?
- Have these wishes been discussed elsewhere? In order to enhance continuity of care please attach documentation arising from any such discussions.
- For older children and young people consider the arrangements to be made for transition from paediatric to adult services

### Communications and discussions

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# What did we need to do?

Over a period of time begin to discuss the child's future care, including:

1. Discuss the child with colleagues involved in their care from the *wider clinical team*
2. Discuss the management of *acute events/illnesses* with the family
3. Discuss the management of *chronic and acute deterioration to the point of cardio-respiratory arrest* with the family in line with *RCPCH ethical guidelines*
4. Discuss the *wishes of the family in the light of these clinical and ethical decisions* and come to an agreement
5. Then agree to *set a time aside to document* this in summary format, as an Advance Care Plan – a *Plan for Life*



# Taking it Out to Embed in The West Midlands

Gave Network Leadership & Gained Network agreement

Gained policy & document approval at BCH:

Seen as approved lead in the region

Had focal point leads in teams across W Mids, building infrastructure:

Hospitals, hospices, locality teams

CCNs/Medics with responsibility to introduce & oversee for their locality

C&W: Pall Care Paed Community alongside CNS Pall Care C & W and Paed CC UHCW

Took to policy groups for ratification in localities:

Acute Units & Community teams, hospices

Trained, trained, trained!...

CCN leads trained all CCNs & acute unit nursing teams & revisited

CPD for W Mids Medics facilitated by Pall Care Paeds W Mids

W Midlands Training Days, Conferences

Sat alongside colleagues during individual ACP completions

Monitored activity across W Midlands:

ACP Coordinators quarterly meetings W Midlands – more ‘living with’ ACP

Looked at local issues to resolve WMAS, schools.



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# The Advance Care Plan and our Collaborative Journey



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ALLERGIES

Name		Date:	
Address			Post code
Hospital No.	NHS No.		



Childrens and  
Young Persons  
Advanced Care Plan  
Collaborative



CYPACP Collaborators: Alder Hey Children's Hospital, Dares County Hospital, Merseyline Hospitals, Naimi Hosse & Robinson, North West Children's Palliative Care Network, Oxford University Hospitals, Portsmouth Hospitals NHS Trust, Royal Manchester Children's Hospital, Solene NHS Trust



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# Child & Young Person's Advance Care Plan (CYPACP)

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Name:		
Address:		Postcode
Hospital No.		NHS No.

## Management of Cardiorespiratory Arrest

(Including DNACPR)\*

\*Delete if not appropriate

Child's Name		NHS No.	
<input type="checkbox"/>	Cardiopulmonary Resuscitation status (CPR) has not been discussed attempt CPR unless clearly not in the best interest of the child/ young person (Only a senior clinician may make this decision)		
<input type="checkbox"/>	Cardiopulmonary Resuscitation status has been discussed and the following has been agreed:		
Name and contact details Diagnosis and reason(s) for decision (also see p8)			
Ambulance Directive			

Clearly strike through unused boxes in dark ink as appropriate (only 1 box to be active)

<b>Attempt full Cardiopulmonary Resuscitation</b> <input type="radio"/> Select Attempt CPR as per Resuscitation Council (UK) guidelines.	<b>OR</b>	<b>Attempt Cardiopulmonary Resuscitation with modifications below:</b> <input type="radio"/> Select INTUBATION <input type="radio"/> Yes <input type="radio"/> No AIRWAY AND BREATHING CIRCULATION PICU <input type="radio"/> Yes <input type="radio"/> No	<b>OR</b>	<b>DO NOT attempt Cardiopulmonary Resuscitation DNACPR</b> <input type="radio"/> Select <b>DNACPR</b> Patient-specific supportive care is documented on pages 7, 8 and 9
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<b>Clinician</b> (usually lead clinician)		<b>2<sup>nd</sup> Clinician</b> (2 <sup>nd</sup> signature may be required if lead clinician has not signed above and countersigns at a later date)	
Clinician Name		Clinician Name	
Professional Role/ Grade		Professional Role/ Grade	
GMC/ (NMC) No.		GMC/ (NMC) No.	
Signature		Signature	
Date		Date	



<https://www.cypacp.nhs.uk>



About us	Collaborative Agreement	Document Downloads	Education / Training
Parents & Families	Useful Links / Documents	Latest News	Administration



## Welcome to the CYPACP Website

If you wish to see a picture of your organisation or of anything else please send a photo to [peter-marc.fortune@cypacp.nhs.uk](mailto:peter-marc.fortune@cypacp.nhs.uk), or [info@cypacp.nhs.uk](mailto:info@cypacp.nhs.uk)



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# Keep Momentum Going...

Infrastructure to gather & disseminate information & issues:

- Networks at regional and local levels

- ACP coordinators

Keep informed of changes such that seen as helpful developments



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Child and  
Young Person's  
Advance Care Plan  
Collaborative

ALLERGIES

Name	DOB	
Address		
Post code		
Hospital No.	NHS No.	Date:



ReSPECT

Interim Version 2.0  
Incorporating ReSPECT



West Midlands Paediatric Palliative Care Network





Name:	
DOB:	
NHS/CHI Health & Care No.:	

## Recommended Summary Plan for Emergency Care & Treatment

1 Preferred Name:	Date completed:
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### 2 Summary of relevant information for this plan (see also section 6)

Including diagnosis, communication needs (e.g. Interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

### 3 Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life,  
even at the expense  
of some comfort

Prioritise comfort,  
even at the expense  
of sustaining life

Considering the above priorities, what is most important to you is (optional):

### 4 Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment  
as per guidance below  
(Clinician signature)

Focus on symptom control  
as per guidance below  
(Clinician signature)

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CPR attempts recommended (Clinician signature)	For modified CPR (as detailed above) (Clinician signature)	CPR attempts NOT recommended (Clinician signature)



# Then and Now

**December 2015 121 children and young people living with an ACP.**

**March 2016 182 children and young people living with an ACP**

**46% Full resus**

**34% Modified**

**21% DNACPR**

**TFSL Categories**

**February 2017 219 children and young people living with an ACP (of figures submitted)**

**38% Full resus**

**32% Modified**

**15% DNACPR**

**TFSL Categories**



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# ACPs

Area	Co-ordinator / Link	Active ACP's existing at 30 July 2015 and new ACPs	Number Died	Alive with ACP	Cancelled (Moved OOA or not wanted or no longer appropriate)	Transitioned	Full Resus	Modified Resus	No Resus	I	II	III	IV	TOTALS
Shropshire	Louise Leather	7		7			2	4	1	2	2		3	28
Walsall	Charlotte Yale	15	1	15			10	2	3	1		5	9	61
Wolverhampton	Steph Friedl	13		13										26
Birmingham CCN Team	Rachel Williams	63		53	2	2	20	17	16	3	9	22	21	228
North Staffs and Stoke	Cathy Morris	16		16			9	6	1	1		6	9	64
Coventry	Julie Redmond	8		8			3	5				4	4	32
Warwickshire	Sue Davies	20	0	20	0	0	10	7	3			5	15	80
Sandwell	Harminder Bahia	15	1	14			4	9	2	2	1	3	9	60
Acorns x3	Mark Hunter	13		13										26
Birmingham Children's Hospital	Nicki Fitzmaurice	7		7			3	2	2					21
Solihull	Claire Nelson Rachel Beere	16	1	15			7	6	2	1			14	62
Worcestershire	Carol Farrell	14	2	12	2	1	8	2	2			3	9	55
Herefordshire	Cathy Norris	8		8			4	4		1		3	4	32
See Saw/Dudley	Nicky Davies	6		6		1	2	4		2	1	2	4	28
Burton	Helen Bailey	7		7										14
Stafford	Alison Totty	11	5	5	1		3	2	0	1		2	1	31
<b>TOTALS</b>		239	10	219	5	4	85	70	32	14	13	55	102	
														848
														848



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# Local and National Initiatives

- **ACP Co-ordinator identified in each area. (Hospital, CCN team and Hospice).**
- **Annual audit**
- **Local Policies**
- **Research Project via University of Birmingham.**
- **Recommendations for ACP within NICE EOL for children guidelines.**



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# Challenges

- Timely reviews
- Generalist v Specialist
- WMAS
- Version Control spreading the word!



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