



Child and
Young Person's
Advance Care Plan
Collaborative

www.cypacp.uk

Advance Care Plans in Schools and Groups

(including Scouts, Guides, Sports Clubs, etc)

To be read alongside the guide:

[Collaborative Planning for end-of-life Decisions](#)

*'Child' is used to represent 'Child and Young Adult' throughout this document.

** Please note this document has been produced specifically for the CYPACP (Child and Young Person's Advance Care Plan) and hence uses an image from this care plan. Many of the principles apply to alternative ACP's available but the exact details may vary.

Introduction

We are aware that ACPs may raise questions and cause some anxiety for schools and other groups, supporting children with an ACP. This is perhaps most evident when people do not have a clinical background and where clinical resources/equipment are not available onsite.

We hope the following guidance and practical information will support schools and communities on how best to manage situations where children have ACPs.

What are Advance Care Plans?

Advance Care Plans (ACPs) are designed to communicate the priorities and goals of care for a baby, child or young person who has a chronic, life-threatening or life-limiting condition.

ACPs provide invaluable information to support all those involved with caring for or supporting a child* with a life limiting condition. An ACP can provide helpful information and advice on how best to interact with, and support the needs of the child when well, and on what to do when a child becomes unwell.

Although not legally binding, ACPs record carefully considered conversations held between the child or young person and their families and medical professionals.

Decisions regarding what to do when a child is unwell may be written in:

- The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)].

- OR the CYPACP (Child and Young Person's Advance Care Plan)
- or a briefer Emergency Management Plan.

Supporting decisions within the ACP

It is recommended that all schools and groups have a local policy and guidance regarding ACPs and know who to contact for advice and support.

Whilst the ACP records recommendations of what to do in emergencies, it is recognised that not all people coming into contact with the child will have the resources or expertise to follow some of these recommendations. As such, we encourage professionals, when preparing ACPs, to discuss with families how they are used by different groups.

We therefore hope that people can use the plans to help guide them on providing support within their environment and capability. Where it is appropriate it may be helpful to discuss with the family about expectations and how the ACP will be implemented.

Additionally, it should be remembered that in life threatening situations emergency ambulance services (999) can help, as described in the child's Advance Care Plan.

Top tips to consider when discussing the use of ACPs within your own environment

- Discuss and explain what is possible in your environment and within your staff's capabilities
 - It may be helpful to go through each of the medical actions listed on the 'Acute Significant Deterioration/ Emergency' page.

- As explained, it is not expected that schools / non-medical environments would do all of these eg clearly schools would not be expecting to intubate a child.
 - Where this is not possible within your environment, agree what would be done – e.g. ‘call 999 to support’.
- Ensure both parties understand what is documented in the care plan in relation to the school or group environment
 - It is helpful to talk with families about how the ACP can be enacted and to ensure mutual understanding of the situation and expectations.
- Ensure the plan details the preferred management if parents / family members are not present (most of the time in a school environment)
 - This can be found in the box shown below on the ‘Management of an Acute Significant Deterioration page’ titled ‘Note any differences to the plan ...’
 - If this is not completed and the family state they would prefer alterations in their absence to those already documented, it would be prudent to contact the medical team who produced the document to ensure this is still in keeping with the child’s interests.

Management of an Acute Significant Deterioration/Emergency

For review with “Management of Anticipated Complications”/”ReSPECT”

If end of life recognised, see “Wishes around End of Life” and consider transfer to preferred place. Allergies listed at front

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 (irrespective of resuscitation wishes)**

Note any differences to plan detailed below if parents/carers are not present

If none recorded, assumption will be made to follow plan detailed below, even in absences of parent/carer

- Discuss if there is anything else in the ACP that falls out of the school / group's usual practice / policy
 - And discuss how this will be managed.
- Ensure the plan provides contact details of professionals who can provide support with future decision-making. If not, agree with families who would be contacted.
 - These may vary from area to area - this includes the local Palliative Care Teams, specialist teams, local paediatricians / hospital wards / Ambulance Services (they do not always have to transport a child to hospital and can provide clinical guidance) or the local children's hospice, if they are involved with a family.
- Document the discussion

Supporting documents

There are multiple educational and supporting documents on ACPs available on the CYPACP website (www.cypacp.uk).

Additionally, we also highlight a link from the National document from the Department of Education
<https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>

“Supporting Families to inform ‘999’ Emergency Operators of Advance Care Plans” – link to be added when document approved.