

# Emergency Health Care Plans

## Core Principles

### Statement of purpose

An emergency health care plan (EHCP) is a tool designed to make communication easier in the event of a healthcare emergency for children<sup>1</sup> with complex healthcare needs and/or life-limiting conditions.

All children have equal rights to full care based on their needs and wishes, rather than any inappropriate or poorly informed judgements about quality of life.

Like all children, those with complex health care needs and life-limiting conditions should have:

- the right treatment
- as promptly as possible
- with the right experts involved in their care.

### EHCPs should be developed:

- in a locally agreed and recognised format
- within an ethical framework
- taking account of statutory guidance
- in partnership with children, families and local services including:
  - Healthcare teams, including ambulance and paramedic services; hospitals; community services, emergency services (including out-of-hours); GPs and hospices
  - Schools and education services
  - Social care including short break facilities
  - Coroners
  - Other services as appropriate in local settings.

It is recommended that training and awareness-raising precede implementation and are included in induction training for all new staff.

<sup>1</sup> Throughout this document the word child is used to encompass infants, children and young people up to the age of 18 years.

### Individual EHCPs need to:

- be drawn up after open and sensitive discussion between child, parents or carers and lead health professional, usually the consultant paediatrician
- take into account the views of the multidisciplinary team who know the child best including the general practitioner;
- keep the child's best interests paramount at all times
- be brief so that information can be communicated quickly in an emergency
- use simple language, free from jargon and abbreviations, so that it can be understood by those without medical training
- show clearly what action should be taken so that this can be understood immediately in a crisis situation
- be signed in ink by the lead clinician – usually the consultant paediatrician.

### Status of statement on agreed levels of care

The EHCP includes a consensus statement about agreed levels of care. Clinicians will need to take into account the stated views of the child wherever possible, and always the family (and others with an interest in the welfare of the child), in order to make this judgement.

The statement on agreed levels of care is not legally binding, unlike an advance decision to refuse treatment made by an individual over 18 years of age

who has capacity (as defined by the Mental Capacity Act 2005) to decide for themselves, which is legally binding. (*Deciding Right* [www.theclinicalnetwork.org](http://www.theclinicalnetwork.org)).

The Mental Capacity Act (2005) applies in full to 16-17 year olds with three exceptions:

- only those individuals aged 18 years or over can make a lasting power of attorney (LPA)
- only those individuals aged 18 years or over can make an advance decision to refuse treatment
- the court of protection will only make a statutory will for an individual aged 18 years or over.

However, the Mental Capacity Act recognises the lack of guidance by saying: “There are currently no specific rules for deciding when to use either the Children Act 1989 or the Mental Capacity Act 2005 or when to apply to the High Court.”

Whilst the guidance provided by the EHCP MUST be taken into account by all health workers in the event of an emergency, the clinical judgment of senior clinicians at the time of the emergency takes precedence. This is because there may be some situations that were not covered in advance by the EHCP, as they could not have been predicted, but where specific interventions may make a positive difference quickly.

It is critical that this is clearly explained to parents so that they understand that it may not always be possible to carry through decisions made and recorded on the EHCP.

## Dissemination and version control

Ideally there should only be one current version of the EHCP and this should remain with the child at all times and in all settings, in order to be available in the event of an emergency. Having multiple versions runs the risk of an out-of-date plan being used in an emergency. This may not contain the most up-to-date information that accurately reflects the child's circumstances or the discussions and agreements that have been reached with families. Where local circumstances require more copies to be available in

order to best meet the needs of the child, there should be a list of all those who hold copies of the plan. A named person needs to be responsible for sending out any reviewed plan to all of those on the list. A named person in each setting listed needs to be responsible for removing the old plan and replacing it with the new one.

Where the hard copy of the EHCP is printed off from a single master electronic EHCP stored on a hospital intranet or other appropriate system, new copies can be made if the original becomes lost or damaged. The hard copy of the EHCP must indicate where such an electronic master is stored and who has permissions to make alterations or update the plan.

The existence of an EHCP should be signposted for all services, including the hospital emergency departments and ambulance service, so that health workers know to ask for it. It is important that parents understand who will need access to the EHCP and why.

## Update and review

- The EHCP should be reviewed regularly as the child's condition changes and at least annually.
- The EHCP should be dated whenever it is changed.
- Some local ambulance services will require an expiry date, but otherwise an EHCP does not time expire and should always be taken into account at the time of an emergency.
- If there are any doubts about the content of the EHCP, especially if the date is distant, there should be a discussion between parents/carers and the most senior available clinician at the time of the emergency to ensure that the EHCP still reflects the child's best interests and current management plan. There should be a contact number on the EHCP saying who to contact if there are concerns about the content of the plan. This should be the clinician who is responsible for reviewing and updating the plan.

## Contents of an EHCP:

- Active health concerns.
- Current treatments and medication can be included or signposted. The weight (dated) of the child upon which doses were calculated is helpful as a reference point. There should be a clear statement reminding those reading the EHCP that treatment changes may have been made since the plan was written, so all treatment should be confirmed with the family and core health team before being administered.
- Guidance as to what to do if the child is unwell, including any scenarios that might be predictable for that child.
- A clear statement about agreed levels of care should a health emergency occur which makes it crystal clear that resuscitation and life support are appropriate (or not). Some local ambulance services will require a DNACPR form in addition to an EHCP for individuals of any age whose EHCP includes a statement to allow a natural death.
- Space for an option for the child to be conveyed to hospital for assessment before deciding on the level of treatment appropriate for the situation.
- Agreed 24 hour emergency contact number, for example: on-call community children's nursing service, or on-call paediatric team. If the child's usual paediatrician is the emergency contact a back up number for an on-call service should also be given.
- Contact details for parents or carers and any key health professionals who should be contacted in the event of a health care emergency
- The child's postcode as this is often the identifier used by the ambulance service rather than the child's name. It may be necessary to also include postcodes for short break carers and school, especially if these are in a different ambulance service's area.
- A statement about arrangements for review, and who to contact if there are concerns or questions about the EHCP or the child's health care.

Some areas may choose to include additional content to that listed above.

## In case of disagreement about what is in the child's best interests

Where there is any doubt or disagreement about what course of action is in the child's best interests, a second opinion should always be obtained.

If the child is critically ill with a significant risk of life-threatening deterioration, and there is disagreement between parents and professionals about what is in their best interests, actions should be taken to stabilise their condition in order to facilitate prompt discussions between child, family and treating healthcare professionals.

Sensitive discussion with the most senior clinician available, preferably the one who knows the child and family the best, should lead to resolution in most cases.

In the event that this is unsuccessful, every effort should be made at mediation. If time permits, the clinicians can seek guidance from the local clinical ethics advisory group. Where agreement cannot be reached, legal advice should be sought in line with GMC guidance. Approaching the court should be seen as a constructive way of thoroughly exploring the issues and providing reassurance for the child and parents that the child's interests have been properly considered in the decision.

## Support for clinicians in decision-making about appropriate levels of care:

'Treatment and care towards the end of life: good practice in decision making' GMC May 2010

Withholding and withdrawing life-sustaining treatment in children. A framework for practice (2nd edition 2004 – currently under review). Royal College of Paediatrics and Child Health

NHS Toolkit for high quality neonatal services (2009) ([www.dh.gov.uk](http://www.dh.gov.uk))

"Palliative care (supportive and end of life care)" British Association for Perinatal Medicine (BAPM)

Deciding Right ([www.theclinicalnetwork.org](http://www.theclinicalnetwork.org))

## Advocacy for children and parents:

Advocating for children (January 2008) Royal College of Paediatrics and Child Health [www.rcpch.ac.uk](http://www.rcpch.ac.uk)

Patient Advice and Liaison services (England) provide support, advice and mediation for children, parents and other carers.

Community Health Councils (Wales) [www.communityhealthcouncils.org.uk](http://www.communityhealthcouncils.org.uk)

Partners in Advocacy (Scotland) [www.partnersinadvocacy.org.uk](http://www.partnersinadvocacy.org.uk)

Children's Advocacy services (Northern Ireland) [www.niccy.org](http://www.niccy.org)

## Organisations with further information for parents, carers and professionals, including suggested templates for EHCPs, care pathways and information leaflets on making critical care decisions:

Council for Disabled Children [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)

Royal College of Paediatrics and Child Health [www.rcpch.ac.uk](http://www.rcpch.ac.uk)

Together for short lives [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

## Other references

User views of Emergency Health Care Plans for disabled children and young people. Jones N, Fetherston A, Horridge K. *Dev Med Child Neurol* 2009;51(7):570-571

Assessment and investigation of the child with disordered development. Horridge KA. *Arch Dis Child Educ Pract Ed* 2011;96:9-20

Personal resuscitation plans and end of life planning for children with disability and life-limiting/life-threatening conditions. Wolff A, Browne J and Whitehouse WP. *Arch Dis Child Educ Pract Ed* 2011;96:42-48

Department of Health (2003) *Confidentiality – NHS Code of Practice*

Department of Health. (2007) *National Service Framework for Children, Young People and Maternity Services: Children and Young People who are Ill: Standard 6. Assessment of the Ill Child.*

Committee on Paediatric Emergency Medicine. Emergency preparedness for children with special health care needs. *Paediatrics* 1999; 104: 53.

The Scottish Government. (2006) *Emergency Care Framework for Children and Young People in Scotland.*

Dyer C. London hospital to face High Court for allegedly refusing to resuscitate disabled girl. *BMJ* 2004; 328: 125.

Dyer C. Hospital breached boy's human rights by treating him against his mother's wishes. *BMJ* 2004; 328: 661.

Links to all of these documents and websites can be found on the CDC website: [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)