Paediatric Guidance for Do Not Attempt Resuscitation Decisions.

Treatment

All treatment and care that is appropriate for children will be offered at all times, it is always the Health Professional’s duty to act in a child’s/young person’s best interests.

For the majority of children the over-riding aim is to return them to their pre-illness level of health, or as near to it as possible. Nevertheless, it is not an appropriate goal of medicine to prolong life at all costs with no regard to quality or the burdens of treatment on the patient. Moreover, to begin therapeutic intervention that the child will clearly not survive is not in their best interests. This implies that not all treatment interventions are appropriate for every child, every time. (Ref 1)

There will be instances when the clinicians, parents or children feel that they are dying, or will go on to die within hours or days. It is of paramount importance to ensure the comfort of the child and family and to be sure that the child and their family/carers, understand what is happening and are able to plan for their future care.

For all of these children, the Trust must ensure that the appropriate resuscitation decisions, which respect the children’s and parents’ rights and choices, are in place, understood by all relevant employees and where applicable families/carers and are accessible to those who need them. These patients must have a clear and explicit resuscitation plan and this must be recorded in their medical notes.

The General Medical Council guidance, “Treatment and care towards the end of life” (Ref 2), acknowledges that the most difficult and sensitive decisions in the patient’s and family’s end of life care are often those around starting or stopping potentially life prolonging treatments such as CPR. Such decision making remains important and should be recorded as part of advance care planning.

Engaging parents and families and where appropriate children, in advance care planning, puts them back at the centre of their care. The importance of such an approach is recognised in the Royal College of Physicians 2009 guide to advance care planning, which states: *“at the core of current health and social care are efforts to promote patient/ Family-centred care, offer choice, and the right to consent to or refuse treatment and care offered…Advance care planning will help.” (Ref 3)*

The NHS End of Life Care Strategy (Ref 4) stipulates that all people approaching the end of their life, need to have their needs assessed, their wishes and preferences discussed, and an agreed set of actions reflecting the choices they make about care recorded in a care plan. This should be shared with families and relatives where applicable.

Who are Children and Young People?

A child or young person is defined as everyone from birth until their 18th Birthday. (Ref 5)

Within practice Paediatric patients may be referred to as a child, infant or baby, terms that commonly refers to a younger child who does not have the maturity and understanding to make important decisions for themselves. However, as the child develops and matures they begin to develop the capacity to understand and evaluate information allowing them to participate in making informed decisions; these children are commonly referred to as Young People. (Ref 6)

Parents and parental responsibility

A person with ‘parental responsibility’ relates to an individual with rights and responsibilities that parents have in law for their child (Ref 7), this includes the right to consent to medical treatment for them up to the age of 18 years.

Mothers and married fathers have parental responsibility from birth, and so do unmarried fathers of children registered since 15th April 2002. Unmarried fathers whose child’s birth was registered before these dates, or afterwards if they are not named on the child’s birth certificate, do not automatically have parental responsibility. If a child is under a local authority care order the parental responsibility will be shared between the parents and the local authority. If the child is adopted the parents lose parental responsibility. Parental responsibility can also be restricted by court orders. (Ref 8)

Civil partners who were civil partners at the time of treatment will both have parental responsibility; non-civil partners will require the 2nd parent to either apply for parental responsibility or by making a parental responsibility agreement or jointly registering the birth.

Step parents and other guardians of a child may also have parental responsibility as long as they have completed the agreement form for step parents and presented this to the local county court of family proceedings and then lodged this with the Principal Registry of the Family Division.

If a clinician has any queries regarding parental responsibility they should seek legal advice.

Resuscitation

Where no explicit decision has been made in advance, there should be an initial presumption in favour of CPR and all other relevant treatment.

Cardio-Pulmonary resuscitation (CPR) can be given to a patient in cardiac and/or respiratory arrest to prolong life. CPR can encompass chest compressions, ventilation of lungs, defibrillation with electric therapy and injection of drugs.

Resuscitation is the emergency treatment that is used to try and revive a child who has suddenly collapsed, for example if their heart and/or breathing have stopped.

In some circumstances, resuscitation can be successful and the child survives with a good outcome. A period of time spent in intensive care always follows the resuscitation attempt. More often however, resuscitation is sadly not successful or the child may only survive with significant handicap.

When a child is very sick and treatment is failing it may be felt by either the child, parent/guardian or healthcare team that in the event of the child’s heart and/or breathing stopped, a decision not to attempt CPR and allow the child to die a natural death would be appropriate.

DNACPR Documents

A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) document (appendix 1) is a form that is completed by a Consultant or General Practitioner (GP) to act as a guide for future clinical decision’s in the event of a child going into cardiopulmonary arrest. **DNACPR forms do not mean do not treat.** (Ref 1)

Who should initiate a child & family wishes DNACPR conversation

Any member of the multidisciplinary team who knows the child and family well can initiate a conversation and begin a discussion. In practice, this is usually a senior clinician or experienced nurse. A wishes discussion, or end of life plan should be recorded in the patient’s notes. To help plan the child’s care a multi-disciplinary team (MDT) meeting may be held to discuss the future care needs of the patient, these meetings will include the parents/carers, health care professionals that are involved in the patients care and if appropriate the patient. These meetings will be led by the Consultant who is responsible for the care of the child and it is an opportunity for all involved to ask questions and look at the future clinical options that will support the patient and family. Medical employees must communicate in a language that patients can understand bearing in mind different learning abilities.

At this time it may be identified that if the child’s clinical condition deteriorates and their heart and lungs stop working, a resuscitation attempt would not be in the best interests of the patient, at this point the Consultant will discuss the DNACPR form with the parents/carers and child if appropriate and raise the document which will be placed in the front of the patient’s notes as guidance for other healthcare professionals.

Capacity/Consent

Assessing a child’s capacity should not be based on age, at 16 it may be presumed that a young person has capacity to consent. However when assessing the capacity of any young person or child they should demonstrate an understanding of the nature, purpose and possible consequences of any treatment the clinician proposes, as well as the consequences of not having that treatment. Therefore, only if the child or young person is able to understand, retain, use and weigh this information, and communicate their decisions to others can they consent to or refuse treatment. (Ref 14)

If a child lacks the capacity to consent, the parent/carer should be asked, it is usually sufficient to have consent from one parent but if parents cannot agree and disputes cannot be resolved informally, a second opinion may be sought. If this does not resolve the dispute it is appropriate to seek legal advice about whether you should apply to the court. Any decisions made should be made with regards to the best interests of the child or young person.

Legally a child (anyone under 18) can refuse to consent to medical treatment. However, this refusal can be overruled by the parents of the child or by a court. However it should be noted that although there is right in law for patients to consent to treatment if they are below 16 (Gillick competence) (ref 9), or aged 16-17 (Family Law Reform Act 1969 s8) (Ref 8), there is no right in law for patients to refuse treatment. Where a young person with capacity refuses treatment, the potential harm caused by violating the young person’s choice must be balanced against the harm caused by failing to give treatment.

A parent/guardian cannot override the competent consent of a young person’s decision, that the Consultant/GP considers is in their best interest, but it should always be encouraged that young people involve their parents /guardians in making important decision.

Children and Young People decisions

Ideally, clinical decisions relating to young people should be taken within a supportive partnership involving the patients, their families and the healthcare team. Where CPR may re-start the heart and breathing for a sustained period, but there are doubts about whether the potential benefits outweigh the burdens, the views of the young person should be taken into consideration in deciding whether resuscitation should be attempted. The Medical Director may need to be contacted and legal advice may be sought in the event of a dispute.

Throughout the UK, if the healthcare team believes that they should attempt CPR for a competent young person who has indicated that they do not want this, legal advice should be sought. Usually, it is possible to reach agreement on whether or not CPR should be attempted if a child or young person suffers respiratory or cardiac arrest. If there is disagreement between the patient, those with parental responsibility and the healthcare team despite attempts to reach agreement, legal advice should be sought.

Parents cannot require doctors to provide treatment contrary to their professional judgement, but doctors should try to accommodate parents’ wishes where there is genuine uncertainty about the young person’s best interests. If legal advice is required, this should be sought in a timely manner. (Ref 2)

Religious, cultural, social and emotional considerations.

When assessing the best interests of a child / young person, the clinician will consider the religious and cultural beliefs and values, they and their parents/carers have, as well as any social, psychological and emotional benefits the decisions being made will have on the patient and their family.

## Responsibility for Decision-Making

Teamwork and good communication are of paramount importance. Where care is shared, for example between the hospital and general practice or between general practice and a care home, the health professionals involved must discuss the issue with each other and with other members of the healthcare team, parents carers and families.

There must be shared responsibility for deciding about the likelihood of a successful outcome from CPR and discussions between teams regarding those patients who lack capacity, where a balance of benefits and burdens is needed. Nevertheless, one individual needs to take charge of ensuring that the decision is made properly, is recorded, and is conveyed to all those who need to know it, including locum workers. In all cases this will ultimately be the Consultant or patient’s GP.

Recording Decisions

Any decision about whether or not to attempt CPR must be readily accessible to all health professionals who may need to know it, including employees of hospitals, hospices and nursing homes, GPs and other community health professionals, out-of-hours medical services, and ambulance employees. **All children or young people should have these decisions recorded on a Paediatric DNACPR decision record** **or appropriate wishes document.**

*The patient’s healthcare record should contain a Paediatric Do Not attempt Cardo pulmonary resuscitation form (DNACPR form) or appropriate wishes document* which demonstrates:

* Clear documentation of the decision.
* Who is responsible for having the discussion.
* Who is the lead clinician at the time the decision was made.
* Date of decision.
* Reasons for the decision.
* The name and position of the person responsible for making the decision.

*If the patient’s Resuscitation status is reviewed and changed:*

* A new DNACPR form or wishes document must be completed.
* The previous forms must be kept in the medical notes and scored through for future reference but clearly marked as superseded

Patients’ individual treatment plans for resuscitation must be recorded with clear, documented evidence of discussions that have taken place with the patient, parent and other relevant Health care professionals The documentation must include how the decision was made, date, and reason for the decision. The documentation must also include the name and position of the decision maker plus the details of the competent registered professional who has had the conversation and completed the form. The original DNACPR document must be held in the patient’s records and should be easily identifiable and accessible in the case of an emergency.

Communicating decisions to other health care providers

The person who makes the DNACPR decision is responsible for ensuring that the decision is communicated effectively to other relevant healthcare professionals in both primary and secondary care. The senior nurse is responsible for ensuring that every DNACPR decision is recorded in the child’s / young person’s notes and that all those nursing the child / young person are aware of the decision.

Any decisions about resuscitation measures must be communicated between healthcare professionals whenever a patient is transferred between establishments, between different areas or departments of one establishment, or is discharged.

Clinical guidelines issued by the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) (Ref 10) (the Mental Capacity Act 2005 Policy and Procedures (Ref 11) ***advise ambulance employees that they should always initiate CPR unless:***

* There is a formal DNAR decision, or valid and applicable, which has been seen by the ambulance crew, and the circumstances in which CPR may be attempted are consistent with the wording of the DNAR decision or advance (Wishes document) decision;

Or

* The patient is known to be terminally ill and is being transferred to a palliative or terminal care facility (unless specific instructions have been received that CPR should be attempted).

When decisions have been made out of hospital: THE WISHES DOCUMENT

A wishes document is a plan designed to communicate the health-care preferences of children who have life-limiting conditions and their family. It sets out an agreed plan of care to be followed when a child’s condition deteriorates. It provides a framework for both discussing and advance care planning, the agreed wishes of a child and his or her parents. It is designed for use in all environments that the child encounters: home, hospital, school, hospice, respite care, and for use by the ambulance service. It can be used as a resuscitation plan or as an end-of-life care plan.

A wishes document facilitates discussion about options for end of life care and offers choice to families. The opportunity to plan ahead is related to better coping after bereavement and is also associated with people being more satisfied with the service they receive. (Ref 13)

If a child or young person is admitted to the hospital with a wishes document this should be reviewed by the lead clinician for the patient and if appropriate the decisions and treatment plan that has been agreed within the document respected, any changes that a clinician feels appropriate should be discussed with parents and if appropriate the child or young person and the document amended as agreed.

To help support staff within the Trust it is suggested that a Great Western Hospital paediatric DNACPR document be completed for children and young people and placed in the front of their notes so that in the event or any deterioration in the clinical condition of the patient the guidance document is immediately available. Wishes documents are very comprehensive and it may not be immediately obvious from the document that the decision not to commence CPR is appropriate and without this evidence staff may commence inappropriate treatment in the delay in finding the guidance.

If a child or young person attends hospital with a wishes document, this should be photocopied and placed in the front of the patient’s notes once it has been reviewed by the lead Consultant and the original returned to the child, young person or appropriate adult.

On discharge it is important that the wishes document is once again reviewed by the lead clinician to amend any changes that have been agreed with the child, young person and/ or parents and those changes communicated to the patient’s community GP and carers.

Review of DNACPR decision

Decisions about CPR must be reviewed whenever changes occur in the child’s / young person’s condition, if the patient is transferred to the care of a new clinician, discharged from a hospital or at the child’s parents’ expressed wishes. The frequency of review should be determined by the health professional in charge of the child’s / young person’s care and will be influenced by the clinical circumstances of the patient.

It is important to note that the patients’ ability to participate in decision-making may change with changes in their clinical condition. It is not usually necessary to discuss CPR with the patient or parents each time the decision is reviewed, although where a child / young person or parent has previously been informed of a decision and it is subsequently changed, the parents and where appropriate the child or young person should be informed of the change of decision and the reason for it.

**Any CPR decision that has been made in the community or on admission of a child or young person to hospital, should be reviewed by the most senior clinician in charge of the child or young person’s care at the earliest opportunity.**

There may also be occasions when an initial decision has been made to attempt CPR but the child’s / young person’s clinical circumstances change subsequent to that decision and it is no longer clinically appropriate to perform CPR when the child / young person’s heart or lungs stop working, as CPR would not be successful. At this point it is important that all who care for the patient, including the parents, are informed of the change in circumstances and included in the final DNACPR decision making process.

Confidentiality

Respecting a child’s / young person’s confidentiality is an essential part of good care, this applies when the patient is a child or young person as well as when the patient is an adult.

If a child or young person has capacity, their agreement must always be sought before sharing information with family and friends. It may also be helpful to ask the young person with capacity who they want, or do not want, to be generally involved in decision-making. Refusal by a young person with capacity to allow information to be disclosed to family or friends must be reviewed carefully by the clinical team as it may be evident that the sharing of information can help to protect the child or young person from harm or is required by law (Ref 12), and that any decisions made are documented appropriately in the medical notes.

For a child or young person without capacity the agreement for sharing information should be sought from the parents/guardian.

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Appendix 1

