Information for families

R©SPECT



Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process

When a baby or child's breathing and heart stops, this is called cardiopulmonary arrest. To help restart the breathing and heart, cardiopulmonary resuscitation (CPR) can be used. This information leaflet describes what CPR involves and how the decision whether or not to try CPR is reached. This leaflet also explains how the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process can be used to support you in having conversations with the team involved in your child's care about the care and treatment they receive.

We appreciate that talking about death can be upsetting for some people, especially in relation to a child. However, we believe that you should understand all aspects of your child's care so that you have enough information to take part in making decisions. Working with you, your child's team will develop a plan just for them in case it is needed in the future.



What is cardiopulmonary resuscitation?

Cardiopulmonary resuscitation (CPR) is used to try to restart the breathing and heart if they have stopped. It can include:

- repeatedly pushing down very firmly onto the chest to move blood out of the heart

Some or all of these measures may be attempted.

In children and young people, the most likely reason to need CPR is that their breathing has become extremely slow or stopped completely. At this point, inflating the lungs with a bag and mask over the nose and mouth may be used to support breathing.

Does CPR always succeed?

The chance of CPR reviving your child will depend on a number of factors, including:



- why their breathing and/or heart stopped
- any illnesses or medical problems they have currently or have had in the past their overall condition.

If a child's breathing is the only thing that stops, then depending on why this happened, they may be able to be stabilised with a bag and mask to deliver oxygen or breathing support from a ventilator. If the heart stops, the chance of success is unfortunately much lower. Even if the heart can be restarted, there can be damage to other parts of the body, especially if CPR is needed for a long time.

If the breathing and heart are restarted, more intensive treatment is usually needed, often in an intensive care unit (ICU). Some children may make a full recovery or perhaps recover but have additional health problems. Other children may never recover due to brain damage and remain in a coma. The longer CPR is needed, the lower the chance of survival and recovery.

It is important to remember that all children are different, even if they have a similar medical condition to another child. The clinical team will talk to you about your child's condition and whether they believe that CPR would benefit them if they needed it.

Will CPR be tried on every child?

It is the default position to attempt CPR, but if it is thought not to be in your child's best interests, then a decision not to start CPR will be considered. The clinical team in charge of a child's treatment must always act in the best interests of that child.

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Treatment such as CPR may do more harm by prolonging pain or suffering, particularly if a child is already seriously ill and near the end of their life.

If the child's clinical team believe that carrying out CPR would prolong pain or suffering, they will discuss why they believe this to be the case with you and talk about other ways to make sure your child is as comfortable as possible towards the end of their life. The clinical team will discuss any changes to these decisions as they occur.

If CPR is started and your child shows no response, the clinical team and emergency team attending must decide whether to stop CPR. Only when they are certain that CPR can no longer work will they take the difficult decision to stop. There is no specific timeframe to providing CPR as each child is different. Sometimes, despite all attempts at CPR, a child cannot be resuscitated and sadly they die.

Why do we need to discuss CPR?

If the clinical team feel that there is a possibility that your child's breathing or heart may stop, they will discuss CPR with you. CPR is an aggressive form of emergency treatment that unfortunately is not successful in all cases. The clinical team will want to involve you in discussions so you can understand what is involved if CPR is tried. Sometimes, a child's breathing and heart stops unexpectedly. If this happens, the clinical team will try to explain things when they can, but will focus on your child's care.

If a decision is made not to attempt CPR, what happens then?

All staff will continue to give your child the best possible care. In addition, other clinical teams will be invited to discuss how best to support your child's need and what treatment options they can provide to keep your child as comfortable and as pain free as possible.

The team will work with you to complete a Recommended Summary Plan and Emergency Care and Treatment (ReSPECT). This contains a summary of the specific care and treatment your child would need in case of an emergency. This document will be added to your child's medical record so that all staff, where your child is being treated and Emergency Response teams, know what treatments are in your child's best interests. You will also be given the document to keep and share with other members of your child's healthcare team. The ReSPECT document can be updated as necessary, as your child grows older or their condition changes.

What happens if we have not yet decided and our child needs CPR?

It is the default position to attempt CPR but the Consultant (or their deputy) in charge of your child's care will decide whether to carry on CPR or stop. As ever, the decision will be based on your child's best interests. If you have completed a ReSPECT document, the clinical team will take these recommendations into account.

Can we change our minds?

You can change your mind at any time, even after you have completed a ReSPECT document. The clinical team are available to help you through this process so ask as many questions as you need.



Can I talk to anyone about this?

The Chaplaincy and Spiritual Care team within a hospital support people whether they have religious beliefs or not. They can also contact representatives of your own faith if you prefer. Many hospitals will also have specialist family liaison staff who can provide support to you.

Please ask ward staff for information on what support is available to you.

If you would like to talk to someone outside the clinical team or have concerns about the decision making process, you can contact the hospital's Patient Advice and Liaison Service (Pals) team.

Further information and support

There are a number of national organisations that offer support and advice to anyone in a similar situation:

Action for Sick Children Call their helpline on 0161 486 6788 Monday to Friday from 9.30am to 4.30pm or visit their website. <u>www.actionforsickchildren.org.uk</u>

WellChild

A variety of support is provided, including the WellChild Family Tree, a growing network of families from across the UK, all of whom have children with exceptional health needs. <u>www.wellchild.org.uk</u>

Together for Short Lives

Call their helpline on 0808 8088 100 or visit their website. <u>www.togetherforshortlives.org.uk</u>

ReSPECT process <u>www.respectprocess.org.uk</u>

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