



Recommended Summary Plan for Emergency Care and Treatment

Information for parents

Version 1.0

Introduction

This leaflet is about a document called a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). It explains how it fits in, with the plans we make with you, about your child's care and treatment in a future emergency. The form can be used on its own or together with a more detailed advance care plan to record your child's wishes.

You may not have seen anything like this before and this leaflet may not answer all your questions but don't worry because your healthcare team will be very happy to discuss this with you and explain anything you don't understand. They will also provide you with extra information about the things that are especially important to you and your family.

What is ReSPECT for?

It is a way of trying to make sure that if your child suddenly becomes very unwell, the doctors and nurses looking after them have some key information about their condition and the treatments that might, or might not, help them at that time. This is important because they may not have met you or your child before and may not know about their usual state of health or what yours and their wishes are.

Usually, a doctor or nurse who knows your child and your family well will take time to discuss your child's care with you, and them, in order to understand what you might want if your child becomes unwell. This may be as part of a more detailed process called advance care planning, or may be a conversation just to address the emergency situation. After this, they will complete a ReSPECT form to summarise the plans that you have agreed.

It's impossible to see into the future and therefore the form cannot be used to force those looking after your child, to do anything that you, or they disagree with at that time.

Who makes the decisions and writes a ReSPECT form?

You will be included in any decisions about your child's care. Wherever appropriate your child should also be involved in these discussions. The doctors and nurses who are looking after your child will give you all the information that you need about both their health and any treatments that they may need, so that everyone can make the right decisions together.

Should I consider having a ReSPECT form for my child?

Some families get reassurance from completing a ReSPECT form, either as part of an advance care plan (ACP), or on its own. Most often it is helpful for you, your child and your healthcare team to consider completion of a ReSPECT form if they have a condition that is expected to shorten their life.

However, it can also be useful if your child has a complex medical condition or disability and you want to make clear what treatments you would (or would not) want in an emergency.

Where is the ReSPECT form completed?

It can be completed anywhere and at any time. Where it is appropriate to involve your child it's helpful to discuss it with them while they are well, so that there is plenty of time for you, them, and your family, to consider the decisions that are right for you. You can then discuss these with your child's doctors and nurses and, if you want to, with other people who are important to you.

Sometimes, a ReSPECT form is needed when your child is very unwell in hospital and there is much more urgency to record a plan for their emergency care and treatment.

What sort of decisions will be recorded on a ReSPECT form?

This will depend on the choices that you, and your child, want to make with the doctor or nurse who is guiding you. They will point out the decisions that might be important to consider. These will be about the types of care and treatment that your doctors and nurses might consider for your child if they become very unwell.

For example, you may decide you want to write down whether or not you would want your child to be admitted to hospital for treatment if they are very unwell. That could guide doctors or ambulance paramedics who are called in an emergency but who have not met you or your child before. If you decide that you would want your child to be considered for hospital treatment, there may be some types of care or treatment that you and they would want and others that you wouldn't. For example, these might include admission to a paediatric intensive care unit (PICU).

The ReSPECT form includes a specific section for writing down whether or not you would want your child to receive cardiopulmonary resuscitation (CPR) if their heart or breathing were to stop (this is explained in the CPR section below).

What sort of decisions will be recorded on a ReSPECT form? (continued)

It is important to emphasise again that the ReSPECT form is completed to help to ensure that your child receives the best possible treatment for their individual situation. It can't be used to request or demand treatments that would not benefit your child.

Is ReSPECT only about treatments that are not wanted?

No. It will have the treatments written down that you would want for your child, as well as those that you would not want or would not work.

In many cases the ReSPECT form is used to make it clear that all possible types of treatment should be offered. Your child's doctor can use it to provide information for emergency doctors and nurses, who may not have met your child before, about what treatments may work well for them (and about those that may not work so well). This can be really valuable if they have a very complex condition.

Can I use a ReSPECT form to insist that my child must have a particular treatment?

No. You can make clear what treatments you would want the doctors to consider and what treatments you would not want, but you may not demand any particular treatment.

When should a ReSPECT form be completed for my child?

The best time will be different for each child and their family

Predicting exactly when they will become more unwell isn't often easy. It is a good idea to consider completing an ACP and/or a ReSPECT form if your doctor thinks that your child is likely to become very unwell within the next year. This allows everyone time for careful discussion with your child's doctors and nurses and your family to make sure that the choices recorded are right for you, your child and your family, without being rushed.

If decisions are delayed until your child becomes very ill, or they are in immediate danger of dying, there may not be enough time for you, or your family to think things through. If this happens it is possible that your doctors and nurses will have to make decisions for your child and your family.

What if I don't want a ReSPECT form for my child?

Then you don't have to have one. If you prefer not to talk this through at this time, your doctors and nurses will continue to care for your child and help you, your child and your family make choices about treatments when needed.

Should your child become very unwell and you are not able to decide or you cannot be contacted quickly enough, the doctors will also choose the treatments that are best for them.

Can I use a ReSPECT form to insist on having treatment?

No. Its purpose is to record treatments that would be wanted if needed and appropriate, as well as those that would not be wanted or would not be effective. There are many individuals whose ReSPECT forms will make clear that all possible treatment should be offered. This can be invaluable for example, to a person with a complex disability.

Can I change my mind?

Yes, always. The recommendations written on your child's ReSPECT form are the ones that are right for you, your child, and your family when they are recorded. If your child's condition changes, or if you, your child, or your family want to change your mind for any reason, the form can be changed. It's important that you speak to the doctors and nurses looking after your child, if you want to change anything that is written on your child's ReSPECT form.

It's important not to forget that if you decide that you don't want a ReSPECT form for your child now, you can always change your mind, and consider having one in the future.

Will completing a ReSPECT form affect my child's care?

No. Decisions that are recorded about your child's future care will not change any other care or treatment that you may need.

Is the ReSPECT form legally binding?

No. It is to guide to assist doctors and nurses who might have to make very rapid decisions about your child's treatment in an emergency. The way they use the information on it will depend on your child's condition at the time. However, they would have to have good reasons for ignoring the advice in written on a ReSPECT form.

Can the ReSPECT form be used wherever my child is?

Yes. It can be used anywhere that your child is getting medical treatment. This means that it is always best to ensure it is with them when they go out. It's important to make sure that your family, friends and other adults that look after your child know about it, and know where to find it in an emergency.

Why is there a special section about CPR?

Cardiopulmonary resuscitation (CPR) is a treatment used when someone stops breathing and their heart stops beating. If this happens, starting CPR immediately can give some people the chance of recovery to be able to enjoy life. CPR may not work as well if it isn't started quickly, so doctors and nurses usually try to start CPR straight away if a person's heart and breathing stop. Deciding in advance if you would want your child to receive attempted CPR helps to ensure that it is started quickly, giving them the best chance of getting better. It also helps to make sure that CPR is not started if you, and your child, would not want it or it wouldn't help them.

Why shouldn't everyone be resuscitated?

CPR does not always work. When it is shown in films and TV 'soaps' they often show people who survive, which happens much less often in real life.

If a person's heart stops as part of the natural process of dying, CPR doesn't stop them dying, but it can prolong the time it takes and be very uncomfortable. It includes very firm pressing on the chest, blowing air into the lungs and possibly electric shocks to the chest. Because of this, many people and their families choose not to have CPR, and health professionals try to avoid attempting CPR when it will not prevent the person dying.

If you would wish that your child be given CPR immediately, should they collapse, a complete ReSPECT form will make this decision clear, and improve their chance of survival.

If you and your doctor or nurse decide that your child won't be helped by CPR then recording this on their ReSPECT form can help to ensure that, as far as is possible, CPR is avoided.

If I don't want my child to have CPR, how do I make sure this is known about and understood?

Your child's ReSPECT form must be available immediately if it is needed in an emergency. It should be kept somewhere obvious in your home. It's important to also remember to make sure it is available when your child goes out for any reason. Also, all the adults that care for your child should know about your wishes and where to find their ReSPECT form in an emergency.

What if we don't want to talk about any of this?

Then you don't have to. Some people find talking about this quite distressing or frightening and if you don't want to discuss this, for whatever reason, that's fine. Please make sure you tell your doctors and nurses and they will support you. If necessary, they will help guide you, your child, and your family through urgent decisions, should the need arise and, if needed, they will make decisions in your child's best interests.

What if my child already has a document like this? (Like a CYPACP that also has information about their wishes)

Both documents work together hand in hand. The ReSPECT form deals only with recommendations that may help doctors and nurses to make an immediate decision about your child's treatment in a crisis.

It is the same for people of any age, so it is easily recognisable by the doctors and nurses who might be helping your child in an emergency, even if most of their patients are adults. If your child has both documents the ReSPECT form will carry details of their CYPACP so that the team know to find it and read it.

In addition, when your child is older and is transferred from children's to adult health services the ReSPECT form can continue to be used.

Should I make all the decisions for my child?

That depends a lot on you and your child. Wherever possible the medical team will be anxious to ensure that your child's views are understood and are taken account of in the plans that are made. This is especially true for older children (young people).

In an ideal situation, you, your child and their doctors and nurses will all be able to agree on whether they should have a ReSPECT form, and what should be written on it. Very occasionally this isn't possible in which case a judge might be asked to decide on the right thing to do.

I still have some concerns or questions – who should I ask?

The doctors or nurses looking after your child will be very willing to talk to you about this or anything else that is worrying you. It doesn't have to be anyone in particular. Ask the person who you find it easiest to speak to, and if they can't answer your questions and concerns they will be able to find someone who can to speak to you.

Who else can I talk to about this?

In addition to the doctors and nurses looking after you, there are other people you may want to talk to about the decisions in your ReSPECT form, for example:

Patient support groups
Spiritual carers or advisers
Independent advocacy services
Together for Short Lives

If you need help in contacting any such people please ask a member of your healthcare team.

The following space is for you to write down any questions that you may want to ask: