



Recommended Summary Plan for Emergency Care and Treatment

Information for young people

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 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 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 doctors and nurses 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.

What is ReSPECT for?

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

Usually, a doctor or nurse who knows you well will take time to discuss your care with you and your parents in order to understand what you might want if you become unwell. This may be as part of detailed process called advance care planning, or maybe 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 you to do anything that you, your parents or they disagree with at that time.

Who makes the decisions and writes a ReSPECT form?

You and your parents will be included in any decisions about your care. The doctors and nurses who are looking after you will give you all the information that you need about your health and about any treatments that you may need, so that everyone can make the right decisions together.

Should I consider having a ReSPECT form?

Some young people 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 parents and your healthcare team to consider completion of a ReSPECT form if you have a condition that is expected to shorten your life.

However, it can also be useful if you have 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. If you can complete it with your family while you are well, so that there is plenty of time for you, and your family, to consider the decisions that are right for you. You can then discuss these with your doctors and nurses and, if you want to, with other people who are important to you.

Sometimes, a ReSPECT form is needed when you are very unwell in hospital and there is much more urgency to record a plan for your 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 parents, want to make with the doctors and nurses who are 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 you if you become very unwell. For example, you and your family may decide you want to write down whether you would want to be admitted to hospital for treatment if you are very unwell, or if you would rather stay at home. That could guide doctors or ambulance paramedics who are called in an emergency but who have not met you before. If you decide that you would want to be considered for hospital treatment, there may be some types of care or treatment that you 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 to receive cardiopulmonary resuscitation (CPR) if your heart and breathing were to stop (this is explained in the CPR section below).

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

Is ReSPECT only about treatments that are not wanted?

No. It will have the treatments written down that you would want, 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 doctor can use it to provide information for emergency doctors and nurses, who may not have met you before, about what treatments may work well for you (and those that may not work so well). This can be really valuable if you have a very complex condition.

Can I use a ReSPECT form to insist that I 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 me?

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

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

If decisions are delayed until you become very ill or 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 you and your family.

What if I don't want a ReSPECT form?

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

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

Can I change my mind?

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

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

Will completing a ReSPECT form affect my care?

No. Decisions that are recorded about your 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 doctors, nurses or paramedics who might have to make very rapid decisions about your treatment in an emergency. The way they use the information on it will depend on your condition at the time. However, they would have to have good reasons for ignoring the advice written on a ReSPECT form.

Can the ReSPECT form be used wherever I am?

Yes. It can be used anywhere that you need medical treatment. This means that it is always best to take it with you if you go out. It's also important to make sure that your family, friends and any other adults that look after you 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 CPR helps to ensure that it is started quickly, giving you the best chance of getting better. It also helps to make sure that CPR is not started if you would not want it or if it wouldn't help you.

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 them dying.

If you are someone who needs CPR to be started immediately, a complete ReSPECT form will make this decision clear, and improve your chance of survival.

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

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

Your 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 you take it with you when you go out for any reason. Also, all the adults that look after you should know about your wishes and where to find your 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 and your family through urgent decisions, should the need arise and, if needed, they will make decisions in your best interests.

What if I already have a document like this (Like a CYPACP that also has information about my 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 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 you in an emergency, even if most of their patients are adults. If you have both documents the ReSPECT form will carry details of your CYPACP so that the team know to find it and read it.

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

Isn't this really my parents' decision?

That depends a lot on you. This is about your care, and you will be involved as much as you want to be. Your parents will also be involved with the discussions and will help you with your decisions. If you don't want to think about all of this, they can do this for you.

Usually you, your parents and your doctors and nurses will all be able to agree on whether you 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 you 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 your family and 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: