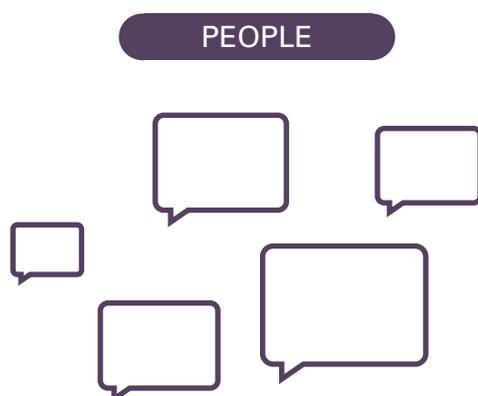


Having a conversation about ReSPECT

Adults

The ReSPECT process is designed to empower the person and the clinician to have a two-way conversation about priorities of care and recommendations for emergency treatment. Some aspects of the ReSPECT conversation may be difficult, such as discussing limits to care and cardiopulmonary resuscitation. The following tips aim to help to prepare for a conversation guided by the ReSPECT process.

Before you have the conversation think about:



Who should lead the conversation?

Ideally, this should be a senior clinician looking after the patient who knows them well, such as their lead consultant or a senior trainee, GP or a senior nurse. In a more urgent situation, the senior clinician holding clinical responsibility for the person should lead the conversation. Involving other colleagues with relevant expertise or significant input into their care may be helpful e.g. critical care outreach or palliative care.

Who are you having the conversation with?

This should be the person, and where possible, their family and other representatives.

If the person has capacity for the relevant decisions, they must be involved fully with the process of shared decision-making. Many people want to have the support of family or other representative in the discussion, and some may choose to have a family member or other representative advise them on what choices to make. If you are asked to speak to the person's family or other representative alone, and the person has capacity, then seek their permission first. If they do not want their family or other representative to know about their condition or their choices, they should make sure that the healthcare team knows about this so that their wishes for confidentiality can be respected.

If a person lacks capacity and has appointed a legal proxy (e.g. with power of attorney for health and welfare), the clinical team must involve them in making shared decisions on behalf of the person. Where there is no legal proxy, the clinical team must consult family or friends about a person's situation and previously expressed views or wishes, in order to make decisions that are in that person's best interests and for their benefit. However, the responsibility for making those decisions rests with the senior responsible clinician. The family must not be burdened with thinking that they are being asked to make these decisions.

Which other team members should be there?

This will vary with the setting, but where possible, it is useful to have another team member with you, so that they know what was said and can reiterate the information to maintain continuity and consistency, and you can reflect on the conversation together. Having a member of another discipline present demonstrates that the team is agreed on the advice and recommendations given, and provides another perspective to support the person's understanding and involvement in decision making. This may also be an opportunity to train junior members of the team.

TIMING



When is best to have the conversation?

Ideally, it is good to have these conversations early and in a non-urgent situation, when the person is able to make decisions and express their priorities. In the community or in an outpatient setting, there may be an opportunity to complete the ReSPECT process over more than one meeting. However, there may also be situations when recommendations are needed relatively urgently; at these times the conversation should be initiated and completed at once.

SETTING

Where possible find a quiet and private place for the conversation. Sit so you are level with the person and other people in the room. It is important that you have the time to have the conversation, and not feel rushed or pressured. Try to turn off phones, beeps or pagers, or where this is not possible, warn that there may be interruptions.

INFORMATION GATHERING



- Gathering relevant information about the person in preparation for the conversation is invaluable, such as their past and current medical history and what they are able to do for themselves. In addition, it is important to seek consensus about what interventions are appropriate should the person deteriorate with members of the multidisciplinary team and other relevant clinicians.
- In a more urgent situation, the clinician with responsibility for the patient should gather as much information as possible about the person within the time frame without compromising best care.

- It is also useful to understand what information the person and those important to them have already been given, their understanding of the current situation, what the future holds, and how they have responded to conversations like ReSPECT in the past.
- It can be a challenge to understand the values and priorities of cultures different to our own and how these may impact on the person's level of comprehension. Such values must be acknowledged and the conversation adapted accordingly, as their perception of quality of life and wishes for treatment may be very different.
- It is essential to arrange for an interpreter where this is needed - try not to use the person's family or other representatives to interpret.
- Ensure those with eyesight or hearing impairments have appropriate aids.
- Consider poor functional literacy, e.g. not being able to read forms or instructions, which may be difficult to detect due to shame and stigma. Look out for clues such as "I forgot my glasses", "I will read it later", or "I don't like filling out forms."

During the conversation:

Explain the purpose of the conversation

Explain that the aim is to reach a shared understanding of the person's current and future health status and to agree and make recommendations about what care should be implemented in a future emergency situation in which they are unable to make or express choices.

"We would like to talk to you about how you are, what has been happening recently, and what might happen in the future, so that we can make sure that you receive the best care and treatment."

Establish how much information the person wants to receive

It is important to establish how much information the person wants, and to give information in line with their wishes. Ask them if they would like to include anyone else in the conversation.

"These conversations are not easy; are you OK to continue?" and "is there someone else that you want to involve who knows about what you think or want?"

"Sometimes people think about what might happen if they were less well in the future; is that something that you would like to talk about?"

Establish what they know already

Establish what the person, and those with them, know already about their health and current situation, and what that information means to them. Where appropriate, you may need to correct misunderstandings at this point.

"Can you tell me what you understand about your illness?", "how do you feel things are going?" or "how do you feel things have been in comparison to a month ago, or over the last few months?"

Establish where possible the priorities and wishes of the person

Explore whether the person, and those with them, have thought about what might happen in the future, and what they would want in an emergency situation.

“What are the things that we need to know about you?”, “have you thought about what is important to you going forwards?”, “have you thought about what you would want in the future?” or “when you think about the future, what matters most to you?”

When there is someone representing the person, use questions like: “What do you think they would want?” or “have they ever expressed any wishes beforehand?”

Explain the current and future clinical situation and treatment(s)

Explain the current clinical situation, what situations might happen in the future, and what treatments are and are not appropriate for the person in those situations.

“You responded so well to the treatment, we need to make sure that if this situation arises again, everyone knows what to do” or “the treatment helped this time, but we are worried that at some stage you may become more unwell – is this something that you have thought about?” or “unfortunately, we do not think that giving you more treatment is going to help, so we need to think about what we can do for you, what you would want in that situation, and what treatments or care we can give.”

Use plain language

Avoid medical jargon and use plain language to de-medicalise and de-mystify healthcare, particularly when in emergency situations. Plain language means that the listener or reader should understand from the first time they hear or read a communication.

Examples: instead of “oral” use “by mouth”, instead of “modify” use “change”, instead of “optimal” use “best way.”

Check their understanding

Do not assume that anyone understands everything that has been said to them. Some people may lack the confidence, experience, or are too unwell to ask clinicians for explanations or to clarify statements.

‘Teach back’ is a simple technique where you ask a person, including if there is an interpreter, to explain what has been said in their own words. If they do not articulate the conversation back correctly, explain again and repeat teach back. This may need to be repeated a few times. In some cases, it may be helpful to ask another healthcare professional to have the conversation. Diagrams and other forms of media can be used to aid understanding.

“I would like to check that we have understood each other, so can you tell me, in your own words, about what we have been discussing?” or “what will you tell your family when you get home about what we have discussed?”

Summarise the conversation

To ensure that a person and those with them understand the what has been discussed and what will be recorded on the ReSPECT form, summarise the conversation, giving them the opportunity to comment on or confirm the recommendations. Ask them if there is anything else they would like to discuss.

People who do not want to engage in such a conversation

Some people may not want to have a conversation – in this case, you should support them in their decision until they are ready to begin discussions. If a decision is needed more urgently, you should explain this to them and explain the need to plan in order to ensure they receive the best care possible. In a less urgent situation, you should support the person until they are ready to discuss their wishes.

What if a person does not want a ReSPECT form?

If a person does not want a ReSPECT form then their wishes should be respected. If there is a clear clinical view that a ReSPECT form could be of benefit to them, the reasons for them not wanting this should be carefully explored and documented. Try to avoid using language such as 'refused'. Try to offer them further opportunities to discuss this again or to change their mind as and when they are ready to do so.

What if the person or their representatives disagree with a clinical decision?

In situations where the clinical team think that a particular treatment or intervention should not be initiated in an emergency because it will not work for the person (and that therefore a ReSPECT document is needed to record this) all attempts should be made to explain this to the person, their family or their representatives. This should be done sensitively and carefully by an experienced, senior clinician. A second opinion should be offered if they do not accept the clinical decision.

If disagreement persists, full details should be documented in their health record. If necessary legal advice and a ruling by the courts may be needed, but the need for this should be very infrequent if the person and those close to them have been properly involved in fully informed discussion.

After the conversation:

Documentation and sharing the decisions

It is important to share the information following the conversation. This should be done by documenting a summary on the ReSPECT form, a more detailed documentation in their health records or in some cases a clinic letter, and informing the wider health and care team. If you had someone with you during the conversation, they can relay the information to their teams to ensure everyone is aware of the plan.

It takes time to do the documentation – however the better the documentation, the better the shared information.

Reflection and feedback

Everyone is different in their approach and style for these conversations. You evolve your own style with time and experience. Just like learning a practical procedure, skills for having difficult conversations need to be practiced and it is helpful to reflect and listen to feedback.

As those who work in health and social care, we can learn a lot by observing our more experienced colleagues and learning from conversations that went well and those that did not. If you are leading the conversation and had other team members in the room with you, they may be able to provide feedback. You can reflect on what aspects went well, what did not go so well, how certain points were phrased, and if those in the room understood what was being said.

