

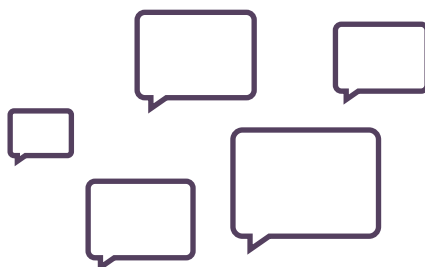
Having a conversation about ReSPECT

Children and young persons

The ReSPECT process is designed to empower the young person, their family 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:

PEOPLE



Who should lead the conversation?

This should be a senior clinician looking after the child who knows them and their family well, such as their lead consultant, GP or a senior nurse. In a more urgent situation, the senior clinician holding clinical responsibility for the child should lead the conversation. Involving other colleagues with relevant expertise or significant input into their care may be helpful e.g. medical/surgical specialists or palliative care.

Who are you having the conversation with?

Depending on the child's age and level of maturity the conversation may occur solely with their parents. However where possible, the child's views must always be sought and given due weighting within the discussions.

- If the young person has sufficient maturity and capacity for the relevant decisions, they should be involved in the process of shared decision-making. Some parents may advise that they wish to exclude their child from these discussions. It is important to explore and understand their reasoning for such a request and to seek an appropriate approach through which to include their child in the process.
- For young people, under the age of 16, a pragmatic line must be steered regarding their involvement in order to establish a position that is ethically acceptable to all those involved. For those over 16 the Mental Capacity Act applies and their involvement in the decision making should be guided accordingly.
- If a young person over 16 lacks capacity their parents will normally act as their legal proxy. As such the clinical team must involve them in making shared decisions on behalf of the person. Where this is not the case, a person will be identified by social services to fulfil the legal proxy role.

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 young person and their family are 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 child and their family 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 child deteriorate with members of the multidisciplinary team and other relevant clinicians.
- In a more urgent situation, the clinician with responsibility for the child should gather as much information as possible about them and their family within the time frame available.

- It is useful to understand what information the child and their family 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 family's interpretation of the situation. Such values must be acknowledged and the conversation adapted accordingly; 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. Wherever possible do not to use the person's family or other representatives to interpret. This is especially important where one parent requires an interpreter and the other does not; it is very difficult to appreciate if there is any disparity of opinion between the parents if one is translating for the other.
- 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 child's current and future health status and to agree and make recommendations about what care should be implemented in a future emergency situation.

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

Establish how much information the person wants to receive

It is important to establish how much information the young person and their family 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 (or their child) were less well in the future; is that something that you would like to talk about?"

Establish what they know already

Establish what the family 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 child's 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 family, 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/your child?”, “have you thought about what is important to you/your child going forwards?”, “have you thought about what you/your child would want in the future?”

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 them/their child in those situations.

“You/your child 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/your child may become more unwell – is this something that you have thought about?” or “unfortunately, we do not think that giving you/your child 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 be anxious about asking clinicians for explanations or to clarify statements.

‘Teach back’ is a simple technique where you ask a person 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 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 parents 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 their child receive the best care possible.

What if a person does not want a ReSPECT form?

If a family 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 parents disagree with a clinical decision?

If there is disagreement between the recommendations of the clinical team and the wishes of the parents and/or a child who is competent, every effort should be made to resolve this through discussion and explanation. A second opinion is often very useful in this regard.

If disagreement persists, full details should be documented in the child or young person's health record. Legal advice should be sought and a ruling by the courts may be required in these circumstances. Whilst involvement of the courts has been an infrequent occurrence, changing societal attitudes are making this more commonplace.

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.

