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Approaching the families of potential organ donors

Best practice guidance

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Contents

Preface	4
Introductory notes	5
1. Introduction	6
1.1 Background	6
1.2 International perspectives and current research base	6
1.3 Objectives for this best practice guidance	7
2. Current professional guidance	8
2.1 National Institute for Health and Clinical Excellence (NICE)	8
2.2 General Medical Council	9
2.3 UK Donation Ethics Committee	9
2.4 Summary	9
3. Involving the specialist nurse – organ donation in the family approach	10
3.1 Planning the approach	10
3.2 Confirming understanding and acceptance	11
3.3 Discussing donation	13
4. Summary	20
Appendix A: NICE guidance on Organ Donation	21
Appendix B: Legal frameworks for deceased donation in the UK	24
Appendix C: References	26
Appendix D: Membership of the Best Practice Development Group	27

Preface

The death of a potential donor is frequently sudden, unexpected and untimely, and when raising the question of organ donation, clinical staff face first hand the apparent tensions and conflicts between caring for a bereaved family and society's need for more donor organs. Approaching the family of a potential organ donor can be a challenging prospect, which requires compassion and sensitivity, and yet it is an aspect of care for which few ICU clinicians have received any specific training.

This best practice guidance, and the accompanying DVD, describes how to approach the families of potential organ donors, and seeks to promote a closer and more effective collaboration between hospital staff and the Specialist Nurse – Organ Donation. It is intended for use by clinicians across the United Kingdom, and represents a synthesis of national guidance and recommendations published by various organisations over the last five years.

The guidance has been prepared at the request of NHS Blood and Transplant by a multi-disciplinary group of clinicians who are closely involved in organ donation. The guidance has been endorsed by the Council of the Intensive Care Society and the Board of the Faculty of Intensive Care Medicine. We believe that all intensive care clinicians will find the guidance insightful and supportive in the important task of approaching the families of potential donors.

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Introductory notes

NHS Blood and Transplant (NHSBT) is a special health authority that supports the coordination of organ donation across the UK. However, different parts of the UK are subject to different legal and health regulatory frameworks, and this has three specific implications for this document.

1. The legal frameworks for deceased donation in the UK are described by The Human Tissue Act 2004 and the Human Tissue (Scotland) Act 2006. Although their similarities are greater than their differences, these two pieces of legislation are distinct and come with their own terminology. Thus, whilst the Human Tissue Act 2004 (which applies to England, Wales and Northern Ireland) uses the term *consent*, the Human Tissue (Scotland) Act 2006 uses the principle of *authorisation*. In order to maintain relevance to a UK-wide audience, wherever possible the terms *consent* and *authorisation* have either been avoided or referred to together (ie *consent/authorisation*).
2. Although the legal framework for consent/authorisation is currently one of a hard opt-in for the whole of the United Kingdom, plans to introduce a soft opt-out system into Wales are at an advanced stage. Whilst it is emphasised that many of the principles presented in this document apply to either system of consent, more specific guidance on the implications of this legislative change will be issued closer to the time of implementation.
3. The contents of this document build in part on the guidance on organ donation issued by the National Institute for Health and Clinical Excellence (NICE) in December 2011. This guidance applies automatically in England and Wales and has also been endorsed for use in Northern Ireland. While the NICE guidance has no regulatory force in Scotland, it is nevertheless hoped that the best practice principles upon which it is based may be adopted by clinicians working throughout the UK.

1. Introduction

1.1 Background

Over the last four years, very considerable gains have been made towards maximising organ donation from intensive care units and emergency departments in the UK. This has been the result of giving due attention to all parts of the donor pathway from initial identification and referral through to better donor management, and in particular is attributable to a continued rise in donation after circulatory death (DCD) and an increased number of donors being identified and referred from Emergency Departments.

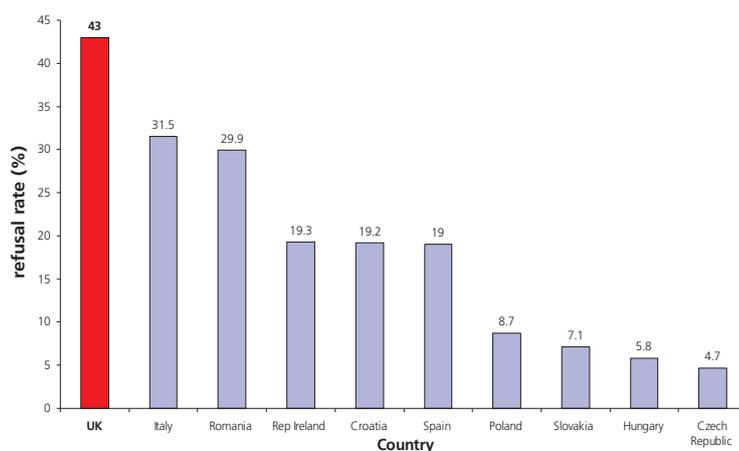
Despite impressive improvements in some elements of the pathway, there is one crucial outcome that has proven stubbornly resistant to change, namely the proportion of families who give their consent/authorisation for organ retrieval to take place. Recent data from NHS Blood and Transplant reveal that consent/authorisation rates for donation after brain-stem death (DBD) are static at just over 60%, whilst those for DCD are actually falling and now stand at just over 50%¹. As such, family refusal represents the biggest 'step down' in loss of potential donors in the whole of the donation pathway.

1.2 International perspectives and current research base

Family refusal rates in the UK are considerably higher than those reported from many parts of mainland Europe, where they are often less than 20% (see Figure 1.1). They are also substantially higher than the levels of public support for donation as repeatedly revealed by a series of opinion polls².

How can family consent/authorisation rates be improved? It is tempting to believe that the solution lies exclusively with public promotion and societal engagement. However, there is also evidence that the way in which the possibility of donation is presented to a grieving family can have a critical impact – both positive and negative – upon the decision that they make. It is particularly important that families are approached at the appropriate time, in the appropriate fashion and by someone with the appropriate skills.

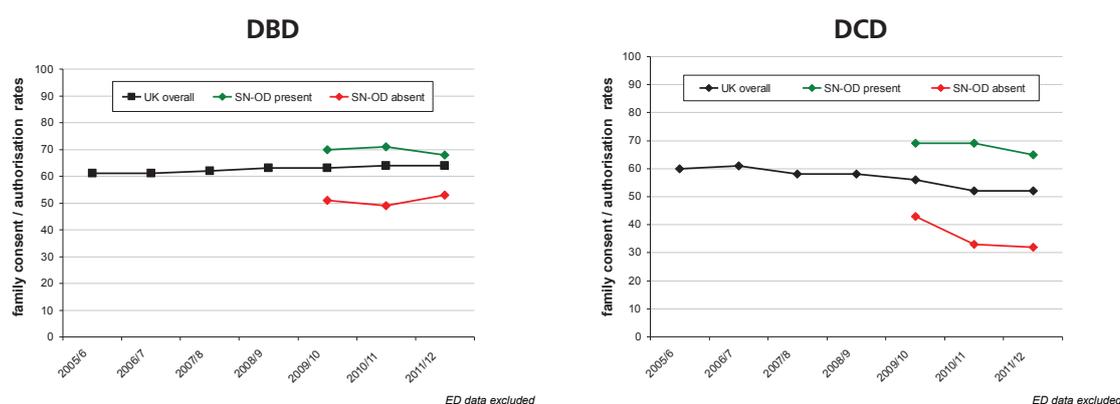
Figure 1.1 International refusal rates for organ donation



Breaking bad news is a core competency for any critical care clinician, and it is also a key element of the family approach. However, few critical care clinicians have ever had any specific training on how to bring organ donation into an end-of-life care discussion. It is not always appreciated how difficult such decision-making can be for many families at this time and how seemingly innocuous remarks can lead to a family closing the door on the donation discussion. If families are to be given the best opportunity to make the right decision, specific factors need to be considered, identified

and planned for by health care professionals who are both knowledgeable and experienced. Furthermore, whilst donation will always be a relatively infrequent activity for the majority of critical care clinicians, it is the core activity of Specialist Nurses – Organ Donation (SN-ODs). International evidence would suggest that co-ordinator led approaches achieve higher consent/authorisation rates. Although the ACRE study failed to replicate this finding in UK practice³, it did not in any way evaluate the best practice as described in this document. Furthermore, audit data from NHS Blood and Transplant repeatedly reveals higher family consent/authorisation rates when SN-ODs are involved at an early stage (Figure 1.2).

Figure 1.2 UK consent/authorisation rates when SN-ODs involved or not involved



1.3 Objectives for this best practice guidance

The consistent message from the available evidence is that approaching families in certain ways arbitrarily prompts a premature refusal, and that avoiding such pitfalls can result – quite legitimately – in improved rates of family consent/authorisation. Such modifiable elements of the family approach include the timing of when donation is raised, particularly in relationship to whether a family have accepted the inevitability of their loss, and the type of language that is used. Proper planning of the family approach is essential if these modifiable elements are to be optimised, and SN-ODs are well placed to lead on many aspects of this. However, there will also be occasions when a SN-OD may not be available on site quickly enough. The key objectives of this best practice guidance are therefore as follows:

- To present a concise synthesis of current professional and ethical guidance on approaching the family of the potential organ donor within the context of the current legal frameworks for donation in the UK
- To de-mystify the role of the SN-OD and to thereby promote as a standard of care their involvement in planning the family approach and discussing organ donation with those close to the patient.
- To provide clinical staff with step-wise guidance on approaching the family of a potential donor when the SN-OD is unavailable, identifying common errors in timing and language and suggesting more suitable alternatives in a series of memorable practice points.

This practice guideline emphasises points that may be considered to represent good medical practice in any type of communication – there is no suggestion of pressure or coercion. The principles adhered to are those of being sensitive to the family's needs, giving them time and privacy, ensuring they understand that either death has occurred or that it is inevitable, and providing the family with sufficient information that is in an understandable format and which anticipates their likely concerns.

2. Current professional guidance

This best practice guidance advocates that SN-ODs should always be involved in planning the family approach and wherever possible in the initial discussions that raise the possibility of organ donation as a part of end-of-life care. Whilst collaboration with SN-ODs in this aspect of care may be contentious for some clinicians, in many areas of the UK this is routine practice. Furthermore, several national bodies (as detailed in sections 2.1 to 2.3, below) have recently issued guidance indicating it represents sound clinical practice.

2.1 National Institute for Health and Clinical Excellence (NICE)

NICE published a short clinical guideline on organ donation in December 2011⁴. This guidance covers two key aspects of the donation pathway – donor identification and referral, and the family approach.

2.1.1 Donor identification and referral

In its recommendations, NICE clearly recognised the need to identify all potential donors, but also acknowledged the need to involve the SN-OD as quickly as possible:

Identify all patients who are potentially suitable donors as early as possible, through a systematic approach. While recognising that clinical situations vary identification should be based on either of the following criteria:

- *defined clinical trigger factors in patients who have had a catastrophic brain injury, namely:*
 - *the absence of one or more cranial nerve reflexes and*
 - *a Glasgow Coma Scale (GCS) score of 4 or less that is not explained by sedation unless there is a clear reason why the above clinical triggers are not met (for example because of sedation) and/or a decision has been made to perform brainstem death tests, whichever is the earlier*
- *the intention to withdraw life-sustaining treatment in patients with a life-threatening or life-limiting condition which will, or is expected to, result in circulatory death.*

The healthcare team caring for the patient should initiate discussions about potential organ donation with the specialist nurse for organ donation at the time the criteria in recommendation [above] are met.

2.1.2 The family approach

In reviewing all available evidence relating to the family approach, NICE recommended that:

A multidisciplinary team (MDT) should be responsible for planning the approach and discussing organ donation with those close to the patient.

The MDT should include:

- *the medical and nursing staff involved in the care of the patient, led throughout the process by an identifiable consultant*
- *the specialist nurse for organ donation*
- *local faith representative(s) where relevant.*

The MDT involved in the initial approach should have the necessary skills and knowledge to provide to those close to the patient appropriate support and accurate information about organ donation.

The MDT involved in the identification, referral to specialist nurse for organ donation, and consent should have the specialist skills and competencies necessary to deliver the recommended process for organ donation outlined in this guideline.

2.2 General Medical Council

The General Medical Council published revised guidance for doctors on end-of-life care in 2010. In this guidance⁵, doctors are reminded of the following responsibilities:

- 81** *If a patient is close to death and their views cannot be determined, you should be prepared to explore with those close to them whether they had expressed any views about organ or tissue donation, if donation is likely to be a possibility.*
- 82** *You should follow any national procedures for identifying potential organ donors and, in appropriate cases, for notifying the local transplant coordinator. You must take account of the requirements in relevant legislation and in any supporting codes of practice, in any discussions that you have with the patient or those close to them. You should make clear that any decision about whether the patient would be a suitable candidate for donation would be made by the transplant coordinator or team, and not by you and the team providing treatment.*

2.3 UK Donation Ethics Committee

The UK Donation Ethics Committee (UK DEC) published guidance on controlled DCD in December 2011. In considering the role of the specialist nurse in the approach to the family of a potential DCD donor, UK DEC advise⁶ that:

Contact between the clinical team treating the potential donor and the SN-OD before the decision has been made to withdraw life-sustaining treatment is ethically acceptable. Advantages include identifying patients who are not suitable donors, and avoiding distressing delays to the family if the SN-OD has to travel some distance to get to the unit.

and also

Supporting the family through the discussion about organ donation requires a team approach. The SN-OD has the detailed knowledge and expertise to lead the process, but needs to be supported by other members of the clinical team.

2.4 Summary

Current professional guidance clearly advocates involving the SN-OD as early as practicable in both the planning and conduct of the family approach, emphasising the benefits to the family of a potential donor. However, there is little guidance on the details of how this can – and should – become part of clinical practice. Section 3 of the Best Practice Guide seeks to provide such advice.

3. Involving the specialist nurse – organ donation in the family approach

Most consultants have not received formal training in approaching the families of potential donors, whereas this is a key and core component of training and development that SN-ODs now receive. It is hard to escape the conclusion that there is some link between this and the higher rates of consent/authorisation seen when SN-ODs are involved in a family approach. However, SN-ODs are not currently involved in all family approaches, even though there are professional recommendations that this should be the case. This section describes how this might be achieved.

The pathway in Figure 3.1 describes three key stages in approaching a family for consent/authorisation for organ donation

- Planning the approach
- Confirming understanding and acceptance of loss
- Discussing donation

Careful attention to all three stages is vital if families are to be given the best possible opportunity to make the right decision. The material that follows includes a step by step guide to this and includes examples of the kinds of phrases that may be helpful (mindful of the difficulty in reflecting the subtleties of communication within the written word).

3.1 Planning the approach

Prior to initiating a family approach, the consultant, SN-OD and bedside nurse/nurse in charge should meet in private to discuss and outline how the request process should proceed. If the SN-OD is unable to attend the unit, they should nevertheless participate in the planning process by telephone. **This is a key stage in the process**, allowing time for:

- clinical issues to be clarified
- the patient's donation potential to be assessed and the implications of organ retrieval to be understood
- evidence of prior consent/self-authorisation such as registration on the Organ Donor Register to be determined
- next-of-kin and key family members to be identified
- specific family issues to be understood, including the recognition of the need to involve other parties (eg faith representative)

This planning stage allows a bespoke strategy for the family approach to be designed in which everyone understands who is going to do what and when. It is an opportunity for staff to align their views and consolidate them around the common goal of presenting the possibility of donation at the right time and in the right way.

Agreeing roles and responsibilities

There may be occasions when clinicians prefer the SN-OD to request alone or when the consultant may have to request alone if the SN-OD cannot attend quickly enough. However, available evidence indicates that as **a standard of best practice the family approach should be a collaborative effort between senior medical staff and the SN-OD**. It is vital that there is agreement in advance on who will cover each element of the process and where the transition in responsibility will be. A common approach would be for the Consultant, ICU nurse and SN-OD to meet the family together, for the Consultant to lead on breaking bad news and to then hand over to the specialist nurse when it is clear that the family have accepted the inevitability of their loss and are ready to consider what may happen next. As discussed below, **it is crucial that the transition to donation only occurs when clinical staff are confident that a family has come to terms with the loss of their loved one**.

When to involve the specialist nurse

SN-ODs have received detailed training in communication and family support, and are thereby able to recognise and avoid factors that inadvertently and unnecessarily lead to a family refusal. Involving the specialist nurse early in the process (eg when breaking bad news) gives time for a relationship between the family and SN-OD to develop and for these factors to be addressed. Despite these advantages, the timing of SN-OD involvement can be considered contentious by some clinicians, not least because circumstances vary, as do some clinical practices, particularly regarding the confirmation of death using neurological criteria and the timings of the two sets of tests. Nevertheless, the NICE guidance has recommended that a patient should be referred as a potential donor as soon as the intention to either withdraw life sustaining treatments or perform brain-stem death tests has been reached.

3.2 Confirming understanding and acceptance

As noted above, as a standard of care the discussion in which the family of a potential donor are to be informed of the inevitable loss of a loved one – sometimes referred to as the breaking bad news conversation – should involve the senior doctor, bedside nurse and SN-OD.

Introducing the SN-OD

Some consultants have expressed difficulty in how to introduce the SN-OD at the start of the discussion, and an example phrase is suggested in the text box. Thereafter the SN-OD may join the conversation naturally or be specifically introduced when it is appropriate to give information regarding donation.

“Mrs Smith this is Louise Green, she is a specialist nurse that we work with on the unit and who helps support families at this time.”

Assessing understanding

Any request for donation is less likely to succeed if the family have been unable to listen to, understand and assimilate over a period of time the fact that their loved one has died (brain-stem death) or that death is inevitable because it will follow the withdrawal or limitation of life-sustaining treatments. Put another way, a family that has yet to understand and accept their loss are unlikely to countenance any discussion of *post mortem* procedures such as organ retrieval. In short, **donation should not be discussed until the family has accepted the reality of the clinical situation.**

Even though families may have been updated on a number of occasions, it is frequently the case that they under-estimate the severity of their loved one's condition. The foundation for breaking bad news is ensuring that all involved have a common understanding of the patient's condition, be it the likelihood or confirmation of brain-stem death, or a clinical consensus that continued life-sustaining treatments are not of overall benefit to an individual. Clinicians frequently establish a family's level of understanding by asking a family member to summarise what they have been told so far.

"I know we have discussed John's condition before – can you share with us what you understand to be his current situation?"

"I know you have been through a great deal in the last few days, but can you briefly tell me what your understanding of the situation is and what has happened to John up until now?"

Understanding brain-stem death

Some families have a particular difficulty in accepting of the concept of brain-stem death, and there is strong evidence that this is associated with family refusals. It is vital to spend time ensuring as full an understanding as possible before discussing donation. The key is to give the family as much time as they need and to use language that leaves no room for any doubt whatsoever that brain-stem death is death – not its likelihood, not its inevitability but death itself. Utilising diagrams and scans or inviting members of the family to witness brain-stem death tests are all ways in which a family can be supported through such uncertainties.

"Mrs Smith, we have now completed the brain-stem death tests that we talked about earlier. As we discussed, the purpose of these tests is to see whether there is any activity in John's brain and these tests have confirmed what we all suspected. [pause] All of John's brain function has been irreversibly lost. This means, not that he might die, not that he is going to die, but that he is dead. I am really sorry." [pause]

Separating the discussions relating to death and donation ('decoupling')

Families who have not yet come to terms with the inevitability of their loss will not be in a position to consider donation. Indeed it would be unfair to expect them to do so at this point. It is essential that clinical staff explicitly consider whether family members are ready to consider donation, and that if there is any doubt suggest a 'time out' that allows the family to reflect upon the clinical reality of the situation and to come to terms with it. This is sometimes referred to 'decoupling'. Clinicians should not underestimate how much time families need to come to terms with the fact that their loved one has died, especially if it involves a child or young adult. However, there are families – frequently those who have already accepted the situation before the formal discussion – who may be ready to move onto the possibility of donation within the same meeting.

"I can see that you are finding this really difficult to come to terms with and I am sure you need some time on your own to talk about what I've just told you. So I will come back a bit later."

3.3 Discussing donation

As noted above, this may be a separate discussion or may run on from the breaking bad news conversation. Regardless of the circumstances, it is at this point where there should be a transition in who is leading the discussion, from the Consultant breaking the bad news to the SN-OD raising or developing the possibility of organ donation. The details on how this transition will be made should be considered in the planning phase. At all times, the language regarding donation should be positive, emphasising the potential benefits for recipients, their families and society in general. The known benefits to donor families in the longer term should also be mentioned, **whilst the use of negative or apologetic language – such as "I'm sorry to bring this up, but..." or "you understand that it is hospital policy that we always ask..." should always be avoided.**

"Mrs Smith, one of the things we would like to discuss with you now is organ donation. Louise here has expertise in this area and is going to give you some information" (allowing the SN-OD to lead this area of the conversation).

"I would like to talk to you now about something you might not be expecting, and that is organ donation. Tonight, John has the opportunity to save and transform the lives of several people."

Specific information should be provided regarding the patient's donation potential and the benefits that this would have for recipients. In addition, further details of timing and procedures (which is of particular importance when considering DCD) should be given. Emphasise the care and respect shown to a donor at all times. As the conversation progresses, it is crucial to be sensitive to the common concerns that families express at this time (which frequently emerge as reasons for refusal, see Table 3.1, on page 17) and to be in a position to address them in a knowledgeable and sensitive fashion. The SN-OD is likely to be the individual with the knowledge and expertise to lead this part of the conversation.

"Organ donation has the ability to save and transform up to eight other people's lives, starting tonight"

Approaching the family of a potential DCD donor

Some clinicians feel conflicted when raising donation after they themselves have been involved in the decision to withdraw life-sustaining treatments. Although there is little (if any) evidence that families recognise this as a conflict, it is perhaps helpful to suggest how the topic of donation might be introduced:

"Mrs Smith, as I'm sure you know, every single decision we have made about John's care and treatment have been based upon doing what is right for John. But as a doctor I have a duty to recognise when those treatments aren't working, and this means that sometimes the right decisions are the hardest ones to make. [pause] As you know, we have discussed it is now no longer in John's interest to continue these current treatments, treatments that are now just delaying his death, rather than giving him any chance of recovery, and you understand why we have made the decision with you to withdraw them and what will happen when we do this. Now, we need to talk about what kind of death John would want, [in case of a child: 'as parents and a family what kind of death you would want for John'] and one of the options available to you, available to John, is organ donation. Louise is here to talk you through this, and give you some information and support you in thinking about it and making the decision."

Approaching the family of a patient whose wish to donate is recorded on the NHS Organ Donor Register

The legal framework for deceased donation across the UK is currently one of a hard opt-in system of consent/authorisation, in which there is no provision at law for any family member to override an individual's wish to donate, regardless of how that wish has been stated or recorded. Such a wish represents that individual's consent or authorisation for donation to go ahead after their death (for further details see Appendix B). Although the NHS Organ Donor Register is only one of the means by which such a wish can be stated, its real advantage is that it can – and should – be checked before the family are approached (see box).

The Organ Donor Register can be checked on behalf of clinicians by the local Specialist Nurse – Organ Donation or directly by contacting the Duty Office at the Directorate of Organ Donation and Transplantation in Bristol on 0117 975 7580 or 0117 975 7581. When making an enquiry, clinical staff will be asked to provide the following information:

- Patient name
- NHS number or CHI number
- Patient date of birth
- Patient address including postcode
- Their own contact details, including the name of the hospital and specific clinical area.

The Duty Officer will return the call within a few minutes via the hospital switchboard, and can provide a facsimile copy of a patient's registration if required to help with subsequent conversations with family members.

Other recognised methods of giving in life legally recognised consent or authorisation for donation include:

- Donor card
- Verbally expressed wishes
- Living will

When an individual has recorded in life a wish for donation to take place, this should be reflected in how donation is introduced to the family, **because consent/authorisation has already been given**. It is important to be aware that the family may have no knowledge of the registration; this information should be presented to them sensitively and can be supported with a copy of the details of the registration that can be faxed to the unit. It is important to avoid any suggestion that the family's permission is also required; the objective here is to describe what will be required for the patient's decision to be respected.

“Mrs Smith, your husband is on the Organ Donor Register. This means he has agreed to donate his organs following his death. I would like to tell you how we can make what he wanted to happen, happen for him.”

“Mrs Smith, you may not be aware of this but your husband is on the National Organ Donor Register. When he registered with his new GP six years ago he made the decision to be an organ donor after his death. What this means is that John has given his agreement that organ donation should occur, and what I would like to do now is explain how we can make this happen for him. If first of all, I explain what is involved, then you can ask me some questions about it.”

Approaching the family of a patient whose wishes are not known

Only a third of the UK population, and a quarter of actual donors, are on the NHS Organ Donor Register⁽ⁱ⁾, whilst data from the Potential Donor Audit indicates that barely half of the consents and authorisations received are based upon a clear knowledge of the patient's wishes to be an organ donor. It is important to recognise that in circumstances where the individual's wishes are not known and cannot reasonably be surmised, **current UK legislation clearly passes authority for decision making on to the 'individual(s) in the qualifying relationship'/'nearest relative' as described in Appendix B.** Furthermore, approaches that are based *exclusively* upon honouring an individual's wishes may fail when it becomes clear that those wishes cannot be determined, particularly when closed questions are used. It is important therefore when exploring a family's knowledge of the individual's wishes that 'open' questions are used so as to maintain the possibility for donation when it emerges that they are not known. Examples of open questions – and the corresponding closed questions that should be avoided – are given in the text box.

Open and closed questions

Open questions are frequently presented as a statement or command and require a narrative response, eg

"Mrs Smith, tell me what your husband wanted to happen when he died."

"Mrs Smith, can you tell me what kind of a person John was?"

"How do you think your husband would feel about organ donation?"

In contrast, **closed questions** limit the respondent to one of a small number of answers, commonly yes or no, eg

"Mrs Smith, do you know whether your husband wanted to be an organ donor when he died?"

"How do you think John would feel about organ donation?"

"Donation is often a gift the family makes on behalf of their loved one."

"You are going to have to make a lot of decisions for John in the next days and weeks, the funeral, and things like that. Right now though, we need you to make a decision about organ donation."

ⁱ Whilst the average age of a deceased donor in the UK is 44 years, the average age of registered donors is 25 years.

Exploring an initial refusal

It is perfectly reasonable (and is in fact good practice) to probe initial family negative responses, as these may be based on misunderstanding, poor information or on remarks taken out of context. Even when the stated reason is that their loved one had expressed views against donation, it is reasonable to ascertain if this was a true and firmly held belief.

The most common reasons for family refusals in the UK are listed in Table 3.1. SN-ODs are trained in very specific ways of sensitively pre-empting and exploring these common initial responses, ensuring that any decision a family makes is done in an unhurried fashion, based on sound information and in an atmosphere of support.

“You tell me John had mentioned he wouldn’t want to donate his organs. Can you remember what it was about donation he objected to? What were the circumstances that led you all to discuss donation?”

“Were there any reasons why you were having this discussion?”

“You mention a TV programme you have seen that has led you to worry about donation. Can you tell me a bit more about what exactly was on it that has given you these concerns?”

“John has of course been through a lot but cannot suffer anymore. The retrieval procedure is performed with the utmost respect and concern for his dignity and I or one of my colleagues will be present in the operating theatre at all times”

Table 3.1 Common reasons for family refusals⁷

Common reasons for family refusals	DBD	DCD
	%	%
Patient had stated in the past that they did not wish to be a donor	16.4	16.5
Family were not sure whether the patient would have agreed to donation	16.2	15.4
Family did not want surgery to the body	11.9	6.9
Family felt it was against their religious/cultural beliefs	9.1	3.6
Strong refusal – probing not appropriate	8.8	9.8
Family were divided over the decision	6.3	6.3
Family did not believe in donation	6.1	3.5
Family felt the patient had suffered enough	5.8	7.3
Family felt the body needs to be buried whole (unrelated to religious or cultural reasons)	5.6	2.1
Family felt the length of time for donation process was too long	2.5	13.4
Other	11.5	15.2

The family stated the patient had said they would not wish to be a donor

Such a statement may indeed have been made sincerely after thinking over the issues in depth and in such cases should be respected. Other possibilities though include:

- The remark may have been made jokingly or flippantly without due consideration. It is likely an individual would not wish a decision of this magnitude to rest on this type of remark.
- The remark may have been based on wrong information or assumptions.
- The family themselves have concerns that become attributed to the potential donor.

Although some families may believe that they do not have the right to make decisions on behalf of their loved one, as noted above, when the wishes of the individual are unknown both the Human Tissue Act 2004 and the Human Tissue (Scotland) Act 2006 clearly pass authority for decision making on to the individual in the qualifying relationship/nearest relative as described in Appendix B.

The family do not wish surgery to the body

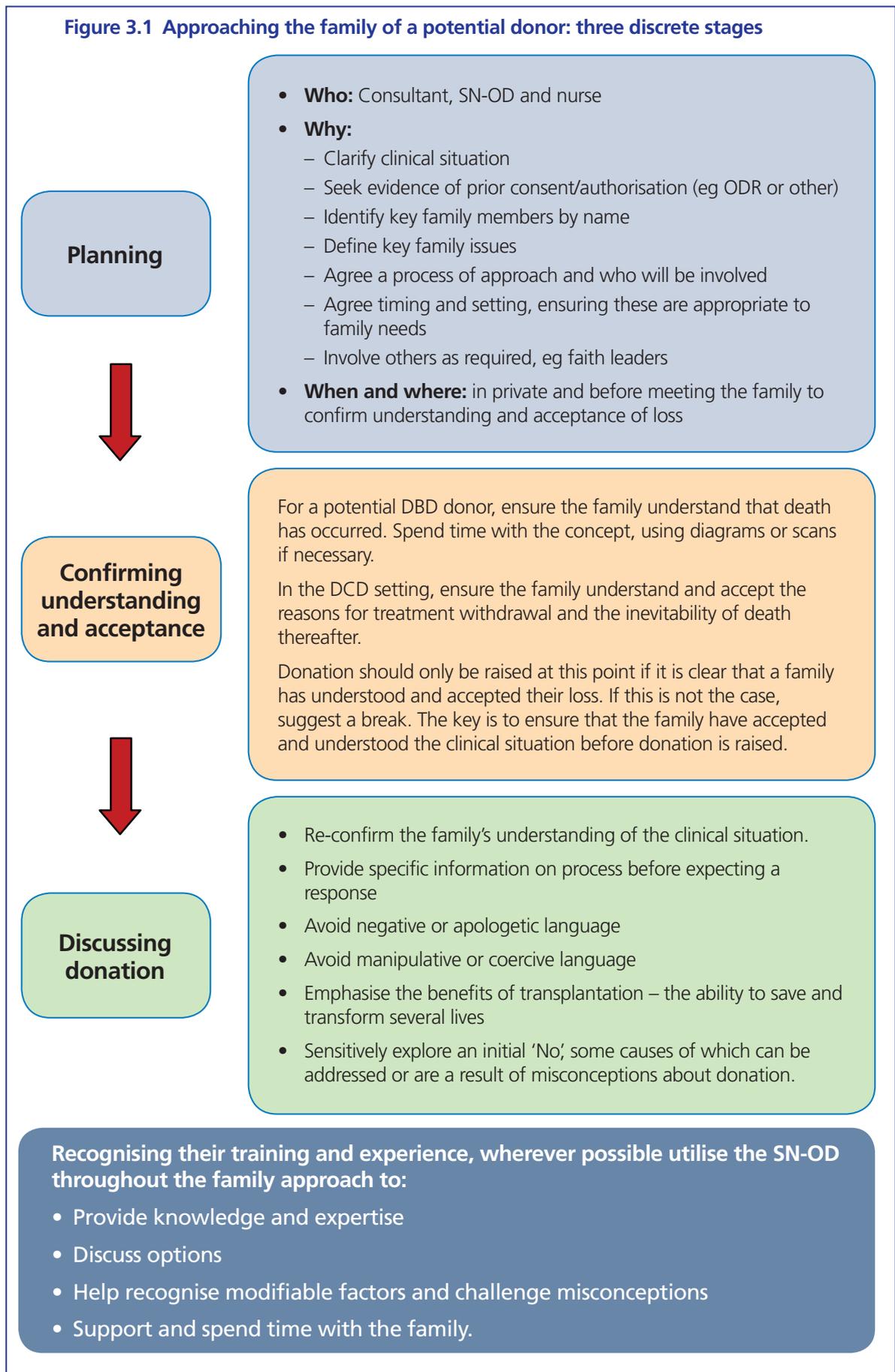
This should be acknowledged as a very understandable and common 'visceral' objection. It may be addressed by gently explaining that their loved one is dead and cannot possibly feel anything, that the greatest of respect and care for them will be shown in theatre and that a SN-OD will remain with their loved one throughout the retrieval process. For some patients for whom a post mortem will be required it may be pointed out that a procedure will be performed in any event.

Families in dispute

Disagreements over donation should be sensitively explored, particularly if they are based on misunderstanding. Families who are in conflict and dispute for other reasons should be reminded that donation is one decision they need to address now.

"It sounds to me that there are some things that you are going to have to sort out in the days and months to come but right now, before you leave hospital, there are some things you are going to have to decide. One of those immediate decisions is about organ donation."

Figure 3.1 Approaching the family of a potential donor: three discrete stages



4. Summary

- Professional guidance advocates that as a standard of care, specialist nurses – organ donation should be involved in planning the family approach and the initial discussions that raise the possibility of organ donation as a part of end-of-life care.
- There are three key stages to approaching the families of potential organ donors:
 - planning
 - confirming a family have understood and accepted their loss (breaking bad news)
 - discussing donation

As a routine, a senior clinician would be expected to lead the breaking bad news conversation before making the transition to the specialist nurse, who will lead on the donation discussion.

- Donation should not be raised until it is clear that a family have understood and accepted their loss. If this is not the case the discussion in which donation is raised should be delayed. Donation should be presented in a way that emphasises its benefits and should never be described in a negative and apologetic fashion.
- Evidence that a patient has given in life their own consent or authorisation (eg via the NHS Organ Donor Register) should always be sought before approaching the family. If such consent/authorisation has been given this should substantially influence how donation is presented to a family.
- Styles that focus exclusively on the wishes of the individual should be avoided since in the absence of a known wish, authority for decision making passes to the family.

Appendix A: NICE guidance on Organ Donation

The National Institute for Health and Clinical Excellence (NICE) published a short clinical guideline on organ donation in December 2011. It is applicable to practice in England, Wales and Northern Ireland, and makes various recommendations on how the family approach should be planned and conducted. The following is a relevant extract from this guidance:

Approach to those close to the patient

The multidisciplinary team

- 1.1.1 A multidisciplinary team (MDT) should be responsible for planning the approach and discussing organ donation with those close to the patient.
- 1.1.2 The MDT should include:
- the medical and nursing staff involved in the care of the patient, led throughout the process by an identifiable consultant
 - the specialist nurse for organ donation
 - local faith representative(s) where relevant.
- 1.1.3 Whenever possible, continuity of care should be provided by team members who have been directly involved in caring for the patient.
- 1.1.4 The MDT involved in the initial approach should have the necessary skills and knowledge to provide to those close to the patient appropriate support and accurate information about organ donation (see recommendations 1.1.17 and 1.1.18).

Discussions in all cases

- 1.1.5 Before approaching those close to the patient:
- identify a patient's potential for donation in consultation with the specialist nurse for organ donation
 - check the NHS organ donor register and any advance statements or Lasting Power of Attorney for health and welfare
 - clarify coronial, legal and safeguarding issues.
- 1.1.6 Before approaching those close to the patient, try to seek information on all of the following:
- knowledge of the clinical history of the patient who is a potential donor
 - identification of key family members
 - assessment of whether family support is required – for example faith representative, family liaison officer, bereavement service, trained interpreter, advocate
 - identification of other key family issues
 - identification of cultural and religious issues that may have an impact on consent.
- 1.1.7 Approach those close to the patient in a setting suitable for private and compassionate discussion.

- 1.1.8** Every approach to those close to the patient should be planned with the MDT and at a time that suits the family's circumstances.
- 1.1.9** In all cases those close to the patient should be approached in a professional, compassionate and caring manner and given sufficient time to consider the information.
- 1.1.10** Discussions about organ donation with those close to the patient should only take place when it has been clearly established that they understand that death is inevitable or has occurred.
- 1.1.11** When approaching those close to the patient:
- discuss with them that donation is a usual part of the end-of-life care
 - use open-ended questions – for example 'how do you think your relative would feel about organ donation?'
 - use positive ways to describe organ donation, especially when patients are on the NHS organ donor register or they have expressed a wish to donate during their lifetime – for example 'by becoming a donor your relative has a chance to save and transform the lives of many others'
 - avoid the use of apologetic or negative language (for example 'I am asking you because it is policy' or 'I am sorry to have to ask you').
- 1.1.12** The healthcare team providing care for the patient should provide those close to the patient who is a potential donor with the following, as appropriate:
- assurance that the primary focus is on the care and dignity of the patient (whether the donation occurs or not)
 - explicit confirmation and reassurance that the standard-of-care received will be the same whether they consider giving consent for organ donation or not
 - the rationale behind the decision to withdraw or withhold life-sustaining treatment and how the timing will be coordinated to support organ donation
 - a clear explanation of, and information on:
 - the process of organ donation and retrieval, including post-retrieval arrangements
 - what interventions may be required between consent and organ retrieval
 - where and when organ retrieval is likely to occur
 - how current legislation applies to their situation, including the status of being on the NHS organ donor register or any advance statement
 - how the requirements for coronial referral apply to their situation
 - consent documentation
 - reasons why organ donation may not take place, even if consent is granted.
- 1.1.13** Allow sufficient time for those close to the patient to understand the inevitability of the death or anticipated death and to spend time with the patient.

- 1.1.14 Discuss withdrawal of life-sustaining treatment or neurological death before, and at a different time from, discussing organ donation unless those close to the patient initiate these discussions in the same conversation.
- 1.1.15 For discussions where circulatory death is anticipated, provide a clear explanation on:
- what end-of-life care involves and where it will take place – for example, theatre, critical care department
 - how death is confirmed and what happens next
 - what happens if death does not occur within a defined time period.
- 1.1.16 For discussions where neurological death is anticipated, provide a clear explanation on:
- how death is diagnosed using neurological criteria
 - how this is confirmed and what happens next.

Organisation of the identification, referral and consent processes

- 1.1.17 The MDT involved in the identification, referral to specialist nurse for organ donation, and consent should have the specialist skills and competencies necessary to deliver the recommended process for organ donation outlined in this guideline.
- 1.1.18 The skills and competencies required of the individual members of the team will depend on their role in the process. However, all healthcare professionals involved in identification, referral to specialist nurse for organ donation, and consent processes should:
- have knowledge of the basic principles and the relative benefits of, donation after circulatory death (DCD) versus donation after brainstem death (DBD)
 - understand the principles of the diagnosis of death using neurological or cardiorespiratory criteria and how this relates to the organ donation process
 - be able to explain neurological death clearly to families.

Appendix B: Legal frameworks for deceased donation in the UK

Patient autonomy

1. The legislative framework for donation in the UK is that of a hard 'opt-in' system of consent. Practice in England and Wales is governed by the Human Tissue Act 2004, whilst in Scotland the Human Tissue (Scotland) Act 2006 applies.
2. The Human Tissue Act 2004 uses the term 'consent'. In contrast the Human Tissue (Scotland) Act 2006 uses the different term 'authorisation'. Practice in Northern Ireland is governed principally by common law, although broadly it follows the legal principles that are applied elsewhere in the United Kingdom.
3. Both the Human Tissue Act 2004 and the Human Tissue (Scotland) Act 2006 give primacy to the wishes of the individual however they have been stated and recorded. This can be done in various ways – verbally, by having a Donor Card, in writing or via the various means of accessing the NHS Organ Donor Register (ODR). All are regarded as equally valid forms of consent/authorisation for organ retrieval after death. **If it is known that an individual has given their prior consent or authorisation, this should be reflected in how the possibility of donation is introduced to a family.**

The role of the family

4. There is no provision in either Act for family members to overturn an individual's wish to donate their organs after death. Scottish legislation requires families to complete a written waiver should they seek to obstruct organ retrieval in such circumstances.
5. If the wishes of the individual are not known or cannot be determined then authority for decision making passes to a nominated representative (England and Wales only), and then to a person in a qualifying relationship to the individual. The hierarchical lists of those in a qualifying relationship as described in the two Acts are listed in the table below:

Human Tissue Act 2004 – England, Wales (and Northern Ireland)	Human Tissue (Scotland) Act 2006 – Scotland
<ul style="list-style-type: none"> • Spouse or partner • Parent or child • Brother or sister • Grandparent or grandchild • Niece or nephew • Stepfather or stepmother • Half brother or sister • Friend of long-standing 	<ul style="list-style-type: none"> • Spouse or civil partner • Living with the adult as husband or wife or in a relationship which had the characteristics of the relationship between civil partners and had been so living for not less than six months; • Child • Parent • Brother or sister • Grandparent • Grandchild • Uncle or aunt • Cousin • Niece or nephew • A friend of longstanding of the adult

6. It is important to understand that although the Acts give **precedence** to the wishes of the patient, when those wishes cannot be established, authority for decision making passes to the individual in the qualify relationship/nearest relative to the patient. Approaches that place **exclusive** emphasis upon honouring the wishes of an individual may lead families to erroneously conclude that donation should not happen when such wishes cannot be established, even though they then have the legal authority to consent to or authorise it.

Donation from children

7. Both Acts recognise the validity of the wishes of competent minors. Where the wishes of the individual are not known or the minor was not competent to deal with the issue, consent/authorisation passes to those with parental rights and responsibilities, or in their absence to an individual in a qualifying/nearest relationship.
8. There is no age restriction for self-registration or self-withdrawal from the register. A parent can register their child, or a child for whom they have parental rights and responsibility, providing the child is under the age of 16 years. Alternatively, a child can register themselves. Children under the age of 12 years at the time of registration are assumed to have been registered by their parents, whilst those 12 years and over are assumed to have self-registered. As a consequence, whilst the parents of a child under the age of 12 years at the time of registration can withdraw this consent/authorisation, if the child was 12 years or over then parents must provide evidence that they (rather than the child) were responsible for the registration should they seek to reverse it.

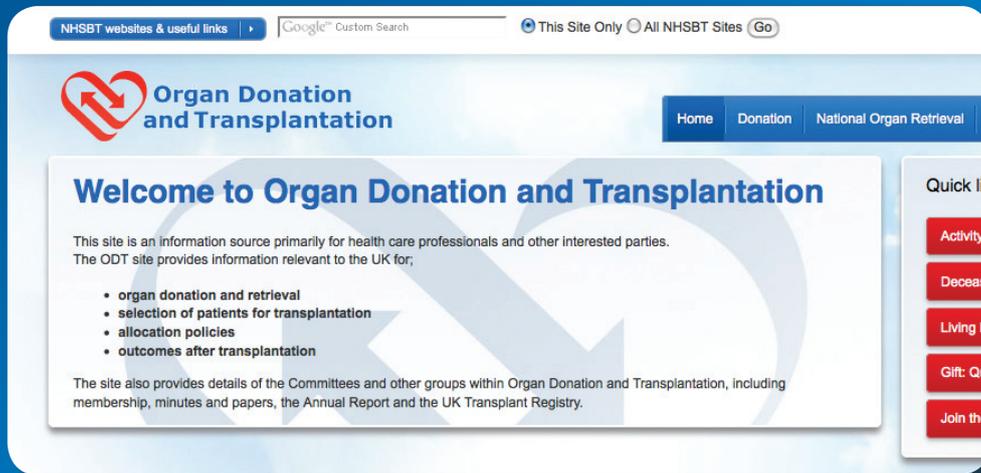
Appendix C: References

1. NHS Blood and Transplant Annual Transplant Activity Report (2012). Available from: http://www.organdonation.nhs.uk:8001/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2011_12.pdf
2. Building on Progress: Where next for organ donation policy in the UK? British Medical Association, 2012. Available from: http://bma.org.uk/-/media/Files/PDFs/Working%20for%20change/Improving%20health/organdonation_buildingonprogressfebruary2012.pdf
3. The ACRE Trial Collaborators. Effect of 'collaborative requesting' on consent rate for organ donation: randomised controlled trial (ACRE trial). Br Med J 2009; 339: b3911
4. National Institute for Health and Clinical Excellence (December 2011). Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. Available from: <http://guidance.nice.org.uk/CG135>
5. Treatment and care towards the end-of-life: good practice in decision making. The General Medical Council, 2010. Available from: http://www.gmc-uk.org/static/documents/content/End_of_life.pdf
6. An ethical framework for controlled donation after circulatory death. UK Donation Ethics Committee. Academy of Medical Royal Colleges, December 2011 Available at: <http://aomrc.org.uk/publications/reports-a-guidance.html>
7. Potential Donor Audit, Summary for the 12 Month Period 1 April 2011 – 31 March 2012. NHS Blood and Transplant. Available from: http://www.organdonation.nhs.uk/ukt/statistics/potential_donor_audit/pdf/pda_report_1112.pdf

Appendix D: Membership of the Best Practice Development Group

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For more information of organ donation and transplantation, please see NHSBT's clinical website



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