

# 7

## CHAPTER

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### FAMILY APPROACH FOR ORGAN DONATION

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## **7.1. INTRODUCTION**

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It is obvious that conducting a family interview to request a process of donation is something that has to be learned, since a system is required for the approach to the family. Although it is true that there are people who intuitively know the most appropriate thing to say at each moment, it has been demonstrated that the family interview is an evidence-based scientific, systematic process,<sup>1</sup> which from experience, allows us to approach the families face to face at the worst moment, but the only moment we have. The end result of our work as transplant coordinators will depend on our skill in handling this situation.

## **7.2. IMPORTANCE OF THE FAMILY INTERVIEW**

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It is often said that one of the reasons for not procuring a donor is the shortage of staff and lack of equipment. It is probable that in some measure this may in effect be a problem. However, the majority of the studies which have assessed the factors that condition or intervene in a donation process have found that the conduct of a good family interview by an expert is one of the most important factors to condition consent.<sup>2-3</sup>

## **7.3. CHARACTERISTICS OF THE FAMILY INTERVIEW**

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The interview takes place at a critical time when, as professionals, it is difficult for us to bring up the subject of donation with the relatives of the person who has died. To do this we must have the psychological and technical communication skills necessary to allow us to conduct the interview in a systematic manner. The family interview is characterised by being semi-directed, structured (beginning, middle and end), and having a content and a direction. The content consists of the subjects which must be discussed:

- Knowledge and understanding about brain death (or asystolic death in the case of tissue donors).
- Request for the donation of organs and tissues.

- Finding out more information about the possible donor's behaviour involving biological risk.
- Adequate explanation of the organ removal and transplant process.

The direction of the interview is the way in which the interviewer presents the contents which allow the families to make a decision.

#### **7.4. GIVING BAD NEWS**

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After the giving of bad news, a series of emotional responses is triggered and the end result of our work will depend on our skill in handling this situation. The people with whom we must talk have just received an emotional impact which to a greater or lesser degree is going to mean a change in their lives. It is therefore logical to expect the various responses which form part of the *grieving process*. From denial, disbelief, bargaining, depression... to reach the point, in the majority of cases, of acceptance of the death. These stages are not gone through in any specific order.

The order can vary and one or more stages may be missed out. However, the important thing to understand is that this impact scenario, to a greater or lesser extent, is what we are generally going to find when informing of a death.

On the other hand, although the response to bad news depends in part on the impact it has, it also depends on the manner in which the bad news is delivered, which can cause it to be taken as an act of aggression and turned back not only on the actual healthcare worker, but also on the transplant coordinator.

The decision to donate or not will be related to the perception the family has of the medical attention, the treatment received, and the manner in which information has been transmitted by the professionals. In the majority of cases, the relatives who refuse to consent to donation consider that the information received about the death has been cold, arrogant and unclear.<sup>4</sup>

Communicating news of a death produces an initial shock, generating a more or less unstructured response. This needs to be responded to immediately in the form of psychological support which will help to alleviate the tensions of the moment.

## **7.5. PREPARING FOR A FAMILY INTERVIEW**

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Aside from the family, but collaborating closely with the medical team responsible for the potential donor, the transplant coordinator has to determine the medical causes that have led to the death (brain death or asystolic death), the medical history, the clinical evolution of the patient, the information that the family has received and the way that the diagnosis of brain death (BD) was reached. Thanks to his/her relationship with the rest of the healthcare staff, the coordinator will then be informed about the make-up and hierarchy of the potential donor's family, visits received, relationship with the hospital staff, etc, and usually, in this way, will be able to predict the make-up of the family group he/she is going to find.

He/she will look for a suitable place to conduct the interview in as comfortable an environment as possible, which will guarantee the family the necessary privacy. The decor and layout of the room should be simple with low tables and a sufficient number of comfortable chairs. Natural light is preferable and it could be decorated with paintings and flowers. Ideally, the room will contain a telephone, paper and pens, tissues, hot and cold drinks, etc, to be able to offer to the family.

## **7.6. SUPPORTIVE RELATIONSHIP IN THE FAMILY INTERVIEW**

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This is a therapeutic relationship arising out of the imminent necessity to provide a response which will allow this situation to be resolved. It is a communication process established by the coordinator with the aim of helping the family to bond together and organise the start of the grieving response.<sup>5</sup>

In this manner, afterwards without intrusions, the coordinator will be able to initiate the process for requesting a donation. This will never be achieved unless we are able to establish an *empathetic* relationship with the family. Acknowledgement of the suffering, recognition of the signals being sent to us; in short, putting oneself in the position of or attempting to understand, in this case the family, is what is meant by empathy.<sup>6</sup> Empathy in the context of the supportive relationship allows us to understand others even though we do not share the same feelings. Empathy forms part of the knowledge and skills in communication which a good coordinator must have in order to do his/her job professionally.

## **7.7. COMPONENTS OF THE SUPPORTIVE RELATIONSHIP**

They will enable the establishment of intervention strategies through skills or techniques which allow the forming of appropriate interrelation between the coordinator and the family,<sup>7</sup> in order to help the initiation of the grieving process. The components of the supportive relationship are:

### 7.7.1. Active listening

In order to establish this, we must proceed to the approach. We must introduce ourselves to the immediate family or the relatives, find out the name of the deceased and if possible the names of the people we will be dealing with. It is advisable to be with the doctor who informs the family of BD, since then we will be able to observe how the different members of the family respond, objectively assess signs of comprehension, understanding and acceptance of the death (if they use the past tense or if they ask about the procedure for the funeral...) and this is achieved when we establish active *listening*. A donation can never go ahead without the family having accepted the death of their relative. When lack of comprehension is observed or the failure to accept the BD, we must go back to the beginning and explain and repeat as many times as necessary, respecting the amount of time that each family needs. Throughout the whole process, active listening helps us to look after the needs of the families.

### 7.7.2. Reflection of emotions

It helps to identify and recognise emotions in order to be able to verbalise the feelings of the person you are speaking to. At this time, when it is very important that the family are able to express their emotions, we can help by identifying the emotion, by giving it a name (fear, anxiety, confusion, etc), and even help to reduce its intensity (in the case of anger, rage, fury, etc). In this way, we let the family know that they have our understanding and support. We have to encourage the expression of feelings, e.g.: "I understand that you're angry, I would be the same..."; "I understand your crying, now is the time for that...". Or, for example: *Relative says*, "I can't believe it..."; *Coordinator responds*, "I can see that you're very confused..." This communication technique is centred on feelings, helping to clarify them, express them and handle them, positively influencing the grieving process.

### 7.7.3. Paraphrasing

Another way of reflecting emotions which corresponds to the area of thoughts is achieved through the use of **paraphrasing**. This involves repeating back the message we are receiving from the family but in different words (e.g.; *Relative*

says, "He had told me that I should wait for him and now I'm never going to see him again..."; *Coordinator responds*, "You say that today you had arranged to...?"). These techniques have the aim of showing the family that we have understood, that we are hearing what they are saying, and facilitate the continuity of the conversation.

## **7.8. COMMUNICATION SKILLS**

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Knowing about verbal and non-verbal communication helps us to communicate well with the people we are speaking to, to create an atmosphere of confidence by letting them know we are listening to them. We give them solutions, we help to give focus to the messages which are confused at the time and we can progress with the interview.

### 7.8.1. Verbal communication

Through our use of language we can help to establish the right supportive relationship and in order to do this we employ:

- **Narrative or summarising techniques:** allow focus on subjects, avoid digression by the family and go over the whole story from the time of admission to hospital, using phrases which start preparing the family to receive bad news (e.g.: "I'm sorry to be bringing bad news...", "In spite of doing everything possible...", "Much to our regret...") or if necessary, other techniques can be used:
- **Metaphors:** allow comprehension of BD as complete and irreversible cessation of functions (a flower: when it is cut, it seems to be still alive but it ends up fading away; a car without an engine: it works going downhill but eventually, when the ground levels off...; a tree which has been cut down ...). On the other hand, the language used has to be the least confusing possible. We have to avoid the use of scientific language and attempt to use:
- **Coherent, reasoned language**
- **Simple, concise language**
- **Open questions:** permit the person you are speaking to keep the conversation going and think of answers (what..., how..., where..., when...); as opposed to questions which can only be answered by yes or no.

### 7.8.2. Non-verbal communication

Its inappropriate use can betray the person you are speaking to and give the idea of indifference. The components of non-verbal communication are:

- **Silence:** respect silences. Pauses of 4 or 5 seconds show respect, express interest and attention to what the family has to say, to their emotions. We accompany them in their silence but make them aware of our presence, that we are available, open to what they want to say. Silence is not a failure in communication. Used poorly, it could suggest impatience and display the anxiety of the coordinator.
- **Eye contact:** seeing is a sense which allows us to make contact with people. Making eye contact is communicating, it displays feelings. Badly used, could suggest indifference.
- **Physical position:** we have to adopt a position of proximity, in a circle and without barriers. Positioning ourselves close to the family, adopting a posture of approach, will indicate interest in and attention to what they want to say to us and will facilitate active listening, physical contact and eye contact. On the contrary, the presence of barriers, brusque gestures, signs of impatience (looking at the clock), a posture of withdrawal, are mistakes which make approaching the family and communication difficult.
- **Physical contact:** while communicating, physical contact can be used for consoling, showing warmth and tenderness. Its use rarely creates indifference, although badly used could suggest a threat or be seen as aggressive.
- **Paying heed, listening and use of gestures:** the family needs time to assimilate the news, for which reason we pay heed to them and listen to what they have to say. The coordinator gives signals to the relatives that he/she is listening, nodding the head, raising the eyebrows, gesturing with the hands, communicating understanding of what they are going through: in short, *actively listening*.
- **A warm and low tone of voice** denotes respect and affection.

## 7.9. REQUEST FOR DONATION

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It is fundamental to establish what the wishes of the deceased were in order to know if, in life, the person had been opposed or not to donation. For this reason, the interview with the relatives must be directed to finding out these wishes (of the deceased person, not of the family). Although the law decides according to the model of presumed consent, the Spanish transplant model favours consultation of the family, considering that to proceed in any other way could



provoke reactions of rejection, which would have negative repercussions on the smooth working of the transplant system.<sup>8-9</sup>

As it has been discussed, it is fundamental that before the request for donation is made, the relatives have understood BD, through use of the techniques mentioned above (narrative or summarising techniques, use of metaphors). To sum up, we must formulate open questions in order to encourage dialogue (What were his/her ideas about donation...?; Had he/she ever talked about donation...?), periodically verifying that the information is being understood, using clear, plain and simple language to give information at each different stage. We must be patient. Each family needs time to assimilate and respond to the news. We have to allow them all the time they need, or risk rushing them into giving a negative response.

## **7.10. ARGUMENTS FOR REQUESTING A DONATION**

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In this situation we have to know the arguments which will contribute to justify our presence in a request for donation process. These are:

### 7.10.1. Solidarity

Refers to society as a whole or to a specific group or individual and may help to secure a donation.

- **Social:** we are all involved. At some point in our lives we might need a transplant. Any of us or our loved ones might need a transplant. Would we like to be able to receive one?
- **Group:** when specific social groups are alluded to (parents, spouses or children) who are waiting for transplants for themselves or their loved ones.
- **Individual:** if the relatives know anyone on a transplant waiting list or on dialysis, asking them to think about these people.

### 7.10.2. Usefulness

Death always seems like a waste, but perhaps it could be useful to someone. Although death signifies a rupture, it could be a form of continuity of life for other people (avoid this being understood as the life of the deceased continuing in other people).

### 7.10.3. Praise, generosity, reciprocity

These are positive arguments, which elevate the image of the deceased. This is especially useful for those people who, in life, felt solidarity with their fellow human beings and for the family to believe that the deceased could continue helping people after death by donating. Find out whether, if the deceased person would have liked to receive a transplant, would he/she do the same for others? We are asking for something which they no longer need but which others do. Remind the relatives that we are not asking for anything for ourselves but that we are representatives for a list of people who are ill and dependent on a transplant in order to live.

### 7.10.4. Facilitation

Help with the formalities which have to be carried out in these processes, explaining them simply and in detail. Allowing unrestricted privacy when it comes time to say goodbye to their loved one, intimacy for the family discussion and help in resolving problems of a legal nature, notifications, etc.

## **7.11. RELATIVES' REFUSAL: REASONS AND STRATEGIES FOR REVERSAL OF RELATIVE'S REFUSAL**

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We have to get away from the idea that the request for donation increases the pain that the family is suffering as a result of the loss. In fact it is quite the opposite. The request for donation is not an attack. It is a difficult question but within the supportive relationship, a donation process may help in facing up to and properly channelling the grief. The families of donors believe afterwards that the donation gave some sense to their tragedy and 90% would do the same again.<sup>10</sup> The transplant coordinator is not an intruder, but quite the opposite. They are experts in the handling of a crisis situation, in that their fundamental role is to lend unconditional support and help to the relatives from the moment they have been informed of the death of their loved one.

Relatives' refusals are the most frequent cause of loss of organs and tissues for transplant. In Spain, although in recent years we may have observed a significant reduction in the number of relatives' refusals, according to Spanish National Transplant Organisation (ONT) data, the rate of relatives' refusals in 2003 was 20%. Even so, there were still more than 4000 people on the transplant waiting list. The growth of the number of organs available for transplant in part depends on the ability to reduce the number of relatives' refusals. Training of the interviewers in strategies which might change the

attitude of relatives who refuse to give consent for donation and helping the relative to initiate the grieving process as smoothly as possible are elements that help people to adapt to the idea of donation.

### 7.11.1. Reasons

The magnitude of the problem is such that numerous studies have been carried out in an attempt to find out what the common factors determining the refusals are, as well as the reasons behind them (Table 1).<sup>11-12</sup>

Reasons for Refusals		
–	Presumed objection of the deceased while alive	24%
–	Refusal by the next of kin	24%
–	Not knowing the thoughts of the deceased	12%
–	Lack of understanding about brain death	11%
–	Concerns about disfigurement and integrity of the body	8%
–	Problems with the healthcare system	7%
–	Problems with the social setting	6%
–	Religious objections	2%
–	The wish to take the patient home	1%
–	Assertive refusal	1%

Table 1.

It is worth emphasising that the most important factors determining a refusal are lack of understanding of the concept of brain death, a feeling of having received poor treatment on the part of the families during the hospital admission, the inappropriate choice of location for being informed of the death and the relationship established with the transplant coordinator. Other variables found in the various studies which might contribute towards a refusal are, among other things, the length of the hospital admission, the age of the deceased, the socio-cultural level, belonging to a certain religion or ethnicity, the proximity of the relationship of the person making the decision, or the absence of the family decision-maker. On the other hand, the studies did not find that the sex of the deceased, the cause of death, the knowing of people on a transplant list or of transplant recipients, or the number of people present at the interview, were factors which affected refusal. Nevertheless, it is recommended that the interview should take place with a minimal number of the immediate family or relatives, ideally involving only the next of kin.

### 7.11.2. Reversal of refusal

Given the lack of information surrounding the reasons for families arguing against donation, a multicentre study group was created which analysed a total of 618 interviews carried out between 1993 and 1994 in 12 Spanish hospitals, with the aim of identifying the motives for refusal of the donation, as well as the strategies employed in trying to reverse these decisions.<sup>13</sup> The reasons for refusals are shown in Table 1. Basically, they were not knowing the wishes of the donor and refusals expressed by the next of kin themselves. In the study, there was initially a 36% refusal rate but with a second approach, it was possible to reverse 54% of these decisions, leaving a final refusal rate of 16.6%. The easiest decisions to reverse were those where the wishes of the deceased were unknown and there was a lack of understanding of brain death and concerns about disfigurement of the body.

In another sense, we must have the necessary resources to be able to confront other problems that may arise as a matter of course, such as responding to suspicions about financial or commercial motives for the organs, making a donation conditional on there being a specific recipient for the transplant, asking for direct information about the transplant recipients, etc. So, as long as donation is an option, society has to be well informed. A social necessity has to be created and a social conscience maintained through the employment of strategies to optimise this conscience about donation within the hospital sphere and among the public in general.

### 7.11.3. Strategies for dealing with relatives' refusals

During the interview, relatives may give us lots of reasons against donation. We must always be prepared to understand these reasons and to accept that the relatives, or even the potential organ donor, refuse donation. However, on some occasions, a refusal is part of a lack of understanding, misconception or fear of making decisions. It is precisely in these situations that we can provide better help to the relatives. MA Frutos et al<sup>10</sup> defined the most common arguments given and some strategies for dealing with them:

#### **Dissatisfaction with the health care**

When the refusal stems from dissatisfaction with professionals, from the idea that something went wrong with the medical care or the evolution of the disease, we recommend, first of all, to accept complaints from the family and avoid trying to justify what has been done. We also have to remove the donation process from an unfavourable context and help them to realise that transplant recipients are not to blame for this situation even if something has gone wrong. And finally, we must help them to understand that organ

donation would not interfere with any claim or later action if they make a legal complaint.

### **Presumed refusal in life**

Although we must accept the deceased's right to refuse donation, we also have to be sure that this belief was reasonable and reliable. We should ask about the circumstances under which this decision was made (e.g. after watching a shocking piece of news about organ trafficking, etc), and find out what the deceased actually expressed in life.

### **Family refusal without reason**

This is a really difficult situation to face but we should try to find out who is pro-donation and separate them from those who are against donation, so as not to distort the natural flow of conversation. We can also use arguments of solidarity.

### **Not knowing what the deceased believed about donation**

Sometimes there is not a definite refusal but the relatives do not know the potential organ donor's wishes; it was never discussed. Perhaps the best strategy in this situation is to insist on the fact that the deceased never expressed his/her refusal and look at positive reasons. Also, use arguments of solidarity, courage or reciprocity.

### **Not understanding brain death**

As it has been discussed, it is fundamental that the relatives have understood brain death before the request for donation is made. It is recommended to use narrative, summarising techniques or metaphorical language to explain the concept of BD and explain the difference between being in a coma and BD. Ask what his/her ideas about death or donation were.

### **Fear of the integrity and image of the body**

Fear of the body being damaged or disfigured is a fairly common reason for refusal which can be changed. Take time to inform them correctly, explaining the retrieval process (follow-up reconstruction surgery), stressing the respect and care with which the body will be treated and guaranteeing prompt return of the body.

### **Delay of the funeral arrangements**

Arguments like social problems or the fact that donation could delay the funeral arrangements are not rare. You should help to resolve this kind of problem as far as possible by offering to help with funeral and bureaucratic arrangements and reminding them that the process is anonymous.

### **Religious objections**

Refusal based on religious objections is actually a misunderstanding, since in fact, all religions accept donation. You should offer the opportunity to consult a religious minister, whatever their religion may be.

### **Assertive refusal**

These are complicated refusals to reverse. They usually come from families with a high socio-cultural level and they very possibly will not change their opinion. Try talking to them, mentioning social arguments, solidarity, asking them if they know anyone on a transplant waiting list, raising the idea of generosity and reciprocity.

## **7.12. SOCIAL-MEDICAL HISTORY: BIOLOGICAL RISK**

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In addition to being a process for the requesting of organ and tissue donation, the interview with the relatives is a way of obtaining useful information for predicting the presence of biological risk factors which might be related to the presence of infectious agents, and could compromise the life of the transplant patient.

Nowadays, the legal recommendations for serological screening in the guidelines for the donation of organs and tissues allow us to rule out the presence of known transmissible diseases and guarantee the quality of donation.

The various techniques used in the detection of markers of infection have high sensitivity, specificity and positive and negative predictive values. However, in certain circumstances, there is the possibility of finding ourselves faced with false negatives, whether due to an incipient infection where we are in the window period or because the serological determination has been carried out on diluted blood samples. On the other hand, in a small percentage, the determinations carried out on cadaveric donors can give false positives.

Blood transfusion, infusion of colloids or crystalloids can be routine practice in the potential donor. As a consequence, due to haemodilution, the serological screening could result in false negatives, on reducing the titration of the markers below the sensitivity of the techniques. In cases where haemodilution is suspected, it must be determined, according to recognised methods, whether the haemodilution has been sufficient to dilute the sample or if possible, it is recommended that determinations are carried out on samples taken before the infusions or transfusions.

In the cadaveric donor, the products of tissue degradation secondary to haemolysis produced once death has occurred can interfere with the serological screening values and be the cause of false positives. In order to avoid invalidating the donation, despite later confirmatory techniques confirming the negative result, it is recommended that blood samples are obtained as soon as possible after the death.

### **Biological risk factors from the interview with relatives**

The carrying out of a proper clinical and epidemiological history is the best method for ruling out those donors who are carriers of infectious processes that might be in the window period (HIV, HBV, HCV) or for ruling out by way of the history, the existence of any diseases transmissible through prions (Creutzfeldt-Jakob disease).

In living organ donors, a serological screen must be carried out 3 months before and again immediately prior to the donation. At the same time, it would also be advisable to conduct a health education programme in order to avoid those activities which carry biological risk of infection by HIV, HBV and HCV.

In living tissue or cell donors, it is recommended that a second serological determination is done 3-6 months before the donation. In the case of haemopoietic precursors or tissues from babies with sudden death, the serum markers will have to be reliably determined on the mother.

In addition to initiating the request for donation process, the interview with the relatives is also the time to conduct a reassessment of the previous medical history which, from the clinical history, we believe needs to be evaluated. From the next of kin or most appropriate people, we can investigate the presence or absence of determining factors for being a carrier of infection which might contra-indicate organ or tissue donation. We assess the existence of activities which carry biological risk (acupuncture, body-piercings, tattoos, street drug injection), as well as finding out where and under what conditions such practices were carried out. We ask about the existence of sexually promiscuous activities or prostitution, as well as recent time spent in prison. It is important to

find out about any specific treatment received recently for sexually transmitted diseases (syphilis, gonorrhoea), or recent travel or stay in countries where infections contra-indicated for donation of certain organs or tissues (Chagas) are endemic, as well as the existence of any family illnesses with a high risk of prion transmission. For this reason, we ask families or significant others to state in writing that, to the best of their knowledge, the potential donor has not been in any of the situations mentioned in the questionnaire.

### **Model of questionnaire for assessing of biological risk**

1. Had he/she had any tattoos, body-piercings or acupuncture in the last year?  
 yes  no
2. If the answer to the previous question was yes, please specify whether or not it was performed using non-reusable sterile needles or equipment?  
 yes  no
3. Had he/she had any sexual relations with different homo/heterosexual partners in the last 12 months?  
 yes  no
4. Had he/she engaged in sex in exchange for money or drugs in the last 12 months  
 yes  no
5. Had he/she had sexual relations with other people with a history of AIDS, hepatitis B, hepatitis C in the last 12 months?  
 yes  no
6. Had he/she spent more than 72 hours in prison in the last 12 months?  
 yes  no
7. Had he/she injected any street drug in the last 12 months?  
 yes  no



8. Had he/she received treatment for syphilis or gonorrhoea in the last year?

yes  no

9. Had he/she travelled to areas where there is malaria or to areas where other infectious diseases are endemic, such as Japan, the Caribbean, Africa or Polynesia?

yes  no

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