

# Taking care of relatives and communication

## Module — 2

Version 2.0 — February 2026



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# 1.0

## Introduction

### 1.1 Taking care of relatives in the organ donation process

Organ donation follows a structured process depending on the medical prognosis. In the initial phase, organ donation is not a primary consideration: the patient is not primarily admitted to hospital as a potential organ donor, as the focus of the rescue and treatment teams is on curative treatment. Nevertheless, this early phase is already part of the detection process. Potential organ donors should be identified as early as possible so that the team in the intensive care unit can take further steps if necessary.

### 1.2 Conducting conversations using the SPIKES model

The letters "SPIKES" stand for the phases and principles of the conversation [1]. The abbreviation suggests a specific sequence. However, if you explore the terms, you will find that only the two "S"s have a fixed place. The other phases/principles can flow smoothly into one another, sometimes run parallel, and also repeat themselves in a conversation.

<b>Setting</b>	<b>Prepare well</b> Organize the premises, involve other people, and prevent disruptions such as noise, phone calls, etc.
<b>Perception</b>	<b>Classify the perception of the conversation partner</b> Clarify/assess the conversation partner's prior knowledge and knowledge of their situation (including their feelings about it). Ask first, then explain. Clarify incomplete or incorrect information.
<b>Invitation</b>	<b>Obtain the invitation from the conversation partner</b> Information is good, but too much can be stressful. As little as possible and as much as necessary. Not all patients/relatives want to be fully informed. Respect if the person you are talking to does not want any more information (at the moment?). What do the relatives need now (distance, appreciation, time, to be seen and accompanied as human beings)?
<b>Knowledge</b>	<b>Conveying information</b> Convey the situation in language that the person you are talking to understands (clarity). Point out possibilities (what is not possible and what is possible). Communicate the next steps (diagnosis, treatment, prognosis, support options).
<b>Empathy</b>	<b>Show compassion</b> Recognize emotions and respond appropriately. Do not suffer along with them, but empathize with them. Recognize and respond to psychological needs. Support the relatives as persons.

<b>Summary</b>	<b>Offer a summary</b> End the conversation by summarizing what has been discussed in the language of the patient/relatives. Outline and plan the next steps. If relatives find themselves in an exceptional psychological situation and you are unable to take action yourself after the conversation, then the caregiver must initiate the next step, e.g., accompany them to their bed.
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## 2.0

### Phases and responsibilities in communicating with relatives

#### 2.1 Phases in taking care of relatives in the context of organ donation

**Medical treatment, taking care of relatives, and communication** run parallel to each other in the context of organ donation. For this reason, this pathway addresses all three elements. Corresponding tasks are listed and specific recommendations for action are described.

The following figure shows the sequence of phases/all chronological process steps in organ donation.

Phases		Comments	
PHASE I Diagnosis and treatment	Ambulance		
	Accident and emergency department / resuscitation room		
	Medical examination and treatment; Preparation for transfer to the ICU		
	Context of end-of-life care: The decision to "stop" leads to → detection process: DBD, DCD, no organ donation		
	Interface and transfer		
PHASE II Detection	Intensive care unit		
	Curative medical treatment		
	Infaust prognosis	Up to the infaust prognosis: full intensive care treatment	
	Next steps (depending on the situation and background):	<b>IMPORTANT:</b> The sequence of these steps may vary from hospital to hospital, or in the case of DBD / DCD; for DCD, brain death diagnosis may not be carried out at all	
	Decision to withdraw treatment		
	Brain death diagnosis		
	Notification of brain death and further steps		
	Question of presumed wishes regarding organ donation		→ If no brain death diagnosis has yet been made, this is no longer carried out in the event of refusal.
Register check			
PHASE III Donor treatment – allocation – removal	Consent to organ donation	Refusal of organ donation	
	Measures to preserve organs Recording of medical data, allocation of organs <sup>1</sup>	Withdrawal of treatment <sup>2</sup>	<sup>1</sup> From the decision to withdraw treatment all the way to and through removal: measures to preserve organs. <sup>2</sup> Cardio-circulatory arrest: no medical measures.
	Removal <sup>2</sup>		
Laying-out / goodbye	Laying-out / goodbye		
PHASE IV Conclusion and follow-up care	Follow-up care of next of kin		
	Process of follow-up care: – Contact with donor's family – Thank-you letters – Meetings of next of kin – Etc	Currently none	

Figure 1: Overview of the phases/process steps in taking care of relatives in the event of a potential organ donation

## 2.2 Responsibilities and tasks in the individual phases

Ward	Responsible and person(s) involved	Tasks
<b>Phase I – Diagnosis and therapy</b>		
<b>Outpatient</b> Emergency / Shock Room	<b>Paramedic</b>	Supporting relatives on site, accompanying them in the ambulance, passing on information to the head of the emergency department
	<b>Head of emergency services</b>	Support and initial discussions
	<b>treatment team</b>	Support Care and discussions
<b>Phase II – Detection</b>		
<b>intensive care unit</b> Curative phase	<b>Head of ICU / treatment team</b>	Care and discussions
	<b>Care team / Pastoral care</b>	Psychosocial care upon request or when indicated (acute symptoms)
<b>intensive care unit</b> Poor prognosis / withdrawal of treatment	<b>Head of ICU / treatment team</b>	Care and discussions, communication Poor prognosis / impending withdrawal of treatment
	<b>FOGS / Donation coordinator</b>	Support Care and discussions
	<b>Care team / Pastoral care</b>	Psychosocial care upon request or when indicated (acute symptoms)
<b>intensive care unit</b> In the case of DBD: Brain death diagnosis → Notification of brain death	<b>Head of ICU / treatment team</b>	Care and discussions, notification Brain death diagnosis / Brain death / Withdrawal of treatment
	<b>FOGS / Donation coordinator</b>	Support Care and discussions
	<b>Care team / Pastoral care</b>	Psychosocial care upon request or when indicated (acute symptoms)
<b>intensive care unit</b> Question about presumed wishes	<b>Head of ICU / treatment team</b>	Care and discussion of presumed will
	<b>FOGS / Donation coordinator</b>	Support Care and discussions / Procurement of information and clarification of uncertainties regarding organ donation
	<b>Care Team / Pastoral care</b>	Psychosocial care upon request or when indicated (acute symptoms)

Ward	Responsible and person(s) involved	Tasks
<b>Phase III – Donor treatment, allocation, removal</b>		
intensive care unit	Head of ICU / treatment team	Care and discussions, support OS process, farewell
	FOGS / Donation co-ordinator	Support Care and discussions during OS process, Coordination
	Care Team / Pastoral care	Psychosocial support upon request or when indicated (acute symptoms)
ICU / OPS / Viewing room	treatment team	Support during the farewell phase, farewell
	FOGS / Donation co-ordinator	Support / Accompaniment
	Care team / Pastoral care	Support upon request / Pastoral care, rituals
<b>Phase IV – Completion and follow-up care</b>		
ICU / OPS / Network	treatment team	Debriefing Thanks to team / participants
	FOGS / Donation co-ordinator	Follow-up care / Thank-you letters

## 3.0

# Support for relatives in the outpatient clinic / emergency room

## 3.1 Ambulance / Medical services

Paramedic services are located upstream of the hospital and provide preclinical treatment, initial medical stabilization, and transport to a hospital. This is where the first point of contact between paramedics and the treatment team at the hospital takes place.

With regard to **taking care of relatives**, there are a number of aspects to consider that prove important in the later course of care and with regard to potential organ donation:

- Paramedics focus on rescuing/medically stabilizing the patient.
- Relatives who are affected by an accident or unforeseen event or who are present at the scene will receive secondary care after the patient.
- Care for and communication with relatives tends to focus on calming the situation and providing initial minimal and clear information about the patient's condition. Relatives who are overly agitated and stressed can unintentionally interfere with a life-saving operation. They are part of the operation and are taken into account.
- Sometimes a relative rides along in the ambulance, which serves to reassure the patient and can also be important for the relatives.
- If the relative does not ride in the ambulance, they will arrive at the hospital emergency room after the ambulance. The ambulance crew informs the emergency team about the involvement of relatives at the scene of the accident and their subsequent arrival at the emergency room.

### Recommendations

The topic of taking care of relatives in relation to organ donation should be integrated into the further training of paramedics: in terms of the basics of organ donation, dos and don'ts in communicating with relatives (e.g., not procuring false hope regarding the patient's condition so that confusion, misunderstandings, or mistrust do not arise later in the intensive care unit).

## 3.2 Accident and emergency department and trauma room

The majority of potential organ donors are admitted to hospital via the emergency department. Special care should be taken when taking care of relatives.

The following **aspects of care and communication** are important in relation to potential organ donation in the emergency room:

- Whenever possible, relatives should be cared for quickly.

- Relatives should not be informed of (presumed) brain death upon arrival at the emergency room.
- Relatives should be given access to the patient's bedside as soon as possible.
- If there is a delay, relatives should be informed that medical procedures currently being carried out do not yet allow access to the bed. An approximate time should be given or an assurance made that they will be informed again as soon as possible. It may be offered that someone from the care team can take time for them (nursing, pastoral care/care team). According to surveys of relatives, the waiting time until they can see the patient is considered one of the greatest stresses [2].
- Suitable, low-stimulus rooms should be found for conversations (not the emergency room).
- Previously team-supported decisions are discussed (e.g., diagnoses, poor prognosis, etc.).
- At this point, the emergency treatment team should not bring up the subject of organ donation with relatives.
- If organ donation is brought up by the relatives, this should be acknowledged with respect. The relatives can be informed that the treatment team will revisit the topic at a later date, if appropriate, i.e., should the time come. According to the guidelines of the Swiss Academy of Medical Sciences (SAMS) [3], consent for organ procurement may only be obtained after the decision to discontinue life-sustaining therapy has been made.

**The above-mentioned aspects of care and communication also apply to the "curative phase" in the intensive care unit.**

## 4.0

### Intensive care unit – poor prognosis/withdrawal of treatment

In the event of a grim prognosis / withdrawal of treatment, the following **care and communication aspects** are important with regard to potential organ donation:

- Anticipate the arrival of relatives. Ensure the flow of information within the treatment team (prompt communication within the treatment team when relatives arrive at the intensive care unit or inform them who is caring for the patient).
- Prepare relatives in advance for the scenario that awaits them at the patient's bedside (e.g., the patient is being ventilated via a tube, may have injuries to the head, or a dialysis machine is replacing kidney function).
- If relatives bring up the subject of organ donation themselves, respond to it and do not dismiss it as unimportant. Tell them that the subject will be discussed at the appropriate time.
- If it becomes apparent that the prognosis is hopeless and curative medical treatment is no longer appropriate, the relatives should be called in quickly.
- Invite the relatives to a meeting and arrange an appointment/time (doctor/nursing staff/FOGS/donation coordinator in consultation). If necessary, ask the relatives whether other important people should also be present at the meeting (take into account the right of representation in accordance with the guidelines of the Swiss Academy of Medical Sciences [3] and, if necessary, determine an "inner circle" of reference persons).
- Prepare for the conversation (exchange and coordinate the information within the team, organize the room, etc.).
- If withdrawal of treatment with potential organ donation is imminent, the relevant medical professionals must be consulted (FOGS / donation coordinator).
- Recap the course of treatment and understand what triggered the change in treatment goals/the grim prognosis.
- Prepare in accordance with the recommendations for a "breaking bad news" conversation [4]. "Breaking" means "breaking the ice," i.e., bad news must be introduced (airbag sentence: "We're sorry to have to tell you some bad news, ..."). This is necessary in order to draw the relatives' attention to the bad news that follows immediately and to prepare them psychologically.
- Prepare for different reactions such as psychological distress, loss, grief, emotions, feelings of guilt, etc.
- If translation is necessary, plan/organize this in advance.
- Greet the present relatives individually, introduce yourself and your role again, and ask who is present. If there are a large number of relatives, consider the right of representation in accordance with the Swiss Academy of Medical Sciences' (SAMS) guidelines [3]. Important: Ask each person about their relationship to the patient (appreciation).

- If possible, the same physician should be involved in key discussions.
- Establish a connection to the last conversation (what was discussed, last shared knowledge).
- Get to the actual message quickly (infaust prognosis / planned withdrawal of treatment / what this means) and avoid long medical introductions (the relatives' need here: quick certainty and clarity about the situation).
- Make clear, unambiguous statements, use short sentences, e.g., "We are sorry to have to give you some bad news, your father, mother, sibling, child is going to die." (Not "the patient").
- Answer the questions clearly and simply, avoiding the use of technical terms. The news of the withdrawal of treatment can trigger a state of psychological distress in relatives, which in turn limits their cognition/thinking ability. Guideline: as little information as possible, as much as necessary.
- State the next medical steps and what they mean.
- Allow for long pauses. Relatives need time to understand/process the information (intrapsychic processes in a possible state of psychological distress).
- Ask whether the message has been understood.
- End the conversation with clear information: What will be done next? When should the relatives come back? What can/should they do until the next conversation? (If necessary, initiate the next action: "We will now accompany you to your relative)

## 5.0

### In the intensive care unit – Diagnosis of brain death / Notification of brain death

When **taking care of relatives and communicating with them**, the following aspects of conversation apply in the case of brain death diagnosis / notification of brain death:

- Invite relatives to a meeting promptly after brain death diagnosis or after the decision for withdrawal of treatment or for a change in treatment goal to palliative care.
- Contact the donation coordinator and ask them to be ready to join the conversation.
- Prepare reasons for withdrawal of treatment and brain death, have visualization aids ready (schematic representation of cerebral blood flow, CT, imaging, etc.).
- Make a connection to the last conversation. Does everyone have the same level of information?
- Inform relatives about the diagnosis of brain death (guideline: as little information as possible, as much as necessary).
- Speak slowly, create a calm atmosphere for conversation, consciously repeat the most important facts, as the relatives' ability to absorb information is limited in this situation.
- Ensure that the relatives have understood that the patient will die/has died.
- Answer questions clearly and simply, without using technical terms.
- State the next steps and explain what they mean: withdrawal of treatment necessary – discuss the options before/after switching off the equipment – explain withdrawal of treatment with versus without donation.
- If the donation coordinator is present on site (depending on the hospital), they can answer specific questions regarding donation.
- End the conversation with clear information: What will happen next?  
When should the relatives come back? Should a care team / pastoral care be called in?

## 6.0

### In the intensive care unit – conversation about presumed wishes

Recommendations for **communicating with relatives** about presumed wishes regarding organ donation:

- Whenever possible, the conversation should be conducted by the same people who communicated brain death (or the most unfavorable prognosis, e.g., in the case of DCD).
- In addition: Early involvement of the FOGS/donation coordinator, both for procuring information and clarifying any uncertainties surrounding organ donation. But also for donor treatment and coordination.
- Include those relatives in the follow-up discussion who should be present for the next steps and possible decisions (prioritization according to guidelines of the Swiss Academy of Medical Sciences [3]).
- Be mentally prepared for different reactions/emotions (e.g., incomprehension, anger, rejection, etc.).
- In order to strive for a decision in accordance with the wishes of the person concerned, the persons conducting the discussion should adopt a neutral stance with regard to the decision.
- The focus is on the patient/deceased. The decision should be made in accordance with their wishes.
- Has the topic of organ donation already been discussed? Are the wishes of the deceased known? Is there a donor card? Do their attitudes/views suggest an answer?
- Every decision is accepted and respected (yes or no to organ donation).
- If there is a wish against organ donation (donor card, living will: "no organ donor/organ donor"), the relatives are informed (transparency).
- Consent to organ procurement is always given by the person themselves or, if they have not expressed their wishes, by their relatives.
- If the FOGS/donation coordinator is present, they can answer questions about donation and provide information on the procedure (what are the preparatory measures, upcoming examinations, surgery/removal, saying goodbye, etc.).
- Care must be taken when explaining both process options, DBD and DCD, as to avoid overwhelming the family.
- Inform them which organs can generally be donated (including tissue). Point out that it is the decision of the deceased or their family which organs would be donated if consent is given.
- In the case of DCD: Inform them that withdrawal of treatment may take longer than 120 minutes and that DCD organ procurement may therefore not be possible.
- Inform the relatives of the time frame available for making a decision and encourage the family to involve important people in a calm and intimate setting. They should come to a decision that will remain stable in the long term.
- Several discussions may be necessary (depending on the case, between 48 and a maximum of 72 hours may be allowed for decision-making, taking into account

preparatory measures and guidelines of the Swiss Academy of Medical Sciences - SAMS).

- Avoid all possible external disturbances (leave cell phones outside, inform the team, etc.).
- Address diverging opinions within the family and shift the focus away from the opinions of individual relatives to the presumed will of the patient.
- Take a meta-level approach. E.g. how is the conversation going? How am I behaving? (Benevolent, reassuring body language) What observations am I making about the relatives? How are they reacting to the situation; to each other? Are all relatives actively participating in the conversation? What stands out in the dynamics among the relatives? In case of resistance, ask: "Do I understand you correctly? / What do you think about that? / Have I overlooked something? / Can you explain to me that...?"
- Do not ignore intrapsychic processes: the loss of a loved one evokes different emotions in each individual. An unforeseen event can trigger a state of psychological emergency.
- Minimize stressful factors: noise, restlessness, time pressure, long explanations. Favorable factors should be encouraged: speak calmly, signal support and time, discuss fears of making the wrong decision and doubts (e.g., lack of visual signs of death in a brain-dead patient).
- At the end of the conversation, summarize the next steps.

#### **Dos**

- Neutral, benevolent attitude
- Minimization of external disturbances
- Take a meta-level approach (observation of conversation dynamics and emotions)

#### **Don'ts**

- Ignoring intrapsychic processes
- Not addressing fears and doubts

## 6.1 Decision on organ donation

Recommendations for taking care of relatives and communication during the removal and farewell phase:

- Social and medical history with the donation coordinator
- Pointing out and explaining which examinations will be performed and why.
- Carefully clarify which organs are to be donated and which are not. Inform relatives that not every organ approved for donation may be allocated.
- Explain that the examinations are being carried out to evaluate the condition of the organs (and no longer to treat the patient).
- Mention that the deceased may be taken away from the ICU for a short time for examinations.
- Explain to the relatives that the patient may experience reflex movements that are no longer perceived and which can be disturbing if not understood (Lazarus phenomenon in case of DBD).

- Record contact details and ask whether information about the outcome of organ procurement and transplantation should be passed on to the relatives.
- Also include the question about tissue. Important: Under no circumstances should the question about cornea donation be asked later by telephone, after the organ procurement has already taken place and the relatives assume that the process is complete. Interviews with relatives [2] clearly show that this is considered disrespectful and inappropriate.
- If the donor needs to be transferred to another hospital for the removal, the possible burdens (change of team, delay) should be carefully pointed out before the decision to donate is made, and consent should be secured.
- Be available for questions at any time during the removal process (provide contact details).
- Communicate each step to relatives in a time-sensitive and transparent manner.
- Allow relatives access to the patient at all times. Relatives also include children who come to the intensive care unit. For questions about dealing with children as relatives, see Appendix 1.
- Point out that relatives cannot be present in the operating room or during the removal (DBD not possible / DCD possible in some cases until cardiac arrest).
- Respect any sudden withdrawal of consent. Involve medical professionals (psychologists) to reduce additional stress in a potentially traumatic situation. Accompany relatives in the event of an actual termination of donation (see procedure for refusal below).
- Relatives can see the patient both before and after the operation (and say goodbye). Even if this is difficult, saying goodbye is beneficial for accepting the loss, the grieving process and for building up confidence that the patient is being treated respectfully.
- Caution: In exceptional cases (such as immediate transfer to the Institute of Legal Medicine), it is not possible to say goodbye after the procurement. It is essential to inform the relatives in advance in such cases.
- If an autopsy is necessary, the relatives must be informed that tubes, IV lines, etc. must not be removed before the autopsy.
- Explain where the deceased will be taken after removal. Accompany the relatives to the viewing room (if possible). Check the room beforehand. Mention the name of the facility as information for the relatives. Later, stay with the relatives in the viewing room for the first few minutes until the initial tension subsides. Discuss how long the family would like to stay. Then pick up/wait for the family again. If the relatives feel the need, discuss their impressions with them (listen).
- Ask the relatives if they would like to speak to a pastoral caregiver.
- Facilitate a ritual appropriate to the culture. Involve the hospital chaplaincy if necessary.
- Arrange a farewell between the relatives and the treatment team.
- Inform them that contact can be maintained even after the process is complete (follow-up phone call, invitation to family meetings, etc.).
- Provide relatives with the documents available in the network: condolence card, contact details, addresses of institutions such as authorities, funeral directors, and possibly others from Swisstransplant, e.g., thank-you letters, leaflet "Organ Donation, Information for relatives").
- Accompany relatives to the hospital exit (whenever possible).

- If the relatives are not doing well or are visibly deteriorating, arrange for support from medical professionals (pastoral care, care team, psychologist).
- Ensure support within the team: exchange within the team, defusing by a psychological specialist, specialist support from Swisstransplant.

### Note on the next chapter 6.2 Decision against organ donation

Certain recommendations from this chapter also apply in the next chapter 6.2. In this case, the recommendations in this chapter should be combined with those in the next chapter.

- Important: respect a sudden withdrawal of consent.
- Allow relatives access to the patient.
- Plan, respect, and accompany the viewing and farewell.

## 6.2 Decision against organ donation

Recommendations for taking care of relatives and communicating without donation and during the farewell phase:

- Allow relatives access to the patient at all times. Relatives also include children who come to the intensive care unit. For questions about dealing with children as relatives, see Appendix 1.
- Intensive care measures are discontinued. Due to brain damage, breathing (previously maintained by machines) ceases and circulation collapses. Relatives are allowed to say goodbye at the patient's bedside before the remaining machines are also turned off.
- Inform the relatives that the deceased will be taken to a viewing room where a longer form of farewell and a farewell ritual are possible, and that other family members can join them, for example. In some facilities, the deceased patient remains in the intensive care unit during the farewell period.
- Ask the relatives if they would like to speak to a pastoral counselor.
- Plan and facilitate a ritual that is appropriate to the culture.
- Point out that the relatives can contact the treatment team at any time if they have any questions after the hospital stay.
- Ensure contact / provide contact details for any subsequent queries from relatives (for information / clarification).

- Allow relatives to access the patient.
- Plan, respect, and accompany visits and farewells in accordance with internal hospital procedures.
-

## 7.0

### Follow-up care for relatives

#### 7.1 Follow-up care in the event of consent to organ donation

**Follow-up care for the relatives of donors** is an important aspect both for the relatives themselves and for the medical professionals caring for them, such as doctors, nurses, and FOGS.

Important aspects of follow-up care for **donor families**:

- Ensure contact for any questions
- Ensuring that families feel "well cared for" even after the event and do not feel left alone" (contact with medical professionals)
- Supportive effect in processing the experience (through lasting "relationship" with medical professionals)
- Exchange with other families (meetings with relatives: you are not alone, exchange experiences, appreciation)
- Follow-up care allows relatives to express/show their gratitude.

#### 7.2 Aftercare services

<b>Contact after removal</b>	<ul style="list-style-type: none"> <li>– Information on the completion of the process</li> <li>– Information about the transplant</li> <li>– Condolence letters from the hospital or thank-you letters for the organ donation</li> </ul>
<b>Contact after completion (after 3 or 6–12 months)</b>	<ul style="list-style-type: none"> <li>– Inquiry about how the family is doing</li> <li>– Follow-ups: Communication of relevant information regarding recipients</li> <li>– Maintaining anonymity regarding recipients</li> </ul>
<b>Thank-you letter(s) Families</b>	<ul style="list-style-type: none"> <li>– Inform relatives that organ recipients will receive a brochure and that they may write a thank-you letter to the donor's family while maintaining anonymity.</li> <li>– It should be mentioned that thank-you letters are voluntary and not every recipient chooses to write one.</li> <li>– It is also up to the relatives to decide whether they wish to receive anonymous thank-you letters.</li> <li>– Thank-you letters are filed in the donor's dossier so that relatives can decide to read the letters at a later date.</li> </ul>
<b>Relatives' meetings</b>	<ul style="list-style-type: none"> <li>– Individual donor networks hold family meetings at regular intervals (approx. once a year).</li> </ul>

<b>Questionnaire Quality assurance</b>	<ul style="list-style-type: none"> <li>– In some hospitals, a questionnaire is sent to donor families one year after the event.</li> <li>– The questionnaire asks how the process was experienced, whether the information provided was understandable (e.g., brain death diagnosis), how the care was experienced, and asks about opportunities for improvement. It is recommended that all hospitals/centers use such a quality questionnaire.</li> </ul>
<b>Swisstransplant</b>	<ul style="list-style-type: none"> <li>– Relatives who contact Swisstransplant directly in person, by telephone, or by email (with questions, feedback, concerns, etc.) will be assisted.</li> </ul>
<b>Bereavement group</b>	<ul style="list-style-type: none"> <li>– Swisstransplant offers regional bereavement groups for people who have recently lost someone who donated their organs. The bereavement group is free of charge and non-denominational. Further information can be found in the brochure "Regional bereavement groups."</li> </ul>

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## Changes

Date	Version	Changes
February 2026	2.0	<p>New chapter structure developed.</p> <p>Focus of the module on caring for and communicating with relatives in the context of organ donation. Previously, general communication principles unrelated to organ donation were also mentioned. Texts shortened accordingly and redundancies removed.</p> <p>Former Appendix 1 (National register query / Addressing the topic in conversations with relatives), Appendix 3 (General checklist for conversation flow), Appendix 4 (Communication principles: Meta level), Appendix 5 (Communication principles: Needs) and Appendix 6 (Communication principles: Dealing with disruptions) removed. Text passages have been integrated directly into the relevant chapters where necessary and appropriate.</p> <p>References: Newly inserted</p> <p>Changes: Newly added</p>
December 2020	1.0	First edition

## Appendix 1: Dealing with children as relatives

Children are part of a family's social system. Adults, especially parents, want to protect their children from bad experiences and events. This is particularly likely to be the case when a death occurs within the family or close social circle. This attitude is human, but it carries certain risks that can be detrimental to the child and their grieving process. Children should be told about death and given the opportunity to say goodbye! First hearing about death and then saying goodbye is important for the grieving process. As medical professionals, it is helpful to be aware of the following aspects regarding children:

- Depending on their age and stage of development, death means different things to children, and they have different perceptions of death. For a child to fully understand death, they must have a cognitive understanding of its irreversibility (finality, cannot be reversed), universality (it affects everyone), and unpredictability.
- Regardless of whether the child already understands all three factors, some recommendations should be taken into account when dealing with children in these situations, even if they contradict the natural impulse to "protect/preserve the child from." Principle: Respond to the child's questions, considering the criteria of truth and clarity.
- Structure. Children cope better with the truth than with silence or lies. Children are part of the social system of a family. Excluding them in situations involving death means that they also feel excluded. Conversely, involving them in the support and discussions means that they feel they belong.
- As a medical professional, you have the opportunity to convey the information in a child-friendly manner and to support the parents in this process.
- At around 3 to 6 years of age, when death is understood as "being gone" or "being broken", life and death are still interchangeable. Magical thinking: "Those who are dead can be brought back to life".
- Between the ages of 6 and 9, children gradually develop a sense of time and realize that death is final.
- As they get older, around 9 to 12 years of age, their emotional world becomes more differentiated and their need for accurate information increases. Children know that all people must die without exception (universality of death).
- Later on, children/adolescents deal intensively with death and also with unpredictability (possibly also with uncontrollability). They may compare their own information about death with that of adults. The concept of death gradually becomes more firmly established.

## Dealing with children

### Do's

- If parents are unsure: recommend keeping children and adolescents close by.
- Tell the children about the death and accompany them as they say goodbye to the deceased.
- If children are sent outside during conversations, ensure that someone is with them outside (pastoral care worker, care team).
- Support parents in a later conversation with the children if they wish.
- If necessary, repeat the message to the children in simpler language.
- Always be honest with children.
- Be guided by the children's questions.
- Only answer the questions that the child asks.
- Answer honestly and immediately and repeat yourself (to help them remember).
- Observe and address the child's emotions.
- Provide reassurance.

### Don'ts

- Trying to spare children the news of death
- Forcing children to be present
- Sending children away against their will
- Prohibiting access to the deceased (farewell)

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