

Taking care of next of kin and communication

Module — 2

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Abbreviations of functions:

FOGS	Fachpersonen Organ- und Gewebespende (Organ and Tissue Procurement Coordinator) – all nominated persons whose function is covered by compensation payments to the hospitals concerned (official function)
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NWC	Network coordinator
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ODC / TxC	Organ donation coordinator / transplantation coordinator
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Other terms that are used in the individual networks are omitted here on purpose. In this document, **the term "FOGS"** is used, unless the specific nature of a function needs to be highlighted (e.g. network head).

The terms "local organ procurement coordinator" and "FOGS" are used synonymously.

The term "organ donation" also includes tissue donation wherever appropriate.

Introduction to “Taking care of next of kin and communication”

The Swiss Donation Pathway and other components (embedding)

The Swiss Donation Pathway provides the basic framework for the work of all persons involved in the organ donation process. It encompasses all processes of organ donation (detection, procurement etc.). Taking care of next of kin is a cross-functional process within the Swiss Donation Pathway. This module describes this care process, which begins in the accident and emergency department and ends with the follow-up care of next of kin.

Swisstransplant and Organ Donation Switzerland provide an overview of the following components as working and training aids for the care process:

- The Swiss Donation Pathway is a set of binding rules for all FOGS
- The “Pathway Angehörigenbetreuung und Kommunikation” is considered a concept in accordance with the strategic goals (only available in German)
- Blended Learning is a mandatory part of FOGS training
- The practical textbook “Gespräche mit hohem Belastungsfaktor in der Medizin” (Discussions involving a high stress factor in medicine) serves as an additional training aid and focuses on communication with next of kin. (available in print in German/ French only)

Basis: Guidelines on taking care of next of kin and communication

- Comprehensive training aid for taking care of next of kin
- Basis of the Swiss Donation Pathway and Blended Learning “Next of kin and communication”
- Integral part of the “Next of kin” training for all FOGS
- Accessible in electronic form for all interested persons

Swiss Donatioin Pathway	Blended Learning	Book “Gespräche mit hohem Belastungsfaktor in der Medizin” (Discussions involving a high stress factor in medicine)
<ul style="list-style-type: none"> – Short version of the guidelines – Quick reference work in daily clinical practice – For FOGS – For all persons concerned in daily clinical practice 	<ul style="list-style-type: none"> – 4 e-learning modules – 1 in-class seminar – Mandatory for FOGS – Voluntary for all other interested persons – Recommended for the staff of ICUs, accident and emergency departments and response organisations 	<ul style="list-style-type: none"> – Accompanying book – Fixed component of the “Next of kin” training for all FOGS – Commercially available for interested persons

IMPORTANT – application of the Swiss Donation Pathway “Next of kin”:

This chapter of the Swiss Donation Pathway is intended **as an everyday reference work**. In contrast to the donation phases (detection – donor treatment – procurement etc. —→ each presented in a separate chapter), taking care of next of kin is covered in only a single chapter.

For everyday reference, it is therefore recommended to read only the brief instructions that correspond to your area of responsibility or to the following step in caring for next of kin. For example: intensive care unit, notification of brain death —→ see chapter 5, pages 19 – 21.

Part B – Communication with next of kin (chapter 8 and following)

The information in this chapter is intended to help prepare for discussions. The more experience and application opportunities you have, the more “naturally” you will be able to use these principles of communication.

Outlook

These guidelines do not yet include certain topics for which there are currently no minimum standards for medical procedures. The following topics will therefore only be integrated later:

- Donation after Cardiocirculatory Death (DCD) donation
- Paediatric donors

1.0

Taking care of next of kin in the organ donation process

Organ donation follows a structured process based on the medical prognosis. However, in the first phase, the topic of organ donation remains in the background: patients do not primarily go to hospital as potential organ donors. For teams in the rescue and treatment chain, the focus is therefore on curative treatment. Nevertheless, even this early phase is already part of the detection process. Potential organ donors need to be identified and treated as early as possible so that the team in the intensive care unit can initiate all further steps.

1.1 Phases in taking care of next of kin in the context of organ donation

The above points will be visually represented in the following chart:

- Taking care of next of kin and related discussions represent a cross-functional process that involves many participants (FOGS and non-FOGS)
- The phases correspond to the main processes of organ donation: detection – donor treatment – removal/procurement – final phase with goodbye to the deceased donor and follow-up care of next of kin
- The individual care phases correspond to the main processes
- The persons involved are specified and assigned
- The tasks are indicated in general terms in the explanations accompanying the chart

The chart illustrates both the chronological process steps in an organ donation and the complexity of cooperation and the various interfaces involved

The explanations will make it clear that the curative treatment team is often in the lead during the first phase, and that FOGS are only involved when the issues of withdrawal of treatment, brain death and organ donation become relevant. Therefore, this Swiss Donation Pathway is also expressly aimed at the non-FOGS of accident and emergency departments and intensive care units.

Medical treatment, taking care of next of kin and communication are inseparable elements and always take place in parallel. They are interdependent, and each element influences the other two. That is why this Swiss Donation Pathway addresses all three elements and specifies the corresponding tasks, identifies interfaces and describes concrete recommendations for action.

The Swiss Donation Pathway is structured as follows:

- Organisational aspects
- Medical/treatment-oriented aspects
- Communication and taking care of next of kin

1.2 Overview of the phases in taking care of next of kin of a potential organ donor

Phases			Comments	
PHASE I Diagnosis and treatment	ANGEHÖRIGENBETREUUNG	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):	IMPORTANT: 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 ¹	Withdrawal of treatment ²	¹ From the decision to withdraw treatment all the way to and through removal: measures to preserve organs.
		Removal ²		² Cardio-circulatory arrest: no medical measures.
		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	

Explanation of the phases

Unit	Person(s) responsible and involved	Tasks related to next of kin (with respect to potential donors)
Phase I: Diagnosis and treatment		
Ambulance, accident and emergency department / resuscitation room	Paramedics	Taking care of next of kin on site, ride in the ambulance, handover of information to head of accident and emergency team
	Head of accident and emergency / treatment team	Care and initial discussions
	FOGS	Support, care and discussions
Phase II: Detection		
Intensive care unit Curative phase	Head of ICU / treatment team	Care and discussions
	FOGS	Support, care and discussions
	Care team / chaplain	Psychosocial care on request or as indicated (acute symptoms)
Intensive care unit Infaust prognosis / withdrawal of treatment	Head of ICU / treatment team	Care and discussions, communication of the infaust prognosis, imminent withdrawal of treatment
	FOGS	Support, care and discussions
	Care team / chaplain	Psychosocial care on request or as indicated (acute symptoms)
Intensive care unit In case of DBD: brain death diagnosis → notification of brain death	Head of ICU / treatment team	Care and discussions, notification of brain death diagnosis / brain death / withdrawal of treatment
	FOGS	Support, care and discussions
	Care team / chaplain	Psychosocial care on request or as indicated (acute symptoms)
Intensive care unit Question of presumed wishes	Head of ICU / treatment team	Care and discussion of presumed wishes
	FOGS (ODC / TxC)	Support, care and discussions; possibly information on organ donation
	Care team / chaplain	Psychosocial care on request or as indicated (acute symptoms)

Explanation of the phases (Continuation)

Unit	Person(s) responsible and involved	Tasks related to next of kin (with respect to potential donors)
Phase III: Donor treatment, allocation, removal		
Refusal of organ donation	Head of ICU / treatment team	Care and discussions, support during withdrawal of treatment, goodbye
	FOGS (ODC / TxC)	Support, care and discussions as required
	Care team / chaplain	Psychosocial care on request or as indicated (acute symptoms)
Consent to organ donation Intensive care unit → operating theatre	Head of ICU / treatment team	Care and discussions, support during organ donation process, goodbye
	FOGS (ODC / TxC)	Support, care and discussions during organ donation process, coordination
	Care team / chaplain	Psychosocial care on request or as indicated (acute symptoms)
Operating theatre / ICU or laying-out room	In case of consent to organ donation: treatment team	Support during goodbye phase, saying goodbye
	FOGS (ODC / TxC)	Support / care
	Care team / chaplain	Care on request / chaplaincy, rituals
In addition: <ul style="list-style-type: none"> – Thanks to the team / persons involved – Debriefing – Thank-you letter from Swisstransplant to the hospital 		
Phase IV: Conclusion and follow-up care		
Intensive care unit Local organ procurement coordinator / network	Treatment team	Available in case of questions
	FOGS (ODC / TxC)	Process for follow-up care / thank-you letters (STATKO), statistics

2.0

Taking care of next of kin in the accident and emergency department with a view to potential organ donation

2.1 Ambulance / paramedics

Paramedic services operate prior to the hospital and provide preclinical treatment, initial medical stabilization and transport to a hospital if necessary. A patient with life-threatening symptoms is first and foremost stabilized by the paramedics and taken as quickly as possible to an accident and emergency department in the nearest hospital. An important interface arises there between the paramedics and the treatment team in the hospital.

With regard to taking care of next of kin, there are a number of aspects to be considered with importance for the later stages of care and potential organ donation. These are briefly discussed here:

- Paramedics focus on saving patients and getting them medically stabilized. Next of kin who are involved in an accident or an unforeseen event or who are present on site are given care only as a secondary priority.
- The care of and communication with next of kin tends to focus on calming them down and providing them with initial information about the patient's condition. However, next of kin who are too agitated and under stress can also be a hindrance during a life-saving intervention.
- Sometimes, next of kin travel with the patient in the ambulance, which is primarily intended to reassure the patient.
- If the next of kin do not travel along in the ambulance, they often arrive at the hospital accident and emergency department later than the ambulance does.
- The report on the transfer from the paramedics to the emergency team is limited to the essential medical information, if necessary / appropriate supplemented by psychosocial and social information. If the emergency team does not specifically ask the paramedics, important information regarding next of kin that may be relevant at a later stage will not be disclosed.
- The topic of organ donation is generally not addressed or relevant at this stage.

Recommendations

Even if the topic of organ donation is not of primary relevance for paramedic services in their everyday work, the following recommendations may be helpful from the point of view of key players involved in organ donation (FOGS / Swisstransplant).

The comments regarding the ambulance / paramedics are intended here to facilitate a transfer of knowledge (ambulance ↔ hospital). This is not a matter of giving advice to paramedics, but of raising mutual awareness:

- The topic of taking care of next of kin with respect to organ donation should be integrated into the training of paramedics: fundamentals of organ donation, important aspects for patients as potential organ donors, dos and don'ts in communication with next of kin (e.g. caution in conveying hope about a patient's condition, which could later lead to confusion, misunderstandings or lack of trust in the intensive care unit)
- Institutionalized exchanges (e.g. one to two times per year): feedback from intensive care units on potential or actual cases of organ donation that were handled by the paramedic services, and that present possibilities for improvement or adaptation in initial care (paramedics) (i.e. "lessons learned")

Dos and don'ts

In general, paramedics are advised to adopt or avoid certain behaviours and language when dealing with next of kin of patients with life-threatening conditions (cardio-circulatory arrest = potential DCD / craniocerebral trauma = potential DBD).

Dos

- Use a clear, authoritative manner in dealing with next of kin
- Involve the care team at the site of the intervention (cantonal regulations vary)
- Provide neutral information regarding the medical prognosis
- Report information about next of kin (what they said, whether anything unusual was noticed) at the time of transfer to the accident and emergency department

Don'ts

- Encourage hopes
 - Destroy hopes (if diagnosis is not yet conclusive / clear)
 - Make confusing / unclear statements, such as "The injuries were incompatible with life".
 - Bring up the topic of organ donation
-

2.2 Accident and emergency department and resuscitation room

This Swiss Donation Pathway focuses on taking care of next of kin, but for the sake of completeness, treatment-oriented and organizational aspects should already be included here with a view to later detection. The majority of potential organ donors enter hospital via the accident and emergency department. For this reason, special attention should be paid to taking care of next of kin. The following organizational and medical aspects are considered relevant, although not exhaustive. Each situation must be assessed individually.

Recommendations on organizational / medical aspects

The heads of intensive care units and FOGS consider the following points to be necessary:

a) Organizational aspects

- There are clear agreements in place between the accident and emergency department and the intensive care unit, or these must be established.
- Medical professionals (including non-FOGS) must be trained in the fundamentals of organ donation.

- Internal hospital treatment pathway / workflow, emergency number and other information known?
- Clarify: Is a donor card / advance directive available?
- Clarify: Is there an entry in the National Organ Donor Register?
→ see annex Register check

b) Medical / treatment-oriented aspects

- Curative treatment with a therapeutic objective: transfer of patient to the ward
- Advance directive: Are there any documents that describe the patient's wishes? Do the next of kin know the patient's wishes for further treatment?
- In case of an infaust prognosis:
- Decision tends towards withdrawal of treatment / palliation
- Are the circumstances appropriate for organ donation? → involvement of FOGS
- Patient intubated? No extubation should be performed without consulting the ICU
- No brain death diagnosis in the accident and emergency department
- Clarification of donor suitability with the responsible FOGS (in the accident and emergency department if the local organ procurement coordinator is based there; or telephone call with ICU / FOGS / TxC)

Recommendations for the interface between the accident and emergency department and the intensive care unit

- Establishment of a common path / common thread
- Organ donation is also always a matter for the ICU doctor, who should be involved at an early stage
- Clarify with the ICU: Is there enough time for a potential organ donation enquiry despite the urgency of emergency intervention?
- Clarification of donor suitability according to the established hospital processes
- If organ donation is already being discussed in the accident and emergency department, it is recommended that the ICU doctor or FOGS be involved (continuity)
- Consultation: When do preparatory medical measures for organ donation begin? (Has consent been obtained for preparatory measures? Patient not intubated: potential DCD)
- Consultation: Timing for transfer to the ICU?
- Nursing staff (from the accident and emergency department or ICU) accompany the next of kin to the patient's bedside ("transfer" of the next of kin from the accident and emergency department to the ICU)
- Ensure transfer of information to the intensive care unit (information about next of kin)

Recommendations on care and communication aspects

- Please always remember: At this stage, it is essential to refrain from already informing the next of kin by telephone about a patient's (suspected) brain death while at the same time raising the question of the patient's presumed wishes regarding organ donation! (In 23 interviews conducted as part of research on next of kin in 2018 / 2021, this was described three times by next of kin.)
- Next of kin should be taken care of as soon as possible when present.
- Allow next of kin quick access to the patient's bedside. In case of a delay, the next of kin should be informed about the various medical measures involved, including an approximate time frame, if possible. They may be offered the opportunity of spending some time with members of the support team (care team / chaplain). According to surveys

of next of kin, the time spent waiting to visit the patient is considered one of the most stressful aspects.

- Find a separate room for discussions (not a resuscitation room); pay attention to the setting for discussions.
- Provide transparent, prompt information to next of kin.
- Communicate decisions based on prior consultation with the team (e.g. diagnoses, poor prognosis etc.).
- At this time, the emergency treatment team should not raise the issue of organ donation with next of kin. Prior consultation with the ICU doctor is recommended.
- If the next of kin bring up the topic of organ donation, the ICU doctor must be involved.
- If it becomes apparent that the patient could become a potential donor, the ICU doctor should already be involved in the discussion (if possible, consult experienced physicians, possibly an organ procurement coordinator).
- For communication with next of kin in a state of emergency: use part B of the guidelines, complete the Blended Learning training from Swisstransplant and seek further training in communication.

Checklist for taking care of next of kin in the accident and emergency department and transfer to the intensive care unit (for potential organ donors = detection)

Organization

- ☐ Are the persons responsible for detection in the accident and emergency department defined?
- ☐ Is cooperation between the accident and emergency department and the intensive care unit organized / agreed upon regarding the detection of potential organ donors?
- ☐ Is the staff of the accident and emergency department sensitized to the issues of organ donation / interaction with next of kin?
- ☐ Is the staff of the accident and emergency department trained in matters relating to detection / organ donation / interaction with next of kin?
- ☐ Do guidelines or an algorithm exist for the interface where potential organ donors are detected in the accident and emergency department?

Medical / treatment-oriented aspects

- ☐ Is the prognosis infaust?
 - ☐ Interdisciplinary decision tends towards withdrawal of treatment / palliation
 - ☐ Are the conditions for (the clarification of) organ donation fulfilled?
 - involvement of FOGS
- ☐ Clarification of donor suitability according to the established hospital processes
- ☐ Is the patient intubated? → no extubation before transfer to the ICU
- ☐ Is a donor card / advance directive / smartphone app available?
- ☐ Is there an entry in the National Organ Donor Register?
- ☐ Has the ICU doctor already been informed, and has a joint discussion been organized?
- ☐ When do preparatory medical measures for organ donation begin?
- ☐ Has the transfer to the ICU been arranged / organized?
- ☐ Is it ensured that the next of kin are accompanied to the patient's bedside (accident and emergency department or ICU)?

Communication and taking care of next of kin

- ☐ Is it ensured that the next of kin receive rapid care?
- ☐ Is there a room available for discussions?
- ☐ Has the extended support team been informed (chaplain, care team)?
- ☐ Did the next of kin provide important information about the patient or situation, or did they show unusual behaviour?
 - Communication to the ICU staff (information might be important later on)
- ☐ Have there been incidents with the next of kin (misunderstandings, conflicts etc.)?
 - Communication to the ICU staff (information might be important later on)
- ☐ Next of kin are escorted from the accident and emergency department to the ICU by an accident and emergency department or ICU professional (next of kin should not have to "wander around" alone / look for the ICU themselves).

3.0

In the intensive care unit – curative treatment phase

Tasks and interfaces

a) Organizational aspects

- The tasks relating to the detection of potential organ donors are clearly defined, and the roles are assigned accordingly. Up to the infaust prognosis: full intensive care treatment!
- The network head and/or local organ procurement coordinator ensure that the team in the intensive care unit is sensitized and trained.
- The interface with the accident and emergency department is taken into consideration. There are clear agreements on how potential donors are detected, prepared and transferred. There are clear rules on when the ICU doctor is called in and how taking care of next of kin and communication are handled.

b) Treatment team aspects

- The treatment team is responsible for providing appropriate curative treatment to a patient.
- If the treatment team comes to the conclusion that the prognosis is infaust or that further medical treatment is not indicated, and if the withdrawal of treatment is being discussed, the head of the intensive care unit should be called in to assess a potential donation situation (detection).
- If the local organ procurement coordinator (= FOGS) is integrated in the intensive care unit, they assess the patient's situation with regard to detection of a potential donor. If the criteria are met, the local organ procurement coordinator informs the team treating the patient.
- The topic of organ donation should not be discussed with next of kin at this stage.

Recommendations for taking care of next of kin and communication during the curative phase

a) Organizational aspects

- The treatment team is responsible for taking care of next of kin and communication.
- It is appropriate to appoint a main person responsible for taking care of next of kin and communication (with the aim of ensuring that procedures are in place and that guidelines and recommendations are applied).
- The same contact persons should always be available to next of kin as far as possible.
- If possible, discussions should always be conducted by two people (nursing staff and doctor).
- Nursing staff and doctors should always consult with each other before a discussion with next of kin (consistent information, avoidance of misunderstandings → provides reassurance).
- In case of changes to the care staff, important information relating to the next of kin should be handed over / recorded.
- Seek support at an early stage if possible (care team, chaplain etc.).

- If a situation with an infaust prognosis / withdrawal of treatment and potential organ donation seems to be imminent, consult the relevant medical professionals (local organ procurement coordinator, organ procurement coordinator etc.).
- Hold the discussion in a neutral, separate room (more on this topic in part B).

b) Discussion aspects

- If possible, meet the next of kin at reception or the entrance to the intensive care unit.
- Get the next of kin to the patient's bedside as soon as possible after their arrival. Sometimes, this conflicts with necessary medical measures that cannot be postponed. However, next of kin say that waiting for the first visit to the ICU is the most stressful time. → need for reassurance and clarity
- Prepare the next of kin in advance for the scenario that awaits them at the patient's bedside (e.g. the patient is being ventilated through a tube, may have head injuries, a dialysis machine has replaced kidney function).
- Organ donation is not brought up at this stage of the discussions.
- If the next of kin raise the issue of organ donation of their own accord: respond to this; by no means simply "brush off" the topic as not yet being relevant. → this is about the need "to be taken seriously".
- Ask the next of kin if there are any other important people who should be present at the discussion.

4.0

In the intensive care unit – phase of infaust prognosis / withdrawal of treatment

Recommendations for taking care of next of kin and communication during the phase of infaust prognosis / withdrawal of treatment

a) Organizational, preparatory aspects

- Ask the next of kin to join you for a discussion (doctor / nursing staff working in coordination).
- Prepare yourself for the discussion (as a pair, reach agreements, verify and coordinate information, organize the room etc.). It may be helpful to consult with experienced colleagues.
- Although organ donation is not yet mentioned at this point, you as a treatment team must be aware right now whether there are any contraindications to organ donation. If donation is not possible at this stage, avoid unnecessary discussions with the next of kin.
- Review the course of treatment and prepare arguments for changing the goal of treatment.
- Prepare yourself mentally for a variety of reactions.
→ See annex "Possible reactions of next of kin".
- Prepare for a "breaking bad news" discussion according to the recommendations
→ See annex "Breaking bad news".
- Contact the local organ procurement coordinator / organ procurement coordinator and ask them to be ready to join the discussion.
- Before starting a discussion, put aside your phone / pager so as not to be disturbed during the discussion.

b) Discussion aspects

- Greet the participating next of kin individually (if necessary, introduce yourself again with your name and role) or ask who is present (if there are a large number of next of kin, consider the rights of representation under the guidelines of the Swiss Academy of Medical Sciences (SAMS), or determine the “inner circle” of contact persons together with the family). Ask about each person's connection to the patient (e.g. “What is your relationship to the patient?”).
- If translation is necessary, plan / organize this at an early stage..
- Specify the purpose of the discussion and possibly the duration
- Build a communicative bridge to the previous discussion (what was discussed, are there still any unresolved questions etc.).
→ See part B: “Principles of communication, discussion process”
- Quickly get to the real point (infaust prognosis / planned withdrawal of treatment) and avoid long medical introductions (need of the next of kin here: quick reassurance and clarity about the situation – long explanations by the doctor do not satisfy this need).
→ See part B: “Identifying and responding to needs”
- Answer questions clearly and simply, without using technical terms.
- Describe the next medical steps and what they mean.
- Clarify that no more resuscitation measures are (or should be) taken on the basis of the infaust prognosis.
- Make clear, unambiguous statements; use short sentences, such as «The patient will die.» (or: “Your father / mother / child” etc.).
- Allow for pauses. The next of kin need time to understand / process the information.
- If the next of kin raise the issue of organ donation, answer their questions and point out that it is not yet clear whether the patient could actually become a donor.
- It may be useful to involve the local organ procurement coordinator / organ procurement coordinator (for answering specific questions about organ donation).
- End the discussion with clear information: What will be done next? When should the next of kin come back? What can / should they do before the next discussion?

Tips for discussions of brain death diagnosis / notification of brain death

Depending on the situation, discussion of an infaust prognosis may be omitted and the withdrawal of treatment may be discussed, along with the notification of suspected or confirmed brain death. In this case, the recommendations in this chapter should be combined with those in chapter 5, “Phase of brain death diagnosis – notification of brain death”.

Check of the National Organ Donor Register in the event of an infaust prognosis with suspected brain death

In the event of an infaust prognosis and a decision to withdraw treatment, and if there are indications that brain death is imminent, the National Organ Donor Register is to be checked by telephone by an authorized person. This applies to both potential DBD and DCD donors.

- Guidance and recommended procedures for checking the National Organ Donor Register are given in the annex.

5.0

In the intensive care unit – phase of brain death diagnosis / notification of brain death

Recommendations for taking care of next of kin and communication during the phase of notifying the next of kin of brain death

a) Organizational, preparatory aspects

- If possible, the discussion should be conducted by a doctor who has already had contact with the next of kin and, if possible, together with a nursing staff member who has already looked after the patient.
- Ask the next of kin to have a discussion promptly after brain death is diagnosed (or, in cases where no brain death diagnosis is made, after the decision to withdraw treatment).
- Prepare yourself for the discussion (as a pair, reach agreements, verify and coordinate information, organize the room etc.).
- Review the course of treatment so far and prepare arguments regarding the reasons for withdrawal of treatment and /or brain death diagnosis.
- Prepare yourself mentally for a variety of reactions.
→ See annex "Possible reactions of next of kin"
- Prepare for a "breaking bad news" discussion according to the recommendations.
→ See annex "Breaking bad news"
- Have visualization aids ready (cerebral blood flow diagram, CT scan etc.).
- Possibly contact the local organ procurement coordinator / organ procurement coordinator and ask them to be ready to join the discussion.
- Check the National Organ Donor Register with Swisstransplant National Transplant Coordination.
- Orientate / summon the care team / chaplain.
- Several discussions may be necessary before it is possible to ask about the patient's presumed wishes.
- The question of organ donation may already be raised by the next of kin during the discussion about brain death. In this case, combine the discussion with the recommendations in the next part, i.e. presumed wishes.

b) Discussion aspects

- Build a communicative bridge between the previous discussion and the current situation: Does everyone have the same information? Do any questions remain unanswered? Has everything been understood?
→ See part B: "Principles of communication, building bridges between discussions"
- Open and conduct the discussion according to the recommendations for breaking bad news.
→ See annex "Breaking bad news"
- Quickly get to the real point (the patient has died /irreversible loss of all brain functions) and avoid long medical introductions (need of the next of kin here: quick reassurance and clarity about the situation – long explanations by the doctor do not satisfy this need).
→ See part B: "Identifying and responding to needs"

- Make clear, unambiguous statements (e.g. "The patient is (brain-)dead/ deceased.", "All brain functions have ceased.").
- Answer questions clearly and simply, without using technical terms.
- Describe the next steps and what they mean: withdrawal of treatment advisable / necessary – discuss the possibilities before switching off the machines – withdrawal with or without donation.
- If the local organ procurement coordinator / organ procurement coordinator is present, they can answer any questions regarding organ donation.
- End the discussion with clear information: What will be done next? When should the next of kin come back? What can / should they do before the next discussion? What will be the goal of the next discussion?

Register check for potential donors

The National Organ Donor Register should be checked before the discussion to see if there is any entry for the patient (if the patient could qualify as a donor according to the relevant criteria). The same applies if a DCD donation is being considered.

- Guidance and recommended procedures for checking the National Organ Donor Register are given in the Annex.

Checklist for taking care of next of kin: notification of brain death

Organization

- ☐ Reserve and prepare the room (tidiness, water etc.)
- ☐ Schedule the discussion (select time [not at night!], duration)
- ☐ Read case documentation: certainty about the technical information
- ☐ Preparation for the discussion: according to the recommendations for breaking bad news / personal preparation
- ☐ Involve the nursing staff, discuss together (team: who contributes to the discussion, and how)
- ☐ Provide aids
- ☐ Avoid all possible external disturbances (log off, leave your phone / pager outside, inform the team etc.)
- ☐ Is a donor card / advance directive available?
- ☐ Is there an entry in the National Organ Donor Register?
- ☐ Has the local organ procurement coordinator / organ procurement coordinator been informed / summoned?
- ☐ Has the care team and / or the hospital chaplain been informed / summoned?

Communication and taking care of next of kin

- ☐ Consider the metalevel:
 - How is the discussion going? How am I acting? What are the effects of my way of communicating? What does my body language express? What can I notice about the next of kin? How are they reacting to the situation / to each other / to me?
- ☐ Calm, focused greeting and discussion atmosphere
- ☐ Build a communicative bridge between the previous discussion and the current one.
- ☐ Airbag sentence (= sentence that introduces bad news): "Unfortunately, we have to tell you some bad news ..."
- ☐ Pay attention to the needs of the next of kin (listen / read between the lines) and respond to them. Don't ignore them!
- ☐ Recognize and process (internal) disturbances during a discussion. Don't ignore them!
- ☐ Are all next of kin actively taking part in the discussion?
 - Who is the spokesperson / decision-maker?
 - Are any open or latent conflicts apparent?
 - What stands out regarding the dynamics among the next of kin?
- ☐ Resist your own urge to talk a lot and for a long time. If possible, create a pause to give the next of kin space to pose questions.
- ☐ Provide brief, clear information on the medical aspects (no technical terms).
- ☐ Verify that the next of kin have understood that the patient is deceased.
- ☐ Note: there is often a time gap between (cognitively) understanding that death has occurred and fully grasping that death has occurred.
- ☐ Provide clear information about the next steps; bring up the prospect of the next discussion.
- ☐ Specify and communicate the time and reason for the next discussion.
- ☐ Would the next of kin like to see the patient after the discussion? → accompany them
- ☐ If the next of kin leave the ICU directly → accompany them to the ICU exit
- ☐ After saying goodbye to the next of kin: Brief consultation between the doctor and member of nursing staff: How was the discussion perceived? What was the outcome of the discussion? Take notes on the discussion.
- ☐ Look after yourself: How am I doing? Do I need anything (defusing / mental hygiene, internal feedback forms etc.)?

6.0

In the intensive care unit – phase of the discussion about the patient's presumed wishes

Recommendations for timing of the discussion about the patient's presumed wishes

- If possible, not before notification of brain death / infaust prognosis or the decision to withdraw treatment (e.g. also consider the issue of DCD or transfer).
 - Once the next of kin have been notified of the diagnosis of brain death, make sure that they have clearly understood it.
 - If the next of kin raise the issue themselves: respond to it (if asked before brain death, explain that it might become an issue OR that there are not enough indications at this stage to suggest that it might become an issue; reassure the next of kin that the issue of organ donation will be raised as soon as there are indications that it may be relevant).
 - If the wish of the patient is "No organ donation" (National Organ Donor Register / donor card), the next of kin will be informed (transparency). It should be stated that the patient's wishes will be respected.
- More information on this can be found in the Annex "Register check".

In this phase, early involvement of the organ procurement coordinators and joint cooperation are also important, both with regard to information on organ donation and regarding donor treatment and coordination. Clear rules and agreement on the relevant tasks are essential.

Recommendations for taking care of next of kin and communication during the phase of asking about the patient's presumed wishes regarding organ donation

a) Organizational, preparatory aspects

- The discussion should – whenever possible – be conducted by the same persons who notified the next of kin of brain death (or the infaust prognosis, e.g. DCD).
- Invite the next of kin for the follow-up discussion, as announced. Inform them that all persons who are to be involved in the next steps and potential decisions should come along to the discussion.
- Prepare yourself for the discussion (as a pair, reach agreements, verify and coordinate information, organize the room etc.).
- Coordinate with the organ procurement coordinator (who should either be present from the beginning of the discussion or should join the discussion later with the consent of the next of kin).
- Review the course of treatment so far and prepare yourself for the question of the patient's presumed wishes: How do you address the topic?
- Prepare yourself mentally for a variety of reactions (especially incomprehension, aggression, denial etc.).
- Have the information from the National Organ Donor Register ready (if available).
- Orientate / summon the care team / chaplain.
- Several discussions may be necessary. Do not put pressure on the next of kin (depending on the case, between 48 and max. 72 hours of decision time can be granted; taking into account preparatory measures, SAMS guidelines).
- The persons leading the discussion should take a neutral position with regard to the decision.

b) Discussion aspects

- Build a communicative bridge between the previous discussion and the current situation: Does everyone have the same information? Do any questions remain unanswered? Has everything been understood?
→ See part B: "Principles of communication"
- Get to the point quickly: The patient will die / has died. It is now a matter of withdrawing treatment (switching off the machines). Before this is done, it is important to ensure that the patient's wishes regarding organ donation are known, as different further steps will be required / so that the patient's wishes can be honoured.
- Let yourself be guided by the questions of the next of kin.
- Answer questions clearly and simply, without using technical terms.
- The patient / deceased person remains the focal point. The decision should be taken considering their presumed wishes.
- Has this subject been discussed? Are the wishes of the deceased person known? Is a donor card available? Is an answer suggested by the deceased person's behaviour / attitude?
- Bring up the entry in the National Organ Donor Register, if one exists.
- Ask how you, as a medical professional, can support the decision-making process.
- Every decision will be accepted and respected (yes or no to organ donation).
- At no time should pressure be put on next of kin in the sense of an "obligation" to donate organs.
- If the local organ procurement coordinator / organ procurement coordinator is present, they can answer any questions regarding donation and provide information on the procedure to be followed in the case of consent to organ donation (preparatory measures, examinations, operation / removal, goodbye etc.); the same applies in the case of refusal.
- Care and consideration should be taken when explaining both process variants, i.e. DBD versus DCD, at an early stage to avoid overwhelming the next of kin (the varying durations of the processes may influence the decision; the longer a process takes, the higher the perceived stress, and the more likely it is that a "no" will be given as an answer).
- Provide information about which organs (and tissue) can be donated in principle, indicating that it is the decision of the deceased person or of the next of kin which organs are to be donated if consent is given.
- In case of DCD: Inform the next of kin that withdrawal of treatment may last longer than 120 minutes, and that consequently DCD organ removal may not be possible. The patient will be transferred back to the ICU.
- Let the next of kin know how much time they have to make a decision. Encourage the family to talk about it calmly in an intimate setting and involve important people. The goal is to arrive at a decision that remains stable in the long term.
- Assure the family that they may keep asking questions about a potential donation until they feel confident about making a decision.
- End the discussion with agreement on what the next steps are and when the next discussion will take place.

6.1 Decision in favour of organ donation

Procedure for taking care of next of kin during the removal and goodbye phase

Explain the next steps in detail

- Social and medical case history with the coordinator
- Identify and explain which examinations are carried out and why.
- Explain that the examinations are carried out to assess the condition of the organs and not to treat the patient.
- Mention that the deceased person may be taken out of the ICU for a short time for the purpose of examinations.
- Consider the time frame: the longer the process takes, the higher the stress level (may have an influence on the decision).
- Explain to next of kin that the patient may exhibit reflex-like movements that can be disturbing when unexpected (Lazarus phenomenon).
- Possibly take contact details and ask whether information on "success" of the removal and transplantation should be provided to the next of kin.

Which organs are to be donated?

- Carefully clarify (again) which organs should be donated and which not.
- Also include the question of tissue donation. **Important:** Under no circumstances should the question of a cornea donation be raised by telephone later when the organ removal has already taken place and the next of kin assume that the process has been completed. Interviews with next of kin clearly show that this is considered disrespectful and inappropriate.
- If the donor has to be transferred to another hospital for organ and/or tissue removal, this should be mentioned at an early stage (in the phase of providing information and before the decision is taken whether to consent to donation). Before the transfer, carefully draw attention to the possible stressors once again (change of team, re-evaluation of diagnoses, delays) and obtain consent.

Care during the removal process

- Always remain available to answer any questions (contact details).
- Provide information about each step in a timely and transparent manner.
- Ensure access to the patient at all times.
- Point out to the next of kin that they cannot be present in the operating theatre during removal (for DBD: not possible / for DCD: partly possible until cardiac arrest).
- Respect any sudden withdrawal of consent. If possible, involve professionals (psychologists) to reduce or prevent additional stress in a potentially traumatic situation. Support the next of kin in the event of an actual cancellation of the donation (see procedure for refusal below).

Saying goodbye to the deceased person

- Discuss the options: The next of kin may see / say goodbye to the patient both before and after the operation. If the next of kin do not want to see the deceased person again after organ removal, respect their wishes. Ask for permission to make a recommendation: that the next of kin should say goodbye after the removal. Although that step is difficult, it is usually beneficial for the acceptance of the loss and for the grieving process. Assure the next of kin that you are there to support them in the process. (Note: It is not possible to say goodbye in hospital if the patient is immediately transferred to an institute of forensic medicine.)
- If a post-mortem examination is necessary, also inform the next of kin that tubes, vein accesses etc., must not yet be removed in the laying-out bed.
- Explain where the deceased person will be taken after organ removal. Escort the next of kin to the laying-out room. Check the room beforehand and change the setup if this is necessary or helpful. Stay with the next of kin in the laying-out room for the first few minutes until the initial tension subsides. Arrange with the next of kin how long they wish to stay. Come back to fetch the next of kin. If needed, talk with the next of kin about their experience.
- Ask the next of kin if they would like to speak with a chaplain.
- Ask the next of kin if they wish to have the personal clothing of the deceased returned to them.
- Allow for a culturally appropriate ritual. Involve the hospital chaplain.

Saying goodbye to the next of kin

- Make sure that the next of kin can also say goodbye to the treatment team if they wish, or vice versa (the treatment team is also part of the experience, and would like to say goodbye to the next of kin for purposes of processing the experience and out of respect).
- Indicate that you will maintain contact even after the process has been completed (telephone follow-up, invitation to meetings of next of kin etc.).
- Give the next of kin the documents available in the network: condolence card, contact details, addresses of institutions such as authorities, undertakers etc.
- Escort the next of kin to the exit of the hospital (respect and appreciation).

Further aspects of support

- If, in the course of taking care of the next of kin, you observe that they seem unwell or are noticeably getting worse, offer them the opportunity of receiving professional care (chaplain, care team, psychologist).
- Also ensure support for the team:
 - Communicate within your team
 - Intervision / supervision
 - Professional support via Swisstransplant
 - Defusing by a professional with psychological training

6.2 Decision against organ donation

Procedure for taking care of next of kin without a donation and during the goodbye phase

Explain the next steps in detail

- The medical measures are withdrawn. Due to the brain damage, breathing stops and the circulation breaks down. The patient also becomes visibly deceased.
- The next of kin may say goodbye at the patient's bedside before the machines are switched off.
- The next of kin are told that the deceased is then taken to a laying-out room, where it is also possible to say goodbye – and, if desired, to perform a goodbye ritual. A ritual of this kind can also be useful in the ward itself.

Saying goodbye to the deceased person

- If the next of kin does not want to be present when the treatment is withdrawn and visible death occurs, please respect this decision. In this case, recommend that they say goodbye in the laying-out room. Although that step may be difficult, it is usually beneficial for the acceptance of the loss and for the grieving process. Assure the next of kin that you are there to support them in the process. (Note: It is not possible to say goodbye in hospital if the patient is immediately transferred to an institute of forensic medicine.)
- If a post-mortem examination is necessary, also inform the next of kin that tubes, vein accesses etc., are not yet removed in the laying-out bed.
- Explain where the deceased person will be taken. Escort the next of kin to the laying-out room. Check the room beforehand and change the setup if this is necessary or helpful. Stay with the next of kin in the laying-out room for the first few minutes until the initial tension subsides. Arrange with the next of kin how long they wish to stay. Come back to fetch the next of kin. If needed, talk with the next of kin about their experience.
- Ask the next of kin if they would like to speak with a chaplain.
- Allow for a culturally appropriate ritual. Involve the hospital chaplain.

Saying goodbye to the next of kin

- Make sure that the next of kin can also say goodbye to the treatment team if they wish, or vice versa (the treatment team is also part of the experience, and would like to say goodbye to the next of kin for purposes of processing the experience and out of respect).
- Point out to the next of kin that they may contact the treatment team or organ procurement coordinator at any time if questions arise afterwards.
- Give the next of kin the documents available in the network: condolence card, contact details, addresses of institutions such as authorities, undertakers etc.
- Ensure that contact is maintained for any subsequent enquiries from next of kin (information / clarification).
- Escort the next of kin to the exit of the hospital (respect and appreciation).

Further aspects of support

- If, in the course of taking care of the next of kin, you observe that they seem unwell or are noticeably getting worse, offer them the opportunity of receiving professional care (chaplain, care team, psychologist).
- Also ensure support for the team:
 - Communicate within your team
 - Intervision / supervision
 - Professional support via Swisstransplant
 - Defusing by a professional with psychological training

6.3 Final phase

Tasks and interfaces

- In both cases (with or without organ donation), the case is closed after the deceased person has been laid out.
- Goodbyes have been said to the family, and the relevant information and written materials (e.g. contact addresses, brochure "Thank-you letters" from Swisstransplant) have been handed over.
- The deceased person is transferred to a mortuary in accordance with the hospital standards.
- The organizational and administrative tasks are completed (billing etc.).
- The hospital documents the death internally in accordance with in-house standards.
- The death is registered in the Swiss Monitoring of Potential Donors (SwissPOD) database by the local organ procurement coordinator.
- The FOGS / local organ procurement coordinator is responsible for ensuring that contact is organized with donors' families (follow-up care), and that the elements of follow-up care are implemented in line with the time requirements (phone call, thank-you letter etc.).
- If applicable, reports are entered into the Critical Incident Reporting System (CIRS) and processed by Swisstransplant.
- The responsible FOGS thanks the participating ICU team, the operating theatre team and the anaesthesiology team for their support and cooperation.
- Swisstransplant sends a thank-you letter to the ICU team.
- FOGS and / or Swisstransplant remain available to answer any questions and to support the team.
- Defusing can be requested by the team if desired.

7.0

Follow-up care of next of kin

7.1 Follow-up care in case of consent to organ donation

The follow-up care of donors' next of kin is an important aspect both for the next of kin themselves and for the medical, nursing and FOGS professionals who take care of them.

Important aspects of follow-up care **for donors' next of kin:**

- Ensuring that contact is maintained for any subsequent enquiries (information / clarification).
- Ensuring that the next of kin feel well taken care of even after the event, and do not feel left alone (contact with medical professionals).
- Support in processing the experience (through a lasting relationship with the medical professionals).
- Communication with other families (meetings of next of kin: not feeling alone, sharing experiences, appreciation).
- Establishing a connection to the organ recipient by means of a thank-you letter for the donor's next of kin (appreciation, meaning, solace).

Important aspects of follow-up care **for medical professionals:**

- It makes it possible to express / show gratitude to the next of kin.
- Feedback from next of kin via ongoing contact can strengthen the sense of purpose for the work of organ donation (for the whole treatment team).
- Feedback from next of kin helps medical professionals to feel valued.

Tasks and options in follow-up care

Offer of contact	<ul style="list-style-type: none"> – The next of kin are offered the opportunity to contact the treatment and care professionals at any time, or to come to the hospital, if they have any questions about the donor's situation – Contact details are provided to the next of kin: <ul style="list-style-type: none"> – Contact persons – Telephone numbers – Websites – Other materials, such as leaflets etc.
Hospital letter	<ul style="list-style-type: none"> – Letter of condolence from the hospital – Letter expressing gratitude for the donation (in some cases after donation and again one year later)
Contact after removal	<ul style="list-style-type: none"> – Information on completion of the process – Information on transplantation

Contact after completion (after 3 or 6 – 12 months)	<ul style="list-style-type: none"> – Enquire how the next of kin are doing – Follow-ups: communication of relevant information regarding transplantation / recipient – Avoid too much information – Maintain the recipient's anonymity – In some cases, visits are paid to the next of kin (after 1 – 3 months)
Thank-you letter(s) for next of kin	<ul style="list-style-type: none"> – The next of kin are informed that the organ recipients will receive a brochure, and that they may write a thank-you letter to the donor's next of kin – If the donor's next of kin wishes to write a letter to the recipient, they will be assisted by the team and the letter will be forwarded to the recipient while maintaining anonymity – A separate process exists for thank-you letters from recipients to donors' next of kin (see below)
Meetings of next of kin	<ul style="list-style-type: none"> – Individual donation networks organize meetings of next of kin at regular intervals (approx. once a year) – The meetings are well-attended and highly appreciated by donors' next of kin
Quality assurance questionnaire	<p>In some hospitals, a questionnaire is sent to donors' next of kin one year after the donation → objective of quality assurance</p> <p>The next of kin are asked about their experience of the process, whether they were given comprehensible information (e.g. regarding brain death), how they felt about the care they received, and how it might be improved.</p> <p>It is recommended that a quality assurance questionnaire of this kind be used in all hospitals / transplantation centres</p>
Post-donation meeting	<p>Optional / if required:</p> <ul style="list-style-type: none"> – Organization of a meeting of the treatment team, coordination team and next of kin
Swisstransplant	<ul style="list-style-type: none"> – Next of kin who contact Swisstransplant directly (questions, feedback, concerns etc.) will be looked after

7.2 Thank-you letters – process

Thank-you letters are the only way for an organ recipient to expressly show their gratitude to the donor's next of kin for the organ they received. For the donor's next of kin, in turn, such letters usually represent a positive aspect – a sign that the donation was meaningful.

To give the professionals entrusted with this task more assurance in the thank-you letter process, a procedure has been jointly defined. This is to ensure that certain standards can be maintained and adverse situations avoided.

→ The topic of thank-you letters is presented and described in detail in the "Leitfaden Angehörigenbetreuung und Kommunikation" (only available in German).

8.0

Communication with next of kin

8.1 State of emergency – next of kin in the face of a life-threatening situation

An emergency occurs: a misfortune takes place in the form of an unforeseen, sudden event that acutely endangers the functioning of a person (and of the social system). As a result of the threat, excessive demands are placed on human comprehension, mental processing and behaviour. A state of emergency occurs; normality is suspended.

The situation of being threatened by the possible loss of a person has a different impact on each individual's cognitive abilities. A state of emergency, which is triggered by intense stress and emotional strain, results in a range of symptoms.

What impact do psychological factors have on taking care of next of kin and communication?

It is not possible to avoid the impact of psychological factors. They often cannot simply be "switched off" to reduce the emotional burden on next of kin. However, for some factors, there are approaches that can contribute to reducing the negative impact at least partially.

Recommendations for how to conduct discussions, taking psychological factors into account

Take the following advice into consideration when taking care of and communicating with next of kin:

State of emergency	<ul style="list-style-type: none"> – Apply the principles of communication – Avoid noise, agitation, impatience and long technical explanations – Speak calmly and get to the point quickly – Bring up the prospect of further support during the reflection and waiting phases (e.g. care team, professionals with psychological training)
Fear of making a mistake	<ul style="list-style-type: none"> – If next of kin have many objections or when they hesitate, wrestle with arguments etc.: ask if there are worries about making the "wrong" decision – Ask what could help them avoid the fear of making the "wrong" decision – Offer further support for the decision-making phase (professionals with psychological training)
Dealing with doubts	<ul style="list-style-type: none"> – When next of kin express doubts or these are implied: ask if there are any doubts, and if so, what they are – Ask what could help them dispel or defuse these doubts – Offer further support for dealing with existing doubts (professionals with psychological training)
Cognitive dissonance	<ul style="list-style-type: none"> – The term "brain death" can cause cognitive dissonance because the visual signs of death are missing – It is better to speak of "irreversibly failed brain functions" that inevitably lead to death (after withdrawing treatment or switching off the machines)
Loss aversion	<ul style="list-style-type: none"> – If you sense that the next of kin are experiencing fear and anxiety, offer further support for the process (professionals with psychological training)
Time factor	<ul style="list-style-type: none"> – Avoid time pressure – Specify the medically indicated time frame for the next steps – Offer further support for the decision-making phase (professionals with psychological training)
Timing	<ul style="list-style-type: none"> – Avoid having discussions in the late evening or at night, if possible – If it is necessary to have a discussion at night: limit communication to information and have discussions about decisions only later during normal daytime hours
Divergent opinions among next of kin	<ul style="list-style-type: none"> – If you perceive tensions or disagreements / conflicts among the next of kin, ask whether you can help clarify anything – Offer further support (professionals with psychological training)

Perception of the doctor's role

- Consciously adopt a neutral position: you have the task of asking about the presumed wishes of the patient
- Accept the decision that is made in all cases
- Avoid statements such as
 "But we have to accept the wishes of the deceased."
 → tends to create internal resistance
 "Was he a generous man ...?" (or similar)
 → tends to create resistance/generosity in life does not necessarily mean willingness to donate organs
- Involve the nursing staff actively in the discussions. Nursing staff often have a closer relationship with next of kin than the doctor and are perceived more neutrally

8.2 How to conduct a discussion using the SPIKES model

The letters in "SPIKES" stand for the phases and principles of a discussion. The acronym suggests a certain sequence. However, if you take a look at the terms, you will find that there is a fixed place only for the two S's. The other phases/principles can flow seamlessly into each other, run partly in parallel or repeat themselves.

Setting	Prepare well Organize the premises, prevent disturbances, if necessary involve other persons.
Perception	Assess the perception of your interlocutor Clarify / assess your interlocutor's existing knowledge about their situation (and their feelings about it). Ask first, then explain. Clarify any incomplete or incorrect information.
Invitation	Obtain an invitation from your interlocutor Information is good, but too much can be overwhelming. Not all patients / next of kin wish to be fully informed. Respect the wishes of interlocutors who (presently?) do not want to have any more information. What do the next of kin need now (distance, appreciation, time, to be recognized and supported as human beings etc.)?
Knowledge	Provide information Communicate facts using language that your interlocutor understands. Present the possibilities. Also provide information on the further steps (diagnosis, treatment, prognosis, support options).

Empathy	Show empathy Recognize emotions and respond adequately to them. Show empathy, not pity. Identify and respond to psychological needs. Support the next of kin as human beings.
Summary	Provide a summary End the conversation by summing up what was discussed in language comprehensible to the patient/next of kin. Identify and plan the next steps.

Source: e.g. Baile, Walter F. et al. (2000): SPIKES – A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist* 5(4): 302 – 311. DOI: 10.1634/theoncologist.5-4-302

Discussions about organ donation and SPIKES

a) The patient becomes a potential donor

If it becomes apparent or is determined that the prognosis is hopeless and curative medical treatment is no longer appropriate, the next of kin must be informed quickly. This means notifying them of the situation and the withdrawal of treatment measures. In this discussion, it is usually not (yet) mentioned that the treatment will be changed to palliative treatment or measures to preserve organs. Organ donation is only discussed if the next of kin themselves ask questions about the topic at this stage.

b) Timing of the discussion about organ donation

When is the right time to discuss organ donation with the next of kin? The current SAMS guidelines (2017) no longer clearly indicate when the question of organ donation should / may be posed.

If there is no reason to raise the issue earlier, the discussion about potential organ donation should generally be held only after a diagnosis of brain death and after the next of kin have been notified of this. However, this sequence is not always feasible. More importantly, it is not always appropriate and may even be detrimental under certain circumstances. The discussion about organ donation may be held earlier if this is deemed necessary for medical or ethical reasons. The transplantation centres follow their own internal procedures here, to some extent.

Allow the next of kin to see the patient before this discussion. Give the next of kin time to grasp the announcement of death in the first place before confronting them with the question of the deceased patient's presumed wishes regarding organ donation.

c) Discussion planning

The sequence and structure of a discussion should convey clarity, trust and credibility, so the planning of discussions is extremely important.

1. Work as a pair (recommendation)

Always plan discussions to be conducted by two people: a doctor and a member of the nursing staff. The attention of the speaker is focused on the conversation and on their own emotions. The second person can better observe and respond to signals.

2. Role allocation

Where necessary and appropriate, clarify the allocation of roles in advance. The nursing professional can, e.g., invite the next of kin to come in, make a transition, pick up the thread of previous discussions etc.

3. Documents

Have documents ready (visualization board, cranial diagram etc.). Use these aids as much as necessary and as little as possible.

4. Content of the discussion

Prepare the content so that no important information is left out. The doctor who raises the question of organ donation must inform the next of kin about all of the steps involved. This includes information on measures to preserve organs and their importance for transplantation. Notification of brain death and information on the next steps for potential organ donation should be given by the same doctor, in the presence of the nursing professional who has been taking care of the patient. The responsible organ procurement coordinator can already be involved in this discussion (see next section).

d) Involvement of the organ procurement coordinator

Inform the next of kin that a coordinator for organ procurement and transplantation will be called in and will be available to answer any questions regarding procurement and transplantation.

e) The question of presumed wishes

- If the prognosis is infaust and withdrawal of treatment is medically indicated or if the patient qualifies as a potential organ donor, check the National Organ Donor Register via Swisstransplant National Transplant Coordination (see Annex).
- Make sure that the next of kin clearly acknowledge the patient's death (can grasp it in all its dimensions) or the hopelessness of the situation / prognosis (e.g. DCD).
- Inform the next of kin of the imminent course of action: It is necessary to withdraw treatment. Before this step is taken, the presumed wishes of the patient regarding potential organ donation must be discussed.
- Answer all questions posed by the next of kin.

f) Specify the time frame

If the next of kin are unsure about making a decision (or if the wishes of the patient are not known), give them a specific time frame for the decision-making phase. This time frame will depend on the medical situation and the capabilities of the hospital, which is why it must be agreed individually in each case. Let the next of kin know that a medical professional is always available to answer any additional questions.

g) The decision has been taken

The decision of the next of kin must be respected in all cases. In case of conflict between the wishes of the patient and the decision of the next of kin, the known wishes of the patient prevail in principle. Whether or not to act against the decision of the next of kin (patient wants to donate – next of kin refuse to donate) is at the discretion of the team providing care. From a psychological point of view, it is not advisable to act against the decision of the next of kin (even knowing that the wishes of the patient will be disregarded).

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Version 1.0

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Annex 1

Check of the National Organ Donor Register / discussion with next of kin

Check of the National Organ Donor Register

When?	<ul style="list-style-type: none"> – If the prognosis is infaust, it has been decided to withdraw treatment, the patient is intubated and there are no contraindications – If brain death is suspected, or has occurred, and has been diagnosed – If the next of kin themselves raise the issue of organ donation at an earlier stage – At the latest when the discussion concerning the patient's presumed wishes is scheduled – Important: Determination of death must be planned within a maximum of the next 48 hours! Each check is recorded and an e-mail to the patient is generated
Who?	<ul style="list-style-type: none"> – In general, the persons authorized to do so, e.g.: – The doctor providing treatment, or a person delegated by this doctor (nursing professional, local organ procurement coordinator), organ procurement coordinator etc. – Knowledge of the register and the check must be made known to all medical professionals involved in the donor recognition process. The network heads are responsible for providing information
Where?	<ul style="list-style-type: none"> – Check by telephone with Swisstransplant National Transplant Coordination – Telephone number: +41 58 123 80 40 (available 24 / 7)
How?	<ul style="list-style-type: none"> – Authorized person performs check by telephone with Swisstransplant National Transplant Coordination – If an entry exists: a password-protected PDF with the patient's decision is generated and sent to the person responsible in the hospital (notification of password by telephone) – The check is also saved if there is no entry (statistics) – When a check occurs, an e-mail is automatically sent to the address of the registered person → take this into consideration when notifying next of kin

Communication about the entry in discussion with next of kin

Situation 1

No entry in the register:

- In this case, proceed in accordance with the recommendations for → Discussion about the patient's presumed wishes

Situation 2A

Entry exists in the register – the patient / deceased person **wishes to donate**:

- Inform the next of kin that you have carried out a register check in view of the situation (following on from the previous discussion, e.g. withdrawal of treatment, brain death diagnosis, notification of brain death).
- Inform the next of kin that an e-mail was automatically sent to the registered person when the register was checked.
- Tell the next of kin that it is important that they are informed about the entry, and that you are available to answer any questions.
- If necessary, agree to a reflection period, even if the next of kin support the donation.
- If the next of kin confirm the donation in accordance with the wishes of the patient, answer their further questions about the steps to be taken. If you have not already done so, get the organ procurement coordinator involved.
- If you notice, or if the next of kin explicitly state, that they have difficulty with the decision of the patient:
 - Tell the next of kin that they may take some time as a family to clarify the situation.
 - Meanwhile, assure them that you are available at all times to answer any questions or hold another discussion.
 - Schedule an appointment for another discussion. Remind them that, in any case, treatment will need to be withdrawn and there will be the matter of saying goodbye to the deceased person (laying-out, ritual etc.).
 - In case of an implicit or explicit conflict, offer support from neutral persons (care team, professional with psychological training etc.).
 - If the conflict persists or if there is a refusal to implement the wishes of the patient: from a psychological point of view, it is not advisable to act against the decision of the next of kin (even knowing that the wishes of the patient will be disregarded).
 - Do not blame the next of kin if they are unable to consent to the donation. Your only role is to discuss the question of the presumed wishes of the patient. The next of kin will also have to live with the fact that they did not respect the wishes of the patient / deceased person.
 - If the removal of organs is refused: present the procedure for withdrawing treatment and the further steps.
- Finally, make it clear once again that you respect the outcome of the situation in any case, and thank the next of kin.
- Assure the next of kin that they may contact the treatment team at any time after the end of care if any questions arise or if there is a need for clarification.

Situation 2B

Entry exists in the register – the patient / deceased person **does not wish to donate**:

- Recommendation: Also raise the issue of organ donation with the next of kin in this case. Say that, for reasons of transparency, you are informing the next of kin that an entry exists, but that the patient had ticked "No".
- Inform the next of kin that an e-mail was automatically sent to the registered person when the register was checked.
- Make sure that the next of kin receive an answer to all questions regarding the register entry, the patient's wishes or organ donation in general.
- Allow the next of kin to express themselves if they feel the need to do so despite a refusal to donate.

Important:

Sensitive or inappropriate comments in the register entry

A person who makes an entry in the register has the option of uploading pictures and storing personal text content. Look at the pictures and read the texts carefully. Is there any indication that the entry could be compromising or difficult for the next of kin? How do you handle this in your discussion with the next of kin?

- If you are unsure whether this content might be sensitive or difficult for the next of kin, consult the Swisstransplant National Transplant Coordination service and get a second opinion about this (possibly also through psychological professionals).
 - If you and / or the Swisstransplant National Transplant Coordination service come to the conclusion that the entries are too sensitive, inappropriate or difficult for the next of kin to bear, consult a professional with psychological training, via Swisstransplant, who can give advice on how to conduct the discussion or, if necessary, can attend the discussion.
 - If you judge the entry to be sensitive or inappropriate and wish to clarify this yourself in the discussion, proceed as follows:
 - Inform the next of kin that there is a personal text (special pictures) in the register entry that might be confusing or might cause unexpected reactions or emotions.
 - If appropriate, say that you have read the comment, but do not judge it in any way.
 - Let the next of kin know that they can talk to you about this comment in confidence.
 - If the entry causes confusion or unpleasant feelings, offer the next of kin a confidential discussion with a professional who has psychological training.
-

Annex 2

Dealing with next of kin who are children

Children are part of the social system of a family. Adults, and especially parents, want to protect their children from bad experiences and traumas. This is true in particular when a death occurs in the family or in the immediate social milieu. This mindset is understandable, but it also carries certain risks that are significant for children and their grieving process.

For medical professionals providing care, it is helpful to be aware of the following aspects concerning children:

- Death means different things for children of different ages, or they have a different image of death depending on their age. For children to fully understand death, they must be able to understand the factors of irreversibility, universality and unpredictability on a cognitive level. This ability depends on the age and cognitive development of a child.
- Regardless of whether children already understand all three factors, some recommendations for dealing with children in these situations should be considered, even if they go against the natural impulse of wanting to protect/spare children.
- Principle: Respond to children's questions and adhere to the criteria truth, clarity and structuring. Children generally cope better with the truth than with silence or lies.
- Children are part of the social system of a family. Excluding them in situations that involve death also means that they feel excluded on a personal level. Conversely, integrating them in the care provided and in the relevant discussions means that they feel a sense of belonging and that you, as a medical professional, have the opportunity to convey information in a way that is suitable for children, thus also supporting the parents.

Interacting with children

Dos

- Let the parents decide whether children should be present during the discussion
 - If the parents are unsure: recommend keeping the children with them
 - If children are sent out, make sure that someone is with them outside (chaplain, care team). If desired, help parents in a subsequent discussion with the children
 - Possibly communicate the information to the children again using simpler language
 - This has the advantage that the parents can "listen in" once more
 - Always be honest with children
 - Let yourself be guided by children's questions
 - Only answer the questions that children themselves pose
 - Answer honestly and immediately, and repeat yourself
 - Address the emotions of children
 - Offer reassurance and hope
 - Admit that you do not know everything, either
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Don'ts

- Try to spare children the news of death
 - Force children to be present
 - Send children out against their will
 - Lie to children
 - Treat children as if they are invisible if they are present at the discussion
 - Deny children access to the deceased person (saying goodbye)
-

Annex 3

General checklist for the discussion process

1. Your own preparation

Facts	<ul style="list-style-type: none"> – Medical facts – Course of treatment – Information already communicated (brain death diagnosis etc.) – Important information from/about the next of kin
Planning	<ul style="list-style-type: none"> – Timing, date and time frame – Setting and room
Participants	<ul style="list-style-type: none"> – Doctor leading the discussion – Nursing professional – Organ procurement coordinator? – Inform the chaplain / care team in advance? – Other parties involved – Clarify roles among yourselves

2. Communication comparison

- Do the medical professionals present all have the same information (congruence, consistency of information)?
- What preliminary information do the next of kin have? From whom? Are there any accompanying written materials?
- Has anything unusual been noticed about the next of kin (emotions, behaviour, conflicts etc.)?
- Are there any unanswered questions from previous discussions?
- Has the issue of organ donation already been addressed in any way? In what context? By whom? How was it handled?

3. The discussion

a) General information

- Follow the recommendations on how to conduct a discussion and use of language, and address needs and disturbances
- If necessary or appropriate, read through these recommendations once again before the discussion

b) Objective and importance of the discussion

- State of affairs, compare the information that the participants have
- Provision of information: infaust prognosis, withdrawal of treatment, brain death diagnosis, notification of brain death, question of presumed wishes etc.
- Clarify any open questions
- Further steps / discuss further procedure

c) Support in decision-making phase (presumed wishes)

- Are the patient's presumed wishes known?
- Do the next of kin prefer to make the decision among themselves? Is support from the team desired?
- Support from other people is advisable (care team, professional with psychological training)

d) Conclusion

- Have all questions been answered and uncertainties been cleared up?
- Is follow-up care arranged?
- Gratitude expressed, contact details provided?

Annex 4

Principles of communication: metalevel

The metalevel, i.e. the overarching perspective – also known as the “helicopter perspective” – is part of the fundamentals of communication skills today. However, awareness of this principle does not necessarily mean that it is applied. A good communicator is able to use the metalevel in a targeted manner **to obtain important information during a discussion about the discussion itself as well as about the participants.**

The following table gives a brief overview of the differences in communication when the metalevel is applied and when it is neglected.

Level:	Principle applied:	Principle not applied:
Metalevel	<ul style="list-style-type: none"> – Observation of yourself and others during the discussion – Observation of the entire interaction – Recognition of actions and reactions among the interlocutors – Adjustment of your own behaviour if the effect is not appropriate (in relation to the objective of the discussion) – Ability to steer and influence the discussion based on observations 	<ul style="list-style-type: none"> – Action / reaction in discussion directly in response to what is said instead of analysing – No chance to perceive important information from the interaction and to adapt your own behaviour – The same patterns are used repeatedly, even though they do not lead anywhere (e.g. discussion goes around in circles, escalates, gets out of hand etc.)
1st position: I	<ul style="list-style-type: none"> – Awareness of your own actions, language and effect on others – Awareness of your non-verbal effect on others – Adjustment of behaviour to meet the needs of others or to support the objective of the discussion 	<ul style="list-style-type: none"> – Preoccupation with yourself – Failure to pay enough attention to your non-verbal language – Failure to recognize, or sufficiently recognize, your effect on others – Pursuit of your own idea of communication instead of adapting to others

2nd position: You	<ul style="list-style-type: none"> – Ability to put yourself in the other person's position – Ability to be empathetic (only possible if you adopt the perspective of the other person) – Recognition of needs and response to them – Recognition and handling of disturbances 	<ul style="list-style-type: none"> – Failure to put yourself in the other person's position, or to do so sufficiently – Risk of being perceived by next of kin as dry and distant rather than empathetic – Failure to recognize and respond to the needs of next of kin, or to do so sufficiently – Failure to recognize and handle disturbances during the discussion, or to do so sufficiently
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Annex 5

Principles of communication: needs

People whose world is shaken by a potentially traumatic event, who suddenly question everything, or many things, and who can no longer think or act as usual generally find themselves in a state of uncertainty that they perceive as threatening. Most persons going through this experience will exhibit psychological needs that should be addressed as a priority in care and communication.

These high-priority needs include the following, in particular:

- Security
- Clarity
- Trust
- Competence
- Understanding
- Appreciation
- Respect

Examples for dealing with needs

Possible need	Good communication	Poor communication
Clarity, security, understanding Repeated questions (although the information was clear), questions about "meaning", "how can it be" etc.	Next of kin: "What does that mean now?" "What is the meaning of that?" "But how is it possible that ...?" or similar phrases Respond to such comments as follows: "It seems that I have not (yet) answered your question. What do you mean by ...?" Pause instead of continuing to provide technical information. Ask what the question/input of the next of kin is aiming at.	<ul style="list-style-type: none"> – Medical professional speaks too much, for too long (→ this is very common) – Constantly supplying further medical facts – Repeatedly responding to questions with medical facts – Growing impatient – Becoming unsettled – Using phrases such as: "As I said before ..." or similar

Trust	<ul style="list-style-type: none"> – Show understanding – Perceive and acknowledge people's distress (= validation) – Leave space – Bear with emotions – Admit errors – All medical professionals involved say the same thing – Clear, simple language – Show yourself to be a human being 	<ul style="list-style-type: none"> – Distant behaviour – Professionalism at any price – A lot of technical jargon (because you feel comfortable with it) – Ignoring needs, not responding to them – Not admitting errors – Beating about the bush – Uncertain manner of communicating – Helplessness in the face of the situation – Different information given by different medical professionals
Competence	<ul style="list-style-type: none"> – Resolve contradictions in medical information calmly without blaming others – Provide simple, comprehensible reasons for decisions and actions – Show awareness of the competence of next of kin (seek their perspective, show understanding for their views and ideas, take their desire for knowledge seriously and respond to it) – Activate resources: "You can help us with ..." 	<ul style="list-style-type: none"> – The following will have a negative impact on the perceived competence of medical professionals: – Not admitting errors – Different information given by different medical professionals – Evasive answers to questions from next of kin – Uncertainties or contradictions in medical information – Responding with irritation to behaviour or questions from next of kin – Making next of kin feel that they are in a "lower" position, that the medical professionals "know everything"
Appreciation	<p>Validate the statements and actions of next of kin:</p> <p>"It's important to you that ..."</p> <p>"You doubt our judgement and you would like to ..."</p>	<p>Ignoring / not perceiving / not validating the statements and actions of next of kin</p> <p>Responding to statements by next of kin with "but":</p> <p>"We understand, but ..."</p> <p>Better:</p> <p>"We understand, and ..."</p>

Respect	<ul style="list-style-type: none"> – Take statements, dissent and objections of next of kin seriously – Take psychological distress seriously – Take fears and other emotions seriously, allow for them, bear with them – Respect wishes, behaviour, needs 	<ul style="list-style-type: none"> – Ignoring objections or dissent – Know-it-all or arrogant effect – Not responding adequately to the psychological distress of next of kin
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Annex 6

Principles of communication: dealing with disturbances

How to deal with disturbances

An important principle in communication is: **Disturbances must be dealt with first.** This means that any (internal) disturbances that occur in relation to a discussion must always be taken seriously and addressed.

Possible internal disturbances include:

- Objection by the next of kin
- A repeated or emphatic "But ..." in the discussion
- Internal retreat / absence
- An objection is repeated several times
- Sudden emotional changes (e.g. sudden anger, aggression, speechlessness)
- Next of kin feel they are
 - not taken seriously
 - misunderstood
 - belittled (treated condescendingly) or treated arrogantly
 - ignored (when it comes to decisions, information)
 - pushed, pressured
 - manipulated ("Your son was certainly a generous person ...")
 - not properly / not fully informed
- Needs are not perceived or responded to / needs are ignored (see previous chapter)

But also:

- (Unspoken) conflicts among the next of kin
- Fears, shame etc.
- Denial (regarding diagnosis, news etc.)

Basic handling of internal disturbances

- Always respond to disturbances as quickly as possible
- Ask if there is something you did not understand or something you missed
- Identify the disturbance itself, for example: "I sense that your thoughts are wandering ...", "You suddenly seem a little irritated (or aggressive). Did I say or do anything to cause this response in you?"

Further examples

Possible triggers for disturbances	Possible ways of dealing with disturbances Goal: connect, take seriously, validate
Objection by the next of kin	"You disagree with me. Can you explain your position to me (again)?"
A repeated or emphatic "But ..." in the discussion	"When you say the word 'but', does that mean you disagree with ..." or "What do you mean when you say 'but'?"
Internal retreat / absence	"I can see that you're deep in your thoughts. May I ask what's on your mind?" or "You seem to be thinking. Do you have any questions, or do you need a moment for yourself?"
An objection is repeated several times	"I apologize for not responding until now. You have raised an objection to which I have not yet replied."
Sudden emotional changes (e.g. sudden anger, aggression, speechlessness)	"Excuse me, did I say something that triggered that reaction?" or "... that you dislike?" or "Did I trigger your xx (name reaction)? What led to that?", or similar
Next of kin feel they are <ul style="list-style-type: none"> – not taken seriously – misunderstood – belittled (treated condescendingly) or treated arrogantly – ignored (when it comes to decisions, information) – pushed, pressured – manipulated ("Your son was certainly a generous person ...") – not properly / not fully informed 	Mention what you specifically perceive: "Could it be ...?" "Have I possibly overlooked ...?" "I notice that ..." "It seems to me that you ..." (name state, formulate hypothesis) Ask for clarification as to what led to the disturbing feeling, and also ask what expectations, if any, the next of kin have with regard to the point discussed. Please also offer an apology (not for doing something wrong, but for failing to notice something).
Needs are not perceived or responded to / needs are ignored	"I sense that there is something in the air right now. Is there anything I didn't understand or didn't hear?" or "Is there anything (else) that is important to you or that hasn't been addressed?"
(Unspoken) conflicts among the next of kin	"I'm not sure. Are there perhaps some tensions among you? Can we help clarify anything?" or "Do you need time (or support) to clarify these points among yourselves?"

Fears, shame etc.	"I perceive xx (a change, tension, withdrawal). Is there anything troubling you (making you upset/uncomfortable etc.)?"
Denial (regarding diagnosis, news etc.)	Verify whether the next of kin (or the patient) cannot or will not accept the news. Not being able to do this is a sign of being overwhelmed. Treat unwillingness as a disturbance: "What can I do or what would help you accept this?", or similar

Failure to deal with internal disturbances

It is important to note that failure to deal with disturbances can have serious and undesirable consequences:

- Loss of trust
- Denial
- Incomprehension (mutual)
- Misunderstandings/ conflicts
- It might even influence upcoming decisions

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