

Information on Organ and Tissue Donation for the Palliative Care Clinician Prepared by the Comprehensive Tissue Centre (CTC)

Why is it Important to Discuss Patient and Family Wishes Regarding Organ and Tissue Donation?

Discussing organ and tissue donation allows patients and families to communicate their wishes with each other and their health care providers so that at the end of life, appropriate action can be taken in keeping with the patient's goals of care. The accompanying patient brochure is designed to provide patients and families with basic information about organ and tissue donation should they be interested.

If patients and families express an interest, medical professionals are to refer to the Comprehensive Tissue Centre (CTC) in Edmonton. The CTC is responsible for follow-up.

Approaching Patients and Families- How Do I Initiate a Conversation about Organ and Tissue Donation?

A conversation about organ and tissue donation can be included as part of any end of life care discussion with the family or patient. Here are some sample phrases you could use in your conversation:

"On the back of your Alberta Personal Health Card is the Universal Donor Card. Have you [patient] and your family discussed organ and tissue donation?"

"Here is a brochure with information about organ and tissue donation. If you would like more information, I can arrange for a Tissue Specialist to contact you. Would you like me to do that?"

"Do you have any questions that I or the Tissue Specialist can help answer?"

Frequently Asked Questions:

Q. If the patient has cancer or other terminal illness, what **tissues** may be donated?

A. Eyes (ages 2-80, for sight restoring surgeries), Skin (ages 15-80, to help burn victims), Heart for valves (birth to 60 years, for life saving valve transplants) and Bone and Tendons (ages 16-70, for joint mobility restoration and bone repair) These tissues may be considered and screening is required for each potential donor. All potential organ and tissue donors are assessed on a case by case basis and every effort is made to consider the possibility of donation.

Q. If the patient has cancer or other terminal illness, what **organs** may be donated?

A. Organ donation may also be possible when a terminally ill person is being cared for in an intensive care unit. Organs for transplant include heart, lung, liver, kidneys, pancreas and small bowel. Possible eligibility to donate organs is determined in the critical care setting.

Q. Are there certain illnesses or diagnoses that would automatically preclude or rule out organ and tissue donation?

A. Every effort is made to ensure that tissues used for transplant are screened to prevent the spread of illness to a potential recipient. Common reasons why people may not be able to donate tissues include, but are not limited to, advanced age of 81 years and older, HIV/AIDS, Hepatitis, MS, ALS, leukemia, and lymphoma. Other criteria exist, and you are encouraged to contact CTC for specific information pertaining to these criteria.

Q. How will the deceased patient be treated if tissue donation proceeds?

A. The deceased patient will be treated with the utmost of respect and dignity. Recovery is done in the OR by carefully trained medical staff and the patient receives the same surgical respect

that all patients are given. Eye donation can sometimes occur in a morgue or on a hospital unit. The donor is reconstructed post-recovery so that there is minimal disfigurement, a very thin amount skin is procured from non-visible areas including the back, abdomen, and legs- this may resemble a strong sunburn after recovery, heart is procured and the chest incision closed. Bone and tendons are removed from the leg, a dowel prosthetic and gauze reshapes the leg and the incisions are carefully closed. The donor is cleaned after recovery and prepared for the Funeral Home.

Q. Can the family have an open casket funeral after donation?

A. Yes. There should be no visible signs that organ and tissue donation has occurred should the family choose an open casket funeral. Every effort is made to ensure the appearance is not visibly altered by tissue donation for normal viewing purposes.

Q. Will donation delay funeral arrangements?

A. No, donation should not interfere with any funeral arrangements that are made and CTC staff will work closely with the family to ensure that any special arrangements are considered and facilitated should donation proceed. MEO involvement in any death may extend timelines.

Q. Is there a cost or fee charged for organ and tissue donation?

A. No, there are no fees or costs charged to the family for organ or tissue donation.

Q. The patient/family wishes to donate the body for medical education. What information do I provide?

A. When individuals choose to donate their bodies for medical education, it is often planned in advance of death. For more information on anatomical gift donation please contact the University of Alberta Anatomical Gifts Program at 780-492-2203. Eye donation may still be possible if anatomical gift donation is intended.

Q. If the patient is not able to participate in the conversation, who has the legal right to decide on behalf of the patient?

A. In the event that a patient is no longer able to participate in the donation conversation, decisions regarding donation can be discussed with the agent for personal directive or next of kin.

Deferral Criteria and Timeline Requirements:

Common reasons for deferral (or exclusion) include:

- Patient age is greater than 80 years (age 81 is a deferral)
- HIV/AIDS, hepatitis, multiple sclerosis, ALS, current sepsis
- Leukemia/Lymphoma. Note: other cancers may still be considered
- History of hard drug use (ex: cocaine or heroin, marijuana not included) in last 5 years

Timelines:

- The CTC has up to 24 hours from time of cardiac death to begin full tissue recovery
- Optimally, eye recovery should occur within 6-8 hours, but can occur up to 15 hours.
- The CTC also works closely with the Medical Examiner's Office (MEO) office should the MEO become involved in the death.

Contact Information:

If you have approached a family or patient about tissue donation and they require answers or want to proceed, **page the CTC Specialist-on-call 24 hours a day, 7 days a week via University of Alberta Hospital (UAH) locating at 780-407-8822 or by calling 1-866-407-1970.** The CTC will respond and answer any related questions, complete all screening, obtain consent, and follow up with the family and/or patient. Ensure a current contact number is available for responding to the family and/or patient inquiry.

Have You Considered Organ and Tissue Donation?

Organ and tissue donation may be an option when considering end-of-life care wishes for yourself or someone you love.

Organ and tissue donation involves the recovery of organs and tissues from someone who has passed away. It is an option available to individuals and families who may wish to consider sharing the gift of life with others as part of end-of-life care. Donor families neither pay for, nor receive financial gain for the act of organ and tissue donation.

There is a critical shortage of organs and tissues available for people requiring transplants. Organs and tissues are used for life-saving and life-enhancing transplant procedures which can improve the quality of life for many people.

The gifts of one organ and tissue donor can dramatically improve the lives of more than 80 people.

Can an individual with terminal illness, advanced disease, or cancer donate?

Yes. Individuals 80 years of age or younger with a terminal illness, advanced disease or certain cancers may be eligible for eye and tissue donation. Organ donation may also be possible when a terminally ill person is being cared for in an intensive care unit. All potential organ and tissue donors are assessed on a case by case basis. Please speak to your healthcare provider or call 1-866-407-1970 if you wish to learn more.

A Tissue Specialist from the Comprehensive Tissue Centre is also available 24/7 to speak with you and answer any questions you may have.

Tissues which can be donated include:

- **Eyes-** for sight-restoring surgeries
- **Skin-** to help burn patients
- **Bone and Tendons-** to aid bone repair or restore joint mobility
- **Heart for Valves-** for life-saving heart repair procedures

Is an open-casket funeral possible after organ and tissue donation?

Yes. Open casket funerals are possible after organ and tissue donation. All efforts are made to ensure that there are no visible signs that donation has occurred. Donation should not interfere with any funeral arrangements that are made.

What should I do if I'm interested or need more information?

It is important to discuss your wishes about donation with your family. This will help ensure that any final requests are honored. The information on this leaflet has been provided to answer questions and to help you make an informed decision regarding donation.

For more information about organ and tissue donation, please speak with your healthcare provider or call the Alberta Health Services Organ and Tissue Donation Referral Centre toll-free at 1-866-407-1970 (Edmonton and Northern Alberta).

Regional Palliative Care Program
'Improving the Quality of Living and Dying'