

Aftercare

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ISSUE DATE: December 12, 2006

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APPROVED BY: Family Services

Authority

Clinical Process Instruction Manual

Written Communications Process Instruction

Policy:

Trillium Gift of Life Network (TGLN) is committed to providing donor families with consistent written communication.

The Organ and Tissue Donation Coordinator (OTDC) involved in the donation facilitates communication to donor families. For cases in which a call-team member provides donor family support, the OTDC obtains the necessary information from the on-call member to write the sympathy card.

The template used for written communication will not include any potentially contentious demographic information such as the race or religion of the donor, or any surgical information, with respect to outcome of transplantation.

Process:

Data Availability in iTransplant

- 1. After a donation case is complete and organs transplanted, the Clinical Services Coordinator (CSC) inputs the following recipient data into iTransplant:
 - organ(s) received
 - age
 - sex
- 2. The Information Coordinator (IC) Organ validates completed donor information in iTransplant against completed donor information in TOTAL.
- 3. The IC Organ ensures the "Family services follow-up" field in iTransplant is marked as "Yes" for all organ transplant cases with an outcome of "Donor". This pushes the next-of-kin (NOK) information into the Family Services Module of iTransplant.

Sympathy Card

4. The OTDC or designate completes the sympathy card and sends it to the family, where appropriate.



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Outcome and Family Services Introduction or Organ Regret Letter

- 5. The Family Services Staff (FSS) logs into iTransplant at least once per week to generate Outcome and Family Services Introduction letter(s) (see Exhibit 1) or Organ Regret letter(s) (see Exhibit 2).
- 6. The FSS reviews the NOK's information in iTransplant for the following:
 - contact preference;
 - alerts;
 - NOK's address.

Note: NOK's address can also be found on the consent form in the "Attachments" section of the donor record on iTransplant. In cases where there are more than one NOK, FSS reviews each NOK's information and mails the aftercare program letters to all NOKs unless otherwise specified.

- 7. FSS reviews the NOK's contact preference and checks if NOK has indicated a "do not contact" and/or "no mail" preference. If NOK does not wish to be contacted, FSS does not send the letter.
- 8. Once donor's and NOK(s) information is reviewed, FSS generates the letter(s).
- 9. FSS reviews each letter for accuracy and grammar errors, and adjusts it as necessary.
- 10. FSS prints the aftercare program letter(s) and saves the electronic copy(ies) in the common drive.
- 11. Once the letter(s) is(are) printed and saved on the common drive, FSS changes the individual donor milestones status from "pending" to "completed". After the status is changed, the donor is removed from the list and only "pending" donors are available for review.
- 12. FSS mails the aftercare program letters to donor families.
- 13. If a donor family contacts the FSS wishing not to participate in the aftercare program, or to provide a change of address and/or telephone number, FSS updates the "contact preference" and/or "alerts" or address fields in the donor NOK information in iTransplant.



Donor and Family SECTION:

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Records:

No Records

References:

- Sympathy Card Process and Statement (Common Drive)
 Templates for letters (Common Drive)



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Exhibit 1: Organ Outcome and Family Services Intro Letter - Template

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«GenerationDateFormal»

«NOK Salutation» «NOK First Name» «NOK Last Name» «NOK Address 1» «NOK City» «NOK State Province Territory» «NOK Postal Code»

Dear «NOK Salutation» «NOK Last Name»,

On behalf of Trillium Gift of Life Network, please accept our deepest sympathy for the loss of your «DonorToNOKRelationship», «Donor First Name». We thank you for allowing «Donor First Name» to be an organ (tissue) donor.

Thanks to this generous gift, NUMBER person/people with (a) terminal medical condition(s)

Select one: A boy/girl (Oyrs -15yrs), A young adult male/female (16yrs - 35yrs), an adult male/female (35 and older) with extensive liver damage received a liver transplant.

Select one: A boy/gri (Oyrs -1Syrs), A young adult male/female (16yrs - 3Syrs), an adult male/female (35 and older), both with end stage renal disease received kidney transplants. These fortunate recipients are now free from the many restrictions of their disease and the rigors of dialysis. An adult male/female received «Donor First Name»'s pancreas and is now living his life without the difficulties of diabetes. Or (An adult male/female with diabetes received a pancreas transplant this ends al lifetime of required insulin injections.)

Select one: A boy/girl (0yrs -15yrs), A young adult male/female (16yrs - 35yrs), an adult male/female (35 and older) with irreversible heart disease received a life saving heart transplant, providing him/her a second chance at life.

Select one: A boy/girl (Dyrs -15yrs), A young adult male/female (16yrs - 35yrs), an adult male/female (35 and older) with terminal lung disease received a lung transplant. «Donor First Name»'s lungs now breathe the gift of life into this grateful recipient. These individuals were given the opportunity for a longer and better quality of life as the result of your decision.

As a result of your compassionate decision, your «DonorToNOKRelationship»'s eyes were recovered with hope of restoring the sight of blind patients.

«Donor First Name»'s vessel/bones/skin/pancreas islets will benefit the lives of recipients through future tissue transplantations. This will be the beginning of a new life for these

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recipients - a life free from the previous restrictions of their illnesses and injuries. This would not have been possible without your thoughtful consideration. In addition, your consent to the donation of your "aDonor Ton Klefkationship" of pancreas for islets will benefit the lives of recipients through future tissue transplantations.

Donors and their families are very special people who have given a unique gift. During your own time of grief, you decided to give other individuals the opportunity to live, or to live a better life. Nothing can diminish the loss of your loved one, but we hope that you are comforted by the knowledge that you and your loved one have helped others with your gift of life.

I would like to make you aware that Trillium clift of Life Network has a Donor Family Program. You will, from time to time, receive communication from us that will include information about support for donor families. The program also provides the opportunity to participate in other Network initiatives honouring organ and tissue donors, when the time is right for you. If you do not wish to receive this communication, please contact me at my number listed below.

If I can provide you with further assistance, please do not hesitate to call me at 416.619.2353 You can also email me at mward@giftoflife.on.ca.

Sincerel

Michael Ward Family Services Advise



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Exhibit 2: Organ Regret Letter - Template

«GenerationDateFormal»

Dear «NOK Salutation» «NOK Last Name»

On behalf of Trillium Gift of Life Network, we would like to extend to you and your family our condolences on the loss of your «DonorToNOKRelationship», «Donor First Name». We also want to thank you for thoughtfully considering organ (and/or tissue) donation on «genderadjectivehisher»behalf and regret that donation was not able to proceed.

Families like yours, who take the time to think about donation during a time of grief, give hope to those who continue to wait for transplant. We hope it comforts you to know that all opportunities for donation were explored.

Trillium Gift of Life Network has an online Grief Library featuring information which may be helpful to you and your family at this difficult time. We welcome and encourage you to visit it. The link to the site is below.

http://www.giftoflife.on.ca/en/donorsupport.htm

Sincerely yours,

Family Services Advisor