Make the Decision
Share Your Life

Cornea Donation
Information

Palliative Care Service
Make the Decision - Share Your Life

Cornea donation information for the palliative care patient and family

This pamphlet will help you and your family learn more about cornea donation.

The cornea is the clear, round “window” of tissue that lets light enter the front of the eye. It looks like a contact lens. If the cornea gets damaged, it can block the path of light into the eye. A healthy cornea is needed to see well.

Every year, hundreds of Nova Scotians benefit from cornea transplants. There are not enough corneas to meet the need, so there are many people waiting to have a transplant. This transplant brings back a person’s sight. It may also relieve pain in people who have certain eye diseases.

Palliative care patients may be able to donate their corneas.

All Canadians should have the opportunity to donate their corneas as part of end-of-life care. The opportunity to donate corneas often helps support and comfort patients and family members through the grieving process.

In Nova Scotia, people are able to register their intent to donate organs and/or tissues
when they sign or renew their health card, or by contacting MSI. In Nova Scotia and across Canada, consent for donation must always be received from the family as well. This is why it is very important to share your wishes about donation with your family.

**Myths and facts**

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<th>Myth: Cornea donation will cost me money.</th>
<th>Fact: There is no additional cost to the family.</th>
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<th>Myth: I will not be able to have a normal funeral or an open casket.</th>
<th>Fact: Surgery to remove the corneas is done shortly after someone has died. It is done with the utmost respect and dignity. Funeral arrangements can then go ahead as you and your family wish, including an open casket if you wish.</th>
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| Myth: Donation will delay funeral arrangements. | Fact: The body is released to the family or funeral home as soon as the corneas are removed (usually within 16 hours). As you know, funeral arrangements are always made by the family. Every effort is made to avoid any delay in making funeral arrangements. |
Am I able to donate my corneas?

Donating your corneas is a generous gift. People under the age of 70 may donate their corneas even if they wear glasses. Corneas are evaluated after death. Donating your corneas is up to you, and completely voluntary. The decision is yours to make.

There are various conditions that may prevent donation, such as certain blood cancers, diseases, and infections.

Your healthcare provider will work with you to determine if you are able to donate.

You can read more at:
www.legacyoflife.ns.ca
www.cdha.nshealth.ca/regional-tissue-bank
Common fears and misunderstandings

Many people may have concerns about donation if they do not understand the donation process. We will try to answer some of the most commonly asked questions about cornea donation.

Can I change my mind after I have chosen to donate?
Yes, you can change your mind at any time. This is a very personal and private decision for you and your family. It has to be the right choice for you.

Will my family know what happens to the donated corneas?
Yes. Your family will get a letter from the transplant program giving some general information. For confidentiality, the names of the donor, the donor’s family, and the person who receives the cornea(s), are not released. This is an anonymous gift.
Testimonials: The legacy of cornea donation

Ross’s story (January, 2014)

“I am the recipient of two donated corneas. I had my first transplant surgery (left eye) in June 2012 and my second transplant surgery in June 2013. Seven years ago I was diagnosed with Fuchs’ Corneal Dystrophy. Fuchs is a degenerative disease of the cornea that affects both eyes. It started out as cloudy vision in the mornings and eventually led to a loss of vision, like looking through wax paper. There is no cure for Fuchs, the only treatment is a cornea transplant.”

“I’m a husband, a father of 3, a business owner, a sailor, and a musician. I lead a very active life. Not being able to see proved increasingly difficult to do the things I needed and wanted to do. The gift that was given to me has given me a large part of my life back and my promise is that I will never waste one moment of my life.”

The gift of sight

“For the first time in over 5 years, I could see across the room without any visual correction. I spent the drive home crying, watching the world through this new eye, thankful for a new life that this donor had graciously given me.”
“Not a day has gone by since May 2003 that I have not celebrated my life or my vision to the fullest. In each sunrise or sunset, rainstorm or rainbow, in each frown or in each smile, I see everything and recognize what a great world we are in and how very fortunate I am to be able to see it. I am forever grateful for my donor and donor family, for the support of my friends, and family throughout my recovery and in the months ahead.”

We trust this pamphlet answered some of your concerns about cornea donation. If you are interested in donating your corneas, please speak with your healthcare provider or team. To learn more, call QEII Locating at 902-473-2220 and ask to speak to the Tissue Bank Specialist on call. You can also contact the Regional Tissue Bank office at 902-473-7360 or 1-800-314-6515.

What are your questions? Please ask.

We are here to help you.
Looking for more health information? Find this pamphlet and all our patient resources here: http://library.nshealth.ca/PatientGuides
Contact your local public library for books, videos, magazines, and other resources.
For more information, go to http://library.novascotia.ca

Nova Scotia Health Authority promotes a smoke-free, vape-free, and scent-free environment. Please do not use perfumed products. Thank you!

Nova Scotia Health Authority
www.nshealth.ca

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The information is not intended to be and does not constitute health care or medical advice.
If you have any questions, please ask your health care provider.

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The information in this pamphlet is to be updated every 3 years or as needed.