Patient & Family Guide

# Make the Decision Share Your Life

# Cornea Donation Palliative Care Service



### **Cornea Donation**

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 light from coming into the eye. You need a healthy cornea to see well.

Every year, hundreds of patients 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 or give them a better quality of life.

## Palliative care patients may be able to donate their corneas.

Donating your corneas may help to support and comfort you and your family through the grieving process.

For more information on the benefits of organ and tissue donation, visit the Legacy of Life website:

> www.nshealth.ca/legacy-life

It is very important to share your wishes about donation with your family so they can support the donation process.

#### Myths and facts

**Myth:** If I donate my corneas, it will cost me or my family money.

**Fact:** There is no extra cost to you or your family.

**Myth:** I will not be able to have a normal funeral or an open casket.

**Fact:** Surgery to remove the corneas is done shortly after death. It is done with respect and dignity. Funeral arrangements can then go ahead as you wish, including an open casket.

Myth: Donation will delay funeral arrangements.

Fact: We make every effort to avoid a delay in making funeral arrangements. Your body is released to your family or the funeral home as soon as your corneas are removed (usually within 24 hours).

#### Am I able to donate my corneas?

People aged 70 and under may donate their corneas even if they wear glasses. Donating your corneas is up to you. It is completely voluntary and is your choice.

Your corneas will be checked after death to see if they are able to be donated. There are some conditions that may prevent donation, such as certain blood cancers, diseases, and infections.

Your health care provider will work with you to see if you can donate.

For more information, visit:

- > www.legacyoflife.ns.ca
- > www.cdha.nshealth.ca/regional-tissuebank

### Common fears and misunderstandings

Some people have concerns about donation if they do not understand the donation process. Here are 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. It has to be the right choice for you.

If you want to change your registered donation decision, you need to update your information with the Health Card Registry. If it's time for you to renew your health card, use the Health Card Renewal Form. If it's not time for you to renew your card, contact MSI Registration and Enquiry to make a change.

#### In Nova Scotia please visit:

 https://beta.novascotia.ca/request-opt-outorgan-and-tissue-donation

#### OR

Call MSI at 902-496-7008.

## Will my family know what happens to my donated corneas?

Yes. Your family will get a letter from the Transplant Program with some general information. For confidentiality, the names of the donor, the donor's family, and the person who receives the cornea(s), are not shared. This is an anonymous gift.

What are your questions?
Please ask. We are here to help you.

## 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."

If you are interested in donating your corneas, please talk with your health care team or contact the Regional Tissue Bank office at 902-473-7360 or (toll-free) 1-800-314-6515.

Notes:			

#### Looking for more health information?

Find this pamphlet and all our patient resources here: https://library.nshealth.ca/PatientEducation
Contact your local public library for books, videos, magazines, and other resources.

For more information, go to http://library.novascotia.ca

Connect with a registered nurse in Nova Scotia any time: call 811 or visit https://811.novascotia.ca Learn about other programs and services in your community: call 211 or visit http://ns.211.ca

Nova Scotia Health Authority promotes a smoke-free, vape-free, and scent-free environment.

Please do not use perfumed products. Thank you!

www.nshealth.ca

Prepared by: Palliative Care Services
Reviewed by: Legacy of Life and Critical Care Organ Donation staff
Designed by: NSHA Library Services

The information in this brochure is for informational and educational purposes only.

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.

WD85-1150 © November 2020 Nova Scotia Health Authority The information in this pamphlet is to be updated every 3 years or as needed.

