The gift of sight: normalising discussions and referral for corneal donation in the inpatient setting

Abstract

For patients with a life-limiting diagnosis, guidance by the General Medical Council recommends exploring patients' beliefs and values about tissue donation with the patient and family towards the end of life. This article gives guidance to healthcare professionals on the process of giving patients the opportunity to donate their corneas, including eligibility, communication and practicalities.

Key words: Corneal donation; Eligibility; Palliative; Patient's wishes; Terminally ill; Tissue

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Introduction

Guidance by the General Medical Council (2010) recommends discussing tissue donation with patients and families towards the end of life, and emphasises that knowing a patient's wishes is essential to delivering personalised care. European countries with opt-out policies (eg Austria, Belgium and France) have significantly higher rates of organ donation than those countries with an opt-in system (eg Netherlands) (Johnson and Goldstein, 2003).

In 2015, Organ Donation Wales changed to a soft opt-out system. A report by the Welsh Government (Young et al, 2017) found that in the 21 months after the new legalisation came into effect there were 104 donors, while in the corresponding period before the act there had been 101. Although these figures relate specifically to organ donation as opposed to tissue donation, there is a belief that the difference in rates of tissue donations was similarly insignificant after the change in the law.

Documentation that had already been in place for many years across Wales to help guide and support a patient's care at the end of life included a question to document patients' wishes relating to tissue donation. Despite this, personal correspondence with NHS Blood and Transplant indicates that patients with anticipated death are not routinely being given the opportunity to express their wishes regarding tissue donation. Table 1 summarises key facts relating to corneal donation.

John and Avril's story

A passionate advocate of science, John wholeheartedly believed in helping others through organ donation. He was a professional cameraman and loved photography, so his sight was especially important to him.

Table 1. Facts about corneal donation and corneal transplantation

Injury and hereditary conditions of the eye can affect the cornea causing reduced vision and blindness
One person donating their corneas can restore or preserve sight in two people
The whole eye is retrieved but only the cornea is transplanted (the rest of the eye can be used for research)
In 2000, corneal transplant surgery was the most commonly performed allograft in the UK (Waldock and Cook, 2000)
In 2000, the overall success rate following transplant surgery was approximately 90% at 1 year (Waldock and Cook, 2000)

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While he was a hospice inpatient, John requested that he donate his corneas after his death if possible. Knowing that he was an eligible donor gave John great comfort. John was the first person to donate his corneas at the authors' hospice for over 4 years. He and his wife Avril's passion for donation inspired the authors to change their practice and to routinely offer the opportunity to consider corneal donation to all eligible inpatients.

Who can donate their corneas?

There is a common misconception that medical conditions such as cancer make someone ineligible to donate. While these patients usually cannot donate solid organs, many can donate tissue, including their corneas. In addition, the use of adjuvant corticosteroids was thought to prevent patients from donating corneal tissue, but this is no longer a contraindication. Eligibility criteria may fluctuate, so it is good practice to liaise with the National Tissue Referral Centre if uncertain. However, there are some absolute contraindications to be aware of (Table 2).

There is currently a shortage of corneal donors. In February 2019, NHS Blood and Transplant reported that they need 350 corneas in the eye bank at any one time to meet demand but that they only had 290 in the bank at that time, equating to a 17% deficit in the corneas required for sight restoring operations (personal correspondence, NHS Blood and Transplant, 2019). Corneal transplantation of replacement human tissue is the only effective means of sight restoration for patients suffering from conditions such as keratoconus and pseudophakic bullous keratopathy.

Keratoconus is a non-inflammatory disease resulting in a cone-shaped cornea (Shajari et al, 2019). It is characterised by protrusion and scarring of the cornea resulting in a loss of vision. It is one of the most common presentations resulting in corneal transplantation (NHS Health A to Z, 2018).

Cornea transplantation, often referred to as keratoplasty, is the procedure which involves removing all or part of a damaged cornea and replacing it with a healthy donor tissue. Penetrating keratoplasty, a full thickness transplant, is primarily performed for advanced stages of keratoconus. Alternatively, deep anterior lamellar keratoplasty is a transplant procedure that involves reshaping or replacing only the anterior layers of the corneal stroma, preserving the descement membrane and endothelium, while endothelial keratoplasty replaces only the innermost layers of the cornea (NHS Health A to Z, 2018). Treatment options for keratoconus have improved over the past decade with the advent of cross-linking, thus transplantation is now only required for advanced disease. In corneal cross-linking, riboflavin (vitamin B2) eyedrops are used alongside ultraviolet light to create a photochemical reaction. This reaction forms new covalent bonds within the collagen fibres and strengthens the corneal tissue, stopping the progression of corneal ectasia (Farjadnia and Naderan, 2015).

Asking the question

The first step in the process of giving a patient the opportunity to donate their corneas is to start a conversation.

Table 2. Absolute contraindications for corneal donation

Haematological malignancies and melanoma
Neurological disease including dementia
Blood-borne viruses, eg HIV, hepatitis B or C
Refractory eye surgery, eg laser eye surgery
Idiopathic disease
Age (>96 years or >86 years if coexisting ocular pathology)

Advance care planning was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate (Rietjens et al, 2017).

For patients with a life-limiting diagnosis or a condition that could possibly lead to an impairment in their capacity, the General Medical Council (2010) guidance on treatment and care towards the end of life highlights the importance of working in partnership with patients, supporting them to think ahead and express their wishes, fears and preferences in relation to their future care. Depending on the patient's circumstances, allowing patients the opportunity to explore their beliefs or values about tissue donation is one of many discussions recommended by the General Medical Council (2010) guidance.

If a patient is in the terminal phase of illness and their views cannot be determined, healthcare professionals should be prepared to have these discussions with those close to them, if tissue donation is a possibility (General Medical Council, 2010).

Admission to a hospital or hospice can be a highly emotionally charged time, and judgement must be exercised over the time to open discussions. In the authors' experience, raising the subject alongside other positive topics, such as when exploring patients' wishes, beliefs and spirituality, typically yields a more helpful discussion than when discussing more challenging issues, such as do not attempt cardiopulmonary resuscitation orders and ceilings of patients' treatment.

NHS Blood and Transplant (2016) figures show that, since April 2010, more than 500 families in the UK have said no to organ donation despite being informed or knowing that their relative was on the NHS Organ Donor Register. In a survey carried out by NHS Blood and Transplant in 2016, 73% of respondents said they thought that the next of kin should not be able to overrule a person's decision to donate after they have died, whereas only 11% thought it was acceptable to do so. To minimise the risk of confusion or unnecessary anxiety after a patient's death, it should be ensured wherever possible that their families are present during discussions about a patient's beliefs and wishes on tissue donation. This was something the authors experienced during the early stages of implementing change of practice at their hospice. However, standardising practice and exploring patient wishes on admission when the closest relatives or carers are most likely to be present has resulted in a reduction in the number of family refusals.

Further information for patients and their families may be provided in the form of patient information leaflets. NHS Blood and Transplant have several such leaflets available, including one specifically for patients receiving palliative care (https://www.nhsbtleaflets.co.uk/Home.html). Providing pre-emptive information prepares the family for a discussion that will need to take place following the death of their loved one (Long-Sutehall et al, 2012).

Once these discussions have been held, recording this information in a way that it is readily accessible at the time of death is key to ensuring the referral process takes place. At the authors' hospice, the electronic patient records allow for coding of this information which triggers an alert to state that the patient has expressed a wish to be a tissue donor. This alert servers as a trigger for nursing staff caring for the patient at the time of death to initiate the referral to the National Tissue Referral Centre.

Practicalities of organising a corneal donation

Before you start

First, contacting NHS Blood and Transplant to foster a relationship is key to initiating the process. You will need to clarify the retrieval route and feasibility for your setting, whether that be hospital, hospice or other location where the patient is based.

Corneal donations can take place at most hospital or hospice mortuaries or funeral homes, but unless there are locally trained technicians with up-to-date competencies, trained staff from NHS Blood and Transplant will need to be available to attend and perform this procedure. The NHS Blood and Transplant tissue and eye services is the largest tissue bank in Europe (NHS Blood and Transplant, 2018, personal correspondence). Its role is to coordinate, retrieve, process, bank and supply human tissue grafts for use in surgery within the NHS.

Key information

- If multi-tissue donation is to take place the donor should be in the mortuary within 6 hours of asystole. However, this is not an absolute contraindication and NHS Blood and Transplant advise that the referral should still take place even if there has been a delay.
- In all cases a blood sample from the potential donor will be needed within 24 hours of death, the usual practice is for the retrieval team to collect this sample.
- When making the referral, have as much information to hand as possible (Figure 1).

Making a referral

To make a referral for tissue donation, a healthcare professional should notify the Specialist Tissue Donation Nurse on 0800 432 0559 as soon as possible after the patient's death.

The Specialist Tissue Donation Nurse will call back as soon as possible, but for referrals made out of hours this may not be until early the next morning.

Once a referral has been made to NHS Blood and Transplant, a Specialist Tissue Donation Nurse from the service will carry out an assessment of the potential donor, obtaining information from both the referring team and frequently the patient's GP.

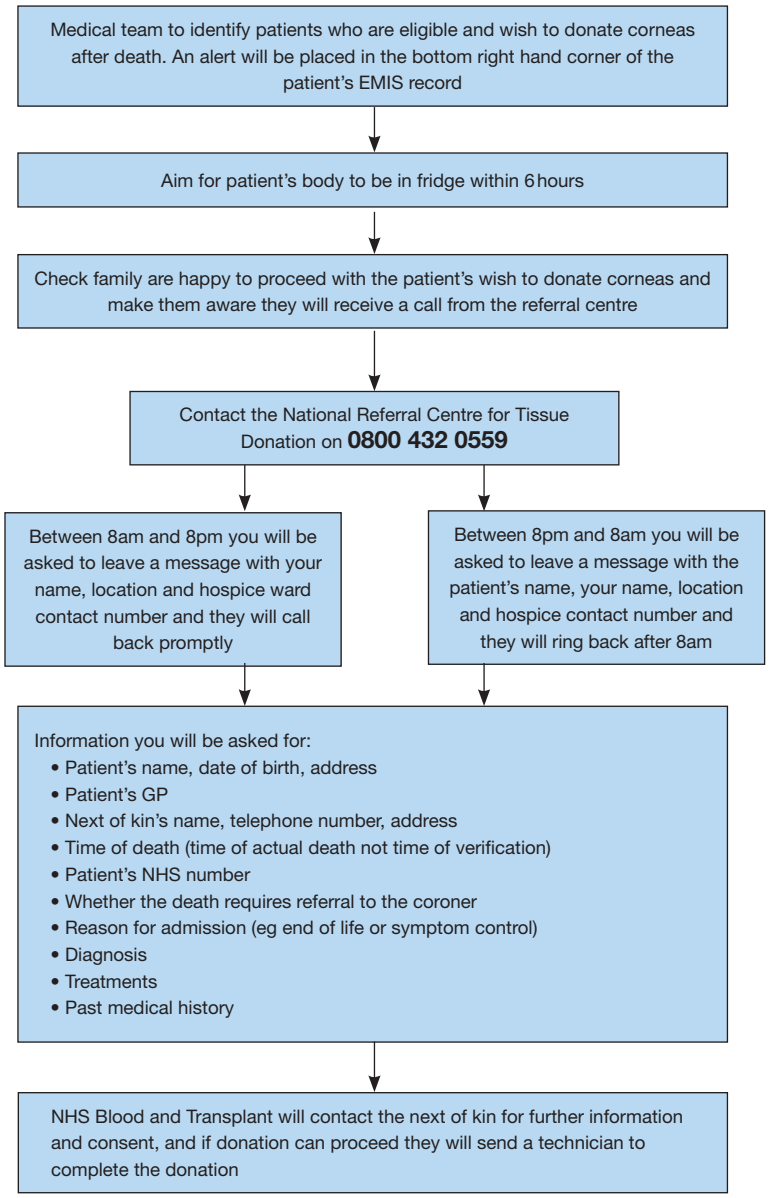

Figure 1. Corneal donation referral flowchart.

The family will be contacted to confirm that the information received by the service is correct and to ensure they are happy to proceed with the donation. At this stage, the family member will be asked additional screening questions to confirm eligibility. It is important to advise the family that the call they will receive may be from an unregistered number. Consent can be given by telephone and does not require any additional paperwork or meeting for the consenting family member. Unfortunately, if the patient does not have a nominated next of kin, despite being on the NHS Organ Donor Register and having expressed verbally or in writing a wish to donate their corneas, the referral is unable to go ahead.

Once confirmed, the service will organise retrieval of the tissue while offering support to the bereaved family (Figure 2). Patients' families should be assured that throughout the donation process the donor is treated with respect and dignity. Great care is taken during the retrieval process to maintain the donor's natural appearance. Reconstruction to restore the original profile of the eyes is performed as part of the retrieval procedure.

Following tissue donation, if the family member consented to follow up, they will receive a letter of thanks from NHS Blood and Transplant. The letter confirms whether the donation took place, and how the tissues were used. Families will be offered further information, including how they may access bereavement services.

Conclusions

For patients with a life-limiting diagnosis, guidance by the General Medical Council (2010) recommends exploring patients' beliefs and values about tissue donation with the patient and family towards the end of life. This article outlines how to broach the subject of corneal donation and facilitate the process when it is the patient's wish.

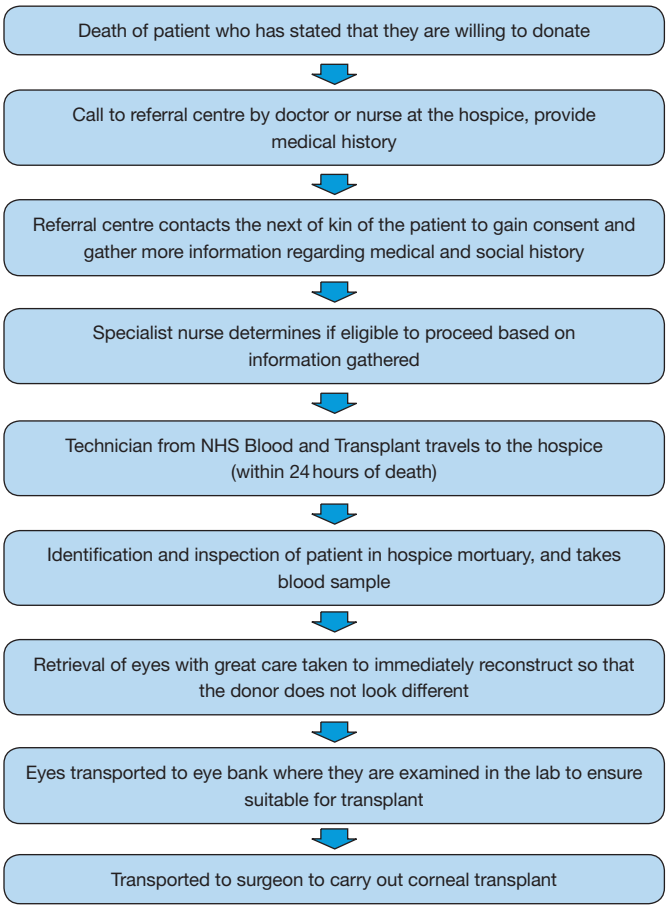

Figure 2. Process map detailing steps of the referral and retrieval process at the hospice.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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