

To: Tissue and Eye Services

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Dear Colleagues,

Re: Update on Max and Keira's Law and the impact of COVID-19

We are writing to update you on the impact that the COVID-19 pandemic has had on organ donation and transplantation across the UK.

As you know from previous communications, it is rare for people to be able to donate their organs when they die - only around 1 in 100 people die in such circumstances. Those who do choose to donate, save and improve the lives of people waiting for an organ transplant.

The COVID-19 pandemic has impacted the UK's organ donation and transplantation services in two ways.

First, it's even less likely that someone will be able to donate their organs when they die, as donation will not be considered for someone suspected to have, or dying with, the infection. Where donation *is* a possibility, our specialist nurses continue to sensitively approach families and to answer any questions the family may have. For example, around how beliefs or culture would be respected if the family supports organ donation going ahead.

Second, we have seen a significant reduction in the number of organ transplants taking place. It is always important to balance the risks versus benefits when considering whether to accept an organ for a waiting patient. The risk is increased at the moment as post-transplant, patients are more vulnerable to infection and many will require intensive care. Therefore, over recent weeks, transplants have only been progressing for those with an urgent need for a life-saving transplant.

Without doubt, the COVID-19 pandemic has been a challenging time for patients waiting for transplants. We are working closely with the wider NHS to ensure that we have robust plans in place to return these vital NHS services to normal as soon as it is safe to do so.

As you know, the law around organ donation is changing in England. The Government remains committed to saving as many lives as possible through the gift of organ donation and to ensuring that the legislative process is successfully completed and comes into effect on 20 May.

In February, the Government laid secondary legislation relating to Max and Keira's Law - the Organ Donation (Deemed Consent) Act. Before the Act can come into effect, Parliament needs to approve the final piece of legislation to clarify the organs and tissues that will be excluded from deemed consent (e.g. face or limb donation) and the Code of Practice our specialist nurses will be following. We are awaiting an update from the Department of Health and Social Care around when the secondary legislation is going before Parliament.

The Government has advised that it is unlikely that transplants will proceed under deemed consent during the current COVID-19 pandemic because people are distanced and communication between relevant parties is more challenging. Therefore, while we continue to deal with COVID-19 within the NHS, where possible and supported by the local donor hospital, we will continue to approach families about donation and will do so with our usual empathy and sensitivity. Where there isn't a recorded or known decision, we will support families to make a decision on behalf of their loved one.

People always have a choice about whether or not to donate and can record their decision at any time – before or after the opt out system comes into effect. Families are always consulted to ensure we know what the person who has died wanted to happen and people's faith, beliefs and culture will continue to be respected.

We will continue to educate and inform people about the law change and this will not change after 20 May. Our awareness campaign was launched over a year ago in April 2019. We reduced our campaign activity over the last few weeks, as it was vital that people heard the coronavirus campaign messages and follow the social distancing guidance to protect the NHS and help save lives. However, we are committed to ensuring that people are aware of the law change and that organ donation is always an individual's choice.

We are planning the next phase of the campaign, which will go live later this year. It is difficult for us to be more specific on plans and timings at this stage, as we need to carefully consider the impact of COVID-19 on media consumption and awareness levels around the law change and organ donation. Also, any face to face engagement carried out by organisations funded by the BAME Community Investment Scheme or by our network of organ donation volunteers is on hold while social distancing measures are in place. It is not possible at the moment to say with any certainty when this work can resume.

In the coming weeks we will be providing the opportunity for you to join a series of online drop-in sessions via Zoom. These sessions will provide an update on progress with Max and Keira's law and give you the chance to ask questions. Further details will be shared shortly.

As always, we remain firmly committed to ensure that people get the information they need to help them in their decision making. Our specialist nurses will continue to approach families with respect and sensitivity about organ donation to ensure that people's donation decisions are honoured.

Kindest Regards,

A handwritten signature in black ink, appearing to read 'John Forsythe', with a long horizontal flourish extending to the right.

Professor John Forsythe

Medical Director, Organ and Tissue Donation and Transplantation
NHS Blood and Transplant

A handwritten signature in black ink, appearing to read 'Dale Gardiner', with a long horizontal flourish extending to the right.

Dr Dale Gardiner

National Clinical Lead for Organ Donation
NHS Blood and Transplant