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Tuesday 19th May 2020

Dear Stakeholders,

Following our communication to you a couple of weeks ago, we wanted to remind you that an opt out system for organ donation is being introduced in England tomorrow.

This means that unless you have recorded a decision to opt out, are in an excluded group or have nominated someone to make a donation decision for you, it will be considered that you have agreed to donate your organs.

The excluded groups are:

* people under 18
* people who lack the capacity to understand the change
* people who have lived in England for less than 12 months or who are not living in England voluntarily

In an opt out system people still 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. Where donation is a possibility, families are always consulted to ensure we know what the person who has died wanted to happen.

In our last communication to you, we explained that COVID-19 has had a significant impact on organ donation and transplantation in the UK.

The Government has advised that it is unlikely that donation will proceed under deemed consent in England 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.

We are working closely with the wider NHS and already have plans in place to return vital organ donation and transplantation services to normal as soon as it is safe to do so. We know that most transplant centres are gearing up to re-open, or extend their service, in the next two weeks. But we must remember that transplantation is only possible if people are willing to donate their organs.

Where someone follows a faith or belief system, we understand that donating organs in line with these can be important to them. That’s why our specialist nurses explore whether this is relevant when discussing the possibility of donation, to ensure that if donation does go ahead it only does so if in line with these beliefs. If a family has any concerns, our specialist nurses will support them to address these and agree the best approach.

Over the last few months we have been working towards introducing some improvements to give greater clarity to people who want to donate but want more reassurance around how their faith or beliefs would be respected if they can donate their organs or tissue when they die.

You may recall that in December 2018, we introduced a new optional question into the online registration form for people registering their decision on the NHS Organ Donor Register to donate some or all of their organs. We introduced this optional question on organdonation.nhs.uk and into the NHS App (which is accessible to patients in England). People are asked whether they want the NHS to speak to their family and anyone else appropriate about how organ donation can proceed in line with their faith and beliefs. If someone responds to this question, the response is recorded on the individual’s record on the NHS Organ Donor Register alongside the information about which organs and tissues they agree to donate.

Since we made those changes, we have been listening to feedback and engaging proactively with representatives across the UK’s major faith and belief groups, to understand how we can further improve the information we provide on organdonation.nhs.uk and in the online registration process itself for the benefit of their communities.

We identified, in particular, a need to provide additional reassurances about the organ donation process to support people in their decision making.

The essential principle we want to reinforce is that a person’s faith and beliefs will be respected in discussions with their families about donation, should the opportunity arise - whether or not they have recorded their decision in the register.

To provide this additional reassurance, we have been:

* + Improving our content on the organ donation website about the organ donation process and how families are involved in recognition of the fact that this is information people are searching for. This website is mainly visited by people living in England as there are separate organ donation websites in the other UK countries
  + Working with colleagues in major faith and beliefs organisations to update the specific faith and belief leaflets and website pages on the organ donation website. We have updated the faith and belief leaflet for the Christian community.
  + Looking to improve the Faith and Beliefs section of the form people complete on organdonation.nhs.uk when registering their decision to donate some or all of their organs and tissue

Over the next few weeks we will testing the introduction of a new ‘Faith & Beliefs Statement’ that can be read alongside the optional faith and beliefs question. This statement clearly articulates the reassurances NHS Blood and Transplant can provide to people of all faiths and beliefs who wish to donate their organs in line with their beliefs. While this website change is being tested, 50% of website visitors will see the statement. Once this testing is complete we expect to make the new version available for all site visitors.

Once this enhancement is fully incorporated into the online registration process, it will be possible for people to download and share the statement from our ‘Tell and Share’ tool, that appears after someone completes their online registration.

We hope the information above reassures you around the way in which we support families through the donation process, when someone wanted to be an organ donor.

Please continue to promote organ donation and help to communicate this important new law change in England over the coming months. You can share assets from <https://www.nhsbt.nhs.uk/how-you-can-help/get-involved/download-digital-materials/pass-it-on/> and as well as our social posts that aim to inform people about organ donation and the new system.

As always, we remain firmly committed to working with you 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.

Working together we can ensure that more people benefit from life-saving and life- transforming transplants.

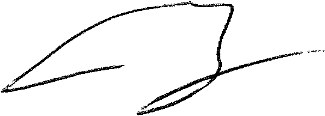
Kindest Regards



Professor John Forsythe

Medical Director, Organ and Tissue Donation and Transplantation

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Dr Dale Gardiner

National Clinical Lead for Organ Donation

NHS Blood and Transplant