

PROCESS AND SYSTEMS Will the unusual become usual? A new legal change that aims to increase discussions around organ and tissue donation in England

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ABSTRACT

UK guidelines recommend that discussions about organ and tissue donation are conducted as part of end-of-life care. However, there are several barriers to discussing organ donation, and this is reflected in a critical shortage of donors. This article explores who should start the conversation about donation and how all healthcare practitioners can maximise their communication skills to have success in this area. It is particularly pertinent to be upskilled in this area in light of the recent legal change in England, where the system moved from an opt-in to a 'soft' opt-out one. Based on a similar legal change that took place in Wales and global data, it is unlikely that the legal change alone will prompt an increase in donation rates in England. This article proposes suggestions to increase awareness and conversations among healthcare professionals and patients with education, public health campaigns and interventions rooted in psychological theory.

KEYWORDS: advance care planning, end-of-life care, communication skills, organ and tissue donation

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Should discussions around organ and tissue donation be a routine part of advance care planning?

National guidelines in the UK recommend that organ and tissue donation discussions should be considered a standard part of planning for end-of-life care.¹ Normalising conversations about organ donation at the end of life has been shown to increase support for bereaved families, as well as improving organ donation rates.² By having separate meetings with families in critical care about end-of-life care and donation, there is evidence to suggest that consent rates for donation decrease significantly when compared with discussing both topics in the

same meeting.³ However, in Australia, donation preferences are considered separately from advance care planning (ACP), with the rationale that potential donors are a different population to those undertaking ACP, and that ACP is not solely about wishes at the end of life.⁴ Whether you consider organ donation a core part of ACP or not, it should feature highly in the thoughts of any healthcare practitioner seeing patients near the end of life.

What are the barriers that stop us from talking about organ and tissue donation?

Despite major changes in the infrastructure for organ donation in the UK since 2008, there are not enough donated organs to meet the current need.⁵ Only 1% of annual deaths in the UK occur in circumstances where the deceased could be a potential donor.⁶ Identification and availability of sufficient donor organs are major barriers for transplantation, but the most important barrier is widely acknowledged as failure to secure consent for organ retrieval.⁵ A lack of knowledge on the part of healthcare practitioners around organ and tissue donation has been identified as an obstacle to discussing donation with patients.⁷ Knowledge varies depending on specialist clinical area, education and length of professional experience.⁸ While donation is generally viewed as a rewarding opportunity, clinical staff do not raise the topic with patients because of concerns about the impact this discussion may have on patients and families.⁹ Healthcare professionals also acknowledge that the organ donation process can be stressful, and their own emotions (such as grief and compassion fatigue) can affect whether they undertake this discussion with patients.¹⁰

Further research has explored the patient perspective about donation. A service evaluation of hospice inpatients who were offered information about corneal donation suggests that the fears of staff about causing distress to patients and families are unfounded.¹¹ Depending on their comorbidities, patients are not always sure about their eligibility to donate tissue and organs.¹² This is in keeping with the literature suggesting suboptimal knowledge among healthcare professionals, perhaps explaining why neither patients nor staff feel comfortable to initiate the conversation.

Who should start the conversation around organ and tissue donation, and when should this happen?

In the UK, specialist nurses for organ donation (SNODs) are trained to facilitate requests for organ donation, and are often

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embedded in critical care departments.¹³ When a patient is near the end of their life in critical care and has been identified as a potential donor, guidelines suggest that a multidisciplinary approach should be taken towards the conversation. Doctors and nurses who know the patient, faith representatives if appropriate, and SNODs are all part of the team who should meet with the patient's family.¹⁴

Palliative care services could be ideally placed to normalise discussions about organ donation near the end of life. This is because there are significant numbers of patients dying outside of intensive care units who are under-recognised as potential organ donors.¹⁵ Palliative care specialists could use their skills to effectively communicate with patients about their wishes and goals of care.¹⁶ However, corneas are often the only tissue that patients with a malignancy can donate. Therefore, palliative care doctors will most commonly only discuss corneal donation as part of ACP with their patients, and would require more training to undertake discussions about organ and tissue donation in full.

Black, Asian and minority ethnic (BAME) groups have low rates of deceased donation, which results in significantly longer waiting times for transplantation when compared with white patients.¹⁷ Low rates of donation are due to uncertainties around religious permissibility and a lack of trust in healthcare professionals by BAME patients, coupled with clinicians' lack of confidence in communicating with and supporting BAME families.¹⁸ There is evidence to suggest that discussing topics such as organ donation and end-of-life care is more acceptable to BAME groups if conversations are conducted by members of their own community.^{18,19}

Regardless of speciality or ethnicity, interviews have found that patients would prefer face-to-face discussions with someone with whom they had established a close rapport, and earlier in their disease trajectory, in order to engage fully in the decision-making process.¹² This, along with the fact that patients are happy to have ACP discussions with any doctor who is willing to open the conversation with them, suggests that it is the responsibility of all healthcare practitioners to broach the topic of donation with patients as soon as a strong relationship has been established.²⁰

How can the way in which we communicate influence rates of organ and tissue donation?

The family perspective has been shown to be important when interviewing patients and family refusal is the largest factor contributing to the loss of potential donors.^{12,14} Most of the background literature on how communication can influence organ donation is in relation to the family experience. While someone with appropriate skills and timing should have the conversation around organ and tissue donation, the way in which the information is presented to the grieving family can have an impact on the final decision made.¹⁴ Guidelines from the UK suggest that negative, apologetic and coercive language should be avoided, whereas in America, clinicians have moved from a neutral approach to one of positivity towards organ donation.^{14,21} This involves advocating for the family of the potential donor, while equally presenting the needs of those on the transplant waiting list.²¹ It is assumed that families will be pro-donation, and this has proved to be an effective communication strategy.³

Clinicians with higher self-confidence in their communication skills have higher levels of comfort with discussing organ and tissue donation, and this is reflected in increased rates of family consent.^{22,23} The amount of time that clinicians spend having the

discussion and family perception that they have been treated in a caring and compassionate manner are both associated with higher levels of family comfort with the organ donation procedure.²³

Similar to the benefits of a strong doctor-patient relationship, relatives are more likely to be comfortable with their decision around organ donation in the long term if they have a strong relationship with the consulting clinician.²⁴ Factors that help bolster this relationship include information giving, openness, trust and empathy.²⁴ Relatives of those who have donated tissue have evaluated their experiences positively, with 83% stating that they would donate again.²⁵ This is important from an ethical standpoint, because the current perspective in the UK is that the deceased's deemed consent and the family's permission to tissue donation is a double veto, with each having the power to override the other's desire to donate.²⁶

How has the law around organ and tissue donation changed in England?

The law changed in England on 20 May 2020, with organ and tissue donation moving from an opt-in to a 'soft' opt-out system.^{27,28} All adults in England are now considered to be potential organ donors when they die and family permission to proceed will be sought, unless they have previously recorded a decision not to donate organs, or are in one of the excluded groups. These groups have been listed as those under the age of 18, those lacking mental capacity to make decisions around organ donation, visitors to England and people who have lived in England for less than 12 months prior to their death.²⁸ The legal change has been implemented because of the shortage of organ donors. In 2018 there were 408 people who died in the UK while on the transplant waiting list, and there were nearly 800 further people who were removed from the waiting list due to deteriorating health.^{28,29}

What can we expect to happen in England based on a similar recent law change in Wales?

In December 2015, a similar legal change took place in Wales where the system is 'deemed consent'. This means that if a person has not recorded an opt-in or opt-out decision, it is considered that they have no objections towards organ and tissue donation.³⁰ Data from Wales could be used to speculate what may happen in England. Trends in organ and tissue donation are likely to be transferable from Wales to England because figures on organ donation and transplant waiting lists are proportionately similar in both populations.^{31,32} Alongside this, rates of organ donation are far lower in England and Wales when compared with the rest of Europe despite favourable attitudes towards donation in both countries.^{33,34} Awareness of the legal change in Wales was high in December 2015, but this awareness had dropped by 2017, suggesting that engagement with the general public needed to be maintained for longer.³⁵ By contrast, in England, the legal change has been overshadowed by the current coronavirus (COVID-19) pandemic, and initial awareness is likely to be lower than it was in Wales. This could be rectified by a stronger communication campaign as pressures related to COVID-19 ease.

The opt-out system has been received positively in Wales with 71% of the Welsh public saying they were in favour of it 1 year after the change in legislation.³⁵ However, positive attitudes among the public and increased knowledge among healthcare professionals have not translated to a rise in donors.³⁵ Analysis of consent data

from Wales shows that more families have given approval for organ and tissue donation since the law change there.³⁵ For example, the upward trend in the proportion of families consenting to donation after brain death in Wales as compared with England reached statistical significance 33 months after the Welsh law change.³⁶ However, this increase in consent has not been reflected in the quarterly donation figures reported.^{35,36} This may be because there has been lower eligibility for organ donation since the legislative change; or perhaps the law change in Wales has not yet had enough time to make an impact. Any complex behaviour change intervention such as this requires public and professional buy-in, both of which can be influenced by the way in which the media presents information.³⁷ It is likely that we will observe the same delay in an increase in donation after the law change in England, and this will probably be compounded by the COVID-19 pandemic.

What can we do to further address the issue of organ and tissue shortages?

On a global scale, the data on organ and tissue donation between opt-in and opt-out countries draw ambivalent conclusions due to dated studies and heterogeneous methodology. Confounding variables include varying economies, public health campaigns and cultural attitudes towards donation. A recent study looking at 35 countries demonstrated no significant difference in deceased organ donation or solid organ transplantation between opt-in and opt-out countries.³⁸ This is in keeping with the short-term data that we have from the recent law change in Wales.^{35,36} Given that the law change itself may not make a difference in England, it is worth thinking about future avenues in education, public health and psychology that can enhance the impact of the new opt-out system.

Healthcare practitioners need to improve their confidence in talking about organ and tissue donation. Confidence and having a successful conversation are directly linked to experience, but simulation-based education can also help in this regard.^{39,40} Clinicians that work in critical care and palliative care are well placed to utilise their communication skills for patients near the end of life, and those who look after patients with chronic conditions are well placed to start the conversation earlier than this. Organ and tissue donation should form a standardised part of trainees' curricula in specialties such as critical care, palliative medicine and general practice.

While the impact of presumed consent legislation for organ donation is uncertain, it is clear that public health interventions can address organ shortages.⁴¹ The American narrative of dual advocacy could be woven into media campaigns to inform the general population about the benefits of transplantation and reframe donation in a positive, rather than a neutral, way.²¹ Although it would not be ethical to give out identifiable information, giving generic information about potential transplant recipients prior to decisions being taken about organ donation could increase rates by letting donors visualise a tangible outcome from their action.⁴² Countries such as Israel and Iran provide incentives to donate.⁴¹ Although this brings up ethical concerns around the commodification and commercialisation of organ donation, we can learn from these countries and consider ways to remove financial disincentives for live organ donors, such as loss of income and reimbursement of added expenses. Among BAME communities where donation rates are low, peer educators have been shown to be effective in sensitively communicating about organ donation and could be a useful public health initiative to

provide targeted information that tackles specific considerations around faith and cultural attitudes.^{17,19}

The psychological rationale of the opt-out system is that it bridges the gap between intention and action, and makes it simpler for a willing person to become an organ donor.⁴³ However, the opt-in system is perceived as being clearer and less ambiguous when it comes to families being involved in the conversation.⁴³ One way that decisions could be made clearer in an opt-out system is where society mandates a choice. For example, people could make a decision in advance and record this in writing on the back of a driving license.⁴¹ The opt-out system normalises organ donation as a choice and psychologically reframes it as an everyday responsibility that is prosocial but low in significance.⁴⁴ Policy makers should use psychology to understand that people will attach less meaning to organ donation under the opt-out law, and this could drive up organ donation rates by implicitly making it the norm to donate.

Conclusion

The new law means that the presumption of donation is now enforceable in England, but there still seems to be a conspiracy of silence with the majority of clinicians finding it too difficult to have the conversation, and it being considered unusual to talk about donation in settings outside of critical care.⁴⁵ Indeed, if an opt-out system is in place, one could argue that there is both an ethical and a legal imperative to make this a more usual conversation. The legal change itself may not encourage increased discussion around organ and tissue donation, and perhaps we should be more explicit that the law will not do ACP for us. However, what this new law can do is give healthcare practitioners in all specialties the confidence to open up the conversation around donation when they have established a good rapport with their patients. ■

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