

## HEALTH AND SPORT COMMITTEE

### HUMAN TISSUE (AUTHORISATION) (SCOTLAND) BILL

#### SUBMISSION FROM Kidney Care UK

Kidney Care UK is willing to support work that will increase the opportunity for more people to receive transplants and welcomes the move from the Scottish Government in this regard. We are the leading national patient support charity which works to improve quality of life for kidney patients through advocacy, direct grants, educating and informing patients, counselling and funding patient-centred research, healthcare professionals and projects. The charity was established 41 years ago to address the many issues associated with kidney disease and kidney failure. Until 2017 we were known as the British Kidney Patient Association. We are a registered charity in Scotland [www.kidneycareuk.org](http://www.kidneycareuk.org)

#### **What do you think are the key strengths and weaknesses of the proposals to introduce 'deemed authorisation' for those who have not made their wishes on organ donation known?**

##### Advantages:

Deemed authorisation enables families to accept donation rather than have to give permission; some families have commented that knowing their loved one has transformed someone else's lives can bring some comfort to them.

Changing rules should lead to further training for staff in how to approach families and support them through the donation process and new rules.

The opportunity to increase transplantation by bringing in opt-out, in conjunction with public education and appropriate staffing, has been shown over time to be effective and is welcomed by us.

##### Disadvantages:

Donation wishes might change but not be recorded, but this is the case in any system, and the option for families to present information on why their loved one would not have wanted to become a donor would be included.

Some people may feel strongly that do not wish for a presumption to donate, but this would be catered for by the opportunity to opt-out online, and it may be that they would never have wished to become donors.

It will be important to learn from Wales about continuing to focus on families and emphasise the importance of an organ donation conversation, whatever the rules.

The differences in age for deemed and self-authorisation will require careful messaging are different to those in other UK countries and could lead to confusion.

What do you think are the key strengths and weaknesses of the plans for authorisation of pre-death procedures?

We do not have any comments.

Do you have any other comments to make on the Bill?

Kidney transplants are the gold standard treatment for kidney failure. For many kidney patients a transplant transforms their lives, returning them to their families, both extending and increasing quality of life. Depending on age, it may enable them to return to work. Study after study attests for better quality of life, whether in younger or older patients, whether with diabetes or not. Kidney Care UK hears from many patients who have benefited from a transplant and share their stories to encourage others <https://www.kidneycareuk.org/get-support/your-stories/>

As one of them, Kim, recently said 'I can't put into words what it means to have been given more time and the chance to look into the faces of my beautiful grandchildren'

When disease causes kidney function to drop below the minimum needed to keep an individual alive, there are three possible choices for a patient:

- To undergo a kidney transplant if they are sufficiently fit and a suitable kidney can be found (they will need to receive dialysis whilst they wait for a kidney or receive a transplant pre-emptively, so before their native kidneys stop working).
- To go onto dialysis treatment for the rest of their life if they are not suitable to receive one or choose not to be listed for a transplant.
- To go onto conservative care, in which case they will receive treatment to give them the best possible quality of life in the time remaining until they die.

However there are fewer transplants than there are people waiting - eight out of ten people on the transplant list are waiting for a kidney. One person will die today whilst they wait. The burden on mental health is also difficult. Transplantation makes an enormous difference and means that patients no longer have to go for dialysis, normally at least 3 times a week for four hours at a time. The burden of dialysis and restrictions of kidney failure are very high. It is also very expensive both for the treatment itself, the medications and cost of getting to and from hospital.

We welcome the move by the Scottish Government to increase organ donation and transplantation, and to work with families to do so. We encourage the Scottish government to make adequate funding available for the essential public education to accompany a change in the law.