

Cystic Fibrosis Trust Response to Welsh Government Proposals for Human Transplantation Bill Scrutiny

What is Cystic Fibrosis?

Cystic Fibrosis is one of the UK's most common, life-threatening inherited diseases, affecting over 9,000 people in the UK. The faulty gene causes CF is carried by 1 in 25 people, and 1 in every 2500 babies in the UK is born with Cystic Fibrosis. It is a life-long illness, affecting a person from birth to death.

While new treatments and better management of care are helping people with Cystic Fibrosis live longer, many will reach a point at which receiving a transplant, be it lung, heart-lung or liver, is their only option to prolong life significantly. Despite this, nearly half of all people with CF on the transplant waiting list will die before they receive a transplant.

About the Cystic Fibrosis Trust

The Cystic Fibrosis Trust was founded in 1964 and is the UK's only national charity working to fund research into a cure and effective treatments for Cystic Fibrosis and to ensure appropriate clinical care and support for people with Cystic Fibrosis. It aims to ensure that people with CF receive the best possible care and support in all aspects of their lives, and provides information, advice and support to anyone affected by Cystic Fibrosis.

While new treatments and better management of care are helping people with Cystic Fibrosis live longer, many will reach a point at which receiving a lung transplant is their only option to prolong life significantly. The Cystic Fibrosis Trust supports efforts to ensure that all those with CF who are assessed as suitable for a lung transplant receive one.

The Cystic Fibrosis Trust are in the process of developing a dedicated programme of work with NHS Blood & Transplant, and other organisations, to develop a national standard for transplant services.

In addition, the Cystic Fibrosis Trust will continue to fund research into ensuring more organs are available for transplant, such as the 'reconditioning' lungs programme.

Our view

Following a consultation with the CF Community including those with CF, their parents and carers and physicians from the CF and transplant field the CF Trust feel able to welcome the Welsh Government proposals to change organ donation legislation. We support a change in the system of how we donate organs, in the hope of increasing the number of transplants that are undertaken.

see off cf

11 London Road, Bromley, Kent BR1 1BY

Tel: 020 8464 7211 • Fax: 020 8313 0472 • www.cftrust.org.uk

Patron: HRH Princess Alexandra, the Hon. Lady Ogilvy, KG, GCVO President: Duncan Bluck CBE

Cystic Fibrosis Trust registered as a charity in England and Wales (1079049) and in Scotland (SC40196)

A company limited by guarantee registered in England and Wales number 3880213

Registered office: 11 London Road, Bromley, Kent BR1 1BY

Although we hope that the introduction of the soft opt out would have a significant positive effect on transplant rates, we know that more needs to continue to be done, as indicated by the Organ Donor Taskforce's 14 recommendations. As people with cystic fibrosis predominantly require lung transplants and donated lungs are especially vulnerable to being damaged prior to transplant, we are supportive of the change of approach to focus on utilising existing donors, not simply recruiting more.

Whilst the emphasis to date has been on getting people to sign the national organ donation register, it is absolutely clear that unless other fundamental problems are also addressed, this will be of modest benefit.

Below are aspects of the bill that need to be considered:

Section 2, relating to the promotion of transplantation

A national debate needs to take place on organ donation and transplantation so that the profile of the issue is increased, and the general public has a better understanding of the realities of transplantation. Many people currently sign up to the Organ Donor Register, but do not discuss it with their family which leaves the family a painful decision at the hardest possible moment. It is only when donating your organs after death becomes usual, not unusual, that we will be on the road to giving people on the waiting list real hope. The CF Trust agree that we need to change culture of organ donation so relatives know patients wishes, and we agree that the 'Have a Heart to Heart' programme is a positive move forward which we support.

We would also support Health Ministers being an advocate of organ donation.

Sections 4-8, relating to consent

To ensure individuals receiving a transplant are able to make informed choices they must be given sufficient information and suitable guidance. A patient needs to be informed of organ donor health before being transplanted to allow make the consent truly informed, and allow them to weigh up the potential risks and consequences following transplantation.

2. Any potential barriers to the implementation of these provisions and whether the Bill takes account of them.

5. The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Part I, paragraph 90 of the Explanatory Memorandum, which contains a table summarising the powers for Welsh Ministers to make subordinate legislation).

see off The 'see off cf' logo, with 'see off' in blue and 'cf' in red.

11 London Road, Bromley, Kent BR1 1BY

Tel: 020 8464 7211 • Fax: 020 8313 0472 • www.cftrust.org.uk

Patron: HRH Princess Alexandra, the Hon. Lady Ogilvy, KG, GCVO President: Duncan Bluck CBE

Cystic Fibrosis Trust registered as a charity in England and Wales (1079049) and in Scotland (SC40196)

A company limited by guarantee registered in England and Wales number 3880213

Registered office: 11 London Road, Bromley, Kent BR1 1BY

Due to the multi organ complications of cystic fibrosis, and the impact of transplant medication on the body, Individuals with cystic fibrosis sometimes need liver and/or lung transplants at different stages of their lives. Individuals requiring a liver transplant will often have transplant care based in Birmingham and lung transplants in hospitals in London or Newcastle. There is a significant geographical distance between Wales and each these hospitals but needs and requirements for patients in Wales should be met optimally, regardless of their location. We want to ensure that individuals are gaining a good standard of care from specialist teams pre and post transplant over the whole of the UK.

It is essential that should Wales increase the rate of donation through these changes in legislation, donor organs are best utilised by being best matched to maximise long term outcomes. It is essential progress is measured in this area, through a national system of monitoring outcomes to ensure each patient attains the best outcome from their transplant and that transplant centres across the country support each other to achieve this.

We would want to ensure that individuals requiring a transplant are receiving adequate psychological support throughout the whole transplant process. This includes pre transplant, waiting for transplant and post transplant. We believe that this will help post transplant health status as individuals can be supported effectively and are able to explore issues surrounding transplant as well as end of life issues if the transplant does not come in time. This psychological support may be extended to family and friends, who often become carers of those requiring a transplant.

Whilst formulating our response to this consultation, the Cystic Fibrosis Trust has consulted with the CF community, including people with Cystic Fibrosis, families of people with CF and physicians within the CF and transplant fields. This response reflects their views and concerns regarding the proposed changes in the organ donation system.

Conclusion

The Cystic Fibrosis Trust supports the Welsh government proposals to legislate for an opt out organ donation register in Wales, but we are aware that legislation alone will not be enough to significantly improve transplantation rates.

We hope that such a change in legislation will lead to a UK wide re-appraisal of the current situation, and a much needed discussion of organ transplantation, ultimately leading to increased donation rates across the UK.



11 London Road, Bromley, Kent BR1 1BY

Tel: 020 8464 7211 • Fax: 020 8313 0472 • www.cftrust.org.uk

Patron: HRH Princess Alexandra, the Hon. Lady Ogilvy, KG, GCVO President: Duncan Bluck CBE
Cystic Fibrosis Trust registered as a charity in England and Wales (1079049) and in Scotland (SC40196)

A company limited by guarantee registered in England and Wales number 3880213

Registered office: 11 London Road, Bromley, Kent BR1 1BY