

Interviews with case studies and spokespeople available on request

More people are waiting for a heart transplant

With the waiting list increasing more than 130% in the last ten years

There are hundreds of hospital patients waiting for a heart transplant across the UK. They are relying on an organ donor to save their life. Ahead of World Heart Day on Sunday (29 September), NHS Blood and Transplant is highlighting that there are more than 300 people hoping for the call that a heart has been found for them.

The waiting list for hearts has increased more than 130% in the last decade*. As awareness and knowledge around heart transplants has grown, more people are being referred for heart transplants. The ability to use ventricular assist devices (VADs) also means patients are able to wait longer. More donated hearts are needed to help the 313** patients currently waiting for a transplant.

One person who knows what the wait for a heart transplant is like is Lyndsey Fitzpatrick. The 34-year-old, from the Wirral, will have been waiting for three years on Saturday (28 September).

She has a series of heart conditions, which meant she needed open heart surgery aged three and a pacemaker, aged 10. She has gone on to have three more pacemakers. In 2015 her health started to deteriorate and in September 2016 Lyndsey went on the waiting list for a heart transplant.

She said: "I have had health problems my whole life. Throughout my life I have struggled with my mobility, breathlessness and exhaustion on a daily basis. I have to use a wheelchair or mobility scooter when I'm out and about.

“I try keep a happy, cheerful and optimistic state of mind throughout it all and enjoy my life even if I do have to take life at a slower pace and rest when needed.

“People say to me ‘You look well’ but I definitely don’t feel well, whatever well is. I guess I have just become good at concealing my illness on the outside but I struggle with it on a daily basis.

“From a young age my family and I have known that I would need a heart transplant but now nearly three years after going on the transplant list I’m still waiting for that all important phone call. A call to say a match has been found for me, a call to say that I can start the next chapter of my life.

“I know it is hard for people to talk about organ donation but for people like me and many others that are waiting for a heart that conversation could save our lives. We are just kindly asking for families to talk about organ donation and decide if it is something they could agree to.”

The average wait for an adult who needs a heart transplant is nearly three years, that is an average of 1,085 days, for patients who have never been on the urgent waiting list and 30 days**** for those adults who have been on the urgent list. These patients are relying on a person or family to say ‘yes’ to organ donation in order to save their life.

Anthony Clarkson, Director of Organ Donation and Transplantation at NHS Blood and Transplant, said: “We can save more lives if more organs are donated, and we urgently need more hearts to help the hundreds of people waiting for a transplant.

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“We want to help as many people as possible so we would urge everyone to think about organ donation and share your decision with your family. It’s a conversation that saves lives.

“Sadly 21 patients died last year before they could receive the heart transplant they desperately needed and 201 people have lost their lives in the last five years in need of a heart transplant***.”

Minister for Care, Caroline Dinenage said: “Heart transplantation is truly a miracle of modern medicine, and has saved countless lives.

“But as we celebrate 40 years since the UK’s first heart transplant, the number of people in need of a new heart keeps growing and tragically many will die waiting.

“My priority as the Minister overseeing organ donation is to ensure that no one misses out on a second chance of life. Ahead of World Heart Day, I urge everyone to talk to their families about donation and register their decision. Together, we can help save countless lives.”

Next year, the law around organ donation is changing in England and Scotland. From spring 2020 in England and Autumn 2020 in Scotland, all adults (those aged over 18 in England and over 16 in Scotland) will be considered as having agreed to donate their own organs when they die unless they record a decision not to donate, or are in one of the excluded groups. This system was introduced in Wales in December 2015.

Families will still always be involved in organ donation so it is vital that they know what your choice is. In the lead up to the change in law, NHS Blood and Transplant is urging families across England to talk and share their decision. If

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the time comes, families find the organ donation conversation much easier if they already know what their relative wanted.

John Maingay, Director of Policy and Influencing at the British Heart Foundation, said: “Hundreds of people across the country are on the waiting list for a heart transplant at any one time, and sadly not everyone will currently receive the transplant that they desperately need. The introduction of Max and Keira’s Law in England and Scotland means we will switch to a soft opt out system, which will provide much needed hope for those on the heart transplant waiting list.

“This is a significant legal change that makes it all the more important for everyone to let their closest relatives know what they would want to happen with their organs in the event of their death. It is also vital that you make sure your decision is registered, so there is no confusion about what you want. Letting people know your wishes for after you die could ultimately save the lives of others.”

Find out more and register your decision by visiting NHS Organ Donor Register at www.organdonation.nhs.uk and share your decision with your family.

Ends

- For additional information please contact Cherry Brown by calling 0151 268 7016 or emailing cherry.brown@nhsbt.nhs.uk or call the press office on 01923 367 600 or email pressoffice@nhsbt.nhs.uk
- For urgent out of hours enquiries please call: 0117 969 2444

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* NHS Blood and Transplant – Transplant Activity Report 2018/19 – pg 62 - The number of patients active on the heart transplant list at year end 2018/19 has increased by 134% since 2010, when there were 126 patients waiting on 31 March 2010 compared to 295 on 31 March 2019

** the active heart transplant waiting list as at 19 September 2019, NHS Blood and Transplant figures

*** NHS Blood and Transplant figures - the number of patients that died on the heart transplant waiting list (or were removed due to deterioration and died)

2018/19 – 21

2017/18 – 31

2016/17 – 39

2015/16 – 51

2014/15 – 59

**** NHS Blood and Transplant – Transplant Activity Report 2018/19 – pg 67 The overall median waiting time to heart transplantation, for adults, was 1,085 days for patients who had never been on the urgent waiting list ('never urgent'). For patients who had been on the urgent list ('ever urgent'), the overall median time on the urgent list before transplant was 30 days. This is for patients registered between 1 April 2011 and 31 March 2016

Notes to editors

- NHS Blood and Transplant is a joint England and Wales Special Health Authority. We provide the blood donation service for England and the organ donation service for the UK. We also provide donated tissues, stem cells and cord blood. We are an essential part of the NHS, saving and improving lives through public donation.
- It is quick and easy to join the NHS Organ Donor Register. Call 0300 123 23 23 or visit www.organdonation.nhs.uk
- Families are always involved in organ donation discussions. You can make things easier for your family by telling them you want to donate.
- Every day across the UK around three people who could have benefited from a transplant die because there aren't enough organ donors.
- Anyone can join the NHS Organ Donor Register, age and medical conditions are not necessarily a barrier to donation.

Media Release



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- One donor can save or transform up to nine lives through organ donation and save and transforms even more by donating tissue.
- The Government has announced plans for a presumed consent system of organ donation to take effect from spring 2020. Under the system, you would be a donor unless you register a decision not to donate. Families will still be able to object to donation so it's important that you make their decision easier at a difficult time by also telling them that you want to donate.