

Understanding the donor experience: looking at the Belfast model

One of the key aims of the Give a Kidney Annual Conference in March 2018 was to focus on variations between donors' experiences. Two non-directed donors gave an account of theirs:

Bob Wiggins initially experienced rather negative attitudes from hospital personnel until he contacted a second, very helpful Transplant Centre.

Despite stating it was the best thing she'd ever done, Kiran Gupta's experience also wasn't straightforward. She sometimes felt let down by lack of communication and support from her local Centre, although the Nephrology Consultants and Surgeon were very helpful and informative. She was not made aware of Give a Kidney's panel of non-directed donor 'mentors' which could have been helpful to her in answering her non-medical queries, or of some of the video clips of case studies and other information which the NHSBT provide. She suggested there could be more flexibility and efficiency with the testing procedure to speed up the process. As a younger donor and from an ethnic minority community, Kiran felt there might be considerations in encouraging younger people to donate; time may be less of an issue for a retired person, for instance, whilst younger donors

may be more willing to travel to have the operation itself at the recipient's hospital, should that make the transplant surgery and co-ordination easier.

The Belfast Brand

Some of these issues were taken up by the next speaker, Aisling Courtney, Consultant Nephrologist from Belfast NHS, who gave a very interesting account of the situation in Northern Ireland, which has a population of 1.8m and just one Transplant Centre. Previously, donor work-up took 18 - 24 months, with a long time between tests and a high drop-out rate.



Kiran Gupta

A much shorter, streamlined process has now been introduced and is proving very successful: an information pack and health questionnaire is sent out, then reviewed alongside the electronic care record. The prospective donor then completes seven of the ten steps in the process all on the same day, starting with the co-ordinator and finishing with the nephrologist who is able to screen for suitability, so everyone has an idea of progress and timing. The wider team, including the surgeons, then discuss each person's assessment, after which the donor

and surgeon meet. 70% of prospective living donors now go on to donate, a rate which far exceeds other UK centres and dialysis cases have declined. The goal is for all altruistic donors to donate to a chain, which is feasible if they start off with a clear timeframe, which will lead to greater numbers of kidney patients being helped.

Lessons can be learned

Belief and trust for the donor is crucial. One person sees all donors in Belfast - who crucially should be enthusiastic about living donation, inspiring confidence and seeing the donor through the whole process. There needs to be a shift in mind-set so that clinicians see the donor as part of the recipient's team. All steps should be donor-friendly, (ie clear time-frames and good communications) - potential donors shouldn't be relegated simply because no match has yet been found.

Give a Kidney can play a role in the psycho-social process that will bring about cultural change, including convincing some clinicians as well as the general public. To this end, the Charity will continue to send a supply of leaflets to all the Transplant Centres once a year.

Kidney donor Alice Green running a marathon

About six months after Alice Green donated her kidney, she felt fit enough to run a marathon. It was a very beautiful location with 2,200 feet of ascent - one circuit of Kielder Lake in Northumbria, famous for its dark skies, so the race started at dusk and ended in the pitch black. She completed the run in 5 hours 11 minutes.

Alice had run eight marathons before her donation and has a further four booked for this year, plus two ultra marathons. The possible impacts on her ability to train

and race had been her main concern prior to her operation, but having had six weeks off running after her donation and gradually building up her strength, she now feels as fit as ever. Her donation appears to have had zero impact on her running since then.

This said, it should be pointed out that kidney donation is a unique experience and not every donor will recover as quickly. It's advisable to read the 'risk' section of the Charity's website (www.giveakidney.org) if you are thinking about donating a kidney.



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Promoting living kidney donation

When promoting awareness of living kidney donation we need to stress how important the issue is. Please take note of these key messages:

- You can volunteer to donate a kidney or part of your liver whilst you are alive to help someone in need of a transplant.
- More than 600 people have donated a kidney anonymously during their life to someone on the National Transplant list, alongside many thousands who have donated to a family member or friend.
- Around 5,000 people in the UK need a kidney transplant.
- The average waiting time for a kidney transplant from someone who has

died is approximately two and a half years. On average, black and Asian patients wait longer than white patients.

- around 40% of all organ donors in UK are living donors.
- A kidney from a living donor offers the recipient the best opportunity of success.

To find out more salient facts, visit: www.organdonation.nhs.uk/livingdonation

World Kidney Day is an opportunity to highlight the decline in living donor numbers and share information and experiences. To help, NHSBT has developed the Promoting Donation Hub online, which includes a Living Donor section. It can be accessed at <http://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/>

Make full use of promotional items available from NHSBT and Give a Kidney. Donors can share their story on social media, talk to local groups such as Rotary, University of the Third Age or with the local press – particularly if you started a chain. Encourage people to join the NHS Organ Donor Register at the same time - and to talk to their family about it.

It's important to break down misconceptions about living donation. For example, you could ask your local hospital to hold an information evening, inviting Trust members, or have a stand during Organ Donation Week. Always direct people to www.organdonation.nhs.uk/livingdonation and giveakidney.org

Jim Newmark's 126 mile cycle on a canal towpath in 24 hours

On 20 August, 65 year old non-directed kidney donor Jim Newmark will be cycling 126 miles on a canal towpath in 24 hours. Jim says: "Canal towpaths, although flat, are sometimes rough and the cycling is not easy. I have actually done this ride before some years ago and found it very tough. A few years older and it will be no easier but at least I hope it will be more comfortable, if slower, on a recumbent trike."

Jim's wife Ann's anniversary present was a voucher entitling him to her full support, and transport, to Liverpool and from Leeds! Other friends have also promised support.

The date may change if it's pouring with rain and Jim plans to undertake the challenge on a week day, in consideration of the many walkers who take to the towpath at weekends. It's a long distance - in cycling terms a "Full Value" ride, but a recent trip to Belgium and cycling there has helped prepare him for the big day.

Proceeds will be shared equally between Give a Kidney and The Williams Syndrome Foundation, as Jim and Ann's young granddaughter, Bessie, was recently diagnosed with Williams Syndrome.

Jim's Mydonate page has already raised £1,015 of his £1,500 target. To sponsor him, please visit: <https://mydonate.bt.com/fundraisers/jimnewmark1>



in an awkward posture. A number of bags of fluid had been placed near his bed, presumably ready for dialysis..."

Jim's donor journey

If you'd like to read an emotive and engaging - and often amusing - account of the thoughts and processes of a kidney donor leading up to the operation and its aftermath, you can do no better than to read Jim Newmark's story, too long to include here but on the website at giveakidney.org Here's a short extract:

"...Then a man enters, slowly self-propelling a wheelchair, looking older but I later learnt only 42, ill, withdrawn, unshaven, head down. He looks as though he has come from sleeping rough. He gets up with difficulty and lies on the bed opposite

Taking Organ Transplantation to 2020 in the Midlands (TOT2020)

Katy Portell was recently appointed Organ Donation Ambassador Co-ordinator with NHSBT. She is developing a national volunteer scheme to promote organ donation in communities throughout the U.K, in alignment with the TOT 2020 Strategy.

In May, an invitation was sent out for individuals who wanted to participate in the Midlands Region pilot of the new Organ Donation Ambassador programme.

Participants in the pilot will help shape the future of this national NHSBT initiative, and include donor family members, recipients and their families, living donors, or others touched by donation and transplant - or indeed anyone who has an interest and passion for promoting organ donation in the area.

Watch this space for an update.

More chains, more transplants!

Since January 2018, all non-directed donors are now included in the UK Living Kidney Sharing Scheme (UKLKSS) quarterly matching run, unless there is a high priority recipient on the national transplant list or, in this 'transition phase', if donors expressed a previous preference that pre-dated the change. This is already making an impact - 55% of non-directed donors are now initiating a chain of either two or three transplants, compared to an average of 25% of donors in 2017. April was the largest matching run to date, with almost 300 registered patients and 82 transplants identified. Non-directed donors have opened up so many new possibilities in the scheme, which means more transplant opportunities for everyone waiting for a kidney.

If you are considering donation...

It is important to be aware that you may not always be able to create a chain if a) there

is a high priority recipient on the national transplant list who you are matched with instead or b) if there is no suitable recipient in the kidney sharing scheme and your kidney is then matched to someone on the national transplant list. This can feel disappointing, but remember that wherever your kidney is destined to be, it is a life-changing gift - not only for that person but for all the people close to them who benefit from a life with a new kidney!

We know that previously more people donated directly to the national transplant list in preference to a chain because the kidney sharing schemes did not offer enough flexibility and choice, particularly about the timing of donation. With the new developments, we want to make the most of your donation by planning ahead and identifying the most suitable matching run that fits with your preferred timeframe for donation. You can have this discussion with your living donor coordinator early on,

so that you are clear about the weeks of surgery that are designated to each quarterly run - usually 5-8 weeks after the run and key dates for your diary.

Last Word

By July, every blood donation centre in England and Wales will have the NHSBT information leaflet 'Can I donate to someone I don't know?' routinely available and updated with all the new changes. A supply of leaflets was distributed to transplant centres and renal units for their leaflet racks last month. Finally, don't forget all the resources that are available to support your promotional activities on the Promoting Organ Donation Hub to order and download at <https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/> Until next time...

*Lisa Burnapp
Lead Nurse - Living Donation
NHS Blood and Transplant*



Give a Kidney and GDPR

At last, the EU's General Data Protection Regulation (GDPR) came into force on 25th May. As a result of related changes to the law, we've all had our inboxes filled with emails from companies which added our details to their mailing lists long ago when we bought something, without the express consent that is now required. We're sorry to have added to that deluge, but grateful to everyone for their help in ensuring we are compliant with the latest regulations.

We have over 600 names on our email list, over half of which positively opted in to the list (we have never used pre-ticked boxes). We have now emailed everyone to explain either that we will continue to email them as usual, or that they need to let us know they are happy to remain on our list, depending on how they originally found their way onto our list.

As a charity, Give a Kidney takes the privacy of our supporters seriously and we have revised our Privacy Policy, so that it explains more clearly what information we collect about you, how your personal information might be used and how it is stored and protected. You can find the Policy at the bottom of every page of our website.

In future, all our emails will include both the offer to unsubscribe from future emails and a description of where to find our Privacy Policy. Do get in touch if you have any questions at all about this by emailing info@giveakidney.org

St Albans locals invited to discover how kidney donation transforms lives



Give a Kidney and Kidney Care UK have combined forces to present a special Living Donation Information event at the Verulamium Museum in St Albans on Wednesday 18 July at 7pm. Local residents are invited along to find out more about how lives can be transformed by donating a kidney as a living donor to one of more than 5000 people in need of a kidney transplant in the UK.

Speakers will include people who have donated a kidney either to someone they love or to someone they don't know on the UK transplant waiting list, those who have received a kidney from a living donor - and specialist clinicians including the Lead Nurse for Living Donation in the UK, Lisa Burnapp.

Fiona Loud, Policy Director of Kidney Care UK, the UK's leading kidney patient support charity said:

"Every single day, three people die waiting for a transplant and around 80% of those who are waiting are waiting for a kidney. There has been a lot of focus on organ donation recently, but we still see that not many people realise that you can donate a kidney when you are alive."

Jan Shorrock of Give a Kidney adds:

"Many people still don't realise that in the same way you can donate blood or stem cells to someone in need, most healthy people can also step forward to donate a kidney. Around 1000 people each year donate in this way in the UK, and around 100 of these donate to someone they do not know, to whoever needs it on the waiting list. Donating a kidney to a stranger can 'trigger' a chain of up to three transplants - so these kinds of donations are incredibly valuable."

Financial incentives or not?

Ethical Kidney Donation Policy Debate at The Buchanan Institute, Edinburgh

Grant Thomson and Colin McLachlan represented Give a Kidney Scotland on the panel for this Policy Debate, held in Edinburgh back in March this year, and Tracey Jolliffe took part from the audience. The topic was whether financial incentives should be offered to encourage non-directed living kidney donation, and if so, what form they could take. The panel also included Dr. Jenni Tocher, Senior Lecturer at the University of Edinburgh (Renal & surgical), Dr. Calum MacKellar, Fellow at the Centre for Bioethics and Human Dignity (Trinity College, Dublin) and Jen Lumsdaine, Transplant Co-ordinator (Royal Infirmary of Edinburgh).

In opening, the panel members were asked to introduce themselves and state their position. Grant Thomson was against financial incentives, saying that even a deferred payment would have actually put him off donating, whereas Colin McLachlan argued that financial incentives could on balance increase the number of kidneys available, and therefore the number of lives saved. Dr MacKellar's stance was that by putting a price on a part of the human body, you are starting to put a price on life, which is immeasurable, and undermines the concept of human dignity. Jen Lumsdaine supported that view, commenting that equity of access in the UK is very important. She quoted a YouGov poll which showed that if awareness of 'altruistic' living kidney donation could be raised, many more kidneys would become available, and argued that legislation for 'opting out' rather than 'opting in' should increase the organs available. However, it was noted that this could have an adverse effect too, giving rise to extremely negative

tabloid headlines where an organ was removed against the wishes of the family - such publicity could be a major setback for organ transplantation.

Calum MacKellar added that research into xenotransplantation could lead to suitable organs being available from pigs, albeit at some time in the future.

Arguments against the proposal for financial incentives included the potential for coercion; some felt that more could be done to encourage people to donate a kidney, or at least to carry donor cards and discuss this with their families, to increase kidneys available for donation. This would promote a change in society, rather than going for the quick fix of financial inducement.

Donors should not be out of pocket, but the effect of financial incentives on the less well off wasn't straightforward. In addition, what would be the effect on current non-directed donors if financial incentives were to be offered in the future? Would the initiative be seen as devaluing the donation already made, or indeed a future altruistic donation? It could be that donors would be viewed in a different light, possibly with the assumption that the motivation for donation was financial. However, others argued that the end result was the most important thing: lives would be saved or greatly improved.

Comments from the audience included comparisons with people volunteering for military service, and discussion on the ownership and value of a person's body. In answer to a question, the Transplant

Co-ordinator explained that a deceased or altruistically donated kidney is allocated purely on a clinical basis, going to the person with whom it could be expected to last the longest.

It was suggested from the floor that the proposal for financial incentives could allow a market to be created by private operators offering more than the NHS for kidneys. However, any scheme introduced would need to be regulated to avoid this happening; a similar system in Iran is an interesting example.

With the continuing problem of the shortage of kidneys for transplantation, how could the number of altruistic donations be increased without financial incentives? National and local publicity campaigns with positive patient stories, speaking to local community groups or charities and at events all helps. Jenni commented that working in organ transplantation was an emotional, ethical, and moral minefield, and discussions with the relatives of deceased donors were particularly delicate, so there is a need to encourage people to talk about deceased donation 'in the very unlikely event of death' with their family, to try to avoid the situation where close family members refuse to authorise the donation in spite of the deceased being on the donor list. Statistics show that where the conversation on donation had taken place, the numbers of donations approved by the family were significantly higher.

This event was not a formal debate, but by the end of the evening it was clear that most people there were against the idea of financial incentives.

One positive result was that some audience members expressed the view that following the discussion, they would personally consider altruistic kidney donation.

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LOVE LOCAL STORIES

Love Local Mag is a local free paper - there are several in Scotland and England, delivered to thousands of homes.

If you live in an area with a similar magazine/paper with local free distribution and you're a kidney donor or recipient, or close to someone who is, why not consider writing an article? Marsha Eastwood from Stirlingshire in Scotland did just that: she submitted an excellent article to her local freebie and

it was published online earlier this year. Remember not to give the date of your operation, to preserve anonymity.

The next meeting of Give a Kidney Scotland will be held on Wednesday 5th September at 6.30pm in the Hilton Edinburgh Grosvenor Hotel, Edinburgh.

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