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TRANSCRIPT OF "FILE ON 4" – "TRANSPLANTS"

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REPORTER:	*Gerry Northam*
PRODUCER:	*Paul Grant*
EDITOR:	*David Ross*

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THE ATTACHED TRANSCRIPT WAS TYPED FROM A RECORDING AND NOT COPIED FROM AN ORIGINAL SCRIPT. BECAUSE OF THE RISK OF MISHEARING AND THE DIFFICULTY IN SOME CASES OF IDENTIFYING INDIVIDUAL SPEAKERS, THE BBC CANNOT VOUCH FOR ITS COMPLETE ACCURACY.

"FILE ON 4"

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EXTRACT FROM NHS ADVERT

PRESENTER: If someone you love was offered a life-saving organ, what would you do? Nothing?

NORTHAM: Across the country, the NHS is trying to persuade us to join the organ donor register.

ADVERT CONTINUED

PRESENTER: Nearly all of us would take an organ, but most of us put off registering as a donor. If you believe in organ donation, prove it.

NORTHAM: The number of transplants is growing, but so is the waiting list – the total is now over eight thousand. Three patients a day are dying for lack of a suitable organ to transplant. Facing a chronic shortage, increasingly surgeons are forced to use organs which they call 'marginal' – some of them from donors with a history of cancer. When a transplant goes wrong, patients naturally ask if the problem was some defect in the organ they were given.

SALLY: I was frightened to death, frightened to death. That's all that was in my head - have I got cancer now from this? Have I been given someone else's cancer?

NORTHAM: File on 4 has learned that organs are sometimes taken from donors over 80, or with a record of drug abuse. Half the lungs used come from smokers. Surgeons acknowledge that the quality of organs is in decline.

BRAMHALL: The donors are getting older, they're getting fatter, they're having more diseases like heart disease and lung disease. What one has to do, as a transplant surgeon, is balance the risks to the recipient from using that organ to the risks of them not having a transplant.

NORTHAM: As the NHS insists that success rates for transplants continue to improve, we investigate the rising problem of marginal donor organs and ask whether patients are being given full information about possible risks.

SIGNATURE TUNE

ACTUALITY IN OPERATING THEATRE

NORTHAM: It's quarter to 8 in the morning and a living donor is about to have a kidney removed here at the largest renal centre in Europe, at London's Hammersmith Hospital. The donor, Lesley Mapletoft, is volunteering one of her kidneys to help her husband David, who's on dialysis for 4½ hours three times a week, which makes it hard to keep up his full time job as a cab-driver. The twelve staff here in the operating theatre are all dressed in blue scrubs, as is their leader, the surgical director Professor Nadey Hakim. And he's about to start the operation to take out one of Lesley's kidneys.

HAKIM: Just holding the knife in my hand, about to make the incision to start the operation.

NORTHAM: How large a cut will you need?

HAKIM: It's got to be a very small incision, I would say 4cm, an inch and a half. I've just visualised the kidney, I can see the kidney nicely …

NORTHAM: Oh there it is, good heavens.

HAKIM: Yes, see the blue structure there you can see?

NORTHAM: Yes.

HAKIM: This is the kidney. Look at what's going to happen now. You see, look?

NORTHAM: Here comes the kidney.

HAKIM: See, the kidney comes out, look, it's like the head of a baby.

NORTHAM: It's quarter to eleven now and David is on the operating table and the kidney is still on the trolley just to my left, and Mr Hakim is preparing David's insides to receive it.

HAKIM: Looks good. I've just finished sewing together the first artery, because now we have the second artery to do, and that will complete the joining of the kidney to the vessels of David.

NORTHAM: So blood is now flowing into the kidney?

HAKIM: Into the kidney, yes. And look at this beautiful colour coming back, reviving the kidney, and then soon we're going to see some urine coming out. I love this operation.

NORTHAM: Two days later, David and Lesley are both recovering nicely.

DAVID: It's a little bit painful, but nothing, nothing out of the ordinary, nothing horrendous. I'm actually starting to feel quite energised. Lying here in a hospital bed, even though I've just had an operation, I feel more energised than I did some of the times when I'd just woken up in the mornings. I feel really good.

LESLEY: I'm a little bit bloated still, but I think if you'd seen me yesterday afternoon I was skipping around quite well. We're hoping once we've, you know, we've settled down and Dave, in particular, can travel, we're hoping to book a holiday, something to look forward to, get out in the sun.

NORTHAM: The great majority of transplant operations in the UK go well and leave happier, healthier patients just like David. But transplanting is a major procedure which can go wrong, particularly if the new organ is itself less than perfect. And for some patients the result is disaster. Recent reports of a veteran of the Iraq War revealed that he had been given cancer by a lung transplant, and that it rapidly killed him under the post-operative drugs to suppress his immune system. Now we have learned of two similar cases involving other organs. In one, a cancerous liver proved fatal, and in the other the patient survived once her transplanted kidney was removed. She's agreed to speak to us in her first interview. We'll call her Sally. Initially it looked as though her operation had been successful.

SALLY: I had the kidney, I woke up the day after, I just felt fantastic. I felt as though my life was going to change. I felt wonderful, even though I'd got all these tubes and everything inside me. When you're on dialysis, your body fills with poisons and it just felt fresh, it just felt clean, I just thought - wow.

NORTHAM: And what happened when you went home?

SALLY: It's the first time my children actually saw me well. For the last 22 years I've always been ill, not been able to do certain things. I was planning the future, doing things, I'd just got a new granddaughter, planning to do things with her. It was just marvellous, they thought it was fantastic.

NORTHAM: And that lasted for how long?

SALLY: Five weeks.

NORTHAM: Then Sally's doctor told her there were abnormalities with her new kidney. Abnormalities so serious that it would have to be taken out again.

SALLY: I asked the question, what are the abnormalities? Why have I got to have it removed? It was me that actually said, 'Is it cancer?' and he said, yes, that's why it had to be removed. I was still given the choice, I could have kept it in, but that was my choice. I may have got cancer from it or whatever, but he strongly advised removing it.

NORTHAM: What did you think when you were told that there was cancer in the kidney that you'd had transplanted into you?

SALLY: I was frightened to death, frightened to death. This kidney had been in me for five weeks and for any cancer to get airborne, that's a long time, five weeks. That's all that was in my head. Have I got cancer now from this kidney? Is it in my bloodstream, is it going through my body? Have I been given someone else's cancer?

NORTHAM: Sally's been through chemotherapy since the new kidney was removed, to be on the safe side. And she's so traumatised that she won't now allow her name to go back on the waiting list for a new organ.

SALLY: It's my personal emotions, I'm just not ready, I just can't even consider going on the transplant list again yet. I don't know in the future, but at the moment it's absolutely no.

NORTHAM: When you look back on this, what do you think about it?

SALLY: I felt as though my life has been ruined, absolutely destroyed. I felt destroyed. My family was destroyed, everybody, it wasn't just me. My husband has to care for me now. When I was on dialysis before, I was coping on dialysis. Now the dialysis is worse.

NORTHAM: And what do you think about all that?

SALLY: Devastated really. It's trying to get my head round it and coping with dialysis and the illness and everything. I still can't get this out of my head, it's just horrendous.

NORTHAM: Sally doesn't know if a history of cancer had been detected in her donor before the transplant went ahead this year. Perhaps surprisingly, even if it had, it need not have prevented doctors using the kidney. Official figures released to File On 4 by the NHS show that last year 34 people with a history of cancer became organ donors. To date, none of their recipients has gone on to develop cancer themselves. The body which co-ordinates the supply of organs is called NHS Blood and Transplant, known as NHSBT. Its medical director for transplants, Professor James Neuberger, recognises how strange it must sound to many people that organs can be used from a patient who's known to have had cancer.

NEUBERGER: The number of cases of donor-transmitted cancers is difficult to assess, but the larger registries suggest it's of the order of perhaps two in ten thousand, so you have the balance of risks. We are understanding now from experience, not only in the UK but around the world, which cancers will preclude transplantation and which cancers will allow transplantation to be done safely.

NORTHAM: But if you were a patient and the surgeon said to you, 'We've got a choice of two organs here, Professor Neuberger. You can have one from a donor who had cancer in their history and another from a donor who didn't,' which one would you choose?

NEUBERGER: That's a hypothetical question, which is a difficult one to answer as a hypothesis. As a patient I would be guided by the surgeon.

NORTHAM: You wouldn't say to the surgeon, 'It won't take me long to make that decision – I'll go for the healthy donor.'?

NEUBERGER: The scenario is not a real scenario as you know. When an organ becomes available, that is the time that a patient and a surgeon have to make the decision. I would certainly myself be very happy to receive an organ from somebody who had had cancer. There is a shortage of organs for transplantation, and therefore surgeons are having to widen the indications for donors. In some cases, this is completely safe for the patient. We're certainly seeing organs from higher risk donors being used in order to meet the ever-growing need for organ transplantation.

NORTHAM: Professor Neuberger released to us statistics which show a substantial increase in the number of imperfect so-called 'marginal' organs used for UK transplants. Ten years ago they were 13% of the total. Today, that's doubled to just over 26%, meaning that one transplant donor in four is officially deemed marginal (that's 235 of last year's donors). These statistics are borne out in the experience of working transplant surgeons.

ACTUALITY IN ICU

BRAMHALL: We're just coming now into one of our intensive care units at the Queen Elizabeth Hospital. This is where patients who are critically ill are transferred from other parts of the hospital, including the accident and emergency department and operating theatres etc. And some, unfortunately, of those patients will develop brain stem death.

NORTHAM: And you can use their organs for transplants, if their families agree?

BRAMHALL: We certainly can, yes.

NORTHAM: Simon Bramhall conducts liver transplants at one of the country's biggest units at the Queen Elizabeth Hospital in Birmingham. He knows that if they don't have transplants, many of his patients will die of liver diseases. So he has to accept an increasing number of less than perfect livers if he's to help keep them alive.

BRAMHALL: The number of young donors has decreased and that's great and that's because of things like seatbelt laws, because of improvements in road traffic accidents etc etc. So what we've done as transplant surgeons is expand our criteria, so we're now much happier to take older donors and, you know, I mean, I've taken a number of organs from donors who are over the age of eighty and transplanted them successfully.

NORTHAM: Eighty?

BRAMHALL: Eighty.

NORTHAM: And it works?

BRAMHALL: Yes.

NORTHAM: What about patients who've smoked heavily?

BRAMHALL: Yes, smoking doesn't seem to affect the liver. Smoking obviously affects the lungs and affects the heart, so smoking is certainly not a contraindication to organ donation.

NORTHAM: Drug users?

BRAMHALL: Yes, we'll happily; I mean, there is almost nothing which is now a contraindication.

NORTHAM: Almost nothing?

BRAMHALL: Even alcohol-related diseases, you know, we would still consider them.

NORTHAM: You're using organs which you're happy to call marginal. Is that a policy, frankly, of beggars can't be choosers?

BRAMHALL: It certainly is, yes, there's no doubt about it, yes. The donors are getting older, they're getting fatter, they're having more diseases like heart disease and lung disease, even kidney disease. What one has to do, as a transplant surgeon, is balance the risks to the recipient from using that organ to the risks of them not having a transplant. And at the moment 20% of my patients are dying on the waiting list.

NORTHAM: The data released to File On 4 show that the total number of transplants is up, helped by a huge rise, 15-fold, in the use of organs from donors over the age of seventy. And last year there were 66 donors with a history of drug abuse. The number of risk factors which a surgeon may be prepared to accept is at the centre of the case of a man who died last year after a heart transplant. John Richardson was a 37 year-old chef who had suffered heart problems since childhood. Four years ago, his health began to decline rapidly and he was eventually placed on the transplant waiting list. He and his wife Karen were told that the shortage of donor organs means that doctors sometimes have to take chances with the organs they have. They understood that, and waited for John's turn to come up.

KAREN: We got an early morning call and we were told that a car would be sent to us to get us to the hospital early morning, which it did. We got there very quickly. We were told to get prepared and obviously there were still tests being done on the donor heart, so that if we were given the go ahead things would happen very quickly, which they did.

NORTHAM: At the hospital, Karen and John found themselves in a hive of activity.

KAREN: Everybody is rushing round doing this and that and you're preparing yourself. Preparing actually how you say goodbye to each other as well, because you don't know if you're going to see that person again and it's a mixture of emotions. John was very upset, he was upset for the donor, said somebody's died to do this, and I'm frightened. It's a mixture of elation that you've got that chance, but also anxiety and sorrow for the other person. It's a mixture of things that you feel.

NORTHAM: A donor heart had been found many miles away and was transported to the operating theatre. John's transplant began, while Karen did her best not to think about the dangers as she waited. She was told that John's heart had been taken out and the new one put in and that he'd shortly be taken off the bypass machine and returned to the ward. Hours later she'd heard nothing, so Karen asked a nurse to find out what was happening.

KAREN: She said that I was advised not to go home because they needed me to stay on the ward, because things hadn't gone to plan and that John was now very sick and that the donor heart needed to be rested because it wasn't working properly.

NORTHAM: And he never recovered?

KAREN: No. He was on a life support for five days, I mean, they did everything possible to maintain him for as long as they could, and I think they were actually surprised that he got through the first night, but he was a fighter by nature and I know that he would have, he would have got better if he had had a good donor heart.

NORTHAM: Did he ever regain consciousness?

KAREN: Never, no, no, not at all.

NORTHAM: John died on the 3rd of August last year. The coroner recorded a verdict of Death By Medical Misadventure, citing the transplant operation, failure of the heart and multi-organ failure as causes of death. But what most surprised Karen was the revelation of a catalogue of factors which troubled her about the new heart John had been given.

KAREN: At the inquest I found out that the donor was a suicide victim by hanging, which was quite a traumatic thing to find out anyway. There was various other issues that suggested that the donor was high risk. He had had an HIV test, he was a smoker and he had taken drugs on one or more occasions.

NORTHAM: What sort of drugs?

KAREN: I believe it was cocaine.

NORTHAM: If he died by hanging, how long was it before his heart was resuscitated?

KAREN: Apparently, when he was found it took the paramedics fifteen minutes to resuscitate him, his own heart, to get a cardiac output.

NORTHAM: If you had been told that this was a young man who had hanged himself, that there had then been a delay in resuscitating his heart and that there were known risks from his lifestyle, what would you have thought?

KAREN: I don't think John would have honestly gone ahead with the operation. I think there was too many risk factors involved to even contemplate it.

NORTHAM: John Richardson's inquest also heard that the heart he'd been given had to have a hole in it repaired before the transplant, and that a problem had arisen while it was being transported. The hospital that conducted the transplant, Papworth in Cambridgeshire, says it operates a careful policy of selection of possible donor organs - going out to assess only 20% of those it's offered, and using only half of them. The Transplant Director, Steven Tsui, pays particular attention to hearts which, like the one John was given, have stopped beating for a time and had to be resuscitated.
If a heart has stopped beating for a substantial time, these things must worry you?

TSUI: Of course that is a concern. One of the rules that we have is that we will make sure that at least 24 hours has elapsed before we assess these donor hearts. In our experience - and we've done studies to look at this in great detail - the outcome is as good as with donor hearts that have never suffered a cardiac arrest.

NORTHAM: What about a donor who had a number of factors about lifestyle which raise high risk?

TSUI: These individually, of course, raises concern but I think it's easy for lay people and the general public to make judgements about lifestyles of donors and so on. We would be alerted to potential problems about infection risk and so on, and so we would be even more rigorous in terms of our assessment process.

NORTHAM: But it seems extraordinary, doesn't it, that so many different risks and compromises can happen to a heart and yet you still use it for transplantation and it goes horribly wrong?

TSUI: When we look at donors, I think we would all like to see young, fit donors with a very clean living lifestyle. The reality is that people with that sort of lifestyle wouldn't die very young. All these donors that we're talking about have died before their time. None of them are in the best of health. So if we want to choose the perfect donor, we may well find ourselves never doing a transplant at all.

NORTHAM: So transplants have to go ahead despite some risks. In a landmark legal case a year ago, a woman patient was awarded £300,000 over her failed kidney transplant. Now Karen Richardson is taking legal advice about Papworth Hospital's treatment of her late husband John's heart transplant. She's taken the case to David Body, head of the Medical Law team at Irwin Mitchell solicitors.

BODY: Cases involving transplanted material are few and far between. It is recognised that NHS Blood and Transplant cannot have optimal material for transplant at all times, but it does seem to us that there are questions to be asked about whether Mr Richardson properly consented and would necessarily have consented to the transplant, whether the transplant procedure itself was as it should be, There are sufficient concerns for us to want to investigate.

NORTHAM: Despite widespread acceptance that the quality of organs available for transplants from dead donors has fallen, the NHS says that results remain good and are indeed improving. But the liver transplant surgeon, Simon Bramhall, is frustrated that the medical advances of recent years have not been fully reflected in better prospects for liver patients.

BRAMHALL: In liver transplantation, the techniques in anaesthesia, the techniques in the intensive care and the technical aspects of surgery have improved enormously over the last twenty years, but actually we haven't noticed a massive improvement in outcomes, and that's really because the donor organs that are available to us are of an inferior quality. The outcome for those recipients is slightly worse, but because we're getting better at it we can compensate. We're now able to make those organs work, if you like, enable the majority of those recipients to come through the transplant process at the end of it. But it often, in my opinion, it takes longer to get those patients to that point, they remain in hospital for longer, they have more complications of transplantation, such as immediate post operative renal failure requiring renal replacement therapy. So there is a whole host of extra problems that we've brought onto our recipient population by using these more and more marginal livers, but we are able to cope with it and the overall results of transplantation are still as good as they were.

NORTHAM: But they should be better?

BRAMHALL: They could be a lot better, yes. Certainly if we had the same quality of organs that we had available to us ten or fifteen years ago then yes, the results of transplantation would be very significantly better than they are now

NORTHAM: For the NHS, Professor James Neuberger insists that higher risk doesn't necessarily lead to worse outcomes for patients. Transplant results continue to improve, he says, and Simon Bramhall's fears are unfounded.

NEUBERGER: Clinical impressions are often misleading and I think this is an example. If you look at the UK-wide figures for liver transplant in 1995, for example, the one year patient survival after a liver transplant was 84%. In 2007 this figure had risen to 90%.

NORTHAM: Well, that's the little increase that he's talking about. He's saying that figure should be well up into the high ninety percents.

NEUBERGER: I think he is probably not taking into account the other factors that are changing. For example, we are doing more patients who are sicker, we are transplanting people who are older, and of course their survival is going to be reduced for natural reasons, so there's a changing case mix. And I think these broad sweeping statements based on an individual's experience can often produce misleading conclusions.

NORTHAM: But it is a fact that one of the things which has changed markedly in recent years is that you are using more marginal organs from donors.

NEUBERGER: The proportion of organs that are classified as marginal has increased, and that may well impact on survival, but it's a far more complex analysis than I think you could just rely on from clinical impression.

NORTHAM: Each transplant calls for a judgment of comparative risk between using the organ that's available, with all its limitations, and leaving the patient untreated and in danger of further ill health or death. Every decision, one doctor told us, is a calculated gamble. So whose decision should it be - the doctor's or the patient's? It's an ethical question raised by another patient's family, the relatives of Stacey Kearns, who died at the age of 38.

ANDERSON: This photograph here of Stacey, proud mum, loved her son to bits, her whole life revolved around him. She was a happy person, she was very involved in the church and went to church every week, of the Catholic faith ….

NORTHAM: Stacey Kearns had a persistent heart problem which wasn't immediately life-threatening. She was given a heart transplant, while her sister-in-law Gail Anderson waited anxiously with her family for news of the outcome. They were told that Stacey's new heart ought to be fine, as it came from a 15 year old girl who'd just died in a nearby town. But Stacey never recovered and was declared dead days later. Gail couldn't understand what had gone wrong, and decided to investigate.

ANDERSON: It just sort of come to our heads that there couldn't have been many local 15 year old girls that had died on the evening in question that the heart was transplanted. So we put it into the internet to see if anything came up, and remarkably

ANDERSON cont: the article that I've got here, the newspaper article came up and we read about the circumstances tragically of the young girl that had died.

NORTHAM: And what does it say about the 15 year old girl in that article?

ANDERSON: Yeah, basically, the 15 year old girl had been found literally dumped outside a police station by her peers, who were not sort of at that point forthcoming as to what had happened; they just said they found her in a collapsed state. The young schoolgirl then had been taken to hospital and it was found at that point that she had died of a stroke, a sub-arachnoid haemorrhage and this was …

NORTHAM: Bleeding in the brain?

ANDERSON: This was bleeding in the brain, and that she had been heavily involved that evening in amphetamine use, alcohol and cannabis use. It actually came out she was known to the police for this as well, this wasn't the first time that this had happened.

NORTHAM: During the inquest process, Stacey's family confirmed that the 15 year old was indeed the donor of her heart. A verdict of accidental death was recorded, the post-mortem cited Acute Donor Heart Failure, Cardiac Transplantation, and Stacey's original heart complaint. The cause of her heart failure wasn't established. Her transplant surgeon told the coroner that he had decided to use the teenager's heart despite knowing of her amphetamine use and also despite hospital guidelines which caution the use of a heart from such a donor. But, he said, the tests conducted on the heart suggested it was an excellent donor organ. A statement to File On 4 from the hospital concerned, Wythenshawe Hospital in Manchester, says it has one of the lowest early mortality rates in the UK, and that in Stacey Kearns' case, the organ was 'a very good functioning heart'. The statement goes on:

READER IN STUDIO: The function was fully assessed by an experienced team, it was considered suitable and a decision was made to go ahead with the operation. Unfortunately there is no perfect donor and transplant teams must look to balance the risks and benefit of a donor organ.

NORTHAM: The hospital doesn't say who took the decision to use the teenager's heart, but it makes no mention of consulting the patient, Stacey Kearns, or her relatives. And that's the point which most concerns Stacey's sister-in-law Gail Anderson. Had Stacey known the origin of the heart that was to be transplanted into her, do you know what she would have done?

ANDERSON: Yes, 100% Stacey would have not had that heart.

NORTHAM: How can you know that?

ANDERSON: She always said, she only ever wanted a perfect heart, she definitely didn't want a heart from anybody who had been taking drugs, because she was so anti drug. I know 100% Stacey would have definitely said no, I don't want that heart.

NORTHAM: And you are confident that she did not know the origin of the heart that she was to get?

ANDERSON: She definitely definitely did not know the origin of the heart that she was going to get. Her family never left her side, I never left her side so I can say 100% she was never never informed of the heart.

NORTHAM: And what do you think about that?

ANDERSON: Ahese surgeons do an absolutely wonderful job and they're very good at what they do and they're saving people's lives, but what I feel they shouldn't be doing is making decisions for people and playing God really, because they're making a decision whether you have that heart or not. It should be an informed decision by the patient whether they want to take that risk and be given all the facts before they make that decision.

NORTHAM: We asked Wythenshawe Hospital to explain its policy on informed consent for transplant patients. Its statement says nothing on this subject.
So who should have the final say over whether an organ from a particular dead donor is to be used - the surgeon who's the professional expert or the patient who's got most at stake?
We've found a wide variety of practice in different transplant centres.

ACTUALITY IN FREEMAN HOSPITAL

DARK: We're going to go in and see Kirsty who's in a cubicle here. She had her lung transplant about five weeks ago and is now making a good recovery. Morning Kirsty, you're looking good this morning.

KIRSTY: I am. I've washed my hair [laughs].

DARK: I think we're now ready to see about you going home.

KIRSTY: Yes …

NORTHAM: At the country's largest lung transplant unit, in the Freeman Hospital in Newcastle, Professor John Dark gives patients a general account of the risks of transplant surgery and the variable quality of donor organs when they join the waiting list. But they learn nothing about their individual donor once the operation is imminent.

DARK: On the night of the transplant we tell the recipient that we have some lungs for them, and that's all the information we'll give them. They know that they may come up here and have the transplant cancelled because the lungs are not satisfactory - that happens in about 30% of cases.

NORTHAM: But that's a decision made by doctors, is it?

DARK: Yes.

NORTHAM: Why don't you tell them the details of the individual donor from whose body they are going to get the organ?

DARK: I'm hoping we've persuaded them of a trust that we will give them the best organ for them and not knowingly give them a badly damaged organ or an organ that wont function well, but they know that in at least 10% of cases the function of the organ will be way lower than normal and some of them will die after the transplant. Lung transplantation is a risky business.

NORTHAM: So you rely on your patients trusting you to make the right decision about the organs you're going to put into them?

DARK: It's the logistically practical way of running the service.

NORTHAM: Is that the same as 'the doctor knows best'?

DARK: Undoubtedly.

NORTHAM: And you're saying the doctor does know best?

DARK: I'm saying the team - and it's usually more than one individual making these difficult decisions - has to have the trust of the patient that they will make the right decision. I think it is fair to say that, whilst patient choice is championed in many other areas of healthcare, it's difficult to reconcile that patient choice with running an efficient transplant service.

NORTHAM: And this approach seemed to go down well with one of the latest recipients in Newcastle, Kirsty, who's 32 and spent the past three years on oxygen for cystic fibrosis.

KIRSTY: Hopefully I've got a good few years, a good quality of life, no breathlessness, no oxygen, just normal life like everyone else.

NORTHAM: What would you have wanted to know about your donor before you had the lungs put into you?

KIRSTY: I don't think I'd want to know anything, to be honest, just that the lungs were good enough to use.

NORTHAM: Professor Dark told me that he wants you to trust him and his team to make the decision and that he thinks that they know best. What do you think?

KIRSTY: Well, I would say yes – better than I do.

NORTHAM: Kirsty's consultant, Professor Dark, fears that giving patients the choice would mean that more organs would be rejected as the most forthright patients decided to wait for a better offer, leaving his waiting list just as long. He makes only two exceptions - he does tell patients if their donor was an intravenous drug user or had a brain tumour. Otherwise, there's no information about the donor. But some other transplant centres regard it as a patient's right to know what risk factors may come with the particular organ they're being offered for transplant. At the Hammersmith Hospital's kidney transplant unit, where we watched David being given a kidney donated by his wife Lesley, the surgical director, Professor Nadey Hakim, argues that patients have the right to know, not the identity of their donor, but relevant facts about them.

HAKIM: You have to tell them, because this is the minimum honesty, you have to make sure you tell the patient there's a remote possibility they can get infected. Otherwise you are really hiding from them very important information and you have to tell them specifically what can potentially go wrong, and some patients will say, 'Well sorry, I'm not having it,' so then we offer it to the next on the list.

NORTHAM: But that decision is the patient's in this hospital?

HAKIM: It is absolutely the patient's decision, obviously advised by the transplant team, surgeons and physicians.

NORTHAM: But if they say no, it's no?

HAKIM: If they say no, of course it's no.

NORTHAM: I've spoken to one surgeon who says the doctor knows best. It's ultimately the surgeon's decision, his decision as to which organs are used and usually the recipients don't get told much about them.

HAKIM: Well, I'm sorry but this is very wrong. We are in the 21st century and I think if it was a member of my family, I would be very offended and upset if the member of my family is not given the choice and given exactly what can go wrong, and the decision is, I'm sorry, not the doctor's decision, it is the patient who has to say yes, I want it done.

NORTHAM: The stubborn fact at the root of this disagreement is that the UK's organ donation rate is low - just over half that of the United States and only just above a third that in Spain. Three years ago, the Government set up a Task Force to get the numbers up. It's found a lack of robust systems around the country for identifying potential donors, consulting their families and retrieving their organs. We are still, it says, 'heavily reliant on a variety of ad hoc arrangements'. There are moves to change this for the better. They'll need to be substantial if transplant patients are to receive the high quality organs they need.

SIGNATURE TUNE