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What you need to know about transplantation

A transplant is widely regarded as the 'gold standard' for a person approaching end-stage renal failure. For some, this may be a pre-emptive transplant (to avoid dialysis) with a live donor, while for others already on dialysis, it is an opportunity to regain control of their life and body. Either way, a transplant is a gift of life, underpinned by love, bravery, generosity and morality, delivered with the dexterity, skill, diligence and care of the transplant team and nursing staff, with its long-term survival secured by research from around the globe.

During the 2012/13 financial year, 1,750 deceased donor (cadaveric) kidney transplants and 969 live donor transplants took place, but over 6,000 people remained on the waiting list for a kidney transplant.¹ This article offers my insights after going through this process twice, having been fortunate enough to have received two transplants – the first a cadaveric transplantation (deceased donor) from a stranger, and the second a live transplant from my wife. Both of these operations have had a tremendously positive impact on my life and the way in which I view things – I think it's fair to say that I appreciate and value the small things, savouring what life has to offer and being mindful of those around me.

While the staff at your renal centre will be able to provide detailed advice, literature and other sources of information before your transplant, nothing quite prepares you like hearing from those who have experienced it already – no matter how many questions you ask, or how many guides, books or information leaflets you read, it is always the 'lived' experience you hanker after (that's why TripAdvisor® is so popular)! With this in mind, I have summarised some practical advice on what to expect before and after the operation, together with tips for your return home and beyond, to be taken in conjunction with advice from your hospital team.

Before the operation

The live donor operation allows you (the recipient) to plan ahead and time when the transplant takes place; it also helps your donor (spouse, sibling, parent or friend) to plan. It may be that you or the donor has certain commitments you need to complete before having the operation.

The cadaveric operation can take place at any time once you have been placed on the national

transplant list. It can be a long wait for some: the average time is approximately three years. While it is obviously difficult not to think about the transplant, it is very necessary to try and get on with your life as best you can.

Hospital transplant co-ordinators, peer groups, support meetings, local kidney patient associations and the NKF (National Kidney Federation) are all useful sources of information to help you prepare emotionally and make informed decisions, as well as to answer any questions.

Time spent in hospital for a transplant is usually seven to ten days; there are, of course, exceptions – it all just depends on your personal recovery. In terms of returning to work, the advised period is anywhere between two and three months, but again, this depends on recovery and your readiness to handle your work commitments. Speak to your employer beforehand to prepare them. Most importantly, find out whether you are eligible for sick pay, for how long and how much. You may be fortunate enough to have the whole period covered by full sick pay; if this isn't the case, find out what benefits you may be entitled to in order to supplement any loss of pay. Remember, if you are having live donation, your donor also needs to consider this.

After the operation

Ask the doctors, nurses and other patients questions. If you don't ask you don't get, so don't be afraid to communicate with those around you. Dietitians and pharmacists will be on hand to give you further advice about food and medication.

Your pain management will be taken care of from the very start. This means that you will have your personal pain relief at the switch of a button (although with a timer). While recovering on the ward you will also have access to tramadol and paracetamol, depending on your pain experience. While no one likes to be in pain, one of the side-effects of too much pain relief is constipation, so my advice would be to go easy!

You will either have stitches or staples on your wound; either way, I would advise that when you feel the need to laugh or sneeze, hold a pillow gently against your wound, otherwise you may feel some pain! This also helps to protect you from developing a hernia.

Let your body acclimatise during the first 24 hours after your transplant: slowly get used to your

surroundings and sip water (you'll be on a saline drip, so there's no danger of becoming dehydrated). If you're hungry, have something small and soft – your digestive system will be sluggish after the anaesthetic.

There's no time for lying around after the operation, so if all goes to plan, mobilise yourself as soon as you can! This doesn't mean you'll be able to go running, or take the stairs instead of the lift for your morning paper, but it does mean getting yourself into the armchair next to your bed and gradually building up movement from there. Not only does this help your digestive system wake up from the anaesthetic, but the movement is good for the rest of your body.

Once the saline drip has been taken out, get plenty of fluid on board. Depending on the advice that you are given, this could be in the region of four litres a day – try to stick to water. This may be an alien concept to those who have been on dialysis for a length of time, but maintaining a hydrated body is an essential part of your recovery, shifting creatinine as your kidney function increases day by day.

Going home

No sooner are you home, you're back for routine check-ups as an outpatient. This could happen three times a week to start with. You'll see familiar faces from the ward and begin to get to know the nursing team. The results you'll be keen to know about are creatinine levels and estimated glomerular filtration rate – both indicators of kidney function – as well as immunosuppressant levels, but also keep an eye on haemoglobin, potassium, phosphate and glucose levels. Your blood pressure and weight will be monitored, and so should your urine. Depending on how your clinic works, you might want to see the same consultant each time you visit; at least that way they get to know you.

Your hospital may subscribe to Renal PatientView, which allows patients to access their blood results online, keeping you informed of your progress. Check with your team whether this is something you can access. I found this extremely helpful – access to my blood results was

reassuring and helped me feel in control; having an awareness of my own blood results before appointments enabled me to prepare any questions about my progress and changes to my medication.

Since you are not driving, and getting a lift to hospital or using public transport might be difficult, make good use of the patient transport that is freely available, usually for a limited period. While it's not flawless, it does take the hassle away.

Once home, the responsibility for taking medication lies with you, which can feel daunting, especially away from the safety of the ward. Don't worry, though. If taking medication is new or you have not taken immunosuppressants before, the trick is to be organised: get yourself a daily pill box, read the instructions carefully and take on

board advice from the renal pharmacist. Set yourself a daily alarm on your mobile phone or digital watch – this will help you get into a routine. It is also useful to have a small pill box to stick in your pocket or bag if you are going to be out all day – keep an evening or afternoon dose with you.

If you were previously on haemodialysis, prescriptions would have been free. Having a transplant means that unless you are receiving certain benefits, your entitlement to a free prescription no longer applies. This may come as a bit of a shock. One way to minimise the burden is to apply for a prepay card: you'll pay just over £100 per year, which can be spread into monthly payments.

It is more than likely that the drugs you are on post-transplant, such as steroids and certain immunosuppressant drugs, could make you more susceptible to weight gain and diabetes. If you are taking a large dose of steroids, there will usually be an urge to eat everything in sight; steroids give you a false sense of appetite and the temptation to pick will be great – believe me! Consider practical things you can do to minimise these pitfalls – for example, not having lots of snacks in the cupboard and keeping a good stock of healthy foods, such as fruit. Understandably, if you've been on dialysis and restricted from eating foods you love, you'll want to enjoy the freedom to eat your favourite foods once more. It's important to strike a balance in relishing these foods once more while avoiding overeating, which is difficult when you're on steroids! Get your loved ones on board to give you a helpful nudge, while the dietitians at the hospital will provide excellent help.

Surgery around the abdomen needs time for the tissue to heal, so it's advisable to keep away from driving – let someone else do it for you! There are no hard and fast rules, but a period of about six to eight weeks away from driving would be sensible.

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Key points

- A transplant is widely regarded as the 'gold standard' of care for patients approaching end-stage renal failure.
- A transplant can have an incredibly positive effect on a person's life, allowing them to resume a 'normal' life – in doing so, giving them a better quality of life.

Once home, it is easy to forget to drink regularly, especially now you are not getting drinks with your meals and jugs of water delivered to your bedside table! Remember to keep hydrated – kidneys love water. Keep yourself regularly topped up, especially while out and about in hot weather, and keep a bottle of water with you.

This is an important part of your recovery once home. My advice would be to take it slowly: gently build up your exercise (find a form of exercise that suits you) and try to do some stretching, too. Walking certainly feels different away from the safety of a hospital setting – once back on the street other people seem to move a lot faster and are not aware of the surgery that you've just had. Be careful – prepare to stop and let people pass! After three months, for the energetic souls among us, incorporate a little running if you feel up to it. Overall, seize the opportunity to be active. The more you do, the more you can do – and your mind, body and soul will appreciate it!

Generally, holidays outside the UK are not advised within the first 12 months, but there are exceptions to this and guidance should be sought from your transplant team.

Immunosuppressants will make you more susceptible to developing skin cancer, so it is imperative that you protect your skin when in the sun. For some, the concept of using sun block might be unusual. My advice is to be careful, use factor 50 and wear a hat – getting sunburnt is not a cool look and it seriously damages your skin.

Conclusions

While it brings renewed health, joy and hope, it is also useful to remember that a transplant can take you (and your live donor) on an emotional journey – before, during and after the operation! It is therefore advisable to draw on support from close family and friends, hospital staff (including renal social workers and psychologists) and patient organisations – don't be afraid to ask for help. It is normal to experience a rollercoaster of emotions, especially immediately after the operation: things are not always straightforward, and at times you may need someone to talk to.

Overall, having a transplant is the ultimate gift, allowing you to resume a normal life, providing the opportunity of participating in activities that make you happy and give quality to your life, sustaining you for years to come. My advice, together with that of your hospital team, should help prepare you well – good luck and good health! ■

Declaration of interest
None declared.

Reference
1. www.organdonation.nhs.uk/statistics/downloads/annual_stats.pdf (last accessed 20/09/12)

Book review

Paediatric Nephrology, 2nd edition

Rees L, Brogan PA, Bockenbauer D, Webb NJA (eds).
Oxford: Oxford University Press, 2012. Oxford Specialist Handbooks in Paediatrics; 656 pages, £39.99

This is a very impressive book, authored by specialists in paediatric nephrology from two major UK centres and assisted by a number of other notable contributors. The information is well up to date, with changes since the first edition in 2007 including simplifications of the concepts of electrolyte balance and renal physiology, as well as knowledge of the rapidly expanding field of genetics.

Wherever children with kidney problems are managed, this handbook provides the basic information and highlights management issues on a whole range of nephrology topics. Symbols and abbreviations are a key point for each speciality, and there are ten pages of these.

Non-invasive ultrasound is the radiological investigation of choice for children and it is good to see renal length for height centiles, which are so crucial for proper interpretation of renal ultrasound measurements. We are also reminded of radiation exposure from other investigations.

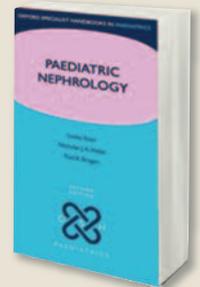
There are good colour plates of renal histology but this seems to be duplicated at the front of the book. It is easy to nitpick, but I was amused to see the 1905 reference for Nicolai Korotkov being quoted in the chapter on hypertension.

In the same chapter I was disappointed that only the values for systolic blood pressure have been moved to the appendices, leaving the terms 'pre-hypertension', 'stage 1 hypertension' and 'stage 2 hypertension' unexplained in the text.

Psychosocial issues such as ethics, adherence and palliative care are included, but there is no reference to the important issue of transition from paediatric to adult-centred care.

This book contains a wealth of information that is readily accessible for practical use. Anyone in contact with children with kidney issues should have it in their pocket, but as paediatricians do not generally wear white coats any more it should be available at clinical stations, as well as with members of the multidisciplinary team ■

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