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Kidney donation journal

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I volunteered as a live donor when my wife needed a kidney transplant. I had surgery to remove my left kidney on 14 August 2013. I have decided to write a brief journal in the hope that it may be helpful or interesting to someone else considering donating a kidney.

Whether to donate is ultimately a personal decision that I cannot really give direct advice on. I do not have any medical qualifications, but my reading of the available evidence suggests that the long term consequences of donating are not particularly significant, keeping in mind that one will need to be quite fit and healthy in the first place to be accepted as a donor. However, the short term costs of organ donation can be significant. This is a relatively time consuming process pre-surgery, with a large number of medical tests. There are also significant opportunity costs in terms of things that you will not be able to do. For example, the direct financial costs in terms of loss of earnings could probably be large for someone who is self-employed. The post-surgery recovery is also not trivial. However, two weeks after my own surgery I would conclude that things have not been as bad as I had feared and I feel as if I can recover relatively quickly from the surgery. (July 2014 update: I believe I have now fully recovered medically, see end of the document for an update.)

Pre-surgery (2010-2013)

My wife and I asked if we could be tested to see if I could be a compatible donor once we knew that my wife eventually might require a kidney transplant. Our local hospital referred us to the Living Donor Unit at Addenbrooke's hospital in Cambridge. They were extremely helpful in answering questions and organizing the relevant tests. The main issue to determine compatibility is your blood type and tissue type. I discovered that I am blood type O and hence a "universal donor". I have often heard the tests for organ donation described as "invasive"; I personally did not find the tests themselves particularly troubling. However, some tests (in particular the Glomerular filtration rate (GFR) test to check how well your kidneys are working) are quite time consuming. Live donation can still be an option even if you are not perfectly matched through an indirect exchange with other donors. I recommend Roth et al. (2004) for a concise discussion on the medical background of renal transplants and how to improve the availability of organs through exchanges.

Week of surgery: 13-19 August 2013

My wife and I checked into the hospital the day before surgery. A number of tests will need to be redone prior to the surgery. A surgeon sees me to do markups for the incisions. Waiting for the

surgery to be carried out the following day is quite strange, but watching the athletics world championship helps pass the time.

1. Day of surgery

The surgery must be carried out sequentially, and the kidney is first removed from the donor. My wife and I can wait together before I am wheeled off to the theatre. I have a nice chat with the surgeon, nurses, and anaesthetist while we wait. I am given an anaesthetic and I must eventually just have dozed off, but I have no recollection of this. I have been told that the surgery itself takes about four hours. I do not recall being in recovery, but I apparently regain consciousness there. I wake up again in the ward. I can remember asking the nurses if my wife has come out of surgery, and I am told that she is still in the theatre. I am woken up later that night by a nurse who says my wife would like to talk to me on my mobile (which I had turned off). Later that night I feel well enough to call my parents. I do not feel extreme pain, although I feel as if I have had something done to me and I cannot sleep on my side. My blood pressure and temperature is very closely watched by the nurses.

2. Day two – day after surgery

In the morning I am taken off the pain release system (which allows you to dispense a morphine based painkiller, although the dose is set quite low and capped at a maximum). My wife gets out of bed before me and comes over for a brief visit. The physiotherapist comes to help me get out of bed. Rolling over on my side is so painful that I curse, but I manage to get up and walk about a bit. I feel quite queasy and vomit, and eventually go and lay down again. In the afternoon I get up again (still a bit difficult, but easier), and walk around without major discomfort. The catheter is removed earlier in the day and I eventually manage to pass water.

3. Day three

I get up (still hard) and walk around without problems. I have a shower and change from a hospital gown to normal clothing for the first time. Our visitors are surprised at how well my wife and I look. I am told that I will be discharged from the ward later that day and move over to a patient hostel at the hospital. My wife will need to be monitored more closely for 5-7 days after the surgery before she can be discharged.

4. Remainder of first week

I am now quite mobile and can walk longer distances. The one thing that remains very painful is coughing, but otherwise I am getting gradually better and able to do more and more day by day. I can do more things now, e.g., reading or watching DVDs, but occasionally get very tired.

Week 2

My wife is finally discharged from the hospital almost exactly a week after we were admitted. All the tests have been fine, and this is about as early as we could have hoped for. Once at home

we can do most things except lifting and driving (which is not recommended immediately after surgery). My wife has some food restrictions, notably grapefruit (which has an enzyme that interacts with an immunosuppressant) and things that contain live culture, which must be avoided for the first three months. However, she is no longer subject to the prior food restrictions on foods high in potassium or phosphate, so overall we have many more options available to us. We can gradually walk longer distances, up to 5km. We were both quite fit before the surgery, and probably benefit from this now in recovering more quickly.

Week 3

We continue to get gradually better, walk faster, and have more energy. I am told by the doctor that I can resume driving. Although we are still not back to normal and my wife will need to be monitored closely for problems for the first three months I start feeling as if we will return to normal relatively quickly.

July 2014

I am now almost 11 months out from the date of the surgery, and my wife and I are both doing well. I believe I recovered relatively quickly from all the direct medical consequences of the surgery. I started running again after one month, and quickly recovered my old level of fitness. (I ran a half marathon in March 2014 and improved on my time from the previous year by 7 minutes). My surgical scar has largely faded, although it still feels a bit lumpy, and I cannot say that I feel any different physically than I did before the surgery at this point. I am a participant in a study the consequences of kidney donation where kidney donors (see Moody et al. 2014), which provides an interesting view into medical research. All in all my experiences since the first journal seem to support the conclusion that the medical consequences of donation are primarily short term and manageable.

This is not to say that recovering from double surgery is trivial. My wife has had to go very frequently to the hospital in Cambridge (a 1.5-2 hrs drive for us), and dealing with the uncertainty can be challenging. It is difficult to start working again after sick leave, much in the same way that it is difficult to try to clear your desk before going on sick leave.

Ultimately, I think in our case the positives of transplantation and donation clearly outweigh any negatives. My wife's health has improved, and she has much higher stamina and can eat a much more varied diet than before the operation.

References

Bradley, Andrew J.; Chris Dudley, Rose Elwell, John Forsythe, Veronica Lennon, and Jen Lumsdaine. ND. *Living Donor Kidney Transplantation: Donor and Recipient Perspectives*. Available at

http://www.organdonation.nhs.uk/how_to_become_a_donor/living_kidney_donation/pdf/donor_and_recip_perspectives-photo-diaries.pdf

Moody, William E., Laurie A. Tomlinson, Charles J. Ferro, Richard P. Steeds, Patrick B. Mark, Daniel Zehnder, Charles R. Tomson, John R. Cockcroft, Ian B. Wilkinson, and Jonathan N. Townend. 2014. "Effect of a Reduction in Glomerular Filtration Rate after Nephrectomy on Arterial Stiffness and Central Hemodynamics: Rationale and Design of the EARNEST Study." *American Heart Journal* 167 (2): 141–49.

Roth, Alvin E.; Tayfun Sönmez, and M. Utku Ünver. 2004. Kidney Exchange. *Quarterly Journal of Economics* 119 (2): 457-488.