

Renal Transplant Patient Experience - “How was it for you?”

On 19th November a new event was held to ask renal transplant patients, “How was it for you” referring both to their personal experience of having a kidney transplant and their experience of the Royal Free Transplant Service

The event was attended by five patients and five members of staff from the renal transplant team; one consultant, the lead nurse, the senior matron, pharmacist and dietician as well as the patient experience team.

Through several presentations and a group discussion, the attendees found out about the future of the service including the decentralization of chronic transplant clinics. Clinics are now being held at Edgware with one nurse led clinic being held there every week and a consultant led clinic once a month. A new unit at Tottenham Hale (which is due to open in the spring of 2014) will also help to bring the clinics closer to the patients. The lead nurse, David Curran also explained that the trust is improving their links with Great Ormond Street Hospital to assist the transition from paediatric to adult patients.

The group also found out about medication given to transplant patients and were told about the possibility of rejection and what happens as a result. Caroline Ashley, the pharmacist explained that transplant patients are now issued with a ‘medication card’ to assist the change from dialysis medication to transplant medication. A pharmacist will go through the medication on the ward with the patient before they are discharged. She also explained that there is a pharmacist now available in clinics for any questions relating to medication.

Dr. Faieza Qasim, Consultant Nephrologist, explained that there is a lot of support for patients in the first three months following transplant as patients attend clinic once a week, but wants to know about further down the line, a year later, for example. She would like to help build a support network for continuing education for patients and carers: from dialysis to transplant and back to the possibility of dialysis again.

One of the attendees said that following their transplant they went online to www.transplantfriends.org where they found it easy to connect with others who have been through the same processes and procedures. For example, if drugs are not working then communicating with others who have had a transplant is a lot better than seeing a psychologist. One member of the group said that a ‘buddy’ system could be a good idea and another attendee explained that she has already told staff she can be contacted by other patients who may need someone to talk to about their experience.

The Royal Free Hospital Kidney Patients Association (RFHKPA) has an email address that anyone can use to contact a member of the RFHKPA committee. Patients should also be told that they can call any committee member and there is a representative for each of the satellite units. The chairman of the KPA was present at the meeting and said that when a ‘buddy’ system was trialed a couple of years ago, there wasn’t much interest. Dr. Qasim wondered if it could be re-launched under the “how was it for you?” branding.

The Royal Free transplant Service would like to find ways of improving feedback about patient/carers/relatives experience so that it becomes a regular part of the care pathway and can be given easily and frequently so that they can evaluate and respond to continually improve.

All of the points discussed at this event will go on to help form the agenda to devise future events for post-transplant patient education, support and feedback. With the support of the Royal Free KPA and colleagues, Dr Qasim is also facilitating the 3rd National Kidney Transplant Patients' and Carers' Forum at Cumberland Lodge on April 10th 2014.