Clinician questions for Dr Hameed Anijeet

1. It's too late for me, but for other patients who don't respond to the normal pathway of treatment and medications what is being done? Are you opening up to more 'trial drugs' or looking into non traditional methods of treatment?

Thank you for your question. Like all the kidney units in the UK we are also linking with primary care to identify chronic kidney disease patients as early as possible. This will help us to identify patients with CKD early and slow down the progression. On the question of trial drugs we do take part in many national clinical trials and hope to undertake some pioneering research locally as well. We are duty-bound to make sure that we only undertake research which has passed through robust safety mechanisms that are laid by national research committees. Unfortunately we will not be able to offer non-traditional treatments if they have not been proven to be beneficial and has been accepted nationally as a treatment choice. I hope you understand the balance all of us have to strike between safety and efficacy of treatment.

2. I would like to ask why it takes months to get on the transplant list and get friends tested for matches. All the tests could be done in a couple of weeks. Total lack of urgency

Thank you for your question regarding this. We do recognise the need for quick assessment and surgery when a suitable donor and recipients are identified. We are going to undertake a quality initiative (QI) project on "transplant first" this will address all aspects of patients being referred to transplantation. May I also point out that sometimes many donors may have to be tested before we can identify the most suitable one to donate. We also may need to undertake sometimes detailed examination and help from other specialities before a donor is deemed suitable. In view of patient confidentiality we are not in a position to divulge details of donor work up to the potential recipient. As you may know to avoid any conflict of interest donor workup is done by a team which has no input to the recipient's clinical care. We will always strive to work with the patient and family to try and improve this and we are quite hopeful with the transplant first quality initiative we will achieve this.

3. I saw an interesting post elsewhere this week - that might be worth asking about - it was discussing when to start on treatment - & would a phased start be beneficial? ie if we currently start treatment on a 12 hour 3x4 treatment plan at an eGFR of say 10 Does Dr Anijeet think it would help preserve kidney function for longer if instead we started with 4 hour 2x 2 hour treatments at an eGFR of 20 to relieve some of the pressure on the failing kidneys?

Thank you for question regarding what is described in the medical literature as "incremental dialysis". The jury is he still out on this issue and at the moment there are no national guidance on this. It is suggested that the patients starting on incremental dialysis may lose their residual function (passing urine) slower but there's no evidence that starting early will relieve any pressure on the failing kidneys. There's also evidence to suggest that the patients started on incremental dialysis are very reluctant to increase dialysis hours and frequency at a later stage. This could be detrimental to their care.

When to start of dialysis always been very difficult to identify and a randomised control controlled trial (gold standard in answering a clinical question), did not show any improvement in patient starting early versus patient starting late. The start of dialysis usually is usually quite individualised depends on the eGFR, symptoms of fluid overload, acidosis, potassium levels etc. It is possible that in some patients incremental dialysis may be beneficial, this will have to be individualised depending on the clinical situation.

In view these uncertainties, I cannot see incremental dialysis becoming a normal practise neither in our unit nor nationally at present.

4. I'd like to ask is there a medical pathway for long term Dx patients in managing the disease in conjunction with other co morbidities and Specialities. If not this is something that is sadly lacking, in terms of communication between specialities and the best interests of the patient.

Thank you for your question regarding long-term management of comorbid conditions in patients who have chronic kidney disease. This has been a particularly important area for our kidney unit and we have started to do some initial work to identify whether these patients can be seen in a clinic with maybe GP or the practice nurse leading on the care, with the secondary care input as and when needed. As you can see this needs a lot of buy in from all the stakeholders and we will continue to try and get everybody on board regarding this. At the moment we do copy our clinic letters to all the different specialities and they also normally communicate with us and the copies of these are available in our electronic system to be seen by all the clinical team. The new electronic patient record that is being implemented between Royal and Aintree is likely to improve communication. I do hope that you understand that there's a lot of work needed to achieve fully integrated clinical care between all the teams looking after a particular patient.

5. I'd like to know why other non renal consultants won't do elective operations and use the line 'well there's no point your a renal patient, if it becomes serious we can think about it then'! It seems no communication between disciplines, why? We're not dead we should have access to other treatments before they become life threatening.

I'm uncertain what the question is regarding but I assume that this is about dialysis line being used by other specialities. Most of our patients do undergo other operations like hernia operation or joint replacement etc

When a patient is dialysing through a line, am sure you agree that this is essential to provide dialysis treatment. When it gets used by clinical teams who do not know how to use them, we have noticed increased risk of clotting and infection. Many clinical teams do not know that these lines are locked with medications to prevent clotting. When they use the line without aspiration first, then they are likely to push the locking solution into the patient and this may lead to problems with anticoagulation and infections. In view of this we do tend to suggest that the dialysis line only be used by the specialist team i.e. the dialysis nurses who is able to undertake the right sterile precautions and is aware of the locking solution.

I hope I have answered your question I'm happy to clarify if this is not what the question was about. May I add and we do try and communicate with other specialities and at the Royal we do have an oncall team, which I can be contacted by any specialities and the teams around the region.

- 6. Also when will Stem cell therapy and mitochondria transplants be looked at? I'm sure many of us would offer to take part, as we have nothing to lose everything to gain.
- 7. Are there any promising lines of research that could lead to alternative treatments to dialysis/transplant, e.g. stem cell treatments, artificial kidneys etc.

Thank you for your question. The therapies that are mentioned are at a very early stage of development. It takes many years for something developed in a lab to become routine clinical practice. This is usually descried as "Bench to bedside" or Translational research. There's Wikipedia website on this https://en.wikipedia.org/wiki/Translational research

As you can see most of these projects have to go through many stages before it becomes part of routine clinical practise. We do need to make sure that safety of patients is not compromised. We do understand the frustration that is expressed but we cannot offer experimental treatments to our patients unless it has gone through the robust processes. Thank you

8. What is the general recommendation regarding transplant and pregnancy is it best to be planned with the renal/transplant team and will it be fully supported throughout if deemed safe?

In general we would recommend delaying trying to conceive for 1 year after transplant. Usually by this time you would have achieved stable kidney functions and stable immunosuppressive drug therapy. If you take Mycophenolate Mofetil it is very important to use reliable contraception as this drug has been shown to be associated with a risk of developmental abnormalities in the baby if used in pregnancy.

Pregnancy in a transplant patient is generally higher risk than in the general population and so does have to be well planned. Some medications may have to be changed prior to you getting pregnant, once pregnant you will require closer monitoring for you and for the growth of the baby. We do have a special Kidney-obstetrics clinic which is run by Dr Brown and Dr Clement-Jones at Liverpool Women's Hospital. When you are thinking of getting pregnant let us know and we will refer you to the specialist clinic for pre-pregnancy counselling. Here they can discuss the implications of pregnancy on an individual basis to allow you and your partner to make informed decisions about pregnancy, they would then look after you during a pregnancy.

9. What is the reason/causes for recurrent UTIs post-transplant?

Thank you for your question regarding UTIs. There are many reasons why post-transplant patients are at a higher risk of UTIs and also other infections.

The main reason is that your immune system is suppressed by the medications you have to take after a kidney transplant. When the immune system is suppressed then this will lead to increased chance of Infection. Females are more likely to get UTIs due small urethra. There may be other reasons like vaginal prolapse, lax pelvic floor muscles, kidney and bladder stones etcetera. If you are experiencing repeated UTIs, please do highlight this to the one of the clinicians in the kidney transplant clinic who will organise further investigations and referral to Urology and/or Gynaecology teams.