

# Questions to ask the doctor

## Introduction

When you see your nephrologist (kidney doctor), or transplant surgeon, they are likely to have a fixed time slot for your appointment and may not be able to answer all your questions during one consultation. Rather than bombarding them with questions, try to plan your questions and ask about one or two topics each time. If there is not time to ask the questions you want to ask, ring the consultant's secretary and see if you can book an extra 30 minute appointment, not during a conventional clinic.

**This article looks at some of the topics you might like to ask about.**

## Cause of renal failure

- What is the cause and name of my kidney problem?
- How did I get this disease?
- Is my condition curable?
- What other factors may have contributed to this condition?
- Do I have any other important illnesses?
- How do these illnesses relate to my kidney disease?

## Genetic/family concerns

- Is the cause of my renal failure genetic/inherited?
- Do I need to suggest to any family members that they should have their kidneys checked?



## Investigations

- What blood tests, urine tests and scans will be necessary?
- What are the risks and benefits associated with these tests? Please tell me straight.

## Haemoglobin

- What is my haemoglobin? (It should be greater than 11 g/L.)
- If it is under 11, how are we going to make it OK?
- What is my ferritin (iron level)? (It should be more than 100 mcg/L unless you are on haemodialysis, when it should be more than 200 mcg/L.)
- If it is under 100 mcg/L, how are we going to make it OK?

## Biochemistry

### Predialysis

- What is my blood creatinine level? (Normal is less than 120 mcmol/L – the lower the better.)
- What is my estimated glomerular filtration rate (eGFR)? (Normal is greater than 90 ml/min/1.73m<sup>2</sup>. The number roughly equates to percentage renal function, so the higher the number the better.)
- These two tests are how doctors now measure renal function and you may be referred to a kidney specialist if your creatinine is above 120 mcmol/L; your eGFR falls quickly, drops to less than 60ml/min/1.73m<sup>2</sup> at a young age, or you have other signs of renal disease.
- What is my potassium? (It should be less than 5.5 mmol/L.)
- How quickly is my kidney disease progressing?
- Is there anything that can be done to slow it down?
- If not, am I going to need dialysis? When?
- Am I on the list for a kidney transplant? If so, please show me the evidence for that.

### Dialysis

- What are my 'figures'? – i.e. am I receiving enough dialysis to keep me well?
- If not, how can we achieve that?
- What is my potassium? (It should be less than 6.0 mmol/L, pre-haemodialysis (if you are on haemodialysis), and all the time if you are on peritoneal dialysis.)
- Am I on the list for a kidney transplant? If so, please show me the evidence for that.

### Transplantation

- What is my creatinine? (Ideally it should be below 120 mcmol/L.)
- What is my eGFR? (See above, although often after transplant eGFR will not return to greater than 90ml/min/1.73m<sup>2</sup>.)
- What does that mean in terms of my percentage transplant function?
- What is my potassium? (It should be less than 5.5 mmol/L.)
- How long will this kidney last for?
- Will I ever need another kidney transplant?
- How do I know if my transplant is failing?

## CKD-MBD (Renal bone disease)

- Do I have any evidence of CKD-MBD?
- If so, how is it being treated?
- What is my PTH (parathyroid hormone)? (It should be less than 10 pmol/L.)

## Blood pressure (BP)

- What is my BP today?
- How often should I have my BP checked? Who should check it? How?
- What is the perfect BP for me?

## Water balance

- Do I have the right amount of water in my body?
- Am I overloaded (water-logged, i.e. too much water) or dry (not enough water)?
- How can we correct this issue?

## Urine tests

- What are you measuring in my urine? (usually proteins.)
- Why do I have protein in my urine?
- How do the results affect me now and in the future?
- How can we reduce the amount of protein I lose in my urine?

## Dialysis

- Which is the 'best' type of dialysis for me?
- Can I change to a different type after starting one?
- What role will I have in my own care?
- Will dialysis be done in the hospital, a 'satellite' (local) unit or my home?
- If I decide to dialyse at home, where will I get the training, equipment and supplies?
- How are equipment and supplies delivered?
- I don't have a car or anyone to drive me, how do I get to hospital/dialysis unit for my treatment?
- How often do I have to have dialysis and for how long?

## Transplant

- What medicines will I need to take? What happens if I run out?
- What side effects should I look out for?
- How often do I need follow-up blood tests, and what other tests will I need?
- Do blood levels need to be done for any of these drugs? What are the desired blood levels?

- How soon can I return to work/have sex after my transplant?
- What am I responsible for over the long-term?
- Where do you get the kidney you use for transplantation from? (Deceased donor, live-related, live non-related.)
- How good are you (or any centre you refer me to) at each of these types of transplant, compared to national and regional averages?
- Can I choose where I have my transplant? (Yes you can.)
- What are the benefits, risks and possible complications associated with a kidney transplant?
- What can I do to make it work, and stay working?

## Diet and exercise

- Could changing my diet help slow or stop the progression of my kidney disease?
- What kind of support is available to help me change my diet?
- Could exercise help to improve my condition? If so, what kinds of exercise can I do and how often should I exercise?
- Could exercise and diet help me to avoid having to take certain medications?

## Contacts

- What are the names of my consultant (doctor-in-charge), nurse and dietitian? How do I contact them? What are their telephone numbers?
- Who/how do I contact someone in an emergency? What telephone number do I ring?

## My mood

- If I am feeling low, do you have someone I can talk to? (Some units have their own psychologist or a counsellor.)



## Research

- Will I be asked to help in research studies? Can I refuse to take part in research?

## Life expectancy

- How long am I going to live for?

## Information

- Can you recommend other sources of information? Books, pamphlets, websites?

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