

Shared Decision Making – established kidney failure

Next clinical update March 2018

Deciding what to do about established kidney failure

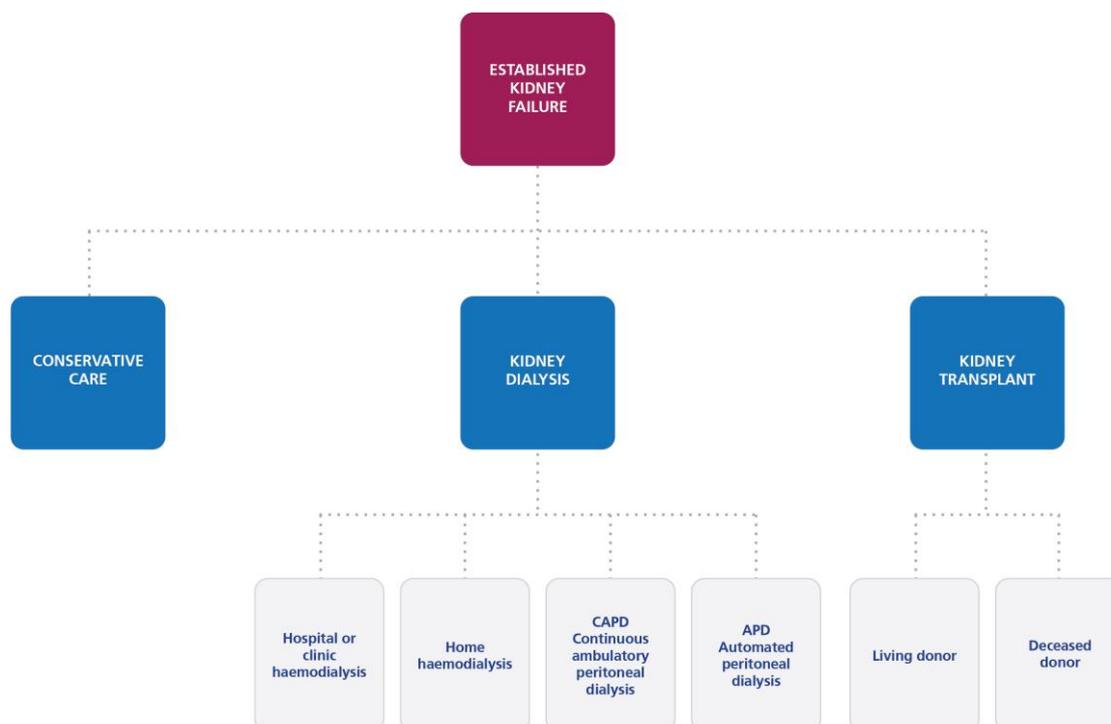
This short decision aid is to help you decide which treatment to have when your kidneys start to fail. If your kidneys stop working you may be told by your doctor that you have established kidney failure. This is sometimes called established renal failure (ERF), stage 5 chronic kidney disease (CKD) or end stage renal failure (ESRF).

You can use this decision aid on your own, or with your doctor, to help you make a decision about what's right for you at this time.

There are three main treatment options if you have established kidney failure. These choices are:

- Conservative care, where your symptoms are managed by medicines. This treatment does not filter your blood or take on the work of your kidneys.
- Dialysis, where treatment filters your blood, taking on some of the work of your kidneys. There are four main ways of having dialysis.
- Kidney transplant, where you have a new kidney from a donor, either living or deceased. Not everyone can have a kidney transplant. There are two main types of kidney transplant.

Note: Dialysis and Kidney transplant are covered in more detail in separate short decision aids.



What are my options?

	Conservative Care	Kidney Dialysis	Kidney Transplant
What is the treatment?	Conservative care is a package of treatments that treats your symptoms. It doesn't filter extra fluid and waste products out of your blood. The aim of conservative care is to make you comfortable and relieve your symptoms, not to extend your life.	Kidney dialysis aims to keep you healthy by filtering your blood, taking on some of the work that your kidneys can no longer do for themselves. Dialysis is a treatment that removes the extra fluid and waste products from your blood. There are two main types of dialysis treatment - haemodialysis and peritoneal dialysis. You may be able to have them at home or in hospital.	A kidney transplant involves getting a healthy kidney from a donor to take over the work of your damaged kidneys. The donor can either be someone who is living (often a family member or a friend) or someone who has just died (called a deceased donor).

	Conservative Care	Kidney Dialysis	Kidney Transplant
What is the effect on your length of life?	<p>Conservative care does not help you live longer. People having conservative care tend to live for one or two years after starting treatment. Your length of life depends on many things, including your age, other illnesses, how much kidney function you have left, and how quickly it's getting worse. Around 47 in 100 people aged 75 or over are alive two years after starting conservative care.[6]</p>	<p>It's common for people to live for many years on dialysis. Your length of life depends on many things, including your age, how healthy you are, how much kidney function you have left, and how quickly it's getting worse. The type of dialysis, and whether you have it at home or in hospital, does not seem to make much difference to how long you live. In the UK, between 95 in 100 and 99 in 100 people aged 18 to 54 are alive a year after starting dialysis.[7] However, for people older than 54 years, these figures may be lower.</p>	<p>Having a kidney transplant can help you live longer. About 89 in 100 to 96 in 100 people are alive five years after having a transplant. And 66 in 100 to 79 in 100 people are alive 10 years after having a transplant. [8] Your age and overall health play an important role in how long you live. Also, people who have a kidney from a living donor tend to live longer than those who have a kidney from a deceased donor.</p>

	Conservative Care	Kidney Dialysis	Kidney Transplant
What is the effect on your symptoms?	<p>The aim of treatment is to improve symptoms. But most people who have conservative care will still have some symptoms. Weakness and tiredness are most common. A poor appetite, pain, itching, and shortness of breath are also likely for around half of people on conservative care.[6] However, it's not always easy to tell which are symptoms of kidney disease and which are caused by other illnesses.</p>	<p>Dialysis should improve your symptoms more than conservative care.[6] But if dialysis is not working well enough, you may have weakness, tiredness, a poor appetite, and pain. The different types of dialysis are likely to work equally well in controlling your symptoms.[9]</p>	<p>Your symptoms should get much better or go away completely after a kidney transplant.[10]</p>

	Conservative Care	Kidney Dialysis	Kidney Transplant
What is the effect on what you can do?	The treatment itself does not restrict what you can do. Your general health and symptoms may restrict what you can do. Around 75 in 100 people say they have trouble getting around.[6]	Your holidays, work, and social life need to fit around your dialysis schedule. Different types of dialysis require different schedules. With haemodialysis, you will probably have dialysis sessions lasting at least four hours, three or more times a week. You can't move around while having this type of dialysis. With continuous ambulatory peritoneal dialysis, you do fluid exchanges four times a day, every day. You can move around while having this dialysis. With automated peritoneal dialysis, you have dialysis by a machine overnight while you sleep.	You should be able to return to your normal activities after a kidney transplant.

	Conservative Care	Kidney Dialysis	Kidney Transplant
What are the unwanted side effects of the treatment?	You don't get side effects from choosing conservative care. This because having conservative care doesn't usually involve taking new treatments. However, you may get side effects from the treatments you're already taking to manage your symptoms.	Possible side effects include tiredness, weakness, shortness of breath, itchy skin, muscle cramps, restless legs, weight gain, a sudden drop in blood pressure, and infections. The side effects you get depend on what type of dialysis you have.	All operations have the risk of complications such as bleeding or infection. But after a transplant, the main side effects are from immunosuppressant drugs. You're more vulnerable to infections and to certain cancers, because the drugs stop your immune system from working as well.

	Conservative Care	Kidney Dialysis	Kidney Transplant
How much time do you spend in hospital or on treatment?	You are likely to spend less time in hospital than if you were having dialysis. You may not need to go to hospital at all for treatment.	You'll need regular checks and blood tests to monitor how well your treatment is working. If you have peritoneal dialysis, you will also need to spend one or two days in hospital having an operation to put in a catheter.	You will probably stay in hospital one to two weeks after your transplant. Then you'll have frequent appointments for several months, which could be several times a week. Eventually you should only need check-ups every three to six months. But you'll need to continue taking immunosuppressant drugs for as long as you have your kidney - usually for the rest of your life.

	Conservative Care	Kidney Dialysis	Kidney Transplant
What is effect on your diet?	You may not need a restricted diet with conservative care, but this will depend on your symptoms. You only need to restrict your fluid and salt if you are getting symptoms like puffiness from excess fluid.	You may need to restrict the amount of salt, potassium, and phosphate in your diet. A dietician can help with this. You may also need to restrict the amount of fluid you drink. The restrictions on diet and fluids are usually stricter for haemodialysis.	Usually there are no diet and fluid restrictions after a kidney transplant. However, some people do need to modify what they eat, because of other health problems (such as high blood pressure and high cholesterol) or their immunosuppressive drugs.

What are the pros and cons of each option?

People with established kidney failure have different experiences about the health problem and views on treatment. Choosing the treatment option that is best for the patient means considering how the consequences of each treatment option will affect their life.

Here are some questions people may want to consider about treatment for established kidney failure:

- Do they want a treatment that will help them live as long as possible?
- Do they find their symptoms intolerable?

- Do they want to be able to do more everyday things than they can at present?
- Are they willing to spend time in hospital, or having treatment?
- How much does restricting their diet bother them?
- Are they willing to take the risk of side effects or complications from treatment?

How do I get support to help me make a decision that is right for me?

People using this type of information say they understand the health problem and treatment choices more clearly, and why one treatment is better for them than another. They also say they can talk more confidently about their reasons for liking or not liking an option with health professionals, friends and family.

References

6. Murtagh FEM, Marsh JE, Donohoe P, et al. Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrology, Dialysis, Transplantation*. 2007; 22: 1955–1962.
7. Castledinea C, Steenkampa R, Feesta T, et al. UK Renal Registry 13th Annual Report (December 2010): Chapter 6 Survival and Causes of Death of UK Adult Patients on Renal Replacement Therapy in 2009: National and Centre-Specific Analyses. *Nephron Clinical Practice*. 2011; 119 (suppl 2): c107–c134.
8. Statistics and Clinical Audit, NHS Blood and Transplant. Transplant activity in the UK. Activity Report 2010/11. Available at http://www.organdonation.nhs.uk/ukt/statistics/transplant_activity_report/current_activity_reports/ukt/activity_report_2010_11.pdf (accessed on 6 June 2012).
9. National Institute for Health and Clinical Excellence. Peritoneal dialysis: Peritoneal dialysis in the treatment of stage 5 chronic kidney disease. July 2011. Clinical guidance 125. Available at <http://www.nice.org.uk/cg125> (accessed on 6 June 2012).
10. Kidney Research UK. Kidney transplantation. Available at <http://www.kidneyresearchuk.org/health/factsheets/ckd-and-issues/kidneytransplantation.php> (accessed on 13 April 2012).