

MAKING CHOICES: Living with advanced kidney disease

A guide to Maximum Conservative Care
for those considering alternatives to dialysis

Is dialysis the right choice for me?

For many patients with renal failure, having regular dialysis will greatly improve their quality and length of life. However, for some this treatment may not be so beneficial. In particular, those who have other significant health problems may experience dialysis as a burden, causing an unacceptable degree of suffering.

It is important to stress that all patients have the right to choose their treatment, or decide not to have certain forms of intervention. There is no obligation to have dialysis and the team at the Sussex Kidney Unit will be fully supportive of whatever choice an individual makes. However, this is never an easy decision and so it needs to be based on full information and open discussion with all those closely involved.

Patients with end stage kidney failure, which means that the kidneys are working at a very low level, usually less than 10% of normal function, will be offered dialysis treatment if they wish to have it. However, dialysis only partly replaces some functions of the kidney and may not improve other health problems. Some conditions, such as heart failure, may worsen through the treatment. Therefore, it is important to have a clear understanding of the likely advantages and disadvantages of undertaking dialysis.

Those who decide not to take up this treatment have differing reasons for doing so. Some may feel that dialysis will have too large an impact on the remainder of their lives, with questionable benefit; for example, travelling to hospital three times weekly, often in addition to other appointments, may feel too demanding. Dialysis is not always straightforward and can be a lifetime commitment, involving changes to a person's lifestyle and daily activities.

Though older age in itself is no barrier to commencing dialysis, some older people may feel they are too frail, or they may have other diseases which make them less likely to do well on dialysis and to feel benefit from it.

Your first decision does not need to be final. It may be possible to choose to have dialysis, perhaps for a trial period to see if it is helpful both from a medical and a psychological point of view; however, starting dialysis in an unplanned way can be difficult.

What happens if I choose not to return to dialysis?

Some people who have had a transplant which then fails may decide to decline to restart dialysis. Again this may be due to a number of personal and individual considerations. The impact of the loss of a transplant may be very great and it may be unbearable for some people to consider a return to dialysis again. This is an understandable and acceptable reaction; though not everyone will feel like this. Others may decline treatment at first and then decide to restart once they have had a chance to adjust.

All patients should have the opportunity to think this through and to feel that they have been listened to. Often people who have been very unwell, or have had a failed transplant or other significant events, may feel depressed or despairing. It may be that with time, increased support or medical interventions the situation could improve. It is important that staff are aware of these feelings in order to offer appropriate help. They will have plenty of experience of working with the different choices people make in managing their kidney disease and their future care.

What if I choose to stop dialysis?

For some there may simply come a point where they feel that dialysis is no longer maintaining or improving their health to a satisfactory standard; what this means will vary from person to person and is difficult for others, not themselves in that situation, to assess. Therefore, the team at the Kidney Unit will be supportive of an individual's decision and respectful of their wishes.

The doctor and staff may offer opinions as to whether someone will benefit from dialysis; however the decision is ultimately up to the person concerned. What is most important is that the decision represents a fully informed choice and that the individual understands the impact of stopping dialysis.

It can be useful to explore feelings openly with family and friends. Many people find it quite difficult to bring up the subject of stopping active treatment and are concerned that their views will not be listened to, or that they will face opposition or be judged by others.

There is help available to assist with raising the topic and health and counselling professionals and members of the chaplaincy team will be pleased to be part of this process. It is essential that the healthcare team also be involved in making this decision, so that they understand the particular problems and concerns of the individual. As much time as is needed should be given to discuss fully the reasons for deciding not to have dialysis.

Some people may worry that deciding not to start, re-start or continue dialysis may be seen as suicide or assisted dying. These worries can be discussed with a counsellor, medical staff or a chaplain, but the 'no dialysis' option is generally seen as a reasonable choice for those for whom dialysis is unlikely to maintain or improve quality of life.

What is Maximum Conservative Care?

For those who decide not to have dialysis, for whatever reason, the best possible medical care will still be offered. This kind of management of a person's health is often known as Maximum Conservative Care. It is a valid and frequently used treatment choice, particularly for those people for whom dialysis is unlikely to extend life, or where it may detract from the quality of life remaining.

The Aims of Maximum Conservative Care:

- preventing and treating symptoms of kidney disease
- preserving remaining kidney function
- achieving the best possible quality of life
- providing psychological, social, financial and spiritual support
- planning for the future
- preventing unnecessary visits and admissions to hospital.

It should be emphasised that a 'no dialysis' option does not equal a 'no treatment' option. Maximum Conservative Care is designed to offer the best possible quality of life and freedom from symptoms for the remainder of a person's life. Though there will be more 'hospital-free' days, and the emphasis will be on comfort and support, this type of medical care has equal importance to other treatments, including dialysis. Patients will still have easy access to the Renal team and be able to contact team members who know their situation best. Care will be managed by the team or by the GP and district nurse team and everyone will work together to ensure the best care and support in order that patients remain active and independent for as long as possible.

Treatment on dialysis can vary and the effectiveness of this will often depend on a person's overall health and on how much kidney function still remains, amongst other factors. For those with a reasonable amount of kidney function and stable kidney disease, good management may mean a number of years of life. With little or no function survival is less, sometimes months or even a few weeks.

People often ask what will happen without dialysis. Those with other serious health problems may die as a result of other illness and not necessarily of renal failure; in these cases choosing not to dialyse may have little effect on their outcome.

Treatment offered in Maximum Conservative Care will aim to protect remaining kidney function (if applicable) and prevent or treat symptoms of kidney failure. For example, as kidney failure progresses, symptoms may develop which can be relieved; these may include:

- tiredness
- itching
- feelings of nausea,
- swelling in the legs from fluid retention.

It is particularly important to report any symptoms in order that the right medication can be prescribed and advice can be given e.g. dietary support.

Without dialysis treatment, people with end stage kidney failure will ultimately die. In end stage kidney failure, if untreated, fluids and toxins will build up in the blood and, as the end of life approaches, symptoms may become more pronounced, such as sleepiness and breathlessness. Again, those looking after a person will continue to address these symptoms and do everything possible to relieve them.

Kidney disease is in general painless, though some individuals may have pain due to other complications or general aches and pains. This will be treated with painkillers in varying strength depending on what is needed to keep a patient comfortable. Anaemia treatment may feature in Maximum Conservative Care, e.g. EPO and iron may be administered by injection.

Although it is not possible to make predictions accurately about survival times in an individual case, there will always be the opportunity to discuss preferences for care at the end of life. This can include where a person wishes to die and how they are looked after, e.g. at home or elsewhere. Indicating these wishes ensures that care providers will know of them and endeavour to carry them out as far as is possible.

Documents such as the 'Preferred Priorities for Care' can be completed to make clear what is important to each individual. This is available from GP surgeries and specialist nurses or from the National End of Life Care website: details below.

Who can I talk to about my concerns?

Please contact the staff at the Sussex Kidney Unit if you have any questions.

Renal Outpatients Department: 01273 664559

Main Dialysis Unit: 01273 696955 extension 4605

Renal Ward: 01273 696955 extension 4057

Chaplain specialising in Renal care: 01273 696955 extension 4122
(at Princess Royal Hospital extension 8232)

Renal Counsellors: 01273 696955 extension 4097

Useful websites:

National End of Life Care Programme
www.endoflifecareforadults.nhs.uk

British Kidney patients Association
www.britishkidney-pa.co.uk

The unit is supported by:



If you do not understand this leaflet, we can arrange for an interpreter.

إذا كنت لا تستطيع فهم محتويات هذه النشرة فيمكننا عمل الترتيبات لتوفير مترجم شفوي لك.

এই প্রচারপুস্তিকাটি যদি আপনি বুঝতে না পারেন, তবে আপনার জন্য আমরা একজন অনুবাদকের ব্যবস্থা করে দিতে পারি

如你不明白本單張的內容，我們可安排口譯員服務。

如你不明白本传单的内容，我们可安排口译员服务。

اگر مندرجات این جزوه را نمی‌فهمید، ما می‌توانیم مترجم در اختیارتان بگذاریم.

Jeśli masz trudności w zrozumieniu tej ulotki, możemy zorganizować tłumacza.

© Brighton and Sussex University Hospitals NHS Trust

Disclaimer

The information in this leaflet is for guidance purposes only and is in no way intended to replace professional clinical advice by a qualified practitioner.

Reference number: 422
Publication Date: January 2012
Review Date: January 2014

