



A PATIENT'S GUIDE TO STARTING HEMODIALYSIS



*A patient's guide to starting hemodialysis.
Written by patients for patients.*

It is not unusual to feel frightened when you start dialysis. Most people feel a mix of emotions. It is a big change in your life that not only affects you, but often your close family and friends too. These feelings are normal but there are things you can do to help you feel more in control.

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*Fearful,
anxious,
tearful and
overwhelmed*

It's life Changing!



Dialysis changes your life, not just in the obvious way, of being tied to a machine at least 3 times a week, but it also affects you physically, emotionally and socially. Many people feel overwhelmed at the thought that this is going to be their life from now on. At times you will feel extremely tired, you may have aches and pains and have moments when you are angry, frustrated, fed up, hopeless and sad. We all have times when we feel like this and sometimes there is not a lot we can do, but just wait for these moments to pass. Remember, tomorrow is another day.

WHAT IS DIALYSIS?

Hemodialysis is a treatment option for people who have end stage kidney disease. None of the treatment options currently available are a cure and this includes having a kidney transplant. When your kidneys no longer work, toxins and fluid build up in your body and dialysis is needed to remove these.





HOW DOES IT WORK?

Hemodialysis involves removing toxins and fluid directly from the blood using a machine and an artificial kidney. A small amount of blood is pumped from your body, through the artificial kidney and then returned. This is a continuous process and each 'run' or dialysis session is at least 4 hours and usually 3 times a week.

Jim

getting his mileage in on the bike during dialysis



WHERE IS THE BLOOD TAKEN FROM?

'Access' is a term used to describe how the blood leaves and returns to your body during dialysis. There are 3 main types: an arteriovenous fistula (AVF), a central venous catheter and a graft. It is generally recommended that a fistula is made, however, your doctor will discuss this with you.

HOW DOES IT WORK?

Most people find the dialysis treatment itself tolerable. What is harder to adjust to is the loss of freedom and spontaneity. Whether it is Christmas, family celebrations or holidays, dialysis still needs to be done. Some people cope by treating it like a part-time job, others do it at night while they are sleeping. It is not easy but people find ways to accommodate it into their lives. Talking to other patients and families living with dialysis is often a big help.

WHO CAN HELP?

You. Adjusting to living with dialysis is a journey and takes time. For some people that adjustment can take 1-2 years. There will definitely be ups and downs, but most people manage to incorporate dialysis into their lives. Again, this is not easy and for some people it is life-long, but it is about adjusting your expectations and aspirations.

Ask questions, make notes, keep a journal, and talk to other people living with dialysis.



Ellie

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It is not a life people choose, but it can still be a life lived to the fullest

Ellie has been on dialysis since she was a child, although she had a couple of transplants along the way. Ellie works full-time and enjoys entertaining and eating out.



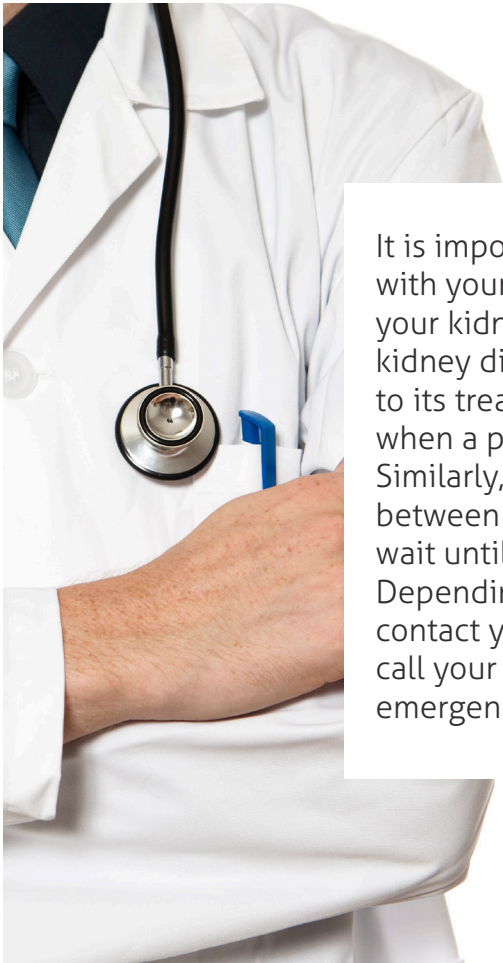
YOUR FAMILY & FRIENDS

Living with kidney disease affects those around you. As much as your life has changed dramatically, so too has the life of those closest to you. We have found that, if you can, sharing your experiences and journey with close family and friends can be a great source of support. Partners in particular, often want to help, but are not sure how. It can be tempting to try and protect family members from your experiences by not including them. However, knowing what you are going through helps them to understand.

YOUR TEAM

Your team will not be aware of a problem unless you let them know. They are interested in how you are doing at home not just during dialysis. Let them know. People find it useful to keep notes or a journal that they take with them to dialysis. This can remind them of questions they want to ask, but also what was discussed and with whom.





It is important to remain in contact with your primary care doctor. While your kidney doctor is an expert in kidney disease and issues related to its treatment, there will be times when a problem is unrelated. Similarly, if you feel unwell in between dialysis sessions, do not wait until your next dialysis session. Depending on your symptoms, contact your primary care doctor, call your dialysis unit or go to the emergency department.

SYMPTOMS

People typically feel better when they initially start dialysis, however, symptoms related to your underlying illness and treatment can persist. It can be difficult to explain to people why, once you have started dialysis, you do not feel completely recovered. A key reason is that dialysis only replaces a small proportion of your kidney function. The number one symptom people complain about is fatigue, which can be overwhelming and frustrating. It can be difficult to plan for events when you are not sure how you feel from one day to the next. Most people find ways to work around their fatigue, typically by pacing themselves and allowing for periods of rest during the day. Talk to the dialysis staff if you are experiencing ongoing problems with symptoms.



SCHEDULING

Your dialysis team will discuss with you where you can dialyze, how often and for how long. Your preferences will be taken into account, however, sometimes there may be a waiting list for the facility of your choice.

HOLIDAYS

Dialyzing away from home is usually possible once you are stable on dialysis, but it takes some planning. You should start planing at least 3 months ahead of your journey. There are a number of people available to help and you should ask your dialysis team. The Kidney Foundation offers interest free loans for holidays.

David and his Dad

Catch up at a basketball game in Nashville, his first trip out of Calgary since starting dialysis.





ON THE DAY OF DIALYSIS

Comfort first: Some units provide pillows and light blankets, but you may feel more comfortable with your own pillow and blanket from home. Dialysis can be boring. There is a television provided but think about bringing your own entertainment. Over time you will know what your individual needs are. Consider having a 'dialysis bag' to keep your personal medical information in. For example, your most up to date medication list, as well as things you want to bring to each session.

We have listed a number of items that patients have suggested are useful:

- Blanket, pillow
- Dialysis journal or notebook to write questions down or changes to treatment
- A light snack
- Something to entertain yourself: a book, puzzle, computer, knitting, iPad and or music
- Ear plugs, head phones



TRANSPLANT

Age is not necessarily a barrier to receiving a transplant but there are a number of health issues that make some people too high a risk to be considered. Talk to your nephrologist about your suitability and the preparation process. More general information can be found at:

Kidney Health Strategic Clinical Network:
<https://www.albertahealthservices.ca/scns/kidneyhealthscn.aspx>

Kidney Community Kitchen:
www.kidneycommunitykitchen.ca/kkcookbook/

Kidney Foundation of Canada:
www.kidney.ca

BC Provincial Renal Agency:
www.bcrenalagency.ca

Kidney School:
www.kidneyschool.org/





THANK YOU!

Thank you to all the patients, family members and supporters who have contributed to the work of PiKS in the past year, without you this would not have happened.



Patient interest in
Kidney Services

ABOUT PiKS

PiKS is a patient, family and supporter interest group centred around helping people live well with dialysis. PiKS provides a forum and support network through which the dialysis community can work together and be a force for action and improvement.

It is a University of Calgary research pilot aimed at initiating, developing, and evaluating a patient engagement program (2018).

To learn more visit: www.dialysisxchange.ca