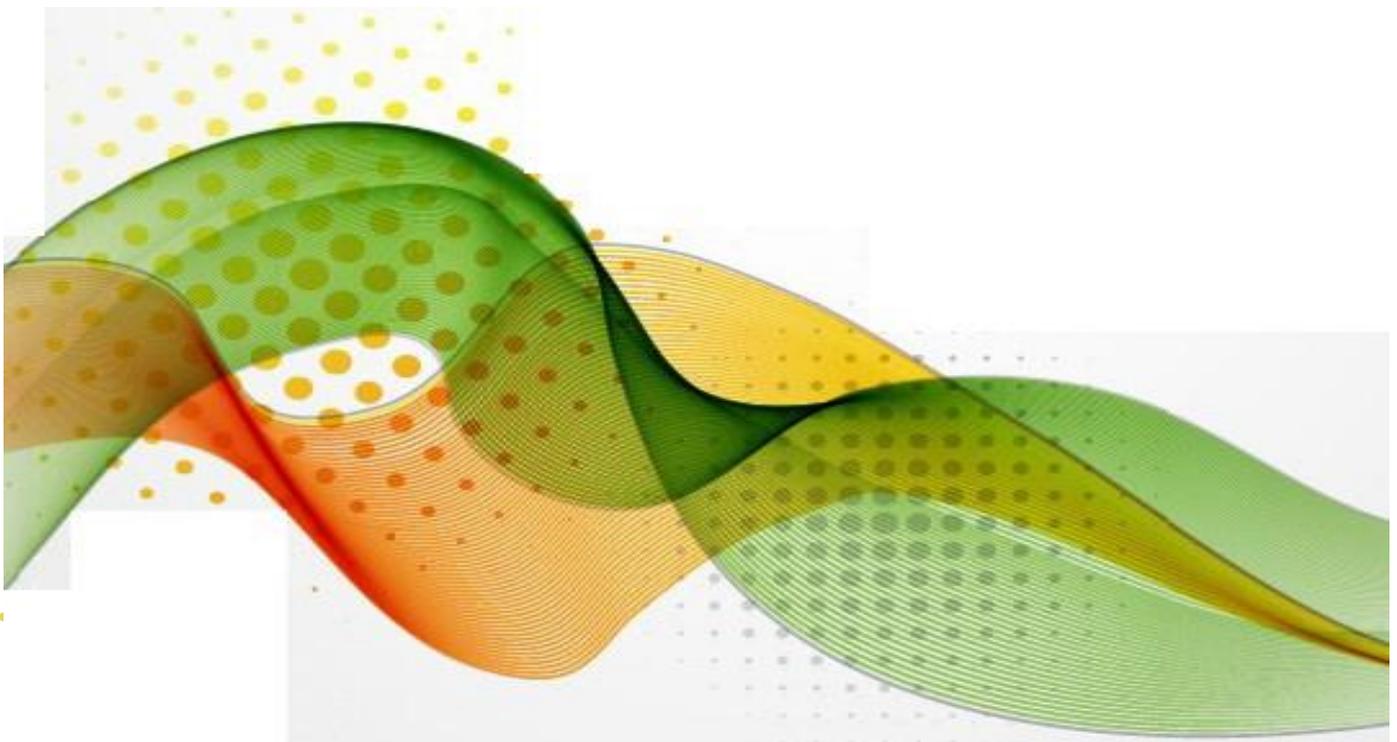


# A decision aid for the treatment of kidney disease for children, adolescents and their families



**CANN•NET**

Canadian Kidney  
Knowledge Translation  
and Generation Network

... With  
support from



Canadian Society of Nephrology/  
Société Canadienne De Néphrologie  
CSN/SCN



# Why am I here?

You have been given this decision aid tool because your kidney care team has determined that your or your child's kidneys are damaged and will probably work less well in the near future. This document is written for the whole family, however through the eyes of the child or adolescent.

While you may feel healthy now, when kidney function drops below 10-15% of that of a healthy kidney (called 'kidney failure'), people usually feel unwell and overall health worsens. You may become more tired and not feel like eating or may start to miss school and activities.

## **Kidney failure affects more than 40,000 people and their families in Canada.**

When someone's kidneys fail, they either need a kidney transplant (the best option) or need to start dialysis. Sometimes, a kidney transplant can be done before needing dialysis, but this is not always possible. That's why understanding all of your treatment options for kidney failure is really important.

You play an important role in choosing your treatment for kidney failure. Your kidney care team will discuss the options available and help you make the right decision to deliver the best possible outcome for you.

This decision aid has been especially designed to guide you and your family through making that choice.



### **EDUCATION is IMPORTANT!**

If you're not sure of your current kidney function level, or you don't feel you know enough about your condition and your options, ask your kidney care team for further information. To learn more about kidney health, visit:

[www.kidney.ca](http://www.kidney.ca)

[www.cann-net.ca](http://www.cann-net.ca)

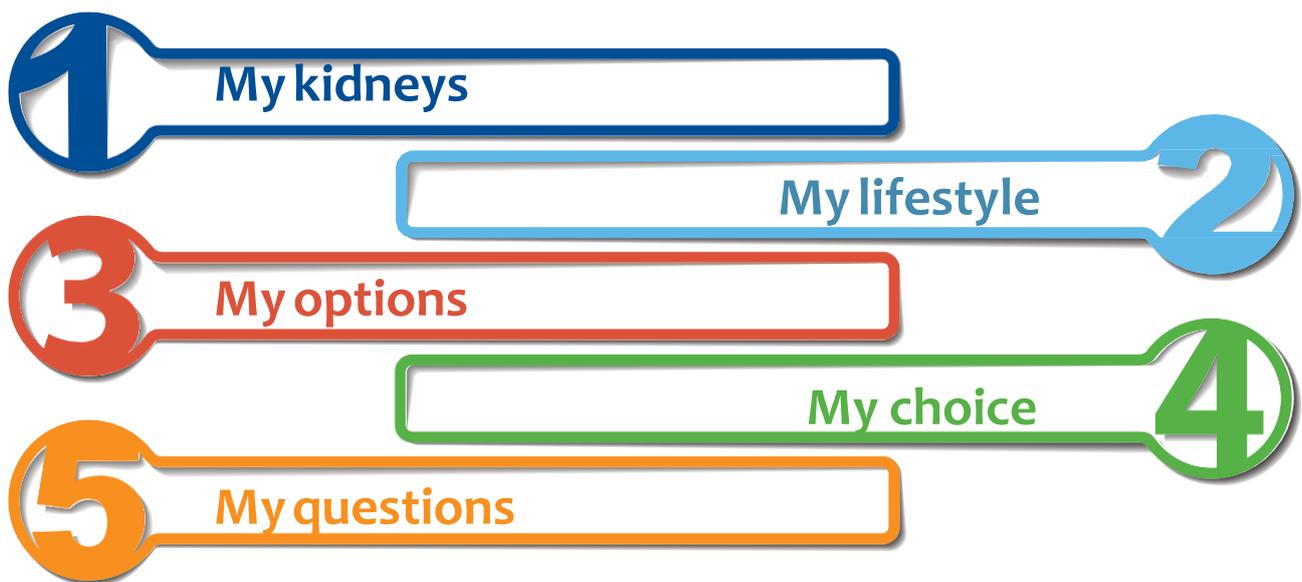
[www.capneph.ca](http://www.capneph.ca)

# How do I use this tool?

Each section of this tool addresses a different thing that may affect your and your family's decision. It is important to go through the sections one by one, as each section builds on the previous one. Please feel free to go back to previous sections if your thoughts change as you work through the tool.

Use this tool to help you make a decision in the way that suits you and your family best. You can work through this tool on your own or with your kidney care team if you need help filling it out.

Remember to bring this decision aid to your next appointment or education session with your kidney care team. Having it at hand may be useful when discussing your treatment options.



## Disclaimer:

This decision aid tool is intended for use in conjunction with the advice of your healthcare team. This tool does not account for individual variation among patients or suggest any particular course of medical treatment. Use of this decision aid tool is voluntary.

## My treatment journey

If your kidney specialist says your or your child's kidneys may fail within six months to one year, NOW is the time to decide on a treatment.

If you have not decided on a treatment and your kidneys fail, emergency dialysis may become necessary. This means your or your child's life is at risk, and the choice of treatment will be taken out of your hands; it will be up to the doctor to decide what treatment is needed. It may also mean more time in hospital and less time enjoying life.

**So plan ahead.** The sooner you start preparing for treatment, the better the outcome. Involving your family and loved ones can also help you make the best decision for you.

The best choice of treatment for when your kidneys fail is one you have made with a good understanding of the treatment itself, thinking about how it will affect you and your day to day life (school, family, friends, activities), and a treatment that your doctors and nurses believe will work for you.

1 in 9 people have early kidney damage

Only some progress to late kidney failure

Decision making is critical, 6 months to 1 year before treatment is needed

3 to 6 months are required to prepare for treatment

Treatment starts

# 2. My Life

Use this guide to help you think about your and your family's life and how the different treatment choices for kidney failure may change how you are living. Weighing up these factors can help you make an informed decision on treatment.

Write down your thoughts under each area below.

**Here is an example:**

My life now	My thoughts
<b>My activities</b> Playing volleyball	<i>I play on a volleyball team 3 days a week. It's something I would really miss.</i>

## What is important to me?

My life now	My thoughts
My school or work	
My family at home (What is unique or special?)	
My parent's work	
My other family and friends (What is unique or special?)	
My boyfriend or girlfriend	
My activities	
My travel or holidays away from home	

## 2. My Life

How I feel about	My thoughts
Having chronic kidney disease	
Being in charge of my own life	
Needing others to look after me	

My life in the future	My thoughts
Finding time for treatment for my kidney failure	
Travelling to a hospital or clinic for treatment	
Being in my own home for treatment	
Storing treatment equipment and boxes in my house or my room	
Not having treatment for my kidney failure	
Explaining my choice of treatments to my family and friends	

## Main types of kidney failure treatment

There are three main ways of treating kidney failure. Your feelings about which choice is best for you may change over time, so it is good to be aware of all the options.

### Dialysis

With dialysis, the job of the kidneys in cleaning blood is done by special equipment instead. There are several types of dialysis, and the following sections will help you think about which one suits you best. Your clinic may not offer all types of dialysis so check with your clinic.

### Kidney transplant

For some people, surgery can be done to transplant a kidney from another person into their own body. Although a transplant is seen

as the best choice when it is possible, it is not always available as soon as someone develops kidney failure. **Kidney transplant may not be possible for some patients.**

### Conservative care

Some people decide not to choose dialysis or kidney transplant to treat their or their child's kidney failure, and instead choose conservative care. This choice lets kidney failure run its natural course and focuses on treating symptoms. Conservative care aims to preserve kidney function for as long as possible through dietary management and medications, but cannot stop the decline in kidney function.

People sometimes choose conservative care when they have or their child has other severe medical conditions and it is felt that the burden and discomfort caused by dialysis or a kidney transplant outweigh the potential benefits.

	Dialysis	Kidney transplant	Conservative care
Summary	Your kidney failure is treated using special equipment to remove waste products from your blood.	You receive a kidney from another person (a "donor"). They may be a living or deceased donor. Children usually receive a kidney from an adult.	Your kidney failure is managed through diet and medication. You will get specialized support when needed for end of life care.
How the treatment is done	Treatment can be done either at home or in a clinic or hospital using a machine or special dialysis fluid.	You will have an operation where you receive a kidney.	You will continue seeing your kidney specialist, who will help manage your symptoms, diet and medication.
My suitability for this treatment (can I have this treatment?)	Most people with kidney failure are suitable. Some types of dialysis can be very challenging in small babies or if you live far away from a children's hospital.	A transplant is suited to patients who do not have any serious, uncontrolled health issues besides kidney disease and is big enough to safely fit a kidney.	This option is suitable for all patients, however is only chosen if you have a poor quality of life or short life expectancy, often due to illness affecting other body systems.
My life and work or school	There are different types of dialysis. Home treatments are more flexible than in-centre (hospital) treatment.	Most people are able to resume school or work and normal activities within 3–6 months after transplant.	Your health will deteriorate, so your life expectancy will decrease

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# 3. My options

## Main types of kidney failure treatment (cont.)

	Dialysis	Kidney transplant	Conservative care
My diet and fluids	There are some things you may need to limit and avoid. Many children don't eat well and need feeding tubes.	It is important to eat healthy. Medications to look after your new kidney may increase your appetite and you will need to drink a lot of fluids. Sometimes feeding tubes are needed for these fluids.	There are some things you may need to limit or avoid.
My travel and holidays	You can travel more easily with some types of dialysis. Others need planning, and travel to some places may not be possible.	You can travel, but discuss safety and how to access a kidney care team while travelling, with your doctor.	You can travel, but discuss safety and how to access a kidney care team while travelling with your doctor.
My treatment costs	There are standard costs for medications. The Health System or a private drug benefit plan covers the majority of treatment costs. You may have travel costs, depending on whether you have dialysis at home or at a centre.	There are standard costs for medications. The Health System or a private drug benefit plan covers the majority of treatment costs. You may have travel costs to visit your kidney specialist very often after transplant (especially the first year).	There are standard costs for medications. The majority of treatment costs are covered by the Health System or a private drug benefit plan.
My health	Your health and wellbeing is less than that of people with normal kidney function or a transplant, but you will feel better than you felt just before you started dialysis.	You will need to take medications for the rest of your life after the operation, to help your body accept the new kidney. Transplant operations can have complications.	You will manage symptoms from kidney failure through diet and medication. Your life expectancy will be shorter than if you receive dialysis or transplant.
My body	You have an operation on your neck, arm or tummy, depending on the type of dialysis.	You have a 2–3 hour operation, and will stay in hospital for 1–4 weeks.	You have no surgeries.
My home	You will have to store equipment and supplies at home or attend a hospital-based dialysis centre. Plumbing and electrical may need to be changed for some types of home dialysis.	No changes/impact at home. Infections are more common after transplant so homes must be free of mold.	No changes/impact at home.

# 3. My options

## The differences in dialysis – which is suitable for me?

This table summarizes different types of dialysis and their effects on various aspects of your life, to help you decide which is best for your situation. However, it's important that you seek further information and education as recommended by your kidney care team. Remember, you may not be suitable for every kind of dialysis.

		Summary	My time on dialysis	My training & support	My life & activities	My diet & fluids
Home dialysis	Continuous Ambulatory Peritoneal Dialysis (CAPD)	Dialysis fluid goes in and out of your tummy through a tube. You change the fluid usually four times a day. Few child dialysis centres offer this option.	Dialysis usually takes 30 minutes, 4 times every day, and can be adapted to suit your lifestyle. You change the dialysis fluid that goes in and out of your tummy.	Training generally takes 1-2 weeks, with ongoing and after-hours support from the clinic.	Dialysis equipment is portable, and treatment is simple. You can do this type of dialysis in most places. You can swim with a protective bag over your catheter.	There will be a few things you should not eat or drink.
	Automated Peritoneal Dialysis	A machine circulates dialysis fluid in and out of your tummy through a tube overnight while you sleep. Most child dialysis centres support this option.	Dialysis usually happens for 8–12 hours while you are asleep, and can be adapted to suit your life. The machine takes about 30 minutes to set up and 15 minutes to clean up in the morning.	Training will take up to 1–2 weeks, with ongoing and after-hours support from the clinic.	Dialysis happens while you are asleep. There are fewer changes to your daytime activities. You can swim with a protective bag over your catheter.	There will be a few things you should not eat or drink.
	Home Hemodialysis	A special filter attached to a machine cleans your blood. This treatment is not offered by all Canadian clinics. Only a few child dialysis centres offer this option.	There are various ways of performing home hemodialysis. Your dialysis times are chosen to suit your life.	Training will take 6-12 weeks, depending on your situation. There will be ongoing and after-hours support from the clinic.	Dialysis is done at your home and your dialysis schedule is flexible. You may have more energy and feel a bit better than with other dialysis types. You will not be able swim or shower if you have a tube in your body for your home hemodialysis.	There may be a few things you cannot eat or drink, but the more dialysis you do, the fewer the restrictions.

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# 3. My options

## The differences in dialysis – which is suitable for me?(cont.)

		Summary	My time on dialysis	My training & support	My life & activities	My diet & fluids
<b>Centre-based dialysis</b>	<b>Hemodialysis</b>	A special filter attached to a machine cleans your blood. Depending where you live, this may be done in a children's or adult dialysis unit. Ask what options are available in your region.	Dialysis takes approx. 3 to 6 hours, 3 to 6 times a week, usually at set appointment times. There will also be travel and waiting time.	You do not need training. Medical staff will perform the dialysis at the clinic.	You need to go to the clinic for your treatments. Daytime activities will need to be scheduled around your treatments. You will not be able swim or shower if you have a tube in your body for your hemodialysis.	There will be a few things you should not eat or drink.

# 3. My options

## The differences in dialysis – which is suitable for me?(cont.)

		My travel & holidays	My treatment costs	My body	My home
Home dialysis	Continuous Ambulatory Peritoneal Dialysis (CAPD)	Travel (even out of country travel) is often possible.	The main dialysis equipment is free and delivered to your home. You may need to pay for some medications and occasional small supplies. Check what your clinic provides.	You will have an operation to put a small tube in your tummy. This needs to be kept clean. You may feel some fullness in your tummy.	You will need a suitable space at home to keep and set up your dialysis equipment. A home assessment may be required to see if your home is safe for dialysis.
	Automated Peritoneal	Travel (even out of country travel) is often possible.	The machine and fluid is free and delivered to your home. You may need to pay for some medications and occasional small supplies. Check what your clinic provides.	You will have an operation to put a small tube in your tummy. This needs to be kept clean. You may feel some fullness in your tummy.	You will need a suitable space at home to keep and set up your dialysis equipment. A home assessment may be required to see if your home is safe for dialysis.
	Home Hemodialysis	You may be able to travel, but it must be planned in advance, and it depends on availability of a dialysis centre close to your destination. Travel outside Canada may be very expensive.	You may notice an increase in your water and electricity bills related to the home hemodialysis machine – these may be tax deductible.	You will have an operation on your arm to form a fistula for the dialysis needles that connect to the machine. Some people need a tube in their neck or chest rather than a fistula.	You will need a suitable space at home to keep and set up your dialysis equipment. Electrical and plumbing work in your home will be necessary for your dialysis machine.
Centre-based dialysis	Hemodialysis	You may be able to travel, but it must be planned in advance, and it depends on availability of a dialysis centre close to your destination. Travel outside Canada may be very expensive.	You may need to pay for travel to the clinic. Check what your clinic provides.	You will have an operation on your arm to form a fistula for the dialysis needles that connect to the machine. Some people need a tube in their neck rather than a fistula.	No equipment is stored at your home.

# 4. My choice

By the time you reach this section, you should have some understanding of the treatment options for kidney failure, including that of conservative care, and how you feel about each one. If you feel you still don't understand your options, ask your kidney care team for more information before you make your choice.

Use the section below to write down your thoughts on the different treatment options available for kidney failure. Remember, your feelings and preferences may change over time.

## My thoughts

Am I considering a transplant?  YES  NO

Am I considering dialysis?  YES  NO

Am I considering conservative care?  YES  NO

	My thoughts	Pros	Cons
Continuous ambulatory peritoneal dialysis (CAPD)			
Automated peritoneal dialysis (APD)			
Home hemodialysis			
Centre-based hemodialysis			
Conservative care			

# 4. My choice

## Am I ready to make a choice?

- Do I understand all the options available to me?
- Have I spoken to my health care team for their input?
- Have I spoken to my family for their input?
- Do I still have questions to help me make a choice?

(Jot them down on the next page.)

**If you have a preferred option for treatment at this time, write it below. Remember, you can change your mind!**

Date	My preferred option	Reason

# 5. My Questions

Write down any questions you may still have that you want to discuss with your kidney care team.

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## What happens next?

Now that you've considered your treatment options and recorded your thoughts on each one, take along this resource and your notes the next time you visit your kidney care team. You will likely spend a significant part of the meeting discussing which choice of treatment is best for you, so this resource will help ensure you have thought through all your options.

## **Acknowledgement**

*This decision aid has been modified with permission. It was developed by a national committee in Australia and New Zealand which was kindly funded by Baxter Healthcare. Distribution and research are via the Kidney Health Australia project 'End Stage Kidney Disease Education – A National Education Programme' which is funded by the Commonwealth Chronic Disease Prevention and Service Improvement Flexible Fund.*

Kidney Health Australia website - [www.kidney.org.au](http://www.kidney.org.au)

