

A decision aid for the treatment of kidney disease

A Guide for Health Professionals about this tool

My Kidneys
My Choice

Contents

Background	2
• What are the current rates of Dialysis Modalities?	2
• What are the findings of the Consumer Perspectives Survey?	3
• What is the value of Lifestyle Focused Education?	4
• End Stage Kidney Disease (ESKD) Education pathway to dialysis	5
• What are the Health Outcomes and Benefits of Various Treatments?	6
What is the value of a decision aid?	7
Steps of Decision Making	8
How do my patients use this tool?	9
1. My Kidneys	10
2. My Lifestyle	11
3. My Options	12
4. My Choice	13
5. My Questions	14
Resources	15
References	16

Acknowledgements

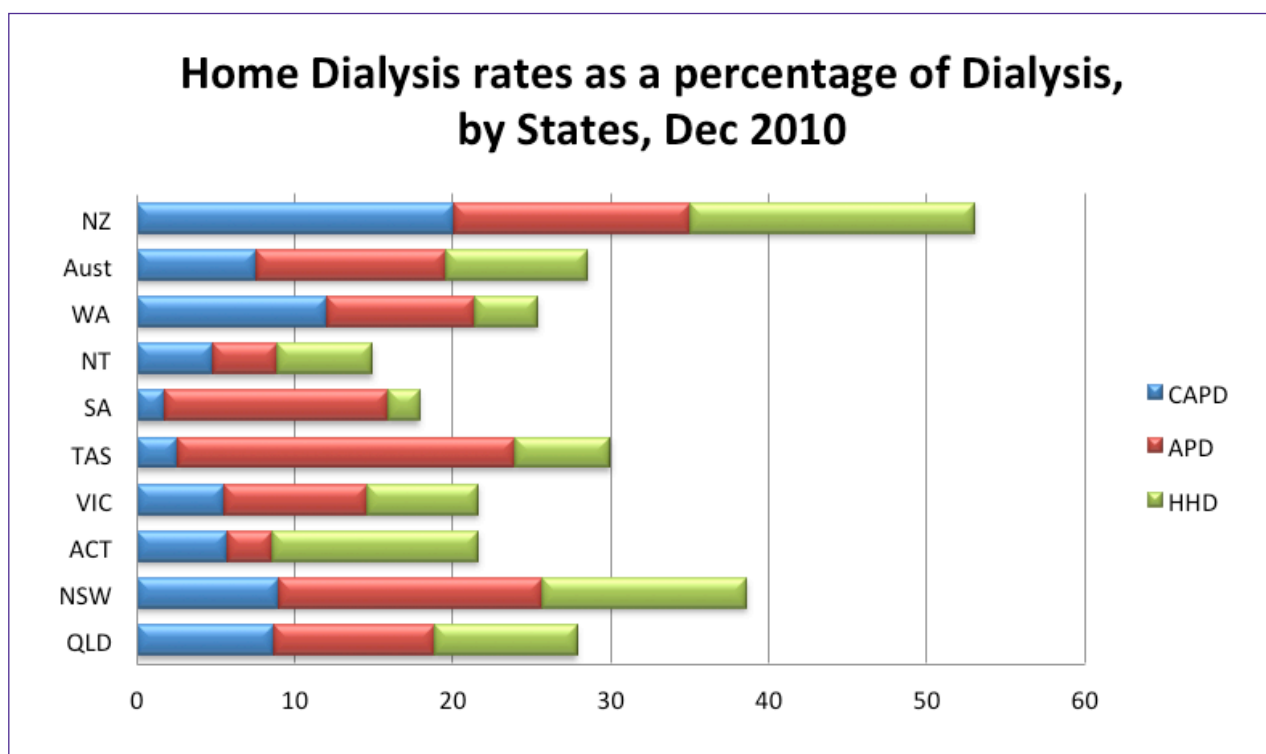
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Background

What are the current rates of Dialysis Modalities?

In Australia, as at December 2010, 28% of patients were on dialysis at home and 72% were on centre based dialysis. Of those at home, 9% were on haemodialysis (HHD) and 19% were on peritoneal dialysis (PD). The rate of each modality varies widely by state and even within each state. In New Zealand 54% of patients are at home with 18% on HHD and 35% on PD, but again this does vary by jurisdiction.¹



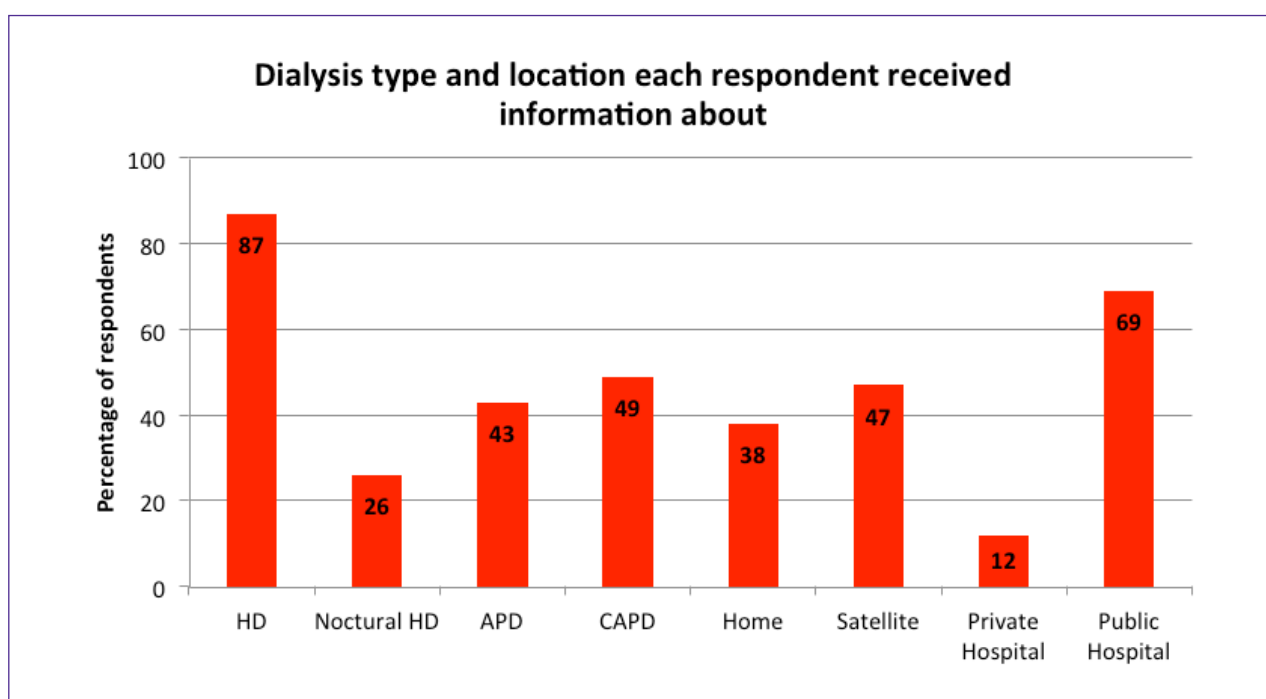
ANZDATA 2011 report

The wide variance that surpasses any demographic variances indicates that it is system factors that impact on home dialysis rates as the main influence rather than patient demographics or choice.

Background

What are the findings of the Consumer Perspectives Survey?

In 2009 the Kidney Health Australia consumer perspectives survey found that 49% of prevalent patients reported that they were not provided with a choice about the type of dialysis they were using. It also found that this was more significant in the centre based HD population.²



Whilst only 7% currently wanted to change their dialysis type, up to 34% were willing to change if certain provisions, including financial support and paid carer support were made available.² For those who wanted to change dialysis type the preferred options were to commence a home therapy.

The consumer survey strongly suggested that the education and decision making processes the patients experienced were not always comprehensive. The survey also demonstrated that the system has patients using centre based treatments that would actually like to go home.

Background

What is the value of Lifestyle Focused Education?

Educational research has determined that end stage kidney disease (ESKD) patients who enter a comprehensive education programme in a timely manner are more likely to choose a home modality.³ In an Australian survey of education practices HHD was more likely to be chosen when longer and more in depth education was offered.⁴ This intuitively makes sense as it would take longer to be reassured that HHD could be completed safely at home. The technology is fairly complex and the consideration of self-cannulating would require some investigation and mental adjustment.

Traditionally ESKD education about treatment options has had a strong focus on how the different types of dialysis work. More recently it has been recognised that the person with ESKD is more worried about whether they can continue to work than about osmosis or diffusion for example. Research also finds that patients would rather have treatment at home.⁵

Traditionally the patient has been asked to choose between HD or PD instead of choosing a lifestyle to suit them that is at home or a dialysis centre. It is now being advocated for that the latter approach is more appropriate and will lead to more self care. In a world that is encouraging empowerment and self-management for any disease process it is appropriate that people are allowed and encouraged to manage their own dialysis at home with multidisciplinary team support.

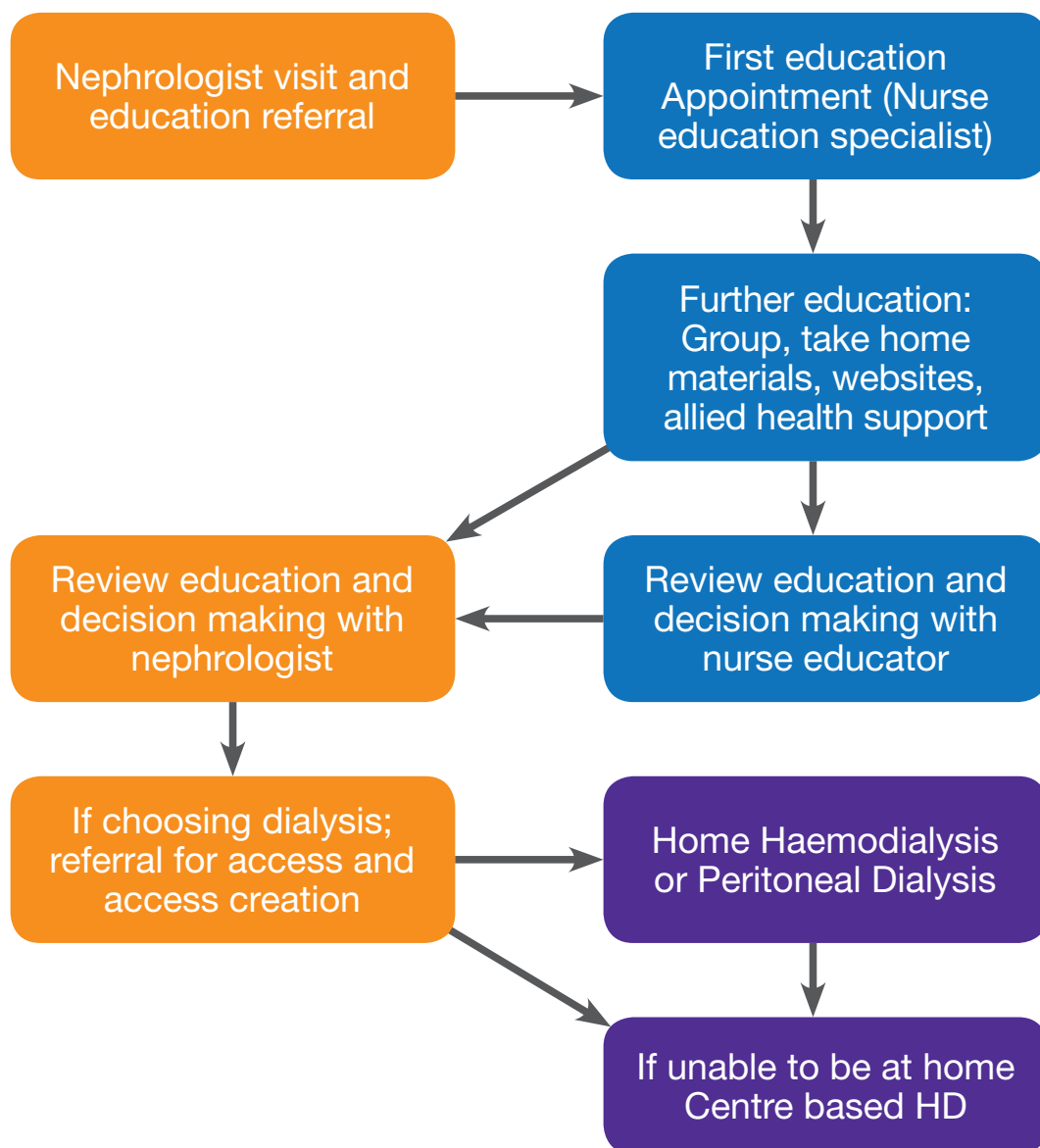
This decision aid was designed to empower patient decision making by supporting comprehensive treatment option education with a structured decision making process.

Background

End Stage Kidney Disease (ESKD) Education pathway to Dialysis

Every patient follows an education pathway as they progress from diagnosis through to commencement of treatment.

In most education systems the patient sees both the nephrologist and a specialist educator or renal nurse, and local resources may change this pathway slightly.



Background

What are the Health Outcomes and Benefits of Various Treatments?

Research about outcomes for treatment methods is usually observational, rather than randomised research.

It is widely accepted that kidney transplant has the best outcomes overall, although for some individuals it may not be successful.¹

Research and ANZDATA strongly suggests for dialysis that home has the best dialysis outcomes demonstrated for most and this can be either peritoneal or haemodialysis. There are no worse health outcomes demonstrated for patients in any study.⁶ Enhanced hours HD can provide outcomes to match transplantation⁷ and APD on average has the highest quality of life.⁸ More liberal diet and fluids, less medications and improved sleep patterns are known positive factors for home patients.

Home dialysis options are financially competitive, offering the most economic modalities of dialysis. The current economic climate for health has limited financial and human resources further supporting the fact that home should be the preferred option where this is practical.⁹

Centre based dialysis offers a therapy away from the home, supported directly by health professionals. For the frail and those with limited home support this may be their best and safest option.

Conservative care outcomes are comparable to dialysis for those who are elderly and have multiple co-morbidities.¹⁰ It is important that the burden of dialysis is considered and for some if it is more than they are willing to experience, they should be offered the supportive option of conservative care without feeling guilty that they have opted out of treatment. It is estimated that 50% of those with stage 5 kidney disease never start treatment and approximately 20% of those who withdraw later do it voluntarily.

Whilst there is a group of patients who are only suited for centre based haemodialysis there are many patients who do not fit this demographic, who are utilising this modality.

The question is why? The answer is likely to be a lack of education, and limited support with decision making.

What is the value of a decision aid?

In traditional models of healthcare the doctor prescribed to the patient the treatment that was determined to be the best for them. Research now advocates for best practice to be the newer model of shared decision making, which has the benefit of moving the focus to the patient. Shared decision making is defined as the health professional guiding the person and their significant others through the process of decision making.¹¹ It removes the temptation for health professionals to make the decision when they are not an expert about the patients' life.

There are many benefits for the patient who uses a structured pathway to decision making. Decision making about health care options is very confronting and often very confusing for those who have been diagnosed with a life altering condition. A structured pathway can bring focus to the process.

Research related to treatment outcomes for kidney failure shows some benefits for survival and quality of life for home dialysis, but this research often acknowledges that the person has to suit the treatment and comply with treatment for the benefits to be maximised. Using the decision aid will promote this outcome.

Finally, informed consent also dictates that a person should know all of their options, even if that option is not suitable or recommended for them. For this reason conservative care and transplant are included, although most people will only fall into the category for considering one of these options.

Overall it is suggested that taking the person on a journey that allows them to reflect on their lifestyle, gain education, compare the treatment options and then reflect on their choices will allow health professionals to better understand the individual and support them towards the best treatment choice for them. It is acknowledged that all treatments are not for all people but intuitive educators and appropriate education materials should bring to light some signs where the individual may realize that they are not suitable. Formal evaluation can also be done, particularly to determine where special care may be needed for a certain therapy to be achieved.

What is the value of a decision aid?

Steps of Decision Making¹²

- Deliberation Become aware of the need to make a decision that will impact on your life
- Choice Talk Acknowledge the fact there are choices
- Option Talk Gather all the facts and be comprehensively educated
- Decision talk Seek opinions from those who are informed (or sometimes not)
 Consider the influence of the decision on your own life (and those around you)
 Make the preferred decision based on personal preference at that time

The steps of the decision making process were incorporated into this tool. The authors consider that it is the individual's life and their treatment, hence the strong theme of 'my choice'. The group who developed the tool included psychologists, nurses, doctors, social workers and consumer input. Australian and New Zealand health professionals were represented. A company with specialist skills in this area supported the tool development process.

The Decision Aid, and the Health Professional Guide are available for electronic download from www.kidney.org.au and www.kidneys.co.nz

How do My Patients use this tool?

The tool was designed to be used at more than one visit and be taken home. It has not been designed to replace education but rather to guide the process and make sure all steps are followed.

Section Title	Recommended completion strategy
My Kidneys	Discuss at the first education appointment when first given the document (Deliberation)
My Lifestyle	Complete during first appointment or take home (Choice Talk)
My Options	This summary is designed to be used concurrent to the education process. It may be used to start discussions about treatment options and also to recap about treatment options (Option talk)
My Choice	This section is for the person to complete and may be done at home or at a follow-up education appointment (Decision talk)
My Questions	A space for patient to note their questions and bring them back to subsequent appointments (Decision Talk)

1. My Kidneys

Key Messages for the person on the decision making journey

- The person has kidney failure and they will need at least one form of treatment
- Timely making of a decision is very important to maximise the opportunity to choose the best treatment and be prepared for that treatment ahead of time
- Education is extremely important in making a decision and there are many resources available
- Kidney transplant is not for everyone
- This is a personal choice
- There are many people with kidney failure undergoing treatment, the person is not alone

Relevance

Adult Learning Principles

Adults only make decisions or learn when they have decided it is relevant to them. Adults may attend education but it does not mean they will leave the room educated.

Without exploring this first basic step some adults will sit through education thinking “I am going to have a transplant – I don’t need to know any of this”. Then they are not suitable or the transplant plan fails and suddenly they are not prepared.

Denial

It is not unusual for those attending education for kidney failure, especially if the diagnosis is quickly made in the late stages to think; “I don’t know why she is telling me this – it couldn’t possibly be something that is happening to me”. If the person is still in denial it will be impossible to educate them. All educators should ensure the person is not in denial, and if they are to work through this, using appropriate social supports.

Generation or Cultural Considerations

Many of the older generations will not understand that they can be part of the decision making process. Empowering them to make the decision should lead to better health outcomes. It will also reduce the feeling of not having control and should promote home dialysis options. Some cultures may also believe health professionals or a certain member of their family should make the decision, and will need encouragement to participate in the process.

Practical Tips

Use the My Kidneys page as a prompt and conversation opener with those who you are educating. Use questions to check if the person is ready for the decision making process to start:

- Did you know your kidneys are close to failure and this means you will need treatment?
- Did you know that you have choices and one type of treatment may suit your lifestyle better?
- How are you feeling right now?
- Are you ready to start the education process?

2. My Lifestyle

Key Message for the person on the decision making journey

- Their lifestyle is important when making their dialysis choice
- Relationships are important, particularly for the ongoing success of a treatment
- Their underlying personality may predict the best treatment, i.e. self-managed for those who prefer to have control over their life
- The future with dialysis treatment will change the daily lifestyle, but choosing the best type for them will change it the least

Relevance

This section is for both the person receiving guidance and the health care professional to gain an understanding of what is important in that individual's life. It hopefully should provide valuable insights into relationships at home and the daily routine of the person that will support the selection of a treatment that can be built into that routine.

My Life Now

My life now is targeted at understanding the person's daily routine, lifestyle priorities and the important people in their life.

How I Feel About Myself

How I feel about myself may reveal interesting information and open discussion about issues that are of a current concern and may impede the ability to make a decision. In the ideal world of finite resources concerns raised in this area may prompt referral to a psychologist or a social worker.

My Life in The Future

My life in the future deliberately highlights some main points of difference between treatment options and may help to focus the education discussions. It was not an exclusive list about expected changes but a step to make the person start to look into the future.

Practical Tips

These pages can be used as a discussion tool, rather than be completed. It could also be done at home and brought back if multiple appointments fulfil the process of education within your unit.

This section can only be completed with the input of the individual and their significant other.

It may be important to ask the same question directed at both the potential patient and their significant other or carer.

3. My Options

This section is split into two parts. The first considers the key factors of dialysis, transplant and conservative care within a series of headings.

The second section considers the home dialysis options and the centre based dialysis options.

It is only designed to be a summary but does provide a take home, quick reference guide to start or finish the education process. It is not designed to replace education.

Key Messages – Main types of Kidney Failure treatment

- There are three main options when your kidneys fail
- Conservative care is a treatment option although it will limit life for those who are younger with less co-morbidities
- Kidney transplant is not for everyone and there may be a waiting time to get a kidney
- Most people can have dialysis but there are different types to choose from

Key Message – The differences in dialysis

- Home dialysis has three options
- Centre based dialysis has one option
- All treatments take significant time out of your week
- Centre based treatments involve more travel and less flexibility
- All modalities have nursing support but this is most intense in centre based treatment
- Home based treatments allow greater personal treatment control
- Holiday Travel is easier on PD
- All options involve some surgery and alterations to body image

Practical Tips

Use these tables for a quick summary to start the education process and provide the first building block of the education process. They can also be used as a summary at a follow-up appointment or phone-call, with questions related to certain headings to determine if the person really understands their options.

It is also important to provide more detailed educational opportunities:

- One on one interviews
- Group Education
- Visits with home dialysis team
- Take home written materials
- Websites i.e. Home dialysis www.homedialysis.org.au
- DVDs
- Connecting to existing patients via local or existing support networks

4. My Choice

This step is to affirm the decision making process and allow the person to write down key factors for them related to choosing or not choosing each of the options. Ideally it would be done at home prior to the final decision making appointment.

Key Messages (My thoughts)

- There are three main choices to choose or reject transplant, dialysis or conservative care
- There are positive and negative impacts related to each choice for each individual

Key Messages (Am I ready to make a choice?)

- Are they ready to make an informed decision?
- This is their opportunity to write on paper what they are feeling

Treatment Outcome Facts that support some questions you could be asked

The balance of research suggests:

- PD, specifically APD, has the best quality of life.¹³
- PD is most effective as a first treatment and is the most independent therapy being relatively quick and easy to learn and cost-effective.
- Unless unit policy or health conditions suggest otherwise PD first is usually the recommended way to go.
- Transplant outcomes are the same whether the person has PD or HD prior to the transplant.
- For HHD if they are willing and able to do longer hours, particularly achievable on nocturnal, the health benefits are widely acknowledged and outcomes may match transplantation.
- For those who are elderly, frail or have multiple co-morbidities conservative care on average offers a lifespan equivalent to dialysis.

Practical Tips

Ask the person to complete this section before they come back to discuss the final decision.

Check if their listed pro's or cons are actually accurate in case they have any misconceptions about a certain treatment type.

Highlight the treatment outcome facts if they are still wavering, or to confirm their choice is informed.

5. My Questions

This page is designed purely to allow the person to write their questions down prior to the final appointment. It is widely recognised that the minute someone walks into a doctor's or health professional's office, they will forget everything they intended to ask. Hopefully this will help overcome this factor.

The questions will also be a good indicator as to whether the person really does understand the treatment options. If not, is it strongly suggested that education is repeated where the gaps are detected.

Resources

Educational websites that are reputable and based in Australia or New Zealand are presented on the back page. These sites offer both written and video educational tools that can be viewed or down-loaded by the individual.

The Renal Resource centre is also recommended as an Australian resource for patient education material. Visit www.renal_resource.com.au

For your own education visit the health professional section at www.homedialysis.org.au for links to many educational resources and online packages, included those by the nephrology educators network.

Another reputable website is provided by Kidney Health New Zealand. Visit www.kidneys.co.nz

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