

KIDNEY HEALTH AUSTRALIA
RENAL RESOURCE CENTRE



An Introduction to
Home Dialysis

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Introduction

A diagnosis of chronic kidney disease means that your kidneys are no longer able to adequately remove the excess fluids and waste products produced by your body every day. Dialysis and in some cases, transplantation, will be recommended by your renal physician when your kidney function is no longer able to keep you feeling well. At this time, medications and diet alone will not be enough to control your symptoms. It can be difficult to come to terms with the need to have treatment, but it is important that you try to take control and find out about all of your options.

Both dialysis and transplantation are very efficient and successful treatments which help to replace kidney function. Home dialysis is possible for most people. Each treatment is carried out in the comfort of your home and allows you maximum control and flexibility.

As you read through the booklet you will begin to understand how home dialysis may be suited to your particular needs. It will help you to understand how haemodialysis and peritoneal dialysis can work at home, with a special focus on your lifestyle. Choosing the right type of dialysis will be easier if you think about how each type of dialysis will fit into your daily life.

The Kidney Health Australia website www.homedialysis.org.au is an excellent source of more detailed information, about all types of home dialysis.

If you prefer printed material it is suggested that you read the booklets; “An Introduction to Haemodialysis” and “An Introduction to Peritoneal Dialysis”, available from the Renal Resource Centre www.renalresource.com

An Introduction to Home Dialysis

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My Options for Home Dialysis

Dialysis is simply the cleansing of your blood, which is part of the work that your kidneys usually do for you. There are different types. Home Dialysis includes peritoneal dialysis and haemodialysis, offering the most flexibility for managing your health and lifestyle. Currently in Australia over 3000 people, of all ages, are at home on dialysis leading full and active lives.

It is important to recognise that dialysis treatment will take up many hours each week. However, home dialysis is the most flexible and this is the reason many people say, that in contrast to clinic dialysis, it “gave them back their life”.

Thorough training and ongoing support will ensure that you can successfully manage whatever type of home dialysis you choose. You control your dialysis every day.

Below is a brief summary of a typical daily routine with each type of home dialysis to help you picture each one as you read more about how dialysis can fit into your lifestyle.

What Can I Expect with My Daily Home Haemodialysis Routine?

Home Haemodialysis (HHD) uses a variety of haemodialysis machines which are safe, reliable, and user friendly, all-important features for trouble-free use at home. Your blood is actually cleansed by your blood travelling to and from the special dialyser or filter. The process is the same as centre-based haemodialysis.

Home Haemodialysis treatments are usually performed **3 to 5 times per week for 5-8 hours** with the longer hours designed for overnight treatment (nocturnal haemodialysis). No treatment is required on non-dialysis days so these are completely free. You have freedom to choose and to change your dialysis days and times. This control and flexibility attracts many people to home haemodialysis.

Haemodialysis can also be done at a dialysis clinic or centre. This entails following a regular schedule, and going to the clinic for up to six hours, three times every week.

Preparation and clean up time can take up to an hour each treatment. This time will likely be reduced once you are familiar with the routine.

It is important to understand why you would choose to do more hours rather than the minimum. Research and anecdotal evidence suggest that your health and well-being improve with increased dialysis hours. It's hard to ignore the benefits of greater freedom with food and drink choices, less medications, better sleep and more energy. This is why many people, in consultation with their health team, choose longer and/or more frequent hours. The quantity and quality debate is yours to have with your health care team.

What Can I Expect with My Daily Home Peritoneal Dialysis Routine?

Peritoneal Dialysis requires a special catheter (tube) which is placed permanently in your abdominal cavity (tummy). Dialysis solution can then be drained in and out of your abdominal cavity. This dialysis uses the special lining in the abdominal cavity, called the peritoneal membrane, to filter excess fluid and waste from your body and into the dialysis solution.

Continuous Ambulatory Peritoneal Dialysis (CAPD)

Continuous Ambulatory Peritoneal Dialysis (CAPD) is the simplest form of dialysis and is sometimes also referred to as “the bags”, “manual bags” or “daytime bags”. With **CAPD**, the 2 litre bags of dialysis solution are regularly connected and then disconnected from your catheter (an exchange - see picture). You can perform it in most safe and dry places. The main requirement is that you can thoroughly clean your hands and have a small clean workplace.

Most people complete four CAPD bag exchanges per day, usually performed first thing in the morning, lunch-time, dinner-time and bedtime. During the exchange, used dialysis solution drains out and fresh dialysis solution drains in. This takes about 30 to 45 minutes. Between these exchanges, dialysis bags are disconnected. Only the catheter remains anchored and protected under clothing.

Exact times are not critical and flexibility for special occasions is encouraged. However, you will need to establish a regular routine which you follow most days. You can eat, use a computer, watch TV or be with your family during the exchanges.





Automated Peritoneal Dialysis (APD)

Automated Peritoneal Dialysis (APD) is also known as “machine” or “cycler” dialysis. It allows dialysis to be performed **overnight during sleep**. The overnight APD machine is connected to your peritoneal dialysis catheter at night and disconnected in the morning. The APD machine takes about half an hour to prepare in the evening.

You must dialyse for at least 8 hours using the machine. So if you are someone who only sleeps for a few hours a night or are easily disturbed and restless at night, you may find CAPD more suitable.

Once you are settled on APD, the nurses will decide how many hours of cycler dialysis you require and if you will need a bag of dialysis solution in your tummy during the day. The great thing about APD is that your daytime is dialysis free. For this reason, it has become a popular form of peritoneal dialysis.



How Will Home Dialysis Affect My Lifestyle and Activities?

Patterns and levels of activity and lifestyle choices vary across stages of life and from person to person. What you value highly may be less or unimportant to other people and vice versa. You may work, study, be retired, travel, play sport or have a family to care for. Think about how dialysis will fit into your life, your regular commitments and activities.

Employment

You can work with all types of home dialysis. Your work routine is a significant factor in your decision about which dialysis will suit you best. Many people who work choose an overnight dialysis. This can be either peritoneal dialysis or haemodialysis. Others choose CAPD or schedule their haemodialysis treatment after they get home from work.

- Peritoneal dialysis on the overnight machine (APD) provides dialysis-free days.
- Home haemodialysis can be done overnight, in the evenings or whenever you are at home.
- CAPD usually requires a lunchtime exchange in a clean and private area. Many employers are very co-operative and will support this.

Travelling to Treatment

Training for home dialysis will require travel for a limited time. Once established at home you are likely to have 1 to 3 monthly check-ups. Once at home, spare a thought for those who are travelling to and from a dialysis clinic three times a week, every week. The reduction in travel that home dialysis offers saves both time and money. For the environmentally conscious, this is also a saving to the environment.

Diet and Fluids

Everyone seems to be different when it comes to diet and dialysis. Generally those on peritoneal dialysis have more freedom than those doing three times a week haemodialysis. Those choosing longer or more frequent dialysis such as second daily or overnight dialysis, are less likely to have fluid or diet restrictions.

If being less restricted in your diet and daily fluid intake appeals to you, then home dialysis will give you the most freedom. Dietitians support everyone with kidney failure and can help you to adjust your diet if needed.



Leisure Activities

Home dialysis will allow you to continue the leisure activities you currently enjoy. In fact, many 'sit down at home hobbies' can be done during dialysis. Restrictions will only occur if you are unable to allocate enough time to your dialysis each week.

Sport, Exercise and Swimming

Continuing sport and exercise is encouraged for everyone on dialysis. With home dialysis you are more likely to have the flexibility to fit your dialysis routine around your exercise routine.

Finding the energy for exercise for anyone who has kidney failure may be more difficult than before kidney failure, but there are many examples of people achieving high levels of fitness and major sports achievements. Improved general health and fitness is easier to achieve with the opportunity home haemodialysis offers for longer and more frequent treatments.

There may be swimming restrictions if you are using peritoneal dialysis. If you swim, strict attention should be paid to the advice of your dialysis nurses about water quality and safety, and how to care for your peritoneal catheter after swimming. Generally, private pools and clean beaches are suitable.

Sleep

Kidney failure can affect the quality of your sleep and a poor night's sleep leads to less than a high quality day. The good news is that sleep quality and patterns can improve for those doing longer or more frequent hours (over 15 hours per week) on home haemodialysis and also for those on peritoneal dialysis. Research suggests that the overnight APD machine can reduce snoring and breathing difficulties at night (sleep apnoea).

Some people struggle with the presence of a machine when they are trying to sleep. If you are a very light sleeper who is up and down all night, you may prefer a daytime routine for your home dialysis. In many cases, persistence can really reap rewards and it always worth trying dialysis overnight if freedom from daytime dialysis is important to you.

Pets

It is recommended that to reduce the risk of infection, pets be kept away from your dialysis treatment area. It is perfectly safe to have pets in other areas of your home.

Travel for Holidays

If holidays are very important to you then peritoneal dialysis is likely to give you the most flexibility to travel, particularly if you travel with the CAPD bags. The APD machine can also be used for travelling. With some planning, supplies can be delivered to your hotel destination here or overseas or packed into the boot of your car.

Most hospitals will cover delivery costs in Australia. For overseas travel, you may be asked to cover freight charges from the nearest dialysis supplier warehouse. It is best to check local funding arrangements with your dialysis unit staff.

For anyone using haemodialysis to travel, you will need to book in somewhere for your dialysis. This may incur a cost and will need advanced planning. Staff can assist with this. Many units appreciate and can more easily accommodate those who are on home haemodialysis, and who are able to manage some of their own care. Some countries have reciprocal health care agreements with Australia meaning that haemodialysis may be free for some treatments.

Will My Health Benefit from Home Dialysis?

Yes it will. Your health will be at least as good if not better on any type of home dialysis, compared to clinic or centre-based haemodialysis. Those on home dialysis are admitted to hospital less often, have improved quality of life and on average, live longer. Annoying problems experienced by those with kidney failure such as restless legs, itch and poor sleep are found by many on all types of home dialysis to be improved. Blood pressure control will usually be better. You may even be able to reduce or stop some medications.

Peritoneal dialysis is continuous and gentle. Daily treatments mean that the fluid and toxins levels in your body are kept at a constant level. This is good for your health and well-being.

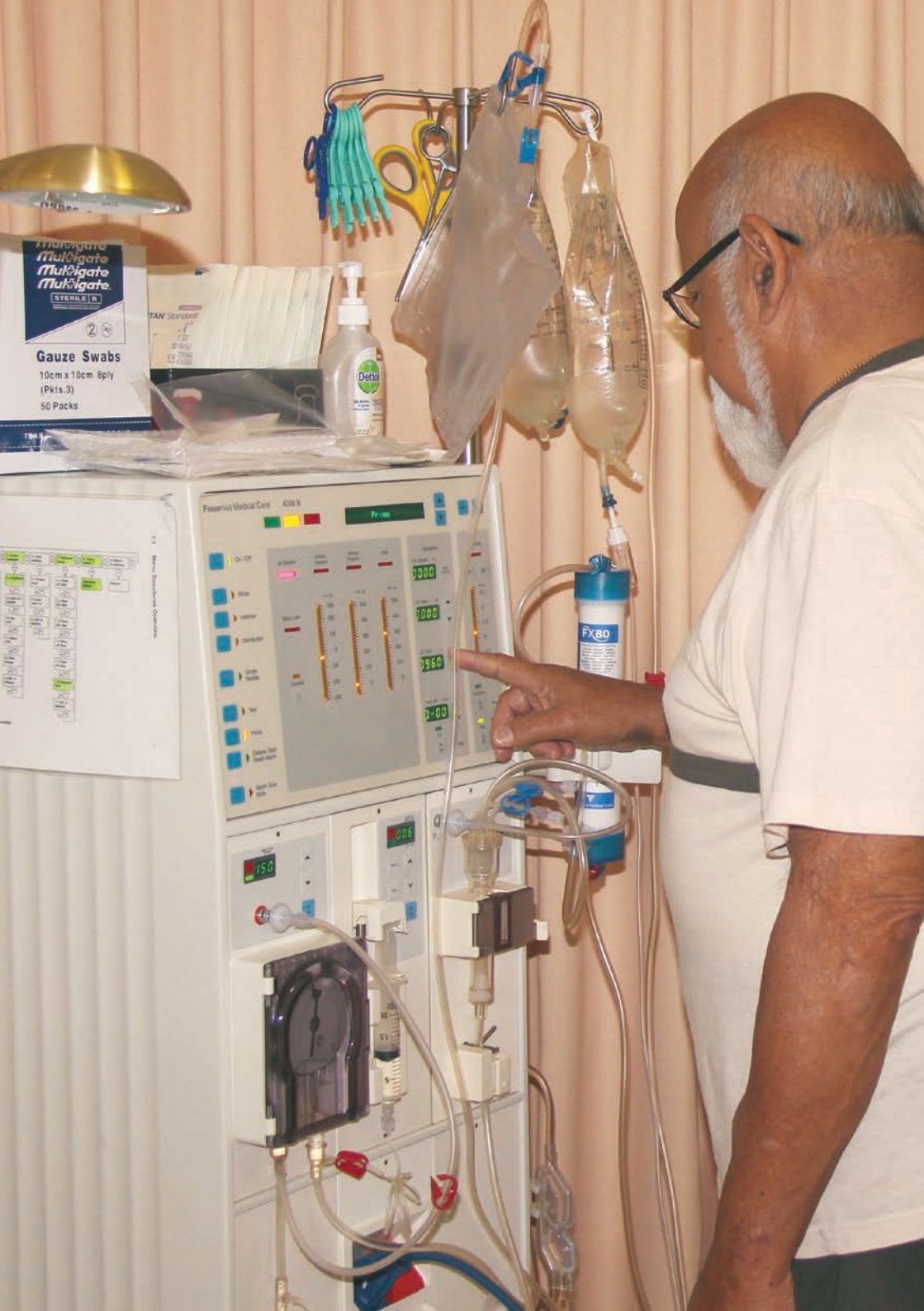
There is strong evidence that more evenly spaced haemodialysis, such as five hours every second day and/or longer hours, such as six to eight hours overnight, three or more times per week, will benefit your health and quality of life. If you dialyse three times a week there is one long break of two days. During the break the toxins and fluid build-up in the body, and this can make you feel tired. You are more likely to have problems on dialysis such as low blood pressure and cramps and be more prone to heart complications. Equally spaced or one extra treatment per fortnight can reduce this problem. This is easier to achieve at home.

Interestingly, research suggests that even if you dialyse for the same number of hours at home rather than at a dialysis centre, health is improved and complications are reduced. This could be because control of treatment at home leads to you taking better care of your own health, or because you have an improved quality of life.

The best people to help you understand the health benefits are those treating themselves at home. Your renal unit team may be able to introduce you to someone already dialysing at home.

Quality of Life

Many people on home dialysis will tell you it is the best decision they ever made. Quality of life is individual to us all. If home dialysis allows you to carry on the rest of your life as close as possible to your life pre-dialysis then you are most likely to enjoy a higher quality of life. Clearly, better health with fewer hospitalisations and complications will also lead to improved quality of life. If you believe that your time is better spent with family and /or friends doing the things you enjoy than spent in hospital, then home dialysis of any type is probably for you.



Fresenius Medical Care 420 b

Gauze Swabs
10cm x 10cm 8ply
(PK1s.3)
50 Packs

Dettol
Disinfectant

FX80



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Is My Home Suitable for Home Dialysis?

Most homes are suitable for home dialysis. Many home dialysis patients live in rural or remote areas, and live in small houses.

If you rent, you may wish to seek permission from the landlord for home haemodialysis. Most landlords are happy to assist, as long as the small alterations made to the property are rectified at the end of the lease. A letter from your renal unit is often helpful in explaining the importance of allowing the installation. Sometimes, temporary plumbing can be arranged if the landlord won't agree to plumbing alterations.

Review the checklist opposite to assess whether your home is suitable for the type of home dialysis you would like.

Requirement	Peritoneal Dialysis CAPD bags	Peritoneal Dialysis APD machine	Haemodialysis
Storage area about 2 metres wide against a wall. The area should be dry, undercover and off the ground.	✓	✓	✓
Electricity outlet in your dialysis room. Adaptations for safety may be made.	Not needed	✓	✓
Water supply: If your home uses tank water, it will need assessment by your local unit*.	Not needed	Not needed	✓
Access to a mains sewer or drain: for haemodialysis, if your home has a septic tank, it will need assessment by your local unit.	Not needed	✓	✓
Handwashing facilities in walking distance (ie bathroom, kitchen, or laundry sinks).	✓	✓	✓
Waste removal: Regular garbage bins can be used but the quantity of waste will increase.	✓	✓	✓

***Recycling of Water.** Where water supply is limited, recycling measures can be used. The local technician can usually set this up. Some people choose to recycle even if water is in good supply.

How Much will Dialysis Cost Me?

There is no charge for your dialysis machine and consumable supplies which are delivered to your home once a month.

Some people choose to buy special items to help organize their stock and you will use extra hand soap and paper towels. Some prescription drugs are also needed for your haemodialysis. Some units assist with the purchase of recliner chairs (optional), digital scales (to weigh yourself and the PD bags) and blood pressure machines. Unfortunately at this time, there is no uniform reimbursement scheme for these items.

Electricity is necessary for APD, the overnight machine. Water and electricity are necessary for home haemodialysis, which relies on power and water for its operation. Assistance with plumbing and electricity set-up costs for haemodialysis varies between units and States, but is generally provided free. **Solar Energy:** Solar panels will reduce the cost of electricity for dialysis. Some units may help with these costs.

Remember when you are comparing costs, that weekly travelling costs can be expensive for centre based dialysis. The average centre-based dialysis patient living only 10km from their local unit travels 60km per week or 3000km per year.

Financial Assistance/Reimbursements Information

The renal unit social worker can assist you in assessing the financial impact of dialysis and provide information about local financial assistance schemes. Financial reimbursements are often highest for those with a concession card.

Across Australia, there are reimbursements that you can claim. Your dialysis unit or the Kidney Health Australia home dialysis website provides financial reimbursement information: www.homedialysis.org.au

For most States you will not be out of pocket.

What Impact Will Home Dialysis Have on My Body?

“Access” for dialysis will be created no matter which dialysis or location or type you choose.

Access for Peritoneal Dialysis involves a permanent soft plastic tube being placed surgically into your abdomen (tummy), fairly close to your belly-button. The surgery is short, with usually only an overnight stay in hospital. There will be a small dressing over the tube and an anchor tape to hold the tube. The dressing may be optional once it is healed. For those who have had past abdominal surgery, there may be difficulties in placing the catheter into the abdominal cavity. Your doctor will discuss the possibilities with you.



Peritoneal Dialysis

For your daily hygiene, showers are recommended because the catheter may get infected if you sit with the catheter under water in a bath.

Access for Haemodialysis requires the creation of a fistula or graft, which requires a small operation, usually with only an overnight stay in hospital.



Haemodialysis

A fistula is the joining of one of your arteries to a vein under the skin, usually in your non-dominant forearm.

A graft is used when your veins are very tiny or delicate. A graft is synthetic material which makes an artificial vein (access) under the skin.

Two needles are inserted into the access: one to take blood through the artificial kidney and one to return the filtered blood to you. The needles are removed after dialysis.

Central Venous Catheter (CVC) is another form of access. The CVC line is put in a vein in the side of your neck or upper chest. There is a higher infection risk and it is not the preferred option, especially for home dialysis. If needed, it is a good temporary measure and in special circumstances, may sometimes be used at home with special training.



Artificial kidney (dialyser)

How Do I Learn to Do Home Dialysis?

The thought of learning a new skill is scary for most people but the good news is that the nurses in home dialysis units can train nearly everyone to successfully manage their dialysis at home. However, like being at school, the effort you make when you are learning is important if you want good results. What is guaranteed is that you will only go home once you are confident with your new skill and able to manage any possible problems.

A list of home dialysis clinics can be found at www.homedialysis.org.au/home-dialysis-clinics/ but not all clinics offer training. Training will be offered at the training unit affiliated with your renal unit. Speak with your renal physician if this is not conveniently located for you and other arrangements may be possible. Sometimes, temporary relocation is required if you live in rural or remote areas. Financial support for travel and accommodation under the State patient assisted travel scheme is available to help with these costs.

Training is a mixture of watching, reading, listening and doing. The training nurses are very experienced and can access information in different languages and to suit many cultures. If required your family can train with you. The sense of achievement at the end of it is something you and your family won't forget. It's empowering!

Being focused only on your training and not worrying about trying to juggle work and training is important. It is recommended that you allow enough time to complete your training. It is also a good idea to plan a quiet week when you first go home so that you can adapt to your new routine.

How Long Should it Take to Learn Home Dialysis?

Peritoneal Dialysis training will on average take about a week of training at a clinic for a number of hours each day. Allow an extra few days if you are learning both the CAPD and the APD machine at the same time. This quick training for peritoneal dialysis may make it your best choice.

Home Haemodialysis training takes an average of 6 to 8 weeks, of 3 to 4 sessions a week. Training times depending on how quickly you feel comfortable and confident in cannulating your fistula or graft and with operating the machine and mastering trouble shooting. If you have to start dialysis in a clinic, rather than a home training unit, then you can start your learning from day one.

Learning to put the needles in is an initial worry for many people. Please be assured that all home HD patients will tell you that despite their initial reservations, they became so confident and competent in inserting their own needles, that they would rather do it themselves in preference to having a nurse do it for them.

Will I Be Supported Once I Go Home?

The nurses should support your first treatment at home and are also available during the day and on call after hours to support you with any problems or queries. They will also see you regularly at clinic or visit you regularly at home. Technical support is also available during business hours for routine maintenance and support, as well as out-of-hours, to help with any urgent technical problems.

You will have access, usually as an outpatient, to visit all of the other support people at home as you would if you dialysed at the hospital, including doctors, dietitians and social workers.

Will My Family Need to Support My Dialysis Treatments?

Both PD and HD can be done on your own at home, as long as you can safely manage the treatment and any trouble shooting independently. It is more common to have someone help with home haemodialysis, but it is usual that the person needing dialysis learns to manage all or as much of their treatment at home as they can independently.

However, grown up children, partners and even parents can help or do the dialysis for their loved ones in some situations. In the case of home HD, support may involve turning on the rinse cycle of the machine, helping to clean up and bringing drinks, food, etc. Sometimes this is by choice to make the process quicker and sometimes by necessity.

Those who need the most support include young children, those who have limited mobility, dexterity or movement and those with failing memory. It is likely that those who are unable to cope with the normal activities of daily living, such as showering and housework, will need more support for dialysis. This includes transport assistance for centre-based dialysis.

In such cases, you and your family will have to think carefully about commitment. Unfortunately, apart from occasional HD respite provided by your parent renal unit or by holidays at other locations and renal units, family support is likely to be necessary at each treatment. Some nursing homes can do peritoneal dialysis permanently or for respite, but these are limited. Ask your social worker and renal nurses if this is available in your area.



Will My Loved Ones be Affected by Home Dialysis?

It is fair to say that no matter what modality of dialysis you choose, your family will be affected, but in different ways. If you choose to dialyse at home, dialysis happens in your world and your family continues to enjoy you being with them.

If you attend a dialysis clinic, then your partner or family members may have to drive you there, and you are away from home for 18-20 hours per week. If you have children, or anyone dependent on you, think about whether having you at home on dialysis or having you visit a clinic would suit your needs better.

You may choose the bedroom, living room or spare room to be your place for dialysis. This choice will depend on where you would prefer to be during dialysis. For example, in the evenings, you may like to have dinner and talk with your partner and children, help with homework, read, listen to music or watch television. Your dialysis place is an individual choice but one that can involve other family members. It is important to discuss your thoughts and preferences so that you have their full support.

Understandably, children may be worried about what is happening to you. However, if they see that you are confident and comfortable with dialysis and are honest with them, children are very adaptable and accepting, especially if the dialysis routine becomes part of the normal daily routine.

What's most important to ask yourself is what will maintain my personal and family way of life and relationships, income and interests best?

How Will My Sexuality and Intimate Relationships be Affected?

It is not unusual to worry that any changes to your body, such as fistulas or catheters, may affect aspects of your sexuality, your confidence and body image. It is worthwhile considering how these body changes might affect your sexual feelings and intimate relationships and activities. Be assured that dialysis does not impose any restrictions at all on sexual activities. Accepting these changes and feeling comfortable with your body will help in confronting any reservations you or your partner may have.

If having an intimate relationship is something you currently enjoy or would like, then the health benefits that home dialysis brings can help you to maintain this important aspect of life. The flexibility of home dialysis, as opposed to attending a dialysis centre, means that you will have more time to spend with your partner or if single, in socializing with friends and dating. Making time for relaxation and pleasurable activities is important in keeping new or established relationships healthy. Even if it sounds as though the time required for dialysis may make this impossible, many couples find that they still have plenty of time for intimacy and enjoy loving and fulfilled relationships.

What if I Am Struggling to Cope Emotionally?

The good news about home dialysis is that people who are in control of their treatment usually have less anxiety and depression. This may be due to the flexibility and freedom and the improved health benefits that home dialysis offers.

However, it is normal to feel anger, despair, fear and other negative emotions during the journey of kidney failure diagnosis and dialysis treatment. These feelings usually improve and resolve with time. Everyone has periods of feeling burdened by life. Adding the need for dialysis to the mix and the changes it can bring can make these feelings stronger and last longer. If the impact of dialysis treatments and the possible changes to your lifestyle are overwhelming you, then it is important that you talk to someone.

The nurses, social worker or doctor at your unit are the best place to start. Social workers are employed in renal units to provide professional counselling to patients and their family members and are very familiar with the issues you are experiencing. There is no need to feel embarrassed or ashamed or suffer in silence. Depression can be addressed by “talking therapy” and by medication. Alternatively, your GP can arrange referral to a psychologist, social worker or psychiatrist in your community. These services can be accessed through Medicare.

Organisations such as Beyond Blue provide a confidential telephone information and advice helpline.

If you find yourself feeling low, try to remember a good and satisfying life really is possible and achievable with the ongoing support of your renal team. Please ask for support.



How Do I Make the Choice?

Education is the first step. Take advantage of the specialized nurses and social workers who offer group and individual education sessions. Use booklets, reputable websites, videos, and consider talking to others in the same position. Your physician can offer advice on any possible reasons why a particular form of dialysis may not be possible due to current, or previous, health issues.

During the education process it is often helpful to work through all the options systematically. An Australian 'Decision Aid for the Treatment of Kidney Disease' is a helpful tool to do this and guides you through the education journey. Your dialysis education staff may also provide this for you or it is available from the home dialysis website www.homedialysis.org.au

It is important to note that many with kidney failure, especially those who are younger, may experience every treatment type at some stage during their kidney failure journey.

Focus on your current lifestyle, and remember, if you choose a dialysis type that has a routine that is acceptable to you, then the decision will be easier to follow through.



Resources

Booklets, Brochures, Fact Sheets and Websites

Renal Resource Centre:
www.renalresource.com

Kidney Health Australia Home Dialysis Website:
www.homedialysis.org.au

Kidney Health Australia – Home Page:
www.kidney.org.au

Department of Renal Medicine, Geelong Hospital:
www.nocturnaldialysis.org

Telephone Information

Kidney Health Australia
1800 454 363

Request the tele-connect service if you would like to talk to someone with experience of dialysis at home

Renal Resource Centre
1800 257 196 or 02 9462 9455



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