

Withdrawing from Dialysis Treatment

**Information for Patients
and their Families**

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Preface

This booklet answers questions that are most commonly asked about withdrawing from dialysis. It is not unusual to think about this when other medical conditions or long term complications of your dialysis treatment are adversely affecting your health and outlook on life. However, even serious complications can often be treated and get better. When this happens, it is sometimes hard to believe that you ever thought about stopping your dialysis treatment.

There are circumstances when no matter what other treatment is undertaken, there is no improvement and the prospect of carrying on in the face of ongoing poor health is unbearable. For example, continuing with dialysis when diagnosed with a terminal illness or other very incapacitating condition may seem pointless. In such cases, stopping dialysis is a very legitimate choice and is regarded by many dialysis patients as a relief.

Arriving at a decision to stop dialysis can be difficult, as it not only means reviewing your life and facing death but also discussing your wishes with family and friends. All of this takes a great deal of courage and family members are often very resistant to such suggestions. Ultimately though, the decision is yours. As much as we may strive to live with dignity, it is accepted that we all wish to die with dignity.

It is therefore important to speak to your renal physician and other members of your health care team whenever you have concerns about your treatment or thoughts about withdrawing from it. They will answer your questions as best they can, provide guidance to you and your family and help you reach agreement and peace of mind, whether you choose to continue dialysis or not. Your well-being and your wishes will always be respected.

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March 2010



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Ending Dialysis Treatment

Introduction

Withdrawal from dialysis is not an uncommon cause of death for dialysis dependent patients. In Australia, withdrawal from treatment was recently reported as the cause for 26% of deaths of dialysis dependent patients, mostly aged over 80 years and in a very small number of cases, in younger patients who were very ill.¹

All patients have the right to receive or refuse life-prolonging treatment. The treating team have an ethical and legal obligation to acknowledge and honour those choices and advise on reasonable treatment options. When a patient has been adequately informed and understands the consequences, withdrawal from life-sustaining treatment such as dialysis is a medically, ethically and legally acceptable choice.

Many religions also uphold the belief that individuals have the right to stop medical treatment when they no longer find it is providing them with a satisfactory quality of life. If you have concerns about this, you may wish to speak with your spiritual advisor.

There may come a time when stopping dialysis is an option to be explored. Such a discussion may be initiated by you, your family or your doctor. In each case, the guiding principle is to ensure your medical and other care provides benefit, avoids harm and maintains your comfort and dignity.

When You Choose to End Dialysis Treatment

You may reach a stage when you consider that dialysis can no longer provide you with any benefit to your health and enjoyment of life. In fact you may consider that it is unnecessarily prolonging a life of ill health and is a substantial burden to you. If this occurs, it is important to know that you have the right to stop dialysis treatment.

It is not at all unusual or unexpected that those with age related conditions such as dementia, those diagnosed with a terminal illness such as cancer or young people with other complex medical problems, decide to end dialysis treatment. In some of these cases, dialysis treatment may offer little or no benefit and may be considered a burden. Therefore, it may be very reasonable to consider ending dialysis treatment and to make this known to your family and doctor. You may even have discussed this with them as a future possibility when you first commenced dialysis or during the course of your treatment (see section on End of Life Decisions).

1. Australian and New Zealand Dialysis and Transplant Registry 29th Report 2006 p.50



If members of your health care team are concerned that your request to stop dialysis may be due to emotional or social issues, they will recommend a consultation with your renal unit psychiatrist and social worker. They will assess your emotional state and social circumstances to ensure that you do not have undiagnosed or untreated depression or other distressing emotional or social problems and are able to offer appropriate counselling and assistance. Treatment and counselling for mental health and other personal matters may help you achieve a more positive outlook on life and hence continue your dialysis treatment.

It is important to note that in the absence of depression or other mental illness, a well considered decision to end dialysis treatment will always be respected, as will the right to subsequently reverse that decision and continue treatment.

When Your Doctor and Treating Team Recommend Dialysis Treatment Should End

Sometimes your renal physician, usually in consultation with other members of the renal team, may advise that your dialysis treatment is no longer beneficial and should end. This situation may arise if your health has significantly deteriorated due to other serious medical conditions and recovery or improvement in your quality of life is not expected. In such circumstances, dialysis will not contribute towards any improvement in your health and attending and undertaking dialysis treatments may contribute to a worsening of your health and quality of life.

Occasionally, family members can have unrealistic expectations about what dialysis can achieve and do not easily accept such recommendations. They may believe they must defend the patient's right to access treatment at all costs. In the event of disagreement, the comfort, dignity, wishes and values of the patient should be paramount.

Family conferences with medical and other staff are useful in helping family members to understand the seriousness of the situation and to accept that treatment is no longer beneficial.

End of Life Decisions

In the case of people who are not well enough or no longer have the mental capacity to make their own decisions about treatment, the renal physician will very carefully discuss the issue of ending dialysis with family members or carers.

You may have already considered such a situation. This would involve making known, when you are well, what medical interventions you would or would not want, in the event that at some future time, you were incapable of making these very important end of life decisions. These decisions can then be documented. This is called advance care planning. An advance care plan will be used to guide future medical decisions ONLY when you lose the ability to make or communicate your medical treatment decisions yourself.

The most important thing is that your renal physician, general practitioner and other key health care providers, plus key family members are aware of your wishes. You may wish to appoint a relative or friend as an enduring guardian or the equivalent in your State. An enduring guardian can make personal decisions on your behalf, such as where you should live and what medical treatment and services you should receive. Many people now choose to have these “end of life” discussions with their families and doctor when they are well, in anticipation of what may occur in the future.

For example, you could specify that under certain circumstances, you would like your health care to be managed in a particular way. So if, for instance, there was a serious deterioration in your health and you were unable to make decisions about your care, you could specify instructions such as the following. “In the event that there is no possibility of a return to independent living, artificial ventilation and CPR (resuscitation) should not be performed.” You may wish to further specify that in such circumstances you would want dialysis to stop.

Discussing these matters with your family and doctor in advance, ensures that your intentions are clear to those who love and care for you.



Emotional Reactions to Deciding to End Treatment

Whether it is your own decision or the recommendation of your doctor and other staff to stop treatment, you and your family may experience the following emotions, all of which are perfectly normal and expected:

- confusion
- sadness
- anger
- fear
- relief
- acceptance
- peace

For many people, making the decision to end treatment can bring a great deal of relief and peace of mind. However, the process of reaching that decision may be very difficult, especially if you are uncertain about what to do or if family members are struggling to accept your point of view. It can be an emotionally overwhelming and draining time for you and those you love.

Discussing Your Thoughts with Family and Friends

Many people find it difficult to talk to loved ones about stopping treatment and worry about how they will feel and react. Your doctor, nurse, social worker or spiritual advisor can provide guidance on how you might approach this. It is often easier to first speak to someone you trust and who makes you feel comfortable.

Although you may find it hard, the best approach is to discuss your thoughts and feelings openly with your family and loved ones. It will become easier if you can all be honest and acknowledge and accept each other's opinions and feelings. If you wish, a family conference with your doctor and social worker present, can be arranged to support you when you speak with your family. In the case of disagreement with your family, your wishes must prevail and will be upheld.

What to Expect When Dialysis Ends

How Long Will I Live?

There is no set timeline. Predicting exactly how long you will live is difficult, as every situation is different. However, your doctor may be able to give you some indication.

People who withdraw from dialysis treatment generally survive for one to two weeks, depending on the amount of kidney function they have left and their overall medical condition.

Symptoms After Withdrawal from Dialysis

As your condition deteriorates, you may experience these symptoms:

- Excessive sleepiness and weakness
- Breathing changes
- Changes in body temperature
- Appetite changes
- Emotional change

Will I Experience Pain?

Death from kidney failure is usually painless and peaceful. It involves slipping into a coma (deep sleep) from which you will not wake up. Some people may experience pain from other concurrent illnesses or as a result of complications from their longstanding kidney failure. Many very effective treatments are available for controlling pain in these circumstances.

Will My Doctor and Treating Team be Involved?

Your renal physician and staff will remain available to you and your family. Usually, they will recommend a consultation with a palliative care physician, who can provide ongoing advice and care.

Palliative care is co-ordinated care provided by a specialist team for people at the end of life. They will ensure you remain as comfortable as possible and that all your physical, emotional and spiritual needs are met as much as possible.

As you have a special relationship with your renal team, the palliative care team will work very closely with them.

Will I Have a Choice About Where I Will Die?

Your wishes about where you will die will be honoured as much as possible. Sometimes people choose to die in the comfort of their own home. If being cared for at home is possible, nurses can visit you at home regularly.

Alternatively, if you are already in hospital, you may be able to remain there. It is also possible for your care to be transferred to a palliative care unit or hospice (a hospital facility or ward specially staffed and designed to provide palliative care).

Your doctor and renal team will discuss all the options available, taking into account your preferences and advise you and your family about the suitability of each for your special circumstances.

Will I be Able to Eat and Drink Whatever I Like?

Typically, there can be some relaxation of your renal diet, so that you can enjoy some special treats. However, drinking excessive amounts of fluid is not advisable when dialysis has ceased. Excessive fluid intake can cause breathing difficulties and distress but maintaining your fluid restriction can control this. Your doctor and dietitian will advise you about how to best manage your diet and fluid restrictions.

Preparing Your Personal Affairs

After a diagnosis of a serious illness such as kidney failure, it is always advisable to ensure financial and personal affairs are in order. This will provide peace of mind to you and your family. It can also prevent a considerable amount of emotional distress, personal conflict and unnecessary legal and other expenses for your family.

It is recommended that you:

- Prepare a last will and testament and discuss any special intentions or bequests with beneficiaries.
- Arrange enduring guardianship or an advanced care plan.
- Arrange enduring financial power of attorney.
- Organise your financial records including bank accounts, insurance policies, real estate etc.
- Ensure a nominated person has the contact details of people who will be involved in the settlement your estate e.g. solicitor, accountant, executor of your will.
- Discuss your preferred funeral arrangements and service with your family.

Reviewing Your Life

Reading this booklet may have stirred many thoughts and emotions about your life, your family and your spiritual beliefs. Speaking with your doctor, social worker or other health care staff, may help to clarify these thoughts and feelings and reduce anxiety.

An issue as complex as the choice to continue or end your treatment can take time to examine and reach a decision. For this reason, you may revisit it several times. If you cannot reach a decision, don't worry. Your treatment will continue until you are more certain about what to do.

Use the blank space on the last page to write down any questions you now have after reading the booklet. You can use these to guide your discussions with your doctor, your family and others whose opinions and advice you value.



Useful Websites

Information on end of life choices
for patients/families:

www.caresearch.com.au

www.respectingpatientchoices.org.au

[www.racgp.org.au/guidelines/
advancecareplans](http://www.racgp.org.au/guidelines/advancecareplans)

www.kidneyeol.org

www.kidney.org.au

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