

CHOOSING WHETHER TO HAVE TREATMENT



WHAT TREATMENT CHOICES DO YOU HAVE?

There are three choices of treatment for kidney failure:

- Dialysis: haemodialysis or peritoneal dialysis
- Kidney transplant
- Conservative or no treatment

CAN YOU DECIDE NOT TO HAVE TREATMENT?

Yes. You have the right to refuse treatment. The decision to refuse treatment for kidney failure will eventually lead to death.

The decision to refuse treatment needs a lot of thought as families may become distressed by the suggestion. Although it is important to consider the feelings of others and explore options, it is important that you make the final decision.

It can be easier to make a decision about treatment when you are informed. Learning about kidney failure treatment is an important part of deciding which option is best for you. Hospitals offer education sessions about dialysis and transplantation. These sessions give you and your family time to ask questions and talk to others in a similar situation. Your doctor can also provide information about treatment, including conservative treatment. Talking to a social worker, counsellor or your spiritual adviser can also be helpful. For more information about treatment options see *Haemodialysis*, *Peritoneal Dialysis* and *Kidney Transplant* fact sheets.

Depression may be linked to kidney failure and can cloud judgment, making the future look gloomy. If you think you are depressed it is important to talk to someone as depression can affect your decision. Professional help and appropriate treatment may be needed.

There are many resources available regarding depression. You may wish to read the *SANE Guide to Good Mental Health for people affected by kidney disease* for more information.

WHAT IS CONSERVATIVE TREATMENT?

With conservative treatment, you choose not to have dialysis but continue to see your health care team and maybe a palliative care team as well. The palliative care team supports you and your family to live as independently and comfortably as you can in the face of serious illness. Diet and medication are often used as part of this treatment.



WHY WOULD SOMEONE CHOOSE TO HAVE CONSERVATIVE TREATMENT?

Kidney failure often causes major changes in your life. Dialysis treatment and transplantation bring about lifestyle changes but most people find ways of dealing with the hassles and new challenges. Quality of life can be excellent, particularly for those who are otherwise in good health. People can enjoy full lives - working, studying, caring for families, playing sport and socialising.

However there is a chance that other illness can cause problems such as a stroke or a heart attack. Gradual worsening of health can make life seem unbearable, particularly when there is a loss of independence. For some, the thought or reality of dialysis treatment or transplantation is overwhelming. Others feel that they have seen enough of life or do not want a complex treatment to keep them alive. Whatever the reasons, some people get to a point where they feel that treatment is a struggle.

Many people start dialysis hoping to eventually have a kidney transplant. However, transplantation is not always successful or available right away so it is wise to see dialysis as a long-term, if not life-long, treatment. When making a decision about treatment, it is important to remember that it is a choice and that conservative treatment is another option. If someone is unsure, it is always possible to try dialysis for a short while to see how things go.

- **Choosing to stop dialysis**

Stopping dialysis treatment is not an uncommon cause of death for people who have been on dialysis for a long time, particularly those who are elderly. Some people, who would like to stop worry that they would be letting their family, staff and other patients of the renal unit down. While they will be sad, most would be aware of the person's reasons.

- **Choosing to stop transplant medication**

Transplantation can offer a better quality of life but it is not without risks. The strong drugs used to prevent rejection can lead to:

- Infections
- Skin cancer
- Serious cancers

The treatment for some cancers is to stop the use of immunosuppressant drugs. This causes the kidney to be rejected so the decision about starting dialysis needs to be made. Some people may have developed other conditions related to kidney failure, e.g. bone disease or access problems. As their transplants fail these people may choose conservative treatment rather than a return to dialysis.

WHAT SHOULD YOU DO IF YOU DECIDE TO HAVE CONSERVATIVE TREATMENT?

Ethically it is wrong to continue to put a person on an artificial life support if it is against their wishes. In fact, a number of Australian states have laws making sure that people have the right to decline or stop life prolonging treatment. In reality it is quite difficult to make such decisions and one that can be very hard

for family or medical staff to accept. The ability to make decisions can be reduced during serious illness and therefore it can be helpful to involve a family member, close friend or spiritual leader.

If you decide to have conservative treatment, you or your Medical Agent (see Medical Power of Attorney or Enduring Guardian) need to make sure that your affairs are in order, for example:

- Make sure you have a will
- Consider appointing a Medical Power of Attorney or Enduring Guardian
- Consider making an Advanced Care Plan
- Make a list of your financial records including bank accounts, real estate, insurance policies, etc.
- Consider appointing a Financial Power of Attorney
- Provide contact details of people who will be helping to settle your estate e.g. solicitor, accountant and the executor of your will
- Let people know about your choices for funeral services

WHAT IS A MEDICAL POWER OF ATTORNEY/ENDURING GUARDIAN AND AN ADVANCE CARE PLAN?

It is important that you consider how to make your wishes known about medical treatment if you are unable to communicate. Different states have different titles and different powers for Medical Agents but generally their roles are similar.

- **A Medical Power of Attorney or Enduring Guardian**

This allows you to appoint a person as a Medical Agent who has the power to make decisions about medical treatment on your behalf. A Medical Agent becomes effective only if you lose the ability to make and communicate decisions about your health care. Medical Agents must meet the terms that you have stated in your advanced care directive about treatment decisions.

- **An Advance Care Plan**

This is different from a Medical Power of Attorney or Enduring Guardian. There are four parts to an advance care plan which include:

- Develop a future healthcare plan together with the GP or health professionals responsible for your ongoing treatment.
- Discuss your wishes for future life-sustaining treatment with your family before you are acutely ill.
- Formally appoint a Medical Power of Attorney or Enduring Guardian.
- Write an advanced care directive. An advanced care directive contains instructions that consent or refuse the use of specified medical treatments. It becomes effective if you no longer have the capacity to make these decisions. The directive should be signed and witnessed.

Discussion between you and those you are close to while you have clear decision-making capacity is the most important element of advance care planning.

There are advantages and disadvantages with advance care planning.

- **Advantages**

- Encourage communication about end-of-life decisions.
- Give directions to treatment decisions if you are no longer able to decide for yourself.
- Make sure that directives in your will are being met, i.e. your independence is respected.

- **Disadvantages**

- You may change your mind about what you want when you are unwell. You can make changes to your advanced health care plan at any time and can discuss this with your GP or treating doctor. An advanced care plan including an advance health directive or an enduring power of attorney only become activated in the event that you are determined to have lost the ability to make your own decision.
- They can be difficult to interpret in the real world, eg. the advance care planning scenario may not match the current medical scenario.
- Discussion about advance care planning can cause anxiety particularly if not sensitively handled.

For more information about kidneys health or this topic, please contact Kidney Health Australia:

Kidney Information Line (freecall) on 1800 682 531 or visit website

www.kidney.org.au

Or

The Palliative Council in your state for more information.

This is intended as a general introduction to this topic and is not meant to substitute for your doctor's or Health Professional's advice. All care is taken to ensure that the information is relevant to the reader and applicable to each state in Australia. It should be noted that Kidney Health Australia recognises that each person's experience is individual and that variations do occur in treatment and management due to personal circumstances, the health professional and the state one lives in. Should you require further information always consult your doctor or health professional.

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