

Standardised informed consent for maintenance dialysis

This policy will help you obtain written informed consent with a patient starting ongoing maintenance dialysis – that is, ongoing regular use of long-term dialysis for permanent end stage chronic kidney disease (ESKD). Victorian renal health services can adapt this policy and accompanying informed consent documents to care for patients with ESKD. This policy outlines the minimum recommended standards for informed consent for maintenance dialysis, to make sure patients understand their condition, treatment options and associated risks, and are involved in decisions about their care.

Specifically, this policy covers:

Dialysis type

- Peritoneal dialysis (PD)
- Haemodialysis (HD)

Treatment location

- Home-based (PD or home HD)
- Delivered in a healthcare facility (hospital HD or satellite HD)

This policy does not apply to:

Temporary or emergency dialysis when you are treating an acute kidney injury and:

- kidney function is expected to recover
- you are uncertain if kidney function will recover, or if the need for dialysis will remain ongoing.

Dialysis access procedures used to allow dialysis to be performed, including:

- inserting a peritoneal dialysis catheter
- creating an arteriovenous fistula
- inserting a central venous catheter.

Kidney transplantation, which requires written consent:

- after the pre-transplant evaluation to get on the deceased donor transplant waiting list, or to receive a kidney transplant from a live donor
- immediately before the kidney transplant operation.

Please refer to your health service's local policies and procedures for informed consent on the above.

Why use this policy?

This policy will help renal patients access consistently high-quality information and care, no matter where they live. Previously, we have found the information renal patients receive when they start dialysis sometimes differs from service to service. We also know through the Victorian Healthcare Experience Survey that renal patients feel less involved in decisions about their care than non-renal patients.

Using this policy will also help your health service comply with the National Safety and Quality Health Service Standards, particularly standard **2. Partnering with consumers**. You can find more information, resources and e-learning modules at www.safetyandquality.gov.au.

Minimum recommended standards for written informed consent for maintenance dialysis

Informed consent should include the following:

1	Information about condition	Tell your patient they have permanent and severe kidney failure. Tell them about the likely outcome of their condition, with and without dialysis.
2	Education about all treatment options	Give your patient information on all relevant treatment options including: <ul style="list-style-type: none">• hospital or satellite haemodialysis• peritoneal dialysis• home dialysis options• non-dialysis options such as supportive care without dialysis• kidney transplant.
3	Risks and complications	Explain that the different types of maintenance dialysis have various risks and complications, including examples of some of the common risks and complications that may occur.
4	Rights and responsibilities	Provide your patient information about their rights, responsibilities and expected conduct in relation to their healthcare.
5	Planned treatment option	Allow the patient to share the decision with you. Support your patient in considering their values, goals and preferences to decide on the best treatment for them. Be clear about what their planned treatment is and include this information on your informed consent document.
6	Regular investigations and monitoring for infection	Explain to your patient that they will need regular blood tests and routine investigations. Include the need for monitoring for transmissible infection, such as viral hepatitis control.
7	ANZDATA registry	Let your patient know that their information will be collected for the ANZDATA registry. <ul style="list-style-type: none">• Tell them this information is used to improve the quality of care and outcomes for people with ESKD in Australia and New Zealand.• Instruct them on how to opt out altogether, if they wish to do so. If your patient wishes to opt out ensure this is clearly documented in their notes and communicated to staff involved in data reporting, according to your hospital's processes.
8	Communication of clinical information	Tell your patient that relevant information from their health record (both electronic and written) will be shared with staff directly involved in their care at the health service or other services they go to. This is to help coordinate their care, no matter who is helping them.
9	Modality change	Inform your patient about the possibility of future changes in the type of treatment they may receive – for example, moving from PD to HD. They will be asked for their written informed consent to start new treatment.
10	Stopping treatment	Let your patient know they have the option to stop dialysis and transition to supportive care without dialysis (conservative care) if they choose to do so.
11	Advanced care planning and goals of care	Talk through the role of advance care planning for patients with ESKD and how important it is to communicate their goals of care to their treating team.

12 Signed written informed consent	<p>Make sure the patient, or their decision maker, voluntarily signs the written informed consent document.</p> <p>See more information below on when you should obtain and update written informed consent.</p>
13 Confirmation of written informed consent	<p>The treating nephrologist must ensure that valid informed consent is obtained from the patient. However, they may delegate certain tasks to suitably trained staff working under their supervision.</p> <ul style="list-style-type: none"> • Tasks that may be delegated include: education, communication of information, help with shared decision making, and signing of documents. • Tasks may be delegated to: renal registrars or senior nursing staff in accordance with local policies.
14 Capacity and understanding	<p>The medical officer and person obtaining and confirming consent must be satisfied the patient has understood and retained the information needed to make their decision.</p> <ul style="list-style-type: none"> • If the patient lacks the capacity to give written informed consent, or does not understand, seek consent from their legal medical treatment decision maker. • If you are unsure, reassess the patient's capacity through (for example) cognitive testing, neuropsychological evaluation or psychiatric assessment.
15 Interpreter use	<p>Please offer to get a professional translator for your patient if they are from a non-English speaking background. This can be provided either in person or over the phone.</p> <p>Note the use of the interpreter on the informed consent document.</p>

When to get written informed consent

You need to obtain written informed consent at the start of the ongoing dialysis process. You do not need to obtain written consent for each individual dialysis session. Verbal or implied consent is appropriate for this.

Please obtain prompt and timely written informed consent, while still allowing enough time for a patient (or their representative) to receive and process the information.

We recommend all patients complete informed written consent within three months of starting maintenance dialysis.

Context	When to obtain written informed consent
You are able to plan the start of treatment	Before or at the time of starting maintenance dialysis.
Treatment is unplanned	As quickly as possible after completion of the necessary education.
Patient starts dialysis for an acute kidney injury and is then later determined to have permanent kidney failure	As quickly as possible after you establish the patient requires ongoing maintenance dialysis.
Patient being treated in a satellite HD facility	Complete consent before commencing treatment in the satellite HD facility. If unable to, then as quickly as possible after completion of the necessary education.
Patient being treated with home HD	Before completing home HD training and starting dialysis at home.
Patient being treated with PD	Before completing PD training and starting dialysis at home.

When to update written informed consent

We recommend you update written informed consent when there is a significant change in the patient's situation, such as:

- the patient transitions permanently from one type of dialysis to another – for example, from PD to HD
- the patient transitions permanently from one service provider to another
- the patient's condition or circumstances change that may affect their ongoing consent – for example, where there is a new lack of capacity to provide informed consent.

You may also want to consider periodic (e.g. annually) re-consenting of patients for dialysis, according to local policies.

This policy was developed by Safer Care Victoria for Victorian renal health services. This policy and accompanying consent forms can be found at safercare.vic.gov.au.

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