ANZSN

RSA
Renal Society of Australasia

Kidney Health Australia

Kidney Health NEW ZEALAND
Prevention • Support • Research

POSITION STATEMENT

ON ‘KIDNEY TREATMENT OPTIONS’ EDUCATION FOR PEOPLE WITH KIDNEY FAILURE

We acknowledge the Traditional Custodians of Country throughout Australia, recognise their unique cultural and spiritual relationships to the land, waters and seas and their immense contributions to society, and pay respects to Ancestors and Elders, past and present. We acknowledge and respect iwi and hapū as tangata whenua of Aotearoa and are committed to upholding the principles of Te Tiriti o Waitangi (the Treaty of Waitangi). To read the ANZSN statement on Indigenous Health click here.

The Australian and New Zealand Society of Nephrology, Renal Society of Australasia, Kidney Health Australia and Kidney Health New Zealand are committed to the vision of optimal kidney care for all people. This care must be person centred and involve shared clinical decision-making in which patients, their families, carers and whānau are appropriately educated and informed on all available treatment options.

WHAT IS THE PURPOSE OF THIS STATEMENT?

This statement outlines the optimal 'kidney treatment options' education that should be provided to those with or nearing kidney failure. There is substantial variation in the level and quality of patient education currently offered by units in Australia and New Zealand.

This statement includes the agreed elements of education to ensure that all people with kidney failure receive thorough and unbiased education about all available treatment options. This will allow for informed consent by patients with or nearing kidney failure and their families and carers, regarding the chosen treatment pathway.

The provision of patient education across the breadth of modalities also provides an expectation of the level of resourcing that should be provided by health services.

WHAT ARE THE EDUCATION OPTIONS FOR PEOPLE WITH KIDNEY FAILURE?

Patient education begins at the point of diagnosis and is ongoing throughout the treatment journey of the patient and their family, covering multiple aspects of kidney disease and care. Patient education, in general, requires the accurate, consistent, and timely provision of information. The most important aspects of patient education include:

- providing clear communication
- tailoring information to the patient's specific condition and circumstances
- ensuring comprehensiveness by covering all necessary topics
- verifying understanding through teach-back methods
- considering cultural safety and personal beliefs, and the impact of existing 'lived experience'
- ensuring materials are understandable for people of all health literacy levels and making alternative arrangements for different languages

- tailoring information and method of delivery to account for individual learning styles and needs, e.g. disabilities which may impact the ability to take on new knowledge, providing educational resources in a range of formats such as digital, audio and written in order to improve accessibility and align with the health literacy needs of a diverse range of patients
- offering ongoing education as the patient's condition changes
- empowering patients, their families and carers to take charge of their care for greater independence and confidence.

For patients who are approaching or have reached kidney failure, the purpose of 'kidney treatment options' education is to support patients, their families and carers to make informed decisions regarding lifestyle, kidney replacement therapy and supportive care. This education ensures understanding of the benefits, risks, appropriateness for the individual, processes, and potential health and wellbeing outcomes associated with each treatment. Knowledge of available treatments empowers patients to choose the option that best aligns with their goals and needs and supports equitable access to care.

PATIENT EDUCATION SHOULD:

- be patient focused, tailoring the patient's specific values, goals, preferences and concerns regarding their healthcare journey to align with treatment planning and decision-making include the patient’s family, carers or significant others, should the patient desire this
- be targeted to the patient and involve the opportunity for one on one, and face to face (kanohi ki te kanohi) discussions
- be provided in a safe, accessible, and private setting if needed
- provide information on all treatment options, including transplantation, in-centre haemodialysis (HD), home HD, peritoneal dialysis, and kidney supportive care
- facilitate discussions on appropriateness of which treatment option is most suitable for the person with kidney failure, considering their current clinical suitability for certain treatments, or availability of treatment options
- recognise that patient preferences, situation, and suitability may change over time
- be mindful of the potential for clinician bias – such as financial bias, cultural bias, lack of clinician understanding or comfort with particular treatment options – and ensure that these biases do not impact on the patient’s ability to make the best treatment choice
- sensitively explain important concepts to patients, their families and carers, at their level of health literacy, when a particular treatment is not clinically suitable
- involve a collaborative process in which health care professionals and patients work together to reach a mutually agreed-upon treatment plan that respects the patient’s wishes and is based on the best available evidence
- be aligned with the patient’s needs, taking into account their understanding of health information, as well as their specific culture and/or language – particularly for groups such as paediatric, indigenous and culturally and linguistically diverse patients, their families and carers
- ideally be provided by a multi-disciplinary team that includes nephrologists, nursing, and allied health professionals with expertise to support the physical and psychological wellbeing of the patient and family e.g. dietetics, social work, physiotherapy, clinical psychology and other disciplines such as podiatry, diabetes educators, pharmacists
- provide opportunities for ongoing contact to provide psychological support, end of life planning, and lifestyle management support (diet, exercise, smoking cessation), and this support should continue as long as required
- include consideration of, and opportunity for, peer support

TIMING OF EDUCATION

Education should be a continuous, individualised process that aligns with patient readiness, and ideally begins proactively before the onset of kidney failure and the commitment to a specific treatment pathway. However, if there has been no opportunity for pre-emptive education prior to the commencement of renal replacement therapy – such as with acute kidney injury (AKI) or other rapid decline in kidney function, challenges in patient engagement, late presentation CKD, or late referral – education should be offered at the earliest time possible, ensuring patients have the opportunity to consider alternative treatment modalities.

Education needs to be considered an ongoing process, re-implemented when there is a necessity or desire to change treatment modality, and further information is sought.

CHECKPOINTS

Education should be delivered in a timely manner throughout the patient's treatment journey. There are times in the patient journey where informed consent and tailored education are required. These time points may include:

- level of renal function, guided by decision-making tools or eGFR thresholds.
- decisions on dialysis access, including creation of a fistula or insertion of a peritoneal dialysis catheter
- commencement of dialysis
- changes to prescribed medications
- necessity to change treatment modality
- commencement of supportive care
- transplant work up or waitlisting
- transplant failure

DOCUMENTATION

Thorough documentation following a discussion on treatment options for kidney failure is essential to ensure clarity, continuity of care, and shared decision-making. Clear and detailed records help communicate the agreed-upon plan to the wider healthcare team, reduce the risk of miscommunication, and provide a reference point for future discussions. Throughout a patient's health journey, their beliefs, values and decisions may change. Any decisions about future treatment, can be readdressed and redocumented at any time without undue pressure, bias or penalty.

Patients should be actively empowered to communicate any concerns, errors or aspects of disagreement in how their decision-making is recorded or characterised.

DIALYSIS CONSENT

We are supportive of a formal consent process for the commencement of dialysis. Commencing dialysis is a significant, life-changing decision for people with kidney failure. Ensuring that patients are fully informed, and able to provide adequate consent, supports patients' autonomy and benefits the entire care team through clearer expectations and shared decision-making.

The consent process should consider the health literacy and cognitive function of the person with kidney failure and the wishes of their family and carers (whānau) where appropriate. The recommendation for a formal dialysis consent process aligns with international guidelines. Examples of dialysis consent forms can be found in Appendix 1, and should be used in accordance with local guidelines, recognising the need for careful attention to the nuances of informed consent.

Dialysis consent forms may address:

- expectations of both patients and clinicians regarding risks, complications, and potential cessation of treatment
- importance of treatment and medication compliance
- collection of data, as appropriate
- screening for blood-borne viruses and infections and appropriate management of any identified infections

CONCLUSION

Education for patients with, or nearing, kidney failure should be comprehensive and grounded in shared decision-making, delivered over a timeframe that is individualised to the patient’s needs and goals. It should include regular check-ins to review their understanding of the treatment options available to them, and revisit preferences at critical decision points.

Robust documentation is essential to capture the education provided, the treatment pathway chosen by the patient and, where appropriate, evidence of informed consent. Adequate resources should be provided to kidney units to support the education process for patients, and their significant others, who are impacted by kidney failure.

APPENDIX 1

Consent forms

Individual hospitals and health jurisdictions may have their own consent forms and process for formal consent prior to commencement of dialysis or may need to develop jurisdictionally approved and stored consent forms. Examples can be found here.

Consent form – Maintenance haemodialysis in a healthcare facility

Consent to Peritoneal Dialysis

Consent to Haemodialysis

GUIDELINES AND RESOURCES

My Kidneys My Choice | Kidney Health Australia

KDIGO-2024-CKD-Guideline.pdf

Kidney Health 4 Life – Better kidney health, for life

The Kidney Failure Risk Equation

An Introduction to Kidney Transplantation

Consensus Framework for Education, Suitability Assessment, and Communication Before Kidney Transplantation