

Ethical considerations

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GUIDELINES

No recommendations possible based on Level I or II evidence

SUGGESTIONS FOR CLINICAL CARE

(Suggestions are based on Level III and IV evidence)

- As dialysis is an accepted and available mode of treatment for end-stage kidney disease (ESKD) in Australia and New Zealand, the decision concerning acceptance onto a dialysis programme should be made on the basis of the patient's need. The cardinal factor for acceptance onto dialysis or continuation of dialysis is whether dialysis is likely to be of benefit to the patient.*
- The patient or their legally recognized guardian should give or refuse consent for dialysis.*
- An expectation of survival with an acceptable quality of life is a useful starting point for recommending dialysis. When the patient and/or their guardian wish not to proceed to dialysis, supportive care should be offered or continued. Supportive care is a recognized option for patients with ESKD.
- Issues of accessibility to dialysis services, mode of dialysis and the risks and benefits must be discussed with the patient and caregivers. It is desirable that the choice of dialysis modality be a joint decision between the patient and the physician; however, patients are entitled to choose for themselves from the available and appropriate modes of dialysis. The patient is entitled to be informed whether the lack of availability of a dialysis modality is limiting their choice.
- Availability of resources should not be a reason to deny a patient access onto dialysis. Decisions to recommend or not to recommend dialysis should not be influenced by either availability of resources or potential litigation.
- When health professionals express doubt as to whether a patient should be offered dialysis, the patient is entitled to receive a comprehensive re-evaluation or further opinions. Depending on the circumstances, this may include consultation with another nephrologist (of the patient's choice), and input from a psychiatrist, social worker, dialysis nurse, occupational therapist, physiotherapist, patient and minority group advocates.

*Additional notes:

1. Lack of certainty about whether the treatment will be of benefit to the patient may suggest the use of temporary

dialysis or a 'trial' so that dialysis as a treatment option can be evaluated.

2. Need should be ascertained through a process of shared decision-making whereby, information has been exchanged between clinicians and the patient and/or their family/legal guardian; there has been deliberation regarding preferences and there is agreement between the patient and/or their family/legal guardian and clinicians about the goals of dialysis treatment.

3. 'Benefit' refers to doing good, other than financially, for the patient. This may be by intention or expectation of acceptable outcome.

4. The process of informed consent should involve information provision, understanding of information, appreciation of the information for the patient's own circumstances, an ability to reason with the information, and the expression of a choice about the treatment.

IMPLEMENTATION AND AUDIT

Survey individual unit documentation of implementation of the above 'Suggestions for Clinical Care' and rates of insertion and completion of the checklist titled 'Approaching ESKD' (Appendix) in patient notes.

BACKGROUND

These draft guidelines do not refer to temporary dialysis, but expressly consider acceptance onto long-term dialysis, which would be terminated only by the death of the patient, successful renal transplantation, inability to maintain successful dialysis or elective withdrawal of dialysis by the patient.

There is broad consensus in Australia and New Zealand that people in our society regardless of age, race, gender, religion and underlying disease have equal rights to access health facilities. Unless the patient has chosen to accept only supportive treatment, individuals and society at large expect that ESKD should not, except in unusual circumstances, be the primary cause of death. There is therefore an expectation of timely referral of patients with chronic kidney disease (CKD).

Currently, decisions about acceptance onto dialysis are usually made by agreement between the patient, their family and health professionals involved in dialysis treatment. There is also an earlier decision point, which involves the decision to refer a patient to a dialysis service, which involves the general practitioner, or other health professionals not directly associated with dialysis services. These guidelines apply to that earlier decision point as well.

Primary among the considerations for acceptance onto dialysis should be the wishes of the patient and immediate family members. In the situation when the patient is unable to give informed consent (i.e. the patient is a minor, or incapable of understanding the issues due to illness, or mental incapacity), it is important that other appropriate individuals or agencies be involved. When there is the possibility of failure to understand the issues involved because of language difficulties, a qualified interpreter must be employed to assist with the consent process.

There are very few circumstances when temporary dialysis cannot be instituted because it is unclear if the individual or their family has sufficient ability to make their wishes known regarding long-term dialysis. The institution of temporary dialysis measures allows individuals and their families sufficient time to evaluate dialysis as a treatment option.

Physicians and health professionals have a responsibility to educate and advise the patient and their family/carers, and to present all the facts available at the time in a manner that assists in making a decision regarding dialysis.

When the physician, other health professionals, the patient and/or the family disagree about acceptance onto a dialysis programme, mechanisms should be available for access without difficulty to second opinions, referral to other units or physicians of the patient's choosing, or to involvement of appointed patient advocates.

Many issues affect the decision-making process. These include the patient's age, comorbid factors such as diabetes, cardiovascular disease, respiratory disease, malignancy, neurological status, dementia, and other chronic illnesses that may predict poor outcomes.

The possibility that length or quality of life will not be improved by dialysis may be a relevant factor for patient and caregivers in making decisions about whether or not to start dialysis.

SEARCH STRATEGY

Databases searched: MeSH terms and text words for kidney disease and predialysis were combined with MeSH terms and text words for renal replacement therapy, dialysis and ethics, and then combined with the Cochrane highly sensitive search strategy for randomized controlled trials. The search was carried out in Medline (1966–April, Week 3,

2004). The Cochrane Renal Group Trials Register was also searched for trials not indexed in Medline.

Date of search/es: 29 April 2004.

WHAT IS THE EVIDENCE?

Ethical considerations do not lend themselves to randomized controlled trials and the above guidelines have been developed on the basis of opinions obtained from health professionals, patients and their families, a wide cross-section of religious leaders, publications on ethical issues in health care, and consensus from the CARI Guideline Group members of the 'Acceptance onto Dialysis' guideline.

WHAT DO THE OTHER GUIDELINES SAY?

UK Renal Association:

Guideline 3.5 – CKD: Preparation for dialysis
'Nephrology Units should provide or facilitate the optimal management of patients with established renal failure who opt for non-dialytic treatment.'

Kidney Disease Outcomes Quality Initiative:

Guideline 1. Initiation of Dialysis

CPG for Hemodialysis Adequacy

1.3 Timing of therapy: 'When patients reach stage 5 CKD (estimated GFR <15 mL/min/1.73 m²), nephrologists should evaluate the benefits, risks, and disadvantages of beginning kidney replacement therapy. Particular clinical considerations and certain characteristic complications of kidney failure may prompt initiation of therapy before stage 5. (B)'

Canadian Society of Nephrology: No recommendation.

European Best Practice Guidelines: No recommendation.

International Guidelines: No recommendation.

SUGGESTIONS FOR FUTURE RESEARCH

1. Centralized (preferably ANZDATA) collection of actual implementation and completion of 'Approaching ESKD Checklist/Consent Form'.
2. Survey health professionals, pre-end stage, dialysis and transplant patients and their families about this topic.

CONFLICT OF INTEREST

Gad Kainer has no relevant financial affiliations that would cause a conflict of interest according to the conflict of interest statement set down by CARI.

Deirdre Fetherstonhaugh has no relevant financial affiliations that would cause a conflict of interest according to the conflict of interest statement set down by CARI.

APPENDIX

Approaching ESKD: Checklist/Consent FormInterpreter needed Yes No

Language required

Please tick the appropriate box shown in the 'Action' Column.

	Action	Date	Comments	Clinician's signature	Patient/and or representative signature
1. Discussion between nephrologist and patient (and/or family/legal guardian) re treatment options (including why not an option):	<input type="checkbox"/> Done <input type="checkbox"/> Not done				
• haemodialysis					
• peritoneal dialysis					
• transplantation					
• supportive care only					
2. Advice given by nephrologist and documented regarding suggested treatment.	<input type="checkbox"/> Done <input type="checkbox"/> Not done				
3. Consultation with multidisciplinary team which may include:	<input type="checkbox"/> Done <input type="checkbox"/> Not done				
• pre-dialysis nurse					
• transplant coordinator					
• vascular access team					
• anaemia coordinator					
• nursing unit manager/s					
• dietician					
• social worker					
• pastoral care					
• other					
4. Invitation to attend education or information session about treatment options and other aspects of ESKD (including advance care planning). Opportunity to meet others in similar circumstances.	<input type="checkbox"/> Done <input type="checkbox"/> Not done				
5. Attendance at education/information seminar about treatment options and other aspects of ESKD (including advance care planning).	<input type="checkbox"/> Done <input type="checkbox"/> Not done				
6. Information provided and written consent obtained for:	<input type="checkbox"/> Done <input type="checkbox"/> Not done				
• collection of data for ANZDATA registry					
• regular/routine collection of blood and other specimens					
• HIV testing					
7. Written consent given and documented regarding treatment option to be pursued.	<input type="checkbox"/> Done <input type="checkbox"/> Not done				