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## National Renal Advisory Board

### Access to Renal Replacement Programmes in New Zealand

#### Introduction

This document has been prepared for circulation by the National Renal Advisory Board (NRAB). It revises and updates the document produced in 2004. It is intended to provide general guidance to health funders, providers and the public regarding assessment and decision making for patients with advanced kidney failure where renal replacement therapy is under consideration. It reflects the current view of renal physicians in New Zealand and has been reviewed by them.

*Caring for Australasians with Renal Impairment* (CARI), the Australian and New Zealand renal guideline group sponsored by the Australian and New Zealand Society of Nephrology and Kidney Health Australia, published guidelines for acceptance onto dialysis in 2000 (currently being updated), which have informed this guidance. It is also informed by the Treaty of Waitangi, The Health Privacy Code and the Health and Disability Code of Rights

#### Background

As in most developed countries New Zealand is facing pressure in its capacity to deliver optimal renal replacement therapy (RRT), dialysis and transplantation, to all patients with end-stage kidney failure (ESKF) who might benefit. The ageing population and the type II diabetes mellitus epidemic are maintaining the growth in prevalent patients ESKF at roughly 6% per annum.

The higher prevalence of type II diabetes mellitus and its impact at an earlier age in patients of Maori and Pacific Island ethnicities contributes to even higher rates of ESKF in these populations.

Despite this the number of patients entering RRT programs in New Zealand is generally lower than for other developed countries such as the US, UK and most members of the European Union, although the New Zealand rate is slightly higher than that of Australia. The incidence of dialysis commencement in elderly populations (greater than 75 years) is considerably lower than most other developed countries.

## **Principles of care for people with End Stage Kidney Failure in New Zealand**

1. Chronic Kidney Disease (CKD) is classified into five stages which define progressive disease activity and diminishing kidney function. Normal kidney function is associated with a glomerular filtration rate (GFR) >90 mls/minute. Stage five CKD correlates with a GFR of <15mls/minute, is ESKF.
2. Treatment of ESKF with dialysis and/or transplantation is life sustaining, without such treatment death is inevitable in days, weeks, or months.
3. Successful treatment of ESKF with dialysis and/or transplantation requires a degree of compliance from the patient in their care.
4. Most dialysis patients consider they have a reasonable quality of life. Programmes that support the optimal functional and vocational rehabilitation of kidney patients are an important component of dialysis treatment.
5. Some patients with ESKF, having severe co morbid disease and/or intolerance of the dialysis procedure which limits their quality of life and shortens their life expectancy, may not consider dialysis beneficial.
6. All patients with progressive kidney disease should be evaluated to assess whether they are likely to benefit from treatment for dialysis therapy regardless of age, gender, religion, sexual orientation, employment status, race, or other physical or mental health conditions or disabilities.
7. People with progressive kidney disease whom clinicians consider might benefit from treatment of eventual kidney failure should be offered, together with their family/whanau, education including information about potential benefits, risks and outcomes of dialysis and transplantation or conservative (or palliative) treatment. Such information must be offered in a language, using an interpreter if necessary, and manner that is most appropriate for the patient.
8. Early referral of patients with progressive kidney disease (according to the NRAB referral guidelines) from primary care providers to renal department is desirable as it enables timely evaluation for RRT, including discussion with the patients and their family/whanau about treatment.
9. Kidney specialists should not recommend dialysis in inappropriate situations (see next section), when there is clearly no expectation of benefit for the patient.

10. Transplantation offers patients the best quality of life and is the most cost-effective therapy for ESKF, and so is the treatment of choice for all medically suitable patients.
11. Home-based dialysis therapy offers the best quality of life and is the most cost-effective therapy for patients requiring dialysis therapy. Patients should be fully educated regarding treatment options and invited to choose a self-care dialysis therapy that suits them best, based on life-style and employment issues, provided that it is medically appropriate.
12. Patients unable to undertake home-based therapy, due to medical problems or complications of their renal treatment, or for social reasons related to their family or housing situation, require dialysis in a renal unit with support from trained dialysis staff. This should be community-based where possible or provided within a reasonable distance from the patient's home. Lengthy travel creates such difficulties for families and patients that this can compromise the quality of life obtained with dialysis.
13. Access to additional medical and surgical therapy, rehabilitation and nursing home and chronic care should not be denied to patients simply because they have CKD or ESKF.
14. Assessment and care of patients with ESKF requires a multidisciplinary team of appropriately trained and accredited health professionals, led by credentialed physicians with specialised advanced training in dialysis and/or transplantation. Renal services should be delivered in facilities that meet relevant national standards. Such renal services must undertake regular audit and contribute data to the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry.
15. Renal departments of DHBs are obliged to offer access to both dependent and independent modalities for RRT (under the renal service specification) to meet the needs of the population they serve. They should seek to support individual patients to choose a dialysis therapy that suits them best, based on life-style and employment issues, and also clinical suitability. However, in providing treatment to an individual patient a renal department can limit the modalities they offer an individual access to, both for medical reasons and also to enable effective management of limited resources.
16. It is desirable that any major innovations in RRT should be formally assessed through a national process to determine if and how they will be introduced by DHBs.

## **Decisions about initiating dialysis therapy**

17. Chronic RRT should not be initiated when:
  - The patient is permanently unconscious
  - The patient has severe dementia necessitating a high level of support
  - The patient is dying from another terminal illness with a short life expectancy
  - The patient is non-compliant with treatment such that he or she requires sedation or restraint to allow treatment
  - There is a lack of informed consent or authorisation to perform dialysis (from the patient, legal guardian or other appropriate authority).
18. Patients with chronic irreversible co-morbid disease, leading to severe functional limitation and lack of independence in activities of daily living, may be unlikely to benefit from dialysis treatment in achieving a reasonable quality of life.
19. In such situations the assessment from a multidisciplinary team (including a renal physician, pre-dialysis nurse and social worker) needs to include the likely benefits as well as the potential burden of dialysis therapy (including the patient's capacity to collaborate in treatment), the impact of co-morbid disease, the likelihood of transplantation, and the expected life expectancy of the patient on dialysis. It may be supplemented, if required, by other health professionals such as a clinical psychologist, occupational therapist, palliative care specialist or geriatrician. Consultation with the patient and their family /whanau is integral to this process.
20. The outcome of the assessment may be a recommendation that the patient undertake dialysis treatment (perhaps in a specific modality), a recommendation against undertaking dialysis treatment, or even a decision that it is not clinically appropriate to offer treatment at all. In the cases of a recommendation against treatment, if, when fully informed of the professional assessment of their situation, a patient chooses to extend their life with dialysis treatment then this should be accepted.
21. In complex and difficult cases, where the benefit to the patient in initiating dialysis treatment is very uncertain, the renal physician may consult peers to assist in reaching a decision.
22. Where there is uncertainty as to the likely benefits of dialysis treatment, it may be agreed a trial of dialysis can be undertaken. If after such a trial for a defined period the patient considers that the burdens of such treatment outweigh any benefits the patient and kidney specialists responsible may agree on withdrawal from dialysis treatment.

23. To allow time for thorough and considered assessment this process should begin well before the need for dialysis treatment and therefore early referral to renal services is paramount. However in some circumstances patients present late and commence dialysis prior to full assessment. It remains important that the above process of patient evaluation be completed for all patients to guide decisions regarding treatment options.

### **Screening tools for patients being assessed for dialysis**

The implementation in clinical practice of a reliable tool to predict outcomes from dialysis would provide predictive information to patients and care-givers considering renal replacement therapy, enable assessment of resources required within a renal centre with different levels of case mix and enhance renal trial and registry comparisons.

Many screening tools have been utilised to predict patient survival on the basis of various mixes of co morbidity and age.(1-9). No consensus has yet developed on the measurement and grading of co morbid illness. There is conflicting evidence regarding whether or not the inclusion of severity grading in co morbidity assessment enhances its predictive strength (7, 9). While it is well established that poor functional status is a powerful predictor of early mortality in dialysis patients (10, 11), only one of these tools included the impact of functional limitation (8, 9) on survival. These tools are able to group patients by mortality risk eg 50% mortality at two years for patients in high risk groups. However no current screening tool can provide a reliable survival or quality of life prediction for an individual patient. As a consequence any consideration of the use of such screening tools to limit access to Renal Replacement Therapy lacks evidential legitimacy and raises important issues of ethics and fairness.

### **Paediatric dialysis**

Dialysis in children (under 15) is offered primarily from one centre based in Auckland. In general the principles of care are the same as for the adult patients. As in adult dialysis the aim is to provide community based dialysis, but this is not always possible for the younger patients, specifically those requiring haemodialysis. Principles of care include the provision of long distance care for those on peritoneal dialysis in their own community, with provision of inpatient paediatric haemodialysis where necessary, preferably in a dedicated facility. Decisions regarding the appropriateness of starting or continuing dialysis are made with parents/ caregivers, and a multidisciplinary team, and may involve referral to an ethics committee as appropriate. The national centre has specific guidelines relating to infant dialysis, reflecting international practice in this area.

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