

CLINICAL PRACTICE GUIDELINE

**Planning, Initiating and Withdrawal
of
Renal Replacement Therapy**

UK Renal Association

6th Edition

Final Version

(based on literature up to Feb 2013)

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Contents

Introduction

Summary of Clinical Practice Guidelines for Planning, Initiating and Withdrawal of Renal Replacement Therapy

1. Timely nephrology referral (Guidelines 1.1-1.2)
2. Nephrology follow-up (Guidelines 2.1-2.3)
3. Preparing for renal replacement therapy (Guidelines 3.1-3.7)
4. Educating patients and carers for renal replacement therapy (Guidelines 4.1-4.3)
5. Initiating renal replacement therapy (Guidelines 5.1-5.5)
6. End of life care: Conservative kidney management and withdrawal of dialysis (Guidelines 6.1-6.7)

Summary of Potential Audit Measures for Planning, Initiating and Withdrawal of Renal Replacement Therapy

(Audit measures 1-22)

Rationale for Clinical Practice Guidelines for Planning, Initiating and Withdrawal of Renal Replacement Therapy

1. Timely nephrology referral (Guidelines 1.1-1.2)
2. Nephrology follow-up (Guidelines 2.1-2.3)
3. Preparing for renal replacement therapy (Guidelines 3.1-3.7)
4. Educating patients and carers for renal replacement therapy (Guidelines 4.1-4.3)
5. Initiating renal replacement therapy (Guidelines 5.1-5.5)
6. End of life care: Conservative kidney management and withdrawal of dialysis (Guidelines 6.1-6.7)

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Declaration of conflicts of interest

All authors have confirmed that they do not have any conflicts of interest nor will acquire any financial gain from developing these recommendations.

Introduction

This guideline provides recommendations on best practice in the planning, initiating and withdrawal of renal replacement therapy. The guideline links with many of the objectives relating to renal replacement therapy described within the National Service Framework for Renal Services Part 1 which is applicable to England and Wales(1). This NSF document highlighted the need for renal units to deliver individualised patient education to allow patients to make an informed choice of treatment modality, timely preparation for renal replacement therapy and empowerment of the patient from the start to the end of their treatment pathway.

The evidence for these recommendations has been assessed using the modified GRADE system. The modified GRADE system defines both the strength of the recommendations of the guideline authors and the level of evidence upon which each of the recommendations is based. This grading system classifies expert recommendations as “strong” (Grade 1) or “weak” (Grade 2) based upon the balance between the benefits and risks, burden and cost. The quality or level of evidence is designated as high (Grade A), moderate (Grade B), low (Grade C) or very low (D) depending on factors such as study design, directness of evidence and consistency of results. Grades of recommendation and quality of evidence may range from 1A to 2D. The GRADE system has been developed to maximise the usefulness of clinical practice guidelines in the management of typical patients.

This guideline has been harmonised with other guidelines and national policy documents (2-5) whenever possible. The recommendations have been reviewed by patient representatives as well as key stakeholders within the multidisciplinary team caring for patients with established renal failure. The preparation of this guideline has identified that there is great need for high quality clinical research and audit in many aspects of the planning, initiation and withdrawal of renal replacement therapy.

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Summary of Clinical Practice Guidelines for Planning, Initiating and Withdrawal of Renal Replacement Therapy

1. Planning, initiating & withdrawal of RRT (Timely nephrology referral 1.1 – 1.2)

- 1.1 We recommend that most patients with CKD stage 4-5 (eGFR $<30\text{ml}/\text{min}/1.73\text{m}^2$) or with CKD stage 3 and rapidly deteriorating renal function should be referred for assessment by a nephrologist (1B)
- 1.2 We recommend that patients should be referred at least one year before they might be anticipated to require renal replacement therapy (RRT) (1B)

2. Planning, initiating & withdrawal of RRT (Nephrology follow-up 2.1 – 2.3)

- 2.1 We recommend that most patients whose eGFR is $<30\text{ml}/\text{min}/1.73\text{m}^2$ and declining should be under the care of a nephrologist (1B).
- 2.2 We recommend that these patients should be managed in a dedicated clinic by a multidisciplinary team (1B).
- 2.3 We suggest that the frequency of nephrology follow-up should be intensified when the eGFR has fallen to $<15\text{ml}/\text{min}/1.73\text{m}^2$ if dialysis treatment is not started (2D).

3. Planning, initiating & withdrawal of RRT (Preparing patients for RRT 3.1 – 3.7)

- 3.1 We recommend that most patients whose eGFR is $<30\text{ml}/\text{min}/1.73\text{m}^2$ and declining should receive timely and personalised information regarding established kidney failure and renal replacement therapy options so they can make an informed decision about treatment (1B).
- 3.2 We recommend that patients who present with advanced kidney failure and are likely to need RRT within 3 months should be able to access an accelerated care pathway to deliver education, information and prepare for RRT (1D). Patients presenting late or starting dialysis without any prior nephrology input should receive similar education and information about renal replacement therapies to inform long term choices.

- 3.3 We recommend that all medically suitable patients should be informed about the advantages of pre-emptive living kidney transplantation and efforts made to identify a potential donor to allow pre-emptive transplantation before the need for renal replacement therapy (1B).
- 3.4 We recommend that all suitable patients should be listed for deceased donor transplantation six months before the anticipated start of renal replacement therapy (1B).
- 3.5 We recommend that where pre-emptive transplantation is not possible, there should be timely referral for either definitive vascular access formation or peritoneal dialysis catheter placement so that the patient starts on their chosen modality of renal replacement therapy by either of these two routes (1B).
- 3.6 We suggest that all patients should be encouraged to perform home dialysis therapy where possible, as part of an integrated approach to renal replacement therapy (2B).
- 3.7 We suggest that, where home dialysis is not possible, patients and their carers/partners should be actively involved in their dialysis treatment, be encouraged to perform as much self-care as possible and be engaged in all aspects of their treatment including medicines management and changes in diet and lifestyle (2B)

4. Planning, initiating & withdrawal of RRT (Educating patients and carers for RRT 4.1 – 4.3)

- 4.1 We recommend that all patients with severe CKD (stage 5 and progressive stage 4), together with their families and carers, should be offered an appropriate education programme aimed at improving their knowledge and understanding of their condition, and to help them choose from the options for treatment (1B).
- 4.2 We suggest that education programmes should be tailored to the needs of the individual, be based on the principles of adult learning and be designed to support patient choice. A variety of approaches should be available. The information imparted should be relevant to the person, the stage of their disease and treatment options available to them with the method, scale, pace and scope of the delivery being suited to the individual's learning

style, capacity and preferences. The programme should also include provision for the education of patients who present late, and initiate dialysis in an unplanned fashion (2C).

- 4.3 We suggest that pre-renal replacement therapy education programmes for patients and their families and carers should be continued into the treatment phase, with the aims of reviewing the original choice made by the patient, optimising patient involvement in their own care, improving treatment adherence, and fostering good communication and collaborative relationships with caregivers (2C).

5. Planning, initiating & withdrawal of RRT (Initiating RRT 5.1 – 5.5)

- 5.1 We recommend that patients known to nephrology services for 3 months or more and who are planned to have renal support should start renal replacement therapy in a controlled manner, without the need for hospital admission and using an established access (arteriovenous fistula [AVF], arteriovenous graft [AVG], PD catheter) or by pre-emptive renal transplantation (1B)
- 5.2 We recommend that the decision to start RRT in patients with CKD stage 5 ($eGFR < 15\text{ml}/\text{min}/1.73\text{m}^2$) should be based on a careful discussion with the patient of the risks and benefits of RRT taking into account the patient's symptoms and signs of renal failure, nutritional status, co-morbidity, functional status, and the physical, psychological and social consequences of starting dialysis in that individual (1D)
- 5.3 We recommend that once a decision has been made to start dialysis in a patient with established access there should be no delay in starting treatment i.e. no waiting list to start dialysis (1D)
- 5.4 We recommend that urgent dialysis via a haemodialysis catheter should only be initiated where there is a clear clinical indication that the patient would come to harm without such treatment (1D)
- 5.5 We suggest that where dialysis is started via an established access (vascular or peritoneal) which fails to work effectively urgent corrective action should be taken and dialysis via a haemodialysis catheter avoided if possible (2D)

6. Planning, initiating & withdrawal of RRT (End of life care: conservative kidney management and withdrawal from dialysis 6.1 – 6.7)

6.1 Estimating prognosis in CKD: We recommend that patients with advanced chronic kidney disease (CKD Stage 4 & 5) should be given an estimate of their prognosis and quality of life both with and without renal replacement therapy (1C)

6.2 Conservative Kidney Care: We recommend that patients with advanced chronic kidney disease (CKD Stage 4 & 5) who opt not to dialyse should undergo conservative kidney management. Patients who have imminent or immediate end-of-life care needs should be identified and their care prioritised (1C)

6.3 Patients deteriorating despite dialysis: We recommend that patients who are struggling to cope on long-term dialysis as a result of progressive deterioration of underlying, irreversible, clinical problems, or sudden onset of a catastrophic clinical event, such as a stroke, should be recognised as being in imminent or immediate need of end-of-life care (1C)

6.4 Maintaining a supportive care register. We suggest that patients who have a predicted life expectancy of less than one year should be identified using a combination of criteria including co-morbidity, functional status, evidence of malnutrition, advanced age and the ‘surprise question’. A register of such patients should be kept, shared with appropriate agencies and reviewed regularly by the health care team to ensure their care needs are being met (2C)

6.5 Advance Care Planning: We recommend that patients with a recognised need for end-of-life care, including those undergoing conservative kidney management and those deteriorating despite dialysis, should be offered the opportunity to create an Advance Care Plan (1C)

6.6: Dialysis Withdrawal: We recommend that any decision to discontinue haemodialysis should be made within the context of ongoing end-of-life care planning. It should be made jointly by the patient and the responsible nephrologist in full consultation with relatives and carers, the family practitioner and members of the caring team. An assessment of competence should be carried out. Depression may need to be formally excluded (1C)

6.7: Care in the last days: We recommend that in the last days of life there should be good communication, symptom relief, psychological, spiritual and culturally sensitive care for the dying patient and their family, whenever possible in their preferred place of care followed by the provision of culturally appropriate bereavement support (1C)

Summary of Potential Audit Measures

1. Percentage of patients commencing RRT referred <3months and <12months before date of starting RRT
2. Percentage of incident RRT patients followed up for >3 months in dedicated pre-dialysis or low clearance clinic
3. Proportion of incident patients on UK transplant waiting list at RRT initiation
4. Proportion of incident RRT patients transplanted pre-emptively from living donors and deceased donors
5. eGFR at time of pre-emptive transplantation
6. Proportion of incidents patients commencing peritoneal or home haemodialysis
7. Proportion of patients who have undergone a formal education programme prior to initiation of RRT
8. Proportion of incident RRT patients who report that they have been offered a choice of RRT modality
9. Proportion of patients remaining on initial treatment modality 3 and 12 months post initiation of RRT
10. Proportion of patients recording satisfaction with initial RRT decision at 3 and 12 months post initiation of RRT
11. Proportion of patients who have initiated dialysis in an unplanned fashion who have undergone formal education by 3 months.
12. Evidence of formal continuing education programme for patients on dialysis
13. Proportion of planned initiations with established access or pre-emptive transplantation.
14. Inpatient/outpatient status of planned initiations.
15. eGFR at start of renal replacement therapy
16. Units should have a register of patients with End of Life Care needs, including those patients undergoing conservative kidney management, those deteriorating despite dialysis, and those withdrawing from dialysis. The register should link with primary care End of Life Registers.
17. The proportion of patients who die who are included on the register
18. The number of patients with Stage 5 CKD who are undergoing conservative kidney management - as a proportion of all patients with Stage 5 CKD
19. The number of patients withdrawing from dialysis as a proportion of all deaths on dialysis.
20. The proportion of those patients identified as having End of Life Care needs that have a workable Advance Care Plan, which includes details of the nominated renal Key-Worker, patient preferences and choices with respect to priorities of care, and details of the individual needs of carers.
21. Proportion of patients who achieve their preferred place of dying.
22. Units in England and Wales should participate in National End of Life Care audits

Full Clinical Practice Guideline

1. Timely Nephrology referral

- 1.1 We recommend that most patients with CKD stage 4-5 (eGFR $<30\text{ml}/\text{min}/1.73\text{m}^2$) or with CKD stage 3 and rapidly deteriorating renal function should be referred for assessment by a nephrologist (1B)
- 1.2 We recommend that patients should be referred at least a year before they might be anticipated to require renal replacement therapy (RRT) (1B)

Audit measure

1. Percentage of patients commencing RRT referred <3 months and <12 months before date of starting RRT

Rationale

The routine reporting of estimated glomerular filtration rate (eGFR) by chemical pathology laboratories helps to identify patients with significant chronic kidney disease (CKD) and may help to promote timely referral to a nephrologist. Over more than 25 years, retrospective and case control studies have demonstrated consistently the detrimental effects of late nephrological referral. These include lack of adequate intervention to delay the progression of renal failure, higher morbidity and mortality, poorer quality of life on dialysis, missed opportunities to have pre-emptive renal transplantation and, for some patients, inappropriate dialysis treatment where conservative care might have been chosen by an informed patient (1-5). However, the 2008 UK NICE guidance on chronic kidney disease found no evidence to guide the optimum timing of referral of patients with CKD (6). The guideline group did recommend the referral of all patients with CKD stage 4-5 or patients with rapidly deteriorating renal function (defined as a reduction in eGFR of $>5\text{ml}/\text{min}/1.73\text{m}^2$ per year or $>10\text{ml}/\text{min}/1.73\text{m}^2$ per 5 years). There may be patients with CKD stage 4-5 who do not require referral because of severe co-morbidity, very poor quality of life or limited life expectancy from other conditions; where there is doubt a discussion between patient/carer, referrer and nephrologist may help to clarify this.

Timely referral provides the opportunity to plan for renal replacement therapy (RRT) or conservative kidney management. Patients who have been under the care of nephrology services for more than 1 month are more likely to initiate haemodialysis (HD) using an AVF (7). A retrospective analysis of 109,321 incident HD patients in the USA found that, compared to patients with at least 3 months of predialysis care, the relative risk of death of patients for patients with one or two months pre-dialysis nephrology care was 1.23 whilst that for patients with no pre-dialysis nephrology care was 1.51(4). Now that most patients with advanced kidney failure, regardless of age and co-morbidity, are considered as potential candidates for RRT, the question of whether or not such treatment is the most appropriate option for the individual patient, has assumed increasing importance. Until recently, acceptance or non-acceptance for RRT in the UK was often determined by whether or not a

patient was referred to a nephrology service. Effectively, decisions not to initiate RRT were taken by family members or referring physicians in isolation rather than in conjunction with the multidisciplinary nephrology team (8). It is often difficult to decide if patients with major co-morbidity will or will not benefit from starting dialysis, even if referred well in advance of the need for RRT, and there have been few studies of the decision not to start dialysis (9-11). Appropriate decision making may be facilitated by referral of all patients with advanced renal failure (eGFR <30ml/min) and a predicted life expectancy of more than 6 months to a nephrology services for consideration of RRT.

Although the principle of early referral to allow preparation for RRT is well accepted, this is not always easy to achieve in clinical practice. The majority of patients with CKD stage 4 will not progress to established kidney failure and at present there are relatively poor methods for predicting those who will progress (12). Furthermore, the rate of decline in eGFR may be difficult to predict even with serial measurements and extrapolation of eGFR v. time plots as various algorithms used fail to predict time to dialysis in between 10-46% of patients (13). Finally, the optimal time to allow adequate preparation is not clear. Many studies have used 3 or 4 months to define late referral but in practice it may take more than a year to prepare fully for renal replacement therapy (14).

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2. Nephrology follow-up

- 2.1 We recommend that most patients whose eGFR is $<30\text{ml}/\text{min}/1.73\text{m}^2$ and declining should be under the care of a nephrologist (1B).
- 2.2 We recommend that these patients should be managed in a dedicated clinic by a multidisciplinary team (1B).
- 2.3 We suggest that the frequency of nephrology follow-up should be intensified when the eGFR has fallen to $<15\text{ml}/\text{min}/1.73\text{m}^2$ if dialysis treatment is not started (2D).

Audit measure

1. Percentage of incident RRT patients followed up for >3 months in dedicated pre-dialysis or low clearance clinic

Rationale

There have been no randomized controlled trials or meta-analyses specifically looking at the influence of frequency of follow-up on outcomes in patients approaching the need for renal replacement therapy (1). However, regular clinical reviews are recommended by most guidelines as there is evidence that progression of renal failure may be prevented or slowed significantly by strict blood pressure control, strict glycaemic control in patients with diabetes mellitus, the use of certain drugs (such as angiotensin converting enzyme inhibitors and angiotensin receptor blockers in patients with proteinuria), and possibly revascularization procedures in selected patients with renovascular disease (1,2).

Patients with eGFR of $<30\text{ml}/\text{min}$ or less should undergo clinical review at least every 3 months which should include measurement of eGFR, haemoglobin, calcium, phosphate, potassium, bicarbonate and parathyroid hormone and dietary assessment (1).

The European Best Practice Guidelines recommend that patients should be followed-up monthly once the eGFR has fallen to $<15\text{ml}/\text{min}/1.73\text{m}^2$ (3). The evidence base for this recommendation is unclear although one study has shown a relationship between the number of nephrology clinic visits in the 12 months prior to commencement of dialysis and lower mortality and length of hospital stay within the first 12 months(4).

There are many studies albeit of variable quality and generally of small numbers, which have shown that a dedicated pre-dialysis (or ‘low clearance’) clinic is associated with improved outcomes and reduced urgent initiation of dialysis (5-8). These clinics should address the complications of progressive CKD such as renal bone disease, nutritional problems and anaemia while still trying to preserve renal function by tight blood pressure control and other measures. Some evidence exists that such an approach increases the quality of life scores and the likelihood of those of working age remaining in employment at the commencement of dialysis(9). Such clinics exist in many nephrology departments in the UK but there is a lack of consensus on a name for such a clinic. Pre-dialysis implies all patients will receive dialysis when some patients will be transplanted and others will receive conservative kidney management. The frequently used alternative, ‘low clearance’, may not be very meaningful to patients.

The precise make up and organisation of these clinics will vary according to local expertise, facilities and resources and there is insufficient evidence to recommend a particular model or staffing structure.

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3. Preparing patients for renal replacement therapy

3.1 We recommend that most patients whose eGFR is $<30\text{ml}/\text{min}/1.73\text{m}^2$ and declining should receive timely and personalised information regarding established kidney failure and renal replacement therapy options so they can make an informed decision about treatment (1B).

- 3.2 We recommend that patients who present with advanced kidney failure and are likely to need RRT within 3 months should be able to access an accelerated care pathway to deliver education, information and prepare for RRT. Patients presenting late or starting dialysis without any prior nephrology input should receive similar education and information about renal replacement therapies to inform long term choices (1D).
- 3.3 We recommend that all medically suitable patients should be informed about the advantages of pre-emptive living kidney transplantation and efforts made to identify a potential donor to allow pre-emptive transplantation before the need for renal replacement therapy (1B).
- 3.4 We recommend that all suitable patients should be listed for deceased donor transplantation six months before the anticipated start of renal replacement therapy (1B).
- 3.5 We recommend that where pre-emptive transplantation is not possible, there should be timely referral for either definitive vascular access formation or peritoneal dialysis catheter placement so that the patient starts on their chosen modality of renal replacement therapy by either of these two routes (1B).
- 3.6 We suggest that all patients should be encouraged to perform home dialysis therapy where possible, as part of an integrated approach to renal replacement therapy (2B).
- 3.7 We suggest that where home dialysis is not possible, patients and their carers/partners should be actively involved in their dialysis treatment, be encouraged to perform as much self-care as possible and be engaged in all aspects of their treatment including medicines management and changes in diet and lifestyle (2B).

Audit measures

1. Proportion of incident patients on UK transplant waiting list at RRT initiation
2. Proportion of incident RRT patients transplanted pre-emptively from living donors and deceased donors
3. eGFR at time of pre-emptive transplantation
4. Proportion of incident patients commencing peritoneal or home haemodialysis

Rationale

The 2004 National Service Framework part 1 for England and Wales emphasises the importance of patient choice and of the need for education in the phase leading up to dialysis, transplantation or conservative care for advanced CKD (1). An important concept is that the different treatment options should be seen as an integrated package where patients may move from one treatment to another over their 'career' of renal replacement therapy (2). There is good evidence this information should be available to patients through a structured education programme which has been shown to have a number of benefits (see section 4). Where patients present with advanced kidney failure and are likely to need RRT in less than three months, this programme should be delivered in an accelerated format.

An important part of the preparation for renal replacement therapy should include planning for pre-emptive transplantation. There is a consensus that pre-emptive transplantation (i.e. before patients are established on dialysis) is associated with improved graft and patient survival (3-5). This is based mainly on large retrospective registry data or case control series; there is no randomized controlled trial. Although there may be issues relating to differences in recipient characteristics, quality of tissue type matching and of donor kidney, the data supports generally a strategy to provide pre-emptive transplantation. However, a short period on dialysis (<6months) may have no influence on outcomes (6). The UK transplant guidelines recommend listing patients for renal transplantation who are predicted to start dialysis within six months (7) – although this is not easy to predict accurately. Where there is a living related donor, the process of donor assessment and work-up should be pursued in a timely manner to allow transplantation to be carried out pre-emptively. However, the optimal time and level of eGFR at which pre-emptive transplantation should be carried out is not clear and there may be a possibility of performing this too early (8).

Although transplantation is shown to have the best outcomes, this may not be possible for many patients due to co-morbidity, lack of a donor or, sometimes, patient choice. When pre-emptive transplantation is not possible, timely referral for placement of either a peritoneal dialysis catheter or formation of definitive vascular access is essential. This is discussed further in two separate clinical practice guidelines.

There are no adequate randomized controlled trials comparing outcomes of peritoneal dialysis (PD) versus haemodialysis (HD) or of home versus centre based therapies but there is considerable observational data which suggests that patients performing home therapies have improved survival and improved quality of life (9,10). These data are difficult to interpret because patients choosing self-care are often younger and fitter with fewer co-morbidities but this advantage seems to persist when corrected for these factors (9,11,12). The UK National Institute for Clinical Excellence commissioned a systematic review of home haemodialysis versus hospital or satellite based dialysis which despite the lack of grade 1 evidence concluded that home HD offered advantages to patients in terms of quality of life, flexibility, reduced travel, improved survival and was cost effective to the NHS (13).

Although the percentage of RRT patients on peritoneal dialysis is decreasing it remains an important modality of renal replacement in the United Kingdom accounting for 7.6% of all prevalent RRT patients in the 2011 UK Renal Registry report (14). There are no convincing data that patient survival on peritoneal dialysis is worse than haemodialysis although the technique failure rate is high at three years. However, patients will still often prefer this

treatment because of the independence, control and flexibility it offers and there is evidence of better quality of life compared to haemodialysis (15).

Self care is now widely promoted for the management of chronic disease (16,17). Home dialysis therapies (either haemodialysis or peritoneal dialysis) are good examples of complex treatments which patient can be taught to self manage. In contrast, many patients within main centre and satellite haemodialysis units are or become very dependent. In part this relates to co-morbid conditions but even in the early days of dialysis the concept of ‘learned helplessness’ was described by Blagg and Scribner and is even more relevant today with the increasing age of the RRT population (18). There has been renewed interest in recent years in improving self-care and self-efficacy amongst patients with chronic kidney disease starting from the time of diagnosis and continuing to patients receiving renal replacement therapy. Many centres in the UK have now established programmes to allow patients to take a greater role in their dialysis treatment even if this is hospital based. However, the evidence that this leads to improved survival or other hard outcomes is limited. This is an area where more research on the benefits of self-care within haemodialysis centres is required (19,20).

The rationale and evidence for hepatitis B vaccination in patients who are predicted to need renal replacement is covered in a separate module in these clinical practice guidelines.

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4. Educating patients and carers for renal replacement therapy

4.1 We recommend that all patients with severe CKD (stage 5 and progressive stage 4), together with their families and carers, should be offered an appropriate education programme aimed at improving their knowledge and understanding of their condition, and to help them choose among the options for treatment (1B).

4.2 We suggest that education programmes should be tailored to the needs of the individual, be based on the principles of adult learning and be designed to support patient choice. A variety of approaches should be available to support patient choice. The information imparted should be relevant to the person, the stage of their disease and treatment options available to them with the method, scale, pace and scope of the delivery being suited to the individual's learning style, capacity and preferences. The programme should also include provision for the education of patients who present late, and initiate dialysis in an unplanned fashion (2C).

4.3 We suggest that pre-renal replacement therapy education programmes for patients and their families and carers should be continued into the treatment phase, with the aims of reviewing the original choice made by the patient, optimising patient involvement in their own care, improving treatment

adherence, and fostering good communication and collaborative relationships with caregivers (2C).

Audit Measures:

1. Proportion of patients who have undergone a formal education programme prior to initiation of RRT
2. Proportion of incident RRT patients who report that they have been offered a choice of RRT modality
3. Proportion of patients remaining on initial treatment modality 3 and 12 months post initiation of RRT
4. Proportion of patients recording satisfaction with initial RRT decision at 3 and 12 months post initiation of RRT
5. Proportion of patients who have initiated dialysis in an unplanned fashion who have undergone formal education by 3 months.
6. Evidence of formal continuing education programme for patients on dialysis

Rationale

The NHS Constitution (1) enshrines the rights of patients to “easily accessible, reliable and relevant information to enable you to participate fully in your own healthcare decisions and to support you in making choices”. An adequately resourced pre-dialysis education programme is an essential pre-requisite for patients with progressive chronic kidney disease who need to make choices about renal replacement therapy. The most appropriate setting for this may be as part of a multidisciplinary clinic which integrates clinical expertise, patient education, and comprehensive supportive services (2, 3) and which encapsulates the flow from diagnosis, through education, to timely referral for access creation or pre-emptive transplantation. To realise many of the potential benefits, such programmes require support by adequate resources for dialysis provision (3).

Patient education aims to provide information about the functions of the kidneys, their derangements in disease, and about available treatment options for kidney failure and their implications for lifestyle. This knowledge is vital to inform treatment choice decisions. Pre-dialysis educational programmes should also aim to link seamlessly to programmes to promote patient self-management allowing them to take a degree of control over living with a chronic condition, and ideally providing links to expert patient programmes (4).

The available evidence suggests that, as well as improving patient knowledge and understanding (5-7), pre-dialysis education confers many additional advantages. These include an improved sense of well-being, enhanced mood, reduced levels of anxiety, and better physical functioning (8). Patients who have received pre-dialysis education also have a lower incidence of unplanned initiation onto dialysis (9-11), even excluding late referrals. Furthermore, fewer patients initiate dialysis with haemodialysis catheters (12). There is also an association between pre-dialysis education and delay in the need for dialysis initiation, often by many months, an effect which has been attributed to improved pre-dialysis management (5,13,14). Another consistent finding is that patients, who as part of pre-dialysis education have received adequate information about available treatment options, were more

likely to choose a self-care based therapy as first modality (10,15-18) - peritoneal dialysis in particular, but also home haemodialysis and minimal care haemodialysis. Patients making a “good decision” about treatment options are more likely to adhere to treatment regimes and tolerate complications better than those not fully involved in the decision making processes (19-20). Incomplete presentation of treatment options may be a major reason for the under-utilization of home dialysis therapies and contribute to delayed access to transplantation (17). Pre-dialysis education may also influence employment status. People who had undergone pre-dialysis education were more likely to continue in work (21,22). Finally, pre-dialysis education may also have a beneficial effect on both short-term (23) and long-term (14) survival. The risk of death in patients who did not receive pre-dialysis education has been estimated as double that in those who had received this education, and similar to that in late referrals (11).

A number of factors highlight the need for individualisation in pre-dialysis patient education. The prevalence of cognitive impairment increases with advancing renal failure independently of age and other confounding factors (24). Twenty percent of patients referred to a pre-dialysis clinic (25) were cognitively impaired. The prevalence is higher in dialysis patients, particularly those on haemodialysis, fluctuates during the haemodialysis cycle, but tends to remain more stable in those on peritoneal dialysis (26, 27). Older pre-dialysis patients have a significantly reduced understanding of their illness (7). Anaemia impairs cognitive function which treatment with erythropoiesis stimulating agents may improve (28). These and other factors have clear implications for patients’ ability to learn, and educational programmes should be tailored accordingly. Patients referred late for dialysis are less likely to receive many potentially helpful interventions than patients referred earlier (29). These include pre-dialysis education. Such omissions can adversely affect outcomes. Patients referred late for dialysis should receive post-dialysis education to lessen the adverse effects of this omission and ensure they are also given the choice to move onto self-care therapies rather than automatically remaining on their initial therapy. Once on dialysis, patients will have a greater understanding of what it means and may be encouraged by this knowledge to move on to self-care therapies.

Other factors are important. Achieving education goals and adherence to the demands of the treatment can be compromised if patients have not accepted the severity and the chronicity of their condition. In addition, people learn more effectively when information is presented in a manner which accords with their own learning style and preferences. Learning style is a description of the attitudes and behaviours which determine an individual’s preferred way of learning (30). Learning preferences refers to the method of teaching that people prefer (31). Learning styles can be classified into at least 4 categories (32), with any particular group likely to contain people with a mixture of learning styles. Rather than attempt categorisation of individuals, it may be more helpful to use a range of teaching methods within one session in order to allow learning to take place whatever the learning style. A variety of approaches should be available including individual conversations, group work, written materials, DVD/CDs, internet resources, decision making aids and access to expert patients appropriately trained. Furthermore, the information should be specifically designed to support decision-making regarding treatment options (33). Where expert patients are used as part of the pre-dialysis educational package, these patients should receive appropriate training for their role.

Though long-term benefits of pre-dialysis education have been demonstrated (14), other benefits may be short lived (8). Participants in a pre-dialysis patient education programme,

showed better functional and emotional well-being than the non-educated comparison group during the first 6 months of initiating dialysis treatment after which the differences reduced, suggesting that education should be ongoing (8). Studies of educational interventions in dialysis patients though are also limited. A recent systematic review of randomised control studies in this setting found 6 short-term, 13 medium-term and one long-term study, many of which were criticised as being of poor quality (34). The studies mainly focussed on adherence to dietary and fluid management regimens, and some benefits of the interventions were observed. The need for good quality randomised controlled trials was emphasized.

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5. Initiating renal replacement therapy

- 5.1 We recommend that patients known to nephrology services for 3 months or more and who are planned to have renal support should start renal replacement therapy in a controlled manner, without the need for hospital admission and using an established access (arteriovenous fistula [AVF], arteriovenous graft [AVG], PD catheter) or by pre-emptive renal transplantation (1B)
- 5.2 We recommend that the decision to start RRT in patients with CKD stage 5 (eGFR < 15ml/min/1.73m²) should be based on a careful discussion with the patient of the risks and benefits of RRT taking into account the patient's symptoms and signs of renal failure, nutritional status, co-morbidity, functional status, and the physical, psychological and social consequences of starting dialysis in that individual (1B)
- 5.4 We recommend that once a decision has been made to start dialysis in a patient with established access there should be no delay in starting treatment i.e. no waiting list to start dialysis (1D)

5.5 We recommend that urgent dialysis via a haemodialysis catheter should only be initiated where there is a clear clinical indication that the patient would come to harm without such treatment (1D)

5.6 We suggest that where dialysis is started via an established access (vascular or peritoneal) which fails to work effectively urgent corrective action should be taken and dialysis via a haemodialysis catheter avoided if possible (2D).

Audit measures

1. Proportion of planned initiations with established access or pre-emptive transplantation.
2. Inpatient/outpatient status of planned initiations.
3. eGFR at start of renal replacement therapy

Rationale

Patients vary greatly in the symptoms they experience at similar levels of renal function as judged by eGFR. By definition, eGFR is an estimated figure derived from a population of patients with CKD excluding several ethnic and age groups (1) and subject to significant variation within and between subjects over time (2). The failure of medical therapy to control or prevent severe fluid overload, persistent severe hyperkalaemia, marked acidosis, or poor nutrition leading to progressive loss of flesh-weight, would probably justify starting dialysis in most patients, though it is important that the patient is included in all discussions regarding initiation of renal replacement therapy. Nutritional status and dietary protein intake decrease progressively as renal function declines and this may become an important reason to initiate dialysis assuming other causes of poor nutrition have been excluded (3). Over the last 10-20 years there has been a trend to starting dialysis at higher eGFR. UK Renal Registry data demonstrates that the mean eGFR at dialysis initiation has increased in a linear fashion from 6.2 to 8.7 ml/min/1.73m² between 1997 and 2010 (4).

In 2010, the IDEAL (Initiation of Dialysis Early and Late) study reported its findings from 828 incident adult patients commencing dialysis in 32 centres in Australia and New Zealand. Patients were randomised to received dialysis early (eGFR 10-12 ml/min/1.73m² based on the Cockcroft and Gault formula) or late (eGFR 5-7 ml/min/1.73m²). Although many of the late starters commenced RRT at an eGFR greater than 7 owing to the onset of symptoms, the study showed no benefit for starting dialysis early, before the onset of symptoms (5). Therefore, there seems to be no evidence to support the commencement of RRT prior to onset of symptoms. This emphasises the need to include patients in the discussion over timing of initiation of RRT.

Additional evidence for this approach comes from studies from the Netherlands and Scotland comparing patients who started dialysis at two different levels of residual renal function. After adjustment for lead time bias, there was no survival advantage in the group of patients

starting dialysis earlier (6-9). Furthermore, in the multicentre prospective Netherlands study, 94 of the 253 incident patients began dialysis later than recommended in the US NKF KDOQI guideline and the adjusted benefit in survival after 3 years on dialysis was 2.5 months in the timely starter group (7). This benefit may be attributed to lead time bias since the average delay in initiation of dialysis in the late starter group was 4.1 months.

During the 1990's there was a trend towards using urea kinetic modelling to design RRT regimes in an incremental way, aiming for a target Kt/V, and suggesting an incremental dialysis dose to maintain target clearances, particularly advocating peritoneal dialysis for this purpose (10-13). However, the absence of clear clinical benefit in terms of improved outcomes and the significant inconvenience experienced by the patient for this approach means that it should probably no longer be considered a rationale for initiating RRT.

Recent studies and registry data have confirmed that patients starting dialysis with a higher eGFR have poorer outcomes (14-16). Age and co-morbidity (2,17,18) appear to influence the starting eGFR presumably because advanced age and co-morbid problems render patients more symptomatic at a higher eGFR.

Therefore, dialysis initiation must be decided in discussion with the patient taking into account the patient's symptoms and signs and the biochemical disturbances weighed against the risks and inconveniences of starting dialysis. These guidelines are consistent with the other guidelines which recommend that renal replacement therapy should commence when a patient has symptoms or signs of uraemia or fluid overload in spite of medical therapy and the patient and multidisciplinary team agree that dialysis is indicated (19, 20).

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6. End of Life Care: Conservative Kidney Management and Withdrawal from Dialysis

6.1 Estimating prognosis in CKD: We recommend that patients with advanced kidney disease (CKD Stage 4 & 5) should be given an estimate of their prognosis and quality of life both with and without renal replacement therapy (1C)

6.2 Conservative Kidney Care: We recommend that patients with advanced kidney disease (CKD Stage 4 & 5) who opt not to dialyse should undergo conservative kidney management. Patients who have imminent or immediate end-of-life care needs should be identified and their care prioritised (1C)

6.3 Patients deteriorating despite dialysis: We recommend that patients who are struggling to cope on long-term dialysis as a result of progressive deterioration of underlying, irreversible, clinical problems, or sudden onset of a catastrophic clinical event, such as a stroke, should be recognised as being in imminent or immediate need of end-of-life care (1C)

6.4 Maintaining a supportive care register. We suggest that patients who have a predicted life expectancy of less than one year should be identified using a combination of criteria including co-morbidity, functional status, evidence of malnutrition, advanced age and the ‘surprise question’. A register of such patients should be kept, shared with appropriate agencies locally and reviewed regularly by the health care team to ensure their care needs are being met (2C).

6.5 Advance Care Planning: We recommend that patients with a recognised need for end-of-life care, including those undergoing conservative kidney management and those deteriorating despite dialysis, should be offered the opportunity to create an Advance Care Plan (1C)

6.6: Dialysis Withdrawal: We recommend that any decision to discontinue haemodialysis should be made within the context of ongoing end-of-life care planning. It should be made jointly by the patient and the responsible nephrologist in full consultation with relatives and carers, the family practitioner and members of the caring team. An assessment of competence should be carried out. Depression may need to be formally excluded (1C)

6.7: Care in the last days: We recommend that in the last days of life there should be good communication, symptom relief, psychological, spiritual and culturally sensitive care for the dying patient and their family, whenever possible in their preferred place of care followed by the provision of culturally appropriate bereavement support (1C)

Audit Measures:

1. Units should have a register of patients with End of Life Care needs, including those undergoing conservative kidney management, those deteriorating despite dialysis, and those withdrawing from dialysis. The register should link with local palliative care End of Life Registers.
2. The proportion of patients who die who are included on the register.
3. The number of patients with Stage 5 CKD who are undergoing conservative kidney management - as a proportion of all patients with Stage 5 CKD
4. The number of patients withdrawing from dialysis as a proportion of all deaths on dialysis.
5. The proportion of those patients identified as having End of Life Care needs that have a workable Advance Care Plan, which includes details of the nominated renal Key-Worker, patient preferences and choices with respect to priorities of care, and details of the individual needs of carers.
6. Proportion of patients who achieve their preferred place of dying.
7. Units in England and Wales should participate in National End of Life Care audits.

Rationale

The prevalence of advanced kidney disease increases dramatically with age. Some elderly patients with this condition are frail, and dependent, with multiple extra-renal co-morbidities. Dialysis in these circumstances adds to the burdens imposed by these conditions, and, in older patients with multiple co-morbidities and poor performance status, may not extend life (1,2). However, this is not consistent across all studies (3). Octogenarians who were dialysed, survived longer than those not offered dialysis, though the latter were more dependent, more socially excluded, more had been referred late, and more were diabetic (4). However, a retrospective study of a large registry of US nursing home residents starting dialysis showed that 58% did not survive 12 months and there was further functional decline in those who did survive (5). Survival of frail elderly patients with co-morbidities is unlikely ever to be the subject of a randomised controlled trial therefore the available evidence has to be used to help patients choose if they would like to have renal replacement therapy. Decision making aids (6) and discrete choice experiments (7) may help some patients to make a decision.

Choosing not to commence dialysis in favour of a more conservative approach is an option for some patients, most of whom are elderly, frail and dependent (1). The conservative approach aims to provide all aspects of clinical care, with the exception of dialysis, including the use of erythropoietic stimulating agents to manage anaemia, together with ongoing support by the multidisciplinary team in liaison with community and palliative care services. Quality of life for patients following a conservative pathway appears to be comparable to that in haemodialysis patients, though data are very limited (8).

At the start of dialysis the median age of UK patients is 65 years (9). Twenty percent have diabetes mellitus, more than 50% have one or more other co-morbidity and over a third are significantly dependent (10,11). A small proportion has dementia and in this group survival is poor (12). Furthermore, dialysis is an invasive treatment, with a significant short- and medium-term complication rate and treatment sessions are often poorly tolerated by elderly patients with multiple co-morbidities. As a result patients on dialysis have a high morbidity and mortality compared with non-uraemic age-matched peers, with a median survival worse than many cancers. The expected remaining life years of a dialysis patient aged 65-69 years is 3.9 years compared with 17.2 years for an aged matched person in the general population (13). Two recent studies have developed risk scores to predict 6 month mortality (14,15). These may be useful in informing discussions with patients but predicting individual prognosis is clearly imprecise. With increasing age and dependency, progression of underlying medical conditions, or the emergence of new medical problems, life on dialysis may become difficult to bear. In such situations, it is important to recognise that end of life may be approaching, signalling the need to re-focus the emphasis of care, from prolongation of life to relief of symptoms, maintenance of comfort and attention to psychological, social and spiritual concerns. There are other triggers (16) for the need for a supportive or palliative approach including substantial weight loss and severe hypoalbuminaemia, and the use of the “surprise” question: “Would you be surprised if your patient were to die in next 6-12 months?”. This may elicit a negative response for a substantial proportion of dialysis patients – 23-30% in two published studies (17,18).

Starting the conversation with patients and carers requires judgement, sensitivity and good communication. A shared view, between patient, family and carers, and all members of the multidisciplinary team, with respect to the patient’s current situation and likely prognosis, is key, though may take time to achieve. Patients differ in their need for information and involvement. Planning should acknowledge this. Advance Care Planning facilitates communication between patients, families, health care professionals, and others, about the patient’s wishes for end-of-life care (19). Offering timely, appropriate, individualised information enhances rather than diminishes hope (20). The plan should emphasise patients’ preferences and choices, and include details of the nominated Key-Worker (21). It should also document the outcomes of on-going assessments and multidisciplinary team meetings, detail communications with primary care and palliative care services, refer to the individual needs of carers, and link with other End-of-Life tools, notably the Gold Standards Framework (16), and the Preferred Priorities of Care document (22). A supportive care register should facilitate communication of this information and integrate care across primary and secondary care boundaries.

Some patients deteriorating despite dialysis will choose to withdraw from treatment. Some will choose to continue, perhaps with reduced sessional frequency and/or duration. For these patients the plan should address the circumstances under which the patient would find continued treatment, including resuscitation, unacceptable. Previously, NHSKidneyCare promoted service development in this area and the now-archived website provides a lot of information and resources to help health care professionals, patients and carers (23). There is evidence that nephrology health care professionals do not currently have these conversations and are poor at predicting patients’ preferences for future care (24,25). Health care professionals involved in these discussions need access to training in advanced communication skills.

Withdrawal from dialysis is now a common mode of death in the dialysis populations of the US (26,27), the UK (28) and in other developed countries (29). Most studies are retrospective; there are few prospective data (30). Withdrawal is more frequent in the elderly (31,32), in those with chronic or progressive co-morbid disease (30, 32) and in those with increased dependency (28, 30) - all features which increasingly characterize the growing prevalent dialysis population. In most cases, withdrawal occurs in the context of increasing dependency associated with progressive clinical decline or a severe, acute clinical event. A small proportion of patients withdraw in the absence of such imperatives. In a UK study, 15% of withdrawals were apparently in this category (28). The issue of withdrawal may be raised by the physician, the dialysis staff, the patient or the family (26,28,29). An assessment of competence to decide is important; many studies report a high proportion of patients as not competent (26,28). Depression may be a factor (33) but “probably does not play a major role in most patients’ decisions on withdrawal, though may be important in individuals” (34). Nevertheless, it is important to exclude potentially treatable depression especially in patients contemplating withdrawal in the absence of significant co-morbidity or dependency. There are sufficient differences between the risk factor profiles for withdrawal and those for suicide in this population, to suggest that these are “diverging outcomes rather than a continuum of a similar underlying process” (35).

The US Renal Physicians’ Association have published recently an updated and expanded version of a previous clinical practice guideline on initiating and withdrawing dialysis. This lists specific situations where dialysis withdrawal should be considered and also gives advice on resolving conflict with families and carers over any such decisions (36, 37).

A number of studies have attempted to define quality end-of-life care from the patient’s perspective. Qualitative interviewing of patients many of whom were on dialysis identified 5 domains - receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the perceived burden on loved ones, and strengthening relationships with loved ones (38). Similar themes have emerged from other studies (39, 40). These provide a focus for improving the quality of care of the dying. A focus on end of life care and use of the supplementary guidelines for prescribing in advanced kidney disease may facilitate good quality care in this setting (41). With good communication and good quality care of the dying, most patients withdrawing from dialysis may experience “good deaths” (42).

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