



# Renal replacement therapy and conservative management

NICE guideline

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# Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the <u>Yellow Card Scheme</u>.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should <u>assess and reduce the environmental impact of implementing NICE recommendations</u> wherever possible.

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This guideline replaces CG125 and TA48.

This guideline is the basis of QS72.

This guideline should be read in conjunction with QS76.

### Overview

This guideline covers renal replacement therapy (dialysis and transplantation) and conservative management for people with chronic kidney disease stages 4 and 5. It aims to improve quality of life by making recommendations on planning, starting and switching treatments, and coordinating care.

NICE has also produced a guideline on chronic kidney disease.

#### Who is it for?

- Healthcare professionals
- Providers of renal replacement therapy and conservative management
- People with chronic kidney disease stages 4 and 5, their families and carers

### Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in <a href="NICE's information on making decisions about your care">NICE's information on making decisions about your care</a>.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

# 1.1 Indications for starting dialysis

- 1.1.1 Follow the recommendations on referral criteria in <u>NICE's guideline on</u> chronic kidney disease.
- 1.1.2 Consider starting dialysis when indicated by the impact of symptoms of uraemia on daily living, or biochemical measures or uncontrollable fluid overload, or at an estimated glomerular filtration rate (eGFR) of around 5 to 7 ml/min/1.73 m<sup>2</sup> if there are no symptoms.
- 1.1.3 Ensure the decision to start dialysis is made jointly by the person (or, where appropriate, their family members or carers) and their healthcare team.
- 1.1.4 Before starting dialysis in response to symptoms, be aware that some symptoms may be caused by non-renal conditions.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on indications for starting renal replacement therapy</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review A:</u> initiating renal replacement therapy.

# 1.2 Preparing for renal replacement therapy or conservative management

#### When to assess

1.2.1 Start assessment for renal replacement therapy (RRT) or conservative management at least 1 year before therapy is likely to be needed, including for those with a failing transplant.

For a short explanation of why the committee made this recommendation and how it might affect practice, see the <u>rationale and impact section on preparing for renal</u> replacement therapy or conservative management – when to assess.

Full details of the evidence and the committee's discussion are in <u>evidence review E:</u> when to assess for renal replacement therapy.

#### How to assess

- 1.2.2 Involve the person and their family members or carers (as appropriate) in shared decision-making over the course of assessment to include:
  - clinical preparation
  - psychosocial evaluation, preparation and support
  - the person's individual preferences for type of RRT and when to start
  - · how decisions are likely to affect daily life.

- 1.2.3 Consider further assessment by a clinical psychologist or psychiatrist for:
  - all children and young people being considered for a transplant, and
  - adults being considered for a transplant if risk factors for poor outcomes have been identified; these may include:
    - lack of social support
    - neurocognitive issues
    - non-adherence (medicines, diet, hospital appointments)
    - poor understanding of process and complexities of treatment
    - poorly controlled mental health conditions or severe mental illness
    - substance misuse or dependence.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on preparing for renal</u> replacement therapy or conservative management – how to assess.

Full details of the evidence and the committee's discussion are in <u>evidence review F:</u> how to assess people for renal replacement therapy.

# 1.3 Choosing modalities of renal replacement therapy or conservative management

- 1.3.1 Offer a choice of RRT or conservative management to people who are likely to need RRT. Conservative management for children should only be considered within appropriate regulatory frameworks. See <a href="NICE's guideline on end of life care for children and young people with life-limiting conditions">NICE's guideline on end of life care for children and young people with life-limiting conditions</a>.
- 1.3.2 Ensure that decisions about RRT modalities or conservative management are made jointly with the person (or with their family members or carers for children or adults lacking capacity) and healthcare team, taking into account:

- · predicted quality of life
- predicted life expectancy
- the person's preferences (see the <u>recommendations on information, education</u> and <u>support</u>)
- other factors such as co-existing conditions.
- 1.3.3 Offer people (and their family members or carers, as appropriate) regular opportunities:
  - to review the decision regarding RRT modalities or conservative management
  - to discuss any concerns or changes in their preferences.

#### Transplantation

- 1.3.4 Discuss the individual factors that affect the risks and benefits of transplantation with all people who are likely to need RRT, and their family members or carers (as appropriate).
- 1.3.5 Include living donor transplantation in the full informed discussion of options for RRT.
- 1.3.6 Offer a pre-emptive living donor transplant (when there is a suitable living donor) or pre-emptive listing for deceased donor transplantation to people considered eligible after a full assessment.
- 1.3.7 Do not exclude people from receiving a kidney transplant based on BMI alone.

#### Choice of dialysis modalities

- 1.3.8 Offer a choice of dialysis modalities at home or in centre ensuring that the decision is informed by clinical considerations and patient preferences (see recommendation 1.3.2).
- 1.3.9 Offer all people who choose peritoneal dialysis a choice of continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis

(APD), if this is medically appropriate.

- 1.3.10 Consider peritoneal dialysis as the first choice for children 2 years or under.
- 1.3.11 For people who choose haemodialysis/haemodiafiltration (HD/HDF):
  - Consider HDF rather than HD if in centre (hospital or satellite unit).
  - Consider HDF or HD at home, taking into account the suitability of the space and facilities.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on choosing</u> modalities of renal replacement therapy or conservative management.

Full details of the evidence and the committee's discussion are in <u>evidence review B:</u> modalities of renal replacement therapy and <u>evidence review C: sequencing</u> modalities of renal replacement therapy.

# 1.4 Planning dialysis access formation

- 1.4.1 Discuss with the person, their family members and carers (as appropriate) the risk and benefits of the different types of dialysis access, for example, fistula, graft, central venous or peritoneal dialysis catheter.
- 1.4.2 When peritoneal dialysis is planned via a catheter placed by an open surgical technique, aim to create the access around 2 weeks before the anticipated start of dialysis.
- 1.4.3 When HDF or HD is planned via an arteriovenous fistula, aim to create the fistula around 6 months before the anticipated start of dialysis to allow for maturation. When deciding on timing, take into account the possibility of the first fistula failing or needing further interventions before use.

1.4.4 Offer ultrasound scanning to determine vascular access sites for creating arteriovenous fistulae for HDF or HD.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on planning dialysis</u> <u>access formation</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review D:</u> when to create access formation and/or list for transplantation and <u>evidence review F:</u> how to assess people for renal replacement therapy.

# 1.5 Indications for switching or stopping renal replacement therapy

- 1.5.1 Offer information on all medically appropriate treatment options when discussing switching RRT modality.
- 1.5.2 Consider switching treatment modality or stopping RRT if medically indicated or if the person (or, where appropriate, their family members or carers) asks.
- 1.5.3 Plan switching treatment modality or stopping RRT in advance wherever possible.
- 1.5.4 Do not routinely switch people on peritoneal dialysis to a different treatment modality in anticipation of potential future complications such as encapsulating peritoneal sclerosis. However, monitor risk factors, such as loss of ultrafiltration.
- 1.5.5 Seek specialist advice on the need for switching treatment modality when women become pregnant or wish to become pregnant.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on indications for switching or stopping renal replacement therapy</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review G:</u> indicators for transferring or discontinuing renal replacement therapy.

# 1.6 Recognising symptoms

1.6.1 Recognise that people on RRT or receiving conservative management may have the symptoms in box 1 and that these may affect their day-to-day life.

# Box 1 Possible symptoms in people on renal replacement

therapy or conservative management	

5
General symptoms:
• breathlessness
• fatigue
• insomnia
• itching
• lethargy
• pain
poor appetite
• swelling
taste changes
• thirst
• weakness
weight loss/gain.
Gastro-intestinal/urological symptoms:
abdominal cramps
change in bowel or urinary habits
• nausea.
Musculoskeletal symptoms:
muscle cramps

restless legs.

Neurological symptoms:

- cognitive impairment
- dizziness
- headaches.

Psychological/behavioural symptoms:

- anxiety
- body image concerns
- depression
- mood disturbances/fluctuations
- sexual dysfunction.
- 1.6.2 Throughout the course of RRT and conservative management:
  - Ask people about any symptoms they have.
  - Explore whether symptoms are due to the renal condition, treatment or another cause.
  - Explain the likely cause of the symptoms and how well treatment may be expected to control them.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on recognising</u> <u>symptoms</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review H:</u> symptom recognition.

#### 1.7 Diet and fluids

- 1.7.1 Offer a full dietary assessment by a specialist renal dietitian to people starting dialysis or conservative management. This should include:
  - weight history
  - fluid intake
  - sodium
  - potassium
  - phosphate
  - protein
  - calories
  - micronutrients (vitamin and minerals).
- 1.7.2 After transplantation, offer dietary advice from a healthcare professional with training and skills in this area.
- 1.7.3 Re-assess dietary management and fluid allowance when:
  - a person's circumstances change (for example, when switching RRT modality),
     or
  - biochemical measures or body composition measures (for example, unintentional weight loss) indicate, or
  - the person (or, where appropriate, their family members or carers) asks.
- 1.7.4 Provide individualised information, advice and ongoing support on dietary management and fluid allowance to the person and their family members or carers (as appropriate). The information should be in an accessible format and be sensitive to the person's cultural needs and beliefs.
- 1.7.5 Follow the recommendations on dietary management and phosphate binders in NICE's guideline on chronic kidney disease.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on diet and fluids</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review I</u>: dietary management and fluid restriction.

# 1.8 Information, education and support

- 1.8.1 To enable people, and their families and carers (as appropriate), to make informed decisions, offer balanced and accurate information about:
  - all treatments available to them (including RRT modalities and conservative management), and
  - how the treatments may affect their lives.

See box 2 for more details.

# Box 2 Information about treatments and how they may affect lifestyle

Information about treatments, including RRT, conservative management and dietary intervention:

- What they involve, for example, availability of assistance, time that treatment takes place, and number of sessions per day/week
- · Potential benefits.
- The benefits of adherence to treatment regimens and the potential consequences of non-adherence.
- Potential adverse effects, their severity and how they may be managed.
- The likely prognosis on dialysis, after transplant or with conservative management.
- The transplant listing process (when appropriate).
- Switching the modality of RRT and the possible consequences (that is, the impact on the person's life or how this may affect future treatment or outcomes).
- · Reviewing treatment decisions.
- Stopping treatment and planning end of life care.

Information about how treatments may affect lifestyle:

- The person or carer's ability to carry out and adjust the treatment themselves.
- The possible impact of dietary management and management of fluid allowance.
- How treatment may fit in with daily activities such as work, school, hobbies, family commitments and travel for work or leisure.
- How treatment may affect sexual function, fertility and family planning.
- Opportunities to maintain social interaction.

- How treatment may affect body image.
- How treatment may affect physical activity (for example, whether contact sports should be avoided after transplantation, whether swimming should be avoided with peritoneal dialysis).
- Whether a person's home will need to be modified to accommodate treatment.
- How much time and travel treatment or training will involve.
- The availability of transport.
- The flexibility of the treatment regimen.
- Whether any additional support or services might be needed.
- 1.8.2 Recognise the psychological impact of a person being offered RRT or conservative management and discuss what psychological support may be available to help with decision-making.
- 1.8.3 Discuss with people which treatment options are available to them and explain why any options may be inappropriate or not advised.
- 1.8.4 Offer oral and written information and support early enough to allow time for people to fully understand their treatment options and make informed decisions. Information should be in an accessible format.
- 1.8.5 Direct people to other sources of information and support (for example, online resources, pre-dialysis classes and peer support).
- 1.8.6 Remember that some decisions must be made months before RRT is needed (for example, a fistula is created at least 6 months before starting dialysis).
- 1.8.7 Be prepared to discuss the information provided both before and after decisions are made, in line with the person's wishes.
- 1.8.8 Take into account information the person has obtained from other

sources (such as family members and carers) and how this information has influenced their decision.

- 1.8.9 Ensure that healthcare professionals offering information have specialist knowledge about late stage chronic kidney disease and the skills to support shared decision-making (for example, presenting information in a form suitable for developmental stage).
- 1.8.10 Offer people who have presented late, or who started dialysis in an unplanned way, the same information as people who present at an earlier stage.
- 1.8.11 Follow the recommendations on enabling patients to actively participate in their care in <a href="NICE's guideline on patient experience in adult NHS">NICE's guideline on patient experience in adult NHS</a> <a href="mailto:services">services</a> and on information and education in <a href="MICE's guideline on chronic kidney disease">NICE's guideline on shared decision making</a>.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on information</u>, education and support.

Full details of the evidence and the committee's discussion are in <u>evidence review K:</u> information, education and support.

### 1.9 Coordinating care

- 1.9.1 Provide the person with the contact details of the healthcare professional responsible for their overall renal care:
  - before they start RRT or conservative management, and
  - when they switch from one modality to another.
- 1.9.2 Coordinate care to reduce its effect on day-to-day life and wellbeing (treatment burden). For example, take account of people's preferences and avoid scheduling appointments on non-dialysis days for people on hospital dialysis wherever possible.

#### 1.9.3 Follow the recommendations on:

- delivering an approach to care that takes account of multimorbidity in <u>NICE's</u> guideline on multimorbidity, and
- continuity of care and relationships, and enabling patients to actively
  participate in their care in <u>NICE's guideline on patient experience in adult NHS</u>
  services.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the <u>rationale and impact section on coordinating care</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review M:</u> <u>coordinating care</u>.

## Recommendations for research

The guideline committee has made the following recommendations for research.

# Key recommendations for research

#### 1 Cardiac assessment

What is the clinical and cost effectiveness of cardiac assessment before transplantation?

For a short explanation of why the committee made the recommendation for research, see the <u>rationale section on preparing for renal replacement therapy or conservative</u> management – how to assess.

Full details of the evidence and the committee's discussion are in <u>evidence review F:</u> how to assess people for renal replacement therapy.

#### 2 Timing of pre-emptive transplant

What is the most clinical and cost-effective strategy for timing of pre-emptive transplantation?

For a short explanation of why the committee made the recommendation for research, see the rationale section on indications for starting renal replacement therapy.

Full details of the evidence and the committee's discussion are in <u>evidence review A:</u> initiating renal replacement therapy.

#### 3 Acute haemodialysis versus acute peritoneal dialysis

What is the clinical and cost effectiveness of initial haemodialysis versus initial peritoneal dialysis for people who start dialysis in an unplanned way?

For a short explanation of why the committee made the recommendation for research, see the <u>rationale section on choosing modalities of renal replacement therapy or conservative management</u>.

Full details of the evidence and the committee's discussion are in <u>evidence review B:</u> modalities of renal replacement therapy and <u>evidence review C: sequencing</u> modalities of renal replacement therapy.

#### 4 Frequency of review

What is the most clinical and cost-effective frequency of review for people on peritoneal dialysis, haemodiafiltration, haemodialysis or conservative management?

For a short explanation of why the committee made the recommendation for research, see the rationale section on frequency of review.

Full details of the evidence and the committee's discussion are in <u>evidence review J:</u> frequency of review.

#### 5 Coordinating care

What is the clinical and cost effectiveness of having keyworkers present in the context of renal replacement therapy (RRT)?

For a short explanation of why the committee made the recommendation for research, see the rationale section on coordinating care.

Full details of the evidence and the committee's discussion are in <u>evidence review M:</u> <u>coordinating care</u>.

#### Other recommendations for research

What is the clinical and cost effectiveness of strategies for switching RRT modality?

What is the clinical and cost effectiveness of using decision aids in the context of RRT?

For a short explanation of why the committee made the recommendation for research, see the rationale section on decision support interventions.

Full details of the evidence and the committee's discussion are in <u>evidence review L:</u> decision support interventions.

What is the optimum timing of laparoscopic and percutaneous peritoneal dialysis access creation?

What is the clinical and cost effectiveness of conservative management versus dialysis in frail, older people?

What is the clinical and cost effectiveness of home haemodiafiltration versus home haemodialysis, taking into account the impact of frequency?

What is the clinical and cost effectiveness of haemodialysis/haemodiafiltration before peritoneal dialysis versus peritoneal dialysis before haemodialysis/haemodiafiltration?

What is the optimum timing of listing for transplantation?

# Rationale and impact

### Indications for starting renal replacement therapy

Recommendations 1.1.1 to 1.1.4

#### Why the committee made the recommendations

The committee agreed that when to start dialysis is a complex decision that should take into account a number of factors (symptoms, patient preference, biochemistry, fluid overload and estimated glomerular filtration rate [eGFR]). Most people start dialysis due to symptoms, but evidence suggested that there was no overall harm or benefit of starting dialysis at an eGFR of around 5 to 7 ml/min/1.73 m² in the absence of symptoms. However, there was evidence that starting dialysis when there are symptoms or the eGFR reaches 5 to 7 ml/min per 1.73 m² was cost saving compared with an earlier start. The committee noted that some people prefer to have an agreed starting point (eGFR), but may need dialysis before this because symptoms are affecting normal daily activities. Some people with slowly progressing chronic kidney disease may not recognise and report symptoms that indicate dialysis is needed. Taking all this information together, the committee acknowledged several indications for starting dialysis and agreed that these should be considered on an individual basis.

The committee agreed that it is important to establish whether symptoms (for example, fatigue and depression) are due to uraemia or not, and to discuss their impact on daily life.

Evidence on the timing of pre-emptive transplant was limited and contradictory, with one study showing a clinically important benefit of transplanting at an eGFR of less than 10 ml/min/1.73 m<sup>2</sup> but another showing no difference. The committee agreed to make a recommendation for research on this to guide future practice.

#### How the recommendations might affect practice

The recommendations reflect common practice for adults and children, and so are not likely to involve a change of practice for most NHS providers or have a substantial resource impact for the NHS in England. If providers need to change from an earlier to a

later initiation strategy, this is likely to be cost saving due to a reduction in time on dialysis.

Full details of the evidence and the committee's discussion are in <u>evidence review A:</u> <u>initiating renal replacement therapy</u>.

Return to recommendations

# Preparing for renal replacement therapy or conservative management – when to assess

Recommendation 1.2.1

#### Why the committee made the recommendation

Some evidence indicated that earlier referral to nephrology services improved survival on RRT at 90 days. The committee were interested in the timing of referral for assessment for RRT and used their experience to recommend that this should be at least 1 year before RRT is likely to be needed. They agreed that this would provide time for clinical and psychological preparation for dialysis or pre-emptive transplantation, and give the person, family members and carers enough time to think about the options. The committee acknowledged that there might be possible harms and costs for people who were referred but did not go on to need RRT, but they agreed that these were outweighed by the benefits of early referral for most people.

#### How the recommendation might affect practice

The recommendation generally reflects current practice so there should be no significant change in practice or substantial resource impact to the NHS in England.

Full details of the evidence and the committee's discussion are in <u>evidence review E: when</u> to assess for renal replacement therapy.

Return to the recommendation

# Preparing for renal replacement therapy or conservative management – how to assess

#### Why the committee made the recommendations

Recommendations 1.2.2 to 1.2.3

The committee recognised that an assessment should involve preparing people for RRT, for example, by explaining the procedures to create vascular access and checking heart function and immunity. Psychosocial preparation is also important for reducing non-adherence and improving outcomes. They also highlighted the importance of discussing a person's preferences and understanding how decisions on RRT or conservative management are likely to affect a person's everyday life.

No evidence was identified on the psychological assessment of transplant recipients or donors. The committee agreed that there were likely benefits for identifying risk factors for non-adherence or morbidity after the operation. These could include substance misuse, current non-adherence or a previous or current mental health condition. Given the lack of evidence and potential resource impact, the committee agreed that assessment could be considered for specific high-risk groups.

There was no evidence on cardiac assessment before transplantation. The committee discussed current practice and agreed it is very variable. They therefore decided to make a recommendation for research to inform future practice.

#### How the recommendations might affect practice

Psychological assessment in people at high risk of non-adherence or morbidity is current practice in many areas. The recommendation is likely to lead to better targeting of psychological assessment in other areas. The recommendation was not considered likely to have a substantial resource impact overall.

Full details of the evidence and the committee's discussion are in <u>evidence review F: how</u> to assess people for renal replacement therapy.

Return to the recommendations

# Choosing modalities of renal replacement therapy or conservative management

Recommendations 1.3.1 to 1.3.11

### Why the committee made the recommendations

#### Renal replacement therapy or conservative management

People who are likely to need RRT should be supported to make decisions about treatment options, including conservative management. There was no evidence of differential benefits or harms in any specific group of people and the committee agreed that the decision needs to be based on individual factors (such as frailty, cognitive impairment and multimorbidity) and patient preference.

#### Choice of renal replacement therapy

Evidence showed that if RRT is chosen, transplantation offers a clear advantage over dialysis in terms of extending life. This benefit was observed in each age group. In the committee's experience, quality of life and hospitalisation are also likely to be improved by transplantation. However, the individual factors that affect the risks and benefits of transplantation, for example, comorbidities, should be discussed. There was no evidence on cost effectiveness but the committee considered transplantation likely to have a lower cost over the long term due to the cost of avoiding dialysis. The committee agreed to recommend pre-emptive transplantation with a living donor or, if this is not an option, a transplant from a deceased donor.

The committee noted that the only available evidence suggested that people with a BMI greater than 30 benefited from transplant (as opposed to dialysis) to a similar degree as people with a BMI of 30 or under, in terms of mortality. The committee agreed to recommend that healthcare professionals do not exclude people from transplantation based on BMI alone.

Limited evidence showed that if a transplant is not possible, peritoneal dialysis and haemodialysis (HD) offered similar benefits and equivalent harms. There was uncertainty about the differences in costs between peritoneal dialysis and HD due to uncertainty in current UK dialysis costs and transport costs. There was no evidence comparing

haemodiafiltration (HDF) and peritoneal dialysis. The committee agreed that peritoneal dialysis and HD/HDF may have quite different effects on a person's life (for example, affecting their ability to travel and the need for self-care) so they agreed that a person should be able to choose the type of dialysis most suitable for them. Peritoneal dialysis should be considered for children under 2 years due to difficulties with vascular access and extracorporeal blood volume.

There was no evidence to suggest clear differences between home and in-centre (hospital or satellite unit) HD/HDF. There is uncertainty in current UK dialysis costs but they may be lower at home. The committee acknowledged that these treatments can have very different effects on lifestyle and recommended patient choice.

Evidence suggested that in-centre HDF was more effective than in-centre HD and was cost effective, so the committee agreed that HDF rather than HD should be recommended when dialysis was in centre. However, they were aware of an ongoing trial H4RT comparing high-volume HDF with high-flux HD and, following stakeholder consultation, changed the recommendation to consider HDF rather than HD for in-centre dialysis. The committee noted that HD may be done more frequently at home than in centre. The benefits of HDF are unknown in people who dialyse more frequently. There was no evidence on the efficacy of HDF at home. The committee was aware that some centres offer home HDF, although some people opt for transportable dialysis machines (which cannot do HDF currently) and these centres also provide home HD. Taking all of this information together the committee could not recommend one option over another for HD/HDF at home. They decided that either HD or HDF could be considered.

There was no evidence comparing HD/HDF and peritoneal dialysis as initial therapy for people who start dialysis in an unplanned way. The committee agreed to make a recommendation for research on this to inform future guidance.

There was no evidence to suggest clear differences between automated peritoneal dialysis (APD) and continuous ambulatory peritoneal dialysis (CAPD). Again the committee acknowledged that these treatments can have very different effects on lifestyle and recommended patient choice.

The committee agreed that people should have regular opportunities to review treatment options.

#### Sequencing

There was not enough evidence to recommend any particular sequence of RRT modalities. The committee agreed that decisions about sequence would mostly be guided by personal circumstances.

#### How the recommendations might affect practice

Currently there is a mix of HDF and HD provision in the NHS in England. The recommendation to consider HDF over HD for in-centre dialysis may affect resource use in areas where this is a change in practice. There are likely to be additional costs relating to consumables and water consumption with HDF compared with HD, but these may be partly offset by reduced use of erythropoietin-stimulating agent (ESA). There may be additional costs for machines where HDF-capable machines are not currently used. However, most centres already have some HDF-capable machines. This will enable them to accommodate any initial increased demand for HDF. Provision can be expanded if demand increases within the usual replacement cycles. These additional costs may result in a substantial resource impact to the NHS in England overall. However, this is uncertain as it is not possible to accurately predict how widely additional use of HDF will be considered.

Although use of different RRT modalities and conservative management varies between areas, other recommendations reinforce current good practice to offer people a choice of modalities and settings, and conservative management, and so are not expected to have a substantial resource impact.

The committee agreed that people are often not offered regular opportunities to discuss the option of switching treatment modality or stopping RRT and so this may be a change in practice in many areas. However, these discussions could form part of current patient reviews and so would not mean a difference in resource use. More regular discussions may lead to more people switching or stopping RRT but this is not expected to result in a substantial resource impact overall.

Full details of the evidence and the committee's discussion are in <u>evidence review B:</u> <u>modalities of renal replacement therapy</u> and <u>evidence review C: sequencing modalities of renal replacement therapy</u>.

Return to the recommendations

# Planning dialysis access formation

Recommendations 1.4.1 to 1.4.4

#### Why the committee made the recommendations

The committee highlighted the importance of discussing with the person the different types of dialysis and their access and the impacts of these on everyday life.

Evidence suggested that the best time for creating access for peritoneal dialysis by open surgery is around 2 weeks before starting dialysis. There was no evidence on the best time for creating other types of peritoneal access so the committee decided to make a recommendation for research to inform future guidance.

Evidence suggested that the best time for creating an arteriovenous fistula (AVF) for vascular access was 3 to 6 months before starting HD or HDF. It suggested that earlier AVF creation may increase the rate of AVF success. The committee agreed that doing this early (around 6 months) reduced the need for additional access procedures. However, when a fistula is created early, some people may never need it, for example, because they have a pre-emptive transplant. The committee agreed that the benefits of establishing a fistula around 6 months before starting dialysis, including the cost savings associated with avoiding additional access procedures, were likely to outweigh the potential disadvantages and increased costs associated with unused fistulae. The committee noted that the precise timing will vary from person to person, depending on the likely success of fistula creation.

Evidence showed a benefit of routine ultrasound scanning in terms of reduced failure of AVF. Cost calculations based on the clinical evidence suggested that routine scanning is likely to reduce overall costs because of fewer repeat interventions. The committee agreed to recommend routine ultrasound scanning to determine vascular access sites.

The committee noted that there was no evidence to guide the optimum timing of transplant listing and therefore made a recommendation for research in this area.

#### How the recommendations might affect practice

Current practice for creating vascular access is variable. A minimum timing from creation to use of 6 weeks has been suggested – however, the committee agreed that creation

around 6 months reflected common practice. The recommendation is not expected to have a significant impact on practice, but should standardise some current variability. It is not expected to have a substantial resource impact to the NHS in England.

Current practice for creating peritoneal dialysis access via open surgery is broadly in line with the recommendation (that is, 2 weeks before use) and so this recommendation is not expected to have a substantial resource impact to the NHS in England.

Current practice regarding ultrasound scanning to determine access sites is variable; some centres use routine ultrasound scanning but others offer a more selective approach. The recommendation would not involve a large change in practice and is likely to be cost saving because of the reduced need for repeat intervention. It is not expected to have a substantial resource impact to the NHS in England.

Full details of the evidence and the committee's discussion are in <u>evidence review D: when</u> to create access formation and/or list for transplantation and <u>evidence review F: how to</u> assess people for renal replacement therapy.

Return to the recommendations

# Indications for switching or stopping renal replacement therapy

Recommendations 1.5.1 to 1.5.5

#### Why the committee made the recommendations

There was no evidence on indications for switching treatment and the committee agreed to make recommendations for research on possible indicators to inform future guidance. There was no evidence that people on peritoneal dialysis should switch modality in anticipation of future complications such as encapsulating peritoneal sclerosis and the committee agreed this should not be routine. They highlighted that healthcare professionals should monitor for risk factors predicting complications (for example, loss of ultrafiltration).

There was also no evidence to support a switch from peritoneal dialysis to HD/HDF for women who become or wish to become pregnant. The committee agreed that the need for

a switch would depend on the adequacy of dialysis, the health of the fetus and the control of urea. They recommended that specialist advice should be sought before any decisions were made.

#### How the recommendations might affect practice

The recommendations broadly reflect current good practice and are not expected to have a resource impact to the NHS in England.

Full details of the evidence and the committee's discussion are in <u>evidence review G:</u> <u>indicators for transferring or discontinuing renal replacement therapy</u>.

Return to the recommendations

### Recognising symptoms

Recommendations 1.6.1 to 1.6.2

#### Why the committee made the recommendations

Evidence identified symptoms that people approaching the need for RRT or receiving RRT or conservative management frequently report as affecting their lives. The committee also identified others (for example, change in urinary habits). People may feel uncomfortable talking about some symptoms (for example, sexual dysfunction) and may not associate them with their condition or its treatment. The committee agreed that healthcare professionals should ask people about symptoms and determine the likely cause. It is important that people understand which symptoms they may experience, which may need further management and if treatment will control them.

#### How the recommendations might affect practice

Currently, not all healthcare professionals ask people about all of the symptoms they are experiencing. They may only ask about specific symptoms and not explore all of them. Healthcare professionals should ascertain whether symptoms are due to the person's renal condition or not and explain this to them. This may be a change in practice for some, but is not expected to have a substantial resource impact to the NHS in England.

Full details of the evidence and the committee's discussion are in <u>evidence review H:</u> <u>symptom recognition</u>.

Return to the recommendations

#### Diet and fluids

Recommendations 1.7.1 to 1.7.5

#### Why the committee made the recommendations

Limited evidence, including in people with a transplant, indicated that people receiving RRT or conservative management may benefit from dietary and/or fluid management. The committee agreed that current practice is for people receiving dialysis or conservative management to have an assessment by a specialist dietitian. NICE's guideline on managing hyperphosphataemia in chronic kidney disease recommends assessment by a specialist renal dietitian for those at risk of hyperphosphataemia, which would include these groups of people. They also considered it current practice for dietary advice to be given after transplantation, although this advice is not always given by a specialist renal dietitian. The committee noted that there is some variation in how long people have to wait for this assessment, and variation in ongoing management. The committee agreed that dietary advice is important for people with a transplant, particularly straight after the surgery. This was supported by the evidence. The committee noted the importance of the person giving dietary advice having specialist knowledge of dietary requirements in transplant patients. However, the evidence was too limited to recommend that dietary advice should routinely be from a specialist renal dietitian for this group given it would be a change in practice in many areas and could result in a substantial resource impact.

The committee agreed that following initial assessment further dietary assessment would be determined by specific circumstances or indicators and made a recommendation summarising what these would be. They highlighted that there is variation in the level of dietitian input available in renal centres, which may affect how quickly people can access services or the level of input following initial assessment. However, the evidence was not considered sufficient to make specific recommendations to address this.

The committee agreed that involving family members and carers in discussions was important for improving adherence to dietary management and fluid allowance. There was no evidence on the benefits or harms of a low protein diet so the committee was not able

to make a recommendation on this. The committee agreed that dietary management and fluid assessment should not be a 'one-step' process and that people's needs should be reviewed when circumstances change (for example, when switching RRT modalities) or when biochemical measures indicate.

#### How the recommendations might affect practice

The recommendations made reflect current practice and are not expected to result in a substantial resource impact to the NHS in England.

Full details of the evidence and the committee's discussion are in <u>evidence review I</u>: dietary management and fluid restriction.

Return to the recommendations

# Frequency of review

#### Why the committee made the recommendation for research

No evidence was identified to support any particular strategy for timing of review for people on RRT or conservative management. Because of the lack of evidence, considerable variation in current practice and the likely resource implications of a practice recommendation, the committee made a <u>recommendation for research</u> to inform future guidance.

Full details of the evidence and the committee's discussion are in <u>evidence review J:</u> frequency of review.

# Information, education and support

#### Why the committee made the recommendations

Recommendations 1.8.1 to 1.8.11

The committee used the evidence and their own experience to update the recommendations on information and support from NICE's 2011 guideline on peritoneal

dialysis (CG125) and to extend these to cover other forms of RRT and conservative management. Key findings related to information being provided well in advance of decisions being needed, multiple formats of information being available, and full information on all modalities being provided. Information should also be provided on the psychological impact of starting RRT and the decision-making process.

### How the recommendations might affect practice

The recommendations broadly reflect current practice and therefore are unlikely to have a resource impact. They focus mainly on the principles of information and support rather than on specific interventions.

Full details of the evidence and the committee's discussion are in <u>evidence review K:</u> information, education and support.

Return to the recommendations

## **Decision support interventions**

#### Why the committee made the recommendation for research

Limited evidence suggested a benefit of structured education programmes although results were inconsistent. The committee noted that decision aids are used in clinical practice but do not replace discussions between the patient, families and carers, and healthcare professionals when making decisions about RRT or conservative management. Education classes and peer support are also important to support decision-making. In the absence of evidence showing clinically important benefits, the committee were unable to recommend that decision aids should be used. They decided to make a <u>recommendation for research</u> to inform future practice.

Full details of the evidence and the committee's discussion are in <u>evidence review L:</u> decision support interventions.

### Coordinating care

Recommendations 1.9.1 to 1.9.3

#### Why the committee made the recommendations

There was limited evidence on the coordination of care but the committee agreed that people should know who to contact with questions about their condition or treatment. This is particularly important when they start or change RRT modalities. The committee noted that people on RRT experience considerable treatment burden and that strategies should be adopted to reduce this. There was no evidence on care coordination by a keyworker so the committee recommended the healthcare professional responsible for renal care as a first point of contact. They made a <u>recommendation for research</u> on care coordination by a keyworker to inform future guidance.

#### How the recommendations might affect practice

Current practice is variable in terms of when a person is given the details of the person responsible for care. This recommendation will ensure that this is done before starting treatment or when switching modalities or to conservative management. Similarly the recommendation on reducing treatment burden standardises and reinforces good practice. Some healthcare professionals may need to change their practice but this would not result in a substantial resource impact.

Full details of the evidence and the committee's discussion are in <u>evidence review M:</u> coordinating care.

Return to the recommendations

### Context

People with chronic kidney disease (CKD) have an irreversible and progressive deterioration in kidney function. Renal replacement therapy (RRT) is a treatment option in people with CKD whose condition progresses to kidney failure. RRT essentially comprises either transplantation or dialysis (artificially removing waste products and excess water from the blood). Transplantation can be from living or deceased donors, and for some people it may involve the transplantation of more than one organ simultaneously (for example, combined pancreas and kidney transplantation for people with type I diabetes mellitus). In some cases, transplantation may be pre-emptive, occurring before dialysis would be needed. There are 2 main types of dialysis: haemodialysis (where the blood is filtered outside of the body using a dialysis machine) and peritoneal dialysis (where the person's abdominal lining is used to filter the blood). Some people choose not to receive RRT but continue to receive other supportive and symptomatic treatment for kidney failure – for example, treatment for their anaemia or dietary modification. This is usually called conservative management. People may also receive end of life care, and this may include both supportive and palliative care.

According to the 19th annual report by the UK Renal Registry (2016), on 31 December 2015 there were 61,256 adults in the UK receiving RRT. Of these, 53.1% had received a transplant, 41.0% were receiving haemodialysis (21.2% in satellite units, 17.8% in hospitals, 2.0% at home), 2.5% were receiving continuous ambulatory peritoneal dialysis and 3.4% were receiving automated peritoneal dialysis. In addition, 769 children and young people under the age of 16 years were receiving RRT. Most had received a transplant (41% live, 34% deceased), with 13% on haemodialysis and 12% on peritoneal dialysis. The median age of all people newly requiring RRT was 59.0 years; 22.7% of people were from minority ethnic groups. The reported 1-year risk of death for people on RRT aged 35 to 39 years was approximately 22.0 times higher than age- and sex-matched controls not on RRT. Survival rates for people with diabetes on maintenance haemodialysis are lower than those of people without diabetes. The number of people receiving conservative management varies between renal units and has been difficult to establish, but up to 40% of people over 70 choose this option. Most of these still receive their care and treatment through renal services.

Approximately 5,500 adults and children are currently on the national renal transplant (waiting) list (NHS Blood and Transplant), with about 3,000 renal transplants performed each year. The median time to transplantation for those on the list is around 1,000 days for

adults and 300 days for children. There is considerable inequality across ethnic groups, with relatively fewer people from black, Asian and minority ethnic groups on the organ donor list. These groups have a higher incidence and prevalence of CKD needing RRT and tend to reach this stage at a younger age.

RRT is an expensive treatment. The total cost of CKD in England in 2009–10 was estimated at £1.45 billion; more than half of this sum was spent on RRT.

This guideline aims to improve the care of people with CKD who need RRT or conservative management. The guideline covers the choice, timing, preparation for and switching of RRT 'modalities' for children and adults, as well as symptom recognition, information, education and support, and coordination of care.

# Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the <u>NICE</u> topic page on kidney conditions.

For full details of the evidence and the guideline committee's discussions, see the <u>evidence reviews</u>. You can also find information about <u>how the guideline was developed</u>, including <u>details of the committee</u>.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

# **Update** information

#### Minor changes since publication

**November 2021**: We added a link to NICE's guideline on shared decision making in recommendation 1.8.11.

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# Accreditation

