



*The National Service Framework
for Renal Services*

Working for Children and Young People

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Foreword



When Part One of the *National Service Framework for Renal Services* (the Renal NSF) was published, the Government made a commitment to publish a good practice guide on the NSF's implications for children.

This document delivers that commitment and goes further. It includes the standards, quality requirements and markers of good practice in the Renal NSF and links them to the standards in the *National Service Framework for Children, Young People and Maternity Services* (the Children's NSF). This document brings together the overarching vision of these publications.

Kidney disease is luckily rare among children and young people. While advancing medical knowledge and a better resourced NHS are producing improved outcomes for children with kidney disease, the social and educational challenges for young kidney patients remain. This document is in keeping with current NHS reform in seeking to create a health service that is centred around the patient. We want to see a service that always thinks about what would be better for the patient, rather than what is easiest to organise or provide. We want to see an NHS where the services available to people are continually striving to better meet their needs, circumstances and individual preferences. Our aim is for a health service that listens and consults with patients and the public, and through doing this offers an improved service.

We have worked closely with members of the paediatric renal community and with the Renal Advisory Group in drawing together this document, which articulates the standards and quality requirements of paediatric renal services as clearly as possible, and makes the Renal and Children's NSFs accessible.



Rosie Winterton

Minister of State for Health Services

Note

Links are provided to many documents mentioned. Click on the underlined text to follow the link.

[The National Service Framework for Renal Services Part One: Dialysis and Transplantation](#)

[The National Service Framework for Renal Services Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care](#)

[The National Service Framework for Children, Young People and Maternity Services](#)

Standard 1, Promoting Health and Well-being, Identifying Needs and Intervening Early

Standard 2, Supporting Parenting

Standard 3, Child, Young Person and Family-centred Services

Standard 4, Growing Up into Adulthood

Standard 5, Safeguarding and Promoting the Welfare of Children and Young People

Standard 6, Children and Young People who are Ill

Standard 7, Children and Young People in Hospital

Standard 8, Disabled Children and Young People and those with Complex Health Needs

Standard 9, The Mental Health and Psychological Well-being of Children and Young People

Standard 10, Medicines for Children and Young People

Standard 11, Maternity Services

Chapter one: Setting the scene

Introduction

1. The outlook for children and young peopleⁱ with kidney disease is better now than ever, particularly as transplants and dialysis can offer good long-term results.
2. There are around 760 children and young people with kidney failure being cared for in 13 paediatric nephrology centres in the UK (compared with over 37,000 adults)¹ and many more with less advanced kidney disease. Kidney disease in children and young people:
 - can be difficult to diagnose as early kidney disease may present few symptoms
 - tends to have different causes from kidney disease in adults and
 - responds differently to the various treatments.

Additionally, children and young people

- have a unique need for play and/or education during their illness and its treatment
 - may have a lifetime of kidney disease and treatment ahead, making them vulnerable to long-term complications such as restricted growth, which can affect physical and psychosocial development
 - have to make the potentially difficult transition to adulthood and adult services.
3. This guide is a supplement to *The National Service Framework for Renal Services* (the Renal NSF).² The Renal NSF deals with services for renal patients of all ages: this document focuses specifically on services for children and young people, and describes in greater detail than the Renal NSF how the standards, quality requirements and markers of good practice apply to the care of children and young people with kidney disease and their families. It also takes into account the standards set out in *The National Service Framework for Children, Young People and Maternity Services* (the Children's NSF).³

ⁱ **Note:** Throughout this document, we have used the term 'parents' as shorthand to include mothers, fathers, carers and other adults with responsibility for caring for a child or young person including, for example, those with responsibilities for looked after children and young offenders.

4. It does not contain the same amount of background detail as the NSFs, nor are the notes and references repeated here. However references are provided to the NSF documents throughout, so that anyone needing further information can go directly to the relevant sections.
5. The first chapter of this guide describes the main types and stages of kidney disease, and its treatment and management. Chapter two focuses on how the recommendations of the Children's NSF can be applied to children and young people with kidney disease. Subsequent chapters follow the pattern of the Renal NSF, explaining the standards and quality requirements in detail and going on to explore how these can be achieved in paediatric services.

What is chronic kidney disease?

6. Chronic kidney disease (CKD) is a complex, long-term condition that has a range of possible causes and complications. It may progress quickly or slowly; it may involve damage to or abnormality in both kidneys (signs of which can be seen in the blood or in X-rays or scans) and/or a loss of kidney function.
7. The final stage of CKD is established renal failure (ERF) and is eventually fatal unless treated with renal replacement therapy (RRT) in the form of a kidney transplant or dialysis. ERF is discussed below.
8. The earlier CKD can be identified, the earlier measures can be taken to minimise the impact and progression of the disease, and to manage such complications as poor growth and development, anaemia and cardiovascular disease.
9. Early diagnosis and optimal management are particularly important for children and young people with CKD as they will have the condition for life and are therefore at risk of long-term complications such as hypertension and renal bone disease. However, early stage CKD produces few if any symptoms, and those it does produce are often non-specific, so it can go undetected for some time. The number of children and young people with CKD is not accurately known, partly for this reason.

What is established renal failure?

10. ERF is an irreversible condition for which RRT in the form of transplantation or regular dialysis is required if the individual is to survive. It is usually the final stage of CKD, or can occasionally be a result of acute renal failure (ARF) (see paragraph 23). It is relatively rare for children and young people to develop ERF.

11. Children and young people with ERF differ from adults in that many have congenital structural abnormalities of the urinary tract and these can be associated with relatively stable but low levels of kidney function (measured as a glomerular filtration rate (GFR)⁴), sometimes lasting for years. However, most of these children and young people will require RRT in order to prevent or minimise the complications of ERF, in particular the effects of poor appetite and renal bone disease on the growing skeleton.
12. When children or young people reach ERF they are likely to feel tired, nauseated, lose their appetite and be less able to cope with life physically and mentally. Clinical signs include fluid retention, pallor and raised blood pressure, and poor growth and development, accompanied by anaemia and measurable biochemical changes in the body. Providing RRT – perhaps in the form of a pre-emptive transplant – before symptoms appear, and while the patient still feels relatively well, is one treatment choice. Once ERF is reached, treatment will last for the rest of the child or young person's life, although they may use several different types of RRT over the years (the different types of RRT are described in the glossary to the Renal NSF documents⁵).
13. A small percentage of children are able to remain symptomless and in a stable condition for months or even years despite low GFR. This is most likely in children with structural renal abnormalities, who often continue to produce large volumes of urine. For this group, although a transplant is still the goal, dialysis may not be needed while they are waiting, as long as their growth rate remains acceptable.

Treating children and young people with established renal failure

14. The introduction of RRT, and transplants in particular, transforms the life prospects of most children and young people with ERF. However, those who start RRT in their youth will almost certainly need to use two or more different types of RRT during their lifetime, including a transplant. The rigours of RRT are considerable, whether in terms of the effects of powerful immunosuppressant medicines that are needed after a transplant to prevent the body from rejecting the kidney, or the time that is taken up by dialysis.
15. Children and young people on dialysis, and especially those on haemodialysis, may also need to change their diet and avoid such foods as chocolate, crisps, coffee and many kinds of fruit and dairy produce. They will have to limit their fluid intake too. Anyone on dialysis can be at risk of becoming malnourished and may need dietary supplements or artificial feeding.

16. Children and young people with ERF will often be prescribed a range of medicines including, for example, erythropoiesis stimulating agents (ESAs)ⁱⁱ and iron for anaemia, medicines to prevent renal bone disease and to reduce the risk of cardiovascular disease and, in some instances, human growth hormone.⁶ Restricted growth and delay in the onset of puberty are common in young people with late stage CKD and ERF, although an improvement is often seen after a kidney transplant. Other potential problems can include complications with the site of access for dialysis, particularly the vascular access required for haemodialysis. See Standard three for more information on dialysis access.

What causes chronic kidney disease and established renal failure in children and young people?

17. The conditions which cause CKD in children and young people vary at different stages of childhood. Occasionally a condition may correct itself as the kidney grows, but when CKD develops it usually results from one of the following:
- **Congenital abnormalities of the kidneys and/or urinary tract.** Abnormal development in the womb accounts for around 50% of cases of childhood CKD and can result in conditions such as dysplastic (very small and/or not fully developed) kidneys or obstructive uropathy (where outflow from the bladder is partially blocked). Boys are over three times more likely than girls to suffer from either of these conditions.⁷
 - **Urinary tract infections (UTIs).** In most cases UTIs, once treated, do not represent a risk factor for CKD. However, repeated UTIs can occur as the result of congenital abnormalities and/or in association with vesico-ureteric reflux (a condition in which urine can leak back up the ureter from the bladder), and carry an increased risk of scarring and damage that could lead to CKD. The National Institute for Health and Clinical Excellence (NICE) is developing guidance on the investigation and management of UTIs in young children.⁸
 - **Inherited kidney diseases and conditions.** This covers a range of conditions that develop in different ways in childhood. Some of them can lead to CKD. These include types of nephrotic syndrome (a collection of symptoms that can indicate damage to filters in the kidneys) and such cystic kidney conditions as autosomal recessive polycystic kidney disease (ARPKD) and autosomal dominant polycystic kidney disease (ADPKD, a more common disease with similar symptoms), although the latter often causes no problems until adulthood.⁹ While some conditions, like polycystic kidney disease, have a clearly recognisable pattern of inheritance, others, such as dysplastic kidneys, also run in families but in a less

ii Previously known as epoetin.

clearly defined way, so that the risk of inheritance for someone with a close family member who has the disease is usually given as a percentage.

- **Other diseases such as glomerulonephritis and vasculitis.** Glomerulonephritis (inflammation of the filters in the kidneys) and vasculitis (inflammation of the blood vessels) tend to be more common in teenagers. They are generally treatable and it is by no means inevitable that they will lead to CKD.
- **Acute renal failure (ARF).** Although often reversible, in some cases ARF can cause permanent damage to the kidneys. This is most likely with newborns who have needed treatment in intensive care and/or have had surgery, especially cardiac surgery. ARF is discussed at paragraph 23.

18. The main primary causes of ERF in children and young people in the UK reflect the causes of CKD listed above. The 2003 report of the UK Renal Registry of the Renal Association identifies the most common causes of ERF as:

- dysplastic kidneys (25.8% overall, with the number of new patients decreasing with time through childhood)
- glomerulonephritis (20.7% overall, rising over time, with most new patients beginning treatment in the first three years of life)
- obstructive uropathy (18.1% overall, with the number of new patients decreasing over time).

ERF can also occur after ARF, particularly if the child or young person already has early stage CKD.

19. Boys are more likely than girls, and children and young people of South Asian origin are more likely than the age-equivalent white population to develop ERF – the ratios are 1.53:1 boys to girls and 2.3:1 South Asian to white.¹⁰

Number of children and young people being treated for established renal failure

20. In April 2002 there were 760 children and young people (under 18 years) with ERF being cared for in the UK's 13 paediatric renal units.¹¹ The true number of children and young people with ERF is probably slightly higher than this as there may be some whose condition has yet to be diagnosed or who have not been referred for treatment, and others who are over 15 and have been referred directly to adult units.

21. Overall the number of children being treated for ERF appears to be growing, but not as fast as the adult population. The number of patients under 18 years of age increased from 570 in 1992¹² to 760 in 2002¹³ – an increase of 33%.

22. Of the 760 children and young people with ERF in 2002, 75% had a functioning transplant and the remainder were undergoing dialysis (two-thirds peritoneal dialysis and one-third haemodialysis), many while they waited for a transplant.¹⁴

Acute renal failure

23. ARF is a sudden decline in kidney function. Babies and infants develop ARF more often than older children, and premature babies are particularly vulnerable.
24. In babies with previously normal kidney function ARF is usually linked with congenital heart defects and/or surgery to correct them, severe bacterial infections or shortage of oxygen due to breathing problems. The resulting ARF is potentially reversible if circulation can be restored quickly enough. This is also true in many cases where ARF is caused by respiratory failure at birth.
25. Structural abnormalities of the urinary tract are another common cause of ARF in newborns. In these cases immediate urological treatment is needed in order to reverse the kidney failure.
26. In older children and young people, a distinct new disease process becomes increasingly likely as a cause of ARF. The most common of these diseases is haemolytic uraemic syndrome (HUS), a disease affecting the blood and circulatory system, with associated kidney damage.
27. Most children and young people with ARF do not go on to develop ERF, but for the minority who do the mortality rate varies with age and, crucially, with the cause of ARF (often the primary condition rather than the ARF is the cause of death). For example, the mortality rate for babies and infants who develop ARF after surgery for congenital heart defects is around 50%,¹⁵ whereas it is very much lower for ARF caused by HUS.

How many children and young people have acute renal failure?

28. ARF is certainly rare in children and young people, but relatively little is known about the numbers who develop it, partly because of varying definitions of the condition. For children overall, ARF is estimated to affect 7.5 to 8 per million of the population per year^{16, 17}, based on referrals to paediatric renal units, although the true figure will be somewhat higher as not all cases are referred to specialist services.

End of life care

29. The death of a child is a tragic but uncommon event in the developed world. It is also relatively rare for children to die of kidney disease. The dying child or young person

and their family require support throughout this period of care. The way in which death and the period leading up to death are managed can make a great difference to the experiences of both the child or young person and their family.

30. The approach set out in Standard one of the Renal NSF, that informed patients should be active partners in decisions about their care, with a care plan designed to optimise their quality of life, is equally important for children and young people with ERF approaching the end of their lives.
31. For the minority of children who die of kidney disease, mortality is generally highest in the youngest patients. Most of these deaths are associated with major disabilities, congenital abnormalities or syndromes whereby the infant suffers from a combination of health problems that include or contribute to ERF.
32. In children and young people of all ages with ERF there will be cases where the decision is made not to start dialysis or to discontinue it, either because dialysis is no longer viable or because it no longer improves the child or young person's quality of life or extends their life expectancy. Once such decisions have been made, provision of sensitive palliative care becomes paramount.¹⁸
33. While it is not always possible to plan end of life care, in most cases of children with ERF there will be some time for parents and families to prepare. Care plans for the end of life can specify where the child or young person wishes to be cared for (whether at home, in hospital or at a hospice), and cover the provision of palliative care, which may include culturally appropriate psychological, social and spiritual support, as well as support for the family after bereavement. Staff may also need support.

How services have been delivered

34. Because children and young people make up a very small minority of renal services users, and because they often have specific diseases, symptoms and care needs that differ from those of adult patients, paediatric renal care is generally delivered separately from adult services. This ensures that children and young people are treated by staff who have the relevant competencies.
35. The 'hub and spoke' model that was developed in the 1990s to allow adult renal units to deliver haemodialysis closer to patients' homes was not adopted by paediatric renal services because it was felt that haemodialysis in children and young people was best carried out at specialised paediatric renal centres. However, peritoneal dialysis has been encouraged and around 75% of children and young people who are on dialysis now choose this method as it allows them to dialyse away from the hospital environment.

36. Currently 8 of the 10 paediatric renal centres in England have transplant units.
37. Although children and young people with kidney disease tend to be referred for specialist care more frequently than adults (for example, any child or young person with suspected CKD is usually referred to a paediatric nephrologist for a firm diagnosis), clinical care networks have begun to evolve, and shared care has an important role to play in monitoring and managing less serious conditions, particularly in view of the long-distance travel that a visit to the nearest paediatric renal centre may entail.
38. The development of agreed guidelines outlining the responsibilities of primary and secondary care clinicians can facilitate shared care, and also ensure that patients get the medicines they need prescribed by the person who best meets their needs in a safe and effective way.¹⁹
39. A renal network can help prioritise the care of children in the Local Development Plan. For a general discussion of the best ways to build a renal health network see the Renal NSF Part one, 29–32.

Where kidney disease in children and young people is treated

40. Primary, secondary and tertiary care have complementary roles in the management of CKD in children and young people, and will be most effective if services are co-ordinated. For example, although diagnosis is usually made by a paediatric nephrologist, management of the disease in its early stages can often take place in primary care or at a local hospital. This can avoid unnecessary travel to specialist paediatric renal centres, reduce pressures on patient transport and strengthen the capacity for primary care staff to care for people in their own homes, whether in a rural or urban setting. Good links with secondary and tertiary care will ensure access to specialist treatment as needed.
41. Children and young people with ARF are usually treated in secondary or tertiary care. Services for these patients are provided in different ways depending on the hospital setting. For example, in children's hospitals they are provided by renal services, critical care services or both. In other cases, an effective clinical network with access to remote specialist advice when needed is the appropriate approach. Children and young people will usually be treated in a paediatric intensive care unit (PICU); babies in a neonatal intensive care unit (NICU). General information on providing care for critically ill children and those in PICUs can be found at Children's NSF Standard 7, 4.45–48. ARF in babies is usually managed without RRT, but if dialysis is required the baby may need to be transferred to the paediatric renal service. Transfer to tertiary services is discussed at Children's NSF Standard 7, 4.40.

42. Many children and young people with ERF have other medical or developmental difficulties and some have had previous transplants of other organs. The majority of patients have had disease from early childhood, which makes them prone to related psychosocial problems. In addition, considerable numbers of children and young people with chronic kidney problems (including ERF) are now surviving into adulthood. Statistics show that the transition to adult services can be problematic for these patients.²⁰ These issues underline the need for holistic care that can go beyond the provision of clinical therapy in order to meet more complex needs.
43. The care of children and young people at the end of their lives may involve tertiary, secondary, hospice and primary care services, especially for those who wish to die at home.

Chapter two: Kidney disease and the National Service Framework for Children, Young People and Maternity Services

44. *The National Service Framework for Children, Young People and Maternity Services* (the Children's NSF) is a wide-ranging document that covers all aspects of care for children and young people. It does not specifically address the needs of children and young people with kidney disease, but many of its recommendations are relevant for this group. In this chapter we focus on those aspects of care that are covered by the Children's NSF, highlighting the key recommendations as they apply to children and young people with kidney disease. This chapter is closely related to Standard one – a patient-centred service (see paragraph 68).

Involving children and young people and their parents in care

45. The aim is to develop a respectful partnership between healthcare professionals, the child or young person and their parents.ⁱ Such a partnership will recognise that parents:
- are usually the experts on their children
 - may have other children to care for too
 - may have to take time off work and could lose pay for repeated hospital visits – their time is valuable
 - may have their own health or other problems to deal with which can affect their role in caring for their child
 - may be suffering financial hardship if, for example, their child is in hospital a long way from home.²¹
46. Family involvement in care is important for patients' well-being and progress, and in many situations, particularly when a child is undergoing dialysis at home, parents may perform the vast majority of care-giving, including tasks that are complex and demanding.²²

i In very rare cases there may be a potential conflict between the interests of the child or young person and those of their parents. This is usually a matter of child protection. In such cases health and social care professionals have a duty to follow statutory government guidance whereby the interests of the child or young person are paramount. (See the Children's NSF Standard 7, 3.12.)

47. If children and young people and their parents are to be at the centre of care and involved in decision-making, they need information about the nature of the condition, its likely progress, the treatment options available and their possible side effects, and the safe and appropriate use of medicines. Information is one of the services most valued by parents – and most often requested.
48. Best practice suggests that structured education programmes work best, supported by written information in suitable formats, tailored to the age, cultural background, literacy levels and so on of the child and their parents. For younger children a play therapist, psychologist or social worker may be able to explain certain procedures.²³
49. Parents from minority ethnic groups may require information to be available in a variety of formats and languages.²⁴
50. Because kidney disease is often a life-long condition, children and young people and their parents have the chance to become informed and involved in care planning and treatment over time, and to develop expert knowledge of the medical condition in question and how best to manage it. This approach and its benefits for patients are explained in *The Expert Patient*.^{25,26}

Support for parents and families

51. Caring for a child or young person with late stage CKD or ERF can place immense strain (emotional, psychological, physical and/or financial) on parents, which can impact on the health and well-being of the family as whole.²⁷
52. The kinds of support that can help families to cope go beyond those generic services offered by the multidisciplinary renal team and can include:
 - specialised support for psychological or emotional difficulties (provided by a mental health professional or social worker)
 - spiritual support (provided by a religious leader or the chaplaincy service)
 - peer support (provided through contact with families in similar circumstances)
 - information on the financial support available (eg to help with travel costs)
 - help with childcare for siblings of the child or young person who is ill
 - help with transport and travel arrangements (through hospital transport schemes)
 - information on support groups and voluntary organisations
 - material support in the form of specialist equipment to help with caring for the child or young person at home.²⁸

53. The Children's NSF suggests services that can make a real difference to the families of children and young people with kidney disease:
- *when a child or young person is in hospital:* facilities for parents and siblings, including provision for them to stay overnight if necessary²⁹
 - *when a child or young person is being looked after at home:* timely assessment, provision and maintenance of equipment. Parents also need training and written information on the use, supply and maintenance of equipment, including emergency and out-of-hours contact details as appropriate.³⁰ Also information about the safe use of medicines in the home, safe disposal, and easy access to medicines especially during the out-of-hours period³¹
 - *transport:* hospital transport services may be able to help and some families may be eligible for assistance with fares. Dedicated parking spaces for dialysis users can also be helpful. Shared care arrangements can play a key role in ensuring that care is delivered locally wherever possible³²
 - *short-term breaks from caring:* including overnight breaks, day care, sitting and overnight sitting, and for haemodialysis patients, care in a unit away from home for holidays. Planning, funding and commissioning such breaks is dependent on close co-operation between health and social services and the voluntary sector^{33,34}
 - *direct payments:* in some cases, where the child or young person is disabled or has complex health needs, the parents may be entitled to payments under the Carers and Disabled Children Act 2000.³⁵

Education and play

54. Children have a basic need for play, even when they are ill. It has been recommended that children in hospital receive daily visits from a play therapist and that play interventions are offered throughout the care pathway. Play can be a particularly effective way to explain complex procedures to young children and to help them cope with feelings of anxiety. The play specialist is a core member of the care team.^{36,37}
55. Children and young people who are hospitalised with long-term conditions such as late stage CKD or who spend a lot of time in hospital (eg those undergoing haemodialysis) can miss a great deal of schooling. In these circumstances good practice suggests that hospital staff need to liaise with the school at an early stage.³⁸
56. The provision of teaching for children in hospital varies, and teachers are appointed by the local authority. Ideally a regular teacher will be in contact not just with the child but also the parents and renal care team. The Department for Education and Skills has produced a set of guidelines on the education of sick children in hospital.³⁹

Transition to adulthood and adult renal services

57. For young people with CKD the journey from childhood to adulthood involves coming to terms with their condition and beginning to take responsibility for their own care as well as coping with all the usual physical, emotional and social challenges of adolescence. Particular challenges for these young people may include:
- *physical maturity.* Children and young people with kidney disease may have restricted growth, which can make them smaller than their healthy peers and can delay the onset of puberty. In addition, body changes at adolescence mean that medicines need to be monitored particularly carefully at this time. Young men and women may also have sexual and fertility problems as a result of their kidney disease (these are often treatable)
 - *emotional maturity.* These young people may have had fewer life experiences than their healthy peers. Because their parents are often main caregivers they may have had less chance to separate emotionally
 - *education.* The effects of an education disrupted by periods of illness can be highlighted during adolescence because of the exam system and decisions about a career
 - *mental health.* Coming to terms with a life-limiting condition can be a profoundly difficult experience for a young person. Chronic illness can be a risk factor for mental health problems, and there is a strong link between physical health, mental health and good social functioning⁴⁰
 - *medical concordance.* Non-concordance (not following prescribed treatments) can be a problem, especially during adolescence. This can have particularly serious consequences after a transplant and is recognised as a significant cause of transplant failure.⁴¹ It is important for young people to be involved in decisions about the medicines prescribed for them; to understand the risks and benefits of treatment; to have medicines which fit in with their daily activities and, as they grow and develop, to take on responsibility for taking their medicines wherever possible.⁴²
58. Standard 4 of the Children's NSF states that 'All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood'. The services of a youth worker and psychologist, for example, may be particularly helpful at this time.

59. More detailed recommendations regarding transition to adult services can be found as part of Standard one at paragraph 76. In addition a good practice guide, *Transition: getting it right for young people*, has recently been published by the Department of Health and the Department for Education and Skills. It examines these issues in more detail, in the context of published evidence and current best practice, and considers how a planned and managed transition to adult services can be achieved. A DVD is also available in which five young people with long-term health conditions tell of their experience of transition and have their say about what is needed from the health services.ⁱ

Medicines for children and young people

60. Medicines are by far the most common form of medical intervention. To ensure that children and young people with kidney disease get the greatest benefit from their medicines, consideration needs to be given to their safe and appropriate use. Standard 10 of the Children's NSF is dedicated to medicines for children and young people.
61. The use of unlicensed and 'off-label' medicines for children is particularly complex and constitutes an important information need for children and young people and their parents.
62. The Children's NSF notes that in ideal circumstances, children and young people have access to licensed medicines that are appropriately evaluated for use in children. However, there is a lack of licensed formulations for children and young people. This means that in practice some of the most effective medicines for children and young people are either:
- licensed adult formulations which are used in different doses or for different conditions when prescribed for children ('off-label' use) or
 - customised formulations specially prepared in the pharmacy (unlicensed medicines).⁴³
63. This can lead to confusion for children and young people and their parents. Particular care is needed when explaining the use of such medicines⁴⁴ and when a child or young person taking an unusual or unlicensed medicine is discharged from hospital. Effective communication between the paediatric renal team (and particularly the specialist pharmacist) and the GP and/or community pharmacist can help prevent problems in obtaining the medicine after discharge.⁴⁵

i *Transition: getting it right for young people* is published at www.dh.gov.uk. The DVD can be ordered by emailing MB-Childrens-Health@dh.gsi.gov.uk.

64. This situation is being addressed by European legislation (the Regulation on medicines for paediatric use) that should result in:
- more medicines being licensed for use for children
 - new information for prescribers regarding contraindications, special precautions for use and monitoring
 - more information for children, young people and their parents.
65. The legislation is expected in 2006. Meanwhile a modernisation programme is under way to ensure that NHS pharmacy services are able to produce customised medicines as needed where appropriate licensed medicines are not available.⁴⁶

Conclusion

66. Diagnosis of CKD in a child or young person can be devastating for the whole family, and requires extensive communication and support to minimise anxiety and uncertainty. The multidisciplinary renal care team will usually become the focus for the family to seek specialist support, advice and guidance, not just in relation to medical care, but also regarding emotional, social and educational issues touched on in this chapter.
67. The challenge for the paediatric renal team is how to meet these needs as part of an integrated, co-ordinated model of service provision within a complex network that includes:
- primary, secondary and tertiary healthcare systems
 - local and specialist social work systems
 - mainstream and hospital-based education systems
 - voluntary agencies.
68. The precise circumstances will differ by hospital (size, funding and staffing levels) and indeed by individual case, as every family will have both different needs and different degrees of need. The challenges for the team, however, will remain largely the same.

Chapter three: The standards and quality requirements of the National Service Framework for Renal Services

Standard one: A patient-centred service

Aim

To optimise the role that people with kidney disease can take in the management of their care.

Standard

All children, young people and adults with chronic kidney disease are to have access to information that enables them to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life.

Rationale

69. This standard applies across the entire Renal NSF and underpins each of the other standards and quality requirements. For children and young people a patient-centred service will by definition also be a family friendly service which supports and involves parents.
70. Information may need to be presented in different ways and formats and at different levels according to patient age and understanding. Parents too will have specific information needs.
71. Many of the issues affecting children and young people with kidney disease go beyond the scope of clinical care, but this does not mean they are necessarily beyond the scope of the care plan or of the multidisciplinary paediatric renal care team.

The care plan

72. The individual care plan can be drawn up after diagnosis, with the involvement of the child or young person and their parents. An agreed care plan can foster a partnership between clinicians, patients and parents, clarifying what each will do to reach agreed goals. For children and young people with other conditions, it can ensure their care is integrated. The plan will usually identify a number of health and social care needs and specify who is responsible for meeting each of them. It may include:

- help with psychosocial issues at various stages, perhaps provided by a social worker, play therapist, psychologist or teacher
 - special arrangements to encourage education to continue with minimum disruption
 - extra support to make the transition to adulthood and adult services
 - the chance to play, even when ill; and social interaction for older children and young people.⁴⁷
73. The need to agree clear lines of communication is closely related to the care plan and can usefully be written into it. It is helpful for the family to have a named contact within the multidisciplinary care team for the child or young person at each stage of the care pathway. Their role is to act as a first point of contact, help the family find their way around the care system and ensure an up-to-date care plan is in place, arranging for it to be reviewed as necessary.⁴⁸
74. An effective care plan will be easy to understand and reviewed regularly and/or when the condition or treatment changes significantly.⁴⁹
75. *National Standards for the Provision of Children's Advocacy Services* were published by the Department of Health in November 2002.⁵⁰ These help to ensure that children and young people using the NHS will receive the help and advice they need, and have their voices heard.

Transition to adult services

76. Helping the young person to take increasing responsibility for their life and for managing their condition is key to a successful transition to adulthood. This can happen step by step; for example:
- a move from parent-held to patient-held records
 - copying-in the young person on clinical correspondence, or writing to them rather than their parents
 - enabling the young person to attend appointments alone
 - involving the young person in decisions about their prescribed medicines, and encouraging them to be responsible for taking them.⁵¹
77. It is also important to agree a plan with the young person and their parents (as part of the existing care plan) that covers the transition from paediatric to adult renal services at an appropriate time between their 16th and 19th birthdays.

78. The Children’s NSF (at Standard 4, 6.10 and Standard 7, 4.62) sets out the key elements of a such a transition process:
- young people are transferred when the supports are in place to ensure a good level of care in adult renal services
 - a written policy on transition to adult units is in place in each paediatric renal unit, and it is the responsibility of a named person
 - where appropriate, GPs are involved as part of their shared care role, as are other relevant local services.
79. Children and young people may need support through other transitions, such as moving to a new area or starting to live at two homes because of family break-up. Any such transition can be made easier if it is planned for by and with the care team. For more guidance see the Children’s NSF Standard 6, 10.10.

Markers of good practice

- Provision of high quality, culturally appropriate and comprehensive information and education programmes. (Level 1)ⁱ
- Education programmes tailored to the needs of the individual. (Level 2)
- Individual care plans, regularly audited, evaluated and reviewed. (Level 4)
- Access to a multi-skilled renal team whose members have the appropriate training, experience and skills. (Level 3)

For children and young people

- For children and young people, meeting the standards of *Getting the right start: National Service Framework for Children, Young People and Maternity Services*.

i For an explanation of the levels of evidence, please see paragraph 175.

Standard two: Preparation and choice

Aim

To provide co-ordinated care to patients approaching established renal failure which is responsive to their individual needs and personal preferences, delivered by staff with an appropriate range of skills.

Standard

All children, young people and adults approaching established renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised.

Rationale

80. In most children and young people, as with most adults, CKD progresses relatively slowly. In general, assuming the child or young person and their family are educated about likely long-term outcomes soon after diagnosis, there should be plenty of time to discuss and explore the various types of RRT available and to plan for starting the most appropriate one. It was noted in the Renal NSF, Standard two, that the optimal time required to prepare for RRT is generally around a year, although there will always be cases in which this is not possible (see paragraph 91). For children and young people, however, timely preparation is especially important to maximise the possibility of a pre-emptive transplant: many living donors are family members, and time is needed to allow consideration of the possible risks and benefits of donation (see Standard five).
81. A key part of care planning for the paediatric renal team involves predicting when RRT will be needed, preparing the child or young person both medically and psychologically, and minimising their complications in the meantime. Children's physiology differs from that of adults and it is vital that any treatment for children and young people is tailored to their changing needs with regard to age, size, development and/or weight.
82. Restricted growth is a common result of late stage CKD in children and young people. This is usually due to a combination of the following:
- inadequate energy intake and/or nutritional deficiencies. This is usually the main cause of restricted growth. It is associated with ERF and usually begins in the pre-RRT period

- metabolic acidosis. This is a side effect of kidney failure in which the acidity of the blood increases. It can lead to weakened bones and is a contributing factor in renal bone disease
 - renal bone disease. This can progress more rapidly in the approach to renal failure and can cause particular difficulties for children and young people. Careful control of phosphate and calcium levels is needed to prevent hormonal imbalances which can, in some cases, necessitate removal of the parathyroid gland. These symptoms are also related to an increased risk of cardiovascular disease in later life
 - anaemia. NICE is developing a clinical practice guideline on anaemia management in CKD, which is due to be published in the autumn of 2006.⁵² This will include recommendations on the haemoglobin levels at which treatment should be considered, and target levels, for children as well as adults.
83. The paediatric dietician plays a key role as part of the multidisciplinary care team in ensuring the child or young person's changing nutritional needs are met. This is particularly important for patients who will be going on to dialysis. The aim is to optimise growth and development while maintaining general health and preventing or relieving other symptoms.
84. Some treatments may have begun at an earlier stage, and some may continue throughout the patient's life. In children and young people approaching ERF they are likely to include:
- correction of anaemia (see above)
 - management of blood pressure. Blood pressure increases throughout childhood. Target levels for children and young people are given in *Treatment of Adults and Children with Renal Failure, standards and audit measures, 3rd edition*⁵³
 - childhood and other vaccinations. Children and young people with ERF, in addition to the standard childhood vaccinations, will need to be vaccinated against chicken pox and measles if they are not immune, have a BCG vaccination, flu vaccinations as appropriate, and also be vaccinated against hepatitis B if they are susceptible⁵⁴
 - management of medicines, throughout all stages of ERF. The involvement of a paediatric pharmacist, where appropriate, could help with many aspects of the safe use of medicines. For more information see *Management of Medicines: A resource document for aspects specific to the renal NSF*.⁵⁵
85. During this period the child or young person and their parents can become involved in choosing a particular form of RRT – namely, a transplant (often the preferred choice),

peritoneal dialysis, or haemodialysis. Clinical considerations may limit their options (for example peritoneal dialysis may be inappropriate because of extensive abdominal surgery) but beyond this, informed choice will be based on an understanding of what each option involves and a clear explanation of the risks and benefits of each form of RRT. Together, the child or young person and their parents and their clinicians will assess the patient's clinical, psychological and social suitability for the preferred option.

86. A child or young person with ERF will have years of RRT ahead of them and is likely to use more than one type of RRT in their lifetime.

Transplantation

87. Transplantation can be the preferred choice and this is discussed in more detail in Standard five. Children and young people for whom transplantation is an option will need to be placed on the transplant list as soon as possible.⁵⁶ Additionally, suitable children and young people close to ERF may benefit from a 'pre-emptive' transplant, that is, a transplant that takes place before dialysis is started. (Around 22% of the transplants performed on children and young people in the UK are pre-emptive.⁵⁷) The guideline published by UK Transplant, which is part of NHS Blood and Transplant, is that people should be eligible for the national transplant list if dialysis is predicted to start within six months.

Dialysis

88. A key factor in choosing a form of dialysis will be how well it is suited to the patient's current home and family circumstances. Dialysis options are outlined in detail in Standard four. For peritoneal dialysis a member of the renal team will need to visit the home to assess its suitability; and the parents will need training, appropriate written guidance, and a contact number in case of problems.
89. Some children and young people do not show the symptoms of ERF even when their GFR indicates a need for dialysis. These children can retain stable GFR even at low levels for many years. As long as growth rates remain acceptable, these patients may not need dialysis while waiting for a transplant.
90. Preparation for either type of RRT will necessarily involve psychosocial support. All members of the multidisciplinary care team can contribute in this area, but key roles will generally fall to the social worker, psychologist and/or play therapist,⁵⁸ according to need and local circumstances. Support for children and young people in hospital and their families is discussed in Chapter two. (The Children's NSF Standard 7, for Hospital Services, covers in detail the following aspects of care: personal and material support at paragraph 3.4; provision for play at paragraphs 3.7 to 3.8; education at paragraph 3.9.)

91. For those children and young people who begin dialysis as an emergency, their first treatment will almost always be haemodialysis via an intravenous catheter (a thin tube inserted into a vein), although once their condition stabilises it will be possible to discuss with the patient and their parents which of the appropriate treatment options they would prefer.
92. Some babies are born with abnormal kidneys and/or develop ERF within a few months of birth. ERF can also, although rarely, be a result of ARE, which can occur for various reasons throughout childhood (see paragraph 23 and Quality Requirement three). The families of these children will benefit from tailored support and education to compensate for the lack of time to prepare for RRT in the normal way.

Markers of good practice

- Referral to a multi-skilled renal team, where possible at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation. This principle should also be followed for people with a failing transplant. (Level 4)
- Accelerated process with intensive input from the renal team for those who present late to renal units or as acute uraemic emergencies. (Level 4)
- People with ERF given information about all forms of treatment so that an informed choice can be made. (Level 4)
- Patients put on the national transplant list within six months of their anticipated dialysis start date if clinically appropriate. (Level 4)
- Anaemia treated to maintain an adequate haemoglobin level.ⁱ (Level 1)
- Management of cardiovascular risk factors and diabetes according to the National Service Frameworks for Coronary Heart Disease and for Diabetes.⁵⁹

i Levels of haemoglobin to be achieved may change in the light of future guidance from NICE. The clinical standard currently recommended by the Renal Association for children is age related, ranging from 9.5 g/dl to >10.5 g/dl.

Standard three: Elective dialysis access surgery

Aim

To improve the outcomes of permanent vascular or peritoneal dialysis access surgery, minimise complications and maximise the longevity of the access.

Standard

All children, young people and adults with established renal failure are to have timely and appropriate surgery for permanent vascular or peritoneal dialysis access, which is monitored and maintained to achieve its maximum longevity.

Rationale

93. 'Access' in the context of dialysis generally refers either to the catheter passing into the abdomen used for the exchange of fluids (for peritoneal dialysis) or to the intravascular catheter, or the place on the body where needles are inserted on a regular basis (for haemodialysis). For children and young people a vital consideration is to avoid damaging veins which may be needed for access in later life.
94. It is important that:
 - whenever possible, patients have early assessment and investigations to agree the best form of access for their chosen treatment method
 - the form of access agreed in the care plan is established early enough to have matured before the start of dialysis
 - the access site is monitored regularly.
95. For best outcomes, all patients likely to need dialysis should be assessed regarding surgical access whenever possible a minimum of six months before their anticipated start date, so that a timely operation can ensure a useable permanent peritoneal or vascular access is in place when dialysis commences.
96. All the procedures discussed in this section require general rather than local anaesthesia when undertaken on children and young people, and appropriate pain management.
97. The two main types of dialysis are summarised below. Peritoneal dialysis is usually preferred for children and young people, partly because it avoids some of the main problems associated with access surgery. More detailed descriptions of the two types of dialysis focusing on the issues of access can be found at the Renal NSF Part one, 74.

- *Peritoneal dialysis.* For peritoneal dialysis a catheter is surgically inserted into the abdomen. Four weeks will be needed to allow the site to heal before use. Children and young people and their parents can play a role in deciding on the best position for the catheter in relation to lifestyle and/or cosmetic factors.
 - *Haemodialysis.* Haemodialysis requires access to the blood vessels, for which surgery is needed. An arteriovenous fistula (AVF), an artificial channel formed by connecting a vein and an artery, provides the best long-term access. An AVF can take two months to form and time is needed to allow for the procedure to be repeated if the first attempt fails. A ‘graft’, where a synthetic tube is connected to blood vessels, can also be used. In emergency dialysis, for those for whom a transplant is imminent and for small children who could not tolerate needling of a fistula, an intravenous catheter can be inserted into a deep vein, usually in the neck.
98. Dialysis access is complex and challenging in children, particularly those under 8 years of age and under 20 kg weight. AVF creation may not be possible in view of the small size of vessels, and needling of fistulae may be impossible due to lack of co-operation from young children. Most children will therefore undergo peritoneal dialysis or haemodialysis through tunnelled central venous catheters rather than AVFs while awaiting renal transplantation. However, for older children and young people and for those on long-term dialysis an AVF has the same benefits as for adults.⁶⁰
99. For the reasons cited above, access procedures in children are more time-consuming than those in adults.

Care of dialysis access

100. The child or young person and their family will need to be taught how best to take care of their dialysis access.
101. In addition, regular monitoring by appropriately trained staff can pick up early such problems as infection, blockage (thrombosis) or narrowing (stenosis), allowing prompt medical, surgical or radiological intervention to keep the dialysis functioning longer. Delay in dealing with complications can lead to premature loss of the access.

Markers of good practice

- Early referral for assessment and investigation for the best means of access, and timely surgery (current best practice being six months before haemodialysis, four weeks before peritoneal dialysis) which enables patients to begin dialysis with their vascular or peritoneal dialysis access established and functioning. (Level 2)
- Monitoring and early intervention to minimise complications of the access. (Level 2)
- Recording and regular auditing of the type of access in use at the start of dialysis, time from referral to surgery, and complication rates for each procedure. (Level 4) Temporary access replaced by permanent access as early as possible. (Level 2)
- Proper training for patients, carers and members of the renal team in the care of the access. (Level 4)

For children and young people

- Dialysis access surgery to follow the principles set out in *Getting the right start: the NSF for Children, Young People and Maternity Services – Standard for Hospital Services*.

Standard four: Dialysis

Aim

To improve the outcomes for children, young people and adults on dialysis and maximise their rehabilitation, quality of life and survival.

Standard

Renal services are to ensure the delivery of high-quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.

Rationale

102. Most children and young people with ERF can expect to receive different types of RRT during their lifetime – probably one or both forms of dialysis and at least one transplant. The different treatments are ideally viewed as complementary; lifelong RRT is best managed by taking an integrated approach to transplantation and dialysis.
103. Approximately 25% of children on RRT in the UK are receiving dialysis. Two-thirds of these are on peritoneal dialysis, one third on haemodialysis. Within these figures there are variations by ethnic group, with Asian patients being more than three times and black patients more than four times more likely than white patients to be on haemodialysis. The reasons for this are likely to include practical medical considerations.⁶¹
104. The main types of peritoneal dialysis used for children and young people are continuous ambulatory peritoneal dialysis (CAPD) and automated peritoneal dialysis (APD). Because CAPD requires no fixed machinery the patient is able to move around and can to a certain extent continue their usual activities. CAPD can take place at school, for example. APD takes place at home overnight, as several fluid exchanges can be made while the patient sleeps. APD leaves the day completely free for work, school or other activities and is generally the preferred peritoneal dialysis method for children and young people.
105. All dialysis patients need ongoing management of underlying disease and the potential risk factors and complications as outlined in Standard two. Key elements of high-quality care provided in renal units can be audited against the clinical standards provided by the Renal Association.⁶²

Which type of dialysis is best for children and young people?

- 106.** As a general rule, children and young people's interests are best served by spending the minimum amount of time in hospital. This makes peritoneal dialysis the preferred choice for many families as it is carried out at home and therefore allows greater freedom and fewer hospital visits.
- 107.** Haemodialysis is rarely suitable for carrying out at home; life-threatening fluid imbalances and metabolic abnormalities can develop rapidly. Instead, children and young people on haemodialysis are dialysed three times a week at one of the 10 specialist paediatric renal centres.
- 108.** Caring for a child or young person having dialysis can put a great strain on the family. The amount of time taken up by dealing with diet, medicines and so on, in addition to carrying out home dialysis every night or travelling to a specialist unit three times a week, can be considerable and involves both financial and psychosocial costs. Support for parents and families is covered in Standard one.
- 109.** Good practice suggests that a child or young person being dialysed and their family will benefit from a clear care pathway from their local GP and paediatric centre to their dialysis centre. This will help to ensure that, wherever possible, conditions not related to their renal failure can be managed locally.
- 110.** When a child receiving dialysis is admitted to hospital for another condition they will need access to specialist renal staff, equipment and care throughout their stay.

Haemodialysis in a unit

- 111.** Haemodialysis for children and young people generally takes place at specialist paediatric dialysis units. There are sound clinical reasons for this, but the distances involved mean that transport is of absolutely key importance to the experience of these patients and their families. Effective hospital transport services, dedicated parking spaces for dialysis units and the availability of help with fares for families on low incomes can all play a part in reducing the stress of travel, thereby increasing patient attendance and improving quality of life for the whole family.
- 112.** The environment in which children and young people dialyse is also important. Patient experience is improved in a child-friendly unit, with suitable toys, books, videos, and so on, and possibly a visiting play therapist. Facilities for the parent or carer accompanying the patient are also important.

113. Since normal school attendance is not possible for children and young people on haemodialysis there will need to be provision for a teacher, but this will depend on arrangements in place locally. Education is covered more fully in Standard one.
114. For a variety of reasons – education, holidays, family visits – it is important that patients can dialyse away from home.⁶³

Markers of good practice

- All dialysis methods available interchangeably for patients, including home haemodialysis and automated peritoneal dialysis. (Level 4)
- Patients receive an adequate and effective dialysis dose. (Level 2)
- Peritonitis rates to be less than one per 18 patient months for adults undergoing peritoneal dialysis, one per 14 patient months for children. (Level 1)
- Patients have their nutritional status monitored and appropriate nutritional support in place. (Level 4)
- Efficient patient transport services available. (Level 3)
- Specialist renal staff, equipment and care available throughout admission, whatever the setting, for patients with established renal failure admitted to hospital. (Level 3)

Standard five: Transplantation

Aim

To optimise access to and the outcome of a renal transplant for all those who could benefit.

Standard

All children, young people and adults likely to benefit from a kidney transplant are to receive a high-quality service which supports them in managing their transplant and enables them to achieve the best possible quality of life.

Rationale

115. Transplantation is the best form of RRT for the vast majority of children and young people, and they are given priority when a suitable kidney becomes available. All appropriate children and young people with ERF should therefore be on the transplant list.
116. The earlier in ERF a transplant is carried out the better, generally, the outcome: this includes 'pre-emptive transplants',⁶⁴ which are now widely used in paediatric transplant units.
117. Transplantation, like dialysis, is more problematic for very young and/or very small patients, who have a higher risk of graft loss. This group in particular may benefit from transplantation with an organ from a living kidney donorⁱ (usually a relative); these have a better long-term survival rate than those from people who have died.⁶⁵
118. Over 100 transplants were performed on children and young people in England between April 2004 and April 2005.⁶⁶ Certain minority ethnic groups (particularly the African Caribbean and South Asian communities) are less likely than average to have a kidney transplant. In many cases their blood and/or tissue types are uncommon in the population as a whole so the majority of donor organs may be unsuitable for them.⁶⁷ However the number of people from these communities joining the NHS Organ Donor Register is rising, by more than 70% in 2003/04; and recent changes in the criteria for organ allocation are likely to lead to a reduction in waiting times for these patients.

i Guidance on reimbursement of living donors' expenses is published on the Department of Health website at www.dh.gov.uk/renal.

119. As children and young people may well need more than one transplant in their lifetime, it is particularly important to avoid sensitisation by exposure to a less well-matched organ, or a blood transfusion, as this can make rejection of a later transplant more likely. However, it is important to strike a balance between the urgency of need for a transplant and the likelihood of a good match becoming available.⁶⁸ UK Transplant produces a ‘matchability score’ for each paediatric recipient which can be helpful in this situation.
120. Of the 10 paediatric nephrology units in England, 8 undertake renal transplants. Children of 15 and under receive transplants only at these units. Some young people of 16 to 18 may also benefit from receiving their transplants at these units, particularly as they may be small or underdeveloped for their age, and in view of the increased likelihood of non-concordance with treatment regimes in adolescence. (See paragraph 57 and Standard one for more on the transition to adulthood and adult services.)
121. Once a kidney becomes available there are three key stages in the pathway to transplantation:
- psychological and physical preparation
 - pre- and post-operative care
 - long-term follow-up.

Psychological and physical preparation

122. Young children in particular may not be able to take in all the complex information about the transplant process. They will need particular support from the transplant team and as much information as they can absorb in a form they can understand. Children’s renal nurses, play therapists or psychologists may be helpful in preparing these children, possibly with input from social workers and others.

Pre- and post-operative care

123. Guidelines for pre- and post-operative care for children and pain management are laid down in the Children’s NSF Standard 7, 4.31–4.33.
124. After the transplant, medicines are prescribed to suppress the body’s immune system in order to reduce the risk of rejection of the donated kidney and to treat rejection episodes if they occur. NICE is developing guidance on immunosuppressive therapy for renal transplantation in children and adolescents.⁶⁹

125. As immunosuppressive therapy plays a vital role children, young people and their parents or carers need accessible verbal and written information about the medicines, why they are necessary, how to use them safely and how to cope with potential side effects. Particular support may be needed during adolescence – a time that carries increased risk of non-concordance with medication regimes – including information about the risks of not taking anti-rejection therapy as prescribed. (See Chapter two and Standard one for more on the transition to adulthood, on medicines and on information needs generally.)
126. The immunosuppressive medicines need to be carefully monitored, particularly at times of rapid growth and development (a period of catch-up growth often follows a successful transplant), such as puberty, at other periods of change (eg move to a new school and/or home, family break-up) and in the transition to adulthood.

Long-term follow-up

127. Long-term follow-up is always needed after a transplant. Although the risks of rejection lessen over time, the recipient will need to be monitored throughout the life of the transplant to see how well it is functioning and to check for any complications, infection or side effects of the immunosuppressive therapy. Children and young people and their parents or carers will want to know how the transplanted kidney is doing and to understand the role of tests and treatments.
128. Ongoing nutritional advice and monitoring is important, particularly to check calcium levels during catch-up growth and puberty, and during any periods of steroid therapy. Supplements may be needed for some time after a transplant. Children or young people receiving tube feeding after a transplant will benefit from having the feed individually tailored to promote growth.
129. Children and young people with renal transplants who are admitted to hospital, whatever the setting, will need access to appropriate specialist advice from the paediatric transplant team.

Markers of good practice

- Early provision of culturally appropriate information; discussion with and counselling of patients, relatives and carers about the risks and benefits of transplantation. (Level 3)
- Application of a national matching scheme using criteria agreed through UK Transplant to optimise blood group and tissue matching for kidneys from deceased donors. (Level 2)
- Effective preventive therapy to control infections. (Level 1)
- Timely operating theatre availability to ensure optimal cold ischemia times. (Level 4)
- Appropriate immunosuppression and anti-rejection treatment in accordance with forthcoming NICE guidance and effective monitoring and treatment to minimise the risks of adverse effects of immunosuppressive treatment. (Level 1)
- Clear explanation for patients of tests, procedures and results (Level 3) and especially information and education about anti-rejection therapy. (Level 1)
- Specialist advice from the transplant team available for patients with a renal transplant admitted to hospital, whatever the setting. (Level 4)
- Organ procurement and transplantation to follow the principles set out in *Saving Lives, Valuing Donors: A Transplant Framework for England*.⁷⁰

Quality requirement one: Prevention and early detection of chronic kidney disease

Aim

To reduce the number of people in the population who develop chronic kidney disease.

Quality requirement

People at increased risk of developing or having undiagnosed chronic kidney disease, especially people with diabetes or hypertension, are identified, assessed and their condition managed to preserve their kidney function.

Rationale

- 130.** Congenital defects are the major cause of CKD in children and young people. The proportion of children diagnosed before birth with CKD or ERF due to inherited conditions and/or congenital defects is increasing because of improvements in antenatal scanning and foetal medicine. However, not every disease or malformation will be apparent at the time of the scan or may not appear clearly enough for a diagnosis to be made. Generally ultrasound scans are carried out at 12–14 weeks and again at 18–20 weeks, although this varies by region. If a potential problem is picked up a later scan is advisable. Where a potential problem is detected parents will generally want to know as much as possible about the pathology of the problem and the genetic implications, so they can be involved in decision-making and care-planning for this pregnancy and, if appropriate, for any future children who could be similarly affected.⁷¹
- 131.** There is clearly a value in tracking the progress of babies who showed abnormalities in antenatal scans. Making up patient records immediately following diagnosis (ie before birth) could be helpful in this, as could using the child's NHS number for follow-up. Electronic records should also make it easier to track these children.
- 132.** Urinary tract infections (UTIs) can be a contributory factor in developing CKD. Because of the risk of scarring and the difficulty of diagnosis, especially in young children, prompt antibiotic treatment is recommended for any suspected UTI. It is also appropriate to check for any possible structural renal abnormalities by ultrasound. If abnormalities are found in both kidneys the child or young person is considered to be at risk of developing CKD. NICE is currently developing a clinical guideline on *Urinary tract infection in children: investigation and long-term management of children up to 8 years*.⁷²

133. Bladder outflow obstructions and other bladder dysfunctions can lead to CKD and ARF.^{73,74} The condition itself may be reversible but can still do permanent damage. Even after an obstruction has been relieved, the patient can be left with abnormal kidney function. For these reasons, children and young people with bladder dysfunctions, including obstructions, benefit from planned investigation and follow-up, with access to appropriate specialists.⁷⁵
134. Diabetes and hypertension as causes of CKD in children and young people are unusual. For this reason there is less opportunity to slow down or prevent progress of the disease in children through lifestyle factors. The main focus in caring for this group of patients is best directed towards monitoring those known to be at risk and referring any suspected cases to secondary care for confirmed diagnosis. Once a firm diagnosis is made, disease management and treatment to prevent or reduce complications can begin.
135. There are difficulties with measuring certain indicators for childhood renal disease. In particular there is a continuing problem in interpreting creatinine levels in blood. A working group set up to resolve the issues for pathology laboratories in reporting kidney function as an estimated glomerular filtration rate (eGRF) (which is more accurate for adults than a simple creatinine level) recommends that eGFR is not calculated routinely for children. However if desired, a measure can be calculated using the Schwarz formula, which requires knowledge of the height (length) of the child, rather than the MDRD formula used for adults.

Markers of good practice

- All people at increased risk of CKD are identified, and given appropriate advice, treatment and support (which is sensitive to the differing needs of culturally diverse groups) to preserve their kidney function. (Level 3)
- People identified as having an increased risk of CKD have their kidney function assessed and appropriately monitored, using estimated GFR. (Level 3)
- Implementation of the NICE clinical guideline on the management of Type 1 diabetes. (Level 1)
- Implementation of the NICE clinical guidelines on the management of Type 2 diabetes: renal disease; blood glucose; blood pressure and blood lipids. (Level 1)
- Implementation of the NICE clinical guideline on the management of hypertension in adults in primary care. (Level 1)⁷⁶

For children and young people

- For children and young people with potential urinary tract infection, accurate diagnosis and prompt antibiotic treatment, and investigation sufficient to identify structural renal defects and to prevent renal scarring. (Level 3)
- For children and young people with bladder dysfunction, planned investigation and follow-up, with access to urology services with paediatric expertise. (Level 4)

Quality requirement two: Minimising the progression and consequences of chronic kidney disease

Aim

To improve the long-term outcomes for people with chronic kidney disease by minimising the progression and consequences of the disease.

Quality requirement

People with a diagnosis of chronic kidney disease receive timely, appropriate and effective investigation, treatment and follow-up to reduce the risk of progression and complications.

Rationale

136. Once CKD has been diagnosed, clinical care focuses on addressing the causes where these are treatable and minimising progression of the disease, including the risk of complications. Long-term complications are a particular concern for children and young people with a lifetime of kidney disease ahead of them, and treatment to prevent and/or minimise them can have a profound effect on future quality of life.
137. Those with CKD arising from conditions which put them at risk of UTIs will need continued management to avoid infection where possible, or treat it effectively, to ensure kidney damage is minimised.
138. The management of blood pressure is also important for children and young people, as for adults, to minimise the risk and complications of cardiovascular disease.
139. The reduction of proteinuria using medicines such as ACE inhibitors is also likely to be of benefit in children and young people, as in adults,⁷⁷ in delaying progression of CKD.
140. Children and young people with CKD may be prone to the following complications, which require active prevention and/or management:
 - growth failureⁱ
 - renal bone disease
 - anaemia

i NICE has published guidance on the use of human growth hormone for children with chronic renal insufficiency.⁷⁸ Advice is also included in Chapter 10 of the Renal Specific Management of Medicines.

- hypertension
 - psychosocial problems.
141. Renal bone disease, which is linked with both growth failure and anaemia, is an important consequence of CKD, leading to bone pain, muscle weakness and calcification of the blood vessels. Treatment with phosphate binders and vitamin D early in CKD may result in improvement of bone disease and prevent the parathyroid glands from becoming overactive.
142. For more information on the psychosocial effects of kidney disease see Standard one.
143. As discussed in Chapter one, the ideal period to prepare a patient and their carers for RRT is around a year. Those who are diagnosed too late for this to be possible need more intensive preparation: around 15% of paediatric patients beginning RRT in 2002 required dialysis as an emergency, according to a survey carried out by the British Association for Paediatric Nephrology.

Markers of good practice

- All people diagnosed with CKD have access to care which is sensitive to the differing needs of culturally diverse groups, to maximise the benefits of treatment and minimise the effects of the disease; and have a care plan. (Level 4)
- Use of the best available evidence to inform the management of
 - blood pressure
 - cardiovascular disease and cardiovascular risk
 - urinary tract obstructions and infections in people with CKD. (Level 3)
- In people with diabetes and CKD, interventions to reduce microvascular complications, in accordance with the *National Service Framework for Diabetes*.
- Implementation of the forthcoming NICE guideline on the treatment of anaemia in CKD. (Level 1)
- Referral from primary care to the specialist renal service at an appropriate stage to optimise outcomes. (Level 4)

Quality requirement three: Acute renal failure

Aim

To minimise the incidences, consequences and complications of acute renal failure.

Quality requirement

People at risk of, or suffering from, acute renal failure are identified promptly, with hospital services delivering high-quality, clinically appropriate care in partnership with specialised renal teams.

Rationale

144. ARF is more common in babies and infants than in older children, often linked to congenital heart defects or corrective surgery, structural abnormalities of the urinary tract or respiratory problems at birth.⁷⁹ More detail is given in Chapter one.
145. Although ARF is potentially fatal, in many cases it is reversible if appropriately treated. Early diagnosis of ARF improves outcomes, as does prompt specialist consultation. It is important to establish as early as possible whether ARF is caused by an underlying kidney condition that has suddenly been made worse or is the result of another illness or trauma in someone with previously normal kidneys, as this will determine treatment. Its management may involve co-operation between paediatric renal specialists, neonatal or paediatric intensive care, paediatric cardiac surgical teams and others.
146. Following an episode of ARF, a minority of children and young people do not fully recover normal kidney function but go on to show signs of CKD and/or to develop ERF. Ongoing care for these groups is covered in Chapter one.
147. Even those who go on to recover completely may have complex rehabilitation needs relating both to their physical and psychological/emotional well-being. Their families may also benefit from support throughout this period. Those children and young people being treated by renal services and their families will ideally have access to the services of a multidisciplinary renal team, which could cover, for example, physiotherapy, dietetics, education, clinical psychology/counselling services and pharmacy services.⁸⁰
148. Physical needs to be addressed commonly include nutrition and problems of muscle wastage. Other needs will vary case by case, depending, among other things, on the underlying cause of ARF.

149. Psychosocial needs may include the patient and family's need for support in the transition from intensive care to a period of convalescence.
150. School-age children may also need the services of a teacher to compensate for missed school time. The need to provide teaching support for children and young people in hospital is covered in more detail in Standard one.⁸¹
151. Recent good practice suggests that a critical care follow-up service is useful for patients and their families. This is particularly important for newborns being discharged from intensive care, as they have a high risk of being readmitted to hospital.⁸²

Markers of good practice

- Timely identification and referral to renal and critical care services for specialist, culturally appropriate advice and assessment. (Level 3)
- Appropriate pre-operative testing and interventions, in accordance with the NICE guideline on pre-operative testing. (Level 3)
- Involvement of local critical care networks in planning, commissioning and monitoring the delivery of critical care services to acutely ill renal patients. (Level 4)
- Liaison with specialist renal services to facilitate optimal management of people with ARF in the most clinically appropriate setting. (Level 4)

For children and young people

- Treatment and care in accordance with *Getting the right start: National Service Framework for Children, Young People and Maternity Services*.

Quality requirement four: End of life care

Aim

To support people with established renal failure to live life as fully as possible and enable them to die with dignity in a setting of their own choice.

Quality requirement

People with established renal failure receive timely evaluation of their prognosis, information about the choices available to them, and for those near the end of life a jointly agreed palliative care plan, built around their individual needs and preferences.

Rationale

152. For children and young people, end of life care needs to take into account the impact on the family as a whole as well as meeting the patient's individual care needs. When a child or young person is dying, their parents and other family members are usually the most important care-givers and will play a significant role in decision-making; though children and young people where possible are also partners in decision-making.
153. Clinicians will have discussed the life threatening nature of ERF with both the child and parents when the need for RRT became clinically necessary, and will need to make the parents aware when they believe the child is approaching the end of their life. It is important for families to be given timely information about the choices available to them, such as whether to continue RRT, and for a palliative care plan to be agreed which captures their needs and preferences.
154. It is a hallmark of good practice to ensure that parents are offered support, understanding, privacy and time to begin to absorb what may be emotionally devastating news or confirmation that their child is nearing the end of their life. Such support will need to be culturally sensitive, with access to interpreters if necessary. Giving bad news is discussed in more detail at Children's NSF Standard 7, 3.20.
155. Where the condition is an inherited one, and especially where the dying child has siblings who may also be affected, this will be an additional cause of anxiety and distress for the family.

156. Where the patient wishes to be cared for at home, plans will need to be made as part of palliative care both to establish a protocol for immediate access to hospital if needed and to put in place arrangements to avoid unnecessary emergency hospital admission.⁸³ Easy access to medicines will also be needed, especially during the out-of-hours period.

Recognising diversity

157. Attitudes to death and dying are influenced by many factors, including religious beliefs, cultural background, level of understanding, and so on. An appreciation of these factors is vital if the renal team is to offer care that is truly sensitive to the needs of the child or young person and their family.

Palliative care

158. Palliative care is designed to reduce pain and anxiety and maximise quality of life for patients who are approaching death and for whom life-saving medical intervention is no longer possible or appropriate.ⁱ
159. Because palliative care is provided by a network of agencies and may need to be delivered in various locations, co-ordination and liaison are vital. The type of palliative care needed, where it is to be provided and who is to co-ordinate provision are topics to be discussed with the child or young person and their family and written into the care plan.
160. Palliative care covers a range of services for the whole family, all of which need to be delivered in a way that is culturally appropriate and sensitive to their needs and preferences. These services can include:
- short-term breaks for carers (respite care)
 - family support services
 - pain management and symptom control
 - provision of equipment to support care at home
 - bereavement counselling.⁸⁴
161. Wherever possible palliative care for children should include play therapy or some other creative element related to their interests or preferred activities in order to improve quality of life.

i Palliative care for children and young people with life limiting conditions is described in *A Guide to the Development of Children's Palliative Care Services: Report of a joint working party of ACT and the Royal College of Paediatrics and Child Health, 2003.*

162. Pain management is a key part of palliative care and covers the prevention, assessment and control of pain. Good practice shows the benefits of involving children and young people as active partners in pain management through the use of psychological therapies, including play, coping skills and cognitive-behavioural approaches, as well as through the use of prescribed medicines. The effectiveness of children's pain management should be demonstrated regularly by audit. (For general guidance see the Children's NSF Standard 6, 12.1–12.4. Hospital-based pain management is covered at Children's NSF Standard 7, 4.31–4.33.)
163. Some children and young people will need palliative care for only a short time; for others it will be the main focus of care after diagnosis. In these latter cases it may initially include such treatments as feeds, medication to treat renal bone disease (which can cause severe pain in the late stages of renal failure) and even occasionally dialysis, all aiming to control symptoms to prolong good quality of life.

After the death of a child or young person

164. After the death of a child or young person it is important that families receive care and support that is sensitive to their needs. Bereavement counselling may be helpful, as may support in dealing with such practical considerations as planning funeral arrangements and registering the death.⁸⁵
165. Information may also be important in helping the family make sense of the death and of the grief reactions of family members.⁸⁶
166. Staff who have cared for critically ill children and young people can also benefit from support at this time.⁸⁷

Markers of good practice

- The renal multi-skilled team has access to expertise in the discussion of end of life issues including those of culturally diverse groups and varied age groups, the principles of shared decision making, and training in symptom relief relevant to advanced non-dialysed ERF. (Level 4)
- Prognostic assessment based on available data offered to all patients with stage 4 CKD as part of the preparation for RRT described in Standard two of Part one of this NSF. (Level 4)
- People receive timely information about the choices available to them, such as ending RRT and commencing more conservative treatments, and a jointly agreed palliative care plan built around individual needs and preferences. (Level 4)
- People who are treated without dialysis receive continuing medical care including all appropriate non-dialytic aspects of CKD, and wherever possible are involved in decisions about medication options. (Level 4)
- Individuals are supported to die with dignity, and their wishes met wherever practicable regarding where they die, their religious and cultural beliefs, and the presence of the people closest to them. (Level 4)
- The care plan includes culturally appropriate bereavement support for family, partners, carers and staff. (Level 4)

Chapter four: Care pathways sensitive to the needs of children and young people

Introduction

167. Since the Renal NSF and the Children's NSF were published the Government has launched a number of far ranging documents aimed at further developing the modernisation programme and placing the patient at the centre of care. It is in this environment that commissioners of services for children with renal disease will wish to take note of the quality requirements and markers of good practice set out in this document.

Creating a Patient Led NHS

168. In *Creating a Patient Led NHS*,⁸⁸ the Department set out its vision for a health service where culture has been radically changed, where the key measurement of any activity is its impact on patients, where authority is devolved to patients and where we are concerned with prevention as much as with cure.

Our health, our care, our say

169. In the White Paper, *Our health, our care, our say*,⁸⁹ the Government outlined a strategic vision in consonance with the principles set out in the Renal NSF. The White Paper proposes that the delivery of community health and social care services is reformed to make them as flexible as possible, giving people better access to more integrated and personalised services which are tailored to their needs. At the same time it aims to put individuals and communities more in control by shifting the focus towards prevention, providing care closer to home and offering more choice to people near the end of their lives.

The wider reform agenda

170. Reforming commissioning, to strengthen the role of GPs working in tandem with even more effective primary care trusts, is a key goal of the Department. The particular expertise of specialist commissioners remains a vital resource for the NHS, not least in an area like kidney disease in children where prevalence is relatively low.

171. Underpinning this reform is the introduction of Payment by Results,⁹⁰ which began in a small way in 2003/04 and continues to be rolled out across the NHS. Payment by Results provides a transparent, rules-based system for paying for NHS care. It rewards efficiency, supports patient choice and encourages a growing plurality of provision.

172. Reinforcing all this is the National Programme for IT,⁹¹ a record programme of investment in information technology in the NHS, which will improve patient care by enabling clinicians and other NHS staff to increase their efficiency and effectiveness.

Care pathways

173. These initiatives were the backdrop against which, as part of its work in preparing this document, the Department of Health held workshops to consider care pathways for children with renal disease. Whilst it will be for local commissioners to decide how best to provide services for their local community, pursuing the guidance set out in *Guidance on Commissioning Arrangements for Specialised Services*,⁹² the results of those workshops and the care pathways developed during them are available for information on the Department of Health website, at www.dh.gov.uk/renal.

The Evidence Base of the Renal NSF

174. The Renal NSF is based on evidence drawn from a range of sources and supported by systematic reviews carried out by a combined team from the NHS Centre for Reviews and Dissemination and the University of Aberdeen. (The evidence base is published at www.dh.gov.uk/renal.) In addition views and experiences were sought from people with CKD, their families and carers; patient groups; professional staff and their associations, and from the private sector and industry.
175. The following typology has been used to distinguish the different levels of evidence supporting the markers of good practice underpinning the standards and quality requirements of the Renal NSF:

Levels of evidence

Level 1: Meta-analyses, systematic reviews of randomised controlled trials, or randomised controlled trials.

Level 2: Systematic reviews of case-control or cohort studies, or case-control or cohort studies.

Level 3: Non-analytic studies, eg case reports, case series.

Level 4: Expert opinion (in the absence of any of the above). This includes the views and experiences of people with kidney failure and their carers.

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