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Foreword

Following a period of formal consultation, we are pleased to be able to introduce this Policy Statement and National Service Framework *Designed to Tackle Renal Disease in Wales.*

Wales has long demonstrated an innovative and visionary approach to the development of renal services, often leading the way in terms of dialysis programmes, satellite dialysis units, organ donation and transplantation. There have also been significant developments to improve children’s services for dialysis and transplantation. NHS Wales now faces the challenge of responding to a growing demand for renal services in the face of an ageing population and finite resources, but also the need to ensure equity and continuity of services. This Policy Statement and National service Framework seeks to build on existing good practice, and to facilitate the sharing of innovative and effective practice across all of Wales.

The development of the Policy Statement and National Service Framework would not have been possible without the contribution of many stakeholders, including, of course, renal patients and carers, members of the Renal NSF Project Board and in particular Professor John Williams, Consultant Nephrologist and Lead Renal Clinician; we thank them all for their hard work and enthusiasm.

The Policy Statement is structured around the themes set out in *Designed for Life* of more prevention, early detection, improved access and better services; it aims to ensure that the right services are provided in the right place at the right time.

The standards in the National Service Framework describe the services and facilities that patients should expect and covers all aspects of the disease pathway, emphasising patient centred care and multidisciplinary team working. The standards of care for children are to be implemented as part of the Children and Young Person’s Specialised Services Project.

The implementation targets largely reflect work that is currently underway and cover the period up to March 2008. Mirroring the approach in *Designed for Life*, there will be further strategic framework covering the period 2008 to 2011.
The scale and complexity of the task of transforming health and social care over the next decade means that change must be managed as a whole. Designed to Tackle Renal Disease in Wales shows how commissioners and providers of renal services, working through the networks that will be established, must target their actions to a national and a local level, working in partnership. Together we can strive to achieve world class services that will improve the health, wellbeing and quality of life of children, young people and adults with or at risk of developing renal disease in Wales.

Mrs Ann Lloyd
Head, Health & Social Services Department; Chief Executive, NHS Wales

Dr Tony Jewell
Chief Medical Officer, NHS Wales
Introduction

In order to meet the objectives set out in the Welsh Assembly Government’s *Designed to Tackle Renal Disease in Wales: A Policy Statement*, a National Service Framework (NSF) for Renal Services has been developed. In broad terms, this NSF will:

- Identify action to improve prevention, early detection and appropriate management of patients with renal disease.[1]
- Set standards for improving the quality of the care and treatment of those at risk from, or who have renal disease.[2]
- Establish a programme of effective integrated Renal Replacement Therapy (RRT) throughout Wales.[3]
- Identify actions to increase the number of renal transplants through an improved programme of organ donor registration and raise both clinical and public awareness.
- Establish protocols, using which, alternative models of care can be delivered.

This set of documents sets out the standards of care for both children and adults with, or at risk of developing, renal disease.

Each aspect of the patient journey must be defined and standards of care established, based on the best available evidence, against which the quality and effectiveness of care will be measured. Within each standard, key interventions are set out, in order to define the models of patient care and service delivery. These Key Interventions set out the services and systems which must be in place through the commissioning process in order to comply with the Standards. National implementation targets will be set through a series of strategic frameworks, with targets currently in place up to March 2008. These targets will direct action by Local Health Boards (LHB), Health Commission Wales (HCW), National Health Service (NHS) Trusts and other providers, to deliver these standards of care. Other programmes of work at a national level will help support implementation at a local level, including the development and subsequent implementation of a dataset to audit compliance with the NSF. Together, the standards, the targets and the programmes of work at a national level form the basis of the NSF.
It should be noted that the words ‘renal’ and ‘kidney’ are often used interchangeably. For the purposes of these documents, the word ‘renal’ will be used unless we refer to terminology where the word ‘kidney’ is more commonplace to use, e.g. Chronic Kidney Disease.

**The impact of renal disease in Wales**

It is thought that up to 10,000 people in Wales have renal disease and it affects all age groups. When advanced, it can impair quality of life significantly and its consequences can be fatal. However, there is good evidence that early detection and effective treatment can delay or even prevent its progression.\[^4\] Early identification and planning of patient care requires ‘a patient centred approach’. Appropriate education and informed decision making will allow patients to understand their condition and facilitate an informed patient choice about their treatment and care, whether it be renal replacement therapy or conservative management.\[^5, 6\]

The incidence of renal disease is rising and will continue to do so for the foreseeable future.\[^7\] Over the past decade, there has been an increased demand worldwide for more facilities and personnel to treat patients with renal disease, and Wales is no exception. Moreover, more people are surviving into old age, which is sometimes accompanied by a decline in renal function. In addition, certain diseases associated with renal problems, such as diabetes and cardiovascular disease, are becoming more common, partly because of obesity and ageing, and as the ethnic mix of the population changes.\[^7\]

This increased demand for renal services has been accompanied by an increased awareness amongst the public and health professionals that renal disease at all ages can be treated and that the vast majority of patients with Established Renal Failure (ERF) benefit from treatment by specialised nephrology services. As a result there has been an increase in referral rates, although not to the extent that might have been anticipated from European trends.

In response, services in Wales have not grown fast enough. A take-on rate of 132 per million of the population in Wales\[^7\] although equal to or better than the other home countries (Scotland 120 per million; England 98 per million; N. Ireland 109 per million) is considerably lower
than in Germany (184 per million) and the United States of America (336 per million). These differences do not mean that a steady state has been reached in Wales but that there is an increase in unmet demand. Although these differences in take-on rate can be partly explained by demographic factors, population ethnicity and patterns of underlying diseases such as diabetes, it appears that there has also been under-identification of patients\(^8\) as well as a failure to develop services fast enough to match demand. These problems have been compounded by the fact that the numbers of renal specialists per head of the population in Wales remain less than in other comparable countries.\(^9\)

**Aims of the NSF**

In line with *Designed for Life*\(^3\), the Assembly Government’s strategy for delivering a world-class health and social care service for Wales, the NSF implementation framework will outline a long-term process where some goals will require early action and others a phased introduction. Commissioners at national and local level, as well as providers, adopting a network approach, will need to determine at an early stage the extent to which their service meets the stated markers of good practice so that planned development can take place with continuous improvement towards the standards set by the NSF.

The detailed work of the Renal Services National Service Framework Project will over time:

- Identify appropriate standards and key interventions to underpin the commissioning process.
- Secure sound baseline data on patients and services.
- Define information management systems.
- Identify workforce and training implications to support future progress.
- Identify the financial implications of meeting the NSF standards.
- Encourage and support the development of best practice across Wales.
- Identify constraints and how to deal with them.
- Identify key research and development needs and priorities.
• Strengthen integrated and innovative approaches by involving all key stakeholders in the management, support and care of people with or at risk from renal disease to enable them to live their lives.

• Develop and update training and professional development to meet current and future needs.

• Ensure that good communication and feedback mechanisms between health professionals, carers and patients are encouraged and supported.

• Set realistic milestones to direct the progress of implementation.

• Develop a set of core clinical indicators to measure the effectiveness of the NSF in improving the quality of care and patient outcomes.

The Development of the Standards

The NSF standards have been developed in a modular fashion as outlined below, and together these will cover the whole spectrum of care for both children and adults through:

• The commissioning and delivery of health care utilising an integrated service with a people centred approach.

• The prevention of renal disease in those with modifiable risks.

• The early detection of impairment in renal function.

• The prevention or the slowing down in the progression of renal disease.

• The management of complications and co-morbid conditions.

• The timely preparation for and informed choice of renal replacement therapy.

• The provision of an integrated and holistic renal replacement therapy service.

• The provision of alternative models of care where appropriate.
The standards have been developed using a very structured approach. Each standard is written in the present tense as it describes and reflect the characteristics of the quality and level of care that a patient can expect. Each of these standards is based on documented evidence, where available. For each standard, key interventions have been identified to inform and underpin the way in which renal services are commissioned and what action needs to be taken in order to achieve the standards. Each module sets out what the standards it covers means for patients.

As well as setting out standards for adult care, this NSF sets out the standards of care for children, developed from the standards for adults but with the needs of children and their families firmly in mind. These standards will be implemented as part of the Children and Young Person’s Specialised Services Project, which is developing and implementing managed clinical networks for specialised children’s services across Wales.

The modular structure underpinning the development of the NSF standards is as follows.

**Standard 1: Care for all**
- A service providing integrated care with the patient at the centre of decision making.

**Module 1:**
**Care for Children and Young People**

**Children Standards 1-10**

**Standard 1** is the overarching standard that sets the general approach to the NSF and patient care.

**Standard 2** identifies the ways that CKD can be recognised early and prevented and complications and progression minimised through monitoring and early management of problems.

**Standard 3** deals with the recognition, and management of ARF.

**Standard 4** describes ERF and preparation for renal replacement therapy.
**Standard 5** is concerned with maximising the access to and effectiveness of transplantation.

**Standard 6** considers dialysis and the way it is provided most effectively for children.

**Standard 7** details immunisations and medication in children with CKD, ERF and ARF.

**Standard 8** defines the requirements of transport and travelling to services and the possibility of delivering services closer to home.

**Standard 9** considers the issues of supporting children and young people who choose not to dialyse, to stop dialysis or who are terminally ill.

**Standard 10** defines the management of the transition of young people from children’s units to adult renal units.

**Module 2:**

**Prevention, Early Detection and Management of Chronic Kidney Disease and Prevention and/or Management of Acute Renal Failure**

**Adult Standards 2-6**

- Prevention of renal disease.
- Detection of renal disease.
- Delaying progression and minimising complications of impaired renal function.
- Recognition and prevention of acute renal failure.
- Treatment of Acute Renal Failure.

**Module 3:**

**Effective Delivery of Dialysis**

**Adult Standards 7-11**

- Preparation for Renal Replacement Therapy.
- Peritoneal Dialysis.
- Haemodialysis.
- Transport.
**Module 4:**  
**Organ Donation and Transplantation**

**Adult Standards 12-13**
- Organ Donation.
- Transplantation.

**Module 5:**  
**Alternative Models of Care**

**Adult Standards 14-17**
- Choosing not to dialyse, conservative management of established renal disease.
- Withdrawal from dialysis.
- Care in the last days of life.

**The Evidence Base**

The standards are supported by a rationale based on evidence. Much of the current practice in renal medicine is drawn from evidence-based guidelines laid out by a number of national and international organisations:

- The Renal Association Standards document; Treatment of adults and children with renal failure.[8]
- The Guidelines of the British Association of Paediatric Nephrology.[9]
- A set of guidelines entitled Caring for Australians with Renal Impairment.[10]
- The National Kidney Foundation (USA) guidelines: Kidney Disease Outcome Quality Initiative (K/DOQI).[11]
- The guidelines of the European Dialysis and Transplant Association.[12]
- Renal Disease in Scotland: A strategy for future management.[13]
- The Renal Association: UK Renal Registry, Seventh Annual Report, December 2004; UK Renal Registry, Bristol, UK.[14]
The Cochrane Renal Group has prepared systematic reviews on a number of topics relevant to the NSF.

Patient representatives/groups and professional bodies have provided additional evidence.

The evidence has been graded according to the Health Care Evaluation Unit of the Department of Public Health Sciences at St George’s Hospital Medical School, using their appraisal instrument for clinical guidelines.[16]

**A** = Evidence from at least one properly performed randomised controlled trial (quality of evidence Ib) or meta-analysis of several controlled trials (quality of evidence Ia).

**B** = Well conducted clinical studies, but no randomised clinical trials; evidence may be extensive but essentially descriptive (evidence levels IIa, IIb, III).

**C** = Evidence (level IV) obtained from expert committee reports or opinions, and/or clinical experience of respected authorities. This grading indicates an absence of directly applicable studies of good quality.

**What will implementation of the NSF standards achieve?**

The aim is to achieve, through the commissioning and delivery of services, a number of key quality objectives within a reasonable period of time. These objectives are:

- To ensure that the care of people with or at risk from renal disease is patient focused and takes a holistic approach. Psychological and social support as well as clinical care is a key factor. Patients and their families are empowered to become active partners in their treatment.
- To deal with the needs of children, young people, their carers and families appropriately.
- To detect renal disease in those at risk, such as people with diabetes.
• To manage co-morbid conditions appropriately especially cardiovascular disease.

• To manage patients in a primary or secondary care setting who are identified as having renal disease or renal impairment according to evidence-based guidelines and where appropriate, refer them for specialist nephrology advice.

• To treat patients with irreversible and progressive renal disease in specialist nephrology clinics with full multidisciplinary support.

• To provide all patients and their families or carers with full information at all stages, and to empower them to make an informed choice between appropriate treatment options, including home-based dialysis therapies. Services, tailored for individual patient needs, will need sufficient capacity to make such choice possible.

• To encourage a proactive approach to ensuring adequate capacity is available to prevent overcrowding of facilities and limiting the availability of dialysis stations.

• To ensure that a reliable and efficient transport system is available to take patients to and from dialysis.

• To establish, a full programme of supportive care, including medical, psychological and social components for people who do not wish to undergo renal replacement therapy or for whom it is not appropriate.

• To ensure that systems of care are based around a set of standards, providing measurable goals, in order to facilitate clinical governance and clinical audit.

• To ensure that these standards and key interventions which they trigger are reviewed regularly and updated in response to both the emergence of new evidence and feedback from clinical audit.
The Commissioning Process

It is the commissioning process which is the key to bringing about the changes that are needed in the way renal services are currently provided and the action that is required in order to meet the NSF standards. Local Health Boards and Health Commission Wales are responsible for commissioning the healthcare of people in Wales who are at risk from or have renal disease. They must take the lead in implementing change by using the NSF to underpin their commissioning decisions. This message is reinforced throughout this set of NSF documents.
The Standards

Standard 1 - Care for all

Introduction

The development of renal services in Wales has centred on the provision of hospital based renal units providing haemodialysis services. Renal specialists based at these units provided an inpatient service and facilities for investigation. With the expansion of ‘satellite’ dialysis centres, many of the main renal units developed a ‘hub and spoke service’ enabling patient care to be provided nearer to patients’ homes. In South Wales, this has developed into a type of Clinical Network with co-operation between the two main renal centres of Cardiff and Swansea.

Despite such development the provision of care for patients with renal disease remains a highly specialist service with care being provided at only a few designated centres. In addition the focus of development has centred on the provision of dialysis services and the promotion of transplantation. In recent years although there has been a move to develop services for patients with early renal disease there has not been a coordinated approach to link the provision of care across primary, secondary and tertiary or specialist services. In addition evidence has been accumulating that early intervention can significantly slow down the rate of disease progression and delay the need for dialysis or transplantation.

The first Standard in the Renal NSF outlines the structure required in order to provide an integrated system of patient care across all levels of the service and involving patients at every step of the way.

What does this mean for patients?

In order to bring about the patient centred service described in Standard 1, there needs to be a much more collaborative and co-ordinated approach to planning, organising and delivering care to patients with renal disease. Commissioning of renal services across Wales will need to be informed by those with an interest in renal services, including patients themselves. These improved commissioning arrangements will need to be informed by a clear understanding
of progress with the implementation of the NSF standards. Multidisciplinary Renal Teams will be established in each renal unit to ensure that each patient is provided with care from a wide range of professionals in order to meet all their needs. At an all Wales level, a Renal Advisory Group will advise and support both the Assembly Government and the NHS and will review the NSF standards to make sure they reflect latest clinical evidence. A formal programme of NHS staff training based on agreed competencies and a means of monitoring improvements in the quality of renal care will begin.

The overarching aim of Standard 1 is to ensure that patients are fully involved in taking informed decisions about their own care, working with health professionals and their families and carers. The way the service will be structured will help patients take these decisions in an informed way with the support of a wide range of appropriately trained health professionals. Renal services will be planned, organised and delivered around the needs of the patients and their families.
Standard 1:

Care for all

Each patient at risk from, or with renal disease and their family and/or carer makes, in partnership with professionals, informed decisions about their on-going care and long-term disease management.

Key Interventions

In order to achieve this Standard, the Welsh Assembly Government, Local Health Boards and Health Commission Wales, working with provider groups must ensure that that action is taken:

1. To establish an All Wales Renal Advisory Group to support the implementation of the NSF through programmes of work at a national level and to advise the Assembly Government on the strategic vision for tackling renal disease in Wales. It will provide an opportunity to develop clinical leadership and will co-ordinate the implementation of the Renal NSF across Wales. The Renal Advisory Group will include representation from all those with an interest in tackling renal disease and will be responsible for the continuing review of the NSF Standards and Implementation Framework. The Group will develop clinically relevant indicators for measuring and demonstrating progress in improving patient outcomes at a national level, supporting the development of care pathways and advising and influencing the research agenda.

To establish two Renal Networks which have access to detailed and specialist knowledge on renal services and their development needs as required by the NSF standards. This will lead to improved commissioning arrangements for the whole patient pathway at local, regional and national level and to support local service quality improvements and sharing of best practice.

2. To establish Multidisciplinary Renal Teams in each renal unit for the care of individual patients in accordance with national workforce planning recommendations. This should also include access to appropriate experts from other specialities. These teams
will be responsible for establishing a care plan for each patient, which is kept under review with a frequency appropriate to his or her condition.

3. To put in place an integrated All-Wales information system involving all those who provide care for people at risk from or with renal disease. This should include:
   a. IT systems in primary care to facilitate the monitoring of all patients requiring regular assessment of blood pressure, proteinuria and/or measurement of renal function. When appropriate these IT systems will integrate with those in secondary and tertiary care (Level C).
   b. The automatic transfer of the results of relevant haematological, biochemical and microbiological tests on all patients known to the local renal unit from the laboratory where that patient's tests are processed, together with a system for bringing these results to the attention of those responsible for monitoring the patient's progress (Level C).
   c. Accurate data collection from all renal units and critical care areas of the numbers, diagnoses, treatments and outcomes of patients with acute renal failure (Level C).
   d. Audit of the access services of all renal units on an annual basis to a protocol agreed with the service commissioners (Level C).
   e. Appropriate audit tools to measure qualitative interventions in patient care.

   This will enable a rolling audit programme to be set up to measure performance against standards.

4. To provide patient information relating to key interventions along the patient pathway that is clear and meets the needs of patients in terms of their linguistic, cultural and educational background.

5. To set in place a series of competency frameworks so that healthcare professionals are educated and trained to the highest level and provide the best and most appropriate care for each individual patient. This should also ensure that there is an adequate medicine management process in place for all patients.

6. To develop integrated care pathways for key interventions within each standard so that equity of access and quality of care can be achieved and monitored.
**Rationale and Evidence Base**

The optimal management for patients with renal disease at all stages requires a fully integrated system comprising input from health care professionals, educationalists, social and psychological care professionals, the patient and, where appropriate, their family and carer.[14]

In order to establish a wholly people centred service providing care closer to the patient’s home, the current informal system will need to be developed and expanded to involve the whole of Wales. To facilitate such an integrated service, intervention and co-operation will be required at primary, secondary and tertiary levels of health care delivery.[3]

To achieve this will require:-

- The setting up of a Renal Advisory Group at an all Wales level. Initially its primary role will be to lead and support the implementation of the NSF and to establish new regional commissioning arrangements for renal services to support and lead the planning and delivery of services and the implementation of the NSF standards at a local level. In the long term the group will be required to keep standards up to date, to advise the Welsh Assembly Government on developments in renal care and to monitor the basic data set and measure outcomes against standards.[17]

- The establishment of specific networked regional commissioning arrangements for renal services, working at the interface between the commissioners and the providers, to deliver the NSF standards through the commissioning process. The structure of renal services in Wales dictates that the system be best served by two renal networks, one for North Wales and one for South Wales, reflecting patient referral patterns from primary care through secondary care and on to tertiary level care. The current service in South Wales has a provisional network linking the renal units of Cardiff and Swansea where dialysis services are provided independently but are linked by a single transplant unit. In North Wales the system is based on three district general hospital renal units whose focus for tertiary services is based in Liverpool.[17]
• An all Wales information system\textsuperscript{[18]}, which allows for regular audit of service provision, a comparison of achievements against national standards and a measure of the success of the implementation of NSF standards.\textsuperscript{[19]}

• The enhancement of the multidisciplinary team approach to patient care, within renal teams and across agency boundaries, with the aim of providing cost effective services and improved outcome via collaborative working.\textsuperscript{[3]}

• The development and implementation of competency frameworks to ensure that numbers and skill-mix of staff throughout Wales are sufficient to meet the requirements of the service, providing the right staff with the necessary skills in the appropriate place at the right time through the development of competency frameworks.\textsuperscript{[20]} The need for flexibility and new ways of working to make the best use of skills and knowledge is recognised.\textsuperscript{[20]}

• The development of care pathways, to ensure equity of access and quality of care. Robust integrated care pathways can be developed and monitored using the guidance within the document, ‘Integrated Care Pathways, A Guide to Good Practice’.\textsuperscript{[21]}

• Agreeing care plans for all patients, as this is the basis of the relationship between each patient and the professionals. This should include a named professional with whom the patient/carer can have direct interaction and who will ensure that the patient’s care plan is followed and regularly reviewed.

• The opportunity for individual patients to be fully involved in their own care. Although some may not choose to do so, the majority will need information, advice, education and active support in order to fully participate. They need to be given the opportunity to participate fully in decision-making processes and choose that pathway of care that best suit them. The partnership between patients and professional staff in planning the care process is central to securing the best outcome.\textsuperscript{[22,23]}
• The alignment of developments in renal services with those required under the NSFs for Diabetes\textsuperscript{[24]}, Coronary Heart Disease\textsuperscript{[25]}, and those planned for Older People\textsuperscript{[26,27]} and for Children and Young People\textsuperscript{[28]}

• The Expert Patients Programme (EPP) is being rolled out throughout the NHS in Wales by 2008, to enable as many people as possible in communities throughout Wales to benefit from self-management training. EPP courses help to promote self care and to empower patients to take more control over their lives, whilst working in partnership with health and social care professionals. There needs to be a mechanism within individual patient care plans to consider the benefits of referral to EPP courses\textsuperscript{[29]}

• Assessment of the education and linguistic needs of all patients. This is particularly important in those groups where difficulties in understanding and comprehension might impair the ability of patients to participate fully in their care\textsuperscript{[30]}
References

11. http://bapn.uwcm.ac.uk.
MODULE 1

Children’s standards 1-10: Care for Children and Young People

Introduction

Children and young people are entitled to safe, effective renal services that meet their needs as children and as patients with renal disease.[1] These services should maximise their quality of life and life expectancy in childhood and in adult life and minimise the negative effects, and the complications of treatments of renal disease. In view of the dependence of the child on parents and family the service must also address the needs of their families and carers.[2] Children are different from adults in many ways; this is reflected in their daily routines and the way they grow and develop from month to month and from year to year. Their minority status, their dependence on adults for care and support, their vulnerability, their health needs, their unique spectrum of illnesses and their need for play and education all require particular attention. Many children with renal problems in early life will grow up into adults with chronic kidney disease (CKD) and established renal failure (ERF) and therefore managing the process of growing up and supporting the transfer of children and their medical care to adult services is now recognised as an essential component of the service.

This set of standards is to ensure that children with acute renal failure (ARF), CKD, and ERF are not disadvantaged because of their age, size or dependency, where they live, their family or social circumstances or because certain services are designed around the needs of adults. These children’s standards are additional to the standards set for adults in this NSF. Unless otherwise stated children’s care should also conform to the standards described for adults as well as the standards described in the English and Welsh National Service Frameworks for Children and the National Service Framework for Renal Services Parts 1 and 2 published by the Department of Health[3, 4] and respect their rights.[1] In addition it must conform to the Children and Young Person’s Specialised Services Project (CYPSSP) currently under development in Wales. It is through the CYPSSP that the Renal NSF as it applies to children and young people will be implemented.
Where children aged 16-19 are treated in adult units their rights and need for protection must nevertheless be acknowledged and honoured. This can be accomplished by establishing a dialogue with a local paediatrician and with the regional paediatric nephrology service through the clinical network.

Plans for a fully resourced outreach service through a managed clinical network[5] will improve local understanding of CKD and ERF and the multidisciplinary approach to care, improve service delivery to the home and locality and reduce the time spent travelling particularly for those families that live far from the tertiary centre.[3, 6]

Children with CKD and ERF are best managed using an electronic clinical information system so that results can be analysed to demonstrate trends and problems. Such systems are integral to collection of data for management and audit through the paediatric and adult renal registries.[7,8,9]

Many of the standards for the care of children with ERF have been described by the Renal Association in their standards document.[10] The outcome of care is monitored by the Paediatric Renal Registry organised by the British Association for Paediatric Nephrology and UK Renal Registry.[7, 8] For the small number of children with ERF it is essential to pool data with the remainder of the UK through the existing registries and to contribute to the European dialysis and transplantation registry.[11, 12]

Research is important for answering questions about the best way to treat patients. When dealing with rare conditions such as renal failure in childhood, valid results can only be achieved through properly designed multi-centre studies involving sufficient patients and centres. This requires a service and organisational infrastructure that supports this process. The British Association for Paediatric Nephrology (BAPN) has co-ordinated such studies nationally and should be supported in the planning and implementation of well conducted scientific studies.[7, 13]

As commissioners, Health Commission Wales has the ability to specify the quality of service which provides an ideal opportunity to ensure availability of and access to appropriate paediatric nephrology services in Wales.[6,14]
This children’s module is concerned with the philosophy of care, the need to ensure that services are child focussed and that children and their parents are empowered to work in partnership with health professionals to achieve the best possible outcomes for them and their families.

This module is split into 10 standards for children. The rationale and evidence base, with the accompanying references are contained at the end of this module.

**What does this mean for children and young people?**

**Standard 1** is the overarching standard that defines how children’s renal services will be set up in Wales and how patient care will be provided through an integrated renal service with a child and family centred approach.

**Standard 2** identifies the ways that renal disease can be recognised early and prevented. It also defines how complications and progression can be minimised through monitoring and early management of problems.

**Standard 3** deals with the recognition, and management of acute renal failure. The aim is to maximise patient survival and recovery of renal function in infants and children with, or at risk of ARF. The interventions outlined will minimise complications through their prevention early recognition, active management and appropriate high quality of care.

**Standard 4** sets out a framework for the preparation of children and young people with ERF (and their families) for renal replacement therapy (RRT). This will allow them to fully understand all the options available and enable them to participate fully in decisions with the help of an expert team. They will then be able to choose the treatment that is most suitable for them medically and most compatible with their needs and family circumstances.

**Standard 5** sets out a strategy for maximising the access to and effectiveness of transplantation.

**Standard 6** considers dialysis and the way it is provided most effectively for children by maximising the benefits and minimising the negative effects of dialysis on the child and family.
Standard 7 details immunisations and medication required by children with CKD, ERF and ARF. The interventions will ensure that children are prescribed and given the medications they need in a safe and effective way.

Standard 8 defines the requirements of transport and travelling to services. It considers the possibility of delivering services closer to home when possible to enable children with CKD and ERF with their families wherever they live to have equity of access to expert renal care through the provision of flexible and responsive transport arrangements.

Standard 9 considers the issues of supporting children and young people who choose not to dialyse, to stop dialysis or who are terminally ill by:

- Providing a framework that will enable the provision of appropriate information and support to children and young people as well as their parents and carers so that a decision can be made not to dialyse if this is in the best interests of the child.
- Ensuring that children with ERF who do not receive dialysis continue to receive appropriate child and family focused care from specialist services as well as in the community.
- Ensuring that if dialysis becomes an intolerable physical or psychological burden or if such treatment becomes futile then it is withdrawn ethically and openly and that under these circumstances children and their families or carers are provided with appropriate psycho-social and spiritual support, understand what the future will bring and what practical support they can have either in the hospital or in the community.
- Ensuring that children with ERF who are in the terminal stage of their illness have access to a range of services to ensure that they and their families physical, psychological, social and spiritual needs are met effectively.

Standard 10 defines the management of the transition of young people from children’s units to adult renal units by achieving a smooth and efficient transition of care from paediatric to adult renal services at an appropriate age for the child, between 16 and 19 years.
Children’s Standard 1:

Overarching Standard

Each child and young person and their parents or carers is adequately informed and involved in their care and is empowered to make joint decisions alongside health professionals about care and treatment. They and their carers make, in partnership with professionals, informed decisions about their treatment, care and long-term management. As the child grows and takes responsibility for their own condition this role is gradually transferred from parents to the child or young person.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To establish a regional strategic commissioning process which will be responsible for commissioning quality of care provided to children and their families throughout Wales wherever they are treated (Level C).

2. To establish a framework through which renal services for children in Wales meet the standards of the NSF for Children in Wales and the NSFs for children and renal services in England (Level B).

3. To care for infants, children and young people with renal disease in a suitable environment with access to all the tertiary paediatric services that they require. Care will be provided through the paediatric multidisciplinary renal team (Level B).

4. To provide structured education programmes for patients and families about renal disease, its treatment and prognosis. This will be supported by written information delivered in suitable formats for the family recognising their differing needs related to age, literacy, disability and culture (Level B).
5. To set up a personalised care plan for each child that recognises the needs of the patient and the contribution of the family. It will describe the aims and responsibilities of the child and family and provide a record of the patient’s results in ways that the family can understand (Level C).

6. To establish clear and agreed channels for communication for advice, support and referral between clinicians involved with children with renal conditions (Level C).

7. To undertake investigations and treatment as near to home as possible without compromising the quality of care (Level C).

8. To underpin the service by an effective and comprehensive information strategy and data collection that meets the needs of children with renal disease and their families as well as the needs of health professionals, managers, commissioners and planners (Level C).
Children’s Standard 2:

Prevention of CKD in Children and Young People

Each child at risk of chronic kidney disease has regular assessment for markers of chronic kidney disease. Each child with evidence of chronic kidney disease or established renal failure has regular, systematic, follow up and appropriate management to reduce the risk of progression, co-morbidity and complications.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To identify those children at risk of CKD and to arrange regular paediatric follow up (Level A).
   a. Creatinine measurements will be interpreted with reference to age related normal values, which will be provided by pathology laboratories. In addition, and provided that clinicians supply an accurate height measurement, the GFR in children will be calculated by the laboratory using a suitable formula (modified Schwartz Haycock). Interpretation will be dependent on the accuracy of that height measurement. Until this function is available, the person requesting the test will estimate GFR using the modified Schwartz Haycock or Counaghan Barratt formulae (Level A).
   b. Kidney size will be measured and expressed in relation to age related centiles (Level A).
   c. Children at risk of CKD will have regular dipstick urinalysis for proteinuria and haematuria. Protein/creatinine ratio estimations must be carried out if the dipstick is positive for protein (Level A).
d. Blood pressure will be taken using accepted techniques and age and gender specific or height specific centiles used to identify abnormal values and target ranges. Children with elevated blood pressure will be referred for further treatment (Level A).
e. In children with diabetes monitoring blood pressure and urine albumin/creatinine ratio is recommended. These parameters should be managed actively with ACE inhibitors when necessary (Level B).

2. To refer to a paediatric nephrologist all children with persistent proteinuria, CKD level 2 or greater and structural abnormalities likely to lead to reduced GFR.

a. There will be agreed pathways of care and referral guidelines for children with evidence of CKD (Level B).
b. The Welsh paediatric renal managed clinical network will provide a mechanism for children with CKD to receive care directed by a specialist as close to home as possible. Some of this care will be delivered by the local paediatric team (Level C).
c. Children with evidence of CKD level 2 or more and all children with persistent proteinuria will be referred to a paediatric nephrologist and monitored to prevent progression and to minimise complications of CKD (Level C).
d. Management of progressive CKD and the prevention of complications will include the monitoring and treatment of blood pressure and proteinuria using age appropriate methods and appropriate drugs to reduce the risk of progression of CKD. The frequency of monitoring will depend on the level of renal impairment (Level B).
e. Children with CKD will receive regular monitoring and management of their anaemia, metabolic bone disease, growth and nutrition according to latest guidelines of the Renal Association and BAPN (Level B).
f. Educational and psychosocial problems will be addressed alongside the medical problems. Children and families will have access to the local multidisciplinary renal team as required (Level B).
3. To provide optimal management of potential antenatal uropathy and pre-planning of postnatal management of infants at risk (Level C).

a. Once a pregnancy involving an infant with severe congenital renal or antenatal urinary tract anomalies has been identified, families will receive advice and support from an expert team to inform their plans and decision-making. The multidisciplinary team will include an obstetrician, geneticist, foetal medicine specialist, paediatric urologist, paediatric nephrologist and local paediatrician working together (Level C).

b. The delivery will be planned with the family and take place at a unit with suitable facilities for managing the problem anticipated. Alternatively, there will be jointly agreed plans for early transfer after delivery agreed with the family and both units (Level C).

c. The management plan will be documented and copied to all those likely to be involved including the mother. The receiving unit will be notified of the impending birth of an affected child if the problem is expected to cause problems in the neonatal period (Level C).

d. Postnatal interventions will include targeted imaging investigation using an evidence based guideline. Assessment of renal function should include proteinuria, BP and serum creatinine as described above (Level A).

e. Paediatric surgical opinion will be available if needed (Level A).

f. Records of fluid balance and active management of fluids and electrolytes are essential for infants with severe anomalies in the first days of life (Level B).

g. Measures to prevent urine infection and to enable early detection will be discussed with the parents and with the GPs who need to be aware of this risk and know how to detect and manage the problem (Level C).

h. Families will be given genetic counselling if required (Level C).
4. To develop evidence based guidelines for a standardised approach to imaging procedures and reporting for children requiring investigation of the kidneys or urinary tract. Wherever possible children should have investigations performed locally, in close liaison with a paediatric radiologist, urologist and nephrologist (Level C).

5. To establish a care pathway for each child with a neurogenic bladder, an abnormal bladder outflow tract or following urethral surgery so that they have their bladder function checked regularly by ultrasound and urodynamics. Paediatric continence nurses should be involved in urodynamic studies and in teaching skills such as clean intermittent catheterisation (CIC) to children and parents. These children are also at risk of CKD and should receive appropriate monitoring (Level C).

6. To set up local facilities to detect and treat UTI promptly in neonates, infants and preschool children (Level C).
Children’s Standard 3:

Prevention, Recognition and Management of Acute Renal Failure in Children and Young People

Acute renal failure in infants and children is recognised early and prevented whenever possible, through the expert management of paediatric services following guidelines recommended by specialist paediatric nephrology and paediatric intensive care teams delivered through paediatric renal networks in an appropriate setting. Established acute renal failure is actively managed with the advice and support of a paediatric nephrologist.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide care for all children with acute renal failure in appropriate paediatric or neonatal facilities by trained paediatric medical and nursing staff capable of managing fluid balance, the circulation and medications in children and recognising the features of ARF in this age group (Level B).

   a. Children with ARF or likely to develop ARF will be referred to or have their case discussed with a paediatric nephrologist. There will be access to age appropriate referral guidelines on the prevention, detection and management of ARF and 24 hour advice from and access to a tertiary paediatric nephrology opinion and a centre with facilities to dialyse children with ARF around the clock (Level C).

   b. 24 hour access will be available to appropriate radiological investigations particularly renal tract ultrasound to identify or exclude obstruction (Level C).
2. To treat all children needing, or likely to need, acute dialysis in tertiary paediatric facilities. ARF with multi-organ failure requires transfer to regional PICU lead centre with continuous dialysis facilities and input from paediatric renal services (Level B).

3. To arrange appropriate follow up plans between the paediatric nephrologist and the local paediatric services at discharge. Children with evidence of CKD require long term follow up (Level C).

4. To set up a database to record the numbers, treatment (conservative, dialysis), location (PICU, renal unit, DGH), survival and sequellae of ARF.

5. To establish protocols for the treatment of adolescents with ARF, taking into account the needs of the patient and their family. Where appropriate liaison should be established between adult and paediatric nephrologists as well as local paediatricians.
Children’s Standard 4:

Established Renal Failure and Preparation for Renal Replacement Therapy in Children and Young People

Each child and their family receive information and education about established renal failure, its complications, treatment and related surgery in a format they can understand. Information is given in sufficient time to enable them to make well informed joint decisions in conjunction with the multidisciplinary renal team about the type of renal replacement therapy that is most suitable for them and their child.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To allocate each child with ERF a named nurse and paediatric nephrologist who will ensure that care is planned and implemented appropriately.
   a. The family will be adequately educated about ERF so that they can understand the condition and its complications and treatments (Level C).
   b. The named nurse and consultant paediatric nephrologist will take responsibility for ensuring adequate information and communications with local services (Level C).
   c. Each child will have an individualised care plan, which provides a summary of past events, recent results, medications and aims and responsibilities of the child and family (Level C).
   d. Blood pressure, anaemia and metabolic bone disease will be managed according to agreed evidence based guidelines and meet the most recent standards for children defined by the Renal Association (Level B).
e. Cardiovascular risk will be minimised by the monitoring and management of blood pressure and lipids using the latest evidence based information for children. Facilities for paediatric ambulatory BP monitoring and echocardiography will be available (Level C).

f. Children will have their weight measured regularly and plotted on European Reference Charts for healthy children (Level B).

g. Nutrition will be assessed by a paediatric renal dietician in all children who are underweight or falling away from the centiles and in any child with significant electrolyte problems or hypertension. Dietary supplements or restrictions will be arranged as required in conjunction with the paediatric nephrologist and renal nurses using nasogastric or gastrostomy feeds if necessary (Level B).

h. Height will be measured regularly and plotted on the European Reference Charts so that growth problems or delayed puberty can be recognised and treated. This may involve a paediatric endocrinology team and use of supplementary hormone therapy will be considered (Level A).

i. Special arrangements will be in place to ensure that every child with ERF completes the normal surveillance checks and receives routine immunisations at appropriate times. Live vaccines must not be given within 3 months of high dose steroids or other immunosuppression. Additional immunisations such as hepatitis B, varicella, BCG and pneumococcal vaccine should be included in the schedule for children approaching RRT (Level C).

2. To provide each family group a full and effective multidisciplinary renal team to address the range of psychosocial issues precipitated by ERF or related to co-morbid conditions as well as addressing any pre-existing co-morbidity or psychosocial problems.

a. Every child with ERF will receive support from the multidisciplinary renal team to address the social physical and psychological consequences of their condition. These will change over time, as the child grows and as treatment modalities change (Level C).
b. CAMHS services must be available to provide support for children with ERF and their parents and siblings (Level C).

c. Play specialists must be available to help prepare children for investigations and treatments, help children to occupy their time effectively to help their emotional development and learning (Level C).

d. Every child with ERF will have the opportunity to benefit from a statement of Special Educational Need with input and advice from the expert multidisciplinary renal team co-ordinated through the local community paediatrician (Level C).

e. Each child will receive educational support, monitoring, and career advice as required to meet the constraints of ERF or additional co-morbid conditions including learning difficulty, sensory deficit or physical handicaps that give rise to additional educational problems. School attendance and performance will be monitored (Level C).

f. Financial support with adequate advice about benefits and charitable funds will be made available to all families (Level C).

3. To provide children and their families with sufficient details of all RRT options so that a valid and informed choice can be made.

a. Where dialysis is chosen as the first treatment modality, vascular or peritoneal access will be arranged in sufficient time. Access surgery must be carried out by a suitably skilled surgeon and for young children a paediatric anaesthetist in accordance with the standards set out in the Children’s NSFs in Wales and England (Level C).
Children’s Standard 5:

Transplantation in Children and Young People

Each child and adolescent likely to benefit from a renal transplant has access to a high quality service at a designated paediatric transplant centre supported by a multidisciplinary transplant team and followed up by paediatric nephrologists.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide appropriate information for children and their families regarding the benefits and risks of transplantation including living related donation and pre-emptive transplantation, with sufficient time for an informed decision to be made (Level B).

2. To provide joint care in the preparation of a child for transplantation by the multidisciplinary renal team and the transplant team (Level C).

3. To put in place arrangements that retrieval and transplantation takes place in the appropriate location by a suitably experienced transplant team.

   a. All children under 16 years of age will be transplanted in paediatric transplant units (Level A).

   b. Adolescents (16-18 years) are often most appropriately transplanted within paediatric units in view of their delayed physical and emotional maturation, and problems with non-concordance. When they are transplanted in adult centres their rights and needs, as a child will be respected (Level B).
c. Living donors will always be managed within adult institutions to ensure their safety. Special arrangements must be made to ensure that the timing of donor nephrectomy is appropriate. Rapid transport of the donor kidney to the children’s unit must be available to minimise the cold ischaemic time (Level B).

d. Adequate practical and psychosocial support must be provided to deal with the needs of the family coping with two sick members at different institutions (Level C).

4. To provide follow up care for children who have received renal transplants by paediatric nephrologists experienced in transplantation (Level B).

   a. Declining graft function will be investigated promptly (Level C).

   b. Children with intercurrent illness or requiring surgery must be managed in close collaboration with the transplant team and paediatric nephrologist in charge of their long term care (Level C).

5. To collect all required data for paediatric recipients wherever they are followed up for management and audit purposes including national returns to UK Transplant (Level C).
Children’s Standard 6:

Dialysis

Each child who requires dialysis for established renal failure receives appropriate, high quality, timely, effective, safe dialysis delivered by an expert paediatric nephrology team in a manner that is centred around the needs of each child, their family and carers.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide comprehensive and focussed education and training for the child and family in how to carry out dialysis and other treatments at home, how to recognise and deal with complications and who to contact in the event of an emergency. Support will be provided from the multidisciplinary renal team with additional help from local services where appropriate (Level B).

2. To provide HD for those children who require it in a tertiary paediatric nephrology centre with a full range of facilities for resuscitation and inpatient care by suitably qualified staff. The child must have access to a full range of complementary tertiary paediatric inpatient services including PICU, paediatric surgery, urology and endocrinology (Level B).

3. To establish a home PD programme based at the tertiary paediatric nephrology centre with as much care as possible being provided on a community basis (Level C).
4. To provide the quality of dialysis which meets the standards for children described in the Renal Association Standards document (Level B).

5. To provide treatment and follow up in a suitably staffed and equipped, child friendly environment with facilities for parents and siblings (Level B).
Children’s Standard 7:

Medicines for Children and Young People with Chronic Kidney Disease and Established Renal Failure

Each child with chronic kidney disease has access to all the medications they need when they need them in appropriate doses and formulations with adequate safeguards.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To ensure that:

   a. All children will have a written record of their medications giving the dose (in mg) and the strength (as mg/ml) updated on a regular basis by their health professionals (Level A).

   b. Patients/carers are able to obtain their medications locally without having to make unnecessary visits to the lead centre (Level A).

   c. Parents will be trained in how to measure doses and give medicines. Where there are multiple and complex regimens parents will be shown how to record the doses given (Level A).

   d. Children and their carers understand the reasons for being prescribed specific medications. Information should be given verbally but must be supported by written material (Level C).

   e. Children and parents are warned about the most common side effects and have access to suitable patient information leaflet (PIL) (Level C).

   f. Children and carers are told about which medications to avoid because of nephrotoxicity and which drugs to avoid because of drug interactions (Level C).
g. Parents are advised about which OTC preparations are suitable for their child (Level C).

2. To educate prescribers so that:

a. They are aware of alterations necessary in drug dosing with respect to impaired renal function in children as well as the special requirements for those on dialysis. This is particularly important for the newborn and for children with ARF where doses need to be reviewed on a daily basis and timed carefully in relation to dialysis (Level B).

b. They are aware of all current medications and possible drug interactions, particularly with immunosuppressive agents (Level A).

c. They have access to a paediatric renal pharmacist for specific advice (Level C).

d. Shared-care protocols are available and used where indicated. Further protocols may need to be developed to cover the full range of drugs used in children with renal disease (Level C).

e. Drug levels are monitored whenever appropriate (Level B).

f. The electronic patient record carries an up to date list of medication (Level A).
Children’s Standard 8: 

Transport

The NHS with other appropriate agencies will develop and implement an integrated approach to transport to support access to specialist treatment for children with CKD and ERF. This will minimise the adverse effect of their condition, age, and social circumstances and where they live on quality of life and medical care.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide an integrated transport package for children with CKD which has flexibility, permitting changes over time and circumstances, treatment modality, disease progression and educational needs (Level B).

2. To encourage self reliance, for all those who are independent of the transport system, supported by appropriate methods such as tokens and passes, or reimbursement of travel costs (Level C).

3. To keep carers and patients fully informed of funding and allowances and to provide assistance in applying for them (Level B).

4. To ensure that children with ERF suffering from an acute intercurrent illness are taken to the most suitable centre for care in an emergency (Level B).
Children’s Standard 9:

Care and Support for those who choose Not to Dialyse, to Stop Treatment or who are Terminally Ill

- A framework is established to ensure that all parents/carers/young people/children with ERF can be given timely, appropriate, and clear information about the choices of treatment available. Information is provided about prognosis, relative burdens and benefits of the different modes of dialysis, and where appropriate, information about local access to supportive and palliative care services.
- Patients who choose not to dialyse are offered continuing support from the multidisciplinary renal team as well as access to appropriate supportive and palliative care services in primary and secondary care.
- When dialysis is withdrawn it is done ethically and openly. Patients, their families and their carers are offered continuing support from the multidisciplinary renal team and palliative care services.
- The diagnosis of dying is made in a timely fashion. At this stage, the model of care moves towards symptom control. The patient and their family have access to generic and specialist palliative care. Where possible, the patient’s/family’s choice of place in which to die is respected.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To ensure that there is an appropriate framework so all decision-making processes and discussions take place within the established framework of the pre-dialysis discussion and involve multiple contacts with the multidisciplinary renal team (Level C).
a. There must be easy access to clinical psychology, social work and play specialist support.

b. Appropriate, up to date, prognostic information will be provided to patients, parents and carers, in a form adapted to their needs during the pre-dialysis decision making process.

c. When a competent patient declines to receive dialysis treatment, this should be clearly documented in the clinical record, including the reasons and rationale. Appropriate specialists should be consulted if there are concerns about the competency of a young person or carer to decline dialysis. Legal advice will be sought where appropriate to ensure decisions are made in the best interests of the child.

d. When dialysis is not offered as a treatment option the reasons for this should be explained to the patient and their family and/or carers in an appropriate format and clearly documented.

Conservative management of established renal disease

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To ensure that each member of the multidisciplinary renal team has expertise and generic training in supportive and palliative care (Level C).

a. Under some circumstances it appears to the multi-professional team or family that dialysis should not be offered. The Hippocratic Oath states that there is no duty on doctors to provide futile treatment. Under these circumstances, the General Medical Council’s “Withholding and Withdrawing Life-prolonging treatment: Good practice in decision making” and RCPCH 2004 document should be used to guide to management.
b. Outpatient follow up should be provided by a paediatrician with whom the child and family are familiar, preferably close to home.

c. Medical management of the complications of renal failure should aim to relieve symptoms rather than to achieve the standards designed for optimum long term outcome.

d. Clinical Psychology and social work support must be available for the team and should be easily accessible for families if required.

e. Each renal unit will develop clear guidelines and pathways for referral to hospital and community palliative medicine services.

f. There will be close liaison with the patient’s GP and other local primary health and social care services.

Withdrawal from dialysis

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To ensure that there is an appropriate framework so that in selected cases the relative benefits and burdens of dialysis are discussed before embarking on dialysis. Should the issue of withdrawal from RRT be raised by the patient, family/carer, or any member of the renal team, this will trigger a full review and discussion with all relevant parties to:

   a. Explore any adverse problems capable of improvement.

   b. Address issues of competence to make an informed choice.

   c. Provide detailed facts on the consequences of withdrawal and explore future care options available. This process should be open, transparent and documented. Time should be provided for patients and families to discuss and review their wishes. Dialysis should continue until a final decision is made, appropriate care has been arranged and the young person has had time to attend to personal matters.
d. Under these circumstances, the General Medical Council’s ‘Withholding and Withdrawing Life-Prolonging treatment: good practice in decision making’ should be used to guide management (Level C).

2. To ensure that the multi-disciplinary renal team and the family have an open and honest review of the decision-making process. Legal, psychiatric, psychological and social work opinion may be needed to ensure that the child’s best interests are being met. If dialysis is required it should be provided while the conflict is resolved (Level C).

3. To respect the wishes of patient/carers whatever the decision and to provide continued support and appropriate services to meet their needs (Level C).

**Care in the last days of life**

**Key Interventions**

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide flexible and high quality paediatric palliative care involving partnership and good communications between the child, family and multi agency team (Level C).

2. To focus on optimising quality of life and facilitating access to education, play and respite care (Level C).

3. To ensure that care is family led. Parents and children (where appropriate) will be supported to make their needs known. Specialist skills are required, to enable young children and adolescents to discuss their situation. Help will be offered to enable families to prepare for the death of a child; provision needs to be tailored, with an identified lead professional (Level C).
4. To involve palliative care specialists in a timely and appropriate manner to advise and help with specialist areas such as symptom control and pain management. Because of the specialist nature of renal disease the palliative care team need to work closely with the renal team in areas such as pain due to metabolic bone disease and choice of medication (Level C).

a. Local teams will have 24 hour access to the renal team and palliative care team.

b. Explicit links will be developed with specialist palliative care services, both in hospital and in the community, and appropriate referrals made.

c. Rapid discharge pathways should be developed to facilitate the timely discharge of patients to their preferred place of care.

5. To ensure that family care needs are reviewed at regular intervals after bereavement and support provided. Nursing team members who have previously developed a relationship with the family will offer follow up with support from the psychosocial team if parents or siblings request this (Level C).

6. To establish circumstances where by after the child’s death, all the professionals involved review the medical and psychosocial care provided (Level C).

7. To give the family the opportunity to meet with the multidisciplinary renal team to discuss their child’s condition and to clarify any outstanding issues (Level C).
Children’s Standard 10:

Transition to Adult Life and to the Adult Renal Services

Services for young people will be provided to adequately address the issues of growing up with CKD including transfer from paediatric to adult renal units.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the CYPSSP Network, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To set up a transition policy and programme which addresses the full range of issues related to growing up, taking control and responsibility and transferring to an adult service. This should include a range of supporting services including joint clinics with adult nephrologists. This policy will be prepared by the multidisciplinary renal team in conjunction with the adult renal units most likely to receive young people when they transfer (Level C).

2. To provide each young person with a named nurse or key worker who will deal with the complex medical, social and psychological issues that arise after transfer. The full resources of the multidisciplinary renal team should be available to support the process of growing up and transferring to an adult programme (Level B).
Rationale and Evidence Base

Children’s Standard 1:

Overarching Standard

The National Service Framework (NSF) for Children, Young People and Maternity Services and the National Service Framework for Children, Young People and Maternity Services in Wales from the Welsh Assembly Government set out the standards of care for all children receiving treatment in England and Wales respectively.[3, 4]

As many children with CKD and ERF in Wales receive some or all of their care in England, particularly in Birmingham, Bristol, Liverpool and Manchester, both publications are relevant to their care and must be reflected in the current publication. The Welsh standards must also reflect the standards for patients in England described in the National Service Framework for Renal Services parts 1 and 2 published by the Department of Health 2004 and 2005.[15, 16].

The presence of parents and family is important to the wellbeing and progress of the sick child and parents have a right to be present, to be involved and to help.[17] Just as with adults, children and their parents want to be included in decisions about their care. They need education and supporting information about the condition, its treatment and prognosis so that they can make important lifestyle decisions. They need to be empowered to take these responsibilities at the appropriate time.[18, 19]

This includes the need for parents to step back at the appropriate time in teenage years, and for staff, both on children’s and adult units, to recognise this need and the associated difficulties, and to encourage and support this process. Judging when and how to transfer these skills and responsibilities from parent to child is a complex task which needs more care and attention than has been given historically.[20]

Children with ERF and their families need access to a range of services. These include other tertiary paediatric services including paediatric intensive care, paediatric urology, paediatric surgery and transplantation which are all adequately supported by specialist children’s services such as radiology, dietetics, social work, physiotherapy, occupational therapy, education and pharmacy.[21-23]
The paediatric renal multidisciplinary team should include a dietician, pharmacist, play specialist, psychologist, social worker, teacher, trained paediatric renal nurses and paediatric nephrologists.[21, 24]

**Children’s Standard 2:**

**Prevention of CKD in Children and Young People**

The causes of CKD in childhood differ from those in adults. Children at risk of CKD include those with antenatal uropathy, with or without obstruction, congenital renal disorders such as hypoplasia, syndromes which include renal disease, familial and inherited renal disease, following ARF, particularly on neonatal intensive care and after neonatal or cardiac surgery.[7, 11, 25, 26]

The severity of CKD can be graded from 1 to 5 according to the K/DOQI (see standard 3) using GFR estimated from the Schwartz or Counaghan formulae.[27-29] The prevalence of CKD in childhood is unknown. Proteinuria and hypertension are important markers of CKD and risk factors for progression and co-morbidity just as in adults. Proteinuria is best assessed using protein/creatinine ratio since this is a reliable measures of proteinuria adjusted for urine concentration and does not require a timed collection.[30, 31] CKD in childhood is often associated with electrolyte problems such as salt wasting, dehydration and acidosis, poor growth and significant psychosocial morbidity.[32]

Blood pressure (BP) varies throughout childhood.[33] Its complications include hypertensive encephalopathy, neurological sequellae and pulmonary oedema which can develop rapidly at levels of blood pressure regarded as safe for adults.[34]

Approximately two thirds of children with CKD have structural urinary tract abnormalities and some of these need paediatric urological intervention to prevent or minimise the progression of disease.[7, 25] The proportion of infants with CKD and ERF due to urological or inherited conditions who are diagnosed antenatally is increasing as expertise in antenatal scanning and foetal medicine develops. The majority of children requiring RRT in the first two years of life have foetal uropathy and many have surgical problems such as urethral valves.[11, 35, 36]
The role of recurrent urinary tract infection (UTI) in causing progressive CKD in children with and without vesico-ureteric reflux is unclear.[37, 38, 39] Progressive damage is particularly likely to develop if infection is combined with obstruction, stones or neurogenic bladder. Some, but not all of these disorders may be detected on routine antenatal ultrasound scan. Children with evidence of CKD identified from within these groups benefit from more intensive monitoring.[16]

The normal creatinine in children is much lower than the adult normal range, so that an abnormal result may appear normal to someone not familiar with children and can easily be overlooked.[27] The techniques used for serum creatinine measurement all have limitations and methods vary from one laboratory to another. In particular, the lower end of the range, where the majority of children’s results will lie, is the area where there is most variation between laboratories. In the first few days of life the serum creatinine reflects the mother’s renal function, but normally the creatinine falls to infant levels by one week. Decision support enabled through the emerging health informatics programmes, linked to the electronic patient record and laboratories, with age appropriate information provides one of the keys for those less familiar with children to recognise abnormal results and act appropriately.[40,41]

Imaging in children is a skilled task. Investigations should be arranged in response to specific questions, to establish or clarify a particular diagnosis or range of diagnoses. Age appropriate centiles give meaningful information which should inform or replace the use of subjective terms such as ‘normal’.[42]

Many children have renal disorders, which need clinical care throughout the whole of childhood; some require intensive management including reconstructive surgery. For complex or progressive cases, early referral to a nephrologist and input from an expert multidisciplinary renal team has important positive implications for children’s physical health, growth, development and emotional well-being because of the range of expertise offered and the holistic approach to management.[22]
Interaction between members of the tertiary paediatric multi-professional renal team and local services through the managed clinical network, will help maintain and develop the skills of professionals near to the child's home and improve quality of care by increasing local support and reducing the need to travel to the tertiary centre.\[43\]

**Children’s Standard 3:**

**Prevention, Recognition and Management of Acute Renal Failure in Children and Young People**

It is difficult to estimate the annual incidence of children with ARF in the UK since some children are managed conservatively by general and non-renal specialist paediatricians and recover renal function fully. The Renal Association has provided some estimated figures for UK\[10\]. In the paediatric population ARF is highest in the neonatal and infant group when pre-renal causes predominate. Major causes in childhood include multi-organ failure on Paediatric Intensive Care Units (PICU), septicaemia, dehydration, major surgery, nephrotoxic drugs, nephritis, Haemolytic Uraemic Syndrome (HUS) and acute on chronic renal failure.\[44-46\]

Appropriate management of the circulation, fluid balance and medication in the sick child has a major role in preventing ARF on the ward, postoperatively and in intensive care.\[45, 47\] Fluid and nutritional requirements at different ages are complex and management of these areas can only be carried out safely by those with suitable training.\[22,48\]

Staff who look after infants and children must be capable of understanding the circulation and recognising and acting on the markers of impending or established ARF including oliguria, polyuria, dehydration and fluid overload, abnormalities of blood pressure and markers of renal disease such as haematuria or proteinuria in infants and children at all ages.\[49\] Advice from an expert paediatric nephrology team may provide the optimal care. Best results will be obtained when children are transferred to specialist centres particularly if dialysis is required.\[50\]
Children who survive ARF usually have full recovery to normal renal function with few progressing to ERF in childhood. A small proportion of children do not recover fully and have a risk of CKD in childhood and adult life.[53]

**Children’s Standard 4:**

**Established Renal Failure and Preparation for Renal Replacement Therapy in Children and Young People**

**Epidemiology of ERF**

The number of children reaching ERF per annum is in the region of 2 per million of the total population. In Wales the number of children starting RRT is expected to be around 6 per year.[7, 11, 52] This equates to an average of 1.5 new cases per year in North Wales and 4.5 per year in the remainder of Wales. The average age at start is 9 years giving a total of approximately 50 children on RRT in the whole of Wales at any one time compared with around 1500 adults, just 3% of the total. In 2002 there were 818 children in the UK receiving RRT. The prevalence of ERF has increased slightly in the under 18-year-old age group over recent years as treatment has improved and survival into adult life has become the norm.

**Information about ERF**

Children, young people and their families benefit from preparation through an educational process delivered by a multi-professional renal team.[22, 53, 54] This will reduce both complications and psychosocial impact of disease. A full complement of skilled professionals with experience of renal disease within the multi-skilled paediatric renal team is needed to address the many and complex issues that surround dialysis in a child.[25] Provision of care and advice at home is particularly effective and reduces the need for stressful hospital visits.[55]

A personalised care plan held by the child and family, which records past events, results and describes the aim of the current treatment mode can be used to set out the information and education needed at each stage and record contacts with members of the multidisciplinary team.[15]
Management of complications

Active and co-ordinated management of pre-established renal failure in children has resulted in improved growth, nutrition and rehabilitation as well as in a delay in the onset of ERF.[56, 57] The rate of decline of function in chronic kidney disease (CKD) in the majority of children allows a crude prediction of the time when RRT may be needed. Children with stage 3/4 CKD are at high risk of the complications of ERF and therefore these problems must be monitored and managed proactively. Complications include hypertension, anaemia, bone disease, poor growth and nutrition, delayed puberty, fluid and electrolyte problems, cardiovascular morbidity and psychosocial problems.[10, 58]

Psychosocial impact

The diagnosis of CKD in a child has a significant psychosocial impact on the whole family with high levels of anxiety and stress amongst parents and siblings, interference with work, family activities and reduced income.[59] Early intervention by a skilled renal psychosocial multidisciplinary team can reduce the morbidity for both the child and family.[22, 60] Occasionally, a child may present late in ERF, in which case there is less time for preparation and planning. This tends to have an adverse effect on the medical course of the disease as well as the adverse psychosocial impact on all concerned. This situation requires intensive input to deal with the family crisis that is caused by such sudden onset of life limiting disease.

Health surveillance and immunisations

For children with CKD the risk of developmental delay, sensory deficit or growth failure is greater than for other children and the need for protection by immunisation is greater. Because of illness and hospital admissions some children with CKD, particularly those on RRT, may miss some or all of these checks and immunisations. Some children need modifications to the standard immunisation schedule, with additional immunisations to meet the requirements of dialysis or transplantation.[61]

Play and education

Play, nursery, school education and career planning are important components of childhood and must be accommodated appropriately
within the healthcare and education settings and addressed in the child's care plan. Understandably, parents are protective of their children and some children with ERF have less exposure to the normal life experiences, particularly, in relation to separation and independence, when compared with their peers. The renal teacher, who is an essential member of the renal multidisciplinary renal team, can initiate or supervise many of these tasks as well as liaising with local schools and co-ordinating the child's special educational needs. This function is additional to the need for lessons and tutorials for individual children.

A trained play specialist with renal expertise is another essential member of the team and has a key role for younger patients, preparing children for dialysis or procedures, occupying them when on treatment and helping the parents develop their own skills in these areas.

**Pain and sedation**

Children are easily frightened by pain or unfamiliar situations and their pain is often overlooked or under treated. Children have a greater need for sedation or anaesthesia than adults. The play specialist and psychologist have vital roles in managing pain and fear and may work alongside an anaesthetist, nurses and parents to develop a joint approach to pain management and sedation as well as working directly with each child.

**Treatment modality**

Children and their parents need sufficient information to enable them to understand ERF, its complications and treatment. They also need adequate training so that they can understand the condition, medications and treatment options, and can enter into informed dialogue with the multi-skilled renal team. They need to understand the short, medium and long term plans for the child so that they can prepare for future events.

Planning for RRT should start in sufficient time to allow for the child and family to learn about ERF and all the treatment options so that informed decisions about the first treatment modality can be made jointly between the family and the multidisciplinary renal team. Although the optimum management for most children is a successful
transplant, for many reasons a pre-emptive transplant may not be possible. Occasionally the difficulties of treatment may outweigh the benefits and in these circumstances the team must be able to support a child and family in choosing a conservative approach (Children’s Standard 8).

**Dialysis access**

Access for haemodialysis or peritoneal dialysis is critical. Without adequate access treatment cannot take place. Children with ERF have a lifetime ahead on RRT and loss of venous or peritoneal access is a life limiting factor.

Best results are obtained when access is planned and carried out well in advance by appropriately trained surgeons working within an expert team including a paediatric anaesthetist and radiologist with experience of vascular access for dialysis.\[69\] Parents and staff must be educated in how to care for the central line to minimise the risk of infection. It is important to avoid canulation of veins that may be required for a fistula in the future.

Planning the peritoneal access site is an important example of joint decision making between the patient, parents, renal nurse and surgeon. In infants this should usually be above the nappy and away from the gastrostomy site, while teenage girls may wish to consider the cosmetic aspects of the exit site position. Care and monitoring by parents and staff can improve outcome.\[70-72\]

**Children’s Standard 5:**

**Transplantation in Children and Young People**

**Epidemiology**

The number of children who receive a transplant in the UK is around 2 per million of the total population per year and the prevalence in 2002 was just over 70% of all children on RRT. Approximately 20% of these were from living related donors. Both graft and patient survival in children is superior to adults.\[11, 24, 25, 73, 74\] The graft survival in children aged less than 10 years is particularly good but there is a marked deterioration in graft survival in teenage children.\[74, 75\]
A successful renal transplant provides the best quality of life for a child and family and is the most clinically beneficial and cost effective treatment for children with ERF. Although the technical aspects of transplantation in older children can be managed by adult renal teams, teenagers aged 15-18 benefit significantly from the range of services provided by the multidisciplinary renal team, and renal paediatric unit.[22, 74]

Pre-emptive transplantation (transplantation prior to the commencement of dialysis) results in improved growth and psychosocial development, and conserves peritoneal and haemodialysis access for future use. The long-term outcome for pre-emptive transplants is superior to transplants performed in children established on dialysis.[73, 76, 77] Pre-emptive transplantation should be considered when the GFR falls below 15 ml/min/1.73m2. The British Transplantation Society recently published national guidelines relating to this.[78]

Live donor transplantation has a significantly improved outcome compared with cadaveric transplantation.[73] The living donor transplantation rate in UK paediatric centres however is lower than that in other European countries and North America.[79] Major steps need to be taken to redress this situation in view of the improved graft survival and the flexibility, which pre-emptive, live donation offers the family. Units must provide families with information about these benefits as well as the risks.[75]

The management of children and adolescents before, during and after transplantation is a multidisciplinary activity. Young children present medical and surgical challenges that differ from those of adult patients. Great care is required in planning and managing fluids and the circulation in the hours before, during and immediately after surgery to ensure that the new kidney is adequately perfused.

The first post operative days are very demanding for some children and their parents and the support of the multidisciplinary team is needed, particularly after live donation or if there are complications or rejection episodes. In the medium and long term there is a need for frequent adjustments of diet and medications in response to changing circumstances and to permit growth.
Kidneys from donors aged less than 5 years are not generally recommended in paediatric renal transplantation, since these are associated with less favourable graft survival in both the short and long-term. The use of kidneys from older adult donors is also associated with poor long-term graft survival, and therefore as a general rule, only kidneys from cadaver donors under 55 years of age are offered to paediatric recipients.\[^{74, 80}\]

Immunosuppressive regimens change constantly with the publication of peer reviewed studies. Currently Tacrolimus based triple immunotherapy appears to have the most favourable outcome.\[^{81}\]
Use of steroid free protocols should be adopted if safe and effective alternatives become available because of the adverse effects of long term steroids on general health.

Non-concordance is the most common cause of graft loss in adolescence reflecting the need for close medical supervision\[^{82-85}\] and adequate structured arrangements for transfer to adult units.

**Children’s Standard 6:**

**Dialysis**

Approximately 25% of children on RRT in the UK are on dialysis, with a third of these on haemodialysis (HD) and two thirds on peritoneal dialysis (PD). This means that on average in North Wales around 4 of the 13 children on RRT will be dialysed at any time, with 1 on HD. In the South around 10 of the 40 children on RRT will be dialysed with an average of 3 on HD.

For children starting dialysis all the complications and co-morbidity of ERF (described in Standard 3) including problems of growth, nutrition, vomiting, anaemia, metabolic bone disease, hypertension, fluid balance and electrolyte problems persist and need continued supervision and management.\[^{10, 86, 87}\] The impact of dialysis on families is significant as one of the parents is often occupied full time in the management of a small child with renal failure, dealing with diet, fluids, medication, tube feeding, monitoring and home dialysis.\[^{19, 59, 72, 86, 88}\] Children on dialysis are clearly different to other children in that they are tied to a machine for many hours each week and are often in hospital. Inevitably this has a financial cost as well as a psychosocial cost to
all the other family members. The effect on jobs and relationships takes a heavy physical and emotional toll. The parents have a huge burden of responsibility and life threatening complications can occur with little warning.\textsuperscript{[89]}

The adequacy of dialysis should be measured and adjusted regularly so that the dose is sufficient for a reasonable quality of life with minimal complications and takes account of growth.

The negative effect on a child's life in terms of lost time and opportunities as well as negative experiences of illness, fear, pain and grief can be profound. A fully staffed, co-ordinated psychosocial team is required to address these predictable but demanding problems and to give these issues the attention they deserve. The chronic demands on time and emotions have a heavy burden.\textsuperscript{[89]}

\textbf{Peritoneal dialysis}

PD is the preferred mode of treatment for many children because it is less disruptive to family life than haemodialysis. Most children use overnight continuous cyclical peritoneal dialysis (CCPD) because this interferes least with normal domestic and school routines. This requires preparatory surgery to place a canula in the abdomen in sufficient time to allow healing before dialysis starts.

These children also require medications and frequently are receiving overnight feeds via a pump. Drugs are sometimes added to the dialysis fluid at home by the carers using an aseptic technique. Peritonitis is a serious complication requiring intraperitoneal antibiotics and sometimes hospital admission.\textsuperscript{[90]}

\textbf{Haemodialysis}

To minimise the risks associated with HD children need to receive treatment in a fully operational tertiary paediatric nephrology centre to ensure effectiveness and safety.\textsuperscript{[91]} Travelling time may be up to three hours each way. Thus the primary carer is occupied fully for at least three days each week and is unavailable for normal household duties, siblings or career. Between dialyses the child may not feel well, is on complex medication and often has fluid and dietary restrictions requiring further care and attention.
Normal school attendance is difficult or impossible for children on HD. Support for lessons should be organised through a teacher who is part of the multidisciplinary renal team.\textsuperscript{[24,91]} A statement of educational need is recommended as this guarantees access to the resources required. School attendance is a valuable measure of quality of life and successful treatment.

**Emergencies**

From time to time emergencies develop at home which need to be addressed by an on call service providing advice on the telephone by experienced paediatric renal nurses and admission facilities to fully staffed paediatric nephrology beds. In an emergency the parents, carers or local health care professionals must have clear advice on what to do and who to contact so that emergencies are managed safely and consistently.

**Children’s Standard 7:**

**Medicines for Children and Young People with Chronic Kidney Disease and Established Renal Failure**

Over recent years there have been significant efforts to rationalise drug prescribing for children in the UK. This has led to the publication of the formulary *Medicines for Children* by the Royal College of Paediatrics and Child Health (2003)\textsuperscript{[92]} and the British National Formulary for Children (2005).\textsuperscript{[93]} Historically there has been only limited research into drug pharmacokinetics and hence dosing in children, primarily because of the relatively small market compared with adults. As a result, many drugs administered to children are either used outside the licensed indication (off-label) or without a license (unlicensed). Further information is available from the RCPCH website.\textsuperscript{[92]}

Children with renal disease often require a significant number of drugs including anti-hypertensives, immunosuppressives, hormone replacement, electrolyte supplements and phosphate binders. These medications will usually be initiated by hospital based staff, but repeat prescriptions may be provided from primary care by doctors less familiar with their use, particularly in children.
The issue of prescribing to children has been analysed in detail in Standard 10 of the English National Service Framework for Children, this document is an important reference[92] and the British National Formulary for Children (2005).[96] In addition, a supplementary document to the English Adult Renal NSF addresses issues with prescribing in renal disease.[94]

Children with CKD or ERF are often on multiple therapies, which may be altered frequently, depending on laboratory and other tests. Although they may have interactions with primary, secondary and tertiary care and knowledge of current medications is important in all settings, communication about current medication is often unavailable. Patient recall of drugs may be variable and an up-to-date written or electronic patient record would be helpful, and could provide an accurate record available to prescribers and additional reassurance for patients. As part of the education for the child and carer, an understanding of the reasons for each drug prescribed and its associated side-effects must be given.

Children with impaired renal function also accumulate drugs, which are excreted by the kidneys. In early infancy, particularly in preterm infants, the kidney is particularly immature and vulnerable to nephrotoxicity.

In transplanted children, the main area of concern is with drugs metabolised by the cytochrome p450 pathway that may affect levels of immunosuppressive drugs such as cyclosporine. Examples of common interactions in childhood are phenytoin, which lowers the cyclosporine level, and erythromycin, which elevates it.

Many of the drugs prescribed in renal disease will not be commonly encountered by general paediatricians, general practitioners or community pharmacists. Advice from paediatric nephrologists and paediatric renal pharmacists regarding prescribing and dispensing of child-friendly preparations may therefore be needed.

Some pain killers are either nephrotoxic or excreted by the kidney. However, this should not be used as a reason not to give children with renal disease adequate pain relief. Appropriate choice of drug, dose and dosage interval can all contribute to safe and effective management.[4, 95]
From time to time parents have resorted to unproven alternative therapies. For the majority of treatments there is no evidence of benefit and a small but significant risk of serious harm. These therapies may raise the hopes of the child and family inappropriately and are therefore not recommended.

**Children’s Standard 8:**

**Transport**

The Children’s NSF for Wales recommends that families should have access to equitable care regardless of geography and social circumstances and should not endure material hardship attending outpatient departments a long way from home.\(^4\) The ethos of this document is that children are treated as near to home as possible whenever possible. Kennedy recognised the need for children to travel further to receive expert care and stated that adequate help with transport should be available to support this.\(^{50, 96}\) Children with serious acute and CKD including those preparing for and undertaking RRT need specialist care, some of which can only be delivered at specialist tertiary paediatric nephrology centres. Many children in Wales must travel to England for this.\(^{21}\)

Whenever a child travels to a hospital for an appointment or for treatment a carer must accompany them. Thus the cost of travel by public transport is greater than for adults and the carer is unavailable for normal duties at home or work. Consequently the impact on the family of a child receiving treatment at a distant site is magnified. Poor transport affects the sick child’s education, the care of siblings and the carer’s ability to work. It also disrupts family life socially and financially.\(^{59}\) A recent survey has demonstrated the significant and variable costs to families. They found the average parking charge for a 24 hour stay is £8.50 and that in one hospital where there is a standard £2.30 per hour charge parents could face parking charges of up to £55.20 per day.\(^{97}\)

Helping patients or carers to learn to drive or to obtain their own transport can promote the family’s independence. Some may be eligible for government or charitable funds, while a patient in receipt of the higher rate of disability living allowance may apply for a driving license from age 16, instead of the usual age limit of 17 years.
Children’s Standard 9:
Care and Support for those who choose Not to Dialyse, to Stop Treatment or who are Terminally Ill

Background

The death of a child is not only untimely but is outside many people’s everyday experience. In renal medicine it is rare for children to need conservative management (without RRT) and subsequent palliative care. The total number of children dying each year is around 20 for the whole of the UK and may be less than one patient per year in a small unit. This means that particular attention needs to be paid to staff training in this complex area in which teams may have limited experience.

These complex management decisions will most often be faced in the following circumstances; all of which present different psychological and logistical challenges to good care.

- When a child is diagnosed with severe renal problems antenatally.
- When a child’s renal disease is part of a complex syndrome involving multiple disabilities and or malformation of organs.
- When a child with renal disease develops a secondary life threatening illness (e.g. cancer).
- Unexpected and sudden deterioration and death.
- When access sites have been exhausted.

Decision-making can be divided into four areas; each of these areas will be addressed in the four modules below.

- Choosing not to dialyse.
- Conservative management of established renal failure.
- Withdrawing from dialysis.
- End of life care.

In the absence of data from formal outcome studies in this area these principles of care have been drawn from practice based evidence and professional guidelines.[98-104]
A child’s primary carers, most often their parents will be crucially involved in treatment and decision making from the outset. Relationships need to be established with the developing child, or young person and their family in order to facilitate effective partnership. Good psychosocial input from the time of diagnosis should create a forum where the burdens and benefits of treatment can be discussed routinely. Communication about changes in health status and discussion of options can then take place in the context of an established relationship with the medical and psychosocial team.[22]

- Children may live in families where there has been disruption and change. The renal team will need a thorough understanding of family structure and relationships in order to involve parents and carers appropriately in treatment choices. The needs of grandparents, siblings and of non-resident parents will need to be considered. In some cases clarity will need to be sought about a child’s legal status.

- Special skills are required to communicate with children of different developmental levels about their illness and to consider issues of consent and competence to understand their situation and to make choices.

- Competence and consent issues may need to be addressed with the help of appropriate specialists. This may be in regard to a child and or adult’s competence and or mental health. Specialist consultation should be easily accessible. Legal advice may be required to clarify the position.

- Timely and effective training for staff in preparation for a rare event presents particular challenges.

- It is especially hard to predict renal prognosis in infants, and frequent and careful reassessment and review of decision making is essential.

- Because children and family circumstances and health status can change unexpectedly, there must be regular opportunities to review decision making. This should take place in an accessible forum involving professionals who are providing continuity of care.
Choosing not to dialyse

Decisions on withholding treatment should follow the guidance published by the General Medical Council and RCPCH 2004.[105] Where necessary, appropriate childcare legislation will be used to ensure that the best interests of the child are met.[106]

Although accurate information about prognosis in CRF is sparse and relates to populations/patient groups rather than individuals, children who are approaching ERF with multiple co-morbidities may not have their quality of life improved by dialysis so that the burden of treatment may outweigh the benefits. Consequently choosing not to dialyse may be appropriate for them.

Supporting information should be available in a range of formats such as audiotapes, videos and pictures or through a play specialist for adult non-readers, young children and adolescents.

Conservative management of established renal disease

When a decision is made not to start RRT a child or young person may well survive for many months or even years. During this time they will need a positive approach, which maximises their physical well being and quality of life. Although they will not receive renal replacement therapy they continue to have specialist needs which should be managed proactively by the multidisciplinary renal team. Since their life expectancy will be relatively short, the goals of therapy will be directed more towards symptom control and quality of life rather than influencing prognostic factors.

As their illness progresses and death becomes closer, their needs and those of their family/carers will change and this will need to be reflected actively in their care plan. Similarly, medical management, its aims and priorities will need to change. Blood pressure control will still be important to slow progression of renal failure but should be balanced against the side effects of medication and low blood pressure. Correction of renal anaemia is particularly important to preserve functional status and a sense of wellbeing. Dietetic advice can be valuable and should vary during the period of conservative management to reflect the child’s current needs. Potassium restriction, which can severely limit dietary choice, is important to prevent sudden cardiac death but may require relaxation as the illness progresses.
Phosphate control may become less important unless symptoms such as pruritis develop.[10]

Withdrawal from Dialysis
Before starting dialysis the relative burdens and benefits of treatment should be discussed in full as they relate to the particular child and family. When appropriate this should include a discussion on the possibility of dialysis being withdrawn at some point in the future, either at the patient’s request or under certain clinical circumstances. There may come a time when the benefit of treatment is questioned. The young person may perceive that dialysis has become an intolerable physical or psychological burden. Under these circumstances, stopping dialysis is a legitimate choice for a competent patient. Many patients do not understand their right to make an informed choice, and fear to raise the issue, for a variety of reasons.

The family, carers or any member of the multidisciplinary renal team may separately feel that the end of life is approaching, and that the burden of therapy outweighs the benefits to quality of life.

Managing withdrawal from an established treatment is a stressful event for all involved. Renal multi-professional staff are wary of the sensitive, ethical issues involved, and the potential for distress or conflict.

Care in the last days of life
Care in the last days of life is a legitimate extension of the renal service, being a final duty of care that requires development and co-ordination. The impact of a renal patient’s death may also have consequences for the staff, and the renal patient peer group and their families, which may need to be addressed.

Children’s Standard 10:
Transition to Adult Life and to the Adult Renal Services
The number of children surviving RRT in childhood and entering adult RRT programmes has increased because of the excellent childhood survival figures. Young people now represent a significant and growing proportion of the younger patients on adult units. In 2003, 36.6% of children with ERF were aged between 12-16.[7, 11, 12] With this increasing number of children with chronic illness surviving into adulthood there
is a growing need for a structured process of transition to adult life, including transfer to an adult unit. This process must be recognised by all those involved including the patient and family and both the transferring and the receiving units.\textsuperscript{[107]}

It is important to consider the long term implications of every decision and treatment. Preserving dialysis access\textsuperscript{[28]}, avoiding transplant antibodies\textsuperscript{[74]}, ensuring good growth\textsuperscript{[25, 103, 108]}, minimising steroid use\textsuperscript{[109]}, minimising bone disease and cardiovascular morbidity, providing young people with understanding and motivation\textsuperscript{[17, 110-112]} and supporting transition to adult life are critical to the successful integration of a child with ERF into adulthood.\textsuperscript{[19, 20]} Cardiovascular morbidity is a major risk factor for adults with ERF making the promotion of healthy diets, reasonable exercise and not smoking particularly important.\textsuperscript{[86]}

Teenage children who are capable of a wide range of social skills may still find coming to terms with life threatening or life limiting disease extremely difficult and some have little ability to manage it effectively or safely.\textsuperscript{[113]} Their communication and social skills may lag behind their level of understanding. Maturation to adulthood does not happen at any one particular point in a child’s life and different aspects mature at different times. However, this difficult maturation process can be made more difficult by the need to transfer from a paediatric renal unit to a very different type of service provided for adult patients.\textsuperscript{[114]} The harsh reality of the quality of life and long term prognosis for dialysed patients is in stark contrast to that of a young person with a successful transplant who often leads a near normal life.\textsuperscript{[75]}

Transformation into an adult from an administrative viewpoint is completed at the 18th birthday when the child finally becomes a legal adult with the right to vote. Some aspects of maturation will already be established while other aspects will be incomplete. Children with renal failure or on steroids tend to be shorter and mature physically more slowly than healthy children.\textsuperscript{[115]} They have often had reduced life experiences and may have been discouraged from separation and independence from parents because of the imperative to ensure that their medical treatment was optimal. Appropriate input from a psychologist and other members of the psychosocial team are crucial to deal with many of the issues associated with renal disease and
growing up. While adults grieve for their child’s health when illness is first recognised the child grieves for loss of normal health as a teenager or young adult, when the full implications of their condition become more obvious, adding to the difficulties encountered at this time of change.

The transition to the adult renal service must be carefully planned and managed both by paediatric and adult staff with involvement of the whole multidisciplinary renal team from both referring and receiving units if the risk of psychosocial upset, graft failure and dialysis complications are to be minimised at this difficult time.[116]

There are a number of separate but related processes for a child to negotiate when moving from childhood to adulthood. This is a difficult time for every adolescent, but much more so for a teenager with renal failure. Some of the steps related to growing up and taking adult responsibilities are listed below:

- Puberty, growth and final height (children with ERF are often shorter than peers and have delayed puberty).
- Independence and separation from parents/carers.
- Leaving school, moving to college, leaving home.
- Planning and developing a career, starting a job.
- Understanding their medical condition.
- Being different from healthy children.
- Understanding about dialysis and transplantation.
- Understanding complications of their condition and its treatment.
- Knowing what to do if something goes wrong.
- Understanding the medications and what they are for.
- Understanding the consequences of not taking medications regularly.
- Coping with side effects of drugs.
- Taking full responsibility for their condition.
- Knowing how to talk to their doctor or nurse about their condition.
• Knowing how and when to make contact with their renal unit in an emergency.
• Relationships, sex, pregnancy, contraception and genetic counselling.
• Prognosis for a life limiting condition.
• Lifestyle choices such as smoking and exercise.
• Financial independence.
• Understanding their rights and how to assert them.

For many children with renal failure the processes listed take place later than for their peers either because of illness and treatment or because of limited life experiences related to their illness and loss of education. The importance of the process of growing up and moving on is now recognised. Paediatric units have a duty to prepare children and young people for this transfer process and adult services need to recognise the particular needs of young people to get a good start on their journey as an adult with ERF or CKD.

Some children present in late teenage years with CKD or ERF and there may be a dilemma about who should treat these children who are often fully grown and have had the benefit of a normal and healthy childhood. These children should be able to choose with their parents and health professionals whether or not to be treated in a paediatric or an adult unit taking into account all the relevant factors such as age, maturity and where they live. However, if a decision is made to have treatment at a local adult centre rather than at a paediatric renal unit it is essential that the child’s needs and rights are considered and respected[117]. This may be achieved by working with a local paediatrician or through the paediatric nephrology clinical network and links to the paediatric tertiary service.
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97. Parking at Hospital Sites - a survey by Contact a Family Wales and the Association for the Welfare of Children in Hospital (AWCH) 2005.


MODULE 2

Standards 2-4:

Prevention, Early Detection and Management of Chronic Kidney Disease

Introduction

There is a growing body of literature highlighting the negative impact of under and late referral for more specialised care of patients with renal impairment.\cite{1-5} Observational studies have uniformly shown higher morbidity, lengthened hospital stay, and increased costs of treatment following late referral of patients starting long-term dialysis. This is partly related to failure to detect renal disease in at risk populations.

Of all patients identified with abnormal renal function, only a proportion will develop progressive renal failure requiring renal replacement therapy (RRT). There is, however, a heterogeneous list of medical conditions that can lead to chronic kidney disease (CKD) including primary renal diseases such as glomerulonephritis, and Autosomal Dominant Polycystic Kidney Disease (ADPKD), secondary renal diseases such as reflux nephropathy, and multi-system disorders such as diabetes, myeloma and Systemic Lupus Erythematosus.

Furthermore, there is a higher incidence of established renal disease amongst people of Indo-Asian and Afro-Caribbean origin as a result of diabetes and hypertension respectively. This highlights the need for renal services to be accessible to all patients; with particular emphasis on high-risk groups either in terms of medical or ethnicity related factors. There is also good evidence that CKD can be prevented in some high-risk groups, and that early detection and intervention can prevent or delay further damage and progression in others. Even when renal disease is established, there are specific clinical interventions to reduce the complications of CKD which, should underpin the commissioning, and delivery of renal services.
At present, there is no evidence to support whole population screening. The focus of this module is, therefore, to address the issue of renal disease in ‘at risk’ patient groups accepting that a large proportion of patients with renal disease will continue to be identified as a result of opportunistic testing.

**What does this mean for patients?**

Standards 2 and 3 focus on the prevention or early detection of renal disease. Standard 4 is concerned with the management of patients with established renal disease with the particular aim of slowing down its progression and preventing or minimising its complications.

- Standard 2 provides a framework to identify those people in the community who are at risk of developing renal disease and puts in place the means to identify those risks and to minimise them. For example patients with diabetes whose blood sugar is poorly controlled are at increased risk of developing renal disease. Levels of blood sugar control are identified which, if applied will reduce the incidence of renal disease in this group.

- In Standard 3 a mechanism is set up to identify patients with renal disease at an early stage so that they can be properly investigated and a plan set up for their long term care.

- Standard 4 is focussed on those patients who have established renal disease. Its interventions are aimed at slowing down the progression of the disease. It also sets out a plan for identifying the complications of renal disease at an early stage and a means to treat or minimise them. For example the early detection and treatment of anaemia and or bone disease.

The implementation of these renal standards will also allow interaction with other linked National Service Frameworks whose standards have an impact on patients with renal disease. In turn, those caring for patients with other conditions or diseases, such as diabetes, will be able to draw on these renal standards.
Standard 2:

Prevention of renal disease

Each patient with detectable risk factors for developing renal disease is identified and has access to the appropriate care and advice and, where indicated, treatment to minimise the risk.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To identify those people at increased risk of renal disease, including those from ethnic minorities. In particular, those identified at increased risk will be educated about the benefits of tight blood pressure control and other interventions that may reduce the incidence of renal disease such as stopping smoking, reducing weight and taking regular exercise (Level C).

2. To identify those people at risk of congenital renal disease for early identification of any renal problem, as well as aggressive management of factors known to accelerate the rate of progression, such as hypertension (Level B/C).

3. To provide genetic screening to the first-degree relative of patients with congenital diseases with known inheritance patterns (Level B/C).

4. To review all medication of those patients at increased risk of renal disease to identify potential nephrotoxicity (Level C).

5. To detect and treat hypertension according to published national guidelines including:
a. Life style assessment and modification as a fundamental part of patient management. This includes patient education as to the health risks associated with hypertension. Patients will also be informed, when necessary, of the potential benefits of dietary modification, smoking cessation, regular exercise and reduced alcohol intake. Pharmacological treatment will be tailored for each individual being, mindful that 50% of patients will not have adequate blood pressure control (Level B).

b. Targeting of blood pressure will be as outlined in the CHD NSF, i.e. less than 130/80 millimetres of mercury (mmHg) (Level A).

c. Treatment of isolated systolic hypertension (ISH) following current guidelines with ISH being defined as SBP greater than 140mmHg with DBP less than 90mmHg (Level A).

d. The first line of treatment for patients with proteinuria and hypertension with Angiotensin Converting Enzyme inhibitors (ACEi). In patients intolerant of ACEi, Angiotensin II receptor blockers will be considered as an alternative (Level B).

6. To reduce the incidence of diabetic nephropathy in all diabetics by tight control of blood sugar to achieve HbA1c- 6.5%-7.5% and treatment of hypertension to achieve a target blood pressure less than 130/80mmHg (Level A).

7. To identify, monitor and treat hyperlipidaemia with appropriate lifestyle and pharmacological intervention (Level B).

8. To identify and appropriately manage patients with bladder outflow obstruction including:
   a. Assessment of renal function in all patients presenting with lower urinary tract symptoms, and men with symptoms suggestive of bladder outflow obstruction (Level B).
   b. Annual measurement of renal function in all patients with chronic outflow obstruction (Level C).
   c. Early relief (within 24 hours) of obstruction co-ordinated by interventional radiology and urology services (Level B).
9. To ensure that patients with renal disease identified by occupational screening programs are appropriately referred and investigated (Level B).

10. To manage proactively those patients undergoing an elective procedure who have been identified as carrying a high risk of developing acute renal failure (Level B).
Standard 3:

Detection of renal disease

Established renal disease is detected early in each patient at increased risk of developing progressive renal impairment.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To measure renal function regularly in all the following patient groups with the frequency to depend on the stability and severity of the renal function (Level C).
   a. Patients with known CKD.
   b. Those with heart failure or atherosclerotic vascular disease (myocardial infarction, stroke, peripheral vascular disease).
   c. Those with diabetes (type I and type II).
   d. Those with a history of recurrent and complicated urinary stone disease.
   e. Those with bladder outflow obstruction, neurogenic bladder and patients with surgical urinary diversion.
   f. Vulnerable patients receiving diuretics.
   g. Patients receiving ACE inhibitors or ATII receptor blockers. In addition, renal function should be checked prior to, within 2 weeks of starting and within 2 weeks after subsequent increases in dose.
   h. Patients receiving long-term treatment with Non-steroidal anti-inflammatory agents (NSAID).
   i. Hypertensive patients of Afro-Caribbean background.
2. Measurement of renal function will be by serum creatinine (standardised to the ID - MS technique) together with a formula-based estimation of creatinine clearance using the four part MDRD equation. The results will be calculated and reported automatically by all chemical pathology laboratories. The results of renal function will also be reported in a format, which allows any measurement to be easily compared to previous results. Only eGFRs’ of <90 ml/min/1.73m² will be reported numerically. A single abnormal eGFR reading will prompt urinalysis for blood, protein and infection; as well as clinical examination and follow up (Level B).

3. All patients with CKD will be stratified according to estimated GFR (Level C).
   a. Stage 1 greater than 90 ml/min.
   b. Stage 2 60-89 ml/min.
   c. Stage 3 30-59 ml/min.
   d. Stage 4 15-29 ml/min.
   e. Stage 5 less than 15 ml/min.

4. The format whereby urinary protein excretion is reported will be standardised. This is to avoid the confusion arising from the use a variety of units of concentration. The use of the protein-to-creatinine ratio is to be adopted as the preferred method other than for the identification of nephropathy in diabetics where albumin-to-creatinine ratio will be used.
   a. Microalbuminuria - albumin: creatinine ratio greater or equal to 2.5 mg/mmol [men] or 3.5 mg/mmol [women].
   b. Proteinuria - protein: creatinine ratio equal to or greater than 100 mg/mmol (Level B/C).
5. To investigate renal function in all patients presenting with:
   a. Microalbuminuria.
   b. Overt proteinuria (after exclusion of postural proteinuria).
   c. Haematuria unexplained by urological causes.
      i. Proteinuria detected on opportunistic assessment using dipstick urinalysis will be confirmed by laboratory analysis of protein: creatinine ratio on an early morning urine sample (Level C).
      ii. Haematuria detected by opportunistic screening will lead to referral to a dedicated haematuria clinic. Renal function will be checked in all patients with haematuria. For those with any impairment of GFR in addition to haematuria, referral to a nephrologist will be undertaken (Level C).

6. To test for microalbuminuria at presentation of all type II diabetic patients and all type I diabetics following puberty and annually thereafter for both groups (Level B).

7. To carry out urinalysis (Urine microscopy for detection of casts and red blood cells; urine dipstick analysis for haematuria and proteinuria) and measure renal function of all patients newly diagnosed with hypertension and annually thereafter (Level C).
Standard 4:

Delaying progression and minimising complications of impaired renal function

Each patient with a diagnosis of chronic kidney disease receives timely, appropriate and effective treatment to reduce the risk of disease progression, and to minimise the development of co-morbid complications.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To establish local shared care agreements between primary care clinicians and renal units for all patients with stage 1-2 CKD. These will address:
   a. Repeat measurement of estimated GFR at time intervals dependent on initial estimated GFR (Level C).
   b. Treatment of hypertension (target BP 130/80 mmHg) (Level A).
   c. Use of ACE inhibitors or Angiotensin receptor blockers in patients with proteinuria less than 100mg/mmol creatinine and in all diabetic patients with microalbuminuria (monitored with regular measurement of renal function and proteinuria) (Level A/B).
   d. Treatment of hyperlipidaemia (Level B).
   e. Advice on smoking cessation (Level B).
   f. Advice on weight reduction if obese (Level C).

2. To refer patients with Stage 3 CKD to a Multidisciplinary Renal Team, even if it is not anticipated that RRT will be appropriate. This multidisciplinary renal team will include input from clinicians, nurses, dieticians, pharmacists, physical therapists, clinical psychologists and social workers. At this stage
management should continue to be shared with the primary care (Level C). The functions of this Multidisciplinary Renal Team will include: (Level C).

a. Renal biopsy to make or exclude specific diagnoses.

b. Management of specific causes of CKD and counselling of families with familial conditions.

c. Management of glomerulonephritides, the nephrotic syndrome and systemic diseases involving the kidney.

d. Management of immunosuppression for certain forms of glomerulonephritis e.g. membranous and lupus nephritis.

3. To base the management of patients with CKD on those standards established by the Renal Association or European guidelines:


i. Patients with chronic renal impairment will achieve a haemoglobin of greater than 11 g/dl within six months of being seen by a nephrologist. Patients must be iron replete to achieve and maintain haemoglobin whether receiving epoetin or not. Adequate iron is defined as serum ferritin greater than 200 μg/ml or transferrin saturation greater than 20% (Level B).

b. Detection and treatment of renal bone disease (Level B):

i. The target phosphate level will be 1.2-1.7 mmol/l.

ii. Total calcium will be maintained within the normal range quoted by the local pathology laboratory, corrected for serum albumin concentration, or normal ionised calcium where available.

iii. Intact parathyroid hormone (iPTH) will be maintained at between 2 to 3 times the local normal range.

c. Detection and treatment of Acidosis (Level C). Serum bicarbonate should be in the normal range, and bicarbonate supplementation should be used to correct metabolic acidosis.
d. Access to renal dieticians to address the following (Level C):
   i. The intake of salt, phosphate, potassium and protein.
   ii. The prevention and/or detection and treatment of malnutrition.
Standards 5-6:

Prevention and/or Management of Acute Renal Failure

Introduction

There is overlap between patients presenting with chronic deteriorating renal function and those with acute renal failure (ARF). Renal damage in some cases of ARF may lead to permanent loss of renal function, such that these patients require long-term RRT. In others, partial recovery of renal function may be associated with less severe renal impairment, although the residual chronic renal impairment may make these patients more prone to further insult. Prognosis for recovery of the renal function and the survival of the patient in some causes of ARF is critically dependent on the speed of diagnosis and initiation of treatment. For this reason, the unexpected finding of abnormal renal function should be assumed to be due to ARF until proven otherwise.

The subsequent management of ARF takes place in a secondary or tertiary care environment. Whilst it does not immediately carry the long-term burdens associated with chronic kidney disease (CKD) and its consequences, it is, nonetheless, a heavy consumer of resources and multidisciplinary expertise.

The need to be able to diagnose, treat and manage the problems arising from ARF or its causes, are an essential component of many other secondary care services. The ARF section of this module focuses mainly on the interventions in diagnosis and treatment, as well as service models required for effective management of ARF. In addition the development of ARF is, in some cases, a significant risk factor for the development of progressive CKD and therefore links in with the section on CKD.

What does this mean for patients?

The aim of Standards 5 is to set out interventions that will minimise the development of Acute Renal Failure.
In Standard 6 the criteria for the management of patients with acute renal failure is set out. Its aim is to maximise patient and kidney recovery.

These standards will:

- Establish a framework for the prevention or early recognition of acute renal failure with the objective of maximising patient and kidney recovery and survival.
- Ensure the timely management of patients with ARF in an appropriate, adequately resourced, specialist and multidisciplinary environment with the objective of maximising patient and kidney recovery and survival.
Standard 5:

Recognition and prevention of Acute Renal Failure

Acute Renal Failure in a patient is recognised at an early stage and prevented whenever possible.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To develop strategies in order to identify all those patients in the community, or in hospital, who are at risk of developing acute renal failure.

2. To investigate all patients presenting with a single abnormal GFR including urinalysis for blood protein and infection. The abnormal GFR must be repeated in a time appropriate with the patient’s clinical condition and degree of abnormality of GFR. Deteriorating renal function must prompt a review of the overall patient management and early discussion with a nephrologist (Level B).

3. To review the medication of all patients with renal failure and adjust appropriately to reduce renal toxicity and/or damage. Where drug levels can be measured to assist dose adjustment and a reduction in renal risk, then this must be undertaken, recorded and acted upon (Level B).

4. To carry out a renal tract ultrasound scan on all patients with ARF within 24 hours of admission. All patients with demonstrated obstructive uropathy, in whom further treatment is considered appropriate, should have the obstruction relieved within 24 hours (Level B). This will require close co-operation between nephrology, urology and radiology specialities.
5. To consider dialysis when there is:
   a. Calculated GFR less than 15 ml/min and/or falling by 50% daily.
   b. Severe fluid overload (current or anticipated).
   c. Anuria or insufficient urine volume to meet patient needs.
   d. Life threatening pulmonary oedema.
   e. Severe acidosis (pH less than 7.1 and/or venous blood bicarbonate less than 10).
   f. Serum potassium greater than or equal to 7.0 mmol/l (Level B).
Standard 6:

Treatment of Acute Renal Failure

Each patient identified with acute renal failure receives timely and appropriate access to a Multidisciplinary Renal Team for diagnosis and treatment.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide level 3 or above critical care support to all patients with multi system organ failure with on-site facilities to carry out continuous dialysis treatments. Such centres will provide multi-disciplinary renal expertise including nephrology input into the diagnosis, management and treatment of patients (Level C).

2. To provide level 2 critical care to all patients with isolated ARF or with ARF not requiring Level 3 critical care for additional life threatening organ failure with on-site access to multi disciplinary renal care (Level C).

3. To provide access to intermittent or continuous dialysis therapies for all patients with ARF when these are needed. The latter may be in hospitals without renal units on site, and will be offered in all Level 3 ITU facilities. Particular attention should be paid to:
   a. Control of fluid balance and prevention of fluid overload.
   b. Prevention/correction of hyperkalemia.
   c. Correction of acidosis and maintenance of acid base status.
   d. Control of uraemia (Level B).
   e. Preventing malnutrition.

4. To dialyse all patients with ARF using synthetic dialysis membranes with bicarbonate buffered dialysate (Level B).
5. To refer all patients with isolated inexplicable renal failure or pulmonary - renal syndromes to a nephrologist with access to facilities for investigation and treatment (Level C).

6. To provide patients requiring plasma exchange with access to units with expertise in those conditions requiring such treatment (including Goodpasture’s disease, ANCA associated vasculitis, thrombotic microangiopathies and hyperviscosity induced ARF) (Level A).

7. To put in place a competence framework to ensure that dialysis/haemofiltration for patients with ARF is undertaken by trained staff, in an area with appropriate facilities to care for the whole patient needs (Level C).
Rationale and Evidence Base

Standard 2: Prevention of renal disease

There is increasing evidence that CKD can be prevented in some at risk groups, and that early detection and intervention can prevent or delay further damage and progression. Whilst there is no evidence to support whole population screening for renal disease, there is evidence to support regular screening of people who have increased risk either as a result of fixed risk factors such as genetic predisposition, or modifiable risk factors such as disease states in which renal disease is a known complication.

Fixed Risks

Fixed risk factors cannot be altered, but all those at risk should be made aware of their risk and the benefits of interventions such as aggressive blood pressure management, lipid control, weight reduction and smoking cessation, that may reduce the likelihood of renal disease. Some familial problems can be identified by genetic screening, which should be available to the first-degree relatives of patients with congenital diseases and known inheritance patterns e.g. first degree relatives of patients with vesico-ureteric reflux.

Modifiable Risks

In terms of modifiable risk, a key element of the primary prevention of CKD is the integrated approach to the triad of diabetes, hypertension and cardiovascular disease. Much of this work will take place in primary care and will involve supporting the primary and secondary prevention principles embodied in other National Service Framework (NSF) documents, in particular those for Coronary Heart Disease and Diabetes.

CKD is associated with increases in mortality particularly from cardiovascular disease. The substantially increased risk is due both to traditional risk factors such as hypertension and dyslipidaemia, in addition to factors associated with loss of renal function such as anaemia and vascular calcification. Many of the risk factors for cardiovascular disease are also risk factors for CKD; strategies to reduce risk of cardiovascular disease will also reduce an individuals risk of
developing renal disease.\textsuperscript{[15, 16]} As most patients at risk of renal disease will be under the care of primary care, the interface with primary care needs to be given special consideration, with local solutions required to deliver health improvements in patients at an early stage in their disease.

Hypertension superimposed upon renal disease can accelerate the decline in renal function and accelerated hypertension can cause renal failure.\textsuperscript{[17-19]} In contrast the role of uncomplicated hypertension in the pathogenesis of established renal failure is controversial. One exception to this in the excess risk of established renal failure amongst ethnic minority populations in the UK, which is at least in part attributable to the increased incidence of diabetes and hypertension in these populations as discussed above.\textsuperscript{[20]} The deleterious effect of elevated blood pressure may be more important in patients with proteinuria, and hypertension may also be a manifestation of sub-clinical nephritis. Aggressive management of hypertension is therefore an important goal.

The overall prevalence of CKD in the population can be reduced by preventing the onset of diabetes (primary prevention of diabetes) and interventions should follow the advice from the Diabetes NSF. In established diabetes there is evidence that the incidence of renal disease may be reduced by aggressive management of glycaemic control, and of tight control of blood pressure (Reviewed in \textsuperscript{[21]}). Although there is evidence that impaired glucose tolerance may be a risk factor for the development of nephropathy, there is currently no evidence to support specific intervention in this patient group.

Bladder outflow obstruction is an important cause of late presentation with established renal disease\textsuperscript{[22]}. The National Institute for Clinical Excellence (NICE) recommends measurement of renal function as part of the initial assessment of all men with lower urinary tract symptoms suggestive of bladder outflow obstruction. The main cause of renal impairment from bladder outflow obstruction is benign prostatic hypertrophy. Particular emphasis should therefore be given for monitoring of renal function in patients with prostatic hypertrophy. Patients with neurogenic bladder and other causes of abnormal bladder voiding are also at high risk of progressive renal disease\textsuperscript{[23-25]}, which can be prevented by early detection and appropriate management.
Certain patients will be at risk of occupational exposure to nephrotoxins. Screening for renal disease in this group are subject to the guidelines issued by the Health and Safety Executive.[26, 27]

Some groups of patients are at high risk of developing acute renal failure (ARF), such as patients with vascular disease, ischaemic heart disease, cardiovascular disease or diabetes. A proportion of patients who develop ARF are at increased risk of CKD (Standard 6).

**Standard 3:**

**Detection of renal disease**

Regular measurement of renal function is logical in patients at risk of progressive renal disease because of the well documented adverse effects of late presentation and late referral on both patient morbidity and mortality.

A single abnormal reading may imply ARF, stable CKD, acute on chronic kidney disease or resolving renal failure. Differentiating between these states can be achieved either by identifying previous measurements of renal function and/or further investigation of the patient. Patients should be considered as having ARF until proven otherwise.

Current practice is to estimate renal function using serum creatinine as a surrogate marker. Serum creatinine concentration is determined not only by the rate of renal excretion of creatinine but also by the rate of production, which is dependent on muscle mass, and may thus remain within the normal range in patients with low muscle mass and abnormal renal function, or conversely may be above the upper limit of normal in individuals with normal renal function and higher than average muscle mass. The Cockcroft and Gault formula[28], gives an estimate of creatinine clearance corrected for body size, whereas the Glomerular filtration Rate (GFR) determined by the MDRD (Modification of Diet in Renal Disease) formula[29], incorporates a correction factor for ethnicity. Although both methods have their limitations the use of either will improve the identification and management of patients with CKD.
The same criteria should be used for assessment of renal function in older people as in younger people. Age-adjusted reference ranges for determination of renal function are not recommended. Although some studies indicate that renal function declines with age, this is not a reason for using different criteria to categorise renal function in older people. A decline in renal function is not, however, an inevitable consequence of ageing and if it occurs it indicates renal pathology and identifies a patient at risk of developing progressive renal disease.[30-32] Adults with CKD, irrespective of age, should, therefore, be entered into a care pathway, as interventions that slow progressive loss of renal function are no less likely to do so in older people. Following identification of individuals with CKD the use of a simple classification of renal impairment has facilitated the development of referral strategies and simplified the understanding of degree of renal impairment between clinical disciplines.[33]

Proteinuria is a potent risk marker for progressive renal disease in both diabetic[34, 35], and non-diabetic renal disease.[36, 37] Annual urinalysis for proteinuria is a useful way of identifying patients at risk of progressive renal disease, and targeting such patients for reduction of protein excretion by antihypertensive treatment of which results in reduction in the risk of progression.

While it is accepted that a 24-hour collection is the gold standard for the detection of microalbuminuria or proteinuria, this in practice can be difficult to co-ordinate. As an alternative, screening can be achieved more simply by analysis of albumin or protein concentration in un-timed urine specimens. However albumin/protein concentration alone in an un-timed collection is influenced by urine volume. This can be avoided by calculation of albumin/protein-to-creatinine ratio in an un-timed urine specimen.[38]

Isolated microscopic haematuria is a common finding. The conventional approach to investigation includes urological referral for cystourethroscopy if renal imaging is normal. Most studies of referred patients with putatively asymptomatic microscopic haematuria have reported a 2-11% prevalence of urothelial malignancies.[39] Glomerular disease is also recognized as a common cause of microscopic haematuria in this younger group.[40]
**Standard 4:**
**Delivering progression and minimising complications of impaired renal function**

Services for people with CKD should be accessible, equitable, effective and culturally appropriate. Special attention should be paid to the needs of vulnerable groups such as those from lower socio-economic groups, the elderly and those of an Indo-Asian and Afro-Caribbean background.

Recent data collected across Gwent, based on analysis of biochemistry laboratory records, confirmed high levels of unreferred renal failure. Using an estimated creatinine clearance (modified MDRD) of less than 60ml/min between 7% and 45% of patients (depending on the hospitals surveyed) were known to the renal services. This variation was related to the degree of nephrology input to the local hospitals and the distance of these hospitals from the regional centre. It is clear that it is not possible for all patients with chronic renal impairment to be seen by a consultant nephrologist, however within the cohort of patients with significant renal impairment in Gwent not under nephrology follow up, between 15-30% demonstrated a significant deterioration in serum creatinine over a 6 month period without nephrological referral. Identification of those patients with renal impairment who can be managed in primary care and those patients who need referral to a consultant nephrologist is therefore essential.

1. **Management of CKD in primary care and secondary care by non nephrologists**
   It is neither possible nor practicable for all patients in the U.K. with CKD to be seen and managed by a consultant nephrologist. It is clear that primary care and secondary care teams have an important role in managing patients with renal impairment. Care of patients with stage 1-2 CKD, in this setting however should be directed by agreed protocols of shared multidisciplinary care, supported by the nephrology services. The format of these care pathways will need agreement at a local level coupled with regular review.
2. **The specific role of the nephrology service**

There is now overwhelming evidence that the morbidity and mortality of patients entering the RRT programme is significantly improved when the later stages of their care are under the direction of a multidisciplinary renal team.\[^{41-43}\] Referral of patients with stage 3 disease, detailed preparation and timely start, will ensure choice of therapy, planned access, and management of co-morbid factors.

It is the responsibility of the multidisciplinary renal team to ensure appropriate preparation for dialysis or transplantation (Standard 8). In addition, when, following full discussion with the patient, renal replacement is deemed to be inappropriate then the co-ordination of active conservative management should be monitored by the multidisciplinary renal team (Standards within Module 5).

The development of co-existing conditions associated with CKD frequently begins early in the course of the disease. Their identification and appropriate treatment will result in the prevention of most complications.

a. **Renal bone disease**

Renal osteodystrophy and other consequences of disordered calcium and phosphate metabolism can cause serious morbidity in ERD.\[^{44, 45}\] Phosphate retention develops with progressive renal failure and contributes to the development of hyperparathyroidism.\[^{46-48}\] Most patients will require phosphate binders to achieve adequate phosphate control. Oral alphacalcidol or calcitriol can be given to pre-dialysis patients to control or prevent secondary hyperparathyroidism without causing deterioration in renal function.

b. **Anaemia**

The anaemia associated with renal failure is of particular importance because of its impact on patient morbidity and perhaps mortality.\[^{49}\] There is now abundant evidence that treatment of anaemia with epoetin leads to improvement in quality of life, exercise capacity, cardiac function, sleep patterns, cognitive function, immune responses and sexual function. As yet it is unclear as to the level to which the haemoglobin should be corrected. As this is an
area of ongoing research it is suggested that updated, current Renal Association Guidelines or European Guidelines for target haemoglobin be adopted.

c. **Acidosis**

Metabolic acidosis develops with progression of renal disease, and results in both increase in protein catabolism and reduced nutritional intake, thus exacerbating the risk of malnutrition.\[50, 51\] Acidosis also increases the risk of osteomalacia and secondary hyperparathyroidism. Bicarbonate supplementation can be used to correct metabolic acidosis and improve the patient’s nutritional state.

d. **Malnutrition**

Low pre-dialysis serum creatinine concentration, low serum cholesterol and hypoalbuminaemia are powerful predictors of morbidity and mortality in patients with ERD.\[52-54\] There is no single measurement of under-nutrition leading to the recommendation that a panel of measurements be used, which reflect the various aspects of protein-calorie nutrition.

Cardiovascular disease is a major complication of renal disease. Intensive management can prevent and/or slow down the progression of cardiovascular disease. Education, medical interventions and lifestyle changes may improve or ameliorate the mortality and morbidity associated with cardiovascular disease.

**Standard 5:**

**Recognition and prevention of Acute Renal Failure**

ARF is a disease that may both have an insidious and rapid onset (days to weeks) and can quickly lead to serious life threatening metabolic and fluid imbalance. ARF is not uncommon but there is a dearth of good data about its epidemiology in Wales. Current estimates suggest a rate of dialysis for ARF of approximately 200-250 patients per million population (pmp).\[55\] The major pathophysiological processes in ARF are salt and water imbalance, potassium retention and acidaemia all of which can be life threatening. ARF may be isolated (single organ) or part of a systemic illness with dual or multiple organ failure.
An abnormal GFR\(^{[28, 29]}\) may indicate ARF, acute on chronic kidney disease, stable CKD or resolving renal failure. Supportive evidence of renal disease can be obtained by testing urine for blood and/or protein.\(^{[56]}\) ARF can be iatrogenic, avoidable and predictable especially in vulnerable patients. In all patients, certain procedures increase the risk of developing ARF. These include major surgery, especially cardiac and vascular; angiography; contrast CT scanning, and drug treatments with e.g. aggressive diuretic therapy, nephrotoxic drugs such as anti-inflammatory agents, and Angiotensin Converting Enzyme Inhibitors/ Angiotensin II Receptor Blocker use. Furthermore, certain groups of patients will be at even higher risk of developing ARF including those with pre-existing renal failure or disease, peripheral vascular or ischaemic heart disease, cardiovascular disease and diabetes.

The decision about when to start dialysis for an individual patient is often a difficult one. It takes into account a number of physical, biochemical and treatment issues, as well as local expertise and facilities. When these are assessed, either alone, or in combination, they contribute to the decision-making process. Critical factors involved include rapidly deteriorating GFR, fluid overload, anuria or oliguria, pulmonary oedema, hyperkalemia and severe acidaemia. All of the above can apply either alone or in combination. Combinations of problems, a rapid rise in serum potassium and a rapid rate of decline in renal function should prompt more urgent action.

The ultimate decision regarding whether or not to dialyse is complex and involved. Multidisciplinary help may be required to decide on, and then plan and institute treatment depending on local facilities and responsibilities. For example, in some hospitals all dialysis is undertaken by the nephrology medical and nursing staff, whilst, in others the decision is taken by the intensivists. As long as the patient has access to appropriate diagnostics, therapeutics and specialist input, the precise model of care is relatively unimportant.

Prevention and amelioration of problems in at risk patients is an essential facet of the management of ARF. Careful attention to hydration/fluid balance, cardiovascular support and drug dosage are all important.\(^{[57]}\) These have been shown to significantly reduce the incidence and extent of renal injury and shorten the time to recovery. The use of iso-osmolar non-iodine contrast media, and n-acetyl
cysteine prophylaxis may ameliorate renal damage during contrast requiring radiological procedures.[38] There is no consistent evidence to support the use of dopamine[59, 60], diuretics including mannitol and loop diuretics[61], in the prevention or resolution of ARF.

The vast majority of cases of ARF are caused by acute tubular necrosis (ATN) and will recover spontaneously with appropriate supportive therapy. There are, however, a significant minority with other causes such as obstructive uropathy, vasculitis, Wegeners granulomatosis and Goodpastures (anti-GBM) disease which require specific and specialised intervention. Early referral permits more timely investigation and treatment with a subsequently improved outcome. ARF due to urinary tract obstruction is common and relatively easy to diagnose using simple investigations. Unrelieved obstruction can lead to sustained and irreversible renal injury.[22]

**Standard 6:**

**Treatment of Acute Renal Failure**

Early treatment of most cases of ARF can be life saving and lead to significant/total recovery of renal function.

The cause of renal failure should be investigated. In multi organ failure or sepsis syndromes this may be a pragmatic clinical diagnosis such as Acute Tubular Necrosis (ATN), since this is the most likely underlying pathology in these cases. However, unexplained/isolated or dual organ (e.g. lung/skin involvement) ARF will need further investigations including renal biopsy and specific blood tests. Such diagnoses include the vasculitides such as Wegener’s granulomatosis and microscopic polyangiitis, or renal involvement in connective tissue and autoimmune conditions such as SLE and anti-glomerular basement membrane (Goodpastures) disease. In hospitals without a renal unit there should be access to specialist nephrological advice and the ability to transfer those patients requiring specialist treatment to a renal unit.

The treatment of multiple organ failure needs specialist critical care with facilities for all major organ support (Level 3 or 3T). There is no clear evidence to support the use of continuous dialytic therapies (e.g. haemodiafiltration) over intermittent ones (haemodialysis) or
vice versa, therefore both have roles to play in the treatment of ARF.\cite{62, 63} They can complement each other in overall management and should be freely interchangeable.

There is very little evidence to support the use of synthetic rather than cellulose dialysis membranes in ARF treatment\cite{64, 65}, though the increasing availability, decreasing cost and theoretical advantages of synthetic membranes makes them the favoured option. The high water permeability of synthetic membranes makes them the only option for continuous dialysis modes, plasmapheresis and haemodiafiltration. There is evidence that the use of acetate buffered dialysis solutions in intermittent dialysis increases cardiovascular instability in patients who are often already at risk of this.\cite{66} Patients with multi-organ failure, especially with liver involvement, may be at increased risk of lactate accumulation if this is used as the buffer. The use of bicarbonate buffered dialysis solutions is therefore preferable to acetate or lactate based solutions. In continuous therapies the more widespread availability of stable bicarbonate solutions should make these the solutions of choice.

Plasma exchange has a role in the treatment multisystem disease with renal involvement including the thrombotic microangiopathies (HUS/TTP), Wegener’s granulomatosis and microscopic polyangiitis.\cite{67} Removal of potentially pathogenic antibodies such as anti-GBM antibody, can lead to reversal of renal failure and permanent eradication of the antibody. In cases of pulmonary haemorrhage associated with anti-GBM disease and vasculitis, plasma exchange is the treatment of choice and can be life saving.

A small but significant minority of patients who suffer an episode of ATN will go on to develop dialysis dependent chronic renal failure.\cite{55} Those patients with non-dialysis dependent CRF will require long term follow up in a nephrology unit. Patients with autoimmune causes of ARF will also require prolonged follow up by nephrologists.
References


42. Dunn EJ, Burton CJ, Feest TG. The care of patients with diabetic nephropathy: audit, feedback, and improvement. *Qjm* 1999;92(8):443-449.


MODULE 3

Standards 7-11:

Effective Delivery of Dialysis

Introduction

Module 2 has emphasised the importance of identifying patients with chronic kidney disease (CKD) so that any deterioration in renal function and the complications associated with CKD can be ameliorated. However, despite the use of screening interventions and the introduction of appropriate treatment, a small but significant proportion of these patients will develop progressive renal dysfunction leading to the need for other treatment such as renal replacement therapy (RRT).

Module 3 is concerned with preparing the patient and their family for RRT and ensuring the effective delivery of dialysis. RRT has a significant psychological, physical and emotional impact on a patient and their family. Renal services should work with patients and their family to minimise the impact of these factors and maximise the patient’s quality and length of life. Achieving these goals requires a patient-centred approach, integrated multi-disciplinary renal care and careful planning to enable a seamless transition from the pre-dialysis phase to RRT.

The effective delivery of dialysis requires both the identification and early referral of a patient with CKD to a Multidisciplinary Renal Team. In addition to delaying the start of RRT and managing co-morbidities, considerable attention must be placed on educating patients to enable them to make an informed choice about the most appropriate form of RRT. Early referral also facilitates the planning and preparation for RRT that accommodates patient choice. In addition, early referral together with careful management allows RRT to be anticipated and planned in such a way that morbidity and mortality are minimised.
Once RRT is initiated, therapy is aimed at ensuring that patients receive adequate dialysis treatment delivered in a way that minimises the inconvenience for both the patient and their family. An infrastructure must be established to enable the effective delivery of this dialysis at a time and in a place that is convenient to the patient.

The development of a patient-centred approach for RRT requires not only careful preparation and planning for both the patient and the Multidisciplinary Renal Team, but also requires the development of a strategic plan to anticipate resources and the capital required to deliver these services. This will require close collaboration between patient representative groups, NHS Trusts and commissioning bodies.

**What does this mean for patients?**

The main purpose of this module is to ensure a patient centred approach to the care of those patients whose renal function deteriorates to the point where dialysis needs to be considered. It looks at the need to educate and inform patients and their families on the decisions they need to take about their treatment. It also highlights the importance of providing dialysis at places and times convenient to patients and for careful planning and anticipation for dialysis so that care is of the highest quality and maximises the outcome for patients. Specifically, the aims of Standards 7-11 and their underpinning Key Interventions are:

- To ensure that all individuals with chronic kidney disease are optimally managed to minimise the progression, complications and consequences of their disease, are able to make an informed choice and be prepared for the most clinically and psychologically appropriate therapy.

- To ensure that patients with chronic renal failure have a seamless entry on to the renal replacement therapy programme, by achieving timely creation of permanent vascular or peritoneal access.

- To ensure that all patients requiring dialysis will have access to all forms of peritoneal dialysis to optimise their quality of life and survival.
• To ensure that all patients requiring dialysis will have access to all forms of haemodialysis in order to optimise their quality of life and survival.

• To ensure that all patients requiring long term haemodialysis have access to a facility and a transport system that keeps travel times to an average of thirty minutes or less for each journey.
Standard 7:

Preparation for RRT

Each patient with advanced or progressive irreversible chronic kidney disease has access to and receives optimal care from a Multidisciplinary Renal Team such that renal replacement therapy is introduced in a timely fashion, following an open and informed discussion.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide support, information and education for patients and their families/carers during the period of preparation for RRT from a dedicated Multidisciplinary Renal Team attached to each renal unit to optimise medical management, nutrition and lifestyle. This multidisciplinary renal team will include input from clinicians, nurses, dieticians, pharmacists, clinical psychologists and social workers (Level C).

2. To refer patients with progressive irreversible CKD leading to ERF to this Multidisciplinary Renal Team to be considered for RRT by the time they reach Stage 4 CKD (GFR less than 30ml/min: Standard 4) (Level B).

3. To set up flexible patient centred education programmes, which will empower patients to become active partners in the management of their condition. This will enable them to choose the most appropriate form of RRT including all forms of HD and PD as well as transplantation or conservative therapies. These programmes should be flexible in order to accommodate different patient needs and clinical presentations. It should also be recognised and accommodated within individual patient plans that their choices may change (Level C).
4. To manage the complications of renal disease and associated co-morbid conditions optimally, during the process of establishing the patient on RRT (Level B).

5. To organise the RRT programme in such a way so that it can accommodate patients with late presentation ERF as well as those patients needing to switch RRT modalities (Level B).

6. To refer patients for whom dialysis is anticipated in a timely manner for vascular/peritoneal access assessment (Standard 8) (Level B).

7. To assess formally all patients approaching ERF for future renal transplantation (Standard 13) (Level B).

8. To agree and implement a planned RRT start date for all patients, which will avoid the problems of a delayed start (Level B).
Standard 8:

Vascular and Peritoneal Access Surgery

Each patient has a permanent, mature and functioning dialysis access before renal replacement therapy needs to begin.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To include the provision of vascular and peritoneal access services in the commissioning plans for all new Renal Units/Satellite Units in order to meet the need of the dialysis population; this should include appropriate investigative and interventional radiology (Level C).

2. To undertake surgical assessment of all recognised patients six to eight months before dialysis is anticipated followed by timely placement of vascular and peritoneal access to allow sufficient time for it to heal and mature before RRT needs to start (Level C).

Peritoneal Dialysis

1. To place PD catheters six weeks before dialysis training with the patient’s preference for position of the catheter exit site being taken into account (Level C).

2. To ensure that catheter insertion is carried out by experienced and trained staff (Level C).

3. To establish protocols for the prevention and treatment of catheter related complications (Level C).
Haemodialysis

1. To provide dialysis using arterio-venous fistulae (AVF) for all suitable prevalent HD patients (at least eighty percent of this patient population) (Level B).

2. To carry out radiological investigations and vein mapping/imaging in those patients whose vessels are of poor calibre when examined clinically (Level C).

3. To carry out surgical and radiological intervention within a maximum of 72 hours of thrombosis of any vascular access (Level B).

4. To put a competence framework in place to ensure that fistulae are cannulated by experienced and trained staff (Level C).
Standard 9:

Peritoneal Dialysis

Each patient requiring renal replacement therapy, who has made an informed choice and for whom this modality is clinically appropriate, has access to all forms of peritoneal dialysis so that they obtain maximum benefits of dialysis adequacy, optimal fluid balance and quality of life. All forms of peritoneal dialysis are seen to complement and support each other and are used as part of an integrated approach to dialysis that may also involve transplantation and haemodialysis.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To deliver PD services through a specialised Multidisciplinary Renal Team with the full range of staff with appropriate training and experience, based in renal units with appropriate facilities and support services including social services, clinical psychology, physical and occupational therapy, pharmacy and dietetics expertise (Level C).

2. To provide training for patients choosing PD as part of a high quality planned home training programme involving specialist nurses and including home visits as appropriate. The process of education and training should be clear to the patient and their carer/s and carefully monitored. Patients will make an informed choice regarding the need for a carer (Level C).

3. To arrange and carry out home visits and stock delivery in conjunction with the patient. Funding for necessary home adaptation requirements must be clearly identified (Level B).
4. To establish protocols and information technology to monitor the quality of dialysis, and make changes to improve care as necessary. Impending failure of PD should be recognised as early as possible. This will enable the patient to be given the opportunity to re-assess dialysis or other therapy options and facilitate planned transfer (Level B).

5. Where appropriate to provide patients with automated peritoneal dialysis (APD) or other options (including a variety of dialysis solutions) to ensure optimal dialysis, technique survival and continued patient wellbeing (Level A).

6. To establish a clear admissions policy for PD patients, taking into account patient flow from other hospitals in the unit catchment area, to avoid delay in treatment (Level C).

7. To establish treatment guidelines and management protocols for peritonitis and exit site infection based on National and International guidelines (UK Renal Association standards, ISPD protocols) and other peer-reviewed publications (Level B).
Standard 10:

Haemodialysis

Each patient requiring renal replacement therapy, who has made an informed choice and for whom haemodialysis is clinically appropriate, has access to all forms of haemodialysis so that they obtain maximum benefits of dialysis adequacy, optimal fluid balance and quality of life. Treatment is provided in a location and at a time of the patient’s choosing. All forms of haemodialysis are used as part of an integrated approach to dialysis that may also involve transplantation and other forms of dialysis.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To establish a ten-year rolling plan for the expansion of HD capacity to ensure patient need is met with expansion taking place as existing capacity reaches 80% (Level C).

2. To provide HD in a facility which will be separate from that providing treatment for acute renal failure and where:

   a. Patients will be managed according to the standards agreed in the latest ‘Renal Association Standards’ documentation. All facilities will maintain defined standards of equipment and water treatment (Level A).

   b. Haemodialysis services will be delivered through a specialised Multidisciplinary Renal Team with the full range of staff with appropriate training and experience, based in renal units with appropriate facilities and support services including social services, clinical psychology, physical and occupational therapy, pharmacy and dietetics expertise (Level C).
c. High flux dialysis and/or haemodiafiltration (HDF) will be considered as alternate therapy to HD in patients who are considered likely to remain on HD for many years (Level B).

d. Treatment will be provided at those times best suited to the patient (Level C).

e. All at risk patients will be dialysed in isolation (Level B).

f. There should be sufficient capacity to allow visiting patients to be treated (Level C).

g. The environment is appropriate with waiting areas, rest rooms, etc (Level C).

h. All patients will have their nutritional status monitored and appropriate nutritional support will be in place (Level C).

3. To provide training for patients choosing home HD as part of a high quality planned home training programme involving specialist nurses and including home visits as appropriate. Appropriate adaptations and installation of dialysis facilities will take place in a timely fashion. All patients on haemodialysis will have equal access to the MDRT. Adequate provision and planning needs to be made for patients who require carers (Level C).

4. To provide sufficient in-patient beds in all ‘Main Renal Units’ staffed by nurses experienced in the management of renal disease to ensure that all patients undergoing HD who require inpatient care can be appropriately managed. They will develop a clear ‘admissions policy’ which pays regard to patient flow from other hospitals in the unit catchment area and avoids delay in treatment. Policies need to be in place in consultation with all appropriate professional groups (e.g. Ambulance services; Bed managers) to enable direct transfer to the renal unit when appropriate (Level C).

5. To provide thirty-seven nephrology beds for each one million catchment population (with an additional eight beds required by a regional transplant centre (Level B).

6. To establish an admissions policy, including transfer arrangements, for inpatient nephrology beds (Level C).
Standard 11:

Transport

**Each patient requiring haemodialysis has access to a dialysis unit within 30 minutes travel time from their home with a flexible and responsive transport system that is an integral part of their health care package.**

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide a transport system for dialysis patients, which is flexible and responsive and aims to keep one-way travel times to less than thirty minutes for most patients. It must be available during the operating hours of the renal unit and be operational at weekends and on bank holidays (Level C).

2. To transport patients requiring HD in vehicles which will comply with the requisite national standards of comfort and safety and have a suitable form of communication system fitted (Level C).

3. To encourage self-reliance, by reimbursing all those who are independent of the transport system with travel costs and providing adequate free car parking at or in the vicinity of the renal unit (Level C).
Rationale and Evidence Base

Standard 7:
Preparation for RRT

Despite appropriate care, many patients with established progressive renal disease reach Established Renal Failure (ERF). Treatment options for patients with ERF require careful planning in order to identify the most appropriate therapy for that individual and their family. There is good evidence to show that individuals with progressive renal disease in whom ERF is anticipated, benefit from early referral to a consultant nephrologist working within a multidisciplinary renal team, with defined protocols, in order to prepare the patient and their family for the treatment options available for ERF.[1, 2]

All patients with Stage 3 CKD should have had advice from or be under the care of a consultant nephrologist (Standard 4). This should enable all patients to receive optimal care for their condition[3, 4] and to reduce development of those complications associated with declining renal function.[5]

The care of these patients with renal disease should form a continuum. The optimum management of the complications has been shown to be most effective if begun early in the course of disease (Standard 4) and continued during the preparation for RRT.[6]

The advantages of early referral to the Multidisciplinary Renal Team include:

- Optimum preparation by professionals with appropriate training and experience, to advise, educate, treat and support people with ERF.
- Time to prepare the patient and those close to them medically and psychologically for RRT. A person may need access to services and/or benefits and wide ranging psychological and social support, both in the hospital and in the community.
- Time to optimise nutritional status, fluid status and electrolyte balance.
• Time for the patient to make their optimum modality choice taking into account their lifestyle, preference and clinical condition.

• Time to assess the possibility of a pre-emptive transplant.

• Time to initiate and complete transplant assessment and thereby placing the patient onto the transplant waiting list prior to starting RRT. This should include the possibility of a pre-emptive live donor transplant.

• Time to consider conservative therapies (Module 5). For those individuals who elect not to undergo dialysis, time is required for the development of a co-ordinated care package between renal services, primary care and palliative care services for that individual.

• If dialysis is required, time to assess the type, place and time best suited to the patient. All those suitable for haemodialysis should be assessed for home haemodialysis.\[7\] Those choosing to attend a dialysis unit should be encouraged to visit the unit in advance to become familiar with the journey to the unit and the unit itself.

• For all those individuals who choose to dialyse at home, whether by peritoneal or haemodialysis, time to make an assessment of the home and make any necessary alterations.

• Time to ensure proper assessment for the creation of vascular or peritoneal access.\[8\]

• Time to start patients on dialysis in a planned fashion and before they become unnecessarily symptomatic. There is uncertainty as to the best time to start dialysis treatment, as the symptoms of renal failure such as tiredness, lethargy, and loss of appetite are non-specific.\[9\] Therefore a combination of clinical symptoms and objective measurements of renal function (GFR) should govern the appropriate starting time. Best evidence would suggest that commencing dialysis at an estimated GFR of between 9-14 mls/min is appropriate if there is any evidence of impaired nutrition.\[10\] Even in the absence of symptoms or malnutrition, to maintain good health, dialysis should be considered when estimated GFR is 7-10ml/min.
People with failing renal transplants will need early referral back to a specialist low clearance team to prepare them for and identify their preference for an alternative form of RRT. Similarly, those moving from one dialysis technique to another will need timely, appropriate preparation.[10]

Evidence has demonstrated that patients presenting with ERF have higher mortality and morbidity than patients who have appropriate pre-dialysis care and preparation for RRT. These patients will require a dedicated education service and accelerated access placement to ensure that the impact of their late presentation is minimised.

Dialysis treatment demands more of the patient and their family than probably any other medical intervention. They face major changes in their lives and life styles. People who dialyse at home (Peritoneal Dialysis (PD) or Haemodialysis (HD)) must understand the dialysis process itself and how to deal with day-to-day problems and complications. All patients must understand the principles of dietary management and fluid balance as well as the purpose of the medication they will be taking. Patients and all potential carers should fully understand what is involved in dialysis and the potential impact on their lives and those of their families. Carers should be given the opportunity to express their views independently of the patients. An opportunity to review the decision to proceed or continue with any dialysis modality should be available in the event of any change in circumstances.

**Standard 8:**

**Vascular and Peritoneal Access Surgery**

Successful access remains the lifeline of dialysis patients. The long-term survival of patients depends on the standards of care applied to the access, in terms of its creation and maintenance. Several surgical procedures may be required in the same patient throughout their life span on renal replacement therapy.

Only when dialysis access has been established can patients commence their chosen form of treatment at a time appropriate to their needs. Access failure is a significant cause of morbidity and mortality.[12]
Vascular access surgery is poorly provided in the UK, in comparison to countries such as France, Germany, Italy and Spain. The UK has the highest prevalence of tunneled catheters compared to AVF’s in patients, both new and those established on dialysis.[13]

The majority of patients in the UK wait more than three months for surgery after referral, unlike other European countries that have waiting times less than one month.

**Peritoneal Dialysis**

Whilst PD procedures constitute a lower level of surgical workload, surgical expertise is required to assess the suitability of the abdomen for PD as well as to insert the catheter.

Ideally, PD catheters should be inserted sufficiently early before starting PD, to allow healing and to prevent leakage. Surgeons, physicians or radiologists can insert catheters, provided appropriate training has been given.

**Haemodialysis**

A good arterio-venous fistulae (AVF) will produce continuous flow into the patient’s dialysis circuit and provide optimal dialysis for that patient. The upper limb is preferred to the lower limb for fistula creation because the success rate is greater and the risk of infections is less.[14] Initially access created distally in the upper limb is preferred leaving proximal sites available for later use. To allow a patient more freedom on dialysis, the non-dominant arm is the preferred site for fistula construction.

Autogenous fistulae creation will only be successful if central and upper limb veins are preserved and damage is avoided from repeated venepuncture or central vein catheterisation during the period of time leading to RRT. At least 80% of prevalent patients will have suitable vessels for the creation of AVF. The development of central vein stenosis following catheterisation severely compromises fistula construction and may lead to permanent access failure in that limb.[15]

In the absence of good calibre peripheral veins, synthetic material may be required to construct a fistula. Alternatively, a tunnelled catheter is placed in one of the central veins (preferably internal jugular vein) for access. Catheter placement must be done under ultrasound guidance.
Such catheters may also be used as a short-term measure when the patients present late with ERF or if an existing vascular access becomes suddenly dysfunctional.

Both arterio-venous grafts and central venous catheters are associated with increased morbidity and mortality.[12] Access-related death due to infection is three times more common with tunnelled catheters and twice as common with grafts when compared with AVFs.

Several methods of monitoring AVFs have been shown to detect early decreases in blood flow across the fistula.[16] Thrombosed autogenous AVFs and AV grafts can often be salvaged by prompt radiological and surgical intervention within 24-72 hours following thrombosis.[17,18]

**Standard 9:**

**Peritoneal Dialysis**

PD and HD are complementary rather than competitive therapies. For many patients, over a lifetime of RRT more than one treatment modality will be necessary and appropriate. Rather than presenting the individual once and for all with an ‘either/or’ choice of modality, the various treatment options should be discussed in the framework of their integrated use.

Support for an integrated programme of RRT comes from evidence showing that patients commencing treatment with PD who are then either transplanted[19] or who transfer to HD fare at least as well[20] and possibly better[21] than their counterparts that started on HD. The rate of decline of natural (residual) renal function is less if a patient starts RRT on PD rather than on standard diffusive HD.[22]

PD is not an option for all as a proportion of patients are not medically suitable.[23] There is however accumulating evidence that where free modality choice is available up to 45% of clinically suitable patients would choose PD.[24,25]

Technical developments and innovations have reduced the rates of peritonitis in PD[26,27,28] thus reducing the incidence of technique failure. The technique survival of PD is still limited. In some reports as many as 25% of PD patients transfer to HD after 3 years of therapy[29] whereas in other centres 70% of patients remain on PD for 5 years.[30] Long-term technique survival is varied.[31]
Exit site infections and peritonitis rates have shown a reduction over the past ten years due partly due to standardised protocols for treatment.\cite{32} New, more biocompatible solutions and those using alternative osmotic agents\cite{33, 34, 35} have enhanced the applicability of the technique. They may offer extended life on treatment, and a reduction in the exposure of the patient and peritoneal membrane to glucose and glucose degradation products.\cite{36, 37} Automated cycling machines (APD) allow the delivery of high volumes of fluid overnight to improve dialysis adequacy and fluid removal. In addition this technique allows patients to choose between PD options that offer quite different lifestyles.\cite{38}

Many PD patients are dependent on maintaining residual renal function to complement ultrafiltration and solute removal achieved through dialysis. As a patient’s native renal function declines, achieving adequate solute and water removal can become difficult.\cite{30} This is compounded by the observation of structural and functional changes in the peritoneal membranes of patients on PD that make fluid and solute removal difficult.\cite{37, 39} The APD mode and the use of new solutions, may then offer a way to achieve fluid and biochemical homeostasis and improve technique survival.\cite{40} Maintaining urine output through the judicious use of diuretics may also extend useful time on PD and delay a switch to HD.

PD has significant merits for motivated patients who value independence from the centre. PD also has particular merits as the preferred modality for new patients. These include good prospects for maintaining employment\cite{38} relative ease of travel in the UK and abroad, with a lower probability of contracting blood borne virus infections.

**Standard 10:**

**Haemodialysis**

Audit since 1996 has demonstrated a 7% increase annually in the number of patients receiving chronic HD.\cite{29} Patients who present late with ERF usually start on HD and remain on this modality.\cite{28, 41, 42} Patients with failing transplants are usually managed by HD and 30% of patients treated with PD have to switch to HD after three to five years of treatment.\cite{29} For these reasons planned expansion of HD facilities is essential for the delivery of high quality RRT programme.\cite{43}
Key elements of the quality of care afforded to patients undergoing HD can be audited against clinical standards provided by the Renal Association.\textsuperscript{[44]} Good practice suggests that the following areas are the key to ensuring the best possible patient well being.

\begin{itemize}
  \item **Frequency of Treatment**
  For most patients HD is a renal unit based service that involves treatment three times a week for between three and five hours on each occasion. For patients using home HD, more frequent but shorter treatments may be preferable. Current difficulties in providing sufficient spaces for HD patients has resulted in:
  \begin{itemize}
    \item Inadequate treatment regimens (twice weekly).
    \item Inappropriate timing of treatment for some patients.
    \item Inappropriate use of inpatient facilities for outpatient dialysis.
  \end{itemize}

  \item **Haemodialysis Adequacy**
  The effectiveness of dialysis can be assessed numerically by measuring the urea reduction ratio (URR) and/or Kt/V. Current evidence shows that for those on thrice weekly dialysis, outcomes are improved if URR is consistently greater than 65% or Kt/V is greater than 1.2.\textsuperscript{[45]}
\end{itemize}

The development of satellite HD units in Wales has enabled some patients who live at a distance from a main renal unit to undergo treatment in a dialysis unit based in their local district general hospital. As a result selection of patients for satellite units is often based on geographical location even though many of these patients dialysing in have significant co-morbidity. This increases the demand for the professional support (medical, nursing, dietetic & social work) that is required in satellite units and the extent to which ‘back-up’ from the ‘related’ main unit is required.

For some patients home HD is the treatment of choice. The benefits, which have been summarised in a recent National Institute for Clinical Excellence (NICE) appraisal, include freedom from the travel and time involved with hospital attendance and an increase in the ability to adjust treatment frequency and timing to the patient’s advantage.\textsuperscript{[46]}
The inpatient care of patients with renal disease is optimised when they are admitted to designated renal beds with ease of access to the multidisciplinary renal team.\[6\]

Patients with ERF undergoing HD or PD are generally elderly and often have other illnesses. If they require admission to another specialised unit (e.g. a critical care unit) close liaison with the renal team is beneficial.

For a variety of reasons, work, education, holidays and family visits it is important that patients can dialyse away from home. Within the UK the main limiting factor has been the availability of resources. For travel overseas other considerations, in particular the risks of blood borne virus infection have to be taken into consideration.\[44\]

**Standard 11:**

**Transport**

Because of their indefinite need for thrice-weekly treatment, patients undergoing HD are more dependent on efficient transport between home and treatment centre than virtually all other patient groups. Surveys of dialysis patients have made it clear that the time and financial implications associated with transport are one of their greatest causes of concern.

Patients concerns include:

a. Distance of treatment centre from home.

b. Travel time between treatment centre and home.

c. Interval between arrival in dialysis centre and start of treatment.

d. Interval between end of treatment and departure from centre.

e. Costs entailed with transport and parking if travelling independently.

For dialysis units, transport of patients has become a major planning and financial issue. Especially in rural areas attempts to use the available transport as efficiently as possible can have major implications on the planning of treatment shifts.
A study of geographic access to renal services in Wales demonstrated that between 13 and 22% of the population of Wales live more than 30 minutes by road from any Renal Unit. Five Welsh towns (Holyhead, Newtown, Haverfordwest, Milford Haven and Llantwit Major) with more than 10,000 residents are more than 30 minutes from a Renal Unit and three towns (Fishguard, Llandrindod Wells and Barmouth) with more than 2,000 residents are more than 60 minutes from a Renal Unit.
References


47. Recommendations of the National Renal Workforce Planning Group 2002 Published under the auspices of The Royal College of Nursing, The Royal College of Physicians, The Royal College of Paediatrics and Child Health.

MODULE 4

Standards 12-13:
Organ Donation and Transplantation

Introduction

The optimal treatment for many patients with established renal failure (ERF) is transplantation. The supply of donor kidneys, however, does not match the demand and as a result there is an ever-increasing waiting list for such treatment.

In Wales, there is one transplant unit based at The University Hospital of Wales in Cardiff, which serves the population of South Wales. Patients in North Wales receive their transplants and initial follow-up in England, mainly at the unit located in the Royal Liverpool University Hospital. All paediatric transplantation takes place in England, at units based in Manchester, Birmingham and Bristol.

UK Transplant (UKT) is an operating division of NHS Blood and Transplant, which is an England and Wales Special Health Authority. Its key role is to ensure that donated organs are matched and allocated in a fair and unbiased way. UKT manages the National Transplant Database, which includes details of all donors and patients who are waiting for, or who have received, a transplant. UKT provides a 24-hour service for the matching and allocation of donor organs and makes the arrangements to transport the donated organs to patients. UKT also maintains the National Organ Donor Register, which records the names of those who have indicated that they would be prepared to donate their kidneys and/or other organs after death.

Around 22% of the eligible population in Wales is registered on the NHS Organ Donor Register. Surveys conducted by The Gallup Organisation on behalf of The British Kidney Patient Association in March 2000, however, suggest that about 70% of the population would be prepared to donate their kidneys after death\[1\], which suggests that a large proportion of the population has not registered its intent. Registration can be completed either by post, by telephone or on-line.\[2\]
Transplanted kidneys (or grafts) come from live or recently deceased human donors (cadavers). Most grafts in the UK come from cadavers but there is a trend to make greater use of live donation. Non-related live-donors are considered, but each donation has to be formally approved. This process is currently undertaken by the Unrelated Live Transplant Regulatory Authority (ULTRA). The ULTRA will be disbanded during 2006, when responsibility for all live donations will pass to the Human Tissue Authority (HTA).

With the demand for cadaver renal transplants greatly exceeding the number of organs available, there is a need to have a system in place to ensure that patients are treated equitably, and that donated organs are allocated in a fair and unbiased way. There are guidelines for placing patients on the transplant waiting list. These have been drawn up in the knowledge that the median survival of a cadaver renal transplant is now about 10 years, but that many patients with renal failure have co-morbid conditions, which will limit survival to a much shorter period.\[3\]

This module seeks ways to try and improve the donation rate from both living and cadaveric donors, and to provide guidance on how each donated kidney can be used to its maximum potential.

**What does it mean for patients?**

The availability of cadaveric kidneys for transplantation has fallen slightly over the last decade and the overall supply of donor kidneys has not kept pace with demand. In part this is due to a reduction in brain-stem deaths related to road-traffic accidents, and reflects the success of seat belt and crash helmet legislation. As a result, different strategies have to be put in place in order to maximise the number of organs available for transplantation through living donation as well as by increasing the pool of cadaver donor kidneys.
Changes in medical practice have also seen major improvements in techniques of organ transplantation, post operative management as well as in the range of immunosuppressive drugs that are available. The aims of standards 12-13 and their Key Interventions set out in this module are:

- To maximise the quantity and quality of kidneys available for transplantation, while respecting the rights of people and those close to them to make informed choices about donation.
- To optimise the outcome of a renal transplant for all those patients who are in receipt of an organ.
Standard 12:
Organ Donation

Each patient approaching established renal failure and assessed as likely to benefit from a renal transplant is given the best possible chance of receiving one.

Key Interventions
In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To increase the number of potential organ donors through continued investment in publicity and in education campaigns to increase public awareness of the need for organ donation, to encourage people to enrol on the organ donor register and to make their wishes known to those close to them (Level C).

2. To provide adequate numbers of donor transplant co-ordinators attached to each transplant unit to ensure a seamless provision of service. Through this system to participate in the organ retrieval pathway established by UK Transplant (Level C).

3. To carry out, and act upon, a continuous audit of deaths of patients in intensive care units, with particular focus on those patients in whom death was confirmed by brain stem testing and whether the subject of organ donation was discussed. This should include verification that a donor transplant co-ordinator was informed before ventilator support was withdrawn. It should be the responsibility of the Chief Executive of each Trust with an intensive care unit to ensure that this audit takes place (Level C).

4. To amend the pro-forma for diagnosis of brain death, which is signed by two examining doctors, to include details of the date and time of referral to the co-ordinator team and the name of the donor transplant co-ordinator informed (Level C).
5. To encourage “collaborative requesting”, whereby an intensive care unit consultant and transplant co-ordinator speak to the relatives of a potential donor together (Level C).

6. To appoint a renal recipient co-ordinator in each renal unit specifically to ensure the inclusion of all suitable patients on to the transplant list and to facilitate live donor transplantation (Level B).

7. To evaluate and if appropriate develop further the Non Heart Beating Donor schemes (Level B).
Standard 13:

Transplantation

Each patient approaching established renal failure and assessed as likely to benefit from a renal transplant has timely access to a high quality transplant service which includes information and education, maximises their opportunity of receiving a graft, supports them in preparing for and managing their transplant and optimises their outcome.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To provide patients being considered for a renal transplant with relevant information and education. It should be presented in a form they can understand so they are fully aware of the benefits and risks of the therapy as well as the post-transplant importance of compliance and the changing social and financial support that will be available to them as they adjust to normal life and a return to work (Level C).

2. To register all prospective recipients on the UKT waiting list. Blood samples for antibody screening will be tested routinely every three months (and following sensitising events such as a blood transfusion or transplant) to update the information on the UK waiting list (Level B).

3. To deliver Transplant services through a specialised Multidisciplinary Team with the full range of staff with appropriate training and experience, based in renal units with appropriate facilities and support services including social services, clinical psychology, physical and occupational therapy, pharmacy and dietetics expertise (Level C).
4. To agree a care plan with patients on the transplant waiting list with an agreed means of being contacted and of travelling to the unit when an organ is offered (Level C).

5. To establish an appropriate screening programme so that patients on the waiting list will be tested for HIV, hepatitis B and C, following written consent, and having been given the appropriate counselling regarding the results. Patients should also be screened for Cytomegalovirus (CMV) so that a decision on prophylaxis for CMV disease or post transplant screening for CMV can be taken at the time of transplantation. If appropriate, antiviral or other prophylactic treatment should be agreed and commenced perioperatively (Level A).

6. To re-assess prospective recipients annually, as a minimum, but six monthly for high-risk adults. Suspension from the waiting list must be explained and the decision reviewed regularly to decide on reactivation or permanent removal from the list as soon as possible (Level C).

7. To provide perioperative care so as to optimise the outcome of the procedure, including provision of adjacent operative theatres for living donor transplantation and a consultant presence for both surgery and anaesthetics (Level C).

8. To tailor an anti-rejection regimen to the individual patient using protocols compliant with NICE guidelines (Level A).

9. To establish agreed shared care protocols for post-transplant care based on national standards but adapted to local circumstances and the needs of the individual patients with both the nephrology service and the primary care team. Live donor follow up should be carried out annually (Level C).

10. To establish open access for renal transplant recipients and their primary care team to the transplant unit and their Multidisciplinary Team to ensure that advice on all matters relating to their health care can be dealt with appropriately and promptly (Level C).

11. To provide timely access to the RRT programme for recipients with failing grafts, and to reactivate the patient on the renal transplant waiting list as appropriate (Level C).

12. To participate in the annual audit run by UKT NHS Blood and Transplant authority (Level C).
Rationale and Evidence Base

Standard 12:

Organ Donation

Renal transplantation provides the most successful and cost effective treatment for ERF. Unfortunately, not all patients with ERF are suitable for transplantation. Furthermore, there is a waiting list for transplantation in Wales, which is getting longer.[2]

Comparative data from other countries in Europe, and even from within the UK, suggest that the rate of transplantation in Wales could be improved, with reversal of this trend. The means whereby this improvement could be achieved include: increasing the number of renal transplants performed from living donors; improving the donation of kidneys from patients in the Critical Care units in whom death has been confirmed by brain stem death testing (heart-beating donors [HBD]) and supporting a programme, or programmes, for patients to be able to donate their kidneys following cardiac death (non-heart-beating donors [NHBD]).

Quality of life surveys have consistently shown that patients with functioning transplants have a better prognosis compared with those receiving dialysis. Information from the transplant waiting lists shows that those who receive a transplant live longer than those who don’t.[4] Furthermore, significant financial savings can be made as a result of an increase in the number of organs available for transplantation. Each successful cadaveric renal transplant potentially saves the NHS up to £250,000 per patient over a 10-year period.[2] The savings from a live donor transplant are potentially even greater because the median graft survival is longer.

The Process of Kidney Donation

Allocation of organs and matching

Rules for allocating organs are determined by the medical profession in consultation with other health professionals, the UK Health Departments and specialist advisory groups. Donated kidneys are given to patients with the nearest tissue type match and compatible blood group, as this improves long-term outcome.[5] Children take priority.
Tissue typing is carried out by analysing blood and cell samples from the patient and donor to identify the extent to which there are similarities between special classes of protein. With the risk of oversimplification, there are three major tissue proteins (antigens) to be considered (A, B and DR), in addition to the blood group antigens (somewhat confusingly also called A and B, and the Rhesus antigen). For each of the three tissue antigens, an individual will have inherited one antigen type from their mother and another antigen type from their father. Sometimes the antigen from each parent will be the same in which case they are termed homozygous for that antigen. Homozygosity makes it more difficult to find a perfect match. A 000 (A,B,DR) mis-match represents a very close, or even identical, tissue type, and is preferred because of the association with better long term prognosis for the graft. Grades of mismatch can be categorised as 100, 010, 110, 111, etc. depending on which of the three antigens do not match. If there is a mis-match, it is better to have this for the A antigen rather than B, and for the B antigen rather than the DR.

A new UK kidney allocation scheme will come into force during 2006, and will rank potential recipients for a kidney in five hierarchical tiers:

**Tier A:** 000 mis-matched paediatric patients who have high levels of antibodies against other tissue types, (usually acquired through previous blood transfusion or transplantation) which would prevent transplantation with less-good tissue matches. DR antigen homozygous paediatric patients.

**Tier B:** 000 mis-matched paediatric cases without high levels of antibodies against other tissue types.

**Tier C:** 000 mis-matched adults with high levels of antibodies against other tissue types. DR antigen homozygous adult patients.

**Tier D:** 000 mis-matched adults without antibodies and favourably matched paediatric patients (100, 010, 110 mis-matches, i.e. no DR mismatch).

**Tier E:** All other patients.
Children in Tiers A and B are then ranked by waiting time. All other patients are ranked using a point score based on seven factors:

1. Waiting time.
2. Tissue match and age combined.
3. Location of the recipient relative to the donor.
4. Donor-recipient age difference.
5. DR antigen homozygosity.

The aim of this new allocation scheme is to reduce the number of patients who receive a poorly matched kidney and to increase the number receiving a 000 (A,B,DR) mis-matched kidney. In addition, it should reduce the number of kidneys being transported long distances, thereby reducing the risk of time-related damage to the kidney whilst it is without a blood supply. It will enable a balance to be struck between patients with differing blood groups (patients with blood group AB rhesus positive can receive a transplant from any other blood group but can only donate to patients who are AB rhesus positive, whereas patients with blood group O rhesus negative can donate their kidneys to patients with any other blood group but can only receive a graft from a blood group O negative donor). There will be more transplants for the young, those with rare tissue types and those who have been waiting for more than three years for a kidney.[6]

Live Donor Transplantation

Renal transplantation from living donors has become the predominant source in the United States where the number of living donors has now overtaken the number of cadaveric donors and the live related transplant rate is about 20pmp.[7] Within Europe, the Scandinavian countries have much higher rates of live donor transplantation, with a rate of 19pmp in Norway compared with 7.3pmp in the UK.[8] Live donor transplants are associated with better graft and recipient survival outcomes when compared with cadaveric transplants.[2]

Laparoscopic donor nephrectomy has distinct advantages for the donor in terms of speed of recovery and return to work, and has propelled the increased use of live donation in the US.[9]
Although live donors are usually blood relatives of the recipient, there is an increasing trend for donation from spouses, friends and even anonymous altruistic donors. In the UK, all transplants from unrelated donors are vetted by the ULTRA in order to prevent unethical conduct, particularly financial coercion of the donor. This responsibility will pass to the Human Tissue Authority in 2006.

Available information suggests that donation from unrelated donors has a good outcome, equivalent to that seen with all but the most closely tissue-matched blood relatives, as long as there is no blood group or crossmatch reactivity between donor and recipient. Renal graft survival rates of about 75% or better at five years are to be expected.\[7\]

Guidelines for evaluation of potential living kidney donors have been drawn up by The British Transplant Society\[10\] and all initiatives in this area must comply with both the Human Organs Transplant Act 1989\[11\] and the Human Tissue Act 2004. The establishment of Transplant Link Nurses in each main dialysis unit in Wales, a recent initiative by The Kidney Research Unit for Wales Foundation, and now supported by the respective NHS trusts, has improved the follow up arrangements for transplant patients and live donors. Early reports suggest that there has also been a positive effect on the live donor rate (UKT, unpublished information).

**Cadaveric Transplantation from heart-beating donors**

All donors in this category are patients who have been treated in an intensive care unit, and have had death confirmed by brain stem testing. The cause of death is usually cerebral trauma or intracerebral haemorrhage.

There is evidence to suggest that the supply of kidneys in the UK from this source could be increased by up to 20% by improving the identification of potential donors and subsequently obtaining the necessary consent for surgery.\[12,13\] This is a stepwise process:

- First, any patient in the intensive care unit in whom death has been confirmed by brain stem testing (for details, see\[2\]) should be considered as a possible donor and their family given the option to consider organ donation.
Second, contraindications to donation must be identified at an early stage. These include metastatic malignant disease and certain infectious diseases, the latter summarised in guidance from the Department of Health.[14]

Third, consent is a fundamental requirement for Transplantation under the Human Tissue Act 2004, which will fully come into force during 2006. The concept of ‘lack of objection’ under Human Tissue Act 1961 will no longer be legal.[15]

Under the Human Tissue Act 2004 appropriate consent to organ donation by a deceased adult will then be possible by his/her consent before death. If no prior consent has been given, then consent can be given by a nominated representative or by “qualifying relatives”, who are ranked in order when consent is being sought. Where there is more than one relative in the same rank in the hierarchy, brother or sister for example, the consent of any one of them will make it lawful (not obligatory) to store or use tissue for a scheduled purpose.[16] The Human Tissue Authority (the regulatory body under the new Act) has consulted on the Codes of Practice[16] under the Act and will be publishing the full set of Codes in March 2006.

Organ retrieval is organised by the Donor Transplant Co-ordinators attached to each transplant unit, who are employed by NHS Trusts but trained and professionally led by UKT.

**Cadaveric transplantation from non-heart beating donors**

In centres in Europe, Japan and parts of the UK there are longstanding programmes retrieving organs from NHBD.[10]

NHBD can be divided into categories based principally on work from the Maastricht (Netherlands) group. This is important both for the logistics of retrieval and outcome following transplantation:

- Category 1: dead on arrival at hospital.
- Category 2: unsuccessful resuscitation.
- Category 3: awaiting cardiac arrest (also referred to as “Controlled NHBD”).
- Category 4: cardiac arrest in a brainstem dead cadaver.
- Category 5: unexpected cardiac arrest in a patient in an ITU.
Transplanted kidneys from NHBD have a higher rate of delayed function compared with grafts from HBD. However, long-term survival rates are comparable. UKT is supporting the introduction of NHBD programmes across the UK as an important source of organs for donation. A NHBD programme was started in Cardiff in the autumn of 2004, focusing on Category 3 NHBD.

**Special Considerations regarding all types of transplantation**

**People from Minority Ethnic Groups**

- The incidence of hypertension and diabetes within the Afro-Caribbean and South Asian population is significantly higher than within the white population. Inevitably this impacts on the demand for renal replacement therapy (RRT) and transplantation in areas of the UK that have higher ethnic minority populations. In contrast, there is a national shortage of Black and Asian tissue type and blood group compatible organ donors. One reason for this shortfall relates to the reduced incidence of brain stem death amongst Black and Asian individuals identified in the national pool.

- The blood Group B patient’s distribution is more prevalent amongst the Indo-Asian community than in the population as a whole. The allocation of kidneys for transplant is based primarily on blood group and HLA matching, which for ethnic minority patients on the waiting list places them at a disadvantage given that the majority of donors will arise in the Caucasian population. The national allocation rules have been changed to allow more organs to go to blood Group B patients.

- Indo-Asian patients have a median waiting time of 1496 days for a transplant compared with 1389 days for African-Caribbean patients and 722 days for Caucasian patients.\[2]\ The problems of matching for ethnic minority patients is being addressed by measures to encourage donation from this community and could be enhanced further by amendments to national allocation rules. For this group of individuals, live donation may be the best option.
**People with Diabetes**

Diabetes mellitus (in the donor) is an absolute contra-indication to living donation. Prospective donors with an increased risk of type 2 diabetes mellitus, because of family history, ethnicity or obesity, should undergo a glucose tolerance test and only be considered if this is normal.\(^7\)

**Standard 13:**

**Transplantation**

A successful renal transplant is the most clinically effective and cost efficient management for a majority proportion of patients with ERF. It will enable a patient to be free of dialysis so that they can lead a relatively normal life. It has been shown that most transplant recipients will appreciate an increase in fitness, a greater likelihood of being able to return to full employment, and an overall improvement in quality of life.

The successful receipt of a renal transplant will increase the life expectancy of a patient with ERF, who would otherwise require dialysis.\(^7\) Nevertheless, patients considering a renal transplant must understand that they will need to take a combination of immunosuppressive drugs to prevent rejection. Failure to comply with treatment is a significant cause of graft failure.

Patients approaching ERF are introduced to the concept of RRT including transplantation by the multidisciplinary renal team (see standard 8). Adequate education at an early stage enables all avenues of dialysis and transplantation to be explored, appropriate care plans to be established and concepts such as living donation and pre-emptive transplantation to be considered.

Some people with ERF are not suitable for renal transplantation, because of co-existing medical or psychological problems. Age in itself is not a contraindication to transplantation, but the risks of co-morbidity are increased with age and therefore influence the possible benefits of a graft.\(^1,7\) Patients assessed to be unsuitable for a transplant should be fully informed of this decision, receive a full explanation as to why this is the case along with psychosocial support to cope with the consequences.
**Preparation for Transplant**

Patients approaching ERF who are assessed as being suitable for a renal transplant will benefit most if they are transplanted, wherever possible, before they start dialysis.\[17,18\]

Patients deemed to be suitable for a renal transplant are entered onto the national transplant list.\[1\] This may take place up to six months before their estimated start on RRT.

It is well recognised that blood group, tissue type and any HLA/specific antibodies may influence the chance of a successful transplant and patients entering the waiting list should be aware of this including the length of time that they may wait for a suitable organ. Individuals on the transplant waiting list should be regularly re-tested for the appearance of antibodies and care should be taken not to unnecessarily expose them to procedures, which may result in sensitisation e.g. blood transfusion.

People with ERF may have other conditions like coronary heart disease and/or diabetes, which increase the risk of surgical complications. The potential benefits of a transplant are different for each person and each individual should decide whether to accept or refuse an organ on the basis of his or her own risk assessment. The pro-active investigation and treatment of patients with increased morbidity will improve their chances of a successful outcome.

The source of the organ may significantly influence graft function and patients should be made aware of this. Kidneys from live related or unrelated donors normally function immediately and have the best long term graft survival.\[19,20,21,22\]

Transplantation carries the risk of transmitting a serious infection. Cytomegalovirus (CMV) is the commonest transmitted infection, although the risk can be minimised by prophylactic treatment of the recipient.\[23\]

In exceptional cases it is acceptable to transplant a kidney from an infected donor into a suitable, fully informed patient (e.g. if both donor and recipient are hepatitis B or C positive). The diagnosis of CJD in a potential donor is a contraindication to organ donation.
The other major risk is transmission of a malignant disease such as cancer of the kidney, breast or bronchus.\textsuperscript{[24,25]}

\textbf{Perioperative Care}

This must include:

- Optimal surgical retrieval of the kidney with minimal warm and cold ischaemic times. National facilities should ensure that cold ischaemic time should not exceed the limit of 24 hours. Kidneys with longer cold ischaemic times should be considered on the individual merits of the case.\textsuperscript{[21]}

- Recipient-donor cross-match\textsuperscript{[1]} including the exclusion of anti-donor antibodies.

- Discussion with the potential recipient about the quality of the kidney and any increased risks associated with that specific organ.

- Optimal anti-rejection therapy, which should be compliant with NICE guidelines.\textsuperscript{[26]}

- Appropriate perioperative care so as to optimise the outcome of the procedure, including provision of adjacent operative theatres for living donor transplantation and a consultant presence for both surgery and anaesthetics.\textsuperscript{[27]}

\textbf{Transplant follow-up}

The survival of the recipient and the continued function of the transplanted kidney will indicate the success of the procedure. The aims of transplant follow-up are therefore to maximise the health of the recipient and maintain the function in the grafted kidney.

\textbf{Immediate postoperative period}

The priorities for the clinical team are:

- Monitoring for post-operative complications, particularly infection. Transplant recipients are more prone to infection because their immune systems are depressed by the anti-rejection therapy.

- Managing the renal failure using dialysis as required until the graft is functioning adequately. In some cases, graft function can be delayed for up to six weeks.
• Monitoring for acute rejection in the graft. A biopsy of the transplant, analysed by a histopathologist fully trained in renal transplant pathology, is required to confirm the diagnosis. Treatment of rejection should be compliant with NICE guidelines.[26]

• Informing the patient about their transplant and teaching them to manage their own medicines.

It is important that a care plan is agreed with the team before discharge so that the patient is assured that appropriate support arrangements are available.

**Discharge to six months post transplant**

During this period, the risk of acute rejection and certain infections such as cytomegalovirus (CMV) are at their highest. Recipients may need considerable psychological and social support in addition to ongoing medical care.

**Six months post transplant onwards**

The patient should have an agreed care plan which includes appropriate precautions and lifestyle adjustments. The aim is early detection of any problems, which can be managed appropriately, and care plans amended accordingly. The risk of rejection is still present but gradually diminishes with time. Regular, but less frequent check ups are required. If the graft is functioning well, most recipients will be adjusting to life with a transplant. Those of working age may be able to return to full time employment. Patients need to understand the risk of ongoing transplant related problems.

The primary concerns are the function of the transplant and the risks of complications and/or side effects of anti-rejection drugs. People with transplants may develop or have progression of a variety of problems such as impaired renal function, hypertension, diabetes, hyperlipidaemia, osteoporosis and certain cancers, particularly lymphoma and skin cancer.[28]

If, despite therapy, the function of the transplant decreases then patients need to be referred to a pre-dialysis multidisciplinary renal team at an optimum time for consideration of the next stage of RRT.
Special Considerations

People with Diabetes

The survival benefit of renal transplantation compared with dialysis is even greater in appropriately selected diabetic recipients than it is in non-diabetics. Thus transplantation is recommended as the treatment of choice for all suitable people with both ERF and diabetes.

A number of pre and post transplant risk factors contribute to increased mortality in people with diabetes. Careful pre transplant assessment and correction where possible of significant coronary artery disease has been shown to reduce post transplant cardiac events in type 1 (insulin dependent) diabetes.

Some patients may benefit from combined renal and pancreas transplantation. These are primarily the younger, type 1 diabetics. Long-term patient survival is better in these patients than for those receiving a renal transplant alone, though the operation has a higher risk of complications. Clear advice is available from UKT clarifying which diabetic patients might be suitable for this procedure. Combined renal and pancreas transplantation has been shown to reduce excess cardiovascular mortality in type 1 diabetic patients.
References

1. www.britishkidney-pa.co.uk.
2. www.uktransplant.org.uk Tele: (0845 60 60 400).
10. www.bts.org.uk.


23. BTS guidelines for the prevention and management of CMV disease after solid organ transplantation. [www.bts.org.uk].


MODULE 5

Standards 14-17:

Alternative models of care

Introduction

Although the majority of patients reaching established renal failure (ERF) will choose to receive renal replacement therapy (RRT), there are a small but significant minority who decline this form of treatment. In addition, the changing demography of the patient population has resulted in a number of individuals who, by the nature of their co-morbid problems such as severe heart or respiratory diseases, will not benefit from RRT since the therapy itself will likely make their co-morbid condition worse.

Despite this, choosing not to dialyse can still be accompanied by a good quality of life. Ensuring such an outcome remains the continuing responsibility of the Multidisciplinary Renal Team at the local renal unit.

Finally, some patients who are receiving RRT may choose to discontinue treatment or may become so unwell that they no longer benefit from treatment. Under these circumstances, dialysis can be stopped, usually resulting in the patient’s death.

This module comprises four standards:

- Choosing not to dialyse.
- Conservative management of established renal disease.
- Withdrawing from dialysis.
- End of life care, particularly in the last 48 hours of life.

These areas are linked in that they are all firmly based on empowering and supporting the patient who may choose not to have RRT or who is too ill or otherwise unable to be considered for RRT. The module considers decision making, supportive therapy and symptom control.
Decisions on withholding and withdrawing treatment must follow the guidance published by the General Medical Council\(^1\) and, for those with impaired competence to consent, the Mental Capacity Act 2005. Care of those patients diagnosed as dying should be planned using the All Wales Care Pathway for the Last Days of Life.\(^2\)

**What does this mean for patients?**

The purpose of Module 5 is to set out a framework of care for those patients who, having developed established renal failure, have either chosen not to undergo dialysis or because of their medical condition are not able to undergo dialysis. Patients need support when they are asked to decide about whether they wish to undergo dialysis and need to be given a clear picture of what their care will consist of whether or not they chose to dialyse.

The aims of Standards 14-17 and their Key Interventions set out in this module are:

- To ensure that a patient who does not wish to dialyse makes the decision having been given appropriate information and support. This will allow them to make an informed decision.

- To ensure that patients who do not receive dialysis continue to receive appropriate and patient focussed care from specialist hospital based services as well as from services in the community.

- To ensure that if dialysis becomes such an intolerable physical or psychological burden to a patient that they can, if they so wish, choose to stop treatment. Similarly if such treatment becomes futile, then that treatment will be withdrawn ethically and openly. It is essential that under these circumstances, patients and their families and/or carers are provided with appropriate psycho-social and spiritual support in order that they understand what the future will bring and what support they will have, either in hospital or in the community.

- To ensure that patients with established renal failure who are in the terminal stage of their illness have access to services that will allow them to die with dignity in a place of their choice.
Standard 14:

Choosing not to dialyse

Each patient approaching established renal failure is given timely and understandable information about their prognosis and the choice of therapies available to them including the option of choosing not to dialyse. They are made aware of the relative burdens and benefits of the different types of dialysis.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To establish a protocol that will ensure that when a patient chooses not to dialyse the decision making process.
   a. Takes place within the framework of the pre-dialysis programme.
   b. Involves frequent contact between the patient and the multidisciplinary renal team.
   c. Is supported fully by both the consultant nephrologist and the patients own GP.
   d. Involves family/friends/carers according to the patient’s wishes.
   e. Provides specific and relevant education and information.
   f. Clearly documents in the clinical record those decisions made by a competent patient who declines the offer of dialysis including their reasons and rationale (Level C).
2. To establish a protocol that will ensure that when, under some circumstances, the Multidisciplinary Renal Team decides that dialysis should not be offered, the reasons for this are explained to the patient and their family and/or carers and clearly documented in the clinical record. Under these circumstances, the General Medical Council’s “Withholding and Withdrawing Life-Prolonging Treatment: Good practice in Decision Making” must be used to guide management (Level C).
Standard 15:
Conservative management of established renal disease

Each patient who chooses not to dialyse is offered ongoing support from the Multidisciplinary Renal Team, and has access to appropriate supportive and palliative care services in primary and secondary care, including advice from specialist palliative medicine.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To put in place a competency framework to ensure that all members of the multidisciplinary renal team have expertise and training in supportive and general palliative care in addition to their nephrology experience. There will be a lead within the team who has Certificate or Diploma level training in palliative care/medicine (Level C).

2. To ensure that patients:
   a. Have the opportunity for referral to specialist palliative medicine services in hospital and the community, with close communication with the GP.

   b. Have their ongoing outpatient care conducted by a nephrologist with whom they are familiar in order to monitor specific complications of renal failure which will continue to require active management including:

      i. Blood pressure control which will still be important to slow progression of renal failure but should be balanced against the side effects of the therapy.
ii. Correction of renal anaemia to preserve functional status.

iii. Ongoing dietetic advice, which will vary during the period of conservative management.

iv. Access to Clinical Psychology support.

v. Access to physical and occupational therapy services.

vi. Identifying the need for social work support at an early stage in the process, to allow for timely referrals (Level C).
Standard 16:
Withdrawal of dialysis

A decision to withdraw dialysis is ethical, open, informed and patient-centred, and concords with the ‘patient’s best interest’ principles. Ongoing support is provided by the Multidisciplinary Renal Team and by palliative care services where appropriate.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To ensure that if the issue of withdrawal from RRT is raised by the patient, family/carer, or any member of the Multidisciplinary Renal Team, this triggers a full review and discussion with all relevant parties to:
   a. Explore any adverse problems and identify which of these can be relieved or resolved.
   b. Address issues of competence to make an informed choice.
   c. Provide information and education on the consequences of withdrawal.
   d. Consider whether it is appropriate at this stage to involve the palliative care team.
   e. Explore future care options available, including funding issues (Level C).

This process of withdrawal should be open, transparent and clearly documented, with time allowed for patients/families to discuss and review their wishes. Dialysis will continue until a final decision is made, appropriate care has been arranged, and the patient has had time to attend to personal matters. When there is disagreement, dialysis should continue whilst there is open and joint review of the decision (as long as this is not contrary to the patient’s competent refusal).
To ensure that in the case of patients who have opted to withdraw from dialysis but who change their minds and wish to resume treatment that they will be offered every support to do so.

The General Medical Council’s “Withholding and Withdrawing Life-Prolonging Treatment: Good practice in decision making” will be used to guide management. Thus whatever the decision, patients/carers have a right to expect respect for their wishes, continued support and appropriate services to meet their needs (Level C).

2. To provide information for family/carers, that for those patients unable to make an informed choice, the decision to discontinue therapy, rests with the Consultant Nephrologist, after full discussion with the family/carer and relevant members of the Renal Team. If necessary, a second opinion on competence should be sought from a senior Consultant of an appropriate speciality. Further legislation is likely in this area and health professionals should take care to act according to any changes in the law (Level C).
Standard 17:
Care in the last days of life

The diagnosis of dying is made in a timely manner. The patient has access to a range of services to ensure that their physical, psychological, social and spiritual needs are met effectively, and to enable them to die in their place of choice if possible.

Key Interventions

In order to achieve this Standard, Local Health Boards and Health Commission Wales, working through the Renal Networks, must commission appropriate patient care from provider groups which ensures that services are in place or action is taken:

1. To put in place a competency framework to ensure that all members of the multidisciplinary renal team have expertise and training in supportive and generic palliative care in addition to their nephrology expertise in order that the physical, psychological, social and spiritual needs of the patients are appropriately met (Level C).

2. To establish explicit links between each Multidisciplinary Renal Team and specialist palliative care services, both in hospital and in the community, and refer appropriately (Level C).

3. To use the “All Wales Care Pathway for the Last Days of Life” as the framework to manage the care of such patients and staff should be trained to use the pathway.[2, 3] Rapid discharge pathways will be developed to facilitate, where appropriate, the timely discharge of patients to their preferred place of care (Level C).

4. To provide bereavement counselling for families/carers for those who need it (Level C).
Rationale and Evidence Base

**Standard 14:**

**Choosing not to dialyse**

Accurate information about prognosis in chronic renal failure (CRF) is sparse and relates to populations/patient groups rather than individuals. There are patients who are approaching ERF with multiple co-morbidities or who are very elderly who may not necessarily have either their longevity or quality of life improved by dialysis.[4] Consequently, choosing not to dialyse may therefore be appropriate for them.

**Standard 15:**

**Conservative management of established renal disease**

Patients who choose not to have RRT may well survive for many months or even years. During this time they will need an approach, which maximises their physical well being and quality of life. Although they will have chosen not to have RRT, they will continue to have specialist needs, which should be managed/provided by the Multidisciplinary Renal Team. Since their life expectancy will be relatively short, the goals of therapy will be directed more towards symptom control and quality of life rather than influencing prognostic factors.

As their illness progresses and death becomes closer, a patient’s needs will change and this will need to be reflected in their management.

**Standard 16:**

**Withdrawal of dialysis**

Patients on dialysis may perceive that the treatment has become an intolerable physical or psychological burden. Under these circumstances, stopping dialysis is a legitimate choice for a competent patient. Many patients do not understand that they have the right to make an informed choice, and are afraid to discuss the issue, for a variety of assumed reasons.
The family, carers or any member of the Multidisciplinary Renal Team may separately feel that the end of life is approaching, and that the burden of therapy seems to outweigh the perceived quality of life.

Decisions to cease dialysing patients who are not competent to consent to treatment being withheld, must be in accordance with any valid Advance Decision the patient has made and in line with the Mental Capacity Act 2005 guidance.

Managing withdrawal is a stressful event for all involved. Multi-professional renal staff are wary of the sensitive and ethical issues involved, and the potential for conflict.

Reliable data on withdrawal from dialysis is not available. The mean survival time for this group of patients is 8 days without dialysis but depends on a number of factors including residual renal function.\(^5\)

**Standard 17:**

**Care in the last days of life**

Terminal care is a core responsibility of the renal service. It is a duty of care to the patient. This process requires sensitive team management and co-ordination.

At present, some patients face an undignified death with uncontrolled symptoms. Most patients on RRT die in hospital, on wards more traditionally equipped for curative and rehabilitative purposes. When the “diagnosis of dying” - the recognition that death is imminent - is made, the model of care should change to focus on comfort and dignity. Recognising this transition is difficult but is vital in ensuring a dignified death.\(^6\)

Renal teams frequently receive no special training in end of life care. The availability of palliative care, psychosocial support and appropriate care facilities and services is patchy and variable.

The impact of a patient’s death may also have consequences for the staff, and the patient’s peer group, which may need to be addressed.
References

## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Access surgery</td>
<td>Surgery to create dialysis access, either vascular access (see entry) for haemodialysis, or peritoneal access (see entry).</td>
</tr>
<tr>
<td>Access to services</td>
<td>1. A patient’s ability to obtain treatment from particular services (e.g. the renal service); or 2. to reach hospital services (e.g. by non-emergency patient transport).</td>
</tr>
<tr>
<td>Acidosis</td>
<td>Accumulation of acid in the body usually due to renal failure or renal tubular defects.</td>
</tr>
<tr>
<td>Acute Renal Failure (ARF)</td>
<td>Rapid onset of kidney failure. May require specific treatment and is frequently reversible. Sometimes referred to as acute kidney injury (AKI).</td>
</tr>
<tr>
<td>Acute Tubular Necrosis (ATN)</td>
<td>ATN is a cause of acute renal failure, which may occur following a period of low blood pressure, ATN is usually reversible.</td>
</tr>
<tr>
<td>Adolescent transition framework</td>
<td>A framework devised for the multidisciplinary team to ensure best practice for children transferring to adult care.</td>
</tr>
<tr>
<td>Albumin</td>
<td>A protein that circulates in the blood. Low levels may be associated with heavy urinary loss, infection or malnutrition.</td>
</tr>
<tr>
<td>Albumin/Creatinine Ratio</td>
<td>A measurement of the amount of albumin lost in the urine after correcting for urine creatinine concentration.</td>
</tr>
<tr>
<td>Altruistic Donors</td>
<td>Unrelated live donors who choose to donate their organs to others as an act of conscience.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<td>-------------------------------------------</td>
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<tr>
<td>Anaemia</td>
<td>A shortage of red blood cells. Haemoglobin in red blood cells carries oxygen around the body, and anaemia causes tiredness and shortage of breath. Normal kidneys produce erythropoietin, a hormone which stimulates red blood cell production.</td>
</tr>
<tr>
<td>Angiography</td>
<td>An X ray investigation of the blood vessels to identify a narrowing or blockage.</td>
</tr>
<tr>
<td>Angiotensin Converting Enzyme (ACE) inhibitor</td>
<td>A class of drug that reduces blood pressure and improves heart function in heart failure.</td>
</tr>
<tr>
<td>Angiotensin II receptor blockers</td>
<td>(ARBs) A class of drug with a similar function to ACE inhibitors, i.e. reducing blood pressure and improving heart function in heart failure.</td>
</tr>
<tr>
<td>Antenatal</td>
<td>Before birth.</td>
</tr>
<tr>
<td>Antenatal Uropathy</td>
<td>Structural abnormalities of the kidneys and/or urinary tract present before birth.</td>
</tr>
<tr>
<td>Antihypertensives</td>
<td>Medicines to control persistently high blood pressure (hypertension).</td>
</tr>
<tr>
<td>Anti-rejection treatment</td>
<td>Medicines to counter the response of a transplant recipient’s immune system and prevent rejection.</td>
</tr>
<tr>
<td>Anuria</td>
<td>No urine output.</td>
</tr>
<tr>
<td>Arteriovenous fistula (AVF)</td>
<td>Created by joining a vein to an artery, usually in the arm, to increase the blood flow directly into the vein: this causes enlargement of the vein, into which a needle can be repeatedly inserted to allow regular access to the bloodstream for haemodialysis.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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</tr>
<tr>
<td>Automated peritoneal dialysis (APD)</td>
<td>A form of peritoneal dialysis in which a machine is used to carry out multiple fluid exchanges, usually overnight.</td>
</tr>
<tr>
<td>BCG</td>
<td>Bacillus Calmette-Guerin is the protein used in immunisation against Tuberculosis.</td>
</tr>
<tr>
<td>Benchmarks</td>
<td>Benchmarks are used as comparators to compare performance between similar organisations or systems.</td>
</tr>
<tr>
<td>Bicarbonate</td>
<td>A substance that is normally present in the blood whose function is to balance the build up of acid.</td>
</tr>
<tr>
<td>Biopsy</td>
<td>The removal and examination of a small piece of tissue for diagnosis. A kidney biopsy is used to establish the cause of kidney disease.</td>
</tr>
<tr>
<td>Bladder outflow obstruction</td>
<td>A condition which impedes the flow of urine out of the bladder.</td>
</tr>
<tr>
<td>Blood borne virus infections</td>
<td>Viruses which can be transmitted by the transfusion of blood products.</td>
</tr>
<tr>
<td>Buffer</td>
<td>A compound that resists changes in pH.</td>
</tr>
<tr>
<td>Cadaveric Donor</td>
<td>An individual who has recently died and whose organs can potentially be used for transplantation.</td>
</tr>
<tr>
<td>Calcification</td>
<td>The deposition of calcium in tissue. Vascular calcification, in which blood vessels become damaged, contributes to cardiovascular disease.</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>Relating to the heart and blood vessels.</td>
</tr>
<tr>
<td>Care pathway</td>
<td>An Algorithm that sets out different stages of a patients treatment plan.</td>
</tr>
<tr>
<td>Care plan</td>
<td>A statement of the treatment a patient needs and how it is to be provided, and a record of its delivery.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
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</tr>
<tr>
<td>Case control study</td>
<td>A non-randomised research study in which results from the case studied are compared with results from a selected ‘control’ (see randomised controlled trial).</td>
</tr>
<tr>
<td>Case report</td>
<td>A report of an individual instance of a condition and its outcome.</td>
</tr>
<tr>
<td>Case series</td>
<td>A report of several cases of a condition and their outcomes.</td>
</tr>
<tr>
<td>Catheter</td>
<td>A hollow tube used to transport fluids into and out of the body.</td>
</tr>
<tr>
<td>Central Vein</td>
<td>Any one of a number of large calibre veins draining blood back to the heart. They include the subclavian vein, jugular vein and superior vena cava.</td>
</tr>
<tr>
<td>Chronic kidney disease (CKD)</td>
<td>Abnormality of the structure and function of both kidneys, lasting more than three months; often progressive.</td>
</tr>
<tr>
<td>Coronary Heart Disease (CHD)</td>
<td>Coronary heart disease is the term used to describe the disease resulting from the gradual narrowing of the coronary arteries that supply blood and oxygen to the heart muscle.</td>
</tr>
<tr>
<td>Clinical Audit</td>
<td>A quality improvement process that seeks to improve patient care and outcomes through systematic review of care against explicit criteria and the implementation of change.</td>
</tr>
<tr>
<td>Clinical Governance</td>
<td>A system through which health organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care, by creating an environment in which clinical excellence will flourish.</td>
</tr>
<tr>
<td>Clinical Indicators</td>
<td>Selected measurements of clinical care, which allow performance to be measured against standards.</td>
</tr>
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</tr>
<tr>
<td>Clinical Network</td>
<td>Linked groups of health professionals and organisations from primary, secondary, and/or tertiary care, working in a co-ordinated manner, unconstrained by existing boundaries, to ensure equitable provision of high quality clinically effective services.</td>
</tr>
<tr>
<td>Clinician</td>
<td>Professionally qualified staff providing clinical care to patients.</td>
</tr>
<tr>
<td>Cockcroft and Gault Formula</td>
<td>A formula to calculate renal function using plasma creatinine, age, weight and patient sex.</td>
</tr>
<tr>
<td>Cohort study</td>
<td>A type of research study in which a group of people who have a particular condition or receive a particular treatment are followed over time.</td>
</tr>
<tr>
<td>Comorbid Factors</td>
<td>Other medical conditions that may or not be related to the primary disease but which affect patient morbidity and mortality.</td>
</tr>
<tr>
<td>Competency framework</td>
<td>A description of the skills and competencies required to carry out a particular task or role.</td>
</tr>
<tr>
<td>Conservative Management</td>
<td>A treatment modality for renal failure which does not include transplantation or dialysis.</td>
</tr>
<tr>
<td>Coronary Heart Disease (CHD)</td>
<td>Coronary heart disease is the term used to describe the disease resulting from the gradual narrowing of the coronary arteries that supply blood and oxygen to the heart muscle.</td>
</tr>
<tr>
<td><strong>Creatinine</strong></td>
<td>A by product of muscle metabolism that is removed via the kidneys and can be used as a surrogate marker of kidney function.</td>
</tr>
<tr>
<td><strong>Cystourethroscopy</strong></td>
<td>A means of looking inside the bladder and urethra.</td>
</tr>
<tr>
<td><strong>Cytomegalovirus</strong></td>
<td>A relatively common viral infection. It may be transmitted, or re-activated, by transplantation.</td>
</tr>
<tr>
<td><strong>Demographic</strong></td>
<td>Relating to the characteristics or composition of a population.</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td>A group of disorders characterised by abnormal glucose metabolism resulting in raised blood glucose levels.</td>
</tr>
<tr>
<td><strong>Diabetic Nephropathy</strong></td>
<td>Damage to the kidney caused by diabetes.</td>
</tr>
<tr>
<td><strong>Diabetic Neuropathy</strong></td>
<td>Damage to nerves caused by diabetes.</td>
</tr>
<tr>
<td><strong>Diabetic Retinopathy</strong></td>
<td>Damage to the retina caused by diabetes.</td>
</tr>
<tr>
<td><strong>Dialysis</strong></td>
<td>A blood purifying treatment in which waste products and excess water are filtered out of a patient's blood artificially. It is used when the patient's kidneys no longer function sufficiently to maintain life (see haemodialysis and peritoneal dialysis).</td>
</tr>
<tr>
<td><strong>Dialysis access</strong></td>
<td>The mechanism allowing access to the body for dialysis to take place; vascular access (see entry) for haemodialysis or peritoneal access (see entry) for peritoneal dialysis.</td>
</tr>
<tr>
<td><strong>Dialysis exchange</strong></td>
<td>In peritoneal dialysis, the process of draining out used dialysis fluid and replacing it with fresh.</td>
</tr>
<tr>
<td><strong>Dyslipidaemia</strong></td>
<td>Abnormal plasma lipid profile.</td>
</tr>
<tr>
<td>End Stage Renal Failure (ESRD)</td>
<td>Another name for Established renal failure.</td>
</tr>
<tr>
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</tr>
<tr>
<td>Erythropoietin</td>
<td>A hormone normally produced by the kidneys, which stimulates the production of red blood cells.</td>
</tr>
<tr>
<td>Established renal failure</td>
<td>Established renal failure (ERF), also called End Stage Renal Failure, is chronic kidney disease which has progressed so far that renal replacement therapy (RRT) is needed to maintain life.</td>
</tr>
<tr>
<td>Exit site infections</td>
<td>Skin infection around the site where a PD or vascular access catheter emerges.</td>
</tr>
<tr>
<td>Extra-corporeal therapies</td>
<td>Therapies which take place outside the body, such as haemodialysis, haemofiltration and haemodiafiltration (see entries).</td>
</tr>
<tr>
<td>Fistula</td>
<td>See arteriovenous fistula.</td>
</tr>
<tr>
<td>Functional capacity</td>
<td>The extent to which someone is able to carry out a defined activity.</td>
</tr>
<tr>
<td>Glomerular filtration rate (GFR)</td>
<td>A measure of the filtration capacity of the glomeruli used as a marker of kidney function. The rate at which the kidneys excrete waste products and excess fluid. There are a number of formulae for calculating estimated GFR which take into account factors such as patient’s age, body mass and ethnic origin.</td>
</tr>
<tr>
<td>Glomeruli</td>
<td>Tiny clusters of blood vessels which act as the filters in the kidney.</td>
</tr>
<tr>
<td>Glomerulonephritis (pleural glomerulonephritides)</td>
<td>A kidney disease caused by the immune system, which results in inflammation and damage to the glomeruli.</td>
</tr>
<tr>
<td><strong>Goodpastures Syndrome</strong> (anti GBM disease)</td>
<td>Goodpasture's Syndrome is an ‘autoimmune’ condition in which there can be severe inflammation affecting the kidneys and/or the lungs.</td>
</tr>
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</tr>
<tr>
<td><strong>Graft</strong></td>
<td>Something implanted or transplanted, so: 1) a tube of synthetic material connected to blood vessels as an alternative to an AVF (see entry), to provide vascular access for haemodialysis; or 2) a transplanted kidney (or other organ).</td>
</tr>
<tr>
<td><strong>Haematuria</strong></td>
<td>The presence of blood in the urine.</td>
</tr>
<tr>
<td><strong>Haemodialfiltration (HDF)</strong></td>
<td>A blood purifying treatment which combines some aspects of haemodialysis and haemofiltration (see entries).</td>
</tr>
<tr>
<td><strong>Haemodialysis (HD)</strong></td>
<td>A form of dialysis in which the patient’s blood is circulated through a machine that filters out waste products and excess water.</td>
</tr>
<tr>
<td><strong>Haemofiltration (HF)</strong></td>
<td>An alternative blood purifying treatment to haemodialysis in which waste products and excess water are removed from the blood by convection rather than diffusion, and some correctly balanced (physiological) fluid is replaced.</td>
</tr>
<tr>
<td><strong>Haemoglobin</strong></td>
<td>A molecule in red blood cells which binds oxygen and carries it round the body (see anaemia).</td>
</tr>
<tr>
<td><strong>Haemolytic uraemic syndrome (HUS)</strong></td>
<td>A syndrome characterised by fragmentation of red blood cells, blood clots and damage to the lining of small blood vessels, with associated damage to the kidneys (and other organs).</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>Healthcare Professional</td>
<td>A person who is a member of a profession regulated by a body mentioned in section 25(3) of the National Health Service Reform and Health Care Professions Act 2002.</td>
</tr>
<tr>
<td>Healthcare</td>
<td>Services provided for, or in connection with, the prevention, diagnosis or treatment of illness, and the promotion and protection of public health.</td>
</tr>
<tr>
<td>Heartbeating donor (HBD)</td>
<td>A person who has died while still on a ventilator in a critical care unit. The circulation is maintained until the organs are removed for transplantation.</td>
</tr>
<tr>
<td>Hepatitis</td>
<td>Inflammation of the liver that can be caused by a virus.</td>
</tr>
<tr>
<td>Histopathology</td>
<td>The examination of stained tissue sections usually by microscopy.</td>
</tr>
<tr>
<td>Human Immunodeficiency Virus (HIV)</td>
<td>This is the causal virus for AIDS.</td>
</tr>
<tr>
<td>Human Organs Transplant Act 1989</td>
<td>The Human Organ Transplants Act 1989 defines the legal conditions under which Transplantation can take place.</td>
</tr>
<tr>
<td>Hyperkalaemia</td>
<td>Increased potassium in the blood.</td>
</tr>
<tr>
<td>Hyperlipidaemia</td>
<td>Increased cholesterol and lipids in the blood.</td>
</tr>
<tr>
<td>Hyperparathyroidism</td>
<td>Persistently excessive production of parathyroid hormone (PTH).</td>
</tr>
<tr>
<td>Hypertension</td>
<td>Persistently high blood pressure.</td>
</tr>
<tr>
<td>Hypoalbuminaemia</td>
<td>A reduced level of serum albumin.</td>
</tr>
<tr>
<td>Immunology</td>
<td>The study of all aspects of immunity, such is the body's resistance to disease e.g. by the formation of antibodies.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
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</tr>
<tr>
<td>Immunosuppressive therapy</td>
<td>Treatment to suppress the bodies immune response.</td>
</tr>
<tr>
<td>Incidence</td>
<td>The number of new people in a population who develop a given condition; in a defined time frame.</td>
</tr>
<tr>
<td>Intravenous catheter</td>
<td>A catheter inserted into a vein (see venous catheter).</td>
</tr>
<tr>
<td>Ischemia time:</td>
<td></td>
</tr>
<tr>
<td>Warm ischemia time</td>
<td>The time between the kidney donor’s cardiac arrest and perfusion of the kidney with a solution at 4°C.</td>
</tr>
<tr>
<td>Cold ischemia time</td>
<td>The time is between cooling on removal from the donor and insertion into the recipient.</td>
</tr>
<tr>
<td>Kt/V</td>
<td>A formula to calculate the effectiveness (adequacy) of dialysis.</td>
</tr>
<tr>
<td>Laparoscopic Donor Nephrectomy</td>
<td>Removal of a kidney from the live donor using laparoscopic (“key hole”) techniques.</td>
</tr>
<tr>
<td>Living donor</td>
<td>A person who donates a kidney when they are alive.</td>
</tr>
<tr>
<td>MDRD formulae</td>
<td>A formula for calculating eGFR.</td>
</tr>
<tr>
<td>Meta-analysis</td>
<td>The integration of the results from a collection of research studies to arrive at an overall conclusion.</td>
</tr>
<tr>
<td>Microalbuminuria</td>
<td>The urinary excretion of more than 30 and less than 300 mg of albumin per 24 hours.</td>
</tr>
<tr>
<td>Microscopic Haematuria</td>
<td>Visibly undetectable blood in the urine. Demonstrated by microscopy or dip stick tests.</td>
</tr>
<tr>
<td>Microvascular</td>
<td>Concerning the small blood vessels and capillaries.</td>
</tr>
<tr>
<td>Morbidity</td>
<td>The state of being ill or diseased.</td>
</tr>
<tr>
<td>Mortality</td>
<td>Death.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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</tr>
<tr>
<td>MRSA</td>
<td>Methicillin resistant staphylococcus aureus.</td>
</tr>
<tr>
<td>Multidisciplinary Renal Team</td>
<td>The Clinical team consisting of individuals from the many disciplines needed to care for patients with kidney disease.</td>
</tr>
<tr>
<td>Multi System Disease</td>
<td>A disease that affect many organs.</td>
</tr>
</tbody>
</table>
| National Service Frameworks (NSFs) | • Set national standards and identify key interventions for a defined service or care group;  
• Put in place strategies to support implementation and;  
• Establish ways to ensure progress within an agreed timescale.                                      |
<p>| Nephritis                 | Pertaining to inflammation of the kidneys.                                                                                               |
| Nephrologist              | A physician who studies the functions of the kidney and treats people with kidney disease.                                                |
| Nephrology                | The study of the kidney and its diseases.                                                                                               |
| Nephropathy               | Disease of the kidney.                                                                                                                     |
| Nephrotic Syndrome        | A syndrome comprising of Proteinuria, Hypoalbumuria, Oedema, Hypercholesterolaemia.                                                        |
| Nephrotoxic drugs         | Drugs that are toxic to the kidney.                                                                                                       |
| Networks                  | Linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner unconstrained by existing professional and existing boundaries to ensure equitable provision of high quality, clinically effective services. |</p>
<table>
<thead>
<tr>
<th>Neurogenic bladder</th>
<th>Bladder dysfunction secondary to impaired nerve supply.</th>
</tr>
</thead>
<tbody>
<tr>
<td>NICE</td>
<td>The role of The National Institute for Clinical Excellence is to provide patients, health professionals and the public with authoritative, robust and reliable guidance on current “best practice”. The guidance covers both individual health technologies (including medicines, medical devices, diagnostic techniques, and procedures) and the clinical management of specific conditions.</td>
</tr>
</tbody>
</table>
| NICE Guidance      | Guidance covering three areas of health:  
  - Clinical guidelines cover the appropriate treatment and care of patients with specific diseases and conditions within the NHS in England and Wales.  
  - Technology appraisals cover the use of new and existing medicines and treatments within the NHS in England and Wales.  
  - Interventional procedures cover the safety and efficacy of interventional procedures used for diagnostic treatment. |
<p>| Non-heartbeating donor (NHBD) | An organ donor whose organs are removed following a cardiorespiratory arrest. |
| Oliguria           | Reduced urine output. |
| Osteomalacia       | Disease of the bone resulting from inadequate levels of active Vitamin D. |
| Osteoporosis       | A disease of the bones characterised by a decrease in bone mass and structural deterioration of bone tissue. |</p>
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatric Intensive Care Unit (PICU)</td>
<td>Intensive care specifically for children.</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Active holistic care of patients with advanced, progressive illness.</td>
</tr>
<tr>
<td>Parathyroid glands</td>
<td>Glands situated close to the thyroid glands. They secrete parathyroid hormone (PTH) and are chiefly concerned with the metabolism of calcium and phosphorus (see also hyperparathyroidism).</td>
</tr>
<tr>
<td>Pathogenesis</td>
<td>An explanation of the cause of an illness.</td>
</tr>
<tr>
<td>Pathology</td>
<td>A branch of medicine which studies the causes and nature of diseases, including changes in body tissues and organs which cause or are caused by disease.</td>
</tr>
<tr>
<td>Pathophysiology</td>
<td>Abnormal physiology associated with disease.</td>
</tr>
<tr>
<td>Patient</td>
<td>Those in receipt of health care provided by or for a Welsh NHS body.</td>
</tr>
<tr>
<td>Peritoneal access</td>
<td>A catheter is inserted into the peritoneal cavity (abdominal cavity) to allow dialysis fluid exchanges in peritoneal dialysis.</td>
</tr>
<tr>
<td>Peritoneal dialysis</td>
<td>A form of dialysis in which fluid is introduced into the peritoneal cavity. This fluid draws waste products and excess water out of the blood using the peritoneal membrane as a filter.</td>
</tr>
<tr>
<td>Peritonitis</td>
<td>Inflammation of the peritoneal membrane which lines the peritoneal cavity.</td>
</tr>
<tr>
<td>Phosphate</td>
<td>A mineral that helps calcium to strengthen the bones.</td>
</tr>
<tr>
<td>Phosphate binders</td>
<td>Medication that prevents the absorption of phosphate from the diet.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>----------------------------------</td>
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</tr>
<tr>
<td>Polycystic kidney disease</td>
<td>A genetic disorder which causes multiple cysts to develop in both kidneys, causing progressive loss of function.</td>
</tr>
<tr>
<td>Polyuria</td>
<td>Passing a large amount of urine.</td>
</tr>
<tr>
<td>Pre-emptive transplant</td>
<td>A kidney transplant carried out before the patient has begun dialysis.</td>
</tr>
<tr>
<td>Prevalence</td>
<td>The number of people in a defined population number who have a given condition.</td>
</tr>
<tr>
<td>Primary care</td>
<td>First-contact health services directly accessible to the public.</td>
</tr>
<tr>
<td>Prognosis</td>
<td>A forecast of the probable course and outcome of a disease.</td>
</tr>
<tr>
<td>Progressive renal impairment</td>
<td>A progressive decline in kidney function.</td>
</tr>
<tr>
<td>Prophylaxis</td>
<td>A treatment used in order to prevent disease.</td>
</tr>
<tr>
<td>Prostatic hypertrophy</td>
<td>Enlargement of the prostate gland. Benign prostatic hypertrophy is the most common form of bladder outflow obstruction (see entry) in adults, which can cause CKD.</td>
</tr>
<tr>
<td>Proteinuria</td>
<td>Excessive amounts of protein being excreted in the urine.</td>
</tr>
<tr>
<td>Protocol</td>
<td>A structured framework to guide an action.</td>
</tr>
<tr>
<td>Pruritis</td>
<td>Intense itching. In advanced kidney failure it can be caused by excess phosphate, which would normally be regulated by the kidneys.</td>
</tr>
</tbody>
</table>
### Public Health
Public health is concerned with improving the health of the population, rather than treating the diseases of individual patients. Public health functions include:

- Health surveillance, monitoring and analysis.
- Investigation of disease outbreaks, epidemics and risk to health.
- Establishing, designing and managing health promotion and disease prevention programmes.
- Enabling and empowering communities to promote health and reduce inequalities.
- Creating and sustaining cross-Government and inter-sectoral partnerships to improve health and reduce inequalities.
- Ensuring compliance with regulations and laws to protect and promote health.
- Developing and maintaining a well educated and trained, multi-disciplinary public health workforce.
- Ensuring the effective performance of NHS services to meet goals in improving health, preventing disease and reducing inequalities.
- Research, development, evaluation and innovation.
- Quality assuring the public health function.

### Pulmonary Haemorrhage
Bleeding into the lungs.

### Pulmonary Oedema
The presence of excess fluid in lungs causing breathlessness.

### Quality Assurance
A systematic process of verifying that a product or service being developed is meeting specific requirements.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiology</td>
<td>A branch of medicine dealing with the use of radiation such as X rays, ultrasound etc, especially in the diagnosis of disease.</td>
</tr>
<tr>
<td>Randomised controlled trial</td>
<td>A type of research trial: e.g. to compare treatments, researchers would randomly allocate eligible people into groups which receive one of the treatments, or none (the control group). The results are assessed by comparing outcomes in the treatment and control groups.</td>
</tr>
<tr>
<td>Reflux Nephropathy</td>
<td>A condition in which urine passes back up from the bladder, through the ureters to the kidneys. The presence of scars in the kidney resulting from the reflux of urine (usually infected) back up the ureters into the substance of the kidney.</td>
</tr>
<tr>
<td>Rejection</td>
<td>Response of the transplant recipient’s immune system, which recognises the transplanted kidney as foreign tissue.</td>
</tr>
<tr>
<td>Renal</td>
<td>Refers to the kidney.</td>
</tr>
<tr>
<td>Renal Osteodystrophy</td>
<td>The result of abnormal bone turnover in renal disease. It is a combination of Osteomalacia, Osteoporosis, overactivity of the parathyroid glands.</td>
</tr>
<tr>
<td>Renal replacement therapy (RRT)</td>
<td>Treatment to augment or replace the function of failing kidneys, by dialysis (peritoneal dialysis or haemodialysis) or transplantation.</td>
</tr>
<tr>
<td>Renovascular disease</td>
<td>Disease of the arteries in the kidney.</td>
</tr>
<tr>
<td>Satellite unit</td>
<td>A unit providing haemodialysis, and sometimes other services, linked to a main unit which provides a full range of services. Usually it provides treatment for more stable patients, closer to where they live than the main unit.</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Sensitisation</td>
<td>Pre exposure to antigens resulting in the formation of antibodies prior to transplantation.</td>
</tr>
<tr>
<td>Sepsis</td>
<td>Infection.</td>
</tr>
<tr>
<td>Septicaemia</td>
<td>Infection of circulating blood.</td>
</tr>
<tr>
<td>Serum potassium</td>
<td>The level of potassium in the blood. Potassium is usually removed by the kidneys, and too high or low a level can cause a disturbance in the rhythm of the heart.</td>
</tr>
<tr>
<td>Serum urea</td>
<td>The level of urea (a product of protein metabolism) in the blood.</td>
</tr>
<tr>
<td>Solute</td>
<td>A substance that is dissolved in water.</td>
</tr>
<tr>
<td>Stakeholder</td>
<td>A person who has an interest or stake in an undertaking or business. In the context of renal services, all those involved in commissioning, delivering or using the service.</td>
</tr>
<tr>
<td>Standards</td>
<td>Standards are a means of describing the level of quality that health care organisations are expected to meet or to aspire to. The performance of organisations can be assessed against this level of quality.</td>
</tr>
<tr>
<td>Stenosis</td>
<td>Narrowing.</td>
</tr>
<tr>
<td>Surgical urinary diversion</td>
<td>A variety of techniques for the diversion and collection of urine, to bypass a diseased or damaged bladder, or following bladder removal.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-----------------------------</td>
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</tr>
<tr>
<td>Targets</td>
<td>Targets refer to a defined level of performance that is being aimed for, often with a numerical and time dimension. The purpose of a target is to incentivise improvement in the specific area covered by the target over a particular timeframe.</td>
</tr>
<tr>
<td>Technique survival</td>
<td>A measure of the longevity of a specific technique.</td>
</tr>
<tr>
<td>Terminal Care</td>
<td>Terminal care is a term that describes the care offered to a patient during the period when death is imminent.</td>
</tr>
<tr>
<td>Thrombosed</td>
<td>A vessel occluded by a clot.</td>
</tr>
<tr>
<td>Thrombus</td>
<td>A blood clot.</td>
</tr>
<tr>
<td>Tissue type</td>
<td>A classification of tissue based on antigenicity.</td>
</tr>
<tr>
<td>Ultrafiltration</td>
<td>The movement of water across a membrane as the result of hydrostatic forces.</td>
</tr>
<tr>
<td>Uraemia</td>
<td>The toxic condition caused by excess by-products of protein metabolism (urea etc) present in the blood.</td>
</tr>
<tr>
<td>Urinary Catheterisation</td>
<td>Passing a tube into the bladder usually through the urethra.</td>
</tr>
<tr>
<td>Urinary tract</td>
<td>The organs concerned with production and excretion of urine: the kidneys, ureters, bladder and urethra.</td>
</tr>
<tr>
<td>Urodynamics</td>
<td>The functional study of the bladder and urinary tract.</td>
</tr>
<tr>
<td>Urology</td>
<td>The surgical speciality that deals with the kidneys and urinary tract.</td>
</tr>
<tr>
<td><strong>URR</strong></td>
<td>Urea reduction ratio: a measure of the effectiveness (adequacy) of dialysis. Urea is a by product of protein metabolism.</td>
</tr>
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<tr>
<td><strong>Varicella</strong></td>
<td>Chicken pox.</td>
</tr>
<tr>
<td><strong>Vascular access</strong></td>
<td>A fistula, catheter or graft allowing access to the bloodstream for haemodialysis.</td>
</tr>
<tr>
<td><strong>Vascular disease</strong></td>
<td>Disease affecting the blood vessels.</td>
</tr>
<tr>
<td><strong>Vascular stenosis</strong></td>
<td>Narrowing or constriction of the blood vessels.</td>
</tr>
<tr>
<td><strong>Vasculitis</strong></td>
<td>A disease which causes inflammation of the blood vessels. Microscopic vasculitis: inflammation of very small blood vessels.</td>
</tr>
<tr>
<td><strong>Venous catheter</strong></td>
<td>A catheter (see entry) inserted into a vein. Central venous catheter: a catheter inserted into a central vein, e.g. through the neck, shoulder or arm.</td>
</tr>
<tr>
<td><strong>Vein Mapping</strong></td>
<td>The use of Doppler ultrasound scans to assess the size and viability of veins prior to an attempt to create a fistula.</td>
</tr>
</tbody>
</table>
Acknowledgements

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