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Kidney Disease Management

a practical approach for the
non-specialist healthcare practitioner

Edited by Rachel Lewis and Helen Noble

Kidney Disease Management

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**A Practical Approach for the
Non-Specialist Healthcare
Practitioner**

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Dr Rachel Hilton received her BA at the University of Oxford in 1985 (physiological sciences) and her BM BCh in 1988. She has been a consultant nephrologist at Guy's and St Thomas' NHS Foundation Trust since 1999, and was lead clinician in nephrology between 2003 and 2008. She has held an honorary appointment in the School of Medicine at King's College London since 2006. She is currently R&D theme lead for transplantation and medical lead in transplantation. Dr Hilton is interested in renal transplantation, living kidney donation, viral infection after transplantation, autoimmune diseases, renal disease in pregnancy and renal disease in patients with human immunodeficiency virus.

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Sheila Johnston is the lead nurse, clinical lead in chronic kidney disease (CKD) at the Royal Free London NHS Foundation Trust. She has been working within the renal specialty since 1995 and moved into specialist practice in CKD in 2003. She has a particular interest in the supportive and palliative care needs of those patients opting not to have dialysis, and in further developing shared decision making in this group to enhance their end-of-life care.

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Rosemary Macri

Rosemary Macri is the Chief Executive of the British Kidney Patient Association (BKPA). Rosemary first worked with the BKPA in 1977 and became a personal assistant to the founder president. Following a break to pursue other opportunities she returned to the charity in 2002, and in 2008 became its Chief Executive. The BKPA provides advice, support and financial help for people with kidney disease.

Beverley Matthews RN

Beverley Matthews is the director of NHS Kidney Care and Liver Care. Originally a nurse, she has worked for many years in renal services as a transplant coordinator and a network manager. NHS Kidney Care aims to improve the outcomes for people with kidney disease, and achieves this by helping to embed evidence-based innovations in everyday practice.

Helen Noble RN, PhD, BSc, PG Dip Academic Practice

Dr Helen Noble is a lecturer in Health Services Research at Queen's University Belfast. Previously she worked as a ward manager, matron and then as a senior clinical nurse specialist involved in setting up one of the first renal palliative and supportive care programmes in the UK. She has research expertise in nephrology nursing, particularly related to those who opt not to embark on dialysis, and their carers, and is interested in developing interventions to support this group.

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Sally Noble has worked as a specialist renal dietitian in both Australia and the United Kingdom. She is currently working as a senior renal/diabetes dietitian in Brisbane, Australia. She is interested in promoting healthy balanced diets for people with kidney disease to prevent and manage their condition, as well as investigating ways to screen and manage patients with poor nutrition.

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Dr Hugh Rayner is a consultant nephrologist at the Heart of England NHS Foundation Trust and clinical lead for the West Midlands Renal Network. He is interested in improving the care of people with all stages of chronic kidney disease and has a long-standing research interest in clinical nephrology, especially through the Dialysis Outcomes and Practice Patterns Study (www.dopps.org).

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Dr Charlie Tomson is a consultant nephrologist at Southmead Hospital, Bristol. He is primarily a clinician and has worked on clinical practice guidelines for the Renal Association, Royal College of Physicians, KDIGO and ERBP. He is interested in quality improvement in kidney care - how to spread the adoption of best practice, and how to support shared decision making in the care of patients with kidney disease.

Graham Woodrow MBChB, MD, FRCP

Dr Graham Woodrow is a consultant nephrologist at St James's University Hospital, Leeds Teaching Hospitals NHS Trust. He has particular interests in peritoneal dialysis, nutrition and body composition analysis in renal disease, and in the management of diabetic renal disease.

Foreword

This is a succinct, comprehensive and well-written book covering optimal care for people with kidney disease across the healthcare system. There is much here for the specialist and generalist, with the focus on the individual patient. What is generally lacking in the NHS is a systematic focus on and accounting to the patient. Similarly, there is a great deal of rhetoric about integration, but unless it produces a transparently better service for individual patients it will simply be yet another word in the bureaucratic lexicon. This publication adeptly addresses that system-wide deficit.

Care for people with kidney disease has, until recently, received insufficient attention compared with other acute and chronic conditions. There are, as ever, excellent exemplars of optimal care - but rarely across the whole system of care. For instance, the increasing challenge of managing metabolic syndrome has only relatively recently been recognised as a system-wide issue, particularly in primary care. To date, the development of locally based, community-focused integrated services, with improved access for people with the spectrum of acute and chronic kidney problems, has not been high enough in the list of local priorities.

This book is much needed and timely, given the opportunities offered by the prioritising of long-term conditions, by a future of clinicians influencing and/or leading commissioning, and by a growing focus on clinical and patient-reported outcomes.

Congratulations to the editors and contributors. This is a good educative read for clinicians and non-clinicians alike, addressing the issues that often prevent the system-wide improvement of care. It also incidentally serves as an excellent template for publications on other long-term conditions.

Dr David Colin-Thomé
Independent Healthcare Consultant, UK

Foreword

How much easier it would be for health professionals if patients presented with just one disease! Sadly, we all know this is rarely the case, and with long-term conditions such as chronic kidney disease there are often many associated comorbidities influencing outcomes - particularly with growing numbers of elderly patients.

It's refreshing to see a book like this providing an invaluable source of knowledge and understanding about the management of kidney disease for non-specialist professionals including nurses, junior doctors, general practitioners, pharmacists and dietitians. No one can be an expert in every field, but it's important to know where to find expert opinion and advice.

This informative book has been put together with the support and input of many clinical renal experts, who have been willing to share their knowledge and years of experience, and I'm sure it will be an excellent resource for those caring for kidney patients for the first time - as well as for those with some years of experience.

Each chapter is informed by patient and family perspectives and adds a valuable practical insight into what it's like to live with kidney disease and how it impacts on daily life and families. These may be particularly useful for service design and care planning.

The British Kidney Patient Association supports local and national initiatives that improve the care and quality of life for kidney patients around the UK. I feel sure that this new information resource will help achieve these aims by enabling optimal management of patients with chronic kidney disease, encouraging improved development of personal care plans and enabling more patient choice.

Rosemary Macri
British Kidney Patient Association, UK

Introduction

Managing Patients with Chronic Kidney Disease in Non-Specialist Areas: a Chronic Illness Approach

Rachel Lewis

Manchester Business School, The University of Manchester, UK

Reasons for writing the book

The purpose of this book is to help optimise the management of patients with chronic kidney disease (CKD) across the healthcare spectrum. It is aimed at a number of non-specialist professionals including nurses, junior doctors, general practitioners, pharmacists and dietitians. It includes a number of health states and settings in which people with kidney disease are managed. In contrast to many other publications on chronic disease management, this book emphasises the multiplicity of influences on ill health and illustrates the necessity to focus on the needs of the individual, particularly within systems of care.

Many patients with established or deteriorating kidney disease will be managed by a specialist team, and this book is not intended to negate the need for specialist renal services. Instead, it highlights some practical considerations necessary to care for people with kidney problems in situations where a specialist practitioner is not always required or may not be immediately available. It provides some general principles for safe and effective care in a number of situations and settings and provides guidance on circumstances in which a specialist should be contacted. It is written by clinical staff and reflects their experiences of managing CKD. It also reflects a number of patient and family narratives, a perspective often obscured by the immediacy of acute settings. In the same way that patients are individuals, so too are healthcare staff; consequently the book includes a number of professional perspectives and styles intended to appeal to a team approach to care management. The book is written in an accessible format, aimed at busy professionals, and cites key material for further information.

1. Managing Chronic Conditions: The Policy Context

Beverley Matthews

The ageing population and the rising incidence and prevalence of chronic conditions suggest that the current organisation of health services within the National Health Service (NHS) is unsustainable. A major driver of costs within the present system is the population dependence on acute care. In response, recent healthcare policy has been directed at reducing the number of hospital beds and moving care for people with chronic conditions into the community. Historically, people with kidney disease have been cared for in different settings, partly because of limited capacity on renal wards, but often because they have required other services such as rehabilitation, general surgery or other specialist provision. In addition, there is a growing cohort of patients with multiple chronic conditions, including CKD, who, with appropriate management, can be safely managed in primary care. Chapter 1 provides an overview of the changing context of healthcare in England: the shift from acute care to the community; the need for more general, as opposed to disease-specific, chronic care; and the current development of policy that aims to promote more integrated and collaborative ways of working.

2. What Non-Specialists Need to Know about Chronic Kidney Disease

Graham Woodrow, Jeanette Denning and David Lewis

The health needs of patients with CKD are not homogeneous and vary over time, but all CKD patients share some health issues that need to be regularly appraised if patient outcomes are to be optimised. Chapter 2 provides an introduction to the different types of renal replacement therapy (RRT), including transplantation, and illustrates some of the technical and practical issues surrounding dialysis. As well as an overview of the clinical characteristics associated with CKD (anaemia, blood pressure management and bone mineral disease), the chapter considers issues associated with particular treatment modalities.

3. A Practical Approach to Chronic Kidney Disease in Primary Care

Hugh Rayner, Rajib Pal and Indranil Dasgupta

People with CKD cover a spectrum of health states, and treatment is generally titrated around the stages of the disease, treatment decisions and individual wishes and circumstances. Chapter 3 focuses on patients with stage 1-3 CKD, who are primarily managed in general practice. The aim of care is to arrest or

slow down any deterioration in renal function. This requires treatment of pre-disposing conditions such as high blood pressure and diabetes, appropriate management of inter-current illnesses, optimising vascular health and promoting general wellbeing through lifestyle advice and support. The chapter also considers some 'common' scenarios in deteriorating renal function and how monitoring estimated glomerular filtration rate (eGFR) over time can inform a systematic approach to identifying those most at risk. Unusually, but pertinently, the chapter includes patients with a transplant kidney in the group with CKD. As the population of patients with a transplanted kidney increases with improved survival, they will increasingly present across the healthcare system. Non-renal practitioners need to be aware of drug interactions, as well as conditions that affect the absorption of immunosuppressive medication.

4. General Considerations Related to Treatment Modalities

Aisha I. Geeson, Charles R. V. Tomson and Lesley Lappin

CKD includes a spectrum of health states, not all of which are suitable for or responsive to all forms of treatment. In addition, increasingly many older patients have a number of other chronic conditions, they may be frail and cognitively impaired, and they may live alone. Although not necessarily a barrier to dialysis, all these factors need to be considered in relation to the likely benefits and/or burdens of treatment regimes. Chapter 4 discusses the importance of early referral to specialist services, the factors influencing dialysis choice, empowering patients and shared decision making. It also discusses some of the clinical contraindications to individual treatment modalities.

5. Psychosocial Aspects of Living with Chronic Kidney Disease

Emma Coyne

This book considers the management of CKD across a spectrum of health states, but for the most part focuses on people who have stage 3-5 CKD. These are people who are likely to require treatment and support for the rest of their lives. This chapter reflects the experiences of patients, partners, families and professionals. It provides an insight into the reality of living with CKD and the impact this has on quality of life, not just for patients but for their immediate families as well. Patients and their partners are often experts in their care and should be involved in planning that care, particularly in non-specialist areas. The intention is to encourage providers to consider the wider manifestations of kidney disease and how their service design can best fit the needs of patients in the context of other services such as primary care.

6. Acute Kidney Injury in Hospitalised Patients

Keith Harkins, Rachel Lewis and Rachel Hilton

Older people are more likely to have additional complications and poorer outcomes than younger adults. It is not possible, or always appropriate, to manage all patients with acute kidney injury (AKI) in specialist units. Chapter 6 focuses on the causes, diagnosis and management of AKI in people whose condition may be complicated by multiple morbidity, frailty and cognitive impairment. It assumes a non-specialist setting and provides a guide to determining the parameters of care that consider the patient's quality of life before AKI and the likely prognosis associated with various treatment options. It emphasises the importance of an ongoing dialogue with the patient (where possible) and close family members and/or carers. It stresses the need for a realistic, holistic assessment of the patient's prognosis by a senior physician and the benefits of pre-empting possible complications.

7. Management of Patients with or at Risk of Kidney Disease on the Surgical Ward

Colin H. Jones and Maggie Higginbotham

Patients admitted to hospital for reasons other than kidney disease are at an increased risk of developing an acute kidney injury. This includes people undergoing a surgical procedure. Some patient groups are at a higher risk than others, and these include patients with pre-existing chronic conditions, including CKD. Identifying those patients at risk, assessing the risks and managing them proactively reduces the likelihood of avoidable harm. Chapter 7 discusses best practice in identifying patients with, or at risk of, AKI, pre-, peri- and postoperatively. It covers the spectrum of management, from those patients with no pre-existing kidney problems to those who require maintenance dialysis. It stresses the importance of determining the extent of the patient's renal impairment and their maintenance regime. Ongoing communication with the renal specialist team is fundamental to optimising outcomes in this population.

8. Medication Management and Chronic Kidney Disease

Aileen Dunleavy

As with other aspects of managing kidney disease, medication regimes, whilst adjusted to complement general health states and treatment modalities, are tailored to the patient's individual circumstances and usually managed by a nephrologist. Chapter 8 explains some of the general principles associated with medication management and the reasoning behind them. Safe and effective

prescribing for people with CKD requires information regarding the extent of renal impairment and some understanding of how the drugs in question are absorbed and excreted. This chapter includes some important resources for prescribing support in the UK.

9. Optimising Nutrition in People with Chronic Kidney Disease

Helena Jackson and Sally Noble

Diet plays an important part in preventing CKD and delaying its progression; it is also one of life's pleasures and is often restricted in patients with stage 3-5 CKD. In most instances, patients with CKD are advised to follow the same healthy-eating guide as the general population. Those with advanced disease usually require modifications to their diet, and individual dialysis modalities are associated with different restrictions, as is the case for patients who have diabetes as well as CKD. Dietary advice and support are provided by renal dietitians on an individual basis as necessary; however, patients and/or their families are generally very knowledgeable about their dietary constraints and can be a useful resource for healthcare professionals.

10. Supportive and Palliative Care for Patients with Advanced Kidney Disease

Sheila Johnston, Helen Noble and Rachel Lewis

All patients with CKD require a palliative care approach in the sense that they will never be cured. However, this chapter is concerned with those patients whose overall health is deteriorating irrespective of their treatment regime. Patients with stage 4 or 5 kidney disease have a much shorter life expectancy than those of a similar age in the general population, and for patients on dialysis it is even shorter. Chapter 10 discusses some of the practical difficulties in identifying and managing deteriorating and terminally ill patients. It illustrates the unpredictability of chronic disease trajectories and the importance (and difficulty) of being prognostically realistic.

Conclusion

This edited collection is aimed at improving the care of people with CKD. It represents 'real life' health care in which effective continuity and coordination of care are often challenged by complex and fragmented systems. Unusually, it includes professional insights into the practicalities of managing complex patients. It emphasises the centrality of the patient and family and the need to share information and expertise across traditional boundaries.

Chapter 1

Managing Chronic Conditions: The Policy Context

Beverley Matthews

NHS Kidney Care and Liver Care, UK

Introduction

The rising incidence and prevalence of chronic conditions presents a serious challenge to the effectiveness and sustainability of current and future health-care services. A major issue is the increasing number of people with multiple chronic conditions and health services that continue to be organised around specific diseases. It is evident that chronic kidney disease (CKD) encompasses a spectrum of health states, and that these can be negatively affected by other chronic conditions and age-related problems such as memory impairment and mobility issues. Similarly, socioeconomic factors such as deprivation also adversely influence health outcomes. In effectively meeting the diverse needs of people with chronic conditions, a population management approach is required whereby the focus of care is based on the level of need and extends beyond traditional disease-specific approaches. Successive health policies reflect this shift with initiatives such as 'Our health, our care, our say' (Department of Health 2006) and the long-term conditions National Service Framework (Department of Health 2005) aimed at services being delivered through a 'whole systems approach'. Continuity of care is required across traditional organisational boundaries through more effective collaboration of professionals. Key to this approach is engaging and supporting the patient in self-management. This chapter provides an overview of the changing context of healthcare services, including the innovative work of NHS Kidney Care in working across healthcare sectors and the current policy work which supports a more integrated and collaborative approach in supporting people with chronic kidney disease.

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Chronic kidney disease in context

The effective management of chronic or long-term conditions poses a significant challenge for healthcare systems across the world. In England, around 15 million people have a long-term condition. While the number of people in England is likely to remain relatively steady, the number of people with multiple chronic conditions is expected to rise by a third over the next 10 years. People with long-term conditions account for 29% of the population in England, but are the most frequent users of healthcare services, accounting for 50% of all general practice appointments and 70% of all inpatient bed days. It is estimated that the treatment and care of those with long-term conditions accounts for 70% of the primary and acute care budget in England. This means around one-third of the population accounts for over two-thirds of the spend (Department of Health 2011). More significant than the impact on resources is the effect that long-term conditions have on quality of life. Each year around 170 000 people die prematurely in England, with the main causes being cancers and circulatory diseases. The proportion of people with a limiting long-term condition in work is a third lower than among those without (Department of Health 2011).

Healthcare services continue to be organised around specific conditions. Even for people with a single chronic condition, care is typically provided across a number of different health professionals and organisations. The resultant discontinuity and fragmentation of care can add to an already high disease burden (Nolte & McKee 2008) at the same time as increasing care costs through the duplication of interventions, omissions in treatment and miscommunication. Patient safety is also threatened (Boerma 2006). Whilst improvement initiatives have typically focused on optimising the clinical aspects of chronic care, this alone has not been as effective as wider initiatives that have included service redesign (Coleman *et al.* 2009, Curry & Ham 2010, Goodwin *et al.* 2012). How and where care is provided has important implications for the effectiveness and sustainability of long-term care, and strong primary care is considered to be central to improving patient outcomes and controlling costs (Roland *et al.* 2007). Patient-centred care, self-management support, improved continuity and coordination have all been identified as key contributors of quality in chronic care but can only be delivered through patients, professionals and organisations working more collaboratively together (Wagner 1996, Greaves & Campbell 2007).

Chronic kidney disease (CKD) describes abnormal kidney function and/or structure. It is common, frequently unrecognised, and it often exists together with other conditions (for example, cardiovascular disease and diabetes). The risk of developing CKD increases with age, and some conditions that coexist with CKD become more severe as kidney dysfunction advances. CKD covers a spectrum of health states including an asymptomatic period which is potentially detectable. Tests for CKD are both simple and widely available, and there is evidence that treatment can prevent or delay progression, reduce or prevent

the development of complications and reduce the risk of cardiovascular disease. In cases where progression cannot be prevented, kidney function may deteriorate to stage 5, requiring life-saving dialysis, a kidney transplant or conservative management.

Estimates suggest that there about 4.5 million people in England with CKD. Since 2006, the prevalence of CKD has been reported annually in general practice and has seen a steady rise from 3% to 4.3% in 2009/10. However, compared with an estimated prevalence of 8.8%, diagnosis and ascertainment nationally is still only around half of the expected prevalence. Overall, there are an estimated 1.95 million people in England with undiagnosed CKD, who are therefore untreated and at risk of faster disease progression.

The policy context

In 2010, the UK government set out its long-term vision for the future of the National Health Service (NHS) and health services in England in the NHS White Paper, *Equity and Excellence: Liberating the NHS*. It committed to put the patient at the heart of services through greater choice and control including:

- greater shared decision making and the principle of ‘no decision about me without me’
- greater choice of treatment and access to information
- a focus on personalised care that reflects individuals’ health and care needs, supports carers and encourages strong joint arrangements and local partnerships

Legislation to support this policy direction has since been enacted in the Health and Social Care Act (2012). The White Paper also committed the NHS to focus on outcomes and the quality standards that deliver them. The government’s objectives are to reduce mortality and morbidity, increase safety, and improve patient experience and outcomes for all. To this end, quality standards, developed by the National Institute for Health and Clinical Excellence (NICE), will inform the commissioning of all NHS care.

This approach builds upon and develops further the improvements achieved by the implementation of the National Service Frameworks (NSFs). The NSFs set clear quality requirements for care, based on the best evidence of what treatments and services work most effectively, seeking to ensure an equity of services irrespective of where they are delivered. The NSF for renal services (Department of Health 2004-05) placed a strong emphasis on identifying the condition early in primary care settings, slowing down its progress and minimising its impact on people’s lives. It led to significant improvements in the way kidney disease is managed. The NICE quality standards take this further and are a set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from the best available evidence

Table 1.1 NHS Quality and Outcomes Framework: five domains, three dimensions.

| | | |
|-----------------|--|---------------|
| Domain 1 | Preventing people from dying prematurely | |
| Domain 2 | Enhancing quality of life for people with long-term conditions | Effectiveness |
| Domain 3 | Helping people to recover from episodes of ill health or following injury | |
| Domain 4 | Ensuring people have a positive experience of care | Experience |
| Domain 5 | Treating and caring for people in a safe environment and protecting them from avoidable harm | Safety |

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such as NICE guidance and other accredited sources, they are developed independently by NICE in collaboration with the NHS, social care professionals, their partners and service users. The quality standards are organised around five national outcome goals or domains, covering the breadth of NHS activity (Table 1.1), and they address the three dimensions of quality: clinical effectiveness, patient safety and patient experience. They enable:

- health and social care professionals to make decisions about care based on the latest evidence and best practice
- patients to understand what service they can expect from their health and social care providers
- NHS trusts to quickly and easily examine the clinical performance of their organisation and assess the standards of care they provide
- commissioners to be confident that the services they are providing are high quality and cost-effective

NICE published its quality standards for chronic kidney disease in 2011 (Table 1.2).

In addition to informing commissioning decisions, quality standards can also be aligned with the NHS funding system to encourage providers to follow best practice. In 2011, a best practice tariff for renal dialysis was introduced, paying significantly more for dialysis sessions that are delivered through definitive access (arteriovenous fistula or graft) than for those that are not. This is known to be better for patients because the faster flow rates result in more effective and efficient dialysis and it is much safer because of the reduced risk of infection. The level of the tariff was set so that providers with 75% (increased yearly by 5% to meet the Renal Association clinical guidelines of 85%) of their patients on definitive access would receive the same level of funding as under the previous system. In addition to rewarding services that do better than this,