Chapter 1
An overview of continence care and the case for care pathways

Good-quality continence care can enhance the lives of people who suffer from this symptom. There has been a revolution in continence care starting towards the end of the last century and continuing into this one that recognises that continence problems are symptoms of an underlying disorder which may be primarily due to bladder or bowel dysfunction or, secondarily, to systemic disease processes. Prior to this, incontinence was simply managed with patient, bed or chair protection and patients were often deemed lazy or difficult. New research into diagnostics, treatments, therapies and lifestyles is regularly published and patients benefit from access to specialist advice and clinics. Many people are now able to maintain a high quality of life and there are even research-based, quality-of-life questionnaires that can validate this.

However, despite guidance there is little mandatory provision, which has led to inequitable service provision. The overall cost of continence care and management is set to rise substantially, as demographic changes affect service provision. In 2008 incontinence cost European health care systems and society £13 billion annually. This figure comes from a worldwide review of health economics literature relating to incontinence by Professor Rosanna Tarricone, health economist at the Centre for Research on Health Care Management at Bocconi University in Italy (Pountney, 2008).

The total expenditure for the United Kingdom is approximately 120th of the cost of the NHS (as at the year 2000) (Getliffe and
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Dolman, 2003). This does not take into account the hidden cost associated with the psychological consequences of the condition, the costs of informal care, the ineffectiveness and inefficiency of some delivery systems and the inappropriateness of using inpatient care for individuals with incontinence.

This chapter seeks to look at the influences which have provoked such changes and details the changes to the traditional role of the nurse. The implications for nurses in continence care and the fact that their extended role has meant increased pressure on time and resources will also be explored. The chapter then goes on to discuss whether quality continence care may be less of a health care priority in the NHS, and considers some of the issues that this raises. The last section in this chapter describes care pathways and the benefits of their use.

Main policy documents

The first major document to bring continence care to the forefront was Good Practice in Continence Services (Department of Health, 2000). This document states that prompt, high-quality and comprehensive continence services are an integral part of the NHS. A review was set up in 1998, but it was an Audit Commission report (1999) – which said that district nurses were focusing on managing the problem of incontinence rather than treating it, despite it being a highly treatable condition – that did much to prompt the drawing-up of guidelines. These guidelines were later enshrined by the Department of Health (2000). However, there seemed at that time to be no political will to endorse the report’s contents. A Royal College of Nursing survey showed that only 8% of Trusts were implementing one of the main recommendations, that of establishing a director of continence services in each Primary Care Trust (PCT), some years after the guidelines were published (Thomas, 2007). In 2001 the National Service Framework for Older People (Department of Health, 2001a) gave teeth to the guidelines by setting targets for having an integrated continence service in place by April 2004. However, subsequent audit showed that, in the majority of cases, this deadline had not been met (Wagg, 2004).

Nevertheless, the guidelines were successful in moving continence up the agenda both locally and nationally, and further papers were published shortly afterwards. Arguably, one of the most
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used was Essence of Care (Department of Health, 2001). The aim of this document was to improve the quality of the fundamental and essential aspects of care. It includes a whole section on continence and bladder and bowel care, giving the components that need to be in place for effective continence management and to implement measures to improve quality, which in turn will contribute to the introduction of clinical governance at local level. The Essence of Care Benchmarking Tool has provided a means of evaluating and comparing services, measuring current levels of performance and setting levels of best practice. This has been widely used and has been demonstrated to improve services to the patient where it has been utilised.

In 2006 the Department of Health published Our Health, Our Care, Our Say: a new direction for community services. This has probably had a significant impact on the provision of continence services, which are predominantly community-based. The aim of this policy is to reform health and social care through ‘a radical and sustained shift in the way in which services are delivered . . . gives people a stronger voice so that they are the main drivers of service improvement’. One of the persistent problems of community care has been the poor coordination between health and local authorities. Historically, there have been incentives to move the costs onto others and disputes about who should provide care. Efforts to promote joint working were made but the fragmentation of health and social services remain a serious problem. The Government’s rationale for this current shift is that people want more convenience, better access and more local coordination between services, described in the White Paper as ‘more choice and a louder voice’. Tackling inequalities in health is also a key driver that focuses on both local need and vulnerable groups. A further driver is technological change, which allows patients to be treated more locally outside of the acute services, utilising, for example, telemedicine.

There is also a goal for more care to be undertaken outside hospital and in the home, with a huge drive to create fairness in accessing GP services (Cartmail, 2006). The other achievement sought is to invest in preventative care to avoid future costs. This ranges from broad public health measures to better care for people with long-term conditions and disabilities, which are sure to be affected by continence issues.

The National Director for Primary Care (Department of Health, 2007) states that the abiding message of Our Health, Our Care, Our
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Say concerns the need to coordinate services. Patients, community nurses, pharmacists, voluntary organisations – even social enterprises and the private sector – should strive to work more closely together in order to provide better services and better outcomes for patients.

Nursing role

Nurses are accountable to the Nursing and Midwifery Council (NMC), which has a professional code of conduct. The twenty-first century has witnessed a growing body of regulation concerning record-keeping and the role of the nurse has extended to include nurse prescribing and the introduction of nurse-led services, such as walk-in centres (WICs), and autonomous roles such as nurse consultant and community matron. This section details changes to the traditional role of the nurse and looks at implications for continence care.

Community nurses are employed by Primary Care Trusts working alongside other members of the primary health care team and are usually responsible for undertaking continence care in the community setting.

From their beginnings as public health nurses, the primary role of community nurses has always been to look after the sick rather than to promote health. Although there have been various initiatives, such as community support teams, these have also been to look after the sick at home, thus reducing hospital admissions rather than promoting health. Our Health, Our Care, Our Say (Department of Health, 2007) aims to deliver better prevention services with earlier intervention, and to tackle health inequalities outside the hospital and in the home. However, this may not always be appropriate for solely the community nurse; more types of health care professional may become involved with the promotion of continence in primary care. Care pathways are ideal for this, as will become clear as we explore these later in the chapter.

The NHS Improvement Plan (2004) describes a new clinical role for nurses. Known as community matrons, these experienced, skilled nurses use case management techniques with patients who meet criteria denoting a very high-intensity use of health care. The case management work of community matrons is central to the Government’s policy for the management of people with long-term
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The community matron will listen to the patient’s views and design care around their needs, and ensure that that care is properly coordinated. It is anticipated that this will help prevent emergency admission to secondary care. Many patients with long-term conditions will suffer from continence problems and will benefit from this holistic approach to care.

One case history was of a patient with chronic obstructive pulmonary disease (COPD) who was a frequent attendee at the local Emergency Department and often requested home visits from his GP. He had been admitted to hospital five times in the last year. The community matron found out that when the patient took his diuretic tablets he could not get upstairs to the toilet in time so he just stopped taking the medication. The solution to the problem was simple and by the provision of aids to continence the hospital admissions reduced considerably, thereby saving the NHS money.

The Secretary of State for Health at the time said that she wanted to see 5% of the NHS budget (£4 billion) per year transferred from secondary care to primary care over the next ten years (Kmietowicz, 2006).

It has been suggested that many aspects of promoting health could carry on outside practice with lay trainers so that nursing professionals would have more time for patients with acute and chronic disease. With the potential shortage of nurses in the community it may be that aspects of care currently in the nursing domain will be commissioned from other sources.

Providers of care

The Labour Party’s manifesto of 2005 committed the incoming Government to work with social enterprises as a stimulus to the third sector wherever possible. The third sector was to be promoted by the Department of Health as an alternative to public sector providers of health and social care services, and the resulting mix of models and sectors, combined with new commissioning priorities, was intended to help realign service provision across a range of organisations. This project was to track and influence the developing policy agenda (Royal College of Nursing, 2007). Our Health, Our Care, Our Say states, ‘we will remove barriers to entry for the third sector as service providers for primary care’ (Department of Health, 2006a).
Timmins (2006) makes the point that for-profit providers are ready to sweep into community and primary care, and that if too much time passes before social enterprises take shape then there may be little left for them. Timmins predicts that this will particularly apply to the new models of general practice, where it expects competition to be particularly fierce, and this could include all nurse-led services. It does admit, however, that there is relatively scant empirical evidence to demonstrate the tangible benefits of social enterprise in health care sectors.

It is proposed that the Primary Care Trusts become commissioning-only bodies and that community care will be wholly commissioned rather than directly provided. Strong commissioning of continence services will be vital, and high-quality commissioning will require strong and innovative leaders who understand the local community and workforce as well as the importance of clinical and organisational quality.

Care pathways can form the basis of standards to be met by the providers of care via the commissioning process. The Government, in its paper *The New NHS: Modern and Dependable* (Department of Health, 1997), states that the process of modernisation will replace the internal market with integrated care. Therefore, it is even more important to find a mechanism that will ensure equity of service provision at the front line in order to reduce variation in care. Care pathways can form the basis of the quality of care which patients should be able to expect from whosoever provides it.

It is not sufficient to state that the assessment should take place but to direct the tool with which to achieve it. Care pathways, because of the fact that they are intended to be dynamic, give immediate and valid access to audit data, which means that the quality of the care delivered is testable throughout the cycle.

**Patient-centred care**

In order to modernise and rebuild the health service the Government has produced some underpinning values that are known as *NHS core principles*. Ten core principles underpin *The NHS Plan* (Department of Health, 2000a), and they are designed to represent common ground between the Government’s goals and what the NHS is capable of delivering. These core principles are the blocks for modernisation and reform that are needed to ‘reshape
the NHS from a patient’s point of view’ (Department of Health, 2000a).

The NHS Plan talks of the need for patients to be at the centre of care, for staff to focus on the patient’s journey and to use evidence-based practice to provide care. Services will be shaped around the needs and preferences of individuals, which will mean health care professionals seeking to meet the various needs of different populations in an effort to improve the quality of service provision for all. The NHS Plan states that patients will receive planned programmes of care based on individual needs. Patients will no longer be recipients of care but will have a real say in the NHS, as ‘we . . . transform the Health Service so that it is redesigned around the needs of patients’, unlike in the past, when it was designed around budgets and tasks.

Background to continence care

The enormous cost of incontinence, as previously described, is an indication of how common the problem is. However, as previously stated, it was not until the 1970s that continence services started to develop. Prior to this no continence assessments were carried out. In the community, district nurses may have, during a general nursing assessment, included an enquiry about the patient’s bladder or bowel function, but did not make any intervention. The outcome and the expectation of both nurse and patient was that there would be a supply of pads. These would be either disposable bed pads made of recycled pulp or a straight bulky disposable pad, which was held in place by plastic pants. For men there was a two-piece disposable device that was strapped onto the penis and was available from a hospital appliance fitter.

Urethral catheterisation was frequently used as a method of management. The catheters used were often of a large diameter and large balloon size, as this was thought to prevent leakage. Research has subsequently shown that it is the smallest catheters which actually prevent leakage. Catheterisation also has a high morbidity rate attached to it and causes considerable demands on services (Kohler-Ockmore and Feneley, 1996).

Continence care was often task-orientated rather than being built around the needs of the individual or their priorities, and no formal training on continence was available. Staff in some residential,
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nursing and long-stay homes would say that they toileted everyone every two hours, rather than recording how frequently the patient used the toilet, which would have established an individual regime that would have suited the patient.

Mobility was often made difficult or impossible for patients by the use of chairs that had fixed trays which did not allow the patient to get out of the chair. The use of open-backed gowns also discouraged independence.

In some areas the policy was not to use incontinence pads. This might have resulted in patients who required physiotherapy being returned from treatment because they had been incontinent. Likewise, not using fixation pants for pads meant that physiotherapy or mobilising was difficult.

In the early 1970s Dame Phyllis Friend, who was the Chief Nursing Officer at the Department of Health, wrote to district health authorities suggesting that they appoint a nursing officer to take responsibility for meeting the needs of people with incontinence (Chief Nursing Officer, 1977).

The nurses who initially became interested in incontinence were research nurses working in urodynamic units. They recognised the need to set up a multidisciplinary interest group, and this led to the formation of the Association of Continence Advisors (ACA) (now the Association for Continence Advice). In 1981 a nurse wrote to health authorities, seeking to identify interested professionals. This resulted in 100 people attending a meeting, demonstrating that there was, indeed, even then concerns about continence care.

A postal survey of urinary incontinence in the community carried out in 1980 had an amazingly high response rate of 89%. It showed a prevalence of 8.5% in females and 1.6% in males aged 15–64 and 11.6% in women and 6.9% in males aged 65 and over (Thomas et al., 1980).

During the 1980s, many continence nurse specialists were appointed and services established and by the end of the decade there were 300 nurse specialists and two physiotherapists in specialist posts (Mandelstam, 1989). It should be noted that many continence nurse specialists were appointed to try to control the vastly overspent disposables budget. However, the quality of care for patients improved owing to:

- the use of continence assessments
- the provision of a quality service and evidence-based care
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- professional input and advice
- continence education programmes
- the promotion of continence
- skilled services being available
- joint specialist clinics
- cost control
- male catheterisation by district nurses
- satellite clinics
- bladder scanning
- the advertisement of services
- improved appliances and equipment
- patient and staff information leaflets.

From the 1980s individual trusts had produced continence assessment forms. Many were not evidence-based, and nor had they been validated but were simply data-collection tools based on the experiences of the continence nurse specialist at the time.

The object of reducing spending on continence products resulted in assessment tools becoming the drivers for controlling costs rather than for the provision of high-quality care to the incontinent person (Bayliss et al., 2000). District nurses referred to the assessment as a pad assessment rather than an assessment of the person’s status.

It was not until the 1990s that public awareness campaigns started to take place. In 1994 the first national public awareness campaign, ‘Don’t suffer in silence’, was supported by leaflets, posters and toilet stickers. Since then each year has had a different theme. Events have been staged in town centres, railway stations, chemists, libraries, gyms and many other venues. Celebrities have been involved. All this has resulted in valuable media coverage. This has helped to change attitudes to incontinence and to encourage patients to seek help.

Information is now readily available on the Internet as continence organisations and manufacturers have easily accessible and helpful websites, giving both clinical advice and product information. Such information is provided in Chapter 8.

To facilitate better levels of continence care continence nurse specialists, physiotherapists and occupational therapists began providing in-house training on the promotion of continence and other related subjects. Now many Trusts make continence training for nurses mandatory. Short courses and modules on the promotion of continence and the management of incontinence are provided by
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universities throughout the United Kingdom, whilst the University of Ulster provides online training with the Foundation of Adult Urinary Incontinence (http://campusone.ulster.ac.uk/potential/shortcourses.php?cid=14).

The evolution of care pathways

Care pathways are known by many different names, some of which are:

- multidisciplinary pathways of care (MPCs)
- integrated care pathways (ICPs)
- anticipated recovery pathways (ARPs)
- clinical guidelines, or algorithms
- care maps
- critical paths.

ICPs used in health care have their origins in the United States of America, where the health care system is insurance-based. They were a means of standardising outcomes of patient care and controlling costs. Their introduction to the United Kingdom in the late 1980s was for a different reason: to achieve quality improvement. The first pathways were used in secondary care in planned surgery. This was because care was more easily predictable than in other sectors, and because some standardised practice was already in place. Since then their use has spread to almost every branch of health care, including continence care. The National Pathways Association has over 250 members representing secondary care, primary care, health trusts and the independent sector.

Structured multidisciplinary care plans identify essential steps in the patient health journey with the expected outcomes. These can be for a variety of conditions and procedures. ICPs have been in use since the 1980s but have become even more important with the introduction of legislation to raise the quality of care and standards across the NHS. An ICP is an anticipated plan of care for use by multidisciplinary teams which provides an appropriate timeframe in order to ensure that patients move through a condition or set of symptoms in order to experience a positive outcome (Middleton and Roberts, 2000). It specifies key events, tests, interventions and assessments occurring in a timely fashion to produce
the best prescribed outcomes, within the resources and activities available for an appropriate episode of care (Wilson, 1996). In practice this describes, in advance, the care of patients within specific case types. The case type may be diagnostic, such as hip replacement, procedural, such as lumbar puncture, or conditional, such as pain.

Whatever the case type, there are common strands which are mapped out on the care pathway, which is then used as a clinical guideline, with the practitioner using their clinical judgement on whether to follow the anticipated care of the care pathway or to deviate from that care. Decisions to deviate from the care may be made for a variety of reasons, such as patient condition, lack of consent by the patient, lack of resources or the inappropriate skills of the caregiver. Such deviations are recorded as part of the care pathway’s documentation, thus providing a facility by which care may be individualised as appropriate (Johnson, 1997). Such deviations are usually known as variances. It is these variances that make the difference between clinical guidelines, protocols and algorithms, none of which have the facility to actually record why the prescribed care was not given. Interventions may have much in common, but patients are different, and the skill of the caregiver comes from being able to differentiate between, and make clinical judgements about, various interventions and how appropriate they are for the individual patient. Care pathways allow clinical freedom, in a way that clinical protocols do not, whilst maintaining a high standard of care.

By using integrated care pathways to provide care for patients, staff are clear about the planned clinical care. The pathway will incorporate best evidence-based guidelines. It will provide a common record for all disciplines involved in the delivery of care. The patient outcomes are measured, and they allow variances to be tracked and performance to be reviewed (De Luc and Todd, 2003).

**Benefits of care pathways**

With the use of integrated care pathways it is clear that there are many benefits for both the patient and the organisation. Randomised controlled trials have been carried out by Sulch et al. (2002), and their findings state that ‘integrated care pathways may improve assessment and communication, even in specialist . . . settings.’ Teams can use integrated care pathways in order to plan
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the journey of the patient through the health care system. As maps are used for road travel, so integrated care pathways can be used for patients’ journeys (Rees et al., 2004). They found that, whilst members of the implementations teams were clear about the potential benefits, team leaders were resistant to the pathway because of a lack of resources and increased administration. The implementation therefore lacked clear leadership. Sulch et al. (2002) report that, even where no direct improvement in patient care arose from the introduction of pathways, there was a significant improvement in documentation and communications with both patients and GPs. Kent and Chalmers (2006) state that pathways are superior to traditional documentation when it comes to recording evidence of best practice. However, it would be speculation as to whether this reflects a direct improvement in delivery or an improvement in the quality of the documentation.

Putting the patient at the centre of the pathway is essential for it to be effective, and service users should be involved from the outset. Evidence has shown that pathways provide patients with a more realistic expectation of their treatment options and care progression (Middleton and Roberts, 2000). In their study Kent and Chalmers (2006) report that 60% of patients described that a pathway helped them understand their own care and helped in discussions with staff. Moreover, 68% reported a reduction in anxiety levels, and 82% thought that pathways were a better way of documenting their care.

It can be seen therefore that there are many drivers for the use of care pathways, from stronger commissioning of services, through equity, an audit trail and patient preference. Together with the Government initiatives outlined in Our Health, Our Care, Our Say (Department of Health, 2006a), which promotes the need for the patient to be at the centre of care and the probable changes in the way in which services should be provided, care pathways are a robust and effective tool for the treatment and management of all continence problems.

Key summary points

- Continence care is becoming more of a national priority.
- The role of the nurse is changing rapidly and more types of providers are involved in the provision of continence care.
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- With the increase in providers care pathways ensure equity of care.
- Pathways demonstrate improvements in the provision of care to patients.
- Continence care has evolved into a real speciality with its own training agenda.
- Care pathways are standards which give the health care professional the clinical freedom to change care to suit the needs of the individual.
- Research shows patients prefer the care pathway approach.