

Long-Term Conditions

NURSING CARE AND MANAGEMENT

Edited by Liz Meerabeau & Kerri Wright

 WILEY-BLACKWELL

Long-Term Conditions

‘We can envision in chronic illness and its therapy a symbolic bridge that connects the body, self and society. This network interconnects physiological processes, meanings and relationships so that our social world is linked recursively to our inner experience. Here we are privileged to discover powers within and between us that can either amplify suffering or disability or dampen symptoms and therefore contribute to care.’

Arthur Kleinman (1988:xiii)

The Illness Narratives – Suffering, Healing and the Human Condition

Basic Books, New York

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Nursing Care and Management

Edited by

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Foreword

This is a very important book. Although there have always been people with long-term conditions (LTCs) on nurses' caseloads, it is only in recent years that we have recognised the breadth and depth of these individuals' needs, and understood how much further we could go to meet them. For too many years, health professionals saw their interactions with people with LTCs as episodic, repetitive and unrewarding.

A better understanding of the nature and impact of these conditions on individuals has changed both attitudes and practice. We are more focused on prevention, both primary and secondary, for diseases once accepted as unavoidable. We are more proactive in finding people with LTCs, and instituting management to reduce their impact. And, most importantly, we now recognise that people with these conditions know a great deal about them, and are usually able and willing to take much more control than we had ever guessed. The advent of portable assistive technology, which can be used at home with minimal training, has helped enormously to shift the knowledge and power in disease management from the professional to the patient.

The timing of these changes is important. The number of people with LTCs in the United Kingdom and worldwide is set to grow exponentially. Lifestyle factors, including obesity and inappropriate diet, environmental challenges as well as some unknown causes, are all leading to sharp rises in conditions such as diabetes, asthma and heart disease. In a world with rising health care demand but caps on health care spending, managing LTCs well is a professional imperative for the sake of the individual patient and the wider health system.

This book is a very welcome tool, which will enable health professionals to understand the complexity, challenge and rewards of proactively managing LTCs. Putting this knowledge into skilled practice, in partnership with patients, will transform the lives of many individuals and their families, and thus fulfil the fundamental purpose of nursing.

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Introduction

It is a curious experience to have written a book during a time when the government was expected to change after many years, knowing that if that change came, many of the policy aspects of the book were likely to change as well, and the documents we refer to may fairly soon become unavailable. Organisations we refer to may also disappear. In addition, clinical guidance is also continually being updated and although we have used the most up-to-date guidance in this book, we are aware that this may soon be superseded and we would direct you to check for any updates.

As we write this Introduction, we do now know the new government's plans for the NHS, as the white paper, *Equity and Excellence: Liberating the NHS* appeared in July 2010. The most commented-upon intention is the devolution of health care commissioning in England to consortia of GPs and the abolition of primary care trusts and strategic health authorities – a high-risk strategy which may exacerbate health inequalities, since the quality of general practice is worst in many areas where the social disadvantage is greatest. There is, however, a stated aim in the white paper to put patients and the public first, in particular by making shared decision-making the norm: *no decision about me without me*. This fits well with the ethos of this book and supporting people with long-term conditions (LTCs).

There has also been much discussion about the election pledge 'the Big Society', in which communities will be encouraged to take action on problems rather than relying on the state; how this will work when many third sector organisations will be getting less funding remains to be seen. Local authority budgets will also be greatly reduced, putting the interface between health and social care at risk. In addition, public health measures such as minimum pricing for alcohol and improvements in food quality have been rejected, so we may return to an individualistic approach to public health, rather than the societal approach referred to in the discussion on health inequalities in our book.

Despite the future changes and the number of 'unknowns', the heart of the book, which is the experiences of people with LTCs, and the need for us to provide the best care we can, will not change. The demographic pressures of an older population, and more people developing LTCs, will remain, as will the complexity of care and support which many people need. In order to do justice to our subject, we have concentrated on the care of

adults and on physical illnesses, although we recognise the importance of mental illness and the difficult interrelationship between social disadvantage, physical illness and mental illness, particularly depression.

The discussion in this book moves from a global and national perspective on some of the issues around LTCs, in chapters 1–3 ('Long-term conditions in perspective', 'Case management' and 'Changing approaches to the management of long-term conditions'), to a more personal and individualistic approach to supporting people living with an LTC with chapters 4 and 5 ('Sociological insights' and 'Psychological effects of long-term conditions') focusing on the effects that living with an LTC can have on individuals and their families. We also move from a generic approach to the care and management of people with LTCs in chapters 6–10, with many issues pertinent to all LTCs, to a more specific and clinical focus on three main LTCs in the final three chapters.

Due to the scope of this book, we have used a range of terminology according to the chapter focus and terms that are more commonly used. To this end, we have used such terms as illness, long-term conditions and chronic illness throughout the book, and referred to patients rather than people when more appropriate to do so.

The aim of this book is for nurses to gain a wider perspective on the issues and experiences of people who are living their life with LTCs. We are keen for the focus to be on the person with an LTC and the management and care of their condition to be aimed at enabling the person to live their life as they choose. With this aim there becomes not one truth for the best way to manage specific LTCs, but many truths which are individual to each person. These truths need to be understood and respected, and used *with* clinical knowledge to plan and manage care. To this end, the focus must be for nurses to develop a true partnership with people living with LTCs based on acceptance, empathy and respect. This involves nurses listening to people's stories and valuing their personal and unique understanding of their condition and how they manage their life with this.

*Liz Meerabeau
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Chapter 1

Long-term conditions in perspective

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Introduction

All developed countries, whatever their political system and overall approach to health policy, face challenges in meeting the rising costs of health care. This increase in health care costs generally exceeds the rate of economic growth; contributing factors include increasing proportions of older people in the population, the development of expensive medical technologies and drugs, and increasingly well-informed people who demand access to these developments in health care. *High Quality Care for All* (Department of Health, 2008a), also known as the Darzi Report after the junior health minister who led the NHS Next Stage Review, identifies six challenges common to all advanced health care systems: rising expectations, demand driven by demographics, the continuing development of the 'information society', advances in treatments, the changing nature of disease and changing expectations of the health workplace (i.e. staff expect a better work-life balance).

An important element of the changing patterns of disease is the increase in prevalence of long-term conditions (LTCs); LTCs are one of the eight priorities for the NHS. Dowrick *et al.* (2005) consider that the management of what they term chronic illness is beginning to develop its own identity as an important component of health care, and that despite clinical differences, there are many similarities in the problems people with different LTCs face and the strategies needed in providing care. These include the proactive identification of relevant populations, supporting the relationships between people with LTCs and health and social care, the development of evidence-based guidelines intended to prevent exacerbations, and the promotion of empowerment, for example through self-management.

This chapter discusses changes in the need for health care due to demographic change and persistent inequalities in health, before going on to outline some of the changes both in service delivery generally and in the provision of health care for LTCs more specifically, such as the use of targets by governments, and the growth of patient-focused care. Generally, like the rest of this book, the chapter has an English focus, in which policy initiatives and service developments include user participation (Department of Health,

2003) and National Service Frameworks (NSFs) with specific standards, for example for coronary heart disease (Department of Health, 2000a) and for LTCs (Department of Health, 2005a). Comparisons with the other three UK countries are also made briefly, and the global context is also discussed.

The global challenge: demographic change

Within the overall trend towards older populations, the most rapidly growing segment is that of people over 80: the Organisation for Economic Co-operation and Development (OECD)(1988) estimated that whereas in 1980 the cohort of older people was made up of 34% aged between 65 and 69, 48% between 70 and 79 and 18% 80 or over, by 2050 these percentages would be 26%, 43% and 31%, respectively.

More recently, *An Ageing World: 2008* (US Census Bureau, 2009) highlights a huge shift to an older population, with great consequences. In the next 30 years, the number of people over 65 in the world will almost double to 1.3 billion, and in 10 years time, older people will outnumber children for the first time. This will affect family structure, patterns of work and retirement. Europe has 23 of the 25 'oldest' countries in the world (including all of the countries of western Europe, with the exception of Ireland and Denmark). In the United Kingdom, the nineteenth 'oldest' country, by 2040 there will be 46 people aged 65 and over for every 100 people of working age (defined as aged 20 to 64); in Germany, the figure will be 58, and in Japan, 68. (This ratio is called the older dependency ratio.) This compares with 16 in South Africa and 23 in India. Japan, Singapore, France, Sweden and Italy all now have life expectancies at birth of more than 80 years. However, although the proportion of older people in the populations of developing countries is much lower, because of the size of these populations, overall most of the increase in the number of older people in the world is actually in these poorer countries. China is one of the fastest ageing countries in the world, since its fertility rate has been below the replacement rate since 1991, due to its long-standing one-child policy. In Japan, 22.5% of the 127 million people are over 65, whereas only 13% are under 15.

It should not be assumed that greater longevity automatically increases the burden of ill health; many people are likely to live relatively healthy lives until their last few years, although it is likely that they will be managing one or more LTCs. The Academy of Medical Sciences (2009) report *Rejuvenating Ageing Research* states that in the United Kingdom healthy life expectancy is increasing at least as quickly as overall life expectancy. Far fewer older people are disabled than was the case in the 1970s, and drug treatments for hypertension and cardiac problems have reduced the mortality from heart disease by 40% since the 1990s. Older people in many countries also contribute towards society in that they pay considerable tax and are major providers of care, both to children and to other older people. Nevertheless, the ageing of the population does result in higher health care costs. In most countries, people over 65 account for at least twice the health care expenditure that their proportion in the population would predict; in the United States, people over 65 constituted one-eighth of the population in 2000, but consumed nearly half of the health care expenditure (the UK figures were one-sixth and 43%, respectively). The OECD (1988) projection was that these figures for expenditure would rise to 63% for the United States and 54% for the United Kingdom, by 2040. Appleby (in Pilkington,

2009) estimates that the NHS needs about 1.5% extra funding every year just to cope with increased need due to demographic change.

The demand for health care

A second important factor in driving up health care costs is the growth of expensive medical interventions. Many medical innovations have not been fully assessed in terms of costs and benefits, although health technology assessment for potential new interventions is well established in Australia, Sweden, the Netherlands, the United Kingdom and the United States (in individual states such as Oregon, which was a pioneer in health technology assessment). In England, such assessment takes place through the National Institute for Health and Clinical Excellence (NICE). The costs of health technologies are assessed against the benefit, which is calculated primarily by means of quality-adjusted life years (QALYs). This measure has proved controversial; treatments for the terminal stages of diseases such as kidney cancer are likely to fall short of the threshold for NHS funding, since life expectancy is short, and in some instances QALYs have been recalculated to allow for this. Although NICE was set up to try to depoliticise decisions about expensive medical interventions, there has been intense lobbying in response to its decisions, and there is concern that services for other less vocal people, such as mentally ill or older people, may get displaced as a result. Arguments about the entitlement to treatment are likely to be tested in the courts, for example in 2006 in relation to Herceptin, a drug for certain types of breast cancer.

It has been recognised that a small percentage of people consume a large percentage of health care resources; therefore, managing LTCs has become an important element in health policy, both for humanitarian reasons and in an attempt to control costs. In England, one-third of the adult population has an LTC; in some areas this rises to half (Department of Health, 2008b). Even in younger age groups, 15% of children under 5 and 20% of children and young people aged 5–15 have an LTC (Wilson *et al.*, 2005). The British Household Panel Survey (2001) found that people with LTCs accounted for 80% of GP consultations; they also account for 72% of inpatient days in England and 65% of outpatient appointments (Haddad *et al.*, 2009). By 2030, the incidence of LTCs in people over 65 is estimated to more than double (Department of Health, 2005b). People with long-term physical conditions also have a 20% risk of depression, a rate which is two to three times higher than that for people in good physical health (Egede, 2007).

Globally, the most common LTCs are cardiovascular diseases such as hypertension, coronary artery disease, stroke and heart failure, various forms of arthritis, respiratory problems, diabetes and epilepsy; such illnesses contribute to nearly half of the prevalence of disability worldwide. HIV/AIDS has also become an LTC in countries where there is adequate treatment. Mental health problems such as depression are also increasingly viewed as LTCs. LTCs are collectively the largest cause of death globally (World Health Organisation, 2005), despite the prevalence of infectious diseases in poorer countries; by 2025, an almost 300% increase in deaths from ischaemic heart disease and stroke is predicted in Latin America, the Middle East and sub-Saharan Africa (Yach *et al.*, 2004). Chronic obstructive pulmonary disease is predicted to be the third main cause of death globally by 2020 (Murray and Lopez, 1997). About 2.8% of the global population has

diabetes; this is likely to increase to 6.5% by 2030 (Murray and Lopez, 1996), and is linked to the increased incidence of obesity.

If current trends continue, 60% of men, 50% of women and 25% of children in the United Kingdom will be obese by 2050 (Foresight, 2007); excess weight is increasingly seen as the norm. It is beginning to be recognised in the United Kingdom that the environment is obesogenic, for example due to the availability of cheap, high-fat food, and that government intervention has not so far been effective; the chair of the International Obesity Task Force, Professor Philip James, gives the current English campaign, Change4Life, only a 10% chance of success (Dent, 2009). Change4Life is an example of a recent approach to addressing health-damaging behaviours which has been adopted from the United States, social marketing. A national centre for social marketing, a collaboration between the Department of Health and the National Consumer Council, was launched in 2006. The aim is not only to raise awareness but also to equip people with ways of changing their behaviour, using solutions which meet their needs, and where necessary, to change policies and structures which reduce people's capacity to live healthily.

As the example of obesity illustrates, reducing mortality and morbidity from LTCs requires individual engagement with lifestyle factors; Wanless (2002) has termed this the 'fully engaged' scenario, in which individuals take responsibility for their own health, and public health goals such as smoking cessation are achieved. If this scenario is not achieved, the costs of health care will become unaffordable. Public bodies also have a key public health role. *High Quality Care for All* (Department of Health, 2008a) refers to the legal duty for the NHS and local authorities to work together to address public health issues, and to cooperate in improving outcomes for their populations, on the basis of a formal assessment of people's needs (Joint Strategic Needs Assessment). These plans involve other agencies, such as the police, and focus not only on health priorities such as smoking but also on broader factors such as poor housing, education, local transport and recreational facilities.

Health inequalities

It has long been recognised that the risks of long-term health problems and premature death are not equally distributed in society throughout the developed world. Since the launch of the *Black Report* in England (Townsend *et al.*, 1992), there has been considerable debate and research to understand the relationship between social inequalities and health. There are two broad categories of explanation for the causes of health inequalities. Cultural/behavioural explanations stress differences in lifestyles and may imply that such differences are matters of choice; such explanations can lead to 'victim blaming' for illnesses which are obviously lifestyle related. However, comparisons between people with similar habits such as smoking show that there are still differences in the effects of these habits between the social classes (Department of Health, 1998a), indicating that structural factors also apply. Structural explanations stress the role of social circumstances; for example, mothers in poorer families tend to feed their families cheaper, higher fat foods, and are also reluctant to cook unfamiliar food which might be refused and therefore wasted. Housing conditions are also a major determinant of health; people in poor-quality housing suffer more from depression and respiratory disease. During the years of Conservative

government in the 1980s and 1990s, the structural causes of health inequalities were not acknowledged in policy, and in the mid-1990s, the term used by the Department of Health was 'variations in health' rather than health inequalities. The establishment of the Acheson Inquiry (Department of Health, 1998b) by the incoming Labour government was recognised as a significant break with previous policy. However, recognising the structural causes of ill health has not led to a reduction in health inequalities, as most recently demonstrated in the strategic review of health inequalities led by Sir Michael Marmot (Marmot Review, 2010).

The 2009 House of Commons Health Committee report on health inequalities comments that a girl born in 2006 in the wealthy London boroughs of Kensington and Chelsea has a life expectancy of 87.8 years, compared with 77.1 years in Glasgow. Poor people have more years of poor health and also less access to health services, although it is socio-economic conditions, rather than poorer quality health care, which are thought to be the main factor in the greater prevalence of LTCs among disadvantaged people. There are also differences between ethnic groups. The 2001 census found that Pakistani and Bangladeshi men and women in England and Wales reported the highest rates of both poor health and limiting long-term illness, and Chinese men and women reported the lowest rates. South Asian people have high rates of heart disease and hypertension; Black Caribbean people have high rates of the latter, and also high rates of admission for severe mental illness, particularly for young men. All ethnic minority groups are reported to have high rates of diabetes. The Men's Health Forum in its evidence to the House of Commons Health Committee argued that men's life expectancy is more severely affected by deprivation than that of women; 67% of men are overweight or obese compared with 58% of women. People who are severely mentally ill, perhaps because they suffer from poverty and social exclusion, are also much more likely to have physical health problems. People with schizophrenia are 90% more likely to get bowel cancer and 42% more likely to get breast cancer. They also have higher rates of diabetes, coronary heart disease, stroke and respiratory disease, and on average die 10 years earlier (House of Commons Health Committee, 2009).

There has been debate for many years on the extent to which health-damaging behaviours such as smoking, poor diet and lack of exercise, which also show a socio-economic gradient, are amenable to change. In 1973, about 42% of the most affluent smoked; the figure in 2004 was about 15%. The figures for the poorest were 71% in 1973 and 61% in 2004, showing that whilst both figures have improved, the gap is now much wider (House of Commons Health Committee, 2009). The report comments that the reasons why poorer people are less likely to adopt beneficial health behaviours may be because they lack the information and material resources, other people in their environment may also have the same habits, making it harder to change, and changing health behaviours may not be a priority when there are more pressing problems such as poverty and local crime.

The poorer health of many black and minority ethnic communities was referred to in the House of Commons Health Committee report, and there is convincing evidence that this is mainly due to social and economic inequalities rather than ethnicity *per se* (Nazroo and Williams, 2005). Differences between dominant and minority cultures tend to be overemphasised in health policy, as if a person's ethnicity determined their whole identity (Ahmad and Bradby, 2007), whereas Atkin and Chattoo (2007) argue that policy makers

and service providers should work with an individual’s own definition of themselves. The interaction between religion and ethnicity has only recently been researched, partly because there were no large-scale data until the 2001 census (Beckford *et al.*, 2006), and there is also increasing recognition of the impact of racism on the health of minority groups (Nazroo *et al.*, 2007).

Many writers argue that relative poverty is an important cause of ill health (Wilkinson, 1996, 2005). Wilkinson and Pickett (2009) argue that in more unequal societies, the effects of inequality affect people throughout that society, not only the poorest people. The most equal of the developed countries are Japan, Sweden, Norway and Finland; the most unequal are the United States, Portugal, the United Kingdom, Australia and New Zealand. In less egalitarian countries, social relations and levels of trust deteriorate, and rates of obesity, mental illness and drug use are higher. Wilkinson and Pickett (2009) argue that relationships based on social exclusion inflict social pain. This is echoed by Mulgan and Buenfino (2006: 1), who state that ‘in a society with relatively less risk of absolute malnourishment, psychic needs come to the fore: loneliness, depression, anxiety, and the misery caused by dangerous and unpleasant environments’. Income inequalities, measured by the Gini coefficient, have become much more pronounced in the United Kingdom since the election of a Conservative government in 1979 and were not remedied by the change of government in 1997; health policy in England has also moved away from the consensus of the post-war years, to a more market-oriented model, influenced by the United States.

Health care systems

As Blank and Burau (2004) discuss, variations in health care policy from one country to another can be explained by historical and cultural features; no two health care systems are identical, and within the United Kingdom, there are now divergences between Wales, Scotland, Northern Ireland and England, the latter having persisted with a much more market-oriented approach in which targets and strong performance management dominate (Greer, 2005). A recent report from the Nuffield Trust (Connolly *et al.*, 2010) has shown the English system to be more cost effective.

The location of political power in a country can be classified along a continuum (see Figure 1.1).

Where power is concentrated, rapid reform is possible; where it is fragmented, as in the United States, even small-scale change becomes almost impossible to implement and deeply contested, as the recent battles by President Obama to reform the US health care system demonstrate. The tendency to stalemate is exacerbated in systems such as the



Figure 1.1 Location of political power (Blank and Burau, 2004).

United States where there is divided government with several branches or levels which different parties control. Conversely, in a highly centralised system such as the United Kingdom (or England) rapid change can destabilise the system. This was the case in New Zealand in the 1970s, where reform was nearly continuous (Martin and Salmond, 2001). Health care systems are always the focus of political struggle, since they are fundamental to society, and consume considerable resources.

Health care systems are obviously shaped by the wealth of the country, generally measured in Gross Domestic Product (GDP) per capita. In 2002, the average GDP per capita of all countries was \$7,081, ranging from \$498 in Sierra Leone to \$22,801 in the United Kingdom and \$35,831 in the United States. The majority of the fairly wealthy countries discussed by Blank and Burau (2004) spent between 7% and 9% of their GDP on health care, the United States being the exception at 12.9%. The percentage coming from public sources ranged from 67.3% in Italy to 83.8% in Sweden, the exceptions being the United States (44.8%) and Singapore (26%). However, the source of the public funding differs; whereas the United Kingdom, New Zealand and Sweden have national health systems funded from general taxation, countries such as Germany and the Netherlands fund their health care systems from compulsory social insurance (the so-called Bismarck system). Countries with the latter type of funding tend to have more private hospitals. Systems may also have a patchwork of funding; New Zealand funds hospital care through taxation, but primary care through direct payment. The United States is particularly notable for its high levels of expenditure on health care but very uneven provision. Millions of Americans have private health care plans, but 47 million have no insurance, and the systems designed to cover old people and the very poor are complex. Unmet health care bills are a major reason for bankruptcy in the United States (Harris, 2009).

Most, if not all, health care systems are now under additional pressure due to the global economic downturn. The United Kingdom has a relatively high use of hospital-based care (£1,009 per capita, compared to £766 in France; Gainsbury, 2009), and there are plans in England, as yet not clearly articulated, to transfer more care to 'polysystems', although the research evidence shows that it cannot be assumed that care in the community is cheaper (Roland *et al.*, 2007). The consultancy firm McKinsey has also modelled a reduction of 137,000 posts in the NHS, of which 1,600 would be district nurses (Gainsbury, 2009), based on assumptions about the 'productivity' of district nurses, i.e. the number of visits they undertake. It is not clear from the report whether these data took account of the relative complexity or acuity of the patients, and the district nursing service has had insufficient attention in formulating health care policy (Edwards and Dyson, 2003), as has home care in general.

Home care

Blank and Burau (2004: 149) argue that provision for LTCs has been marginal in the development of health policy:

'Health systems are concerned first and foremost with the provision of medical care and focus on acute illness. Doctors are the key professionals shaping the delivery

of health care and hospitals are the primary location. The emphasis is on *curing* as opposed to long-term *caring*.’

In addition, much of the care for LTCs takes place in the home, where it, and deficits in care, are less visible than in acute settings which are by their nature much more public. Like other aspects of health care policy, home care policy varies from country to country, but it can be argued that it is more variable, and more influenced by cultural assumptions, than acute care. Blank and Burau (2004: 151) state:

‘Home care policies are pushed by demography and costs, but are shaped by country-specific factors. Key factors include how the funding and provision of health care is organised, where health systems draw the boundary between health and social care; and cultural assumptions about appropriate divisions of labour between the state and the family.’

International statistics on home care are almost non-existent and it is difficult to know what is happening underneath the political rhetoric. The majority of countries spend very little on long-term care, generally around 1% of GDP, and home nursing is even more marginalised. Of the countries discussed by Blank and Burau (2004) only Britain and Sweden have public home nursing services. In other countries, the provision is more mixed; a legacy of informal care (Germany, Japan, Singapore), or liberalism (the United States and Australia). Sweden has a well-established home nursing system, but it is very localised and therefore variable. As in other countries, eligibility for home care has also become more restricted:

‘Public funding is often not secure and hardly sufficient, and it has to be supplemented by out-of-pocket payments. Publicly funded services are also increasingly targeted . . . and the entitlement to publicly funded services is being hollowed out. Furthermore, often the level of service provision is basic and involves a whole range of providers. As a result, the emphasis on welfare mix competes with the policy goal to integrate services across different providers and the boundary between health and social care.’

(Blank and Burau 2004: 167)

The percentage of people over 65 receiving formal help at home varies widely from 3% in Italy to 12% in the Netherlands, with the United States as an outlier at 16% (Jacobzone *et al.*, 1999). The latter is not a consequence of state generosity, but of the vigorous marketing of private insurance plans.

In England, a number of concerns have been raised about the provision of domiciliary services, although the picture is mixed. Overall, the evidence suggests some gains for people with complex needs, but fewer improvements for people with lower levels of dependency, and particular inadequacies in services for people from ethnic minorities (Patel, 1999). The number of home help hours purchased or provided by local authorities in England increased from 2.2 million in 1994 to 3.4 million in 2004 (Babb *et al.*, 2006), but whereas in 1994 81% of these were directly provided by the local authority, by 2004 this had fallen to 31%. The provision was also increasingly focused on the people with

greatest need, which on the face of it is logical, but as with other targeted provision, can lead to the loss of preventative care.

A recent development is to pay cash benefits directly to dependent people, for them to purchase their own care. Personal budgets were first developed in social care under powers available to local authorities in England since 1996; uptake was slow until a pilot in 2006–2007 showed positive results. The possibility of extending the system to health care was ruled out in the white paper *Our Health, Our Care, Our Say* (Department of Health, 2006) on the grounds that it would erode the principle of the NHS as being free at the point of delivery, but this view was reversed in the NHS Next Stage Review and provision was made in the 2009 Health Bill, together with the announcement of a pilot scheme in 20 primary care trusts (PCTs). There are three ways in which a personal health budget could operate: a notional budget in which no money changes hands but the person talks to their clinician or care manager about the sum earmarked for them and how it should be spent, a real budget held by a third party, or direct payment. However, recent research (NHS Confederation, 2009) showed that health leaders were concerned that the scheme is not high priority nor likely to be welcomed by the NHS, may be complex to implement, and may compromise both patient safety and the quality assurance of services. These concerns were echoed in the experience of social care leaders, who concluded that achieving the cultural change needed was a far bigger challenge than the mechanics of implementing the scheme, that voluntary organisations were crucial as providers, trainers and advocates, and that a coordinated approach across health and social care was also needed.

A particular focus for policy analysts for many years has been the coordination, or lack of it, between health and social services in England, whereas in Northern Ireland structures have been integrated since 1973 (House of Commons Health Committee, 1998). This lack of focus was considered to result in duplication, fragmentation and delays in providing services, issues which may often impact upon people with LTCs. Intermittent attempts have been made to achieve more ‘joined-up’ government (Bogdanor, 2005) and to address policy ‘silos’ both nationally and locally. Legislation has permitted the pooling of budgets for several years, and the most recent attempt to coordinate local public sector budgets is the Total Place pilots, one of which, in Dorset, addresses services for older people (Smulian, 2009). It remains to be seen whether this is successful, whether it can be rolled out, and indeed whether it survives a change in government; however (premature) projections from the 13 pilots have already been made to argue that public service costs could be cut by 15% (Curtis, 2010).

Informal care and social care

Duff (2001) states that the costs of home care are largely borne by the community (so-called informal care). Whilst the role of the state is generally residual in the provision of home care, this is particularly marked in countries which have a strong cultural heritage, such as Germany where the role of women in providing care is still heavily influenced by Catholicism, and Japan, where the cultural honouring of older people results in a legal requirement for near relatives to provide financial support. Politicians and policy

makers assume that families should want to take on the care of dependent members. Land (1991: 18) refers to this expectation, which falls particularly on women, as 'compulsory altruism' in that it is difficult to decline. The balance between individual and state responsibility in welfare, established after the Second World War, shifted in the 1980s back to a greater emphasis on the individual. This was explicitly expressed in the National Health Service and Community Care Act 1990, which greatly curtailed state expenditure on residential care.

The 2001 census identified 1.9 million unpaid carers in the United Kingdom, who each provided at least 20 hours of care a week. The highest levels of unpaid care were mainly in poorer areas such as South Wales, Merseyside, and in the London boroughs of Newham and Tower Hamlets. Estimates suggest that in the United Kingdom carers save the government £34 billion a year (Pickard *et al.*, 2003). Therefore, supporting carers has become an important policy goal, and in 1995 the Conservative government passed The Carer (Recognition and Services) Act. *Caring about Carers: A National Strategy for Carers* (Department of Health, 1999) recognised the need for primary care teams to improve communication with carers, provide support, and with the consent of the cared-for person, work collaboratively with them. Explicit standards and guidelines for supporting carers were also part of the NSFs, such as the NSF for Coronary Heart Disease (Department of Health, 2000a) and for Older People (Department of Health, 2001a). For example, para 3.28 of the latter states that 'The care plan should demonstrate user and carer involvement in decision making and each user and carers should hold their own copies of the care plan.'

Financial benefits for carers in the United Kingdom did not exist until the 1970s, when the invalid care allowance was introduced; it was a means-tested benefit for people under retirement age who gave up paid employment to care for a dependent, although married women were unable to claim until 1986, when the European Court ruled that their exclusion was sex discrimination. The introduction of the carer's allowance in the 1990s has improved the levels of support since the 1980s, when they were severely criticised (Glendinning, 1983), but they are not generous and there are concerns that higher levels might encourage carers with inappropriate motivations. Carers also suffer loss of income, since they are less likely to be in employment, and when employed, tend to be in lower paid jobs (Carmichael and Charles, 2003).

Although care homes fulfil a key role in providing social care, Henwood (2002) considers that we are ambivalent about them, through guilt at 'putting away' older people or people needing care. The sector has been placed under considerable pressure, squeezed between the need to invest and improve the physical fabric, the inadequate fee paid by local authorities, and a mobile workforce. In Henwood's view, the Royal Commission on Long-term Care, established under Sir Stewart Sutherland in 1997, could have addressed fundamental questions about the provision of care, but its terms of reference were limited to examining funding. Its recommendation, that the costs of care arising from frailty or disability should be met by the state, was accepted in Scotland but not in England (and is currently under review in the former due to financial pressures). More recently, the Wanless review of social care (Wanless, 2006) proposed a new funding model, but the issues remain the subject of considerable debate, since many people have not made sufficient provision for old age or illness, and the state is limited in its capacity unless more

money is raised by taxation. A National Care Service was proposed in a 2009 green paper, which proposed that on retirement, people who could afford it should pay a lump sum of about £20,000 to pay for future care; this was superseded by an unaffordable promise of free care for 'critical' needs. In early 2010, a personal care at home bill was proposed, but with no published regulations on how it would work; a political row then ensued when it was suggested that £20,000 should be deducted from estates after death to help pay for the system.

Policy and practice developments in managing LTCs

The reforms of the NHS enacted by the Labour government elected in 1997 were set out in the white paper, *The New NHS* (Department of Health, 1997), followed by *The NHS Plan* (Department of Health, 2000b); key elements were greater partnership, and the elimination of unacceptable variations in care. Developments included new national standards, greater performance management, improved clinical governance and the creation of organizations such as NICE, the National Institute for Clinical Excellence which later subsumed the Health Development Agency, and the Modernisation Agency (which later merged with other elements to become the NHS Institute for Innovation and Improvement). A more recent example is NHS Evidence (www.evidence.nhs.uk). These are examples of the development of knowledge transfer, aided by the growth of information technology; knowledge transfer has also been promulgated through the creation of clinical networks and collaboratives, of which the first was the cancer network, set up after the Calman–Hine report (1995). The Coronary Heart Disease Collaborative, part of the Modernisation Agency, started in 2000 with 10 programmes, and expanded to 30, one in each cardiac network. Edwards (2002) considered that networks could make the best use of scarce clinical expertise, standardise care, improve access, and enable a faster spread of innovation.

NSFs have also been an important means of standardising care and promoting innovation. The Diabetes NSF was published in December 2001, followed by a delivery strategy, providing a 10-year programme of change. The progress of the Diabetes NSF was reviewed after 2 years (Department of Health, 2005c), as was the Coronary Heart Disease NSF (Department of Health, 2005d) exemplifying the process of service audit which has become central both to performance management in the NHS, and as a source of data for lobbying by clinical interest groups. A further example of the former is *Getting to the Heart of It* (Commission for Healthcare Audit and Inspection, 2005), a review of progress on the Coronary Heart Disease NSF. Examples of the latter are the third national COPD audit, funded by The Health Foundation (Royal College of Physicians *et al.*, 2008), the national audit of services for people with multiple sclerosis (Royal College of Physicians and Multiple Sclerosis Trust, 2008) and the pilot audit of intermediate care services carried out by the British Geriatric Society (Greenwood, 2009).

Since the NHS Plan, a whole suite of policy documents, such as *Commissioning a Patient-Led NHS* (Department of Health, 2005e) have developed patient choice and patient information as a means to driving up quality. Patient and public engagement are supposed to be integral to the work of the NHS, and from April 2010 a new system, run

by the Care Quality Commission, will legally require all health and social care providers to gather the views of their service users. Currently, the evidence from the Picker Institute Europe (2009) is that the standard of engagement is variable.

As discussed in other chapters, the concept of the expert patient (Department of Health, 2001b) has been an important feature of the new approach to managing LTCs. The original programme, developed at Stanford University in California, recognised that many issues were common across a range of illnesses, including cognitive symptom management, exercise, nutrition and communication with professionals. There are two main types of self-management programme, those which are professionally led and usually condition specific, focusing on adherence to treatment regimes, and those which are user led and take a wider view on how people can take more control over their lives. A randomised controlled trial of the Expert Patients Programme by the National Primary Care Research and Development Centre (Kennedy *et al.*, 2007) found that it increased self-efficacy and energy, although it did not change patterns of health service use.

By 2010 everyone with an LTC should be offered a personalised care plan, which enhances self-care and records the discussion between the patient and the health care professional, and decisions made. The five elements of self-care support are information, healthy lifestyle choices, support networks, skills and confidence training, and tools such as self-monitoring devices, also called assistive technology. *2020 Vision* (Queen's Nursing Institute, 2009) considers that the use of this technology is vital. A £30 million programme of assistive technology is being piloted in three sites in Kent, Cornwall and the London borough of Newham, involving more than 6,000 people with LTCs and focusing on COPD, heart failure and diabetes. The experience in Cornwall has been positive (Lyndon and Tyas, 2010); patients have reported being able to manage their condition better, and feeling more empowered and confident.

A range of initiatives has been developed nationally to improve clinicians' skills in working in partnership with patients, for example the Department of Health (2009a) publication, *Your Health, Your Way*, and partnership is also at the heart of recent NICE (2009) guidance on medicines adherence, which highlights a 'no-blame' approach. The Health Foundation has invested over £6 million in a 3-year-demonstration programme of partnership based on eight sites, called Co-creating Health.

Another key element in the Labour government reforms of public services has been the use of targets. A national Public Service Agreement (PSA) target was set by the government to reduce emergency bed days by 5% by 2008 through improved care in primary and community settings, coupled with a PSA target to increase the number of people over 65 supported to live at home, by 1% per year in 2007 and 2008. *Supporting People with Long-Term Conditions: An NHS and Social Care Model to Support Local Innovation and Integration* (Department of Health, 2005f) builds on the intention stated in the *NHS Improvement Plan* (Department of Health, 2004) to move away from reactive care based in acute systems, to a systematic, patient-centred approach. It argues that improved support for people with LTCs requires wholesale change in the way that both health and social care services deliver care. They are required to identify all people with LTCs in their community and identify the level of care they need, using a model of care based on that used by the US health care provider, Kaiser Permanente. The case management of people in level 3 is discussed in Chapter 2.

Level 3: Case management for the most vulnerable people and those with highly complex needs, to anticipate and coordinate care.

Level 2: Disease-specific care management, which involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways.

Level 1: Supported self-care, developing knowledge, skills and confidence.

As discussed in Chapter 2, in addition to the Kaiser Permanente model, another American model which has been used in England is Evercare, which is reported to have reduced hospitalisation and improved care in the United States, although the evaluation of both models in England has been inconclusive (Hutt *et al.*, 2004). This may be because the comparator arm of the clinical trials, i.e. existing primary and community care services, are already more comprehensive in England than in the United States and so elements of case management are already in place.

As concerns about the affordability of health care have deepened with the huge growth in the national debt, it is increasingly being argued that much care takes place in inappropriate, and expensive settings. For example, currently the ability of GPs to provide care for people with type 2 diabetes varies widely, and as a result outpatient clinics, which should be concerned mainly with people with type 1 diabetes and complex diabetes, are seeing patients who should be managed in primary care. The Darzi Report (Department of Health, 2008a) introduced the concept of polyclinics as a way of providing some hospital services and also aggregating primary care services, although there are no evaluations of their cost-effectiveness (Imison *et al.*, 2008) and the concept has proved vulnerable, since it was closely linked to a Labour junior minister. More recently, the concept has been modified to the polysystem, where services may be networked rather than co-located. Again, the Department of Health has not marketed its vision with any degree of clarity or energy, and as a result the debate is captured by the campaigners against hospital closures.

Pharmacy services are being developed, under a contract which has three categories; essential, advanced and enhanced. The white paper *Pharmacy in England; Building on Strengths – Delivering the Future* (Department of Health, 2008c) encouraged a move from dispensing to clinical services, such as ‘compliance support’. However, there has been little development to date as pharmacists have generally required financial help to minimise the risk of the shift (Clews, 2009).

Ambulance services are also being reconfigured in some parts of England, moving from being the medical part of emergency services to being the emergency part of medical services, that is, part of a system which can triage 999, NHS Direct and GP out-of-hours calls (Kendall, 2009). Three quarters of the increase in 999 calls in the last decade has been due to four problems; falls, breathing problems, chest pain and unconsciousness (often alcohol related). The second and third of these have particular relevance to the management of LTCs; the government is determined that more health care should be managed effectively in primary care (Department of Health, 2009b), for example through the development of paramedic practitioners who can assess, treat and maintain the person in their own home.

It is widely considered that community services, which cost about £10 billion a year, or 10 per cent of the NHS budget, are key to reducing health care costs, although the

evidence base is slim and the workforce implications are often not fully spelt out. Six *Transforming Community Services* guides were launched by the Department of Health (2009c) in June 2009, of which one concerns the care of people with LTCs:

- Use a proven tool to stratify risk.
- Support and enable people to manage their own health needs.
- Use case managers to proactively manage very high intensity users and those with complex needs. Develop shared care planning.
- Invest in telehealth and telecare to empower patients to take, maintain and maximise their health potential.
- Develop personalised care planning using joint or integrated assessments.
- Engage service users by offering choice and personalisation through expert patient programmes or encouragement to hold individualised budgets.

Nursing provision

Currently, it can be argued that practice nurses (and primary care in general) have a clearer policy focus than their colleagues in district nursing (and community care). A recent study (Griffiths *et al.*, 2010) found that after controlling for a number of practice and population characteristics, higher levels of nursing staffing in general practice were associated with better outcomes in relation to the clinical indicators used in the Quality and Outcomes Framework for reimbursing GP practices, of COPD, CHD, diabetes and hypertension. There is little research evidence on the impact of the increasing use of health care assistants.

Community matrons have also been proposed by the government as a key element in managing people with LTCs. *Supporting People with Long-term Conditions: Liberating the Talents of Nurses Who Care for People with Long-Term Conditions* (Department of Health, 2005g) set out the principles of case management and the skills required of a community matron, such as managing risk, medicines management, and managing cognitive impairment. PCTs were required to have 3,000 community matrons in post by March 2007 and to implement the Expert Patients Programme. More generally, in the report of the Prime Minister's Commission on the Future of Nursing and Midwifery (2010) LTCs are one of the six dimensions identified.

Overall, then, there is currently considerable turmoil in the NHS, but amidst this change there are perhaps more opportunities for nursing. Corner (2010) proposes that nurses should move fast to acquire skills such as prescribing, assessment and motivational interviewing, and that (using a phrase from Christensen *et al.*, 2009) we should become a 'disruptive technology' which has a widespread impact on the services in which we work. However, as the examples above demonstrate, there has, perhaps, been a policy overload. *Commissioning a Patient-Led NHS* (Department of Health, 2005e), which required PCTs to divest themselves of their community staff, was heavily criticised by the Commons Health Select Committee (HSC, 2006) in its report *Changes to Primary Care Trusts*. In particular, it was criticised for lack of consultation and poor timing, since it was issued in late July. Overall, the committee felt that the proposals anticipated the outcome

of consultations to shape out-of-hospital care, and that this ‘made a mockery of the consultation process’ and created an impression of ‘policy-making on the hoof’. Its effect in destabilising a valuable workforce was also recognised. In the intervening time, the timescale for implementing the change has been extended, and at the time of writing a variety of models, such as social enterprises and becoming part of another NHS Trust (such as an acute Trust or a mental health Trust) have been created, in some cases causing considerable union disquiet. In recognition of this, the *Operating Framework for the NHS in England 2010/11* (Department of Health, 2009b) stated that direct provision would remain an option, and also that ‘commissioners and providers must maximise security of employment across their health economies’ (para 3.47). Recently there have also been mixed messages from the Department of Health as to whether the NHS is the ‘preferred provider’ for services, or whether other organisations, such as those within the third sector, can also bid with a reasonable hope of success.

The role of the third sector

The term ‘third sector’ covers both voluntary and not-for-profit organisations, and also social enterprises, defined as businesses with primarily social objectives, whose surpluses are reinvested in the business or in the community. This sector is diverse, and ranges from very large organisations such as Macmillan to small charities with few or no paid staff, but common principles include operating on trust, management by values rather than by rules or profit margins, and user involvement. A growing role for voluntary organisations has been in developing expertise and lobbying, for example in relation to AIDS (Epstein, 1996).

In the nineteenth and early twentieth centuries, voluntary organisations played a central role in meeting welfare needs such as unemployment benefits, health insurance, and beds in the voluntary hospitals, by both mutual aid and charitable giving. Both district nursing and health visiting had their origins in such philanthropic provision and, as with other voluntary provision, both were absorbed into state provision. With the founding of the welfare state in 1948 the voluntary sector became marginalised, but the late 1960s saw a renaissance as campaign groups such as Shelter were established, influenced by the civil rights movement in the United States. As noted in Chapter 4, campaign groups have been important in addressing issues such as stigma, and disability groups have campaigned successfully for the reform of services through the provision of personal budgets.

The most recent phase has been the participation of the voluntary/third sector in the mixed economy of care. In the 1990s, the Conservative government used both incentives and pressures to ‘roll back the state’, arguing that it did not provide care which was tailored to people’s needs. A market was created, and local authorities were required to shift much of their commissioning to the independent sector, defined as any provider not owned, managed or controlled by the local authority. The public, however, did not support a wholesale shift in provision, preferring that voluntary provision should complement, not replace, the statutory provision (Jowell *et al.*, 1995). The Labour government which came to power in 1997 also embraced the voluntary sector, not only on economic grounds but also as a way of addressing the decline in active citizenship (Fyfe and Milligan, 2003).

In relation to health care, it went further than its Conservative predecessor in creating markets and encouraging a range of provision. This has not only advantages but also risks in that the voluntary sector is often underfunded and too reliant on short-term contracts. This is illustrated in end-of-life care. The first modern hospice in the United Kingdom was founded in 1967, and funded mainly from public subscription. Dean (2005), reflecting on the death of its founder, Dame Cicely Saunders, argued that the hospices have never been properly funded by the NHS. They raise about £300 million of their own funding a year, with the equivalent of another £100 million in volunteer time; however, they have been hit by rising costs and the financial crash (Stratton, 2009). It is, therefore, essential that core services continue to be provided by the state, in order to provide stability.

Conclusion

This chapter has considered the context in which the care and management of people with LTCs takes place, by briefly reviewing the global context such as demographic and epidemiological change, and the social and health inequalities which result in increased morbidity and mortality for disadvantaged people. Health policy in all the developed countries is grappling with these issues, although the main focus tends to be on acute services. Home-based health care is generally more hidden from view and is more vulnerable to cuts as there are greater – though culturally variable – expectations of the role the family should play in providing care.

In the United Kingdom, and England in particular, the health service has been through a period of great instability with even greater to follow. However, there are also optimistic developments, such as a growing emphasis on patient involvement, and the legacy of the great investment in the NHS in the early years of the twenty-first century will hopefully be an infrastructure which includes better sources of data and assistive technology to enable this involvement to grow.

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