Chapter 2

The development of residential and nursing home care in the United Kingdom

Sheila Peace

Introduction

Reflections on the past history of institutions tell us a great deal about how their present day culture has evolved. In this chapter, the scene is set for understanding the position of present day nursing homes and residential care homes as places where older people live and die; a position formed of people and places where practice has evolved within a specific history. Attention here will focus on the last two centuries until the present day. This has been one of two stories—for nursing homes, and for residential care homes—coming together at times and being treated separately at others. It has not been until the recent Care Standards Act 2000 that we have seen both terms being replaced by the words 'Care Homes' for institutions which provide accommodation, together with nursing or personal care (Standard 3 CSA 2000) and the development of National Minimum Standards (DoH 2001a). The reality of this unity is yet to be seen.

In this chapter, I begin by considering the historical development of both services before focussing on the past 25 years. During the latter period recognition of the changing nature of our ageing society has developed alongside ideological debate and policy development concerning the provision of long-term care for older people. Consideration will be given to the current characteristics of this provision within residential care homes and nursing homes examining the nature of the people and the places that make up these services, and recent changes in policy that have affected them. Finally, the chapter will end by reflecting on how the culture of care has evolved within these settings and how issues regarding dying and death have only relatively recently been recognized as key aspects of the purpose of long-term care (Abel-Smith 1964: 1).

Early developments

But first to return to the past, whilst groupings of poor and destitute people have been recorded over the centuries (Townsend 1962), it is common to acknowledge that the English Poor Laws imposed the first legal responsibility on society for the care of the aged. During the eighteenth and nineteenth centuries parallel histories of voluntary hospitals and workhouses evolved. Abel-Smith (1964) reports that when hospitals were first categorized in the 1851 census only 7619 patients were enumerated. Until that time illness of any kind was usually managed at home where people, especially the sick poor, were cared for by kin. People with financial resources could seek care within voluntary hospitals set up by founding charities, the majority of which were in London (Abel-Smith 1964: 46).

From the times of the 1834 Poor Law, a system based on 'lesser eligibility' meant that those without employment, money or shelter, and those who were sick and without family support, were obliged to seek 'relief'. 'Indoor' relief was given through workhouses where men and women were separated and where people laboured for their keep. Consequently, during the nineteenth century there were a greater number of sick people living in workhouses than the gradually developing hospitals. Under the Poor Law Amendment Act of 1851, Boards of Guardians who oversaw the workhouses at parish level were empowered to subscribe to voluntary hospitals and send pauper patients to them. However few did and hospitals became more concerned with cases of acute rather than chronic illness. In 1861, 11 000 patients were enumerated in voluntary hospitals whilst 50 000 sick persons were under the care of the workhouse medical officer (Abel-Smith 1964: 34).

Older people would live in the workhouse until they died:

> . . . If the old man was dying they'd maybe let the old lady come and see him or vice versa. And at the end they used to have a jingle:
>
> > Rattle his bones over the stones;
> > He's only a pauper that nobody owns.
>
> And that's what it was. That's why they built the cemetery up close to the workhouse, so they could take them over on a barrow.
>
> > (Albert Funnel, a child in Brighton in the 1900s
> > quoted in Thompson *et al*. 1990: 38)

Outside of the workhouse system many people had to pay for their burial. In the nineteenth century, those managing developing hospital institutions did not want to incur the expense of funerals and people often had to guarantee funeral expenses before admission (Abel-Smith 1964: 11–12).

The late nineteenth century saw the beginning of the reform of the workhouse system and a gradual acknowledgement that it was the duty of the state

to provide hospitals for the poor—pauper hospitals which later became public hospitals. As Abel-Smith states, 'the principle of need had triumphed over the principle of less-eligibility' (1964: 96).

Moving out of the Victorian era, the early twentieth century saw the gradual emergence of a liberal and socialist philosophy developing the labour movement and recognizing the importance of family life, and the needs of children, the unemployed, and the sick. However, the institutional arrangements of older people were slow to change (Townsend 1962). The report of the Royal Commission on the Poor Laws, in 1909, indicated that almost half of the institutional population living in workhouse accommodation were older residents (Peace *et al.* 1997: 7). At this time recognition of the needs of an ageing society had not surfaced as a twentieth-century issue, older people in these situations were part of the sick poor who may or may not be in need of health care. Their situation within the workhouse system was due to their poverty and not their age.

However, the debate concerning 'to pay' or 'not to pay' for health care continued. Small pox epidemics led a wider variety of people with different financial status to seek hospital care which led to the development of convalescent care (Abel-Smith 1964). From the 1880s onwards separate nursing homes, pay hospitals and pay beds developed:

> The movement to find accommodation for paying patients had arisen largely out of the nursing reform movement: it became more advantageous to provide institutional care for those of modest income who could not be conveniently nursed at home. This led to the creation of separate nursing homes and Home Hospitals.
>
> (Abel-Smith 1964: 150)

Nursing homes offered a range of medical assistance—maternity care and surgical treatment which included the needs of some older people. These became procedures that could no longer be carried out in a person's own home. Abel-Smith reports that: 'In 1891 there were about 9500 beds in England and Wales in nursing homes and convalescent homes; by 1911 this number had increased to 13 000' (1964: 189) which then doubled to 26 000 by 1921 (1964: 339). The quality and provision within nursing homes was hotly debated throughout the early twentieth century. But it was not until the 1920s that the conditions of some of these homes and the care provided especially for the chronic sick which was causing concern to nurses and medical officers of health paved the way for the appointment of a Select Committee on Nursing Homes (Registration) (Abel-Smith 1964: 338–42). Evidence to the Committee (Ministry of Health (MoH) 1926) reported on the terrible circumstances of some patients:

> They frequently develop bed sores due to prolonged neglect. They are rarely washed. The bed linen is changed at very infrequent intervals, even when soiled.

> The rooms are verminous. No adequate protection is taken to prevent dissemination of contagious or infectious diseases.
>
> (Abel-Smith 1964: 341)

As a consequence the Nursing Homes Registration Act 1927 introduced the first system of registration and inspection for these privately run homes (see discussion of regulation, p. 30).

The historical development of the workhouse and the nursing home provides important background for the ideology concerning the development of the National Health Service and issues of payment for health care. When commenting on the views of the Select Committee of Nursing Homes, Abel-Smith points to the class-based divisions between those living in nursing homes and workhouses—stating:

> The real problem was the 'senile and chronic sick' among the class of persons who did not desire to incur the stigma of a Poor Law institution. For this group the committee recommended 'the provision of proper paying accommodation by the local authorities'.
>
> (Abel-Smith 1964: 342)

But to return to the workhouse population. It was not until the late 1920s that a reclassification of workhouse institutions saw the creation of Public Assistance Institutions (PAIs) and the transference of powers from the Poor Law Board of Governors to county and borough councils. In 1939 there were still nearly 400 public assistance institutions, accommodating 149 000 residents, 60 000 of whom were classified as sick—a majority of whom were older people (MoH 1939).

Circumstances during the period of the Second World War brought change. Various factors came together: there was a need to discharge patients from existing hospitals in order to accommodate war casualties which meant that many frail and sick elderly people were forced either to seek admission to a PAI or to fend for themselves; some older people living in cities became homeless due to air raids, and the consequence was the overcrowding of PAIs. Different forms of small hostel accommodation were suggested at this time (Means and Smith 1983) and the findings of the 1947 Nuffield Survey Committee of PAIs recommended a radical move away from mass establishments to small homes with 25–30 places (Nuffield Survey Committee 1947). Consequently, Section 21 of the National Assistance Act 1948, placed a duty on local authorities to provide 'residential accommodation for persons who, by reason of age, infirmity or any other circumstances are in need of care and attention not otherwise available to them'; and the annual report of the MoH in 1948–9 recorded the demise of the

workhouse with these words:

> The old master and inmate relationship is being replaced by one nearly approaching that of hotel manager and his guests.
>
> (MoH 1950: 311)

In framing this Act, a distinction was made between nursing homes and residential care homes that focused on accommodation or 'board and lodging' in relation to residential homes.

The postwar years

In the postwar years building materials were in short supply and many public sector residential homes for older people were developed out of upgraded workhouses and old, converted buildings. The small home of up to 35 places was an ideal at this time. In 1948 PAIs were still providing indoor relief for 130 000 people in England and Wales. These were split into three groups: 100 PAIs were transferred to the MoH for use as hospitals under the National Health Service Act; a further 100 went to local authorities to be used as residential homes, and the remaining 200 were called 'joint user establishments' as they housed a mix of sick people and others and were therefore divided between Regional Hospital Boards and local authorities (MoH 1949; Townsend 1962).

Concern over the well-being of individuals was only beginning to emerge and little regard was being given to those who cared for them. Whilst the National Assistance Act 1948 had not sought to exclude ambulant older people from publicly supported residential care homes, gradual shifts in policy saw provision targeted at those who were more frail. Guidance issued during the 1960s and 1970s drew distinctions between health care and social care—seeing residential care homes as primarily for those people failing to cope at home even with domiciliary care and yet not in need of 'continuous care by nursing staff' (see Judge 1986: 7). The official concerns during this time had not been related to the objectives of care but rather to the development of new homes; the number of people to be accommodated, and subsequent costs. Indeed, concerns over costs and the number of users led to economies of scale and a proposal for 60-bedded homes (MoH 1955).

Whilst local authorities became the major providers of residential care homes, a small but growing number of older people lived in nursing homes and residential homes run by owners/proprietors in the private and voluntary sectors registered with local authorities (see regulation, p. 30). In the postwar period these were the relatively small homes commonly utilizing large domestic houses extended for this purpose.

Table 2.1 Number of residential institutions, beds, residents, and residents of pensionable age—England and Wales, 1 January 1960

Type of Institution or Homes	Institutions or Homes		Beds		Residents of all ages		Residents of pensionable age	
	Number	%	Number	%	Number	%	Number	%
Former public assistance	309	9.3	36 934	33.3	34 781	33.3	29 615	31.0
Other local authority	1105	33.1	36 699	33.3	35 139	33.7	33 677	35.2
Voluntary	815	24.5	25 491	23.0	24 360	23.3	22 410	23.5
Private	1106	33.2	11 643	10.5	10 120	9.7	9825	10.3
Total	3335	100	110 767	100	104 400	100	95 527	100

Note: Some local authorities were unable to supply detailed information about residents (and residents of pensionable age) in voluntary and private homes and the numbers were assumed to be in the same ratio to total beds as in other areas.

Source: Townsend, P. (1962) *The Last Refuge*. Routledge and Kegan Paul, London. Table 6, p. 43.

Learning from Townsend

In 1960, Peter Townsend carried out his seminal study of residential care homes and institutions—*The Last Refuge* (1962). At this time he shows that in England and Wales there were 3335 residential institutions or homes accommodating 110 767 people—95 527 (86 per cent) being over pensionable age. A third of the residents were accommodated in former public assistance institutions (31.0 per cent); a third in local authority homes (35.2 per cent) and the final third split between voluntary (not for profit) (23.5 per cent) and private (for profit) provision (10.3 per cent) (see Table 2.1). He was not concerned with nursing homes.

Whilst, *The Last Refuge* forms a key text for understanding why the quality of life experienced by older people living in this form of accommodation and care needed to be reformed, it also gives us a limited understanding of what happened to older people at the end of their lives. In discussing his survey data, Townsend comments on the flowing admission and discharge of residents. Taking the period of one year, 1959, his analysis of data from 147 local authorities shows that 35 803 people were admitted to homes from their own homes, hospitals, and other residential institutions whilst 33 785 people were discharged (Townsend 1962: 51). Of the later group 25 per cent died within the homes whilst 37 per cent were discharged to hospitals and 38 per cent to other settings. He comments that the death rate varied widely from 3 per cent of residents to 26 per cent in different homes with the explanation being seen

in varied hospitalization rates, and reports that this was at odds with the government policy of the time which advised '*local authorities to avoid hospitalisation if possible during terminal illness*' (Townsend 1962: 52). He also noted that the Ministry of Health's definition of the responsibilities of the welfare authority includes the care of those elderly persons:

> who have to take to bed and are not expected to live more than a few weeks (or exceptionally months) and who would, if in their own homes, stay there because they cannot benefit from treatment or nursing care that can be given at home, and whose removal to hospital away from their familiar surroundings and attendants would be felt to be inhumane.
>
> MoH Circular 14/57 [Footnote (1) 1962: 52]

In his more detailed study of specific accommodation, Townsend visited a wide range of institutions—old workhouses (39), local authority postwar homes (53), private homes (42), and voluntary homes (39). Interviews were undertaken with all officers-in-charge and residents across the homes and details were collected on all the social and physical characteristics of residents and issues to do with staffing, amenities and furnishings. Within his analysis he has something to say about how dying and death was handled in these various institutions.

Within the old workhouses he found a few who commemorated the death of individual residents whilst in the main there was little acknowledgement:

> Generally, however, a death was hushed up and the body removed swiftly and silently. No doubt the staff were anxious to avoid giving cause for anguish but they failed to realize that by their attitude they provoked insecurity. Many of the old people were aware that their lives were drawing to a close. Some were fearful, it is true, but most were reconciled to the idea or even welcomed it. The death of others disturbed them less than the concealment of it. And the way death was treated was perhaps a crucial test of the quality of the relationship between staff and residents. Dishonesty in this most serious of matters created distrust over minor affairs. And to avoid the rituals observed in an ordinary community had other consequences. Prompt removal of the body was not only, old people felt, the final indignity which a resident suffered but it gave no chance to those who were left of paying their last respects to someone who had lived amongst them, however remotely, and of thereby giving a little more strength, dignity and feeling to the slender relationships between those who continued to share the life of a ward. Perhaps these observations have less force when considering some hospital environments. But for old people in residential institutions they seem to be of considerable importance.
>
> (1962: 96)

In postwar local authority homes he comments on the way in which a room may be separated and used either for committee meetings or as a 'sick bay' or 'death room'. For one matron this room was used for people who were dying, '*I put them in the front lounge if they are dying. I don't let them die in a room*

with others'. (1962: 115). He describes a range of scenarios from many homes where death is hidden, nothing is said and no one goes to the funeral, to a few homes where residents are informed, may visit the body and say goodbye, club together for a wreath, and go to the funeral if they wish to. The psychological and social consequences of death were little understood and Townsend felt that the quality of death in homes symbolized failure. He says:

> There's a hush for an afternoon but no one talks about it and everything's the same by the evening. 'They take it in their stride. Old people don't seem to care.' We came to believe that this reported reaction symbolized the fundamental failure of the post-war Homes. They did not create a substitute community or a network of social relationships which could sustain a sense of individual purpose or pride.
>
> (Townsend 1962: 148)

The last twenty-five years

But the failure to recognize the needs of those experiencing life and death continued. In 1975, there were 195 100 residential places (66 per cent local authority; 13 per cent private; 21 per cent voluntary) and 24 000 nursing home places run by the private and voluntary sectors. In addition there were 49 000 long stay geriatric places in hospitals (Table 2.2).

This was the situation of the long-term care sector for older people at the start of a period of immense ideological change in policy development since the break-up of the workhouse system. It also came at a time when demographic and household change within an ageing society was now beginning to be recognized.

The ageing society

From the beginning of the last century the population of the United Kingdom has been increasing, life expectancy has improved considerably with a longer life for women over men, and as a consequence so has the number of people over 65 years of age (Social Trends 2002). The number of older people has doubled since 1931 and whilst there will be some minor rises and falls, this trajectory of growth will continue until 2030 when it will slow down (The Royal Commission on Long Term Care (RCLTC) 1999: 13–14; DoH 2001). During the first-half of the twenty-first century the greatest relative increase in older people will be amongst those over 85 years and it is the experiences of these people that will have the most important implications for long-term care given that more than 20 per cent of this age group live in residential care and nursing homes (Laing 2002).

Factors that will affect how frail older people live their lives are varied and relate to personal health, social support, financial position, and service development through political action and ideological influence (see Fig. 2.1).

- *Individual:* growing number of very old people, especially women; the compression of morbidity may lead to a shorter period of chronic illness and disability prior to death (see Royal Commission on Long Term Care, p. 15; Sidell 1995).
- *Social support:* changes have occurred in the pattern of family structures and responsibilities of work and at home; several million people provide hours of unpaid care especially children/children-in-law and spouses; some families live at a distance from each other.
- *Economic position:* the improved financial position of many older people means that some are making a positive choice over long-term care; housing circumstances throughout life can affect decisions over accommodation and care in later life.
- *Ideological influence:* the 1980s saw an increasing popular support for a pluralist approach to welfare; in the 1990s and moving into the twenty-first century growing reliance on the market within health and social services.
- *Political action:* early stimulation of independent sector provision through public funding; an attack on institutional care through community care legislation; changes in funding; increased regulation and standard setting.
- *Service development:* increased pressure on long-stay hospital beds; more effective use of acute hospital beds; development of intermediate care and rehabilitation services; increased direction through National Service Framework for Older People.

Fig. 2.1 Factors which have affected the demand for long-term care in later life—1980 onwards.

Source: Derived from Peace *et al. Re-evaluating Residential Care*. Open University Press. 1997; Long Term Care Commission 1999; Sidell 1995; Laing 2002; DoH 2001.

Providing accommodation, and social and health care

The election of the Thatcher Conservative government in 1979 formed a dividing line in the history of residential care for older people. Until the 1980s local authority old people's homes formed the main avenue for those moving into residential care. But in the 1980s, residential care homes started becoming market commodities. Of particular importance were the 1980 Supplementary Benefits (Requirements) Regulations which enabled people entering private residential care to obtain financial support through board and lodgings payments, thus enabling many poorer old people who qualified for income support to enter more easily using public funds. This system was channelled through the benefits system, without requirement for people's care needs to be assessed by the Local Authority.

These financial changes were fundamental to the exponential increase in private sector provision. As Table 2.2 shows, between 1983 and 1985, the number of private residential places grew by 60 per cent; and yet between 1985 and 1990 public provision of residential care fell by 8.4 per cent whilst places in voluntary homes remained relatively static and private provision increased dramatically by 82 per cent. Overall, during the 1980s, provision overtook demand as predicted by demographic change (see Fig 2.1) (Higgs and Victor 1993; Laing 2002).

Table 2.2 Nursing, residential, and long stay hospital care of elderly, chronically ill, and physically disabled people, places by sector, UK 1970–2001

	Residential places			Nursing home places		Long stay geriatric places
	LA	Private	Voluntary	Private	Voluntary	
1 April						
1970	108 700	23 700	40 100	20 300		52 000
1975	128 300	25 800	41 000	24 000		49 000
1980	134 500	37 400	42 600	26 900		46 100
1983	136 500	54 700	45 300	29 000		46 900
1985	137 100	85 300	45 100	38 000		46 300
1987	135 500	114 600	42 200	52 000	8300	43 000
1990	125 600	155 600	40 000	112 600	10 500	47 200
1995	79 700	169 300	56 700	193 400	17 900	33 000
1998	68 000	180 700	53 500	203 200	18 200	24 500
2000	60 000	185 000	54 500	186 800	18 000	21 000
Proj. 2001	57 400	185 100	55 100	178 800	18 000	19 700

Note: The private or 'for-profit' and the voluntary or 'not-for-profit' sectors became known as the independent sector.

Source: Adapted from—Laing (2002) Healthcare Market Review 2001–2, Laing and Busson, London, p. 173.

Growth continued to a peak of 321 200 residential places in 1990 which was followed by lower percentage growth in the residential sector. These changes followed the implementation of the 1993 NHS and Community Care Act reforms which sought to reduce the 'perverse incentive' towards institutional care through the facilitation of home care (CM 849 1989). In 1993 state funding for care homes was transferred to local authority budgets and care management was developed to assess individual needs for both home care and institutional placements. Of course this assessment did not include those people who paid for their own placement in these settings—known as 'self-funders'.

In contrast to the residential sector, the nursing home sector saw a gradual increase throughout the 1980s and 1990s with a particularly marked growth since 1985–6, especially within the private sector. In 1985, the ratio of residential care home places to nursing home places stood at 7 to 1; but by 1990 this had become 3 to 1 and projected figures for 2001 put this at 1.5 residential

care home places to 1 nursing home place. The changing fortunes of the nursing homes sector reflect the steady decline in NHS geriatric and psychogeriatric beds, particularly since 1989 and the increasing nursing needs of residents. Consequently, whilst beginning from a much lower historic base than residential care homes, this sector has increased dramatically from 123 000 beds in 1990 to a high of 224 400 (+82 per cent) in 1997 followed by a more recent decline to 196 800. The residential care home sector has seen a more long-term gradual decline of approximately 7 per cent of places from 1990 to 2001 with projected beds of 297 700 (all figures based on Laing 2002).

These more recent changes relate predominantly to the characteristics of the institutional population and developments within the long-term care industry. In particular, residential care homes and nursing homes have been affected by:

(1) the debate and consequential funding arrangements concerning accommodation and personal and health care—which followed the Royal Commission in 1998 (RCLTC 1999). Free nursing care was introduced in England and Wales from October 2001; whereas free personal and nursing care has been adopted in Scotland;

(2) the development of intermediate care and rehabilitation services[1] to enable some older people to move from hospital or their domestic home into a residential care or nursing facility for a short stay in order to re-establish/ maintain a level of supported independence within the community (Laing 2002);

(3) the introduction of national regulatory bodies working with National Minimum Standards for provision.

   All of these initiatives have impacted on the financial requirements of accommodation and care that are beginning to change the long-term care market.

The characteristics of people and places

But what do we know of the characteristics of older people and staff living and working within care homes today?

The residents

The literature concerning institutional care for older people shows us that certain people are more likely to become residents than others. Factors affecting

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[1] The National Beds Inquiry in 2000 reported that two-thirds of hospital beds were occupied by people aged 65 years and over and that a proportion of older people occupying acute hospital beds could have been treated in alternative facilities. These findings led to the development of intermediate care and rehabilitation services (Laing 2002).

the likelihood of current placement include advancing age, gender, and being of white British culture (Bebbington *et al.* 1996; Bauer 1996), social factors such as living alone, levels of care needed, social support, and housing (Sinclair 1988; Sinclair *et al.* 1988), and health issues relating to a decline in physical and cognitive functioning and the ability to undertake activities of daily living (Levin *et al.* 1994; Brown *et al.* 1997). It is the combination of these factors which lead some older people to no longer cope, or wish to cope, with living in their own homes. Currently they are most likely to be of white ethnicity (Bauer 1996) although the ageing of minority ethnic groups and their experience of changing social support will alter this situation.

Of all those aged 65 years and over, approximately 4 per cent live in care homes. However, this percentage increases dramatically with age, so that over 20 per cent of people over 85 years live in care homes with at least three quarters of residents being women (Laing 2002). More than half of the residents living in independent sector care homes currently have their fees paid by local authorities whereas 30 per cent are self-funders (Netten *et al.* 2001; Laing 2002). A crucial factor in the future development of these communal services is the level of resources made available from central government to local authorities to fund community care and enable people to stay at home if that is their choice (Laing 2002).

But, as we have seen, the circumstances of people in later life are changing and this will affect where people live and die. Data from the 2000 Health Survey for England adds to this picture (Bajekal 2002). In Bajekal's study, 2400 people living in care homes were interviewed as well as 1600 people living in private households. This study showed that two-thirds of permanent residents had moved from private households whereas 14 per cent moved from hospital, and that the majority had been living in the care home for between 2 and 4 years. Many of the people admitted to care homes were older women who had been living alone. Whilst residents were less likely to have social support than people living in their own home, 64 per cent were visited by their relatives or friends at least once a week.

The health status of older residents is particularly revealing when compared with people living in their own homes. Whilst self-assessed general health did not differ greatly, residents were more likely to be underweight, suffering from anaemia and a majority suffered from long standing illness and severe disabilities. The survey reports that three in four of all residents in care homes were severely disabled although, as expected, severe disability rates were lower in residential care homes (c. 70 per cent) than dual-registered homes (85 per cent) and nursing homes (91 per cent). Whilst, difficulty with walking and using stairs was the most common condition reported for both men and women, senile dementia was the most frequently reported cause of disability in care homes. Ninety-five per cent of people living in private households

showed no signs of cognitive impairment whereas 49 per cent of those tested in care homes did, of which a third showed signs of having severe impairment. This was especially true of residents aged 80 years and over.

Consideration of the health and social circumstances of many residents in care homes show that whilst they are a diverse group, they do reveal a range of vulnerabilities which undermine their personal resources. It is therefore not surprising that mortality statistics for 1999 show that among those people over 85 years of age whilst the greatest number die in hospital, a comparable number of older women die in other settings including nursing homes and residential care homes (see Table 2.3). The future development of assessment for older people will have an important part to play in how choices are made over where people end their lives as outlined in the National Service Framework for Older People (DoH 2001*b*; 2002).

Staffing

It was not until the 1980s that legislation determined that a registered medical practitioner, or first level registered nurse should be in charge of a nursing home (see regulation, p. 30) and for many years there has been little information about the exact staffing levels of residential care homes and nursing homes which relate to the levels of resident need for personal and nursing care. The recent move to further develop pre-placement assessment and determine nursing and personal care will impact on staffing (DoH 2002).

The National Minimum Standards for Care Homes (DoH 2001*a*) say this:

> It is necessary to achieve a balance between drawing up standards which are specific enough to avoid the need for local negotiations, but which are broad enough to apply to the diverse nature of the clientele catered for (e.g. those who are physically frail; those who have dementia). Drawing up standards for staffing exemplifies some of the greatest difficulties of this kind. Where residents have a high level of dependency (in relation to capacity to perform the activities of daily living), staffing levels will need to reflect the needs of those residents. Where they require significant nursing attention, the skill mix of the staffing establishment must be adjusted accordingly. Residents with dementia also require care from appropriately skilled staff—and so on. In determining appropriate staffing establishments in all care homes, and in nursing care homes in particular, the regulatory requirement that staffing levels and skills mix are adequate to meet the assessed and recorded needs of the residents at all times in the particular home in question must be met.
>
> (DoH 2001*a*: 33)

These comments reflect current debates about multidisciplinary assessment (DoH 2002); discussions which reflect the need for a quality workforce where training is expected. Again the National Minimum Standards for Care Homes for Older People state that '*Staffing numbers and skill mix of qualified/unqualified*

Table 2.3 Place of death in England and Wales by age and sex, 1999

	NHS hospitals[1] and communal establishments (inc. nursing homes)		Non-NHS hospitals[2] and communal establishments (inc. private nursing homes)		Other[3] communal establishments (inc. aged person accommodation)		Hospice[4]		At home[5]	
	M	F	M	F	M	F	M	F	M	F
Aged 65 years and over	119 735	131 647	18 483	38 837	11 760	33 698	8373	7753	43 219	38 866
Aged 85 years and over	28 679	52 356	8199	25 127	6375	24 755	893	1124	7201	11 876

[1] NHS hospitals and communal establishments for the care of the sick does not cover NHS psychiatric hospitals but includes: *nursing homes*, general hospitals, sanatoria, geriatric hospitals and units, establishments for the chronic sick, mental hostels, homes or hostels for the mentally handicapped, maternity hospitals, and multifunction sites such as large hospitals.

[2] Non-NHS hospitals and communal establishments for the care of the sick does not cover non-NHS psychiatric hospitals but includes: *private nursing homes (including those for the aged)*, general hospitals, establishments for the geriatric and chronic sick, homes or hostels for the mentally handicapped, maternity hospitals, military hospitals, and multifunction sites such as large hospitals.

[3] Other communal establishments—schools for the mentally retarded and subnormal, holiday homes and hostels, common lodging houses, *aged persons accommodation*, assessment centres, schools, homes for the disabled or handicapped, rehabilitation centres, convents and monasteries, nursing homes, university and college hostels and halls of residence, approved schools, borstals and custody centres, detention centres, prisons, remand homes, YMCA, and YWCA hostels.

[4] Includes: Sue Ryder Homes, Marie Curie Centres, oncology centres, voluntary hospice units, and palliative care centres.

[5] Includes: those at the usual residence of the deceased (according to the informant), where this is not a communal establishment.

Source: Mortality Statistics: General (1999) England and Wales DH1 No. 32 ISSN 1469–2805, pp. 78–9.

staff are appropriate to the assessed needs of the service users, the size, layout, and purpose of the home at all times' and propose that at least 50 per cent of care staff should be trained to National Vocational Qualification (NVQ) Level 2 or equivalent by 2005 (excluding staff who are registered nurses) and that registration will mean that staff induction, training, and supervision arrangements are put into practice (DoH 2001*a*, Standards 27, 28, 36).

But what do we know about staffing? It was not until the Independent Sector Workforce Survey 1996 from the Local Government Management Board that we began to get more of a picture of independent sector provision (Local Government Management Board 1997). Based on a sample of 2791 private and voluntary homes (73 165 registered beds), this was the first comprehensive account of this workforce and it provided information concerning residential care homes, nursing homes, and dual-registered homes for a range of groups, the majority being for older people. The survey estimated that 74.1 per cent of staff were nursing and care staff and 23.4 per cent had support roles—cooks, cleaners, gardeners, and administrative staff. Only half of nursing and care staff worked full-time; a majority in all sectors and types of home were women with the proportion of male staff highest among managers and supervisors. The research also showed that 19.2 per cent of staff had worked in the home for less than a year and that this was higher in privately run homes than voluntary homes. The turnover rate was highest in dual-registered homes and the vacancy levels were highest for nursing staff who proved difficult to recruit.

In terms of training, not surprisingly, the proportion with qualifications was higher in nursing homes and amongst managers. In all sectors a small proportion of staff were studying for nursing qualifications or NVQs; some had reached NVQ assessor status. Unsurprisingly, training needs were identified in many homes. In a recent study of the skills and competencies of care assistants working with older people, Dalley and Denniss (2001) report findings from 418 surveyed care homes from all sectors of provision where 13 204 staff were employed of which 61 per cent were care assistants. The minimum wage was introduced in April 1999 at £3.60 per hour and in these homes the average for all homes was £3.88 per hour with local authority homes being part of a national local wage agreement offering around £4.50 per hour. In Chapter 8, we return to the training needs of care staff—suffice to say that in the main they are low-paid staff with little incentive to develop their employment potential.

The settings

The internal environment of care homes has changed over the years from the Victorian workhouses to the institutional settings that Townsend described, to

adapted domestic houses used for nursing homes and care homes often enlarged through the addition of a modern extension to the group-living homes of the 1980s which tried to re-create the family group to newly built extra-care facilities (Peace *et al.* 1982; Willcocks *et al.* 1986; Peace 2002). To some degree all of these building types still exist. They have all been buildings that have combined public and private spaces for residents and staff to coexist. The working and living and dying environments have all 'rubbed shoulders' alongside each other, and the design of space can affect behaviour.

Patterns of staffing, needs of residents, and the impact of collectivity all have a bearing on how the daily routines of care homes have evolved. Issues of privacy and enabling older people to master their own personal space have been slow to legitimize. But there has been a growing recognition that in moving to collective care older people have a right to bed-sitting space that is adequate for personalization if so desired. However, the tension surrounding the cost of space remains for whereas improved environmental standards are now expected within newly built homes, these adaptations will no longer be required within existing premises (DoH 2001*a*, DoH 2003).

Of course another determinant of the capacity to obtain privacy is the opportunity to have a bed-sitting room of your own and the facilities it contains. Consequently the single-room ratio and the proportion of rooms with en-suite WCs have become markers of standards of amenity. Since the 1980s both of these trends have been developing and Laing (2002) shows that whereas in the late 1980s more than 50 per cent of rooms in for-profit nursing homes for older people were for more than one person and less than 20 per cent of rooms had en-suite WCs; by 2001 almost 80 per cent of rooms were single and en-suite WCs were provided in nearly 50 per cent of bed spaces. Of course there is variation between homes and the lack of shared facilities and provision of en-suite WCs is more common in for-profit nursing and dual-registered homes than residential care homes.

Regulation emerges and evolves

But who has been concerned with the quality and standards of such homes? Throughout the last century the reporting of poor practice and stark conditions led to the development of regulation through registration and inspection. This system began with private and voluntary sector provision moving at a much later stage to the public sector (Department of Health and Welsh Office 1990).

The Nursing Homes Registration Act, 1927 was the first statute to set down the now familiar procedures for registration: application accompanied by a fee; reasons for refusing registration; certification; cancellation of registration;

bye-laws concerning record keeping and notification of deaths, and the power to inspect (Abel-Smith 1964; Department of Health and Welsh Office 1990; HMSO 1990). This legislation also provided the first definition of 'nursing home' and 'maternity home' to appear on the statute:

> 'Nursing home' means any premises used or intended to be used for the reception of and the providing of nursing for persons suffering from any sickness, injury, or infirmity, ...
>
> (Nursing Homes Registration Act 1927: Section 10)

As Fig. 2.2 shows this early legislation was amended over the years giving both central and local government powers over the conduct of and facilities and services provided by nursing homes. Not-for-profit homes run by the voluntary sector were brought into the regulatory system in 1963 and the regulation of nursing and mental nursing homes were brought together in 1975.

The Nursing Homes Act 1975 delegated power for registration and inspection first to Area Health Authorities and later to District Health Authorities. Further legislative amendments followed and the types of regulated premises, including those offering medical and surgical services, expanded. Amendments made to the Nursing Homes Act 1975 and the Health Services Act of 1980 also related—for the first time—to the qualifications and residency of the 'person-in-charge' of the home and the level and qualification of nursing staff. All nursing homes had to be in the charge of either a registered medical practitioner, or qualified nurse, or in the case of maternity homes a certified midwife. The Health Circular HC(81)8 outlined that where a nurse was in charge of a home, they had to be a registered nurse and health authorities were able to determine staffing levels given the number and types of patients within particular homes.

Whilst they can be viewed in parallel the regulation of residential care homes followed a slightly different path. The 1948 National Assistance Act gave local authorities powers to arrange for the provision of accommodation within premises maintained by voluntary organizations (Section 26) and in 1968 this arrangement was extended to private sector homes (Section 44 Health Services and Public Health Act 1968). The first statutory requirement to regulate a private or voluntary home for people who were disabled or aged by a local authority was set out in Section 37–40 of the 1948 National Assistance Act and dealt mainly with registration being tied to what became commonly known as the fit person, fit building, and fit conduct of the home (Townsend 1962). Regulations concerning the 'Conduct of Homes' were not issued until 1962 and whilst covering a wide range of issues concerning health and medication did not comment specifically on practice for dying and death other than notification (Department of Health and Welsh Office 1990).

	Residential care homes	Nursing homes
Governing Acts	Public Health Act 1936 National Assistance Act 1948 Mental Health Act 1959 Residential Homes Act 1980	Nursing Homes Registration Act 1927 Public Health Act 1936 Nursing Homes Act 1963 Mental Health Act 1959 (beginning of regulation of mental nursing homes)
	Health and Social Services and Social Security Adjudications Act 1983	Nursing Homes Act 1975 Health Service Act 1980
		Health and Social Servics and Social Security Adjudications Act 1983 (did not repeat all legislation concerning nursing homes and mental nursing homes as it did for residential care homes)
	Registered Homes Act 1984	
	Children Act 1989	
	NHS and Community Care Act 1980	
	Registered Homes (Amendment) Act 1991	
	Care Standards Act 2000 (setting up of National Care Standards Commission and National Minimum Standards)	
Regulations	National Assistance Act (Registration of Homes) Regulations 1949	Nursing Homes and Medical Nursing Homes Regulations 1981
		Amended and replaced by:
	National Assistance Act (Conduct of Homes) Regulations 1962	Nursing Homes and Mental Nursing Homes Regulations 1984
	Amended and replaced by:	
	Residential Care Homes Regulations 1984	
	National Care Standards Commission (Registration) Regulations 2001	
Codes of Practice	*Home Life* (Centre for policy on Ageing, 1984)	*Registration and Inspection of Nursing Homes: A Handbook for Health Authorities* (National Association of Health Authorities, 1985)
Standards	*Care Homes for Older People: National Minimum Standards* (DoH, 2001)	

Fig. 2.2 Legislation and documentation forming the basis of the regulation of residential care homes and nursing homes in England and Wales.

The 1960s, 1970s, and early 1980s saw growing concern over the quality of life provided for a variety of residents in care settings (Townsend 1962; Miller and Gywnne 1972; Kings Fund Centre 1980; Booth 1985; Willcocks *et al.* 1986) and a greater understanding of the impact of institutionalization on individual lives (Goffman 1961; Foucault 1977). Important research took place and of particular interest and influence were a series of publications arising out of the Residential Care Working Group of the Personal Social Service Council (PSSC 1977) which saw a need to develop further the function of registering authorities. Legislation and influential policy documents led to debate concerning the nursing care of older people living in residential homes and the need for a code of practice to improve the quality of care (DHSS and Welsh Office 1982).

The Health and Social Services and Social Security Adjudications Act 1983 (the HASSASSA Act) saw the development of *dual registration*. This was a recognition that there were residential homes where some residents required nursing care and others who only required residential care without the nursing component. The Act required that some homes providing both types of care should be registered with both District Health Authorities as nursing homes and with local social services authorities as residential care homes. These early developments in regulation culminated in The Registered Homes Act 1984 which began to develop a more systematic form of regulation for the growing independent sector of residential and nursing home provision.

Initially local authority based registration and inspection officers were called upon to develop tests of fitness for owners, managers, environments, and plans for care, and alongside these developments came accompanying guidance through the codes of practice: *Home Life* which covered older people and other vulnerable groups was developed at the Centre for Policy on Ageing (CPA 1984) and the *Registration and Inspection of Nursing Homes* (NAHA(T) 1985; 1988) by the National Association of Health Authorities and Trusts.

Over time both local authority provision and small homes with less than four residents became regulated (Peace *et al.* 1997) but during the 1990s the quality of care and the current system of regulation came to be questioned (Burgner 1996). The Burgner Report called for the development of national standards for care homes to overcome acknowledged inconsistencies within regulatory procedures. Since 1997, with the election of a New Labour government, a great deal of policy change has been introduced. In 1998, a white paper *Modernising Social Services* (DoH 1998) endorsed ideas surrounding changes to the system of regulation legislated through the Care Standards Act 2000. National Minimum Standards have been developed for a range of services currently regulated in England through the National Care

Standards Commission to become part of the Commission for Social Care Inspection. In England, the national minimum standards for care homes for older people were originally outlined in a consultation document *Fit for the Future* (DoH 1999) also developed through the Centre for Policy on Ageing and these were finally published in 2001 (DoH 2001a). In addition devolution of responsibility to the nations of the United Kingdom have seen the development of slightly different systems. For example, the Regulation of Care (Scotland) Act 2001 transferred powers and duties from local authorities to the Scottish Commission for the Regulation of Care.

Guidance on dying and death in care homes

With the development of these codes of practice and national minimum standards the issues of dying and death have been recognized alongside a great deal of information that is given regarding the development of a better quality of life. *Home Life* allocated a small section to the topic recognizing that those running residential care homes needed to identify whether they would be providing care until death and that if this was the case, their staff would need to develop necessary skills and communicate with outside experts:

> The importance of obtaining proper support from the community nursing services, the GP and, if necessary, specialists such as a visiting hospice nurse, cannot be over-emphasised.
>
> (CPA 1984, Section 2.7.5)

They emphasized that residents should feel secure within their care home and within their own room without the anxiety that they may be moved unnecessarily either internally or externally. Obviously, if a resident had requested specialist care such as within a hospice then these wishes should be followed. *Home Life* proposed that residents should be able to talk about their feelings and discuss requests concerning their end-of-life care such as relationships with family, friends, and religious staff. There was concern for informing relatives and enabling people to stay in the home if need be, and that records should be kept of any specific details concerning wills or property issues.

Alongside concerns for the residents, *Home Life* also considered the position of the staff recommending that they should understand the procedures to be followed when a death occurs and how they should be able to tell the other residents. They saw that there was a need for staff to understand local and cultural customs, and preferences of the deceased person and her family. But also *Home Life* recognized that this would be a time of stress for the staff and that they would need support, possibly from outside the home.

The documents provided by NAHA(T) (1985, 1988) gave little guidance concerning practice at times of dying and death in nursing homes.

Dying and death

68 When a home has admitted a resident with an assurance of 'care till death', the use of external sources of care, such as community nursing, or hospice service, is strongly recommended.

69 Intensive or terminal care should be given in a resident's own room and not in any special unit.

70 If a resident is aware he is dying, he should be consulted about his wishes on terminal care and funeral or cremation arrangements.

71 Contact should be made, if the resident wishes it, with the appropriate minister of religion.

72 When a resident is dying, the need for support to relatives, staff, and other residents should be recognized and met.

73 Local, cultural, and religious customs surrounding the death of a resident should be observed.

74 Proprietors should ascertain at an early stage who will take responsibility for a resident's property pending the proving of a will.

Checklist of recommendations from *Home Life*—(1984) CPA, p. 66/67.

Consideration is given to notification of deaths and the special needs of older people and people determined as terminally ill. While comment concerning older people centres on aspects of daily living from accommodation to occupation and leisure, that relating to the needs of the terminally ill makes this observation:

> Care for the terminally ill is not, however, restricted to hospices. All types of nursing homes need to be aware of the special needs of the dying...
>
> Staff need to consider both the physical needs and the emotional and spiritual problems of both the patient and the family. The use of pain control techniques and a consideration of the patient's individuality are necessary.
>
> (NAHAT 1985: 121)

As codes of practice were being developed for regulators, research and practice within residential care for all client groups was also brought together within the Wagner Report and published as *Residential Care: A Positive Choice* (NISW 1988*a,b*). However, it is interesting that neither the two volumes of the Wagner Report including the review of research (Sinclair *et al.* 1988) nor the report of the Wagner Development Group (NISW 1993) mention issues of dying and death within their discussion of residential living for older people. Only the subgroup reporting on 'Black Perspectives on Residential Care' considers

Announcing a death

News of a resident's death should be announced in a dignified and gentle way. It may be best to announce it quietly to individuals or staff groups to begin with but some more public announcement may also be appropriate in due course. Some people may find this public recognition comforting. It should never be assumed that people with dementia do not understand when someone has died. Some of the following possibilities might be appropriate:

◆ a minute's silence at an appropriate time;

◆ a photograph or some other personal tribute in a suitable place;

◆ opportunity to visit the dead person and pay last respects;

◆ a memorial or thanksgiving service or some other religious or cultural ceremony;

◆ lighting a candle;

◆ playing a favourite piece of music or reading a poem;

◆ a plant, picture or piece of furniture in memory of the person.

Plaques should be kept discreet so that the home is not overrun with Memorials.

From CPA (1996) *A Better Home Life*, p. 120.

issues of shared faith and spiritual experience in developing the culture within homes (NISW 1993: 68–85).

During the early 1990s, members of the CPA decided to revise the code of practice, *Home Life*. Whilst they still had confidence in that document, the circumstances of long term care for older people had changed. The NHS and Community Care Act 1990 had altered the way in which care was assessed, managed, and financed, and recognition of the growing numbers of older people living with dementing illnesses and the spectrum of accommodation and care found in sheltered housing, residential care homes, and nursing homes, led to a focus on the needs of these groups within a new code of practice.

In recognizing change the new publication *A Better Home Life* was able to focus in far more detail on issues of dying and death (CPA 1996). There was a recognition here—perhaps for the first time—that the culture of care surrounding living that had been the focus of attention for so long could now encompass dying and death. A whole chapter of the code was devoted to this topic and careful consideration was given to policies and procedures that would be able to recognize the wishes of the individual resident and allow for

some non-intrusive planning to be made so that information concerning financial affairs, living wills, advance directives, and instructions for next of kin could be gathered. The period of dying was discussed looking at care and comfort and the use of external professionals; the situation of the resident within the home, and the involvement of relatives, other residents, and staff. The procedures to be carried out when someone has died are also considered by looking at how a death may be announced or recognized; what might happen regarding a funeral and how bereavement may touch many people. In this code the boundary between life and death is overcome and valued.

New developments

More recently it is hoped that research, policy, and practice will merge as regulators now work with National Minimum Standards when assessing the quality of care that is provided within care homes.

Death and dying

Outcome

Service users are assured that at the time of their death, staff will treat them and their family with care, sensitivity, and respect.

Standard 11

11.1 Care and comfort are given to service users who are dying, their death is handled with dignity and propriety, and their spiritual needs, rites, and functions observed.

11.2 Care staff make every effort to ensure that the service user receives appropriate attention and pain relief.

11.3 The service user's wishes concerning terminal care and arrangements after death are discussed and carried out.

11.4 The service user's family and friends are involved (if that is what the service user wants) in planning for and dealing with increasing infirmity, terminal illness, and death.

11.5 The privacy and dignity of the service user who is dying are maintained at all times.

11.6 Service users are able to spend their final days in their own rooms, surrounded by their personal belongings, unless there are strong medical reasons to prevent this.

11.7 The registered person ensures that staff and service users who wish to offer comfort to a service user who is dying are enabled and supported to do so.

Death and dying *(continued)*

11.8 Palliative care, practical assistance and advice, and bereavement counselling are provided by trained professionals/specialist agencies if the service user wishes.

11.9 The changing needs of service users with deteriorating conditions or dementia—for personal support or technical aids—are reviewed and met swiftly to ensure the individual retains maximum control.

11.10 Relatives and friends of a service user who is dying are able to stay with him/her, unless the service user makes it clear that he or she does not want them to, for as long as they wish.

11.11 The body of a service user who has died is handled with dignity, and time is allowed for family and friends to pay their respects.

11.12 Policies and procedures for handling dying and death are in place and observed by staff.

DoH (2001a) *Care Homes for Older People*, National Minimum Standards, p. 13.

As noted earlier, the new standards were initially developed by the CPA and the final standard on dying and death reflects the more well developed code of practice outlined above in *A Better Home Life*. Standard 11 is given above and a comparison of the two documents allows us to move from standard to practice.

Alongside this guidance we also have a *National Service Framework for Older People* (DoH 2001*b*) where person-centred care is acknowledged as an essential standard. Here attention is given to the behaviour of staff during end-of-life care:

> Supportive and palliative care aims to promote both physical and psycho-social well-being. All those providing health and social care, who have contact with older people with chronic conditions or who are approaching the end of their lives may need to provide supportive and palliative care.
>
> (DoH 2001*b*: 25)

They outline the main facets of this type of care as listed in the box opposite.

Future research will need to monitor the reality of the application of these standards. Nevertheless the quality of the time that residents spend within a care home still very much depends on the culture of care and the relationship developed between residents and staff.

Dignity in end-of-life care

Information and communication

- to facilitate choice about treatments and care options for older people and their carers
- control of pain and other distressing symptoms
- to anticipate, recognize and treat pain and distressing symptoms, and provide timely access to appropriate specialist teams, equipment or aids. There is evidence that older people are less likely to receive proper pain management.

Rehabilitation and support as health declines

- to ensure that quality of life and independence is maximized, and that an older person can remain at home (if that is their wish) until death or for as long as possible, through providing therapy and personal care and housing related support services.

Social care

- to maintain access to safe and accessible living environments, practical help, income maintenance, social networks, and information.

Spiritual care

- to recognize and meet spiritual and emotional needs through the availability of pastoral or spiritual carers reflecting the faiths of the local population.

Complementary therapies

- to provide evidence-based complementary therapies that support emotional, psychological, and spiritual well-being and help with symptom control.

Psychological care

- to anticipate, recognize, and treat any psychological distress experienced by the older person, carer, and their family.

Bereavement support

- to ensure the needs of family, friends, and carers are provided for, relieving distress, meeting spiritual needs, and offering bereavement counselling.

DoH (2001b) *National Service Framework for Older People*, p. 26.

An evolving culture of care

In setting the scene for the discussion of end-of-life care this chapter has reviewed the historical development of nursing homes and residential care

homes showing how a concern over ways of living in frail old age has over-shadowed the issues of dying while living which are only just beginning to emerge as important. It is true that the conditions of collective living and poverty gave rise to a fear and loathing of care homes that permeated popular consciousness for much of the twentieth century and some would say beyond:

> What we also 'know', but, it may be argued, generally choose not to know, is that a silence persists, about the essence of residential living—a silence on the part of those older people who never enter residential care, but for whom the institutional option casts a shadow of deep anxiety and uncertainty in later life, as they fear its imminence; and a silence on the part of those who do actually cross the threshold into care.
>
> (Peace *et al.* 1997: 4).

The question is 'has this changed?' Older people living in care homes may lack some of the social capital of those living within their own homes but the difference continues to evolve. Living *en masse* has often led to a form of living managed for the organization rather than the person and the pressures of institutionalization. Consequently ageism and neglect have had to be faced before acknowledging individual need. As we have noted researchers over time have recognized the 'social death' of institutional care where residents have been seen as 'less than whole persons' and have sought to define accommodation and care that older people may value. In doing this they have failed to confront the experience of dying and death (Sinclair 1988; Peace *et al.* 1997). Will there be a change to a philosophy which understands that the existence of each resident is recognized through their life and their death. This concern forms the basis of this book and was recognized in *A Better Home Life*:

> As important to residents as the quality of their lives while they are living in the home will be the way in which they are cared for during the process of dying.
>
> (CPA 1996: 113)

To move us forward we therefore need to know more about who dies in care homes and begin to understand more about the people involved and those things that are important to them.

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