



The Millennium Papers

The Future of
Health and Care
of Older People:

The Best is Yet to Come



The Debate of the Age was established by Age Concern, England to help promote an understanding of how changes in the structure of the population will affect everyone. The balance of the population is shifting, with fewer young people and more older people. Such changes will have far-reaching implications. The Debate has concentrated on five themes:

- The Future of the Built Environment
- The Future of Health and Care
- Paying for Age
- Values and Attitudes in an Ageing Society
- Future Work and Lifestyles

Five expert groups were established to explore these issues in depth, and to inform the wider discussion of such matters in different debate settings throughout the country.

This is the final report from the Health and Care group. It represents the views and conclusions of the individual members of the expert group, who served in a personal capacity. Those views are not necessarily those of any organisations with which members are associated, nor those of Age Concern.

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Acknowledgements

This report was written by Melanie Henwood, rapporteur of the Health and Care study group. However, it is the result of wide ranging discussions which took place within the group over a dozen meetings across a three year period, under the Chairmanship of Rabbi Julia Neuberger. It is, therefore, much more than the work of one person, and is an attempt to reflect a richness and diversity of views which characterised the meetings of the group. Three years is a long time to commit to any project, and the continued support and loyalty of members must be acknowledged. Inevitably some people have been unable to remain part of the group for this length of time owing to other demands, and changes in membership have occurred since our interim report in 1997. This final report therefore reflects the contributions in particular of: Terri Banks CB; Dr June Crown CBE; Prof Sir Michael Drury OBE; Prof Sir John Grimley Evans; Pauline Ford; Evelyn McEwen; Prof Alan Maynard; Elizabeth Mills; Dr Chai Patel; Baroness Jill Pitkeathley OBE; Dr Anne Roberts; Martin Shreeve, and Sir William Utting CB.

Special thanks are also due to Sally Lewis, Director of the Millennium Papers, and to Sonia Brewin, Millennium Papers Assistant, for all their hard work in supporting the work of the group, and in assisting in the production of this report.

Chairman's foreword

When Age Concern, England established the Debate of the Age in 1996 and invited me to Chair the study group on health and care, I had little idea what to expect. I was no stranger to spending time in meetings and committees, but to commit to being part of a study group which would work together over three years, and contribute a serious discussion paper on the future of health and care of older people in the new millennium, was a new experience.

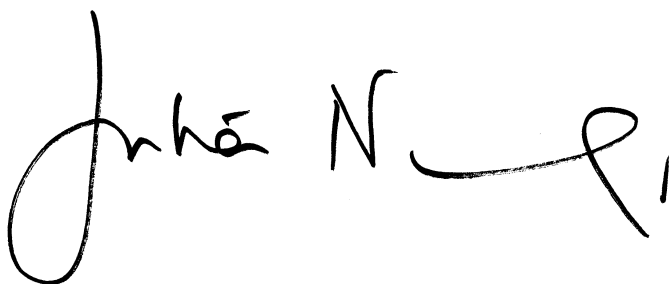
We travelled a long way during the three years, not least because so much changed around us. The change of government in May 1997 has been followed by a series of White and Green Papers, consultation documents, and other policy papers (including the report from the Royal Commission on Long Term Care), all relevant to the area in which we were working.

The concept of the Debate of the Age is an excellent one. The ageing of the population is something which has implications for us all – young and old alike – and the chance to consider some of the issues which we must face *together* if society is not to become split by inter-generational competition and conflict.

This is the final paper from the group. It sets out the agenda which we believe has to be addressed to transform the nature of later life, and to offer the prospect of good health and genuine social inclusion. These objectives are realistic and attainable, but they will not be reached without deliberate and strategic decisions across a number of linked areas, addressing not just health and social care, but the wider agenda of education, employment, housing and the built environment, transport, and social and leisure opportunities.

Our conclusions are optimistic, but not naive or complacent. We hope that this report will stimulate debate and prompt decisions among policy makers at both central and local levels, and among individuals. If it achieves that, we will have succeeded, not only in meeting our commitment to the Debate of the Age, but in helping to bring about a better future for us all.

I am extremely grateful to all my colleagues on the health and care group for their enduring patience, integrity and determination.



Rabbi Julia Neuberger
Chief Executive, King's Fund

Executive summary

At the close of the 20th century the life experience of many older people is one of poor quality, characterised by ill health and limited opportunities. Getting older is viewed negatively, and typically any discussion about older people is couched in terms of how 'we' can cope with the 'problem' of an ageing society. The gloomy forecasts of the imminent 'demographic timebomb' have become commonplace. It is time to challenge these negative perspectives, and to set out an agenda for change. In the 21st century the experience of older people could be radically different. Not only will more people live longer lives, but the quality of those lives could be transformed. However, for this to happen, much needs to change.

The social inclusion of older people has implications for multiple areas of public policy, not only health and care, but also education; employment; housing; transport; social and leisure opportunities etc. The rhetoric of 'joined up Government' acknowledges the importance of such a holistic approach, but the reality still lags some way behind. In focusing on health and care issues we are well aware that these cannot be tackled in isolation from the wider agenda.

The work of the health and care study group has focused on four themes. These are not the only issues which are central, but we believe that they are of particular importance, and hold the key to determining the quality of life for older people in the next century. These are: prevention and the compression of morbidity; models of support; rationing and inequality; and the end of life.

Prevention and compression of morbidity

Chapter 1 addresses how disability can be reduced, and the onset of chronic disease delayed and symptoms controlled. The health status of older people needs to be much improved; there are no illnesses or disabilities which are an *inevitable* part of ageing, and it is time to break the link between ageing and dependency. It is essential that this compression of morbidity should be adopted as an explicit objective of health policy. This will require changes at many levels, from clinical research and practice, to wider change in social attitudes and values. Despite welcome recognition of the importance of tackling prevention, and developing public health strategies aimed at improving the health status of the population, there is a continued absence of a clear policy deliberately focused on reducing morbidity, particularly among older people (indeed, the improvement targets are all focused on the population aged under 75).

We address a number of areas in which there is enormous scope for improvement, and recommend how this should be approached. Without a strategy for improvement in areas such as strokes; osteoporosis; osteoarthritis; dementia; sensory impairment, and incontinence, the scope for reducing disability and chronic ill health among people who are currently elderly, or who will enter old age in the future, will be seriously compromised.

We do not deny the significance of individual responsibility for health and well-being. This is true throughout the life cycle, and in later life the messages of health promotion need to be acted on just as they do among younger people. It is not easy to persuade people to change their behaviour, but often the belief that there is no point in doing things differently after a certain age is the sticking point. In fact, there is powerful evidence that there are benefits from changed life styles at almost any age. However, there are considerable barriers to making the choices for healthy living, not least the structural barriers of unsafe and inaccessible environments which discourage physical activity, and low incomes which limit choices in all aspects of life.

The potential benefits of achieving healthy and active later lives are many, and should be something in which we all have an interest both as individuals, and collectively. Reducing the need for medical intervention and for long term care is better for all of us, and offers the prospect of less onerous demands on public expenditure. These benefits will not just happen; they are not something that can be left to chance, and to the hope that over time there will be a natural development of morbidity compression. There *has* to be investment: in ageing research, and in prevention and rehabilitation, as well as in treatment and cure. In short, there has to be a commitment to a strategy for healthy ageing.

Models of support

Of course, whatever the achievements in reducing disability and postponing chronic illness, there will always be some older people in need of care and support. In Chapter 2 we explore the models which will be needed, and how these can be promoted. We are not interested in offering today's solutions to tomorrow's challenges, and we are therefore reluctant to be prescriptive about specific models of support. A service straightjacket will stifle imagination and innovation. In place of particular models we therefore urge the adoption of a set of core principles as the foundation for *all* models of support.

The principles are ones which would command widespread support, and which reflect the values and concerns of older people themselves, and of their carers. However, they are also tests which many patterns of support would currently fail. Services should:

- maintain independence
- maximise personal dignity
- support social inclusion
- be based around individual needs
- be flexible and responsive
- support carers
- be provided by staff with appropriate skills, knowledge and expertise
- be integrated and comprehensive.

We make recommendations for change which have implications both for central and local policy. A major impediment to the development of service models is the continued uncertainty about the Government's response to the recommendations of the Royal Commission on Long Term Care. We support the main proposal of the Commission that personal care should be free, and we urge the Government to accept the recommendation.

Rationing and inequality

In Chapter 3 we consider health inequalities and the rationing of health care. We do not believe that it is possible to develop a health care system which excludes all rationing. However, the basis on which rationing takes place needs to be agreed. We do not see that the establishment of the National Institute for Clinical Excellence will, of itself, end variations in treatment quality or the postcode lottery of care, but we believe that there is scope for NICE to address national and local priority setting. A clearer framework is required to facilitate fairer approaches, and to clarify the scope and objectives of the NHS.

The end of life

Throughout the paper, the themes of control, autonomy and independence are recurrent. These are central issues in the lives of older people. The wish to retain control and autonomy over life is a powerful motivation, and there is no reason why this should change as the end of life approaches. As we enter the new millennium, we believe it is time to break the final taboo of the 20th century, and to enable people to take back control of their final days. We recommend the adoption of the following set of principles of a good death, to provide the foundation for the approach of all palliative and terminal care. We are *not* seeking to lay down rules about the withdrawal of treatment or the introduction of euthanasia, but we support steps to increase people's control and autonomy over the final stages of their lives, and to attain a good death.

Principles of a good death

- To know when death is coming, and to understand what can be expected.
- To be able to retain control of what happens.
- To be afforded dignity and privacy.
- To have control over pain relief and other symptom control.
- To have choice and control over where death occurs (at home or elsewhere).
- To have access to information and expertise of whatever kind is necessary.
- To have access to any spiritual or emotional support desired.
- To have access to hospice care in any location, not only in hospital.
- To have control over who else is present and shares the end.
- To be able to issue advance directives which ensure wishes are respected.
- To have time to say goodbye, and control over other aspects of timing.
- To be able to leave when it is time to go, and not to have life prolonged pointlessly.

Conclusions

We conclude the paper by outlining a fictional scenario for the future. It is the story of a life begun in the 1980s and continuing well into the next century. It describes a life of diversity, fulfilment and well-being. It is a scenario which we believe to be achievable, and not mere fantasy. The recommendations which we make could do much to increase the likelihood of its realisation. We summarise the recommendations which have been made throughout the paper, and indicate the respective responsibilities for central government; health and social care purchasers and providers; and for individuals themselves. We are not complacent about the challenges of an ageing population. While we do not line up with those who are alarmed by the scale of demographic change, neither do we side with those who say there is no problem to be addressed. We know that the growth of the older population poses real challenges, not least because the response to earlier and current increases has been so poorly managed. However, if our recommendations are adopted, we believe we can look to the future with hope and optimism. The best is yet to come.

Introduction

Agnes: 1910–1999

In January 1999 Agnes was 89 years old and living alone, having been widowed since she was 74. She had lived in her home for over sixty years. It was a large Victorian terraced house which estate agents would describe as having an abundance of original features. Whatever the charm of the cornices and the fireplaces, this also meant it had the less attractive qualities of no central heating and ill-fitting windows. There was still an outside lavatory, but a ground floor bathroom and toilet had been added to the back of the kitchen in the 1950s. Agnes kept the house as clean and tidy as she was able to, but it hadn't been decorated in over 20 years and looked very dilapidated. The house was damp, and even in the summer it felt cold and musty.

Agnes had problems getting about, and going up or down stairs was a major effort. She had chronic arthritis, and her mobility was further restricted by emphysema. In recent times she had rarely left the house. A neighbour from down the road used to collect her pension for her and get her shopping in. She had few friends or visitors. Most of the people she had known nearby had died or moved away. Her family lived many miles away, and although they telephoned regularly, they only visited once or twice a year. Despite the urging of her family, Agnes had not been in touch with social services to see if she could get any help. She was a proud woman, suspicious of the 'welfare', and unwilling to have strangers coming into her home.

One night in March Agnes needed to get out of bed to go downstairs to the toilet. The bulb in the landing light had fused some days before and she was unable to put a new one in herself. Groping in the darkness, Agnes lost her footing and fell downstairs. She was found late the following morning, still lying at the foot of the stairs after her neighbour noticed the curtains were still closed. An ambulance was called and Agnes was taken to hospital. She had broken her hip. Following surgery and a few days on the ward, the social worker explained that they were going to move her to a nursing home, at least for the time being, to give her some time to recover and get back on her feet. But Agnes didn't recover. She was unhappy in the nursing home, where she was put in a room with two other women. She desperately wanted to go home. She became confused and withdrawn, and less aware of what was happening around her. She stopped eating. Four weeks after her fall, Agnes died in the night. No one was with her.

Agnes's tale is not unusual. In the late 1990s, similar stories could be told about hundreds – perhaps even thousands – of older people. The life it describes is a pitiful one of poor quality and great loneliness. Some help could have made her situation easier, but the help on offer was not acceptable, nor what was wanted, so she managed without. Her death was also miserable. She died among strangers, wishing she was at home.

Such a life is not one which most people would choose to live. Moreover, it is not one which anyone should *need* to live. Changes in attitudes, as well as in practical services and in technological developments, will be required if Agnes's story is not to still be commonplace in 2020, or 2040.

As the twentieth century draws to a close, there is – inevitably – much reflection not only on the past century, but on the past two thousand years which have brought us to the eve of the next millennium. It is easy to become cynical about the significance of this almost arbitrary date which is subject to so much commercial hype. However, this *is* an opportunity to think about the future, and to plan for how that future can be shaped and improved.

The dawning of 1 January 2000 will be much the same as any other day; the new century will not be immediately and obviously different from the old. But it doesn't have to continue as simply more of the same. One genuine benefit of *fin de siècle* sentiments may be a greater willingness to embrace change and break with the past.

What type of society will we see in the next century? There are any number of scenarios; some are certainly more appealing than others. The 21st century will be one in which older people are more and more in evidence. Is this to be a recipe for conflict and tension, or for greater tolerance and social cohesion?

The ageing of the UK population is well known. The pattern in which falling death rates and dropping fertility coincide to produce a population with an increased proportion of people in the older age bands is characteristic of all developed countries. This population ageing has often been regarded less as a testimony to progress, than as a problem which must be solved. The fear is of too great a burden falling on the working age population who must struggle to support the nation's children, but also its retired citizens. Furthermore, so this argument goes, while supporting the young makes sense as an investment in the future, older people are simply an uneconomic drain, and the cost becomes greater with each year as the health status of older people deteriorates and they need more costly support from the NHS, and from social services. At the same time, the inadequacy of pension arrangements for many of today's pensioners means that further payments have to be made through taxation and other contributions falling again on the current generation of employees. The dangers of this line of thought are all too apparent, and could easily lead to a culture in which the generations are set in competition with one another for limited resources.

But *does* the prospect of an ageing society have to be this grim? Thankfully there *are* alternative perspectives, and there is an increasing consensus that the most pessimistic scenarios are almost certainly wrong. In the UK, the conclusion that there is no imminent 'demographic timebomb' has been increasingly emphasised (Health Committee, 1996; Royal Commission, 1999). Nonetheless, this does not imply grounds for complacency: the achievement of the most successful models of healthy ageing will not simply happen by default. Moreover, confidence in the conclusion that *because* the UK has already lived through the most dramatic changes earlier this century, "the future is much more manageable" (Royal Commission, 1999, Para 2.18), would be stronger if there were evidence that the past challenges had been well managed.

We can speculate about the future, but we do not have the capacity to forecast developments with certainty. This applies to every aspect of our lives: the type of homes and communities we will live in; the means we will use to travel; how and where we will work. The technological revolution which has occurred in the last 15 years, which has seen the mobile phone, the personal computer and the Internet all become accessible and commonplace, points to the rate of change. In the field of medical research and technology, there are similar advances which – even a few years ago – would have been dismissed as the stuff of science fiction: in a couple of decades we have come from the first test tube babies to the realistic (if alarming) prospect of human cloning. Similarly, organ and tissue transplant have become almost routine, and in future the ethics of donation may be less debated as organs are artificially 'grown' or laboratory produced.

The health and care implications of an ageing population are many. The agenda which needs to be tackled is large. However, in exploring this subject as part of the Debate of the

Age, the study group identified four core themes which were judged to be especially important. These are:

- prevention and the compression of morbidity
- models of support
- rationing and inequality
- the end of life

Each of these themes is examined in the chapters which follow. We do not claim that we have all the answers to many of the difficult questions which are raised. However, raising those questions is, in itself, important. The purpose of this report is to stimulate debate and to inform decision making. Ageing is everybody's business; how we respond to the growth of the older population is, in some respects, an individual issue. Governments cannot legislate for a change of attitude; but they *can* make decisions which fundamentally affect what it is like to be an older person. For many people today that experience is not a positive one: poor health and increasing dependency greatly limit the opportunities to participate in society. When other inequalities are added – low income, poor housing, an inaccessible community – the disadvantage is compounded. The issues which we address in this report, and the recommendations which we offer, could go a long way towards redressing the balance, and ensuring that in the 21st century the life of older people is richer, more fulfilling and a time of genuine opportunity.

1 Prevention and the compression of morbidity

Projections of the numbers of older people are provided in Appendix 1. The size of the overall older population, and the relative size of the oldest age groups, are fairly crude indicators of the likely health status of that same population. In December 1997 the Secretary of State for Health established a Royal Commission on Long Term Care. The Commission reported in March 1999, and made detailed recommendations for funding mechanisms to support long term care for older people (Royal Commission, 1999). In reaching their conclusions, the Commission collected the best available evidence about factors which affect the future demand for, and costs of, long term care. We did not attempt to replicate this analysis.

The main features of changing demography can be highlighted.

- 1 person in 6 in the UK is aged at least 65, by 2031 this will be true of around 1 in 4.
- Almost half the older population is aged at least 75, and the most rapid increases are among the very elderly cohorts.
- Between 2001 and 2041 the numbers of people in the UK aged at least 85 will more than double, from 1.1 million, to 2.3 million.

The population of the United Kingdom has been both growing and ageing throughout this century. With increasing life expectancy occurring alongside falling fertility (birthrates), the number and proportion of older people has risen. Since the turn of the century, the number of older people has increased by 400%, and the older population has doubled since 1931 (Royal Commission, 1999, Chapter 2). The general trend is expected to continue until around 2030 when the population will cease growing as the result of earlier low birthrates (see Appendix 1 for further details). The largest relative increases are now taking place in the growth of the oldest old – those people aged at least 85. While these trends are characteristic of developed nations, the Royal Commission also pointed out that the UK is facing *smaller* increases than many other countries (see Box 1).

Box 1: International Comparisons

Population ageing is taking place throughout the developed world, but there are two patterns evident. In Europe the population aged over 80 is projected to rise by at least 200% in the period from 1960–2040, although in Switzerland this is expected to be more than 400%, and over 600% in Finland. The scale of growth in the non-European industrialised countries is considerably greater: more than 500% in New Zealand; 800% in the USA; 900% in Australia and Canada, and over 1,300% in Japan. In the UK the increase is estimated at around 250%, and we are halfway through this trend at the present time.

Royal Commission (1999), *Research Volume 1*, Chapter 6.

Alarm at the prospect of an ageing population is nothing new, and typically this takes two forms. First, there is concern over the size of the non-productive retired population, relative to the population of employees. The simple assumption that this will place too great a burden on a depleted pool of workers can be criticised on a number of grounds. In particular, it is mistaken to assume that retired people are ‘unproductive’. Similarly, in an advanced economy the numbers of people in employment can be a poor guide to the level

of productivity. The second area of concern arises from the assumption that all – or a very large proportion of – elderly people will experience poor health, and with even longer lives people will have longer periods of ill health and high dependency.

The debate over age specific dependency is unresolved. The likely trends have been increasingly scrutinised since the idea of the ‘compression of morbidity’ was proposed in 1980 (Fries). According to Fries, there would be an upper limit to the extension of life expectancy (the ‘rectangularisation of mortality’), but the onset of morbidity (illness and incapacity) would be postponed until around the age of 85. The period of healthy life would thus be extended, and the period of morbidity would be ‘compressed’ into the brief interlude between 85 and ‘natural death’. Fries’ thesis has been presented as the more optimistic interpretation of changing mortality and morbidity. Other interpretations have offered more pessimistic scenarios and argued that people are living longer because the fatal consequences of certain illnesses have been controlled, but the chronic effects of the underlying illness remain, ensuring that people spend an *increasing* proportion of the extra years in poor health. Between these two extremes, a third interpretation has been offered – the concept of ‘dynamic equilibrium’. This sees the prevalence of chronic disease increasing, while the progression of some degenerative diseases has been reduced, with the result that people might suffer chronic illness for a longer period, but with less serious effects (Manton, 1982).

Conclusions in this area are of far more than academic interest. The Royal Commission identified three possible scenarios for health expectancy:

- If people experience *fewer years of ill health*, the needs of individuals for long term care may fall, and the total need for care (i.e. for the increasing elderly population) could increase only slightly.
- If future generations experience the *same* needs as current generations, individuals’ need for care will not increase, but the total care needs of the older population *will* rise.
- if people experience *more ill health for longer*, the need for long term care will increase both for individuals and for the total older population (Royal Commission, 1999, para 2.21).

The Department of Health Working Group on Health Expectancy Measures (Bone *et al*, 1995) examined data on activities of daily living and limiting long standing illness. Their analysis indicated some compression of morbidity in the ability to perform activities of daily living. At the same time, there has been an increase in the duration of long standing illness or disability (as measured by the presence of limiting long standing illness). An analysis of US data indicates an increasing rate of decline of chronic disability among older people (Singer and Manton, 1998). Weighing up the available evidence, the Royal Commission concluded:

“...the factors which are causing us to live longer are also resulting in the extra years of life being free from severe disability. Research from the USA tends to support the view of a general improvement in health expectancy.” (Royal Commission, 1999, para 2.23).

As the Commission observed, such a conclusion offers reason for optimism. At the same time, however, the Commission cautioned that any conclusions are limited by available data (and therefore assumed in its base case projections that the years spent with disability will remain roughly constant in proportion to total life expectancy). In particular, the absence of longitudinal survey data in the UK, and the reliance instead on ‘snapshot’ information, must raise *some* questions about forecast validity. The importance of establishing such longitudinal data was emphasised by the Commission, as it had also been by the Health Committee in 1996. **We also endorse the need for improved data, and recommend that a national longitudinal survey be established to facilitate the monitoring of trends in health expectancy.**

The Commission's modelling of the future demand for and costs of long term care built in five main variables: demography; health expectancy; the supply of unpaid (informal) care from family and friends; use of services; and the costs of care. In constructing a 'base case' and projecting it forward, the Commission accepted that there remained "wide margins of uncertainty" contained within a "funnel of doubt". In 1996 the Health Committee had been similarly frustrated by the unpredictability of the future. We do not attempt to add to the analysis that has already been carried out by experts in this field. We accept that the best evidence available is flawed, but nonetheless, there would seem to be grounds for some optimism in the improving health expectancy of older people.

1.1 Strategies for compressing morbidity

There may be any number of factors which are 'spontaneously' contributing to the compression of morbidity. Higher standards of living, improved housing conditions, better diet and healthier lifestyles can all play a part. To recognise this, and to accept the inevitably complex pattern of cause and effect, should encourage the search for strategies which can accelerate the compression of morbidity and delay the onset of chronic disease. **We recommend that the compression of morbidity should be adopted as an explicit objective of health policy.** However, this will require changes at many levels, from clinical research and practice to wider change in social attitudes and values. The prevailing attitude towards old age is still one which is problem focused and which sees the increase in numbers of older people negatively. One reason for this is that the experience of old age often *is* negative, and is characterised by the experience of chronic ill health and conditions which people learn to live with and manage for themselves. There is a dearth of research on such conditions, and on the factors which could alleviate them, reduce symptoms, delay deterioration, or prevent them developing in the first place.

While many of the variables which are likely to affect the need for, and cost of, long term care are beyond direct control, this is much less true of the health status of older people. Future developments in bio-medical research, such as in the identification and production of crucial stem cells, *could* revolutionise the treatment of many degenerative diseases. However, there would be many demands on such highly technical interventions, and we do not see this route as the panacea to the chronic health needs of many older people. **We believe that there is major scope for improving health status in later life, and recommend that reducing the need for long term care by reducing chronic illness and disability should be a central and explicit objective of health policy.**

There is increasing awareness of the importance of prevention and rehabilitation within Department of Health policy objectives. The 1998 social services White Paper (Secretary of State) announced the establishment of new grants to support preventive work, and the promotion of independence has been identified as a priority for health and social services authorities (Department of Health, 1998).

Box 2: Prevention and rehabilitation

"We want to put a new emphasis on helping people achieve and maintain independence wherever possible. And when someone does need care, social services must aim wherever possible to help them get better, to improve their health and social functioning rather than just 'keeping them going'."

Secretary of State for Health (1998), *Modernising Social Services*, para 2.12

The promotion of independence is recognised by the Department of Health to represent “good value in both human and financial terms”. What strategies are needed for the achievement of this goal? Current guidance emphasises reducing the risks associated with unplanned and avoidable hospital admissions; developing and targeting “a range of preventive services for adults, including respite care”; supporting carers; and improving older people’s opportunities “for optimal recuperation and rehabilitation”. These are undoubtedly the right themes, but are they enough? The loosely defined objectives may be insufficient to direct strategies other than in the broadest terms, and among the most enthusiastic torch carriers.

Community care policies emphasise supporting people to live in their own homes wherever possible. It is now accepted that “community care reforms and resource pressures have focused provision on those with greatest need, so older people may receive very little support until their needs (and their carers’ needs) become acute” (Department of Health, 1999a, p 1). To counter-balance this trend, the Department of Health is simultaneously encouraging an approach to “target low level support for people most at risk of losing their independence.”

The role of social services in prevention is only one component. Other important variables include strong links with local communities; the involvement of older people as partners; and joint initiatives with health services and with housing agencies (Department of Health, 1999, Lewis et al, 1999). The development of Health Improvement Programmes, Primary Care Groups, Health Action Zones, and the Better Government for Older People initiative, all provide opportunities for further progress with local preventive strategies.

Public health strategies in the past have been criticised for failing to recognise the wider environmental and social factors which contribute to health and well-being, and for over emphasising individual responsibility for health. The latest approach of New Labour is therefore to be welcomed for addressing these shortcomings and for emphasising the importance of an integrated approach bringing together individuals, communities and Government (Secretary of State for Health, 1999a).

The twin goals of the public health White Paper are the following:

- to improve the health of the population as a whole by increasing the length of people’s lives and the number of years people spend free from illness; and
- to improve the health of the worst off in society and to narrow the health gap (Ibid, para 1.17).

However, the specific targets which have been proposed *all* focus on tackling ‘the four main killers’ and dramatically reducing death rates (by 300,000 within 10 years) for people under 75 from cancer, coronary heart disease and stroke, accidents, and mental illness. These are important objectives, and reducing deaths in these areas could also improve the health status of the population, but there is an absence of a clear strategy deliberately aimed at reducing morbidity, particularly among older people.

A new *Expert Patients* programme is to be established with the objective of helping people with chronic disease “maintain their health, improve their quality of life and slow the progression of conditions which can lead to pain, serious incapacity and premature death” (Secretary of State for Health, 1999a, para 3.48). Such a programme rightly recognises that people with chronic illnesses and disabilities can, and do, play a central part in managing their own condition, and can be assisted in doing so. At the same time, we would emphasise the need not to focus simply on individual responsibility for managing chronic ill-health, and the importance of research which will identify proven strategies for reducing symptoms of chronic conditions and thereby reducing disability.

The Government's first annual report on tackling poverty and social exclusion (Secretary of State for Social Security, 1999) is to be welcomed for its recognition that poor health status is a key barrier to social inclusion of older people. However, while it is right to emphasise the impact of socio-economic variables in the unequal experience of ill health and disability, it is a massive over-simplification to assume that the introduction of the National Service Framework will address these inequalities *and* deliver "an increase in healthy life expectancy at the age of 65" (Ibid).

What is still absent is a clear strategy for *preventing* disability and chronic ill health. The major causes of disability and chronic illness in later life are many. In addition to cardiovascular diseases such as coronary heart disease and stroke, are cancers, musculoskeletal disorders including arthritis and osteoporosis, degenerative disorders causing visual and hearing loss, and dementia. The current public health strategy has little to offer on many of these areas. **We recommend that the targets for saving lives be matched by strategies for reducing ill-health and morbidity.** Without a parallel strategy of this nature, the scope for reducing disability and chronic ill health among people who are currently elderly or who will enter old age in the near future, will be seriously compromised. Below we address a number of core areas in which there is scope for improvement, and recommend how this should be approached. Many of our recommendations focus on the need for further research and better understanding of the underlying processes of ageing, as well as of the chronic diseases and disabilities which become more common with old age, and where improved knowledge could do much to prevent or alleviate symptoms.

1.2 Strokes

The public health strategy rightly identifies deaths from coronary heart disease and strokes as a target for action. Over 200,000 deaths are attributed to such causes every year, and there are marked inequalities in death rates (Prophet, 1998). The risk factors for heart disease and strokes are similar: smoking, poor diet, obesity, lack of exercise, high blood pressure, and – for strokes – excessive alcohol.

The nature of the risk factors means that there is considerable scope for improvement through lifestyle changes. Life-long healthy living offers the greatest prospect for avoiding the risks for heart disease and other cardio-vascular illness, but the benefits of adopting healthier lifestyles are evident at any age. In fact, because of the higher risks among older age groups, the benefits of preventive action are actually *greater* than among younger people (Health Education Authority, 1996). **We recommend that the health promotion messages for reducing the risk of cardio vascular disease are extended to the population aged over 75.**

But what of people who *do* suffer strokes? Three out of four strokes occur among older people, and survival rates are poor, with around one third of stroke patients dead within six months (Ebrahim, 1996). Both survival rates and levels of disability could be improved by more effective rehabilitation. Reviews of stroke services have identified the features which seem to have a particularly important effect on outcome (Stroke Unit Trialists, 1997). These include: co-ordinated multi-disciplinary care, education and training and specialisation of staff (Sinclair and Dickinson, 1998). Despite this evidence, specialist stroke units are not the norm, and it has been observed that "disorganised stroke care prevails" (Young, Robinson and Dickinson, 1998). **We recommend that preventive strategies be matched by the development of specialist rehabilitation services to increase survival rates and minimise disability following stroke.**

1.3 Osteoporosis

Hip fractures are a major cause of death and disability among older people. Their incidence reflects the interaction of propensity to falls on the one hand, and to the loss of bone density which increases the likelihood of fracture, on the other. Every year in the UK there are 60,000 hip fractures, 50,000 wrist fractures and 40,000 vertebral fractures due to osteoporosis. It is estimated that this costs £900m a year (AgeNet, 1998). The social and personal costs are even more striking; hip fracture typically leads to long term disability and is often the precursor of admission to residential care, with less than half of all hip fracture patients returning home following surgery. It is also evident that the incidence of hip fracture has doubled in Britain during the last thirty years, for reasons which are not fully understood (Khaw, 1997).

In seeking to reduce death and injury from accidents, attention needs also to be directed towards not only improving the care of older people following accidents, but to preventing falls and reducing the likelihood of fractures occurring in the first place. Exercise has a preventive effect by increasing bone mass and strength, although not all exercise is equally effective (AgeNet, 1998). In later life, especially among women, some loss of bone density is inevitable *despite* exercise. The increased risk of fracture can be counteracted through hormone replacement therapy (HRT). Other lifestyle factors are also significant: diet, alcohol intake and smoking can all increase the risks of osteoporosis. Dietary supplements – of Vitamin D or calcium – have potential for fracture prevention. In the longer term, primary prevention which focuses on encouraging bone formation during childhood and adolescence offers the best prospect for reducing the risks of osteoporosis in later life.

HRT is the most effective treatment to reduce bone loss among older women; exposure to HRT for a duration of 3–10 years is associated with a 30–50% reduction in the incidence of fractures (Prophet, 1998). Further research is needed to determine the effectiveness of commencing HRT for older women, although there is some evidence to suggest that HRT for women aged over 65 can be cost-effective (Prophet, 1998). HRT also has a protective effect in relation to cardiovascular disease, but is associated with a slightly increased risk of breast cancer. **We recommend that effective screening methods should be developed to identify women with low bone mass which increases their risks of osteoporosis, and to offer them HRT at menopause.**

Why older people have falls which increase their risks of becoming disabled is a complex area. Risk factors are complex and multifactorial, and include: poor diet, environmental hazards, side effects of medication, lack of exercise and poor physical condition; deteriorating cognitive function and poor sight. There is little evidence on the relative efficacy of different interventions in reducing falls and injuries, and **we recommend that further research should be undertaken to establish the most effective strategies for reducing falls and their consequences.**

The care and rehabilitation of people with fractured neck of femur is critical in determining their prospects for independence. There are widespread variations in the management of fractured neck of femur, and rehabilitation can take place in orthopaedic wards, specialist orthogeriatric wards, in general elderly rehabilitation or through supported discharge or hospital at home schemes. The evidence for the optimal pattern of care is unclear, but there *is* evidence that delays in surgery are associated with poor outcomes, and that the involvement of elderly care physicians is associated with shorter length of stay and a greater likelihood of returning home (Audit Commission, 1995). **We recommend that treatment of fractured neck of femur should maximise opportunities for rehabilitation through the timely involvement of elderly care physicians. Further research is needed to establish the most effective models of rehabilitation.**

1.4 Osteoarthritis

Osteoarthritis is a further skeletal condition often associated with ageing, and some degree of osteoarthritis is present in virtually all older people. It is characterised by thickening and distortion of joints caused by cartilage degeneration. The condition causes great pain, and significant disability as affected joints become stiffer and less functional. In addition to the impact on individual quality of life, the increase in incapacity reduces the ability of older people to maintain independence and undertake vital self-care tasks and routine activities of daily living such as turning on taps, opening containers, and managing clothing fastenings.

No specific cause has been identified for osteoarthritis, and there is no cure. However, symptoms can be reduced, and function improved. The general public health messages of maintaining sensible body weight and undertaking regular exercise are important. Excess weight places too much pressure on stressed joints, and exercise can build up muscle to better support weakened joints. Rheumatoid arthritis also causes joint inflammation and disability, but is not restricted to older people (on-set is most common in middle age, but can occur at any age). Early diagnosis and treatment is important because of the joint damage which can occur early on. Treatment to-date has largely used anti-inflammatory drugs, however a new generation of drugs (the Cox-II inhibitors) is emerging, and clinical trials suggest considerable reduction of disease activity, enabling people to resume daily activities, although the long term risks and benefits are, as yet, unknown (Weinblatt et al, 1999). These new drugs are being eagerly anticipated, and demands are likely to be considerable. It will be essential that they are made available to people most likely to benefit. Further trials are needed to develop predictions which, as an editorial in the *New England Journal of Medicine* cautioned, "will ultimately show which patients will benefit most and when in the course of the disease these therapies should be used in order to achieve a balance among toxicity, efficacy and cost" (O'Dell, 1999). The proposal from the Department of Health that in early 2000 the National Institute for Clinical Excellence (NICE) should include attention to the Cox-II inhibitors and issue guidance to ensure appropriate targeting is welcome (Department of Health, 1999c).

Surgical replacement of hip and knee joints also plays a central role in the treatment of people with severe arthritis. Evaluation of the effectiveness of joint replacement has demonstrated long lasting improvements in health-related quality of life measured against reduced pain, improved mobility, and enhanced social interaction and well-being (Prophet, 1998).

The proposal to include hip prostheses among the initial topics for examination by NICE is welcome. It is vital that patients have equal access to the best quality and longest lasting implants, and that the need for further surgery because of poor performance is minimised. It will be essential that the approach of NICE focuses – as it has pledged to do – on the clinical and cost effectiveness of interventions. **We recommend that joint replacement should be treated as a higher priority given the proven effectiveness of intervention and the scope for extending the period of independent living. Research should also be prioritised into identification of the risk factors for osteoarthritis; early detection, and alternative therapies which might reduce the need for surgical intervention.**

1.5 Dementia

There is a general deterioration in the functioning of the central nervous system with ageing and many older people become more forgetful. However, this is quite different from the specific degenerative disorders which cause dementia. The most common form of dementia is Alzheimer's disease, which accounts for 50–60% of all dementias. The risk of developing dementia rises with age, and the incidence doubles in each five year age group aged over 65. Among people aged over 80, one in five are likely to be affected, compared with only 1% of those aged 65.

The consequences of dementia are devastating. The brain tissue deteriorates and becomes affected by lesions and tangles, with a resultant loss of awareness, memory and reasoning powers. The person becomes less engaged, more confused and disoriented. For carers and relatives, there is the distress of the person they know still being a physical presence, but with the loss of everything that made them the personality they were. Advanced dementia is a major factor precipitating admission to nursing home care.

Being able to postpone the onset of Alzheimer's disease, and alleviate the worst symptoms, could have an enormous impact, both in reducing the need for institutional care, and in improving the quality of life for thousands of people. It has been estimated that if it is possible to delay the onset of Alzheimer's disease by five years, the costs of caring for these patients could be reduced by half (Alzheimer's Disease Society, 1996). Understanding of the causes of dementia is incomplete. Different forms of dementia are likely to be caused by different factors. There is some indication of a genetic risk factor for Alzheimer's disease, but this is uncertain. Other risks have been hypothesised around aluminium absorption, and the presence of the cold sore virus, herpes simplex (Kirkwood, 1999).

Alzheimer's disease can often only be conclusively diagnosed in the course of a post mortem examination when distinctive changes in the brain can be established, although the use of Magnetic Resonance Imaging (MRI) can also demonstrate brain shrinkage. There is a need to be able to establish diagnosis at an early stage, particularly as treatments are likely to be most effective before the disease is well advanced. If biological markers could be established before significant cognitive decline was evident, there would be capacity for screening and intervention (American Federation for Aging Research, 1995).

Because of the complex causality of dementia, a 'cure' is unlikely in the immediate future, although there is speculation over the possible development of a vaccine in the treatment of Alzheimer's. Experimentation on laboratory mice showed immunisation reversing plaque formation in the brain, and human clinical trials are expected to follow (Josefson, 1999). The most promising approach to reducing the effects of dementia is likely to be through pharmaceuticals. Two drugs are currently in use: Tacrine and Aricept. Aricept has performed better in clinical trials, and has shown some improvement in the symptoms of mild to moderate dementia, and short term improvement in mental abilities. Claims have also been made for the effects of antioxidants, vitamins and HRT. Anti-inflammatory pain killers are also thought to have some preventive effect in reducing the risk of Alzheimer's (Kirkwood, 1999).

The indication that NICE will review treatments for Alzheimer's disease during 2000 is welcome, but limited. **We recommend further research into dementia, both to improve understanding of the aetiology of the disease, and to explore the scope for pharmaceutical and other treatment which may delay and reduce the onset of symptoms.**

1.6 Sensory impairment

Impaired vision, and loss of hearing are further conditions associated with ageing. Loss of sight can result with ageing from the effects of cataract, macular degeneration, glaucoma and diabetic retinopathy. Cataracts cause clouding of the lens of the eye and loss of vision. Cataracts can be surgically removed, and lenses replaced. However, preventing or delaying the onset of cataract formation could reduce the need for surgical treatment. Macular degeneration reduces sharp central vision. It usually develops slowly among people aged over 60. Reduced ability to drive, to read newsprint or to recognise faces, all compromise the capacity to continue living independently or to do so with an acceptable quality of life. Glaucoma causes optic nerve damage and can lead to blindness. It is known that there is a hereditary risk of developing glaucoma. Diabetic retinopathy (bleeding in the eye) can lead to partial or total blindness. It is associated with long term and poorly managed diabetes.

Further research is required to improve understanding of the normal process of retinal ageing and to identify the risk factors for developing conditions which can lead to blindness, and to indicate possible prevention and treatment. Early detection and treatment are vital, and we applaud the restoration from April 1999 of free eye tests for people aged over 60.

Impaired hearing is also widespread among older people. It is estimated that between 30–60% of people aged over 65 have some level of hearing loss (Laing & Hall, 1991). The loss of hearing can have substantial impact on an older person's sense of self-esteem and confidence, and can greatly reduce their social interaction. Inability to hear can also increase a sense of vulnerability and can jeopardise the continuation of independent living. Some causes of hearing loss can be alleviated by better detection and improved primary care (such as in dealing with hardened wax). While most hearing loss is due to problems with the inner ear, changes in the auditory system due to a reduction in neurotransmitter production may also be involved (American Federation for Aging Research, 1995). Research suggests that hearing loss may not be inevitable, and that there is scope for identifying individual risk factors, prevention and treatment. **In the absence of prevention, it is important that hearing aids are made available to people who could benefit from their use. Technological advances have improved both the design and performance of hearing aids, but there are great inequalities in the availability of these newer models.** Guidance from NICE is expected to address 'basic standards' as well as considering the benefits of newer aids. This is a welcome development, but it is important that it is linked to adequate public information about detecting hearing loss and encouraging uptake of testing.

1.7 Incontinence

Urinary incontinence remains a taboo subject. It is a cause of significant disability and dependency, and can be a major contributory factor leading to residential admission. It is estimated that 6–8% of older people living in the community are affected, and almost one third of the older population living in residential care (Prophet, 1998). Up to 85% of those affected are women. The risk factors are well known and include weakened pelvic floor muscles (caused during pregnancy and childbirth), and – in the case of older males – pressure resulting from an enlarged prostate gland. There is considerable under-diagnosis of the condition, reflecting social stigma and embarrassment on the part of both patients and clinicians. Too often there is acceptance of urinary incontinence as an inevitable part of ageing. In fact, there is good evidence that incontinence responds well to treatment, and teaching people to strengthen muscles and regain bladder control can be highly effective.

The importance of appropriate education and training of health and social care personnel, alongside improved public awareness of both causes and treatment of urinary incontinence, must be emphasised. Early detection and treatment can have major benefits in restoring normal social function to people who are isolated by their condition. There are also substantial savings which could be achieved in health and social care expenditure through reducing the need for more costly interventions and prophylactics.

We recommend further research into the effectiveness of different therapies in the treatment of urinary incontinence, allied to awareness raising of prevention and treatment among the population in general.

1.8 Holding back the years: Vision or nightmare?

In seeking to delay the onset of chronic illness (i.e. to ‘compress morbidity’), we are not attempting to deny the reality of ageing. Whether average life span will continue to rise, and whether – as some claim – it will be commonplace in the next century to live well beyond 100, 120 or 150, is not the issue. The question is whether the additional years will be of good quality, or merely years of additional survival. Living to 100 and beyond will not be desirable if the last quarter – or more – of those years are lived in pain and poor health. The trick to be accomplished is, as the World Health Organisation has succinctly phrased it, to add both years to life, and life to years. **We recommend that the target of healthy ageing should be adopted as an integral part of a national strategy for improving public health.**

Ageing is inevitable. But many of the illnesses which are assumed to be inevitable accompaniments of ageing, need not be so. There is much that individuals can do for themselves to live longer and healthier lives. The combination of good diet and regular exercise is now well known. Perhaps what is less well understood is that this not only improves general well-being and reduces the risks of heart disease, but that this can also reduce the risks of many other conditions associated with ageing. Diet is increasingly being linked to a wide range of conditions. The associations are clearest in relation to cardiovascular disease, but diet is also implicated in many other chronic conditions including osteoporosis, cancer, arthritis and dementia. Khaw has concluded that:

“Eating at least five daily servings of fruit and vegetables appears to reduce the risk of developing most chronic diseases, but we know little about which specific foods and nutrients are protective, or why.” (Khaw, 1997).

The messages of health promotion may be familiar, but the implications for individual life style are often not well understood by the general public. In 1997 the Debate of the Age commissioned questions within the ONS Omnibus Survey, which included exploration of respondents’ understanding of why some people are more healthy in old age than others (Jarvis et al, 1998). The most frequent answer (chosen by 42%) was that people who have tried to live healthier lives are more likely to enjoy good health. However, almost as many respondents (39%) favoured the fatalistic explanation that differences were attributable to some people being ‘naturally healthy’, regardless of the way they live their lives, and 17% believed that circumstances beyond individual control were largely responsible for the differences. Such beliefs are likely to influence behaviour. One in seven respondents could think of nothing that would persuade them to adopt a healthier lifestyle. The older the respondent, the more entrenched their attitudes appeared to be: 41% of women aged 75+ and 35% of men indicated that no source of advice would be likely to have any effect on them, compared with only 9% of men and women aged 25–44 (Jarvis et al, 1998). It is probable that as people get older they are less likely to think there is any point in changing their behaviour: can there be an antidote to a lifetime of poor habits or unhealthy lifestyle?

In fact, the evidence indicates that giving up smoking, or adopting moderate exercise even at advanced years can have positive effects on health and well being.

However, the responsibility for a healthy old age does not lie solely with individuals determining that they will change their lifestyles. There is also a collective responsibility. The choices associated with healthy living are not equally available to all citizens. A healthy diet requires an adequate income; healthy lifestyles require access to healthy environments. As Professor Grimley Evans has observed:

“...the most important intervention in terms of primary prevention and disability would be opportunities for continued exercise, particularly among women because increased disability in later life among women is almost certainly due to muscular weakness (...) That would imply not only swimming pools but safe environments in which people were able to walk. It would imply streets where you could bicycle and walk without being put into danger from fumes and traffic. It has a lot of implications for urban design in particular.” (Grimley Evans, 1995).

The postponement or avoidance of chronic illness is something in which we all have an interest. Reducing the need for medical intervention and for long term care is better for all of us, and offers the prospect of less onerous demands on public expenditure. If we are all to live longer, and to do so in much better health, the association between ageing and dependency will be less and less evident. Fit and healthy older people will not only enjoy a better individual quality of life, but will have the resources to continue to participate in society. The conditions which have been highlighted in this chapter (notably: strokes; osteoporosis; osteoarthritis; dementia; sensory impairment; and incontinence) are by no means the only areas in which there is opportunity for prevention and morbidity compression. However, they are probably the most important areas in which to begin. Interventions in these areas could also have important benefits elsewhere, such as in the field of mental health. Depression is common in old age, not least because of its association with isolation and poor health status. Improvements in health, and improved capacity for active lives, could therefore have significant additional effects in reducing depression.

With people living longer, the idea of fixed retirement will be less relevant, and more older people will both want and be able to continue in paid employment, and in other productive activity (including voluntary work and care giving), as well as participating in a range of education and leisure opportunities. Clearly, not all people enjoy the same access to such opportunities. Flexible employment is more likely to be available in some occupations than in others, and far from extending their working lives, the experience of many older people is of premature or ‘early’ retirement. Such issues have been explored in greater depth by the study group on Work and Lifestyles. In order to reap any of these benefits of healthy and active later lives, we must first invest. That investment must be in ageing research, and in prevention and rehabilitation, as well as in treatment and cure. In short, there must be a commitment to a strategy for healthy ageing.

2 Models of support

Whatever the achievements in reducing disability and postponing chronic illness, there will always be some older people in need of health and care support. In this chapter we explore the models which will be needed, and how these can be promoted.

It is widely accepted that the central objectives of models of care for older people should be the promotion of independence and autonomy. This was an explicit objective of the community care reforms introduced in 1993 (Secretaries of State, 1989), and has been reinforced by the Labour Government's emphasis on promoting independence, and treating people with dignity and respect (Secretary of State for Health, 1998). The report from the Royal Commission on Long Term Care (1999) has similarly endorsed the promotion of independence and the need to shift the balance of care in favour of non-institutional alternatives. This model of 'community care' is one which – in principle – attracts considerable support. For example, the attitudinal research commissioned by the Debate of the Age through the ONS Omnibus Survey, found 82% of respondents indicating that they would want to be cared for in their own homes if they were no longer able to manage tasks of daily living without help (Jarvis et al, 1998).

The analysis and recommendations of the Royal Commission are especially welcome for their emphasis on principles of social inclusion, and improved access to the components of 'normal life' (including housing, education, transport, shopping, social and leisure activities). These values have been promoted for some time in models of support for people with learning disabilities, and for younger people with physical disabilities. Other commentators have pointed out that the promotion of autonomy and inclusion in mainstream life have been far less central to services for older people (Harding, 1999). Instead, the emphasis has tended to be placed on safety and security. Achieving a shift towards genuine autonomy will be a major undertaking. Why social inclusion has rarely been considered as a goal of services for older people can be debated. However, the most important reason may be that there has been a lack of dynamic and positive models of what an ordinary old age should be like; old age is typically viewed as something out of the ordinary.

Tackling social exclusion is a core theme of this Government's agenda (Secretary of State for Social Security, 1999). We believe that this presents an excellent opportunity to address the social inclusion of older people. However, while poverty is often a key factor in social exclusion, it is not the only one, and without a parallel emphasis on the other variables which exclude people from full participation in normal life, the achievements will be limited. If the objectives for compression of morbidity are achieved, we can anticipate that the number of years which people can expect to spend in a healthy later life will increase. People will enter old age with high expectations of an active and stimulating retirement. The stereotype of the older person as a burden, or as a passive recipient of care, will be less and less accurate.

In thinking about models of support for the future, we should not be prescriptive. Imagination and innovation can be limited by a service straightjacket. However, we can establish some core principles which should guide planning and development in both the immediate future and the longer term. A review of alternative models conducted for the Royal Commission included intensive home support, co-resident care, very sheltered housing, and assistive technology (Tinker et al, 1999). We believe that all of these models are likely to be relevant, but so too will other approaches which have yet to be developed. Rather than being prescriptive, we would therefore recommend the adoption of the following principles as the foundation for all models of support. We recognise too that everyone is an individual, and these principles focus on *individual* needs and wishes. In adhering to these principles, attention to the *differing* needs of individuals, and of black and minority ethnic groups, can also be assured.

2.1 Principles of support

The evidence from consultation with older people is that there is an overwhelming preference for remaining in one's own home for as long as possible (Henwood & Waddington, 1998; Royal Commission, 1999; Harding, 1999). Such hopes are also expressed by younger people when asked to speculate about their own later life. There are no grounds for anticipating that this fundamental desire for independence and autonomy will change in the foreseeable future. Moreover, as Harding has pointed out:

“It is important to stress that these aspirations are common to *all* older people, not just those who are relatively active and healthy (...) the evidence from older people themselves is that inclusion and quality of life are just as important to those whose health or mobility are impaired as it is to more active older people. Ill-health and disability may make it more difficult to achieve quality of life, but they do not change its definition: they simply present additional barriers that have to be taken into account and overcome in order to achieve it.” (Harding, 1999, p. 44).

In seeking to promote independence and social inclusion for older people, there are implications for a wide range of services and infrastructure – going much wider than the traditional range of health and social care. While most older people want to be able to continue living in their own home, for many this is far from being a positive experience. Living in poor quality and deteriorating housing, isolation from full participation in ordinary life, being visited by a succession of service providers, or being reliant for support on a relative who is overstressed, do not add up to a positive picture of independent living.

Changes will be needed which ensure that staying at home is not only a realistic option for more people, but that it is a choice which enhances independence and inclusion, and promotes a good quality of life. **We recommend that the following principles should be used to guide the development of models of support:**

Box 3: Principles of support

- services should support people to maintain independence wherever possible;
- services should maximise personal dignity;
- social inclusion should be an explicit objective of services;
- services should be based around individual needs;
- services should be flexible and able to respond to changing needs;
- carers should be supported by appropriate services;
- services should be provided by trained staff with appropriate skills, knowledge and expertise;
- services should be integrated and comprehensive.

2.2 Independence and social inclusion

From these general principles, a number of specific objectives can flow. The support of independence does not mean that services should leave people to ‘get on with it’. Support for independent living may actually require considerable service input, but the objective of such service should be to assist people to live lives which are as ‘normal’ as possible. The idea of social inclusion is that people should have access to the ‘normal’ services and lifestyles available to other members of the community. As noted previously, such principles have been most developed in the field of learning disabilities where the idea of

'ordinary lives' has supported integrated rather than segregated services. The adoption of these principles in services for older people could have a dramatic effect. For example, supporting older people in maintaining their social networks and leisure activities could produce a radically different pattern of services from the current pattern of day care. Research with older people by Henwood and Waddington (1998) found an under use of traditional day care services which were perceived as providing a restricted and narrowly focused range of activities which people rarely wanted. Similarly, following the principle of integration would suggest a different emphasis within models of housing and care, and the adaptability of 'ordinary' housing which can more easily support ageing in place, rather than necessitating moves to segregated sheltered housing, retirement communities, and residential homes. This theme has been explored more fully in the Millennium paper on the future of the built environment.

One lever for influencing the shape of services can be through consumer pressure, and it will be interesting to see how the extension of Direct Payments to people aged over 65 works in practice. Direct Payments have been supported as a means of "giving service users new freedom and independence in running their own lives" (Secretary of State, 1998, para 2.15). **We recommend that principles of independence and social inclusion should be adopted as underlying objectives of all service development for older people.**

Enabling people to be independent also requires a positive approach to risk taking, and supporting choices (such as continued living at home) when other options might be easier and safer from a professional perspective. These principles should apply to any social care support, regardless of whether that is provided in the community, or in a residential setting. There has been increasing recognition of the need for residential and nursing home provision to be less institutional and more homely, but this is an area where considerable progress is still required. This has implications not only for physical and material standards and quality of facilities, but with the nature of the care 'regimes' which are adopted. For example, the routine use of 'cot sides' on beds in residential and nursing homes may be justified by staff concerned about residents falling out of bed, but such containment and restriction compromises individual dignity, and can *increase* the risks of falls and injuries for people who struggle to get out of beds so equipped. Where care homes are large it can be especially difficult to ensure that the approach is non-institutional.

Nonetheless, there *are* models of good practice, and good design can be replicated (Centre for Policy on Ageing, 1984; Department of Health, 1989; Peace et al, 1997). **We welcome the approach of the consultation document issued by the Department of Health on developing national standards for residential and nursing homes** (Department of Health, 1999e). However, it is regrettable that the development of standards is being approached piecemeal. The White Paper Modernising Social Services (Secretary of State for Health, 1998) committed the Government to developing greater consistency in standards for all regulated services, within the framework of a new independent regulatory structure. **We believe this would be much enhanced by the development of a clearly integrated approach to national standards across all services, grounded on a core set of common principles and values which is currently absent.**

Even where physical standards are good, and design is more domestic than institutional, there are issues about the engagement and stimulation of residents. Lack of meaningful activity is a common criticism of care homes. Moreover, activities need to be appropriate and dignified. The standard fare of Bingo or community singing, or continuous background television, may be easily organised, but how much it meets the needs or wishes of residents is a different matter. Organising alternative activities is more demanding and requires greater investment and attention by care staff, as well as adequate physical space and recreational facilities. The issue of choice is also closely related to matters of independence and inclusion, and opportunities for meaningful choices in care settings are often few. People should be encouraged and supported to make choices about

how they spend their time and live their lives, from decisions about menu preferences, to choices about activities and the balance between solitude and social interaction.

The need to improve service quality and to promote good practice is of increasing importance. New ways need to be found of encouraging and supporting such activity. This has implications for the training and qualifications of staff in particular. McCormack (1999) has advocated the development of a model of 'teaching care home': "a centre of excellence that provides opportunities for teaching, learning, research and development activities to multidisciplinary teams." In practice, the experience of developing similar models in the USA has not been a positive one, with little success in developing multidisciplinary models of teaching and learning. It is possible that the approach has been too heavily focused on a 'teaching hospital' model, and has tended therefore towards an over-medicalised approach, rather than on developing a genuinely multi-disciplinary style. However, in principle the development of resource centres which could serve as a focus for education and practice development is a proposal which merits further consideration. **We recommend the piloting of new methods of developing and disseminating good practice in the support of older people, including investigation of the viability and relevance of models such as the 'teaching care home'.**

Increasingly, we can anticipate pressures for standards and conditions to be substantially higher than at present. Future cohorts of older people will be less likely to accept low standards, or to put up with models which they dislike or with inappropriate restrictions on choice and liberty. Research evidence consistently points to younger people recognising that they will be more demanding and less acquiescent when their time comes for needing help and support (Henwood & Waddington, 1998). Dimensions of quality which include room size and facilities are changing rapidly, and proposed national standards already indicate likely shortfalls. For example, more than half local authority homes for older people, and some 20–25% of private residential homes are thought to have rooms smaller than the proposed minimum size of 10 square metres (Department of Health, 1999e).

The key to continued independence for many people is not the provision of intensive support so much as the availability of what is often referred to as 'low level' support. Having 'a little bit of help' can be vital in supporting people to care for themselves, but the type of help which is most useful is rarely that which is available (Henwood, Lewis and Waddington, 1998; Qureshi, 1998; Harding, 1997; Clarke, Dyer and Horwood, 1998). The practical help which is needed with keeping a home clean and maintained – from basic housework and window cleaning to minor repairs and maintenance – is extremely difficult to get, or is obtainable only through the private (unregulated) market. There is increased recognition within Department of Health policy that services must address the prevention agenda as well as responding to the immediate requirements of people in most need of help (Secretary of State for Health, 1998). However, since 1993 the emphasis within community care policy has stressed personal care rather than practical support. A change of emphasis to focus on both dimensions will be difficult to achieve, particularly when it is not easy to demonstrate the proven worth of much 'low level' support, beyond the subjective evidence that it is greatly valued by service users. There is a dearth of research evidence on effectiveness in this area, although preliminary findings of research in Australia "points favourably towards the value of low levels of support for some home and community care clients" (Turvey and Fine, 1996). **We recommend that further guidance should be issued on the focus of prevention work and low level support, to assist the development of local strategies. Evaluation should also be commissioned to determine the value of specific low level services in preventing or postponing deterioration and increased dependency.**

2.3 Focusing on individual need

The accurate assessment of peoples' needs must be at the heart of any model of support. The shortcomings of current approaches to assessment are, however, widely reported. The Royal Commission on Long Term Care itself identified the "wide variations in the approaches to and quality of assessments across the UK" (Royal Commission, 1999, para 8.12). Similarly, a review of 50 assessment documents found "wide variation in content and quality of the information and no clear linkage between identifying problems and formulating a proper response (...) Variability of assessment tools is high and their comparability and capacity to generate standardised information is low" (Challis, 1999).

'Assessment' is not a term which has a clear and unambiguous meaning. The definition typically varies between health and social care professionals, and in the case of the latter, assessment of need can be clouded by assessment of financial means. The timing of assessment is critical, and there is particular concern that unnecessary (or avoidable) residential placements result from assessments undertaken in the absence of efforts to maximise rehabilitation potential. Admissions to residential and nursing homes typically take place in crisis situations (often following emergency hospital admissions), and with little time or attention given to the exploration of alternatives. 'Rehabilitation' is also a term which may convey different meanings to medical and social care professionals. We are using it in its broadest sense: rehabilitation is a process which aims to restore maximum independence in those areas of daily living which are most important to the person and their family (Sinclair and Dickinson, 1998). **We agree with the Royal Commission that maximum opportunity for rehabilitation should be included within care assessment, and that this should happen before irreversible decisions on long term care placements are made.**

Despite the emphasis on needs-led approaches to assessment, and recognition that assessment should look at the needs of the person as holistically as possible, in practice much assessment is mechanistic and over-reliant on the use of tools which are geared to assessing *functional dependency*, as indicated by inability to perform specified Activities of Daily Living (ADL). There is a considerable debate over which tools are 'best', and whether or not there should be a move towards greater standardisation of assessment tools. The advantage claimed for such an approach is that this would improve consistency, reliability and validity. On the other hand, critics of standardisation point out that a 'techno-scientific' approach is inappropriate and fails to engage with people as individuals:

"Standardised assessment ignores older people as individuals by ignoring their biographies, and by failing to identify their aspirations and needs across the widest possible range of factors."
(Ford, 1999).

Just as there is debate over how to undertake assessment, so there is disagreement over who is best placed to do so. The different emphases of medical and social models of care are inevitably reflected in different understandings of assessment. Professional defensiveness and mutual suspicion can undermine approaches which require trust and respect for the integrity of completed assessments. There is also confusion over different levels of assessment, and initial 'screening' which determines access to assessment and eligibility for services may be undertaken by relatively untrained staff lacking the requisite specialist skills and knowledge. In view of these difficulties, there is increasingly a view that assessment needs to be genuinely multi-disciplinary. The Royal Commission on Long Term Care certainly endorsed this perspective:

"Experience in both Northern Ireland and Australia suggests that a multi-disciplinary team in which true mutual understanding of skills has been developed to a high degree is a key factor."
(Royal Commission, 1999, para 8.12).

The multi-disciplinary model *does* seem to be successful in the Australian context where Aged Care Assessment Teams (ACATs) bring together the skills and resources of all stakeholders in order to determine the needs of people referred for assessment. In Australia too, there is interest in developing a National Framework for comprehensive assessment (Lincoln Gerontology Centre, 1998). This has described the core purposes of comprehensive assessment in the following terms:

- providing a consumer focussed assessment
- identifying strengths, resources and needs
- providing opportunities for maximising levels of functioning
- coordinating and collating information
- providing information
- identifying broad objectives
- indicating level of need, level of risk/vulnerability.

Multidisciplinary assessment is advocated in Australia as a model which

“ensures that the potential for professional bias or outlook of a single assessor restricting the identification and evaluation of needs is minimised. A multidimensional orientation ensures that access to opinions from assessors from different disciplines or with different areas of expertise is available to the assessor (...) The range of opinions and core expertise that may need to be sought to establish a multidimensional approach to assessment includes: health and key allied health disciplines such as nursing, social work, occupational therapy, physiotherapy, as well as areas of expertise and experience relevant to the needs of clients from different life stages.” (Lincoln Gerontology Centre, 1998, p. 29).

Should national standards, or a national framework for assessment of needs be developed in the UK? Work on *Fair Access to Care* being developed by the Department of Health is intended to introduce greater consistency in determining eligibility for services (Secretary of State for Health, 1998). **We recommend that further guidance should be issued on assessment, in relation to *what* should be included in assessments and *how* these should be undertaken. While not wishing to be prescriptive of a particular tool or methodology, we would endorse the development of a multidisciplinary model and the establishment of consensus over the framework which should guide assessment, and which focuses on the person and involves them wholly in the process, including respect for the contribution of self-assessment.**

2.4 Improving support for carers

The future availability of family or informal care is an unknown quantity. It is often hypothesised that the combined impact of a number of demographic and social trends including changes in marriage and fertility patterns, increased geographic mobility and changed patterns of female employment, will reduce the ‘supply’ of carers. The willingness of families to provide support may also diminish. In considering the likely trends, the Royal Commission acknowledged that the likelihood of being married (and therefore having a spouse potentially available as a carer) can be seen to be in decline, but conclusions about the supply of care by other relatives are much more difficult to draw (Royal Commission, 1999).

The ONS survey questions commissioned in 1997 through the Debate of the Age asked respondents whether they thought that adult children should have a responsibility to look after aged parents needing care, and found similar proportions agreeing and disagreeing (41% said Yes, and 40% said No). The youngest age group of respondents (16–24) were untypical in that a clear majority agreed with the proposition (59% of men and 64% of

women). From age 25 onwards, women were less likely than men to support the proposition. People from Indian, Pakistani or Bangladeshi ethnic groups overwhelmingly supported the statement that adult children should look after their parents (86%). People from black ethnic groups were less adamant (51%), but still indicated considerably more support for family obligation than people from white ethnic groups (40%). Such information provides us with a snapshot of attitudes. What it does not do is indicate how these have changed in recent decades, or how they might do so in the future.

In view of the uncertainty which surrounds the future availability of informal care, the need to support those who *are* carers becomes increasingly important. **We agree with the Royal Commission that on the grounds of equity and justice carers need more support.** This is consistent with the prevention agenda, since it can be argued that early and adequate support for carers is likely to prolong the duration of caring.

The objective of supporting carers has been an explicit feature of community care policy since 1993. However, as in the case of preventive work in general, it is likely that this endeavour has been given a relatively low priority. Most support has been directed towards elderly and other service users who do *not* have the support of carers. Moreover, many traditional models of social care are inappropriate or poorly suited to the needs of carers.

The Royal Commission recommended that the assessment process should be ‘carer blind’ – so that the presence of a carer will not lead to a failure to offer service, or to a withdrawal of support. We understand the reasons for this recommendation, but believe that the principle, and terminology, of being ‘carer blind’ is a dangerous one. In practice, there are risks that this could lead to carers’ needs being overlooked even more, since there is a danger of misinterpretation on the part of assessors.

The National Strategy for Carers announced in early 1999 identified additional resources (£140 million over three years) directed towards improving respite support for carers. In addition, the strategy emphasised improved support to carers on a number of fronts (Caring About Carers, 1999). We welcome these developments. In particular, we support the emphasis that services to allow carers to take a break from caring should include a range of different models. Too often, respite services are unimaginative and are focused on residential based solutions which may be inappropriate and can lead to additional problems for the carer because they are disruptive of the normal routine. There is a movement away from the term ‘respite’, which many regard as too negative, and an emphasis instead on the provision of ‘short breaks; from caring involving the provision of support within people’s own homes, or residential breaks within specialist short stay facilities, which are more able to offer a holiday-style break (rather than in regular long stay residential establishments). **We recommend that regular breaks for carers should be built into care plans from the outset; respite should not be introduced only when emergency measures are required to keep carers going.**

It is not only social care services which are important to carers. The role of the NHS is potentially of great importance, both in providing carers with information and in early detection and response to problems arising from caring stresses. Despite this there is considerable evidence that the health service is relatively poor at responding to carers (Henwood, 1998). The Government’s National Priorities Guidance for health and social services requires GPs, primary care teams and social services staff to identify carers. We welcome this development, which should improve awareness of carer issues. However, **we recommend that the requirement to identify carers should be matched by requirements to use this identification data in planning local strategies to meet carers’ needs.**

To-date, legislation has prevented carers from receiving help and support *in their own right* (services have been provided only if they are also to support the person being cared for). However, this is to change, and in future carers *should* be able to receive help for themselves. Carers are usually the best judge of what type of help and support they

require, and more innovative and flexible services will need to develop in response to these needs. One way of meeting carers' needs may be through offering direct payments. **We recommend the further extension of Direct Payments to carers to enable them to exercise choice in organising services which are of most direct value.** Direct Payments should *not* be seen as income replacement, and carers would need approval of their proposals for using such payments. However, we believe that this should be interpreted very flexibly and carers would be able to use their payments to organise support in ways which were most relevant to their own situation. We recognise that there can be tensions between meeting the needs of the person being cared for, and those of carers themselves.

An overriding need of carers which has been repeatedly identified in the research literature is for improved and accessible information. The difficulty is often in finding a way into the system and establishing where information is located. **We recommend the establishment of a single point of contact, ideally through a national freephone number, which would act as a clearing house for all information requests. The agency contracted to provide this service would be able to send carers information packs directly, but would also be able to make referrals onto other local services.**

Financial support, and flexible employment, are further areas in which the carers agenda needs to be better developed. The National Carers Strategy has paid limited attention to both areas. There is growing recognition that 'family friendly' employment practices need to include carers as well as parents. The White Paper *Fairness at Work* included proposals which would give all employees, including carers, the right to time off to deal with a family emergency. The subsequent Employment Relations Act 1999 enshrined the right of employees "to take a reasonable amount of time off" to provide assistance, or make arrangements, when a dependant falls ill, or when normal care arrangements unexpectedly break down. This is an important first step, but it is not enough.

A review of the research material indicates that while flexible working arrangements which support carers are increasing, they are often inequitable:

"..they often exclude male employees and are often not available in employment situations where women are typically concentrated. The majority of employers seem to be unaware of the specific needs of employees caring for elderly relatives and are unlikely to provide services of relevance to these employees." (Pickard, 1999, para 163).

The new right to time off under the Employment Relations Act provides only for a brief (but unspecified) amount of time off, to make arrangements to deal with specific circumstances or crises. The amount of time taken off is intended to be reasonable, and while there is no set limit, it is expected that one or two days will usually be sufficient. Clearly, while this may be adequate to deal with an immediate crisis, it is of little help in managing the on-going demands of caring alongside employment. It has been proposed that statutory leave for carers (comparable to parental leave) would help in raising awareness of carers issues and would encourage employers to develop better support (Pickard, 1999). **We welcome the increased recognition that is being given to carers in employment, but we urge the Government to go further in supporting statutory carers leave.**

The financial support available to carers is limited and can lead to carers being impoverished both during their time as carers, and during their own old age because of the impact of lost earnings on pension entitlements, and the depletion of capital savings while caring (Glendinning, 1992, Hancock and Jarvis, 1994). Invalid Care Allowance is a taxable non-contributory benefit for people of working age (16–65) who are caring for more than 35 hours a week for someone in receipt of Attendance Allowance (ICA). The benefit is widely seen to be inadequate because of its limited scope, restricted criteria for eligibility, and its low level. It is inadequate as income replacement, it excludes many heavily committed carers and does not easily support carers in employment (Pickard, 1999). The Government is committed to keeping under review financial support for carers, including

the ICA. However, we believe that major reform is required and **recommend that Invalid Care Allowance should be reformed to make the benefit level at least comparable to other benefits, and to revise the eligibility criteria to include carers currently excluded on grounds of age, and to remove qualification for ICA from being contingent on the benefits of the person cared for.**

We welcome the reform of pension arrangements which should benefit carers by giving them entitlement to a second pension through crediting contributions for carers who are not working or who are on low earnings. However, making entitlement to such credits conditional on receipt of Invalid Care Allowance is problematic given the restrictive nature of that benefit. **We recommend that the entitlement of carers to second pensions should be broadened.**

2.5 Comprehensive and integrated service models

The development of models of support which offer comprehensive and integrated response to needs is frustrated by two major issues. We have already indicated the importance of a holistic approach which goes beyond health and care to include the vital areas of housing, transport, education, leisure, and employment. These are all essential components of a strategy for meeting the health and support needs of an ageing population, and could indeed *reduce* the need for costly interventions by preventing or delaying the onset of ill-health and dependency. We welcome the increasing attention which is being paid to this issue, and the potential for progress through local Health Improvement Programmes, Health Action Zones, and Better Government for Older People. However, there remains a major impediment to integrated service because of the structural fragmentation of health and social care.

The problems which the two parallel systems create for service users and their carers are well known, and have been extensively documented in the research literature. While services make a distinction between health and social care, the *needs* of people do not follow this broad classification. The result is a system in which people can be passed from one agency to another, where needs can be overlooked, and where the objective of 'seamlessness' is virtually impossible to achieve. The boundary between the services is further complicated by the fact that the NHS is free at the point of use, while social care is subject to means testing and charges.

Recognition of the importance of joint working between health and social care has led to a series of government measures aimed at improving coordination mechanisms, and emphasising the development of partnership (Department of Health, 1997, Secretary of State, 1998, Department of Health, 1998b). Proposals for introducing pooled budgets between health and local authorities, developing lead commissioner arrangements and facilitating integrated provision, have all been designed to increase flexibility and to remove legal impediments to better joint working (Department of Health, 1998b).

The House of Commons Health Committee has concluded that despite improvements:

“..we consider that the problems of collaboration between health and social services will not be properly resolved until there is an integrated health and social care system (...) we believe it is the only sensible long term solution to end the current confusion.” (Health Committee, 1998, para 68).

Nonetheless, the Health Committee acknowledged that they “found no widespread support for a major reorganisation of the health and social care system”. This is, perhaps, unsurprising. There has been extensive and continuing reorganisation and change within both health and social services since the early 1980s, and the prospect of further reorganisation is unwelcome. The Government has also indicated that such major reform is

not envisaged, and there are no plans to integrate health and social services (Department of Health, 1999b).

The Royal Commission on Long Term Care concluded that what is essential is a single budget, and a single delivery route. If this principle is accepted, many of the problems of health and care fragmentation can be addressed. The Commission proposed a restructuring of responsibility for long term care based around the principle that personal care costs should be met by the state (subject to an assessment of need for care). In developing the concept of 'personal care', the Commission proposed a potential way forward which avoids the confusion surrounding debate about whether needs should be judged as health or social care.

The Commission identified three components of long term care costs: living costs, housing costs, and personal care costs. It argued that both in the community, and in residential settings, people should be responsible for the first two elements (subject to income and means testing), but that personal care costs should be seen differently:

"These are the costs which, unpredictably and through no fault of their own, old people have to incur when unfortunately they can no longer be looked after at home or cannot be sent home after hospital treatment. They reflect the true risk and 'catastrophic' nature of needing long term care. In our judgement it is right for the state to exempt personal care from means-testing altogether. This is our key recommendation." (Royal Commission, 1999, para 6.32).

On grounds of equity and simplicity, we are attracted to this solution. It offers a response to the uncertainty and confusion which currently surrounds entitlement to 'free' versus means-tested care. The needs for personal and nursing care would be treated in the same way as any other health care needs. We recognise, however, that there could be some practical difficulties in distinguishing between some areas of personal care costs and normal living costs, but we do not believe these to be insurmountable. **We support the main proposal of the Royal Commission on Long Term Care that personal care should be free, and we urge the Government to accept the recommendation.** The Millennium Paper on Paying for Age has explored possible alternative models for financing long term care.

However, we recognise that there are problems with the Commission's proposals, as evidenced both by the 'Note of Dissent' written by two of the Commissioners, and by the Government's delay in responding to the recommendations. The Government has indicated that it will announce "how it intends to tackle the issues raised in a way which will be fair to both the taxpayer and the individual, which will stand the test of time and will place services on a better footing for the future" (Department of Health, 1999b). The Note of Dissent by Joel Joffe and David Lipsey disagreed with the recommendation that personal care should be provided free of charge, funded from general taxation, on the basis of assessment of need:

"Because it would provide public funds irrespective of income, it would weaken the incentive for people to provide for themselves privately. It would transfer income and wealth to the better off members of society and their heirs, at the expense of those most in need. It would pre-empt the state's resources in this area so that it is unlikely that some of the Commission's other proposals would be funded." (Joffe and Lipsey, 1999, para 4).

Joffe and Lipsey proposed, instead: a modification of the means test so that people of moderate means would be less harshly treated than at present (and would not be forced to sell their homes); the development of a public-private partnership involving both private savings and private insurance, and making nursing care free in nursing homes (but more restrictively defined). Joffe and Lipsey were concerned over the costs projected by the Royal Commission, and by the fact that the main beneficiaries would not be the least well off. Fundamentally, Joffe and Lipsey rejected the analogy between health and social care, and did not accept that "just because much health care is free, it does not follow that personal care should be free too " (Joffe and Lipsey, 1999, para 42).

We do not support the Joffe and Lipsey argument against making personal care free, but we recognise the concerns reflected in their proposals, particularly over the public expenditure costs. The Commission's proposal for making personal care free in both residential and domiciliary settings would cost an estimated £1.1 billion in the base year, rising to an additional £6.4 billion by 2051. Personal care was defined by the Commission in the following terms:

"Personal care is care that directly involves touching a person's body (and therefore incorporates issues of intimacy, personal dignity and confidentiality)...It falls within the internationally recognised definition of nursing, but may be delivered by many people who are not nurses, in particular by care assistants employed by social services departments or agencies." (Royal Commission, 1999, para 6.43).

The Commission estimated personal care costs to represent approximately 50% of weekly residential care costs, and two thirds of nursing home costs (respectively £122 and £217 a week). **We believe that these figures need to be considered critically, and recommend that further modelling needs to be undertaken considering the implications of different figures being assigned to the balance between personal care costs, living costs and housing costs.**

Moreover, while the Commission's definition of personal care acknowledged that much of the work *need not* be undertaken by nurses, the cost estimates suggest that personal care has been costed on the assumption that all – or most – personal care *is* nursing care. We believe that further work is needed to examine in greater detail the costs of making personal care free, and in particular to look at more flexible ways of using different nursing and care staff more appropriately. The costs of employing properly trained care assistants are less than those of employing nursing staff. It is imperative that staff are used appropriately, and that the right skill mix is developed. This is, in no way, an argument for providing *less* skilled support for older people than is available to others. We are concerned that at present the only alternative to care by nursing staff is too often that provided by untrained and inexperienced care assistants.

In the consultation document on national care standards, the Centre for Policy on Ageing recommends that "nursing homes should have a ratio of one third qualified nurses to two thirds untrained staff". The Government has indicated that establishing standards for staffing ratios is problematic. While it could help ensure minimum levels of care, there may not be sufficient flexibility to meet varying needs (Department of Health, 1999e, p9). We share these concerns, and we would not support the involvement of 'untrained staff' in the care of older people. The Department of Health suggests that staffing levels might be better linked to other factors such as the layout of the home, the purpose of care, and the assessed needs of residents using a recognised assessment tool. This may or may not be a preferred approach, but we would be similarly sceptical about the virtue of any apparently mechanistic and reductionist approach to determining appropriate staffing levels and models in the absence of well grounded evidence. **We recommend that further work be undertaken to look at the skill mix required in providing personal care in different settings, and to develop the most appropriate models.**

Not only could this offer a less expensive solution to meeting the costs of personal care, but it could do so by developing new types of staff which are better suited to meeting people's needs for long term care. Care Assistants are often poorly trained, and have an inadequate career structure to encourage professional development. The use of National Vocational Qualifications (NVQ) could be enhanced in this area, providing a better standard of training and accreditation. The development of new types of care assistant would provide a higher standard of professional care, while not using the specialist skills of nurses inappropriately.

We have set out a number of principles which we believe should underpin the development of models of support for older people. Thus, the promotion of independence and social inclusion, the development of flexible services based on needs of service users and their carers, and integrated and comprehensive support, should be core objectives. **The Royal Commission on Long Term Care proposed the establishment of a National Care Commission to oversee the development of long term care. We support the establishment of such a body, which we believe could play a key role in developing and promoting models of support consistent with the principles framework which we have outlined.**

3 Rationing and inequality

Controversies over health inequalities, and the apparent rationing of health care are nothing new. All health care systems operate some form of rationing – whether by cost, or by waiting list, or through the operation of different types of eligibility criteria. The need to ration reflects the simple economic fact that demand exceeds supply, or that the combined impact of rising expectations, together with technical and medical advances, is such that there will always be a gap between the need or demand for care, and what can be afforded through a publicly financed system. Latterly there has been increasing attention paid to the ‘postcode lottery’ whereby access to care and treatment operates differentially in different parts of the country. The National Institute for Clinical Excellence (NICE) is to address such matters by developing guidelines for the treatment of particular conditions.

We do not believe that it is possible to develop a health care system which excludes all rationing. However, the basis on which rationing takes place needs to be agreed, and the implications of any such approach for elderly people need to be addressed.

3.1 Opinion on rationing

The ONS Omnibus Survey commissioned by the Debate of the Age explored attitudes to rationing. The great majority of respondents (83% of men and 85% of women) indicated that they believed all people should have equal rights to medical treatment, regardless of age (Jarvis et al, 1998). There was very little difference between respondents of different ages, and only among people aged 75 and over did support for equal access drop below 80%. Very small proportions of any age group believed that priority should be given to younger people, and most of these believed that lower priority for older people should depend on the amount of care they required. There was evidence of some differences between ethnic groups, thus while 85% of white respondents believed in equal access for people of all ages, and only 6% would give greater priority to older people, 20% of people from black ethnic groups, and 28% of respondents from Indian, Pakistani and Bangladeshi ethnic groups believed that *priority* should be given to older people.

A number of Citizen’s Juries were organised by the Debate of the Age to provide further qualitative information on particular themes of the debate. One such jury explored the question of prioritising the use of NHS resources, and agreed the principles set out in Box 4.

Survey evidence in this area is, however, complex and contradictory. There is some evidence that older people accept that younger people should have priority in certain circumstances, and representative samples of the population generally favour treatments for the young over the old (Bowling, 1996; Lewis and Charny, 1989). The apparently opposing view taken by the Citizen’s Jury, which did not support age as a relevant criterion in health care prioritising, may be partly explained by evidence that such deliberative techniques can produce different results from opinion polls, based on a deeper understanding and discussion of the issues involved.

Box 4: Citizen's Jury view of factors to be used in NHS priority setting

Criteria which should always be used in setting priorities

- Immediate need and degree of pain
- Effectiveness of the treatment
- Patient's wishes and family views

Criteria which should sometimes be used in setting priorities

- Statistical success rate
- Cost of the treatment
- Whether the treatment is available elsewhere

Criteria which should never be used in setting priorities

- Age (where it is a non-clinical consideration)
- Whether patient has any dependants
- Usefulness to society of individual patient
- Financial contribution to society of individual
- Whether the patient can afford private treatment
- Whether the condition is self-inflicted
- Race, religion and gender of patient.

3.2 Rationing by age

Other feedback within the Debate of the Age also indicates an aversion to the idea of rationing by age. This is an issue which polarises views, and the two perspectives have been encapsulated by Prof Alan Williams and Prof Grimley Evans (Williams, 1997; Grimley Evans, 1997). Williams has cautioned against the "vain pursuit of immortality" which, he argues, implies:

"...that no one should be allowed to die until everything possible has been done. That means not simply that we shall all die in hospital but that we shall die in intensive care." (Williams, 1997).

In the final chapter of this paper we address end of life issues, and we agree with Prof Williams that immortality should not be pursued at all costs. However, this is a separate argument from one which supports rationing on the basis of age. Williams argues that there comes a time when the inevitability of death must be accepted, and that "a reasonable limit has to be set on the demands we can properly make on our fellow citizens in order to keep us going a bit longer." Older people, he argues, are less likely to have the capacity to benefit from health care interventions, and have had their "fair innings", and in general, therefore, greater weight should be given to the needs of younger people.

The counter argument, put by Prof Grimley Evans, is that it is unethical to "use age as a criterion for depriving people of health care from which they could benefit". The assumption that older people respond less well to treatment fails to allow for consideration of individual circumstances, and many older people "function within the normal range for people much younger". It is therefore wrong, it is argued, to exclude people from treatment on the basis of their age, without reference to their physiological condition. The 'fair innings' argument assumes that there should be a 'right' only to a certain number of years, and beyond that period health care intervention should be palliative but not therapeutic. Prof Grimley Evans argues:

“..the fair innings approach will not necessarily save money unless we apply its corollary of compulsory euthanasia at the end of the innings. Palliative care can be more expensive than therapeutic care; the money saved by not providing coronary artery surgery for an elderly woman may be spent several times over if she has to live for months in a nursing home because of her angina.” (Grimley Evans, 1997, P 824).

3.3 Implicit and explicit rationing

With limited resources allocated to public spending on the health service, it is inevitable that some rationing (or prioritising) takes place. At present, it is clear that such decisions take place covertly, and are often the result of judgements by individual clinicians. There are arguments both for and against implicit and explicit approaches to health care rationing (New, 1996a).

Implicit rationing can be criticised for being “uninformed, arbitrary, and inequitable”. Where systems rely on implicit rationing there are risks that more articulate, knowledgeable, educated and pushy patients will be more successful in being heard and having their needs met than more compliant patients. Other criticisms of implicit rationing point out that the system allows doctors too much discretion, and while it is their *clinical judgement* which is supposed to guide decision making, in practice this can also reflect their own prejudices, preferences, and knowledge (Mechanic, 1995).

There is evidence that age-related rationing of health care does take place (New, 1996b). In particular, in the area of coronary care (Dudley and Burns, 1992), cancer care (Fentiman et al, 1990), and in end-stage renal disease (Wing, 1984; Mallick, 1993), there is evidence of restricted access to care, or of poorer quality care, for patients aged over 65. These findings also reflect the ageism inherent in much clinical and pharmaceutical research. For example, while around half of all malignancies occur in people aged over 70, people of this age are excluded from virtually all clinical trials of cancer treatments, with the result that older patients “receive either untested treatments, inadequate treatments, or even none at all, at the whim of their clinician” (Fentiman et al, 1990). A topic review by the Medical Research Council (MRC) also documented instances of age based discrimination. At the same time, the MRC also found that where elderly people were not excluded from particular treatments because of their age, they often responded as well as – or even better than – younger people (Medical Research Council, 1994).

Those who argue in favour of a more explicit approach to healthcare rationing point out that this offers a more consistent and fair method than the current variation resulting from discretion. The Rationing Agenda Group established by the King’s Fund argued the case for promoting “an ongoing, open and informed debate on how to make the hard choices about who should benefit” from NHS resources (New, 1996a). Deciding on a formula to guide such decision making is by no means simple, and there have been various high profile attempts to develop models. Klein has pointed out that the Oregon attempt to rank different procedures according to the balance of costs and benefits, and commissions in Holland, New Zealand, Sweden and Norway, which sought to establish principles of what should (and should not) be offered, have all offered various ways forward “but there is no sign of a consensus” (Klein, 1996).

Mechanic argues that some combination of explicit and implicit approaches is required: there needs to be an explicit framework, but because that cannot take account of all eventualities, there needs to be informal resolution within those boundaries; “implicit rationing embedded in an appropriate value framework offers the best among admittedly imperfect alternatives” (1995, P. 1659). Klein has argued a similar case, although recognising that leaving so much to the discretion of individual doctors is far from ideal.

3.4 Rationing: The way forward

The establishment of the National Institute for Clinical Excellence (NICE) will not, in itself, end variations in treatment quality or the “postcode lottery of care”. NICE was established “to give new coherence and prominence to information about clinical and cost-effectiveness” (Secretary of State for Health, 1997). NICE is charged with responsibility for identifying developments which best improve patient care in a number of treatment areas (Department of Health, 1999c). We welcome the establishment of NICE, and the appraisal of both new and existing drugs and interventions. We believe that the establishment of national guidance will be of considerable value in identifying the proven best options for different conditions, and accelerating the spread of evidence based good practice. However, we also believe that there is considerable scope for NICE to expand its role to address the rationing debate. While clinical guidelines may reduce the variation in effective practice, it is hard to see that they will have any impact on the postcode lottery if they do not also address the issues of national and local priority setting. Without agreed principles for rationing, inequitable and inefficient allocation of NHS resources will continue. One major obstacle to progress in this area is the ideological insistence by the present Government that there is no rationing within the NHS (Secretary of State for Health, 1999a).

We recommend that the Government accepts responsibility for making rationing decisions within the NHS explicit and transparent. In common with a number of other commentators, including the IPPR (Lenaghan 1996), and the Rationing Agenda Group (New, 1996a) we believe that a clearer framework is needed to facilitate fairer approaches to rationing, and for clarifying the scope and objectives of the NHS.

The development of such a framework leads into a complex territory of ethical and moral dilemmas. However, we believe that it is preferable for such matters to be addressed collectively and publicly, than to allow them to be tackled covertly, inconsistently and inequitably. We do not believe that rationing decisions can all be reduced to a formulaic approach, or to a defined menu which addresses all possibilities, but we do believe that there would be benefits from establishing clearer guidelines on the general principles which should inform judgements in specific circumstances. Moreover, we see this as an approach which is consistent with (and, indeed, would enhance) the development of National Service Frameworks, and the National Institute for Clinical Excellence.

3.5 Tackling inequalities

The rationing debate is part of a wider debate on equity in health care, and inequalities exists on a number of levels. It is not our intention to review all of the evidence on inequalities, which requires a more detailed exploration than we are able to give. However, any consideration of the implications of an ageing population must recognise that this is a population in which there are great inequalities in terms of age, gender, ethnicity, and socioeconomic factors. Such inequalities have been documented in detail (Department of Health, 1980; Acheson, 1998). As the Acheson report observed:

“Although average mortality has fallen over the past 50 years, unacceptable inequalities in health persist. For many measures of health, inequalities have either remained the same or have widened in recent decades.” (1998, P xiii).

Moreover, these inequalities are evident throughout the lifecycle – from pregnancy to old age. The Acheson report adopted a socioeconomic framework of analysis and explanation. Thus absolute and relative health inequalities are attributable to the determinants of income, education and employment, as well as material environment and lifestyle. The Government has followed a similar analysis in underlining the complex interaction

between personal, social, economic and environmental factors (Secretary of State for Health, 1999a; Secretary of State for Social Security, 1999).

The Acheson report adopted the standard definition of premature mortality as death before 65, which is, arguably, a conservative interpretation in the light of increasing longevity. However, in following this definition, it is apparent that the chances of living into old age are unequally distributed:

“If all men in this age group (20 to 64 years) had the same death rates as those in classes I and II, it is estimated that there would have been over 17,000 fewer deaths each year..” (Acheson, 1998, P.20).

Men and women enjoy different health. Average life expectancy at birth for females exceeds that for males, and throughout life age-specific mortality rates are higher for males. Life expectancy is 2.6 years greater for men and 2 years greater for women from social classes I and II compared to men from classes IV and V (Acheson, 1998, P. 145). Morbidity and disability, as well as mortality, reflect socioeconomic differences, particularly for males.

The Acheson Report’s focus on “a socioeconomic explanation of health inequalities” led to a series of recommendations across a broad front, many of which were acknowledged to be beyond the remit of the Department of Health. Tackling health inequalities, it was argued, requires policy development in areas including: poverty; income; tax and benefits; education; employment; housing and environment; mobility; transport and pollution; and nutrition (Acheson, 1998). As we have noted above, the Government’s approach similarly sets out to offer a more integrated approach to tackling poor health, and acknowledges the challenges of health inequality:

“Health inequality runs throughout life, from before birth through into old age. It exists between social classes, different areas of the country, between men and women, and between people from different ethnic backgrounds. But the story of health inequality is clear: the poorer you are, the more likely you are to be ill and to die younger.” (Secretary of State for Health, 1999a, para 4.2).

The specific recommendations of the Acheson Report were addressed in a further document issued by the Department of Health in conjunction with the public health White Paper (Department of Health, 1999d). The report addressed the action needed “across Government, and through partnerships between the various local and regional organisations in England, to reduce health inequalities”. Moreover, for the first time, Health Authorities have been charged with responsibility for setting local targets to reduce identified inequalities, and to address these through Health Improvement Programmes. We welcome this strategic approach by Government. However, we are disappointed at the limited nature of ambition in targets for improving the health of older people. As others have also observed, the development of local strategies for tackling inequalities in health requires further guidance on establishing targets, measuring progress and demonstrating effectiveness (Kendall, 1998). **We reiterate our recommendations made earlier in this report that there needs to be a comprehensive strategy for healthy ageing, and morbidity compression, which is currently absent from policy, and which needs to be addressed within strategies for reducing health inequalities.**

4 The end of life

The work of the five different expert groups established by the Debate of the Age has inevitable areas of overlap and common interest. End of life issues have also been considered by the Values and Attitudes group, particularly in terms of advance directives, refusal of treatment, euthanasia, and philosophical debate about the meaning of death. We do not intend to replicate that work. However, we believe there are other issues to be addressed, particularly in relation to the quality of life at its end.

Throughout this paper, the themes of control, autonomy and independence, have been recurrent. We recognise the centrality of such issues in the lives of older people. The wish to retain control and autonomy over life is a powerful motivation, and there is no reason why this should change as the end of life approaches.

Death, it is often said, is the final taboo of the 20th century. As we enter the new millennium we believe it is time to break the taboo, and to take back control of an area which has been medicalised, professionalised and sanitised to such an extent that it is now alien to most people's daily lives. In earlier decades death was more familiar than it is today. More people died at home, with the result that families, friends and neighbours would have been accustomed to the experience of death among them, and often directly involved in the care of the dying person, or in helping with the preparation of the body. Today this is the exception. Few people will have paid their last respects to the dead and dying within their own homes.

Many people may be content with this situation. The professionalisation of areas of life which used to be personal or domestic responsibilities can be welcome. The development of the service economy which paralleled the industrial revolution effectively took responsibility for many functions out of the home, in order to create a flexible labour force. Few people wish to return to self-sufficiency and to be responsible for producing their own food or making their own clothes. However, there is evidence that many people are not happy with the management and professionalisation of death. There are issues both in relation to dying, and in the management of death and its rituals (Neuberger, 1999).

4.1 Death and dying

Most people fear death, or perhaps more accurately – most people fear dying. The prospect is often one of dying in hospital, perhaps in great pain, wired up to equipment and enduring uncomfortable interventions, suffering indignities and having little or no privacy, being sedated in such a way that there is little or no awareness of circumstances or surroundings, and no opportunity to say goodbye. We believe that this scenario can be and must be changed. In order for this to happen, values and practices need to change. We recommend that the following principles be adopted as the foundation of all support for palliative and terminal care.

Box 5: Principles of a good death

- To know when death is coming, and to understand what can be expected.
- To be able to retain control of what happens.
- To be afforded dignity and privacy.
- To have control over pain relief and other symptom control.
- To have choice and control over where death occurs (at home or elsewhere).
- To have access to information and expertise of whatever kind is necessary.
- To have access to any spiritual or emotional support desired.
- To have access to hospice care in any location, not only in hospital.
- To have control over who else is present and shares the end.
- To be able to issue advance directives which ensure wishes are respected.
- To have time to say goodbye, and control over other aspects of timing.
- To be able to leave when it is time to go, and not to have life prolonged pointlessly.

The end of life matters. How people are treated in their final weeks, days or hours is of fundamental importance. Guidelines developed by the National Council for Hospice and Specialist Palliative Care make the point:

“Dying is a very important, individual event that has profound psychological, as well as medical consequences. If patients do not have symptoms controlled, their distress escalates and may become extreme. Relatives are also deeply affected as they cope with the prospect of losing someone they care about. The grieving process is more traumatic when the patient’s physical distress is not relieved.” (Working Party on Clinical Guidelines in Palliative Care, P. 3).

The aim of palliative care is the achievement of the best quality of life for patients and their families. The palliative care approach reflects a number of core principles:

- focus on quality of life, including good symptom control;
- whole person focused approach, taking account of the person’s past life experience and current situation;
- care which encompasses both the person with the life-threatening disease, and those people that matter to the person;
- respect for patient autonomy and choice;
- emphasis on open and sensitive communication with patients, informal carers and professional colleagues (Addington-Hall, 1998).

Palliative care does not seek cure of the patient, but to offer relief from distressing symptoms and pain, and support to the patient and family. Hospices and specialist palliative care units are most likely to be able to offer the type and level of care required. However, most people do not die in such facilities, but in hospital, or in residential/nursing home care, or (less often) at home. Staff working in the community or in residential and nursing homes may be less experienced and skilled in dealing with people in their final days, and may have an inadequate training in appropriate palliative care. Care staff need access to training from their local hospice or specialist palliative care service, and need to know when they should call on the direct support of the palliative care service. We welcome the inclusion of dying and death within the consultation on national care standards (Department of Health, 1999e).

Hospice and specialist palliative care services focus almost exclusively on the care of patients with terminal cancer. However, such deaths account for only around one quarter of all deaths, and while there is a need to continue to improve care for people with cancer,

attention needs also to be directed to the majority of people who die from other causes. Nonetheless, the needs of people dying from other causes, are, in many respects, similar to those of people dying from cancer:

“There is convincing evidence that many patients who die from non-malignant diseases have unmet need for symptom control, psychosocial support, open communication, control over their final days and choice about the care they receive.” (Addington-Hall, 1998, P. 9).

This is not to argue that such care can only be provided through hospices or specialist palliative care services. Rather, it is to emphasise the importance of a palliative care approach being adopted in all health and care settings, both in the hospital and in the community. For this to happen, there needs to be a fundamental shift in attitudes and approach of medical and other health service personnel. In order to ensure that the principles of a good death are satisfied, it is a pre-requisite that the person knows they are dying, and that this has been explained to them with honesty and care. Too often, the death of a person is viewed as a failure of medicine. The curative imperative can drive continued interventions beyond the point of any realistic hope of benefit. The decision to end the search for cure should be made, wherever possible, in full discussion with the patient, and attention refocused instead on palliative care.

The understanding and engagement of the dying person will not always be easily secured. The presence of dementia, or other mental incapacity, for example will reduce awareness and response to the situation. Nonetheless, work with dementia patients does indicate that meaningful communication is possible, even in advanced states, when undertaken by appropriately trained and skilled staff. Where it is impossible to achieve such communication, the involvement of relatives and others should be sought, and this will often be within the context of existing arrangements for guardianship or power of attorney.

We recommend that medical and nursing education and training, and that of others involved in caring for people, should embrace the care of the dying patient and ensure that the values and principles of palliative care are widely shared and adhered to. We also recommend the further development of disease-specific clinical nurse specialists in palliative care.

The nursing care needs of the terminally ill patient, or of a person in the end-stage of a chronic disease, are well known, and there is a considerable literature addressing good practice (for example, Johnson and Lancaster, 1997; Working Party on Clinical Guidelines, 1997). We support and endorse such practice, and do not seek to offer an alternative. Rather, it is our intention to ensure that such support and care is more widely available, and that the expertise developed in palliative care is disseminated effectively. As Julia Neuberger has commented, where palliative care works well, it can be quite wonderful, but it needs to be available for everybody, everywhere:

“The NHS has got this right. We ought to shout it much more loudly, show it to other countries where people still die hospitalized, intubated deaths. But, first, we must make sure it is possible for everyone here in the UK to receive such care – because it feels absolutely right” (Neuberger, 1999, Preface, P x).

People will have different needs and wishes at different stages of their final illness. The National Council for Hospice and Specialist Palliative Care suggests three levels may be appropriate:

- consultancy services – a one-off or time limited involvement of, usually, one member of the multi-professional team to advise on the management of a specific problem;
- short-term intervention whereby the whole multi-professional team may be involved but will withdraw once therapeutic goals have been achieved, or
- full hospice and specialist palliative care, whereby a limited number of patients who have complex and ongoing needs and who are close to death are offered the full range of locally available palliative care services (Addington-Hall, 1998, P.9).

Guidelines for managing the last days of life recognise care in the final stages, when death is imminent, can be seen as distinct from other palliative care, and requires a 'gear change' in approach (Working Party on Clinical Guidelines (1997)). The care of the dying person should not be solely the responsibility of health care or other professionals. As we noted above, it is important that the dying person, their family and others close to them are given the opportunity to participate in making decisions and retain control as far as possible. Families and carers will often want to participate in the physical care of the patient, especially if they have been caring for them previously. Often, however, this is not made easy:

"There is anecdotal evidence that relatives are often sent out of the room while nurses carry out certain procedures but they should be given the choice of remaining with the patient and even assisting the nurses. This helps them to build up their confidence and feel that they have been enabled to do as much as possible for their loved one. Occasionally there are relatives who need to participate in laying out of the body after death. They should be allowed to do so."
(Working Party on Clinical Guidelines in Palliative Care, 1997, P.8).

Death may be approached with fear by patients and their families because of insufficient information, or lack of understanding of what they can expect to happen. Such fears need to be addressed by medical, nursing and other care staff who are in a position to provide information. This needs to be done with honesty, but also with compassion and skill, and requires training in the right approaches and methods to use. Problems and fears of the patient and their family may be concerned not only with the physical aspects of dying, but also with the psychological, emotional and spiritual dimensions. Palliative care specialists require expertise in all of these areas, but they need also to be able to call on the skills of others when necessary, and when the dying person indicates they would welcome such help.

There is relatively little research on the palliative care needs of non-cancer patients, or on the effectiveness of specialist care in meeting those needs. It should not automatically be assumed that approaches developed in cancer care will necessarily be wholly transferable. Moreover, support for people who are terminally ill has implications for services other than those of the NHS. The Nuffield Foundation's Phoenix Fund has supported a number of projects concerned with death, dying and loss, which have included a therapeutic garden in a hospice; a Crossroads care attendant scheme supporting carers looking after someone with a terminal illness; support for carers of dementia sufferers in need of counselling with bereavement; and support for elderly people with HIV and AIDS (Smith, 1995).

We recommend that the Government encourages the spread of specialist palliative care, perhaps through the establishment of a special grant or ear-marked funding, and that the effectiveness of interventions should be subject to evaluation.

4.2 Death education

Many of the difficulties which people experience in talking about death, or dealing with the process of death, reflect the problems which society in general has with such matters. Because of the success in extending average life expectancy, most deaths occur among older people. However, the terminal illness and death of some younger people, has, in recent years allowed a more honest exploration in the media of the experience of dying. The deaths of journalists Oscar Moore from Aids, and of Ruth Picardie from cancer, were both shared with the public through weekly columns in *The Guardian*, and *The Observer*, and in the subsequent publications in book form. There has been much debate over the rights and wrongs of this style of confessional journalism, and of the vicarious response of the public sharing in the intimate details of the life and death of people they do not know. Whatever the arguments, it is undeniable that such experiences have allowed death and dying to be explored more honestly and publicly.

We believe that more needs to be done to facilitate such honesty, and to help people to engage with dying as a part of living. The media has a role to play here in how it presents death, and how it portrays modern deathbed scenes.

The Dead Citizens Charter was developed by the National Funerals College in an attempt to improve the quality and relevance of modern funerals:

“Funerals most often fail to provide comfort and an opportunity for remembrance when nothing is said about the life of the person who has died. If the life of any dead person is to be respected, then funeral practice needs to be relevant to them as individuals. Whilst some funeral services today achieve this, many are open to criticism for being hypocritical and bureaucratic, dull, impersonal and hurried. They replace mystery with mistrust and can trample over the wishes of the person who has died and the need of survivors to say goodbye in their own way.” (National Funerals College, 1998, P. 4).

The Charter addressed four areas in which funerals need to change to meet the needs of the dead and their surviving family and friends:

- To exercise informed choice.
- To be confident that expressed wishes will be respected.
- To expect that survivors will be helped and supported in the future.
- To post-funeral care of graves and memorials.

Informed choice covers a broad territory from the right to information and the right to choose between burial and cremation, to the right to arrange a funeral without the services of a funeral director, and to choose who should conduct the funeral service, and what happens to the body before the funeral (for example, whether it should lie at home and what clothes should be worn).

The Natural Death Centre has similarly set out to “provide information and support for families caring for the dying at home, to research improvements in care for those dying at home and elsewhere, and to help families arrange funerals with or without undertakers, providing consumer research on the funeral trade” (Smith, 1995, P. 26). The Centre is not a pro-euthanasia organisation, but encourages people to take responsibility for planning their own death and dying. A ‘death plan’ proforma has been developed which allows people to record not only their wishes about how they want to be treated in the event of a terminal illness, but also details about who and what should be present in the final days, the type of music that should be available etc. A similar document on funeral wishes allows for instructions to be recorded on preferences for laying out, type of coffin, instructions for the funeral etc (Smith, 1995). The Centre has also promoted cheap ‘do it yourself’ funerals and established the Association of Nature Reserve Burial Grounds to allow woodland burials. **We regard all of these issues as important steps in the deprofessionalisation of death, and would encourage the further removal of unnecessary legal impediments.**

Just as there are education and training implications for the professionals involved in the care of the dying, so there are implications for the ‘death education’ of us all. The concept of citizenship is now recognised as something which should be taught in schools – that young people should be aware of their rights and responsibilities in society. Similarly, sex education, and preparation for adult relationships is seen as important for young men and women, particularly in the light of concern over high rates of teenage pregnancy (Department of Health, 1999d). We believe that there would be considerable merit in extending this approach to embrace not only exploration of the process of growing up, but also issues about growing older and reaching the end of life. **We recommend that schools’ responsibilities for education for life should include positive consideration of ageing, and understanding of the nature of dying, and the rituals of death.**

As we enter the 21st century and technological progress continues apace, our lives will become more dominated by computers and other technology. The pace of change over the last decade or so hints at what may be to come. Some of this is welcome and can be liberating, but some of it is less benign. Technological advances in medicine, as in other aspects of life, are extending the realms of what is feasible in terms of interventions, treatments and continued maintenance of life. We believe that there need to be limits to such intervention. We are not seeking to lay down rules about the withdrawal of treatment, or the introduction of euthanasia, but we *do* support steps which will increase individuals' control and autonomy. This includes having control over the nature and form of the end of life. The quality of life is all important. Throughout this paper we have addressed issues which we believe will contribute to improving the quality of life of older people. There is every reason why such principles should also be reflected in the final stages, and that the over-riding objective should be the attainment of a good death.

5 Conclusions

Angela 1982–2085

Angela's life was a long and healthy one. Born towards the end of the twentieth century she, and her younger sister Katy grew up in a comfortably off (although by no means wealthy) family. Like most of her peers, Angela went on to University, and then travelled for a while before starting work. Together with three friends, Angela set up her own business, offering computer maintenance and software consultancy.

Angela married her long time partner, Steve, when she was 31 and they had already had two children together. When she was 40, Steve left her to live with a woman he had recently met. Although initially devastated by this development, Angela and the children picked up the pieces and carried on. She had supportive friends around her (including her business partners) and her family also played an important part in helping her move on, even though they did not live close by. Her financial independence with her business meant that Steve's departure did not have catastrophic consequences for her income. She carried on working and had little time to feel depressed by the situation.

Angela was not a fanatic about her health, but she did care about eating properly and taking exercise. Since she was a child she had been a regular swimmer, and when she couldn't be bothered going to the gym after work, she usually spent time at home using the exercise bike and weight machine. She looked after herself, and saw her doctor for a general health check once a year. Her great fear was of developing dementia. Her grandmother had died following several years of Alzheimer's disease and Angela had been appalled by its effects and how her grandmother had ceased to recognise the family or to know who she was. Angela did not go on to develop Alzheimer's herself, but she had a friend who had begun to show symptoms in her mid-70s. The symptoms were controlled, and the disease halted by medication which had been hailed as a breakthrough in 2020, but which – like penicillin in her parents' day – was now commonplace and had been considerably refined and improved.

As she got older, Angela did not suffer the pain and disability of arthritis – as so many people had done in her grandparents' day. Anti-inflammatory drugs had been developed which not only relieved pain and swelling, but if used early enough in the disease were highly successful in controlling further degeneration. Such treatments had, to a large extent, been overtaken by stem cell therapies which were able to regenerate damaged tissue and stop recurrence of the condition without the need for continuing medication.

By the time she reached her 100th birthday, Angela was still in excellent health and enjoying a high quality of life. She had remained as a partner in the company which had grown enormously, and which provided her with a good income. Although she had stopped full time work in the business when she was 55, she had continued to work on a consultancy basis for the company, and for a number of others.

Most of her friends and contemporaries were still alive, although over the last ten years of her life Angela found herself attending more and more departure parties. When her own grandfather had died in 1998 when he was 78, Angela had visited him in hospital. He had a major stroke and she had been alarmed by the sight of him wired up to machines. He had stayed like that for several weeks before he eventually died. Angela was determined that she would not end up the same way.

In 2085 Angela was 103 and feeling very tired. She had been feeling unwell for the previous three months and her doctor had told her that her body was beginning to shut down. She deteriorated quite quickly, and it became clear she was dying. She asked her granddaughter to get in touch with her friends and family and to invite everyone for her departure day. It was a great day. Angela was aware of what was happening; she was surrounded by people she cared about. Although she felt weary and worn out, she was not in great pain or discomfort, thanks to the care of her doctor and other support staff. People came and went through the day – old and young alike. Towards evening she died peacefully, there were just her closest friends and family remaining with her. It had been a day of laughter and memories, good food and wine, and Angela had been delighted to see everyone and say goodbye.

5.1 Vision or fantasy?

Angela's story is one scenario of how the future could develop. The future must remain uncertain, and we cannot know whether the vision for Angela's life will be fulfilled. However, we believe that it *could* be. On the eve of the new millennium, there are reasons to believe that the scenario which has been outlined is achievable, and not mere fantasy. This is not about the discovery of the magic solution to overcome the reality of ageing; we are not searching for Roald Dahl's 'Wonka Vite', where each pill taken makes you younger by 20 years (Kirkwood, 1999). However, today there are too many experiences which are far closer to those of Agnes than of Angela. The challenge for the future is to ensure that the opposite becomes true.

We have made numerous recommendations throughout the paper. We believe that these need to be variously addressed at a number of different levels. In this final chapter, therefore, we draw together the key recommendations.

5.2 Prevention and compression of morbidity

RECOMMENDATIONS TO CENTRAL GOVERNMENT

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- 1 Poor demographic data present serious limitations for planning and forecasting, and it is recommended that a national longitudinal survey be established to facilitate the monitoring of trends in health expectancy.
- 2 Reducing the need for long term care by reducing the incidence of chronic illness and disability should be an explicit objective of health policy.
- 3 Public health targets for reducing mortality must be matched by clear strategies for reducing ill health and morbidity.
- 4 The target of healthy ageing should be adopted as an integral part of a national strategy for improving public health.
- 5 Health promotion messages, for example in relation to cardio vascular disease, should be extended to the population aged 75+.
- 6 Further development is required of specialist rehabilitation services to increase survival and minimise disability following stroke.
- 7 Effective screening methods should be developed to identify women at particular risk of osteoporosis, with a view to offering HRT at menopause.
- 8 Further research is required to establish the most effective strategies for reducing falls and their consequences among older people.
- 9 Further research is required to establish the most effective models of rehabilitation following fractured neck of femur, and other fractures.
- 10 Further research is required to identify the risk factors for osteoarthritis, and the scope for early detection and effective treatments which minimise the need for surgical intervention and reduce disability.
- 11 Further research is required to improve understanding of the aetiology of dementia, and to explore the scope for pharmaceutical and other treatment which may delay and reduce the onset of symptoms.
- 12 Further research is required into the effectiveness of different therapies in the treatment of urinary incontinence, allied to awareness raising of prevention and treatment among the population in general.

RECOMMENDATIONS TO HEALTH AND SOCIAL CARE PURCHASERS & PROVIDERS

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- 1 Local public health strategies should develop plans for reducing ill health and morbidity, and establishing targets for healthy ageing, alongside targets for saving lives.
- 2 Further development is required of specialist rehabilitation services to increase survival rates and minimise disability following stroke.
- 3 Protocols for treatment of fractured neck of femur should seek to maximise rehabilitation potential through the appropriate and timely involvement of elderly care physicians.
- 4 Joint replacement should be given higher priority given the proven effectiveness of intervention and the scope for extending the period of independent living.
- 5 Improved take-up of eye tests and hearing checks should be encouraged among older people.
- 6 Improved awareness raising of prevention and treatment of urinary incontinence should be promoted.

RECOMMENDATIONS TO INDIVIDUALS

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There is much that individuals can do for themselves to reduce ill health and maximise well being, including:

- 1 Undertaking regular physical exercise, eating healthily (particularly including fresh fruit and vegetables) avoiding smoking and drinking alcohol only within recommended limits.
- 2 Ensuring that good dietary and exercise habits are established in childhood, and maintained throughout adulthood.
- 3 Taking up opportunities for tests and detection of health problems, and seeking attention early on.

5.3 Models of support

RECOMMENDATIONS TO CENTRAL GOVERNMENT

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- 1 Models of health and social care support should be grounded on an explicit framework of principles which include: maintaining independence; maximising personal dignity; promoting social inclusion; focusing on individual needs; ensuring flexibility; supporting carers; ensuring staff are skilled with appropriate knowledge and expertise, and ensuring services are integrated and comprehensive.
- 2 Achieving social inclusion for older people requires a policy strategy which is coherent across not only health and social care but also: housing, education, employment, transport, social and leisure activities etc. The rhetoric of 'joined up government' needs to be matched in practice.
- 3 The development and promotion of models of support consistent with the principles framework could be a core responsibility of a 'National Care Commission', and we endorse the establishment of such a body as recommended by the Royal Commission on Long Term Care.
- 4 An integrated approach to the development of national standards across all services is required which reflects common principles and values.
- 5 New methods of developing and disseminating good practice in the support of older people should be piloted.
- 6 Further guidance is required on the focus of prevention work and low level support to assist the development of local strategies.
- 7 Evaluation is required to determine the value of specific low level services in preventing or postponing deterioration and increased dependency.
- 8 Further guidance is required on assessment – indicating what should be included, and how this might best be undertaken within an overall framework which focuses on the person, and actively involves them in the process.
- 9 The requirement for health and social services to identify carers among their patients and clients should be matched by requirements to use this data in developing local strategies.
- 10 Direct Payments should be further extended to carers.
- 11 Carers' needs for information might best be met through a single point of contact to act as a clearing house and referral agency.

- 12 The right to time off for carers under the Employment Relations Act 1999 is a welcome development, but further recognition is required to provide statutory carers' leave.
- 13 The Invalid Care Allowance should be reformed both to improve the level of benefit, but also to revise the eligibility criteria which exclude many carers on the grounds of age or because the benefit is contingent on the benefits paid to the person cared for.
- 14 Further improvements are needed to give carers entitlement to second pensions.
- 15 We support the key proposal of the Royal Commission on Long Term Care that personal care should be free, and we urge the Government to accept the recommendation.
- 16 Further modelling is required to explore the balance between personal care costs, living costs and housing costs, as recommended by the Royal Commission.
- 17 Further work is required to examine the skill mix required in providing personal care in different settings, and to develop the most appropriate models.

RECOMMENDATIONS TO HEALTH AND SOCIAL CARE PURCHASERS & PROVIDERS

- 1 Models of health and social care support should be grounded on an explicit framework of principles which include: maintaining independence; maximising personal dignity; promoting social inclusion; focusing on individual needs; ensuring flexibility; supporting carers; ensuring staff are skilled with appropriate knowledge and expertise, and ensuring services are integrated and comprehensive.
- 2 Maximum opportunities for rehabilitation should be included within care assessment, and this should happen before irreversible decisions on long term care placements are made.
- 3 Regular breaks for carers should be routinely built into care plans, and not introduced only as emergency measures to 'keep carers going'.

5.4 Rationing and inequality

RECOMMENDATIONS TO CENTRAL GOVERNMENT

- 1 We recommend that the Government should accept responsibility for making rationing decisions within the NHS explicit and transparent; a clearer framework for any proposed rationing would clarify the scope and objectives of the NHS.
- 2 Strategies for reducing health inequalities should address the inequalities of ageing.

RECOMMENDATIONS TO HEALTH AND SOCIAL CARE PURCHASERS & PROVIDERS

- 1 Strategies for reducing health inequalities should address the inequalities of ageing.

5.5 The end of life

RECOMMENDATIONS TO CENTRAL GOVERNMENT

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- 1 Medical and nursing education and development, and that of others involved in caring for people, should include the care of the dying person and ensure that the values and principles of palliative care are embedded.
- 2 Further development is required of clinical nurse specialists in palliative care, and evaluation of their contribution to palliative care.
- 3 Specialist palliative care should be actively promoted through special grant funding, and the effectiveness of care should be evaluated.
- 4 Unnecessary legal impediments which over-professionalise the process of death should be removed.
- 5 Educational responsibilities for education for life should include positive consideration of ageing, and understanding of the nature of dying and the rituals of death.

RECOMMENDATIONS TO HEALTH AND SOCIAL CARE PURCHASERS & PROVIDERS

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- 1 All palliative and terminal care services should be based on a clear and widely understood set of principles for a good death, which maximise individual autonomy and control over the end of life.
- 2 Continuing professional education and training of all staff involved in the care of the dying patient should ensure understanding and adherence to values and principles of palliative care.
- 3 Health and social care professionals must recognise that the end of life should be approached as a positive experience, and not as a failure. The job of such professionals is to support people in achieving a good death, and to help them, their families and loved ones, to maintain control of the situation as they want it to be.

RECOMMENDATIONS TO INDIVIDUALS

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- 1 Control of the end of life is dependent on you making your wishes known to close friends and relatives.
- 2 If the nature of the end matters to you, think about setting out a 'death plan' which records your wishes about how you want to be cared for, who you want to be present, and the arrangements for your funeral.

5.6 In conclusion

We have emphasised that the key to addressing the health and support needs of an ageing population is to achieve the social inclusion of older people. Throughout this paper we have addressed the steps which need to be taken in order to bring about this transformation. We have not attempted to consider the entire canvas of the future of health and care. To do so would require a series of major reports. Rather, we have focused on the four core themes which we believe to be central in considering the challenge of an ageing population, that is: prevention and the compression of morbidity; models of support; rationing and inequality; and the end of life. How to improve the health and well-being of older people is *the* key issue. With longer *healthy and active* lives, the crude link between ageing and dependency can be broken.

We are not complacent about the future, but neither are we pessimistic. We do not line up with those who are alarmed by the scale of demographic change, but neither do we side with those who say there is no problem to be addressed. We know that the growth in the numbers of elderly (particularly very elderly) people *does* present challenges, not least because the response to earlier increases has been so poorly managed. However, if our recommendations are adopted, we believe we can look to the future with hope and optimism. The best is yet to come.

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Appendix Population projections

Table 1 Projected Population of the United Kingdom, aged 65+, 1996-2061, by age and sex (thousands)

| Age | 1996 | 2001 | 2011 | 2021 | 2031 | 2041 | 2051 | 2061 |
|-----------|------|------|-------|-------|-------|-------|-------|-------|
| 65-69 M | 1242 | 1233 | 1472 | 1622 | 2126 | 1719 | 1721 | 1764 |
| 65-69 F | 1404 | 1339 | 1574 | 1708 | 2161 | 1738 | 1761 | 1806 |
| 70-74 M | 1068 | 1052 | 1123 | 1545 | 1657 | 1821 | 1470 | 1637 |
| 70-74 F | 1344 | 1269 | 1282 | 1721 | 1794 | 1923 | 1566 | 1752 |
| 75-79 M | 732 | 811 | 847 | 1059 | 1191 | 1583 | 1285 | 1296 |
| 75-79 F | 1092 | 1134 | 1066 | 1292 | 1417 | 1809 | 1458 | 1484 |
| 80-84 M | 453 | 471 | 552 | 640 | 909 | 1007 | 1115 | 910 |
| 80-84 F | 849 | 827 | 840 | 912 | 1243 | 1322 | 1424 | 1168 |
| 85-89 M | 206 | 225 | 278 | 332 | 444 | 517 | 701 | 570 |
| 85-89 F | 522 | 523 | 549 | 572 | 737 | 826 | 1069 | 862 |
| 90+ M | 67 | 89 | 118 | 160 | 211 | 314 | 374 | 439 |
| 90+ F | 273 | 324 | 351 | 394 | 488 | 688 | 783 | 897 |
| Total 65+ | 9252 | 9297 | 10052 | 11957 | 14378 | 15267 | 14727 | 14585 |
| 75+ | 4194 | 4404 | 4601 | 5361 | 6640 | 8066 | 8209 | 7626 |
| 85+ | 1068 | 1161 | 1296 | 1458 | 1880 | 2345 | 2927 | 2768 |

Source: Government Actuary's Department (1999), *1996-based National Population Projections*, Prepared by the Government Actuary in consultation with the Registrars General. Office for National Statistics. Series PP2 No. 21

Table 2 Projected Age Structure of the UK Population 1996 – 2061

| Age | 1996 | 2001 | 2011 | 2021 | 2031 | 2041 | 2051 | 2061 |
|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| 0-4 | 3763 | 3602 | 3412 | 3482 | 3336 | 3228 | 3209 | 3115 |
| 5-9 | 3905 | 3772 | 3478 | 3458 | 3441 | 3269 | 3232 | 3181 |
| 10-14 | 3690 | 3914 | 3618 | 3429 | 3499 | 3354 | 3247 | 3228 |
| 15-19 | 3523 | 3727 | 3817 | 3524 | 3504 | 3487 | 3317 | 3278 |
| 20-24 | 3803 | 3613 | 4037 | 3743 | 3556 | 3626 | 3482 | 3374 |
| 25-29 | 4577 | 3858 | 3862 | 3953 | 3664 | 3644 | 3629 | 3458 |
| 30-34 | 4843 | 4603 | 3679 | 4101 | 3812 | 3626 | 3696 | 3553 |
| 35-39 | 4289 | 4858 | 3887 | 3892 | 3984 | 3697 | 3678 | 3664 |
| 40-44 | 3803 | 4286 | 4604 | 3692 | 4112 | 3826 | 3644 | 3714 |
| 45-49 | 4130 | 3781 | 4814 | 3860 | 3869 | 3961 | 3680 | 3663 |
| 50-54 | 3466 | 4070 | 4202 | 4518 | 3632 | 4046 | 3768 | 3590 |
| 55-59 | 2986 | 3378 | 3645 | 4655 | 3741 | 3757 | 3850 | 3579 |
| 60-64 | 2773 | 2858 | 3821 | 3979 | 4294 | 3463 | 3862 | 3598 |
| 65-69 | 2646 | 2572 | 3046 | 3330 | 4287 | 3457 | 3482 | 3570 |
| 70-74 | 2412 | 2321 | 2405 | 3266 | 3451 | 3744 | 3036 | 3389 |
| 75-79 | 1824 | 1945 | 1913 | 2351 | 2608 | 3392 | 2743 | 2780 |
| 80-84 | 1302 | 1298 | 1392 | 1552 | 2152 | 2329 | 2539 | 2078 |
| 85-89 | 728 | 748 | 827 | 904 | 1181 | 1343 | 1770 | 1432 |
| 90+ | 340 | 413 | 469 | 554 | 699 | 1002 | 1157 | 1336 |
| TOTAL | 58801 | 59618 | 60929 | 62244 | 62822 | 62256 | 61022 | 59581 |

Source: Government Actuary's Department (1999), *1996-based National Population Projections*, Prepared by the Government Actuary in consultation with the Registrars General. Office for National Statistics. Series PP2

Table 3 Per cent of total population in each age band

| Age | 1996 | 2001 | 2011 | 2021 | 2031 | 2041 | 2051 | 2061 |
|-------|------|------|------|------|------|------|------|------|
| 0-4 | 6.4 | 6.0 | 5.6 | 5.6 | 5.3 | 5.2 | 5.2 | 5.2 |
| 5-9 | 6.6 | 6.3 | 5.7 | 5.5 | 5.5 | 5.3 | 5.3 | 5.3 |
| 10-14 | 6.3 | 6.6 | 5.9 | 5.5 | 5.6 | 5.4 | 5.3 | 5.4 |
| 15-19 | 6.0 | 6.2 | 6.3 | 5.7 | 5.6 | 5.6 | 5.4 | 5.5 |
| 20-24 | 6.5 | 6.1 | 6.6 | 6.0 | 5.7 | 5.8 | 5.7 | 5.7 |
| 25-29 | 7.8 | 6.5 | 6.3 | 6.3 | 5.8 | 5.9 | 5.9 | 5.8 |
| 30-34 | 8.2 | 7.7 | 6.0 | 6.6 | 6.1 | 5.8 | 6.1 | 6.0 |
| 35-39 | 7.3 | 8.1 | 6.4 | 6.3 | 6.3 | 5.9 | 6.0 | 6.1 |
| 40-44 | 6.5 | 7.2 | 7.6 | 5.9 | 6.5 | 6.1 | 6.0 | 6.2 |
| 45-49 | 7.0 | 6.3 | 7.9 | 6.2 | 6.1 | 6.4 | 6.0 | 6.1 |
| 50-54 | 5.9 | 6.8 | 6.9 | 7.3 | 5.8 | 6.5 | 6.2 | 6.0 |
| 55-59 | 5.1 | 5.7 | 6.0 | 7.5 | 6.0 | 6.0 | 6.3 | 6.0 |
| 60-64 | 4.7 | 4.8 | 6.3 | 6.4 | 6.8 | 5.6 | 6.3 | 6.0 |
| 65-69 | 4.5 | 4.3 | 5.0 | 5.3 | 6.8 | 5.6 | 5.7 | 6.0 |
| 70-74 | 4.1 | 3.9 | 3.9 | 5.2 | 5.5 | 6.0 | 5.0 | 5.7 |
| 75-79 | 3.1 | 3.3 | 3.1 | 3.8 | 4.2 | 5.4 | 4.5 | 4.7 |
| 80-84 | 2.2 | 2.2 | 2.3 | 2.5 | 3.4 | 3.7 | 4.2 | 3.5 |
| 85-89 | 1.2 | 1.3 | 1.4 | 1.5 | 1.9 | 2.2 | 2.9 | 2.4 |
| 90+ | 0.6 | 0.7 | 0.8 | 0.9 | 1.1 | 1.6 | 1.9 | 2.2 |

Source: Government Actuary's Department (1999), *1996-based National Population Projections*, Prepared by the Government Actuary in consultation with the Registrars General. Office for National Statistics. Series PP2 No. 21

Figure 1 Composition of UK Population 65+, 1996-2061