Supporting frail older people

Independence and well-being 3
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Introduction

1 New models and approaches to supporting frail older people

2 Making it happen

References

Acknowledgments
Introduction

1 This is the third report in the Audit Commission’s series looking at ways to promote the independence and well-being of older people. It aims to provide an overview of the many emerging models from the US and the UK with potential to promote the independence and well-being of frailer older people. This report has been produced in partnership with Better Government for Older People (BGOP).

2 Independence and well-being come under particular threat when older people become frail or ill. The likelihood of frailty and illness increases as people age (Exhibit 1). This, combined with a lack of the right kind of support, can place limits on older people’s ability to continue enjoying life to the full. Over half of all people aged 75 to 84 reported that they have a long-term illness that limits what they do (2001 census), and this rises to over 70 per cent of people aged over 85. Many older people have more than one condition (‘multiple pathologies’), severely limiting their abilities.

3 But most older people still want to maintain their independence and sense of well-being, and to minimise the impact of these limitations on their lives. A clear message from research carried out with focus groups of older people for the Audit Commission and the Department for Work and Pensions by Age Concern England, is that independence is not just about being able to do things for oneself. Many attending the groups were receiving substantial amounts of help from statutory services, relatives and friends, but they reported that they continued to feel independent so long as they were able to exercise choice and control. Interdependence; this is giving help to others, as well as receiving it; was also crucially important to older people.

4 The findings of this research were summarised in the first supporting report of this series (Ref. 1). That report looks at what independence means for older people and concludes that, to be independent, older people need to feel they have choice and control over how they live their lives. It also reports the key factors that older people themselves said were important for keeping them independent:

- suitable well-maintained housing;
- a safe and friendly neighbourhood;
- good social activities and networks, keeping them busy;
- an ability to get out and about;
- adequate income;
- good information when they need it; and
- health and healthy living.

Being able to play an active role in the life of the community and having their contribution recognised and valued were also extremely important.
The first report also summarised the large and growing body of Government policies and initiatives that help people to stay independent.

The second report focused on what local authorities working with other agencies can do to promote independence and well-being for all their older citizens (Ref. 2). It explored:
- how to engage effectively with older people;
- what should be included within the scope of a local strategic approach;
- how to develop a strategic approach;
- how to get started; and
- how to show that the work is making a difference to older people.

This third report looks specifically at some of the new ways to sustain and support frail older people, rather than reacting only when things go wrong. It is supported by two further reports that look at
- the role that assistive technology can play (Ref. 3); and
- how support for carers can also help (Ref. 4).

**Exhibit 1**

**Limiting long-term illness for people aged between 50 and 85 & over**

Illness and disability increase with age.

Source: Audit Commission analysis of Office for National Statistics data

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1 Older peoples comments (in italics) are quoted from reference documents.
Older people who are frail or who have long-term illnesses need extra support to manage their health conditions so that they can maintain the aspects of their lives that they most value. They still report that the key factors set out in paragraph 4 are crucial, but they need additional and different types of help to overcome the limitations of their condition. Approaches to supporting frail or chronically ill older people therefore need to go beyond clinical issues to include the whole range of factors that older people see as most important, such as being able to maintain interests and social networks, having a comfortable home, an adequate income and being able to get out and about (Case study 1).

**Case study 1**  
A whole person approach

Jim is a 78 year old man living in the north west. His repeated emergency admissions for severe chronic obstructive pulmonary disease (COPD) brought him into contact with the local COPD team, who worked closely with him to bring his medical condition under control and explore with him other areas of his life he would like to improve. Jim’s great passion was growing primulas for competition, and his horticultural successes were a source of enormous pride and pleasure to him. However, since his medical condition had worsened, a year or so previously, he had been forced to abandon this. The greenhouse was located at the bottom of Jim’s long and narrow garden and he felt anxious about the possibility of having breathing problems while working there, so far from help. Jim had always been active and since his retirement had spent a great deal of time working with his plants, so he was becoming increasingly frustrated and depressed at being confined to the house. The COPD team installed an oxygen supply in the greenhouse so that Jim felt confident about returning to his primulas. As well as reducing Jim’s emergency admissions, by improving his medication and increasing his confidence at managing his COPD, the team’s intervention transformed Jim’s sense of well-being and his quality of life.

*Source: Audit Commission*

Services for older people have traditionally focused on a narrow range of intensive services that support the most vulnerable in times of crisis. Over the years there have been many attempts to develop and change the way that services are delivered to older people who are frail or who have long term illnesses – key processes like case and care management have been defined and re-defined many times. Yet research has highlighted many problems and shortfalls in these arrangements and little evidence of ‘intensive care management’ beyond a few successful projects (Ref. 5).

At the same time, emergency admissions to hospital have been rising. Although people aged 65 and over make up only 16 per cent of the population, they occupy almost two-thirds of general and acute hospital beds, and account for one-half of the recent growth in emergency admissions (Ref. 6). This may reflect inadequate availability of the right support, at the right time. The Government has indicated that it wishes to see the future growth in the number of emergency admissions limited to 1 per cent.
If emergency admissions are to be reduced, or at least contained, then the incidence of acute episodes needs to be reduced. This, in turn, requires better management of any underlying chronic diseases, combined with support to maintain confidence, community engagement and quality of life.

Supporting and sustaining frail older people and promoting their independence and well-being requires approaches that help them to manage their health in a proactive way, while maintaining quality of life, as part of a comprehensive, whole system approach (Ref. 7).

Development in this area is rapid, and initiatives are being established at both local and national levels. Because of this state of flux the report cannot present a comprehensive picture, nor does it attempt to. It seeks to draw out the early lessons from key initiatives and to offer advice about areas for potential future development. It focuses on the organisation of services and not on clinical care.

- chapter 1 describes a range of initiatives from the UK and the US and presents the available evidence on their impact, both on the well-being of older people and on the wider system; and
- chapter 2 highlights the key steps and factors to consider in implementing a proactive approach to older people.

The language that is commonly used to describe many of the approaches included in this report is problematic. Terms such as ‘chronic disease management’, for example, do not sit comfortably with the older person-centred values and citizen focus that underpin this series of Audit Commission reports. The terminology reflects the starting point for many of these initiatives, which is to reduce pressure on hospitals, rather than to promote well-being and independence. We have, however, adopted this terminology where it is widely understood and no accepted alternative yet exists.

The report focuses on the needs and aspirations of the group that we refer to as ‘frailer’ older people. We have used this term to include:

- older people with one or more chronic, long-term condition, such as heart disease or COPD;
- older people who may not have a specific, diagnosed condition, but who may nevertheless require support from care services in order to live independently; and
- older people who are on the threshold of either of these two groups.
Despite the growing proportion of NHS care that is provided to patients with an underlying chronic disease (many of them older people), the focus of health service provision is still very much on the care of acutely ill people. Yet many people who become acutely ill have an underlying chronic problem. In a proportion of these, better management of the underlying chronic disease may prevent or reduce the chances of an acute episode occurring (Ref. 8).

In the UK, chronic illness is the single largest cause of poor health and mortality, with people with chronic illness make greatest use of healthcare resources. Acute episodes of conditions such as heart failure, diabetes and respiratory problems (such as COPD), account for a high proportion of emergency hospital bed days. Other emergencies, such as falls and fractures, are often caused by an underlying long-term condition. Levels of chronic illness are predicted to increase as the population ages. However, as well as being costly, the effects of chronic illness on older people’s quality of life and well-being are also severe. Successful strategies to manage chronic illness and its effects proactively will, therefore, not only reduce pressure on hospitals, but will also transform lives, as case study 1 illustrates.

At present, many NHS and social care communities are struggling to meet shifting needs. This section looks at a number of new approaches and models of care that are being developed in the UK and the US. Such approaches could contribute to tackling this struggle, as well as to improving well-being. In a number of cases, approaches that have been developed in the US are being adapted to fit the UK context, in particular, by strengthening the contribution of social care and other agencies, including housing, advice services and voluntary organisations. This section looks at:

- approaches that tackle a single chronic disease; and
- examples of intensive case management that are being developed to support frail older people with a variety of conditions;

These approaches cover a broad range of needs, from people who may need limited support to manage a single disease, to frailer older people with complex needs, who are likely to need a large amount of care and support from health and social care, as well as from other services. The earlier supporting reports in this series, together with the Audit Commission’s previous work on whole system working, conclude that initiatives to support frailer, or chronically ill older people should be underpinned by a number of principles:

- increasing choice and control, by enabling older people to play a more active role in managing their own health and care and by building partnerships between older people and professionals;
- proactively promoting health, by focusing on ‘upstream’ interventions that aim to enhance well-being and avert crises;
- adopting a whole-person approach, by exploring the whole range of issues that have an impact on older people’s well-being, based on broad assessment processes; and
building a whole-system response, by ensuring that not just the NHS, but also social services, housing, the pensions service and a range of other agencies are appropriately involved.

Many of the initiatives described in this section fulfil at least some of these principles, although, at the moment, very few fulfil them all. In many cases the starting point for such developments was the need to reduce pressure on acute hospitals. While there is growing evidence to suggest that many of the initiatives described in this report do achieve these goals, equally importantly, proactive approaches can bring enormous benefits to older people, as well as to the wider NHS and social care system (Box A).

Box A
Benefits of proactive approaches

For the older person:
- increased confidence;
- ability to maintain valued aspects of life, such as interests or friendships;
- independence through greater choice and control; and
- greater role in decision-making.

For the NHS/social care system:
- fewer hospital admissions;
- shorter average lengths of stay;
- reduced A&E attendances;
- less use of GP services;
- increased capacity; and
- more efficient use of resources.

Source: Audit Commission

Disease-specific approaches

A good understanding of the incidence of chronic conditions is needed if we are to plan and respond effectively. It is important to:
- investigate the volume of emergency admissions over time;
- identify why people are being admitted; and
- identify which groups of people are being admitted.
Chronic obstructive pulmonary disease

21 In 2000, the King’s Fund examined Hospital Episode Statistics (HES) data for 1997/98 to 2000/01 in London (Ref. 9). By looking at when people had been admitted, they noted that people with respiratory problems were more likely to be admitted over the Christmas period (Exhibit 2). Although this group constituted only 13 per cent of all emergency admissions, a high proportion of cases were concentrated into a short space of time. A peak like this can place enormous pressure on services – particularly if it takes place just after an extended holiday period.

22 The real pressures were coming from older people admitted with COPD, pneumonia and other acute lower respiratory infections (Exhibit 3, overleaf). Rates of admission were higher in some parts of the city than in others. These rates correlated with the socio-demographic characteristics of the population, such as the number of older people living alone, the extent of poverty, the number of residents from black and minority ethnic groups and the way that people use healthcare. There may also be a relationship with the quality of primary and community health services, the availability of hospital beds, or the quality and availability of social services.

23 These research findings point to some clear opportunities for care communities to develop more effective ways to support older people with COPD in the community. Evidence from existing initiatives focusing on COPD suggest that many people with COPD are not clear about how to use their medications effectively and have high levels of anxiety about their breathing difficulties. This anxiety can limit older people’s activities and affect their quality of life. In some parts of the country, services are developing proactive approaches to supporting people with COPD.

24 A useful starting point is to identify people who attend A&E regularly. Assessment and case management can lead to a better appreciation of the wider issues that precipitate their A&E visits and to a better strategy for dealing with respiratory attacks (Case study 2).
Exhibit 2

Number of emergency admissions per week in London with respiratory problems

People with respiratory problems were more likely to be admitted over the Christmas period.

![Chart showing number of emergency admissions per week in London with respiratory problems.](chart)

*Source: King’s Fund*

Case study 2

Tameside and Glossop Community Rehabilitation Team – targeting people who have had multiple admissions

In Tameside and Glossop, the Community Rehabilitation Team has developed a case-management approach for supporting people diagnosed with COPD. Here, again, a survey of admissions to the local acute hospital established the high use of hospital beds by people with COPD. The Team felt that with better-managed care, people with COPD would have a better quality of life, gain control over their condition and make more appropriate use of healthcare resources.

The Team offers older people with COPD, who are beginning to show a pattern of multiple admissions to hospital, a six-week package of rehabilitation, followed by a period of support. A key-worker develops a therapeutic relationship with each person in order to develop a thorough understanding of their needs and those of any carers they have. The key worker sets up a programme of visits that relates to patterns of exacerbation and anxiety. Visits are usually very frequent to begin with, but are reduced as education and support becomes effective, and confidence builds.
The model starts with a multidisciplinary assessment of needs, which involves both the older person and any carers. A ‘respiration pathway’ is identified based on evidence. A maintenance plan and an exacerbation plan (what to do in an emergency) are prepared. The Team provides an on-call system and protocol for emergencies. It also undertakes a programme of proactive contacts with the older person. All of the documentation used by the Team is held by the person with COPD.

Source: Audit Commission

Exhibit 3
Number of bed days for selected respiratory conditions, by age 1997 – 2001.
Pressure arises from the level of admissions of older people with COPD, pneumonia and other acute lower respiratory infections.

Source: King’s Fund

In Sheffield, an approach is being adopted that is aimed at everyone with COPD. This is part of a broader strategy to improve both prevention and mainstream services and to develop intensive support for people with more complex needs (Case study 3). The programme highlights the importance of developing a range of services to meet the different needs of people with COPD.
Case study 3
Sheffield pathway of care for people with COPD

In 2000, a survey of the management of COPD in general practice showed that those with COPD were not being identified systematically. Care was fragmented and not always based on evidence. It was poorly resourced and access to care depended on where people lived – particularly for people who were housebound.

To address this problem, COPD was initially identified as a local priority condition in the Health Action Zone programme, and subsequently in the local primary care trust (PCT) business plans. An evidence-based, integrated pathway of care was developed and is in the process of being implemented. The aim is to ensure that care is delivered in a standardised and consistent manner across the city by both primary and secondary care with good access for everyone with COPD.

The initial focus of the work has been to:
- develop an effective strategic planning group with effective partnership working;
- identify and engage with key stakeholders, champions and resources;
- identify and register those with COPD;
- improve the skills of health professionals in both primary and secondary care; and
- produce shared primary and secondary care protocols.

A core package of care is now delivered to people with COPD. This includes:
- influenza and pneumococcal vaccines;
- smoking cessation advice;
- optimisation of therapy; and
- self-management plans.

A specialist package of secondary care has also been developed. This includes:
- a supported discharge service;
- out-patient COPD clinics;
- oxygen support service; and
- pulmonary rehabilitation.

Source: Audit Commission
Heart failure

In 2001, two studies were undertaken, funded by the former NHS London Regional Office, to obtain information about how chronic illness was affecting health services in the local area around Whipps Cross University NHS Trust. The studies involved the two local PCTs: Walthamstow, Leyton and Leytonstone PCT and Chingford, Wanstead and Woodford PCT. The aim of the work was to develop a new model of care for chronic illness (Ref. 10).

In order to understand how local resources were being used, detailed quantitative research was conducted to identify the chronic conditions that consumed the most resources, in terms of hospital admissions, bed days and prescription costs. Chronic illness was confirmed as being a major contributor to local difficulties, responsible for 44 per cent of non-elective admissions and consuming 64 per cent of all hospital non-elective bed days. This was caused by the high prevalence of chronic illness in the population, long inpatient stays and high re-admission rates, resulting from the fact that most people with chronic illnesses were old and frail.

Following consultation with local clinicians and senior managers, asthma and heart failure were identified as the focus of the studies. Each service involved in the study was staffed by 2-3 specialist nurses, who managed between 100 and 150 patients each. The nurses focused on the most vulnerable people, as these were the ones most likely to gain the greatest benefits from the service. The new services operated across the community/hospital interfaces so that people were reviewed in hospitals, clinics, over the phone and at home.

The nurses’ key role was to educate people about their condition and to promote better self-management. Proactive support was an important part of the model in order to ensure compliance, review care plans and identify early signs of difficulties. The nurses managed care according to agreed protocols, which included initiating or changing medications and ordering diagnostic tests.

The heart failure service focused on improving standards of care and improving quality of life, in the belief that this would, in turn, reduce the use of secondary care resources. In the first four months after its launch, 68 people were referred to the service, who were used as the evaluation group. Of these, 37 per cent were over the age of 75 and 56 per cent were male (Case study 4).

The experiences of a number of older people who took part in the study were also evaluated in order to determine the impact on their lives and to assess how well their needs were met (Ref. 11). People felt that the care they received from the nurses increased their feeling of confidence. They felt better informed about their condition and about how to manage it. And they also benefited from the reassurance of being able to get in touch with the nurses for further advice.
Case study 4
The impact of a new model of care for chronic illness in north London

The total number of bed days used by the intervention group reduced by approximately 60 per cent, and bed days associated with admissions of people with a primary diagnosis of heart failure reduced by over 50 per cent. Assuming that each nurse managed 100 people a year, a saving of 2.0 to 2.5 hospital beds per year, per nurse was the end result. At full capacity, this equated to £600,000 a year in net savings for the team. A&E attendances also saw a reduction of 56 per cent.

A comparison was made of the savings in bed days and the cost of providing the nursing team in order to assess the impact on resources. After taking into account the time spent on recruitment and training and the length of time for the service to reach full capacity, it was estimated that a cost benefit ratio of 1:6 was potentially achievable by the third year.

Source: Ref. 10

The majority of the service users and carers agreed that another key advantage of the scheme was that it reduced the number of visits they had to make to GPs and to hospital out-patient clinics. They were also pleased that it reduced re-admissions to hospital. They were able to have tests carried out at home and they gained a greater knowledge of how to manage and control their condition. The team was able to introduce changes in medication.

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33 All people using the service, and their carers, expressed high levels of satisfaction with the care they received from the teams. While this evaluation looked at the experiences of a small number of older people with chronic conditions, the findings of the study were consistent with what older people say is important to them. The scheme helped them to feel more in control and confident about their condition by providing them with better information, reassurance and access to ongoing advice when needed.

Phase III of primary care collaborative

Phase III of the primary care collaborative, which is led by the National Primary Care Development Team, will focus on chronic disease management, initially COPD and diabetes. It will include all practices in England from 2004.

Managing chronic disease in the USA – the Kaiser Permanente experience

Kaiser Permanente is a non-profit, health maintenance organisation in California. In many ways, it is like the NHS, providing a similar range of services for a population equivalent to that of a small country. Costs per head (adjusted to correct for local variations) are similar. Founded in 1945, it is slightly older than the NHS. The Kaiser Foundation Health Plan and Hospitals are integrated with independent physician group practices called Permanente Medical Groups (Ref. 12).
In 1999, Kaiser Permanente launched chronic disease management programmes targeting diabetes, coronary artery disease, hyperlipidemia, asthma and congestive heart failure. At the centre of their approach was a strong focus on the management of people with chronic diseases and the breaking down of barriers between primary and secondary care.

Research has shown that Kaiser uses only one-third of the acute bed days compared to the NHS for the population served. It achieves these results through:

- a strong emphasis on the integration of care and services;
- giving priority to self care and shared care;
- actively managing patients at all stages of their treatment;
- ensuring that people are looked after in the community whenever appropriate;
- using information to provide high-quality care and to ensure effective co-ordination; and
- involving doctors and other clinicians in leadership and management.

NHS clinicians and managers visited California in early 2003 to see how Kaiser works and to learn lessons. They are now incorporating these lessons into their plans by:

- introducing new approaches to chronic disease management;
- developing intermediate care services;
- adapting Kaiser’s use of care pathways to reduce lengths of stay;
- promoting new forms of collaboration between primary and secondary care;
- giving priority to self care and shared care;
- engaging clinicians in service developments and reform; and
- exploring better ways of using the NHS estate, including the development of primary care facilities that support integrated approaches.

More recent research that compares Kaiser with the NHS, found that the NHS could learn from Kaiser’s integrated approach, the focus on chronic disease management and self care and the leadership provided by doctors in supporting this way of working.

Many organisations in the US use a model developed by the MacColl Institute for Healthcare Innovation in Seattle. The model, which has gained widespread credibility in the US, recognises that chronic care takes place within three overlapping ‘galaxies’. These are:

- the wider community;
- the healthcare system, including its payment structures; and
- provider organisations.

I realised the importance of taking the dosage suggested whereas before I thought, oh well, I’m not coughing anymore, perhaps I don’t need to take it. So, that’s helped me considerably.
It provides a multi-dimensional solution with six components (Case study 5).

In the US, the six components that make up the model are treated as interdependent and are very much part of a dynamic approach. The model highlights the importance of a whole range of wider factors that need to be considered if we are to develop more effective ways to manage and support people with chronic conditions.

**Case study 5**

**Chronic care model**

- **Community** – mobilising community resources to meet people’s needs.
- **Healthcare organisation** – creating a culture, organisation and mechanisms that promote safe, high-quality care.
- **Self-management support** – empowering and preparing people to manage their health and healthcare.
- **Delivery system design** – assuring the delivery of effective, efficient clinical care and self-management support.
- **Decision support** – promoting clinical care that is consistent with scientific evidence and individual preferences.
- **Clinical information system** – organising individual and population data in order to facilitate efficient and effective care.

*Source:* Ref. 14

**Intensive case management**

Approaches to manage specific diseases, such as COPD and heart failure, are becoming widely adopted. But most frailer older people do not have one disease in isolation. Often they have several, combined with concerns about a range of other issues, such as benefits or housing. A paper from the King’s Fund highlights the fact that while the National Service Frameworks for single conditions, such as heart disease, have been successful in improving the management of these conditions, it would now be helpful to develop a more generic approach (Ref. 15). Approaches that address a range of health conditions are starting to simultaneously emerge. Many of these originated in the US, where the need to contain rising healthcare costs for people with chronic conditions has led to the growth of new models and approaches.

In the UK, a number of developments are taking place that should help to develop more effective ways to support frailer older people. Intensive case management has been developed in a number of care communities in the UK. This is starting to achieve better outcomes for older people as well as benefits for health and social care services. While UK examples build on experience from the US, most are starting to increase the role played by social care and other services in order to offer a more whole system, older person-centred approach, in line with the principles highlighted above.
Intensive case management is a proactive, community-based approach that combines the contributions of health, social care and other agencies. The approach identifies and targets people who already receive a large amount of support from health and social care services.

The approach was pioneered in the US, where researchers found that a small number of older people use a disproportionate amount of health and social care resources. Systems were introduced to monitor people with chronic health problems living in the community. There is evidence to show that hospital admission rates and lengths of stay have been reduced as a result, as well as the use of other services. While the initial drivers for this may have been primarily financial, each ‘high resource user’ is likely to represent an older person whose life is fundamentally affected by repeated episodes of illness, anxiety about their health and feelings of lack of control.

Various different service models of intensive case management have started to emerge across the country. These include individual case managers, jointly co-located teams and ‘virtual teams’. These are generally located in the community, in PCTs, social services departments or, in some cases, across the two settings. While these models vary, the specific skills and knowledge that case managers must have, have been identified. These include:

- the ability to listen and work with the older person, rather than making plans on their behalf;
- interpersonal skills to ensure effective negotiations with others;
- good team and collaborative working skills;
- excellent communication skills;
- the ability not to be confined by their own professional role;
- close working knowledge of needs of client group and local service and community resources;
- technical skills in assessment and knowing when more specialist input is needed; and
- experience of working across a range of agencies and understanding each of their roles (Ref. 5).

There is growing evidence to suggest that a number of models of intensive case management can improve outcomes for older people, both practically and in terms of their quality of life, as well as reducing admissions to institutions and hospitals (Refs. 4 and 16). The following section describes a range of initiatives that are underway, or that have been piloted, in the UK and presents data on outcomes, where this is available.
EverCare

EverCare, a subsidiary of United Health Group (UHG), provides enhanced medical care and co-ordinates services to frail, chronically ill and disabled older people. In the US, the program focuses on people in nursing homes, using a Primary Care Team model, where physicians, nurse practitioners and care staff work together to improve outcomes. The core principles of the approach are to:

- apply an individualised, whole-person approach to care, with all interventions focused on promoting maximal function, independence, comfort and quality of life;
- use primary care as the central, organising force for healthcare;
- provide care in the least invasive manner, in the least intensive setting;
- avoid adverse effects of medication and polypharmacy; and
- use data to strengthen decision-making.

Older people identified for the scheme are allocated a nurse practitioner, who sees them regularly, providing more than the usual episodic care. They monitor the older person, but also liaise regularly with family members and primary care doctors. By delivering medical management in a timely fashion, EverCare has successfully improved outcomes for people and, at the same time, reduced hospital stays dramatically (Ref. 17). Evaluations have shown:

- a 50 per cent reduction in the hospitalisation rate of those enrolled in the scheme, without any apparent increase in mortality, as compared to a control group (Ref. 7);
- a reduction in the number of prescription drugs taken while maintaining health. This reduces the side effects associated with taking a large number of medications and achieves cost savings; and
- a 97 per cent satisfaction rating among families, as well as an extremely high physician satisfaction rating.

In the UK, the NHS Modernisation Agency is overseeing a project involving ten PCTs that are working with, and learning from, UHG’s experience. Nine of these PCTs are implementing the EverCare model and one is developing modelling tools (http://www.natpact.nhs.uk/cms/2.php).

The project is being taken forward in two phases. During the first phase (November 2002 to February 2003) a team from EverCare met managers and clinicians from the PCTs to consider how the model might be adapted for use in the NHS. This resulted in a pilot project being designed to implement the agreed elements of the EverCare model within each PCT’s own care community during the second Phase (April 2003 – August 2004).
As in the US, the adapted model uses a primary-care-led team to deliver the EverCare model to older people living in the community. Nurses are at the centre of the model and work closely with the older person, hospital geriatricians, GPs, social services and family members in order to develop appropriate care plans. As with the other models of intensive support described in this report, the starting point for implementing the adapted model in the NHS is identification of the high-risk population. The approach then involves development of a model of care, where the role of the GP is extended through a collaborative partnership with nurses and where consultants are engaged as part of a community-based team to enable more proactive management of people at high risk of reaching a crisis.

The introduction of the adapted model to PCTs reflects the principles underpinning the National Service Framework for Older People: assuring standards of care; extending access to services; and developing services that promote the independence of older people. Results of an evaluation of the EverCare model in the PCTs will be available in 2004.

Pursuing Perfection

Pursuing Perfection is an international programme developed by the Institute for Healthcare Improvement (IHI), based in Boston, Massachusetts. The initiative aims to improve individual outcomes by striving to:

- provide high-quality care to people at the right time, in the right place and by the right person;
- identify the most effective clinical and managerial processes for individual service users through the detailed examination and redesign of health systems;
- reduce risk and adverse incidents, thereby providing a safe environment for people, their carers and healthcare staff; and
- respect the unique needs and preferences of individuals.

Over a two-year period, four UK pilot sites are testing the approach with the support of the NHS Modernisation Agency (www.modern.nhs.uk/scripts/default.asp?site_id=40). The model places a strong emphasis on working in partnership with service users and, in the UK, is based on cross-organisational working within whole health and social care communities. While Pursuing Perfection does not focus on older people alone, some areas have chosen to prioritise developments for older people. Improvements are measured against six dimensions of quality. These are:

- **Safety:** provide a safe environment.
- **Effectiveness:** the care system should reliably match care to science, avoiding overuse of ineffective care and underuse of effective care.
- **Patient-centredness:** healthcare should reliably respect the individual in terms of informed choice, culture, social context and specific needs.
- **Timeliness**: care should continually reduce waiting and delays for both service users and those who give care.
- **Efficiency**: the reduction of waste and, thereby, the reduction of the total cost of care should be unceasing.
- **Equity**: the system should seek to close ethnic and socio-economic gaps in health status.

A key part of the programme is to set ambitious improvement goals in the form of ‘promises’ to service users (Case study 6).

**Case study 6**

**Lambeth and Southwark**

Lambeth and Southwark are one of the pilot sites where a number of organisations are working in partnership to deliver the programme. These include the PCT, acute trusts and the local authorities. One of the areas that the team have initially chosen to focus on is testing ways to improve the management and assessment of frail older people. The initial phase of this part of the programme will focus on improving care and support in two GP practices, whose lists form the target population.

Currently, over 450 people aged over 75 years attend the local acute trust each month. The project aims to shift service provision and access to care and support away from reactive, emergency care to proactive, planned care. By doing this, they hope to reduce A&E admissions for the two local practices by 25 per cent. To achieve this, local services are working together to identify vulnerable older people and meet and manage their needs by providing a number of new services. These include improved care co-ordination, one-to-one appointments with older people’s specialists and multidisciplinary reviews. Data analysis is used to help staff to have a better understanding of how services are currently used and to provide a clear indication of the impact of the changes. Central to the approach of the Pursuing Perfection programme is the introduction of new ways of working on a small scale, testing them out and then spreading the learning across the whole system once the impact of the changes is fully understood. The overall ambition is to ensure that the whole population of frailer older people within Lambeth and Southwark receive ideal care.

*Source: Audit Commission*

**London Older People’s Development Programme**

The London Older People’s Development Programme (LOPDP) was a two-year improvement programme covering most of London between 2001-2003 ([www.london.nhs.uk/olderpeople](http://www.london.nhs.uk/olderpeople)) It brought together health, social care and other agencies to work in partnership to improve services for older people. The programme used the techniques pioneered in the UK by the national collaboratives on cancer, heart disease and primary care.
The programme involved 25 borough-based project teams, involving, as a minimum, the PCT and social services department, although some teams also included voluntary organisations and acute hospitals. Each local team had a project lead, project manager and steering group, working throughout London to promote a whole-systems approach to service co-ordination and improvement. Each project undertook either targeted case finding of older people at risk of functional decline, or intensive case management of known high-resource users, as a way of introducing the single assessment process (SAP) (Ref. 4).

Those involved in the programme identified some significant reductions in hospital stays or in A&E attendances. For example, in an inner London borough, five older people were observed to have used a total of 292 bed days before intervention (over an eight-month period) and 31 in the five months after. Savings were calculated at 218 bed days in a year and rough estimates suggest a total saving of over £120,000 depending on the type of admission and type of ambulance transport used.

In another London borough, patterns of service use involving 29 older people from pilot practices were monitored for six months prior to and six months following the introduction of intensive case management. The following reductions were noted following the changes:

- hospital admissions decreased by 47 per cent;
- the number of nights spent in hospital decreased by 48 per cent;
- A&E attendances decreased by 53 per cent;
- GP home visits decreased by 53 per cent;
- use of the GP out-of-hours service decreased by 82 per cent; and
- GP appointments decreased by 19 per cent (Ref. 4).

Halton PCT

Halton PCT set up a pilot in one practice, the Castlefields Practice, to provide intensive case management to the group of older people who were making most use of NHS and social care services. The pilot drew heavily on US experience, adapted to a UK context. The initiative was led by a nurse, who worked closely with a social worker. The criteria for selection are outlined below (Case study 7).

**Case Study 7**

**Halton PCT – Criteria for case management**

People over 65 who meet at least three of the following criteria were eligible for case management:

- four or more active chronic diagnoses;
- four or more medications, prescribed for six months or more;
- two or more hospitalisations, not necessarily as an emergency, in the past 12 months;
two or more A&E attendances in the past 12 months;
- significant impairment in one or more major activity involved in daily living;
- significant impairment in one or more of the instrumental activities of living, particularly where no support systems are in place;
- older people in the top 3 per cent of frequent visitors to the practice;
- older people who have had two or more outpatients appointments;
- older people whose total stay in hospital exceeded four weeks in a year;
- older people whose social work contact exceeded four assessment visits in each three month period; or
- older people whose pharmacy bill exceeded £100 per month.

Older people meeting the criteria are contacted by the care management nurse for assessment and follow-up, which can include health education, practical advice or referral to other services, many of which are low level community-based support services provided by voluntary organisations. The assessment focuses on the older person’s views about how they would like to see their life improve and on setting goals for change.

Source: Ref. 18

The impact of the case management project in Halton, was positive (Case study 8).

Case study 8
Impact of Halton care management

The results of the pilot included:
- the number of admissions among older people at the practice fell by 15 per cent;
- average length of stay in hospital fell by 31 per cent (from 6.2 days to 4.3 days); and
- the total number of hospital bed days used by this group fell by 41 per cent.

In addition, links between practice staff and other agencies in the community improved, leading to a range of benefits for older people. These included more appropriate referrals to other services and much faster response times for social services assessments. Based on the results of the pilot, case management is being rolled out across the PCT and part-time care managers for older people are to be located in every practice in the PCT.

Source: Audit Commission
Support for people with dementia

63 These new approaches can also benefit those with dementia. A great deal can be done to restore the well-being and independence of this group of people. To be successful in this we must set aside ageism, stereotyping and ignorance (Ref. 19). Over the last 20 years, the work of key academics has challenged the way that many people think about dementia. Much of their work has aimed to encourage people to consider the person behind the dementia, focusing on their unique needs, rather than seeing people as having an incurable medical condition about which little can be done.

64 Good, person-centred dementia care, including the use of therapeutic approaches that enable people to regain and maintain their skills to their fullest capacity, can be critically important to the quality of life of people with dementia.

65 Yet it is clear from a previous Commission report on mental health services for older people, that a significant number of health and social care agencies struggle to provide good care for people with dementia (Ref. 20), as well as for older people with a range of other mental health problems. Indeed, it is often people with dementia – especially those with challenging behaviour – that health and social care services find it most difficult to support.

66 Most people with dementia wish to remain at home as long as practically possible. They also need routine and familiarity. Most carers want this too, but only if they are given the support they need to cope. The challenge to services is to embrace this, ensuring that person-centred care is provided consistently at home and at an early enough stage to minimise the need for residential care. In some parts of the country, a range of services are developing that are designed to support this aim.

67 Listening to the experiences of people with dementia, in order to better understand their needs, is important if appropriate care and support is to be delivered. Where this has been done, new services, such as home-based respite provision, have been set up in response to the clear message from people with dementia and their carers that their needs were not being met in traditional respite services (Ref. 21). Similarly, specialist home care teams have developed in response to the need to provide more person centred home care (Ref 22).

68 Specialist multidisciplinary teams are also being set up in some parts of the country to help to improve the quality of care and support (Case study 9).
The Queen Mother Award
The JackDawe Service

The JackDawe Service is a joint initiative between Nottingham City Social Services and Nottingham City Primary Care Trust that provides specialised home-based support to people with dementia to help them to live at home longer.

It is staffed by homecare workers, community psychiatric nurses and occupational therapists – all with a specific interest in the client group and specifically trained in this area. The service aims include:

- helping people with dementia to remain living safely in their own homes;
- improving their quality of life and that of their carers;
- addressing social inequalities to help people maintain links with, and remain active in, the community; and
- improving links with other health professionals.

The results of an evaluation of this scheme will be published next year.

Source: Department of Health website, Health and social care award 2003

This type of service can also help to prevent inappropriate admissions to hospital, which often causes distress and further confusion to the person with dementia and can result in lengthy admissions.

There is also a growing understanding of the role of assistive technology and its potential role to enable people to remain at home. A further report in this series on independence and well-being focuses on the role of assistive technology. It specifically identifies schemes that help people with dementia to remain independent (Ref. 23).

While there are many examples of good practice in dementia care, developments are patchy. Perhaps one of the greatest challenges is to put into practice what is already known. The reasons for doing this are compelling, both in terms of improving the quality of life of people with dementia and in terms of the potential benefits to health and social care services.
Conclusions

All of the models and approaches described above are developing, although some have been established for longer and are based on firmer evidence than others. Chronic disease management that focuses on a single condition is well established for a number of conditions and a growing clinical evidence base exists. Intensive case management, which tends to address a range of complex health and other issues, and which is also based on US experience, appears to be showing some early successes. Initiatives from the US are being adapted to ensure that they suit the very different UK context, for example, by building in an enhanced role for social care and other agencies as part of a whole system approach. In all cases, further UK testing of these approaches is needed, in addition to research that evaluates their impact on older people’s confidence, well-being and quality of life, as well as on their health status and use of hospital care.

However, it is clear that traditional models of care will not meet the needs of increasing numbers of older people in the future. Challenging existing models through the development of proactive approaches such as those described in this chapter will become a necessity for all care communities rather than the pursuit of a trailblazing minority.
Whatever model is chosen to fit local circumstances, it needs to be implemented carefully if it is to deliver greater independence and well-being to frail older people, giving them greater choice and control. This requires a number of key steps, described in this chapter:

- building a case for change;
- making sure that everyone understands what is involved;
- identifying people who can benefit;
- carrying out thorough assessments;
- helping people to retain control and choice;
- shifting control and decision making from the hands of professionals, to partnership with older people;
- involving older people in decision making about services that meet their needs;
- developing professional support;
- managing the whole process into being; and
- anchoring new developments in commissioning plans.

Building a case for change

The examples set out in the previous section of this report provide the foundation for a local business case for change. PCTs have a crucial role to play in shifting services over time towards a proactive approach that emphasises well-being and independence, as well as responding to crisis. If they are sensitively implemented, the models described in this report are likely to have a significant impact at two levels:

- tackling pressures on the NHS and social care system and creating capacity; and
- improving older people’s well-being by averting crises and increasing choice and control.

Box A, page 7, outlines the likely benefits on these two levels.
Making sure that everyone understands what is involved

Changing the approach to one that truly puts the wishes of older people and their families at the centre – focusing on what older people themselves say helps them to remain in control of their lives – is an important challenge. If new patterns of care are to develop, professionals and care staff will need to change some of their working practices and develop new roles and working relationships. The Commission’s previous work on whole system approaches to the care of older people showed that change in this area is a long-term endeavour that requires the involvement of older people from the outset as well as vision, leadership and a positive organisational culture that supports innovation (Ref. 7).

Whatever the model, teams made up of different professionals are likely to be central to its delivery. Over the last five years, many new community-based teams have been set up to deliver older peoples’ services, and, while much of their activity has been focused on rehabilitation and intermediate care, their experience should be highly relevant.

The Centre for Health Service Organisation Research at Aston University has published a report on the effectiveness of 400 teams (Ref. 24). They found that teams work well together when alternative and competing perspectives are carefully discussed. Such openness also leads to better decisions about care (Ref. 25). They also developed additional information and materials to support managers and team members to meet the new challenges (Refs. 25, 26 and 27).

Identifying people who can benefit

The next step is to develop ways to identify the people who can benefit from the new approach. Most of the initiatives in the previous section focus on people who are already very frail, and some use quite stringent criteria (for example, Case study 8). But waiting until people meet these criteria after previous acute episodes of illness have already taken their toll can be self-defeating. It would be much better to identify people before a pattern of ill health has become established. A variety of techniques (known as ‘case finding’) that actively seek out people at risk before a pattern of ill health has become established are being developed.

Some techniques aim to identify people with specific diseases, such as diabetes. Disease registers are one example, listing everyone who has been diagnosed with diabetes in a locality, in order to assist with the planning and delivery of effective services.
Generalised targeted case finding is another approach that uses tools with validated risk indicators (Case study 10) to identify older people with known risk factors. Such people are then invited to take part in an assessment so that their needs can be identified and addressed. Many who are identified in this way are able to benefit from low levels of support, advice and information that boost their ability to live independently in their own homes.

The LOPDP (para 57) screened over 10,000 older people in London through various different case-finding projects. It identified people whose quality of life was poor, but who were unlikely to ask for help before reaching a crisis – putting their independence at risk (Case study 11).

Case study 10

Examples of validated screening tools – Sherbrooke postal questionnaire

This involved a simple, validated postal tool consisting of six basic screening questions to identify risk:

- Do you live alone?
- Do you take more than three different medications every day?
- Do you use a cane, a walker or a wheelchair to move about?
- Do you see well?
- Do you hear well?
- Do you have problems with your memory?

The tool has been tested in several countries including the UK (Ref. 28).

Source: Ref. 28, quoted in Ref. 4

Case study 11

Barnet case finding project

A case finding project in Barnet identified a 79-year-old man who had fallen on five occasions in the last year. Despite the fact that the man and his wife were struggling, they did not seek any help because they thought his falls were a ‘sign of old age’.

The man was unsteady on his feet, which meant that his walking was restricted and he was also breathless because of COPD. A number of specific problems were identified:

- the man had a wheelchair but the tyres were worn out, so he could not leave the house;
- he had not had his flu vaccine because he could not visit the surgery to receive it – despite being in a high-risk group because of his respiratory problems;
- he had difficulty taking a bath because the bath board was broken and unsafe to use; and
- his wife, who was his main carer, was struggling to cope.
The following interventions occurred as a result of the Barnet project:

- the man was referred to a falls clinic where he had intensive physiotherapy to help with his muscle wasting due to his inactivity;
- he has had his wheelchair repaired and is now also registered with dial-a-ride to give him more flexible transport options;
- he now has his flu jab at home; and
- his wife now visits a carers’ centre, where she has aromatherapy and a massage, and is getting much more support.

Source: Ref 4

Case finding can appear an alarming prospect to professionals who are already struggling to cope with current caseloads. Going out to find yet more people who need help can seem foolhardy. But a key finding of the LOPDP was that, contrary to initial fears, case finding did not uncover large numbers of people with significant health and social care problems, unknown to services, who needed immediate support. It did not overwhelm GPs with additional work. While some older people were found with serious undetected problems, most were at an earlier stage (Ref. 4). All that was needed for them was a relatively small amount of co-ordinated support from a number of agencies, often from the voluntary sector, to improve their immediate quality of life and reduce the risk of a crisis in the future. Signposting people to other sources of information/advice and community resources/amenities was identified as a crucial component of case finding by participating boroughs. In other words, a key feature of successful case finding is the ability to work as a whole system – linking primary health and community-based social care services to a wider network of local public, voluntary and independent sector services and opportunities.

Timely ‘upstream’ support of this type has an important contribution to make to the delivery of a broader and more balanced system of help and support for older people. It is frequently provided by voluntary organisations and community groups, rather than by statutory agencies. Without it, opportunities may be missed to intervene before circumstances become much worse. Many of the LOPDP projects highlighted the fact that people often need help with a broad range of issues best addressed by voluntary agencies – rather than issues normally addressed by health and social care agencies (Case study 12).

**Case study 12**

Islington Case Finding Project

An 84-year-old woman living alone in her own house had recently become housebound because of a general deterioration in her health. She had not seen her GP for six years. An assessment revealed that she was worried because she had not made a will and had no living relatives to help her or to inherit her property. She wanted to sell her home and buy a flat in a supported housing scheme, but she was not sure how to go about either of these tasks. She also had high blood pressure and a severe urinary tract infection that was causing her pain and affecting her mobility.
Project outcomes

The project was able to refer the woman to Age Concern. She was put in touch with the local law centre, who in turn found her a local solicitor. The Council sent her information about how to sell her property and provided information on suitable supported housing schemes available in the area. The woman’s physical problems were less of a concern to her (although they were quickly addressed by her GP). But the need to get her ‘affairs in order’ had been a major worry for her for years. The project gave her the opportunity and ability to make informed decisions and to plan for the future.

Source: Ref. 4

Carrying out thorough assessments

85 Once identified, frail older people need a thorough assessment if they are to receive the right support, in the right way at the right time. Understanding the complexity of people’s individual situations through an assessment process that is meaningful to older people and focused on their personal goals and aspirations, is critical and lies at the heart of person-centred care. The Government has placed great emphasis on the development of the SAP, recognising that effective assessment is pivotal to improving older people’s services. Implementation of the SAP is a key requirement of the Older People’s National Service Framework, so most areas are working to introduce a suitable scheme.

86 At a practice level, new ways of supporting frail older people need to take full account of local arrangements for implementing the SAP. This is already happening in many of the new models of intensive care management and case finding that are currently being developed.

Helping people to retain control and choice

87 The assessment process should highlight what people feel they need to keep them independent and in control. A common feature of the approaches described in this report is that they all involve a partnership between professionals and older people and their families.

88 The Expert Patient Programme is an approach that focuses on helping people to help themselves (Case study 13). There is strong evidence from North America and Britain that people with chronic conditions can become key decision makers in the management of their condition, if they are given the right support and training (Ref. 10). Giving people with chronic conditions sufficient knowledge and insight to take some responsibility for its management allows them to gain greater control over their lives and builds their confidence.
The Expert Patients Programme is based on the chronic disease self-management programme (CDSMP) developed at Stanford University by Professor Kate Lorig and colleagues over 20 years ago. The programme is based on a number of assertions:

- people with chronic conditions have similar concerns and problems;
- they must deal, not only with their disease(s), but also with the impact that it/they have on their lives and emotions;
- lay people with chronic conditions, when given detailed material to work from, can be as effective as professionals in delivering self-management programmes; and
- the way that the CDSMP is taught is as important as, if not more important than, the subject matter.

The programme is not simply about educating people about their condition or providing relevant information. It does not involve a health professional educating or instructing people about their condition and then measuring success in terms of their compliance. Rather, it is based on developing people’s confidence and motivation so that they feel more able to use their own skills and information, in conjunction with professional services, to take effective control of their condition.

**Case study 13**

**Expert Patient Programme**

Two waves of pilot programmes to train Expert Patients are currently taking place. They consist of six weekly sessions of 2.5 hours. Each week, two volunteer tutors lead 8-16 participants through topics such as breaking the symptom cycle, diet, exercise, communication, medication and pain management.

Approximately 60 expert patient trainers have been appointed to develop pilot work with primary care trusts, to train volunteer course tutors and to deliver courses. The pilot programmes are tasked with developing an evidence-based training programme that can be used across the NHS.

The first programme began in 26 PCTs across England in May 2002 and a further 33 began in September 2002. It is estimated that up to 15,000 patients will receive training in this pilot phase.

*Source: [www.doh.gov.uk/cmo/progress/expertpatient/index.htm](http://www.doh.gov.uk/cmo/progress/expertpatient/index.htm)*
An important feature of the Expert Patient Programme is that it is based on a set of core skills:

- knowing how to recognise and act upon symptoms;
- dealing with acute attacks or exacerbations;
- making most effective use of medicines and treatments;
- understanding the implications of professional advice;
- establishing a stable pattern of sleep and rest and dealing with fatigue;
- accessing social and other resources;
- accessing chosen leisure activities;
- developing strategies to deal with the psychological consequences of the illness; and
- learning to cope with other people’s response to their conditions.

Helping older people with complex problems to learn these skills can have a significant impact on the quality of their lives, reducing their need for intensive health and social care services.

Flexible use of funds

If external help is needed, older people can retain greater control if they can directly influence the way that any funds are used. Direct payments are cash payments made by local councils to individuals who have been assessed as needing community care services. They are paid in place of services such as home care, respite care (‘breaks’), or equipment, that would normally be provided by the local council. People receiving direct payments can purchase the help and support they need, that best fits their daily routines (Case study 14) (www.doh.gov.uk/directpayments). They may be particularly helpful for older people who:

- need help on an irregular basis, perhaps because they have intermittent problems that only arise every few days;
- require particular help that is not available through mainstream community care services, for example, because of their cultural or ethnic background. Older people whose first language is not English may prefer to employ someone from their own community rather than an English-speaking home carer, or they may want help to attend their mosque or temple rather than a local authority day centre;
- have mental health problems, such as depression or dementia, and who are particularly likely to benefit from employing someone that they already know well. This can also reduce problems that result from the turnover of staff employed in conventional home care services; and
- need help with activities that may not be covered by mainstream community care services, such as support to go out shopping, prepare meals, manage finances, or attend family or community social activities instead of going to a day centre.
Case study 14
Independent living fund

A group of disabled older people who received payments through the Independent Living Fund to help them live independently described the advantages of receiving help in this way:

People come in when I need them, not when social services or an agency can send them.

I feel as if I’m still in control of things, even if I can’t do anything for myself.

I can ask her [employed personal assistant] to do the things I want because I’m paying for it.

Source: Ref. 29

To date, direct payments have not been widely taken up by older people, or their carers. This may be because there are a number of issues that need careful consideration if older people are to make best use of them. Also, while local authorities are now required to offer direct payments as an alternative to conventional services, the extent to which this is promoted as an attractive option will depend on the knowledge and skills of individual staff.

Many older people may want to use their direct payments to pay a close relative to help them to avoid the risks involved in recruiting and employing strangers. At present, it is not possible to use direct payments to pay a spouse, partner, or other close relative who lives in the same household, unless the local council is satisfied that this is the only way of meeting the person’s needs satisfactorily. However, it is possible to use direct payments to employ a relative who lives in a different household.

At present, direct payments can only be made to an older person who is able to manage them, either by themselves or with help. A third party, such as a relative, can take responsibility for the day-to-day management of the finances, as can someone who has power of attorney, but, to be worthwhile, the older person must be able to exercise choice and control over how the services are actually provided.

For many older people, particularly those who are frail or forgetful, direct payments will only be an option if extensive support is available to help them to:

- recruit their own staff or deal with agencies that supply care staff;
- manage wages, insurance and tax and submit regular accounts to the local council;
- arrange cover in emergencies (for example, when an employee is off sick or on holiday); and
- manage any disagreements that arise.
Many councils will need to provide support services, either directly or through a local independent-living organisation, if frail older people are to be able to discharge these complex management tasks. However, it is essential that these support schemes do not take over, but help older people stay in control.

Alternatively, funds (and all the practical difficulties of managing them) can remain with care managers – but this requires flexible, devolved budgets. A number of small-scale projects have piloted more flexible arrangements with positive outcomes. For example, care managers in community care projects in Darlington and Gateshead provided intensive care management to very frail older people using flexible budgets. They had the authority to allocate the time of multi-purpose care workers, who combine the role of home help, nursing aide and paramedical aide. Satisfaction was high among older people receiving the service. Carers were less stressed and the service was cheaper than the alternative, which, at the time, was a long stay in hospital (Ref. 30). The national evaluation of partnerships set up under Section 31 of the 1999 Health Act suggests that pooling budgets between health and social care agencies can help to overcome practical obstacles that stem from separate funding arrangements (Ref. 31).

Involving older people as partners

If direct payments or flexible funds held by care managers are to work properly, a range of flexible services must be available that can be purchased to meet people’s needs. Some of these may need to be developed, but what form should they take? If future developments are to be grounded in the needs and aspirations of older people, new developments must involve older people as key partners and contributors from the start.

Paradoxically, older people, who are the heaviest users of health and social care services, are the group most likely to be excluded from discussions about future services. It is important that older people who are less mobile and who find it particularly difficult to get to meetings, including those who are housebound, are involved (Case study 15).

Case study 15
Age Concern Scotland

Age Concern Scotland set up a project in Fife to enable the ‘quiet voices’ of frailer older people to be heard. Participants were recruited through home carers, social workers and district nurses; all had health problems or disabilities. They met together as local Panels to talk about growing older and their experiences of using health and social care services.

- Venues for meetings were accessible and comfortable.
- Loop systems were organised for those with hearing problems.
Notes were taken of meetings and distributed afterwards; blind panel members received tapes of discussions.

The provision of transport to meetings was essential, but journey times were limited to 30 minutes.

Project workers had to be skilled in organising and chairing meetings so that all panel members could have their say and learn from each other.

Evaluation of the Panels found that:

- participants learned from each other, felt more confident and benefited from the opportunity for social contact;
- officials welcomed the informal setting within which they could consult with frail service users; and
- the panels largely retained control over their own agendas, rather than responding to requests for consultation by officers.

**Source:** Ref. 32

There is also a growing recognition that people with dementia are able to provide accurate and valid reports of their experiences of services, particularly daycare and respite care. While it is often easier to ask carers for their views, they can have very different needs from those of the person with dementia. Both informal discussions and more structured approaches have been used successfully to collect information from people with mild to moderate dementia on factors affecting their quality of life (Case study 16).

**Case study 16**

**Involving older people with dementia**

One recent study involved a series of formal and informal group discussions with users of a resource centre for older people with mental health problems. As well as the researchers, a community psychiatric nurse and a member of the resource centre staff also attended to provide a familiar face. The people with dementia who took part reported that the following things were important to them:

- having companionship and the opportunity to socialise, including the chance to talk to people other than their main carer;
- feeling part of the local community;
- taking part in meaningful activity, with an opportunity to get out of the house;
- feeling ‘in control’ and maintaining a sense of autonomy, despite their declining abilities;
- retaining their personal identity and a sense of themselves as a competent and valued human being;
- feeling safe and secure, particularly from possible crime;
- receiving help with the management of personal finances; and feeling clean and presentable.
So far as services were concerned, people with dementia wanted:

- to be able to influence what help was provided, when and by whom;
- to be treated as a normal person, despite their mental difficulties; and
- to retain their independence and do as much as possible for themselves.


Developing professional support

If people are to be supported wherever possible in their own homes, sound professional services are vital in order to underpin whatever arrangements are introduced.

Better ways of working: pathways and protocols

Much has been made of the need to develop ‘patient’ or care pathways in order to establish clearer ways of providing care and agreement of the most appropriate ways to meet the needs of particular groups. But greater clarity is not helped by there being two different concepts of pathway: integrated care pathways and care or user pathways (Ref. 33).

Integrated care pathways are templates outlining best clinical practice for people who share a particular diagnosis or set of symptoms. They provide a single plan of care for all disciplines to use, based on guidelines and evidence, and they lead each person towards a desired objective. They have been developed to promote greater consistency, ensuring that patterns of care for particular groups of people are evidence-based. They are often applied in a single-service setting – for example, in the care in acute hospitals of people who have suffered a stroke (Ref. 34).

The term care or user pathway is also used to describe the physical route that an individual takes through a care system. Such a pathway will sometimes involve transfers between settings (hospital to home) and other times, between agencies (NHS to social services) and/or professionals. A good understanding of current pathways of care and support can help to highlight gaps or pressure points in a care system. They can highlight where things go wrong – particularly as people are transferred between agencies and/or professionals. Practitioners with knowledge of how older people enter and move through the system are best placed to review arrangements.

Clear arrangements are also needed to ensure that there is appropriate access to specialist medical input, assessments and diagnostics when needed. If these are not in place, other professionals have little choice but to refer people to acute hospitals for assessment and diagnostics when it may not in fact, be necessary. This input can be provided in a number of ways, including salaried GPs with a specialist interest in older people and support from a geriatrician who is contracted to carry out a number of community-based sessions.
Better medicines management

As people get older, the number of medicines they take tends to increase – 80 per cent of people over 75 take at least one prescribed medicine, with 36 per cent taking four or more medicines. This means that for many older people, particularly those with chronic illness, medication forms a part of their daily routine and contributes significantly to their health and well-being.

Poor medication management, allowing adverse drug reactions or non-compliance to go unchecked, can contribute to a breakdown in independent living and unnecessary waste of money and resources. The NSF for Older People outlines a whole range of ways that things can go wrong – affecting the ability of older people to manage their own medication safely and effectively. Examples include under and over use of medicines, inadequate or misleading dosage instructions, poor follow-up and lack of medication review (Ref. 35). A number of developments are taking place to address some of these issues (Case studies 17 and 18).

Case study 17
Hull – pharmaceutical care for vulnerable people

This service offers people over the age of 75 a home visit by a pharmacist. In partnership with GPs and community nurses, pharmacists are available to visit people at home to discuss all the medicines they are taking, any problems they may be having and ways to get the most benefit from their treatment. The home visit provides an opportunity for support to be given, including medication review, reminder charts, large print labels, explanation of treatment or supplying compliance aids all according to individual needs.

Future plans include working with the local acute trust and social services to extend this service to an intermediate care day centre.

Source: Audit Commission

Case study 18
London – medicines management project

The project consists of three sites in Lambeth, Croydon and Enfield, and is designed to test the development of a care pathway that integrates medicines management and medicines review within the single assessment and case management processes. It is a joint initiative between the London Older People’s Collaborative, (former) London Directorate of Health and Social Care, London Local Pharmaceutical Committee Forum, London Specialist Pharmacy Services and primary care.

The project adopts a planned, proactive approach to identified pharmaceutical care needs, with the overall aim of improving medication outcomes for older people. It has the following objectives:

- to pilot the use of questions on medicines as part of SAP that could then trigger a more detailed assessment, using a pharmaceutical assessment tool;
to develop a referral pathway from the SAP for detailed pharmaceutical assessment;

- to identify, train and support a cohort of pharmacists to undertake detailed medication assessments; and

- to identify community pharmacists to provide appropriate packages of pharmaceutical care.

A detailed training and support programme for pharmacists in PCTs has been developed. In the short time that the project has been running, a wide range of medication problems has been revealed from the in-depth medication assessments carried out so far.

The project is also demonstrating improved outcomes for older people, better communication between GPs, pharmacists, home care and social services, and the huge potential benefits to the whole system of health and social care of adopting this approach. The project is being evaluated and key learning will be disseminated.

Source: Audit Commission

Introducing new technologies

Assistive technology has a very significant role to play in the future care of older people and those suffering from chronic diseases. The introduction of computer and telecommunications technologies has the potential to revolutionise the way we provide people with care at home through telecare and telemedicine (Ref. 23).

The IT issues relating to implementation of these models are also significant. Developing integrated care is hampered by IT systems that fail to connect. While NHS Net should go some way towards addressing difficulties within the NHS, linking NHS and social services systems remains problematic. A previous Commission report highlighted the progress that some care communities have made in this area (Ref. 7).

Providing better advice to older people and carers

Many of the approaches described in this chapter rely on providing older people and their carers with better information to help them to take control and exercise choice. The expert patient programme and direct payments both depend on handing control to the older person. Better medicines management and assistive technology give older people the benefits of developments in technology. But better advice generally can help. Examples have been given of older people being given advice on housing and making wills. Such advice and information helps to empower older people and their families.
Policy developments over the last 17 years have meant that carers’ issues have been given more attention. Despite this, there is evidence to suggest that, in practice, there can be a reluctance on the part of professionals to acknowledge the contribution that carers make to care packages (Ref. 6). For many older people, the involvement of carers is a key component of support. It is important that this is acknowledged, that carers are supported – and, critically, that involving carers is seen as part of providing new ways of supporting frail older people. This is of such critical importance that the Commission is publishing a separate report in this series on Independence and Well-being on support for carers (Ref. 36). One of its key conclusions is that carers in particular can benefit from better advice and information, both about the older person’s circumstances and about options and services.

A key aspect of the partnership between health and social care staff and older people and their carers is, therefore, the sharing of information. Knowledge is power, and good information empowers older people and their carers to make the most of the models described in this paper.

Managing the whole process into being

All of the above steps need to be carefully choreographed if a coherent service is to emerge. Good project management is key to ensuring that developments are co-ordinated at an operational level and that clear links are in place with strategic planning and commissioning.

The importance of the economic dimension in the planning, delivery and evaluation of proactive, community-based support services for frail older people is becoming more widely recognised. Such initiatives can be very cost-effective, which is one of the reasons why they have been developed in the US, with its greater emphasis on costs and cost-effectiveness. Cost considerations are now higher up the policy and practice agenda in the UK. At the same time, the increasing policy emphasis on well-being and person-centred services places the older person’s experience at the centre of the modernisation of public services. The King’s Fund has reviewed current policies in order to assess the extent to which they help or hinder the implementation of chronic disease management. This also applies to the implementation of other proactive approaches to supporting frailer older people, as described in this report.

However, whether a particular policy helps or hinders depends not so much on the policy itself, but the extent to which it is implemented as part of a clear strategic vision (Box B).
Box B

Current policies that potentially help or hinder more effective chronic disease management in the NHS

Likely to help:
- greater investment in services and staff;
- national service frameworks;
- development of PCT commissioning;
- foundation trusts (from the perspective of community engagement);
- the work of the Modernisation Agency (developing leadership, collaboratives);
- the Expert Patient Programme;
- the new GP contract;
- development of Information Management and Technology;
- personal Medical Services pilots;
- local pharmaceutical services schemes;
- developing new professional roles; and
- patient choice programme (from the perspective of empowered patients).

Likely to hinder:
- foundation trusts (from the perspective of more autonomous behaviour);
- new financial flows (cost per case reimbursement);
- diagnostic and treatment centres;
- focus on ‘targets’, particularly waiting lists; and
- patient choice programme (from the perspective of its focus on hospital care).

Source: Ref. 15

A body of evidence on cost effectiveness is beginning to emerge as a result of various national and local initiatives. The evidence from some of these is quoted in the previous section of this report. Most projects have highlighted significant system benefits from taking a more proactive approach to providing health and social care services for older people. Many project evaluations have rightly considered both the cost of different models of service delivery and the outcomes for older people and their carers. The brief summary of the benefits to the system, and to older people, that appears in paragraph 19 provide the basis for a local business case.
Pressures will continue to build. As the numbers of older people rise over the coming years, the numbers of carers are likely to fall. Middle-aged women, who have traditionally been the main care providers, are more likely to have jobs. Family members often live far away and there are rising numbers of people without children. With supplies of informal carers uncertain, there is likely to be an increase in demand for care from public services. At the same time, older people’s expectations are likely to change, as the ‘baby boomer’ generation, who were young adults in the 1960’s, grows older. The need to adopt some of the options set out in this paper will grow, because the next generation of older people is unlikely to tolerate anything less than services that allow them to continue living life to the full, and also because the costs of reactive care may become unsustainable. Increasingly, there are also sound economic reasons for ensuring that older people remain healthy, as they continue working and contributing to the economy for longer. Change needs to be introduced in a systematic way, as described in the next section.

Anchoring new developments in a whole system approach

If new developments, such as those set out in this report, are to be accepted and adopted more widely, they will need to take their place as one component of a whole system approach to care for older people and be reflected in strategies and commissioning plans. Many health and social care communities have been introducing an increasingly diverse range of services for older people – following the NHS Plan and subsequent guidance, such as that on intermediate care.

Many of the new initiatives (rapid response schemes, intermediate care services) reduce the need for admission to hospital or, more commonly, support people to return home quickly afterwards. The initiatives described in this chapter complement these developments, and provide a more extensive range of options for intervening at an earlier stage to keep people independent and at home (Exhibit 4).
This exhibit shows an illustrative range of the options available from independence at home (at the bottom) to acute care in hospital (at the top). The options on the left represent increasingly intensive interventions to keep people independent (moving clockwise from bottom to top); those on the right decrease in intensity as people move from hospital back to independence (from top to bottom).

Above the horizontal line, emergency intervention is required to tackle a crisis. Below the line, people are either being maintained at home or are returning home (or, where necessary, and where they choose to do so, moving to a new home).

The options in the previous section are primarily focused in the bottom left hand quadrant, although they can contribute to the bottom right hand quadrant as well – by providing ‘pull’ models of care that move people out of hospital more quickly. The Commission’s previous work on whole system approaches to older people’s services found that it is this area that tends not to be given a sufficiently strong emphasis (Ref. 7).
In practice, a balanced range of services is needed. Experience in the US – especially at Kaiser Permanente – indicates that a significant shift from the upper half of the exhibit to the lower half is possible by developing closer integration between primary and secondary care, by actively managing chronic conditions and enabling people to take greater control of their own health, making use of intermediate care and encouraging doctors to support the development of these approaches. A review of NHS and US data found that bed day use in the NHS, for 11 leading causes of admission, is three and a half times that of Kaiser's. These results are achieved through a combination of low admission rates and relatively short stays (Ref. 13).

The central role of PCTs in shaping services through integrated commissioning, working with local authorities that are exercising their new duty of community leadership and promoting well-being, could be a powerful lever for the development of the new models and approaches described in this report.

Conclusions

This report describes a number of developments that have the potential to transform the ways in which the independence and well-being of older people can be maintained in the future. Greater emphasis needs to be placed on promoting good health across a lifetime rather than on episodic care. While the starting point for such initiatives has often been the need to reduce pressure on hospitals, with sensitive implementation, they could also have an enormous impact on older people's quality of life. This will require a new approach to commissioning and delivering public services that:

- increases choice and control for older people;
- proactively promotes health;
- focuses on the whole person and the range of their aspirations and needs; and
- builds a whole system response.

As we have highlighted in this series of reports, building such a whole system response calls for a new strategic approach to older peoples' services. Building a strategic approach that views acute response to crisis as the last resort, rather than a first line of defence is crucial. PCTs, supported by Strategic Health Authorities, have a central role to play, working in partnership with local authorities.

Government and regulators too have a contribution to make by placing appropriate emphasis and importance on services that promote independence and well-being. Performance management systems and assessment criteria must reflect this shift of emphasis in the future.

Finally, a strong message from all our work in this area is that older people themselves have a crucial contribution to make in the design and evaluation of services. Care communities that genuinely place older people at the centre are able to tap into a reserve of energy and insight that makes successful change more likely.
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**Forget Me Not – Mental Health Services for Older People (Update 2002).** This update reviews progress made by trusts in the provision of mental health services for older people since the Commission’s 2000 national report Forget Me Not.


**Integrated Services for Older People – Building a Whole System Approach to Services in England.** This report tackles the issue that care for older people is not well co-ordinated. It offers advice on how to work towards a more “whole system” view of services for older people and draws on some good practice examples.


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This is the third in a series of five papers looking at ways to promote the independence and well-being of older people. A report summarising the series is also available.

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