CHAPTER 5

Support for people with longer-term needs
This chapter on ongoing care and support includes discussion of:

- empowering those with long-term needs to do more to care for themselves, including better access to information and care plans;
- investment in training and development of skills for staff who care for people with ongoing needs;
- new supports for informal carers including a helpline, short-term respite and training;
- collaboration between health and social care to create multi-disciplinary networks to support those people with the most complex needs.
Introduction

5.1 People with longer-term or more complex health and social care needs want services that will help them to maintain their independence and well-being and to lead as fulfilling a life as possible.

5.2 Independence, Well-being and Choice set out a vision and aims for adult social care and wider services and these have been warmly welcomed by the public and stakeholders. This is the vision that we are adopting and which we will support towards implementation.

5.3 Participants in the Your health, your care, your say consultation told us that they have seen significant improvement in services. People with asthma, diabetes, heart disease and cancer said that services had improved substantially and praised the specially trained staff and specific clinics that were now in place.

5.4 The wider use of a range of evidence-based good practice, including the National Service Frameworks for most of the common long-term conditions and the NHS and social care long-term conditions model, have helped to bring about these improvements. Key elements of best clinical practice for some conditions are also now embedded in the Quality and Outcomes Framework (QOF) for GPs (see Chapter 2). In addition, the Social Care Institute for Excellence (SCIE) has been working with people and organisations throughout the social care sector to identify useful information, research and examples of good practice.

5.5 In spite of this, people remain concerned about poor co-ordination between health and social care services, and want more support for independent living. Overall, the current interface between health and social care appears confusing, lacking in co-ordination and can feel fragmented to the individual. There are also still too many people in need of emergency care because their day-to-day care has broken down. In too many cases, this is distressing and would not be necessary if care were better maintained. For many people barriers to the use of universal services create problems in daily life.

The strategic challenge

5.6 There are over 15 million people in England with longer-term health needs. They are a large and growing group. We estimate that every decade, from ageing of the population alone, the number of people with long-term conditions will increase by over a million. The number of people aged 85 years and over is projected to rise by nearly 75 per cent by 2025. The number of people with severe disability will also increase as prevalence rises among children, partly due to the increased survival of pre-term babies.

5.7 Over two-thirds of NHS activity relates to the one-third of the population with the highest needs of
these kinds, and an estimated 80 per cent of costs. This will have significant resource implications both for health and social care, unless we change our current approach.

**5.8** Recent national surveys show that we still need to do more to empower people with long-term health and social care needs through greater choice and more control over their care. Over a third of those receiving social care had not had a review in the last year. Half of all people with long-term conditions were not aware of treatment options and did not have a clear plan that lays out what they can do for themselves to manage their condition better. As a consequence a significant proportion of all medicines are not taken as intended.

**5.9** Health and care services still do not focus sufficiently on supporting people to understand and take control at an early stage of their condition. As a result, resources are wasted, medication goes unused, people’s health deteriorates more quickly than it should and quality of life is compromised.

**Figure 5.1 Responses from people with long-term conditions**

Services that could be made available – which are relevant to you and which would you use?

![Bar chart showing responses from people with and without long-term conditions](source: Your health, your care, your say questionnaire)

*Total out of those who said it was relevant"
5.10 The four central aims of this White Paper – derived as they are from people’s responses to our consultation – have special force and relevance to those with longer-term problems:
- better health and well-being;
- convenient access to high-quality services;
- support for those in greatest need;
- care in the most appropriate setting, closer to home.

These concepts come together in looking at how to improve care for this group. As a result of this group’s higher level of need, they also had higher interest and perceived value from potential additional services.

5.11 Our aim for people with longer-term needs is the same as our aim for all people who use services. Services should support people to take greater control over their own lives and should allow everyone to enjoy a good quality of life, so that they are able to contribute fully to our communities. They should be seamless, proactive and tailored to individual needs. There needs to be a greater focus on prevention and the early use of low-level support services, such as those provided through the Supporting People programme.

5.12 People need to be treated sooner, nearer to home and before their condition causes more serious problems. Individuals need information, signposting and support, so that they...
can take control and make informed choices about their care and treatment. Wherever possible, they should be enabled to use the wide range of services available to the whole community, for example housing, transport and leisure.

5.13 We need to move from fragmented to integrated service provision, from an episodic focus to one of continuing relationships – relationships that are flexible enough to respond to changing needs. Long-term conditions do not mean a steady decline in well-being. People’s needs may fluctuate markedly and health and social care must be able to respond to these.

5.14 We will empower people to take more control of the management of their needs and take steps to ensure that people with ongoing needs are assessed more quickly and effectively. Finally, we will ensure there are effective programmes of support available, including for people who care for others.

Helping people take control

Supporting self care

5.15 People will be supported to take better control of their care and condition through a wide range of initiatives. These include a major new focus on self care and self-management. We will also provide additional support to carers.

5.16 A comprehensive framework with guidelines on developing local strategies to support self care for people with long-term conditions will be published by the Department of Health shortly after this White Paper. The following initiatives will strengthen this integrated approach.

Helping individuals manage their own care better

5.17 The Expert Patients Programme (EPP) provides training for people with a chronic condition to develop the skills they need to take effective control of their lives. Training is led by people who have personal experience of living with a long-term illness. We will increase EPP capacity from 12,000 course places a year to over 100,000 by 2012. The EPP course needs to be able to diversify and respond better to the needs of its participants. The EPP also needs a sustainable financial future in the context of a developing market place and Practice Based Commissioning (PBC).

5.18 To achieve this, and create security and continuity for supported self-management, a community interest
5.19 The new community interest company will provide the opportunity to develop new courses, make its products available in new markets and develop new partnerships with all stakeholders involved in self care support.

5.20 So we plan to treble investment in the EPP and support its transition to a social enterprise organisation.

5.21 Alongside the specific EPP programme, our health reform drivers will also encourage primary care providers and others to focus their efforts more strongly on promoting individuals’ abilities to manage their support for people with longer-term needs.
own conditions better. Individual budgets in social care have this personal empowerment at their heart. Our proposals to strengthen patient choice of primary care practices will do the same. Practices that offer support to expert patient groups and other ways of empowering self care will attract more registrations, gain resources and develop specialist expertise.

5.22 Finally, we will get a much stronger focus on improving self care through both the QOF and the standards published by the Department of Health.

Engaging general practice in self care

5.23 One of the main ways these initiatives can be brought together and delivered is through general practice, building on their responsibility for co-ordination of care. The new focus on health and well-being outcomes in the QOF will help. We need to go further. We will seek to ensure that practices use the information in their QOF registers to effectively commission services that support self care for patients with long-term conditions and ask NHS Employers to consider the involvement of general practice in promoting self care as one of the highest priorities for future changes to contractual arrangements.

Improved health and social care information

5.24 Chapter 8 lays out a broad strategy for co-ordinating and developing information for individuals across health and social care. In addition, we propose that services give all people with long-term health and social care needs and their carers an ‘information prescription’, which we are currently developing. The information prescription will be given to people using services and their carers by health and social care professionals (for example GPs, social workers and district nurses) to signpost people to further information and advice to help them take care of their own condition.

5.25 By 2008, we would expect everyone with a long-term condition and/or long-term need for support – and their carers – to routinely receive information about their condition and, where they can, to receive peer and other self care support through networks.

Better assessment and care planning

5.26 People have told us that they would like greater integration between different services. A Common
Assessment Framework is in place for children’s services. We have already developed a Single Assessment Process for older people’s services. Work is underway to build on this to develop a Common Assessment Framework to ensure less duplication across different agencies and allow people to self-assess where possible. An integrated health and social care information system for shared care is planned as part of the NHS Connecting for Health strategy. It is an essential requirement for effective care co-ordination.

5.27 An integrated health and social care information system will enable a shared health and social care plan to follow a person as they move through the care system. We will ensure that, ultimately, everyone who requires and wants one has a personal health and social care plan as part of an integrated health and social care record. Initially we will focus on offering integrated care plans to those individuals who have complex health and social care needs. By 2008 we would expect everyone with both long-term health and social care needs to have an integrated care plan if they want one. By 2010 we would expect everyone with a long-term condition to be offered a care plan. We will issue good practice guidance early in 2007.

UK best practice – joint working in Scotland

Joint Future is the Scottish policy on joint working between local authorities and the NHS in community care. The Joint Future Unit is charged with developing, implementing and monitoring policy. After initially focusing on systems such as Single Shared Assessment (SSA), the emphasis is now on outcomes, with partnerships demonstrating through Local Improvement Targets (LITs) how they are meeting the national outcomes.

Examples of good practice include:
- faster access to services and more holistic assessment through full implementation of SSA, with electronic information sharing and substantial access to resources across agency boundaries (North Lanarkshire);
- faster access to equipment through an integrated occupational therapy service with electronic, direct access to joint store (Fife);
- outcome-led, whole-system working, with joint management and joint resourcing of services (Glasgow);
- faster decision making through budgets being delegated to frontline staff (Aberdeenshire).

Support for people with longer-term needs 115
Integrated care for those with complex needs

5.28 Improving the health and care of people with complex longer-term needs is a major challenge for the health and social care system. Success would bring relief to a large number of people who in the past have had a high burden of suffering. And as this group is a significant user of the health service, both of primary and secondary care, success here could bring better health outcomes with a more effective use of resources too. It would mean that far more people could be helped to live independently at home or be treated in local community facilities – as most say they would prefer – and far fewer would suffer episodic health crises or be held for long periods in hospitals.

5.29 Where needs are complex, it is essential to identify a skilled individual who can act as a case manager and organise and co-ordinate services from a wide source of providers, following the guidance set out in the National Service Frameworks and the NHS and social care long-term conditions model.

5.30 An estimated 250,000 people with complex needs would benefit from case management, as required by the current Personal Service Agreements (PSA) target for long-term conditions. This target is only the start and will require continual improvement once achieved. The current commitment to 3,000 community matrons, which is already part of the local delivery plans (LDPs), will help deliver the skilled workforce required to support this group. Social workers and occupational therapists have always played major roles in this area of work and will continue to do so.

5.31 We will encourage the creation of multi-disciplinary networks and teams at PCT and local authority level. They will use a Common Assessment Framework, with prompt and ongoing access to an appropriate level of specialist expertise for diagnosis, treatment and follow-up where necessary. They need to operate on a sufficiently large geographic scale to ensure the involvement of all the key players, including social services, housing, and NHS primary, voluntary, community and secondary care services. These teams will also need to work closely with existing community palliative care teams.

5.32 By 2008 we expect all PCTs and local authorities to have established joint health and social care managed networks and/or teams to support those people with long-term conditions who have the most complex needs. Models for this can already be seen in mental health and intermediate care teams. In mental health, the Care Programme Approach will be reviewed during 2006 with the aim of improving consistency of approach and practice.

5.33 People with complex care needs require a single point of contact to mobilise support if there is an unexpected change in their needs or
They can use modern technology and web links to share information; technology is not being used to its full potential.

PARTICIPANT AT THE CITIZENS’ SUMMIT IN BIRMINGHAM

CASE STUDY

Integrated care in West Sussex

People with complex needs require an integrated service, involving support from both health and social care professionals. Western Sussex PCT and West Sussex County Council (WSCC) are working in partnership with district councils and the voluntary and community sector to do just that through the Innovation Forum: Reducing Hospital Admissions project.

The main objective is to redesign care for older people with long-term chronic or complex health conditions around their needs and priorities, rather than around historic service models and professional roles. The project is being implemented in three sites, based in Bognor Regis, Selsey and the Midhurst rural area, and comprises a number of initiatives, which focus on providing care close to people’s homes.

The partners have established an intensive care at home service, which integrates intensive nursing, health therapies and hospital-at-home services with social and caring services home care service providing care for up to six weeks.

“This way is so much better. I’m getting more individual treatment, I’m eating better and I’m sleeping better than I was in hospital. In a hospital ward, you are just one name among many. At home you are getting personalised health care. The care staff who come here have more time for me than they would do in hospital.” Hip replacement patient, home within five days of receiving treatment

Importantly, the partners are also listening to what people are saying they want and have used innovative ways of engaging with local older people and voluntary and community sector providers. They have organised knowledge cafés which provide an informal café-style atmosphere where people feel relaxed and able to express their needs and concerns.

“The Innovation Forum project has encouraged creative thinking, in particular about social enterprise, which offers a new way to help local communities find their own solutions to meeting the needs of their vulnerable people”. WSCC, Voluntary Sector Liaison Development Officer

a failure in agreed service provision. Further work needs to be done to establish how this can be achieved on a 24/7 basis by, for example, linking case management with out-of-hours services.

Disabled children

5.34 Many severely disabled children have health conditions requiring long-term management and/or nursing care and require help with the everyday activities of life such as bathing, feeding and toileting. The Department of Health will work with the
Department for Education and Skills and other stakeholders to implement the standard on disabled children in the National Service Framework for children, young people and maternity services and the recommendations in the Prime Minister's Strategy Unit report, *Improving the Life Chances of Disabled People*, to improve the support for disabled children and their families and to provide advice and support for disabled young people making the transition to adult services.

5.35 Drawing on the experience of key workers for disabled children, *Every Child Matters: Change for Children* recognised the importance of a named professional carrying out a co-ordinating role and contained proposals for a lead professional for children with additional needs to enable more children to experience this type of support. The lead professional role is intended to support those children who do not already have a keyworker or a professional from a statutory service overseeing co-ordination of their care/support. More detail can be found in the *Lead Professional Good Practice Guidance for children with additional needs* and the *Common Assessment Framework for Children and Young People: Guide for Service Managers and Practitioners*.

**Pointing the way to the future**

5.36 There is now good international evidence, supported by small scale pilots in this country, that really dramatic improvements in the care of those with complex needs – including significant reductions in the use of unpopular hospital-based care – can be achieved. For example, the Veterans Health Administration in the United States has achieved dramatic improvements in care through its TELeHEART programme for veterans with high risk of cardiovascular disease. Through a comprehensive approach, with a strong focus both on helping people to help themselves and use of remote health technologies, there were significant improvements in health outcomes and far higher patient satisfaction, as well as substantial reductions in hospital use – admissions down 66 per cent, bed days of care down 71 per cent and emergency visits down 40 per cent.

5.37 Our challenge is to demonstrate on a wider scale that this significant shift from hospital care is now possible and that more people can be supported to retain their independence in the community. We need to provide credible evidence that it will benefit the
individual and their carer’s quality of life, and deliver gains in cost-effectiveness of care.

5.38 In doing so, we need to take full advantage of the exciting new possibilities opened up by assistive technologies. Many local authorities in this country have already shown that assistive technology can help people retain their independence and improve their quality of life. This capacity has been strengthened by an allocation of £80 million to local authorities over the next two years as part of the Preventative Technologies Grant. This will enable social services authorities to support even more people in their own homes by using telecare.

5.39 For example, remote monitoring enables people to have a different relationship with the health and social care system. It enables people to feel constantly supported at home, rather than left alone, reliant on occasional home visits or their capacity to access local services.

5.40 So for people with complex health and social care needs, we plan to bring together knowledge of what works internationally, with a powerful commitment to new, assistive technologies to demonstrate major improvements in care. This demonstration will include:

- a strong emphasis on patient education and empowerment, so that people are fully informed about their condition and are better able to manage it;

**The future is now**

Assistive technology already in use in or near the home, includes:

- house alarms linked to a call centre staffed by a nurse, co-ordinated by the local council;
- ‘Well Elderly Clinics’ for people living on their own but requiring some simple monitoring, including blood pressure, heart rate and glucose measurements;
- local intermediate care programmes that provide in-home support during recovery, aim to prevent unnecessary acute admission and maximise independence;
- spirometric and cardiac readings from in the home to detect acute episodes early and minimise or eliminate the need for hospitalisation – currently in place for chronic obstructive pulmonary disease, cardiac and pulmonary patients in limited geographies;
- in-home touch-screen and video link-up for patients to self-monitor and feed information to health professionals;
- bed sensors that determine if the resident has failed to return to bed by a set time.

- comprehensive and integrated packages of personalised health and social care services, including systematic chronic disease management programmes;
• joint health and social care teams, with dedicated case management through a single expert case manager, 24/7 service contact and an information system that supports a shared health and social care record;
• good local community health and care facilities, offering a better environment for the care of people with complex needs, and greater involvement of specialist nurses in care;
• health and social care commissioners with the right incentives to deliver better care for those with complex needs, mandatory risk stratification so that they can identify those most at risk, and accountability for their performance in improving the lives of those with complex needs;
• intensive use of assistive and home monitoring technologies.

5.41 These demonstrations will be challenged to achieve significant gains in quality of life and reductions in acute hospital use. We will work with a number of NHS, social care, private and voluntary sector partners, including NHS Connecting for Health and NHS Direct, to establish them. We will ensure that the resident population covered is at least 1 million and from a variety of geographical contexts so that gains are on a credible scale, and we will motivate all commissioners to drive services in this direction. The project will provide an opportunity to pilot a shared health and social care record. We aim to commence this demonstration project by the end of 2006 and share early findings by the end of 2008.

5.42 We shall carry out this project in close collaboration with the Department of Trade and Industry so that the findings can inform a joint approach to our work with business and the research community to develop technology that will better meet the challenges identified.

A balanced scorecard approach
5.43 We will develop a balanced scorecard to provide a comprehensive and meaningful assessment of progress against many of the commitments outlined. This will be more outcome-focused and will draw on feedback from the people using services. It will also benchmark relative use of community and voluntary sector providers. In time, we expect to make use of outcome measures to assess the impact and effectiveness of services and new service models. We will make the scorecard available to PCTs, practices and local authorities for local use.

Incentives for better care for people with longer-term needs
5.44 The reforms described recently in Health reform in England will provide a fundamental underpinning to improvements in the care of those with longer-term needs. Under PBC, primary care professionals will control the majority of health care resources through indicative budgets and be able to use them accordingly. Payment by Results (PBR) makes real to
commissioners the benefits of improving care for people with long-term needs, by making clear the costs of preventable illnesses, avoidable emergency admissions, poor medication prescription and use, and lack of preventative investment in social care. The combination of PBC and PBR will encourage commissioners to seek out providers who offer better quality care, particularly for those that are the most intensive users of health care.

5.45 To do this, commissioners will often need to work with a range of local providers to develop comprehensive, integrated and more effective packages of care. For all parties to develop such packages and to share the benefits from this improved care, co-operation will often be needed. The national tariff, currently for activity in an acute setting, provides the transparent financial framework within which such co-operation and benefit sharing between commissioners and providers can be negotiated for care delivered in primary and community care. To ensure this is as effective as possible, we will explore whether there are refinements to the current tariff that could provide incentives for such benefit sharing, to support co-operation between commissioners and providers in delivering integrated long-term conditions care.

5.46 We will examine carefully the ‘year of care approach’ that is currently being developed for people with diabetes. In so doing we will bear in mind the fact that there will be a year of care for commissioners at local level.

Figure 5.3 Carers by age and sex

Source: Census, April 2001, Office for National Statistics.
through practice based budgets, that PBC is designed to give flexibility as to how those budgets are best deployed and that people with long-term conditions often have co-morbidities and multiple needs that are not easily disaggregated into discrete conditions.

5.47 We will also work with NHS Employers and the professions to explore how the QOF can continue to develop to provide stronger incentives for effective management of people with long-term conditions, building on the recent agreement for 2006/07.

**Investing in professional education and skills development**

5.48 We will take action at each stage of the professional education and regulatory process to change the underlying culture profoundly and encourage support for individuals’ empowerment and self care. We will be taking forward work that not only creates a clear self care competency framework for staff, but also embeds key elements, including values and behaviours around assessment and support in appraisal and continuing professional development requirements. This will include:

- work with Skills for Health and Skills for Care to develop a self care competency framework for all staff;
- work with NHS Employers to embed self care in the Knowledge and Skills Framework, so that it is embedded in job descriptions/annual appraisals under Agenda for Change;

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Figure 5.4 Carers by profession

Source: Census, April 2001, Office for National Statistics
It would be very helpful for me to understand and be trained and equipped to deal with dementia to help me care for my aunt.

RESPONDENT TO INDEPENDENCE, WELL-BEING AND CHOICE

CASE STUDY

Who cares for carers?

If you are a carer it can be difficult to respond to an urgent problem, such as your own health failing. When someone depends on you, you can't just drop everything. However, the Carers Emergency Respite Team (CERT) in Sefton on Merseyside has pioneered a unique service offering an instant response when a carer faces an emergency that would stop them being able to continue caring.

Dilwyn James, Development Manager at Sefton Carers Centre, says that: “Team members can be at a carer’s home within an hour of them calling us.” A pre-briefed member of the CERT team steps in and provides emergency respite care.

But the Carers Centre is not just for an emergency. Dilwyn says: “We have a broad range of services here at the centre, such as therapies to help deal with stress and counselling support, and we offer advice on welfare rights for the whole family.”

There is also a sitting service so that a carer can go to the hairdresser’s or to lunch with friends.

- work with the professional bodies to embed self care in core curricula.

A new deal for carers

5.49 There are 6 million carers in this country. Caring for someone can have life-altering consequences. People caring more than 50 hours a week (1.25 million people) are twice as likely not to be in good health as those who are not carers. Three-quarters of carers are financially worse off because of their caring responsibilities. In addition, 400,000 people combine full time work with caring more than 20 hours per week.

5.50 The Your health, your care, your say listening exercise revealed considerable public support for carers. Better support for carers came third in the ‘people’s options’ at the national Citizens’ Summit.
5.51 We therefore propose to offer a new deal for carers to improve support for them through a range of measures.

5.52 We will **update and extend the Prime Minister's 1999 Strategy for Carers** and encourage councils and PCTs to nominate leads for carers’ services. The updated strategy will reflect developments in carers’ rights, direct payment regulations, carers’ assessment and carers’ grants. We will work with stakeholders to consult, develop and issue a revised cross-government strategy that promotes the health and well-being of carers, including the particular needs of younger carers, and includes the use of universal services.

5.53 **We will establish an information service/helpline for carers, perhaps run by a voluntary organisation.** Carers have difficulty accessing the right up-to-date information to assist them in their caring role. They need reliable, detailed information to help them make decisions about their personal support, opportunities for them and the needs of the person for whom they care.

5.54 A dedicated helpline for carers would offer information in the widest sense – from legal entitlements, to contact numbers for ‘help’ groups and training, to advice on benefits.

5.55 **In each council area, we will ensure that short-term, home-based respite support is established for carers in crisis or emergency situations.**

5.56 We will also **allocate specific funding for the creation of an Expert Carers Programme.** Similar to the EPP, this will provide training for carers to develop the skills they need to take greater control over their own health, and the health of those in their care.

**NHS Continuing Care**

5.57 Finally, during 2006, as part of care planning between the NHS and social care, we will support NHS and social care professionals’ decision making on responsibility (and funding) through a national framework for NHS-funded continuing care and nursing care. This will provide clarity and consistency for both patients and professionals about what the NHS will provide for those with the most complex long-term care needs. We will also clarify how the NHS Continuing Care strategy should work for children.
References

1 National Service Frameworks for Coronary Heart Disease, Diabetes, Long-Term Conditions, Mental Health, Renal Services and the NHS Cancer Plan

2 Supporting people with long-term conditions. An NHS and Social Care Model to support local innovation and integration, Department of Health, January 2005

3 Wittenberg, Pickard, Comas-Herrera, Financing Long-Term Care for Older People, PSSRU Bulletin No.14, 1999

4 A Common Assessment Framework for children and young people has already been developed and is being used by health practitioners for children with additional needs

5 The PSA target includes promises to improve health outcomes by offering personalised care plans for people most at risk, and to reduce emergency bed days by 5 per cent by improving care in primary and community settings by 2008

6 Lead Professional Good Practice Guidance for children with additional needs, Department for Education and Skills, July 2005

7 Common Assessment Framework for Children and Young People: Guide for Service Managers and Practitioners, Department for Education and Skills, March 2005

8 Health reform in England: Update and next steps, Department of Health, December 2005