

Supporting people with long term conditions to...



Self Care

A guide to developing local strategies and good practice

Improving Care
Improving Lives

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Supporting people with long term conditions to self care

A guide to developing local strategies and good practice

**Improving Care
Improving Lives**

What 'self care' means

In this document, the term 'self care' includes both self care and self management. **Self care** is all about individuals taking responsibility for their own health and well-being. This includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; the better use of medicines; treatment of minor ailments and better care of long term conditions. The term '**self management**' has been defined by Rethink as: "whatever we do to make the most of our lives by coping with our difficulties and making the most of what we have. Applied specifically to people with a schizophrenia diagnosis it includes how we manage or minimize the ways the condition limits our lives as well as what we do to feel happy and fulfilled to make the most of our lives despite the condition." (Martyn, 2002)

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Self care – the patient’s perspective

Self care by definition is led, owned and done by the people themselves. It is the activities that enable people to deal with the impact of a long term condition on their daily lives, dealing with the emotional changes, adherence to treatment regimes, and maintaining those things that are important to them – work, socialising, family. The NHS cannot do self care to people, but what it can do is create an environment where people feel supported to self care. This can be done through developing organisational structures and networks, appropriate information, interventions and technology, to give people the opportunity to improve their quality of life, and feel that they are still contributing in their community.

Self care support can be effective in two ways. It can be generic, supporting a number of different types of people individually or in groups. This is exemplified by the NHS Direct Self Care Guide and the Expert Patients Programme. Self care support can also be individualised and specific to a person’s needs and circumstances, based on an understanding of the person’s beliefs, capability, knowledge base, acceptance of their condition, attitude, confidence and determination. Often these aspects differ from person to person and fluctuate over time. For example, an individual could be newly diagnosed with a long term condition, or seeking self care support following an acute episode, or a life-changing event. It is also important to understand a person’s motivation to self care – for example, do they want to be more active, return to paid employment, reduce levels of pain, or maybe to have fewer admissions to hospital? Often people articulate this with statements such as, “I don’t want to feel this way”. It is important to work with people to achieve the treatment outcomes and longer term goals that they want, at a pace they want, with the support they want. Some illustrations of individualised self care support would be the Personal Health Guides as proposed in the *Choosing Health* White Paper; *My Healthspace*, which will have information for individuals based on their needs; and personalised Care Plans following an acute illness or for people with long term conditions.

Local self care strategies should be based on a combination of generic solutions, good planning, and individualised self care support that people may want to be able to improve and maintain a sense of control and well-being. People should be involved and consulted in the development of an integrated package of self care support, and local facilities should be reviewed based on feedback from people who use these. If self care is based on this approach it is likely to be more effective, and achieve significant benefits for people as well as the NHS.

Introduction



There are over 15 million people in England with longer term health needs. They are a large and growing group. Recent national surveys have shown that we need to do more to empower these people with long term health and social care needs through greater choice and more control over their care. 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.

People with longer-term conditions have better lives when they are supported to take care of their conditions themselves. If people have a clear understanding of their condition and what they can do, they are more likely to take control themselves. This is what people have told us they want. One of the priorities from participants in the 'Your health, your care, your say' consultation was for services based around their needs which help them take control of their health, support their well-being; and enable them to lead an independent and fulfilling life.

That is why helping people to take control is a key theme of the 'Our health, our care, our say: a new direction for community services' White Paper. The proposals in the White Paper and this comprehensive self care guide will help local organisations develop local strategies to deliver self care support for people with long term conditions.

Many patients, especially those with longer-term conditions, do not want to spend anymore time than is necessary visiting their GPs and going to hospital. Many are already experts on their conditions. We need to empower these people to manage their own care, with the help of skilled healthcare staff. We need to reach the stage where doctors, nurses, pharmacists, allied health professionals and others recognise that self care is a real choice and actively support the individual in this choice.

Delivering effective self care support also needs greater cooperation between organisations with PCTs, GPs, local authorities and others working together with the community, voluntary and private sectors to provide local solutions to embed supported self care into service delivery as a practical option. These changes are vital if we are to create a health and social care system that is fit for the 21st century.

Norman Warner

Norman Warner
Minister of State for NHS Reform

Foreword

Self care is something that we do for ourselves. This may be self care to live healthy lives, such as brushing our teeth, or looking after ourselves to prevent illness, or helping ourselves to recover from short term illness. However, for people living with a long term condition self care can become a more fundamental part of their everyday lives, to ensure independence, self worth, and the ability to lead as near a normal life as is possible.

There are a range of approaches to self care. The NHS can support people in taking these through a partnership with the person self caring, recognising that they should make the choices, decisions and take the actions themselves.

Self care is an under-utilised resource. People with long term conditions are experts in themselves and how their condition affects them and their lives. People should be supported and enabled to self care. This is not just about a change in service provision, but about a cultural change, allowing patients to be partners in their care, letting them decide what support they need, when they need it and how.

The NHS will need to think differently to be able to be responsive to those needs, respecting and valuing the contribution people can make to improve health.

The various approaches to self care and how the NHS can support people to use them are set out in this document. We welcome this guide which will begin to shape local organisations in delivering self care support for people with long term conditions.



A handwritten signature in black ink that reads "Harry Cayton".

Harry Cayton
*National Director for
Patients and the Public*



A handwritten signature in black ink that reads "David Colin-Thome".

David Colin-Thome
*National Director for
Primary Care*

Executive summary

People with long term conditions want to live as normal a life as possible. There is a growing body of evidence that demonstrates what works for them and how they can achieve this. This document draws on that evidence and explains how health and social care services can support self care through an integrated package consisting of a range of elements at a local level, providing an adequate number of options for people to choose from. These elements will include self care information, self monitoring devices, self care skills education and training and self care support networks. These elements could be provided by a mix of providers, including private and voluntary sector agencies. Delivering a self care support package will entail training of professionals and practitioners to raise their self care awareness and skills to develop a better partnership between themselves and the public.

This is a time for organisations to be innovative and creative, working across health, social care and voluntary sector boundaries. We can learn a lot from the way social care and voluntary sector organisations pioneer services.

Why is self care important?

When people self care, and are supported to do this, they are more likely to:

- ✓ experience better health and well-being
- ✓ reduce the perceived severity of their symptoms, including pain
- ✓ improve medicines compliance
- ✓ prevent the need for emergency health and social services
- ✓ prevent unnecessary hospital admissions
- ✓ have better planned and co-ordinated care
- ✓ remain in their own home
- ✓ have greater confidence and a sense of control
- ✓ have better mental health and less depression.

How does the health service benefit?

Supporting self care should already be part of local plans. Health and social care agencies, practitioners and professionals now have several incentives to provide an integrated resource to support self care in their local economies. By investing early in local strategies, value for money will be improved and the long term conditions PSA target¹ and older people's target² will be delivered.

International evidence³ from some approaches to self care support also suggests that investment could reduce:

- visits to GPs by up to 40%
- visits to outpatient clinics by up to 17%
- visits to A&E units by up to 50%
- drug expenditure

Patients are the health service's biggest untapped resource. If patients and the health service are to benefit, then services need redesigning so that patients and the public are truly partners and co-producers in their care.

What do we want to achieve?

Our goal is to create a fully integrated system, with appropriately trained front-line staff, to enable people with long term conditions to take greater responsibility for their own care. This will be done through the following:

- Providing understandable and easily accessible information that will enable people to:
 - assess their own condition
 - know what is 'normal' for their condition
 - know when, where and how to get further help and advice.
- Helping people to understand why it's so important they take their medicines and how to do so.

1 To improve health outcomes for people with long term conditions by offering a personalised care plan for vulnerable people most at risk, and reduce the number of emergency bed days by 5% by March 2008 through improved care in primary and community settings.

2 To increase the number of people over 65 supported to live at home by 1% a year in 2007 and 2008.

3 *Self Care – A Real Choice*, DH, January 2005

- Enabling people to recognise and monitor their symptoms.
- Allowing people to undertake strategies to aid their recovery.
- Enabling people to book routine tests as and when they need them, rather than requiring them to go to a GP for 'permission'.
- Supporting people to have the confidence and skills to better deal with their condition.
- Involving people in interpreting results so they understand what action needs to be taken and why.

Supporting self care requires a major transformation in health and social care services and means challenging the organisational structure and staff roles we currently use to deliver services. The approach set out in this guide will play a key role in bringing about and sustaining this change. It focuses on what healthcare organisations can do to develop and implement a self care strategy to support people with long term conditions.

Key local actions

Local strategies to support people with long term conditions to self care require everyone who is involved in the process to start thinking differently. In developing such strategies it is important that you:

- Make sure front-line staff and care professionals receive appropriate training so they understand the principles of self care.⁴
- Identify what information people may need in the future so they have access to the required information, as and when they want it, and are supported to use it.⁵
- Ensure that health and social care professionals have details about other community contacts and support networks that people can access.
- Make sure patient education and training programmes are included in the range of self care options.

4 *Case management competences framework for the care of people with long term conditions*, DH, August 2005 – specifically the Supporting Self Care, Self Management and Enabling Independence competences.

5 *Better information, better choices, better health*, DH, December 2004

- Make sure that self care support options also include access to self monitoring devices and assistive technologies.
- Provide access to services in a co-ordinated and consistent way, including health care, social care, benefits, housing, transport and voluntary and community services.

Developing a self care support strategy

Key actions

When developing a self care support strategy for your area, the following should be considered:

- Involve patients and the public through new and established mechanisms – any strategy needs to be based on their requirements and preferences.
- Assess the self care information and support networks which already exist within your health economy. Are there any gaps in knowledge, availability and quality?
- Ensure that the EPP is fully integrated into your strategy.
- Invest in people and resources to support partnership-building across health and social care communities. Make good use of Local Strategic Partnerships.
- When re-designing your services, work with all agencies, the community, the voluntary sector and people with long term conditions and their carers.
- Involve patients, lay experts and appropriate local professionals in identifying best practice in approaches to needs, information and communication.
- Think about the best way of commissioning self care support approaches to meet local needs.
- Work with your Local Pharmaceutical Committee to ensure that community pharmacists are using the new contractual flexibilities to support self care and medicine management.
- Explore what national initiatives link into self care support initiatives, for example: assistive technologies, integration with Social Services, Partnerships for Older People Projects, Connecting for Health, Community Pharmacy/Medicines Management, Patient Choice and the National Primary Care Development Team (NPDT).

Why we need to focus on self care support

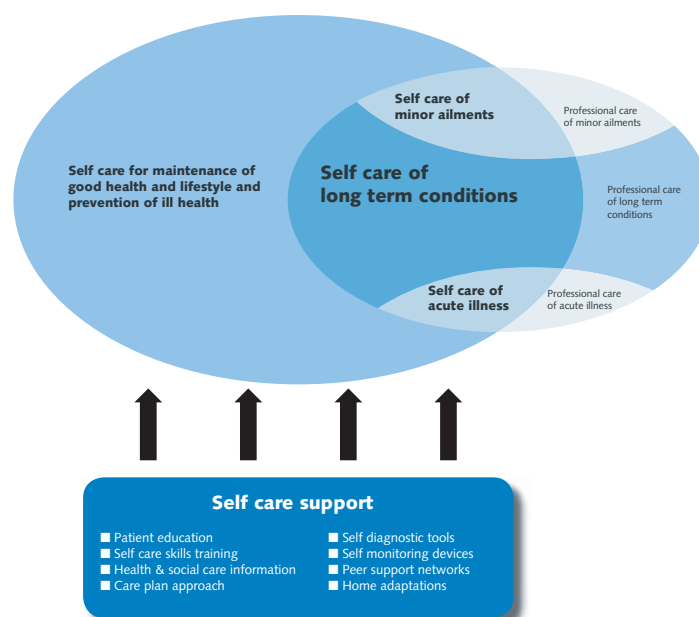
When someone has been diagnosed with a long term condition, even though this may not be clear to them at the time, they will be embarking on a life-long journey. This journey will involve the development of an understanding of their needs in terms of both internal resources and external support in order to incorporate the condition and its management into their lives such that they can enjoy as full a quality of life as possible.

This journey requires several fundamental psychological and social changes to engage in active participation and collaborative relationships with their families or carers and a range of health and social care professionals.

A strategy to support people with long term conditions to self care should reflect these psychological and social changes and incorporate a wide range of approaches and models of self care support, including finding ways of providing funding, information, facilities, equipment and technology to forge its development.¹²

Not everyone wants to take a proactive part in their own care. It's important that individual preferences about who takes decisions about different aspects of health and healthcare are respected too.

Supporting self care across the whole system



12 Derek Wanless, *Securing Good Health for the Whole Population*, Feb 2004

How we will achieve sustained self care

We need to promote a change in perception about the role of everyone involved in supporting people with long term conditions. These changes in role need to take place not just within the health and social care services, but in the individuals with a long term condition and their carers.

To achieve this we need to recognise and understand what motivates people to take care of themselves. The impact of any long term condition and the individual's ability to optimise self care are related to:

- The perceived or actual severity and nature of their underlying condition.
- The short, medium and long term impact of the condition on the individual's ability to undertake normal activities of daily living.
- The person's beliefs, understandings and expectations around the condition – and the perceived role health and social care can play in providing a cure, care or support.
- How much the patient participates in or avoids active self caring as a result of these beliefs.
- The effect of symptoms, loss of control and loss of role on a patient's morale and mental health and the way in which they want to live their lives (their aspirations).
- Healthcare professionals' beliefs and expectations in providing care, cure or support.

People with long term conditions will not fully engage with self care until each of the above has been discussed and they have a clear understanding of the role of each factor in their overall condition. People can only begin to embrace self care once they have become reconciled to the fact that their condition is being optimally managed medically.

If we are to embed this approach into our systems and change processes and their outcomes, we need to think differently and train differently.

Putting people at the centre of our services

A new approach based on outcomes for people, and health and social care professionals working together requires a radical shift in the balance of power, with the patient at the centre.

A patient-led system can be achieved by:

- Fully involving and consulting with people to plan their care according to their understanding, abilities, needs and preferences.
- Organising flexible, responsive services based on a person's needs and preferences.
- Recognising that health and social care professionals are part of an interdependent system where visions, objectives and resources are shared.
- Ensuring there are no artificial boundaries between agencies and organisations, so that individuals experience a seamless care pathway.

Providing people and their carers with choice as to how their care is personalised is a central tenet of a patient-led NHS.

Integrating care and support across sectors

We must work together across care services to deliver high-quality, modern health and social care. Quite often, people have a range of health and social needs. For example, incorporating self care of a long term condition into someone's life may require psychological support, advice about re-training, adaptation, employment, benefits and housing advice.

There is a growing body of evidence showing that social care can reduce, prevent or replace the need for hospital services. Studies have found that an increase in the use of community social and health services reduces the use of hospital services – an increase in the provision of these services can improve not only people's immediate outcomes, but also their future health outcomes.¹³ For example, one primary care trust with a specialist falls service reduced the number of people admitted to hospital after a fall by 12%, saving around 1,000 bed days a year.¹⁴ The National Falls Collaborative, in 2003, achieved a reduction in falls of 32% and is now in its third year. This is something we cannot ignore.

13 King's Fund, *Social Care Needs and Outcomes*, July 2005

14 Dr Gillian Dalley, *The Counsel and Care National Falls Survey: Progress in Implementing Standard 6 of the National Service Framework for Older People*, July 2005

Timely diagnosis and treatment, plus rapid access to services when necessary

There are some conditions, such as rheumatoid arthritis and schizophrenia, for which early diagnosis and treatment can make all the difference to a person’s quality of life. If the condition gets worse, everything should be done to ensure it is dealt with quickly: prompt diagnosis, pain and symptom management, appropriate treatment and information all have short- and long-term benefits. Enabling people to access healthcare as they require it is a powerful incentive for people in terms of self care.

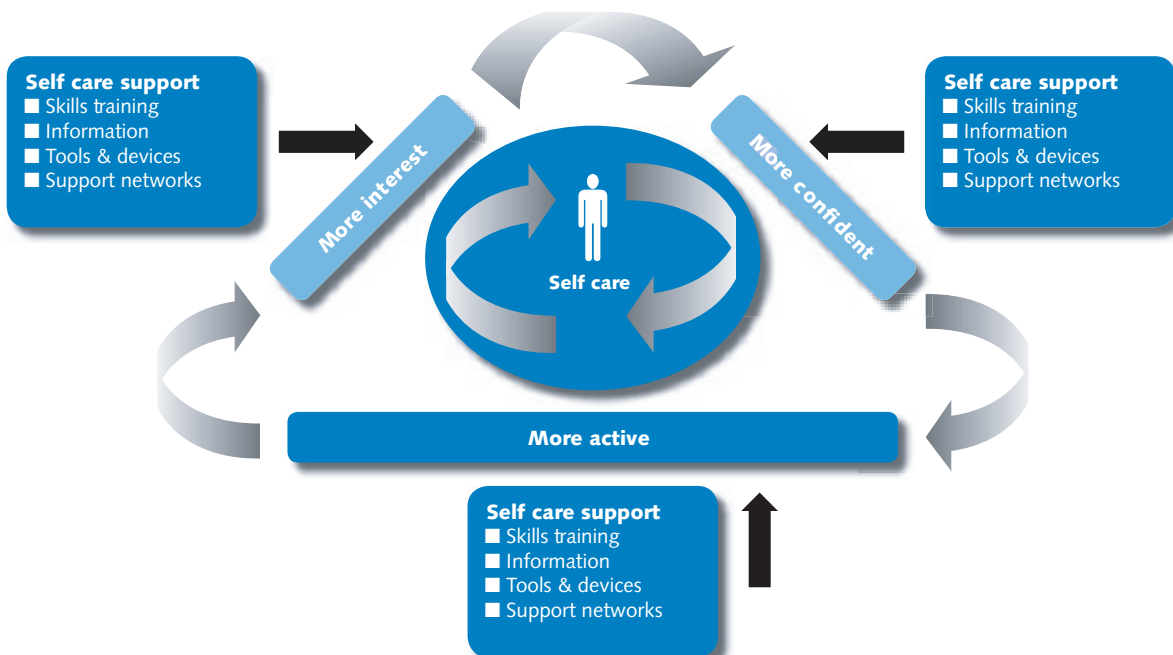
Getting patients involved

One of the best ways to build a patient-centred health and social care service is to get patients involved in shaping it.

People who have lived with long term conditions have the valuable knowledge and experience of living with their condition which they can share. By involving and consulting with them during the process of developing local healthcare policies and practices, we can gain a unique perspective not available to most healthcare professionals.

The delivery of services can often be improved through imaginative solutions that ensure people’s needs are met. Self care is by definition undertaken by and for the benefit of the individual – so services should be developed to support this.

How supporting self care can help improve the quality of people’s lives



The diagram shows how better skills education and training, information, tools and devices, and support networks can all play a role in helping people with long term conditions to become more confident when it comes to self caring. As people's confidence grows, they become more active and more interested in helping themselves.

Some areas of the NHS need to 'catch up' with social care organisations in terms of delivering patient-focused services. It is for this reason that this publication is aimed mainly at health service organisations. Building on the NHS and Social Care Long Term Conditions Model¹⁵, it focuses on how people can be supported to self care through skills and training, information, tools and devices, and support networks.

In the following chapters we explore each of these areas, setting out what healthcare organisations and professionals need to do to achieve specific goals for people with long term conditions.

15 *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration*, DH, January 2005

Skills and training – helping people to take care of their condition better

Key actions

To help people gain the skills and understanding to care for their condition better:

- Offer patients self care support, disease-specific education and self management skills; for example, the Expert Patients Programme (EPP) should be available to people with long term conditions through the NHS by 2008.
- Find out about and evaluate with patients other condition or disease specific education programmes, such as DAFNE and DESMOND for people with diabetes.
- Make sure you engage appropriately trained front-line staff who understand the principles of self care to help boost patients' confidence.¹⁶

Putting patients at the centre

To participate fully in taking care of their own health, every patient needs to understand the role they have to play and feel they are able to take part in the decision-making process. Without the confidence, skills and insight to seek out information, understand, question and sometimes challenge health and social care professionals, people cannot feel in greater control of their care.

There are many different educational approaches that can help to support people with long term conditions. These include the EPP, health literacy programmes and condition- or disease-specific education. There is clear evidence that disease-specific education can have a profound effect on people's symptoms and health, significantly improving their quality of life.¹⁷

16 *Case management competences framework for the care of people with long term conditions*, DH, August 2005 – specifically the Supporting Self Care, Self Management and Enabling Independence competences.

17 *Structured Patient Education in Diabetes*, DH/Diabetes UK, June 2005

Most of the time, it is people rather than professionals who make the day-to-day decisions about taking care of their condition.

The Expert Patients Programme (EPP)

The NHS Expert Patients Programme and other self care skills training courses provided by voluntary and community sector agencies (often in partnership with health organisations) help people with long term conditions to build their confidence and improve their quality of life. They provide people with the skills to better manage symptoms such as depression, anxiety, breathlessness and pain, and empowering techniques such as goal setting and problem solving which enable them to live more fulfilled lives, independently and at home. Many people who attend the EPP course report a perceived reduction in the severity of their symptoms, which then interfere less with their lives. They also report improvements in their consultations with health professionals.

In practice

Helping people with Parkinson's disease in Tyne and Wear

The Northumbria Parkinson's Disease Service was established in 1995 and serves a population of 500,000. It operates an open-referral policy, which includes self referral.

All general/local and community hospitals hold clinics so that people with Parkinson's disease do not have far to travel. Parkinson's disease nurses run their own clinics in the same locations and offer home visits and telephone support.

The service offers an eight-week education and support programme that teaches people about their condition and symptoms. People with Parkinson's disease attend the programme with their carer and can choose which topics they would like to cover.

The team is also developing a *Professional Care Guide* to help professionals promote standard practice across the catchment area.

To find out more, contact Annette Bowron, Nurse Consultant, tel: 0191 293 4167

In practice

The COPD Passport for people with chronic obstructive pulmonary disease

Central Cornwall PCT has developed a COPD Passport for people living with COPD. It was created in response to reports that many people with COPD suffered from a debilitating fear of further exacerbation. Not only did this result in them being repeatedly admitted to hospital, but it severely restricted the way they lived.

The COPD Passport was developed by patients and representatives in both primary and secondary care at the first learning workshop of the National Primary Care Development Team (NPDT) Long Term Conditions Collaborative programme. A simple document, it gives advice to help reduce the 'fear factor' and enable patients to lead more fulfilling lives. In addition, it provides paramedics and admitting staff with important information in the event of the patient exacerbating, thus allowing him or her to be fast-tracked into the Respiratory Unit.

The COPD Passport has been used successfully in the Respiratory Out-patient Clinics and will be rolled out to selected GP practices for a trial period of six months. It will then be made available across the county.

To find out more, contact Katrina Cledes, Project Manager – NPDT Long Term Conditions Collaborative, Central Cornwall Primary Care Trust.
E-mail: Katrina.cledes@centralpct.cornwall.nhs.uk

In practice

Getting patient advisors involved

Phase III of the National Primary Care Collaborative has put patients in the role of 'improvers'. Drawing on their experience, they have helped to redesign the service, influenced change and delivered local improvements. As a result, many patient advisors have seen their own skills and confidence increase. They have learnt more about their own condition, are helping others take care of their condition better and are engaged in wider PCT service developments.

The Diabetic Patient Advisor for Langbaugh PCT attended group education sessions run by a local diabetic specialist nurse. He now offers hands-on advice to people who have been recently diagnosed and advises on the group education sessions.

Malcolm Collier, team member and Diabetic Patient Advisor for the Bristol North PCT team, says: "I try to get as involved as I can with issues relating to diabetes. It can be frustrating as improvement can be slow. Working with the Bristol North PCT team on the NPDT Long Term Conditions Collaborative has been a breath of fresh air. The collaborative actually listens to my ideas, asks questions and is moving things forward, having taken account of my views. I am happy to be part of an initiative as refreshing as this and feel my input is truly valued."

The role of professionals

During a consultation, professionals may not be used to asking themselves how they can help a patient to manage their own condition. This focus needs to change in a patient-led NHS. Professionals should be working towards the following:

1. To change the way consultations are conducted. Currently, there is a tendency to focus on identifying an illness, deciding how to treat it and making sure a medication regime is followed.
2. To enhance their own understanding, skills and confidence as they interact with people with long term conditions. A confident, well-informed patient is not a threat to professional practices. In most cases the person knows more about living with their condition than anyone else.

3. To develop a more equal relationship. The professional/patient relationship is a meeting between two experts, sharing different knowledge.¹⁸
4. To help modify the way people seek help by challenging their beliefs about their health and condition.¹⁹ A motivational style of discussion that promotes contemplation of change can be helpful in supporting people through the process of planned lifestyle change towards optimal self care.

By sharing their experiences with others, health professionals may improve their own skills and empathy.

The role of PCTs and NHS trusts

1. To commit to training front-line staff. This is vital if we are to change the way we think about self care and the role of individuals in their health care.
2. To work with local education providers to ensure that the appropriate type of training is developed and provided.
3. To understand the wide range of self care and self management skills training provided by the voluntary sector. Such services make a valuable contribution.
4. To provide structured patient education as one of the many self care support options available.

18 Tuckett D, Boulton M, Olsen C and Williams A (1985) *Meetings Between Experts: An approach to sharing ideas in medical consultations*. London, Tavistock Publications.

19 "The exceptional potential in each primary care consultation suggests that four areas can be systematically explored each time a patient consults – management of presenting problems; modification of help-seeking behaviours; management of continuing problems; opportunistic health promotion." Stott and Davis (1979).

Supporting self care is key for the disease-specific National Service Frameworks (NSFs), such as the Diabetes NSF. Standard 3 of the Diabetes NSF aims to ensure that people with diabetes are empowered to enhance their personal control over the day-to-day care of their diabetes. Structured patient education and effective care planning play important roles in reaching this standard.

In practice

Development of comprehensive guidelines for methotrexate therapy

A rheumatology nurse practitioner, the rheumatology consultants, and the head of pharmacy developed comprehensive guidelines for methotrexate therapy for patients with inflammatory arthritis at Norfolk and Norwich University Hospital.

An increased number of patients were attending secondary care for methotrexate injections after it was identified that some GPs were reluctant to prescribe and manage patients on injectable methotrexate in the community.

The rheumatology nurse practitioner:

- participated in the working party which developed the guidelines for oral and parenteral Methotrexate for the treatment of inflammatory arthritis,
- developed an education programme for patient self-administration of subcutaneous methotrexate and;
- organised study days for all health professionals.

This resulted in:

- improved service provision for patients,
- promoted existing shared care practice between primary and secondary care and;
- addressed the safety issues around methotrexate therapy.

To find out more, contact Marie McGee, Lecturer in Adult Nursing, University of East Anglia, tel: 01603 597 103, e-mail: m.mcgee@uea.ac.uk or Carol Edwards, Deputy Director of Nursing and Education, Norfolk and Norwich University Hospital, tel: 01603 286 633

The role of the Department of Health

One of the commitments in the White Paper²⁰ states that at each stage of the professional education and regulatory process action should be taken to change the underlying culture profoundly and encourage support for individuals' empowerment and self care. The Department of Health 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;
- work with the professional bodies to embed self care in core curricula.

Information – more informed patients are more empowered people

Key actions

- Find out, through new and established mechanisms, what information and support people with long term conditions want. What formats and languages do they need?
- Review the information you already provide for patients and carers, and decide what you need in the future: people need access to good-quality and comprehensive information they can understand, as and when they want it.
- Make sure that health and social care professionals know about other community contacts, associations and websites.
- Get involved with patient organisations and groups to understand the best way to provide information and services.
- Make good use of Local Strategic Partnerships to help with the sharing and distribution of information.

Putting patients at the centre

While information on its own is not enough to affect people's behaviour, quality of life or clinical outcome,²¹ there is good evidence to suggest that better understanding of a long term condition can positively affect people's understanding of their symptoms and long term health.

Much disease-specific information is written by doctors, who often describe health conditions in pathological terms. However, information implicitly designed to support self care for certain conditions is available – for example, *The Back Book* (www.coventrypainclinic.org.uk/spinalpain-thebackbook) and the Angina Plan (www.anginaplan.org.uk).

There is, however, a group of people who are less likely to have access to the internet and tend to make little use of self care information.²²

21 *Transforming Chronic Care*, HSMC Birmingham, 2005

22 *Views on self care of people with long term conditions*, DH, February 2005.

More must be done to help them understand and use information, especially if they have a long term condition or have low health literacy.

Improving people's knowledge and understanding is key to creating a patient-led NHS.

People need to know how to connect with the wider community and professionals working in GP practices, local hospitals and health centres, pharmacists, community groups, social groups and voluntary groups. They may also need support with finding the right housing solution or adapting their own home to make living with a long term condition easier.

People do get information from professionals. But informal sources of information are trusted more and encourage self caring behaviours with greater consistency. (MORI, April 2005)

Where to find useful information

People can find information – such as leaflets, videos and audio tapes, including those that focus on a specific disease or service – from many different sources:

- Workshops, courses, classes and self care support networks and groups (both local and national).
- Adult education facilities and libraries.
- The internet and online or digital services such as NHS Direct Online, HealthSpace and interactive TV.
- Some housing-with-care services, such as the Extra Care Charitable Trust, offer a well-being service that provides health advice and information for people living in their own homes. Visit: www.extracare.org.uk.
- Connexions provides advice on education, careers, housing, money, health and relationships for 13–19-year-olds in the UK and can help younger people with long term conditions. Visit: www.connexions.gov.uk.

By becoming central to the discussion about their care, people feel more confident, independent and empowered.

In practice

Empowering patients to influence service re-design

South Wiltshire PCT organised a chronic obstructive pulmonary disease (COPD) process mapping event which was attended by 23 people, including patients, clinicians from both primary and secondary care and managers.

The aim of the session was to establish the care currently being provided to COPD patients by mapping the key aspects of the 'patient journey', including:

- recognising symptoms
- diagnosis
- advice and education received following diagnosis
- exacerbations/admissions to hospital
- living with COPD as a long term condition and self care
- follow-up appointments
- prognosis.

The session identified the need for more patient information to be available in GP surgeries to people when they are first diagnosed. Subsequently, leaflets were developed by Specialist Respiratory Nurses from Salisbury District Hospital and approved by the patient forum. These are available on the Integrated Clinical Information Database (ICID), and can be downloaded and printed during consultations.

To find out more, contact Louise Fowler, Lead Manager, West Country NPDT Centre, tel: 01749 836 555, e-mail: louise.fowler@mendip-pct.nhs.uk

In practice

Giving people direct access to help with rheumatoid arthritis

The University of Bristol Academic Rheumatology Unit and the Clinical Rheumatology Service at United Bristol Healthcare Trust have worked together to assess the benefits of making multidisciplinary secondary care expertise available to patients with long term rheumatoid arthritis when they need it most. A six-year trial²³ compared providing routine hospital outpatient care with situations in which patients or their GPs initiated reviews with a rheumatologist, physiotherapist or occupational therapist through a nurse-led telephone helpline. Fortnightly direct access clinics meant no patient had to wait for longer than ten working days for an appointment and patients could receive immediate advice from the nurse.

Two concerns were that patients would either overwhelm the system with frequent requests for review, or that they would be reluctant to access the service, not come for review, and suffer avoidable declines in their health. However, neither problem occurred. After six years, patients who initiated their reviews through direct access were clinically and psychologically at least as well as patients having traditional reviews initiated by a physician. They requested fewer appointments, found direct access more acceptable, and had more than a third fewer medical appointments.

Tested initially with about 100 patients, this service has now been successfully rolled out to nearly all the 600 patients with long-term rheumatoid arthritis in the department. A committee including several patients from the original study managed the roll-out. On their advice, a short education session and information leaflets have been introduced for patients entering the scheme.

To find out more, contact Professor John Kirwan, email: John.Kirwan@bristol.ac.uk or Dr Sarah Hewlett, email: Sarah.Hewlett@uwe.ac.uk

23 Hewlett S, Kirwan J, Pollock J, Mitchell K, Hehir M, Blair P, Memel D. and Perry M. Patient initiated outpatient follow up in rheumatoid arthritis: six year randomised controlled trial. *BMJ* 2005; 330 (7484): 171.

The role of professionals

1. To see self care support as one of the best examples of how partnerships between the public and professionals can work.
2. To support people by promoting self care, helping them feel more in control of their lives through appropriate information, supporting problem solving and self confidence.
3. To direct people towards the type of support and information they need. Professionals need to be familiar with both primary and secondary care services in their area, together with voluntary sector, housing, education and other services.
4. To provide meaningful information about specific conditions and guidance on how to access it so that people feel confident enough to use it. Access to effective self care options should be the first item on the 'shopping list' that is discussed with patients during a primary care consultation.
5. To make best use of community pharmacists. Under the new contractual framework for community pharmacies, pharmacists will hold details of health and social care providers or support organisations. They can be a valuable source of information for people suffering from long term conditions for the following reasons:
 - They are among the most accessible healthcare professionals in the country, with nearly half the population living within 500 metres of their local pharmacy.
 - They are often the only places where some people can get expert health support, especially in a rural or inner city area where no GP is nearby.
 - People can simply walk in; there is no need to make an appointment.
 - Advice and support are often available during longer hours.
6. To provide patients with copies of letters written about them by clinicians. The benefits of providing patients with copies of their letters includes:
 - Better informed patients: Patients and carers have a better understanding of their condition and how they can help themselves.

- Better compliance: Patients who understand the reasons for taking medication or treatment are more likely to follow advice.
- Health promotion: The letters can be used to reinforce advice on self care and life styles.

The role of PCTs and NHS trusts

1. To make local health and social care information more widely available. Since 2000, local authority social services, housing departments and PCTs have worked together to produce Better Care, Higher Standards charters. These charters can be useful sources of information for anyone wanting access to local services.
2. To work closely with local authorities who have excellent information about voluntary organisations, which can be shared across health and social care organisations. Local Strategic Partnerships have a crucial role to play.
3. To have the infrastructure in place to help people make day-to-day choices and manage their condition and own care independently, so they become true participants in making decisions about their care.

The role of the Department of Health

At a nationwide level, the Department of Health is developing the following as set out in Our health, our care, our say: a new direction for community services:

- A pilot involving a local authority and a PCT to develop an integrated approach to information. The ambition is for PCTs and local authorities to jointly maintain an accessible database of all services and support groups in their local area.
- Services will give all people with long term health and social care needs and their carers an 'information prescription'. 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.

In addition, the Department of Health is developing the following as part of the implementation of the Better Information, Better Choices, Better Health framework:

- A health 'find' engine which allows people to search for and find the information they need.
- An accreditation scheme for information providers to help people easily find quality information that they can trust.

The new *NHS Direct Interactive* TV services also support people with long term conditions. It is now available to about 20 million people in the UK especially as a pathway to support self care for "hard to reach" groups (e.g. elderly living alone) who feature disproportionately highly amongst those with long term conditions. NHS Direct is keen to develop these and the online services further to meet PCTs' requirements and has experience of working with organisations such as the Diabetes Care Line and the Wakefield Asthma Project.

Everyone has a role

To increase awareness of the importance of self care, patients, parents, carers, teachers and employers all need to get involved in finding the best way to provide useful information by communicating between themselves.

Important links can be made between Patient and Public Involvement Forums, the Patient Advice and Liaison Service (PALS), local community groups and support networks and voluntary organisations. Valuable information that has been created by patients and support groups, as well as strategies to encourage people to get more involved in their own care, can be provided by many community and voluntary organisations.

Tools and devices – helping people to monitor their condition and control their medicines

Key actions

- Explore ways of making available more self care tools, self monitoring equipment and assistive technologies – plus information, access and support for their use.
- If you are a pharmacist, ensure you maximise your expertise in the effective and safe use of medicines and the promotion of healthy lifestyles, particularly for people with long term conditions.
- Forge close links with voluntary and community organisations and social services networks to understand what services are provided in respect of tools and devices to support self care and how people can access them.

Putting patients at the centre

Regulating their own medicines can be a challenge for some people, especially those who are older and suffer from long term conditions. Their inability to take medicines correctly can be a major reason why they end up moving to a nursing home: as many as 23% of older people move into a nursing home because they cannot manage their medicines. Many other people with a long term condition are admitted to hospital, often as emergency cases, because they are not taking medicines correctly.

A great deal can be done to help people use their medicines effectively. Support, information and someone to talk to if they have a problem all help them manage their medicines so they can remain safely at home and enjoy the best possible quality of life.

Monitoring people remotely through clinical networks or collaborative initiatives can also play a major role in helping people to look after themselves at home. For example, elderly or vulnerable people can be monitored at home by sensors, while people with diabetes have for some time been able to measure their own blood sugar levels.

The voluntary and community sector has an important role in terms of providing equipment and tools to help people to self care. Housing and care services, such as home improvement agencies, will install aids and adapt and repair people's homes to help them live independently in their own home. The value of these services should not be under-estimated, and close links with social services can provide great benefits for patients.

In practice

Helping people to maintain a dignified standard of living

For the past nine years, the British Red Cross Community Equipment Services in Leicester has managed all the community equipment services for Leicestershire and Rutland.

Helping over 20,000 people each year, the small call centre handles up to 7,500 calls a month. It delivers almost all the equipment – 70% of which is recycled stock – within seven working days.

To find out more, contact the British Red Cross Society, tel: 0116 254 4547.

When people know how certain medicines might affect their daily lives, they can share in the decision-making process of how and when to take them.

In practice

Supporting self care on the high street

In a DH sponsored pilot across Greater Manchester, up to 6,000 people with diabetes and/or cardiovascular disease are being offered the choice of having their next consultation carried out in an approved pharmacy. The choice is offered as part of GP-delegated care and the visit to the pharmacy to collect medicines will now include point of care blood tests for HbA1C(marker of diabetes control) and cholesterol/HDL-cholesterol (markers of lipid lowering therapy, lifestyle and diet). The pilot supports the integration of pharmacy into healthcare delivery under the new Pharmacy Contract and enhances patient choice, convenience and access to healthcare outside hospitals. The service will start to be offered by 22 pharmacies late 2005 onwards, running for 18 months in each and with funding for a minimum of two consultations per year.

To find out more, contact Gilbert Wieringa, Greater Manchester SHA, tel: 07980 958092

Reminders by e-mail, text message or phone have also proved successful in pilots, although many people from hard-to-reach groups will not have access to these technologies.

The role of professionals

1. To be aware of the tools and devices – both technological and non-technological – that can make a significant impact on a person’s ability to live independently with a long term condition. People need to be able to gain access to information relating to these technologies as and when they want, so front-line staff should be able to offer appropriate guidance.
2. Self care support is included within the essential services component of the new contractual framework for pharmacy, which all pharmacies will normally be expected to provide. Within this service description, pharmacies will provide several different aspects of self care support such as advice on the treatment of minor ailments and long term conditions; and advice on the selection and use of appropriate medicines. Other essential services include:
 - sign posting to other health and social care providers when appropriate
 - for people with diabetes or heart disease, providing prescription-linked healthy lifestyle advice on stopping smoking, nutrition or physical activity
 - online prescription ordering
 - repeat dispensing – an essential service for patients to have their medicines dispensed in several episodes rather than going back to their GP for a new prescription each time; at each dispensing episode, the pharmacist will discuss the patient’s medicine and give appropriate advice to them.
 - reviewing medicine use, as and when appropriate ²⁴

24 For reviews of medicine use, see *Management of Medicines: A resource to support implementation of the wider aspects of medicines management for the NSFs for diabetes, renal services and long term conditions.*

Evidence suggests that using computers and telecommunications systems to monitor conditions may improve care processes and be associated with improved clinical outcomes, especially for people with diabetes. (*Transforming Chronic Care*, HSMC Birmingham, 2005)

In practice

Improving understanding and self care for people with diabetes

People with diabetes in Hillingdon can now get support through the Hillingdon community pharmacy diabetes service. This is a personalised programme of health monitoring (blood glucose, blood pressure, cholesterol), health education and medicines management offered at ten community pharmacies in the area.

A questionnaire forms the basis for an initial discussion about lifestyle and medicines with the pharmacist. Follow-up appointments, which give an opportunity for further discussion on issues such as weight management and giving up smoking, occur as often as the person with diabetes and the pharmacist think appropriate.

Results from the scheme show not only indications of improved health but also that participants achieve a greater understanding about diabetes. This enables them to become more confident about self monitoring their condition and self administering their medication.

Contact: Shailen Rao, Hillingdon PCT, e-mail:
Shailen.Rao@hillingdon.nhs.uk

The role of PCTs

1. To use the guidance on the Preventative Technologies Grant, issued by the Department of Health in June 2005, accompanied by implementation support material and best practice guidance developed by the Care Services Improvement Partnership (CSIP). This will help local authorities and their health partners to facilitate the change required to bring telecare into the mainstream of service provision.
2. To look at what services, tools and devices are already in use in your area.
3. To find out from patients what has been or would be useful to them.

In practice

Radio Pager Service

The Oliver Zangwill Centre for neuropsychological rehabilitation, part of East Cambridgeshire and Fenland PCT, has developed an award-winning 'text-to-voice' technology which will run alongside their existing NeuroPage service and offer clients with visual impairments the opportunity to receive memory and attentional alerts.

The NeuroPage service (a radio-pager worn by the individual to receive written text messages) is already used by a number of clients across the UK. Message alerts are delivered to help with problems such as forgetting or initiation. A computer, based at the Centre, automatically sends alerts at pre-arranged times. However, this system may not be accessible to people with acquired visual impairments or reading difficulties. For this reason the 'text-to-voice' system was developed.

Andrew Bateman said, "We felt that these people could benefit from recent advances in technology. Integrated circuit technology is readily available to convert written text to digitally produced spoken output."

For further information, contact Andrew Bateman, Neurological Services Manager, tel: 01353 652165, e-mail: Andrew.bateman@ozc.nhs.uk, www.neuropage.nhs.uk

Support networks – boosting confidence and getting involved in the community

Key actions

- Find out what voluntary and community support groups are running in your locality. Make a point of engaging with social care and local authorities, who have a wealth of information and knowledge.
- Establish ways to ensure that primary and secondary care professionals are able to access and share this information.
- Encourage and forge partnerships between patients and practitioners when establishing formal and informal support networks.
- Encourage people to be part of relevant local networks which in turn will support them as well.

Putting patients at the centre

When it comes to helping people to take greater responsibility for their own care, a balance between minimising risk and helping them to become more independent must always be found.²⁵

A paternalistic and overly cautious approach can stop people from taking control of their own lives and care. All health and social care workers need to focus on boosting people's confidence rather than encouraging their dependency.

Community and voluntary groups play an important role in boosting people's confidence and getting them involved in their community. Many local community groups focus on specialist areas such as sickle cell, Parkinson's disease, care for the elderly, HIV/AIDS, improving physical access, learning disabilities, mental health and testicular cancer.

25 *Independence, Wellbeing and Choice: Our vision for the future of social care for adults in England*, DH, March 2005

Many are formed to:

- support people living with specific conditions
- provide specific and detailed advice and information
- arrange respite care and support for carers and relatives
- provide disease-specific education and training
- allow peer support with people in similar circumstances
- provide advocacy support
- lobby for service change and improvements.

Support groups and networks may be particularly useful to people from ethnic minority communities, where language and culture can be a real barrier to long-term self care and fostering a sense of social inclusion.

In practice

Social Action for Health creates 71 health guides in East London

“Such a simple idea – why has it never been done before?”

A small advert in a local paper attracted 600 enquiries from people wanting to train as health guides. Eventually 75 applicants took part in the eight-week training, with 71 completing the course.

The aims of the initiative were:

- To establish and support local people to act as health guides in their community.
- To enable people from ethnic minorities to access health information and guidance, plus increase understanding and awareness of self care, in their own language.
- To empower local people to access their own community-based knowledge.

Over five months, 2,000 local people took part in health guide sessions in Bengali, Somali or Turkish.

To find out more, contact Elizabeth Bayliss, Social Action for Health, The Brady Centre, 192 Hanbury Street, London, E1 5HU, e-mail: ElizabethB@safh.org.uk

The role of professionals

1. To ensure that patients contribute as much as possible to their own needs assessment and care planning. The starting point for this is a person's view of his or her abilities, needs and ambitions. Person-centred care planning is one of the most important ways in which health and social care can be transformed into integrated services with the individual or their carer at the centre of the package of care.²⁶
2. To work closely with the individual, their carers and other professionals across health and social care services. This will provide huge benefits when it comes to supporting and improving the quality of life of the patient, making improvements to the design and delivery of services, and patient satisfaction.
3. To know and understand what support is provided outside the health and social care arena. Being able to point someone in the direction of a specific support group could make the difference between someone living independently with a condition, or just living with it.
4. To encourage people to join local networks to receive and give support as necessary.

In practice

Improving the quality of care for older people in hospital

The multidisciplinary Southampton Older People's Outreach and Support Team is made up of an occupational therapist, a social worker, a consultant nurse, two senior nurses, a physiotherapist, a consultant geriatrician and an administrator. Aiming to improve the quality of care older people receive in hospital, the team is looking at reducing complication rates, shortening lengths of stay, improving discharge planning and ensuring that people are more independent when they leave hospital.

Nadia Chambers, who co-ordinates the team, says: "As soon as a referral is received from either A&E, Medicine or Surgery, the team carries out a range of assessments. This includes discharge planning and flagging up social care needs."

To find out more, contact Nadia Chambers,
e-mail: nadia.chambers@suht.swest.nhs.uk

In practice

Supporting stroke patients to live independently

Carers, and stroke patients belong to the Stroke Rehabilitation User Group, where they were supported by health and social care professionals to discuss questions and suggest improvements that could be made to stroke services in Bradford. They meet at St Luke's Hospital, Bradford.

Denise Beck, the user group co-ordinator, says: "The user group has worked far better than we ever imagined. Their feedback has been very, very useful.

Rehabilitation of stroke patients is very important. It's been shown that if you go into a rehabilitation unit you are less likely to die from another stroke and 30% more likely to return home and be more independent."

Nick Farrar says: "the group has developed tremendously in confidence over the last year and are themselves now running annual Bradford-wide stroke events to ensure services keep improving. The staff have learnt a huge amount about the real patient experience"

To find out more, contact Nick Farrar, tel: 01274 437 996, e-mail: nick.farrar@bradford.gov.uk

In practice

Newham COPD pathway development project

Newham Health Care and Newham PCT have jointly funded a project director to manage long term conditions. In addition, they are working together to implement the COPD pathway development project at Newham University Hospital. Here, expert patients, the local 'breath easy' group and physicians, nurses and physiotherapists are working together to develop a seamless COPD pathway across primary and secondary care.

To find out more, contact Project Director, LTC Newham, tel: 020 8555 4832, e-mail: angela@ajsingle.co.uk

The role of PCTs and NHS Trusts

1. To link up with social care organisations and explore what voluntary and community sector resources and expertise are available.
2. To understand the available level of advice and the degree to which local groups can support self care. The most important aspect of this is to ensure that information can be easily shared throughout your area so that those who need it most can benefit.

In practice

Working to rebuild a sense of independence

The HomeBridge 'bridge to home' project has been launched in Ashford to provide recuperative care and rehabilitation for adults and older people. Seven purpose-built bungalows adjacent to a sheltered housing complex act as a half way house between hospital and home, residential care and living independently, or for people experiencing difficulty in their own homes. Service users can stay for up to six weeks, during which time they receive intensive support and recuperative care to promote independence, rebuild skills and confidence to help them return to their own home.

The project involves joint working between SSD - care management and support workers, housing - the scheme manager, and PCT - nurses, occupational therapists, physiotherapists and rehabilitation workers. The service also works with the Age Concern Day Centre adjacent. In 2005 46 clients accessed the service of which 38 returned to their own homes or were re-housed to sheltered housing, a high proportion of whom would in the past have gone into residential care.

To find out more, contact: Barbara.Sleator@kent.gov.uk, Christine.Beaney@kent.gov.uk, or jane.stallwood@ashfordpct.nhs.uk, tel: 08453 302967

Want to know more about self care?

This publication is the latest in a series from the Department of Health setting out the strategy for a patient-centred health care service.

The NHS Plan (July 2000) and Securing Our Future Health: Taking a Long Term View, Final Report, Derek Wanless (April 2002). We are now halfway through a ten-year programme of reform which began with the NHS Plan and the Wanless Report. These identified the need for a programme of sustained investment in and reform of the NHS to ensure that it could deliver its core aim: providing high-quality care for every patient, responding to need, not ability to pay.

Better information, better choices, better health (December 2004). The strategy is a framework to develop resources nationally and locally that meet everyone's need for information so they can make informed choices about taking better care of their own health and treatment options. It will make consistent, quality information available in more places and in more ways than ever before, for example in people's homes through interactive TV and the telephone, in the community and in health settings through face-to-face contacts and by using language people understand.

Self Care – A Real Choice, Self Care Support – A Practical Option (January 2005) contains more information about self care support.
www.dh.gov.uk/selfcare.

Supporting People with Long Term Conditions (January 2005) outlined a new NHS and social care model for the care of people with long term conditions. It aims to match need to support by providing personalised, yet systematic health and social care to people with long term conditions. It spells out a more proactive approach to identifying and responding to needs as they emerge.

Independence, Wellbeing and Choice: Our vision for the future of social care for adults in England (March 2005) signalled a move towards providing a more proactive, seamless and person-centred care.

The National Service Framework for Long Term Neurological Conditions (March 2005) aims to transform the way health and social care services support people to live with long term neurological conditions. Key themes are independent living, care planned around the needs and choices of the individual, easier and timely access to services and joint working across all agencies and disciplines involved. The principles of the NSF are also relevant to service development for other long term conditions.

Creating a Patient-led NHS (March 2005) signalled a radical change in the way the NHS works. It looks at changing the culture as well as systems so that they are truly patient-led with a focus on health promotion and prevention.

Commissioning a Patient-led NHS (July 2005) and Health reform in England: Update and next steps (December 2005) brings together many policies which together create a framework for change. The changes are necessary to ensure that the NHS provides high quality care, led by the needs and wishes of patients, in the most efficient way. Many of the initiatives are well known: patient choice, a wide variety of providers, more freedom for hospitals, stronger commissioning, new payment mechanisms and independent inspection of quality.

For examples of Self Care Devices and Assistive Technologies to Support Self Care (July 2005), visit www.dh.gov.uk/selfcare

Our health, our care, our say: a new direction for community services (January 2006) sets out a vision and package of proposals designed to address the expectations and outcomes that people want for themselves; maintaining a sense of well-being; and leading an independent life. There is solid evidence that care is less effective if people feel they are not in control. This self care guide for supporting people with long term conditions complements the proposals set out in the White Paper and both reinforce our existing programme of reform.

To read case studies about self care support initiatives that are being implemented locally across the country, visit: www.dh.gov.uk/SelfCare.

www.dipex.org – DIPEX shows you a wide variety of personal experiences of health and illness. You can watch, listen to or read their interviews, and find reliable information on treatment choices and where to find support. The site covers cancers, heart disease, mental health, neurological conditions and screening programmes, and there are plans for new areas on pregnancy, teenage health, long term conditions and many others.

The *Working in Partnership Programme* (www.workloadmanagement.nhs.uk or e-mail: louise.jarvis@wipp.nhs.uk) is running showcase pilots to help PCTs and care professionals to work closely together to support self care. Airedale and Bradford, Central Cheshire, Southwark, Lambeth, Oldham and South Tyneside PCTs are involved in the pilot.

Through the collaborative with the *National Primary Care Development Team*, Cheshire West PCT has involved Patient Advisors and their carers in developing patient information leaflets which include personal management planning and information about recent test results. E-mail: denise.midgley@centralliverpoolpct.nhs.uk

Kent Telehealth gives people the technology to monitor their own health. People can communicate with health and social care professionals from home via a hi-tech computer. The scheme also allows people to measure, record or take blood pressure, blood sugar, blood oxygen, temperature, weight, lung capacity and ECGs. E-mail: claire.skidmore@kent.gov.uk

Glossary

AHP	Allied Health Professional
NSF	National Service Frameworks
EPP	Expert Patients Programme
PSA	Public Service Agreement
PALS	Patient Advice and Liaison Service
NPDT	National Primary Care Development Team



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