

*Chronic disease  
management and self-care*

National Service Frameworks

A practical aid to implementation in  
primary care

August 2002

## Key Messages

- Many chronic conditions can – and should – be managed within the primary care setting
- Ensuring that patients with chronic disease fully understand and are empowered to manage their condition is a major priority
- Helping patients to take their medicines effectively is crucial – pharmacists are a key resource in this respect
- GPs with special interests, specialist nurses and allied health professionals can all play a key role

## Introduction

Cardiovascular disease, hypertension, diabetes and dementia are conditions that can, to a large extent, be managed within the primary care setting (as can cancer, following initial treatment). Clearly, many patients, particularly older people, may suffer from more than one of these conditions – primary care can, and does, take an holistic approach. Disease registers (including call and recall systems), effective prescribing and medicines management, and the enabling of self-care and patient empowerment are all key to effective management within primary care.

### Effective management of CHD

*The practices taking part in the CHD Collaborative (part of the Modernisation Agency's Service Improvement agenda) are enacting a system that ensures validated CHD registers and proactive call and recall for patients, often nurse led. They track the percentage of patients on appropriate medication, using the NSF measures. In the first year, the Collaborative practices have delivered:*

- *a 20% increase in CHD patients on aspirin (from a high base)*
- *a 60% increase of CHD patients on statins*
- *a 60% increase of patients on beta-blockers 12 months post myocardial infarction*
- *a 25% increase of CHD patients with blood pressure less than 140/85.*

*More information on the CHD Collaborative is available at [www.modernnhs.nhs.uk](http://www.modernnhs.nhs.uk) (follow the Service Improvement then CHD links).*

## Self-care and patient empowerment

On average, a diabetic spends around three hours per year with a health professional. This means that the patient is left to manage his/her own condition for the other 8757 hours of the year. These figures graphically illustrate why helping patients with chronic disease to understand and take responsibility for their condition is so important if patient outcomes are to be optimised.

Standard three of the Diabetes NSF centres on patient empowerment:

*All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.*

Clearly, similar principles apply to other chronic conditions and, indeed, all of the NSFs emphasise the importance of self-care in managing long-term disease and (in the case of the Older People's NSF) the promotion of independence. Evidence supports the idea that self-management of chronic conditions leads to improved psychological well-being, reduction in pain and lower levels of depression, enabling a better quality of life. In addition, training in

self-management programmes at early stages of a condition may help prevent the onset of compounded conditions and further disability.

For patients to take control of their condition, they need good information services - at the right time and in the right form (see also 'Patient involvement and education' in the *Organisational Development* leaflet). This will need to include well-validated references and websites for further information, and translation facilities, where appropriate. Advice and support on how to *use* the information is crucial if patients are to be able to make fully informed decisions about their care. Patient-held records can also facilitate self-care.

There are many initiatives – both local and national – that support self-care; primary care is uniquely positioned to work with patients and local partners to promote the concept and provide access to services which support it.

### Expert Patient Tutors

*The Heart of Birmingham Teaching PCT is investing in an Expert Patient initiative. Six members of the public, who all have diabetes, have been recruited to become expert patient lay tutors. The PCT is funding their training via a Chronic Disease Self Management course, followed by locally delivered training around diabetes-specific issues. This will prepare the Expert Patient Tutors to go out and run courses in the community for people with diabetes. The project is overseen by a steering group which includes a dedicated project manager, a nurse consultant in diabetes, a regional Diabetes UK manager and other health care staff. A small sum of money was made available by the (then) Health Authority to set up the project, and ongoing funding is being met through the mainstream PCT budget for diabetes.*

### Prescribing and medicines management

Responsibility for prescribing is already being widened to include members of the primary health care team other than the GP. In some cases, having a nurse trained to prescribe may speed up patients' access to medicines, whilst helping with meeting NSF targets. Guidance on the current extension to nurse prescribing, and details of the medicines contained in the Nurse Prescriber's Extended Formulary, can be found at [www.doh.gov.uk/nurseprescribing](http://www.doh.gov.uk/nurseprescribing). Information on the progress of supplementary prescribing for nurses and pharmacists can be found at [www.doh.gov.uk/supplementaryprescribing](http://www.doh.gov.uk/supplementaryprescribing).

However, up to 50% of patients with chronic conditions fail to take their medicines properly. In diabetics alone, 20% with type two diabetes forget to take their medicines at least once a week, whilst around 80% are unable to test their glucose even once a day because they have not obtained enough testing strips<sup>7</sup>. Clearly, for patients to be able to take an active role in managing their condition, they not only need to have fast and convenient access to medicines but also help to get the most from using those medicines. The Medicines Management Collaborative aims to do just this.

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<sup>7</sup> Figures from Royal Pharmaceutical Society of Great Britain

## Medicines management

*Nationally, a Medicines Management Collaborative has been established. Its main aim is to help patients get the best from their medicines – the right medicines, in the right quantities at the right time – to help improve health and reduce waste. A total of 66 sites are involved in pilots, helping to establish and spread good practice. Results from the first 26 pilot sites are encouraging, with indications that patients are having their medicines reviewed more often and receiving help when they need it. For example, community pharmacists in Coventry are working with their local GPs to review patients' regular medicines, whilst those in South Birmingham are offering a more accessible service for patients collecting medicines. This is helping to save GPs' time and improve patient care.*

*More information is available from the National Prescribing Centre – 0151 794 8137 or visit [www.npc.co.uk](http://www.npc.co.uk) and follow the 'Medicines Management' link.*

Whether part of a Collaborative or not, pharmacists can play a key role in helping primary care organisations to achieve the aims of the NSFs and, in particular, can make a significant contribution to the management of people with chronic diseases. Interventions that have proved effective include:

- one-to-one review with patients to simplify their medication
- helping patients to understand and take their medicines for best effect.

The Royal Pharmaceutical Society of Great Britain has produced two relevant publications:

- *Realising the Potential of Pharmacists* (May 2002) is an information sheet for PCTs, Social Services Departments and Care Trusts which outlines ways in which local health services can benefit from pharmacists' expertise and gives some short case studies. Copies are available from Carole Mitchell, RPSGB (telephone 0207 572 2338 or email [cmitchell@rpsgb.org.uk](mailto:cmitchell@rpsgb.org.uk))
- *Pharmacists and the New Intermediate Care Agenda* identifies opportunities for pharmacists in this area, and demonstrates to service commissioners how pharmacists can contribute to the delivery of intermediate care services. Copies are available from Karen Turnham (telephone 0207 572 2218 or email [kturnham@rpsgb.org.uk](mailto:kturnham@rpsgb.org.uk)).

## Tools and protocols

- Protocols can be very helpful in improving the delivery of care and, indeed, are required in certain cases as part of implementing NSFs. For example, from April 2002, every practice is expected to be actively using protocols for the assessment, treatment and follow-up of people with CHD. The Modernisation Agency\* is putting together a booklet to help organisations develop protocol-based care, which should be available by the end of 2002.

\* The Modernisation Agency is an executive agency of the Department of Health

- The National Electronic Library for Health ([www.nelh.nhs.uk](http://www.nelh.nhs.uk)) contains the full text of national clinical guidelines in the following NSF related areas:
  - Smoking cessation
  - Stroke
  - Primary care management of stable angina
  - Primary care management of dementia
  - Aspirin for prophylaxis
  - Choice of antidepressant for depression in primary care
  - ACE inhibitors for heart failure
  - Type 2 diabetes (foot care)
  - Non surgical management of breast, lung and prostate cancer
- An 'NSF Navigator' for CHD has been developed in conjunction with the NSF Expert Reference Group for CHD, to assist in the implementation of the CHD NSF in primary care. A resource pack in the form of a hard copy folder and an interactive CD, the package contains: key information; guidance; discussion of implementation issues; examples and case studies; practical resources and implementation tools. For further information, please contact: Healthcare Operations Group, Pfizer Ltd, Ramsgate Road, Sandwich, Kent. Tel 01304 645479.
- Local tool: Sheffield Diabetes in General Practice: a guide and resource pack [www.shef.ac.uk/seek/diabetesgl/](http://www.shef.ac.uk/seek/diabetesgl/)

### *The Heart Manual*

*Developed by The British Heart Foundation Rehabilitation Research Unit at the University of York, the Heart Manual provides:*

- *a facilitated introductory session*
- *a workbook with a phased programme of home based exercise, stress management and written information.*
- *two audio tapes – one focusing on relaxation training, the other a scripted doctor-patient interview aimed at helping the patient understand what has happened.*

*The Heart Manual is used by around 70 health care providers, reaching approximately 5000 patients per year. Around 1500 health professionals have been trained to administer the manual, covering an estimated 10 per cent of cardiac rehabilitation in the UK.*

*Source: The Expert Patient – A New Approach to Chronic Disease Management for the 21<sup>st</sup> Century*

## What the practice can do

- Utilise nursing skills in patient education and self-care by developing the role of nurses on managing chronic disease in the practice.
- Provide information about, and access to, self-management programmes for patients with chronic diseases.
- Provide accessible information and advice to patients on self-monitoring.
- Make effective use of computer-based disease management templates (see also *Developing the information systems*).
- Implement NICE guidelines on drugs.
- Review prescribing practice to ensure that it reflects the NSF objectives.
- Implement guidance on nurse prescribing (see below for reference).
- Ensure there is a suitable forum for learning from others' experiences across the practice – for example, how a difficult or unusual case/presentation was handled.

## What the PCT can do

- Consider employing a nurse with specialist or advanced skills and/or AHPs to work across the PCT. (For example, East Leeds PCT has appointed a Specialist Cardiology Nurse to provide expert clinical care and facilitate delivery of the NSF with a partial educational role).
- Explore ways of supporting GPs to develop their 'special interest' in an NSF-related disease area – for example, by funding locum and training costs, or by employing salaried GPs across the patch to cover for special interest GPs. Teaching PCTs also have a role to play in supporting the development of GPs in this way. GPs can also apply for prolonged study leave which pays a contribution towards locum costs and educational allowance.
- Work with voluntary agencies and others to commission user-led self-management programmes.
- Support practices with the installation and use of disease management templates (see also *Developing the information systems*).
- Set clear standards/guidelines for repeat prescribing, including therapeutic alternatives (the Rxlist is available on [www.rxlist.com](http://www.rxlist.com)).

### Improving the quality of care in East Kent

*A Primary Care Clinical Effectiveness programme (PRICCE) has been running in East Kent since 1998. Its aim is to help GPs and PHCTs to improve quality of care. The programme consists of a package of evidence-based criteria and developmental support to help primary care teams improve their care in a systematic way. A series of proxy measures complement the standards to allow progress to be measured. Practices are rewarded for demonstrating that they have met the clinical standards. Thirteen disease areas are covered, including angina, chronic heart failure, hypertension, MI, diabetes and depression. Incentives are provided via a grant, entry criteria being:*

- *disease registers set up*
- *written protocols undertaken by team members*
- *complete audits undertaken to demonstrate compliance*

*GP Support Groups allow problems being faced by individual GP and practices to be discussed and resolved. These are centred on local hospitals so that hospital consultants can support them.*

*Although the programme has not been formally evaluated, feedback indicates successes. Practices are creating disease registers to allow them to recall patients so that their treatment can be reviewed. Even when the practice standards have not been met in full, significant improvements in outcomes for patients are already being secured. In addition, participation in the programme is changing the ways in which practice teams work together and placing emphasis on teamwork as well as clinical practice.*

*For more information, or to purchase an information pack, contact Tony Snell on 01304 222230 or by email on [Tony.Snell@CCMAIL.ekent-ha.sthames.nhs.uk](mailto:Tony.Snell@CCMAIL.ekent-ha.sthames.nhs.uk).*

- Review practice incentive scheme to ensure that it reflects the NSF targets (for example, encouraging the prescription of statins in appropriate circumstances) and generally emphasises the importance of chronic disease management via incentives relating to self-care.
- Consider participating in the Medicines Management Collaborative.
- Work with local secondary care trust on prescribing issues (for example, the development of joint guidelines for selected therapeutic areas).
- Explore the potential for widening the prescribing role of nurses, in accordance with the guidance (see [www.doh.gov.uk/nurseprescribing](http://www.doh.gov.uk/nurseprescribing) and [www.doh.gov.uk/supplementaryprescribing](http://www.doh.gov.uk/supplementaryprescribing)).
- Explore different ways of providing services to help practices cope with rising demand (eg phlebotomy support in surgeries, community-based chiropody service).

- Be aware of what support is available from industry around funding, training and carve-outs and provide guidelines to practices, taking into consideration ethical issues, and not compromising the needs of the patient or service delivery.
- Help practices to ensure effective leadership is available (whether at practice or PCT level) in major disease areas and in clinical governance (see *Organisational development: NSF leadership*).
- Encourage the sharing of approaches and good practice across the PCT – for example, via the PCT website and regular inter and intra-professional meetings/educational events.

### Department of Health funded support

National initiatives to support chronic disease management and self-care are too numerous to mention here. However, brief details of key ones that support NSFs are outlined below.

- *The Expert Patients programme*

The traditional model of patients as the passive recipients of care is beginning to change – especially for those with chronic diseases, who are often more informed about their condition than the practitioners caring for them. The Expert Patients Programme aims to tap into this resource by creating lay-led self-management programmes for patients with chronic diseases. To obtain more information, or to download the report: *The Expert Patient – a New Approach to Chronic Disease Management for the 21<sup>st</sup> Century*, visit [www.ohn.gov.uk](http://www.ohn.gov.uk).

- *Medicines Management Collaborative*

See case study on page 3 or visit [www.npc.co.uk](http://www.npc.co.uk)

- *NHS Direct*

A 24-hour service, NHS Direct is staffed by nurses and gives telephone advice on whether symptoms can be safely managed at home. This is supplemented by NHS Direct online which provides interactive health care information.

NHS Direct 0845 4647

NHS Direct online – [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

## Further contacts/references

### Organisations

*Diabetes UK* provides advice and support on managing diabetes, aimed at both patients and health care professionals. For more information, visit [www.diabetes.org.uk](http://www.diabetes.org.uk).

*The National Osteoporosis Society* (NOS) has an NOS Health Service Liaison department to help the NHS to implement the National Service Framework for Older People, specifically Standard 6 on Falls and Osteoporosis. Help ranges from the provision of nurses to run an audit within a practice, to setting up and running local or regional osteoporosis training sessions. For more information, contact: Gloria Lewis, Health Service Liaison on 01761 471771 or e-mail: [g.lewis@nos.org.uk](mailto:g.lewis@nos.org.uk). Alternatively, visit [www.nos.org.uk](http://www.nos.org.uk).

*The Stroke Association* has produced guidance on good practice in stroke care in primary care settings. This can be viewed at [www.stroke.org.uk/about.htm](http://www.stroke.org.uk/about.htm) or, for a hard copy, contact the Association on 0207 566 0300.

*The Alzheimer's Society* provides a wide range of information on coping with dementia. This is available at [www.alzheimers.org.uk](http://www.alzheimers.org.uk).

*Cancer Bacup*, provides information and support to people with cancer, their families and friends. Visit the website at [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk).

### Publications

*The Expert Patient – a New Approach to Chronic Disease Management for the 21<sup>st</sup> Century*. Visit [www.ohn.gov.uk](http://www.ohn.gov.uk).

*Extending Independent Nurse Prescribing within the NHS in England – A guide for implementation*. Available from the Department of Health Publications, PO Box 777, London SE1 6XH or by emailing [doh@prolog.uk.com](mailto:doh@prolog.uk.com).

*Evidence based prescribing for older people* – developed on behalf of NICE by the Clinical Effectiveness and Evaluation Unit, Royal College of Physicians of London, 11 St Andrews Place, London NW1 4LE. For more information, contact: Rob Grant on 0207 935 1174 ext: 378 or email [ceeu@rcplondon.ac.uk](mailto:ceeu@rcplondon.ac.uk)

The National Association of Primary Care ([www.primarycare.co.uk](http://www.primarycare.co.uk)) is producing a booklet entitled: *Reducing the burden of diabetes in primary care: working with patients to manage blood glucose levels in primary care*. It should be available in autumn 2002.





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