

17 million reasons

Improving the lives
of people with
long-term conditions

The partnership on long-term conditions



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This is the first time that such a diverse group of organisations, including patients, managers and professionals, have come together to make the case for a better deal for the 17 million people in the UK living with long-term conditions. Together, as a partnership, we believe we need to:

- **start right** – by ensuring people have rapid access to expert diagnosis and needs assessment
- **put patients in the driving seat** – with proper access to information and advice to help people make the right choices to maximise their quality of life
- **personalise services around each individual** – with a Care Plan to ensure people have the care they need, when they need it.

This manifesto sets out our shared vision for people living with long-term conditions. It outlines a series of practical proposals which we believe, taken together, could transform the lives of one third of the population. We are calling on politicians from all political parties to include these proposals in their manifestos and to put people with long-term conditions at the heart of the health agenda.

A new debate

Over 17 million people in the UK are currently living with a long-term condition like asthma, arthritis, diabetes or some cancers.¹ Nearly half of this group experience more than one condition. It is estimated that 60 per cent of GP consultations relate to chronic disease management² and that patients living with a long-term condition or its complications use over 60 per cent of hospital beds.

Public debate and health policy continues to prioritise waiting times for surgery, A&E and other aspects of hospital care. However, it is increasingly recognised that more responsive services, greater choice and more control for patients with long-term conditions hold the key to improving the quality of life for the majority of health service users.

Progress is already being made. The challenge now is to share this good practice across the NHS and to explore what additional changes are required to put the needs of people with long-term conditions at the heart of service design and delivery.

The members of the partnership on long-term conditions have joined forces to help make this happen. Drawing on existing good practice, we believe it is time to set out a common vision of the principles which should underpin effective care for all people with long-term conditions. We have also jointly identified a small number of practical proposals – drawn up in consultation with patient groups and professionals – which should be available to everyone. Taken together, we believe these changes would transform the care provided to the one in three people in the UK living with a long-term condition.

¹ Chief Medical Officer, 2001: *The expert patient: a new approach to chronic disease management for the 21st century*. Department of Health

² Office for National Statistics, 2002

A new vision

Some people receive first-class care for their conditions. But, if this is to be true for everyone, we believe we need a new vision for our health services, based on five key principles:

1

People as partners in their care

People with long-term conditions do not want to be passive recipients of services but active participants in their own care. Many are already experts in their condition. Harnessing this expertise can enable people to manage their own care, based on a partnership between health professionals and patients working together to maximise the individual's quality of life.

2

A personalised service

People with long-term conditions want tailored services delivered in an environment that meets their needs: services which recognise that they are a person, not just a series of separate diagnoses; services which take account of their emotional and psychological well-being as well as physical needs; and services which reflect their individual choices and personal preferences at different stages of their life and disease progression.

3

Integrated provision

People with long-term conditions often rely on a complex web of separately managed services, and need all of these to work in order to live well. The best services are those that are integrated across organisational boundaries, bringing together specialist and primary care and the resources available in the public, voluntary and private sectors.

4

Easy access to high-quality information

People with long-term conditions need high-quality, appropriate and accessible information to gain more control over their lives and help them become informed decision-makers about their care. This needs to be provided proactively, ensuring patients have up-to-date information on their treatment, options for self-management and the availability of voluntary organisations and support groups. We need a holistic approach that recognises people have different needs at different times. Good information is equally critical for NHS organisations to enable them to identify individuals in the community who need more effective chronic care.

5

A focus on quality of life

People with long-term conditions are living with their conditions day-in, day-out. Their care needs to be based on improving and maximising their quality of life, including end-of-life care, as well as reducing medical symptoms. The aim must be to enhance people's ability to live independent lives.³

³ See the Ten Principles of Independent Living as set out in the Cabinet Office Strategy Unit Analytical Report, *Improving the life chances of disabled people*, June 2004, page 160.

Our proposals

Access to rapid and expert diagnosis and needs assessment

Why it matters

Chronic conditions shouldn't mean a chronic wait for a diagnosis. Delays in receiving a diagnosis can cause tremendous stress and anxiety for individuals and can also mean delays in accessing services. Tackling delays and ensuring that people's wider needs are assessed may improve clinical outcomes, produce cost savings and provide a better quality of life for people living with long-term conditions as a day-to-day reality.

People with long-term conditions have changing needs as their conditions and lives change. Reassessment of an individual's health and social care needs is vital to make sure that people receive the right care, medication is not wasted and interventions are timely to prevent crises.

However, a diagnosis shouldn't be the only passport to services. We need to ensure that individuals have their needs met even if their condition is yet to be diagnosed.

Where next

We need greater investment in GP services, nurses and other healthcare professionals with special interests to develop assessment and diagnostic capacity in GP surgeries, pharmacies and elsewhere. In addition, individuals with long-term conditions should be given direct access and the option of self-referral to specialists, including GPs and nurses, where this is agreed as part of the Care Plan.

While a medical diagnosis is important, this must be one part of a more holistic assessment of an individual's needs. This means greater investment and more incentives to develop multi-disciplinary assessment and diagnostic teams, working in appropriate local settings, with expertise in particular groups of conditions.

We need to learn from existing good practice in the NHS, particularly services that have established a continuing relationship between the individual and the healthcare professional, a right to reassessment, and more flexible access routes to diagnosis and reassessment. Working within national standards, NHS organisations should have the freedom to establish local agreements about how particular conditions will be assessed and diagnosed, and how health professionals can work in new ways to assess people's needs in the round.



North Staffordshire Musculoskeletal Clinic

In North Staffordshire, a gap was identified in services for people with musculoskeletal problems. Concerns arose that there was inadequate access to rapid diagnosis and appropriate treatment for patients with conditions such as spinal pain, osteoarthritis and chronic widespread pain, who were often inappropriately referred.

In response, the local trust redesigned its services to really meet the needs of the local community. A musculoskeletal department was established involving a broad multi-disciplinary team bringing together rheumatologists, orthopaedic surgeons, GPs with special interests, specialist nurses and physiotherapists. A system of assessing patients for referrals means that patients are now able to see the most appropriate specialist for their condition as a first point of contact. This system has reduced waiting times and reduced the number of patients being incorrectly referred to surgeons when they have non-operative conditions. Future plans in North Staffordshire include extending the service into more accessible settings within the local community.



Tracey Fox

Tracey Fox remembers well the day she was told she had multiple sclerosis. "The diagnosis was a shock to the system, a frightening thing", says the 32-year-old mother of two.

But, there are positive memories too. Alongside Tracey's neurologist was an MS-specialist nurse, part of the multi-disciplinary MS team at the Royal Hallamshire Hospital in Sheffield. By the time she left, Tracey knew she was not fighting her MS alone but had the support of the complete team of health professionals, providing nursing care, physiotherapy, pain control and other skills, working together. "It's wonderful to feel you're not out there on your own and to be dealing with real people, real voices, real faces."

Tracey also took part in a course to help people recently diagnosed to understand more about MS and living with the condition. "We heard about the new MS drugs, about health and fitness and many other things. It wasn't just getting information. It was meeting other people in a similar situation to me."

Access to information and advice

Why it matters

Better informed patients lead to better clinical outcomes. The proactive and systematic provision of accessible information to people with long-term conditions, and their families and carers, needs greater recognition and investment by the NHS and Government. Proper access to information helps people become informed decision-makers about their care and enables them to live their lives with their condition.

People with long-term conditions, and their families and carers, often lack the information they need to make informed choices about their care and to navigate their way around the system. Meeting patients' complex needs for different types of information and advice should be as important as treating an individual's physical symptoms.

The provision of information is a common theme throughout the voluntary sector. There is a wealth of information and advice provided by national organisations and local groups, but there is not enough of an understanding of the benefits of access to information amongst the health community.

New ways of helping patients to navigate the system are already being pioneered. For example, patient care advisers have been critical to the success of the first pilots of patient choice in London. Key workers in mental health and specialist nurses in cancer are demonstrating

the difference that can be made if people have a familiar face to whom they can turn for advice, support and help in accessing the services they need, when they need them.

Where next

People with long-term conditions need a simple way of accessing the range of information they need. A clear information and advice checklist, given to them by their healthcare professional, that details where to find out more about their condition and the services available to them, could be a way of achieving this.

The information and advice checklist would include:

- how to access information about your medical condition
- how to contact other patients living with the same condition
- how to access other support services, such as benefits advice
- how you can be put in touch with a personal adviser, if wanted, to help co-ordinate your care.

The checklist should be personalised and named individuals, whether health service staff, voluntary groups or people with a similar condition, should be identified as sources of support, available on an on-going basis to act as the first port of call for the individual.

Healthcare professionals need to be able to more easily access electronic information on services available throughout the NHS and voluntary and independent sectors during consultations with patients. Providers of such

information, including the NHS, voluntary and independent sectors, need to be willing to sign up to quality standards to ensure a uniformity and high standard of information and advice is available to people with long-term conditions.

Hadleigh Practice Information Service

An information service was set up in the Hadleigh Practice around three to four years ago with some initial funding from Macmillan Cancer Relief, a local carnival and the Friends of the Practice. Although it had its origin in cancer information and support, the service now covers all areas of health. It is one of the only services of its kind based in a GP practice.

A room has been set up as a mini library for the 17,000 patients registered at the two-site practice; it is also used by some of the partners at the practice who pick up resources to pass on to patients. The room contains a PC for internet access, a video recorder, racks of leaflets and books. There is also a blood pressure monitor and scales that patients can use themselves.

On diagnosis, patients can be given an 'information prescription' from their GP to inform them about the service and how it can be accessed. They are encouraged to drop in at any time and three mornings a week the service is staffed by volunteers who can guide patients and put them in touch with local support groups

or provide recommended website addresses. They act as a listening ear and are careful not to convey their own view. Bob Wilson, a volunteer at the Practice, explains: "Patients appreciate being able to take their time, with no pressure, and rummage through our literature, whilst also having the option to ask for help if they need it."



A care plan

Why it matters

Experience to date of person-centred Care Plans in some conditions has shown that they can be excellent if done well. Evidence from the use of Care Plans in asthma has shown that for every £1.60 spent on Care Plans, £7.00 is saved in NHS care.⁴ As well as saving the NHS money, Care Plans improve the quality of patients' lives and improve clinical outcomes.

When done well, Care Plans put patients, not professionals, in the driving seat. However, there is evidence, particularly from the mental health field, that where Care Plans are not taken seriously they can become a box-ticking exercise and, to the individual, little more than a piece of paper.

Care Plans need to be personalised, negotiated and holistic, and should ensure that care is tailored around the needs of the individual and reflects their personal preferences and choices. The Care Plan should be a route map for an individual's care so they know what they can expect from services and when. The Care Plan will enable patients to actively manage their own condition and maximise the opportunities for self-care.

Where next

Whilst we welcome the Government's target of offering a personalised Care Plan for vulnerable people, we believe the aspiration should be that Care Plans are available to everyone with a long-term condition who wants one. The Care Plan needs to be jointly negotiated between the clinician and individual patient, and their carer and family if appropriate. The Plan should match the individual's particular conditions, personal preferences and choices with the best services and support available. In addition, the Care Plan needs to reflect the patient's own goals and set out what a person could do to maximise their own quality of life.

The Care Plan would be given to the patient and would form part of their electronic patient record, to be accessed by all health professionals working with them. The Care Plan would be regularly reviewed, with any changes made by joint agreement with the patient. A named individual would be accountable and responsible for the professional delivery of the Care Plan to ensure people didn't slip through the gaps between different services. Care Plans should be externally audited to assess them against clinical best practice and to ensure they are actually delivered.

⁴ *BMJ*, Vol. 319, 18 September 1999

There is no one-size-fits-all approach to Care Plans. The contents of an individual's Care Plan might range from agreement about check-up timings and when to take particular medicines, to a Care Plan bringing together different services –

not just the NHS, but also other services, including social care and housing. The Care Plan should be a person's evidence of entitlement to services, that they can take with them if they choose to use services delivered elsewhere.

Charlotte Palmer

Charlotte has moderate asthma that was diagnosed when she was a baby. However, due to lack of help from her GP, it is only in recent years that she has finally been able to get it under control.

Despite visiting her GP after suffering an asthma attack and using a nebuliser three times, as well as oxygen, to control her asthma, the GP said that Charlotte now looked fine and did not require further help. It took an emergency visit to A&E before she was referred to an asthma specialist who then asked Charlotte the history of her asthma. Together, the specialist and Charlotte devised a personal asthma action plan. Her treatments, and the importance of taking them, were explained to Charlotte as part of the consultation.

Charlotte now follows her personal asthma action plan and measures her peak flow regularly. This helps her to recognise when her symptoms are getting worse and helps her to control her condition.

Charlotte still has the occasional asthma attack but these are far less frequent now that her asthma is under control. Charlotte says: "I lived for so long with poorly controlled asthma that it ruled my life. However, now that I have a personal asthma action plan, I know how to control my asthma and recognise when my symptoms are worsening. Now, I control my asthma and I feel much healthier and happier as a result."



Making it happen

Taken together, we believe that these proposals could revolutionise care for the 17 million people in the UK living with a long-term condition. We are calling on the political parties to include our proposals in their manifestos for the next general election and to test all of their policies against the principles we have outlined in this document.

If you have any comments on our proposals or would like to get involved, please take a look at our website www.17millionreasons.org or e-mail betterdeal@17millionreasons.org

Alternatively, you may wish to contact one of the partner organisations direct:

Alzheimers Society
www.alzheimers.org.uk

ARMA – the Arthritis & Musculoskeletal Alliance
www.arma.uk.net

Arthritis Care
www.arthritiscare.org.uk

Asthma UK
www.asthma.org.uk

Breakthrough Breast Cancer
www.breakthrough.org.uk

British Society for Rheumatology
www.rheumatology.org.uk

CancerBACUP
www.cancerbacup.org.uk

Continence Foundation
www.continence-foundation.org.uk

DANDA – The Developmental Adult Neuro-Diversity Association
www.danda.org.uk

Diabetes UK
www.diabetes.org.uk

Epilepsy Action
www.epilepsy.org.uk

Long-term Medical Conditions Alliance
www.lmca.org.uk

Macmillan Cancer Relief
www.macmillan.org.uk

MS Society
www.mssociety.org.uk

National Society for Epilepsy
www.epilepsynse.org.uk

New Health Network
www.newhealthnetwork.co.uk

NHS Confederation
www.nhsconfed.org

Parkinson's Disease Society
www.parkinsons.org.uk

Rethink
www.rethink.org

Stroke Association
www.stroke.org.uk

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