Chapter 3 - Going Forwards with Long Term Conditions: Towards a True Health System

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From: Developing Holistic Care for Long-term Conditions.

Edited by Carl Margereson**,** Steve Trenoweth.

Price: £25.99. **ISBN:** 978-0-415-46081-1**.**

Published by: Routledge**.**

Publication Date: 7th October 2009**.**

Pages: 384

Introduction

Long term conditions are common, costly and becoming more common. Health systems which developed to deal with acute episodes of ill-health are finding themselves poorly designed and poorly prepared for the current epidemics of chronic illness and long term conditions. Many are engaged in radical transformation efforts to make themselves fit for purpose.

This chapter outlines the historical and current drivers behinds this transformation effort, describes some of the policies put in place to push / pull the system forwards, and makes some suggestions as to what a true health system might look like. The focus of the chapter is the UK National Health Service, but reference is made to issues and developments from elsewhere.

Socio-economic context and drivers

The current and future cost of caring for people with long term conditions is one of the key factors driving healthcare reform, along with concerns about the poor quality of care being delivered to so many voters and taxpayers. People are living longer with ongoing health problems and increasing numbers are living with more than one disorder.

In England, people with chronic illness account for 80% of general practice consultations and the roughly 15% of people with three or more problems account for almost 30% of inpatient days (Wilson et al 2005). In the UK treatment and care for people with long term conditions accounts for almost 70% of the primary care and acute budget, and chronic illness care may consume 75% of the total cost of national healthcare expenditure in the US (Hoffman et al 1996). 85% of deaths in the UK may be from chronic disease. Some studies suggest that long term conditions can consume up to 7% of a country's gross domestic product (Oxford Health Alliance Working Group 2005) - not just a result of the impact they have on health service costs (Jonsson 2002) but also due to their impact on decreased work productivity (Oxford Health Alliance Working Group 2005). The UK economy may lose £16 billion over the next 10 years through premature deaths due to heart disease, stroke and diabetes.

And of course all these statistics are merely one way of representing the huge and growing burden of suffering, impairment, chronic pain, loneliness, fear and grief experienced by millions of individuals and families year upon year.

The Policy and Initiative Response

For all the difference in the aetiology and pathophysiology of long term conditions, chronic illnesses have several things in common, including the need for healthcare systems and health and social care professionals to activate, empower and support the person with the condition to ensure optimum outcomes.

The Wider Policy Context

In the UK, the NHS reforms (DH 2000, DH 2007a) must be considered part of a wider and ongoing reform of the public sector as a whole which aims to transfer more power to parents, pupils and patients and to enable public sector workers delivering services to respond in new and innovative ways. Perhaps the two main principals of public sector reform in the UK are:

- Putting people first by placing power in the hands of those who use public services
- Personalising services and providing greater choice

In the health and social care sector this is being done via a wide range of policies, initiatives and programmes, some of which are outlined in this chapter. A key aim is to providing people with personalised budgets and accurate information so they can choose the specific care they most need, underpinned by an "information revolution" to enable patients to share information and experiences on the performance of the services they receive.

Specific Policies and Initiatives

The UK Department of Health (DH) is currently managing one of the largest organisational development projects the world has ever seen - attempting to transform one of the world's largest organisations into a semi-coordinated network of lean and nimble organisations delivering timely, effective, integrated and quality controlled care to people with and without long term conditions. The aim is that people with long term conditions pull what they value (treatment, care, advice, support, reassurance, etc) from the system on an as needed basis to increase their choice, health, wellbeing and sense of control, whilst the government "pushes" screening and preventive services towards people backed by social marketing initiatives to try to change peoples health behavior so they don't develop long term conditions in the first place

A vast array of semi-aligned policies, initiatives and programmes are pushing and pulling the UK health and social care system in the direction of a first class service for people with long term conditions, including:

Common Assessment Framework (CAF) for Adults (DH 2009a):
A commitment of the White Paper *'Our Health, Our Care, Our Say'* (DH 2006a) was to develop a generic, common assessment framework for adults which would:

- Improve outcomes for adults by ensuring a personalised and holistic assessment of need, focussed on delivering individual outcomes
- Support improved joint working between health and social services, and
- Increase efficiency through better information sharing

Common Core Principles to Support Self Care (DH 2008a):
A document aiming to help all those who work in health and social care (e.g. commissioners, service providers, educators, etc) make personalised services, enablement and early intervention to promote independence a reality. The government wants health and social care organisations to embed these principles in their organisational policies, agreements with other agencies, and their own culture and practices. Developed by Skills for Health and Skills for Care in partnership with people who use services, carers and other stakeholders, these principles are also making their way into skills and competency frameworks to shape training and professional development.

The Dignity in Care Campaign:
A programme aiming to eliminate tolerance of indignity in health and social care by raising awareness and inspiring people to take action. If patients and their carers were treated with more respect, health and wellbeing outcomes for people with long term conditions would likely improve (See Chapter 19).

Direct payments and individual budgets (DH 2007b, Samuel 2009):
A major strand of policy aiming to accelerate the transformation in social care. Direct payments and individual budgets will place more power in the hands of people with long term conditions, giving them more choice and control, bringing together separate income streams and helping people secure more joined-up packages of support. Once people know the level of resources at their disposal, it can help them plan and control how their support needs are met.

Caring with Confidence Programme (Caring with Confidence 2009):
Previously referred to as the Expert Carers Programme (ECP)this is designed to support and train carers, helping them to develop new skills to manage the condition of the person they care for and manage their own health needs better on a day-to-day basis. Many carers suffer ill-health as a result of their caring activities, and if their health breaks down, so care the care arrangements. Helping them care for the person they care for, and themselves, more effectively and with less stress makes good sense.

The Expert Patients Programme (EPP) (DH 2007c):

This is run by the EPP Community Interest Company, a not for profit social enterprise (EPP CIC 2006). This relatively long-running programme provides training for people with chronic or long-term conditions, delivered by trained and accredited but lay tutors who are also living with a long term health condition. The programme aims to give people the confidence better manage their own health, whilst working collaboratively with health and social care professionals.

NHS Direct:
Now multi-media, the telephone service launched in 1998 and now gets over 6 million calls a year. The Internet service *NHS Direct Online* was launched 1999 and gets over half a million hits a month, whilst the digital TV service *NHS Direct Interactive* covers 60% of the population and has about one million page viewings a month, and the NHS Direct self care guide delivered to 20 million homes

Personalisation (2008b):
The personalisation of health and social care services is a shared ambition across Government, and a common theme throughout health and social care policies. The intention is to put people first through a radical reform of public services, helping people to live their own lives as they wish: confident that services are of high quality, are safe and promote their individual needs for independence, well-being and dignity. The government sees personalisation as:

> *"the way in which services are tailored to the needs and preferences of citizens. The overall vision is that the state should empower citizens to shape their own lives and the services they receive".* (HM Government 2007)

Personalised Care Planning:
Personalised care planning is another main strand of policy, designed to address "*an individual's full range of needs, taking into account their health, personal, family, social, economic, educational, mental health, ethnic and cultural background and circumstances"* (DH 2009b). To skillfully develop a personalized care plan, collaboratively with an individual, taking the above factors and others besides into consideration, is a very different task from assessing someone with an acute illness and deciding how best to treat them. This illustrates the nature of the change required by healthcare systems to meet the needs of people with long term conditions.

Integrated care pilots (DH 2009c):
This programme aims to test and evaluate new models of integrated care, models which aim to empower clinicians to work more closely with patients and other partners. Integration in this context may refer to partnerships, systems and models as well as organisations, and the pilots have been chosen for geographical spread as well as examples crossing boundaries across primary, community, secondary and social care. The insights which flow from this programme should be substantial, and this is a good example of how innovation and risk taking can be stimulated in a sometimes slow to react public service.

Pharmacy in England (DH 2008c):
A White Paper setting out the Government's vision of the future role of pharmacists and pharmacy services, including the promotion and support of healthy living and healthy lifestyles, advice and support on self care, offering services to people with minor ailments and supporting people living with long term conditions with routine monitoring, vascular risk assessment and support in making the best use of their medicines. Another example of how the government wants to make local support available to help people with long term conditions look after themselves better, and avoid complications of their condition.

Practice based commissioning (DH 2007d):
Practice based commissioning aims to place decisions about which services should be commissioned for a patient closer to the patient, helping to deliver a more personalised service with more choice. Practice based commissioning should be supported by PCT's to help them deliver "world class commissioning", helping them in turn to commission services more responsive to the needs of local people identified, in part, via the personalised care planning process.

Supporting People with Long Term Conditions to Self Care: a guide to developing local strategies and best practice (DH 2006):
This document explains how health and social care services can support people with long term conditions to self care through an integrated package including information, self monitoring devices, self care skills education and training and self care support networks.

Year of care programme:
A three year project to test a commissioning, care planning and service delivery approach - initially around diabetes. This programme will produce practical guides, training programmes and insights for service improvement along the way, and like some of the other initiative and pilots mentioned in this chapter, the results of this programme will inform future policy development in what people hope will be a cycle of continuous improvement.

Elements and Models

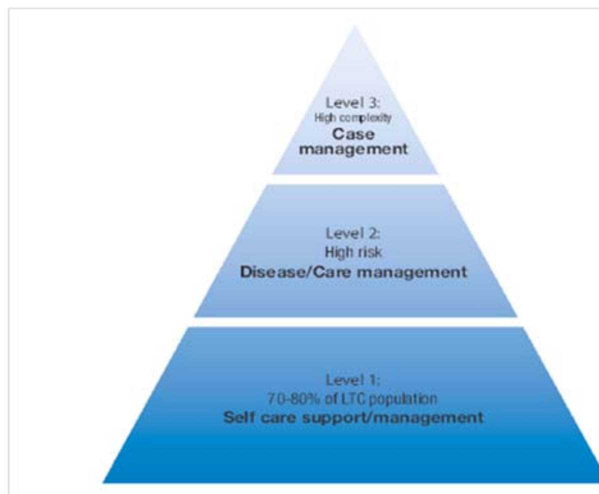
The above policies, programmes and initiative are designed to bring a better healthcare system into existence. Much is known about the elements or components of a healthcare system required to deliver superior outcomes for people with long term conditions (Renders et al 2001, Bodenheimer et al 2002, Weingarten et al 2002, Ouwens et al 2005, Tsai et al. 2005, Singh 2006) – indeed, there have even been reviews of systematic reviews! (Ouwens et al 2005). One review (Singh 2005) found evidence to support the beneficial impact of a range of initiatives on patient and system outcomes including: the use of broad chronic care management models; involving people with long term conditions in decision making; greater reliance on primary care; providing accessible structured information; self-management education and the use of nurse led strategies.

Models are abstractions that help us understand how the world works and what causes what. They simplify things – leaving some things out, and focus our attention on what the model developers consider to be the most important features and relationships. The following models were developed by different organisations for different purposes and one is not necessarily better than another.

The Kaiser Permanente triangle

A useful way of stratifying populations to inform service planning, service delivery and workforce development, the model divides the population into three levels (DH 2005a) (Figure 1):

Fig 1.
The Kaiser Permanente triangle



- *Level 3: People with complex needs requiring skilled case management.* Individuals in this group may be high intensity users of unplanned secondary care, and the case management approach involves anticipated their future needs and co-ordinating and joining up health and social care services

- *Level 2: People experiencing high risk of disease progression and complications requiring skilled disease / care management*. Individuals in this group may have a complex single need or multiple conditions and benefit from responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways (such as the National Service Frameworks). Skilled disease management may deliver better health outcomes, slow disease progression, reduce the associated disability and ensure better management of the any sudden deterioration. Good care management for this group involves identifying their needs early and responding promptly with the right care and support with systematic and tailored programmes for individual patients.

- *Level 1: The remainder of the population requiring help and support to care for themselves.*

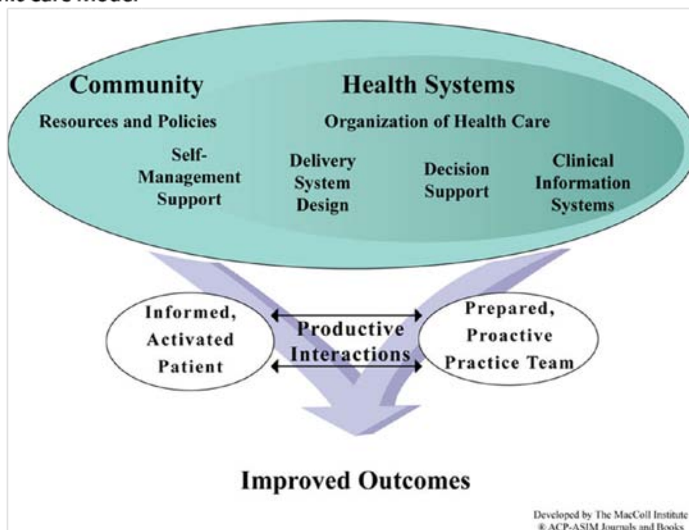
The Chronic Care Model

The main elements of a system designed to improve care for people with long term conditions is depicted in the Chronic Care Model (Fig 2). This empirically informed and extensively tested model was developed by Ed Wagner and the MacColl Institute

(Wagner et al 1999, Wagner et al 2001) and implementation of the model has led to favourable outcomes in a range of long term conditions (Asch et al 2005, Mangione-Smith et al 2005, Vargas et al 2007).

The model emphasises a "productive interaction" as the essential element of chronic illness care, an interaction in which the work of evidence-based chronic disease care gets done in a systematic way with patient needs being met. The whole system is designed to help co-produce "informed, activated patients". These are patients who have goals and a plan to improve their health, along with the motivation, information, skills, and confidence required to manage their illness well. A recent article by Anstiss (2009) shows how Motivational Interviewing can help healthcare systems deliver these essential elements of high quality care for people with long term conditions.

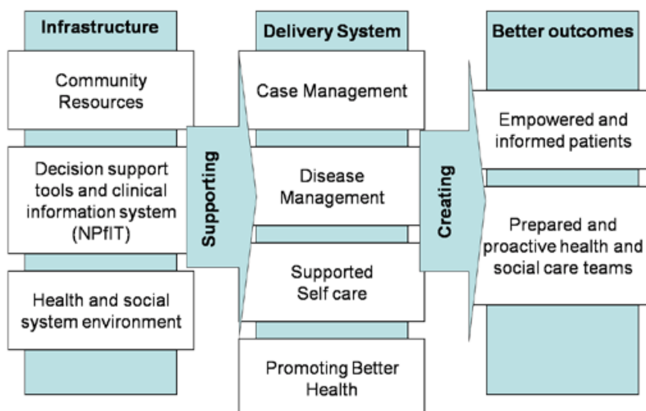
Fig 2.
Chronic Care Model



The NHS and Social Care Long Term Conditions Model(DH 2005a)

The Chronic Care Model has been combined with the triangular population model of Kaiser Permanente to create The NHS and Social Care Long Term Conditions Model (Fig 3). The Model builds on UK and international experience and is designed to help improve the health and quality of life of those with long term conditions by providing personalised, yet systematic on-going support. It details the infrastructure available to support better care for those with long term conditions as well as a delivery system designed to match support with patient need.

Fig 3.
The NHS and Social Care Long Term Conditions Model



Lean Healthcare

Improving care and outcomes for people with long term conditions can be seen as one big lean transformation package, redesigning care and support around the patient / service user. When organisations decide to "go lean" and deliver better services whilst driving up efficiency, many follow a 5 step programme of:

1. Understanding what service users truly value (as opposed to what providers want to give them)
2. Understanding how this value flows to service users, and how and why it often doesn't (commonly using mapping tools)
3. Making this value flow to service users (by continuously identifying and eliminating causes of waste, delay and complexity, as well as by innovating)
4. Enabling service users to pull what they want and need from the system when, where and how they want it
5. Striving for perfection in service delivery

The desired end state of all the policies and initiatives described above could be considered "lean consumption", in which the health and social care system gives people with long term conditions exactly what they want, in exactly the right amount, at exactly the right time and place with minimum delay, waste and cost (Womack and Jones 2005)

Promoting and Supporting Self Care

Promoting self care is a major strand of policy and a core element of chronic care models. Self care has been defined as:

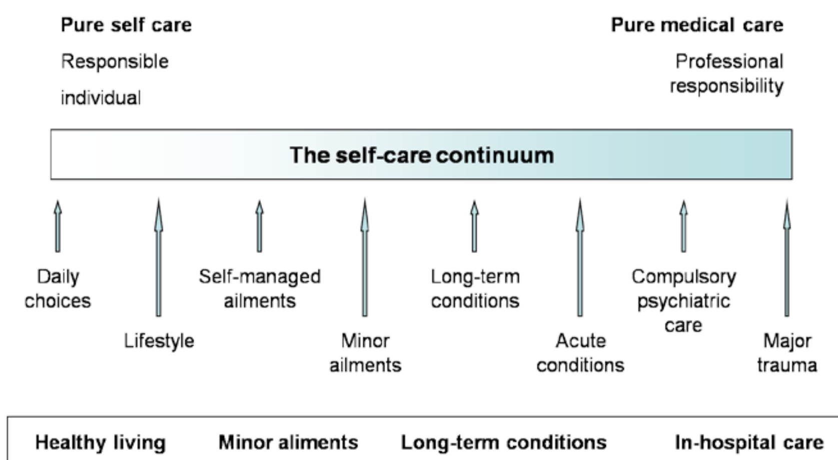
> *"the activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health"* (Kickbush and Hatch 1983, 4)

and

> *"the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and well-being after an acute illness or discharge from hospital."* (DH 2005b)

Self care can be considered as existing towards one end of a care continuum (Figure 4) with professional care at the other end. Wearing a safety belt can be considered 100% self care, and abdominal aortic surgery 100% professional care. Shared care lies between these ends of the spectrum. (DH 2005b)

Fig4.
The Continuum of Care



A recent UK study suggested that most people treat their minor ailment themselves, that nearly two-thirds of people often monitor their acute illness following discharge from hospital and that over 80% of people with a long-term health condition say they play an active role in caring for their condition themselves. (DH/MORI survey DH 2005c). People also seem interested in engaging in more or better self care, especially if support is provided. Over 75% of people in the survey said they would be far more confident about taking care of their own health if they had guidance and support from an NHS professional. However, over 50% of people who have seen a care professional in the previous six months said they have rarely been encouraged to self care and a third say they have *never* been encouraged by their professional to do self care.

In view of the importance of self care in long term conditions, The White Paper Our health, Our care, Our say (Department of Health 2006a) gave the approach a big boost by:

- Stating that the Expert Patients Programme will increase capacity from 12,000 course places to over 100,000 and investment in this initiative will be trebled
- Outlining plans to improve self care through assistive technology, health checks, health trainers and NHS Direct
- Providing primary care providers with a much stronger focus on improving self care through both the Quality and Outcomes Framework and on commissioning services that support self care. Self care considered as one of the highest priorities for future changes to contractual arrangements.
- Describing professional education to encourage support for individual empowerment and self care with a clear self care competency framework for staff and work with the professional bodies to embed self care in core curricula
- Stating that everyone with a long term condition or long-term need for support, and their carers, would routinely receive self care support through networks

To help the health and social care system deliver better more holistic care for people with long term conditions, the UK government has set out seven principles it wishes to see embedded in local policies and agreements, as well as local culture and practice (DH 2008a)

- Ensuring individuals are able to make informed choices to manage their self care needs
- Communicating effectively to enable individuals to assess their needs, and develop and gain confidence to self care
- Supporting and enabling individuals to access appropriate information to manage their self care needs
- Supporting and enabling individuals to develop skills in self care
- Supporting and enabling individuals to use technology to support self care
- Advising individuals how to access support networks and participate in the planning, development and evaluation of services, and
- Supporting and enabling risk management and risk taking to maximise independence and choice.

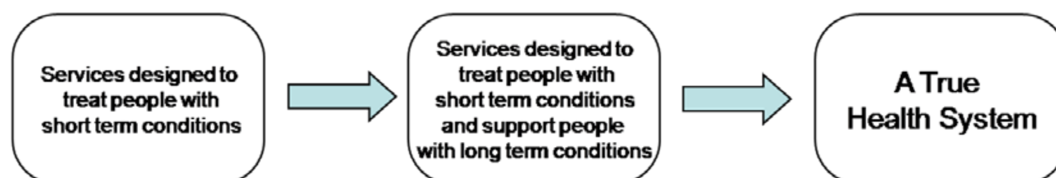
Two sector skills agencies (Skills for Care and Skills for Health) are piloting these principles in an attempt to embed them into people's daily working practice, whilst also embedding them the National Occupational Standards and qualifications for health and social care.

Towards a True Health Service

Continuous improvements in the care we offer people with long term conditions must progress in parallel and harmony with continuous improvements in the care we offer people with acute conditions. These improvements in turn must progress alongside improvements in primary prevention and of the social, economic and material environments in which we all live, move and have our being. Continuously reducing the stress and allostatic load experienced by the less well off will help reduce the intergenerational transmission of poor health, wellbeing and life chances that blight our communities and will help us control the growth of future health and social costs (Case et al 2005).

Delivering Holistic Care for people with long term conditions can be considered a vital stepping stone along the path from a healthcare service focused on treating acute injury and illness to a true health system as focused on keeping people healthy and helping them flourish (Figure 5).

Fig 5.
Stepping stones to a true health system



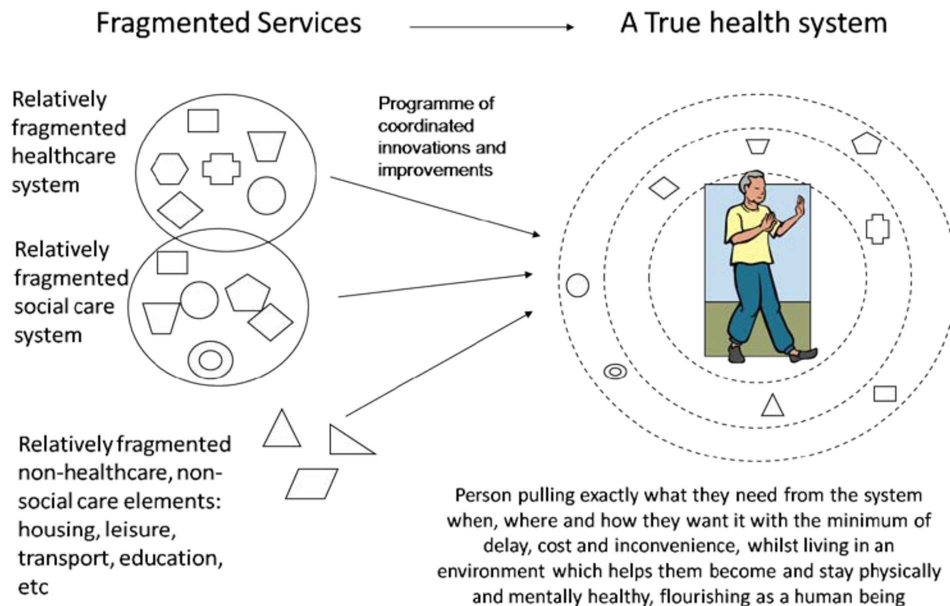
But changes in health services alone will never be enough to create a true health system, a fact that has been recognised for decades if not centuries:

"A real Health Service must surely concern itself with the way people live, with town and country planning, houses and open spaces, with diet, with playgrounds, gymnasia, baths and halls for active recreation, with workshops, kitchens, gardens and camps, with the education of every child in the care and use of his body, with employment and the restoration to the people of the right and opportunity to do satisfying creative work. The true 'health centre' can only be a place where the art of healthy

living is taught and practised: it is a most ominous and lamentable misuse of words to apply the name to what is and should be called a 'medical centre' "

The White Paper Reviewed. VI. By an urban practitioner.
Lancet 1944, 443

Fig 6.
Evolving a True Health System



The emergence of a true health system out of today's somewhat fragmented, variable quality health and social care services (Figure 6) requires policy development, clinical leadership and public service of the highest order. But if we can work together to create a true health system then the rewards, like the challenges, are great – including having contributed to the one of the world's outstanding feats of human co-operation.

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