

High Council for Public Health

Report on Care and Social Protection For People with Chronic Illness

Synthesis and recommendations November 2009

In France, 28 million people receive periodic treatment (at least six times a year) for the same pathology, whilst around 9 million people are declared to have a long term illness (administrative status delivered by social security system).

Increase in life expectancy, resulting not only from improved living conditions but also treatments and care for illnesses, paradoxically leads to increasing the social and economic burden of chronic diseases in all developed countries by increasing the number of old people. The high cost of major therapeutic progress recorded over the last few years accentuates this burden.

Due to their lasting and evolutionary nature, chronic diseases can lead to disabilities and significant personal, family, professional and social difficulties. They constitute a real adaptation challenge for health systems that were designed and developed to respond to acute illnesses, also in their way of thinking, organisation and financing. The medical-administrative system known as long term illnesses (LTI) that aims to manage both medical and financial cover for these illnesses has progressively become less adapted to the situation: today it does not constitute a basis for improving practices or maintaining any control over health costs, or assuring equal co-payment distribution.

For several years, the health system has been involved in structural reforms aiming to improve organisation for this cover, and in 2007 an ambitious Plan to improve the quality of life of people affected by chronic disease was launched, that must be enforced until 2011. In this perspective, the High Council for Public Health Chronic Diseases Commission proposes recommendations aiming to support reinforce or propose measures adapted to these issues.

Relying on a purely biomedical approach and on the whole representing the professionals' point of view, the health system uses a restrictive list of diseases as recognised from a biomedical approach to define a chronic disease without taking into account its duration or consequences. From this point of view, it is responsible for serious intra and inter-disease inequalities.

Global models (favouring the model developed and described in the International Classification for Impairments, Disabilities and Handicaps (ICIDH)) aim to prioritize an approach focusing on the consequences of the disease on the patient's daily life; recognition of a chronic state is, in this respect, recommended.

The main difficulty for health professionals and people affected by chronic diseases revolves around how the health system is partitioned, segmenting skills and responsibilities among professionals, between outpatients care and hospital care and even among hospital stays between medical and medical-social sectors. Anyone affected by a chronic disease, limited in their activities by the disease, has neither the skills nor the resources required to manage their care path relevantly. The patient can neither get a sufficient level of autonomy to tackle the illness nor get a place in a professional support process. There have been considerable, recent improvements and experiments in this field, although they still have a limited impact.

Foreign experiences of managing illness and cases, of developing therapeutic education and the mode of financing are also a starting point to consider changes required in our health system that must include an organisation model for chronic care [Nolte *et al.* *Managing chronic condition. Experience in eight countries. EOHSP, 2008*].

Spreading knowledge and information to professionals and people affected by chronic diseases must be improved by developing care protocols adapted to the severity and the stage of the illness.

De-partitioning of the health system must be targeted, particularly by encouraging experiments relating to cross-discipline cooperation, networks and health centres, particularly on a territorial basis. This should clearly identify the function of managing a care path involving all organisational aspects of the medical, administrative and financial cover for the illness.

Activities boosting implication and control by the chronic disease patient concerning their care path must also be encouraged, particularly therapeutic education and the use of principles known as *disease management* and their implementation for each person affected by a chronic disease (*case management*).

It is essential to develop cross-discipline research in public health and this field must be nurtured, questioning the concepts of illness, repercussions, care organisation and providing factual elements, as a basis for real public health medicine founded on proof. Initial and continuous training for health professionals must spread a common culture around the issues raised by chronic diseases as a medical, social, cultural and organisational concept, following the example built around tackling acute diseases.

From an economic point of view, the current system is organised with long lasting illnesses (LTI) revolving around limiting co-payment from people affected by a chronic disease identified according to an etiological definition from a list of thirty groups of diseases, to which two more widely defined categories have been added: the first being independent of etiology (ALD 31), and the second dedicated to poly-pathologies (ALD 32). These two codes are rarely used.

This system is not fair because it recognises diseases that are actually not very expensive, whilst excluding others that cost more and it does not take into account the variable nature of severity, evolutions and costs.

The LTI system is, in its current state, only very slightly open to reform: any additional pathology on the list is perilous for the others that would then not enter the system and any removal would be socially and politically difficult to swallow.

The question of controlling health expenses from a macro-economic point of view is outside the field of the commission that is interested in analysing the consequences from the point of view of people affected by chronic diseases and recommends focusing on reducing their co-payment.

The High Council for Public Health insists that disassociating financial and medical cover should be viewed as a good alternative and opportunity. If recognising a status for chronic diseases is built upon a definition based on the consequences of the illness and no longer only on the etiological nature, the financial cover system would have every advantage to be independent of the type of illness, whilst being founded only on a spending criterion.

From this point of view, health shield type solutions would represent a considerable advantage. Taking into account their possible consequences, they must be subject to analysis and a democratic debate on the alternatives to the current LTI system within the perspective not of limiting health spending but improving equal distribution of the co-payment.

Finally, the increase in economic weight for chronic diseases, a major factor for health expenses rising, cannot actually be controlled by just reforming financing methods but by an ambitious prevention policy that is effective to delay or even prevent the occurrence of the diseases involved.

As a result of this analysis, the HCSP has formulated ten recommendations with two aims:

- Access to good quality care for all people affected by chronic diseases,
- Reduction of inequalities in co-payments made by people affected by chronic diseases.

RECOMMENDATIONS

Defining chronic diseases

Recommendation No.1

Define chronic diseases according to the following characteristics:

1. The presence of a physical, psychological or cognitive pathological state that is going to last

2. Dating back for a minimum of three months, or supposedly so,

3. An impact on daily life including at least one of the following three elements:

Functional limitation on activities or social participation

Dependence in terms of medication, diet, medical technology, apparatus or personal assistance

The need for medical or paramedical care, psychological help, adaptation, surveillance or specific prevention that could be part of the medical-social care path.

This definition relies not only on etiology implying specific treatments linked to the illness but also on consequences in terms of impairment and handicap, leading to repercussions on health (e.g. aftermath of accidents).

Making changes in chronic disease cover

Recommendation No.2

Make the health system evolve towards separating financial and medical criteria for tackling chronic diseases in order to avoid the confusion and inter and intra-illness unfairness currently seen in the LTI system.

□ **Recommendation No.3**

Predict and formalise evolutions required by the health system towards financially tackling chronic diseases independently of their etiology and organising a democratic debate on the alternatives proposed for the current LTI system, such as the health shield.

□ **Recommendation No.4**

Improve the cover and make the health path and its coordination effective for all people affected by a chronic disease.

1. Adapt care protocols to the severity, stage and nature of the illness, according to the recommendations in force;
2. Widely develop therapeutic education for the chronic disease patient;
3. Develop support within the care path; particularly by promoting a management function for the care path that consists of helping chronic disease patients at all stages for medical, social, administrative and financial cover. This function must be defined, recognised and assigned to existing professionals or developed as a new profession.

□ **Recommendation No.5**

Assure financing and legal adaptations required for good operation:

1. of territorialised health networks
2. of health centres and medical centres, depending on the modalities adapted to caring for chronic disease patients: fixed base according to the principle of general interest assignments in force in health establishments and *per capita* variable part depending on the seriousness of the pathology,
3. Management of the care path, by proposing remuneration systems that are an incentive for best practices within care.

□ **Recommendation No.6**

Strengthen prevention for chronic disease patients to improve the quality of their lives, limit the severity of their illness and delay deployment of long, costly and difficult care.

Find out more and teach more about chronic diseases

□ **Recommendation No.7**

Strengthen the information system, particularly by implementing personal medical files that must contain information on the nature of the illness, risks and severity of the complaint, the treatment followed and the staff providing care.

□ **Recommendation No.8**

Promote the WHO international classification for impairment, disability and handicap (ICIDH) in health professionals' initial and continuous training and make caring for people affected by chronic diseases (particularly therapeutic education) a priority topic for medical training and assessing professional practices.

□ **Recommendation No.9**

Improve the spread of knowledge and information to be used by professionals and people affected by chronic diseases:

1. Draw up and diffuse guidelines for all people affected by chronic diseases, doctors and carers, for all chronic complaints.
2. Develop a health portal within competent structures in this field, such as for emerging illnesses developed by Inist-CNRS.

□ **Recommendation No.10**

Develop research relating to how pathologies affect everyday life of chronic disease patients from the point of view of both health professionals and patients.