Promoting Healthy Work for Employees with Chronic Illness – Public Health and Work (PH Work)

The challenge of the sustainable employability of workers with chronic illnesses

Date    July 2011
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Number of pages  15
Type  Background report PH Work

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1 Introduction

This draft is part of a PH Work Project concerning the issue of promoting healthy work for employees with a chronic illness. This project aims to demonstrate those good practices within companies which provide suitable and productive jobs for people with chronic illnesses and disabilities in cooperation with service providers and other stakeholders.

In this first stage of the project, TNO (the Netherlands), WRC (Ireland) and ANACT (France) were responsible for researching background information, developing the questionnaires and organising data collection in the 13 countries involved. In the next stage each National Contact Office will trace these good practices in their own country, complete the questionnaires and provide the project team with additional information. A separate document discusses these proceedings in detail.

This draft is intended to provide the NCOs with some background information on the issue of workers with a chronic condition. Definitions and concepts in this rather complex domain are clarified to give this transnational project a common ground. Furthermore, this information may be of assistance to the NCOs to promote the importance of the issue in their country.
2 New opportunities for workers with chronic illness?

2.1 Policy reform in many countries

In many EC countries in recent decades, sickness absence and return-to-work policies have been highlighted by new legislation in the fields of occupational health and safety, social security and the labour market. These policies have been successful to a certain extent in reducing sickness absence and the number of disability benefit recipients. There is also a growing body of knowledge on evidence-based interventions and best practices, and with respect to musculoskeletal disorders in particular there is ample evidence on best practices and their positive return on investment for employers, employees and various insurers alike.

However, there is still much room for improvement through institutional reform and in everyday practice. A study of sickness absence in a Dutch working population showed that 21.5% of the sickness absence rate is avoidable. Factors attributed to this unnecessary absence are related to the home situation, the workplace, occupational health care and health care providers. One major reason for this – as other research points out – is the lack of collaboration and coordination between the various professionals, institutions and agencies, which is common in many countries. A 2010 OECD study concluded that: ‘Too many workers leave the labour market permanently due to health problems or disability and too few people with reduced work capacity manage to remain in employment. … Economic and labour market changes are increasingly proving an obstacle for people with health problems to return to work or stay in their job’. The recent economic downturn will only aggravate this situation. Moreover, the focus on institutional and policy reform over the previous decade has left day-to-day practice in companies and on the shop floor somewhat underdeveloped.


4 For example, Kärreholm et al. showed that improved face-to-face collaboration between agencies (including clients), though more expensive in the short run, was much more cost-effective in the long run; J. Kärreholm, K. Ekholm, J. Ekhom et al., ‘Systematic co-operation between employer, occupational health service and social insurance office: a 6-year follow-up of vocational rehabilitation for people on sick-leave, including economic benefits’, J. Rehabil Med 40 (2008), 628-636.
2.2 Technology and demography

After the age of 45 the chance of contracting a chronic illness rises significantly, while at the same time survival rates continue to improve through new medical technology. In addition, demographic change is currently leading to a rapid ageing of the working population in most regions and labour market shortages are to be expected as a result. Both the ageing working population and medical technology are responsible for the growing number of workers with chronic illnesses and disabilities who remain productive or partly so and whose productivity will be very valuable in view of the projected labour market shortages. Moreover, new technology will deeply influence the conditions behind the promotion of occupational safety and health in the workplace. The emerging psychosocial risks are the consequence of the growing use of ICT, the expanding service sector, new forms of work (telework, self-employment, flexible work, lean organisations, etc.). Consequently, the opportunities for workers with chronic illnesses and disabilities will change.

2.3 A paradigm shift is needed

The rapidly changing world of work calls for renewed attention to be paid to the work and health of people with a chronic condition, which not only focuses on their current employability but above all on their prolonged employability. The paradigm shift concerns the sustainable employability of workers with chronic illnesses and disabilities.

Demographic challenges in Europe and the rising costs of health care are forcing companies to focus more sharply on sustainable employability strategies. Postponing retirement, qualitative and quantitative mismatches in the labour market and the need for an innovative and creative workforce are key issues. In developing these strategies the potential of workers with disabilities and chronic illness should be emphasised. Being at work not only enhances their wellbeing and income, but also contributes to national productivity and social cohesion. From this point of view rehabilitation costs are also an investment in national productivity.

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3 Sustainable employability and chronic illness

3.1 Sustainable employability: more than OSH and HR

Return-to-work and reintegration programmes focus predominantly on the present job situation of the worker with health problems. This may not be sufficient for resolving problems in the workplace. Future career prospects may be equally important for workers with chronic illnesses and disabilities. Their disabilities are more or less permanent and their optimal performance and productivity as well as the prevention of future absenteeism are dependent on the work context. In the post-industrial era these contexts will become increasingly flexible and variable. Flexibility in relation to tasks and responsibilities as well in working hours, the workplace and contracts may be a barrier for disabled workers but may also provide better opportunities for work adjustments needed for participation. Skills development and learning at the workplace are probably even more important for the disabled worker than for workers in general. In our view this means that human resources issues and occupational safety and health issues are becoming more and more interrelated. This is reflected in the concept of sustainable employability, illustrated in Figure 2.1 below.

Figure 2.1: Interrelatedness of OSH and HR policies and tailor-made measures for the individual disabled worker in securing sustainable employability, and the productivity of workers with disabilities and chronic illness (TNO)
In the ideal situation, company policy on sustainable employability concerns enabling a worker with a chronic condition to perform well and be motivated to undertake productive work in their present and future jobs. This means that company policy is not only directed towards preventing risks (absenteeism, unemployment, disability benefits), but also towards promoting opportunities and skills. This stresses the interrelatedness of OSH and HRM with respect to sustainable employability and may actually concern all company workers. For workers with disabilities in particular, the adaptation of the environment to their individual circumstances, including their home situation, is extremely important (the square and arrow in Fig. 2.1). This calls for customised work redesign, ‘job carving’\(^7\), training facilities and career counselling. Again, the focus should be on the abilities and resources of the individual and not only on the disabilities. The family and home situation should also be considered here.

Finally, company strategy should also include some sort of monitoring and evaluation to improve its policies and demonstrate the return on investment of its efforts in sustainable employability.

### 3.2 Chronic illness: definition and prevalence

Chronic conditions are defined by WHO as ‘health problems requiring ongoing management for a period of years and cover a wide range of conditions that go beyond the conventional definition of chronic illness such as heart disease, diabetes or asthma\(^8\). They also extend to cancer, mental disorders, musculoskeletal disorders and communicable diseases such as HIV or hepatitis. Although in wealthy developed countries most debilitating chronic conditions occur after the age of 65, their occurrence in the labour force population is by no means rare.

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\(^7\) Job carving involves melding job seeker and employer needs through systematic workplace analysis and person-centred career planning. Carving is based on the concept of determining a person’s unique capacities and matching them to an employment setting. See for example, C. Griffin and D. Hammis, *Self-Employment For Transition Age Youth and Adults with Disabilities: A How-To Manual* (Baltimore, MD: Brookes Publishing, 2002, and in preparation).

**Chronic illness in the PH Work Project**

The PH Work Project does not use a specified list of chronic illnesses as there are too many and they are too heterogeneous. Moreover, from a company point of view the occurrence of a specific illness is rare, while this is certainly not the case when we take all chronic illnesses together. Therefore, the project simply employs the WHO definition:

‘All illness that means health problems requiring ongoing management for a period of years’.

Nevertheless, should the participating countries provide information concerning a specific chronic illness related to work, this will be very useful for the project. We will not exclude any disease from the outset.

Common well-known diseases are diabetes, heart failure, asthma or chronic obstructive pulmonary disease (COPD), cancer, epilepsy, multiple sclerosis, rheumatoid arthritis, Crohn’s disease, prolonged infectious diseases such as hepatitis and HIV and last but not least mental health problems such as depression and alcohol/drug abuse.

With respect to the high social economic burden of disease and loss of productivity, especially relevant are cardiovascular disease, COPD, depressive disorders, breast and lung cancer and the mixed group of musculoskeletal disorders.

Due to the variety of chronic illnesses it is not an easy task to determine the prevalence of these conditions in the labour force population nationally or internationally. It is even more difficult to assess the impact they have on employment status. However, population surveys which rely on self-reported conditions are an accepted way to record health status and disability. For the most recent EU Statistics on Income and Living Conditions data (EU-SILC 2008) respondents were asked whether they suffered from any chronic/long-standing illness or condition/health problem (yes/no) and whether they experienced limitations in their daily activities and work for six months or more due to health problems⁹.

In total, 23.5% of the working age population in the EU-27 reported chronic conditions, whereas 19% of employed persons reported long-standing health problems. Over 80% of the long-standing problems were considered not to be work related. There were also large differences between the countries in relation to self-reported health status, so it can be presumed that the answers at least partly reflect cultural differences in health perception. At present we need not to go into this issue.

3.3 Chronic illness: impact of disability

The International Classification of Functioning, Disability and Health (ICF)\textsuperscript{10} – officially endorsed by all 192 WHO member states – acknowledges that every human being can experience a decrease in health status and may thereby experience some degree of disability. In other words, this is not something which only happens to a minority of people.

The ICF model recognises three main elements – a \textit{health condition} which may lead to an \textit{impairment in function}, which may in turn lead to a \textit{disability within an unsupportive environment}. Disability is therefore due to an interaction between these three elements and is not solely a function of a health condition in itself. An impairment refers to a physiological problem (e.g., difficulties in seeing, fatigue or reduced muscle power), while disability concerns the daily problems which arise due to these impairments in the context of the daily environment. Thus, not only the health condition itself but also the environment (e.g., household, work) may influence the extent of the disability. It is important to note that most people with defined impairments, such as visual impairment or paralysis, do not consider themselves to be ill or to have an illness.

The ICF thus ‘mainstreams’ the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places diverse health conditions on an equal footing and takes into account the social aspects of disability. Moreover, it not only focuses on disabilities but also on abilities and resources which are important for the daily performance of people with a chronic condition.

The work and family environments are of course essential social contexts for workers with a chronic condition. To make a correct assessment of the situation and to optimise participation, not only working conditions and workload but also family obligations and support should be taken into account. This comprehensive approach was presented in Figure 2.1.

As mentioned above, the list of chronic conditions and disabilities is very diverse and since the progression of an illness can vary considerably, the impact of illness is highly individualised at each point in time. The common element, however, is that all of these conditions require a complex response, including within the work environment, over an extended period of time that involves coordinated inputs from a wide range of health and other professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment. Unfortunately, health care is still largely based on an acute episodic model of care that is ill-equipped to meet the requirements of people with chronic health problems\textsuperscript{11}. Moreover occupational health care and health promotion in companies are insufficiently geared towards the needs of workers with a chronic condition, and communication between the various parties is often poor. In fact this is the key-issue in our PH Work Project in search for good practices: \textit{In which way companies within their health promotion activities can pay special attention to workers with chronic conditions and their employability.}

\textsuperscript{10} <www.who.int/classifications/icf/en>.
\textsuperscript{11} Ibid.
3.4 Self-management

A lack of coordination between all of the parties involved is at the heart of many failures in the reintegration process. The key actor in this coordination issue may well be the worker him or herself. Several reports and studies mention the importance of self-management when organising the active participation of people with chronic illness in a treatment\textsuperscript{12}. There is an increasing recognition that reduced risk and improved outcomes cannot depend solely on the actions of health or other professionals but are also contingent on the individual’s own actions\textsuperscript{13}. In health care, various approaches and methods have been developed to support the self-management by individuals, in terms of assessing their own health risks (risk perception) and health problems (diagnosing) and in finding and applying effective approaches and methods.

Self-management support includes the education and training of chronically ill people, the collaborative use of a wide range of behavioural-change techniques to foster lifestyle change, the adoption of health-promoting behaviours and skill development across a range of chronic conditions\textsuperscript{14}. Chronically ill people are trained in problem-solving, goal attainment and the use of evidence-based standardised interventions in chronic conditions. Well-known supports include shared decision-making tools, which are usually designed for specific illness categories (cancer patients and people with heart failure)\textsuperscript{15}.

These self-management support tools are not particularly intended to support the sustainable employability of workers with chronic illness within the workplace. However, there are many ways to make these shared decision-making tools applicable to the work environment by including work aspects in self-management protocols and by involving line managers and health and safety professionals in self-management processes. In this way, workers with a chronic illness now have the opportunity to become the pivotal point between the worlds of health care and work. A well-informed worker (who functions as a data carrier) can facilitate communication between health professionals and stakeholders on the employer’s side (company doctors, HR manager, line managers and colleagues). A feasible good practice in this respect is the multidisciplinary protocol for ‘participative work adaptation’ used in the case of low back pain, in which employees and employers have an active role under the

supervision of a health and safety professional\textsuperscript{16}. The essence of the protocol is that, after an inventory of bottlenecks, work adaptations chosen by the employee and employer together on the basis of consensus are introduced under the supervision of a trained health and safety professional.

However, it is not always clear whether applying self-management tools in the workplace creates health risks for workers and safety risks for their colleagues. An incorrect assessment of a syndrome by the worker could have far-reaching consequences. It is of interest to find out the ways in which good practices deal with such problems.

### 3.5 Chronic illness: impact on work

The variation in the impact on work is as great as the diversity of chronic conditions. However, some common elements can be identified. Because in many cases communication between peers and line-management on this subject is covert, one should be on the lookout for the following consequences (Table 2.1)\textsuperscript{17}.

#### Table 2.1: General consequences of chronic conditions at work (note that every case is unique) (ANACT)

<table>
<thead>
<tr>
<th>• Fatigue</th>
<th>• Unexpected low performance</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Feelings of depression</td>
<td>• Frequent spells of absenteeism</td>
</tr>
<tr>
<td>• Feeling alone</td>
<td>• Presentism</td>
</tr>
<tr>
<td>• Lack of understanding colleagues</td>
<td>• Annoying for colleagues</td>
</tr>
<tr>
<td>• Extreme job-orientation</td>
<td>• Illegitimate work adjustments</td>
</tr>
<tr>
<td>o Fear of losing job or</td>
<td>• Unnoticed work adjustments</td>
</tr>
<tr>
<td>o Work as diversion</td>
<td>• Replacement is doing too well</td>
</tr>
</tbody>
</table>


\textsuperscript{17} ANACT, \textit{Maladie chronique evolutives, pluridisciplinarité et maintien dans l’emploi en Aquitaine, une nouvelle approche} (Bordeaux, 2008).
Fatigue is a common complaint and sometimes difficult to assess\textsuperscript{18}. Other major characteristics (apart from being chronic) are the often unpredictable prognosis and variability in the course of the disease. Moreover, there is often not much to see ‘from the outside’ (e.g., pain or fatigue)\textsuperscript{19}. There are also illness-specific issues which we need not to go into at this moment. It is always important, however, to consider the consequences for occupational safety and health. Job adjustments should be tailor-made. Some jobs may even be contraindicated by some diseases. Chronic obstructive pulmonary disease (COPD), chronic hepatitis or eczema are examples of illnesses which would make some jobs unfeasible.

Although the impact-centred approach of the ICF is essential in all return-to-work policies for workers with a chronic condition, the cause of illness matters to the assessment of specific impairments and the prognosis. It also matters because many countries and systems make a distinction between conditions caused by occupational activities and those which are not. In the case of occupational disease and accidents, the employer or the insurance system acknowledges responsibility for vocational rehabilitation and, in general, more resources are available to adjust workplaces or offer re-education, etc. However, as stated in section 3.2, over 80\% of long-standing problems are considered to be not work related.

When an illness or disability has no clear causal relationship with a job – for example, heart failure or diabetes – employers and colleagues are often more reluctant to become involved. There is a tendency to consider such illness a private matter and the worker may be reluctant to discuss the consequences of the illness with their employer (e.g., in the case of HIV or cancer). Certainly this will hamper any appropriate job adjustments and sustainable employability. This situation is only aggravated while the treating physician seldom has sufficient expertise in the vocational counselling of the chronically ill worker.

### 3.6 Work/life balance and autonomy in the workplace

As mentioned above, chronic illness confronts workers with the need to alter their behaviour and engage in activities that promote physical and psychological wellbeing. In this ‘rebalancing’ of the situation, job requirements and resources as well as private and family requirements and resources should be equally taken into account. Optimal performance on the job is very much dependent on this ‘re-balancing act’. Appropriate levels of job control and autonomy are of the utmost importance if a worker with a chronic illness is to realise adequate job performance. (see Figure 2.2). Naturally this has to proceed in close cooperation with management and peers. Vocational guidance and mutual trust between employer and employee are also important.


3.7 A practical guide for the worker

How can a worker with a chronic disease (and the main actors around him/her) effectively deal with this complex illness?

ANACT has developed a practical guide which may support self-management by the worker. It is summarised in the table below\textsuperscript{20}.

The left side of the table presents key observations about common characteristics of the situation. The right side presents recommendations for handling such situations.

\textsuperscript{20} ANACT, Maladie chronique evolutives, pluridisciplinarité et maintien dans l’emploi en Aquitaine, une nouvelle approche (Bordeaux, 2008).
<table>
<thead>
<tr>
<th>Observations</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes twenty or more professionals and other actors are involved in the guidance or intervention</td>
<td>Make an exhaustive list, ascertain roles in the context of: - health care - work - institution - home/family</td>
</tr>
<tr>
<td>Conflicting concepts between professionals, medical confidentiality hindering communication</td>
<td>The approach has to be multidisciplinary, a case manager organises the process, the worker is the medium of information transfer, the occupational health physician should determine the appropriate working conditions</td>
</tr>
<tr>
<td>Collaboration between actors is limited: even medical advice may vary</td>
<td>The case manager facilitates the participation of the main actors, monitors commitment, translates between the various domains, is aware of the appropriate rules and regulations, attempts to establish a shared frame of reference</td>
</tr>
<tr>
<td>Tunnel vision of each discipline underestimates the incidence of problems related to chronic disease and also the opportunities for strengthening abilities</td>
<td>Case manager supports self-management and self-assessment of the worker</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unnoticed stress on colleagues who try to compensate for the worker with the chronic illness, risk of the eventual rejection of the worker, line management not aware</td>
</tr>
<tr>
<td>Fatigue is a common denominator, but there are many differences between the various illnesses and conditions</td>
</tr>
<tr>
<td>The chronicity and variability over time of the illness makes job performance variable and makes it difficult to adapt job demands to the individual</td>
</tr>
<tr>
<td>The rather unpredictable course of the illness leads to uncertainty and the over- or underestimation of worker capabilities</td>
</tr>
<tr>
<td>The employer is not aware of family support or support from non-vocational agencies or providers</td>
</tr>
<tr>
<td>The worker may compensate diminished performance at work by working at home or after working hours, sometimes with the support of the family, management may be unaware</td>
</tr>
<tr>
<td>Ad-hoc solutions are usually technical and within working hours</td>
</tr>
</tbody>
</table>
It should address:
- organisational issues (job autonomy, seeing the job in wider perspective)
- social issues (in coordination with other actors)
- working hours, travelling time
- technical issues (accessibility, aids)
- stepwise partial return to work

<table>
<thead>
<tr>
<th>Follow up</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>The chronicity and variability over time of the illness makes job performance variable</td>
<td>Put in place a periodic monitoring procedure with all the relevant actors evaluating the situation and performance (inside and outside the company)</td>
</tr>
<tr>
<td>In the long term it is more difficult for a small or medium-sized company to accommodate a worker with disabilities, there may be less room for job variability</td>
<td>Mobilise external support from outside the company, exchange jobs with other small companies, retraining of worker</td>
</tr>
<tr>
<td>Long-term illness may question the competences and future career of the worker</td>
<td>Career counselling, consider re-education and retraining, financial support and benefits (temporary) from social security may be required</td>
</tr>
</tbody>
</table>

The most important issue for the company and the worker alike is to adopt a methodical stepwise approach which:
- secures open communication in the workplace between the worker, peers and management
- involves all relevant actors and aims to establish a common frame of reference and clear case management
- is flexible and open to re-adjustment and periodic evaluation
- is embedded in general health promotion policies of the company.
3.8 What we already know about good practice in vocational rehabilitation

While the focus in the preceding sections has been on company practice, providers of vocational rehabilitation also play an important role in the support of workers with disability and chronic illness. Case studies and other literature have already provided much information on good practice in vocational rehabilitation and return-to-work programmes.

Using evidence-based empirical research we can draw up 7 criteria for success. In brief these are:\n
1. Key features of the rehabilitation programme: multidisciplinary, early involvement of actors in the work environment, a high standard of assessment with a clear distinction between the treatment and intervention phases, time contingent case management customised to individual needs

2. Well-educated cooperative team, continuity in training new team members motivated by continuous feedback on the results of their actions

3. Transparent organisation, management, process and logistics

4. Commitment of local stakeholders, channels of referrals, creating awareness of each other’s practice

5. Strengthening commitment and self-management of clients, empowerment (‘help to self-help’), ‘shared decision-making’

6. Continuous critical evaluation of the programme itself by the team (process and outcome), i.e. by users/clients/employers, and monitoring of results

7. Institutional breakthroughs in financing interventions and cooperation vis-à-vis HR, OSH and (public) healthcare.

4 Epilogue

This draft intended to present a preliminary overview concerning the issue of promoting healthy work for employees with a chronic illness. It is part of a PH Work Project with the same title. During the project we will undertake further study of the literature. We will also ask the NCOs to collect documentation in their own country which they consider should be included in our analysis.

Ultimately, the analysis of the various good practices, together with up-to-date findings from the literature will lead to the development of practical guidelines and policy recommendations which have a transnational impact.

If you have any questions or suggestions, please do not hesitate to contact the project team at PREVENT:

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