

Protection of employment rights: still work in progress

→ Peter McIntyre

Despite an EU directive outlawing job discrimination, cancer patients are still routinely forced out of work by employers who don't want them or refuse to accommodate their need for lighter work or a shorter working day. Changing attitudes and improving the information and support available to patients will be key to turning the letter of the law into reality at work.

Women with early breast cancer in Quebec, Canada, lose more than a quarter of their income in the year following diagnosis. A study published in the *Journal of the National Cancer Institute* (26 February 2008) shows that women who had jobs when they were diagnosed lose 27% of their income, on average, even when sickness benefits and other forms of compensation are taken into account. One in ten women lose more than two-thirds of their income.

The most severe impact is felt by women who are less educated, live further from the hospital where they are treated, and have more serious disease and less social support. The Laval University team, which conducted the study, concluded, "wage losses resulting from breast cancer can substantially and negatively affect the financial situation of working women and their families."

In both North America and Europe improved treatment of cancer and greater public understanding has helped drive a trend for younger cancer patients to return to work. Barbara Hoffman in her 2005 paper *Cancer Survivors at Work: a Generation*

of Progress (*CA Cancer J Clin* 2005; 55:271–280), reported that in North America more than 70% of cancer survivors of working age returned to work within a year of diagnosis, and more than 80% did so within four years. Young breast cancer survivors had the same employment rates five years after diagnosis as they did at the time of diagnosis.

Yet nearly half of supervisors admitted that they would be less likely to hire someone who had had a cancer diagnosis. Hoffman concluded that, "from the time of diagnosis, survivors need team-based, long-term support in managing their employment opportunities."

In Europe, there are no data on how many cancer patients return to work and how easy they find it to do so. In many European countries, employers still discriminate against people who have had a cancer diagnosis, and patients often come under pressure to resign their posts, or are sacked.

The European Employment Framework Directive, which came into effect in 2004, obliged EU Member States to introduce legislation to outlaw unreasonable discrimination against people with disabilities. The way this legislation has been implemented across the EU varies widely.



JANINE WIEDEL / ALAMY

Legal loophole. Cancer patients are often not up to working as hard as they did when they were healthy, yet many countries do not count them as 'disabled' for purposes of job protection

THE LAW

In the Nordic countries, the Netherlands and the UK, for example, people with long-term illnesses such as cancer are specifically included in the definition of disability, and are therefore protected. Other countries define disability much more narrowly.

The Brussels-based European Disability Forum recently presented the European Commission with a 1.2 million signature petition calling for stronger anti-discrimination legislation. Policy officer Javier Güemes says that better guidance is needed for countries to ensure that people with long-term illnesses are not left out.

"In the European Union we have many realities. We have some countries, like Sweden and Denmark, where it is completely accepted that a person with a chronic illness is a person with a disability. You have other countries where it is still very difficult to convince the disability movement and the public authorities to accept that.

"In Hungary, 5% of the population is considered

WHAT THE DIRECTIVE SAYS

The Council of the European Union approved a Directive on Equal Treatment in Employment in November 2000 to establish a framework to combat discrimination on grounds of religion or belief, disability, age or sexual orientation.

The Directive affirms the importance of giving specific attention to recruitment, retention, training and lifelong learning for people with disabilities. Employers are required to take effective and practical measures to adapt premises and equipment, patterns of working time, distribution of tasks or training.

However, the Directive is silent on whether someone with a long-term illness, such as cancer, is considered in the same category as someone with a disability. The Directive does not protect someone who is "not competent, capable and available to perform the essential functions".

Adaptive measures must not cause the employer a disproportionate burden, taking into account the scale and financial resources of the employer and the availability of public funds. Member States were given a final deadline of December 2006 to comply and must report to the European Commission every five years.

For more about the Directive see: <http://europa.eu/scadplus/leg/en/cha/c10823.htm>



PHOTO GALLERY asbj FOR EDF

Turning law into reality. The European Disability Forum (www.edf-feph.org) wants anti-discrimination legislation to be backed by concrete measures, targets and objectives, at regional, national and European levels. Last November, they presented Margot Wallström, vice-president of the European Commission, with a 1.2 million signature petition calling for more effective protection for disabled people's rights

disabled, and in Poland it is close to 6% or 7%. When you go to the Nordic countries, 23% are considered to have disabilities. It makes no sense. Maybe between these extremes we can find equilibrium. The European Commission is quite reluctant to take any action because this is an issue of national competence, but they should provide some kind of guidance that can be used by national governments.”

Nowhere is the need to clarify anti-discrimination legislation greater than in the field of employment. Under the Directive, employers are supposed to make a ‘reasonable accommodation’ to adapt the working environment to the needs of people with disabilities, but this may not take into account the needs of people living with cancer.

Güemes says, “Maybe an employer just thinks about ramps for access, or a table for a person in a wheelchair, or a speech reader for a blind person. But when we are talking about people with chronic illnesses, people with chronic fatigue or with mental health problems, then we have to think about reasonable adjustments in another way, such as the time that people can work.”

The need for clearer guidance has been made more urgent by a 2006 ruling from the European Court of Justice over the dismissal of a Spanish woman from her work. Chacon Navas was sacked after being away from work ill for eight months. The Spanish courts asked for a ruling to see whether she was covered by the European Directive.

The European Court defined a disability as “A limitation which results in particular from physical, mental or psychological impairments and which hinders the participation of the person concerned in professional life.” It said that for a limitation to count as a disability it must be probable that it would last a long time, but also ruled that, for the purposes of the Directive, disability is different from sickness. There was nothing in the Directive to suggest that workers are protected as soon as they develop a sickness.

Chacon Navas lost her appeal, but the European Court has not settled the issue. Her illness was not specified in the court hearings and it was not clear whether she would ever have been able to return to work. The Court did not therefore address the question of whether someone who suffers long-term

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impairment because of cancer or other chronic illness, but who can still work, should be given protection.

Some countries have already taken this step. In Italy, the 2003 ‘Biagi law’ includes a specific right for cancer patients to switch to part-time work during or following treatment, and to switch back later to full time work. In 2006, a campaign by the Federation of Italian Cancer Patients’ Associations (FAVO) led to a rapid improvement in the temporary disability certificate process, reducing delays from about 12 months to 15 days. This gives patients access to many benefits more rapidly.

Elisabetta Iannelli, a lawyer and a cancer patient since the age of 24, is currently vice-president of the Italian Association of Cancer Patients (AIMaC) and secretary of FAVO. She believes that patients who are able to work should be encouraged to do so. “It is of utmost importance for their quality of life so they can feel an active part of their society.”

So far, no data have been collected on the impact of the Italian changes, but the national social security agency INPS has agreed to send out AIMaC leaflets spelling out the new rights. Iannelli says, “We strongly believe that correct information on the patients’ rights is fundamental for the quality of life of the patient and his/her family, and is the first tool towards defending one’s right to maintain an active role in society.”

In the UK, the Disability Discrimination Act was extended in December 2005 to include people with long-term illness such as HIV or cancer. Employers are expected to make ‘reasonable adjustments’ to help people stay in work, for example, by altering working hours so that someone whose medication affects them in the morning can start work later in the day, and by allowing home working during a period of rehabilitation, and absence from work for rehabilitation, assessment or treatment.

THE REALITY

However, good legislation does not guarantee good practice. In the eight months that followed the extension of the law to people with chronic illness, the Dis-

ability Rights Commission took 174 calls from workers with cancer who were experiencing discrimination at work. Most were about a failure to adjust working patterns, but there were also cases of overt discrimination. A woman who worked for a major high street retailer was dismissed when she could not give a firm return to work date following radiotherapy. A care assistant about to return to work following cancer treatment was asked to resign and then dismissed. A woman who had worked for a security firm for 19 years was told she was a ‘bad investment’ when she asked for time off for reconstructive surgery.

Nicola Pazdzierska, who works for the newly created Equality and Human Rights Commission in the UK, said, “There is good practice out there, but some people with cancer are still being treated appallingly. This happens when people are at their most vulnerable and a lot of employers are not aware of their obligations under the law. Employers have to make reasonable adjustments to help people with cancer to stay in work.”

Countries of the ‘new Europe’ have actually lost some protection, since under the former system jobs were generally protected, even during long-term sickness.

Sanja Rozman has a unique insight into the strengths and weaknesses of protection for people with cancer and other long-term illnesses. As a doctor at the Institute for Rehabilitation in Ljubljana, Slovenia, she assesses how the demands of the workplace will impact on a patient, and how they can be modified. She herself was diagnosed with breast cancer at the age of 46, when she was a working mother with a four-year-old child.

She says that, despite strong formal protection in Slovenia, legal protection is often not enough, especially for workers on short-term contracts. “I encounter every day patients who report on discrimination, subtle and direct psychological pressure. For a survivor in a psychologically vulnerable position these pressures are a real threat.”

She says that whether patients want to return to

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work depends on the severity of the disease and on personal circumstances. “It depends not only on the type of illness or the type of job, it also depends on whether you have a big family or other interests in life or whether the job is your prime source of self-esteem. This experience of cancer shakes your value system – you have to reassess which is more important, your health and family or doing the job you like.”

In her own case, Rozman returned to work part time ten months after surgery, working four hours a day and no longer doing hospital night shifts. “I am a doctor and this is a vocation, not something you do because you have nothing else to do. For me the job is very important, but I would not die for it. I have had to learn to work more efficiently. I was aware I must not exhaust myself. I must work up to my limit and not past it.”

Rozman is on the board of Europa Donna, the European Breast Cancer Coalition, and its Slovenian affiliate. She notices differences in attitudes to work and protection, depending on the status of the women affected.

“The women I meet at a European level are mostly middle-class women who are well-off with a high level of education. Often when I speak with colleagues in western Europe about work, they see themselves sitting in an office speaking nicely with nice people. They don’t have any idea of what it is to work in a factory 9–10 hours a day, to be physically active when in pain and ill and in an environment that is hazardous.

“On the other hand, I am in touch every day in my clinic with patients who have done physical work for 40 years and still have to do difficult physical work. They consider it a privilege to be protected and transferred to a lighter job. There are a lot of these women, especially in eastern Europe, who have to support their family. For them, work is not an option, it is the only way they can survive.”

Corina Alexandru, President of the *Asociatia Oncologic Rom*, the Romanian Association of Cancer Patients, often meets employers to sort out problems when cancer patients are denied the right to return to work.

“The law is upside down in Romania. Normally, the company has to keep your place open for you, but the law also says that if the company needs someone to do your work when you cannot, they can hire someone else. Cancer patients may have worked for many years in the same company. We do not get cancer because we want it! It is not our fault, and when we have paid for medical insurance then the company has to keep our place until we are able to work again.”

Daniel Alexandra was diagnosed with osteoblastoma in his hand at the age of 21. He had a medical certificate and should have been legally protected. But after a year and half, the harbour company where he worked as a driver fired him. He is now having treatment in Spain. “When he comes back to Romania we will have to help him find a job. There are many people like this. After they have finished treatment the company won’t accept them back to work – they say they have taken on other employees and don’t have any places at the moment.”

Alexandru was not able to return to work after her own cancer treatment began eight years ago, but she was able to get a medical pension. The *Asociatia Oncologic Rom* helps survivors to stay active and learn new skills. Alexandru herself has learned to work in stained glass.

Bulgaria, another recently joined EU country, also has good protection under law, with cancer classified as a ‘temporary disability’ for up to five years from diagnosis, and a board to help employees keep their jobs. But Evgeniya Adarska, who founded what has become the main cancer patient group in Bulgaria, *APOZ*, says that employers know how to lay off cancer patients without violating the rules.

“A young woman, working in the Bulgarian office of a big international company, was diagnosed with breast cancer. She underwent an operation, had chemotherapy, radiotherapy and hormone therapy, and even before the treatment was over she returned to her office, happy to have a new chance for a life and her own job, far away from the hospitals. But two months after her return, her employment was terminated without notice.

“The end of her contract was a very good excuse to get rid of an employee with an unclear health future. The young woman was heartbroken. The lawyer she talked with did not give her much hope, so she was unemployed only two months after the cancer ordeal. That young woman was me in 2000, the year I decided to set up my first anticancer organisation.”

Since then, APOZ has helped many people facing discrimination. Adarska cites a campaign to help two women cancer survivors with excellent work records, who were twice threatened with dismissal. Once APOZ intervened directly and the second time, in 2007, it called on the trade union for support, and on both occasions the jobs were saved. “The two women still work for that company. In 2007, cancer patients in Bulgaria are much stronger and able to fight for their human patient rights. It’s extremely important that every patient has the right to choose his or her future life after treatment. I believe that nobody deserves to be harassed because of health problems.

“It is obvious that the law itself is not the only means to help cancer patients, especially in Bulgaria, where going to the court in some cases can be just a waste of time. We are still in the situation where we need to campaign heavily.”

There have also been some very positive experiences in Europe. In Finland, Mikael Jungner, was diagnosed with prostate cancer in early 2005 at the age of 40, just as he was about to take up a new post as director-general of the Finnish Broadcasting Company, YLE. The board gave Jungner its full support, and it was not regarded as a big deal for a top executive to be treated for cancer and to carry on working.



Progress. Lawyer and cancer survivor Elisabetta Iannelli helped secure legislative changes that give Italian cancer patients the right to switch to working part time

It may be a long time before this positive experience is translated into the same support and rights for men and women throughout the EU – especially for cancer survivors who work in less glamorous fields.

Javier Güemes from the European Disability Forum says that Europe has to focus on the social barriers that stop people with many conditions playing a full part in life. “Things are changing, but we are far from a perfect situation, that’s for sure, and we have to continue fighting. There are wonderful laws, not just in the UK but in Spain, Italy and France etc, but the problem is that the laws are not respected and people with disabilities are not informed of their rights.

“Changing legislation is the first step. Now we have to change the minds, and have to change society to accommodate this new philosophy regarding people with disabilities and people with chronic illnesses. This will take time but I think that things are improving.”

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