

# Just the job?

It's time to try out the new disability rights laws

→ Anna Wagstaff

By now, all EU Member States should have outlawed discrimination at work on the grounds of disability. Will this be enough to protect cancer patients from being forced out of their jobs, and give them the right to continue working at the level they want? If not, now is the time to contact the Commission and complain.

October marked the deadline for European Union Member States to introduce legislation outlawing discrimination at work on the grounds of disability. How this legislation will affect cancer patients remains unclear. Typically of EC Directives, the European Employment Framework Directive is short on detail, leaving key concepts, such as the definition of 'disability', for each Member State to decide. To date there are six countries that have failed to implement the Directive at all, while many of the countries that claim to have implemented it may in fact fall short of full compliance.

Over the coming year, the EU will be reviewing the measures taken by Member States, and may take action against those that are out of compliance. If the laws don't protect the rights of cancer patients to remain in paid employment, then lobbying the EC over the coming months may help ensure the necessary improvements are made.

Fighting disability discrimination at work is not usually associated with cancer patients. Traditionally, this has been taken up by people

with physical disabilities and, increasingly, by people with learning disabilities. Cancer activists, by contrast, have concentrated on research, treatment and care. Yet when more than 100 delegates from across Europe gathered for the first meeting of the European Cancer Patient Coalition in Milan this June, discrimination in the workplace generated more heat than any other issue.

Delegates who had remained silent for the rest of the weekend lined up to tell their stories. Common to many was a continuing sense of bitterness.

One delegate, from Austria, talked about his attempts to move to an office job after prostate surgery left him with mild incontinence. "I was all day on the road, with a 15 kilo pack, and after the second customer, on the second floor, I was wet." All larger companies in Austria have a disabled workers' representative, so he went to ask for support from the one at his workplace. He found none. The representative, a man who had lost a hand, said, "You've got two arms, you've got two legs, you're not blind, you can hear and you're not in a wheelchair. What's the problem?"

## Patients often see keeping their job as an indicator that there is a future ahead of them

Another delegate, from Ireland, was forced from his job as a commercial artist because the combined effects of treatment for prostate cancer and chronic asthma left him needing a short nap half-way through the day. "So long as I can lie down for half an hour, my batteries can recharge and I can work with no problem whatsoever," he said. He felt he had been treated unfairly, but doubted he would have got anywhere by taking a case for discrimination: "My employer would simply say: 'This guy keeps falling asleep at work.'"

### FEELING WORTHLESS

Similar experiences were reported from Germany, where one delegate complained of a vicious cycle in which cancer patients suffer stress and depression associated with their disease, which can affect their work. Employers who are not supportive and understanding put further pressure on the patient, by making them feel that they are worthless and not pulling their weight. "Even if they have every right to remain in their job," she said, "the company will offer them money to leave, and usually they end up leaving."

The stories from the European Cancer Patient Coalition seem, sadly, to be representative of what happens throughout Europe. Vesela Kapitanska is a breast cancer survivor who works as a family therapist in the Cancer Patients' Association in Bulgaria, where protection for workers rights has traditionally been strong. She tells of a cancer survivor, Tzveta Manikatova, who has been forced out of her job because of heart disease she contracted while undergoing radiotherapy following a mastectomy five years ago. Before her cancer diagnosis she had been doing a physically undemanding job at the Bulgarian Telecommunications Company. After her treatment, she returned to work, and for five years everything was fine. But when the company was recently privatised, a

new manager took over. He told Manikatova and other workers with chronic health problems to sign a 'voluntary' redundancy agreement or be discharged without compensation after three months. With two children to care for, and a husband who was earning less than she was, she had no choice but to take the compensation, and is now looking for alternative work.

"It's not just an economic problem," says Kapitanska. "Most cancer patients want to return to their jobs to forget about the troubles they had and get back to their friends and normality. Working keeps them busy and stops them dwelling all the time on their disease. It also makes them feel useful and able to contribute, rather than ill and dependent."

Sandra Hunton, Director of a cancer support centre in Bradford, UK, strongly agrees. "Patients often see keeping their job as an indicator that there is a future ahead of them. They try to hang on because they have to believe that they are going to get well and will go back to work. Losing your job is a bit like losing the future. It's a bit like giving up."

Hunton has learnt from experience that even if employers are trying to force you out of the door, giving up your job is often not the best move. "Sometimes family or nurses and doctors, with the best of intentions, advise people to give up work, because they are caring and don't want the patient to be worried. But it may not be the best thing to do, for economic reasons or psychologically."

### MARGINALISED

Elisabetta Iannelli, an Italian attorney, has represented many disabled and ill people on employment and benefits issues, and is herself a cancer survivor. She has written a guide to the rights of cancer patients.

At the Milan meeting, she insisted that the right to work is essential. "Imagine a 45-year-old man, with a family. He is diagnosed with cancer

but treated successfully. Then there is another threat. If he loses his job, he may become depressed, marginalised, a burden on his family. His family may also be discriminated against. Medicine gives him back his life, but society gives him other problems.”

“We want to keep on working. It should be possible to change from full-time to part time jobs and afterwards maybe to change back again.”

It is clear that cancer patients across Europe face similar problems at work. But can the European Employment Directive provide an effective remedy? “Probably yes,” says barrister Catherine Casserley, who is senior legal advisor to the UK Disability Rights Commission, “But only under certain conditions.”

For cancer patients, a key issue is how Member States choose to define ‘disability’, which is not spelled out in the EC Directive (see box, pages 50-51). Ireland, for instance, has a broad definition, and its legislation would clearly cover cancer patients. In the UK, by contrast, the definition is far more restrictive, and the majority of discrimination cases that have failed since the UK Disability Discrimination Act for employment came into force in December 1996, did so because the person was deemed not to fit the criteria. One employment tribunal ruled that a man with mild incontinence following surgery for prostate cancer was not disabled. He won his appeal, but only after he was obliged to reveal in court information so personal that he had never even talked about it with his wife.

#### TAKING CASES

Even with a well-framed law, however, many people will be unaware of their rights, or lack the confidence and money to take a case. “If the law is to be effective,” says Casserley, “there has to be a body like the Disability Rights Commission in the UK that is responsible for

raising awareness and has the power to take cases against employers.”

Most important of all, she says, is that people facing discrimination take a stand. “The only way cancer patients are going to get anything out of this legislation, is if they use it.”

Casserley cites two examples. A man had been accepted for a job at a large company as a senior software coordinator. While on holiday before starting his job he was diagnosed with multiple myeloma. He told the company he needed immediate treatment and explained his start date would be delayed. The company withdrew the job offer.

The second example involved a man who developed cancer while in employment. He told his employer he would need four weeks off. The employer said, “We don’t think we can use you after you come back.”

“Because of the Disability Discrimination Act,” says Casserley, “we were able to do something about both cases. In the first case, the man got another job, and the employer paid £12,000 [17,350 euros] for injury to his feelings. In the second case they withdrew the threat of dismissal.”

The European Directive covers discrimination on the grounds of religion, belief, disability, age or sexual orientation. It lays down a principle of equal treatment, which it defines as ‘no direct or indirect discrimination’. This means that you cannot be treated differently from a colleague merely because of your disability (direct discrimination), unless it is strictly relevant and there is no reasonable adjustment that can be made to help the person do the job. It also means that companies may not use criteria, provisions or practices that effectively discriminate against people with disabilities, unless they are able to show that the aim is legitimate and that it cannot be achieved by any other means (indirect discrimination).

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## The most important provision obliges employers to make changes to the way they organise the work

For cancer patients, the most important provision is probably the one that obliges employers to make 'reasonable accommodation', in other words, to make changes to the way they organise the work to make working easier for employees covered by the Directive. This explicitly includes adjustments to 'patterns of working time and the distribution of tasks' if necessary. The right to switch, temporarily or permanently, to part-time working is not spelled out, but there is a strong basis for arguing that such a right is at least strongly implied in the wording of the Directive.

Casserley is convinced that, despite the vague terminology, the 'reasonable accommodation' requirement will provide protection for cancer patients and others. But she says that many European judges are sceptical. "They find it hard to get to grips with the idea that you can require an employer to change the way they work. But that is what they have to do."

### PYRRHIC VICTORIES

As with other employment legislation, there will be a gap between what the law says and what

#### SPAIN

##### **Ley de no-discriminación y accesibilidad universal para personas con discapacidad 2003 (Article 1 para 2)**

*(Anti-discrimination and universal accessibility for disabled people Act 2003)*

"For the purposes of this law, disabled persons shall include all those who have a grade of handicap of 33 per cent or above. In all cases, any person receiving a social security pension for a permanent incapacity graded as a total, absolute or serious handicap, as well as any person receiving a social security pension having been retired from work due to permanent incapacity shall be considered as having a grade of handicap of 33 per cent or above."

**This is one of the more restrictive definitions, which would exclude most cancer patients from being covered by the law.**

#### IRELAND

##### **Employment Equality Act 1998**

*Disability is defined as* "the total or partial absence of a person's bodily functions, including the absence of a part of a person's body, (b) the presence in the body of organisms causing or likely to cause chronic disease or illness (c) the malfunction/malformation disfigurement of a part of a person's body (d) a condition or malfunction which results in a person learning differently from a person without a condition or malfunction or (e) a condition, illness or disease which affects a person's thought processes, perceptions of reality, emotions or judgment or which results in disturbed behaviour, and shall be taken to include a disability which exists at present, or which previously existed but no longer exists, or which may exist in the future or which is imputed to a person."

**This is a broad definition. Although very medically based, it does not require the person to have a condition for a particular length of time, nor does it require a certain degree of symptoms. This means there are few disputes, if any, about whether or not someone meets the definition.**

employers do. One of the UK delegates to the Milan conference argued that many 'successful' actions under the anti-discrimination legislation were pyrrhic victories. "The cases were won, and compensation was paid, but the employees still lost their jobs."

Worse still, many cases never even make it to a tribunal. Alison Rooks, who works as a benefits advisor at Bradford Cancer Support, says that workers are often nervous about taking up the issue and asking their employer to change the way they work. "The question is whether people have the energy and confidence to challenge their manager, and take a case through a tribunal, at the very time when they have to devote their energies to struggling with the disease."

The situation is not helped by low levels of unionisation, and poor provision of good-quality free advice on employment matters.

Rooks cites a recent tribunal in which a woman won financial compensation after being edged out of her job following cancer treatment. Ironically, the employer was a medical General Practitioner.

So how much is the European Directive really worth? A great deal, according to Casserley. "The real successes are the cases we don't hear about, because they don't come to court. People ring up, they find out about their rights, and they say to their employers: 'You can't do this to me.' It's at that point that it has the most effect. That's why it's important to raise awareness so you solve these situations before they get that far."

The point was well taken in Milan. Yet, it was also clear that joining a broader campaign for fair treatment at work involves defining where cancer patients fit into the disability lobby. Many people with disabilities and chronic conditions like epilepsy see their disability as an important element in how they define themselves. Most cancer patients, in contrast, refuse to allow the cancer to define who they are. For many patients, defining themselves as 'normal' and 'healthy' is an important part of defeating the disease and of putting the trauma of diagnosis and the misery of acute treatment behind them.

Yet cancer patients do often suffer effects from illness or treatment, including fatigue (which affects up to 80% of patients), lymphoedema and other circulatory problems, and incontinence. If these are to be recognised under discrimination legislation, they have to have some kind of a name. "I prefer the term 'impairment' to disability," said one delegate. "I'm not sure we want to be called handicapped or disabled or impaired," said another. In the end, it was agreed that the discussion of how cancer patients should define themselves should be revisited at a later date. (Such a discussion has long been going on in the wider disability movement, which would argue that while people may have impairments, they are only handicapped by other people's ignorance or prejudice.)

## HOSTILE RECEPTION

Delegates from Austria and Italy reported a hostile reception from some national disability

## UNITED KINGDOM

### **Disability Discrimination Act 1995 (section 1)**

"A person has a disability for the purposes of the DDA if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities."

'Long term' is defined as "lasting 12 months, likely to last for 12 months or for the rest of the person's life" (if their lifespan is likely to be less than 12 months)

'Normal day to day activities' is defined as "mobility, manual dexterity, physical co-ordination, continence, ability to lift, carry or move everyday objects; speech; hearing; sight; memory; the ability to learn, understand or concentrate; the perception of risk or physical danger"

*The definition also covers those with 'progressive' conditions, if they have some symptoms and the condition is likely to develop so that it will in future meet the full test of definition of disability.*

**This definition has the scope to be broad, depending on how the courts interpret it. The time limit may be a problem, for instance, for patients experiencing cyclical episodes of acute illness and remission**

## People with disabilities or chronic illness must be the ones who take decisions about themselves

organisations. “The trouble is,” said the Austrian delegate, “organisations and laws for disabled people in Austria centre on the needs of veterans from World War II – they are brilliantly organised, it works for them, and they don’t want to let us share it.”

However, this attitude does not seem typical, and indeed there are many other people with disabilities that do not involve the loss of a limb or an obvious physical impairment who have lobbied effectively at a European level.

Carlotta Besozzi, Director of the European Disability Forum (EDF), services a committee that was recently established to deal exclusively with the needs of people with chronic illnesses.

Besozzi says that the situation varies across Europe. In Sweden, for instance, people with chronic illnesses – including people who suffer allergies – have long been considered as people with disabilities. She also cites the Netherlands as an example of a country which has set up a single national platform explicitly for “people with disabilities and people with chronic illness”.

Besozzi says, “People on our committee would also say that many people with chronic illness do not want to consider themselves as disabled and many of the organisations have in the past focused a lot on research issues and health issues. It is quite a new move that there is a growing interest in employment and rights in society, social inclusion. It’s an ongoing discussion.”

Does she feel the European Directive has something to offer cancer patients? “I think the

legislation will have an impact. Not only should it protect you against discrimination because of your health situation, but it requires that your workplace be adjusted to help you work to your full potential. These are important issues for cancer patients.”

She says that the EDF would be willing to cooperate and work with cancer patients’ organisations. “The important issue is that people themselves, whether they are with disabilities or with chronic illness, are the ones who take decisions about themselves. We want to make sure nothing about us is decided by somebody else.”

Cancer patients are beginning to find their own voice. They should now use it to ensure that in every country the Directive is implemented in such a way that it protects their rights at work.

This will mean working with other patient and disability groups to raise awareness of the legislation, to take test cases, and to submit complaints to the European Commission, if the outcomes of these cases indicate that the legislation falls short of the terms of the Directive. Helping people make full use of the legislation will also be important. This means not just patients, but health workers, trade unions – and employers – need to be aware of the legislation and give support to patients who need it.

The ultimate aim in all countries must be an employment culture that is far more inclusive and supportive of the needs of workers with cancer and other chronic illnesses.

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*For information and advice about the the Directive, about national disability discrimination laws and national disability organisations, and about how to complain to the European Commission, contact the European Disability Forum at [info@edf-feph.org](mailto:info@edf-feph.org) or by telephone on +32 2 282 4600*