

**A short ECL report from a questionnaire**  
**about employment issues**  
**Summer 2009**

The Patient Support Work Group in ECL has carried out a small survey in the Spring of 2009. The purpose was to get a picture of what employment issues cancer patients approach the leagues with, and how the leagues are responding to them.

The questionnaire contained only 4 questions, and the leagues were encouraged to give rather short answers. The questions were:

- What main problems concerning the work place do cancer patients typically bring to your cancer league / organisation?
- How does your cancer league address the main problems presented to you by cancer patients?
- Do cancer patients lack basic rights in your country, i.e. the entitlement to sick leave, or the right to be absent from work because of treatment / rehabilitation? Are the basic rights the patients do have applied in daily practice?
- Please describe briefly the political initiatives you have taken in order to improve the rights and the support to employees getting cancer

## **Respondents**

The questionnaire was completed and returned by 14 leagues: Turkey, the 2 Belgian leagues, Ireland, Faroe Islands, Slovakia, Hungary, Greece, Northern Ireland, Cyprus, Iceland, Switzerland, Luxemburg and Denmark.

The leagues gave a number of different answers and comments, so we have extracted the main problems and typical reactions presented below.

## **Main issues**

The reported problems presented by cancer patients to the leagues were roughly related to three areas: workplace conditions, economic problems and legislative issues.

### ***A need for special considerations in the work place***

- Some employers do not understand challenges cancer patients face in returning to work, i.e. fatigue, reduced memory and ability to concentrate. So there is a major need to be able to return to the job gradually by working part time – both for psychological, physical and social reasons
- Communications between colleagues and employers can be rather awkward, because no one knows how to handle the situation
- Some cancer patients feel very insecure, because they do not know how secure their job is – lack of communication about this may also cause uncertainty and anxiety
- Necessary adjustments at the workplace do not / cannot always take place. Some jobs cannot be altered and small companies may have limited possibilities to make changes in work procedures, i.e. avoiding heavy lifting for a someone with lymphodema
- Some workplaces show little or no confidence in an employee who has or had cancer. The consequences can range from the cancer patient feeling afraid not doing the job properly to, experiencing discrimination from employer and colleagues, or even dismissal

### ***Economic problems***

- In most countries it is a problem that there is a time limit on economic support for cancer patients – the limits are usually six months or one year. But in a number of cases the disease lasts longer than six or twelve months. Some of the afflicted patients have to retire and accept a pension although they would prefer to go back to work
- Reduced income is a distinct problem for some cancer patients in some countries, but conditions differ very much from country to country
- Spouses also need rights – i.e. the right to take time off work when taking a sick spouse to hospital etc.
- The self employed are often insufficiently insured and their financial situation is perhaps more fragile when they get seriously ill

### ***Legislative needs***

- A flexible / individual time frame should be applied in the legislation regarding sick leave and economic support for cancer patients
- Getting cancer often leads to both a loss of income and extra expenses. There is a need for adequate economic compensation lasting the whole period of sick leave

- All companies should be instructed to have a policy that allows cancer patients to return to work gradually by incorporating part time work, flexible work hours, adjustments of the job content etc)
- Spouses should have the right to take care of a cancer sick husband / wife / child. This means no risk of losing one's job and a right to receive some financial compensation.

## **Typical actions taken by the leagues**

The leagues seem to be rather in agreement about how to respond to the problems. The following list shows common actions taken by leagues; the ones practiced the most are at the top:

- Providing general information about patients' rights, sick pay, pensions etc.
- Offering expert advice about patients' rights, sick pay, pensions etc either by the league itself or by referring to other people i.e. from public offices
- Advocacy and political lobbying on a regional or – more often – national level
- Publishing booklets and folders
- Using the media as a strategy – i.e. bringing case stories
- Organizing conferences and hearings
- Collecting patients' experiences through research or - less formal - from patient groups

## **Basic rights**

The basic rights for cancer patients are described as OK and implemented on a daily basis in most countries – although with a few marked exceptions.

## **Conclusion**

The two main issues brought to the leagues by cancer patients are

- The need for special considerations at the work place when returning to work, and
- Acceptance and acknowledgement by both the companies and the legal authorities that a cancer disease can last longer than one year.

The most common response from the leagues is to offer information and advice as well as to use advocacy and lobbying strategies in order to improve conditions for cancer sick employees.

The Patient Support Working Group is considering how to use these results in an effort directed at the EU. We want to lobby for changes in legislation so it will reflect a better understanding of the nature and the consequences of cancer diseases. Vital elements will include;

- adequate financial support for one year followed by an individual assessment of the needs of the patient after that period of time with a few to possibly continuing financial support
- legal protection against getting fired while having treatment – at least not without a) securing their economic situation and b) providing help to find a new position when well again

Another line of action to be considered is how to work on the attitude and the readiness of companies in the EU so they will provide suitable support and help for cancer patients returning to work.

July 9, 2009

Jutta Ølgod, The Danish Cancer Society