

Employment Issues for Cancer Patients



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Association of European Cancer Leagues

www.europeancancerleagues.org

- Pan-European umbrella organisation created in 1980
- Members are cancer charities at regional and national level across Europe e.g., Dutch Cancer Society, Hungarian league, Italian League against Tumours
- Thematic Areas for information exchange and lobbying:
 - Tobacco Control
 - HPV Vaccine / Cervical Cancer
 - National Cancer Control Plans
 - Skin Cancer
 - Patient Support Working Group
 - Pharmaceutical Issues e.g., access to innovative medicines
 - Fundraising

ECL Patient Support Working Group

Current areas of work:

- Services for Youth
- Subgroup on Cancer Patient Information (CPI)
- Subgroup on Employment and Financial Issues (EFI)

Employment and Financial Issues Subgroup (EFI)



Purpose

- A. lobby the EU on patient support issues, and
- B. provide an international platform for knowledge sharing

Aim

To improve conditions and rights for the cancer patient in the workplace, by evaluating the current climate of cancer patients in order to provide suggestions on supporting cancer patients in the workplace.

EFI Questionnaire

Spring 2009

1. What main problems concerning the work place do cancer patients typically bring to your cancer league / organisation? Please describe the 3 most common.
2. How does your cancer league address the main problems presented to you by cancer patients?
3. 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?
4. Please describe briefly the political initiatives you have taken in order to improve the rights and the support to employees getting cancer

Existing Resources

- When an Employee Develops Cancer Booklet (ECL)
 - Based on booklet by Danish Cancer Society, written for managers and others with responsibility for human resources in workplaces in Denmark
 - Offers practical solutions and aims to improve employers' knowledge of cancer and of the special situation of cancer patients in order to reduce the risk of their exclusion from the labour market.
- Macmillan (UK)
 - Cancerbackup focus, merged with Macmillan
 - “Working through Cancer” toolkit for employers and employees
<http://www.macmillan.org.uk/GetInvolved/Campaigns/WorkingThroughCancer/SupportForEmployees.aspx#orgs>
 - “Work and Cancer” booklet
<http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/WorkingThroughCancer/Workandcancer.pdf>

Existing Resources (con't)

Study: Cancer and in general long-term illnesses at workplaces – 2008

Commissioned by European Parliament's Employment and Social Affairs Committee (EMPL)

<http://www.europarl.europa.eu/activities/committees/studies/download.do?file=22828>

Includes background research with results from survey among ECL, UICC orgs, etc.

Report Findings - Issues:

1. Legislation: no separation of disability and long-term illnesses at the European or national level legislation. i.e. cancer patients (or others with chronic or long-term illnesses) and survivors are not specifically catered for in the workplace.
2. The type of benefits a patient receives is mostly dependent on which healthcare model the government uses
3. Some countries provide days off and psychological support for families or friends who are looking after patients, some don't.
4. Even within the remit 'cancer patient' different needs arise

Existing Resources (con't)

Study: Cancer and in general long-term illnesses at workplaces – 2008

Issues (continued):

5. Early return to work is the preferred route for most survivors both for financial reasons and to feel 'normal' again. However problems are faced due to debilitated health, concentration, memory loss and a change in life priorities from work to family.
6. Most individuals suffer from a 25% decrease income in the first 12 months after diagnosis. At the household level this rises to 50% on average with many households rising to a loss of 70%.

Existing Resources (con't)

Study: Cancer and in general long-term illnesses at workplaces – 2008

Recommendations:

Improve Labour Laws

Provide distinct definitions between disability and long-term illness

Create policies that address the structural barriers to social inclusion

Welfare Support

A mix of private sector and state initiative to reduce burden on the State without depriving individuals of care and opportunities for working

Support for Job Reintegration

Work with Civil Society

The EU should include patients and NGOs on their boards before implementing decisions relating to employment policies for people with long term illnesses

Existing Resources (con't)

- FECAPS--Fair Employment for Cancer Patients & Survivors (USA)
(<http://fecaps.com>) = cancer support group specializing in workplace issues
- Employment Rights as a Cancer Survivor booklet (USA)
<http://www.canceradvocacy.org/resources/publications/employment.pdf>
- “A resource for working women with cancer”
<http://www.cancerandcareers.org/>
- IOM (Institute of Medicine) - Employment and Health Insurance Concerns
<http://www.iom.edu/~media/Files/Report%20Files/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition/factsheetemploymentandhealthinsurance.aspx>
- Issue mentioned in blogs, forums, other social media means
- Many articles in peer-reviewed journals

www.cancerandcareers.org

For Working Women with Cancer: career coaching, cancer diary, wigs, support, legal - Windows Internet Explorer

http://www.cancerandcareers.org/

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Employees with Cancer: ECL Set of Basic Rights for Lobbying - *for discussion*

1. Patients should have the right to take time off for treatments without having their pay or holiday leave docked
2. Patients or survivors should have the right to paid absence for a year or more, or until settled in a new job
3. Patients should also have the right to paid prescribed absence for rehabilitation with no time limit
4. Patients should have paid time off for follow ups
5. Patients should have at least two meetings with the leader (i.e. the manager and/or HR manager) including mutual expectations, side effects, late effects and the need for temporary special considerations.

Employees with Cancer: ECL Set of Basic Rights for Lobbying - *for discussion*

6. Employees should have the right to be reintegrated into their jobs or retrained for a new position or offered a special job or given help to find a new job
7. Survivors and/or patients should have the right to a gradual return to work; the specifics need to be sorted at the individual and company level, accompanied by the right to renegotiate the tasks that you do.
8. Parents, guardians, relatives or a carer nominated by the patient should have the right to take paid time off in order to care for the patient when prescribed by a medical professional.
9. Agree or disagree? What else????

***** DISCUSSION *****

THANK YOU!

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