European Cancer Patient Coalition

The ECPC - LNCP
Survey on the socio-economic Burdens of Cancer
Best practise: Italy

Avv. Roberto de Miro

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ECPC LNPC decided to launch the project for a survey just 1 year ago.

GOALS

- Trace a complete frame of social disparities in Europe
- Indicate issues and suggest remedies
- Point out and highlight eventually existing best practices

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The current Survey has a large field of interest,
covering different aspects of socio-economic difficulties of :

- people affected by cancer

- people taking care of a person affected by cancer, e. g. parents, relatives, other non professional caregivers

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Survey questionnaire is divided in 5 main sections:

A: After diagnosis, steps to certification or assessment of a DISABILITY conditions
B: Difficulties for EMPLOYED patients and/or carers
C: Difficulties for SELF-EMPLOYED patients and/or cares
D: PENSION prejudice for patients and/or carers
E: INSURANCE, Loans, Mortgages ond other discrimination

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A: After the diagnosis

Most countries' legislation provides for assessment of a disability status of the patient

Such assessment may be necessary to achieve access to financial or other assistance

Italian patients obtained that assessment is made in 15 days (Law n.80/2006)

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A: After the diagnosis

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B: Employed patient and/or caregiver issues:

- (paid?) sick-leave
- flexibility
- prevention of dismissal
- facilitations in employment

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B: Employed patient and/or caregiver issues

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Paid sick-leave on an average range of 6 to 12 months

Caregiver paid leave of 3 days per month (Law 104/1992)

Right of cancer patient to switch to part time and reverse (Law decree n. 276/2003)

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C: The Self-Employed

The SE patient or caregiver suffers a restriction in his capacity of carrying on a job.

Many families face bankruptcy for this reason.

ECPC tried hard to obtain an amendment to the Work/life balance directive, based on the Social Pillar, in order to include the self-employed caregivers among the workers entitled to earn loss indemnity (in that draft equivalent to just 5 days!) - which was rejected.

We shall stand for this furthermore and for the extension to the self-employed patients of benefits equal to those available for the employed.

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C: The Self-Employed

According to §12. (Social protection) of The European Pillar of Social Rights

Regardless of the type and duration of their employment relationship, workers, and, under comparable conditions, the self-employed, have the right to adequate social protection.

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D: Pension rights

Together with loss of earnings, both patients and carers face a detriment of pension credits.

In most countries, there is a protection for the employed patients, but nothing for caregivers

nor for the self-employed.

It is an issue of outstanding importance.

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E: Insurance / Loans and Mortgages/Adoption

Just a couple of decades ago a cancer survivor would not be considered as having a long life expectancy.

Targeted and immunotherapy, among other progress, changed this concept in MEDICINE. It is time to change this in CULTURE.

In most countries Cancer Survivors are discriminated as if they had a shorter life expectancy and they get

no access to long term mortgages, insurance, adoption.

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NEXT STEPS

We ask you all to cooperate in collecting data.

As soon as the survey is completed, the LNCP of ECPC will be able to

1) Describe with accuracy the discriminations against Cancer patients and Caregivers and existing inequalities among EU member states

2) Indicate best practices and suggest innovative provisions to ensure socio-economic rehabilitation.

3) Demonstrate to legislators the convenience of a more equal welfare given that poorer conditions engender higher costs for the community

Thank everybody for your attention and cooperation!

Roberto de Miro, JD, SD
Chair ECPC-LNCP
studiodemiro@tiscali.it