



**United Against Cancer CEE Patient Summit,
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LESS PATIENTS MORE SURVIVORS

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STATISTICAL DATA FOR SLOVENIA (1)

- As per June 30, 2003:
 - Inhabitants: 1,996.773
 - Older than 65 years: 277.143
- Source: Statistical Office of the Republic of Slovenia



STATISTICAL DATA FOR SLOVENIA (2)

- In 2003 discovered cancer cases in: 9997 people
- In 2003 died from cancer: 5058 people
- Source: Cancer incidence in Slovenia 2003, Cancer registry in Slovenia, Institute of Oncology Ljubljana, Slovenia 2006



STATISTICAL DATA FOR SLOVENIA (3)

- In 2003 affected by:
 - **Breast cancer:**
 - women: 1083
 - men: 13
 - **Colon- and Rectum cancer:**
 - women: 525
 - men: 673
 - **Cervix uteri cancer:**
 - women: 208



STATISTICAL DATA FOR SLOVENIA (4)

- Five-year surviving period (period 1993-97) compared with the same surviving space of time in EU in %:

	Slovenia	EU
• breast	65,6 %	74,8 %
• colon	36 %	48 %
• rectum	30 %	44 %
• cervix	56,2 %	59,9 %

- Source: The EURO CARE-3 study



REASONS FOR WORSE SURVIVING CHANCES IN SLOVENIA (1)

- 1.) Insufficient cancer awareness of people
- 2.) Poor conditions for early diagnosis of the disease, immediate and efficient treatment and rehabilitation

ESSENTIAL CONDITIONS HAVE TO BE ESTABLISHED BY THE HEALTH POLITICS, PROFESSIONAL FIELD AND HEALTH INSURANCE SCHEME!!!



REASONS FOR WORSE SURVIVING CHANCES IN SLOVENIA (2)

3.) The state programme ZORA for early discovery of cervix uteri cancer has been indeed introduced but the women's response is not as good as expected



REASONS FOR WORSE SURVIVING CHANCES IN SLOVENIA (3)

4.) The state programme DORA for early breast cancer diagnosing is still at its infant stage

5.) We still lack organized and specific primary and secondary centres for treating breast cancer according to the European and Slovene professional guidelines



REASONS FOR WORSE SURVIVING CHANCES IN SLOVENIA (4)

- 6.) Cancer, not just breast cancer, is a disease which demands diagnosing, treating and rehabilitation at specialized institution with additional adequate equipment and experts with improved oncological knowledge
- 7.) Treatment of cancer requires a complex approach and must be performed by multidisciplinary and multiprofessional teams



REASONS FOR WORSE SURVIVING CHANCES IN SLOVENIA (5)

**SURVIVING RATE OF CANCER
PATIENTS TREATED AT SPECIALIZED
INSTITUTIONS IS HIGHER!!!**



DIFFICULTIES EXPERIENCED AFTER THE DISEASE (1)

- Cancer is getting more and more curable and increasingly more people are after successful treatment returning home and into their professional life
- After the treatment consequences may remain which manifest themselves in impaired fitness for work either psychological or physical
- Only a few employers are willing to take this into account



DIFFICULTIES EXPERIENCED AFTER THE DISEASE (2)

- Commissions for the disabled are also reluctant to listen to these arguments especially when considering to grant part time work or possibilities for modified qualification in order that the survivors could remain professionally active as long as possible
- **TODAY WE PATIENTS – SURVIVORS ARE NO LONGER SATISFIED JUST TO SURVIVE BUT WE WANT TO LIVE A FULL AND DECENT LIFE!**



RELATIONSHIP DOCTOR - PATIENT (1)

- It is hard to be encountered with cancer – a disease that not so long ago was only whispered about
- In a moment a healthy man can turn into a seriously ill patient (psychically and physically)
- At that time it is extremely important who will be the attending doctor



RELATIONSHIP DOCTOR - PATIENT (2)

- The doctor must be an excellent expert – oncologist
- He/she must be a good person who is:
 - able to listen attentively
 - willing to help us overcome the worst problems
 - prepared to explain in an understandable language everything about our disease
 - ready to explain in a reasonable way all the available treatment methods, furthermore



RELATIONSHIP DOCTOR - PATIENT (3)

- We must feel free to ask any question we want;
- The doctor must not reject us if we wish to acquire a second opinion of some other expert or decide not to accept the suggested treatment;
- The doctor must be someone we trust and feel sure that he/she will help us choose the best possible treatment;
- We also expect to hear from the doctor in what way our life will be changed by the disease.



RELATIONSHIP DOCTOR - PATIENT (4)

IN THIS SENSE ALREADY YOUNG MEDICAL STUDENTS SHOULD BE EDUCATED:

- They should learn the pristine basic principles of communication
- They should become acquainted with the difficulties and fears of patients with cancer – this increasingly occurring disease



RELATIONSHIP DOCTOR – PATIENT (5)

**IN ORDER THAT THE DOCTORS COULD ACT
ACCORDINGLY THE RESPONSIBLE PEOPLE
SHOULD CHANGE THE NORMATIVE
PROVISIONS FOR THE WORK OF DOCTORS
AND OTHER MEDICAL STAFF**

**IN THIS WAY THE DOCTORS COULD DEVOTE
MORE TIME TO EVERY SINGLE PATIENT**



ROLE OF THE CIVIL SOCIETY ORGANIZATIONS (1)

- **EQUAL POSSIBILITIES FOR ALL
CANCER PATIENTS REGARDLESS OF
THEIR PLACE OF BIRTH, THEIR
FINANCIAL STATUS, EDUCATION OR
CONFESSION**

*(free version of the European Breast
Cancer Coalition EUROPA DONNA
slogan)*



ROLE OF THE CIVIL SOCIETY ORGANIZATIONS (2)

- Organized groups of patients know and understand in detail what the various needs of every single patient are
- Especially for this reason they should take part in designing an efficient health system for individuals as well as the society as a whole.
- We the survivors, who are able, wish and are willing to collaborate voluntarily, are only seldom invited to take part



OUR ACTIVITIES (1)

- We are raising awareness about:
 - cancer
 - healthy way of life
 - importance of including the patients into clinical research studies
- We are giving lectures accross Slovenia
- We issue publications and brochures
- We appear in media



OUR ACTIVITIES (2)

- In order to be able to render help in overcoming difficulties, choosing the right treatment and acquiring a second opinion we have:
 - self-help groups
 - personal counselling
 - SOS telephones



KEY TASKS (1)

- Constantly reminding the health politics that numerous lives depend on the organization of a complex cancer treatment in Slovenia:
 - well organized preventive programmes could save numerous lives
 - well organized palliative care which should help that the patients who have lost their battle with the disease may die decently and in peace



KEY TASKS (2)

- We wish to be involved in designing such an efficient health- and professional politics

- Why?

BECAUSE WE ARE PERFORMING A VERY IMPORTANT WORK DUE TO WHICH THE LIFE OF MANY A CANCER PATIENT AND HIS/HER RELATIVES HAS BECOME MUCH MORE VALUABLE.



KEY TASKS (3)

- Closer cooperation between organizations:
 - our voice could be louder
 - professional field and health politics should more frequently pay attention to our suggestions and seek a more intensive cooperation with us
 - lives of many Slovenian citizens could be better
 - **and cancer could slowly lose the touch of death.**