



EUROPEAN  
**C A N C E R**  
**P A T I E N T**  
COALITION

## **Cancer Patients and Cancer Nurses: Strategic partners?**

**Jan Geissler, ECPC Director**

**ECPC SPEAKS WITH A SINGLE VOICE FOR ALL CANCER PATIENTS**

# European Cancer Patient Coalition (ECPC): "Nothing about us without us"

- **Representing >300 cancer patient groups in 41 countries**
- **All cancers** – common and rare
- Promoting the fundamental rights of patients
- **Run and governed by patients**
- Increasing cancer patients' **influence** over European health and **research policy**
- Promoting **timely access** to appropriate prevention, screening, early diagnosis, treatment and care for all cancer patients
- **Reducing disparity** and inequity across the EU
- Encouraging the **advance of cancer research & innovation**
- High visibility with **EU Commission, EMEA, EU Parliament**



# Cancer: The rollercoaster patient journey

- **Time is of essence in cancer:**  
quick access to experienced doctors and treatment.
- Taking tough decisions is difficult



# After diagnosis, Cancer patients need to take informed decisions crucial

1. Find the right doctor
2. Understand the disease
3. Decide on therapy
4. Understand therapy
5. Comply to therapy



# Patient advocacy groups have a crucial role



## Support

- "Understand your disease", share & cope
- Finding the right doctor and information
- Reduce fear & help navigate the journey



## Represent & advocate

- "Nothing about us without us":  
Giving patients a unified voice
- Advocacy Toolbox and best practice sharing



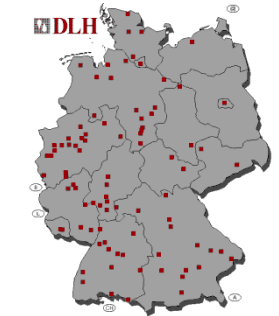
## Accelerate advancement in therapy

- Addressing "overarching problems"
- Cooperate with research, make or break trials
- (Inform doctors!)

# Different categories of patient groups

## 1. Internet-based communities

- Information dissemination, anonymous location-/time-independent sharing
- Often grassroots initiatives



## 2. Local support groups and national federations

- Disseminating information, individual sharing



## 3. Umbrella groups and networks

- "Nothing about us without us"



# Unresolved key issues in cancer care

## Some examples:

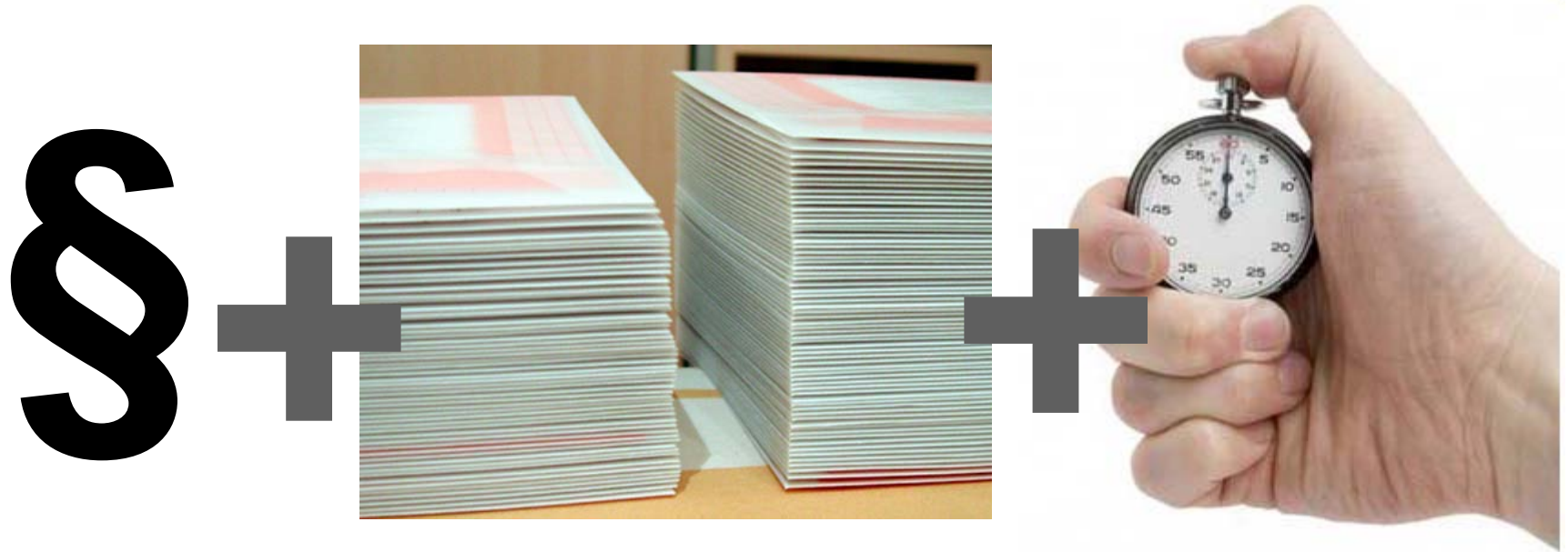
- Unmet needs in **patient information** & informed consent
- **Compliance/adherence** issues to (oral) therapies
- Severe interactions and side effects with **CAM**
- Lack of **psychological support** to cope with disease

# Doctor-patient communication



- Healthcare systems do not incentivize detailed consultation: 12 minutes from door to door!
- Non-medical language barrier
- Lack of information leads to e.g.
  - lack of trial participation,
  - lack of compliance,
  - interactions with CAM
  - unnecessary suffering and hospitalization

# Reality check: Constrains in patient information



- Full of safety information, technical terms and time pressure
- Does this really improve patient safety and informed consent?

# The result: The Internet has become one of the most popular resources for health information

- Despite any efforts of "quality assurance evangelists", Google will not go away!



- ~55% of EU adults go to their doctors
- **~45% EU adults use the web** to obtain health information.
- 1/3 of patients talk to their doctors **about what they found online**
- 1/3 of health searchers **use** Wikipedia, online forums etc on health-related topics



WIKIPEDIA  
*Die freie Enzyklopädie*



# Adherence issues: Some cancer patients owe their life to the "magic bullets" ...

## Patients



- **Oral** therapies are increasingly used in oncology
  - 10% of treatments today, >25% estimated in next 5 years
- Do we take it seriously enough, in comparison to in-patient care?

## Doctors

- Healthcare systems do not incentivize detailed consultation
- Doctors: **"This is cancer! Of course my patients take their drug"**.

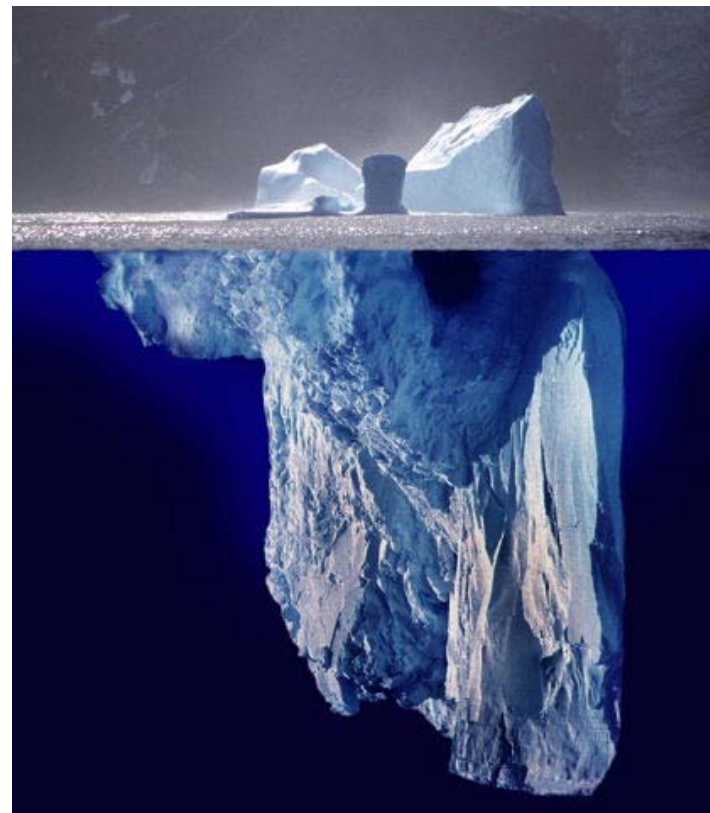


# Potential consequences of non-adherence to therapies

- **Decreased effectiveness** of treatment (e.g. CML)
- **Development of resistance**, causing progression or recurrence
- **Drug interactions** or treatment discontinuations

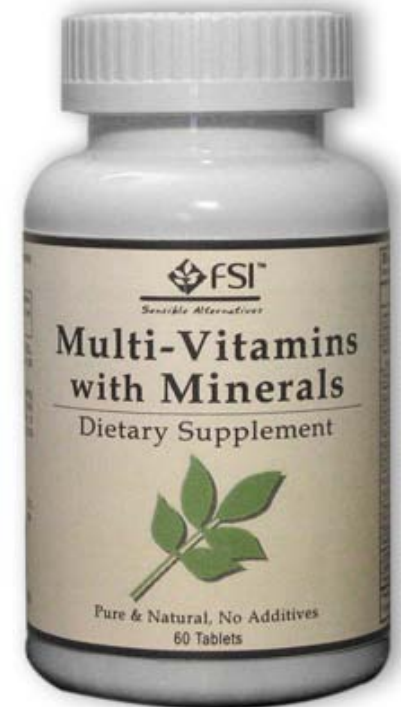
"Increasing the effectiveness of adherence interventions might have a far greater impact on the health of the population **than any improvement in specific medical treatments.**"

-- RB Haynes, Cochrane Collaboration



# Complementary medicines heavily used – without consultation

- Larger studies revealed that between 30% and 69% of cancer patients use CAM therapy (herbal remedies, vitamins, and special diets)
- Most hear about CAM from friends, family and media – less than 20% from their doctor
- CAM may just impact the **patients' pocket, reduce side effects or render cancer therapy ineffective** – dangerous if doctors don't take it serious
  - St. John's wort, Grapefruit, Vitamins, Herbs, apricot seeds, amygdalin,

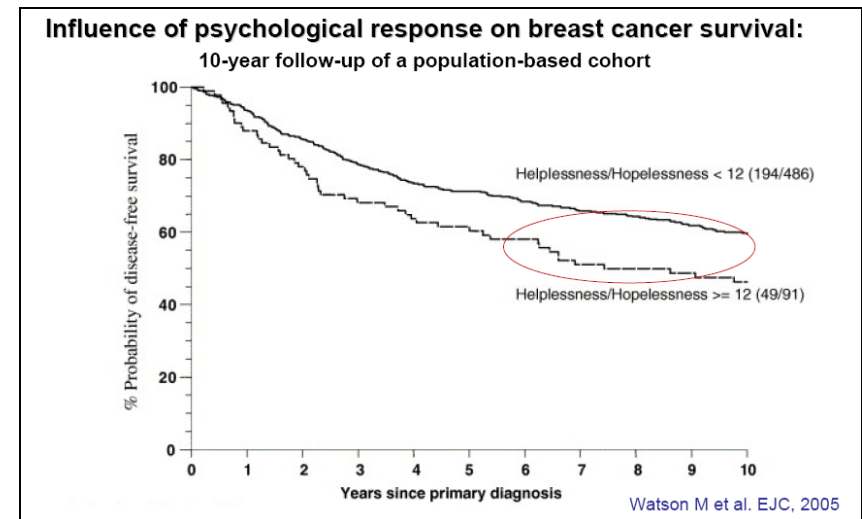


# Lack of psychological support

- “The emotional trauma of having cancer diagnosis and treatment can be as potentially harmful for the patient as the disease itself”

-- Meyerowitz B,  
Psychological Bulletin, 1980

- 35% of cancer patients suffer from distress, and some will develop psychopathological conditions (ZaboraJ et al. Psycho-Oncology 2001)



- Yet not all patients have access to psychosocial care, or they are not being told it exists

- ~70% of this suffering goes unrecognized

# Cancer Nurses have a key role

- **Education, monitoring and support of cancer patients** (also emotional support, hygiene, rehabilitation, life style advice, application of therapies, patient self-management)
- **Translational role** between the medical advice and the patient's level of knowledge.
- Often the **key contact for relatives** of cancer patients
- Sometimes acting as the **patient advocate in a hospital setting**, flagging up issues to the multi-disciplinary team

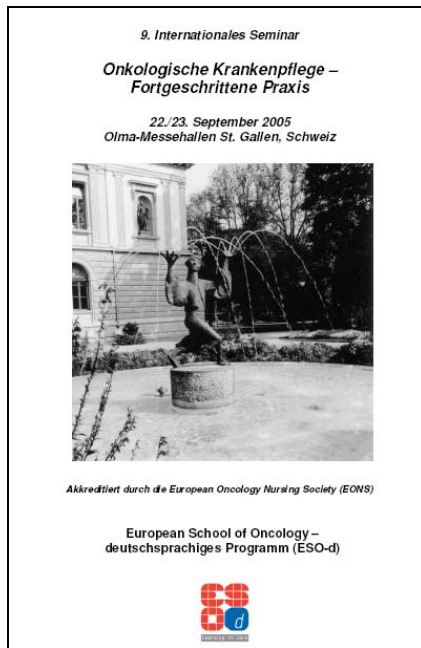
# Cancer Nurses have a key role

- **Referral of patients to patient groups**
- **Persuade other professionals** about the legitimacy of the services patient groups can offer.
- **Supporting or assessing compliance/adherence** to cancer therapies (incl. developing routines to take medication)
- **Side effect management** (in the hospital, but also at home)

# Cancer Nurses and Patient Groups - natural allies?

- **Cancer Nurses and patient advocates are natural allies**
  - often treated paternalistically and patronised by doctors.
- **Strategic alliances** between both groups could make each more powerful.

# Collaboration between Nurses and Patients happens – but not yet strategically



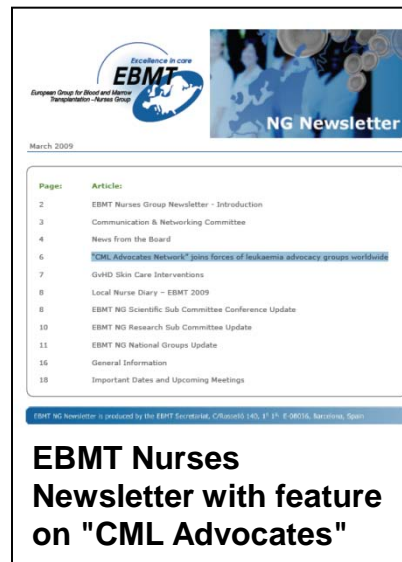
**ESO Nurses Seminar  
Switzerland, 2005  
with patient perspective  
on "we want to live – not  
only survive".**



**New Horizons in treating CML/GIST  
Italy, June 2008  
on TKI side effect management**



**New Horizons in treating CML/GIST  
Portugal, June 2009  
on compliance**



# How are we more strategic in collaboration?

## Issues for discussion

- We have common goals and challenges
  - but **we need to be more strategic in collaboration**
- Examples
  - Joint development of **patient information**
  - Joint development of a **toolbox for improving compliance**
  - Assess and address issues of **quality of life**
  - **Dissemination of PAG-created patient information** to the place of diagnosis and treatment
  - **Educational activities for nurses and other professionals** (understanding patient needs, quality of life; train the trainer...?)
  - **Policy initiatives** (e.g. the role of nursing in cross-border EU policy)

# Thank you!



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**CANCER**  
**PATIENT**  
COALITION



**Nothing about us – without us!**

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**CHAMPIONING THE INTERESTS OF EUROPEAN CANCER PATIENTS**