

A decorative graphic on the left side of the slide consists of several vertical lines in various colors (red, orange, yellow, green, blue, purple) that curve and swirl upwards and to the right, creating a dynamic, abstract shape.

# Dementia and society: a wake up call

Luxembourg, 2 October 2010

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# Dementia: Everybody's business

- **Nobody remains indifferent – fear, rejection**
- **Social representation: “part of the illness”**
  - **Build the social reality of people with dementia and their carers**
  - **Condition the treatment and the people's attitudes**
- ***Not armed “to fight against dementia”?***

**We can all help people “to live well with dementia”!**

**We can all contribute to “broaden the dementia debate”!**

# Dementia: Everybody's business

## 1. New ways of communicating

To tackle stigmatization

## 2. A community perspective

To reduce social exclusion

## 3. A rights-based approach

To protect and empower the patient

## 4. Advanced care planning

To empower the (future) patient/to keep control of « life decisions »

# King Baudouin Foundation

- Independent, public benefit foundation in Brussels
- Working at local, regional, national, European and international level
- Activities on dementia since 2006
- Action plan for Belgium (2008)

# King Baudouin Foundation

- **Activities (2009 - 2011)**

- **Communication (“framing”)**
- **Legal aspects**
- **Dementia-friendly municipalities**
- **Advance Care Planning**
- **High-level Conference on Dementia (Belgian presidency of the EU)**
- **Belgian partner in the Joint Action on Dementia (EC)**
- **European Foundations Initiative on Dementia (NEF)**

# New ways of communicating

- **Research by Prof. Baldwin Van Gorp (University of Leuven)**
- **Objective: Most frequently used frames to represent dementia**

**Frame:** metaphors, catchphrases, visual images, lexical choices, stereotypes which (implicitly and through interpretation of the reader, viewer, ..) define a problem, assign responsibility, pass a moral judgement and suggest possible solutions

- **Phase 1: Inductive framing analysis**

**Material: novels, newspapers, movies, leaflets, documentaries, ... (more than 2000 sources)**

- Results: 6 dominant frames and 6 counterframes

- **Phase 2: Effectiveness of counterframes**

**On-line survey (1000 participants)**



# New ways of communicating

« Know your values and frame the debate » (G. Lakoff)

- All aspects of the disease and the related emotions are discussable
  - The disease should not be reduced to its later phase
  - Autonomy and dignity
  - Personhood
  - Citizenship (rights)
  - Empowerment and inclusion
- 
- Research report to be presented at conference of Belgian EU presidency
  - Recommendations on communicating on dementia for all stakeholders (workshops)
    - In Belgium
    - In other countries (NEF)



# A community approach

- Patients and carers experience social exclusion
- Support to maintain the social network: community engagement
- « Dementia friendly communities »
  - Demenzfreundliche Kommune (Germany) – Robert Bosch Stiftung
  - Communes Alzheimer Admis – Dementievriendelijke gemeente (Belgium) in collaboration with the Associations of Cities and Municipalities
  - European approach: EFID (awards)

# A community approach

- **Characteristics:**
  - Foster participation in the local community
  - Promote interaction between patients, their carers and other members of the community
  - Give a voice to patients and their carers

# Hekla (Hemiksem, Edegem, Kontich, Lint, Aartselaar)

Local police dealing with people with dementia



# Dementia-friendly municipalities



DEMENTIEVRIENDELIJK  
**BRUGGE**

[www.dementievriendelijkbrugge.be](http://www.dementievriendelijkbrugge.be)

# A rights-based approach

- **Legal actors: notaries, judges and attorneys**
  - **Assessment of the application of laws that influence the quality of life of the person with dementia**
  - **Raise awareness of legal actors to consider the specificities of dementia**
  
- **Public at large**
  - **Information brochure**

# Advance care planning

- Entails consultations between « patients », their representatives and healthcare providers
- In anticipation of a situation in which patients will be unable to take decisions
- More than advance directive of living will
- Ideally before first symptoms of cognitive decline

# Advance care planning

- Overview of current scientific knowledge (End-of-Life Care Research Group, Vrije Universiteit Brussel)
- Focus groups with citizens, health care providers (GP's, geriatricians, nurses ...) in Belgium
  - Ignorance, but many people are interested
  - Empowerment of elderly people, respect for autonomy and dignity
  - Breaking the end-of-life taboo
  - Citizens prefer often broader perspective than health care providers (« fourth age planning »)

# A wake up call: towards social citizenship

- We can all help to reframe dementia
- We can all support and take part in community based initiatives that foster social inclusion of patients and carers
- We can all contribute to raise the awareness on legal aspects
- We can all reflect upon our own old age and entail a dialogue

« We can all contribute to a dementia-friendly society »



Thank you for your attention!

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