Ordinary or peculiar folk?
Volunteers in the End of Life Care in Czech Republic

Martina Špíková, EAPC Congress, Prague, 2013
Milestones

- **1993** the volunteer national centre established
- **1996** the first in-patient hospice in CR established
- **2001** Cesta domů established
- **2008** Czech Society for Palliative medicine established
- **2013** 15 in-patient hospices + 4 mobile hospices

There is no association of volunteers working in palliative care in CR.

**10 to 60** volunteer work in hospices in CR, training: from **2 hours up to year - long course**
100 000 people/year die in CR
75% of the population don’t want to die in hospitals and nursing homes,
75% of the population die in institutions: lonely, without their relatives, often without pain- and symptom control. Only 3% die in palliative care.
There is high „technical“ level of medicine services.. (accessibility of drugs, cutting edge equipment...)
...but

- insufficient or poor pain management
- poor or even bad communication between the physician and the patient
- patients and their families are not openly informed about their situation
- death and dying is taboo, people are afraid of speak about it
- lack of experience with dying of close ones
- lack of rituals
And that is where volunteers step in to help make the things better...
Who are these people?

Ordinary or peculiar folk?
I've asked the volunteers who work at patients' homes several questions:
For instance...

- ...how did your close ones react when you had told them you were going to work in hospice?
- ...is it easy for you to tell people around you that you work with dying people?
- ...what question was the most difficult for you to answer them?

(December 2012 – February 2013 interviews with 30 volunteers working close with families, age 25-55)
The answers

- were colourful as the volunteers are
- but in a way similar to each other

They were like a mirror which reflected the society around us.
Analogy - prophets

- were often refused because they seemed weird
- thanks to them "illness" of their age was diagnosed
- our ambivalent relationship to the prophets has much to do with what we expect to see in the mirror
Volunteers

- indicate something important about us
- show us some of the „diseases“ from the period of communist era (whatever stood apart was suspicious)
- often are considered to be peculiar
We all are in hurry...

...they have time enough
These questions help to answer:

• We are harassed and sad...
  ..... how is it that you are happy?

• We come home exhausted...
  ..... how can you work more?

• We only want to see the pretty things...
  ..... why do you want to see people die?

• We have little money...
  ..... how is it that you are doing it for free?

• After all day at work we need to recover –
  ..... how is it you don’t need it?
These questions reveal something important about our society today

We have already lived in the external freedom for two decades...
...but internal freedom which help us to be ordinary people is still missing
Volunteers in palliative care

are helpful, brave, nice and admirable people

but also silent builders of inner freedom

and so the people who enrich our society.

Ordinary folk.
...thank you