

END OF LIFE CARE: SOME REFLECTIONS FROM A PATIENT PERSPECTIVE

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“A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE”



About the European Patients' Forum



- European Patients' Forum
 - Umbrella organisation
 - Active since 2003
 - Independent & non-governmental
 - EU patients' voice across disease-areas



- Our members
 - 74 patient organisations, both disease-specific at EU-level and national coalitions



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Mission and vision



Our Vision!

“All patients in the EU have equitable access to **high quality, patient-centred** health and social care.”



Our Mission!

“To ensure that the patient community drives health policies and programmes that affect them.”

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EPF and end of life care?



- EPF does not have an official position on this
- This presentation: raising some issues, conveying thoughts for reflection



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Unmet needs



- End of life is not only relevant for old people
- What matters to patients: Quality of life (but each individual is different)
- Access: is appropriate care, e.g. Hospice available for all? Are best practices in end of life care applied everywhere? Not the case currently
- Pain medication for children = specific issue ?
- Staff shortages / expertise – lacking in both respects in many settings – how can we expect staff to practise person-centred, compassionate care if they are themselves burned out, or lack expertise in EOL care?

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Patient empowerment: what it is and what it is not



- Empowerment is “a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important” – also at political/policy level
- The process manifests itself in the interaction between patient and system (people, structures...)
- It enables people to make meaningful choices – and to get involved to the extent they wish (desire to opt out of decision-making also needs to be respected)
- No-one is beyond empowerment, though some people may need more support
- Empowerment is not about turning patients into “health consumers”

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The importance of dignity

EPF European Patients Forum

Empowerment charter

- EPF Charter, point 1:
 “I am more than my health condition.”
 - Healthcare is fundamentally about human interactions. Being treated with respect, dignity and compassion, and being seen as a human being... is the starting point of empowerment.
- EPF survey on quality of care (2016) also strongly highlighted this aspect
 - Being listened to and taken seriously; the experts’ first question should be to ask what matters to you – and take that as their guidance

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The importance of dignity

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Empowerment charter

- EPF charter, point 3: I am an equal partner in all decisions related to my health
 - Partnership – shared decision-making is absolutely fundamental – and this includes discussing the goals together, planning together and reviewing plans
 - Relationship should be based on mutual respect, information sharing and engagement in a dialogue about treatment preferences but also patients’ values and priorities

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Examples from our members

EPF European Patients Forum

National Voices “Every moment counts” – narrative

(recommendations for person-centred, coordinated care at end of life – complements general person-centred care recommendations)

Five domains:

- “We work for my goals and the quality of my life and death
- I have honest discussions and the chance to plan
- The people who are important to me are at the centre of my support
- My physical, emotional, spiritual and practical needs are met
- I have responsive, timely support day and night “

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The National Voices narrative

EPF European Patients Forum

Key reflections

- Professionals work in a team with me – I remain in control as much as possible
- Continuing information and explanation of unfamiliar concepts
- Preferences respected (e.g. where I want to be)
- Right to change my mind at any point
- Decide what I want – and don’t want – to happen
- I am helped to feel to feel safe, in control of my pain, comfortable, dignified, with as little fear as possible

Domains

- My goals and quality of life and death
- The people who are important to me
- Person centred coordinated care near the end of life
 “I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carers!”
- Honest discussion and planning
- My physical, emotional, spiritual and practical needs
- Responsive and timely support

www.nationalvoices.org.uk

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Examples from our members

EPF European Patients Forum

Alzheimer Europe Position on use of advance directives

- AE supports use of advance directives for wide range of decisions – treatment, care, welfare, research, appointing proxies...
- AE supports concept of healthcare proxies and calls for legal frameworks and appropriate safeguards for their involvement
- Difficulty of having right level of precision (neither too vague nor too specific) → encourage people to write statements of values
- AE outlines certain criteria for validity of advance directives
- Patient’s wishes should always be ascertained – even when there is an advance directive
- Need to increase availability and quality of palliative care/services/facilities

More info: <http://www.alzheimer-europe.org>

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Communication patient/family & professionals

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- Medical professionals need to shift to a shared decision-making approach – this requires specific communication skills and attitudinal change but also resources
- With patient and also the family
- Important to accept and discuss uncertainty (e.g. treatment outcomes): patients are often more accepting of uncertainty than professionals realise
- For the patient it is essential to have a conversation and “to be heard”
- Other HCP besides doctors can have a valuable role to play here (e.g. due to lack of time) but doctors’ attitude is key


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Concluding remarks




Human relationships are at the core of healthcare

- Patients want to be seen as a person, not only a diagnosis or number or a case
- Empathy and respect are key
- Holistic approach means attention to psychological, emotional social, mental and family aspects of illness together with the physical aspects
- End of life care is not as well developed as it could be – important gaps and inequities => our role
- Services need to be co-created with patients and families as partners




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From doing “to”... to doing “with”




“Patient-centred care”...



... change in medical culture
“Patient-driven care”?

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“to define the liberty of all,
not to mandate our own moral code”

U.S. Supreme Court
in
Planned Parenthood of Southeastern Pennsylvania v. Casey

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THANK YOU

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