Ethics and assistive technologies in dementia care

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Topics of today's presentation

1. Background to Alzheimer Europe's work on ethical issues

2. A few definitions

3. Ethical issues linked to the use of AT for/by people with dementia

4. Your thoughts and feelings

1. Background:

The European Dementia Ethics Network (EDEN)

- Initially funded by the German Ministry of Health

- Steering committee set up

- Multidisciplinary working groups (2010 – 2012)

- Literature review, debate on relevant issues, report and recommendations

- Topics addressed to date: assistive technology, dementia research and restrictions of freedom

The AT working group

- Alistair Niemeijer, the Netherlands

- Cees Hertogh, the Netherlands

- Dianne Gove and Jean Georges (Alzheimer Europe)

- Heike von Lützau-Hohlbein, Germany

- Inger Hagen, Norway

- James and Maureen McKillop, Scotland

- Maria McManus, Ireland

- Luiza Spiru, Romania

- Päivi Topo, Finland

- Sirkkaliisa Heimonen, Finland

- Stefania Kapronczay, Hungary

Assistive technology

- **Assistive technology is the term used to describe devices or systems which allow people to perform tasks which they would otherwise be unable to do, or to increase the ease and safety with which tasks can be performed (Royal Commission on Long-Term Care, 1999).**

Ethics

Ethics is a branch of philosophy which seeks to address issues related to concepts of right and wrong. It is sometimes referred to as moral philosophy.

Ethical theories

1. **Utilitarianism: the greatest happiness for the greatest number of people**
2. **Deontological: Consistent with moral rules & principles**
3. **Virtue ethics: Emphasises character of the moral agent**
4. **Particularism: Related to specific culture or individual choice**
5. **Egalitarianism: Fair procedures in problem solving**
6. **Liberalism: Equal access to rights but also to duties**
7. **Personalism: Promoting and enhancing the good of the individual**
8. **Individualism/subjectivism: Proceed as one believes appropriate using one's own judgement**
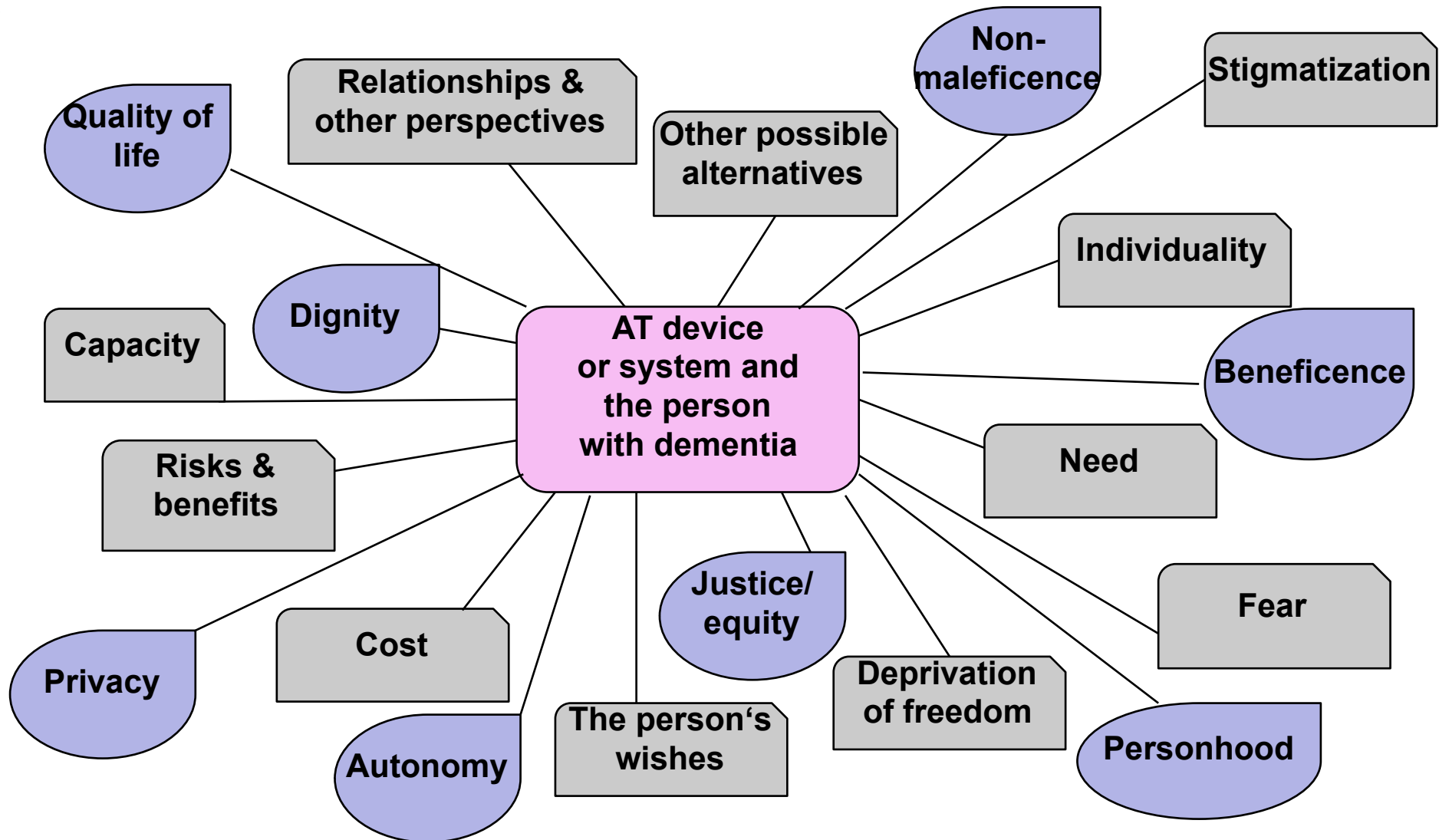
Ethical principles

Expressions of agreed values which serve to guide people's actions in order to achieve the best possible ethical outcome, thereby encouraging people to consider the broader context and respect other people rather than being preoccupied with their own interests
(State of Victoria, 2006)

Moral principles and the codes which spell out their applications can only be guidelines for thinking about the decisions individuals need to make in specific cases.
(British Psychological Society, 2009)

3. Ethical issues linked to the ethical use of assistive technology

Example 1: Tracking and surveillance devices or systems

- tracking devices

- tagging devices

- access control systems

- movement detectors

- video monitoring

Related ethical issues

a) Balancing autonomy, freedom and safety

b) Respecting personhood and dignity /avoiding
    devaluation and stigmatization

c) Proportionality, privacy and confidentiality

a) Balancing autonomy, freedom and safety

- Beneficence
- Desire to maximise freedom
- Freedom to decide where to walk
- Freedom to decide when to go somewhere
- Quality of life (exercise, social contact, self-esteem etc.)
- Aimed at providing a safe environment

Versus

- Nonmaleficence
- Desire to protect/minimise risk
- Loss of freedom of movement
- Loss of the right to choose
- Increased dependency
- Frustration
- Social control/coercion
- Concerns about litigation in case of harm

a few points to consider….

- Allowing for some degree of risk
- Communicating with all concerned
- Appropriate and timely use of AT
- Addressing staff shortages
- Obtaining consent or assent
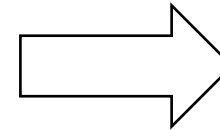
more about consent….

- Shared decision making, involving people with dementia, carers and health and social care/service providers.
- Necessity to seek consent irrespective of the complexity of the technology or stage of disease.
- Capacity to consent should be considered as being separate from other forms of consent.
- In case of incapacity, the consent of his/her carer or legal representative should be sought.
- Necessity to consider past , current, presumed or known wishes/preferences of person with dementia.
- In case of incapacity, the assent of the person with dementia should be sought and s/he should be kept informed of any further decisions made.

b) Respecting personhood and avoiding devaluation and discrimination

- **Labelling**
- **Stereotyping**
- **Separating "us" from "them"**
- **Loss of status**
- **Discrimination**
- **Power relations**
- **Emotional reactions**

(Conceptualization of stigma of Link and Phelan, 2001; 2006)

The importance of meaning

a few points to consider…

The importance of:

- how people make sense of the device
- how people feel about the use of the device
- the visual aspect of the device of system
- its concealability
- control/the exercise of power
- how staff respond to alerts/signals
- attitudes towards users
- respecting all residents

c) Proportionality, dignity, privacy and confidentiality

- **Proportionality/justification**
- **Drawing attention to deficiencies/dignity**
- **Privacy**
- **Confidentiality**

Example 2: AT for recreation, interaction and well-being

- – socially assistive robotics

- – devices/tools to facilitate social
  interaction and promote autonomy

- – computerized leisure activities

Possible ethical implications

AT for recreation, interaction and well-being

- Quality of life
- Safety
- Autonomy
- Attachment
- Dignity

4. And now over to you.

In your opinion...

Alzheimer Europe

- What are the most important ethical issues linked to the use of tracking and surveillance technology?

- Which measures should be taken to ensure that tracking and surveillance technology is used in an ethical manner?

The lady and the seal cub

A robotic animal with the capacity to respond to human touch and recognise familiar voices was introduced into a nursing home. One of the residents adored it and interacted a lot with it. Before she had been very withdrawn and apathetic but the animal also helped staff to interact with her.

Her son was horrified. He felt that it was demeaning for her to behave in such a way and that staff were not respecting her dignity. Staff felt that she had become much happier since the introduction of the robotic animal and that it gave her a feeling of being needed.

What are your views on the use of this kind of assistive technology with people with dementia?

Thank you for your attention