

# Technology, Ethics and Dementia

A guidebook on how to apply technology in dementia care

Written by partners in the EU Biomed II project  
Technology, Ethics and Dementia

*Edited by Sidsel Bjørneby, Päivi Topo and Torhild Holthe*

Norwegian Centre for Dementia Research  
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# Introduction

## **Aim, background and target groups of the Ted Guidebook**

The aim of the TED Guidebook is to give practitioners in dementia care a tool in their daily work. The intention is to help them make ethical decisions when contemplating the use of technology for people with dementia.

The TED Guidebook is based on the work of the partners in the European Union research program Biomed. II funded project TECHNOLOGY, ETHICS AND DEMENTIA (TED), 1996-99. It is edited by Sidsel Bjørneby, Human Factors Solutions, Norway, Päivi Topo, STAKES, Finland and Torhild Holthe, Norwegian Centre for Dementia Research.

The project was a Concerted Action. Multidisciplinary groups from the six countries in the TED project have worked in the project, and shared their experience, research and discussions in the meetings.

### *Project co-ordinator:*

Richard Pieper, University of Bamberg, Germany

### *Project participants:*

- Mauro Colombo and Silvia Vitali, Geriatric Institute Camillo Golgi, Abbiategrasso. II.P.P.A.B. of Milano. Italy
- Päivi Topo, Marjo Rauhala and Anja Leppo, National Research and Development Centre for Welfare and Health, (STAKES) Finland
- Outi Mäki and Marja Jylhä, University of Tampere, Finland
- Professor Mary Marshall, Dementia Services Development Centre, University of Stirling, Scotland
- Murna Downs, Centre for Social Research on Dementia, University of Stirling, Scotland
- Steven Bonner, Edinvar Housing Association, Edinburgh, Scotland

- Marij Sweep and Ad van Berlo, Eindhoven University of Technology, The Netherlands
- Erwin Riederer, Institute for Communications Engineering, München, Germany
- Arnfinn Eek and Torhild Holthe, Norwegian Centre for Dementia Research, Sem, Norway
- Sidsel Bjørneby, Human Factors Solutions, Oslo, Norway

The target groups of the TED guidebook are the carers, intermediaries, therapists, relatives or others who are in the position of having the responsibility of helping people with dementia to achieve a better quality of life. Personal contact and adapted environment are the most important and accepted ways of improving the daily life of people with dementia. Acknowledging this fact, the project has been discussing whether technology can supplement personal care to some extent, if it is used in a way that systematically takes ethical dilemmas into consideration and makes decisions accordingly.

The guidebook may also help designers and producers of technology to understand the impact of technology on the situation of people with dementia, and their formal and informal carers.

### **How to use the guidebook**

Consider the TED guidebook as a support for the difficult procedures of discussing, choosing and implementing technology for people with dementia. There are several ways to implement technology. In this book we have tried to outline the ethical dilemmas that formal and informal carers experience, that may call for procedural guidelines.

The guidebook has some chapters with general information about people with dementia and some relevant background information. Chapter 2. represents the main contents of the guidebook. It goes through the steps in the decision process, whether to use a technology or not and how to use it. We advise the reader to focus on this chapter, and use the other chapters as support information. The other chapters can be read as baselines and additional information when going through the steps.

Chapter 2, Steps in the decision process, suggests nine steps to follow. At each step there is a suggestion of what to do on one page, and on the opposite page there is background information and references that can support the decision process.

## CHAPTER 2

# Steps in the decision process

### **General introduction to the steps**

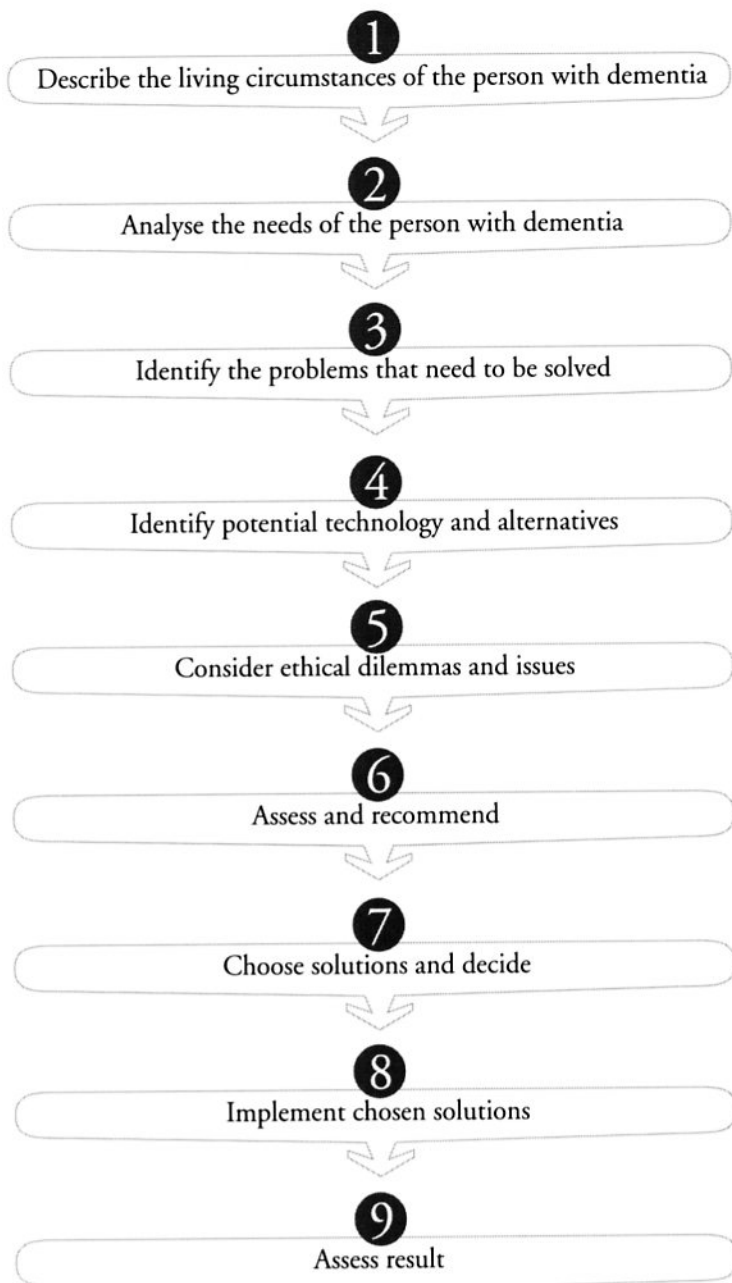
The steps are intended to guide practitioners in the process of deciding whether technology can supplement the care of people with dementia to improve the quality of life of this person, as well as the formal and informal carers involved in his/her daily life.

The procedures described by the steps in this chapter are what the partners in the TED project recommend from their experience. But we emphasise that there are several solutions to working with these issues, the situation will most likely be different for each person with dementia, therefore each intermediary helper must find appropriate procedures.

At each step there will be various professional or supporting persons involved, but the main issue is not to forget to respect the opinions of the person with dementia through the entire process.

Each step has recommended actions and some background information and advice on the opposite page.

## THE STEPS IN THE DECISION PROCESS



## STEP 1

### Describe the living situation of the person with dementia

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It is necessary to get an impression of how a person's living situation is in order to understand the needs and problems that may occur as the dementia develops further.

*Examples of questions to analyse:*

- Does he/she live alone or with somebody else?
- What is the person's social network and support?
- What is the availability of services, from whom does she/ he get help and support?
- Does he/she live in an individual house or group setting or in a nursing home?
- Is he/she planning to or going to move to another home?
- Aspects of the house that need changing?

## STEP 2

### Analyse the individual needs of the person with dementia



Emphasise needs, not problems!

- First try to get a clear and fresh view of the situation and the attitudes of the person with dementia.
- The analysis should aim at supporting the good things in his/her life
- There are several ready made scales to assess the situation of a person with dementia and her/his needs, even though most of them are more problem oriented than needs oriented.
- The result of the analysis should end up with a systematic description of the needs in his/her daily life.

## STEP 3

### Identify the problems that need to be solved

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- Try to describe the problem and situation as completely as possible.
  - What happens?
  - Under what kind of circumstances does it happen?
  - When does it happen?
  - How often?
  - Why do you think it happens?
  - Which people are involved?
- Define individual functional requirements
- Always put emphasis on quality of life
- Do not overestimate problems, only what has an impact on quality of life
- Define possible conflict of interest between the person with dementia, care givers, family members and other actors involved.
- As a result, specify the goals of the person with dementia, and formal and informal carers

Do not be too eager to identify and solve another person's problems. It is very important to gather information about the situation first. This makes it possible to describe the situation. Without enough information it is not sensible to think about solutions. It is important to be able to point out the exact problem - and not the wrong problem or idea of the problem. It happens too often that caregivers are trying to solve a problem without knowing what the actual problem is. If you are not able to answer the questions above, there is no sense in trying to solve the problem.



## STEP 4

### Identify appropriate technology and alternatives



- Perform this step according to the issues and functional requirements described in Chapter 6 and the goals from previous step.
- It is vital not to become too eager at suggesting technology. To this user group technology is probably not very familiar, and confusion can easily occur.
- The technology should preferably be unobtrusive or not visible, to avoid confusion and errors in use.
- It is necessary to distinguish between technology to improve safety and security, for example passive alarms, and technology to improve the person's mood or own abilities to manage activities in a daily life.

Technology must always be seen only as a supplement to housing adaptations and personal care, never as an isolated solution; it must always be discussed and used in a social context.

## STEP 5

### Discuss ethical dilemmas and issues around potential technology and alternative solutions

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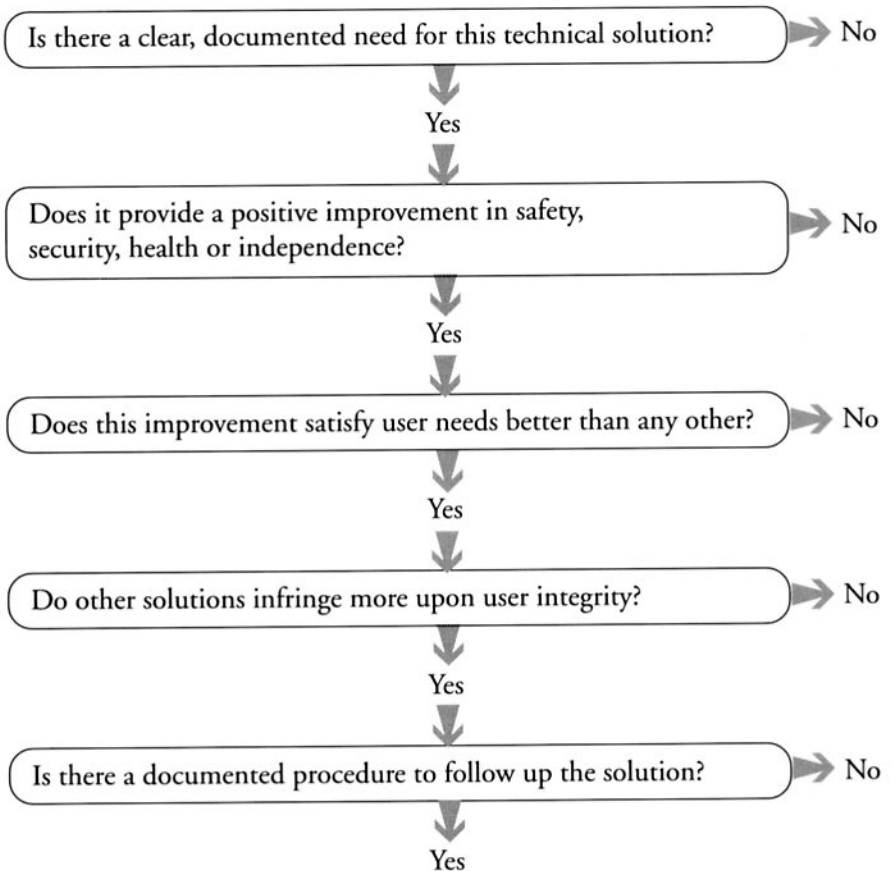
- Identify the responsible person in charge of the discussion
- Identify the alternatives to technology for each problem and goal, and discuss the ethics of those as well as of the technology. This is necessary because technology may be more or less ethical to use in relation to other solutions, like for example locking the door or medicating a person with dementia to keep her/him passive.
- Identify quality assurance and who is responsible for it (laws and regulations) in your country or region.
- Assess availability of technological and other solutions (costs, who pays them and so on)
- Consider the non-intrusiveness of the potential technology
- Ask “uncomfortable” questions about one’s own and other persons motives
- Take time to consider and reconsider
- The process should result in a basis for evaluation and recommendations

## STEP 6

### Assess and recommend technology

Once you have decided that technology use may be a good idea, *each particular technology* must be assessed according to the goals and needs of the person with dementia and the others involved in his/her life and care:

If you can answer YES to all these questions, you may recommend the technological solution to be chosen by appropriate persons. If any of the answers is NO, you should not use the technology.



## STEP 7

### Choose solutions and decide

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This is done after evaluating the ethical issues. In many cases there is no need to perform such a thorough ethical procedure, because there is no surveillance or other discussible aspects in the technology being suggested, however, the ethical issues should always be considered to some extent.

The persons involved in the choice situation are:

- The person with dementia (or by proxy decision makers or power of attorney)
- The informal carer/s
- The formal carer/s

In order to achieve informed consent or nonconsent, effort must be made to inform all the functions, implications and pros and cons of the technology solution.

- Respect nonconsent and discuss implications of alternative solutions.
- Discuss “ombudsman” possibilities and reconsideration possibilities.
- If possible, have a signed contract about which solutions are chosen and by whom.
- Decide who is responsible for the quality and reconsideration of the decisions.
- Some decisions have legal aspects, for example the issue of informed consent, others have merely ethical aspects, like the issue of beneficence.

## STEP 8

# Implement the chosen solutions



Before implementing the chosen solutions ask

- Who is in charge of the quality assurance in relation to the goals?
  - Supervising the installers?
  - Testing and approving finished installation?
  
- Who is responsible for the information/ teaching of the person with dementia and informal and formal carers?

In the implementation process “hands on experience” is essential for all the different users, and emphasis must be made that they understand functions and have access to simple, good manuals.

- Identify clear responsibility for maintenance and service

Identify the responsible persons close to the person with dementia and responsible persons at the supplier and installer.

- Make a written contract about who does it, how soon and who pays for repairs and periodic maintenance.

## STEP 9

### Assess result

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It is always necessary to assess the effects of implementing technology into the life of people with dementia. Many of the same assessment tools that are used when assessing the recommended technology can be used, but the same questions may give different answers after a while than before implementation.

- Assessment must be done in relation to
  - ethical issues
  - usability (how easy is it to use the technology)
  - utility (how useful is it)
  - acceptability (is the solution acceptable by the persons using it and as cost benefit)
  - how easy is maintenance
- Did the solution really meet the needs identified?
- What are the conclusions of the assessment and if adjustments must be done, who does what and who pays?
- Assessment in relation to the goals should be done within a month, and adjustments if necessary.
- Assessment should be done on a regular basis, and when changes or problems occur
- Assessment must be done in relation to the principles of good practice.