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# Guidance to Activity in Dementia Care

A checklist and design guide to promote  
enjoyable activity for people with dementia



# Contents

<b>Overview and instructions for use</b>	<b>2</b>
<b>Checklist headings</b>	<b>6</b>
<b>Information about the research</b>	<b>7</b>
<b>Guidance for ethical use of technology in dementia care</b>	<b>8</b>
<b>References and resources</b>	<b>10</b>

## **The Checklists**

1. Social
  - 1.1 Personal, intimate or private exchange
  - 1.2 Space for personal conversation - interaction among good friends
  - 1.3 Space for socialising - interaction among acquaintances
  - 1.4 Social gatherings, parties
  - 1.5 Dining
  - 1.6 Social exchange in the community
2. Entertainment, communication
  - 2.1 One or two people using entertainment media – e.g. radio, music player
  - 2.2 One or two people using a computer screen to communicate
  - 2.3 Group entertainment
3. Work/hobby
  - 3.1 Seated in a chair (reading, knitting, crosswords)
  - 3.2 Seated at a table/desk (writing, drawing, jigsaws, board games)
  - 3.3 Computing
  - 3.4 Dance, exercise, physical activity, Tai Chi
  - 3.5 Creative activity (art, modelling, sculpting)
  - 3.6 Creative activity (music)
  - 3.7 Housekeeping (cleaning, dusting, laundry)
  - 3.8 Cooking and baking
4. Natural world
5. Spirit and aspiration
  - 5.1 Meditation, contemplation, prayer alone or with another
  - 5.2 Religious or spiritual practice in a group
6. Circulation

## **Key Space Requirements for Activities in Dementia Care**

## Overview and instructions for use

### ***What is it?***

*Guidance to Activity in Dementia Care* is a tool designed to help people with dementia continue to enjoy activities. It is a series of checklists identifying the things that need to happen in order for people to experience fulfilment or pleasure. The checklists are questions about the person themselves, their social and care support and their physical environment. What *Guidance* can do is find out why activities are not occurring or increase the likelihood of success for an activity before it is attempted. It can also be used as a design guide to create more enabling environments. Because it is evidence-based, it can be used to promote good practice in dementia care.

### ***Why is it necessary?***

People with dementia should be able to participate in activities that are meaningful and enjoyable, bring happiness and make life worth living, but for many reasons they may be unable to do things that once brought them pleasure, like playing music or going for a walk. The reasons may derive from the person themselves, their care provision and support, or the physical environment. Individually these barriers to activity may seem trivial, but cumulatively they may prevent activity taking place. The evidence suggests that many people with dementia have low levels of participation. By identifying the needs and barriers to activity *Guidance* can help caregivers produce more stimulating environments.

### ***Who is it for?***

*Guidance* is designed to be used by people who care for people with dementia (both family and professional caregivers). It may be useful for as care managers, design professionals, commissioners of buildings and services, policy makers and others involved in dementia care environments.

### ***Where does it work?***

*Guidance* can be used for people living in private homes, sheltered housing or care homes.

### ***How does it work?***

*Guidance* was developed during the INDEPENDENT research project (see below) involving people with dementia and their caregivers. *Guidance* starts by analysing the needs of the individual person, to establish whether a particular activity would be appropriate for them. Social factors affect activities, so *Guidance* considers the person's care, support and culture. Physical factors have an impact on activities, so *Guidance* includes questions about the physical environment, for example furniture, room size, lighting, acoustics and access. When the obstacles to participation have been identified it is hoped that caregivers will be able to

use their insight and imagination to remove them if possible to produce more enabling environments where the design actually prompts interaction.

### ***What about ethics?***

The ethical considerations associated with using technology to support activity by and for people with dementia are summarised in the next section.

### **How Guidance to Activity in Dementia Care is organised**

*Guidance* is organised around six kinds of activity and the places where they happen. The activities covered were identified by people with dementia and their carers as things they most enjoyed doing. The six activities and the places where they happen are referred to as *archetypes*. The idea of an archetypal environment is one that is easy to recognise and understand from its physical design and from the activities that take place within it. For example, if you visit a church or a school, or a hairdresser, it's obvious from the physical design of such places – as well as the social interactions that take place in them – what sort of activities you might expect to happen there. The archetype is a powerful concept when planning for a person with dementia because it is related to long term memories and experience; archetypal environments provide a spectrum of information about the purpose of the space. Here are the 6 thematic areas with examples of activities that might occur in them:

#### **Thematic areas & Checklist**

##### **1 - Social**

- 1.1 Personal, intimate or private exchange
- 1.2 Space for personal conversation – interaction among good friends
- 1.3 Socialising – interaction among acquaintances
- 1.4 Social gatherings, parties
- 1.5 Dining
- 1.6 Social exchange in the community

##### **2 - Entertainment & Communication**

- 2.1 One or two people using entertainment media – e.g. radio, music player
- 2.2 One or two people using a computer screen to communicate
- 2.3 Group entertainment

##### **3 - Work, Hobby & Physical**

- 3.1 Seated in a chair (reading, knitting, crosswords)
- 3.2 Seated at a table/desk (writing, drawing, jigsaws, board games)
- 3.3 Computing
- 3.4 Dance, exercise, physical activity, Tai Chi
- 3.5 Creative activity (art, modelling, sculpting)
- 3.6 Creative activity (music)
- 3.7 Housekeeping (cleaning, dusting, laundry)
- 3.8 Cooking and baking

##### **4 - Natural World**

##### **5 - Spirit & Aspiration**

- 5.1 Meditation, contemplation, prayer alone or with another
- 5.2 Religious or spiritual practice in a group

##### **6 – Circulation (moving around)**

The checklists contain a series of questions about both the social and the physical environment to help you find out how ideal the environment is for a certain type of activity. The environment means both the building, and the physical space surrounding someone, and also the social environment – the way people interact with one another within this physical

space. The questions are grouped into those that are about the person and those that are about the place. This division into people and place reminds us that the environment surrounding the person with dementia is both social and physical, and his or her ability to enjoy activities depends on support from both.

Answering these questions may indicate how inclined a person is towards participating in activities and will help you understand if there are any obstacles in the environment of a person living with dementia that prevent them from doing things that perhaps they may previously have enjoyed, or might enjoy now.

Person questions are about the person with dementia (for example their personality, interests, dexterity and eyesight) and their care, support and culture, for instance friends, neighbourhood, community, peer group or care plans.

Place questions are about physical aspects such as the size of the space, furniture, storage, the design of the outdoor spaces, lighting, electricity, heating, and so forth. Place questions may also relate to specific activities such as drawing, cooking, dancing, exercise, painting, knitting & embroidery, having a meal or playing music.

### How to use Guidance to Activity in Dementia Care

#### Step one

Choose the checklist which best fits the type of activity you have in mind. If the person with dementia would enjoy social interaction, then choose **Social**. If they might enjoy woodworking or painting, choose **Work, Hobby & Physical**. If they would like to stroll around the building, pick **Circulation**. To listen to live music, watch a movie or use a CD player pick **Entertainment & Communication**. The checklists often overlap, so you may need to choose more than one to adequately cover the activity. For instance, to enable social activity outdoors take a look at the checklists for **Social**, **Natural World** and **Circulation**. To enable talking on the phone or sending an email, look at both **Social** and **Entertainment & Communication**. Download the checklists you need.

#### Step two

Go through the questions on the selected checklist(s) and decide which ones are relevant. Tick (✓) if the answer is 'yes' and mark with a cross (X) if the answer is 'no'. The questions are all factors that would enable, in some way, the activity to happen for people who are still living in their own home or in residential care. However this isn't a recipe. Everybody is an individual – so all factors will not be relevant for everyone and 'no' answers will not necessarily prevent the activity from happening. But if the factors can all be answered with a 'yes' then it is more likely the person will be successful in being able to pursue this activity. To put it another way, it's more likely that the physical or social environment won't present insurmountable obstacles to the person with dementia being able to pursue the activity or take part in something.

Here's an example. In the checklist for **Knitting** there are questions about lighting:

Is there ample sunlight reaching the space where they are sitting and working?	
If not is it bright enough to see what they are doing?	
Is there task lighting?	
Does the task lighting come from overhead and one side rather than in front?	
Is there a lack of bright light coming through the window into the person's eyes?	
Are light bulbs shaded from view so the person cannot see them directly?	

Natural light improves one's ability to see and differentiate colour, so it is helpful for an activity such as knitting providing that there is no distracting glare. Sunlight is also of great benefit physiologically. So answering 'yes' to the first question would be ideal, but answering 'no' does not rule the activity out. Task lighting compensates for lack of daylight, but also makes the activity possible at any time. If the person knits near a sunny window in the afternoon, then task lighting is not essential. But you can see that one or the other needs to be 'yes'.

Guidance is not intended to be a prescriptive tool. It is still vital to use understanding, empathy, tact and common sense. The intensity of the light and the amount of heat generated by the sun will also be important factors to think about, and lighting may in some cases be irrelevant. For example, there will no doubt be people with severe visual impairments or people who are blind who can knit beautifully. It is hoped that the tool can offer a way in which you might be able to see things better from the point of view of the person living with dementia.

The **PLACE** sections of the checklists contain sub-sections about *specific* activities. So if you're looking for one of these, finish the **PERSON** section and then jump down to one of the sub-sections. For example:

### 3 - Work, Hobby & Physical

- 3.1 Seated in a chair (reading, knitting, crosswords)
- 3.2 Seated at a table/desk (writing, drawing, jigsaws, board games)
- 3.3 Computing
- 3.4 Dance, exercise, physical activity, Tai Chi
- 3.5 Creative activity (art, modelling, sculpting)
- 3.6 Creative activity (music)
- 3.7 Housekeeping (cleaning, dusting, laundry)
- 3.8 Cooking and baking

#### **Step three**

Once you have completed the checklist you will have identified potential obstacles or challenges to the activity. Few of these will make the activity impossible, but the more you can resolve, the greater the likelihood that the person with dementia will be successful in the activity.

#### **Design Professionals**

The final section *Key Space Requirements for Activities in Dementia Care* is a summary of design guidance and recommended space standards for various activities.

## Checklist headings

The lists are arranged under the following subheadings where relevant:

### The person

#### PERSON WITH DEMENTIA

Character and personality

Interests and activities

*Groups*

*Travel*

*Media*

Privacy choice and control

Psychological and emotional

Physical and medical

Accessibility and mobility

Sensory

*Sight*

*Hearing*

*Taste*

*Smell*

*Touch*

Cognitive and intuitive

#### CARE SUPPORT AND CULTURE

Caregivers

Friends and family

Neighbours

Peer group

Community

Culture

Care home

### The place

#### SPACE PROVISION

#### NEIGHBOURHOOD

Transport

Amenities

#### PERSONALISATION AND PRIVACY

#### ACCESSIBILITY AND MOBILITY

#### COGNITIVE SUPPORT

#### BUILDING INTERIOR

#### FINISHES

#### FIXTURES

Fixed furniture

Fitted units

Signage

#### FURNITURE

Chairs

Tables

#### SUPPLIES

#### STORAGE

#### EXTERNAL STRUCTURES

#### COMFORT, SUPPORT FOR THE SENSES

Vision

*Daylighting*

*Shading*

*Sky view*

*Glare*

*Artificial lighting*

*Glare*

Acoustics

*Sound quality*

*Background noise*

*Acoustic isolation*

*Sound absorption*

Heating and ventilation

#### SERVICES AND SYSTEMS

Water supply

Electrics

Phone, cable and IT

Systems and controls

#### SAFETY AND SECURITY

#### EQUIPMENT

Space provision

User needs

Accessibility & mobility

Cognitive support

Fixtures

Support for the senses

*Vision*

*Acoustics*

Technical support

Safety and security

## Information about the research

The INDEPENDENT Project has been studying the environments where people with dementia live, looking for ways that technology could assist a person to live more enjoyably. The 3 year project was funded by the Engineering and Physical Sciences Research Council (EPSRC) in the EQUAL 4 Programme. It involved the Division of Primary Care at the University of Liverpool, the Bath Institute for Medical Engineering (BIME) at the University of Bath, and the School of Architecture at the University of Sheffield in partnership with Dementia Voice, Northamptonshire County Council, Sheffcare and Huntleigh Healthcare. One aim of the project was the development of technologies to enable people to continue to participate in activities they found enjoyable, or to stimulate interest in new areas. Much of the technology developed for dementia care to date is concerned with safety, security and health monitoring. INDEPENDENT set out to look at the role of technology in improving quality of life. The project successfully developed a music player and a 'Window on the World,' as well as feasibility studies for a conversation prompter and an activities sequencer.

Valuable assistance was received during the development of the activities and ethical guidance from project partners, Occupational Therapy students Claire Power and Lineth Mutamiri at Sheffield Hallam University, and from staff and management at Springwood Residential Care Home.

## Guidance for ethical use of technology in dementia care

### **Ethical considerations**

This section summarizes the ethical issues associated with the use of assistive technology by and for people with dementia.

- It is primarily concerned with the use of technology for enjoyable activities.
- It recognises and builds upon important earlier work by others in the area of technology, ethics and dementia - for example the ASTRID project and TED.
- It reflects current legislation such as the Mental Capacity Act 2005.
- It promotes evidence-based good practice and person-centred care.

It is designed to be used by people caring for someone with dementia or anyone interested in the ethical use of technology by and for people with dementia. It suggests a set of principles, some ethical issues to consider and a process to guide the implementation of technology in the living environment of a person with dementia.

### **Principles in the use of technology by and for people with dementia:**

1. Dementia should not be seen to limit a person's access to the benefits of technology, including opportunities to explore, interact, have fun and learn new things.
2. It is important before implementing technology to consider potential impacts this may have on a person's social and physical environment.
3. For assistive technology to address a person's needs they must first be accurately identified.
4. Introducing technology into a person's life will raise a set of ethical issues. Some are predictable. Others will arise during use.
5. Ethical issues must be questioned and debated in order to reach ethical decisions.
6. Ethical use of technology is an ongoing process with steps to follow and revisit.

### **Ethical issues to consider:**

#### **Capacity**

- The person with dementia should be assumed to have capacity to make her or his own decisions, unless there is evidence to the contrary.
- Can the person be given appropriate help in making decisions?

- If the person lacks capacity to make their own decisions, and if the technology was chosen for them, is it in the best interests of the person with dementia?

### **Rights & freedoms**

- If the person lacks capacity to make decisions is the technology the least restrictive of their basic rights and freedoms?

### **Need**

- Has the person with dementia identified a need or have assumptions been made?
- Is there evidence that this technology is capable of meeting their needs?
- Can it be met in other ways, or is technology necessary?

### **Choice, freewill & consent**

- Does the technology offer the person choices or options?
- Is use of the technology offered but not insisted upon – can they decline it?
- Is consent ongoing - can they agree and then later change their mind?

### **Risk**

- Is the person at a low risk of failing when using this technology - does successful use of the technology NOT rely on having accurate short term memory?

### **Opportunity**

- Does the technology enable the person to enjoy the same opportunities as everyone else - for example voting?
- Will there be equal opportunities for others to access this technology - for example, in a communal living environment, will all persons have the same opportunity?

### **Ownership & control**

If the person is expected to use the device by physically interacting with it:

- Is it clear to them that it belongs to them and they are allowed and invited to use it?
- Is the device personalised, placed where they can touch it, and under their control?

### **Availability & sustainability**

- Will the technology continue to be available?
- Is using the technology sustainable given the human resources it may require?
- Will there be the necessary technical support?

### **Cost**

- Is there little or no cost associated with use of the technology?
- If there is a cost, is it seen as good value by those who would be paying?

### **Usability & reliability of the device**

- Is the nature and purpose of the technology understood by the person?
- Does it satisfy their needs for familiarity and aesthetics?
- Are the controls logical, intuitive and self-explanatory to the person?
- Is it safe, reliable and easy for the person to use?

## References & resources

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### Mental Capacity Act 2005

In England and Wales the Mental Capacity Act of 2005 provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. Key principles involve a presumption of capacity, the right to be supported in decision-making, best interests and least restrictive intervention. It further states that a lack of capacity cannot be established merely by reference to a condition, for instance dementia.

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*Guidance to Activity in Dementia Care* was produced by the INDEPENDENT PROJECT, an EPSRC funded consortium