

# Chapter 2

## Creating Technologies with People Who have Dementia



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### 2.1 Introduction

Dementia is a syndrome that has multiple causes, each of which produces different challenges for the individual but all of which are characterised by irreversible brain damage and progressive worsening over time. As age is the greatest risk factor for developing dementia (Prince et al. 2015) increasing life expectancy means the number of people with dementia is rising rapidly. Worldwide in 2015, 46 million people were estimated to have dementia, predicted to rise to 74.7 million by 2030 and 131.5 million by 2050, with the fastest rate of growth in low- and middle-income countries (Prince et al. 2015). There are currently no disease-modifying therapies for dementia, i.e., no medication that can stop or reverse the disease process (Mehta et al. 2017). In the past 15 years alone, over 400 drug trials have failed to deliver (Bennet 2018).

Over the course of dementia, people experience progressive decline in their cognitive abilities such as memory, attention, executive functions and aspects of language. These cognitive abilities support all aspects of our behaviour and as such their gradual erosion undermines the skills that allow people to look after themselves. For example, impaired executive functions can interfere with an individual's ability to plan, initiate and monitor activities such as shopping, cooking, route planning and driving. In some types of dementia, it is the behavioural changes that are most

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noticeable. These cognitive and behavioural changes unsurprisingly interfere with an individual's independence and autonomy, and they increasingly turn to other people for support, primarily family members (Prince et al. 2016). In the UK, recent estimates value the unpaid support provided by families at approximately £17.4bn per annum, accounting for two-thirds of the total estimated cost of dementia of £26.3bn, which includes loss of productivity from family members giving up work to look after a relative, (Prince et al. 2015). In the US in 2016, 18.2 billion hours of unpaid support were provided to people with dementia, valued at \$230.1 billion (Alzheimer's Association 2017). Worldwide, the total global estimated cost of dementia in 2015 was US\$818 billion, predicted to rise to one trillion US dollars by 2018, equivalent to the 18th largest economy in the world (Prince et al. 2015).

The growing numbers of people living with dementia puts the current model under the spotlight as more countries around the world look for ways to respond. The rising costs, mounting pressures on healthcare systems and lack of medications suggest we need new approaches to dementia.

## 2.2 Current Context

At present dementia is primarily viewed through a clinical-lens, i.e., that dementia is a clinical issue and thus requires clinically-based responses. This has pros and cons for individuals who have dementia. The major benefit is a diagnosis, a label which provides an explanation for the changes in cognition and behaviour that a person is experiencing. Knowing that these changes have a cause (neurological disorder) and a name (dementia or Alzheimer's disease for example) brings relief to individuals and their families (Dubois et al. 2016). In addition, a diagnosis can help people to access services and clarify their wishes for the future. However, the majority of people with dementia across the world do not have a diagnosis as recent estimates suggest that only 20–50% of cases are documented in high-income countries, with a much lower percentage in low-to middle-income countries, which have far fewer resources and specialized services (Prince et al. 2015). Other barriers to receiving a diagnosis include “stigma, suicide risk, lack of training, diagnostic uncertainty...and the reluctance of healthcare providers to make a diagnosis when no effective disease-modifying options are available” (Dubois et al. 2016, p. 617).

This latter point is especially telling as many countries are currently focusing their public health efforts on increasing diagnostic (memory clinic) services. For most people, a medical diagnosis is usually accompanied by some form of medical treatment. In dementia there are very few options available for healthcare providers, especially for the less common types of dementia. As stated above, there are no drugs to reverse or cure any type of dementia. The only available medications—acetylcholinesterase (AChE) inhibitors—target Alzheimer's disease, aim to bring symptomatic relief, benefit approximately 50% of people, have only modest impacts (small gains in cognition or activities of daily life or no change), which last for a short (up to 12 months) period of time (Wattmo et al. 2012). There

are no medications specifically for the other causes of dementia although people with vascular dementia may be offered drugs that target cardiovascular risk factors, such as high blood, pressure, high cholesterol and blood clotting.

In the absence of medication there is also a lack of nonpharmacological interventions. In the UK, the National Institute of Health and Clinical Excellence (NICE) recommends that people be offered group cognitive stimulation therapy (CST) and additionally, group reminiscence and cognitive rehabilitation “be considered” (<https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#interventions-to-promote-cognition-independence-and-wellbeing>). The most common version of CST lasts for 14 sessions and is offered shortly after diagnosis. This leaves people with dementia to manage as best they can, often over many years, with little or no input from health services, except for dealing with comorbid health conditions or when crises occur.

What is missing are practical solutions to enable people to live day to day with dementia. This means being able to continue with their daily activities for as long as possible and to minimise or delay placing demands on their families or formal services. To achieve these aims, we need to work with people who are living with dementia to identify the things they wish to keep doing and co-create solutions that work for them, in a similar way to efforts for empowering people with developmental conditions such as autism spectrum disorders (Huijnen et al. 2017) or Down’s syndrome (Augusto et al. 2016). A recent scoping review (Lindqvist et al. 2016) identified several factors important to people living with dementia in relation to activities they want to keep doing. These include activities that convey social values and wellbeing through staying connected to friends or social activities such as dancing or other hobbies; activities that support significant roles such as being a good host or a sociable person; activities that reduce demands on others to avoid being a burden; and activities that increase health and safety, such as getting around safely in the local environs (Lindqvist et al. 2016). However, another recent study found that 99% of people living at home with dementia had at least one or more unmet needs, including managing other health conditions, safety at home and outdoors, opportunities for meaningful activities, and assistance with day to day activities (Black et al. 2013). As such there is huge potential for developing new approaches to empower people to live well with dementia.

## 2.3 Technology for Dementia

Technology has the potential to bring about the required step-change in how we think about and approach dementia. This means expanding our view beyond dementia as a clinical condition limited to what medical services can offer. People who are living with dementia must be valued as fellow citizens, whose needs, wishes and desires are as important as everyone else’s, not dehumanized as a list of symptoms or problems that have to be solved. For too long the bulk of technology developments have been doing things ‘to’ or ‘for’ people who have dementia (Astell 2006). Most technology

solutions have focused on the issues prioritised by caregivers, particularly safety and security. For example, the use of wearable sensors to track people with dementia in and out of the home (Landau and Werner 2012) or installation of sensors in their homes to monitor their behaviour (Karakosta et al. 2015). While outdoor navigation and safe use of appliances are a concern for many people who have dementia, these specific issues have been the focus of much technology development as they are frequently the aspects of supporting a relative with dementia that families find most challenging. As such, much technology development to date has focused more on meeting the needs and wishes of family caregivers, or organisations, and working with them, than with the individuals who have dementia.

Whilst these efforts are usually well-intentioned, they often present ethical issues relating to decision-making, privacy, data sharing, etc., (see for example discussion of the use Robotic carers with people with dementia: Felzmann et al. 2015; and GPS tagging of people with dementia: Landau and Werner 2012). Working primarily with caregivers also reflects a paternalistic approach to people living with dementia. This stems from the prevalent ‘deficit’ model of dementia whereby people with dementia are considered less able to participate than other members of society due to the changes they experience in their cognitive and behavioural abilities. Caregivers on the other hand are able to articulate their needs and concerns. This results in many projects focusing on caregiver needs, in part because they are perceived as ‘easier’ to work with. In addition, there has been a long-tradition of treating family members as proxies for people with dementia. However, the extensive literature on family caregivers clearly demonstrates they have their own, separate needs, wishes and desires. Whilst these may overlap with those of their relatives with dementia, these must be approached as two separate sets of user requirements. Additionally, formal caregivers have a third set of needs in relation to dementia.

The negative perception and low expectations of people with dementia are very powerful and can be found everywhere in the copious descriptions of what people are unable to do, their limitations and inabilities relative to people who do not have dementia. The consequence is that people with dementia are continuously excessively disabled by the attitudes and reactions of other people and the environment in which they operate (Astell 2013). This means that they are frequently not included in decisions, have interventions secreted (e.g. sewing sensors into their clothing) or imposed (e.g. disabling the cooker) on them and are treated as objects to be ‘managed’.

Unsurprisingly, it is still very unusual for people with dementia to be included in research projects or development of technologies in their own right. This situation is not unique to dementia, as other commentators have pointed out similar attitudes in development of technologies to ‘disadvantaged’ populations in general (Rogers and Marsden 2013). Rogers and Marsden (2013) named this the “rhetoric of compassion”, which they argue has dominated the HCI field in respect of groups deemed to “need help”, including people living with dementia, and those with vision loss, mobility challenges, and developmental delays. To address this rhetoric, Rogers and Marsden propose a “hand-over” (p. 54) model that extends user-centred and participatory design methods to ones that empower people to be fully engaged at all stages of the process.

To achieve this demands that we stop thinking in terms of “deficit and compensation”, especially in respect of ageing and people with age-related changes, which has traditionally been framed as “a problem that can be managed by technology” (Vines et al. 2015, p. 39:1). As indicated above, the ‘managing a problem’ focus tends to reflect the views of people—service providers or family caregivers—who are actually articulating their own problems or priorities. Moving away from this dominance creates some very interesting design challenges for people living with dementia as they undoubtedly experience decline in abilities compared to previous levels of functioning. However, people with dementia cannot only participate as partners in research (Astell et al. 2009, 2014), they are developing their own solutions to enable them to live as well as possible with dementia. For example, at a recent public event I hosted looking at the functionality of current smart devices, one of the attendees with dementia spontaneously demonstrated the apps he uses on his smartphone and how he utilises the calendar function to carry out all activities and appointments he has planned.

As this example indicates there are existing devices and functionality that could benefit people with dementia right now. To be successfully applied and adopted, we need to recognise and address the cognitive-behavioural aspects of everyday life where people with dementia could benefit. That is, we need responses that not only recognise the cognitive-behavioural components of each of the dementia subtypes—which are differentiated by their cognitive and/or behavioural features—but can compensate for or mitigate the impairments associated with them to provide a way for people to keep carrying out desired and meaningful activities. This means understanding the cognitive and behavioural elements of activities people wish to continue and providing interventions to enable people to keep carrying them out (Astell 2015). As indicated above, current mainstream technology can support cognitive functions such as memory and activity planning, as well as communication, entertainment and enjoyable pastimes. Some of these devices, such as touchscreens (Jodrell and Astell 2016) and motion-detection systems (Dove and Astell 2017a) have already been shown to have applications for people with dementia. These benefits could be massively extended to reach more people with dementia and more aspects of their lives, if we look at their wants, needs and desires as collections of cognitive and behavioural challenges in need of creative solutions.

## 2.4 Reconceptualising Dementia

The first key point to changing our understanding of dementia is to comprehend that dementia is not a single entity. There are multiple causes of dementia and each of these are characterised by different effects on cognitive and behavioural function. As such people with different types of dementia can be expected to face different difficulties and require different solutions to empower them. In addition, each type of dementia leaves different aspects of cognition and behaviour relatively unaffected, and these can be leveraged to develop targeted support.

The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association 2013), uses the term ‘Neurocognitive Disorders’ (NCD) rather than dementia, to refer to a range of conditions including delirium, Mild Cognitive Impairment (MCI) and what was previously called dementia. The DSM-5 identifies six domains of cognitive function: executive function, learning and memory, complex attention, language, perceptual-motor, and social cognition, with different profiles of impairment corresponding to the different aetiologies of the condition (Sachdev et al. 2014). In the DSM-5 a distinction is made between mild or major levels of severity where major NCD is characterised by the cognitive impairment interfering with a person’s daily functioning. DSM-V includes 10 different specific causes: Alzheimer’s disease, Frontotemporal lobar degeneration, Lewy body disease, Vascular disease, Traumatic brain injury, Substance/medication use, HIV infection, Prion disease, Parkinson’s disease, Huntington’s disease, another medical condition, Multiple aetiologies, or Unspecified where there is no obvious cause (see Table 2.1 for main types with the major cognitive and other changes).

Estimating global prevalence of different dementia subtypes is challenging due to lack of consistency in diagnostic criteria, differences in mean population ageing and global variations in education and vascular risk factors (Rizzi et al. 2014). However, it is accepted that the most common cause of dementia is Alzheimer’s disease (AD) which is thought to account for approximately 60% of cases (Rizzi et al. 2014), although estimates vary considerably. Vascular dementia is associated with stroke or another acute event and accounts for about one-fifth of cases of dementia (Rizzi et al. 2014). However, these numbers are estimates as a considerable number of people experience cognitive challenges associated with both AD and VaD, so-called mixed dementia.

Among the less common dementia types are Dementia with Lewy Bodies (DLB) and Fronto-temporal Dementia (FTD), which commonly occur in people under 65 years of age. There are three subtypes of Frontotemporal dementia that all affect language—non-fluent aphasia, semantic dementia and logopenic aphasia, known as Primary Progressive Aphasia (Onyike and Diehl-Schmid 2013). Difficulty with speech severely limits social interactions in all sorts of situations from the workplace (PPA primarily affects people between 45 and 65 years), public transport, shopping, socialising and personal relationships. Unsurprisingly, individuals with Primary Progressive Aphasia commonly report depression, including loss of interest and social withdrawal (Medina and Weintraub 2007) as well as other behavioural changes such as irritability and apathy (Moddirousta et al. 2013). Posterior Cortical Atrophy (PCA) or Benson’s syndrome (Benson et al. 1988) is another uncommon type of dementia that occurs most often in people between 50 and 65 years of age. PCA is thought to be a variant of Alzheimer’s disease, although other underlying causes have been found in some people (Crutch et al. 2012). PCA has a distinct cognitive profile of impaired visual processing that includes difficulties judging distances, distinguishing between moving objects and stationary objects, reading a line of text, disorientation, and difficulty identifying and using common tools or objects. People with PCA have relatively well-preserved long-term memory and insight into their condition at least at the early stages (Crutch et al. 2012).

**Table 2.1** DSM-V (2013) Main causes of neurocognitive disorders

DSM neurocognitive disorder		Cognitive features	May also occur
Alzheimer’s		Progressive decline in learning and memory and at least one other cognitive domain, often executive function	Depression, apathy
Vascular		Decline in complex attention, executive function	Personality and mood changes, lack of initiative, depression, and emotional lability
Frontotemporal—frontal type		Disinhibition	Major behavioural changes—apathy, inertia, loss of empathy, stereotyped or ritualistic behaviour, dietary changes
Frontotemporal—primary progressive aphasia	Nonfluent /agrammatic	Effortful, dysfluent, agrammatical speech	Depression, anxiety, agitation, apathy, irritability
	Semantic	Impaired single word comprehension	
	Logopenic	Impaired word finding and production	
Lewy body		Fluctuating cognition, attention and alertness	Visual hallucinations, REM sleep disorder, Parkinsonian movement disorder (later)
Parkinson’s disease		Changes in memory, concentration and judgment Trouble interpreting visual information Muffled speech	Apathy, mood disturbances, psychotic symptoms, personality changes and sleep problems

The patterns of cognitive impairment do not just differ across dementia subtypes, they also change over time, with some aspects of function affected early and others preserved far into the disease process. Understanding the likely patterns of change over time and the ways different cognitive domains are affected is another critical element for thinking about ways in which technology can be helpful for people with dementia. Understanding the cognitive challenges and how these change over time is also crucial for developing efficient and appropriate strategies for approaching and working alongside people with dementia as experts in their condition.

## 2.5 Creating Digital Solutions

Given the lack of current interventions and the growing numbers of people with dementia, both the opportunity and need for new approaches are huge. For those people new to this area or with technologies developed for other populations, Table 2.1 should provide inspiration for ‘things’ that could be beneficial. The need for new things (devices, services, apps) spans all dementia types, with each making a compelling case for innovative solutions. Alzheimer’s disease because of the sheer numbers but also PPA or PCA, for example, which affect fewer people, but those people are younger, usually working and often with children or other responsibilities.

In addition to creative thinking, developing effective technologies needs to take the cognitive and behavioural aspects of dementia into account, both in terms of thinking about what a digital solution could look like as well as for establishing a co-creation model with people with dementia. A number of recommendations for working collaboratively with people who have dementia (and their caregivers) can be found in a reflective article myself and colleagues wrote based on our experience over two projects using touchscreen devices (Astell et al. 2009). For people new to the field I would also add the MAREP PARTNERS guidelines<sup>1</sup> for engaging people with dementia in technology creation.

Additionally, in 2009 I also proposed the REAFF framework (see Table 2.2) to highlight key issues to consider in approaching development of technologies for people with dementia. The four REAFF—Responding, Enabling, Augmenting and Failure-Free—principles are intended to encourage thinking about the intended technology user and what they need. To these, based on further experience, I now add priorities, context and accessibility.

**Priorities.** As indicated above, much technology development to date has reflected the priorities of caregivers who tend to focus on the challenges they experience. Less is known about the priorities, needs and wishes of people with dementia, particularly when their dementia is past the early stages. Identifying their priorities aligns with the current or third wave of HCI, which embraces experience and meaning-making of the technology user(s) (Bødker 2015). User Experience (UX) has emerged as central to the design process, which requires an understanding of the individual’s motivation

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<sup>1</sup>[https://uwaterloo.ca/murray-alzheimer-research-and-education-program/sites/ca.murray-alzheimer-research-and-education-program/files/uploads/files/partners\\_guide\\_1.pdf](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/sites/ca.murray-alzheimer-research-and-education-program/files/uploads/files/partners_guide_1.pdf).



**Table 2.2** REAFF framework

Principle	Definition
Responding	Technological solution must be responsive to the needs of people with dementia
Enabling	Technological solutions must enhance the life of the person with dementia and not disable them in any way
Augmenting	Technological solutions must build on and extend the retained abilities and skills of people with dementia
Failure-free	Technological solutions must be intuitive and accessible and not undermine the confidence of a person with dementia

to use a product (Hassenzahl 2011). For too long, there has been a strong belief that people with dementia are unable to convey their priorities and motivations, hence the reliance on caregiver’s views. To examine this issue, we recruited eight couples comprising one person with dementia and their partner who lived at home together. Each couple was asked to keep a two-week log of their daily activities. From these logs we asked the individuals with dementia to select one activity that was important to them to be able to keep doing. Six couples completed the log and from these variously prioritised: independently using the television and digital programming remote controls (2 individuals), using a digital camera, taking medication, preparing a meal and hanging out laundry.

All of these activities are fairly commonplace and the sorts of activities one takes for granted in daily life. They illustrate the proposal that people with dementia prioritise activities that maintain their identity and previous roles in the family or home (Lindqvist et al. 2016). However, because they are fairly routine activities, little attention has been paid to understanding their component parts and why they might become challenging for people with dementia. One exception is Wherton and Monk’s (2010) very elegant analysis of the difficulties people with dementia face carrying out activities in the kitchen. They developed a framework based on the Action Coding System (Schwartz et al. 1991, 1995) to break down the individual steps of the tasks. This approach produced insightful and illuminating descriptions of the exact difficulties people with dementia face. Whilst this approach produced very useful information, it is labour intensive and highly individualised, limiting its scalability, but definitely recommended reading for people interested in supporting home-based activities.

At this time, innovative solutions that reflect the priorities of people with dementia are starting to emerge. One example is Read Clear—<http://www.readclear.co.uk>—a free-to-download app developed by the Cortical Posterior Atrophy Group at University College London, with people with PCA, to enable them to read books and news items. This was created specifically to address the challenges reported by people with PCA and their desire to keep reading, another routine activity that we take for

granted from an early age. Understanding what is important to people with dementia and their priorities for their everyday lives are crucial for developing technologies that they will want to use. This can be seen through work within the ‘maker movement’ in HCI (Bardzell et al. 2017), which emphasises empowerment through making. Elegant illustrations include of people with dementia creating and sharing art work (Lazar et al. 2016) and making music (Müller-Rakow and Flechtner 2017).

### 2.5.1 Context

In addition to their priorities, another crucial aspect for developing successful interventions with people who have dementia is to understand the context in which people operate. Context includes their home, the physical environment they interact with, including shops, banks, transport, etc., and their social environment, including family, friends and other important relationships. A common response to questions about implementing and maintaining technology with people who have dementia, for example, “how will they remember the login?” “will they keep it charged?” “will they remember to take it with them?” is that “the caregiver will do it!” This not only presumes the presence of at least one or more people in a caregiving role, it reveals that the technology is not really for people with dementia.

Context is central to UX but can be difficult to operationalize, particularly since the rise of mobile devices which has transformed how we operate in the world (Holtzblatt and Beyer 2017). Designing technologies that both support human activities and fulfil their motives requires techniques that can delineate a structured way of gathering (and analyzing) contextual data for interaction purposes and conveying contextual information in a useful way for interaction designers (Holtzblatt and Beyer 2017). When working with people who have dementia, this requires a focus on the way they interact within their environment and the people and objects within it. For example, we started developing CIRCA (Computer Interactive Reminiscence and Conversation Aid: Alm et al. 2004) at the suggestion of a care home manager who was concerned that families reduced the number and duration of visits to her residents as they “could not have a conversation”. The problem was initially characterised by caregivers as an inability of people with dementia to communicate efficiently. However, when the team examined the conversation context it was clear that one specific aspect of cognition—working memory—was causing the communication breakdown. Essentially working memory allows you to keep in mind what is being said long enough to process it. People with Alzheimer’s disease have a working memory difficulty and so they struggle to answer direct questions, such as “what did you have for your lunch today?” “did you see the doctor?” To support conversations CIRCA circumvented the working memory problem through a multimedia database presented on a touchscreen, with whatever was on the screen as the current topic. Working with people who have dementia using paper prototypes, wireframe mock-ups and physical objects, we iteratively developed a touchscreen interface for them to access photographs, videos and music. CIRCA was designed so that there is no need for people to remember what was previously discussed or keep track of conversational

turns and this positively improved relationships and caregiver's perceptions of people with dementia (Astell et al. 2010).

### **2.5.2 Accessibility**

As already demonstrated currently available technology can be useful to people with dementia if they know about it and how to access it—no small barrier for many people. Over the past five years my research group has hosted a number of public interactive technology workshops which includes Technology Interaction—an activity where people get to try existing technologies in their original packaging. At these workshops across the UK and Canada with different populations (i.e. not just people living with dementia), similar issues come up time and again in relation to accessing existing technology. These encompass specialised assistive devices as well as off-the-shelf items that could be beneficial. Key feedback includes lack of knowledge about available technologies (including apps, devices and web-based services) and where and how to access them (i.e., through doctor, pharmacy, electronics store, on-line, etc.); lack of opportunity to try out technologies before making purchase decisions; and lack of personal experience or skills or lack of available/accessible support to set things up and learn how to use them. These findings cut across all groups of technology users including older adults with and without age-related challenges, people of any age with vision, hearing or mobility loss and many frontline staff in services supporting these user groups.

Accessibility also includes the features of any device or application either existing or being created. Since 2010 we have been working with people with dementia in the Netherlands, UK and Canada to identify accessibility features of apps and tablets (Groenewoud et al. 2017; Jodrell and Astell 2017). This includes features of tablets that help or hinder users with dementia, such as passcodes, system updates, need to have an online account to download apps, and keeping the device charged. We have also created an app accessibility framework to test existing apps for their suitability for people with dementia (Jodrell et al. 2016). So far this has focused on gaming apps that people with dementia would like to play, including digital versions of familiar games (Astell et al. 2016). The framework addresses issues including modes of interaction of the game, app settings, design, customisation and age-appropriateness. Working with people with dementia we developed a website for people to search for games they would like to play based on our recommendations using the app evaluation framework (<https://www.actodementia.com>).

We also worked with two game studios to modify their existing apps to make them more accessible for people with dementia (Jodrell and Astell 2017). Based on our observations of people with dementia playing a familiar game (Solitaire; Mobilityware) and an unfamiliar game (Bubble Xplode™; Spooky House studio) we identified where certain features of the app were hindering people with dementia or where additional features could be added to aid them. One of the studios, Mobility Ware, launched version 4.10 of their Solitaire app on 9th November 2016 with the

notice “After working with a University in England we have added accessibility features for people with dementia” (Joddrell 2017).

As already mentioned, another aspect of accessibility relates to learning how to use technology. This applies to projects where new technologies are being created as much as when adopting existing ones. Out of the box most devices require some practice and time to be able to use them efficiently, irrespective of whether the user has dementia. To advance knowledge about this aspect of accessibility we have been working with people with dementia to look at how to empower them to use motion-based technology (MBT; Dove and Astell 2017b). From a review of the literature we identified multiple examples of motion-based technologies being used with people who have dementia. The review confirmed that people with dementia are able to learn to use MBT and these have been used for cognitive, physical and leisure activities (Dove and Astell 2017a). However, we also identified a major lack of information about how to introduce, train, and support people with dementia to use MBT.

To address this, we conducted a participant observation at a local specialised day program that used an Xbox 360 Kinect once a week as part of their weekly group activities (Dove and Astell 2017b). The participants included 23 older adults with complex needs including 16 with dementia. Through 20 weekly observations of approximately one hour each we identified the strategies the day program staff and volunteers used to introduce games to the clients, train them to play and support them to take their turns (Fig. 2.1). These included breaking the movements down into steps, verbal prompts and encouragement (Dove and Astell 2017b). Based on our observations and literature review, we then developed a 24-session group Kinect bowling activity and tested this in another adult day program for people with dementia. Eleven people played together as a group for one hour twice a week for 12 weeks (Dove and Astell 2018). We found that task breakdown, verbal prompts and encouragement enabled the participants to learn to play and the activity became so popular that the day program purchased an Xbox at the end of the project and continue to bowl twice a week.

## 2.6 Conclusions

There is a need for practical, affordable and scalable solutions to empower people to live as well as possible with dementia. To achieve this requires that we embrace dementia as a set of complex and challenging puzzles that require out of the box thinking. For example, working with people who have dementia to create their own technologies. We also need to apply creative techniques to ensure their motivations and contexts are fully appreciated, such as those employed by Rodgers (2018). Given that the different types of dementia can disrupt functioning in different ways, one approach is to focus not on the dementia as the starting point but instead to consider the activities people carry out and de-construct them into their component parts (Astell 2015). Linking these components to the specific cognitive processes and behaviours needed to carry them out should facilitate the development of interventions appropriate to different types of dementia that maximize spared abilities



**Fig. 2.1** Accessing motion-based technology

while minimizing impaired ones, i.e., creating ‘cognitive prostheses’. This is particularly important for ensuring that engineering and ICT solutions take full account of cognitive and behavioural needs of all people with dementia. This approach should also facilitate more rapid development of interventions for less common dementia subtypes. In terms of the five temporal lenses of participatory design (Saad-Sulonen et al. 2018), working with people who have dementia is invariably phasic, retrospective, prospective and long-term but most importantly it is emergent, “an in the moment, continuously unfolding phenomenon entangled with other ongoing activities” (Saad-Sulonen et al. 2018, p. 2).

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