Alzheimer Europe

Discussion paper and guidelines for the ethical use of technology for and by people with dementia

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European Working Group of People with Dementia
ALZHEIMER EUROPE

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Technology used by and for people with dementia: why this is an issue

This year's joint work by the members of the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) is about technology and dementia. The term "technology" is derived from the Greek words 'tekhne,' which means art or craft, and 'logos,' which means speech or expression. It typically refers to the application of science, technical processes, methods or knowledge to develop any kind of equipment, tool or system to make people's lives easier. We might associate technology with spaceships, smartphones and robots. However, it includes almost everything that people have been using in their daily lives for centuries from printing presses, to lawnmowers, credit cards, rainfall shower heads and speech recognition tools. This has generated significant societal progress and growth across numerous domains. On the other hand, it could also be argued that people are no longer fully free to decide whether to use technology and if so, to what extent. For better or for worse, our realities have become to some extent inextricably bound to the use of technology. It shapes our world, our values and ourselves.

Technology has the potential to assist people with dementia in certain aspects of their daily lives. It can help them overcome various obstacles and challenges, resulting not only from their impairments but also from the way that society is organised. This can include technology developed to address the specific needs associated with dementia. It can also include technology that was not developed for people with dementia but which is used by people with and without dementia. Several factors and circumstances can affect the potential positive or negative impact of various forms of technology on people with dementia and carers. For example, technology that is simple to use (like credit cards) can support and promote independence and reduce carers' potential burden. However, it can also create additional challenges. If, for example, people need to use a Personal Identification Number (PIN), they may forget it or write it down somewhere, thereby putting themselves at risk. People with dementia often have no alternative but to use technology or be excluded from some part of social, political, commercial or cultural life. This, combined with the unprecedented rate at which technology is evolving, has resulted in some groups of people feeling "left behind" or excluded from the increasingly technological society in which we now live. Technology does not, therefore, make everyone's life easier.

As dementia is a disability, it is important that appropriate modifications are made and measures taken to ensure that people with dementia have the same rights and opportunities as other members of society. Indeed, this is enshrined in the concept of "reasonable accommodation" described in the United Nations Convention on the Rights of Persons with Disabilities. This calls for all members of society to make adjustments to services and support designed for the benefit of the general public to ensure that they also meet the needs and wishes of people with disabilities. Many products, services and systems not only fail to achieve this goal but eventually become the only option. This represents structural discrimination against people with dementia. Initially, it may be targeted or indiscriminate, reflecting disregard for the needs and rights of some groups of people, based on ignorance, lack of effort or financial interests. Either way, this cannot go unchallenged.

How people with dementia and carers developed this discussion paper

In 2025, the European Working Group of People with Dementia (EWGPWD) and the European Dementia Carers Working Group (EDCWG) joined forces to explore the ethical, social and practical implications of

the use of technology by and for people with dementia, and to develop recommendations. This work builds on an extensive report developed several years ago by a multidisciplinary working group, with expertise in technology, including researchers, ethicists, people with dementia, carers and health care professionals, led by Alzheimer Europe, targeted at developers and policy makers.

This discussion paper has been developed to promote reflection, raise awareness and hopefully bring about change in relation to the development and use of technology. Members of the EWGPWD and the EDCWG singled out eight key issues that they found particularly meaningful and relevant. This could be of particular interest, for example, to developers, providers, policy makers, users and funders. The two working groups met separately in person and online, each time building on each other's work. Staff at Alzheimer Europe supported the working groups who identified the topics, debated the relevant issues, provided quotes, commented on drafts and agreed on the final text. The paper addresses a broad range of technologies. It covers the multitude of technological devices and systems that have become an integral part of our everyday lives, not just those that were developed for the specific needs and wishes of people with dementia.

The scope of this report

Technology could be divided into different categories (e.g. according to its broad purpose, its technical features, precise function, the area of life in which it is used or the target users) but with considerable overlap. In this report, a distinction is sometimes made between technology designed, adopted or adapted for use by/for people with dementia and that which is used by broader society, including people with dementia (often with no alternative available).

Technology impacts on, is impacted by and exists alongside other aspects of our lives and of society that are equally and some would argue more important. The pursuit of technological advancement, some of which is extremely valuable, should not result in neglect of other important human/societal values. Contact with nature, exercising the senses, building relationships, mutual respect, developing a more positive outlook on ageing and disability, promoting diversity, thinking about the environment and sustainability and recognising interdependency are all important. However much technology is or is becoming an integral part of society, we need to bear in mind that it does not exist in isolation from other major societal priorities. Global events can bring about widespread, rapid and unprecedented change (as happened during the COVID-19 pandemic) for which technology can provide certain solutions but also leave us stranded, and having to turn to the natural, built and human environment for solutions. We would like to draw attention to the vast and complex area of inter-related issues but acknowledge that, unfortunately, this lies beyond the scope of this report.

"Technology is great but it can't replace a hug": Recognising the value and limitations of technology

1. Technology has great potential to contribute to the quality of life of people with dementia and carers. Nevertheless, the use of technology needs to be carefully balanced with the importance of human contact, meaningful relationships, trust, respect for autonomy and other ethical challenges.

   - Technology can support people with dementia in many aspects of their daily lives, promoting their autonomy, independence, privacy and social connection, and contributing towards greater freedom of movement and/or safety. Examples include memory and communication aids, round-the-clock supervision, monitoring of movement or falls and safe management of household appliances. In this way, technology can help them to continue their lives "as is" for as long as possible.
   - It may also be experienced as an invasion of privacy and restriction of freedom, sometimes resulting in reduced social contact, social isolation and stigma.
   - Technology, however advanced, cannot fully replicate the emotional support and comfort provided by personal relationships. Therefore, it should never replace human contact and relationships as these are fundamental to well-being and quality of life.
   - Moreover, some level of trust needs to be placed in the technology (e.g. that it will function as intended and not be harmful to users) and in other people involved in its use.
   - The usefulness and value of technology is therefore often a matter of how, when, where, why and by whom it is used, and of whether this respects the wishes and needs of the person with dementia.
   - Technology can also be helpful for carers, providing them with respite, peace of mind, much needed sleep, less work or better ways of coping with or dealing with the disease. Greater insight is needed into carers' needs so that technologies can be developed to support them in their role as carer, whilst also promoting their wellbeing and health.

"The tracking system on my smartphone makes me feel safe. I can leave the house without having to worry about getting lost and I don't need someone to come along and 'hold my hand'."

"We have a tablet to make video calls. It is a big screen, the calls are set up and my husband doesn't have to do anything, just talk."

"With the debit card my husband can buy anything he needs. However, he has to trust the other person because he can't read the amount anymore. It is also good for me as the debit card expense is sent to me, wherever I am in the world."

"It is important to remember that we sometimes need to be hugged. Technology may be there but machines cannot comfort you, hold your hand or be there when you die."

“I can still use it, but for how long?”: A progressive disorder that poses specific challenges

2. Dementia affects the ability to use technology. The extent of this impact varies, depending on factors such as the stage of the disease, type of dementia and individual abilities. People have different preferences and values and everyone experiences dementia differently. Technology should therefore be accessible, appropriate and adapted to different stages of the disease, as well as to different skills, backgrounds, preferences and values.

- The cognitive and functional changes associated with dementia can have an important impact on the use of technology. This becomes more challenging as the condition progresses. Technology that requires the active involvement of users should be designed to be simple, intuitive, adaptable to varying cognitive abilities and easy to operate. Developers should also consider the need to develop more technologies that do not require an active involvement of the user (or very little) and which could be helpful or support people at the more advanced stages of dementia and people who live alone. A person’s level of digital literacy should not prevent them from using technology.
- Things like passwords, PINs, apps, QR codes, double authentication methods and a multitude of updates become increasingly problematic as dementia progresses. They rely on memory, concentration, attention, understanding instructions, managing numbers and following procedures, all of which require cognitive skills.
- We need to recognise that people’s circumstances vary. Not everyone with dementia has a carer and not every carer feels confident using technology. Technological solutions should be tailored to address the specific needs, abilities and preferences of each person. While dementia can create common challenges, each person’s experience is unique. A “one-size-fits-all” approach is not helpful. Factors such as cognitive ability, prior experience with technology, personal preferences, lifestyle and values all influence how a person interacts with and potentially benefits from technology. Individual preferences should guide the design and implementation of technological solutions, ensuring they support autonomy, dignity and meaningful engagement rather than imposing standardised solutions. Accessible, intuitive and culturally appropriate devices can help reduce barriers and promote diversity.
- Clear information and instructions, ongoing support and training, if needed, should be available for people with dementia and carers.

“I used to love computers but now I can’t use them, can’t use a mouse or multitask either, so I use a tablet now... but for how long still?”

“I find it difficult and frustrating that my wife can no longer use the remote control. It seems that technology now is not something helpful but a barrier. This worries me a lot.”

“If I had an AI assistant for travel on the bus, all I would need to do is simply ask where to get off, that’s all.”

"Who decides?": The transition of responsibility in relation to the use of technology

3. The progressive nature of dementia means that responsibility for using technology often moves from people with dementia to others. The role of carers, at all stages, should be recognised, and support and guidance provided to them when needed.

- Some technology that is initially used or controlled by people with dementia may eventually need to be managed or used by other people on their behalf.
- This sudden or gradual transition of control of the use of technology is often accompanied by a transition of decision-making responsibility to carers who may experience some degree of uncertainty or stress. In some cases, the person with dementia may be living alone, in a care home or have no close or trusted relatives/friends. Such transition would, in this case, create additional challenges.
- Some carers may find it challenging to address issues related to privacy, dignity, confidentiality, freedom of movement, risk taking, personal choice and financial cost. They may be more cautious about accepting certain risks than people with dementia, who are often more willing to balance risk against independence.
- Carers may need support to make such decisions in the absence of clear preferences or explicit consent. Sometimes decision making is exacerbated by rapidly evolving technologies and circumstances. Guidance should be provided to carers to help them come to a decision that "feels right", bearing in mind everyone potentially impacted by the decision and the broader context. Even when a person lacks the capacity to make a particular decision in a particular context about the use of technology, every effort should be made to determine and take into consideration their preferences, wishes and concerns.
- While technology might have been considered as part of advance care planning, its rapid development means that decisions about newer forms of technology cannot always be guided by previously expressed wishes.

"I am wondering about having a sensor installed on the front door. Would Mum have been ok with that? She was always a very private person and it might have bothered her. Does this threaten her dignity?"

"If we want people with dementia to use apps, they should be developed to be used by both the carer and the person with dementia, as at some point they will not be able to use them."

"At the moment, I am using this digital reminder and it is really good, but at some point, I may not be able to change or add a new reminder. Who will do this for me then?"

"I have dementia. That doesn't mean I am stupid": Stereotyping and stigma

4. Although people with dementia may face challenges when using various technologies, this should not result in stereotyping, particularly around age or dementia. Instead, appropriate support should be offered to anyone who needs it.

- Stereotypes based on age, diagnosis, ability, technological competence or acceptance of technology should be avoided. Assuming that older adults, or people with dementia, are resistant to or incapable of engaging with technology overlooks the skills, adaptability and interests many people possess. Such generalisations may result in technologies being underdeveloped, underutilised or inappropriately implemented.
- On the other hand, it should not be assumed either that everyone is familiar with technology, comfortable or open to using it. Some people (with or without dementia) do not like using technology and prefer to use it as little as possible. Instructions for the increasingly widespread and often unavoidable use of technology in today's society (such as for passport applications, buying theatre tickets, shopping online, or completing tax returns) often rely on assumptions about users' familiarity with digital concepts and terminology.
- They do not take into account lack of familiarity, reluctance to "fail" or concerns about the consequences of getting it wrong, and may contribute to the reinforcement of negative stereotypes. Neither having dementia nor being "older" is the sole root of the problem. Rather, it is the way that such technology is implemented and the lack of support available to use it for those people, of any age, with or without dementia.

"My Dad doesn't have dementia and he can't even make a call or use WhatsApp. Although we should be attentive to the needs of people with dementia with regard to technology, I think we are too quick to stereotype people with dementia as being unable to use it."

"Just because you are young or older, it doesn't mean you are or not interested in technology and that you like to use gadgets or devices. Some people like technology and others don't."

"People often assume that because I have dementia I can't use technology. Sometimes I pick things up quickly, other times not. It's not just my dementia, it's the fact that so many systems are made for people who understand it. When I get stuck, others may think I am not capable. I just need clearer guidance, not judgement."

“If it is not on the market, what’s the point?”: Equal access to technology

5. Once developed, technology can only have an impact on people’s lives if it is available and affordable to them. Its long-term sustainability should also be considered during its design and implementation.

   - It is essential to ensure that all people with dementia and/or carers can benefit from technology if they so wish. Technologies should be widely available and affordable, wherever people live and whatever their financial situation.
   - Financial cost should not be a barrier to accessing technology that people with dementia need. The financial burden of dementia is already high so technological solutions intended to support people with dementia must be realistically priced or freely accessible. Developers and policymakers should be clear from the start about costs and how the technology will be funded, so that no one who could benefit is excluded.
   - Technologies should work reliably over the long term, with technical support and compatibility as systems evolve. They should be designed for sustainability, avoiding unnecessary updates or redesigns that may increase confusion, frustration or cost.

> “Technologies that have been specially designed for people with dementia can be very expensive. It is not easy for people with dementia who don’t have the money to get them.”
>
> “We need large companies and developers to make technologies for people with dementia that are cheaper. That would be a good idea.”

“Involve us right from the start”: Ensuring that technology responds to the needs and wishes of people with dementia

6. Involving people with dementia and carers in the design or adaptation of new or existing technologies is essential. They should also participate in earlier discussions and decisions about what needs to be addressed, as well as the types of technology that could meet their expectations, preferences and needs.

- Involving people with dementia and carers in the design, development and adaptation of technology is essential for ensuring relevance, usability and trust. This requires meaningful collaboration from the earliest stages when identifying needs, setting priorities and determining which technologies should be prioritised.
- A great deal of innovative, technological design is produced simply because it is possible, marketable or because it will save or reduce costs. Potential commercial gain and scientific advances should not be the sole driving force but should be balanced against people’s real needs, preferences and wishes.
- The diversity of experiences and abilities among people with dementia means that flexibility and personalisation must be a guiding principle. What works well for one person may not be suitable or desired by another. Involving people with dementia and carers in the design and development of technology can help address this provided that people from diverse backgrounds, cultures, ages and gender are included.
- Even after technology has been designed or implemented, it should be reviewed to ensure that it actually is beneficial to people with dementia (based on experience of its use, not commercial or academic claims or goals). This feedback can help identify whether the technology works as intended and highlight any problems people may have encountered when using it in real world settings, outside of research and development.
- Despite the existence of good practices in some countries, this is not the case throughout Europe. Many people with dementia still feel that their lived experience is often overlooked or not taken sufficiently into account.

"Many developers are really creative but they don't have the understanding of dementia that we have and may well miss the point."

"If they had told me they wanted to develop a device that could make tea on command, I would have said that wasn't a good idea. Being British, making tea is a tradition and a sign of hospitality. My Grandma's day revolved around making tea and asking people if they would like a cup. So something like this would just not make sense."

"The real problem is the commercial interest in robotics. That doesn't mean that technology is bad but we need to think about the regulation of technology for people with dementia and distinguish between social innovation and technological innovation."

“Can we do without it?”: Overreliance on technology

7. We are becoming increasingly reliant on technology. The risk of technological failure, along with its potential impact on people’s feelings, dependency and self-esteem, is not sufficiently considered. Ensuring that alternatives and human support remain possible is crucial for everyone in society, and even more so for people with dementia.

- Technology sometimes plays a very important role in people’s lives, to the extent that they become somehow “dependent” on it. While technology can make it possible to maintain a skill or interest, it can result in the premature loss of abilities that were previously easy. This becomes particularly problematic when technology or systems fail or become inaccessible. Power cuts, loss of connectivity or broader disruptions (such as natural disasters, war or conflict) can expose the fragility of a highly digital society. Some of these problems or challenges cannot be anticipated and may be completely new to the person and even to society.
- This overreliance on technology is not limited to dementia or to specific devices or systems. It reflects a broader societal dependence on technology for communication, mobility, financial management, leisure and even healthcare. A person with dementia may sometimes require support to use such technology and this can make them dependent on this supporter who might not always be available due to changes in circumstances, health or relationships. We are all, to some extent, dependent on others, daily, at different stages of our lives and in various situations. Such support should be viewed in the context of interdependency (i.e. as an everyday reality that applies to everyone, not just to people with dementia).
- Preparing for technological failure and maintaining alternative or “low-tech” solutions is essential. This includes continued access to analogue systems (such as landline phones) or support from neighbours. Human contact provides not only practical assistance but also emotional reassurance and continuity, especially in situations where digital systems fail. Social bonds, trust and human connection are key elements that no digital system can replace. Ensuring that there is a human alternative should be a core principle in innovation and technology development.

“If, in the past, there was a power cut or technology failed, we had back-up plans that didn’t involve technology. We could use the landline. There were alternative plans for banking. Now there are no plans if the system breaks down, everything relies on some form of technology.”

“I was in Spain on holiday when there was a long power cut. We couldn’t get the car out of the garage and there was no food or way to communicate with other people. It was crazy and nobody knew what to do.”

“My back-up plan for when everything is gone is to walk to my neighbour’s house. Even if he can’t do anything, it is just to be with another human being, the ‘human connection’. We need to always be able to go back to basics and get human contact.”

"Don't let people take advantage of me but don't wrap me in cotton wool either": Balancing protection from harm with autonomy

8. Vulnerability and protection from fraud or harm are important at all stages of dementia. Measures must be implemented which take into consideration, not only the level of cognitive decline but also individual circumstances, social context and the evolving sophistication of technology.

- People with dementia can be especially vulnerable to fraud, exploitation or misuse of personal information at all stages of the condition. Cognitive changes as the disease progresses may affect a person's ability to recognise scams, misleading offers or unsafe situations linked to technology, increasing their exposure to risk of financial, emotional or digital harm. Such vulnerability is not limited to the advanced stages of dementia. People in the earlier stages may, in some contexts, be even more susceptible to harm, as they often maintain higher levels of independence and may not fully recognise potential risks or lack adequate support systems. Emerging technologies, such as artificial intelligence and automated communication systems (e.g. cold calling using familiar numbers or AI-driven scams) can further increase these risks.
- Different approaches and solutions may be helpful at different stages of the disease, reflecting different abilities and scenarios where fraud or unsafe situations may occur. Approaches should therefore be flexible and proportionate to the person's needs and contexts, recognising that the right balance between protection and independence may vary. For some people, maintaining autonomy and independence may be a priority, while others may prefer greater protective measures and less exposure to potential risk or unsafe situations.
- Preserving privacy and dignity must be a central consideration in the design and use of technology. Monitoring systems, tracking devices or communication tools should be implemented in ways that respect people's autonomy and consent, while still providing appropriate safety measures. Overly intrusive systems may compromise dignity and trust, whereas inadequate safeguards can leave the person exposed to harm.
- Carers and families should be supported with guidance on how to use technology ethically and safely, including strategies to prevent scams, protect personal data and maintain confidentiality.

"In many ways, people in the early stages may in fact be even more vulnerable, as we may not be aware of our vulnerabilities or may not have a support system in place."

"I feel I can make my own decisions but I realise I might not always be seeing the full picture. My husband sometimes says what he thinks I should do as he is concerned about me and it's then difficult for me to decide whether to do what he is suggesting."

"There is also the issue of more sophisticated AI, the cold calling and the use of numbers that are local or familiar. This can be dangerous, particularly if you are having a bad day."









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European Working Group of People with Dementia 2025

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