

## Annotated case study: How people with moderate to severe dementia responded to a prototype digital world<sup>1</sup>

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### Background<sup>1</sup>

All too often, people with dementia are locked out of a digital life because the software fails to accommodate their needs. At the same time, we know that having a digital life helps us to communicate, learn, build connections and live well. With 13.8 million people in the USA forecast to have dementia in 2050, many of whom will have used digital tools in their everyday life, digital inclusion is an important part of well-being – and so it is a prominent research challenge. What would it take to enable people with dementia to share in such activities? To explore this question, I undertook a four-year Ph.D. (2012-16) within the field of Media and Communication, with an additional focus on Gerontology and HCI, at Swinburne University of Technology, Melbourne.

A deep investigation into how best to deliver creative and enriching digitally-enabled activities led to a proof-of-concept prototype, which, uniquely, takes inspiration from some 800-million people throughout the world who play interactive video games that draw them into new realms of engagement and possibility. After a 4-month period of co-design with residents at an assisted living community, Emmy Monash<sup>2</sup>, a naturalistic usability evaluation of the prototype was undertaken, with the same cohort (n=10).

### Method

The naturalistic method of evaluation seeks to understand responses to the characteristics of a software program by giving participants an open brief to explore the technology in any way they choose.<sup>3</sup> A naturalistic evaluation takes place in a user's natural setting. Over a reasonable period, the researcher observes participants' experiences to form an understanding of a range of user-attempted tasks.

In this study, both a “primary” player and a “support” player (the player pair) were involved. It was, therefore, important to consider the impact of the support player's prompting and guiding role. Upon consideration, the dyadic interaction arising from the support player's involvement was intrinsic, with each member of the dyad contributing to an engagement effect. Any interactions that were initiated by the support player were seen not to contravene naturalistic inquiry principles.

### Case Study

Peter (not his real name) resided at memory care unit within the assisted living residence. He had worked in business for most of his life. Peter took the request to help us trial a new product earnestly and enjoyed giving his opinion throughout. Peter and Eli, a member of the lifestyle team (he player pair) worked their way through the world.



**Left: the player pair in shared concentration.**  
**Right: Peter makes his music selection.**

[Permission to show faces]

<sup>1</sup> Salomon, M. *Building a virtual world for dementia care*, Australian Journal of Dementia Care, Vol 3 No 5 pp17-19

<sup>2</sup> Emmy Monash Aged Care, <http://emmymonash.asn.au/>

<sup>3</sup> Siegel, D. (2012). *Usability for engaged users. The naturalistic approach to evaluation*. In J. A. Jacko (Ed.), *Human Computer Interaction Handbook (3rd ed., pp. 1243–1247)*. Boca Raton: CRC Press. <http://doi.org/10.1201/b11963-52>



*We asked Peter how he had managed to make the birds “fly”. Peter often jumbled his words, but on this occasion, his words were clear: “If I knew how to do that, I wouldn’t be here.”*

What underlies this comment? That Peter possessed a self-deprecating brand of humor; that he knew he was “here” rather than somewhere else, possibly his home; that he was aware of the implications of his impairment. Significantly, in distinguishing his current self from his past self, Peter had indicated a high level of self-awareness.

**Peter was forthcoming with advice:**

P: “Already on the market? Is it already?”

...It’s fantastic. Have you got a price?”

M: (It’s free).

P: [Quizzical] “It’s free?”

M: “Ok. How about five dollars?”

P: “That’s all?” [Thinks] “Start with 10 dollars and see how it goes. When you make the first million, you will let me know. Sell it straight away.”

[Pauses] “Well, as I say, it’s fantastic.”

Peter’s session had helped us learn about the prototype’s usability, but in the process, we also learned about Peter. Furthermore, in spite of a Psychogeriatric Assessment Scale (PAS) score of 16,<sup>4</sup> which placed him in the ‘severe impairment’ category, Peter had actively participated in the session.

**Findings**

Peter’s actions and comments indicated that he expected representational objects to perform the same way as their actual world counterparts. For example, he acknowledged that graphical flowers were representations of actual ones. Interestingly, he also accepted that rules of the world: that tapping on the flower would make it “grow” which of course does not happen in the actual world. Similarly, he accepted

that the digital representation of piano keys equated actual piano keys, and played them. He demonstrated an understanding of scene transitions from one scene within the world to another, with comments such as “The bedroom?” and “Oh, back again.” The fact that he took steps to interact unaided may have contributed to a sense of control and agency. He was in good spirits at the end of the session and asked about the price (see text box, above).

The support player commented after the session that her experience as a Montessori practitioner “helped a lot”. She expressed a desire to do it again, and added: “I think the more I do it, the more I know what to do.” A staff observer commented that Peter returned to his group “happy”, and settled”, and was talking about the app “all the way down the corridor”. When asked about how the activity compared with a one-to-one session looking at a book, she replied, “There was no comparison”, which was taken to mean that the book would not hold Peter’s attention in the same way. When asked if she would like to try being a support player, the observer answered firmly: “Yes”.

**Conclusion**

The evaluation suggests that people of diverse backgrounds and experiences can understand the spatiotemporal construct of a 3D digital world. The specially designed interactive environment acted as a scaffold for a range of communication styles such as nonverbal or non-English. The caregiver partner, in the role of supporter, managed to bring the primary player to an “optimal zone” of play and she found this to be an enriching activity.

**Acknowledgement:** Thanks to the Staff and Residents at Emmy Monash Aged Care, Caulfield, Victoria, Australia for their generous time and participation in this study. The PhD was supported by Smart Services Cooperative Research Centre and Alzheimer’s Australia, Victoria.

<sup>3</sup> Australian Government Department of Health. Aged Care Funding Instrument (ACFI) User Guide, 2017 p.28 [https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/02\\_2017/final\\_acfi\\_user\\_guide\\_2017.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/02_2017/final_acfi_user_guide_2017.pdf)