

## **Exploring the Use of Virtual Reality Technology in People with Huntington's Disease to Improve General Well-being**

The Following report was prepared on behalf of HDANI by;

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HDANI is part of a network of global Huntington's Disease charities that exist to raise awareness of HD, and advocate for effective services, but also promote well-being in the HD affected population.

As part of the latter remit, they were awarded a small grant in 2021 by the ADDOR Foundation to explore two non-pharmacological interventions that were beginning to take traction in other neurodegenerative conditions. One of the interventions was virtual reality (VR) headsets.

The use of VR headsets (and what are called wearables) has started to be used by themselves and in more immersive settings such as rehabilitation and assessment of symptoms, but this is the first project (to our knowledge) that has trialed them for well-being and leisure.

The HDNI gathered (non-standardised) data from the users and their families and carers on the practicality of the devices but also any positive or negative feedback. This included verbal & written feedback from those who were able to give it but also proxy feedback from companions from those who were unable to (i.e., observations of body language indicating well-being/or frustration).

Whilst not part of a formalised study and with a small group of participants, the outcomes still demonstrate useful knowledge for people with HD and their families and for those considering the use of this technology with people with HD across their lifespan.

8 participants volunteered to take part – all at various stages of their illness, 3 in the early, 2 in the mid and 3 in the late stage. Ages ranged from 44 through to 69 years old. There were 7 males and 1 female.

The participants living arrangements varied from living at home with their children to being in or having full time care and no longer mobile. 2 at the time of the intervention were still working.

An infographic has been produced to show outcomes but also considerations relevant to future use of VR headset use with people with HD.

# TIPS ON USING A VIRTUAL REALITY HEADSET WITH SOMEONE WITH HUNTINGTONS DISEASE

## 1. WHY?

- VR has been shown to support wellbeing in other forms of neurodegenerative disease
- People with HD can struggle to engage in meaningful & therapeutic activity due to neuropsychiatric, cognitive symptoms & physical symptoms



## 2. PREPARATION

- Think positioning (only use when seated/upright in bed)
- Know your user (their likes/dislikes/fears)\*
- Know the kit (supporter must know how to operate)\*\*
- Whats the purpose? (i.e. relaxation, stimulation, social interaction)



## 3. DON'TS, MUSTS

- VR should not be used as a substitute for quality human interaction
- Do not leave the person alone, they will need support
- Build up tolerance to the headset with a maximum of 30 minutes at a time\*\*\*
- VR experience is not for everyone so don't continue if there is clear discomfort\*\*\*



## 5. MAINTENANCE

- Do not share headsets if person smokes (the material absorbs smell and is off putting to others)
- If headsets are shared - an infection control procedure should be put in place



## 6. PRACTICE IMPLICATIONS

- Wearables such as VR headsets are increasingly being explored for assessment of early symptoms in neurodegenerative diseases
- This project shows they also represent a cost effective and safe way to engage people with HD in meaningful activity even when communication and mobility is limited



(\* D was a fisherman so loved sea scapes. He smiled and slept better when using it daily

(\* M could only tolerate 5 minutes as it made her feel nauseous

(\*\*\*) R could not communicate verbally and despite being supported, he indicated discomfort

(\*\*) M's carers did not charge the battery, or position the straps and this caused him irritation

(\* (\*\*\*) Try the experience for yourself / carers that did were more confident but also knew how it made them feel (i.e. anxious) and therefore for those they worked with