



Exploring the Use of Weighted Blankets 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 neuropsychiatric conditions. One of the interventions was the use of weighted blankets.

Weighted blankets can be part of a package of measures used in individuals who have difficulties regulating the information between their brains, bodies, and the outside world because due to their condition, they may perceive that information differently. Interventions that might use weighted blankets are thought to try and modulate this sensory information (so can be called sensory modulation). Whilst there have been no large studies that have shown the effectiveness of sensory modulation for groups of people with HD, there is growing literature on cases in which it has helped particularly with agitation and aggression. People with HD and their families have been trying them informally and some have noted a benefit in reducing chorea at night, but this is the first project (to our knowledge) organised through a HD charity that has trialed them for the effect on improving overall wellbeing.

Each family who volunteered was given king size, 6 kg blanket for up to 21 days to trial.

The HDANI gathered (non-standardised) data from the users and their families and carers on the practicality of the blankets 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, their families and for those considering the use of weighted blankets with people with HD across their lifespan.

13 participants volunteered to take part – all at various stages of their illness, early through to late. Ages ranged from 36 through to 76 years old. There were 7 males and 6 females.

In addition, some of their companions also used the blankets. One of the companions also had early HD and cared for a family member so was able to compare their responses.

All of the participants were living at home either without care or having supportive or full-time care.

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

WEIGHTED BLANKETS

Considerations for use in Huntington's Disease (HD)

1 Practical

- Start with low weight blanket
- Grade tolerance (even if only once a week for 5 minutes, go low, go slow)
- Consider use and therefore size needed
- Consider risk (i.e. falls)
- Consider temperature instability
- Think about hygiene (i.e. putting a duvet cover on to catch spills)

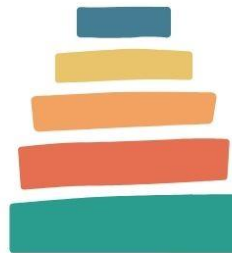


2 Stage/presentation of illness

- Can be used across life span
- Weight may cause agitation in non verbal, more cognitively impaired individuals
- May increase attention to problems with pain in cognitively intact individuals

3 Use ?

- Reduces anxiety (in 10 out of 13 taking part in this project)
- May minimize nocturnal chorea (5 out of 13)
- May improve sleep (5 out of 13)
- May improve day time chorea (4/13 specifically mentioned this)
- As part as a range of measures / or as a solo intervention

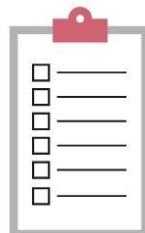


4 Carers/companions

- Carers/companions (who may or may not have HD even if presymptomatic) - they noted benefits in reduction of anxiety/better sleep

5 Summary

- Weighted blankets are safe to use at all stages of the illness and a real alternative or adjunct to medication
- They should only be used with support in mid to late stage illness



10 out of 13 participants will continue to use them