

Title: Co-creating a physical activity resource for carers of people with Huntington's disease

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Background

People with Huntington's disease (HD) often struggle to sustain regular physical activity despite evidence that exercise is beneficial. Caregivers collaborate with people with HD to support their physical activity but have indicated that they would benefit from training and support. We aimed to develop a physical activity support package for carers of people with HD.

Method

A virtual workshop was held with five carers. Discussion focussed on experiences of supporting physical activity; sources of support and needs of carers. Data from the workshop were analysed using framework analysis.

Results

Data indicated that a carers physical activity resource should be simple to use and easy to read, and should include tips on planning activity, safety and examples of activities.

A co-design team including a carer and representatives from the Huntington's Disease Association of England and Wales (HDA) and Carers Trust, Wales used the information that emerged from the workshops to develop a prototype resource. Content includes a tool to set physical activity goals and examples of flexibility, strength, balance and fitness exercises.

Conclusion

The prototype resource will be user tested by five carers and further amendments made. A physical and electronic version of the physical activity resource is being refined and will be available through the HDA website in Autumn 2022.

The resource will be translated and licenced to global HD Associations. Impact will be assessed via data mining of the ENROLL-HD database in three- and five-year's time.