The impact of Boleh sailing trips on those affected by Huntington's disease

Huntington's Disease Association

A day on Boleh was massively appreciated by those affected by Huntingtons Disease on three separate days afloat. THANK YOU!



Group 1: Young people and their families affected by HD

Huntington's disease (HD) is a cruel neurodegenerative inherited condition that affects movement, thinking and mental health. As the disease progresses, people become dependent on others for care as they lose ability to walk, speak and swallow. Around 8,000 people in the UK live with HD, with a further 32,000 at risk of developing the condition. Each child of someone with HD has a 50/50 chance of inheriting the faulty gene, symptoms starting between 30 and 50 years old.

HD families face caring responsibilities for multiple generations and uncertainty about the future, especially young people who worry about developing HD themselves while caring for a parent or sibling. Opportunities to take a break from these challenges and meet others who understand what they are going through makes a real difference.

Offspring of those affected by HD not only watch a parent get gradually more unwell, but watch what could happen to them in future. Its scary and surrounded by stigma; their mental health usually suffers. Understandably its hard for our charity youth workers to get children to meet others " in the same boat", yet when they do the peer support is hugely valuable.

Jack, our HDA Youth Worker enabled the two young people's groups to sail on "Boleh"this summer. He works at building meaningful connections with the young people he works with, and provides a safe space for them to express themselves. Getting a group of young people together on "Boleh" enabled them to have a good day of respite, as well as connecting with others affected by the same challenges.



Group 2: Young people and their families affected by HD









Group 3: Individuals living with symptomatic Huntington's disease.

There was also a trip for a group of three men affected by HD, sailing with spouses or carers to support them on board. Here are some quotes from the group:

"It was really uplifting to see a positive fun activity distracting them from the difficult daily tasks they face. Memory is not affected by HD, in spite of it being a type of dementia. Those positive memories are vital for families affected. In addition, each physical task is an achievement to be celebrated. HD causes a very wobbly abnormal gait so people get accused of being drunk . But in fact, when you are climbing along a side deck, or balancing at the tiller EVERYONE looks somewhat wobbly! Sailing a sturdy boat like "Boleh" seemed a great leveller."

Alex, Marc, Michael, Ken and Clare had an "awesome day sailing right up the Portsmouth estuary, to Fareham and Portchester and then back through the harbour and out into the Solent, they all had a go at helm, pulled up and packed away the sails and built great relationships and memories. It was amazing, such wonderful, knowledgeable volunteers, could have stayed onboard forever. We would like to thank Ant, Jonathan and Geoff."

"What a fantastic day! Was lovely to get away from everything else and also see what our HD heroes can do - helming, winching and having a great time!"

"All of us in the Hampshire and Isle of Wight branch of HDA value and prioritise *making great memories with loved ones* which:
A) are significant personal achievements when disabled by serious terminal illness
B) will lift and trigger positive emotions when struggling further down the timeline of a progressive illness.

The very name "Boleh" encapsulates how families have to tackle life when HD throws different challenges as the disease progresses, such as losing mobility to walk and speak then swallow. When our Branch Secretary Annette met "Boleh" at the Southampton Boat Show, the name struck a deep chord. You have to get on with life, with a "can do" attitude. Annette met her husband, who has now died with HD, on a Tall Ships Race. She still sails with her adult daughters who live at risk of developing the illness.

A huge THANK YOU from Hampshire and Isle of Wight Branch of the Huntingtons Disease Association

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