

# The benefits of using correct seating for people living with Huntington's disease

**Huntington's disease (HD) was first written about by George Huntington, a practicing GP working in New England in 1872. Originally a European disease, it was spread around the world by European sailors and travellers. But how can appropriate seating help?**

It is a genetic disease with people carrying the gene having a 50% chance of passing it onto their children. A brief review of the number of patients cared for by the Huntington Disease Association in the UK indicated that approximately 6,700 individuals are currently living with HD. This means that 12.4 per 100,000 persons or one out of every 8,065 individuals may be affected by HD15, although these numbers at best provide a minimum prevalence estimate in the UK.

Mike Wooldridge's passion is working with people with HD and he has an enormous amount of knowledge in disease with over 30 years experience.

Mike is also a member of the European Huntington's Disease Network as he explains: "I started working in large mental institutions in 1969 and the first person I met with Huntington's was a woman in her 40s. "As I walked around the building and came to the room where she was the person showing me round said: 'pay no attention to her she's got Huntington's, there's no hope for her, she knows nothing about what's going on so don't trouble yourself'. I was

new to nursing and I could not believe that a human being would have no understanding of what was going on. This experience made me want to explore the disease and find out what help and support could be provided to maximise the quality of life of patients with Huntington's.

Healthcare wasn't like it is today and

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we didn't have any equipment that supported people with different care needs.

In the mid-70s people started looking at solutions that might help people with Huntington's and one of the first things they looked at were chairs that would accommodate their individual needs. People with HD have strong involuntary movements and a suitable robust chair was needed that would stop them sliding down or falling out.

Hospitals in the '70s used to put them in what were called geriatric chairs which were big chairs that had a table on the front screwed into place, the idea being people would not fall out as the table would prevent this. However, they would just slide down under the table. You could also tilt the chairs back as another way of trying to keep them safe but that didn't deter them, if they were determined to get out, they would".

Over the intervening years, Mike has seen various new developments in seating solutions and has recently been working with specialist seating company Repose Furniture and its resident occupational therapist Kate Sheehan in the development of the Harlem Porter Chair which Mike believes to be one of the best seating solutions he has seen for people with Huntington's. "To have input from someone with Mike's knowledge and experience is invaluable to us as a manufacturer and I know our customers will benefit from this when they see the Harlem Porter chair for themselves," commented Lisa Wardley, Repose's managing director. Kate Sheehan explains how she

worked with Repose and Mike and what should be considered when looking for suitable seating for someone living with HD:

"When I joined Repose, the initial design work on the Harlem had taken place. I reviewed it with Helena from Repose and suggested some alterations to ensure the chair's frame was structurally robust enough to take the involuntary movements associated with Huntington's and provide the necessary levels of support. A demo model was then taken to Mike at Rapkyns Care Home in Sussex to gather feedback from him and his staff with regards to how the patients found the chair in terms of comfort and practicality.

## What should be taken into consideration when designing furniture for someone with Huntington's disease?

"The involuntary movements associated with HD can be extremely powerful despite the patient appearing frail, and their constant movement puts a huge amount of pressure and wear and tear on all parts of the chair. There are also issues with pressure sores from force and friction. The constant movement back and forth and repositioning means that someone with HD might need up to 5000 calories a day just to maintain body weight due to the constant movement to give you an idea of their strength and how much they are moving. Weight loss can be significant which puts the client at greater risk of pressure related issues.

"It is extremely important to provide people with HD with the correct level of support around the head, neck and body to prevent them getting into positions which do not support good posture. There are also issues regarding manual handling as when they stand up they will not necessarily follow exact instructions due to

their involuntary movements. All these concerns were taken into consideration during the design of the Harlem. For example, reinforcing the footrest was to ensure it could withstand somebody standing on it without it moving. The original structure of the chair was also reinforced so when someone moves



Helena Greaves from Repose (left) with Mike Wooldridge

in an unusual way they would still receive the core support from the chair with their body shape maintaining a good position. Another factor we took into consideration was maintenance costs. People with HD put an incredible amount of stress on furniture. For example, if someone continually puts their leg over the arm of the chair it will



eventually wear out the fabric, so we designed each part to be easily replaceable if required.

"It is also important that carers can move the patient whilst they are still sitting in the chair from one room to another to enable them to engage in as many activities as possible, so the Harlem has been designed to be extremely manoeuvrable.

"We also adjusted the seat width and depth to make it slightly longer with longer arms to accommodate movements, as people tend to slide forwards, so it was about allowing that movement without causing extra pressure on the body. It was very much a compromise between what you can achieve whilst still producing a chair that is aesthetically pleasing as HD is such a complex condition. There is nothing else like it on the market"

A final word from Mike: "I have worked with people with HD for over 30 years and I would certainly recommend the Harlem to people who are looking for a seating solution that meets the needs of someone living with the disease".

Available in small, medium and large, the Harlem Porter has a maximum user weight of 20 stone. Standard features include an independent back rest recline with a range of angles and seat angle adjustment to reduce the risk of a patient falling out due to severe involuntary movements. There is also a deep padded seat area for additional safety and comfort, a choice of six interchangeable back styles facilitating different pressure management and posture solutions and four different seat cushion options to accommodate different comfort and pressure management solutions. Further safety features include high arms and a sliding padded footplate for ease of patient movement.

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