



Susanna from the New Hope Uganda UK charity has written to us with the following story about John.

The charity has given us permission to share John's story, which also describes how the Symmetrisleep System has helped to improve John's life.

John, New Hope Uganda

John is a 15 year old boy with cerebral palsy. He is wheelchair dependent, tube fed, and unable to move himself. He only has a little active movement in his arms. He needs full care and has lived at a children's centre called New Hope Uganda since he was a young baby. The special needs project "Treasures in Jars of Clay" started in 2009 when Kate Tolhurst, a British special needs teacher, went out to Uganda to care for John. Sadly, in the early years, John's tone and spasms were very difficult to manage, and he has long-term contractures in both his arms and legs. These have got worse over time, and John has also developed a scoliosis of his spine and windsweeping of his hips. For the last 6 months, John has been in a lot of pain, especially with one of his hips.

Unsupported Lying



After sharing John's story with Symmetrisleep, we were very happy to receive a sleep system to try with him. For the first few weeks, we used it for a couple of hours in the afternoons. This meant the care staff could be taught and practice using it, and that John could gradually get used to the new supports and position. Each afternoon, John quickly settled almost going straight to sleep! The care staff could instantly see how relaxed and comfortable he was.



Supported Lying



John has now been using the sleep system every night for nearly a month. The care staff are diligent in using it each night, because they can see the difference it is making. John is sleeping for longer, more comfortably and in much better positions. He is not crying in pain at night. It is still early days, so we don't know if in the long-term there will be improvement in his contractures or scoliosis. But we are thankful that we can now support John in good positions where he is not in pain, and where his body shape is protected. The care staff are now also more aware of John's body position during

the day, and we are using some of the cushions to support him when he is in his wheelchair and lying on the sofa.

I am hopeful that the sleep system will not only help John, but also other children in our care, as many have seen and been impacted by the difference that good positioning can make to a child's life. We need to pass this understanding on to parents and other care givers, and to work out simple ways to position children better using local resources. I look forward to seeing this affect the way that we care for all our residential children, and those we support through our special needs school class and in our community.

These are the comments from a few of the staff:

"The sleep system is helping John because his back and legs are not twisting. He is sleeping better and is not crying as much in the day or night." (R., Care Staff)

"The sleep system is good for John especially when he is lying on his back. He is more relaxed." (M., Care Staff)

"I am amazed at how easy the sleep system is to use, and how quickly John has got used to it. It has been easy to teach to others, and after only a few nights the care staff are very confident using it. Having seen the positive effects that a good position has on John's pain, comfort and joints, this is affecting the way he is being cared for not just at night, but also during the day." (S., Physiotherapist)



Students and Staff

Our thanks to John, Susanna and the staff for sharing this story. If you want to know more about the charities here are the links. <http://newhopeuganda.org>
<http://www.newhopeugandauk.org/treasuresinjarsofclay/>



