

# Connor Hill's Personal Health Budget Story



**Connor Hill is 21 and lives in Halton, Cheshire. He suffers from Duchenne Muscular Dystrophy. He took up a Personal Health Budget in April 2014. This was used to enable Connor to live independently in his own home and employ a dedicated team of Personal Assistants. This is his story...**

Connor was diagnosed with Duchenne Muscular Dystrophy when he was aged 4 when his mum noticed that Connor was having difficulty with his mobility.

Duchenne is a genetic disorder that causes progressive weakness in the muscles.

As part of his treatment, Connor underwent a weekly course of physiotherapy. After a while Connor was required to wear night-splints on his legs which were used to keep his ankles straight.

Over the next few years, Connor's mobility deteriorated to such a degree that by the time he was 11 he was unable to walk and needed the use of an electric wheelchair. Connor's night-splints were replaced by splints worn during the day.

It was at this time that Connor required outside help from a care agency. He had a care assistant come in to assist him get up in the morning and help him into bed in the evening

Being in a wheelchair had its ups and downs but Connor refused to let Duchenne get in the way of his daily life. In fact, Connor enjoyed many wheelchair sports including wheelchair slalom in which he won three gold medals at regional and national levels.

Through the process of a Direct Payment funded by the local authority, Connor was allocated respite care so that his family could do activities, etc

Due to curvature of the spine, an effect of his condition, Connor underwent spinal surgery in 2008. Spinal rods were inserted to straighten his back.

As his condition progressed, funding was increased to enable him to have a 2<sup>nd</sup> P.A. This was to assist him with personal care in the mornings and the evenings. He was also assigned time for social pursuits which was under the care of a PA.

As a result of this surgery, Connor's wheelchair was fitted with an arm-support which enabled him to independently raise his arm up to a level whereby he could continue to feed himself and do other tasks such as control a computer mouse.

During this time, Connor was having Duchenne-related respiratory issues.

After numerous bouts of severe chest infection which led to admissions into hospital, physiotherapy was arranged. Due to the severity of the attacks Connor was advised to use a Cough Assist, a piece of medical equipment which helps clear the

lungs of any build-up of secretions.

During this time, Connor was also diagnosed with cardiomyopathy, another complication arising from Duchenne. This condition is treated with AC Inhibitors and beta-blockers.

In 2010, Connor had a very poor appetite and was losing weight. Concerns were raised and so he underwent a gastrostomy and a peg-feed tube was inserted into his stomach. Using an overnight feed pump allowed him to supplement his dietary needs to keep his weight stable.

In December 2010, when Connor was 17 he and his family moved into a bungalow in which he had input with designing.

Due to these matters, Connor needs expanded to the degree that he needed knowledgeable carers who had the skills set to meet his needs.

In May 2012, funding for Connor's care was changed. Continuing Healthcare took over and he had to get used to a different set of carers with different care agencies. After having been used to his own P.A.s for such a long time, this adjustment proved difficult for Connor.

# Connor Hill's Personal Health Budget Story



When he was 19, Connor was forced by his step-father to leave this home.

NHS Continuing Healthcare found Connor a temporary place to live in a residential home in Liverpool far from his friends and family.

This proved to be a somewhat unsettling experience so in December 2012 Connor moved to Bredon, a temporary sheltered accommodation run by Halton Borough Council. This placement was supposed to last for three-months. Due to his complexity of his needs, Connor remained there for almost a year.

By now, Connor required 24 hour care and he was able to maintain a high level of care. Due to him coming to an agreement with the care agency they allowed him to have some input on weekly rotas, he became very familiar with some of the Agency carers.

It was during his stay here at Bredon that Connor first heard of a Personal Health Budget.

On Hearing about the Personal health budget Connor set about

researching everything about this Idea.

In November 2013, Halton Housing Trust offered Connor a purpose-built bungalow in Widnes. He has made this his home.

In January 2014 Connor had a care review meeting. At this meeting he discussed the possibility of moving over to a Personal 2Health Budget. After many meeting with professionals a support plan was written up.

In April 2014 Continuing Health Care made the decision to allow Connor to have a Personal Health Budget via a Direct Payment.

Connor took up a Personal Health Budget to provide his own care. He has employed 3 part-time and 3 full-time Personal Assistants that provide him with 24-hour care.

Halton Disability Partnership gives professional advice and support to Connor as and when required.

Connor decided to have a Managed Account, he makes use of a payroll service which organises wages for his PAs, sorts out income tax and N.I. contributions.

Connor interviews and hires his own Personal Assistants, with the help of Halton Disability Partnership. He organises his own rota system.

Connor applied for funding Through Skills for Care, this is for all training requirements needed to care for Connor. He is also assisting his P.A.s to attain more professional qualifications as and when they need them.

Connor runs the personal health budget as if it was his own business, has created a corporate identity with his newly designed Logo. He is now in the process of creating a website to help all people who want to find information on the subject all in one place.