

Case Study - Edward

Edward, aged 21, has a very rare condition called tetrasomy 9p which means that his number 9 chromosome is 'abnormal'. When he was born doctors told his parents that he would never be able to even lift his head and at the age of 2 this seemed to be the case. Edward would lie on a bean bag unable to support himself. He was unable to hold his head up and could do nothing for himself.

At the age of 4 Edward was put on the MOVE Programme. The family set goals which were broken down and worked on at every opportunity during the day until Edward began to learn new skills. Through MOVE he started to sit, stand and eventually walk when he was 7. He is now able to walk independently, as long as someone guides him around dangers, e.g. when a pavement ends, as he has no perception of danger. His parents are now even able to take Edward on weekend rambling trips and he can walk for up to two miles! Edward loves to go out walking and will always go and fetch his shoes when his parents say. Although Edward has been on the MOVE Programme for so long (he was one of the first in the country) he continues to improve.

The MOVE Programme has also helped to improve Edward's health. Before he had any mobility skills Edward's circulation was poor. His hands and feet were always blue and they would often bleed and blister. With increased mobility this was no longer a problem for Edward, not only meaning less discomfort for him but also relieving his family of having to bathe and cream them daily.

Edward has a twin brother, Greg and an older brother aged 22, he loves to play with his brothers and this includes playing football, wrestling and play fighting with them. Edward's mum Carole says "*the Programme has got him moving. Edward can now walk out with our other two sons. It's given him a life.*"

When his family go shopping Edward loves the fact that he can walk around with his brothers, rather than just being with his mum or dad. He also loves the hustle and bustle of the people there. His father says that they need to give Edward time when they go shopping and cannot hurry him, mainly because Edward knows exactly which shops he wants to go to, and where they are. He always chooses shops that have TV screens as he loves to see himself on TV!



For Edward, being mobile means that he can manage stairs by himself and that his family hardly ever need to use his buggy. In fact about 5 years ago they stopped taking it on their annual month long trip to France, which means that they can fit much more into the car!



Edward is very sociable and uses his two main words 'hiya' and 'hello' all of the time. He loves to interact with people and is interested in what is going on around him, so much so that sometimes he is so engrossed he won't eat his dinner as he is too busy looking at what other people are doing!

With help from the MOVE Programme Edward can now express choice and his main ways of communicating are to gesture, and take someone where he wants to go, for example if he wants to listen to music, he brings the CD to his family, and if he is thirsty he collects a beaker from the kitchen. His mother Carole Holt said, "*It's given Edward choice instead of having his life dictated to him by others. Because MOVE is focused on everyday movement, he's using the skills he's learning through the programme when he's at home so it's a constant learning curve.*"