

Conor's speech

Hi, My name is Conor Hughes and I am a young carer. I help my Mam provide care for my sister Christina, who is 15 and suffered a stroke when she was 10 which has left her wheelchair bound and partly paralysed. I also help with the care of my little brother Odhran who is 4 and has autism.

When people hear the term "young carer" they are often puzzled as to what exactly it means. A young carer is a child or young person 18 or under, carrying out significant caring tasks and assuming a level of responsibility for another person, which would normally be taken by an adult. In my case I am supporting my Mother in caring for my two siblings but in some cases young carers are the primary providers of care in the home.

When I look back on the last five years since my caring role began, the issues that stand out for me are firstly the disbelief and sadness of my sisters sudden illness. The initial coming to terms with this and the stress that it caused for the family were immense. The lack of information and emotional support at that time for both my mother and myself sticks in my mind.

As time moved on the main issues or challenges that I faced were missing out on school and classes. While my school were supportive and aware of family situation my caring role still placed me at a disadvantage with my education. While I never missed exams I did miss time during the year.

Another aspect of my life which I feel has been adversely effected by caring is my social life. As Odhran, my younger brother, will only stay with me or my mother, I am restricted in going out and taking part in social activities like other people of my age. I did take up rugby for a short time but it clashed with hospital appointments and so I couldn't keep it up.

Lack of sleep when Odhran was younger was also a common occurrence. It could take from 30 minutes to a few hours to get him settled some nights and he always wanted his big brother to do this.

Financial pressures have always been a factor in our caring as both Christina and Odhran require a lot of medication and hospitalisation. For my Mam this has always been difficult to manage with limited financial support for caring. Things like school trips abroad were just not possible due to this.

Now that I am 18 and have started college my life has changed somewhat. However I still live at home and travel in and out to college every day. I don't think I could have considered a college outside of Dublin after school as the commuting would have been too much each day. I have a part time job on Friday evenings now for 5 hours but couldn't work any more than this as Odhran needs his big brother at home at nighttime, if my mam is out. I still take my sister Christina shopping which is not my favourite hobby but she certainly enjoys it and that's what counts.

When asked recently what do I want as a young carer I answered somebody to talk to who is in a similar situation to me either in person or through chat room, better information and financial support for young carers and to attend support group meetings with other young carers who can relate to my issues.

I think that anybody who cares for a loved one, whether they themselves are young or old, must feel the physical and emotional stress that it can bring. However they must also feel the great sense of love and personal satisfaction that comes with knowing that you have made that persons life a little easier. To me that's what caring is about.

Conor's Mother

"Conor is Odhran's safe place – he is his hero, his protector – not just his big brother. Odhran has a special bed time routine and Conor is always there to settle him in. This can take 30 minutes or a couple of hours". Conor also helps Christina with her physio sessions and goes to her hospital appointments with her. This helps keep Christina's spirits up and keeps her motivated. "Conor does all of this without payment, without complaint and with much love and grace."

Before Christina's and odhrans diagnoses I was a working mother and life was going well. Over the course of summer 2005 our family life was changed radically by illness. Conor, who was 13 at the time, was my life saving help. He minded Odhran while i did physio and OT with christina. He helped with everything from making a cup of

tea to taking time off school to attend hospital appointments with me. I needed him to wheel either the wheelchair or the pram.

He sits with Odhran if I need to go to the shops. He takes Christina to the library so that I can work with Odhran at home. My outlet is line dancing and this is what recharges my battery to keep going with caring for two special needs children. Conor always makes sure to be home to babysit so I can get to my dancing. He does this and his friends all know he won't go out on my night off!

Conor is my extra hands and feet, without him I could not do the work I do with Christina and Odhran. If Conor was not my helpful carer i would have no choice but have some professional help at home and we, as a family, cannot afford that. Conor has had to fast forward his growing up process and I, his mam, am ever grateful and proud for the way he has coped and for all the work he does.