

Family Carer:	John Hutchinson MBE
Age:	81
Cared For:	Darryl
Situation:	Lives at home with John and Pauline
Age:	49
Other Children:	One daughter who lives out of county
Years of caring:	49

“It’s just something you have been doing all your life”

John spent the majority of his life working in the leather industry which involved a lot of travelling. This meant that Pauline was the main family carer at home. They moved to Oxfordshire when Darryl was 18. John retired at the age of 65 and as he did not have a hobby he became involved with the Ridgeway NHS Learning Disability Trust, attending meetings and eventually becoming independent chairperson when Ridgeway was forced to join another NHS Trust. His aim was to get a better understanding of the family carers’ situation. He went on to work with MENCAP and has set up four other organisations, three of which he still chairs. He was awarded an MBE in 2016 for services to people with Learning Disabilities.

When Darryl was born and it became apparent that he had some difficulties the specialist told the family that he was ‘not a normal boy’ and that they could either keep him at home or he could go into care. Without hesitation Pauline said that she would continue to care for Darryl. Living at home was not without its issues. At the age of five, Darryl could not get a place at his local school so they had to ask their Doctor to intervene. Between them, John and Pauline had to work around Darryl’s time table because he could not be left on his own which meant that Pauline was doing the vast majority of the care and was not able to work fulltime. Holidays have always been chosen with Darryl in mind. Over the years he has progressed from going on caravan holiday’s when he was small to now only going to hotels with a swimming pool. Having Banger Racing nearby is an added plus.

The best thing about being a family carer has been getting to understand Darryl and helping him through life and seeing him achieve new things however small. However, Darryl’s autism means he does not respond well to change. Trying new things is difficult and for 31

years John has continued to take Darryl swimming every Saturday morning to a club that he and other parents set up.

However, the impact of caring for Darryl has meant that as a couple John and Pauline do not often get the chance to celebrate together as it is hard to get support for him. Pauline was only able to attend John's MBE ceremony because another family kindly let Darryl use their respite allocation so Pauline would be free to go. Even now they have to juggle their diaries to ensure someone is always at home for Darryl. Invites to attend events often do not include Darryl unless it is a family occasion which means that neither of them will go. When asked what the biggest impact on their life has been, John immediately said 'no spontaneity'.

If John had the chance to do change anything he said he would have done his job differently as he felt he never gave Pauline enough support.

Looking ahead John's biggest hope and dream is that Darryl will end up in a situation such as supported living where he is happy. His biggest worry is that Darryl may be placed elsewhere in the country in a place which he is unfamiliar with and with people he does not know. He does not want his daughter to have to look after Darryl although this is something she would willingly do. She has a life of her own bringing up her own two children although she and the grandchildren are all very involved with Darryl's life.

John does not class himself as a family carer – 'it's just something you have been doing all your life'. He and Pauline are Mum and Dad.