

Grant 4 Alan & DI Pagett October 2019

ADDOR is pleased to announce a further grant in support of the continued fight against Huntington's disease (HD), providing financial assistance to help an HD sufferer Alan Pagett and his family.



Alan & Dianne (Di) Pagett Story

Every story told to ADDOR by family and carers of sufferers, living with HD, is sad and tragic. Alan and Di's story is the most emotional heart breaking situation we have encountered.

Alan and Di met on holiday in Ibiza, in the 1980's and spent 18 months travelling between their respective homes, keeping their romance alive, before Di moved from Bedfordshire to Somerset. They married shortly afterwards.

Alan is now 65 years old and lived with Di in Axbridge, Somerset. Three years ago Alan collapsed with a seizure and after a scan at the Musgrave Hospital the family were told, he had a glioblastoma brain tumour. Alan was then transferred to the Southmead Hospital, Bristol for assessment and prognosis. The Doctors at Southmead said without surgery Alan had three months to live but they could partially remove the tumour and with chemo and radiotherapy, hopefully prolong his life for 13 months!!!

During the visit, an attending nurse noticed Alan's twitching movements and mentioned to Di that she felt that he may have HD. As a patient needs to remain still whilst having radiotherapy, medication was prescribed to control his movements to ensure a successful procedure. A blood test was also undertaken, the results some 6 weeks later confirmed Alan also had Huntington's disease.

This was shattering news to a family, trying to come to terms with the brain tumour diagnosis. Di who had helped care for an HD sufferer in the past, understood the devastating impact for someone living with HD. Looking back, she realised that certain health issues Alan had previously suffered from, could have been due to the onset of HD. 10 years before Alan had broken his shoulder and both collar bones after unexpected falls at work and when playing football.

Which side of Alan's family he inherited the HD gene from, is not certain, as his father died of a heart attack some years ago. However Alan's mother who is 87 and in a residential home, has shown some of the characteristic symptoms of HD, with her lack of co-ordination and she

has suffered a number of falls. Doctors are reluctant to do blood tests to check for HD, with a lady of her age, concerned as to how she will react and worried about possible confusion, if she is given counselling. It is highly probable that Alan's mum, carries the defective gene.

Alan has two siblings, his sister has been tested for HD and thankfully she does not carry the gene. His brother, as yet, has chosen not to be tested.

Alan and Di have three children, Vicki 37, who has MS and is reliant on a very expensive drug to help her cope with her condition. Stacie 34 who is married, with two children Pippa 5 and Jude 2. Son Joseph, who with his partner, have a daughter Sienna 3 and a recent addition with the arrival of a little boy, Finley.

When I first spoke with Di, she said "at the present moment the children are extremely worried about having the blood test to confirm, whether or not they have inherited the HD gene, for myself I would want to know". Attempting to alleviate Di's concerns and anguish over this decision, I said "for me there is no right decision, the decision to test or not has to be a personal one, made within your own feelings and circumstances. Daniel, my grandson chose to be tested and it was confirmed he had the faulty gene. He is showing strength and courage in facing the reality of his future. Others tested have been unable to cope with the positive result and in some cases, taken their own lives. Nancy Wexler 74, who heads the Huntington's disease Association (HDA) in the USA, her mother and other family members died from Huntington's related diseases, she and her older sister Alice, decided not to be tested. My words may not have calmed Di's worry, but they seemed to give her a measure of comfort.

Di went on say "Alan worked as a self-employed plasterer and general builder. He was a very fit active man, loved playing football and enjoyed a game of skittles or darts in the local pub. We have been married for 36 years and I can't imagine my life without Alan. I tried very hard to keep Alan at home, with two carers visiting daily to enable me to carry on working, however he began to suffer frequent falls and after a three week period in hospital, when he became more immobile, the only option was to get him the needed specialist help and move him into a care home. Alan is now resident in the St Michael's Cheshire Home in Axbridge, fortunately this is literally 2 mins away from me in the car. He now has one to one specialist care, 24 hours a day".

She continued "our lives, until now, have been happy, with so many wonderful memories, but my future does feel like it will never be the same, as I watch my husband deteriorate daily and every time I see him, he looks so sad. He was and still is the very lovely man, I met, fell in love with and married and everybody loves him".

Our conversation was very emotional, for me because of my grandson and understanding what Di is going through. For Di, it was coming to terms with her husband's imminent demise, trying to cope with the everyday strains of family life, making sure she visits and spends time with Alan every day, keeping on top of her job, concerned she might lose it, worried about her family, her daughter with MS, the children's fears of living with the HD ticking time bomb and the potential risk to their children and her grandchildren. There are other problems, Alan was refurbishing the family home, before he became seriously ill, that work is in-complete and there is much still to be finished, the flooring needs to be fixed, the boiler is not working, the only hot water available is from the electric power shower. In addition Di is at a financial crisis point, as she is co-signatory to the Business Account, Alan had with a bank. As a result she is now responsible for the outstanding overdraft debt on the account and must pay this off. The bank does not help her situation, adding unnecessary

pressure by pushing for the monthly payments before the agreed due date. If Di had not been a co-signatory, when Alan went into the Care Home, the debt would have been cancelled. Di said "I am at my wits end, with the stress and daily pressures of life", struggling to come to terms with, as she put it "living with the impact of this cruel and heartless disease."

Di's local HDA Special Adviser Shirley who initiated the request to ADDOR for a grant wrote "I have a family that would greatly benefit from financial help. The gentleman, Alan shortly after a scan showing he had a brain tumour, was diagnosed as having HD. He is terminally ill and been moved into a Nursing Home to provide the 24 hour specialist care needed.

His wife is amazing. She works fulltime caring for adults with learning difficulties and visits Alan for several hours every day. Unfortunately they still have a mortgage. Before Alan was taken ill he had been doing work on the house until he became too unwell to carry on. There is lots of unfinished work and although Di has had help from friends, she does not wish to ask too much of them. Di is currently having to work more hours to pay the mortgage and utility bills.

When I speak to Di she naturally becomes emotional, is upset and stressed most of the time but still somehow manages to hold it together to visit Alan and to go to work. Many people would have taken time off work but she is a hardworking lady dedicated to helping people. She is always grateful for visits and a listening ear.

I would be very grateful if this family could be considered for a grant to help financially, possibly a respite break."

When ADDOR advised Shirley we were giving positive consideration to the request she wrote "Di is overwhelmed with emotion that she is being considered for a grant to help her."

Di herself wrote "thank you for contacting me, I know from our conversation that you totally understand how I feel."

ADDOR is very pleased to provide a grant of £500 to Alan and Di to help them at this difficult time. We only wish we could do more.

When ADDOR confirmed the grant, Shirley wrote "Thank you so much for your kindness to Di, Alan and their family. They are a remarkable couple coping incredibly with all the challenges that face them. This will mean so much to them."

Di herself responded "O my god you will never know how you have helped me. You are my guardian angel, I've literally got no funds until I get paid next Friday. I am so grateful, again thank you so much, I am crying with gladness".

ADDOR is merely a conduit, the guardian angels are our donors without them we could not carry out our work.

In conclusion it is hard to see how the family cope, hold themselves together and remain positive at this time. Sadly Alan has only a short time left, living with his terminal illness. It would certainly be a kind "caring in the community" gesture, if the Bank cancelled the Business debt to help his family. ADDOR wishes Di and her family well and if we are able to again help in the future, we will do so.

If you would like to help us in the continuing fight to defeat HD, fund research and help other sufferers and their families, like Alan and Di

please donate using the PayPal buttons at the top and bottom of this site.

Grant 5 Alan & Di Pagett November 2019

ADDOR is pleased to announce an additional grant made in support of the continued fight against Huntington's disease (HD), by providing further financial assistance to help an HD sufferer Alan Pagett and his family.



Alan & Dianne (Di) Pagett

In October 2019 ADDOR made a grant to help Alan, Di Pagett and their family. Alan sadly not only has a terminal brain tumour but also has Huntington's disease (HD). The family are suffering severe financial hardship from the impact of living with HD, despite Di working overtime to try and pay her way. Di is also responsible for debts arising from Alan's business bank overdraft, which is an additional burden on the family.

Di was extremely grateful for the original grant in October but in desperation reached out to ADDOR to see if we could further help the family.

ADDOR is very pleased to provide an additional grant of £200 to Alan and Di to help them at this difficult time.

If you would like to help us in the continuing fight to defeat HD, fund research and help other sufferers and their families, like Alan and Di please donate using the PayPal buttons at the top and bottom of this site.