

What is good care for me, for my partner and for our patients.

What do you think is important in order to take care of all family members involved.

A diagnosis of Huntington's Disease in a family is a traumatic and devastating diagnosis. For families who have lived with HD, it never gets easier no matter how many diagnosis you have dealt with before. For families who receive this news for the first time where there has been no previous or obvious history, it is almost impossible to comprehend and even harder to accept. That was the case in my family when my mother in law was diagnosed with HD completely out of the blue. When my husband was diagnosed three years later we had to take HD on board as this had now become our reality.

Initially what was good for us – **time**. The first thing we did was contact the Huntington's Association and got as much information as we could about the disease. Informing yourself with correct information is essential. Then we began the process of dealing with shock and grief, the five stages that we know so well, Denial, Anger, Bargaining, Depression and finally Acceptance, we all needed that time for the progression of our thoughts and feelings and to come to terms with it, only then were we in a position to move forward.

After that time, we approached the Association again, this time being more able to engage. Talking to someone in the association was reassuring to us. Meeting other HD families through planned events organised by the Association was very educational, helpful and empowering and it also gave us a feeling that we were not alone. You cannot underestimate the power of peer support, talking and being with people who are thinking your thoughts, feeling your feelings and living a life exactly like yours. You meet people who are further along the HD road and they provide

excellent advice and wisdom. They and the Association advise you on what services you will need and the best way to go about linking in with these services.

It is so important from the outset to set up a strong team around you, a Neurologist, Psychiatrist, GP, District Nurse, Physiotherapist, Speech and Language Therapist, Occupational therapist and Nutritionist. It may not be necessary to engage with all of these services from the very beginning, but having them on board means it is easier to access their services when the time arises. I know that some areas within countries and indeed from county to country availability and access to services differ. Some places have better services than others but it is vital that you link in with as many areas of expertise that is possible to access. Ideally, what would be good would be to have some appointed person like a case manager who would liaise with all the specialised disciplines, thus taking that weight off your shoulders. In my case I did not have a case manager to help me and it did add a considerable burden to my daily life in caring for my husband.

What is really important also within a HD family is communication. When my husband was diagnosed through diagnostic testing, he was already very symptomatic. Our children were very young at that time, all under the age of 10. We did not have any real family support, my husband's family were in denial and most of my sisters did not want to know. We decided from the very beginning to have a totally open approach to HD within our own family. We did not hide the disease from our children; we told them about it and answered any questions they had about it. We made the information as simple as possible in a way that they would understand. Every month or so I would have a little tea party and we would discuss how they felt dad was, could we do things differently or what new things did they think we should try. By including them and involving them in these discussions, it made a very difficult situation normal for them. As time went on I saw that two of our children had no problems interacting with their dad but one had. She found it difficult to deal with his symptoms so I put her in charge of the paperwork. I prepared and updated a list of his appointments, when he needed new prescriptions and when his next sick certificate was due. It was her job to look in the file and remind me when things had

to get done. She was very good at this and in her mind she was just as actively involved in his care as her siblings were. Gradually, at her pace she then became more involved with dad.

When it came time for my husband to give up work I had already sourced a day centre to which he could go. Initially it was difficult for him to go there but after the first week, he loved it and looked forward to going. This centre provided him with a forum to keep him involved with people and many activities to participate in, such as art, pottery and gardening to name a few. It was so good for his mind and his wellbeing, he was involved and active, he had a purpose in life and he felt good that he had his contribution to make at family dinner time conversations. Consequently, his happiness and fulfilment in life had a very positive effect on all of the family. It also allowed me to continue to work and I had to, to support the family.

For partners it is crucial that you keep your own identity, and not just become “the carer”. Surround yourself with people who care about you; be there for you in good times and in bad times. People who will support you, make you laugh and offer a shoulder to cry on when needed. Try if possible to continue with your own hobbies and make time for yourself, even if it is only for short periods of time. You are the one who will shoulder the responsibility of holding a family together. If you do not take care of your own physical and emotional needs, then it could have a very detrimental effect on the family as a whole. It is also important that children, especially if they are young can also maintain their own interests and hobbies and not be totally taken up with caring for their parent. Over time my husband’s physical symptoms became so bad that it became almost impossible for me to bring him and the children safely out on trips, thus making our lives very isolated. So then I open our house, everyone came to us since we could not go to them. Our home became the meeting place and the children did not lose out. My husband is in full time care for ten years now but even to this day, our home is the place where all friends congregate.

What really worked for us too was having the “end of life” talk as soon as my husband was diagnosed. I was very lucky that he felt very strongly about that. He wanted to make his will and also an enduring power of attorney. He knew what he wanted to happen and more importantly, what he did not want to happen. He insisted on no peg feeding, no intervention and no resuscitation. When he eventually went into full time care he talked to the doctor and made his wishes very clear. That was recorded on his file. Having that talk with his doctor empowered him, he knew that he had a final say in his care, right to the very end. Every six weeks or so I would ask him “have you changed your mind”. He always said no. I am very confident in my own mind what his wishes are, and so, when it comes to the end of his life, the decision is already made. That in itself gives me a huge amount of comfort as I think no spouse or partner wants to have to make that decision. It is so difficult sometimes for families to broach the subject, they just do not know how to. Within our own HD Association, we have organised that someone from the Hospice come to our annual meeting and gave a talk on end of life issues. They also brought booklets and leaflets. Having this talk was very beneficial to our members as it introduced the topic, gave people time to think about it and made it easier for them to communicate. You could also ask a doctor or social worker to broach the subject if it too difficult for you to do it.

I know every family’s situation is different, but these are some of the ways that worked for us, that gave my husband the best care possible but also for the children and myself to maintain a good quality of life.

Thank you for your time.