

# Partner stress.

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## Extracts:

.... . Now the whole family is in my bedroom and we are all in tears yet the words keep on going, I thought the worst was over until I heard my husband say to my son, you have no idea how much pressure I am under. Just walk one day in my shoes (and then he directs the next comment by pointing towards me and says,) and then deal with this. This!!!! I am now being referred to by the disease, what happened to who I use to be, a wife a mother? For the first time I felt like such a burden, all I could do was cry. I wanted desperately to be left alone. This is not the true picture of my husband who is a very loving man who would do anything for his family but he appeared to be transforming as a result of the pressure this disease brings with it. He works long hours, cleans, drive the kids all over, grocery shop, you name it but it is now taking its toll on him. This is a man who has so much stress on him I worry now for his safety. I refuse to let this disease destroy our family> I know how difficult it was when my dad was carer for my mom. I use to worry he was going to have a heart attack. THERE IS A LOT OF STRESS ON CARERS WE NEED TO ALWAYS BE LOOKING OUT FOR THEM. I will do what ever it takes to bring us closer rather than pull us all apart. Today we all talked. We communicated our feelings as EQUALLY everyone's feelings should count. There will always be the good, the bad and the ugly, but if a family is going to stay healthy, it will take everyone working together and respecting each other to not let ALS destroy everything on its path. I am thankful we had a wake up call and hope we now have what it takes to never let it get that out of control.

**(2008)**

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Carers from outside your home can be a huge stress reliever and we are not wealthy and have adjusted

our budget accordingly to ensure that life is not overwhelming for my husband. It works even if no one really likes the intrusion.

**(2008)**

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My husband Tom (pseudonym) was diagnosed with MND in November 2006 and died September 2009. At the point that Tom died he was still about to speak and eat/swallow, but was unable to walk or use his arms. This meant that he was totally dependent on other people to meet his daily needs ie showering, dressing, feeding and toileting. The first six months following Tom's diagnosis was emotionally particularly difficult. Nobody was able to mention Tom's diagnosis to me without me dissolving into tears. ... The first year in our new house was in many ways quite exciting. Tom and I planned a garden together. As he got progressively weaker I took on more and more of the manual tasks, with Tom doing the directing. I developed skills and interests that I didn't know existed. The second year things were more difficult because Tom's arms became so weak I had to take on more and more of his personal care challenges. Community nursing support kicked in just short of a year from diagnosis. I continued doing Tom's personal care, and the community nurses did the weekly housework so that I didn't have to worry about that as I was still working full time. Tom and I decided it was important for me to continue working, and I did so right up until 4 days before he died. I used to feel guilty as I left the house in the morning. I was able to continue working, whereas Tom was not able to. The second year following Tom's diagnosis became increasingly difficult and nursing hours were increased. Walking became more difficult, but Tom

was still able to hold his own weight for short periods of time.

The last 9 months of Tom's life was the most difficult of all. We had 28 hours per week of nursing time. Days began at 5am when I would get Tom out of bed using a hoist, put him on the toilet, shave and shower him, set him up on his laptop computer before heading to work. Generally I would return home from work by about 4 -5pm, finish dinner that had been already prepared by a community nurse, feed Tom, complete evening ablutions, and use a hoist to transfer him from his chair, eventually his hospital bed to our bed. At that point I would collapse into bed myself, completely exhausted, not having had any down time or time to myself. I couldn't even leave the house for a walk as Tom needed 24/7 monitoring.

In the last nine months I began to feel my life was on hold, I was at Tom's beck and call. I began thinking about what life would be like when he was no longer here. On some days I felt that I couldn't continue on. Tom became short tempered when he felt that I wasn't being considerate enough, or careful enough when I was moving him. He would occasionally say that he was a burden, even though I tried to reassure him that he wasn't, but in fact sometimes I felt that he was. For the last 3 months of Tom's life my sister would come one evening a week to give me a night off. I used to look forward to those evenings with excitement. I would sometimes go and meet a friend for a meal. Sometimes I would stay home and my sister would do the evening ablution routine.

I attended a counselling session provided by the hospice in an attempt to provide me with some emotional support about six months before Tom died. I found the session was not helpful at all. The reason for this was that when I gave some examples of the sorts of things Tom would say to me, the counsellor would assure me that I didn't deserve to be spoken to in that way. What I said to the counsellor was I knew that if it were me in Tom's position, I would be an absolute Cow, and not nearly as patient as Tom was. I came to the conclusion however, that the situation was temporary and I needed to bite my tongue when I was upset at

anything and let it go. I did find this so difficult though, and resentment did build.

Following Tom's death I have felt guilty - that I could have been more patient, that I could have been more understanding. I know though, that I did the best that I could with a situation that was so difficult and challenging. I believe that Tom knew I was human, and that I was fallible.

Give yourself space, allow yourself to have a life separate from the disease because it can take on a life of its own. Be prepared, plan, read - be informed. Tom did not read about the disease whereas I read all I could get my hands on. My role was to be Tom's advocate, to fight his fights, to put things in place before they were needed (wet area shower) and to ask the difficult questions. It can be a thankless task at the time but remember you have to live with yourself when the person you love has passed. Be confident that you did the best you could while allowing yourself to human.

**(2010)**