



PROFILE

Joyce Stokes

LIVING WITH MULTIPLE SYSTEM ATROPHY

“Being mistaken for a drunk when you are trying to do some shopping and ask for something is a real trial”

Joyce Stokes from Wicklow was diagnosed with the neurodegenerative disease, multiple system atrophy (MSA) in 2014, she was just 41, with a young family to look after, when her initial diagnosis of Parkinson’s Disease was reassessed and MSA was diagnosed.

She feels very lucky that her local doctor has been willing to research and find out about the disease to enable her to get the support she needs from speech and language therapists, physiotherapists and other services. So many professionals in the health and care sector have never heard of MSA and when Joyce was admitted to hospital recently because of a fall she found it hard having to explain what was wrong with her that caused her fall.

Affecting all autonomic functions, MSA causes a person to become trapped in their own body. As Joyce says: ‘being mistaken for a drunk when you are trying to do some shopping and ask for something is a real trial.’ She needs time to form her words and with her speech slowing down even further, Joyce wonders why everyone must rush so much.

The disease is slowly denying Joyce of all opportunities to mix with other people. She feels embarrassed about speaking or walking in social situations. She is becoming more confined to the house.

She finds Katie, the MSA Trust Nurse

Specialist who travels to Ireland for a week every quarter to meet with people who have MSA at support groups and MSA clinics, a lifeline. Her family has the opportunity to discuss any changes in symptoms with Katie and ask for advice when medication is changed, or dose altered. Katie also communicates via email when Joyce is too tired to speak.

One of the hardest things for Joyce is trying to support her children as they watch their mother deteriorate and they get upset by the lack of empathy from their peer group and unkind comments when they see their Mum struggle with her walking or speech. Lack of understanding about Joyce’s condition is incredibly hard on all the family.

RARE DISEASE

About Multiple System Atrophy (MSA)

MSA is an indiscriminate neurodegenerative disease affecting around 3,300 adults in the UK and Ireland. Roughly 4 people per 100,000 are affected. Its cause is unknown, and average lifespan from initial symptom onset is just 7 years. There is no cure.

Affecting all autonomic functions, MSA causes a person to become trapped in their own body. Over only a small number of years, they experience problems with swallowing ranging from uncontrollable drooling to choking on the smallest piece of food; vocal cord paralysis rendering communication with loved ones virtually impossible; impotence; and total incontinence. They become unable to walk, and eventually become entirely bedbound. Towards the end of their life they require around the clock care. Intellect, along with the ability to feel pain, does not diminish in any way.

Due to its appalling symptoms, it is unsurprising that in MSA Trust's recent survey, 80% of members with MSA reported feelings of depression, and 82% said that a reduced ability for them to carry out social activities had led to social isolation.