

The state of play October 2021

I can't speak, eat, drink or swallow anything except foul saliva and thicker liquids, all produced by the body. The mouth, mostly paralysed, is under permanent attack: sudden disgusting tastes, then sudden total dryness, then sudden flooding. At any time, unexpectedly, coughing starts, and can lead on to choking as some thick liquid blocks the air pipe. Many times I don't have the strength to cough it up, and when I do I pray that I can then easily swallow it. Awful.

Head drop and teeth. The human head is heavy. With no muscles left to support it, mine is on my chest, total weight, teeth clenched, with difficulty breathing. The only relief is by wearing a very uncomfortable neck brace which I can stand for 10 minutes, or to find a seat position with a particular support for the lower spine. In my flat the sofa has it; and the garden lounger now in the living room and tilted back; and an arrangement of pillows in bed. When walking without the neck brace I hold my head up with my ever-weakening right hand. Without support the head slumps on the chest with the teeth in the wrong position – the lower teeth outside the upper. This puts a strain on the upper teeth. They are becoming loose.

I can walk very slowly but can't balance so I need a stick or a walking frame. The left foot drags along the floor so I wear a leg/foot brace which lifts it. For exercise either I go up and down the 12 steps inside the flat, or I use the walking frame to do static stepping. 30 steps tire me out.

The left hand and arm are almost useless. The right hand and arm are weakening noticeably. I fumble and drop things all the time. Almost everything I try to do manually is ineffective or extremely difficult. Typing is now more or less one-fingered. Hand writing is easier – fortunately I'm right-handed. When the right hand fails, communication will be a real problem

Sleep: the interruptions are fewer but to get some hours sleep during the night the pillows have to be arranged, and then later rearranged, for different positions. Sleep deprivation is adding to the troubles.

Energy level is close to zero. The daily pattern? Bed to sofa to bed to lounger to bed to sofa, etc.

Tim is here now, and helps with almost everything. I do need 24/7 care.

Let's not prolong this. I could write so much more, giving graphic examples of the multiple difficulties each day, but why? This is enough. The motor neurone disease is accelerating. I will have to make a decision about the future in the next few days.

That's all for now.