

STATE OF PLAY as of Tuesday 8 December 2020

In the last 18 months there have been so many new words and long words – medical terms. I'm not unintelligent; I understand them and how they relate to my condition; but I often prefer to use more commonplace words (don't tell the doctors!). It seems more human.

Brief background:

Early 2019 some strange feelings in the mouth, and some slurring in speech. Tests. July 2019 diagnosed with MND/ALS. More tests. October 2019 MND/ALS confirmed. It's terminal – no treatment, no cure. It will spread at its own pace and so far no one can stop it. For ease I'll use 'MND' from now on.

MND can start in many parts of the body, often manifesting itself when someone starts dropping things, or when a foot doesn't behave properly. In my case it started in the mouth and throat. I have MND 'bulbar onset'. That was the first new word, 'bulbar'. Quote: "The brain stem (also known as the bulbar region) controls the muscles needed for swallowing, speaking, chewing, and other functions"

As of today:

The mouth has mostly stopped functioning. The lips have no power and they can't close without strong jaw effort, which doesn't last. As a result they can't prevent anything that is in the mouth coming out, and the mouth is open virtually all of the time. The tongue is completely paralysed, so it can't direct food or liquid down the throat (risk of blocking the windpipe – no need to say what *that* might lead to). Because the mouth is mostly open the tongue is completely dry. The muscles used for swallowing have 99% stopped working also, so there's no point in me trying to eat or drink. With lips, tongue and other bits permanently unemployed, I can't pronounce most consonants. Normal speech is at an end.

Here's an exercise for you, and maybe some fun: Say this without sounding any consonants: "What's the weather like today?" It should come out like "Wa er e'er I o'ay?" Challenge others! Spend 10 minutes chatting like that! New Christmas game!

There's also a paradox, at least in my body. Most people produce between 1 and 1.5 litres of saliva each day. The tongue and other muscles direct the liquid round the mouth, lubricating every part, and then back, tidily, down the throat. Mine don't. The only way saliva can leave the mouth is out through my helpless lips. It's a well-known phenomenon of MND, and the medics have tried three ways to slow it down: a 3 -day patch behind the ear, special liquid to be swallowed, which I can't now do, and botox injections into the salivary glands. Had 'em all. Not much effect. Spend my days with cloths held to the mouth, catching the darn stuff. Then there's the tongue, so dry that I'm having to take gels and sprays, but they're not working. So how can it be that so much saliva doesn't lubricate the tongue? Probably because the tongue needs to move to get itself lubricated, and it can't move.

What's the visible result? I've been called an idiot many times over the decades, but now I *look* like one: mouth open, strange sounds, drooling. The new me!

The rest of the body:

Brain working more or less OK I think, but very short term memory is suffering. I'm forgetting many recent things, and that has happened quickly, too quickly for it to be just 'ageing'. That might be why I'm also fumbling: co-ordination of arms and hands is a noticeable problem.

Weight down to c.74 kilos, from 90 a year ago, but it's stable and I feel well at this weight.

Tiredness: a serious problem but it comes and goes. Doesn't seem to correspond with sleep: there are days where I feel I've slept well but then exhaustion hits me around 10.am. Unpredictable.

The 'bulbar affect': note *affect*, not *effect*. This is another annoying and embarrassing result of MND and, I think, of other illnesses. If something makes me laugh I can't stop: the giggles go on and on despite my inner fury. Sometimes it then turns to crying, for no logical reason and with even more fury. Similarly there's this: we're all emotionally moved at times by something said or seen, and some people cry easily. DP doesn't ... or didn't. Now I find that a phrase, a look, a moment of pathos, can trigger instant tears, and I can't control that either. I'm one of the few who can say "Thank goodness for lockdown!". Hardly anyone can see and hear this. When we're all unlocked I'll put out a warning before anyone visits!

Energy: sadly very depleted at the moment, but I hope it's a result of the last 12 weeks, not permanent. What should have been a single hospital experience ended up happening three times: taken to hospital, settled in, six days each time of nil-by-mouth, cannulas and drips, continual checks even to midnight and starting at 6.30am, stretchered by ambulance to another hospital, briefed on the operation, put on the operating table, sedated twice, ambulanced back, more days of cannulas, final transport home. And since the last and successful one, just over three weeks ago I've been struggling with the new way of getting nutrition down, through the pipe.

Walking: I'm a bit flat-footed. It's the peroneal nerve palsy, slightly numbing the toes and ankles and apparently not a result of MND; just a coincidence. It could have been caused by long hours sitting cross-legged while isolating during lockdown. I pride myself that it's related to Housemaid's Knee. And one has to be careful with spelling – and autocorrect – these days: it would be easy to write 'perineal'. I'll say no more!

Communication: speaking, telephone, video chats, almost impossible. Tapping the keyboard is the only way. I'm not a bad typist but often I type and then check and correct. The software and the machines that turn text to sound 'speak' when told, and it can take a while to get the text right. That's frustrating. The brain works reasonably fast, but people will have to wait for any utterance.

The PEG: it's in, just in time. Swallowing was difficult in September; more so in October; and almost impossible in November, so I'm very relieved. Hate the darn thing, but have got used to it. Six sessions of pushing the special liquids in take about 2.5 hours a day. At one point there were over 400 bottles of Ensure or ProCal – google them if you wish – under the

bed or in cupboards. The company provides a specialist nurse and delivers more each month. It's all free, on the NHS.

There's one other thing, and it's serious: coughing and choking. I'd expected that when the PEG was fitted the risk would reduce because I wouldn't need to eat or drink or swallow. Surprisingly nothing's changed since the operation. In fact at the moment there's a lot of phlegm or mucus or whatever the right term is, as well as saliva. Coughing fits continue and at times turn into choking. So far they've been controllable, but the medics have been asked for more help on this.

I think that's it. Life is rather slow: I've been out of the flat just twice since the operation but that's partly due to the weather. The MND will spread, so we must expect a general deterioration. The PEG is now keeping me going with good nutrition, so I hope that will always be a help, and if I can get my energy back it might delay further MND problems for a while. Not sure of that but hope so.

I'm hugely grateful for everyone's support and good wishes, and especially to Tim, blogmaster and great friend, for helping me through this. Thank you all.

Or as I now say "A U Aw"