Dear World,

I have issues with my eyesight, caused by a fault in my brain rather than by the optics of my eye. It’s called cortical visual impairment but I prefer to call it seeing things which aren’t really there - and that’s what people do with dementia ….they see things which aren’t really there.

They see the old ladies in the high back plastic chairs sitting in the corner of the care home drawling and dribbling. What they don’t see is Ron writing his musical - what they don’t see is Gerry organising the self-help groups; what they don’t see is Ian reminiscing about his time in the Navy; what they don’t see is Christine going on holiday with her friends; me painting pictures and podcasting, Irene in her campervan travelling around Scotland, Audrey standing up in front of a conference for the first time in her life. Mike, Gordon and Anne running that online course. The group in Stirling having that wild party, the team in Kirriemuir doing craft, the folk in Fife writing songs with Gus.

What they think they know is that dementia is all about losing your memory but I haven’t lost mine and I’ve got Alzheimer’s disease.
.Gerry has Alzheimer’s too but he is losing his memory - you see it’s all about which parts of your brain have been affected…so it’s all a bit more complicated than you think it might be

What they don’t see is the people getting together on zoom and consulting with the Scottish government about future strategy; what they don’t see is people with dementia doing things because what they think they see is people who are incapable, people at the end of their lives, who have lost touch with reality.

I didn’t want Alzheimer’s - in fact I needed it like I needed a hole in my head and that’s exactly what I’ve got and the precise location of the hole in my head determines my diseas. It doesn’t unfortunately determine what will happen in the future. I’ve got no idea and nor has anybody else - that’s one of the things that people just don’t know about this illness. The speed of progression or lack of it. Somehow people seem to only know about the end stages and talk of the tragedy and bleakness. Of losing personality. I call it misery porn.

Well bugger that. I’m in the early stages and I want to make the most of things. I know that clinically that’s good for me. I know staying active mentally socially physically is what I should do.

But we just not geared up for it: we’re not geared up to provide decent social care nor to provide decent housing. We’re not geared up for children to learn about dementia and mix with people with dementia - we prefer to hide people away and pretend it’s not happening.

And some of the charities are complicit in that because they need people to know about the misery so they can raise more money. Well, a pox on your misery a plague on your determination but we should all suffer… we’ve had enough

From now on we want things to change. We want services that involve us. We want a real say in our futures. We’re tired of being Guinea pigs in research programmes, of being passive recipients of charitable largesse. We aren’t sufferers from dementia, we are people who just happen to have dementia. We are people with individual wants and needs. People who think our terminal illnesses should be treated with the same care and concern as other such conditions.

We look around and see the funding that goes into heart care. We note the Maggies Centres for cancer patients, with its free counselling and support services. We note that dementia is the number one cause of death, but dementia research has one eighth of the funding of cancer research.

We see the cavalier way that people with dementia are too often discarded as worthless. And we say that this is an abuse of our human rights, and needs to change.