A few years ago I began to fall over - I couldn't run, I banged my knees, became clumsy, cantankerous, and withdrew from the world. After 25 years as a performer and maker, both with my brother in Ralf Ralf ,with my own company, then solo work, and with "Hot Mouth" in New York, I tried to ignore the falling but people said you really should find out what is happening to you.

I didn't want to admit there was something wrong. I went to doctors who after many X-rays, electrical nerve tests, MRI scans , eventually gave me a diagnosis. On March 30th 2017 after a genetic test at UCL Hospital in Queen Square I was diagnosed with Spino-Cerebellar Ataxia 17. 'Incurable degenerative genetic condition', the doctor told me. Eventually I would slur and slobber, lose limb control and end up in a wheelchair.

I was relieved to be diagnosed, to put a name to my condition, but it scared and disorientated me. I found out more: "a 76% chance of developing dementia", a supposedly helpful fact sheet told me. When it actually undermined me. My confidence was in tatters already and the diagnosis amplified my physical and mental vulnerability.

I started using a stick for my balance, but after a few months, I realised my fear made things worse. Fear tenses muscles and tight muscles are less able to do many simple things, and less able to flow, less able to feel and deal moment to moment with the world. To tackle this diagnosis I needed to feel and be aware of what was happening to me.
'Pretend it doesn't exist" someone said. 'Its all psychological!'
'Er yes', I would say, 'But it does exist! I fall over! I bleed!'

Although I was depressed and scared, giving in felt wrong. I wanted to be cognisant of what fortune had dealt me and then deal with it. I had a chance meeting with a neurologist who explained epigenetics to me. Briefly, scientists used to believe genes determined everything- how your life went, when you got ill, when you die etc, but recently its been shown that its what triggers genes that determines what happens. So even though my diagnosis is indisputable, even though my walk was funny, the genes that will stop me walking and speaking and put me in a wheelchair haven't been triggered yet.

But I am now 62. I have always made performance.
What am I going to do?
How do I adapt my life towards a pragmatic way of living?

Now, with my physical limitations, I can no longer jump around stage, but I still have hand-eye co-ordination, and am able to sing, speak, think and write.

There has to be a way of recovering from my diagnosis and adapting my life. Focussing on what I do know about performance, about working across cultures, about audiences, about music. I am tired of people saying it is unrealistic now, to expect to make a living as a performer, but it is what I do. For me, t's more about finding freedom within my physical limitations.

In performance I like using mistakes, keeping going whatever … I'll use any mistakes that my Ataxia causes..I try to get it right, but if I mess up, so what? Shrug it off! I always used the analogy of the performer being the doctor and the audience the patient. Now, post diagnosis, that seems more important than ever.

It is part of the craft of the performer to communicate with your audience; This is not, 'pandering to the audience's taste', it is treating your audience with respect, with intelligence, being aware of the issues of the zeitgeist. Meeting your audience. And what kind of performance?
I make music and I write. I have worked as composer and within groups.
I have written novels and devised performances..
I am not my diagnosis
I am a performer, writer musician.