

## **Can you hear me.**

I am honoured this year, to be delivering the annual Jack Ashley Memorial lecture, and would like to thank Mrs Jackie Ashley, President of Lucy Cavendish College, in the University of Cambridge, and Kamran Mallick, Chief Executive of Disability Rights UK, for inviting me to address you this evening. I understand Kamran Mallick is unable to be here this evening. I therefore welcome Sue Bott, as Deputy Chief Executive.

I remember listening to Jack Ashley during his time as a Labour politician from the sixties onwards. After suffering the total loss of his hearing in 1967 at forty-five years of age, he considered quitting as an MP. But was persuaded not to do so by his peers, and is later quoted as saying, I think there is nothing I can't do as an MP. That is my philosophy exactly. Jack Ashley was deaf for nearly all of his Westminster career, but tirelessly worked to support the disabled and disadvantaged communities. As Chair of the All Party Parliamentary Group for Disability he initiated many of the bills which helped to create the Disability Discrimination Act in 1995. Through this role he also helped to establish The Chronically Sick and Disabled Persons Act 1970. His political career was influential in the lives of the disabled and disadvantaged in so many different ways. He remains to this day an inspirational role model for us all.

The plan for my talk this evening is to say something about my life with MND. To start my story, some of you may have seen from the film, The Theory of Everything, in which Eddie Redmayne plays me, in my third year as

a student at Oxford, I noticed that I seemed to be getting clumsier. I fell over once or twice, and couldn't understand why. I was somewhat disgruntled to be told by a doctor at the time, to lay off the beer. A year went by, and I had moved to Cambridge to undertake my PhD, but one Christmas, I went skating on the lake at Saint Albans, my home town, and I fell over again. But this time I couldn't get up, so my mother took me to the family doctor, who referred me to hospital for tests. I was just over 21 years of age.

It was 1962, and the tests then, were somewhat more primitive than they are now. A muscle sample was taken from my arm, I had electrodes stuck into me, radio-opaque fluid was injected into my spine, and the doctors watched it going up and down on X-rays, as the bed was tilted. After all that, I still wasn't told what I had, and gathered from the doctors' conversations, that it, whatever it was, would only get worse, and there was nothing they could do, except give me vitamins. I could see that they didn't expect them to have much effect. I didn't want to ask more questions, but I learnt, years later, that I had motor neurone disease. The realization that I had an incurable disease was a bit of a shock. I felt it was unfair. How could something like this happen to me.

I had no idea what my future would turn out to be, so I returned to Cambridge, to carry on with my research into general relativity and cosmology. While struggling with my illness, I was still able to make important advances in our understanding of the universe. In particular I showed that the universe had to have had a beginning, in a

singularity or Big Bang.

But it was a confusing time, and I discovered Wagner with gratitude, as he seemed to me to be as tragic a figure as I felt at the time. It was also around then, that I met Jane, my first wife, and at the same time was awarded a research fellowship at Gonville and Caius College, in Cambridge. Incidentally, this is the same alma mater as Jack Ashley, we both attended the same Cambridge college. Things were looking up. I had a job, and the fellowship meant that Jane and I could marry, which we did, in July 1965. The disease progressed rapidly at first. But it then slowed down, and I got through the rest of the sixties and then the seventies, with some increasing disability. The birth of our three children, Robert Lucy and Tim, helped enormously with the difficulties of the motor neurone disease symptoms. I felt lucky, I never imagined that we would be able to have three beautiful and accomplished children.

It was a few days after the birth of Lucy, in 1970, that I had a eureka moment. While getting into bed one evening, I realized that the area of a black hole's horizon could only increase, not decrease. This eventually led me to discover that black holes were not really black, they had a temperature, and would glow red like hot coals. I had discovered a concept which is named after me, Hawking Radiation. My discovery was actually very controversial at the time. It is now accepted and understood, as being the key to unlocking the nature of quantum space-time. However, another thing it proved, and which is relevant this evening, is that a disability need not stop people thinking, achieving, and getting on

with life. We just have to find new ways of doing things. For example, my plan next year is to accept invitations to America and Europe, and, in the words of Jack Ashley, I can see no reason why I should not accept.

By the early 80s, I continued to get worse, and had prolonged choking fits, because my larynx was weakening, and was letting food into my lungs as I ate. In 1985, I caught pneumonia on a trip to Cern, the European Centre for Nuclear Research, in Switzerland. This was a life-altering moment. I was rushed to the Lucerne Cantonal Hospital, and put onto a ventilator. The doctors suggested to my wife, Jane, that things had progressed to the stage where nothing could be done, and suggested to her that they turn off my ventilator to end my life. But Jane refused, and had me flown back to Addenbrooke's hospital in Cambridge, by air ambulance.

As you may imagine this was a very difficult time, but thankfully the doctors at Addenbrooke's, tried hard to get me back to how I had been, before the visit to Switzerland. However, because my larynx was still allowing food and saliva into my lungs, they had to perform a tracheostomy. A tracheostomy, as most of you will know, takes away the ability to speak. For a while, the only way I could communicate was to spell out words, letter by letter, by raising my eyebrows when someone pointed to the right letter on a spelling card. It is pretty difficult to carry on a conversation this way, let alone write a scientific paper. Your voice is very important. If it is slurred, as mine was, people can think you don't understand things, and treat you accordingly. Before the tracheostomy, my speech was so indistinct,

that only people who knew me well could understand me. But at least I could communicate. Life went on.

Luckily, and somewhat surprisingly, a computer expert in California, named Walt Woltosz, heard of my difficulties. He sent me a computer programme he had written called Equalizer. Today I use a program called acat, developed by Intel, which I control by a small sensor in my glasses via my cheek movements. When I have typed what I need to say, I then send it to a speech synthesizer, which relays it in the voice which is recognizable as belonging to me. I identify with this voice, and have no intention of changing it for a more naturally-sounding one. When I controlled the programme with a hand switch, I could boast that I could talk with my mouth full. Now that I use a cheek switch, I can no longer say this, because chewing activates the switch, and what I would say would be nonsense.

However, the situation with my larynx was not improving, and I was finding it increasingly difficult to eat and breathe. It was then a second life-altering coincidence occurred. In 1998, my second wife, Elaine, and I, were on a flight to Crete to attend a conference. A fellow passenger on that flight was David Howard, an Ear Nose and Throat surgeon. He introduced himself as he had been watching me struggle to eat and breathe, and he told us that he could probably solve the problem for me, as he was a surgeon in London specializing in reconstructive throat surgery. We exchanged contact details, and I began to consider David's offer. After a couple of weeks, David Howard came to our home, to explain what his surgery would involve. It was clear, the

risks of the laryngectomy surgery, were overwhelmingly outweighed by the risks of no surgery. I decided to have the operation. I was admitted to the old Victorian hospital, the Royal National Throat Nose and Ear Hospital, in Gray's Inn Road, London, on the fourth of May 1999, less than a year after that coincidental meeting on the flight to Greece. I was discharged sixteen days later. That was 18 years ago.

Thanks to David and his team, my laryngectomy made my lungs safer, and my work of breathing easier, and I was able to breathe on my own for a further five years. However, in two thousand and four, my levels of oxygen began to fall at night, and I was rushed into hospital, where I remained for four months. I was eventually discharged with night-time ventilation, and the doctors told my wife that I was coming home to die. I have since changed my doctor. For the last six years, I have been on full-time ventilation, using a ventilator on the back of my wheelchair.

Sometimes I have had to challenge medical opinion, to get the care I need. But the important thing is, that the principles of the NHS, mean that there is good care available, and that it is provided, at the point of need, to everyone, without regard for personal circumstance, or ability to pay. These are the principles of universal and comprehensive provision, on which the NHS was founded. It is important that care is available, without any of the added burdens for people, that come with private health insurance. My team and I have had experience of dealing with health insurance companies in the US, and that disappointing experience shows that

a health insurance company will try its best not to pay.

In September 2016, together with Professor Robert Winston, and Professor Neena Moedee, President of the Royal College of Paediatrics and Child Health, I co signed a letter to the Guardian newspaper, calling for health care policy, to be based on peer reviewed research, and proper evidence. The specific issue on which the letter was based, was the so called, weekend effect. Secretary of State for Health, Jeremy Hunt, had claimed that thousands of patients die unnecessarily, because of poor hospital care at the weekend. He used this, as an argument that we need to implement a seven day a week NHS.

I had mixed feelings about the issue. Having spent a lot of time in hospital, I would like there to be more services available in hospitals at weekends. It has been frustrating for me personally, when everything slows down at the weekend in hospital. Also, it seems possible that some patients spend more time in hospital than is necessary, because certain diagnostic tests can only be done on weekdays. So in principle, a seven day service could be of benefit to patients, and to the NHS as a whole. However, any change like this, must be properly researched.

Let me quote from our letter, as it illustrates the point I want to make. We wrote, The evidence for these claims is not supported by reliable research. Of the eight papers cited by Hunt, only four are peer-reviewed. Three use data from the same population, and are not independent, with just two from the last decade. The

remainder are not peer-reviewed medical literature, and are only opinion pieces. Critically, when his claims began, at least 13 independent peer-reviewed papers were available to the secretary of state, that refute his definition of a weekend effect. Hunt has cherry picked research.

Speaking as a scientist, cherry picking evidence is unacceptable. When public figures abuse scientific argument, citing some studies but suppressing others, to justify policies that they want to implement for other reasons, it debases scientific culture. One consequence of this sort of behaviour, is that it leads ordinary people to distrust science, at a time when scientific research and progress are more important than ever.

There are two ways to think about a national health care system. One is that the most humane and civilized system, is one in which all people are provided for equally, based only on their needs, no matter who they are, rich or poor, young or old. I believe this, and have made public statements, that we must prevent the establishment of a two tier system, with the best medicine for the wealthy, and an inferior service for the rest.

The other way to think, is that a healthcare system needs to be organised in the most efficient way, so that there is as little waste of labour and resources, as possible. International comparisons indicate, that the most efficient way to provide good health care, is for services to be publicly funded, and publicly run. The more profit is extracted from the system, the more private monopolies grow, and the more expensive health

care becomes. For that reason, I have also made public statements, that the NHS must be preserved from commercial interests, and protected from those who want to privatize it.

So, these two things coincide. The most humane system is the most efficient system. This means that when politicians and private healthcare industry lobbyists, claim that we cannot afford the NHS, this is the exact inversion of the truth. We cannot afford not to have the NHS.

What is to be done. The NHS, and the question of how to provide good quality health care to everyone, is hugely complex. That doesn't mean that we cannot understand it in broad terms. To a first approximation then, one can see the situation facing health care in this country, in terms of forces with different interests. On the one hand, there is the force of the multinational corporations, which are driven by their profit motive. In the US, where they are dominant in the health care system, the corporations make enormous profits, health care is not universal, and is hugely more expensive for the outcomes, than in the UK. We can see a move towards this in the UK. Towards a US style insurance system, run by the private companies, because the balance of power right now, is with the private companies.

On the other hand, there is the force of the public, and of democracy. Opinion polls consistently show that the majority of the public agrees with me, and is in favour of a publicly provided NHS, and opposes privatisation, and

a two tier system. So the public already supports the core principles of the NHS, as the fairest system. But more than this, it should be recognized the NHS, is also the most efficient and cost effective system. The NHS reaches its 70th birthday next year. Let us hope that by then, we all have helped to influence much needed change in our much loved health care system.

I feel lucky, my disability has not been a serious handicap in my scientific work, and it has not prevented me from leading a full and active life. I celebrated my 75th birthday, with an international scientific conference in Cambridge, in June this year. I still have a full-time job as Director of Research, at the Centre for Theoretical Cosmology, at Cambridge, and am soon to publish another scientific paper on quantum black holes, with two colleagues. This is an exciting time to be a theoretical physicist. For example, the recent announcement of the detection of gravitational waves, ripples in the fabric of space-time, by the LIGO-Virgo collaboration, verified a longstanding prediction of Einstein's general theory of relativity. The detection of gravitational waves, was something I worked on at the very beginning of my career, so this advance in fundamental physics spans my whole scientific life.

Earlier, I said that we, as disabled people, must find new ways of doing things. Who would have thought that I would undertake international travel, visit Antarctica, dive into the depths in a submarine, and experience gravity-free space flight. I have written books – A Brief History of Time has now sold 20 million copies, world-wide. I have appeared in many television programmes,

including The Big Bang Theory, with its quirky scientific humour, and have lectured in the Albert Hall. I am not showing off. I am explaining that disabled people can do anything if they have a fierce will to succeed.

I plan to do much more, and I usually achieve my plans. All my international travel involves an entourage of dedicated assistants and nurses, and my fame protects me against some of the types of indignity that we often suffer. I campaign for the disabled community and enjoy doing so. Some of you may have seen my eyes staring down at you in the summer from a huge billboard in Victoria station. This looked quite scary, but was to raise awareness of the Motor Neurone Disease charity, and I was delighted with my Big Brother appearance.

I see everything that has happened in my life since I was diagnosed with MND, as a bonus.

Thank you for listening.