Disability lecture 2015 by Hilary Lister

Event details

Delivered 5 May 2015 at 6.00 p.m. at Corpus Christi College, Oxford.

Welcome by Professor Andrew Hamilton, Vice-Chancellor

Lecture by Hilary Lister

Vote of thanks by Dr Kylie Murray

This event was organised by the Equality and Diversity Unit and the Disability Advisory Group of the University of Oxford. For further information please contact equality@admin.ox.ac.uk

These are the speakers' notes which are provided to make the lecture accessible to a wider audience. They are not a verbatim transcript of the event.

Welcome by Professor Andrew Hamilton, Vice-Chancellor of the University of Oxford

Ladies and Gentlemen, I am delighted to welcome you all, and an especial welcome back to our speaker, Hilary Lister, who was an undergraduate at Jesus College, and to members of her family who are here today. We are pleased to see Professor Pauline Rudd, Hilary's mother, who was a member of the Glycobiology Institute here for many years, until her research group moved to Dublin.

We are here for a very special event: the University's first Disability Lecture, which has been organised by the University's Disability Advisory Group and the Equality and Diversity Unit. The University is committed to ensuring an inclusive environment where all members of the University can flourish. Many of you will be familiar with the activity to support greater gender and race equality. Those are areas where differences are very visible. However some aspects of equality are less visible, such as sexual orientation or religion and belief. Disability is an interesting area, since it encompasses both visible and invisible differences. There is further complexity about language, since many people who might fall within the definition do not consider themselves 'disabled'. This is a group of people may need to do things differently in order to achieved the desired end result.

I hope that you will all be able to stay after the lecture for refreshments, and I'd like to encourage you to talk to people you haven't met before and to have conversations about how to enable disabled people to flourish at this university.

When we are discussing what support disabled students or members of staff need to enable them to carry out their work, the concept of 'reasonable adjustments' is often used. This recognises that to get to get the desired outcomes, disabled people may need to do things in different ways to non-disabled people. Sometimes that means using technology to carry out particular tasks, which the person finds difficult to do because of their disability. Hilary pushes this further than most, in relying on her technology for controlling her boat at sea.

As a University we are proud of our long history, but we recognise that in order to remain successful we need to change. Our present surroundings provide a very good example of how this can be done on physical access: Corpus College has built a modern, accessible venue that anticipates that disabled people will be active participants in events. An inclusive environment for our disabled

students and staff is about far more than physical access, or even about providing creative and flexible support for individuals, important thought that is. It is also about attitudes and expectations. When we think of people who excel at extreme sports, I suspect that the first image that comes to mind is of a strong, powerful man and not a disabled woman with very little independent movement. Hilary shows us the limits of our thinking. Sometimes disabled people are limited in their aspirations at work and outside work, whether by their own fears or by the protectiveness of others. Hilary is an inspiring example of someone who refused to be confined, who has been setting her own challenges and meeting them.

We like to believe that an Oxford education equips our Oxford graduates to do anything. Hilary is someone who has made the most of her transferable skills. Clearly she is an expert at strategic thinking and has great problem-solving skills. She has well-developed executive skills to direct others to carry out her instructions. She definitely has very strong persuasive skills, to convince other people to lend her equipment and support her in achieving her goals. Finally, she clearly has great leadership skills: that solo sailor leads a loyal support team.

I am looking forward to hearing her speak.

Lecture by Hilary Lister

Vice Chancellor, Ladies and gentlemen, thank you so much for inviting me to speak to you tonight.

I knew at the age of 3 that I wanted to be a biochemist. We kept chickens, and I was desperate to understand "how they worked." It was probably just as well that my mother is a chemist, as I think I would probably have driven anyone else even further up the walls than I managed …!

I was born able-bodied and would generally describe myself as the third of four boys! I was consequently into any sport that involved a ball and contact – rugby, hockey – that sort of thing. It wasn't until the age of 11 when, coming away from the pitch with knees that ached, I first suspected I might have growing pains. At 13, experiencing pain every day, I was still pretty certain that I would grow out of it. It was only at 15 when I could no longer put 1 foot in front of another and was struggling to get to lessons that I thought I ought to go and see a doctor about it for the first time.

"Well, there's good news and bad news"… I thought I would go for the bad news first on the grounds that the good news would then cheer me up. "Unfortunately you are going to be in a wheelchair with both legs in plaster from ankle to thigh". The good news was going to have to be very good news! "On the positive side after two years, everything is going to be okay". Other than the fact that he had squeezed in a piece of bad news (two years sounded like forever), that would have been very good news had he actually been right. Here I am almost 30 years later, with a degenerative neurological disease that means I'm paralysed from the neck down with only the sensation of pain in all my joints.

At first everything carried on pretty much as before, just on four wheels rather than two legs. I still had holiday jobs, drove my car and played my clarinet, my second love after science. Teaching it also provided me with some useful extra cash whilst I was a student.

I sat my GCSEs and A-levels and, although by then I was paraplegic, came to Jesus to read biochemistry (my father is a vicar and more than a few people started to offer their condolences when told that "Hilary's gone to Jesus"!) I think that I was the only person besides the master and bursar to be allowed to bring my car into college (it was a huge perk to have parking spaces in

Oxford, both in college and at the Department). I was also unable to drink alcohol due to the drugs I was prescribed, so you can imagine that I was very popular as a taxi driver! I was extremely unwell during my 3rd year and, as a result, had to do my **finals** by dictation whilst flat on my back with a diamorphine pump into my spine. I'm sure that the heroin opened up parts of my brain that otherwise would have been inaccessible as I came away with a respectable grade, something that no one, least of all I, expected! I had always believed that I had got into Oxford through some sort of administrative mixup … The illness did, however, leave me with numb fingers, something which I tried to ignore (doctors not being my strong point). After Oxford, I went down to Canterbury to do my Ph.D.

It was only when the disease progressed to the point where I couldn't feel my hands at all that things got tricky. Despite concentrating hard on whatever I was holding, I started to drop things. As the value of the things I dropped increased, so did the pressure to go and get treatment. Finally, having dropped four months work and £12,000 worth of sample on the floor (I managed to save the sample) my supervisor threw me out of the lab "until I was better". Reluctantly, I went to see my specialist.

"Well, there's good news and there's bad news" … Here we go again. Let's have the good news first on the basis that it really didn't work out last time. "There's a treatment". Wonderful! When can I start, I thought, before realising that I had missed a bit… And the bad news? "It's experimental – it could end up killing all the nerves in your arms". With my luck and medicine, the result was almost a foregone conclusion, but I had to try. I could not have foreseen the ramifications in my worst nightmares. I became unable to feed myself or wash my face, let alone follow my career or play my clarinet, always my emotional outlet in the past, the world became a very dark place.

I had been in the house for about 2 years, and hadn't even found the courage to go into my garden for three months when a man I had met once knocked on the door and asked me if I would like to go sailing. To my astonishment there was still a part of me that seemed to think I was worth the space I took up on the sofa. It woke up and I heard myself accepting. When the day dawned, I wasn't so certain. I ran through every excuse in the book – I had a headache, I felt unwell, I was tired – you name it, I had it…. Eventually I decided that these people had gone to so much trouble that I couldn't let them down, so I forced myself to step out of my front door. For the first time in my life I was a disabled person who needed help. This was, and will always be the hardest thing I will ever have to do.

[Display slide] Fortunately, everyone at Westbere Sailing Opportunities seemed oblivious to my disability. They had strapped a garden chair into a dinghy, then put a board under my legs and another down my back to support my head. As a final "Health and Safety" touch, they used duct tape to hold my head in place. (This the first rule of sailing: there is nothing duct tape cannot fix!) Within 30 seconds of being on the water I had simply fallen in love. I had found my second vocation.

Not everything was rosy. With no systems to help me operate any part of the boat, I was always going to be a passenger and was soon frustrated. One day, though, I had a particularly good time on the water. We were haring along, when the man sailing the boat for me, who was kneeling on something akin to the back 18 inches of a very narrow sea kayak said. "This is the best sailing we've had all sea…" Splosh! For a few seconds, I found myself completely alone on the boat before he popped back on board. It was wonderful! That day I came off the water and said I was going to sail

the Channel, solo. For the first time ever, they treated me like a disabled person. They almost patted me on the head and said “that’s a nice dream to have…” Like in a million years. When I called them just 2 days later, having done some research, and said we were doing it the following summer, I couldn’t possibly repeat what they said in such polite and august company. Suffice it to say that they had to put the phone down to recover themselves!

[Display slide] I attended my first boat show in 2005 and, by some miracle, managed to find sponsors for kit, and practical help, but still had no boat or (crucially) any money to buy the ONLY sip-puff system on the market. We sat down, exhausted, to eat lunch outside a bookstore, which had a sign saying “Emma Richards signing books here”. To be honest, Emma was the only sailor I had heard other than Ellen MacArthur. To my amazement she wasn’t interested in talking about adventures sailing (many times) around the world, she wanted to know about my plans. In addition she not only agreed that I could come and look at her boat, but, unbeknownst to me, at the Guinness bar she persuaded her sponsor, Andrew Pindar, to lend me a boat(the second rule of sailing is, ALL THE BEST DEALS ARE DONE THERE, although other beers are available). I couldn’t believe my luck – until we put it in the water when it sank so fast it was still in the cradle… It turned out to have a rather large crack in its rudder stock!

Crack well and truly fixed, I still had one small—ish problem. No system with which to sail the boat and no money to buy one. I had thought about it and reckoned my electric wheelchair wasn’t SO different, I used sip and puff to go forwards, backwards, left and right. Left and right could obviously translate to the rudder for steering, forwards and backwards could let the sails out and pull them back in, at least that was the theory. *[Display slide]* So we dismantled my chair…. It started off as just “borrowing” the control system, but soon everything from batteries and motors to seat and wheels was “borrowed” and used on the boat. The NHS were very understanding!

One of our biggest problems was finding the right lifejacket as, it turns out, quadriplegics (and therefore possibly unconscious people?) float facedown. We must have thrown me into the water in every conceivable position wearing a pre-inflated lifejacket. I still floated facedown. The moral of the story? If you can possibly avoid it, don’t inflate your lifejacket until just after you are unconscious!

[Display slide] I spent a morning on the water when the phone call came in to tell me that, if I was going to make the sail, the boat would have to come out of the water on the Solent and travel up to Dover that afternoon. So, with 2 ½ hours on the water to learn to sail in a boat whose crucial parts were mostly string and duct tape (during which time I found two relatively major glitches, one of which meant I had to leave a note on someone’s boat apologising), and whose design included EVERY three-quarter inch block on the Isle of Wight, I found myself crossing the world’s busiest shipping way dodging everything from ferries to supertankers. The next six hours and 11 minutes flew by far too fast. For the first time in six years I was going where I wanted to go and getting there by myself. It was a truly indescribably wonderful feeling. I can only liken it to an able bodied person being given the ability to fly.

When I got back to Dover someone stuck a microphone in my face and asked me “what next?” Since I’d spent the last six months living and breathing this project, I honestly hadn’t thought about it. So when the words “I’m going to sail around Britain” fell out of my mouth, I was as surprised as anyone. I then compounded it by saying (live on BBC radio five, as it turned out) “and I’m hoping that if I buy my sponsor a drink he might just help me out again…”

[Display slide] Together with Artemis Investment Management, Pindar decided that I needed a boat with some "proper systems" (and no cracks) to do this, so I found myself the lucky recipient of an Artemis 20 and, crucially, the electronic system I so desperately needed to sail her. At 6 m long and just 1½m wide, she is tiny, but fast. I must have some sort of special ability, though, that makes me a great *solo* sailor. It's not time on the water, it is certainly not technique, it is my (as far as I know) **unrivalled** ability to "lose" people off my boat. One of the team who was supposed to be looking after me on the water fell off five times in four months. The water around Britain is distinctly chilly. Thank goodness for dry suits.

[Display slide] I sail the Artemis using three straws – essentially just switches that recognise positive or negative pressure. One is dedicated to the tiller, one is a "menu select", and the third actions whatever I have selected on the menu straw. It's really not as complicated as it sounds. Rather than showing you endless pictures of the coast of Britain, beautiful as it is, I have a short piece of film that shows how my system works with some of the coastline thrown in for free…

[Insert video clip]

After sailing solo around Britain I was invited to take my boat to the Extreme 40 sailing event in Cardiff in 2011 (I recommend you look it up on YouTube, the crashes are spectacular!) There I met Albert Whitley from Oman Sail, who asked me to come to Oman the following spring and to bring my boat so that their sailors could sail it. It's only really by seeing it that it is truly possible to understand the sense of freedom it gives me. Oman is very forward thinking, particularly when it comes to women. *[Display slide]* It has female sailing instructors and an all women sailing team which races all over the world. They wanted me to talk to their sailors and staff. We worked from 6 in the morning until 10 at night and loved every second of it! To this day I am not quite sure how it happened, but whilst I was out there Albert offered me the use of his then brand-new Dragonfly 28 trimaran *[Display slide]* to sail across part of the Indian Ocean, from Mumbai to Muscat, around 850 nautical miles. The only stipulations seemed to be that I take an Omani lady sailor with me and that we have a "fairy godmother" just in case we needed to be bailed out. These seemed entirely reasonable, so I grabbed the opportunity with both hands and refused to let go!

In February last year I flew out to Oman for the second time with all 3 of my carers. Needless to say they weren't desperate to stay at home for seven weeks of winter! *[Display slide]* I am extremely lucky in my friends, and the father of one of them, Roger Crabtree, designed and built a new sip-puff system to my specifications even though he had never seen the boat. Since he lives in New Zealand, we met for the first time in Oman. Until that point meetings using Skype had been formal affairs with one or the other of us in our pyjamas. He and the team who programmed the PLC which controls the boat, did an incredible job as it all worked as soon as it was on the boat and kept going for the whole 9 days with only the occasional reboot required. The real beauty of the system is that it is relatively cheap and easy to build, so other disabled people can exploit the design.

Most importantly for me, it controls Harken's reversible electric winches (which really do what they say on the tin). My system allows them to be worked both separately and in tandem, with one winch letting out whilst the other pulls in. This means that I can tack a boat with a normal jib on my own, giving me control over almost everything almost all of the time. On this occasion I got the luxury of a whole three hours to learn the new system and the boat. One of my carers had to make the trip with us and, since Lisa was the only one who had spent any time on the boat (a whole 9 hours – which

made her practically a veteran sailor) she was the obvious choice…. Boy, was she ill! But somehow she managed to keep going.

We left Mumbai at 6 o'clock in the morning *[Display slide]* – a relatively civilised hour for sailors at least– on March 11th. We had been warned by Albert, who had sailed the boat over from Oman, that many of the abandoned oil platforms just off the coast were not lit, which made our plan to sail north up the coastline of India before sailing almost due west across the Arabian Sea, seem like an even better idea than it had done back in Oman as it avoided the oilfields (but not fleets of Indian fishermen in every type of craft from dugout canoe with no lights upwards. Most of them can't afford proper lights, so use disco balls, if anything, to alert you to their presence). As it turned out, it meant that what wind there was (and there was precious little) was right on our nose, so we ended up motoring for 36 hours, using up all 9 jerry cans of fuel in the process. This was something we had planned for, and had picked what looked, on Google Earth, (there are no charts) like a relatively large harbour and fishing town as a port of refuge and somewhere to stock up on more fuel if needed.

Luckily for us, Nashwa, my Omani colleague, spoke Hindi and Urdu so was able to ask where the petrol was (we assumed it was going to be on the quayside). This story serves as a warning about how far Google maps can lead you astray, and how naive we were as Western sailors. The fishermen kept pointing further into the port. The channel got narrower and narrower and shallower and shallower until we had taken up the centre board and were steering with just the back edge of the rudder. The smell was horrific as the harbour acted as both sewer for a medium sized town and dumping ground for fish entrails … Eventually we rafted up against fishing skiffs, by which point the whole village had come out to see these mad foreigners who sailed "for fun".

It turned out that the fuel was not, as we had assumed, either on a barge or in the harbour. It was ashore, 40 minutes ashore. And so an ever so slightly illegal trip was made by Niall (our "fairy godfather") and Nashwa in something that looked like a moped with a wheelbarrow bolted to the back. This left Lisa and me on board with the entire populace wanting to have a look round our boat. I'm sure they had never seen anything like it, at least not at such close quarters. Of course everyone had to come and say hello. Once the English teacher worked out that my legs didn't work and I added that neither did my arms, they all had to come and say hello again!

Luckily enough, Niall and Nashwa were back on board when "security" came round. Men in an unmarked white "booze cruise" type powerboat with machine guns turned up demanding to know who we were, why we hadn't contacted the harbour master and what we were doing. We had tried to contact the harbourmaster as we came into port, but got no reply. Since we didn't have a photocopier on board, they wanted to take our customs clearance form from Mumbai. There was no way we were handing it over, especially as it was only at this point that we realised the boat's official papers had been taken off on arrival in Mumbai and the crew had forgotten to give them to us, instead choosing to fly them home to Oman in their suitcases.

Security issued a direct threat to arrest us all if we tried to leave. They disappeared back to shore to get someone far higher up the chain of command; but in the meantime we started a lengthy radio conversation with the harbourmaster who had miraculously reappeared (i.e. finished his lunch and post-prandial nap). He had an incredibly long form to fill in, including gross tonnage (one, possibly?), Cargo (***please don't say people!***), and, of course, the name of the boat "Balarion", spelt phonetically.

It was at this point that Niall tried to kill me for the first time. Lisa was giving me my medication, something that needs to be done carefully as my gag reflex is non-existent. All went well to start with (bravo-alpha-lima-alpha-romeo… Silence). He had forgotten that "i" in the phonetic alphabet is India. With a mouthful of water, I started to laugh and managed to splutter out the word "India" as water descended into my lung! Oscar and November, also had to be spluttered at him. It was only 15 minutes later when Lisa was still beating the living daylights out of my back and he'd finished laughing that he realised anything was wrong.

Eventually, a Customs man arrived in a helicopter and was more than happy to take Niall's word "as a gentleman" that we had our Mumbai customs clearance, sealing it with a handshake. He didn't even come aboard. As we left, the village called out "don't forget Porbana". I don't think there is any risk that any of us will, I also hope that I will never want or have to leave anywhere in such a hurry again!

The Arabian Sea was a whole new experience (it was warm, for a start!). We went through 36 hours' worth of the most amazing phosphorescence anyone had ever seen. It was as if the whole boat was lit from below by neon lights and travelling, not through water, but through a thick soup. In England, we get excited at the smallest glow behind the boat. This was so thick, we could see fish beneath the surface and it was phosphorescing spontaneously in a way that would normally only be made possible by Disney. All we could do was wonder at the beauty of it and, of course, play with it. It had Niall, a professional sailor with hundreds (if not thousands) of sea hours under his belt, throwing buckets of water onto the trampolines and then jumping up and down to watch the glowing water droplets bounce!

During the day, the temperatures got into the upper 20s, and they don't fall all that much at night, at least at sea level. You are left sailing in a sea mist which is so dense that it feels like you can only see about two boat lengths in any direction. It's incredibly eerie, and magnifies every noise so that the hull creaking sounds like the crack of gunfire. Since there are pirates around (although generally they are well south of where we were) it does make you wonder, at least to start with.

On one of my night watches, around 3 AM, whilst Niall was trying to sleep on deck, he came a little closer to the local wildlife than he would have liked. A flying fish hit him on the back of the head. Of course I laughed, although for some reason he seemed not to find it funny, when I said, "there's nothing like being slapped in the face with a wet fish." The following night, however, he more than got the joke when one hit me square in the face and fell into my lap! They are strange fish. They don't flap about when they are out of the water, they just keep their "wing fins" open – presumably in the belief that they will end up back in the water by some sort of magic. Flying fish is by no means a misnomer. Although they glide, rather than "fly", they can travel up to 100 or 150 m through the air.

[Display slide] We arrived back in Oman on March 20th, the first Omani and first disabled women to make the crossing. As usual, I experienced the familiar feeling of my heart sinking when I saw land, whilst everyone else was busy dreaming about what they were going to eat that hadn't been dehydrated, rehydrated, forgotten about and finally eaten cold!

So what next? There is **always** a next with me… I am hoping to sail with Nashwa from the Seychelles to Muscat. I then hope the to show the boat off all over the world before sailing the Atlantic, a dream I've had ever since that first trip across the Channel when I very definitely got salt in my veins.

I just need someone to lend me a 40 foot boat for a few years (a monohull is fine, and I promise I'll return it in one piece!)

I have to say thank you to a few people because, although this is what the media portrays *[Display slide]* , the reality is more like this… *[Display slide]*

[Display slide] My choice – *Either give in to my condition or strive to make my dream a reality…*

Thank you for listening to me.

Vote of thanks by Dr Kylie Murray

Good evening Mr Vice Chancellor, Hilary, Ladies, and Gentlemen. I am Dr Kylie Murray, Fellow in English at Balliol College, and member of the University's Disability Advisory Group.

Thank you all so much for attending; there has been quite an extraordinary expression of interest in this event. We hope the Disability Lecture will become an annual high-profile event in the Oxford calendar, and today has seen us get off to a promising start.

I know everyone will agree that Hilary's talk has been powerful and compelling. We are so proud to welcome you back as an alumna of the university, Hilary. In addition, you embody the core values of creativity, resilience, and aspiration, that we want to communicate when we talk about disability at Oxford. It has been a privilege, a delight, and an inspiration to hear you speak today, Hilary. Thank you so much for sharing your story with us.

You took the whole audience with you when you described your earlier loss of independence and the barriers that brought. To hear your story of empowerment on the water was fascinating and uplifting. Through this, you have shown us that with lateral thinking and creativity, we can overcome barriers, and achieve remarkable things. There is a universal lesson we can all take away from today. No matter how great the obstacle, or the adversity is: with resilience, determination, and creativity, we can succeed.

It only remains for me now to wish everyone a safe journey home, and to remind you that you are very welcome to join us for drinks now, where you can meet our speaker and reflect on her incredible talk. Thank you again, Hilary, for 'breaking the mould', to take the title of your lecture today. For showing us all the importance of aiming high, of not giving in, and following our dreams.