



Ollscoil na hÉireann
National University of Ireland

Text of the Introductory Address delivered by Dr Patrick O Leary, Registrar NUI, on 9 November 2023 in the Royal College of Physicians on the occasion of the conferring of the Degree of Doctor of Literature, honoris causa on Orla Tinsley

A Sheansailéir, leas-sheansailéir, baill den Seanad agus cairde OÉ. Is mór an onóir dom Orla Tinsley a chur chun tosaigh le haghaidh dochtúireacht sa litríocht inniu.

Universities are centres of learning. Academics are both learners and generators of new knowledge. We use our experience to imagine what the next step might be and then take that step to benefit those around us. A good academic also brings people with them; teaches, educates and stimulates curiosity in those coming after to take the next step.

Orla Tinsley is a font of knowledge, much of it gained through hard personal experience and they use that knowledge to benefit those around them to educate, stimulate curiosity and change hearts and minds. Their knowledge, and related advocacy, spans medical, social justice and LGBTQI+ issues along with a lifelong commitment to communication and creative writing.

Sometimes in universities we bump against accepted truths and we have the concept of academic freedom to allow us to safely ask awkward questions and take the next step without worrying about what others might say, think or do.

Orla Tinsley hasn't been able to lean on academic freedom and yet is a Warrior who has been willing to take the next step and ask the awkward questions throughout their life. They have not settled for the status quo and, certainly to the outside world, it seems they don't worry about what those a step or two behind might say, think or do.

In one of their articles they were writing generally but, I think Orla captured an essence of a university education:

‘our goal is to create something that will last beyond our lives on earth and catapult into reality new ways of thinking’.

Orla is a Kildare native, born in a rush 11 weeks early and has been rushing ever since. Their mother Patricia has been a rock for Orla balancing the life of a parent with the expertise she has as a nurse a tricky balancing act for anyone. Their father Brian’s story-telling when they were young and his involvement with creative arts found fertile ground in Orla with them getting their first typewriter at 6 and a role in ‘Babes in the wood’ at 10.

Reading Orla’s books, you can see how they developed the skills to self-advocate. They were confident in their knowledge of their body and treatment. Anyone in the audience with dodgy veins, like myself, will admire the confident child saying to a doctor ‘They disappear when you go in so don’t try there’. It’s hard as an adult to push against the ‘doctor knows best’ attitude, never mind as a kid. But in their youth, there was also experience of the complexity of life where they came across secrecy, othering and bullying due to lack of knowledge about cystic fibrosis.

In 2005, when Orla was 18, they came to national attention as they wrote compellingly in the Irish Times about the state of healthcare in Ireland for those with CF. They have written about the transition to adulthood and the shock of moving from Temple Street to St Vincent’s. It was around this time when Orla brought their writing, advocacy skills and life experience with illness and the Irish healthcare system together and moved into the realm of activism. They focused not on themselves but on the profound wrong of a country with the highest prevalence of CF in the world not having the required support. That campaign was one of repeated cycles of promises made and not kept followed by Orla calling people to account. Their articles in the Irish Times along with work with RTÉ Prime time, Liveline and numerous other articles and interviews raised awareness and applied pressure that led to the opening of a dedicated CF ward in St Vincent’s seven years later. That campaign had broad impact beyond CF; Orla has continued to campaign on a wide variety of health advocacy issues since. Orla was named Tatler Magazine woman of the year and young medical journalist of the year. Orla has, on several occasions, successfully campaigned for the approval of drugs which, given their expense, had not been available in Ireland.

Orla has also actively campaigned for the rights of transgender people to get gender recognition in Ireland and was a winner of a Journalist of the Year award from the Gay and Lesbian Association. I encourage everyone to look at Orla's articles around 2013 on this issue. There you will find knowledge and insight that Ireland is yet to fully embrace ten years on; Orla's work has had a positive impact but there is still much to be done.

The Leinster Leader named Orla Kildare's All Time Great - beating Dermot Weld, Earnest Shackleton and Arthur Guinness, which is not a bad list to be leaving in your wake. And leave Orla did, they enrolled on a Master in Fine Arts (Creative Writing) programme at Columbia University in 2014. They would continue to study even as Cystic Fibrosis affected their health badly - that degree is a proud achievement.

In 2017, Orla needed new lungs and was put on the transplant list in the US. They recorded their daily battle and through social media kept the world up to date with the slings and arrows of life on the transplant list. Orla tweeted to their 24,000 followers about the ups of being called for a potential transplant and the downs when they didn't work out. Down to 13% lung function and having been called six times regarding potential lungs that did not work out, they tweeted 'Still waiting, still believing'. Through it all, Orla brought the reality of transplants to a wide audience. The seventh call led, finally, to a successful transplant. The frankness about their personal journey again served a much wider constituency and led to a huge upsurge in donor card-carrying in Ireland.

Later, when Orla's documentary 'Warrior' came to our screens, we saw the respect they felt for the donor, the acknowledgment of their joy coming hand in hand with the pain for the donor's family. The documentary also laid bare how low Orla was, how it affected their family and friends. The documentary not only helped us to understand better what it is to live with this disease, but also prompted many to sign up for a donor card. This was not to benefit Orla but to help those coming after them. They used their voice, appearing on the Late Late Show, advocating for those with invisible disabilities, those needing transplants. They have written about the long road to appropriate organ donation legislation in Ireland – always thinking of those on the road with them.

I'll paraphrase a statement from the Irish Kidney association:

What is commendable about the work of Orla, Isabel and many others is that their promotion of the organ donor card is selfless. They have their own stories but they understand that there is a bigger picture with many others waiting and their impact has been extremely positive in increasing the number of organ donor card requests and in so doing increasing the hope of those awaiting the call for a transplant.

Orla is delivering their creative writing courses even when ill and continues to write regularly for the Irish Times. They are still holding the world to account most recently revisiting the 'doctor knows best myth' when they broke their leg but weren't believed. Again, though the experience is personal, the advocacy is broad and inclusive: Orla wrote in the Irish times that.

Medical gaslighting – which is more likely to happen to women and people of colour and the LGBTQI+ community – happens when a physician or healthcare professional downplays a patient's symptoms or pain and wrongly attributes them to a patient's psychological state.

Orla is a talented and passionate advocate for improvements in medical care and for social justice issues. They are a skilled and engaging writer and a dedicated inspirer of those they teach.

We're glad you could step off the long, hard road of advocacy and activism for today, at least. This honorary degree is a recognition of all you have achieved and all you have done in service of others on the road with you.

I'll close with an observation. At the start of the documentary Warrior, for a brief moment, the title reads 'wounded Warrior' and then the wounded disappears to leave Warrior. Though there are wounds, the disappearance of the word is, I believe, a signal to not focus on the wounds but rather to look at the substance of the person, the Warrior, the Ninja.

Praehonorabilis Cancellarie Totaque Universitas Praesento vobis hoc nostrae universitatis decus, quod scio tam moribus quam doctrina habile et idoneum ad Gradum Doctoratus in Litteris, honoris causa; idque tibi fide mea testor ac spondeo, totique Academiae.