Good morning to you all, and thank you for joining me for the opening session of today’s Young Dementia Annual Conference 2018 here in Birmingham.

My name is Desmond O’Sullivan. I was born in Dublin in Ireland, but I have lived most of my life in Oxford, where I worked as an educational editor and publishing consultant. I am married to Valli, and we have two great kids, Yasmina, who is 19, and Youssef, who is 15.

So far so good – or at least I thought so until 18 months ago, when I was unexpectedly diagnosed with Young Onset Dementia with Lewy Bodies.

To be frank, 18 months ago I had no idea what Young Onset Dementia was. Now, at the age of 62, I am still surprised to be referred to as ‘young’. But the fact is, I’m under 65, so it seems that whatever I think, I have to accept that I’m still a youngster!

And as for Lewy Bodies? Well, I didn’t have the vaguest inkling as to what this august title describes. And if truth be told, I still don’t know very much at all.

This much I do know. It seems, my condition affects the efficient (or inefficient) functioning of my brain: my cognition. Sadly, this condition is degenerative. Regrettably, it’s incurable.

And so, if I trip or I forget my lines, or I generally screw things up as I deliver this talk, please forgive me … and feel free to blame it on my Dementia!

But I’m not alone. I’ve learnt that some 42,000 people in the UK under the age of 65 have been diagnosed with Young Onset Dementia. Clearly there is a lot of it about. And, like a pebble dropped in a pond, the ripples in the water spread out in every direction, affecting everybody associated with the person diagnosed: family, friends, colleagues, acquaintances – the list goes on and on and on.
So, what does it mean to be diagnosed with Dementia (with or without the dreaded Lewy Bodies subtitle)?

Stress, anxiety, depression – these three words sum up many people’s experience of Dementia, direct or vicarious. However, in addition to those three terms, something else is rotten in the state of Denmark.

Dementia doesn’t necessarily exhibit visible signs in the way that a physical injury might do, but that doesn’t mean it’s not there. As with an iceberg, most of the destructive force lies far below the surface. [PHOTO 4 -- Iceberg]

Spike Milligan’s infamous epitaph (‘I told you I was ill.’) reminds us all of the invisibility of much mental disability. PHOTO 5 – Spike Milligan]

It seems that no-one was listening to poor Spike.

So, if ever there was a cry for help from beyond the grave …

then here is a plea from the patient to be taken seriously.

Sadly, Dementia comes in a huge variety of shades and flavours. In my case my symptoms range from:

– a loss of former cognitive speed and sharpness

– a frustrating reduction in short-term memory
(Has anybody seen my bag, my glasses, my keys, my pen, my watch, my wallet …?)

And the list goes on.

Basically, what I lose in the morning, I search for in the afternoon, until worn out and frustrated, I eventually find it, in the evening, having wasted another day.

I admit, I have various coping strategies.

For example, as a way of not losing my bike in town, I’ve taken to photographing it next to a shop where I have left it.

Ah look, there it is, tethered outside some well-known store (Boots, M&S, Tesco, Gap and so on). [PHOTO 6 - Bike]
Other symptoms include a sometimes frightening struggle to organise and find my way through once familiar places, organisations, numbers, times, dates, schedules, sentences, addresses, names and faces.

With such symptoms, you clearly need to make adjustments to your daily life.

My friend and respected poet, Jacqui Peedell, lives with and writes eloquently about her experience of Dementia. With discomforting accuracy, Jacqui documents the compromises with which she courageously carries on her life: compromises which are also reflected in my own life.

And so, with this in mind, I’d like to read you a short extract from one of Jacqui’s poems.

[PAUSE 3 SECONDS]

[JACQUI PEEDELL’S 1ST POEM: From Evening]

I can’t amble through life  
Like I could when I was normal.  
The more precise I can be  
About what it is I need to do,  
The better it is.

Because I don’t like spanners in the works.  
I don’t like surprises.

I Google everything,  
So, I can get a real picture  
Of what it’s like before I go there.

And with people  
I have to anticipate  
Their mood,  
Their reaction,  
Their intention.

I have to know.  
I have to absorb.  
I have to put everything in its place,

So that I have an answer ready,  
So that I give the right reaction,  
So that I say the right thing.
Jacqui’s message is clearly sobering, but living with Dementia doesn’t have to be unrelentingly grim.

These days I feel very fortunate again. Early on after my diagnosis, one of my support workers pointed out to me that, if I was going to have Dementia, then Oxford was probably the best place in the UK to have it.

And, thankfully, experience has proven this to be true.

(Be sure to check out *The Good Dementia Guide*)

So, I’d like to take the opportunity to give a grateful shout-out to at least some of the many networks of people who have helped me and continue to help me through my difficult times of loss and of being lost.

So, a sincere thank-you …

**[PAUSE 3 SECONDS]**

– To Dr Sian Thompson and Dr Sanjay Manohar, my neurologists at the Oxford John Radcliffe Hospital. You weren’t afraid to give me the bad news clearly and unsparingly.

– To Dr Katy Long, my ever-patient local GP. Thank you for always making time for me.

– To Tessa Gutteridge, Anna Eden and all my support workers from Young Dementia UK: Mandy Blair, Deborah Crawshaw, Emeline Keown, Michelle Francis, Kate Fallows, and Liz Rose. You guys keep me balanced and firmly on the rails.

– To Dr Nils Detert, my Mindfulness tutor. You keep me calm and collected.

– To Helen Knott, my wonderful Physioterrorist. You keep me as fit and as healthy as my poor body allows.

– To my fellow volunteers at the Oxford Food Bank. You keep me laughing every Tuesday on our shifts around Oxford, delivering fresh, wholesome food. PHOTO 7 – Food Bank]

– To my precious family: what more can I say? PHOTO 8 – Family]

And to all of you who have helped me to look forward to living long and well and not just put up with dying early and unhappy.

Honestly, I never realised so many people cared.

Thank you. All of you.
And so, to finish up this talk, I’d like to read another short extract from Jacqui Peedell’s poems. It’s a poem that thankfully sends out an encouraging message of hope.

[JACQUI PEEDELL’S 2nd POEM from Flow]

My philosophy has always been
That whatever it is you want to do,
You can do it.

I don’t believe
That if you are disabled,
Or depressed,
Or poor,
It changes anything –
Nothing is out of reach.

So, always have goals,
No matter how small or how big.
We are only on this Earth
One time.

No matter what you believe,
Anyone on this Earth at this moment
Is only living this moment
Once.

So, live this life,
As it is,
Now.

And in that spirit of hope, let’s always remember individually and together President Barack Obama’s simple but timelessly inspiring mantra.

[PHOTO 9 – Yes, we can]

Yes, we can.

[PAUSE 3 SECONDS]

Thank you for listening.
Be sure to enjoy the Conference.
Be sure to enjoy your Life.