Alzheimer’s A Quiet Story

**Slide 1**

This afternoon, I’m going to be talking about a photographic project I did about Alzheimer’s Disease – and what I intend to do is talk through my process in creating this work, how it developed and changed and was resolved, as far as it has been into a series of images and text.

**Slide 2**

I’m going to start off with a short introduction about where the work came from,

talk a bit about the research I then did - and where that led me to,

and then show you the work itself, and explore some of the thinking behind the images.

I think it is useful to start with where this work came from.

As my parents were getting older, I thought I would photograph the house they had lived in for the past 50 years. This was where I’d grown up and whilst this was not the kind of photography I normally do – I felt that I wanted to make images of this space that, on the one hand I knew really well, and on the other I had left behind some decades earlier.

But, as much as it was a process, with no real direction, it was also an excuse to visit and spend time with my parents – in London.

So there I was, visiting, taking photographs, coming home, looking at them, going back and shooting more.

It was the process that mattered, there was no plan, no outcome, just a process.

**Slide 3**

My parents were managing, but both with health issues, - my father with his breathing and my mother with Alzheimer’s, but they were getting on with life and it’s routines . However as I continued to visit them I became aware of my own ‘issues’ or challenges around my mother’s memory – as you repeat the same answers to the same questions, respond to the repeated story - I could feel my own discomfort

and how that was easier to deal with in a one-to-one conversation with her, than with other people around, because I knew they also heard that repetition, - whilst for my mum, this was the first time the conversation had happened.

It made me think – about cultural expectations, and behaviours and what happens when you are outside of those

 I was struggling against my own social expectations, whilst she was struggling with parts of her brain letting her down, and so I began to explore Alzheimer’s.

**Slide 4**

Alois (Alwis) Alzheimer described the disease in 1911, having worked with a patient, Augusta Deter – pictured here. Alzheimer drew the tangles he found in her brain after her death, and whilst we know a lot about the disease today, the presence of tau protein and the sticky plaques of amyloid beta, we are still some way from a cure – the photograph of the tangles are little different from those original drawings.

During my investigations I met with a leading researcher in the field, Dr Charles Harrington at Aberdeen University and his work on neuro- de-generative diseases. I wanted to have some level of understanding of what happens inside, the brain

**Slide 5**

- it is a disease of the hippocampus, and it is the hippocampus - we have 2, one either side of the brain, - that are key to moving short-term memory into longer term memory – our filing system.

Rather pleasingly the word hippocampus comes from the Greek, a mythological sea horse – and the seahorse, is what the hippocampus looks like.

Something that resonated for me was when Dr Harrington said he’d spent many years researching Alzheimer’s disease and what was happening within the brain, but had then learnt so much more about it, when his father-in-law became ill with it. That was my dilemma, understanding the internal ‘gumming up of the brain’s wiring’ – what was that telling me about living with Alzheimer’s disease?

**Slide 6**

I then spent some time in an Alzheimer’s care home, and whilst I took photographs, these were only as a record of what I’d seen – so these photographs are snaps - acting as my memory! –

**Slide 7** and of course what I saw was the extensive use of photography

**Slide 8** –people had photographs on their doors and in their rooms,

**Slide 9** – helping the patients to find their own rooms and

**Slide 10** - telling the story of who the person had been

**Slide 11** - Pictures of themselves,

**Slide 12**- Pictures of their families,

**Slide 13** - Pictures of who they were. Pictures to remind all comers of who they were

**Slide 14** - Many of these will have been put there by family and friends

**Slide 15** – some were recent

**Slide 16** – some old

**Slide 17** - and then on the walls and corridors were photographs that were recent history and more generic such as famous people, **Slide 18**

**Slide 19** - and some particular to the local area - the city,

**Slide 20** - and the local football teams,

**Slide 21** - things that the residents might remember, a time that might be more vivid than the present day.

Throughout the research, I went on photographing at my parents house, the images changing as I understood better what I was trying to do, and the process that had been just a way to visit my parents, shifted into a piece of work that was to have a life beyond that process.

**Slide 22** – This was the first iteration of the work - this piece was shown as a single image on a billboard, in 2011, well before the work was resolved into the series, as part of *Civic: The first international festival of billboard* *art*

led by the Photography department at Sunderland.

**Slide 23** - And so to the final series. My fascination with photography is as much about what it struggles to do, as with what it does well.

We want the photograph to hold our memories, but it often fails to do this

and we want it to be able to show us things and enable us to understand them, - but so often it can’t.

Seeing images of people with Alzheimer’s Disease doesn’t tell you what it’s like to have the disease - it tells you what people who have it, look like.

The title of the series, Alzheimer’s: A Quiet Story, positions it, or as Carol McKay writes in her essay in the catalogue the title ‘draws emotional attention to itself’.

**Slide 24**

Within the series, I use text to further layer the image – So, forgotten, clearly a marker of Alzheimer’s, but also, in the photograph, a smaller portrait, valued and on display but perhaps also forgotten? Who is the portrait of? Is the portrait valued because it is not forgotten?

**Slide 25** - I was making work using photography about a disease that destroys your memory. When photography is so often what we use to hold our memories.

I wanted to think about what it might be like to have Alzheimer’s, to be constantly fighting the disease in your head. To not understand why people sigh as you ask a question or tell a story, to not be sure what’s just been said, or who you are talking to, or where exactly you are, or to be able to be sure what is beyond the room that you are in.

**Slide 26** - For things that have been part of your everyday for so many years to stop making sense to you. But at the same time, there is something unusual about a place where the same people have lived for 50 years, and I wanted to know if that was something that could be photographed.

**Slide 27** – In the images there are impressions from the people in the space – the cupboard door ajar, the book left open, but there is no one there. The photograph evidences presence but becomes a metaphor for the struggle to remember what once was and also what is now.

**Slide 28** – So the images were made in a place I thought I knew well, but also strangely didn’t know and had to re- explore with my camera.

Time had changed this house, had marked it through the wear and tear of the repetitive routines that provide us with security.

**Slide 29** – We’ve all experiencedwalking into a room and then wondering what on earth we came in for, – looking at the familiar space around us and yet trying to search our brains for what the reason was that brought us here. At other times we will have checked and double checked that we undertook a simple task– turning the gas off, locking the door, because we do it so often we can’t remember if we really did it this time.

**Slide 30** – For someone with Alzheimer’s that checking and re-checking can become overwhelming and cause a cycle of anxiety

**Slide 31** – Of course, what you are seeing today is the work in the context of my own family experience, however the work, when shown, does not come with that information.

Again to quote Carol McKay’s essay ‘The enlarged detail of the balding carpet in one photograph here, like the worn tread on the steps, implies again something of the individual sufferer’s imperative for sameness, for the preservation of things as they are.’

**Slide 32**– Sometimes people use photographs on doors and cupboards and draws, to enable the person with dementia to know what is beyond. If you think about drying up crockery and cutlery in a friend’s house and then try to put them away – you can only guess where things might go, it may seem familiar but is not, as you open one cupboard and then another, looking for the right place.

**Slide 33 –** In the photographs, the layers of dust, the worn and the damaged, sit alongside the placed, the carefully positioned – on show, the treasured. The faded glory of a domestic environment.

The single words that accompany the work speak both about the experience of the illness as well as the domestic everyday. The ambiguity of the single word provides a multitude of apparent meanings,

**Slide 34** – But, through the confusion of Alzheimer’s disease, the everyday becomes out of reach, the immediate gets lost and the individual works hard to understand the confusion of others.

**Slide 35** – We talk about a ‘photographic memory’, - being able to remember information in great detail – as a photograph does, and often with Alzheimer’s, the sufferer can do just that, with earlier periods of their life, locked into the past but unable to remember now.

**Slide 36 -**  In the main, my photographic practice, whilst dealing with subjects such as criminality and insanity, has always been constructed, the environments have been controlled and directed by me.

**Slide 37** – so this work was a different approach for me – requiring a more responsive approach in terms of looking for the details and traces left in the environment, rather than creating them.

**Slide 38 –** and so the images in this series are both found and constructed, using at times what was there, and then intervening into the scene.

**Slide 39** – and as for my parents, they tolerated my taking pictures in their house in they way that parents do. I think they wondered whether I was making a record of everything they owned, to secure my inheritance. I remember showing some of my pictures to them, and they said it was a shame I was picking up on all the faults,

**Slide 40** –Again a quote from Carol McKay’s text ‘An aging suitcase with a hand-written label is a mysterious presence in another of the photographs. We might wonder what it is that is ‘preserved’, whose writing it is, what journeys it has seen, what stories it could tell, what secrets it keeps. But, rather like the not-quite-decipherable writing on the suitcase label pictured, our access to such historical memory is partial and imaginary.’ Interestingly, that suitcase, which has been in the house for over 20 years, and which I photographed several times, I only opened for the first time a few weeks ago, because although I was snooping around this space – there are still rules.

**Slide 41** - We have a fear of Alzheimer’s disease – Of the top ten killers in the world, Alzheimer’s is the only one that we cannot prevent, cure or even slow down.Sadly there are estimated to be about 40M people living with Alzheimer’s in the world today and that number is predicted to double every 20 years. There are over ¾s of a million sufferers in the UK, with 1 in every 14 people 65 years old or over. But, if Augusta Deter were here today, her medical treatment would be little different than it was in 1900.

**Slide 42** - and whilst nearly as many people die from Alzheimer’s disease as die from cancer world-wide, we currently put about half a Billion dollars into research as opposed to the over 5 Billion dollars going into cancer research, - and at the same time care costs for sufferers are double the care costs for cancer patients.

**Slide 43** – And here is the last piece in the series. The conversation in our society about Alzheimer’s is limited and uncomfortable. This work is not a campaigning piece and neither is it a personal story. I would like to think that in a small way it opens up that conversation.

**Slide 44.** Thank you.