

Distance

by Seán O Sullivan

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As I write, I am looking back and forth between the words and a photograph of a woman superimposed onto a grey background. She is dressed in a blue knit jumper, and wears four pieces of dull-coloured gold jewellery. Her face carries the subtle specks of red that come with age and those distinct, dark wrinkles that mark the areas where her expressions must have taken shape so many millions of times.

Marie Brett and Kevin O'Shanahan's Egress records and responds to the experiences of a group of people affected by Alzheimer's disease. The project contains a collection of interviews, portraits and scenes—all crossing between the strangely significant and intensely personal moments that make themselves a part of dementia. And knowing this, I keep looking at the woman's portrait, trying to find a trace of her character and her feelings, wondering what she thinks of being seen in this photograph. Her eyes are such a dark blue that they are barely separable from black; her head is cocked and she peers right into the camera lens, back to me, with a look half-made of intensity and half of distance.

At the beginning of the Egress interviews, there is a brief and hypnotic sequence of music: a violin and cello refraining over one another, harmonising against a few intermittent electronic notes. Hearing this is a signal to prepare for the intimacy of the scenes to follow—for how delicate they are. The score fades into a story told by a daughter, explaining that although her mother can recall things that happened years ago, she has trouble with what happened five minutes ago and might spend a day explaining the same memory over and again. She says that her mother still thinks everything is normal.

There are small segments of music that divide the junctures between each monologue, and in the next story, a man talks about how he needed to give up driving. But, in the years that he could drive, he travelled to theatres in different towns and cities, and had seen a few shows in London's West End. He talks about this comfortably enough before pausing to remember the name of a singer—the story stops there. The pause continues for the next few minutes, and he spends the time trying to force the singer's name up to the surface. It's a difficult wait. The memory never makes an appearance, so he mentions again that since he became sick he hasn't been able to travel, and that he misses it terribly.

The music fades in to end the interview. It swells up to a brief and simple tune played on the violin. The stories recorded for Egress are poignant, and distressing in many places, so it is a relief that hear the music keeps rising up over the words to soften their effect.

Part of what is so distressing about listening to these interviews is the way the stories seem so familiar and ordinary in their tone, but then stop cold when certain basic information is mentioned: the name of a hometown or a university for example. The damage that dementia causes is not limited to removing those memories of life, it also simplifies the mind's facility for language, slowly taking away words that used to exist inside. It's a terrible thought to arrive at, the idea that a disease not only takes memories, but also the capacity to think. In its ordinary use, thinking helps us to move our emotions out from their abstract beginnings and into concrete, expressible words. And at the lowest moments, we use thinking to remind ourselves of our own dignity.

My own grandfather was diagnosed with Alzheimer's when he was in his late-seventies. He was a strong man: he'd left school early, and was known locally for having built a terrace of stone farm sheds near to the family home as a fourteen year old—they still stand today. It was difficult to see his mind betraying him. In the beginning, our small, daily interactions with him became flatter and simpler. He lost his passion for going through old photographs. As the losses progressed, he began to imagine his food was poisoned. We visited often, and I'd catch myself hoping that one of those days would coincide with a moment where he would become lucid enough to have an ordinary chat of the kind we'd lost. You feel selfish for wanting those things, but you want them nonetheless.

The music appears again to close out the recording; it's a short song, where a man repeatedly sings the words 'going home'. Music is one of those rare pleasures that can invade a mood without any invitation, and the act of listening to it is still pleasurable even when the tune escapes memory. The song ends on this note—going home.

At the end, there is no one moment to certify the loss. Instead there are years of tiny erasures, one after the other. Alzheimer's robs life of its ending—it robs the part where you get to say goodbye.

Seán O Sullivan is a writer and curator based in Dublin. Edited projects include a book on the Red Stables Summer School (2012), and a short book entitled The Wheel (2011). He is part of the board of directors for the Black Church Print Studio, Dublin.