

St John's Memorial Essay

A Battle until the Death - Alzheimer's Disease: in Remembrance of Norman Chappin

Monday 19th July 2004; the official beginning of the summer holidays; the day my grandfather died. He was cremated the following Friday. The initial summer holiday euphoria was extinguished, replaced instead with an unremitting desolate and tenebrous atmosphere. At just 11 years old, my entire world came crashing down around me as I began to contemplate for the first time how utterly unscrupulous the world could be. Aside from my dog, the demise of my grandfather was my first irrefutable experience of the devastation associated with bereavement. When my dog's life had been prematurely ended at just five years old following a prolapsed disc in his back, the downpour of tears had lasted incessantly for the entirety of three days. Subsequently the hollowness that now enveloped me was utterly inimitable. As the melancholic hymns reverberated throughout the church I reflected upon the tragic story which had been my grandfather's life; at just 11 years old I was unable to perceive the ceremony as, in actual fact, the celebration of his life.

My grandfather, Norman Chappin, died at 69 years of age; he had been the victim of the treacherous degenerative disorder known as Alzheimer's disease for the 6 years prior to his death. Seven years prior to his diagnosis of AD, it was determined that he was a diabetic. My grandfather retired from working for the world renowned company Vauxhall Motors at the age of 59; at the age of 60, he suffered the affliction of a severe heart attack. Being a mere toddler at the time of his heart attack, I was oblivious to the implications, however for the duration of his Alzheimer's ordeal, I had clung to the faint hope that some miraculous cure would materialize. Subsequently, despite the fact that his death was perhaps not unanticipated, I was most certainly not prepared for it.

Alzheimer's disease is the most common form of dementia. The disease is named after the German psychiatrist and neuropathologist Alois Alzheimer, following his initial identification of the condition in 1906. Alzheimer's is infamous for its terminal, incurable and degenerative characteristics which escalate in it being notoriously renowned as a formidable malignant. Most predominantly it is diagnosed in people over 65 years old, however the less prevalent early onset Alzheimer's can develop much earlier. It is estimated that in excess of 25 million people worldwide currently have Alzheimer's disease and this figure is forecasted to quadruple by 2050 as a result of the worldwide aging population. Currently, in the UK alone, 42% of the population are affected by dementia through knowing either, a family member or, a close friend suffering from the condition. In the most simplest of terms, one in three people over the age of 65 will die with some form of dementia.

The exact cause of this inexorable condition remains intangible. However, research indicates that both genetic and environmental issues are accountable; for example, the risk of developing Alzheimer's disease increases significantly as you get older. Family history is another common risk factor. Similarly to other types of dementia, the progression of Alzheimer's disease coincides with the deterioration, and eventual death of increasing numbers of brain cells. Microscopic examination of a sample of brain tissue abstracted from a sufferer ensuing death reveals colossal amounts of two abnormal structures called plaques and tangles. Plaques accumulate between nerve cells, whilst tangles form inside dying cells. It is speculated by experts that it is these entities that are responsible for the immutable destruction of nerve cells that ultimately causes both structural and chemical complications in the brain.

It is at this stage that I begin to rely on my grandmother's recollection of events immediately prior to my grandfather's initial diagnosis. Being just 5 years old, I interpreted my grandfather's behaviour as merely slightly strange and intentionally amusing. Nonetheless there is one feat that I can vividly recall my grandfather performing on numerous occasions which subsequently has escalated into an act that I associate with him to this day. In my grandparents' bungalow there were two doors painted with semi

obscure glass that separated the kitchen and dining areas. Whilst my elder brother, Joe (three years my senior), and I had engrossed ourselves in jigsaw puzzles and board games in the dining room, my grandfather would conceal himself behind one of the doors, whilst ensuring that the other door remained open. To our great amusement, he would then project his limbs through the open door at randomly dispersed intervals, under the false assumption that we were unaware that it was in actual fact him.

The initial recognisable symptoms are usually erroneously considered to be either concerns relating to aging, or manifestations of stress. In the primitive stages, the most commonly observed symptom is memory loss in relation to recently attained facts and an inability to acquire new information. My grandfather was not the first person within the family to suffer from a form of dementia. Both his mother and elder brother were also victims of Alzheimer's disease. Subsequently, not only was my grandfather unfortunate enough to witness his dearest ones losing their cognition before his very eyes, but tragically his life was destined to shadow their heartbreaking ordeals. As a consequence, when my grandfather initially began to forget that he had literally moments beforehand requested a tea or coffee or that he had in actual fact not taken a shower - despite his unremitting insistence to the contrary - my family's prior experience of the matter prepared them for the merciless diagnosis.

My grandmother committed herself to caring for my grandfather; it was her express wish that he would remain living at home and would not be subjected to the rumoured horrors associated with care homes. As the disease progressed, my grandfather's ability to be independent gradually deteriorated. His loss in cognition accumulated to him conversing with his reflection in mirrors and becoming increasingly agitated when the television was switched on as he became irrationally convinced that there were strangers in his house. After approximately a year he became utterly dependant upon my grandmother; AD slowly and painstakingly stole away his identity. My grandfather began to incessantly shadow my grandmother's every movement, to the extent that he would attempt to accompany her to the bathroom. Begrudgingly, my grandmother began to relent to the idea of seeking assistance and support through respite care as the intensity of the unrelenting condition began to take its toll upon her; subconsciously she had undertaken the role of my grandfather's full time caregiver. It is with profound emotion that I depict his response upon arrival at the centres on these occasions; he was abandoned like a naughty schoolboy in an unfamiliar environment - the only assumption that he could derive was that he had misbehaved; he was being punished. In desperation he would implore: "have I done something wrong?" His behaviour began to progressively resemble that of a child; if in a restaurant he saw a child with an ice cream, he would demand one too. If he had to wait for his food, he would become increasingly agitated and be liable to throw a tantrum. As my grandfather's Alzheimer's progressively enveloped him, his sleep patterns became increasingly capricious; he would be prone to midnight wanders, arising just half an hour after going to bed, under the fallacious pretence that morning had already emanated. My grandmother could not cope. Following just eighteen months of living with the uncompromising condition, my grandfather began to attend a day care centre; Mondays to Fridays, 9.30am until 3.30pm; at 64 years of age, my grandfather's routine was reminiscent of a schoolchild's.

As a sufferer progresses into the moderate stages of AD, damage occurs in regions of the brain that are responsible for the control of language, reasoning, sensory processing and conscious thought. On a parallel, the progressive deterioration hinders independence preventing subjects from the effectuation of common activities related to everyday living. Speech impairment becomes increasingly evident as sufferers struggle with the ability to recall vocabulary, resulting in ubiquitous paraphasias. During this phase, memory loss is augmented in terms of austerity, and the failure of the sufferer to recognise close relatives becomes the catalyst of emotional turmoil for caregivers. At this stage, long-term memory, that was previously unblemished, becomes debilitated. Wandering and irritability are common manifestations as behavioural and neuropsychiatric fluctuations become more customary. This prevalently escalates into the experiencing of hallucinations, delusions, paranoia and impulsive behaviour alongside crying, outbursts of unpremeditated aggression and resistance to care giving. Sufferers also begin to lose insight of their limitations and the process of their disease.

My grandfather's transition into the moderate phases of Alzheimer's was heartbreaking; my mother, Mandy, had always been exceptionally close to him. However, his gradual failure to recognise even his closest relatives was indicative of the oppressiveness of his condition; when he began to address me as "Mandy", my mother's inner torment was evident. It was nevertheless indicative of a vague connection between the young, blonde girl before him, and the one that he himself had nurtured a lifetime ago. Whilst a few months previously, he had been susceptible to uncontrollable anguish at the prospect of separation from my grandmother's side, she, like the rest of us, had now become a mere presence from my grandfather's perspective. Agonisingly, he had gradually begun to fail to recognise each and every one of us. My grandmother continued with the role that she had assumed as my grandfather's primary carer up until 3 years after his initial diagnosis. At this stage, the circumstances dictated that practically, it was imperative that he was in an environment where he could be cared for by professionals. During the course of his final few months living with my grandmother, his condition deteriorated rapidly. It is not uncommon for sufferers of AD to experience urinary incontinence. Not only was my grandfather prone to this, but when he voluntarily urinated, it was inside the wardrobes. Furthermore he would wrap his faeces in little bundles and ensconce them at the bottom of the wardrobes. We were advised that by urinating and excreting, he feared he was misbehaving, and subsequently attempted to conceal what is a normality for everybody else. We were the witnesses of the diminishment of a proud, dignified man to a mere skeletal existence.

As Alzheimer's progresses into its advanced phase, the patient is utterly dependant upon caregivers. Whilst during earlier phases, the patient at least retains the ability to attempt to use word substitutions, throughout the duration of the final stages language is reduced to elementary phrases or even isolated words, and eventually complete loss of speech. Although uncharacteristic aggressiveness may still be prevalent, acute apathy and fatigue are extensively more typical. Plaques and tangles now envelop the entirety of the brain matter resulting in a significant reduction in brain tissue. Ultimately, patients are unable to perform even the simplest of tasks without assistance. As muscle mass and mobility deteriorate, the subject is bedridden as their bodies begin to shut down, and they lose the fundamental ability to even feed themselves.

And so my grandfather's life mirrored that of his mother's, and of his brother's, and of every other victim of Alzheimer's disease. He lost the ability to interact with others, he lost the intrinsic ability to execute everyday skills; he couldn't wash himself, nor dress himself, or even feed himself. He was stripped of all humanity in the most undignified manner imaginable. My grandfather's one remaining enjoyment in life was his love of food; sweet food in particular. Being a diabetic worked only to accentuate the tragic nature of his predicament; the care homes restricted his intake of sugar. His everyday existence was merely dominated by pills, pills and more pills. And so, whenever we visited him, we would surreptitiously present him with a small chocolate bar. It was by no means much, but it gave us the illusion that we could at least contribute to some form of happiness in his harrowing existence.

Alzheimer's disease is a terminal illness; it has no survivors. It is responsible for the destruction of brain cells and the consequential irretrievable memory loss, erratic conduct and loss of bodily functions on behalf of the sufferer that makes it such a pernicious, unrelenting condition. Not only does it peculate a person's integrity, but AD takes away a person's ability to think, eat talk and walk independently, connect with others and find their way home. The disease is the seventh leading causation of death, albeit, the actual cause is typically from an external factor - not the disease itself.

Pneumonia or infections from pressure ulcers are common catalysts in the eventual demise of AD sufferers. My grandfather had a tendency to wander; unlike many sufferers, he remained remotely active. However, in June 2004, we received a phone call informing us that Norman had been taken to hospital; he had fallen and broken his hip. To our profound anguish, we discovered that his supposed 'carers' had been completely oblivious to the incident for the duration of an entire week. In my opinion, this highlights the failure of care homes; the staff were trained in their profession to notice such things, yet my grandfather remained in agony for an inexplicable period of time. Following his operation, he never

walked again; my grandfather lost the will to live. He was bedridden; a month after his operation, he contracted pneumonia and died.

My grandparents lived in Luton - a two hour journey from us. On the morning of July 19th 2004, my grandfather's care home contacted us advising that Norman was on the brink of death. Immediately we set out on one of the most agonisingly perpetuated journeys conceivable; all the time not knowing whether or not we would make it in time to say goodbye. We arrived at midday; Norman was still with us. In retrospect, relief can hardly be deemed an appropriate term to characterise our emotions upon receiving this news, considering the heartbreak that awaited us. My grandfather bore resemblance to no living being; he was skin and bones, unnaturally pale, cadaverously emaciated. His gaunt, blemished skin clung to his skeleton, as if to a carcass. He was not conscious; saliva oozed from his parched lips, and his bed sheets were sodden. We stayed at his bedside until 5.00pm, at which time it was recommended that we left. In turn we all said our final goodbyes in states of profound pensiveness. As my lips brushed his ice-cold cheek, an overwhelming despondency engulfed me and I could suppress the tears no longer; I never saw my grandfather alive again. Within ten minutes of arriving home later that evening, we received a final call from my grandfather's care home; Norman Chappin had lost his battle with Alzheimer's disease at 6.40pm.

Alzheimer's disease stole my grandfather from me; not only a grandfather, but a husband, a brother and a father. Eleven years prior to his death, Norman was tormented by the initiation of the destruction of his brother, Roy, at the pitiless hands of the disease. My father recalls how, at the time, Norman declared that he'd prefer to be shot dead than to relinquish life in such a devastating fashion. And yet, deplorably, he was destined to meet exactly the same end as both his mother, brother and every other unimpeachable victim of the implacably merciless condition. At 11 years of age, the tragic nature of his demise haunted me; five years on, I appreciate his life, and the legacy he left behind in his daughters, and grandchildren. There are no definitive answers regarding Alzheimer's disease currently; I can only hope that in the foreseeable future, we will find a means of combating the ruthless condition that affects so many lives today.

