

## Chapter 4

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### **Crossing the Divide: Dementia and Developing Understanding between Young and Old in Contemporary Children's Literature.**

An increasingly ageing population across Europe raises the issue of understanding between the young and older generations which is especially important in the light of the continuing rise in dementia in older people. Alzheimer's Research UK predicts an escalation in cognitive problems in the aged, stating that "[t]here are 850,000 people with dementia in the UK. This will increase to over one million by 2025 and over two million by 2050" (Alzheimer's Research UK 2019). Hence the question arises as to how such relationships are represented in fiction for children, for fiction vicariously enables the reader to engage with the gaps between generations. The following discussion considers how contemporary writers for children have approached crossing the divide between the young and the old. Understanding and trust, key factors which alleviate the problems caused by Alzheimer's disease and dementia, are now more widely represented in contemporary fiction for children as they are part of present day reality.

*The Granny Project*, originally published in 1983 by Anne Fine; *Billy Elliot* (2001) by Melvin Burgess and Lee Hall; *Unbecoming* (2008) by Jenny Downham; David Walliams' *Grandpa's Great Escape* (2015), and *The Dementia Diaries* (2016) by Matthew Snyman and the Social Innovation Lab Kent, each take differing approaches to the problems of dementia however, they have a common intention of demonstrating how intergenerational understanding and solidarity can be developed in living with those suffering from dementia and Alzheimer's disease.

My discussion of approaches towards dementia and Alzheimer's disease in English children's literature begins with Anne Fine's *The Granny Project* as it was one of the first, if not the first, to deal with this subject. Short-listed for the prestigious *Guardian* Children's Fiction Award in 1984, and since published as a play as well as a text for older children, it is used in schools in the UK to educate children about living with and caring for someone with these conditions. It is a ground-breaking work interrogating the effect on a family who are caring for a grandmother with degenerative disease which is both physical and mental. There are four children in this middle-class family; their father, Henry, is a teacher and their mother, Natasha, is Russian. This is a family which is somewhat out of control. The opening

scene is of the doctor's visit to discuss the grandmother's condition whilst the teenage children Ivan, Sophie, Tanya and Nicholas are eating their meal. Their table manners are appalling. Neither parents are eating with the children, as they are conversing with the doctor about the grandmother. The doctor's diagnoses are all associated with ageing. He uses formal, dehumanizing language to identify her problems, such as "characteristic volar subluxation and ulnar deviation of the phalanges instead of saying 'bent fingers'" (Fine 5). In the same manner he describes her deafness and deteriorating cognitive functions. The information Natasha and Henry supply in response to the doctor's questioning reveals the grandmother's behaviour as bizarre. She will eat anything, including ornamental garden plants and feathers, and she shuffles because she has taken her son's slippers which are far too large for her. The doctor's conclusion is that she is not actually technically ill at present. His action is to put in process the paperwork to have her removed to a care home. Fine's representation of the doctor's approach is indirectly critical, for he makes no sympathetic comment on the pressures on the family resulting from the old woman's behaviour. His approach is coldly clinical, drawing satisfaction from the fact that he can complete his forms rather than an humanitarian concern for his patient. The grandmother's odd behaviour generates tension, for Tanya describes her grandmother as greedy whilst Natasha declares "She is not *my* mother!" (7). Natasha's comment epitomizes both a lack of empathy for the old woman's condition and the pressures of looking after an in-law. However, the emotional climate is not as clear cut as it might at first seem as the children are shocked when they realise that the decision may very well be to put their grandmother into care. The parents are also uncomfortable about their pending decision, with Henry telling his children that there is nothing to worry about, whilst Natasha's response is a folk proverb which she delivers in Russian, the translation being "You can't hide sharp steel spikes in soft cloth bags" (8). Throughout the text Fine uses various Russian proverbs which Natasha says come from her village. They act as pithy comments on the various situations which arise, acting as it were, as a summary of the emotional and practical situation at the time.

Following their parents' decision to place their grandmother in a home, the children hold a secluded meeting. The first question they ask of themselves is whether they actually care. Their response is unanimously positive. They then have to decide on a course of action to persuade their parents not to go ahead with the placement. They consider anti-social behaviour directed at their parents, such as a code of silence, not helping with chores or putting emotional pressure on their parents by their disturbing their sleep with the younger children faking nightmares supposedly brought about by the threat of losing their

grandmother. Their deliberations then move in a more calculated and organized direction. The two teenage children, Ivan and Sophie, have been set a project for Social Science which they decide to use to put pressure on their parents. They combine information about the general circumstances of older people in the UK with a case study of their own family dynamics. Thus their “Granny Project” is born. The brilliance of Fine’s creation is that within the fiction embeds factual information about the actual circumstances of older people in the UK, enabling her readership in the twelve plus age group to engage with these problems. Furthermore the family story built around these characters reveals the realities of the pressures on carers such as the hard and often unpleasant work and the draining fulltime physical and emotional commitment. Fine also demonstrates how understanding and empathy can be developed and grow; how the generations can come to know each other. This does, however, take time, work and patience, which is reflected in Fine’s narrative being organized around a series of climaxes. The first is the doctor’s visit; the second the children’s decision to engage in their “Granny Project” and the third is the moment when a place becomes vacant in a local care home. The grandmother is left with Sophie, while the rest of the family visit the care home. Being confronted with the reality of taking his mother to the care home for good, Henry breaks down in tears. The family return home: a decision is put on hold. Sophie then hands over “the Granny Project” notebook entirely to Ivan. Although Ivan is intellectually very able, he lacks empathy. His focus is on facts and information. Ivan carries on with the project in order to blackmail his parents into abandoning the care home proposition by using the study to confront them with the actualities of their treatment of the grandmother and to make them feel guilty.

The fourth climax comes when the “Granny Project” is complete. Ivan leaves the notebook on the kitchen table for his father to find. Henry is shocked, furious and deeply upset at what he reads, for Ivan has not softened the account in any way. He has recorded all of the unsympathetic thoughts generated by the pressures and fatigue of caring for someone with cognitive impairment that would otherwise remain unspoken. For instance, he records Henry’s comments on the costs of electricity required to keep his eighty-seven-year-old mother warm:

*A calculation of the exact number of hours that her fire was actually on in one typical winter week gives the lie to the frequently expressed claim by Mr H. that ‘If it weren’t for her and her multi-kilowatt gobbling fire, I reckon all our heating bills would be a quarter of what they are,’ (97, italics in the original)*

Ivan's account is unflinching and unsympathetic, revealing personal and painful information and conversations concerning the impact his parents' looking after their elderly relative has on them. Henry is understandably enraged and hurt. The situation is exacerbated by the fact that Ivan attends the school where Henry teaches. If Ivan does submit his project, then many of the details would very likely become part of staffroom gossip. Henry's reputation would be ruined and he would be exposed as shameful and uncaring. Both Ivan and Henry know that the presentation of the "Granny Project" is a means of blackmail to enable the grandmother to be kept at their home.

Henry and Natasha share their reaction to Ivan's actions and the content of the "Granny Project" and are so upset and angry that they contemplate beating him up or throwing him out of the house. Fortunately, Natasha comes up with a new plan; since the prospect of putting their grandmother in a care home is so repulsive to the children, then they should take over looking after her. Ivan is to become the sole carer for his grandmother, whilst the other children will take the responsibility for the other household requirements, such as cooking, shopping and cleaning. This leaves the parents free time to enjoy their own pursuits which have been put aside for years. The children have no option but to accept. The irony here is that when Sophie looked after her grandmother for one evening when the rest went to see the care home, she found it challenging and exhausting and at one time felt very frustrated and angry. On the other hand, Ivan has to date had little individual contact with his grandmother as he prefers not to engage in normal emotive relationships. The children happily agree to the proposition, having 'won', but their triumph is short-lived when they realize what they will have to do and it is even more so when they actually start running the household and Ivan cares for his grandmother.

This turn of events enables Anne Fine to show both how challenging it is to look after a person with the problems of cognitive and physical deterioration which come with old age. The grandmother can be difficult and demanding; she may be in the present or living in a world of her memories. She will need her food prepared in a particular way so that she can easily eat and she will want her routines in terms of television programmes, she will need her environment completely attuned to her desires and needs, which she expects Ivan and the others to know irrespective of whether they have been told of her requirements. Her behaviour may also be eccentric and strange at times. For Ivan, the learning process is taxing and draining. He is not used to or willing to have to fully accommodate someone else's needs and demands over his own but he has no option. The other children also learn that running a household takes a lot of work and organization and a lot of their personal time, a series of

facts to which they have previously been oblivious. In contrast, Natasha and Henry have regained their freedom and now have personal time to spend together as when they go dancing, something they have not been able to do for years.

Fine uses the interaction between Ivan and his grandmother to demonstrate how intergenerational understanding can be developed. With being forced to spend so much time looking after his grandmother, Ivan? gradually comes to know her and earns her trust . In her more lucid moments she uses her childhood memories to tell him about her life. Ivan writes them down in his new version of “The Granny Project”, which has become a personal account rather than a cold exercise in facts and figures. He now understands why his parents may have expressed their frustrations in negative ways and also why his grandmother’s behaviour was seemingly eccentric, for she is living out her memories in the unfamiliar context of the present day. For Ivan, the learning experience is not only one of how to be a carer, but also of how to engage with his emotions, to understand himself. The story concludes with the grandmother’s death. As a family they now have an understanding of this woman who was initially seen only as a burden and a stranger lost in her own world. Thanks to Ivan’s record of her life and his time with her, they now have memories to cherish. The change brought about in Ivan is that he is determined in his forthcoming adult life to help others, knowing now that small changes can bring about positive revolutions through caring. The intergenerational understanding and sense of solidarity brought about by initially adverse circumstances will continue to make a difference in the future.

Whereas the focus in Fine’s *Granny Project* is on the depth and breadth of the effect of dementia, in *Billy Elliot* by Melvin Burgess and Lee Hall the occurrence of the grandmother’s Alzheimer’s disease is part of a much wider plot which examines the difficult times of the miners’ strike in England in the 1970’s and the experiences of a Billy whose talent and passion for dancing make him an outsider in this very male-orientated community. Prime Minister Margaret Thatcher’s decisions to close coal mines for economic reasons caused hardship, anger, distress, and rioting against the police in the mining area of the North of England. Against all cultural mores of this community, which is very conscious of protecting its identity in these stressful times, Billy has a desire to be a ballet dancer and he secretly joins a ballet class. Matters are compounded by the fact that Billy’s mother is dead. His father is raising his two boys and looking after the grandmother, who suffers from Alzheimer’s disease. The taxing nature of their lives is exacerbated by divisions in the once close mining community caused by those men who are on strike and those who break the picket lines of strikers and continue to work. Solidarity was an important concept to the

miners who were pitted against the government and the police. Paradoxically, it is this miners' sense of self and masculine identity the masculine persona which threatens to break the solidarity of Billy's family. When Billy's secret is out, he faces a tense discussion with his father. Billy tries to defend himself and courageously expresses his point of view:

"So what's wrong with ballet?" I said.

Confounded and increasingly angry Billy's father responds:

"What's wrong with ballet? Look at me, Billy. Are you trying to wind me up?"

"It's perfectly normal," I said, turning to face him.

"Normal?" I was scared. He'd gone all white round the lips. (48)

The grandmother unusually enters into the conversation, breaking out of her enclosed world when she says "I used to go to ballet" (48), which would have been exceptional for a working class woman whose young years would have been in the early decades of the twentieth century. The episode with Billy and his father wakens her memory of her love of ballet, for a few days later she plays a recording of *Swan Lake* which had lain silent and neglected for years. Nan begins to dance. Billy had seen her dance before but, now he recognizes her movements as balletic for she used to take classes as a girl. She tells Billy that she could have been a professional dancer. The demonstration of how much dancing means to her and what it could potentially mean for Billy eventually results in his becoming a professional dancer, in a way fulfilling her own crushed ambitions. In the grand finale of the novel, Billy is principal dancer in *Swan Lake* at Covent Garden. The importance of the link across the generations is paramount, for this is an example of intergenerational solidarity at the heart of a family which is potentially being rendered asunder by cognitive disease, stress, poverty and cultural norms. Links have been made between Billy and his Nan through the creative experience of dance and the love of music and movement. Nan can express herself through the memory of movement in ways that are lost to her through more usual means of communication and simultaneously she can make an important difference to her grandson's life.

Jenny Downham's *Unbecoming* also features a grandmother suffering from Alzheimer's disease and dementia. Mary is the grandmother of the family from which she has been estranged for years. Initially reluctant, they help Mary to make sense of her history and unlock the silences of the past. The novel begins when Caroline, a single parent, is called unexpectedly to the hospital to collect her mother. Much to her surprise and discomfort, Caroline has been identified as the next-of-kin being named on a medical bracelet. Katie, the teenage daughter, has accompanied her mother to the hospital. Mother and daughter are faced with Mary, who is confused, non-communicative and detached from reality. Mary will have

to go home with them as there is no provision available from Social Services. This is a complex situation, for Mary had left her illegitimate baby Caroline in the care of her sister Pat. Caroline is angry and resistant to having an unwanted stranger, albeit her blood mother, foisted upon her. Katie is more sympathetic as she does not have the complex emotional relationship her mother has with this stranger, who is her grandmother.

Memories come and go for Mary and reality appears and fades; people are known to her and then she is unable to recognize or remember them. Mary's inner experiences, which are hidden from outsiders, are captured in italics. Here the reader has insight into the confusion, desperation, and heartbreak of someone suffering from Alzheimer's disease and is made aware of the difficulties of communication and language. Fortunately for Mary, Katie breaks through by her persistence, curiosity, and compassion. The strategies which Downham writes into the approaches taken by Katie are those used in accord with the recommendations of bodies such as the National Health Service involved in research into dementia and care. These strategies emphasize the need for the recognition of personhood for those who are cognitively challenged (NHS, "Simple Ways..." 5). Like Ivan in *The Granny Project*, Katie persists with conversation and keeps a diary of their exchanges, using notes to remind Mary of everyday matters such as her name and those of family members. A relationship is gradually built up between them. For Mary, it also means regaining a knowledge of herself. Storytelling is at the center of this approach; the diary is a series of stories, building the fragments which Mary recalls from the fog of her past. What they discover is that Mary had been a lively and outgoing person; one who was in love with life and unafraid to embrace the richness and the sorrows that it brought. Unlike her grandmother, Katie is shy and reserved but is spurred on by Mary to confront the girls who are bullying her. Encouraged by Mary, she accepts her own sexuality and finally tells her mother that she is gay. Mary's condition will only worsen, whilst, with the strength given by her grandmother, Katie will confidently emerge into her chosen lifestyle. *Unbecoming* is a complex novel which begins with a family fractured over generations. Through compassion, striving to understand, and the courage to confront difficult and disturbing memories, they piece together and consolidate the past, so that finally they can move together with the strengthening attitude of solidarity across the generations into a healed and more positive future. Although at times emotionally searing, *Unbecoming* is a novel of encouragement and hope.

David Walliams' *Grandpa's Great Escape*, is a high speed comic adventure which is emotionally lighter as it is for younger children, but nonetheless centers on coping with dementia and Alzheimer's disease. Twelve-year-old Jack's Grandpa was in the Royal Air

Force in World War Two. He was as a Spitfire pilot and was thus involved in the vital Battle of Britain, one of the turning points in the war which moved Britain towards victory. However, the glory of those days is far from the lived reality of Grandpa in his old age. Walliams begins with a Prologue which charts Grandpa's deterioration from being somewhat forgetful – making tea and forgetting that he had done so, or leaving the bath taps running flooding the downstairs flat (23).

*Over time , Grandpa started to forget bigger things. What year it was.*

*Whether his long-deceased wife Peggy was alive or not. One day he even stopped recognizing his own son.*

*Most startling of all was that Grandpa completely forgot he was an old age pensioner. (25 italics in the original).*

Grandpa now lives in his past. The stories he told Jack of his war-time adventures have become his reality. Jack is the only member of the family to understand this situation. Jack is a shy and retiring boy who is happiest playing out the air battles of World War Two with his model aeroplanes. In his games and his dreams he can be a hero like his grandfather, the games and dreams which are far from the reality they both live. Jack's favorite time is when he is with his grandfather. At one time they had regularly visited the Imperial War Museum in London. Afterwards Grandpa would regale Jack with his stories of war time. Now, sadly, Grandpa's condition has deteriorated to the extent that he is not safe to be out by himself. Throughout Walliams inserts comic scenes of the disjunction between Grandpa re-living his war exploits and reality as when he decides that a supermarket trolley is a Lancaster bomber plane which he "pilots", "hurtling down the aisles on a top -secret mission, hurling huge bags of flour", thinking they were bombs (42). He is consequently banned from the supermarket. Comedy is also juxtaposed with the sadness of his condition as when 'the old man would call for his Darling Peggy as if she was in the next room.' (43) Matters come to a climax when Grandpa can no longer be trusted to live independently, for he develops a tendency to wander and go missing. As with *The Granny Project*, the question of the elderly person being moved into a care home becomes the crux of the story. Here it is both for Grandpa's safety and to relieve pressures on Jack's parents. As a mid-way decision Grandpa moves in to live with Jack and his parents, where he shares a room with Jack. Now their time together is more than Jack listening to the stories, for Grandpa incorporates the boy into the memories he is re-living. On his first night with Jack, Grandpa stands listening acutely for any sound of Luftwaffe planes. Jack joins in as he is bidden:



[he] cleared his mind of thoughts and concentrated hard on listening. It was absurd, if you thought about it. Here they were in 1983, listening out for planes that hadn't flown over the British isles for nearly half a century. But it was so real in grandpa's mind, Jack couldn't help believe it too' (126).

As their adventures develop, Jack plays up more and more to being a war-time character, with Grandpa being his respected commanding officer. Jack is therefore able to gently guide and persuade his Grandpa as required, thus averting difficult situations. For example, when Grandpa goes missing from home after a long search in the local area Jack thinks that he will have returned to a place which reminds him of his wartime adventures and subsequently finds him at the Imperial War Museum fast asleep in the cockpit of the Spitfire which is suspended high above the ground. Jack rescues his Grandpa in a slapstick comic scene. As a result, Grandpa is sent to a local care home which is actually a cover for a fraudulent scam. The inmates are poorly treated, locked in their rooms and drugged with sleeping pills; the 'nurses' are local criminals and the matron is the vicar in disguise.

This all sets the scene for a quasi-wartime escape headed by Grandpa and helped by Jack, who breaks into the care home. The model Grandpa initially uses is what is known as The Great Escape, when British soldiers dug a tunnel to escape from the prisoner of war camp Stalag Luft III. However, Grandpa is persuaded by Jack, who fully plays the part of Grandpa's Squadron Leader, that this will take far too long. The final great escape for the elderly inmates is via a daring descent from the top floors using ladies silk knickers knotted together. To get to this point, Grandpa has shown the other inmates how to circumvent their being drugged with the sleeping pills and led them through the window and across the roof to safety, with the dastardly 'matron' and 'her nurses' being arrested by the police and their true identities being revealed. Grandpa is now the hero of the hour in real time as well as in his memories. Thus the way in which Walliams portrays Grandpa is both sensitive and demonstrates respect, for despite his loss of contact with reality he is still able to solve problems as for him the realities are embedded in a wartime context which he understands. Grandpa is hailed as a hero, while Jack also knows that he has played an important part in helping the old man triumph. Jack no longer needs to hide behind his shyness, for his Grandpa has given him confidence.

Whilst *Grandpa's Great Escape* is a rollicking fantasy comic adventure built around the serious realities of the problems of dementia, *The Dementia Diaries* (2016) by Matthew Snyman and the Social Innovation Lab Kent is firmly based in reality. The diary entries which

have been shaped by a professional writer, draw on the experiences of teenagers who have grandparents suffering from dementia. In her foreword Angela Rippon, a celebrity and advocate for older people and Co-Chair of the Prime Minister's Dementia-Friendly Communities Champion Group, makes the following comment:

I think it's brilliant to see Brie... representing a dementia aware generation who will mature into a society in which dementia is understood, dementia patients are respected and the word "stigma" will no longer be part of the Dementia Dictionary.

These aren't just diaries; they are beacons of hope for the future. (7)

Brie writes that she wants to 'share the sort of stories that are hard to talk about' (13). The diaries recount important and painful times in the relationships across the generations, for instance when the grandparent first tells of their condition, or the teenager fully realizes that something is wrong and that it will not get better. In addition to these personal accounts the third chapter focusses on ways of coping with dementia, such as keeping to a regular timetable for family meals and at times of heightened stress just to "relax and accept them as they are" (45). Activities are suggested at the end of each chapter as the text makes a progression through various stages of the illness and its potential effects for the grandparent, the teenager and their family. The text also points out the things that teenagers should look out for in their grandparents, such as loss of memory, mood changes and difficulties in communication. *The Dementia Diaries* is informative, poignant and also funny, stressing human communication across the generations where the young and old are working together with a sense of solidarity so as not to allow this disease to destroy their quality of life.

In conclusion, the above readings of selected texts for young readers demonstrate how children's literature authors engage the younger generation in concrete approaches aimed at reducing the generational divide and bringing about greater solidarity. It is notable that over the past decade the number and range of books which address dementia has increased considerably, with lists now available from associations such as The Book Trust (Book Trust UK 2019) or Young Dementia UK, (Young Dementia UK 2019). Picture books designed to appeal to younger readers which displace the subject into a fantasy world of animals are also becoming more common. For example, *Lovely Old Lion* by Julia Jarman, (2015), or *The Forgetful Elephant* by Irene Mackay, (2013). Across the age range authors are taking imaginative approaches to the problem of dementia as has been demonstrated. The drive toward intergenerational understanding is becoming stronger as writers for children use their

creative and powerful imaginations to address dementia using their work to help and support the increasing number of children who are having to cope with this problem.

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