

Thesis RMA Comparative Literary Studies
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Literary Representations of Dementia

**...Evoking Empathy through the Use of Narrative
Devices**



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Table of Contents

Introduction	4
Chapter 1. Theoretical Framework on the Representation of Dementia in Fiction	
1.1 Putting the Seemingly Invisible on Paper	22
1.2 Involving the Reader in the Representation of Dementia	25
1.3 Paratexts as a Way to Encourage Active Readership	28
1.4 Ellipses, the Withholding of Crucial Information, and Gaps to Involve the Reader	31
1.5 The Use of Temporalization to Create a Distortion in The Reader's Experience	34
1.6 Focalization as a Way to Give a Sense of Loss	37
1.7 Outline of the Theory	40
Chapter 2. The Use of Paratexts	
2.1 Introduction	42
2.2 Foreboding in Advance of the Narrative	43
2.3 Apprehension within the Spaces of the Story	48
2.4 Pictures: A Deviation from Words on Paper	50
2.5 In Conclusion	53
Chapter 3. Ellipses, the Withholding of Crucial Information, and Gaps	
3.1 Introduction	55
3.2 Omission of Information in Scenes in the Narrative	56
3.3 Omission of Information in the Form of (Unspoken) Diagnoses	61
3.4 Missing Information in the Form of Ellipses	65
3.5 In Conclusion	68
Chapter 4. The Use of Temporalization	
4.1 Introduction	70
4.2 Indications of Time in the Novels: Clocks	71
4.3 Maarten's and Alice's Reflections: Whiteness of the Mirror	76
4.4 Maud's Split Sense of Personality in the Mirror	80
4.5 In Conclusion	82
Chapter 5. The Use of Focalization	
5.1 Introduction	84
5.2 Providing Insight into the Protagonist's State of Mind	85
5.3 The End Illustrates a Limited Perspective	90
5.4 In Conclusion	94
Conclusion	95
Works Cited	99

Introduction

Dementia as a Social Dilemma

Questions on how to deal with dementia in society have become increasingly relevant over the past few decades. Dementia receives a large amount of attention, because it is the most common disease of memory loss across all levels of Western society (Swaab 396).¹ The number of people suffering from dementia is likely to increase from 46.8 million in 2015 to 131.5 million in 2050, making it a worldwide dilemma of how to deal with it (Alzheimer's Disease International, "World Alzheimer Report" 1).

The growing amount of literary fiction on memory loss reflects the social dilemma of providing for a worldwide ageing population. Society as a whole must deal with the consequences of an increasing number of people suffering from this disease. The increased number of people suffering from this disease intensifies a need to understand how this disease affects us, not only on a societal level, but also on a personal level.² The sciences are working on understanding how the brain functions and what medical solutions there might be towards slowing down the process of dementia. However, as Dick Swaab explains in his book *We Are Our Brains: A Neurobiography of The Brain, from The Womb to Alzheimer's*, no concrete answers have been found yet as to how memory loss can be cured and research

¹ This thesis focusses on dementia and the early onset of Alzheimer's disease. The diagnosis of these diseases comes at different stages in time: early onset of Alzheimer's disease can occur when someone is in their 40s or 50s, and dementia can occur when someone is in their 60s. Dementia is an overarching term for a set of symptoms that occur when someone suffers from memory loss, language difficulty and motoric dysfunction. Alzheimer's disease can only be diagnosed with certainty after death, by analysing the brain tissue. This means that it is possible that someone who was diagnosed with dementia might have been suffering from Alzheimer's disease. Therefore, this thesis can discuss both early onset of Alzheimer's disease and dementia simultaneously.

² Dieguez and Annoni emphasize that "amnesia is by far the most prominent representation of memory disorders in fiction" (159), Sako explains that "[a] growing number of literary and cultural texts include characters affected by dementia and address their concerns" (1), Vassilas illustrates with examples from literature that "[t]here is an increasing awareness among the general public of the terms dementia and Alzheimer's diseases [which] is reflected in the arts [...] with several major authors having recently published books exploring the experience of dementia" (439), and Zimmermann explains that "Alzheimer's disease [is] increasingly picked out as a central theme in fictional literature" (101).

into effective medicine is slow (Swaab 412). Through fictional literature an understanding of dementia can be created that might be hard to find through clinical literature, as Sebastian Dieguez and Jean-Marie Annoni make us aware in their article “Stranger than Fiction: Literary and Clinical Amnesia”:

[T]he intuitive understanding of memory impairment could turn out to rely on perception of radical personality changes, out-of-character claims, behaviours incongruent with previous events, repetitive actions and utterings, or lack of emotional reactions to familiar items. (166)

Fictional literature can explore the effects of dementia, by focussing on well-known symptoms that this disease of the brain brings about. In this way, analysing literature on dementia can offer an apprehension of the change that a person goes through because of this disease. At the same time, fictional literature can be far more holistic than a medical one, because it can show us a person in her or his environment, and therefore allows us to go beyond the symptoms alone and to consider one’s personality more in-depth.

Since the discovery that our memory is stored in the hippocampus, and with that the increasing attention that it receives in medical research, more attention has been given to this disease in cultural representations too. For example, in artworks, books and films an attempt is made to comprehend what it means to deal with dementia.³ Cultural representations can address the impact that dementia has on the lives of those who suffer from dementia and those directly involved with the sufferer. The fictional accounts, concentrating on imagining an individual experience of dementia, are more accessible to a wider public than scientific literature. As someone with dementia loses touch with society and their social life, this can

³ Dieguez and Annoni state that: “With the advent of neurological and psychiatric sciences[,] as well as the multiplication of published case reports of amnesia patients, literary characters began displaying amnesia in a more clinical [...] context” (140). Vassilas says that: “There is no doubt that there is an increasing amount of literature published in which dementia and its consequences are discussed [in] novels, plays, poetry and short stories” (444).

cause other problems such as depression and loneliness. Elizabeth Barry, in her article “The Ageing Body,” states that “the ageing subject’s experience might add a crucial dimension lacking when a perception of the body as medical object holds sway” (133). Again, fictional literature can thus show us much more than a medical diagnosis. As I will demonstrate, fiction gives a writer the liberty to contextualize a disease and to explore its repercussions on the lives of those affected by it and their social environment.

People want to understand why something happens in the body, with which the representation of a disease can help. The human body, and the consequences of distortions that can occur within it, have always been a fascination of the arts. In *The Cambridge Companion to The Body in Literature* David Hillman and Ulrika Maude state: “[O]ver the last three or four decades, [writers] have found myriad ways of addressing the representation of the body and embodied experience in literature” (3). The article “Body Representations in Art and Photography” by Ben Baruch Blich adds that much attention has been devoted to the body: “The human figure, the body and its parts [...] are still to these days in the focus of the arts. Bodies were painted, sketched, sculptured, engraved, etc. Poets and writers were inspired by the human body and eloquently described it” (Blich 108). One of the fascinations of art is the representation of the ill body, including the representation of dementia. Dieguez and Annoni explain that medical research has limited knowledge of how to cure diseases of memory loss, such as dementia. They make us aware that the representation of dementia in literature allows for much consideration: “Because we still do not fully understand the mechanisms [of dementia, and the symptoms hereof, such as memory loss], it seems premature at this stage to criticize or condemn literary works as inaccurate regarding their portrayal of memory disorders” (Dieguez and Annoni 143). While medical as well as fictional accounts of dementia can only make limited stakes on being truthful representations

of dementia, they are nevertheless both exploring causes and consequences of a disease. Especially the latter is tackled in literature, a focal point that will be explored in this thesis.

By giving the reader insight into the mind of a fictional individual with dementia, literature can represent some of the issues that come from dealing with this disease. For example, first is the need to support both the sufferer of dementia and their families and carers. Second is the sort of care and the approach one can take towards someone with dementia, that shows empathy and relates to that person. Questions arise such as: does it matter if the person suffering from memory loss is moved from his or her familiar surroundings? Is it imperative that a person with dementia stays self-sufficient for as long as possible? How can memory aids enhance the life of the person with dementia, and how can one help a person with dementia, through empathetically engaging with that person, and through recalling memories or reminding that person of arrangements in the day-to-day life? Understanding the changes that dementia brings about can lead to greater empathy for the sufferer of dementia. As I will show in this thesis, literature can help to address these crucial questions on how to deal with people with dementia. Literature can not only be used to point out what problems people suffering from dementia have, but it affects us with those problems by binding readers to its narrative. This thesis will show how this is brought about by focussing on narrative devices that help us to understand and empathize with those suffering from dementia.

Reader Involvement in Representations of Dementia

If the narrative devices of fictional works manage to bind the readers actively into engaging with the story content, the reader might empathize with the protagonist suffering from dementia. Katsura Sako states in her article “Dementia and Detection in *Elizabeth is Missing* and *Turn of Mind*” that “narratives that offer access to the internal reality of the character

[...] can produce great empathy in the reader” (6). While previous research has mentioned in passing the use of empathy in literature on dementia, this thesis will ask how this empathy is brought about in three different novels, focussing on the novels *Hersenschimmen* by Jan Bernlef (1984), *Still Alice* by Lisa Genova (2009), and *Elizabeth is Missing* by Emma Healey (2014). The focus of previous literary research lies on asserting how these empathy enhancing narratives, as Sako calls them, influence social discourse through their illustrative examples, by concentrating on the narrative. The critic Christopher Vassilas states in his article “Dementia and Literature,” that novels can “reflect how the wider world views this condition [of memory loss]” and that they are “able to point out universal themes” (444). These universal themes are, for example, pointing out the destructive nature of this disease, and considering what approach to take towards it, dealing with a loss of language, memory, and the self. He further states that fictional accounts can provide understanding about “how patients and carers feel,” because these accounts focus on the individual perspective (Vassilas 439). In addition to this, the critic Abraham Verghese states in his article “The Physician as Storyteller” that there is a “link between reading and writing and empathetic care” (1013). Fiction can illustrate that someone who suffers from this disease loses touch with reality, they lose their sense of self, and lose all sense of who they were before. In fact, one is not considered capable of making coherent decisions anymore, because “the impairment is one of access to past, and especially personal, information” (Dieguez and Annoni 143). Without that information about one’s personal past, a person can feel lost in his or her own social and familiar life. In a similar vein, this thesis will have a look at the symptoms of dementia displayed in the fictional works. However, instead of focussing on the alliance of these representations with social discourses, I ask how narrative devices are evoking feelings, in particular of empathy. I will thereby situate myself firmly within studies that see literature as a (semi-)autonomous system of representation whose structuring mechanisms should be

researched on. Thus, it can be claimed that my research adds to the above-mentioned approaches towards fictional writings on dementia, because it shows the conditions that need to be met in literary representations, in this case of people suffering from dementia, should they influence social discourses.

Furthermore, I will show that representations on dementia might also evoke empathy in the reader through the portrayal of those who are involved in the care of the sufferer of dementia. Thus, I will not only focus on characters suffering from dementia, but also on their social environment and the important role that carers play in the lives of the affected ones in keeping their sense of self and their ability to maintain a “normal” life for as long as possible. David Orr and Yugin Teo argue in their article “Carers’ Responses to Shifting Identity in Dementia in *Iris* and *Away From Her*: Cultivating Stability or Embracing Change?” that representations can serve as examples of how someone with dementia could be better cared for, as these representations address “the question of how the carers might suitably respond to the inexorable decline of memory,” namely by describing examples in the narrative of how the sufferer of dementia can be included in everyday life through small gestures (81). In my thesis, I will illustrate this point, for instance, when I look at the novel *Hersenschimmen*, Maarten’s wife, Vera, keeps on reminding Maarten of arrangements he has made, or when it is time to have his coffee or tea, because otherwise he loses touch with reality. Martina Zimmermann explains in her article “Deliver Us from Evil: Carer Burden in Alzheimer’s Disease” that novels can represent real people through imagined characters, and deal with memory loss in an informal manner (102). She suggests that “[o]nly this discipline [of fictional literature] is allowed to pronounce – and able to tell our society in a memorable manner – what science only observes and describes when it is already too late” (Zimmermann 102). The point that I would like to make, namely that literature is an important means to create empathy with people suffering from dementia connects to

Zimmermann's research, adding to its general claim by making feasible how literature activates readers to connect to people suffering from dementia. I will do so by researching on those narrative devices that are the most prominent in the chosen novels, namely paratexts, representations of time and temporalization, focalization, and the withdrawal of crucial information, that, as Reader-Response-Theory and narratology have shown, asks for active engagement by readers who fill in the gaps that are thereby created.

As has become apparent, several studies already exist regarding the representation of dementia in literature and how literature might evoke empathy. However, those who have looked at dementia in literature have not yet looked at the role of narrative devices. In establishing this empathetic relationship to dementia and to people who suffer from it, I will therefore provide the necessary research into the question with what means fictional works help to establish this connection. A critic who has analysed the representation of dementia in fiction is Rebecca Anna Bitenc, in her article called "Representations of Dementia in Narrative Fiction". She discusses in-depth the two novels *Hersenschimmen* and *Still Alice*, and focusses on the narrative techniques that each uses so as to create understanding for the situation of the protagonist with dementia. These narrative techniques include flashbacks (Bitenc 308), metaphors (Bitenc 310), point of view (Bitenc 321), the use of brackets (Bitenc 321), imagery (Bitenc 321) and repetition (319-321). She states that fiction on dementia can "enhance our understanding" of this disease and that through these representations of dementia empathy can be created, namely what the sufferer of the disease goes through: loss of memory and loss of self (Bitenc 303). She indicates that there is a connection between narrative techniques and the creation of empathy. I extend upon her study of the use of narrative devices in novels on dementia by focussing on paratexts, ellipses, the withholding of crucial information, gaps, temporalization, and focalization, particularly because novels that put dementia central in the story use these narrative devices to bring dementia to the fore.

By evoking a feeling of solidarity with the protagonist who suffers from dementia, the reader can reflect on the social dilemma of how to react, behave and interact with those in society who suffer from this disease and consequentially show empathy towards those suffering from dementia.

Alluring Storylines on Dementia

The novels *Hersenschimmen* by Jan Bernlef (1984), *Still Alice* by Lisa Genova (2009), and *Elizabeth is Missing* by Emma Healey (2014) are exemplary, because they put dementia central and use the narrative devices of paratexts, ellipses, the withholding of crucial information, gaps, temporalization and focalization extensively to represent dementia. This differs from the depiction of dementia in other novels, in which dementia is mostly used as a secondary motive, for example as “a structuring device” or “a theme” (Bitenc 308). This occurs in *The Notebook* by Nicolas Sparks (2008) and *The Arsonist* by Sue Miller (2014), or in (auto)biographies such as *The Iron Lady* by John Campbell (2012), and *Elegy for Iris* by John Bayley (1999).

The novels *Hersenschimmen*, *Still Alice*, and *Elizabeth is Missing* give the impression of granting those with dementia a voice, giving, as I will show, the reader the impression that he or she can experience dementia along with the protagonist. For people suffering from memory loss it can be comforting to read about the experiences of a fictional character going through similar processes, and not feeling alone with it (Vassilas 444). Each of these novels connects to dementia through the overarching theme of this disease and the protagonist’s loss of one’s former self. The variant plotlines create awareness about the possibilities of which ways work best to deal with someone suffering from dementia, and an understanding of this disease. In *Hersenschimmen* the story starts off as being that of a normal old age pensioner, enjoying life, but a few pages in it turns out that there are gaps in the story, such as Maarten’s

forgetfulness of simple things like time and whether or not he has drunk his tea and coffee. These gaps enable the reader to recognize Maarten's decline of memory and first symptoms of dementia. *Hersenschimmen* focusses more on the aspects of the final stages of dementia and steps in at a point in the story at which Maarten has already been suffering from dementia for a while. In *Still Alice* the plotline follows the rapid decline of Alice's memory as she suffers increasingly from Alzheimer's disease; she tries so hard to keep up the act of being in charge of her life, but Alzheimer's disease gets the better of her, and brings uncertainty in both her work and home situation. In *Elizabeth is Missing* the chosen plotline of a murder mystery in the past and the admission of a friend to hospital in the present, leads to confusion in Maud's state of mind. The three novels illuminate the impact that memory loss can have on one's social life or job, the influence that the inability to make decisions has on daily life, the changing relationships with next of kin, and the loss of one's self in society.

The popularity of the three novels becomes apparent when reading how many appraising reviews they have received. They are bestsellers and have been translated into other languages. To mention a few examples, *Hersenschimmen* was named the fourth highest ranking Dutch book of all times by the Dutch newspaper NRC ("Het Beste Boek voor Mannen én Vrouwen") and it has also been translated into twenty-four languages since its publication in 1984 ("Translation Database," *Nederlandse Letterenfonds*). It is considered to be the best Dutch novel on dementia. It was published thirty years earlier than the other two novels, but it is still relevant and popular for its subject material. The fact that it was republished in 2007 reiterates this (Reenders 147). In 2016 *Still Alice* was named a New York Times Bestseller, and was adapted into a film in 2014 ("How Blockbusters Are Becoming Best-sellers," *MailOnline*). *Elizabeth is Missing* has been translated into twenty languages and was listed, amongst others, in the Sunday Times Best Seller List ("Best-selling Author Praised for Depiction of Dementia," *The Guardian*). Emma Healey's novel *Elizabeth is*

Missing is praised for its intriguing portrayal of dementia which is combined in the plot of a detective mystery.

Literary critics have also already called attention to these novels as being good examples of representing memory loss in fiction. For example, *Hersenschimmen* is discussed in “Dementia and Literature” by Christopher Vassilas. In this article Vassilas emphasizes the positions that the carer and the wife of Maarten have in the regressive state of dementia in the novel, and he looks at where Bernlef got his inspiration from, namely from William Faulkner’s novel *The Sound and the Fury* (1929) (Vassilas 439). I will use Vassilas’ insights on the position that the carer and Maarten’s wife Vera take in the novel *Hersenschimmen*, but shift the emphasis to giving a close-reading of this novel and *Still Alice* and *Elizabeth is Missing* on how the narrative devices of paratexts, ellipses, the withholding of crucial information, gaps, temporalization and focalization are utilized to illustrate the dementia of the protagonists. *Still Alice* is briefly touched upon in *The Neuroscientific Turn: Transdisciplinarity in The Age of The Brain* by Melissa Littlefield and Jenell Johnson, which discusses Genova’s background as both a neuroscientist and a novelist, but does not give a close-reading of the novel, *Still Alice* (98). *Elizabeth is Missing* is discussed in “Dementia and Detection in *Elizabeth Is Missing* and *Turn of Mind*” by Katsura Sako, which focusses on how the novel *Elizabeth is Missing* (and the novel *Turn of Mind*) can be placed both in the genre of detective fiction and also in that of dementia writing. Sako states that: “[T]hese novels use the narrative of detection to explore the experience of dementia” (3). In this work, Sako pays attention to dementia in the novel *Elizabeth is Missing*, but focusses on the narrative itself, instead of the narrative devices that can emphasize dementia, and the creation of empathy. She states that this novel “tells a story of life with dementia, and it interrogates the problematic discourse that surrounds the condition” (Sako 11). Furthermore, she states that novels on dementia “can potentially generate strong empathy in the reader towards a

character with dementia” (Sako 6). I will take into account Sako’s insights on the novel *Elizabeth is Missing* and extend upon her argument of this novel and how it can promote empathy, by focussing on the use of narrative devices in this novel and in the novels *Hersenschimmen* and *Still Alice*.

Hersenschimmen and *Still Alice* are discussed in Rebecca Anna Bitenc’s article “Representations of Dementia in Narrative Fiction”. She mentions the use of brackets as narrative technique in *Hersenschimmen* to get the message across (Bitenc 310). She also mentions focalization in *Still Alice* “as a means of offering an imaginative insight into how Alice’s mind works” (315). Bitenc’s focus lies on “interactions of narrative technique and narrative content” (309). In my research, I build upon her insights to show how different narrative devices in novels about dementia create empathy. Suzanne Keen states in her article “A Theory of Narrative Empathy” that: “The confirmation of many of the hypotheses about specific narrative techniques and empathy has yet to be undertaken in most cases” (Keen 216). Sako and Bitenc’s articles are one of the few accounts made to undertake the analysis of how empathy is created in novels on dementia. This thesis will extend upon their accounts by analysing more in-depth the narrative devices of paratexts, ellipses, the withholding of crucial information, gaps, temporalization and focalization in the three novels *Hersenschimmen*, *Still Alice* and *Elizabeth is Missing*.

Using Narrative Devices to Encourage Active Readership

To justify my focus on narrative devices and narratology as an approach, I will be exploring the question of capturing memory loss in fictional accounts. Literary studies on fictional representations are brought together with the concept of empathy which is stimulated through the use of certain narrative devices. Narrative devices actively involve the reader in understanding what the protagonist of a novel experiences. I will take the approach of the

critic Elaine Scarry in her book *The Body in Pain: The Making and Unmaking of The World* in which she looks at the ways in which pain can be represented in literature. There is a problem with objectifying the body, as Scarry explains that “it is precisely because it [pain] takes no object that it, more than any other phenomenon, resists objectification in language” (Scarry 5). Similarly, the disease dementia cannot in itself be portrayed, but the symptoms of dementia, that is to say memory loss, changes in personality, experiencing difficulties in communication, and impaired reasoning, can be represented through narrative devices. Dementia cannot be seen from the outside, but the symptoms of this disease can. Narrative devices in literary fiction on dementia can make the symptoms of dementia available “to accommodate this area of experience normally so inaccessible to language,” and can be those “avenues of objectification” (Scarry 6). The narrative devices help the reader to feel involved in the story, because the reader is made to participate in understanding what the protagonist is undergoing.

Furthermore, I will use Suzanne Keens’ theory on empathy in literature, which she discusses in her article “A Theory of Narrative Empathy”.⁴ She proposes that literature evokes empathy through narrative devices, such as “character identification” (Keens 214), “negative emotions [of] fictional characters” (Keens 214), “[g]enre, setting and time” (Keens 215), “aspects of the plot and circumstances” (Keens 215), “foregrounding” (Keens 216), “gap-filling mechanism[s]” (Keens 217), and “paratexts” (Keens 220). She explains that the reader empathizes with the character, precisely because the reader “internalize[s] the experience of empathy with possible later real-world responsiveness to others’ needs” (Keens

⁴ Suzanne Keen’s book, called *Empathy and The Novel*, discusses existing theories on how empathy is encouraged in fiction. The emphasis in the book is more on establishing what has been said on this topic than what is relevant for this thesis. Therefore, it is more beneficial to concentrate on her article called “A Theory of Narrative Empathy” which both encapsulated the most important ideas on empathy in fiction and focusses furthermore on the practical approach of how (literary) devices in fiction portray empathy. Having said this, Keen draws a connection between the notion of empathy created in fiction and how this might become clear in society, stating that “the experience of empathy [includes] its literary form, with outcomes of changed attitudes, improved motives, and better care” (207-208).

221). Similarly, the reader shares in the experience of someone else, and his or her emotional state that is affected by dementia. By focussing on symptoms of dementia such as confusion in one's own environment, communication difficulties, disorientation with time, and a loss of independence, I will be able to go beyond the boundaries of the representation of dementia cuts across the boundaries of that which might not be immediately visible but can be perceived through narrative devices.

While the narrative devices of paratexts, ellipses, the withholding of crucial information, and gaps, temporalization, and focalization are not unique, in literary fiction on dementia they are used to emphasize the symptoms of dementia that the protagonist suffers from. Empathy is created because the focus lies on the portrayal of "negative emotions," that the protagonist experiences as a consequence of dementia (Keen 214). While these narrative devices might invite other feelings as well, it is the feeling of empathy that could evoke a change in attitude towards dementia. As Keen states, they can advocate "changed attitudes, improved motives, and better care" (Keen 208). Each narrative device emphasizes symptoms of memory loss that the protagonists suffer from; these symptoms influence their surroundings and the position they take in society. These aspects include the fact that the protagonists lose their memory, and therefore lose touch with reality.

Three Different Texts with a Daunting Outcome

The novel *Hersenschimmen* by Jan Bernlef is about Maarten, a pensioner in his seventies, who is showing increasing signs of dementia. Fifteen years ago he moved from Holland to Gloucester in America with his wife Vera, but their two children called Kitty and Fred stayed in Holland (Bernlef 22). Maarten and Vera live a quiet life, with Maarten taking their dog Robert for regular walks, and interacting a little with the locals. The novel begins at a point when Maarten is already suffering from dementia, but the signs of dementia are not very

obvious; hence Maarten's forgetfulness was not noticed as being a sign of dementia. A few pages into the novel it becomes apparent that Maarten's memory loss is becoming increasingly worse, and he can barely keep track of his memories. He starts to confuse his past and present: he often does not recognize Vera, he goes out for long walks with Robert but forgets how long he has been gone, and he even forgets that he has his dog with him. By portraying the daily life of Maarten, it becomes clear how dementia prevents him from continuing his everyday pursuits. He cannot separate day from night, he forgets recent events, and does not recognize his own house anymore. When dementia has taken over and all of Maarten's former abilities have been drastically decreased, he does not know anymore who he himself is, and does not recognize his surroundings. The novel ends in Maarten only being able to think in loose, separate words that make very little sense.

The novel *Still Alice* by Lisa Genova describes the heart wrenching story of Alice, a Harvard university professor in linguistics, who is diagnosed with the early onset of Alzheimer's disease. When she first discovers the change in her memory and behaviour she tries to ignore it and wafts away the symptoms of memory loss. She blames her condition on her working too hard, being away from home too much, and thinking that it could be because she is entering the menopause at an earlier age than she had expected. She goes in to see her general practitioner and is referred to a neurologist; after several tests she is told that she has early onset of Alzheimer's disease (Genova 60). She tries to hide the diagnosis from her husband, but once the truth comes out, it means that people with whom she is directly involved keep a watchful eye on her; all of them have to deal with the consequences of Alice losing her memory. What makes this novel such an intriguing case study is how Alice's perspective portrays both Alice's point of view on how she feels and what she experiences throughout the process of the disease taking over her life, and it also it describes how her family reacts to her changing behaviour. The novel lets the reader closely follow her

worsening situation through the process of Alice's experience from the moment that she starts going through the system of tests, doctors, and care.

The novel *Elizabeth is Missing* by Emma Healey describes how the protagonist, Maud, deals with the consequences of dementia. She is an elderly lady, living by herself, as her husband had died years ago, and she has help from her daughter Helen and a carer. She is determined to stay independent, but cannot because dementia makes her forget what she did last week, yesterday and more often even what she did only an hour ago. She frequently forgets much about recent events and instead remembers more about moments from her past. This has everything to do with the fact that she is trying to solve two mysteries. The first mystery is that Maud is searching for her friend Elizabeth who disappeared recently. The reader does not find out exactly how long ago Elizabeth went missing, because Maud has forgotten about that. As she has forgotten, she does not realize that Elizabeth is in hospital, following a stroke. The other mystery that Maud feels she has to solve is that of her sister Sukey's disappearance. Maud tries very hard to tell Helen about Sukey, but uses the wrong name over and over again, and says that Elizabeth is missing; hence the title of the book. In the end Helen realizes who Maud is talking about, and helps her solve the mystery (Healey 258). In fact, Sukey was murdered by her husband Frank seventy years ago, and was buried close to where Maud still lives. Maud's dementia gets worse, and even after Helen takes her to see Elizabeth in hospital, Maud forgets about the visit, and in consequence the novel ends with Maud believing that Elizabeth is still missing.

Approach

I will approach the aforementioned issues in chapter one, the first and theoretical chapter of this thesis. From that point onwards, the hypotheses discussed in the theoretical chapter can be further implemented in the following four chapters of this thesis. Each chapter analyses a

different narrative device that functions in fiction on dementia. The three novels *Hersenschimmen* by Jan Bernlef, *Still Alice* by Lisa Genova, and *Elizabeth is Missing* by Emma Healey will serve as examples throughout the four chapters of how the narrative devices are used to represent the experience of dementia of the protagonist and how they can encourage empathy.

In chapter two, I will portray how the chosen novels use paratexts to provide additional information on dementia to readers; information that explains the state of mind of the main protagonists, who, suffering from successive loss of their mental capacities, are themselves not capable of providing this information. In the chosen novels, paratexts therefore simultaneously provide information and reflect upon the state of mind of the main protagonists. They foreshadow or reflect upon the memory loss of the protagonists by adding another layer of information that is available to the reader only, as Gérard Genette has so famously shown using James Joyce's *Ulysses* as an example: "[H]ow would we read Joyce's *Ulysses* if it were not called *Ulysses*?" (262). As paratexts provide additional information to readers, they also influence the reading process. They can "unleash [the reader's] emotional responsiveness," because the reader must actively get involved in understanding what is occurring in the novel (Keen 220).

Chapter three will show how ellipses, the withholding of crucial information, and gaps in the narrative emphasize how the protagonist cannot express through language and words, either because he or she has lost the ability to speak in a coherent manner, or because he or she cannot remember events because of memory loss. Using Wolfgang Iser's Reader-Response Theory, I will show how it is the missing information in the text – or what Iser calls gaps – that serve to stimulate the reader to interact with the text. In this way, gaps represent that which cannot be expressed through words alone, and are an intrinsic and important aspect in representing memory loss. Iser's theory can be connected to the way that literary

fiction on dementia is used for the creation of empathy, because the reader will naturally feel an interest in wanting to understand what the protagonist is going through and will therefore feel the need to try and fill in any gaps in the text and make connections in the story.

Furthermore, as Mieke Bal explains in her book, ellipses can be used to indicate “a gap in the flow of information” (90). As Keen states: “[E]mpathy may work as a gap-filling mechanism” (217).

In chapter four, time and its representation will be central. I will focus in particular on the motives of mirrors and clocks that repeatedly surface in the novels, to show that these motives reflect the state of mind of the protagonists, in particularly their experience of time. The reflection in the mirror gives a sense of the state that the protagonists are in, which changes as the dementia worsens. The use of clocks in the narratives emphasizes the role that time plays in the lives of the protagonists: namely that with the passing of time, the protagonists are also losing even more of their memory. With the image of a clock standing still, or time slowing down, the novels illustrate that the protagonists experience dementia as being less and less aware of who they are or who they used to be. Making use of Mieke Bal’s enabling research on time and temporalization, I will show how the representation of time can go against the grain of chronological, commonsensical understandings of it. A distortion is created between what seems to be quite normal for the reader: the progression of time, and what the protagonist experiences: time ticking by unchronologically. With this distortion emotions are released and the reader actively seeks to understand the situation of the protagonist. Keen explains that the confusion of time can “make the difference between a dutiful reading and an experience of emotional fusion [with the protagonist]” (215).

In all of the novels that I analyse, the protagonists suffering from dementia experience a loss of agency as a consequence of dementia, which urges other characters to take over. As I will show in chapter five, this sense of loss is shown in the novels through the internal

focalization of the protagonists. Mieke Bal explains that “[t]he subject of focalization, the focalizer, is the point from which the elements are viewed” (152). As the condition of dementia of the protagonists worsens, they experience a loss of independence, which coincides with emotions such as frustration and annoyance. The protagonist’s point of view enables the reader to perceive the loss that the protagonists undergo. Besides Mieke Bal, the critics Arthur Graesser and Bianca Klettke analyse the use of agency in literature in their article “Agency, Plot, and A Structural Affect Theory of Literary Theory Comprehension”. They explain how this concept can be used to influence the reader’s view of the plot and its characters. Focalization prompts the reader to empathize, because one experiences it through the protagonist’s point of view. One sees how the protagonist’s state of mind changes as a consequence of dementia, without them perceiving the full extent of their tragic decline, as a consequence of dementia.

In this thesis, I want to show that narrative devices can encourage active readership and thereby can evoke empathy with people suffering from dementia. Narrative devices serve to represent dementia and can encourage active readership. An understanding of what a person endures in suffering from dementia can be deepened through fiction. Narrative devices, which are often used in literature in general, are used by literary fiction on dementia to involve the reader in the story of the protagonist who suffers from dementia. These devices can then help encourage empathy from the reader, it can help patients, and a society as a whole that is facing dementia to deal with this disease.

Chapter 1. Theoretical Framework on the Representation of Dementia in Fiction

1.1 Putting the Seemingly Invisible on Paper

Dementia, as a malady of the brain, is a disease that poses certain problems for its representation. Medical research makes it nowadays possible to point out through, for instance, brain scans, which parts of the brain are affected when someone suffers from dementia. Yet these images do not represent dementia itself, but rather locate it. It can therefore be stated that dementia in itself is a disease that remains unrepresentable. In this thesis, I have therefore chosen to focus on the literary representation of dementia's symptoms instead. My focus on the narrative devices of paratexts, ellipses, the withholding of crucial information, gaps, temporalization, and focalization will align themselves with these symptoms. One of the symptoms is that of feeling confused in one's old and familiar environment, which correlates with paratexts, because these give extra information on the protagonist's story, which the protagonist him- or herself cannot give. Another symptom, that of impaired communication and blanks in one's memory correlates with ellipses, the withholding of crucial information, and gaps, because the protagonist cannot put into words his or her experiences. The symptom of one losing one's sense of time correlates with the use of temporalization in novels, and the symptom of a loss in independence and control can be represented through focalization.

The problem of unrepresentability of afflictions of the body is a larger one. James Elkins, in his research on representations of the body in art, states in his book *Pictures of The Body: Logic and Affect*, a body suffering from dementia cannot be objectified because, "the body is the most powerfully unsystematic object that we can know" (xi). Elaine Scarry, in her book *The Body in Pain: The Making and Unmaking of The World*, argues in a similar vein

that bodily pain remains unrepresentable, since pain is objectless. For her, pain is part of an interior part of bodily existence that: “[I]t is easy to remain wholly unaware of [another person’s interior] existence; even with effort, one may remain in doubt about its existence” (4). Another person’s interior distortion to his or her body could go unnoticed, but as Scarry goes on to explain: “[W]ith the best effort of sustained attention one successfully [can] apprehend [that person’s interior existence]” (4). While Scarry specifically discusses the representation of pain in her book, and this is another kind of problem than dementia, both require a way of being represented, without having an object that can represent them. As Scarry says: “[P]hysical pain – unlike any other state of consciousness – has no referential content. It is not of or for anything. It is precisely because it takes no object that it [then] resists objectification in language” (5).

Interior life lacks an object that can stand in for it indexically. Therefore, any interior life needs to be represented through, for instance, the use of visual or verbal symbols, or by narrative means. The interior of the body, which suffers, “is usually invisible to anyone outside the boundaries of the sufferer's body” (Scarry 47). Scarry argues though that pain *can* be expressed, but there is no bodily representation for pain, which is not already a symbol: one needs to “move beyond the boundaries of his or her own body into the external, sharable world” (5). Similarly, dementia *can* be expressed in symptoms, because it is connected to the loss of memory and language, which can be perceived by outside observers of the body. So, to achieve an understanding of another person’s experience of dementia, one needs to move beyond the boundaries of the body and make it a sharable experience. Hence my focus on those literary representations that concentrate on the consequences of dementia. Tying in with this, in the article “The Ageing Body” Elizabeth Barry states: “The condition of dementia – the most foreign country of them all – only strengthens this perception [that a story told from the sufferer’s point of view can create understanding]” (143). The “condition of dementia”

that Barry speaks of here can then be represented because it consists of symptoms whose effect can be perceived by others and that have consequences in social life (143).

The symptoms can be represented, because they originate in the body and because they clearly influence the perceptions and interactions of dementia patients. As I will argue, precisely these perceptions and interactions can be given a voice in literary representations. In the report called “Dementia: Ethical Issues” the Nuffield Council on Bioethics describes the disease dementia as the following: “[A] collection of signs and symptoms such as memory and communication problems, changes in mood and behaviour, and the gradual loss of control of physical degeneration of nerve cells” (xvii) and “loss of independence and control over one’s own life” (12). It does not immediately become apparent that one is suffering from dementia by simply looking at someone who suffers from this disease. Through communication with someone suffering from dementia, one can become aware of the symptoms of dementia. The symptoms come from within the body into the exterior world, and can be noticed. As Suzanne Keen explains in her article “A Theory of Narrative Empathy,” the style of representation can show the interior of the protagonist. She states that “the relation of the narrator to the [other] characters, and the internal or external perspective on characters, include[s] the style of representation of characters’ consciousness” (Keen 216). Literature then can express the symptoms of dementia by giving a representation; by exploring the effect of dementia's symptoms in the life of literary characters, they translate the personal and social outcome of dementia into literary discourse. The disease itself is not represented, but it can be represented through its symptoms and expressed through the narrative. Dementia cannot be seen from the outside, but the symptoms can.

What should be remembered is, as Scarry states: “A great deal, then, is at stake in the attempt to invent linguistic structures that will reach and accommodate this area of experience normally so inaccessible to language” (6). Instead of focussing on the

unrepresentability of the disease dementia, one can look instead at the symptoms that occur when someone suffers. Symptoms like memory loss, difficulty in planning, confusion about one's whereabouts, difficulty with dealing with money in shops, and communication difficulties, can be represented through narrative devices ("Symptoms of Dementia," *NHS Choices*). Through the development of the narratives in the novels *Hersenschimmen* by Jan Bernlef, *Still Alice* by Lisa Genova, and *Elizabeth is Missing* by Emma Healey we see, as readers, what the protagonist must endure, as in experiencing disorientation, blanks in memory, a feeling of time warp, and a loss of agency. These are represented through the narrative devices paratexts, ellipses, the withholding of crucial information, gaps, temporalization and focalization. As was suggested in the introduction of this thesis, the representation of the symptoms of dementia can evoke empathy. To materialize this though, an understanding of the state of an ill body needs to be created before empathy can be shown to the sufferer. Empathy can be created when readers need to participate in the making of the story, when they actively become involved. In the next subchapter, I will show how this involvement is achieved by literary means.

1.2 Involving the Reader in the Representation of Dementia

When portraying dementia, literary fiction needs to make readers identify with the reality of the sufferer of this disease, because, as Elkins explains: "[W]e prefer to have bodies in front of us, or in our hands" (xxii). This can be achieved through the representation of the symptoms of dementia. In fact, David Hillman and Ulrika Maude make us aware in *The Cambridge Companion to The Body in Literature* that "the body is, for us, always already mediated through representation" (3). The reader is given the impression that one is seeing the world from the protagonist's perspective, and then experiences the memory loss of the protagonist along with him or her. Keen states: "[I]magine another in an emotional state

activates automatic representations of that same state in the onlooker” (211). To understand how a reader might be inclined to become involved in the story, we then must consider the active readership of the reader. In her book *The Power of The False* Doro Wiese researches how readers become involved in the creation of the storyline. When analysing the novel *Everything is Illuminated*, she shows that it is precisely imprecisions in the text that create an active reading position, because “[i]t is the reader’s responsibility to link the different phrases, fragments, and hints to each other, to make sense out of the surfacing bits and pieces, to unravel the strands that have been caught up in each other” (65). Active readership then involves readers into another’s emotional and interior state, and could possibly evoke empathy (Keen 208). In the article “Dementia and Detection in *Elizabeth is Missing* and *Turn of Mind*” Katsuro Sako states: “[N]arratives that offer access to the internal reality of the character [...] can produce great empathy in the reader” (6).

While one needs to be aware that empathy is not the only reaction that could be evoked by reading novels on dementia, Keen states that this reaction could “emphasize the adaptive function of our social relations. Given the basis in human shared intersubjectivity, empathy thus appears to many to be a key element in our responsiveness to others” (Keen 212). So while empathy is not the only reaction that a novel can evoke, empathy is a reaction that many respond to, and see as the right response to novels that describe someone else’s suffering. Fiction encourages the imagination of the reader, and as it has no repercussions in reality, the reader can experience the emotions of the protagonist without feeling any constraints as to what might be expected to be the ‘correct’ response to the protagonist’s situation. Moreover, in the article “How does Fiction Reading Influence Empathy? An Experimental Investigation on the Role of Emotional Transportation” Matthijs Bal and Marijn Veltkamp explain: “[W]e can allow ourselves to sympathize strongly with a character of a fictional story, because we do not have obligations towards the characters of a fictional

story” (2-3). In this way, the reader has more freedom to come to an understanding of how one might feel the need to react to someone suffering from dementia. The fictional narrative is a safe environment to imagine one’s own reaction: “When reading a novel [...] we become immersed in the world presented to us [and i]n these narrative worlds we experience a simulated reality and feel real emotions in response to the conflicts and relationships of story characters” (Bal and Veltkamp 408).

Our attention is drawn back to the crucial question that needs to be addressed, namely that of how the state of the ill body in question can be brought to the fore. This needs to be done in such a way that this does not take away the attention from those who are suffering in real life. Scarry suggests the following:

[R]eaders’ perception of a text’s fictionality plays a role in subsequent empathetic response, by releasing readers from the obligations of self-protection through scepticism and suspicion. Thus they may respond with greater empathy to an unreal situation and characters because of the protective fictionality, but still internalize the experience of empathy with possible later real-world responsiveness to others’ needs. (220)

For this kind of reaction to be evoked, it means that “narrative empathy invoked by reading must involve cognition” (Keen 213). This apprehension needs to be supported by a balance of enough information given in the novel to get the readers involved, and a lack to keep them working towards understanding what exactly develops in the story. To ensure that there is a sense of control guided by the text, the gaps are always set within the story: “What is concealed spurs the reader into action, but this action is also controlled by what is revealed” (Iser 1527). Sako explains that by “focus[sing] upon the subject with dementia [one] allow[s] the reader vicariously to experience life with dementia [and] to empathize with the subject” (17). This is possible because fictional representations could “disarm readers of some of the

protective layers of cautious reasoning that may inhabit empathy in the real world” (Keen 213).

Keen carefully suggests that empathy can be created through the use of narrative devices, because representations can create readers’ involvement: “Aspects of plot structure and narration [can] have a role in invoking readers’ empathy” (217). Involvement of the reader is the starting point for empathy. As Iser explains: “Central to the reading of every literary work is the interaction between its structure and its recipient” (1524). This interaction is one that can result in feelings of empathy, which then subsequently allows readers to become involved in a disease that is problematic in society. As Wiese explains, when analysing the novel *Everything is Illuminated*, this can be achieved through “narrative devices [that] involve readers in the production of meaning, thus transforming the reading contract from an agreement to suspend disbelief into an agreement to bestow credibility, and this involvement is crucial if the story is to be effective” (91-92). Empathy then can be created through the involvement of the reader, evoked through the narrative devices paratexts, ellipses, the withholding of crucial information, gaps, temporalization, and focalization in novels on dementia: [t]he involvement of the reader “can be triggered by [...] narrative devices such as [...] temporalization and duration, [and] focalization” (Wiese 7). Involving the reader in the text through the use of narrative devices can create empathy for the situation of the protagonist. The reader is actively drawn into the text, and can feel connected to the plotline. In the following paragraphs, I will show how the chosen narrative devices allow for the readers' participation.

1.3 Paratexts as a Way to Encourage Active Readership

Wiese explains that “[p]aratextuality consists of the nonnarrative elements of a text” (211) and paratexts can be “titles, prefaces, dedications, notes[, but also] illustrations” (216). A

paratext takes place “between the inside and the outside, itself without rigorous limits, either towards the interior (the text) or towards the exterior (the discourse of the world on the text), a border” (Genette 261). In the article “Introduction to the Paratext” Gérard Genette explains that a paratext is external to the story of the plotline, and in that sense serves as a “threshold” to the story in a novel (261). In the context of my analysis, paratexts are important because they tie the literary discourse to social discourse. This is the case, as Genette has argued, because a paratext “make[s the text] present, to assure its presence in the world, its ‘reception’ and its consumption” (261). While paratexts have not specifically been paid attention to in consideration of novels on memory loss, I argue that it is useful to look at them precisely because they allow readers to put different forms of literary, medical, and social knowledge into contact with each other. As Genette explains “there never has existed a [literary] text without paratext” (263). Even before the novels begin to tell the stories of the protagonists, they make use of the paratext as a way of foreboding what can be expected from the narratives in these novels, and foreboding the protagonists’ fate, by drawing attention to the point in time that the protagonist has no memories left. For example, in the novel *Hersenschimmen* the novel starts off with the lines “A touching dream to which we all are lulled[, b]ut wake from separately” (Bernlef 5). In this way, this paratext forebodes the reader to a point in the life of the protagonist Maarten at which he cannot give that perspective himself anymore, and has no memories left. There is no page number, indicating that it stands outside the narrative.

The novel *Elizabeth is Missing* uses the paratext within the pages of the narrative itself, in the form of illustrations. It has, as Genette has defined this function, an “aesthetic aim” of anticipating what will materialize in a chapter that follows the paratext. as a hinge between different discourses (Genette 272). Each chapter is headed by a different illustration, which seem to have been placed there at random. The title draws the general public to open

the novel and read it, while the passages in the novel itself are for the reader of the novel (Genette 267). Scarry proposes that “[t]he goal [...] is not simply to make the reader a passive recipient of information[,] but to encourage his or her active assistance” (Scarry 9). The use of paratexts contributes to the encouragement of the “assistance” of readers, rather than just providing information (Scarry 9). In the novel *Elizabeth is Missing*, for instance, little pictorial miniatures introduce each chapter. However, the images mislead and disorientate us, because the illustrations do not have any clear reference to the chapter they head. But precisely through the disorientation that the miniatures provide, are we helped to understand the disease dementia from which Elizabeth is suffering, since they allow us to grasp the disconnection that takes place when the meaning of an image gets lost. Therefore, they are another layer in the story, and they can help us understand the symptoms that are explored in that novel or chapter. In this way, the reader must actively read the narrative of Maud and is reminded at the start of each chapter that her point of view might not be the most reliable. Keen proposes that “paratexts cuing readers to understand a work as fictional unleash their emotional responsiveness” (220). They evoke emotions in the reader, and the reader must actively search for any clues in the narrative as to how it connects to the illustrations at the beginning of each chapter.

Abraham Verghese states in his article “The Physician as Storyteller” that paratexts can “call up colourful imagery to describe disease [such as dementia]” (1016). A disease described in fiction must be comprehensible for the reader, which means that “technical language [can be] necessary and important in diagnosis, but we might lose our ability to imagine the patient’s suffering” (Verghese 1015). Therefore, there must be a balance between the representation of the symptoms of the protagonist suffering from dementia in a fictional account, and the story portrayed from the protagonist’s point of view. Through the use of paratexts the reader can receive information on the state of mind of the protagonist, even

when the protagonist is unable to portray his or her own state of mind because dementia has taken over too much. This is the case in *Still Alice*, in which some technical language is used to bring across the seriousness of dementia to the reader in paratexts; they serve as extra information for the reader. Readers have this extra information, which can then evoke understanding for the protagonist Alice, because the reader recognizes that her state is deteriorating without her realizing it herself. The reader is stimulated to empathize with Alice's situation, because the symptoms of dementia have become too severe for her to act the way she would like. The descriptions of Alice's state of mind, and consequentially of dementia, is brought forward at different stages in the novel (Genova 1, 196).

Paratexts portray the impact of dementia in the protagonist's life as the symptoms worsen, the protagonist suffers more from these symptoms. As dementia limits the protagonist's point of view, and therefore also the reader's point of view, the paratext can force the reader back out into the broader view, giving perspective. It can show that the world still exists outside the person, and that it is the person that is destroyed from the interior, because of dementia. Through paratexts, the reader is drawn into the story, becomes aware of the implications of dementia, and in that way might empathize with the protagonist who loses his or her memory as a consequence of this disease.

1.4 Ellipses, the Withholding of Crucial Information, and Gaps to Involve the Reader

Disruption in the plot makes reconstruction of the story for the reader difficult. Yet exactly this missing or distorted information makes the reader active, who therefore becomes involved in the construction of the story. Ellipses, the withholding of crucial information, and gaps disorientate the reader and come in the form of omission of information in the narratives, unspoken diagnoses, and ellipses in the novels on dementia. In his text "Interaction between Text and Reader" the critic Wolfgang Iser explains Reader-Response

Theory; the reader is drawn into a literary text and is connected to the narrative that is told, especially through the use of gaps in information. While he does not specifically consider novels on memory loss, his theory is helpful in understanding how the novels use gaps in information as a way to communicate the symptoms of dementia that the protagonist is enduring. He explains that “[w]henver the reader bridges the gaps, communication begins. The gaps function as a kind of pivot on which the whole text-reader relationship revolves [and] stimulate the process of ideation to be performed by the reader on terms set by the text” (Iser 1527).

When there is information missing, this makes us work with the text. The reader feels involved in trying to understand what is happening to the protagonist, and is encouraged to make sense of the situation that the protagonist is in. In this way, the reader is “made to supply what is meant from what is not said” (Iser 1527). For example, in *Still Alice* the chapter ‘Summer 2005’ includes two months instead of the other chapters that each include one month. This is a very subtle way of emphasizing that Alice’s brain has stopped functioning well, because the meaning of the different months does not mean to Alice what it used to. Another example can be found in *Elizabeth is Missing*. Maud’s dementia is left unspoken; the word itself has never been written once in the whole novel. The blanking out of this very word ‘dementia’ illustrates the absence of Maud’s comprehension that she suffers from dementia, and of the symptom of memory loss. The reader needs to fill in what is going on, and then needs to work out what is happening, and can empathize with Maud’s situation. She is on a quest to uncover the murder of her sister Sukey, and the reader comes to understand that as a consequence of dementia she is unable to keep up with the world around her. This ‘blow’ comes across much harder than if the reader were to be informed elaborately about the symptoms of her dementia.

The novels make use of ellipses to portray the feeling of loss of words in situations that overcome the protagonist. Scarry states that “[t]hough the total number of words may be meagre, though they may be hurled into the air unattached to any framing sentence, something can be learned from these verbal fragments” (6). For example, a form of ellipses can be found towards the end in *Hersenschimmen*: “Veel zingen en neuriën uit alle hoeken en gaten...gezichten: fijngetrapt...uitgerekt...opgeblazen...verschilferd (en dan nog zo wat van die woorden” (Bernlef 150). Maarten tries to express himself, but can only speak in fragmented sentences as a consequence of dementia, and these fragments are connected by ellipses. To feel connected to Maarten’s sense of loss, the reader must try to fill in the ellipses that are created and try to understand what Maarten is going through when he himself fails to fill in these gaps. Mieke Bal, in her book *Narratology: Introduction to the Theory of Narrative*, also calls ellipses, “lack of information” (90). They can offer a means of expressing that which is difficult to represent through words alone, and it can be a way to illustrate to the reader the disorientated feelings of the protagonist. This then disorientates the reader, and these are “gaps in our knowledge of potentially empathetic narrative techniques” (Keen 214).

Ellipses, the withholding of crucial information, and gaps can make more of an impression on the reader than if the text only consists of well written and coherent sentences. This can emphasize, as Lisa Caddell and Linda Clare explain in their article “The Impact of Dementia on Self and Identity: A Systematic Review,” that the sufferer of dementia does not know how to express him- or herself in words, until in the end “only ‘emptiness’ remains,” which in turn can encourage empathy in the reader (115).

1.5 The Use of Temporalization to Create a Distortion in The Reader's Experience

Time is presumed to take place in a linear manner, in which past, present and future follow chronologically. In the novels on dementia, temporalization is used to create confusion and to show the temporality in regard of a character's position in the story. The protagonist does not always experience time as linear. The future has not happened, but is influenced by how the protagonists perceive their past and present, and forms a threat to the protagonists because they do not know how the symptoms of dementia will influence the time that they still have left. In her book *Narratology: Introduction to the Theory of Narrative* Mieke Bal states that time can "complicate th[e] apparently self-evident temporality" (77). She explains that one must look for those subtle indications in the tenses (Bal 79). We are so used to the existence of time that the changes in time might not be noticed: "The time that regulates our lives, by means of clocks, schedules, and other means of uniforming lives, is so incorporated, interiorized, or naturalized that is it difficult to imagine that there are conflicts built into it" (Bal 77). The chosen fictive works on dementia, however, by defying a linear understanding of time, put conflicts in its perception central. Thereby, they make accessible how the fictional characters struggle with a loss of temporal understanding, which is also one important aspect of clinical dementia.

In the book "Time, Narrative, and Fiction: The uneasy relationship between Ricoeur and a Heterogeneous Temporality" Harry Jansen explains that the presence of clocks in a narration can emphasize the "discontinuity of the narrated time" (19). The focus then lies on the memory loss or change of perception of the protagonist rather than only on the action taking place in a specific scene. This is because different times converge in the same scene, which influences the further storyline as well. The time on the clock may stand still in a scene, while a temporal action continues, giving us an illusion of temporal progression. Keen explains that there are "aspects of the discourse that slow the readers' pace" (216). The

slowing down of pace can be achieved through nothing actually happening in a scene, someone just looking at the clock, when the passage of time is highlighted, rather than made felt through progressing action. For example, in *Hersenschimmen* Maarten knows where the clock hangs in the kitchen, for it has not been moved since they came to live there fifteen years ago; but he does not know what to do with the information on the clock any longer: “Ik loop naar de keuken, ga aan de keukentafel zitten en kijk naar de felrode plastic keukenklok aan de muur [...] Ik laat mijn ogen er geen moment van afdwalen” (Bernlef 21). He sees the hands on the clock go round, and understands that they indicate something, but cannot comprehend what he should do with that knowledge. One can see that he has lost an understanding of linear time, and thereby loses an important means for coordinating his actions with other. In the text, the two senses of time, the slowing down of pace as Maarten experiences it and chronological time, rub against each other.

The feeling of being lost in the present is also in other novels, for example, in *Still Alice*: “The clock on the fireplace mantel ticked loudly, like someone had turned its volume up” (Genova 116). For the protagonist time seems to tick by slower than it does in reality. Wiese explains:

[N]arrative duration implies that readers have to endure greater time spans until literary signs make sense and/or are explicated. During the reading process, readers might have to keep in mind layers of hints, descriptions, characters’ actions and reactions before they can reach a conclusion about what meaning they want to assign to a narrative event. (166)

Alice’s experience of the loud ticking of the clock leaves the reader to decipher what this means for Alice’s perception of time. The passing of time is being emphasized by the depicted clock in the passage, portraying Alice’s perception. As Keen explains, the reader

reads along with the protagonist's thoughts, and one can identify with him or her; it "invite[s] more active reading that opens the way for empathy" (Keen 217).

The constant use of mirrors in the narrative of dementia also enhances a disorientation in time. The protagonists suffering from dementia in the chosen novels are frequently shown as not recognizing themselves in mirrors, so the connection of the body in front of a mirror and the image in the mirror becomes distorted. This failure or reduction of reference is unexpected for readers and portrays how the protagonists lose their sense of being a self, embedded in a constantly progressing time. It is unexpected and portrays how differently the protagonist experiences time. In the article "Crossing into the Space-Time of Memory: Borderline Identities in Novels by Yvonne Vera," Ranka Primorac explains that mirrors can have the following purpose: "[The mirror] has temporal significance: in telling the story [it] touche[s] both the past and the future" (88). In the article "Reflections of Self and Other in Sylvia Plath's 'Mirror' Imagery," Parvin Ghasemi states that a mirror renders one's "true reflection" (59). While Primorac and Ghasemi's analyses do not in particular concern novels on dementia, their insights can be beneficial to the analysis of the novels of this thesis. Through the protagonist's reflection in the mirror, his or her interior point of view, the novels use temporalization to illustrate the deterioration of the protagonist. For example, in *Still Alice* Alice sees her own reflection at different times in the mirror throughout the novel and ends up not recognizing her reflexion. She sees a much older person than she expected, and does not recognize that person as her own reflection (Genova 315-316). The mirror emphasizes the distortion of temporalization that is caused because of the symptoms of dementia. Through the representation of the protagonist's deteriorating state reflected in the mirror, the reader can identify with the protagonist and imagine how it feels to be disorientated by one's own reflection. Scarry states that "split[ting] the human being into two, [is] to make emphatic the ever present [and] latent distinction between a self and a body (49).

The reflection of the protagonist in the mirror emphasizes the split between the experience of the protagonists, what they see in the mirror, and what those around them observe. This then causes distress to the protagonist. For example, towards the end in *Hersenschimmen* Maarten sees himself in the mirror but does not recognize himself as being seventy years old (Bernlef 146). When Vera helps Maarten dress, he thinks that it is his mother helping him: “Een das strikken moet je nooit voor een spiegel doen [...] Voel opeens vreemde smalle vingers in mijn nek. Ze peuteren aan de opstaande boord van mijn overhemd [...] ‘Kan het zelf wel, moeder’” (Bernlef 95, my emphasis). In this passage, Maarten believes that he is at home with his mother, and she is helping him. Interestingly, as he is convinced that he is living about sixty years ago, the reflection in the mirror does not help him recognize that he is not a young boy any more, but an old man. The reader can empathize with Maarten, seeing how he has lost his sense of time, and that he has lost his realistic image of the world around him. He does not partake in real-life any longer, but lives in his own distorted mental perception.

Clocks make the protagonist aware that they are losing and missing time; that they are not aware of time anymore in the way that others not suffering from dementia are. They are a symbol of what the protagonist has lost. The protagonists have forgotten how to use time, and the reader empathizes with their situation. Because the protagonist cannot comprehend what they are missing they focus instead on the clock as something important but they do not know why. Mirrors can reflect how protagonists with dementia relate to the world: looking into the mirror makes them feel disconnected from reality.

1.6 Focalization as a Way to Give a Sense of Loss

Someone suffering from dementia experiences a “loss of independency and control over one’s life (Nuffield Council on Bioethics, “Dementia: Ethical Issues” 12). It is precisely through the focalization of the protagonist that one can acquire a good impression of how the

protagonist experiences dementia, because he or she can only give a limited point of view as a consequence of dementia. In the article “Agency, Plot, and a Structural Affect Theory of Literary Theory Comprehension” Arthur Graesser and Bianca Klettke explain that with a limited perspective of a single character, “the filter may be incomplete or distorted, but readers will better be able to keep track of the character’s point of view” (64). The focalization that the protagonists with dementia provide can indeed only portray to a certain degree how this takes form towards other characters in the story. But it is precisely through the focalization of the protagonist that the reader experiences the plot along with the protagonist.

In her book *Narratology Introduction to the Theory of Narrative* Mieke Bal explains that “[t]o talk about narrators, for example, is to impute agency to a subject of narration” (12). It is about the inner and outer side of characterization, how the protagonists are depicted if we consider that they think and act as we react to them. As William Sewell states in his article “A Theory of Structure: Duality, Agency, and Transformation”: agency “always [means] acts of communication with others” (21). This becomes apparent in the way that the protagonist reacts to his or her relatives. For example, in *Elizabeth is Missing* Maud is told by her daughter Helen how she should behave in a restaurant, and Maud thinks to herself: “My heartbeat quickens and I clench my teeth [...] I feel I might start screaming” (Healey 19). She then goes on to break a plate, just to prove that she can still decide to do something if she wants to (Healey 19). Through the first-person perspective, illustrated through the use of the pronoun “I”, the reader experiences Maud’s frustrations in that moment, because we see her story from her point of view. We experience this occasion along with Maud, from her perspective, and see how she responds to Helen. While Bal and Sewell do not consider literature on dementia in particular, their concept of focalization can be helpful in creating an understanding of how the novels on dementia use this narrative device to represent the loss of

independence – or what Graesser and Klettke call agency - of the protagonists. “The internal focalization thus invites us to contrast [one’s] former conceptions of a meaningful life with [one’s] developing experience of life” (Bitenc 320).

When the protagonist’s consciousness of situations diminishes, the reader continues to follow the story from the protagonist’s point of view. Every protagonist has relatives who play an important role in their lives as dementia takes over. Caddell and Clare explain that “it is friends, relatives and staff members who [try to] preserve the self of the person with dementia, by either assuming or pretending that the person is competent” (115). The protagonist experiences the help of relatives as interference in their feeling of being independent. For example, in *Hersenschimmen* Maarten walks away from the house without telling anyone, and then gets lost outdoors, so Vera locks the doors of the house, as a way to keep him from going off on his own (Bernlef 44). Maarten merely experiences this act as being imprisoned in his own house, and instead opens the door with force, and the help of a screwdriver (Bernlef 44). As the reader observes this scene from Maarten’s point of view, one can empathize with his feeling of being confined, while also observing that his behaviour to use force to open the door is not normal behaviour either.

Keen states that “characters [can] possess independent agency” (221). This insinuates the power of the protagonists to speak their own mind. However, as the dementia worsens this becomes impossible for the characters suffering from this disease. When the protagonists lose their agency because of dementia, they become incompetent to make right decisions, and empathy can be evoked through “the relation of the narrator to the characters” (Keen 216). However, this is still portrayed from the protagonist’s point of view. The protagonist focalizes his or her thoughts on the relationship. The reader follows the change in the lives of the protagonists. There is a limited perspective from the protagonist, but through the conversations with and inclusion of bystanders this perspective is provided. Through the

development of the narrative we can see that independence and control over one's life is lost, which is one of the symptoms of dementia. People want to keep control over their own lives and there is a struggle to do this in the novels. The protagonists lose this control over their lives because of their disease. This loss evokes negative emotions in the protagonist, which then can provoke empathy in the reader: "[E]mpathetic responses to fictional characters and situations occur more readily for negative emotions" (Keen 214). The protagonist experiences negative emotions because one's agency is taken away. This is illustrated through the focalization from the protagonist, and so the reader empathizes more with the protagonist than if the story were narrated from, for example, the relatives of the protagonist, because then the focus would not be on the way that the protagonist feels, but on the perspective that the relatives take on the protagonist.

1.7 Outline of the Theory

Through the use of the aforementioned narrative devices, paratexts, ellipses, the withholding of crucial information, gaps, temporalization, and focalization, the symptoms of dementia can be represented. The disease dementia, as damaging the brain, is absent of a proper object that could represent it. However, the symptoms of dementia, such as disorientation in one's environment, reduced understanding of communication, a decreased sense of time, and a loss of self-sufficiency can be observed, and therefore represented by narrative devices. These symptoms are acknowledged as affecting the sufferer of dementia and those who surround him or her. Scarry states: "From no matter what perspective pain is approached, its totality is again and again faced [and] repeatedly acknowledge the breadth of its presence" (55). As in the representation of pain that Scarry describes here, the different narrative devices in the representation of dementia give perspectives on the disease that all point towards the devastating effects of this disease. Comprehension through a literary representation of

dementia can encourage empathy from the reader for the disease and its sufferers, because the reader experiences dementia with the protagonist, who is the real sufferer in the story. In answering the question on how, through the use of the narrative devices literary representations on dementia create reader involvement, the remainder of this thesis will concentrate on the analysis of the three novels *Hersenschimmen*, *Still Alice* and *Elizabeth is Missing*.

Chapter 2. The Use of Paratexts

2.1 Introduction

Novels that put dementia central, represent the symptoms of this disease through the use of narrative devices and involve the reader in the story of the protagonist suffering from this disease. The use of paratexts in the novels *Hersenschimmen*, *Still Alice*, and *Elizabeth is Missing* contribute to representing the symptom of “confusion in one’s own environment” as a consequence of dementia (Nuffield Council on Bioethics, “Dementia: Ethical Issues” 52). Paratexts are an important narrative device through which the novels can encourage active readership. In the article “Introduction to the Paratext” Gérard Genette explains the paratext as following: “[T]he paratext, in all its forms, is a fundamentally heteronomous, auxiliary, discourse devoted to the service of something else which constitutes its right of existence, namely the text” (269). They convey a sense of foreboding, making the reader aware of the story that is about to be told. This chapter will therefore show how in novels on dementia paratexts are used to make the reader understand the sorrowful situation of the protagonist because he or she cannot escape the outcome of dementia. In that way, the reader can empathize with those suffering from dementia. Paratexts are used most frequently at the beginning of the novels, and can help the reader to interpret the narratives in the novels by focussing on points in time that the protagonist’s dementia worsens, as in *Hersenschimmen* and *Still Alice*. The exception to this is *Elizabeth is Missing*, in which paratexts function only in the “interstices of the text itself” (Genette 263). The novel has illustrations at the top of each chapter to emphasize the objects that play a role in Maud’s life, and in that way help frame the story of Maud coping with dementia. This also happens in *Still Alice*, where the loss that Alice experiences is emphasized through the paratexts in two places in between the chapters, but simultaneously they emphasize that she enters a new stage of Alzheimer’s

disease. The paratexts, both at the beginning of the novels and further on in the novels, frame the narratives and emphasize the message of dementia. Paratexts can emphasize the seriousness of the impact of dementia on the protagonists.

2.2 Foreboding in Advance of the Narrative

In many instances a paratext is placed at the beginning of the novel. This takes the form of a few lines from a poem or essay, as in *Hersenschimmen*, or a scientific explanation, as in *Still Alice*. *Hersenschimmen* leaves out the page numbers of the page on which the paratext is projected. In this way, the materiality of the text is stressed, but it also emphasizes that the paratext is a separate entity from the rest of the novel. The chosen quotations used as paratexts originate from authors other than the writers of the novels. The identity of the paratext's author is not deemed important to the message that the novel wishes to convey. As Genette states: "The addresser of a paratextual message [...] is not necessarily the person who actually wrote it, whose identity matters little to us [...] the addresser is defined by putative attribution" (266). The "addresser" of the paratext is responsible for its message, but it is the novel in which the message is implemented that makes use of the "putative attribution" of the passage (Genette 266). The effect that the paratext creates, namely that of foreboding the protagonist losing his or her memory and trying to find a way to cope with this, is meant for the novel in which it is depicted.

The novel *Hersenschimmen* starts off with three lines of text, while the rest of the page is left blank. The paratext is a citation by Philip Larkin from his poem "The Building".

The first page of *Hersenschimmen* depicts the following paratext:

A touching dream to which we all are lulled

But wake from separately.

Philip Larkin. (Bernlef 5)

In connection to the plotline of the novel, this paratext can be seen as foreshadowing Maarten's end. The novel gives an account of the process of dementia that Maarten endures. Towards the very end of the novel he is placed in a care home, he does not know where he is, who he is or what is happening around him (Vassilas 440). At times he thinks Vera is his mother, and he needs help with dressing, eating and walking. While Vera and a nurse, help Maarten get his clothes on, he says: “‘Kan het zelf wel, moeder.’ [And Vera replies] ‘Noem mij geen moeder’” (Bernlef 95).

At this point in the story, Maarten's state has already declined to such an extent that he has lost all ability to make his own decisions and to distinguish the present from the past; this influences his relationship with his wife. He is merely able to distinguish that there are people in his close vicinity, but does not recognize his own wife any longer: “[G]een namen...geen gezichten meer...alleen ademen...zuchten...allemaal bekenden van hem toen ze nog leefden...stuk voor stuk...” (Bernlef 160). Vera is with him at this point, and tells him that everything is alright. Maarten though, only follows half of her sentences, because as a consequence of dementia he cannot create whole sentences any longer. He also has difficulty following someone else's sentences, which is shown when he repeats for himself, and for the reader what Vera is telling him, in incomplete sentences: “[D]e stem van een vrouw en je luistert...je luistert met gesloten ogen...luistert alleen naar haar stem die fluistert...dat het raam is gemaakt...dat waar eerst die oude deur voor zat gespijkerd...dat daar nu weer glas zit” (Bernlef 160). It seems that she is telling him that it is alright for him to let go now, that everything has been put right again, and that he does not need to keep holding on to life any longer. In this way, the paratext at the beginning of the novel connects to the story and alludes to Maarten's death. It refers to the fact that at some point every person must die.⁵

⁵ Janice Rossen points out in the book *Philip Larkin: His Life's Work* that, in connection to Larkin's poem “The Building” that Larkin “[s]crupulously record[s] the inevitability of ageing and death. [He] does not argue against death so much as against our illusions about it” (142). In the book *Philip Larkin: The Poet's Plight* J. Booth states that Larkin “[t]hroughout his life [...] expressed ingenuous fear of death” (197).

Maarten's and Vera's life is characterized by the fact that they have been together for nearly fifty years. Maarten mentions halfway through the novel how well he knows his wife, and how connected they are: "Bijna vijftig jaar liggen we al zo naast elkaar. Het is haast niet te bevatten wat dat betekent. Het gevoel twee communicerende vaten te zijn. Haar stemmingen, haar gedachten; ik kan ze bijna van haar gezicht aflezen" (Bernlef 117). Through the course of those fifty years they have become very familiar with one another, recognizing each other's movements and understanding what the other is thinking. Maarten clearly appreciates having spent so many years with his wife, which makes it even more tragic that dementia has taken away even his recognition of her.⁶ He does not want to end up separated from Vera at the end of this long time together.

The part "wake from separately" in the paratext at the start of the novel can be speculated on as to whether it means that Maarten physically dies or that his mind turns to oblivion at the end of his story. Further on in the poem by Phillip Larkin, which is not cited in the novel itself, it is stated that "[a]ll know they are going to die" (9). The choice for leaving this part of the poem out at the beginning of the novel *Hersenschimmen* forebodes that how and when exactly Maarten comes to the end of his life is left open. It is left to the imagination of the reader, but it is clearly expressed that Maarten and Vera end up separated from one another. Maarten, towards the end of his life, behaves like a different person than he or Vera recognize, because of dementia.⁷ He cannot identify Vera as being his wife any longer, but merely recognizes her as "een vrouw" (Bernlef 160).

In the novel *Still Alice*, the first page of the novel gives a scientific explanation of what occurs in the brain when a person suffers from Alzheimer's disease:

⁶ "As his memory functions become more and more impaired, Maarten has trouble recognizing people's facial expressions and with time even their faces [...] Maarten finds it increasingly difficult to attach meaning to facial expressions" (Bitenc 311).

⁷ "Maarten's grasp of the world fades away, he can no longer makes sense of the information he is given. He hears the voice of a woman, who he assumes is Vera [...] but he no longer recognises her" (Vassilas 440).

Even then, more than a year earlier, there were neurons in her head, not far from her ears, that were being strangled to death, too quietly for her to hear them. Some would argue that things were going so insidiously wrong that the neurons themselves initiated events that would lead to their own destruction. Whether it was molecular or cellular suicide, they were unable to warn her of what was happening before they died. (Genova 1)

This paratext conveys to the reader what can be expected from the story that will follow, and that there is no way back from the inevitable outcome of the disease. As this passage illustrates, the function of a paratext can be to “communicate pure *information*,” (Genette 268). Rebecca Anna Bitenc calls this sort of paratext a “neurological prologue” (316). The passage accommodates this function because Alice cannot explain through language alone everything that happens inside her head, as her brain is affected by Alzheimer’s disease. Rebecca Anna Bitenc explains the following in her article “Representations of Dementia in Narrative Fiction”:

The prologue introduces the central theme of *Still Alice*: the relationship between mind and self, brain functioning and identity. While Alice’s sense of self resides primarily in her extraordinary mental capacities[, Alzheimer’s disease] takes its toll, [and] both the reader and Alice come to recognize that previous criteria of self-worth have to be re-thought. (316)

The content of the paratext at the start of *Still Alice* explains to the reader before he or she begins to read Alice’s story what Alzheimer’s disease in Alice’s head causes as a consequence, namely severe damage to her neurons.⁸ The last few words from the paratext,

⁸ Interestingly, the paratext at the beginning of *Still Alice* is comparable to a scientific explanation from Swaab’s book of what occurs in a brain with Alzheimer’s disease: “Every active neuron sustains damage [...] Tiny flaws remain and mount up over the years, causing the degeneration that is the ageing process. In the case of individuals whose brains aren’t good at repairing themselves [...] this degeneration is more serious and occurs faster, resulting in plaques and tangles, which lead to the onset of Alzheimer’s” (401, 402).

namely “before they died,” convey that the process of Alzheimer’s disease inside Alice’s head cannot be stopped. The aim seems to be to convey a human experience that appeals to the empathetic side of readers by focussing on Alice’s individual situation, while also giving the impression of a general scientific explanation of what happens in the brain, in stages, as the dementia takes over. This is done by concentrating on a female character, as women run a higher risk of developing Alzheimer’s disease than men (Altmann 10).⁹ The paratext anticipates the point at which Alice will not be able to remember at all, and that Alzheimer’s disease destroys her brain cells and hence they die (Genova 1). This point is reached in the epilogue of the novel, in which Alice is unable to continue her own story, because quite frankly she has very little understanding of what role she takes in her own life anymore, and what is happening around her. She is taken care of by a caretaker, who is employed by her family, but she has no idea who this person is: “The woman smiled, nodding enthusiastically. Alice smiled and nodded back. She had no idea what she was agreeing to, but it was probably fine with her if the woman thought so” (Genova 324). Furthermore, she does not recognize her daughter and grandchild at all anymore, calling Lydia “the woman” and “the actress,” her grandchild “the baby” (Genova 324).

Interestingly, the paratext at the beginning of *Still Alice* does not originate from another author, but still has the same function as in *Hersenschimmen*. The paratexts in the novels are used to point towards certain moments in the lives of the protagonists; in *Hersenschimmen* and *Still Alice* the paratexts point towards the end of Maarten’s and Alice’s lives, when they will have no memories at all anymore. With this tragic premonition, the reader empathizes with the protagonist, knowing that as the situation of the protagonist worsens, the reader will understand that there is no way back from this condition.

⁹ Andre Altmann et al. explain in the article “Sex Modifies The APOE-Related Risk of Developing Alzheimer Disease” that women run a higher risk of developing Alzheimer’s disease: “A critical and commonly overlooked feature of the APOE4 link to Alzheimer’s disease is that several case-control studies suggest that it is far more pronounced in women” (2).

2.3 Apprehension within the Spaces of the Story

As becomes apparent in the novel *Still Alice*, paratexts can also be used in different places than merely at the beginning of a novel. At the end of the chapter “August 2004”, a paratext predicts what the final development of Alice’s Alzheimer’s disease entails. While the other chapters in the novel simply end with a conversation between Alice and one of the other characters, the chapter “August 2004” diverts from this pattern (Genova 176, 196). At the end of this chapter, after an awkward conversation between Alice and her daughters Anna and Lydia, it becomes apparent that Alice does not recognize her daughter Lydia and thinks that she is an actress.¹⁰

After an uncomfortable conversation between Alice and her family, about Lydia’s performance, who Alice does not recognize as being her daughter, but merely as another actress, the chapter ends. However, the story does not merely continue into the next chapter, but leaves a space for another scientific explanation, just as at the beginning of the novel.¹¹ The reader is confronted with this scientific explanation, positioned as a paratext, after which he or she understands that Alice’s condition is diminishing (Genova 197, 261). The two pages in between the chapters “August 2004” and “September 2004” are not numbered.¹² The page numbers are deduced from the pages before and after the unnumbered pages. The first page in between the chapters has the following explanation of how neurons work in the brain:

¹⁰ “‘You were brilliant, beautiful to watch,’ said Alice. ‘Thank you.’ [said Lydia] ‘Will we get to see you in anything else this summer?’ asked Alice,” as Alice thinks her daughter Lydia is merely another actress (Genova 195).

¹¹ “Genova believes good storytelling and good science go hand in hand [...] She explains that she uses her background in neuroscience to provide people with a view into a world they would normally be unable to access” (Littlefield 98).

¹² See pages 197 and 198 in *Still Alice*.

The well-being of a neuron depends on its ability to communicate with other neurons. Studies have shown that electrical and chemical stimulation from both a neuron's inputs and its targets support vital cellular processes. Neurons unable to connect effectively with other neurons atrophy. Useless, an abandoned neuron will die.

(Genova 196)

The second page is left completely blank (Genova 197). Yet again this paratext helps to frame the novel, emphasizing what the paratext at the beginning of the novel already indicated would happen, namely that Alice would lose her memory and would not be able to return from that state. While Alice does not realize that her condition has worsened, the reader empathizes with Alice, because one understands her changing and diminishing state, with the help of this paratext. The blank space on the rest of the page with the paratext specifically draws one's attention to the paratext on that page. The paratext starts at thirty percent spaced down the page, the other seventy percent of the available page area is blank. This draws attention to both the paratext and the blank space. Two lines of thoughts can be construed from the position of the paratext: the text is the most relevant part, if you invert this thought, it can be that the blank is predominant, it is the most important part of the text, indicating that the memory loss has become widespread in Alice's mind. In either case, the two components of the page, the text and the blank space, compliment and emphasize each other.

While the paratext at the start of the novel foreboded Alice's final stage of dementia, in which the symptoms of this disease take over completely, the paratext in between the chapters forebodes the chapters that are still to come, in which Alice rapidly loses her abilities because of dementia. In the chapters preceding this paratext, the emphasis lies on her finding out that she suffers from early onset of Alzheimer's disease and then on her determination to delay the disease as much as possible. From this paratext on, it becomes

painfully clear that her determination to defer the disease from her “[n]eurons unable to connect effectively,” and that she rapidly deteriorates into a state in which she has little understanding of what is happening to her and what takes place around her (Genova 197). For example, when Alice attends the graduation ceremony of one of her former students at Harvard University, she is more concerned with understanding the words that John uttered than who will be at the ceremony, namely her graduating student and former colleagues.

John, Alice’s husband prepares her for the ceremony:

‘Alice, please, put your robe, hood, and cap on, we need to leave.’ ‘Where are we going?’ asked Alice. ‘Harvard Commencement.’ ‘She inspected the costume again. She still didn’t get it. ‘What does commencement mean?’ [To which John replies] ‘It’s Harvard graduation day. Commencement means beginning.’ (Genova 306)

In *Still Alice*, the different spaces in the novels, other than at the beginning of the novel that portrays a paratext, serve the same purpose as the paratext at the beginning of the novel: they emphasize the consequences of dementia for the protagonist. The paratexts written within the pages of the narrative can draw the reader’s attention to the different stages of dementia in the story which are about to be narrated in a particular part of a chapter in the novel, and in that way emphasize how badly Alice is affected by Alzheimer’s disease.

2.4 Pictures: A Deviation from Words on Paper

The novel *Elizabeth is Missing* applies the paratext in a different form than *Hersenschimmen* and *Still Alice*. At the start of each of the eighteen chapters a different picture is portrayed; these serve as paratexts. Genette explains that illustrations can have the function in a novel to “surround [the text] and prolong it, precisely in order to *present* it [and] to *make it present*” (261). The pictures at the beginning of each chapter introduce a theme that plays a role in the novel. For example, the first chapter in *Elizabeth is Missing* shows a heading of a can of

peaches. Maud enjoys going to the shop to buy groceries, like “Eggs, milk, chocolate” and always takes a few cans of peaches back with her from the shop, because she forgets what she came for and decides to take at least something home with her (Healey 7). Maud forgets, as a consequence of dementia, that she had already bought them the day before, and the day before that as well. Even when the shopkeeper reminds her of this, she does not understand what he is implying and feels he is being rude. She answers in a brusque manner: “If I want to buy peach slices, I can buy them” (Healey 8). While the text suggests that Maud keeps on buying peaches, and while a similar episode does not come back in the novel, it is insinuated that each day she has this routine of going to the shop and buying groceries. Each chapter concentrates on portraying a situation which is implicated by the picture heading a chapter: in chapter five there is a garden spade (Healey 62), in chapter seven there is chocolate (Healey 88), and in chapter ten there is a hair comb with birds on it (Healey 129). The different miniatures at the top of each chapter emphasize Maud’s disorientation in daily life, as one cannot be sure what role the miniatures will take in each chapter.

The choice for depicting an object at the start of each chapter can be interpreted as a way to create awareness of how Maud feels and the relevancy of the objects to her that are illustrated. For example, the illustration of the garden spade in chapter five could indicate her general interest in gardening, but also the morbid reference to Maud’s sister Sukey who was murdered seventy years ago and who was buried in the garden of Maud’s friend Elizabeth. In chapter eighteen Maud and her daughter dig up Sukey (Healey 261). In this way, it is not clear to the reader what the illustrations at the top of each chapter exactly entail for the storyline, and are prompted to unravel Maud’s story, which is distorted because of dementia.

In another way, the novel utilizes the pictures as a way to emphasize that Maud desperately tries to not forget items and events that are important to her in her day-to-day life. She needs to focus on one task at a time, realizing otherwise that she will forget. If these

images were merely discussed in the text, and not portrayed as pictures at the start of the chapters, Maud's difficulty with memory would not be emphasized to the same degree. In the text the focus lies on the event taking place at a given time, but the pictures can emphasize the importance of a specific item which is then elaborated on in a scene in the text, though the reader cannot be sure when these will be elaborated on. The mystery of the pictures can help the reader to empathize with Maud's state because one only has a vague notion of what the pictures refer to. In fact, Maud herself states that "I have an idea there was something I had to remember", but the words on paper do not make any sense to her (Healey 6). Furthermore, she states: "[T]he words begin to lose meaning and are like a chant" (Healey 8). Instead she tries to keep an image in her mind, like the ones at the start of each chapter, in order to try to remember.

The intention of using the pictures at the top of the chapters, serving as paratexts, is to propose an "interpretation" of the narrative (Genette 268). Partly through the pictures at the beginning of the chapters, the intention is to give the false impression that Maud knows what she is doing. However, once one starts reading the chapters themselves, it becomes clear that the pictures only indicate a situation in which Maud has forgotten what she is doing in that situation, or why something is happening in that way. For example, chapter fourteen is headed by a picture of a suitcase (Healey 180). The chapter discusses Maud's move into Helen's house, because Maud cannot safely live alone anymore. However, Maud has already forgotten that this is happening, for as Helen says: "O mum, you agreed months ago. It's not safe for you to live on your own any more" (Healey 182). So, the image of the suitcase at the start of the chapter suggests that this chapter is about Maud packing a suitcase for something, which at that point is unknown. In fact, as a consequence of the dementia, Maud, packing her bags, forgets that she is going to move in with her daughter Helen. Having read thirteen chapters before coming to this chapter in which a suitcase is portrayed, one is aware that this

suitcase could mean several things; since the beginning of the novel Maud's memory loss has become steadily worse, and the suitcase could be interpreted at this point as Maud needing to pack to leave for a care home.

The pictures in this novel, serving as paratexts, forebode in one way a sense of an occurrence in Maud's life that will be discussed in a chapter, and in another way convey an awareness of Maud's sense of memory loss by creating confusion in the reader as to what will take place in the chapters. Realizing how serious Maud's memory loss is, indicated by the different miniatures above each chapter, the reader can empathize with her situation. The reader follows her narrative and experiences this confusion together with Maud. She cannot control how the episode, which includes peaches in chapter one and a suitcase in chapter fourteen, will turn out, and the illustrations do not indicate that she will remember that these events took place.

2.5 In Conclusion

In this chapter I have shown how popular novels in which the protagonist suffers from dementia use the narrative device of paratexts to provide additional knowledge on the state of the protagonists' dementia. The reader is actively involved in comprehending the story of the protagonist, and can observe that the protagonist does not have the same knowledge as the reader has. They are used at different points in the novels for various purposes: used at the start of the novel, they foreshadow to the point at which the protagonist has no memory any longer and the memories will not return. The empty whiteness of the page on which the paratext is depicted refers to that memory loss. Used in the different spaces in the novel, they forebode to a particular stage of dementia that is about to be discussed in the subsequent chapters of the novel. Presented as illustrations, the paratexts are used to emphasize a sense of the confusion that the protagonist experiences. Paratexts connect to my main research

question on how narrative devices help to bring dementia to the fore and help us to understand and empathize with those who suffer from dementia; they reflect the state of mind of the protagonists, and give additional information that the protagonists themselves cannot provide.

Chapter 3. Ellipses, the Withholding of Crucial Information, and Gaps

3.1 Introduction

Through the use of narrative devices, novels on dementia can represent the symptoms of dementia, and can involve the reader in the story of the protagonist who suffers from this disease. The three novels *Hersenschimmen*, *Still Alice* and *Elizabeth is Missing* use the narrative device of ellipses, the withholding of crucial information, and the creation of gaps in diverse ways to represent the symptoms of dementia, such as “memory and communication problems,” of the protagonists (Nuffield Council on Bioethics, “Dementia: Ethical Issues” xvii). They are an important narrative device through which the reader is involved in the story. This chapter will therefore show that by leaving out parts of information in a scene, the reader feels inclined to fill in the missing information, to try to fully understand what is taking place. Interaction between the reader and the text takes place through the diagnosis of the protagonist’s dementia being left unspoken, as in *Hersenschimmen* and *Elizabeth is Missing*, or through the diagnosis not being further elaborated on, as in *Still Alice*. This affects the way that the reader views the protagonist, namely by emphasizing how the memory loss is expressed in the text and in the daily life of the protagonist. To ensure that the reader has a sense of being guided by the text, missing information – or gaps, as Wolfgang Iser calls them in his text “Interaction between Text and Reader” - are always set within the story: “What is concealed spurs the reader into action, but this action is also controlled by what is revealed” (Iser 1527). In the chosen novels gaps in information can help the reader to identify with the protagonist and empathize with him or her. This often also means that the reader must connect situations from different parts in each of these novels:

He [the reader] is drawn into the events and made to supply what is meant from what is not said. What is said only appears to take on significance as a reference to what is not said [,] as the unsaid comes to life in the reader's imagination, so the said 'expands' to take on greater significance than might have been supposed. (Iser 1527)

Another way to illustrate missing information is through ellipses. Mieke Bal explains in her book *Narratology: Introduction to the Theory of Narrative* that through omission of information "ellipsis – the omission of an element that belongs in a series – gains its power of signification" (217). While *Hersenschimmen* makes use of ellipses at the very end of the novel, it mainly emphasizes Maarten's lack of words which cause him to have difficulty to communicate his thoughts, while in *Elizabeth is Missing* ellipses emphasize Maud's general decline of memory. The reader feels connected to the protagonist, following his or her experiences of memory loss. Consequently, the reader also feels confusion as to what the meaning is of certain events at a given time in the novel, because these are not always explained fully, and because the full extent of what exactly occurs is left to the interpretation of the reader. The purpose of this is to emphasize the protagonist's dementia. An important motive is that of creating empathy for the protagonist, and simultaneously for the relatives that are involved. The reader is constantly searching for ways to fit together the different scenes, enabling him or her to interact with the text and understand what is happening to the protagonist.

3.2 Omission of Information in Scenes in the Narrative

The consequences of memory loss on the protagonist and his or her environment is often implied in situations by leaving out information occurring in the narrative. As becomes apparent in the following examples from the novels, creating these gaps also creates empathy for the protagonist.

In *Hersenschimmen* the gaps that Maarten experiences as a consequence of dementia can be perceived through his actions. As the dementia takes over in his brain, he cannot place many of the people relevant to his normal day-to-day life, and when he tries to communicate with them he only talks about events which happened a long time ago.¹³ Iser explains: “[G]aps [can] function as a basic inducement to communication. Similarly, it is the gaps, the fundamental asymmetry between text and reader, that give rise to communication in the reading process” (1526). When Ellen Robbins, a friend of Vera, comes to visit her, Maarten walks in and joins them in their conversation. He thinks he is being polite when he asks Ellen how her husband Jack is. It seems trivial talk. However, the reader can perceive from the scene that Maarten’s question is actually rather inappropriate, and as such the reader must fill in what is not said in so many words:

‘Hoe is het met Jack?’ vraag ik. Hun gezichten verstrakken. Raadselachtig hoe snel mensen van gelaatsuitdrukking kunnen wisselen. [...] ‘Ik herken mensen altijd het best aan hun stem,’ zeg ik. [...] Het gesprek moet voortgang vinden. Hun gezichten, aan weerskanten van het ronde lampschijnsel, vertonen nog steeds die starre gipsachtige uitdrukking. ‘En als iemand dood is,’ zegt Ellen Robbins. Haar stem beeft en Vera legt in een beschermend gebaar haar hand op Ellens arm. (Bernlef 40)

The scene does not communicate outright that Jack is dead, but Ellen implies this when she answers Maarten with “[e]n als iemand dood is” (Bernlef 40). Maarten has forgotten that Jack is dead, and does not understand what Ellen is talking about. He simply blames the changing facial expressions as being the reason that the conversation is so stiff and uncomfortable. The text offers the reader not just Maarten’s view in the conversation with Ellen Robbins about her deceased husband, but also provides insight into the painful situation that Maarten’s

¹³ “Het brein van Maarten is nu zo brokkelig geworden en gedesintegreerd, dat herkenning van Vera of van de omgeving ontbreekt” (Reenders 147).

memory loss is causing. The reader realizes that Ellen is referring to Jack when she answers, although she does not say this in so many words. Vera and Ellen do not realize that Maarten has forgotten that Jack is dead. In this way, the reader empathizes with Maarten. He does not realize that he suffers from memory loss or how it affects Vera and Ellen. The reader can also empathize with Vera and Ellen though, because they are hurt and embarrassed by Maarten's remark.

A similar situation occurs in *Still Alice*, when Alice and her family go to see Lydia, Alice's daughter, perform in a play. Attending a play seems an event that is of little significance for the narration. However, it is precisely from this scene that the reader must deduct for him- or herself what is left unspoken:

Alice became easily and completely absorbed in the imaginary world the actors created. [...] Afterward, the actors came out into the audience. *Catherine* beamed. John gave her flowers and a huge, emphatic hug. 'You were amazing, absolutely incredible!' said John. 'Thank you so much! Isn't it such a great play?' The others hugged and kissed and praised her, too. 'You were brilliant, beautiful to watch,' said Alice. 'Will we get to see you in anything else this summer?' asked Alice. She looked at Alice for an uncomfortably long time before she answered 'I'm moving back to L.A. at the end of August, but I'll be back this way a lot to visit my family.' 'Mom, that's Lydia, your daughter, said Anna [Alice's other daughter]. (Genova 195-196, my emphasis)

This scene takes place at the end of a chapter, which is aptly chosen, because in this way, a gap is created before the next scene starts. The remainder of the page on which this scene ends is left blank, which leaves some time for the reader to contemplate what has just happened before turning the page to the next chapter. What is implied here is emphasized by what is not said. In this way, as Janet Pérez states in her article "Functions of the Rhetoric of

Silence in Contemporary Spanish Literature”: “Literature [is] replete with [all] those things not presented [and] not told” (117). When Alice is talking to “Catherine,” she thinks she is talking to the same person as in the play; that Catherine, the character, stepped out of the play to talk to her (Genova 195). It is actually Alice’s daughter Lydia who Alice is talking to. Alice does not manage to distinguish the play from real-life. While everyone else, Alice’s husband John and their other children congratulate Lydia in a way suitable for someone they know well, Alice thinks that they are just overjoyed with the outcome of the play and that this is the reason that they react in an exaggerated way towards “Catherine” (Healey 195). The reader can, however, perceive that it is Alice who does not understand the situation she is in. She does not realize that it is her own daughter Lydia who has been performing in the play. In this way, the reader can empathize with both Alice, for not recognizing her own daughter, and with her family members, John, Anna and Lydia, who have to witness Alice’s deterioration.

In the novel *Elizabeth is Missing* Maud’s memory loss also causes uncomfortable situations. The text only conveys a recollection of Maud having bought peaches today and yesterday. The shopkeeper Reg reminds her of this, saying ““Are you sure this is what you’re after?” [...] ‘Only you bought a lot of peach slices when you came in yesterday’” (Healey 8). It is through a conversation between Maud and her daughter Helen that the reader comes to understand that Maud visits the grocery shop every day. This is actually unnecessary, because Helen could go to the shop for her:

‘Mum!’ [Helen] says. ‘Where have these cans come from? How many bloody peach slices do you need?’ I [Maud] tell her I don’t know how many. I tell her Carla must have bought them. I say I’ve been at home the whole day [...] ‘She holds up a plastic bag. [Helen says] ‘Why would Carla leave tins of peach slices in the hall?’ [...] ‘You have to stop going shopping. I’ve told you I can get anything you need. I come every day.’ (Healey 10)

The fact that Maud goes out each day for peaches is not literally stated here, only insinuated by Helen’s suggestion that as she “come[s] every day” to see Maud, there is no need for Maud to go out to the shop each day (Healey 10). In one way, the reader will be inclined to commiserate with Maud, because she is not taken seriously and because Helen gets cross with her. In another way, the reader will empathize with Helen, because her outburst towards Maud implies that this is not the first time that this has happened, and that this same conversation between Maud and Helen has taken place many times before. In this way, the reader must fill in information that is not directly provided, but only implied by Helen’s irritated response. While the situation seems less of any issue than the one in *Hersenschimmen*, where Maarten cannot remember that Jack is already dead, or the one in *Still Alice*, where Alice does not recognize her own daughter, Maud’s memory loss, as portrayed in the scene above, creates empathy for the situation she and her daughter are in.

The three novels often display similar ways of implying information in a scene without actually explaining it; this prompts the reader to interact with the text and interpret what is going on. The gaps in the particular scenes create empathy for the protagonist suffering from memory loss, because the reader has to interpret the emotions that are present in that scene, which are often unspoken by the characters. Simultaneously, empathy is also created for the people surrounding the protagonist, because they are part of the awkward situations that the dementia of the protagonist creates.

3.3 Omission of Information in the Form of (Unspoken) Diagnoses

Another way in which the novels use gaps in information in the text as a way for the reader to interact with the text more closely, is through excluding details of the diagnosis of dementia. The actual articulation of the diagnosis of dementia is often left unspoken and left up to the reader to interpret. As Iser explains: “[T]he unsaid comes to life in the reader’s imagination, so the said ‘expands’ to take on greater significance than might have been supposed” (1527).

In *Hersenschimmen* Maarten’s dementia is never actually mentioned. Throughout the novel, Maarten blames the winter and the snow for his loss of memory, and these are symbolic for his dementia (Bernlef 7). He used to be quite happy with the snow when he was younger. When he reminisces about the good old times back in Holland, he states that: “En ’s winters kon je daar eindeloos schaatsen” (Bernlef 59). This is directly in juxtaposition to how he views the winter now: “Buiten ligt overal sneeuw. Ik houd niet van de winter, bal mijn vuist ertegen” (Bernlef 96). Maarten does not realize himself that he is suffering from dementia. In fact, he thinks that he has suffered a small stroke; “Ik kan alles volgen [op televisie]. Ja, het moet een kleine beroerte geweest zijn, een hele lichte. Ik vertel het Vera niet, ze zou zich maar zorgen maken” (Bernlef 74). By leaving out the actual information which the word ‘dementia’ would provide, the reader is left to determine what Maarten is suffering from. Coming from Maarten’s perspective, he thinks that he is in control of situations, but the underlying truth is that he is not. Even if Maarten does not realize himself that it is memory loss the reader does, for we can read of his forgetfulness about drinking his tea or coffee and not remembering his dog Robert on walks outside. Vera reminds him each time of his tea and coffee, showing that the mention of this is not a solitary incident, but that it happens more often, indicating his memory loss.¹⁴ The reader then can empathize with

¹⁴ The following passages illustrate that Vera has to tell Maarten more often that he has forgotten his tea or coffee: “Vanmorgen heb je je koffie koud laten worden” (Bernlef 11), “je thee wordt koud” (Bernlef 88), and “[Maarten says] ‘[m]ijn thee is koud’ [to which Vera replies] ‘Je bent hem vergeten op te drinken’” (Bernlef 89).

Maarten's situation, because one recognizes that he is suffering from memory loss, and this interferes in his life, but that he himself does not see this.

Similarly to *Hersenschimmen* the word 'dementia' is never mentioned in *Elizabeth is Missing*. The reader is left to discover that through the narrative itself. However, the reason for not mentioning Maud's official diagnosis is for a different reason than in *Hersenschimmen*, which was for the reader to focus the attention on his daily rituals which point towards memory loss. It is more important that the reader takes Maud seriously in her endeavours, while simultaneously recognizing that memory loss reduces her sense of what is happening around her. It seems more important than in the other novels for the reader to follow Maud's steps in the narrative to uncover a great mystery, as Katsura Sako suggests in her article "Dementia and Detection in *Elizabeth Is Missing* and *Turn of Mind*": "[D]etective fiction [is] a particularly effective vehicle for interrogating [...] the meanings of dementia" (2). Through the detective elements the reader is more compelled to follow Maud's endeavours to solve the mystery of where Elizabeth is, because the reader wants to know how the story will end. Simultaneously, the detective elements emphasize "Maud's cognitive failure, presenting her as an incapable detective" (Sako 6).

As the novel begins, the reader is immediately introduced to a sense of mystery. Maud is standing in her garden, and thinks she is talking to Elizabeth, and says: "'Elizabeth?' [...] 'Did you ever grow marrows?'" (Healey 2). This passage makes the reader feel on edge, because there is only Maud's carer there with Maud (Healey 1). Maud turns away from her carer and walks outside into her garden, where there is no one, from this the reader infers that Maud is talking to an imaginary person. There is time for the reader to contemplate who Elizabeth is, because the remainder of the page is left blank and the chapter comes to an end. However, as this takes place so early on in the novel, the reader has no storyline to follow, and can only conclude at this point that Elizabeth must be someone close to Maud, but will

stay confused as to whom she is exactly, until the text reveals more. This does not happen until the end of the novel, when Maud goes to visit Elizabeth. It then also becomes clear that the writer has deliberately delayed communicating this information to the reader until the end of the novel; as is shown when Helen says when they visit Elizabeth: “[Elizabeth] was in hospital, Mum, a stroke unit, remember? Remember we talked about it? Again and again and again” (Healey 251). Keeping this information until the end of the novel illustrates that throughout the novel Maud has been suffering from memory loss, because she cannot remember that Helen has spoken to her about this many times before already. It creates the “suspension of connectability between textual perspective[s]” (Iser 1531). While the text discloses the information of where Elizabeth is in the end, it still does not say anything about how long Elizabeth has been in hospital, nor how much time has passed. It emphasizes “the incompleteness of the narrative” (Pérez 121). At this point, the reader realizes that as a result of Maud’s dementia, there was a gap in Maud’s memory as to where Elizabeth was, which means that the reader is not informed either. In reality, Elizabeth has been in hospital throughout the narrative. The element of suspense, which is created through the unspoken diagnosis of Maud’s dementia, enables empathy in the reader: the realization strikes the reader that Maud has no idea of what is happening in her life, and that this affects Maud’s life to an extent that she herself does not realize.

In the novel *Still Alice* the fact that Alice suffers from Alzheimer’s disease is not kept a secret in the novel, for the diagnosis is made early on in the novel, as her doctor tells her: “When I put all of this information together, Alice, what it tells me is that you fit the criteria of having probable Alzheimer’s disease” (Genova 78). However, the stages of the disease are not described as such in the narrative itself, but they only become apparent during the course of the narrative, and need to be interpreted through, for example, the last but one chapter called “Summer 2005”. It comprises of the two months July and August of 2005 (Genova

320).¹⁵ Here the novel seems to deliberately change the division of the chapters into months to cover two months instead of one. Taking these two months together as one chapter is a subtle way of showing that Alice has entered yet another stage in Alzheimer's disease. It is not stated specifically that she enters a new stage, but this becomes apparent through her not recognizing her family, and after a while knowing who she is anymore. It is shown by the fact that: "She ran her fingers over her cheeks and forehead, feeling her face on her fingers and her fingers on her face. That can't be me. What's wrong with my face? The girl in the mirror sickened her" (Genova 316). In the earlier stages Alice was still able to remember the names of her children, and who she was herself, because her memory was not completely gone, but by the time this chapter is reached the disease has taken over. The quotation above, in which Alice sees her own reflection in the mirror, emphasizes the change that is taking place in Alice, and which is irreversible. The chapter "Summer 2005" affects the reader (Genova 320). A gap is created in the timespan of the novel, emphasizing Alice's memory loss, making the reader ponder on the effect that Alzheimer's disease has on Alice.

Furthermore, the gap in the timespan in the novel involves the reader by him or her having to work out what is happening to Alice. Through this involvement, the reader can empathize with Alice, because the reader understands that she does not have control over her life any longer, and does not comprehend what is taking place in her life. In this way, the text is communicating "a basic inducement" to the reader to keep reading (Iser 1526). So, in *Still Alice* the text interacts with the reader by insinuating that which Alice cannot perceive herself, namely the memory loss that rapidly encroaches, but without expressly stating it.

The novels *Hersenschimmen*, *Elizabeth is Missing* and *Still Alice* use the narrative to illustrate the diagnosis of dementia of the protagonists to the reader through gaps in

¹⁵ It should be noted that the previous chapter of this thesis, chapter one on paratexts, discussed a passage in the novel *Still Alice* that serves as a paratext which forebodes Alice losing her memory. As is discussed here, Alice's story itself also illustrates that Alice goes through different stages of Alzheimer's diseases.

information. In Maarten's case, the reader is expected to piece together the different scenes in which his memory loss is illustrated, even though the word 'dementia' is not mentioned; in Maud's case the reader is expected to believe Maud in her endeavour to find Elizabeth. This would be more difficult if the diagnosis of dementia were established at the beginning of the novel. In both Maarten's and Maud's case, the diagnosis is blanked out for the benefit of their narrative. In contrast, Alice's diagnosis is made early on in the novel, but her deterioration of memory is not conveyed in stages of Alzheimer's disease, but more through gaps in the structure of the text.

3.4 Missing Information in the Form of Ellipses

Bal states that ellipses can be used for "specific reasons that characterize a story" (90). In the case of novels on dementia, they could be implemented in the text to draw attention to the memory loss of the protagonist. Sako adds to this that by "focus[sing] upon the subject with dementia [one] allow[s] the reader vicariously to experience life with dementia" (17). A person living with dementia means that one experiences memory loss, and does not comprehend what goes on around oneself. This can be emphasized through the use of ellipses, as the following examples illustrate.

The ending of *Hersenschimmen* is also called an "open ending," because the reader does not discover whether it is Maarten's fate to die, or live on in total oblivion (Pérez 119). To reach either conclusion, the reader has to have interacted with the text actively, otherwise the ending of the novel, consisting of very few words, short sentences and ellipses will not make any sense: "...naar buiten...het bos in en de lente die bijna begint...zegt ze...fluistert ze...de lente die op het punt staat te beginnen..." (Bernlef 160). The reader needs to use information provided earlier in the novel, when Maarten was still able to speak, to create a more complete picture from the fragmented pieces. This loss of language causes Maarten

immense devastation, because it is only through language that he is able to express himself, as the passage above portrays. The ellipses in Maarten's sentences portray not just a loss of memory, but also a loss of language (Bitenc 10). Maarten is unable to convey how he feels about his situation without coherent sentences, he has lost his hold on his own life. Rebecca Anna Bitenc explains this in her article "Representations of Dementia in Narrative Fiction" as follows: for Maarten "[l]osing language means losing himself, which possibly represents the most painful aspect of his struggle with dementia" (9). Furthermore, the ellipses illustrate to the reader how far gone Maarten is, and they draw attention to Maarten's final decline into a state that he cannot return from. Having followed Maarten's decline throughout the novel, in which he first gives the impression that he has full agency over his own life, to losing all that control in his life, and not being able to communicate clearly to others any longer what he is thinking or wants, affects the reader in that one empathizes with his worsening situation.

Another example of ellipses that, similarly to *Hersenschimmen*, emphasizes the decline of memory of the protagonist, can be found in *Elizabeth is Missing*. Maud is waiting in the car for Helen, who is collecting some flowers to put down at the grave of Maud's husband, when a woman taps on the window. Maud does not recognize her:

She smiles and nods and says something I can't quite hear through the glass [...] The woman shrugs, waves, blows a kiss, and walks away. I wonder who she was. What she wanted. Helen gets in suddenly, bringing a warm petrol smell with her. 'Was that Carla?' she says. 'Just now?' 'No,' I say. 'I don't...' Who did you say it was?' (Healey 225)

The reason for including this anecdote in the novel is not elaborated on further. Partly because of the lack of information about this passage the reader is confused but stimulated to consider what the role of this anecdote plays in the larger storyline. In a subtle manner, through the ellipses, it illustrates Maud's memory loss. If the ellipses were not used in the

passage, one might think that Maud is merely staring out of the window without any other reference to her suffering from dementia. However, the ellipses emphasize that the memory loss, as a consequence of dementia, affects her feeling of being in the here and now, and that she cannot keep track of what is taking place around her. This is shown, when, as soon as Helen gets in the car with her, Maud has completely forgotten what had just occurred; she has forgotten that she is supposed to know who the woman was who walked by. As Sako says: “Maud’s dementia requires the reader to exercise more memory and deductive skill than otherwise and makes the reading of the text a challenging yet engaging one” (8).

Ellipses do not always have such a dramatic portent as in *Hersenschimmen*, where they are particularly used at the end of the novel to portray Maarten’s total decline because of dementia. In *Elizabeth is Missing* ellipses are used to emphasize Maud’s loss of language, without leading to one particular point of decline. As she and Helen are on their way to the hospital in the car, Maud’s thoughts are described as being very matter of fact, and in the moment, only focussing on what she sees around her: “There is a car now and driving, and a bird flying up from the road and someone sits on a bench by a shop and a dog is tied to a lamp post. ‘Helen...’ I can’t think what else I want to say. I pull the seatbelt away from my body and let it snap back” (Healey 252). As she decides to speak to Helen, she does not finish her sentence, because her memory lets her down. Sako explains the following: “[T]he text often contains clues that help the reader to guess at Elizabeth’s hospitalization before it is fully disclosed towards the end of the novel, while it remains a mystery for Maud because of her inability to remember” (8). The ellipses in the passage from *Elizabeth is Missing* serve as the “clues” that Sako describes. Up to the point that Maud wants to ask Helen a question, Maud is thinking silently to herself, although the reader reads along with her thoughts. The ellipses emphasize Maud’s state of dementia. She is unable to relate to time around her, but only experiences the here and now, and when she wants to ask Helen a question out loud, she

is unable to utter her thoughts. They have disappeared before she can pronounce them. The reader can only guess at what she might have wanted to say.

The novels *Hersenschimmen* and *Elizabeth is Missing* both make use of ellipses, but portray that these can be used for slightly diverse purposes, namely that of portraying the general decline of memory of the protagonist, as in the case of Maud, and also to emphasize language impairment of the protagonist, as in the case of Maarten; this causing coherent communication to stagnate. Ellipses require fuller attention of the reader to the text, and can create understanding for the condition of the protagonist, namely that he or she cannot partake in situations that occur, because he or she cannot oversee the situation.

3.5 In Conclusion

In this chapter I have argued that the popular novels in which the main character suffers from dementia use the narrative device of ellipses, the withholding of crucial information, and gaps to actively involve the reader in the story, because the reader wants to understand what is occurring in a given scene. Active readership is encouraged through the need to fill in the missing information from the text, and at the same time the reader can then distinguish that the protagonist cannot fill these in by him- or herself. This evokes empathy in the reader, seeing that the protagonist misses this sense of understanding. Gaps in scenes help the reader observe the uncomfortable situations of the protagonist, as a consequence of dementia, creating empathy. Gaps in, or the blanking out of, the diagnosis of dementia, adds another layer to the story, because the reader actively needs to pay attention in order to understand what is wrong with the protagonist, and so follows his or her story more closely. With ellipses in the text the reader needs to pay attention to detail, for a lack of information helps one understand the severity of the protagonist's situation. Ellipses, the withholding of crucial information, and gaps connect to my main research question on how narrative devices help to

bring dementia to the fore, because they help the reader connect to those who suffer from dementia. They give a sense of experiencing the dementia along with him or her, and recognizing the decline in memory and empathizing about the hopeless future that is awaiting the sufferer.

Chapter 4. The Use of Temporalization

4.1 Introduction

Novels on dementia can represent the symptoms of this disease and involve the reader in the story through the use of narrative devices. The reader is able to relate better to, and empathize with the protagonist suffering from this disease. The novels *Hersenschimmen*, *Still Alice* and *Elizabeth is Missing* use the narrative device of temporalization to give a sense of the memory loss that the protagonists have to deal with. This chapter will therefore show how through the portrayal of the motives of clocks and mirrors, the emphasis lies on giving a sense of how the protagonist feels at that particular moment in time. A distortion often occurs through the description of the loud ticking of clocks, or clocks that are completely silent and the reflection of the protagonist in the mirror. In the case of *Elizabeth is Missing* this also means attention being drawn to Maud's murder mystery. The reference to time accentuates the "disorientation or memory loss" of the protagonists and the way that they perceive themselves (Nuffield Council on Bioethics, "Dementia: Ethical Issues" 17). Harry Jansen explains in his article "Time, Narrative, and Fiction: The Uneasy Relationship between Ricoeur and a Heterogeneous Temporality," that someone who is confronted with time as being discontinued or erased, experiences this as a state in which "the past no longer exists, the future is not yet here, and the present is slipping by so quickly that it is impossible to grasp" (1). In the novels on dementia, the way that the protagonist experiences temporalization is different to that of actual time progressing. The clock is a symbol for the chronological passing of time, but the novels elaborate by using it to show being in the moment and losing the past. Temporalization is an important narrative device, because it encourages active readership: it makes the readers aware of how time can feel different to someone suffering from dementia. In the different narratives, the protagonist often does not

recognize him- or herself, which is expressed by the reflection in the mirror. Towards the endings of *Hersenschimmen* and *Still Alice* the protagonists do not even realize that it is their own reflection in the mirror. In *Elizabeth is Missing* the mirror portrays Maud's necessity to keep remembering a moment in the past, when her sister disappeared, and in that way the mirror emphasizes the inconsistency between herself in the present and herself in the past. This makes the reader aware that it is important to empathize with someone with dementia if he or she cannot keep up with the world around, because time does not take on the same meaning anymore.

4.2 Indications of Time in the Novels: Clocks

In the three novels the clock is often illustrated as either ticking particularly loud, or making no sound at all. While the clock is an object associated with keeping time, Mieke Bal suggests in her book *Narratology: Introduction to the Theory of Narrative* that "temporality can even be concealed behind apparent chronology" (80). The clock assumes a different meaning than merely displaying time, as Jansen explains that "[t]he erasure of time measurement [can be] symbolized" through the clock (Jansen 9). Furthermore, Bal explains that "[t]he time that regulates our lives, by means of clocks, schedules, and other means of uniforming lives, is so incorporated, interiorized, or naturalized that it is difficult to imagine that there are conflicts built into it" (77). By placing time, symbolized by the clock, at the foreground of an episode in the novel, the reader is made to reconsider our "interiorized" sense of time, and to think of how dementia affects the protagonist (Bal 77).

A good example of this symbolism of conflicts experienced by sufferers of dementia can be found in *Hersenschimmen*. Maarten struggles with time and this is illustrated when Vera heats up a pizza for herself and Maarten in the oven one Sunday evening. She instructs

Maarten to take it out after ten minutes, while she goes to another room (Bernlef 21).

Maarten does not have time to ask her further questions, and sits down to watch the clock:

Ik wil het haar nog vragen, maar ze is de kamer al uit. Tien minuten. De grote wijzer staat nu op de zeven. Als hij op de negen staat zijn de tien minuten om. Maar wat dan? Wat moet er dan gebeuren? Ik sla het boek dicht en schuif het van me af. Ik staar naar de zwarte wijzers van de goudkleurige wandklok. Er zit geen secondewijzer op. Het lijkt alsof de klok stilstaat. Het is een modern, hij tikt niet. (Bernlef 21)

At this point in time, early on in the novel, Maarten still recognizes that the clock represents what time it is in the present. However, he thinks that the clock has stopped, because there is no indication of the seconds passing by. He understands that something must happen when the hand on the clock reaches the number nine, but he does not remember what that can be. In the article “Functions of the Rhetoric of Silence in Contemporary Spanish Literature” Janet Pérez calls time used in this way: “Silencing of specific time and place via the use of temporal [...] evasion” (126). Maarten experiences this as being in the present moment, time standing still, and nothing else occurring except for him staring at the clock. His specific observations of how the clock works emphasizes the concentration he needs to discover what the clock represents. Through the use of the simple present tense in the passage, it becomes even more evident that Maarten undergoes this moment as stationary. As Rebecca Anna Bitenc states in her article “Representations of Dementia in Narrative Fiction”: “The present tense heightens the immediacy of the experience and also builds up the dramatic tension[. It] allows the reader to follow the workings of his mind, and emphasises his experience” (310). Specifically for Maarten it feels odd that he does not know what time it is, as he states: “Ik ben altijd een man van de klok geweest. Punctueel. Dat kun je van anderen niet zeggen” (Bernlef 21). However, the novel begins at a point at which Maarten already suffers from dementia and does not have a clear sense of time anymore. The novel portrays Maarten

during the stages of dementia in which his memory loss is clearly noticeable. The passage, as described above, takes place early on in the novel. The reader perceives the trouble that Maarten has with time, and also sees how his trouble of understanding linear time has not been noticed by Vera yet. In that way, empathy is already created for Maarten's situation early on in the novel.

As time passes chronologically in *Still Alice*, the clock serves to emphasize that time is not on Alice's side, which becomes apparent when she tells her children that she has been diagnosed as suffering from Alzheimer's disease:

'I've been experiencing some difficulties with my memory for some time now, and in January, I was diagnosed with early-onset Alzheimer's disease.' The clock on the fireplace mantel ticked loudly, like someone had turned its volume up, the way it sounded when no one else was in the house. Tom sat frozen with a forkful of frittata midway between his plate and mouth. She should have waited until he'd finished eating his brunch. (Genova 116)

No specific time is indicated here, merely that time is passing by, alluded to by the sound of the ticking of the clock. In Alice's daily life time overshadows her existence, because she experiences it as running out to the point when she has no memories left. In this passage she still has a reasonable amount of awareness of her surroundings, being able to tell her children about her condition. However, while this is the first time that she tells her children about it, she already experiences time as running out, because her memory is failing her. This is emphasized by the "loudly" ticking of the clock, which also draws attention to the helplessness of Alice's situation (Genova 116). There is no way back from this disease for her.

At the end of *Still Alice* it becomes clear that Alice's sense of time has completely gone, and that she has lost all understanding for the chronological course of time:

Alice sat in a big, comfortable, white chair and puzzled over the clock on the wall. It was the kind with hands and numbers, which was much harder to read than the kind with just numbers. Five maybe? [John] looked at his wrist. ‘Almost three thirty’.

[Alice replies] I think it’s time for me to go home.’ [John replies to Alice] ‘You are home. (Genova 313)

John’s answer is very specific, and shows that Alice is unable to tell the time. At this point she recognizes that the object on the wall is called a clock, but has no idea of how to read it. Five o’clock is indicated very differently on a clock by the hands than three thirty is. Alice tries to make sense of the clock, but instead as she sits there with John, she merely perceives “the ticking of the clock” (Genova 314). While the passage is partly written in the past tense, “the ticking of the clock” is in the present continuous tense, emphasizing that Alice will be in this state of memory loss forever (Genova 314). As Bitenc explains: “The use of the present tense contributes to the sensation of being plunged into[one]’s immediate thought processes” (309). The passage above indicates that Alice still realizes what the function of a clock is, but does not have the ability any longer to use this knowledge. All that is left is her focus on the sound of the clock. Before Alice’s brain was affected to this degree by Alzheimer’s disease, she was able to make sense of the hands on the clock and to read the time from them. For example, at the beginning of the novel, Alice mentions what time it is and what has to happen then: “It was 7:30 according to their alarm clock which she guessed was about ten minutes fast. She knew from the approximate time and the escalating volume of his racing that he [John] was trying to leave, but he’d forgotten something and couldn’t find it” (Genova 3). This passage shows that, before Alzheimer’s disease had progressed, Alice was perfectly capable of telling the time and that she could know from the time on the clock what should be happening next. At 7:30 in the morning John is in a hurry to get to work on time. The novel follows the process of Alice’s memory loss from a point that she is still able to discern time,

to the point that time makes no sense anymore; in this way, the destruction that Alzheimer's disease causes Alice is emphasized, and the reader emphasizes with Alice's situation exactly because one can follow the drastic change from the beginning to the end.

In the novel *Elizabeth is Missing* the mentioning of time through clocks portrays that Maud cannot keep up with life around her. She realizes that time still passes by as it used to, but now she does not know how to fill in that time:

When I've finished eating I wander back to the sitting room. It's so quiet in here; even my clock doesn't tick out loud. It shows the time, though, and I watch the hands slowly moving round on top of the gas fire. I have hours of the day to fill and at some point I have to switch on the TV. (Healey 5-6)

There is no indication of what time it is exactly, merely an implication that it must be quite early in the day as Maud says she has "hours of the day to fill" (Healey 6). The lack of noise of the clock suggests that Maud experiences life at this moment as standing still. She cannot make out what time it is, and therefore cannot keep up with life going on around her. It feels to her as if it is taking a very long time for the day to progress, as the passage above suggests with "I watch the hands slowly moving round" (Healey 5). Because of dementia, she cannot think how to fill in her time otherwise: "A few years ago I would have been appalled at myself – watching TV in the day! But what else is there to do? I occasionally read, but the plots of novels don't make sense anymore and I can never remember where I've left off" (Healey 6). As a consequence of her memory loss, she cannot remember what she did a few minutes ago, making reading books very difficult. The portrayal of time as passing by very slowly emphasizes that Maud suffers from memory loss, because time does not make the same sense as it used to. Katsura Sako explain in her article "Dementia and Detection in *Elizabeth is Missing* and *Turn of Mind*" that memory is "an ability to recognize one's self in time and this narrativizes one's life in a coherent order" (7). Through Maud's portrayal of her

loss of memory, through not comprehending time any more, the reader recognizes that she cannot keep up with life around her; she has no control over it any longer. This causes the reader to empathize with Maud, because one observes that her sense of time does not coincide with the passing by of chronological time.

The novels use the motive of clocks as a way to portray how the protagonist feels in specific moments of time. It emphasizes time as passing by very slowly, or very fast, by the descriptions of the soundlessness of the clock or the loud ticking of the clock. Maarten, Alice and Maud do not realize what the clock means in the final stages of their dementia. There is no general pattern of time being portrayed in one particular tense, but the motive of clocks does emphasize the memory loss of the protagonists. The diverse ways in which the novels use the motive of clocks illustrate the various ways in which time can be used indicating memory loss.

4.3 Maarten's and Alice's Reflections: Whiteness of the Mirror

One sees one's reflection in a mirror, an image that gradually ages. As Primorac suggests: "[A] mirror [is] an object reflecting framed space back at the person looking" (89). However, these features are not entirely applicable for Maarten in *Hersenschimmen* and Alice in *Still Alice*. Instead, the motive of the mirror, as Bal suggests, "provide[s] insight into the broken sense of self [making] the reader experience it with [the protagonist] on an emotional level as well" (82). The protagonists suffering from dementia do indeed experience their reflection in the mirror as being different than the age they are in reality. In this way, the motive of the mirror emphasizes the story of the protagonist who experiences memory loss. Through descriptions of how Maarten and Alice see themselves in the mirror their sense of their "true reflection" is given (Ghasemi 59). At the same time, the way that they perceive themselves

changes over time. This also portrays their “loss of the power to express [their] identity in [their] own terms” (Ghasemi 59).

Initially, in the novel *Hersenschimmen* Maarten still recognizes himself in the mirror bathroom: “Ik bekijk mijn gezicht in de wastafelspiegel. Niemand kan eraan zien hoe ik er vroeger uitzag. Ikzelf ook niet” (Bernlef 38). He registers that he looks different than he used to when he was younger. The present tense “Ik bekijk” states that he realizes that he is in the present, while “vroeger uitzag” shows that he realizes that this lies in the past (Bernlef 38). In this way, he understands that there is a present and a past, and that in the past he looked younger, but that he has now grown older. This seems an obvious observation, but as the novel continues, it becomes apparent that Maarten loses the ability to recognize such seemingly minor details: “Moet mijn ogen wel opendoen nu en zie een oude man in de spiegel, een oude man met een slap gerimpelde buik vol strontvegen. Ik glimlach opgelucht. Dat ben ik tenminste niet!” (Bernlef 122). This passage takes place towards the end of the novel, so the reader can deduce that Maarten’s memory loss has increased. He does not recognize himself anymore. Maarten does not realize this, and thinks that he is years younger than he really is at this point in time. He has lost his sense of identity, and cannot understand that the mirror shows his reflection.

Maarten’s self seems to be divided into different parts, which he does not comprehend and he cannot connect the images with himself to see who he is at this moment in time. He is only experiencing the present moment; there is no past anymore, this is made clear through the use of the present tense. For example, towards the end of the novel Maarten takes hold of a tiny mirror, which he looks into:

[E]en blikkerend spiegeltje. Ik kijk erin. Weg met dat ding! [...] Men wordt weggedrukt. Ze hebben een ander binnengehaald. Dat heb ik net in een spiegel kunnen constateren [...] Ergens moet nog energie voorhanden zijn. Ergens in Maarten Klein moet toch nog een Maarten Klein zitten, is het niet? (Bernlef 144)

Maarten is talking about himself, but does not realize that “een ander” is his own reflection in the mirror (Bernlef 146). We notice that he is only talking in the present tense, with verbs like “kijk,” “wordt weggedrukt,” and “hebben” (Bernlef 144). Simultaneously, he talks in the third person about himself, having lost the sense of his own identity. This is demonstrated through the fact that he does not recognize his own reflection in the mirror he is holding. Maarten’s total decline of memory loss becomes fully apparent when we read that he cannot even comprehend that the mirror reflects something: “Ik pak de tandenborstel en kijk in de spiegel. Er is niemand daar. Alles is wit” (Bernlef 123-124). He expects a younger person, the one in his head that is still him, but instead sees only blankness. In reality, time has progressed, but Maarten perceives time as standing still. Having followed the deterioration of Maarten’s state of mind through the course of the novel, and finally reading about him no longer recognizing his own reflection in the mirror, makes the reader empathize with him.

Similarly to the novel *Hersenschimmen*, in *Still Alice* Alice’s own reflection in the mirror changes over the course of chronological time in the novel. Her lack of comprehension here is an indication that her memory loss worsens. At the beginning of the novel she perceives herself in the mirror and is able to discern that it is her own reflection in the mirror: “She caught their reflection [of her and John] on the hallway mirror – a distinguished-looking, tall man with white-flecked brown hair and glasses; a petite curly-haired woman, her arms crossed over her chest” (Genova 5). She calls herself “woman,” which is appropriate as she is fifty years old, and shows that she is aware of her age (Genova 5). As time progresses, this image that Alice has of herself changes:

Alice studied her image in the mirror. The reflected older woman's face didn't quite match the picture that she had of herself in her mind's eye. Her golden brown eyes appeared tired even though she was fully rested, and the texture of her skin appeared duller, looser. (Genova 39)

In this passage she still realizes that the reflection in the mirror is that of herself, but simultaneously she is in doubt about how it is possible that the image she has of herself does not coincide with that in the mirror. In one way this could simply be seen as Alice perceiving herself as ageing, but in another way, in the perspective of her being diagnosed with Alzheimer's disease, this can only be seen as the disease slowly taking over. As Ranka Primorac states in the article "Crossing into the Space-Time of Memory: Borderline Identities in Novels by Yvonne Vera": "[T]he mirror [can] describe the process of ageing in a spatial image" (87). In Alice's case this process takes place too quickly.

The increasing memory loss that Alice undergoes, becomes painfully clear when at the end of the novel she does not recognize her own reflection in the mirror:

The girl in the mirror had sunken, darkened circles under her eyes. Her skin looked loose and spotty all over and wrinkled at the corners of her eyes and along her forehead. Her thick, scraggly eyebrows needed to be tweezed. Her curly hair was mostly black, but it was also noticeably gray. The girl in the mirror looked ugly and old. (Genova 315-316)

Alice merely sees a "girl" in the mirror, one who looks "ugly and old"; these two images are quite paradoxical (Genova 316). One would expect the use of 'woman' for the descriptions given here, especially as Alice has already called herself a "woman" earlier on in the novel (Genova 5, 39). Alice has lost all sense of herself; she feels as if she is fractured into parts, an older and younger self. In reality they are one and the same, but she does not recognize that.

The novels *Hersenschimmen* and *Still Alice* portray a similar use of the motive of mirrors in the narratives. Maarten and Alice both lose their ability to see their own reflections as they really are; on the inside they feel years younger than they are in reality. As dementia progresses the changing image that Maarten and Alice have of themselves represents well that they increasingly lose their memory. As the dementia takes over in the protagonist's lives, the reader follows their regression into losing themselves. The use of the motive of mirrors at different stages in the novels help the reader understand the decrease in the protagonists and that understanding can make the reader empathize more strongly with the protagonists, because one imagines how awful it must feel to lose one's sense of identity and not even being able to recognize oneself in the mirror.

4.4 Maud's Split Sense of Personality in the Mirror

The novel *Elizabeth is Missing* also makes use of the motive of mirrors as a way of portraying the dementia of the protagonists. However, this is illustrated in a different manner than with Maarten and Alice. Maud experiences her image as having stopped at a point in time, which does not correspond with who she is in the present. As Parvin Ghasemi suggests, in his article "Reflections of Self and Other in Sylvia Plath's 'Mirror' Imagery," it seems that "the notion of a divided self or the projections of two selves" is represented through the motive of the mirror (61). In this way, as in *Hersenschimmen* and *Still Alice*, the novel *Elizabeth is Missing* gives insight into "the broken sense of self" of Maud (Bal 82).

The motive of the mirror conveys a sense of Maud being confused between the past and the present. She tries to solve her sister Sukey's disappearance seventy years earlier. Ralph Freeman suggests in his book *The Lyrical Novel: Studies in Herman Hesse, Andre Gide and Virginia Woolf* that the motive of the mirror in literature can symbolize "the protagonist's quest and represent [...] it" (14). This plays an important role in, for example,

how the motive of the mirror is used in *Elizabeth is Missing* in order to connect past and present. Maud feels she cannot rest until she has found out what actually happened to her sister. Flashbacks reflect this and help shape how Maud experiences time, namely as being confusing and incomprehensible. It puts the focus on giving a sense of the distortion that Maud experiences. Without the mystery of Sukey being solved, Maud feels she must preserve the memory of the person she used to be in the past, when her sister was still alive, but also the person in the present with the knowledge that her sister disappeared. Connecting these two parts of her happens at the end of the novel, so up until that point, Maud feels divided in time between the past and the present. Primorac explains that in novels “the causal and temporal links between episodes are not explicitly stated, nor are the episodes within the flashback ordered strictly chronologically” (79). This is emphasized by the flashbacks Maud has to the past in which the mirror helps reflect her past:

I take a hand mirror from a table and put it on another bit of newspaper. When I look at it closely I can see an eye staring back at me. ‘Oh,’ I say. ‘Is it something to do with the mad woman?’ Helen turns to me. ‘What?’ I point at the mirror, whispering, ‘Is she hiding in here?’ (Healey 183)

This passage takes place during the present day, with Maud and Helen packing Maud’s belongings for her move to Helen’s house. She cannot live alone anymore, because dementia has become too severe for Maud to function properly alone (Healey 182). While this scene takes place in the present, it refers back to Maud’s past. Maud uses the present continuous tense “is [...] hiding,” because she thinks that the mad woman is staring back at her through the mirror (Healey 183). This indicates that Maud does not realize that the mad woman is someone from her past and has now long gone. Maud does not recognize “an eye” in the passage as being her own eye, which conveys a sense of how her remembered younger self does not feel as if it is connected to her present, older self (Healey 183). Bal explains that

“[t]he movement back and forth from present to past to present is the story’s basic rhythm” (82).

Maud solves her sister’s disappearance at the end of the novel, but the dementia causes her to forget that and so not realize she has actually solved the mystery, and she keeps on thinking that she “must do something. I must, because [she] is missing” (Healey 275). In this way, Maud is trapped in a moment in time, in which she cannot move forward, she does not know whether she is in the past or the present. The mirror emphasizes that Maud feels divided between a period from her youth, the one she is reminded of in the mirror, and the time in which she is now an elderly lady, which is outside of the mirror. She gets them mixed up, and cannot connect them.

The novel *Elizabeth is Missing* uses the motive of the mirror in the narrative to convey how the dementia affects Maud. Her split sense of self becomes apparent through the mirrored image of her past: she feels disconnected from reality taking place in the present time. The reader can empathize with her, because we see how her reflection in the mirror is incongruent of her self-image.

4.5 In Conclusion

In this chapter I have shown how popular novels in which the protagonist suffers from dementia use the narrative device of temporalization to provide the reader with a sense of how the protagonist experiences time. The reader is prompted to observe the protagonist’s sense of time, and this then indicates that the protagonist perceives time in a different sense than the reader: the protagonist has lost his or her awareness of linear time. By observing a sense of loss and understanding of time, the reader empathizes with the protagonist, for one can discern that his or her understanding of time differs from what the reader expects.

Temporalization is particularly established through the use of the motives of clocks and

mirrors. The motive of clocks illustrates the protagonist's struggle with reading time and living in the present. The motive of mirrors portrays the distorted reflection of the protagonist, and illustrates the sense of losing oneself when not recognizing oneself in the mirror any longer. Temporalization connects to my main research question on how narrative devices bring dementia to the fore, because of how it helps create empathy for those suffering from dementia. It illustrates how the protagonists with dementia experience time as being warped.

Chapter 5. The Use of Focalization

5.1 Introduction

Through the use of narrative devices, novels on dementia are able to bring the symptoms and the social consequences of memory loss to the fore. Through the use of a first-person point of view or a limited third-person point of view, the protagonist focalizes his or her experiences, and the reader can feel connected to the protagonist (Abrams 303). The three novels *Hersenschimmen*, *Still Alice* and *Elizabeth is Missing* use the narrative device of focalization to represent the symptom of a sense of “loss of independence and control” that the protagonist has (Nuffield Council on Bioethics, “Dementia: Ethical Issues” 16). It is an important narrative device through which the reader feels involved in the story. This is possible through the internal focalization of the protagonist. Suzanne Keen explains in her article “A Theory of Narrative Empathy” that “the interior representation of characters’ consciousness and emotional states – as devices supporting character identification, [can] contribut[e] to empathetic experiences” (213). This chapter will therefore show how a first or limited third-person perspective enables readers to experience how protagonists lose their agency.

The protagonist experiences a loss of independence, because another character tells them what to do, or prohibits them from doing what they want to do. Another word for having independence – the term that William H. Sewell uses in his article “A Theory of Structure: Duality, Agency, and Transformation” - is agency: “[it should] entail an ability to coordinate one’s actions with others and against others” (21). The protagonists with dementia lose this ability as their dementia worsens. It is precisely the internal focalization of the protagonist’s thoughts, that could not be portrayed by any of the bystanders, that gives the reader a sense of how the protagonist feels. These feelings are often expressed as frustrations

and annoyance. As the dementia worsens, the protagonists are unable to voice themselves any longer, and it is through conversations with other characters that the reader then comprehends that the protagonist has lost one's independence and control in one's life. Through the focalization in the novel, empathy is then evoked in the reader, because the protagonist's sense of loss is experienced through the protagonist's point of view. The reader perceives that loss of independence and the reactions of the protagonist as a consequence of the dementia – an observation that the protagonist is unable to make.

5.2 Providing Insight into the Protagonist's State of Mind

Mieke Bal explains in her book *Narratology: Introduction to the Theory of Narrative* that the point of view that is used in a story “is often of decisive importance for the meaning the reader will assign” (77). The internal focalization of the protagonist with dementia allows the reader to empathize with the protagonist, because one experiences each situation from the protagonist's point of view. Each protagonist's experience with dementia is unique; no bystander could observe it that aptly. Thus, the focalization of the protagonist allows the reader to experience the protagonist's loss of independence as close as possible. The novels *Hersenschimmen* and *Elizabeth is Missing* are narrated from a first-person point of view, illustrated by the pronoun “I”. In this way the emphasis lies on Maarten's and Maud's perception of events and situations: “[it] limits the matter of the narrative to what the first-person narrator knows, experiences, infers, or finds out by talking to other characters” (Abrams 303). The novel *Still Alice* is narrated from a third-person point of view, illustrated by the pronoun “she”, but as in *Hersenschimmen* and *Elizabeth is Missing*, also entails a limited perspective. The focus lies on illustrating Alice's thoughts and interpretation of occurrences: “[it] stays inside the confines of what is perceived, thought, remembered, and felt by a single character [...] within a story [and] is limited to the consciousness of a

character within the story itself (Abrams 303). In the three novels, the protagonists are not deemed capable by their relatives, and cannot be trusted to make decisions which will not endanger them in some way or another. However, the protagonists themselves do experience the interventions of their relatives as intrusions on their independence, and are not aware of there being a problem.

To prevent Maarten from wandering off on his own, Vera keeps the doors of the house locked, so Maarten cannot go outside by himself. As Maarten wants to leave the house, he gets frustrated with Vera for keeping the doors shut, as he thinks to himself: “Zoeken. Als ik ergens een hekel aan heb. Waar zijn mijn sleutels? En welke idioot heeft alle deuren op slot gedaan? Robert loopt braaf achter mij aan terwijl ik de keukendeur, de deur van het washok en de buitendeur probeer” (Bernlef 44). This passage illustrates that Maarten has no idea that Vera has locked all the doors for his safety. He simply experiences the locking of doors as an annoyance. He does not see the reason for Vera locking him in. The reader can follow each action of Maarten, first his annoyance at being locked in, then his solution to the problem, namely opening the door with force:

Ik pak de schroevendraaier en de hamer uit de houten gereedschapskist en loop naar de deur van het washok. Het gaat gemakkelijker dan ik gedacht had. Ik wrik de schroevendraaier tussen de deur en de deurpost. Na een paar klappen sprint hij naar binnen toe open. (Bernlef 44-45)

This passage portrays Maarten's reasoning for breaking open the door: he needs to get outside. He wants to feel independent, to decide for himself when he goes away and not. The focalization that Maarten provides emphasizes his loss of control over his own life. Vera now controls where and when Maarten can go. If the story were told from, for example, Vera's perspective, the reader would come to see all the reasons for Maarten needing to be locked inside the house, because his dementia causes him to forget where he is. Maarten's

perspective allows for the reader to experience the dementia along with him, and allows one to focus on the feelings that come with that. He himself does not realize that he has dementia, but the reader can, and then can perceive that Maarten's loss of independence is because of the disease dementia. For the reader to empathize with Maarten it is important to experience this loss with Maarten, and not to simply look at his situation as one in which he needs help, because then the reader does not experience his feelings of loss with him. It creates empathy for his situation, in which he has no say in the matter. The reader empathizes with Maarten's feelings of frustration and loss of independence, but also sees that his reaction (to open the door with a screwdriver) is not normal behaviour.

In the novel *Elizabeth is Missing*, Maud is treated in a similar way to Maarten. Maud wanders off around outside the house for hours, resulting in her being locked up in her own house by her daughter Helen to prevent her getting lost: "The front door clicks shut and I hear Carla locking it after her. Locking me in" (Healey 5). Helen takes care of Maud by making sure she cannot leave the house easily on her own, because Maud forgets where she is going, and buys too many unnecessary groceries. Nevertheless, she feels independent when she can go out to buy herself some shopping. As she is at the store, she thinks to herself: "That'll do. I put a few more tins in my basket, tucking its handles into the crook of my arm" (Healey 8). The passage shows that Maud is quite content with her purchases. However, the shopkeeper questions her:

'Are you sure this is what you're after?' Reg asks. [And Maud replies] 'Quite sure, thank you,' I say, my voice firm. 'If I want to buy peach slices, I can buy them.' He raises his eyebrows and begins typing prices into his till. I keep my head high[,] but my cheeks are hot. (Healey 8)

This passage illustrates that despite Helen trying to restrict Maud, she still goes out on her own, because she likes the feeling of independence it gives her, and gets frustrated about the

way others, like Reg, treat her. The full extent of Maud's frustration becomes apparent as she thinks to herself, as she and Helen are sitting in a restaurant together: "[Helen] won't listen, won't take me seriously [...] I'm tired of the sympathetic smiles and the little pats people give you when you get things confused, and I'm bloody fed up with everyone deferring to Helen rather than listening to what I have to say" (Healey 18-19). Maud feels she is not taken seriously, and does not understand why. She thinks that she is simply suffering from a little memory loss, but does not see the full implications of the dementia she suffers from. This only becomes apparent as the story continues, and Helen keeps on reminding Maud of what is taking place. The focalization from Maud's perspective helps the reader understand the amount of frustration that Maud feels with losing her independence, of not being allowed to make her own decision any more on whether she goes outside or not, or how many groceries she buys. The reader empathizes with Maud's feelings about the loss of control in her life, but also recognizes that she suffers from memory loss, because she forgets how much she has bought.

In *Still Alice*, Alice also suffers because of a lack of independence. She enjoys going off running, as she always has done, but John does not allow her to go off on her own anymore, because she forgets where she is and he deems that unsafe. As Alice goes off on one of her runs "[s]he knew exactly where she was. She was on her way home[,] and knew exactly where she was" (Genova 109). Alice's thoughts on her run show "how Alice's mind works" (Bitenc 315). She feels confident, and enjoys the sensation of being off on her own. However, as Alice arrives home again after her run, John is waiting for her and asks Alice: "'Where have you been?' asked John. 'I went for a run.' [says Alice. John replies] 'You've been running this whole time?'" (Genova 111). As John does not like her answer of that she went off for a run on her own, he forbids Alice from going off on her own again, as she stayed away a lot longer than she normal does. Alice does not see this herself though, and just

experiences the running as a way to feel independent. Through Alice's focalization, the reader experiences this feeling along with Alice, as the reader follows her on her run, and perceives how she felt during that run. This is a feeling that John cannot perceive, because he is more concerned about keeping her safe, and not with the feelings that are evoked in her for her losing her sense of capability and control. He also does not share Alice's perspective the way that the reader does, which is why the reader can empathize with Alice: the reader perceives Alice's thoughts.

John writes on the whiteboard: "Do not go running without me" (Genova 231). Alice's reaction is twofold: "Provoked, she wanted to scream[,] that she didn't need a babysitter, and she could manage just fine alone in her own house." (Genova 231). However, instead of acting on her feelings, she "sat in her study, hugging her knees, staring out the window at the darkened day[,] waiting for John to return from New York so she could go for a run" (Genova 232). This passage provides the reader with a point of view of how Alice really feels about losing her independence. She feels like John has taken away her independence by ordering her not to go running. Her initial reaction is that of annoyance, that John would stop her from doing what she enjoys so much. Instead of acting on this feeling though, her reaction is to sit and wait. The reader can empathize with Alice. On the one hand, the reader experiences this loss of independence with Alice, and on the other hand, sees that Alice's state is dilapidating to such a degree that she has accepted that she should wait for John, instead of just going off when she wants.

The three protagonists Maarten, Maud and Alice, all experience a loss of independence. This is emphasized through the focalization in the novels. The relatives of all three protagonists tell them what to do. The protagonists lose the control over their own lives that they used to have before dementia took over. The focalization portrays the frustration that the protagonists experience as they lose their independence. Each protagonist acts

somewhat differently, depending on the situation at hand. Through the internal focalization of these novels, the reader can empathize with the feelings of the protagonists during these experiences.

5.3 The End illustrates a Limited Perspective

Interestingly, towards the end of each narrative, the focalization of the protagonist gives a limited perspective of the world around them, as their dementia reaches its final stages. While Maud and Alice coherently convey their narrative, including dialogues with relatives, Maarten's story becomes very difficult to follow. There is a lack of dialogue, and instead he focusses on his own rather disorganized thoughts. In all three novels, the protagonists are unable to join in on conversations any longer, nor to remember them, merely perceive them. Through their focalization the reader is then able to discern that the protagonists are suffering from dementia, and that they have lost any control over their lives that they used to have. The focalization of the protagonist does not limit the reader's understanding of the protagonist's situation, because in the conversations with other characters, the reader receives the same information as the protagonist, but while the protagonist does not remember or understand these conversations, the reader does.

When Maarten is moved to a care home, his dementia has worsened to such a degree that he is unable to think coherently any longer. This influences the picture that the reader receives from the story. Maarten's move means that there are people around him who he does not recognize, because he finds himself in a completely new and different environment in comparison to where the rest of his story takes place, namely in and around his home. The reader cannot discern from his point of view who is with him or what exactly is happening. This limited perspective offers the reader insight into Maarten's situation, his experience of losing his sense of control and total loss of self-determination, because he has no control

anymore: “Boek. Woorden. Ik steek mijn handen er begerig naar uit. Ik koester en streel het boek [...] Ik geef het terug aan die bewuste mevrouw daar” (Bernlef 145). Maarten is only concerned with the book that is in front of him, he does not even think about the room he is in, namely the care home he has been transferred to. He does not even question himself on what he feels about the place he has been transferred to, nor who the person is who is holding the book. He has lost any sense of his surroundings, which is emphasized through his point of view. He is the only one who can convey what he feels about this. The reader can empathize with him, through his focalization, because one sees how his mind has disintegrated.

In *Still Alice*, as a consequence of Alice’s memory loss, her husband and children take over her decision making, and as she loses track on daily life, she cannot do anything about it. They settle on a plan of action to make the necessary decisions for her. Alice’s relatives seem to forget one crucial fact, namely that Alice is in the adjacent room when they are discussing her future. While Alice does not understand exactly what is happening, because memory loss has caused her to forget that those people in the next room are her husband and children, she does come to realize that they are talking about her:

‘She doesn’t want to live in New York,’ said the actress [Alice’s daughter Lydia].

‘You don’t know what she wants,’ said John. ‘She’s said she doesn’t want to. Go ahead and ask her. Just because she has Alzheimer’s doesn’t mean she doesn’t know what she does and doesn’t want [...] *Oh, they’re talking about me.* [...] ‘It’s like you don’t get that she’s not gone yet, like you think her time left isn’t meaningful anymore. You’re acting like a selfish child,’ said the mother [Alice’s daughter Anna].

(Genova 294)

Alice does not recognize her daughters anymore, but calls them “the actress” and “the mother” instead, referring to the time that she saw Lydia perform in a play (Genova 195), and Anna recently became a mother (Genova 288). Alice is not included in the conversation

about where she is going to live. The fact that there is a discussion about what Alice can or cannot do, and where the best place for her would be to live, shows that by this point she has lost her independence. Alice can hear the whole conversation, but is not included in the making of the decision; it is made for her. The reaction differs immensely from how one would expect one to react if one knew that people in the adjacent room were talking about oneself. It also differs from how Alice reacted previously to having agency taken away from her. It portrays the devastating consequences of Alzheimer's disease. Through this the reader empathizes with Alice, for being incapable to react in any way whatsoever. Alice's focalization communicates to the reader that as a consequence of Alzheimer's disease, she is unable to participate any longer in a conversation, even when she is the subject matter of the conversation. This evokes empathy in the reader, for he or she can discern that Alice's state of mind has deteriorated to such an extent that she has become unresponsive. If the point of view would have been given from one of Alice's relatives, the emphasis would have been on their discussion on what to do with Alice, and not on Alice's feelings. Now, through Alice's focalization, the reader perceives both what Alice thinks to herself, and what her relatives say, because Alice still hears them talk, but cannot do anything with that information.

In *Elizabeth is Missing*, through Maud's focalization the reader perceives the extent of her memory loss. From one moment to the next she has no idea what is happening around her, and so the reader can empathize with her state of mind. Maud walks away leaving the gas on, and Helen walks in to find Maud in a different room, while the gas is still on: "Mum! You've left the gas on! [Helen shouts] I've told you not to use the hob. You could have blown the whole bloody house up!" (Healey 86). Helen could think that Maud's indifferent response means that she does not care. The reader sees, through Maud's focalization, that she merely has already lost track of what is occurring in that moment. Maud's reaction is not one of shock, but instead focuses on Helen's posture: "I look at the underside of her chin. It's

very soft-looking. [...] I wonder if she will get me a cup of tea in a minute” (Healey 86). Maud’s thoughts are very disparate from what the reader might expect given the situation when one leaves the gas on. One can empathize with Maud’s deteriorated state of mind for her not comprehending the seriousness of the situation.

Furthermore, towards the end of the novel, Maud does not recognize her own daughter anymore. The reader can discern this from the narrative, because even though Maud does not realize who her daughter is, the reader follows her conversation with Helen. As Helen and Maud are at Elizabeth’s funeral, Maud observes the following:

A tall woman brings me out a slice of fruit cake. She tells me it’s fruit cake as she hands it to me [...] ‘How are you feeling?’ she asks, sitting down. Have I been ill? ‘At least you got to say goodbye,’ she says. ‘Oh. Have they gone already? I wasn’t there to catch the bouquet.’ ‘Mum, it’s a funeral. They don’t throw bouquets at funerals.’ [...] I stare past her at the bobbing flowers. (Healey 274)

Helen calls Maud “[m]um”, which elucidates to the reader that even though Maud does not recognize Helen, her own daughter, this is the person that Maud is describing in the text (Healey 274). Maud does not react in any way to the word “[m]um” (Healey 274). The reader then comprehends that Maud has lost all control over her memories and her independence. She is not concerned any longer about this, but rather is concerned with what is taking place in this specific moment. She says: “I stare past her at the bobbing flowers” (Healey 274).

Towards the end of the three novels, the protagonists hardly respond to their environment any longer, and if they do, they only have eyes for things they perceive in a particular moment. The way this is portrayed differs somewhat: through Maarten’s focalization the reader receives a disordered view, but through Maud’s and Alice’s focalization, the reader still observes a coherent narrative. The response of the protagonists

themselves is gone. In all three of Maarten's, Maud's and Alice's stories, the reader needs to work to understand the full implications of the dementia that the protagonists suffer from.

5.4 In Conclusion

In this chapter I have shown how popular novels in which the main character suffers from dementia use the narrative device of focalization to allow the reader to experience the dementia along with the protagonist. The loss of agency, disorientation, and disconnection that comes along with their inability to connect to the activities of their former life and to people that had been central for them. Focalization stimulates the reader to experience the dementia of the protagonist with him or her. Simultaneously, the reader becomes aware that the way that the protagonists experience the world is different, and that his or her mind deteriorates as a consequence of dementia. This is emphasized through the first- and limited third-person point of view that often enough does not give rise to an adequate response to a situation, and that thereby clashes with the expectations that readers have of people who are capable of leading their lives independently. The reader can empathize with the protagonist's sense of loss of independence, but also can discern that towards the end of the novels there comes a point that the protagonist is unable to be independent and have control over one's own life any longer. This is emphasized through the narration of the protagonist's thoughts. If the stories were portrayed from the point of view of a bystander, like one of the protagonist's relatives, the reader would not be confronted with the full extent of the difficulties of memory loss that the protagonist experiences. Focalization connects to my main research question on how narrative devices help bring dementia to the fore, by allowing the reader to experience the dementia with the protagonist. It makes the reader aware of, and also empathize with, the detrimental prospect of dementia that awaits the protagonists, namely that of experiencing a loss of independence and of control over one's life.

Conclusion

At the beginning of this thesis the question was posed as to how literary fiction on dementia uses narrative devices to represent the symptoms of dementia and to involve the reader in the story of the protagonist who suffers from dementia. Through a close reading of the three novels *Hersenschimmen* by Jan Bernlef, *Still Alice* by Lisa Genova, and *Elizabeth is Missing* by Emma Healey in which dementia stands central, namely in which the main protagonist suffers from dementia, I have shown how narrative devices such as paratexts, ellipses, the withholding of information, the creation of gaps, the establishment of time and temporalization, as well as focalization, ask the reader to engage with the story and to relate to the protagonist. These stories can lead to an empathetic relation towards those who suffer from dementia in society. The reader can reflect on the social dilemma of how to respond to, behave, and communicate with those in society who suffer from this disease.

Through my research, I have added a new perspective towards analyses of fictional work on dementia. Previous research has paid little attention to how narrative devices in literary representations of dementia are used to evoke a feeling of empathy in the reader. As I have shown, the narrative devices are used to represent the symptoms of the disease, because dementia, as a disease that affects the brain, lacks a proper object that could stand in as its representation. Symptoms, however, can be traced in the loss of speech and the loss of understanding how to relate adequately to one's environment. These can be observed on the exterior of the body. The selected narrative devices are specifically suited to represent the suffering of those afflicted with dementia, because they relate in particular to the symptoms of this brain disease. As a matter of fact, in the report called "Dementia: Ethical Issues" the Nuffield Council on Bioethics defines dementia as follows:

The term [dementia] is used to describe a collection of signs and symptoms such as memory problems, communication difficulties, difficulties with organising and planning one's day-to-day life, changes in mood and behaviour, and the gradual loss of control of physical functions. (4)

As I have shown in the chapters analysing the three novels *Hersenschimmen*, *Still Alice* and *Elizabeth is Missing*, these symptoms can be represented through the use of narrative devices. In chapter two I reflected upon the use of paratexts, which illustrated a discrepancy between the knowledge of the protagonist and the reader. The reader is given more information through the paratexts than the protagonist is capable of provide in the narrative. As has been central in chapter three upon the use of ellipses, the withholding of crucial information, and gaps, "memory problems [and] communication difficulties" that the protagonist experiences as a consequence of dementia are represented (Nuffield Council on Bioethics, "Dementia: Ethical Issues" 4). The reader experiences the process of dementia along with the protagonist, and becomes aware that the protagonist cannot make sense of the world any longer, in the way a healthy person can. In chapter four, when I reflected upon the use of temporalization, it was illustrated that there is a disparity between the way that the reader is aware of progressive time, and the way that the protagonist has lost his or her ability to understand time, which includes "difficulties with organising and planning one's day-to-day-life" (Nuffield Council on Bioethics, "Dementia: Ethical Issues" 4). The reader is given insight into the protagonist losing their grasp of time, and can then empathize with the sufferer of dementia for their loss. In chapter five I discussed the use of focalization, which showed that there is a deterioration of the protagonist's state of mind, which causes "changes in mood and behaviour, and the gradual loss of control of physical [and mental] functions" (Nuffield Council on Bioethics, "Dementia: Ethical Issues" 4). This becomes apparent through the lack of reaction of the protagonists as decisions are made for them, and so illustrates their loss of

agency. The reader empathizes with the protagonist, seeing from their point of view how the consequences of dementia affect them.

The narrative devices help to make the experience of dementia, and the consequences of this disease, available to the reader. The discrepancy in experience between the reader and the sufferer of dementia becomes painfully evident in the novels as the protagonists endure a change in which they completely lose their sense of self. The reader observes this change, but the protagonists are unaware of the change because of dementia. It is important to be mindful that there is a difference between the way that a sufferer of dementia experiences the world around them, and those who do not suffer from this disease. Through this understanding one can then show empathy for and to a person afflicted by dementia. A society dealing with more and more sufferers of dementia must find the best way to aid those with dementia. This starts with an awareness and an understanding that someone who suffers from dementia undergoes a loss of both neurological and physical capacities. Fiction then is a powerful way of depicting dementia, because it enables the reader to experience the symptoms of this disease along with the protagonist, creating awareness of the experience of dementia and consequentially decreased state of mind. Furthermore, fiction enables the reader to empathize with the sufferer of dementia in a playful way. The readers can, in a safe, fictional environment test out new relations towards a disease without the pressure of an immediate response that real-life would bring about.

This thesis has shown that through literature an understanding can be deepened of what a person endures in suffering from dementia, and that the repercussions of this disease on the lives of the sufferers can be explored. Conclusively, these works of literature have encapsulated the anguish of the protagonists Maarten, Alice, and Maud trapped within a time warp caused by dementia: the past and the future for them becomes distorted in the present in which they feel alienated. The severity of the disease dementia affects the protagonists of the

novels much worse than they could ever have anticipated. This feeling is aptly described in the novel *Still Alice*, as Alice's doctor tells her that she is diagnosed with Alzheimer's disease: "I was expecting something temporary; something you would get past[, but t]his isn't a temporary problem we are looking at" (Genova 204). Dementia is a disease that probably will not be curable for some time to come. It is therefore crucial that society establishes greater compassion for and solidarity with those afflicted by this disease. This thesis has shown what literature can do to add to this task. Through narrative devices, literature can help to establish a playful and safe bond for the reader. One can identify at a distance with protagonists shown to lose their sense of self and their ability to relate to their environment. Instead of delegating the disease thus to medical professionals and to nursing facilities, dementia, its conditions, and its consequences are brought closer to the reader and made relatable, too.

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