

Careful Clowns

An anthropological study of how clowns in Forglemmigej care for people with dementia.

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Resumé

Omsorgsfulde klovne – et antropologisk studie af hvordan klovnene i Forglemmigej drager omsorg for mennesker med demens.

Klovnen har mange roller og bruges i mange forskellige funktioner. De senere år er klovnefiguren især blevet kendt i hospitals- og omsorgssektoren. Klovne besøger indlagte børn på alle børneafdelinger i Danmark, og der er klovne, som besøger flygtningelejre i verdens brændpunkter. I 2014 blev foreningen Forglemmigej stiftet. Foreningen er specialiseret i at klovne for mennesker med demens og har siden 2014 haft over 80 besøg på forskellige plejehjem i Danmark.

Antallet af mennesker med demens er stigende. De sidste år er interessen for demensomsorg steget markant. Den danske regering har indført en demenshandleplan, og Danmark har fået sin første demenslandsby.

Dette speciale omhandler demens, klovne og omsorg. Specialet undersøger, hvad klovnefiguren tilføjer til omsorgen for mennesker med demens, som ikke allerede er til stede i det officielle system. Derudover diskuteres det, hvad det vil sige at være en social person, og hvordan klovnenes omsorg understøtter mennesker med demens i fortsat at være og føle sig som sociale personer.

Specialet er blevet til på baggrund af et seks måneder langt feltarbejde med klovnene i foreningen Forglemmigej. Feltarbejdet fulgte klovnene på deres besøg på forskellige plejehjem i Danmark. Det empiriske materiale består af feltnoter og interviews med klovne og plejepersonale.

I opgaven præsenteres det hvordan klovnen som liminal figur introducerer en stemning af karneval på plejehjemmene (Turner, Bahktin). Den liminale figur er en figur med en status, der placerer den imellem det at være fuldt accepteret og ikke accepteret i samfundet. Liminaliteten gør klovnene i stand til at annullere almengældende regler og normer, og den kan vende magtstrukturer på hovedet. Dette resulterer i en pause, en form for frikvarter, for både beboere med demens og plejepersonalet. I denne pause muliggøres nye handlemåder og derigennem en anderledes omsorg. Specialet undersøger de forskellige ”logikker af omsorg” (Mol), som er på spil i plejehjemssektoren. Der undersøges, hvordan klovnene drager omsorg igennem deres særlige måde at se, høre, møde, føle og huske på. Klovnenes ’omsorgslogik’ sammenlignes med plejepersonalets. Plejepersonalets omsorg bygger på det princip at både omsorgsgiver og omsorgsmodtager kan udskiftes; dette kan ses som *anonym omsorg* (Stevenson).

Specialet belyser, hvordan demens forstås, og hvordan opfattelserne af sygdommen påvirker, hvordan vi behandler og ser mennesker med demens. Derudover anskueliggøres det, at omsorg er et dobbeltsidet begreb, der relaterer sig til de fysiske og sociale behov. Specialet viser, at klovnenes omsorgslogik drager omsorg for hele den sociale person. Omsorgen får beboere på plejehjemmet til at føle sig som levende, sociale væsener. Igennem introduktionen af karnevalsstemningen vendes orden på hovedet og beboerne får magt til at udtrykke sig som personer og mulighed for at føle fællesskab med de ansatte på plejehjemmet. Klovnenes omsorg giver desuden beboerne følelsen af at høre til. Den understøtter dem ved at se, møde og huske beboere med demens som levende, sociale personer.

Klovnenes omsorgslogik har vigtig betydning for den måde, vi ser og behandler mennesker med demens på. Specialet belyser, hvad det vil sige at være en socialt, levende person. Denne forståelse af, hvad det vil sige at være et menneske og møde andre mennesker er en forståelse, som kan få indflydelse på, hvordan vi møder ikke blot mennesker med demens, men også mennesker som har andre psykiske sygdomme.

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Chapter 1 Introduction

There is a feeling of summer in the air although it is in the middle of September. The nursing home is quiet; most residents are attending a music session in the common room. A group of caretakers is drinking coffee around a table in the living room area. They laugh and talk with each other. A small woman, elegantly dressed, with white hair sits in a wheelchair a bit further down the hallway from the living room. She cries “help¹”, but none of the caretakers react to her cry. She calls out again, her voice sounds desperate. Suddenly a young woman in a blue dress with white dots, a yellow t-shirt and bare legs walks towards this woman. Her hair is gathered in a loose bun on the side of her head and two yellow curlers point out on her forehead. Her cheeks are painted red and her nose is rather big, brightly red and attached to her face with an elastic band. She gives the woman a big smile. The woman sighs with relief, sends the clown a huge smile and says: ”How lovely that you came” [hvør er det dejligt I kom]. The clown smiles at her and says: “how lovely to see you”. The old woman smiles again and says that she is happy to see the clown (Fieldnote, 21.09.2016).

The clown figure has been present throughout different cultures and historical periods. It has been part of originating myths, religious acts, political debates and entertainment. The image of the clown is well known in Denmark, but what makes a clown special and why do they work in a nursing home setting?

This thesis explores the role of clowns in the care for people with dementia and questions what the figure of the clown brings to care that is not offered through the official system of care.

I will uncover the different “logics of care” in the nursing home. I describe and analyze the specific practices of care which the clowns do, and the way the clowns think, speak and relate to elderly with dementia. I argue that the dementia clowns provide a careful care. It is a care which attunes to the person with dementia as a living, social being. This care differs from the official system of care which mainly focuses on bodies as standardized entities.

This thesis also considers what it means to be socially alive. Dementia is seen as a disease which mutilates crucial aspects of personhood, such as memory and identity. Being a person not only

¹ All translations are made by me, when deemed necessary the Danish sentence is added in brackets

involves having a body, it also entails having a social identity, being heard, seen, respected and remembered. Careful care cannot overlook this aspect.

The way the clowns care provides us with a different understanding of what it means to have dementia. I will, through the logic of clown-care, show how the clowns understand residents with dementia. This understanding differentiates from the understanding caretakers, relatives and health care professionals have. I argue that this understanding is a crucial contribution to the study of dementia and for the continued practice of care for people with dementia.

This thesis builds on Mikhail Bakhtin's notions of carnival as well as Victor Turner's development of liminality. With their liminal being and their introduction of carnival, the dementia clowns provide a break in the nursing homes. This break allows for different social interaction and shapes a different form of care. This shows us what is missing in the official system of care. To provide this break it requires that one has a sensitive, listening body (Kontos et. Al 2015, Hendriks 2012). Both Ruud Hendriks and Kontos et. al. have written about elderly clowns and their relationship with residents in nursing homes. Both scholars hint at care, however, they do not use the framework of care in their work. I build on these scholars, but I focus on the "logic of care" and contribute to anthropology by investigating care through the dementia clowns.

1.1 Dementia

There are 80.000 people who live with a dementia diagnosis in Denmark and there are approximately 8000 new cases each year. Dementia is an umbrella term for more than 200 different diseases; the most commonly known are Alzheimer's, vascular dementia and frontal lobe dementia (Waldemar & Arndal 2011: 11, 15). Dementia influences different areas of the brain and affects a person's memory, attention, language, behavior and executive functions.

Dementia stems from the Latin word *demens* which means "without mind" (McKeith & Fairbairn 2011: 8). People with dementia are seen as losing their personhood and self. Both Susan Behuniak and Janelle Taylor write about this stigmatization of people with dementia. Behuniak points to how literature about Alzheimer's invoke images of the disease as *death in slow motion* and *the death before death*, while Taylor points to how the basic narrative premise for dementia is that the body may continue to live, but the person is dead (Behuniak 2011: 71, Taylor 2010: 38). Both scholars criticize this stigma and point to how it creates fear for the disease and potentially changes the behavior towards people with dementia.

Daniel Davis discusses how personhood is perceived in regards to people with dementia. Davis uses Heidegger's concept of *Dasein*. *Dasein* is an understanding of the human being as a self-interpreting existence in the world (Davis 2004: 373). To be a person means that one must be aware of one's existence. According to Davis, dementia deprives a person of this awareness; therefore dementia will dismantle the self. While Davis urges for a dignified and respectful treatment of people with dementia, he does not see them as persons. According to him this loss of personhood must be acknowledged in order to better support the relatives. Davis further suggests that "*relatives would do better to be removed from this final process*" (Ibid: 375, 378). Davis thus, seems to stop caring for the person with dementia since, in his reading; this is no longer a person. However, one could question whether it is the disease or the stigmatization of people with dementia which undermines the personhood?

Psychologist Tom Kitwood understands dementia differently from Davis. He states that it is possible to sustain personhood despite a dementia diagnosis. He defines personhood as "*a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being*" (Kitwood 1997: 8). His definition focuses on relations with other people. Kitwood does not think that *dementia* undermines personhood; rather he states that it is the *behavior* towards them which does. He calls this behavior *malignant social psychology* and lists ignoring, disempowering, infantilization and stigma as part of this behavior (Ibid: 46, 47). By ignoring patients and treating them in depersonalizing ways, caretakers undermine the personhood and thus, worsen the disease. Kitwood makes his agenda clear; he wants a new paradigm for people with dementia, a paradigm where the person is centered. This person-centered care focuses on the person and how his personhood can be supported. Kitwood's ideas on care have been important for the development of nursing home care and person-centered care has been largely adopted.

Taylor, the daughter of a mother with dementia, writes auto-ethnographic about dementia and recognition. She states that despite the changes her mother has gone through because of her dementia illness, she is still the person Taylor has always known her to be. Taylor shows how recognition is connected with care, by referring to philosopher Avishai Margalit. Margalit divides human relations in two types. One is thick relations, relations to parents, friends, lovers etc. These relations are anchored in a shared past or a shared memory. The other type of relations, thin relations is category like, relations with others based on their category as human or woman etc. (Margalit 2002: 7). Margalit states that recognition and care is interconnected, if one does not

remember a person, one does not care for him. By remembering a person, one shows that this person is important. Taylor disagrees with Margalit that the inability to remember means that a person does not care. She shows how her mother still tries to care for her child in different ways. Taylor turns the argument around and says that a dementia diagnosis instead often means that others stop recognizing and caring about that person (Taylor 2010: 34). She, agrees with Kitwood, that the person with dementia, does not lose her personhood because of the disease, but instead the way she is treated results in a different relationship with other people in the world.

Dementia does change how a person acts and is. Memory, communication skills, cognitive abilities, and personality may be affected by the dementia disease. People will change their actions towards a person with dementia because this person changes. Neither Kitwood nor Taylor denies this. However, they point out that others tend to give up on the person because of these cognitive changes and treat them in a way which tends to be almost dehumanizing (Ibid: 32).

Steven Sabat and Rom Harré take a constructionist view on selfhood. They distinguish between self and selves. Self is the personal identity, which is expressed through the use of first-person pronoun I, while selves are the different personae, roles, a person has. Selfhood is to be understood as both personal and social. A person has a self, the personal identity, and different selves, the social identity, which he or she presents and performs socially and publicly (Sabat & Harré 1992: 445, 446). Sabat and Harré argue that through the course of a dementia disease the personal self is not lost. However, they argue that the selves may be lost, not because of the disease, but of the way others understand and treat people with dementia (Ibid: 444). People with dementia lose their memories of certain people, in Margalit's understanding this means that they stop caring for those they have forgotten. If people feel that they are no longer important to a person because his memory fails to recognize them, then they will no longer treat this person as important. Thereby the selves will be affected.

Anne Basting builds on the understanding of both social and personal identity. However, she understands them to be two ends of a continuum. To her both identities are affected culturally and through interactions with others (Basting 2003: 97). Basting disagrees that the social and personal identity can be separated, both are affected by the way others treat and interact with them. Basting focuses on the relationship between memory and identity. According to her, memory and identity are understood to be symbiotic in a Western thought. Therefore, when one loses memory, people understand this to mean they lose their identity (Ibid.). Basting points out that memory and identity

are never solely individual acts; they are confirmed and created socially (Ibid.). Basting and Taylor both point to how the loss of memory might change how others understand a person's identity and selfhood. Yet, they both criticize this connection between loss of memory and loss of personhood.

Lawrence Cohen writes about the senile body in India and the United States and shows how dementia is understood. He focuses on how people with dementia are treated and how it affects their bodies and possibilities of acting in the world. Cohen points to how dementia in the United States situates the person with dementia as a non-person. He also shows how dependency seems to be equivalent with loss of identity (Cohen 1998: 7, 50, 59). Thus, because of the label 'dementia' and because people with dementia are dependent on others, they seem to have lost both identity and the status of being persons. Therefore, their voices and actions are not taken serious. Cohen builds on Karen Lyman and points to how behavior exhibited by persons with dementia is interpreted as disease symptoms and deviant behavior, although this behavior would not be considered abnormal if exhibited by a non-demented person (Cohen 1998: 62, Lyman 1989: 600). Cohen explains that a person with dementia is denied the opportunity to give voice to their personal experiences and their meanings (Cohen 1998: 184).

Roma Chatterjee builds on Cohen's work when she examines the different discourses a man with dementia, Mr. Rijder, is embedded in, in a nursing home in the Netherlands. Chatterjee describes Mr. Rijder's journey from receiving the diagnosis of dementia, attending day-care activities and finally being institutionalized. She shows, how the family leaves him in the nursing home without saying goodbye and how although he speaks, nursing home staff and family do not listen. Chatterjee points to how voice depends not on coherence, but on the act of listening (Chatterjee 1998: 357). She suggests that people with dementia are not heard, not because they do not speak, but because people around them do not listen.

Thus, dementia is, as Cohen suggests a moral world (Cohen 1998: 38), which affects how bodies are situated and understood in time. If dementia is understood as a death in slow motion and as disappearance of personhood, then people with this diagnose will have difficulties making themselves heard in society. The way they are treated and cared for will also impact them in a specific way. However, this view of dementia is not the only view and if we begin to listen more to people with dementia and argue against Davis, as Taylor does, then this will impact the understanding of dementia and the way we care for people with dementia. I will now show how dementia is understood in Denmark and how people with dementia are cared for.

1.2 Dementia in Denmark

Dementia has been viewed as a normal result of aging and in Denmark people have called it “to go into childhood” [at gå i barndom]. The image of going into childhood makes it more likely that people with dementia are treated as children. They may be infantilized, treated in a patronizing way and spoken to as small children are spoken to. Understanding dementia as going into childhood does not urge people to take a person with dementia serious. Until the 1970s people with dementia were admitted to psychiatric wards. During the period of 1970 to 1999 the system changed, people with dementia were taken out of psychiatric wards and placed in dementia nursing homes (Timeline, Demens Centrum, See Appendix A). Today most nursing homes have special wards for dementia; yet, according to my informants 90 percent of all elders living in nursing homes have some sort of dementia diagnosis (Fieldnotes 27.10.2016, 23.11 2016). Some people with dementia are cared for in their private homes, but it is most common that they are placed in a nursing home. Recently there has been an increased interest in dementia research and care in Denmark. The government released a dementia action plan in 2016 and a special village for people with dementia opened in the fall of 2016.

1.3 Nursing homes in Denmark

There are approximately 1000 nursing homes in Denmark which are run by the municipalities. The majority of staff in the homes consists of social and health care workers and social and healthcare assistants. These educations take between two and four years. Students are trained in practical help, hygiene and cleaning. They do learn about common diseases, but they do not get specific training in dementia. Nurses do also work in the nursing homes, but they are far outnumbered by the social health care staff. The majority of caretakers are women.

In most of the nursing homes, where I conducted fieldwork, staff was both in charge of practical care-tasks and of arranging activities with residents. In one nursing home, however, they had five staff members who were activity staff. They did not take part in the personal care-tasks but arranged different activities for the elderly. Each nursing home has an assessment of how many staff members they can hire for each ward. In one nursing home, the dementia unit had nine residents and their staff assessment allowed for three caretakers in the morning, two in the evening and one during the night (Fieldnotes, 24.10.2016). The homes I visited were different in size and structure. They had between 25 and 123 residents. Each home was run by a leader or manager. Their

educational background differed from midwife to occupational therapist to nurse. The leader runs the nursing home budget.

When staff members arranged activities these consisted of cooking or baking, going for a walk or perhaps a music session. During the last couple of years different activities are offered to the nursing homes by external organizations. Nursing homes may choose to receive visits from babies, dogs, horses and clowns. Some of these activities are free while they have to pay for other activities. The managers of the nursing homes where I conducted fieldwork explained that they had different activity offers to make sure residents experienced something else than just everyday life. One manager said that if they did not offer different activities and had visits from the clowns, there would be a: *“huge gap, where people just sit and stare, you become old of just sitting and starring”* [det kæmpe tomrum hvor folk bare sidder og glør, det bliver man altså gammel af hvis man bare sidder og glør]. (Interview, B, D). The managers saw the different activity offers as entertainment and as a way of keeping residents more active. It is impossible to cure dementia, therefore, caring for people with dementia has until recently focused on the physical needs of patients. With Kitwood's introduction of person-centered care this has changed. The social aspect of being a person is also to be considered. Care thus has a dual aspect. Arranging activities and taking residents serious takes the duality of care into consideration.

I have now given a description of dementia in an anthropological context and dementia and nursing homes in Denmark. I will now account for my understanding of care and how I analyze and use this in my thesis.

1.4 Care

Care is a broad concept with many different understandings attached. According to Tatjana Thelen care has been brought into anthropological debates through feminist studies. Scholars have discussed how care has belonged in the unpaid sector, and how this has affected the status of care jobs (Thelen 2015: 501). Gillian Dalley has written about the ideology of care in 1988. Her main focus is on how women, as a gendered category, are pushed into care jobs. Dalley distinguishes between caring *for* and caring *about*. Caring *for* relates to the tasks of tending to a person's needs, while caring *about* relates to the feelings for a person (Dalley 1988: 13, 14). Dalley explains how these two concepts are deemed to form an integral and unitary part of women's nature (Ibid: 14). Women are expected to both care for and about people regardless of their personal relationship with

them. Dalley's distinction between caring for and about is a useful distinction in the nursing home settings with the clowns. I will show how the dementia clowns have a care *about* approach, whereas the nursing home staff primarily represents a care *for* approach. I further argue that it is important for the residents that they are both cared for and about.

Annemarie Mol has written about the "logic of care". While Dalley focuses on gender and works on an ideological scale, Mol is interested in how health care professionals operate. Mol investigates how we care by looking at the different care practices which health care professionals provide. She looks at care in relation with diabetes in the Netherlands. Mol sees care as an interaction which moves back and forth between patients, doctors and caregivers (Mol 2008: 21). Mol underlines that care does not consider what people want, it considers what they need (Ibid: 20, 25). A diabetes patient does not want to have diabetes and be cared for, but because of his diabetes he needs to be cared for by others and by himself. People with dementia do not want the disease, but because they have dementia, they need to be cared for. I use Mol's method to look at the care practices in caring for people with dementia. I will look at the differences between how clowns and nursing home staff practice care.

The concept of care can be defined in different ways. Mol sees care as practice, a practice which people invent and adapt to their circumstances. She wishes to disentangle care from the notions of love and tenderness (Ibid: 5). Emily Yates-Doerr builds on Mol's work and ideas about care. Yates-Doerr however, defines the concept differently. She understands care as *an effect of tenderness, empathy, compassion and respect* (Yates-Doerr 2012:139). She shows how empathy and compassion is important in the caring relationships between patients and nutritionists in Guatemala. Yates-Doerr also builds on John Borneman who states that we experience ourselves through others and that care belongs to every human being (Borneman 2011: 43).

Lisa Stevenson writes about care in relation with the Canadian State and the Inuit. Where Yates-Doerr looks at how health care professionals care in a tender way in Guatemala, Stevenson points at the difference in understandings of care between the state and the Inuit. Both scholars focus on the relationship between the one who cares and the one who is cared for. Stevenson sees care as a dual process. It is both a process of how people come to matter, and how they are then attended to (Stevenson 2012: 595). Stevenson introduces the concept of *anonymous care*. Anonymous care is a care where it does not matter who the provider or receiver of care is. The Canadian state is

indifferent to whom it cares for, the care the state provides is anonymous. Stevenson calls anonymous care the prototype of modern care (Ibid: 601).

In this thesis, I argue that the logic of clown-care builds on both caring for someone and being cared for. I will show that the clowns care, by creating situations where residents with dementia can care for them. The logic of clown-care can be understood through Yates-Doerr's definition of care as tender, empathic and compassionate. As a contrast the nursing home care resembles the care the state provides for the Inuit. In the following I explain further how I see nursing home care.

1.4.1 Nursing home care

In January, Ida, one of my clown informants contacted me and asked if I could join them for another visit in a nursing home where I had previously conducted fieldwork. The clowns were going to be in the Danish news and the broadcasting company thought it would be interesting to ask me, a master student, about the clown work. While we drove to the nursing home, Ida and the other clown Line asked me what I was going to say. When I said that I was going to talk about care, they both looked disappointed. Line told me that I could of course say what I wanted, but that she would be careful with using the word care, since this was what the nursing home staff provided. She did not seem to see her own work as a clown, as care (Fieldnote, 13.01.2017).

In the nursing homes, staff does care for the elderly. They help them with personal hygiene, they serve meals and help residents eat, they drive them to doctor's appointments and comfort them when they get restless or sad. However, this care is not adjusted to the single resident, rather this care is indifferent to who the care-receiver is. The nursing home care has, as does other medical settings, a standardized approach to care. In biomedicine, the human body is conceived of as standardized. This affects how bodies are treated. When bodies are seen as biologically equivalent, it is possible to standardize treatment and care (Lock & Nguyen 2010: 43-44). Nursing homes are both homes for people who cannot manage to live alone and a place for bodies affected by disease and age. Bodies of residents are seen as a standard thing and therefore cared for in a standardized way. Nursing home care is an anonymous care. This does not mean that the elderly do not receive food, medicine and help with personal hygiene. It just means that there is a lack of recognition and responsibility towards the specific other the caretakers are caring for. The caretakers care *for* and not *about* the elderly.

It is not true that all caretakers provided anonymous care, I heard them talk affectively about specific residents, and I saw them hug and caress residents. However, this care was highly affected

by time pressure and the economical situation in nursing homes. Budgets were low and there were often shortage of staff. A premise for care in nursing homes is, as Chatterjee shows, that the care is routinized and relation-free. Chatterjee points out that both caregivers and patients are roles which can be exchanged (Chatterjee 1998: 371, 376). This is also the case in Danish nursing homes. The care which is performed in nursing homes is interchangeable so that the care is dependent on neither who receives nor who performs the care. Nursing home care is an ongoing care. This care continues until the person with dementia dies.

A final comment on nursing home care is that in Denmark it is not a job with high status. One informant, a leader of a nursing home told me that the nursing home sector is not a privileged sector to work in. She felt it was a general impression that: “*if you cannot become anything else you can always work in a nursing home*” [*kan man ikke blive andet så kan man komme til at arbejde på et plejehjem*] (Interview, B). This statement was something several informants agreed to or pointed towards.

I concur with Stevenson that “who one is matters intensely” (Stevenson 2014: 32). Care cannot be given in a standardized way in which individual particularities and individual needs are erased. It is not that nursing home care is bad, but through professionalization, through sticking to the orderliness of care-giving in a nursing home context, people tend to lose sight of the human being which is being cared for. Thus, the dual aspect of care is lost.

This anonymous care is different from the way the clowns relate with the elderly. While my clown informants did not think of their actions as care, they described their actions with affective terms. Line said she wanted to give the elderly love (Interview, L). The other clowns mentioned respect and presence [*nærvær*] as important things they wanted to give the elderly. Yates-Doerr’s definition of care considers the actions of the clowns as care, and therefore I have chosen to call the clown practices care although my informants were reluctant to use this term for their own actions. While I see the nursing home staff care as anonymous care, I see the clown-care as affectionate and relational. I will now describe how the clowns work in the nursing homes and the relationship between clowns and caretakers.

1.5 Clowns and nursing homes

Visits from dementia clowns are not a common thing for nursing homes in Denmark. The clown organization Forglemmigej, with whom I did my fieldwork, has had 83 visits from 2014 until

March 2017. These visits have taken place in 31 different facilities all over Denmark. When a nursing home wishes to hire the clowns they contact the chairman of the organization, who is one of the clowns. She makes arrangements with them regarding specific time, wishes and payment. The nursing homes have to pay for the visits. Some facilities pay with money from their own budget; others use money they have inherited, and some homes seek specific funding for the clowns. Sometimes the clowns are paid for by either relatives or a special interest group. In these cases the nursing home has not made the decision to receive visits from the clowns. When the clowning takes place depends on the wishes from the nursing home, and it also depends on the schedules of the clowns. While I conducted my fieldwork the chairman had to postpone clown visits to a couple of homes for several months because the clowns did not have the time to fulfill the request for more visits.

Some nursing homes choose to arrange for several visits from the clowns. For instance one home has had 13 visits from the dementia clowns since September 2016. These visits have taken place almost every second week. Another home has had 12 visits since 2014. Half of the visited nursing homes have only received one clown visit in total. This could be because they did not find it interesting, however, since the nursing homes have to pay for the clown visits there is also a financial aspect of why they have only received one clown visit. Whether a nursing home only receives one clown visit or has a course of clown visits, it must be noted that clown visits are temporary. Even when nursing homes arrange for a course of visits, they cannot plan these visits for more than half a year onwards because of the clowns' busy schedule and the financial situation. The clown-care is thus, a temporary care.

Visits consist of two clowns who come to the nursing home for two hours. They prefer to talk with staff before they start clowning and to evaluate the visit afterwards. The clowns prefer to clown in the residents private rooms and like to interact with the residents one by one. They try to make clear that they are not there to entertain, but there to *meet* the resident. I will analyze what this means in chapter four. Their interactions are not preplanned, but improvised. The clowns prefer to have a staff member who follows them around. They think the caretaker makes the residents feel more secure.

I conducted fieldwork with the clowns in eight different facilities during the fall. Two of these received several clown visits during the fall, while the six other homes only had one visit during the fall. While two of these nursing homes arranged for a new clown visit in the spring, the four

remaining have only received one visit and have so far not arranged for more visits. In six of the nursing homes it was the leader of the nursing home who chose to hire the clowns. In one home it was an external interest group, and in another it was the activity staff who decided to hire the clowns.

Because the nursing homes hire the clowns, it could be argued that the clowns are in fact part of the official system of care. However, the clowns only visit a very small number of the total number of nursing homes in Denmark. I see dementia clowns as a care-offer which is not admitted completely into the official system yet. When I show which care the clowns contribute with I acknowledge that some facilities have implemented this, although sparse and temporary, into the official system of care. Clowns are thus, a supplement to the official system of care.

1.6 Relationship between caretakers and clowns

During my fieldwork I discovered the clowns were met by two different attitudes by staff members. In most nursing homes staff loved the clowns. They looked forward to the visits and told the clowns that they could see that their residents benefitted from the visits. In one nursing home staff was very moved by especially one meeting with a male resident and the clowns. They later informed the clowns that this resident was a troublemaker and it had been great to see him smile and enjoy the clowns. In another home a caretaker told me that the clowns had a way of creating joy for a resident whom she, as a health care staff, could no longer reach because of the dementia (Fieldnote, 01.10.2016, 10.10.2016).

In other nursing homes the clowns were met by staff that either did not want to participate in or seemed indifferent to the clowns. I encountered different types of indifferent or negative attitude from staff towards the clowns. In a couple of facilities staff seemed surprised to have a visit from the clowns. It seemed that the communication between the leader who hired the clowns and the staff had not been clear. Either staff did not know that the clowns were coming or they were not prepared for how the clowns worked.

In other homes staff hesitated to follow the clowns around or they simply took off while the clowns were visiting residents. During November and December the clowns made six coherent visits at one nursing home for six weeks straight, one visit each week. Here staff did not have the time to work with the clowns and rushed around while the clowns visited. At two different nursing homes I conducted fieldwork in, staff simply disappeared during the clowning and the clowns had to wait and spend time searching for them.

I experienced that the reluctance to take part in the clowning either was because staff felt they could take a break while the residents were entertained by the clowns, or they felt they would do more good working on another task than following the clowns around. They sometimes chose to pay more attention to residents who the clowns did not visit or on practical tasks, such as cleaning or laundry.

Sometimes staff seemed annoyed by the clown. In one particular home most of the caretakers did not seem to appreciate the clowns. The nursing home was divided in two and the clowns were supposed to make visits in both parts. The first caretaker, who showed them around, informed the clowns that they were only going to visit three residents, since the remaining would be too upset by activities. The clowns visited the three residents and then engaged in conversation with a man they met in the hallway. While they talked, the caretaker looked very annoyed (Fieldnote, 07.12.2016).

Later that day the clowns and one male resident Bjarke started a choir. The choir consisted of health care staff, clowns, four residents, and me the anthropologist. After singing, Bjarke started to thank all choir-members for this experience. He went around to everyone while he hugged them or kissed their hands. He came over to me and he was very excited and happy. He held my hand and told me that I should: "*look at the sun, it was up because of us*" [*se solen, det er på grund af os*]. He then returned to the clowns. While he engaged in playing yet another song with the clowns, two staff members discussed what they should do with him. One caretaker seemed very unhappy about his exaltation and annoyed that the clowns had met him (Fieldnote, 07.12.2016).

While the clowns and I felt that the visit with Bjarke had been a great success, it seemed as if some staff members felt that this visit would cause problems for them the rest of the day. I think this annoyed, reluctant behavior towards the clowns stems from staff members who feel they get more work. Residents who are excited or exalted may wander around or may be more talkative, which causes staff to spend extra time taking care of or keeping an eye on them. The clowns were aware that staff sometimes felt that the clowns left them with troublesome residents. Ida explained to me that they tried creating a frame with a clear beginning and end of their visits to keep residents calm. She also told staff that they did not want their visits to cause extra work for them (Fieldnotes, August 2016).

Nursing home staff thus, reacted differently to the clowns. Most staff however, expressed admiration for the clowns. During my fieldwork there has been an increased interest in and requests

for clown visits. While the clowns only had 4 jobs in the spring 2016, in the spring 2017 they have had more than 28 clown visits scheduled. It is not only visits from the clowns which see an increased interest. Forglemmigej also offers courses where they teach clown methods to nursing home staff. These courses do not teach staff to be clowns, but introduces them to different modes of communication and to use humor and music with the residents. During the last couple of months Forglemmigej has received several requests for these courses. There is thus an acknowledgement from nursing home leaders and staff that the clowns bring something different and valuable to residents with dementia.

1.7 Methodology

The ethnographic material for this thesis is based on my fieldwork with the dementia clown organization, Forglemmigej, which I conducted during the period from August 2016 until January 2017. I observed 14 clown visits, 13 in the fall and one in January 2017. Fieldwork is a messy practice and my plans changed until the last minute. When I began my fieldwork I was not sure how many clown visits the Danish group would have. I therefore made arrangements to follow Klokkeklovnene, a Norwegian clown troupe, to get enough data. At one point I was prepared to follow both groups. However, after two weeks in Norway I decided that it would be better to focus my attention on one group, and chose to focus on Forglemmigej.

Forglemmigej was founded in 2014, although most of the clowns had visited nursing homes for several years before that. Forglemmigej had six clowns while I conducted fieldwork. Besides working in the nursing homes in pairs, the group tries to attend courses together to improve skills and to create a better work atmosphere between them. The clowns meet approximately once a month, where they have group supervision and discuss the work progress and where the organization is heading.

Throughout visits I stood in the corner and observed the clowns. I did not take notes during the visits, since I did not want to disturb or interrupt. During some visits I was barely noticed, through others I was included in the interaction with the elderly, singing in a choir, answering questions or holding hands with a resident (See Houmøller 2016). Besides observing visits I took part in the groups meetings and I interviewed the six clowns. I also interviewed two clown educators who gave me an understanding of what is important for being a good clown and how to become a clown.

I wanted to understand the nursing home context better and to see what everyday life in a nursing home was like without the clowns. Therefore, I did participant observation twice in a nursing home without the clowns. I followed one staff member during her work in the dementia unit. I had lunch and coffee with residents and staff. I interviewed staff members from and leaders of different nursing homes. I also spoke with relatives of people with dementia.

To keep the anonymity of my informants, nursing home staff, residents with dementia and clowns, I have chosen not to mention which nursing homes the particular visits take place in. I have changed the name of all informants; I have also given their clown figure new names. Furthermore, in the cases where I refer to a meeting with specific residents, I have chosen to assign them with a different name each time I refer to a visit with them. Interviews are referred to with a capital letter.

1.8 The different chapters

In this chapter I have provided a brief description of my contribution to anthropology, my theoretical approach and my methods during fieldwork. I now present a brief overview of the different chapters in my thesis.

In chapter 2, I unpack the clown figure. I give a brief overview of clowns working in care settings. I will explain what it requires to be a dementia clown and present the different ways of becoming a clown working in care in Denmark.

In chapter 3, I introduce the concept of carnivalistic mode and show how the clowns introduce this mode and thereby overturn social rules and norms. I explain how this transgressing of borders and overturning of power is part of the clown-care logic.

In Chapter 4, I analyze the clown-care logic by looking at how the clowns meet the elderly. I focus on how they see, hear, meet, feel and remember with residents. I will contrast the clown-care logic with the nursing home staff-care logic.

In Chapter 5, I show how clowns provide us with a different understanding of people with dementia. I argue that this understanding can teach us about care. Clowns in care are becoming more popular worldwide. I discuss why their popularity has increased and what impact this has on care.

Chapter 6 is my conclusion.

Chapter 2 The clown figure

In this chapter I unpack the clown figure. I present the history of care clowns, when did they enter into care settings and why? I will describe how one becomes a care clown in Denmark. Furthermore, I show how my informants understand the clown figure. Finally, there will be a description of some of the clowns from my fieldwork.

2.1 The history of care clowns

The clown figure is a multipurpose figure. In the circus it serves an entertaining function, Pueblo clowns in the Zuni tribe participate in rituals and dances, and according to William Willeford some clowns share magical and religious functions with priests and medicine men (Parson & Beals 1934: 494, Willeford 1986 [1969]: 4). Bernie Warren and Peter Spitzer, who use clown techniques in their work as medical doctors, state that clowns have been part of healing rituals for centuries. The two scholars explain that the famous clown trio, the Fratellini brothers were some of the first clowns to visit hospitals back in the late 19th century (Warren & Spitzer 2014: 7). Since then clowns have visited hospitals, some places they put up a show for the hospitalized children, but more often, clowns work in hospitals and go on rounds, where they visit patients. They work together with medical staff, supplementing nurses and doctors. How much they are involved depends on the hospital.

Which clown group or country started the hospital clowning as it is today appears not yet known. Patch Adams, a medical professional is stated to be the first hospital clown. While he trained to be a medical doctor in the 1970s he discovered that fun was as important as love and life. He started dressing up and clowning with patients in different hospital wards (Adams 1993: 9). In 1986 Big Apple Circus clown care was established in New York (nicklauschildrens.org). Through the following years hospital clown groups were founded in England, Holland and Israel, to mention a few countries.

The word clown originated from the English word clod and used to refer to a country fool or bumpkin. The red nose, which now symbolizes a clown, referred to them being drunk (de Graan 2012: 42, Willeford 1986 [1969]: 12). The hospital clown groups all wear red noses; yet, the groups dress up differently. In England and New York the groups call themselves clown- or giggle doctors. This can be seen as an attempt to equal their importance for the hospital setting with the doctor's

role. The clowns typically wear white doctor's coats with different decorations on them. In Israel the hospital clown education is a university degree and they call themselves Dream Doctors. In Denmark they call themselves Danish Hospital Clowns [Danske Hospitals Klovne].² DHK hardly use any makeup. The organization was founded in 2003 when Birgit Bang Mogensen, who was trained by Patch Adams, started a project in a children's ward in Aarhus. The individual clowns receive payment from the organization and not from the hospital budgets.

2.2 Why care clowns

There are several reasons why hospital clowns are accepted in the hospital setting. Different research show that humor has positive effects on health. The clowns function as funny or entertaining justifies their visits. The clowns furthermore provide support to the hospitalized children and their families. Atay Citron, who designed the first hospital clown program in Israel, and Amnon Raviv, a medical clown, both point out how patients lose their identity and independence when they are hospitalized. This happens when they are dressed in hospital gowns and put through treatments and examinations by hospital staff (Raviv 2014b: 601, Citron 2011: 253). The clowns help the patients by empowering them and by being their ally. Clowns mock order and transgress regulations and borders. By mocking hospital order and rules, they give power to patients. Although there is a focus on patient autonomy and choice, as Mol points out, an ill person is not capable of making real choices (Mol 2008: 7). It is very difficult as a patient to reject being examined by doctors and nurses. The clowns offer their company to patients. Patients are not forced to meet the clowns; it is an offer (Interview, C). Both Mogensen and Citron points out that the clowns relate to the healthy part of the child. They do not talk to the disease but to the playful child inside (Gladkova & Mogensen 2003: 14, Citron 2011: 259).

2.3 Elderly clowns

While clowns have visited hospitalized children since the late 1980s, clowning for adults is a growing, but relatively new concept. Clowns are part of daily life in several adult's wards at hospitals, such as oncology, dialysis, and fertility (Raviv 2014: 226). Besides visiting adults at hospitals, clowns have begun to visit nursing homes. Most clowns who work with elderly call themselves elderly clowns. There are elderly clowns in Israel, Scotland, Norway, Denmark and

² Hereafter DHK

several other countries (Raviv 2014, Symnons 2012). In some countries, for instance Scotland, hospital clowns and elderly clowns belong to the same organization (Peacock 2009: 145). In other countries, such as Norway, the groups are separated in two, although some clowns work in both organizations (Fieldnote, 12.09.2016). In Denmark there is no exact number of how many clowns work with elderly. Clowns in DHK have visited nursing homes since the organization started in 2003. This was however, done in secrecy and most visits were unpaid. Forglemmigej is the only organization who only specializes in clowning with people with dementia, however there are other clowns who visit nursing homes alone or in pairs³. I will now describe how one becomes a care clown.

2.4 Becoming a care clown

How does one become a clown? According to Caroline Dream, who is a professional clown, everybody can become clowns, although not everyone can become professional clowns (Dream 2014: 17). The clowns in Forglemmigej have had different educational backgrounds and ways of becoming a clown. In this section I first describe how one becomes a hospital clown, since four of the clowns in Forglemmigej also work as hospital clowns. Then I describe how Forglemmigej accepts new clowns. There are two specific abilities needed to become a care clown. A care clown must be empathetic and good at relating with other people, and he must have some artistic skills to build on.

2.4.1 Hospital clown education

The process of becoming a hospital clown in Denmark takes one and a half years and costs 25,000 DKK. The education admits new students once a year. Before being accepted into the program, potential students must pass two auditions. Applicants submit a short video where they present themselves. Based on these videos the educational board decides who they invite to the first audition. The educational board consists of the artistic leader, two hospital clowns and a psychotherapist.

Applicants have various backgrounds such as nurses, artists, actors, pedagogues, and teachers. The board encourages people with artistic backgrounds to apply. However, they stress that a potential clown must be empathetic. The artistic leader told me: *“We want to feel that person, we are looking for people who are funny, who move us and who are calm with themselves”* [vi vil gerne kunne

³ One pair I will mention here is the clown duo Tut & Tut who I also met during my fieldwork, see tutogtut.dk

mærke den person, vi leder efter folk som er sjove, som rammer os som gør noget som er rolige med sig selv] (Interview, C). Feeling a person is a way of ensuring that a person dares to be himself and work with himself. The artistic leader told me that an optimal clown student is one who can do a little bit of everything. One of the hospital clowns on the board said that they look for unique personalities but that the most important thing is that applicants are able to work with their feelings and imagination (Interview, I). They want potential clowns to be robust, because the job is quite demanding. The board invites everybody, who they feel have something interesting to contribute with, to the first audition.

For the first audition applicants present a short clown act followed by an interview with the board. Then the board chooses who continues. Before the second audition applicants have to observe the work of an established hospital clown. This is required so students understand what their job will consist of, if they are admitted to the education. For the second audition applicants have to speak of their observations and experiences at the hospital. Then they are put through several days of different workshops. After the second audition the board decides who they admit on the education. In 2015 DHK had 100 applicants, 42 were invited for the first audition, 17 continued to the second audition and 8 were allowed to start on the educational program (Interview, C).

The education consists of different workshops and internships. Each student has two clown mentors, who they work with, in the hospitals. The workshops focus on the artistic aspect of being a clown and on working in the hospital settings. Students are taught by clown teachers from all over the world, nurses and psychotherapists. The education is founded in the individual students since they come from different backgrounds and therefore have different needs (Ibid.). Students who complete the education are secured a job in hospitals all over Denmark.

2.4.2 Becoming a clown in Forglemmigej

Forglemmigej has only existed for two and a half years, and most of the clowns, who appear in my fieldwork, founded the organization together. However, one of my informants was accepted into the group in the spring 2016 and two others are at the moment trying to become clowns in the organization. They will most likely be accepted into the group during spring 2017. To become a dementia clown in Forglemmigej a person must be invited by the clown group. Then he must observe three clown visits before he tries out being a dementia clown. The potential clown participates in five visits where he clowns with one, and is observed by another of the established clowns. Then the clown group decides if he can become a member. Among the six clowns I did

fieldwork with, two were actors, one was a circus clown, one a nurse and two were pedagogues before starting in Forglemmigej. One was a self-taught care clown, one was educated by the others in Forglemmigej and the other four were educated hospital clowns (Fieldnote, September 2016).

2.5. A good dementia clown

How does one become a skilled clown? To understand this it is necessary to understand what a dementia clown does. What characteristics belong to these clowns? The clowns in Forglemmigej all mentioned different aspects of the clown figure as the most important. I have chosen to present four aspects or abilities here. They are: a certain way of communicating, attention, awaiting and to show a connection between clown and human being. I will go further into detail with how the clowns work in chapter four.

2.5.1. Communication

“A clown is a way of communicating” Ida told me during our first meeting (Interview, I). She said that a clown communicates on several levels and by a certain presence or attention to other people. Communicating with a person with dementia is difficult since their cognitive abilities are damaged by the disease. Several of the clowns mentioned that when a person with dementia says yes this does not necessarily mean yes, it could also be a no (Interview, M & F). The clown therefore has to adapt the communication to work with a yes that could be a no. During my fieldwork I noticed that communication with residents could be based on dialogue, upon gentle touching and eye contact or it could be based on dance movements. A clown often has to communicate on different levels at the same time. Working in a hospital a clown has to communicate in one way with a child, another with the nurses and perhaps a third way with a doctor or the child’s parents. In the nursing homes a good clown is able to communicate with several elderly with different stages of dementia. Clown communication does not necessarily follow general social rules for communication.

2.5.2 Attention

To ensure a good communication a clown must pay attention to subtle cues from their audience and from the surroundings. Cues could come from speech, but often it could also be subtle movements, a flicker of the eye or a twitch in the face. The clowns also pay attention to their surroundings. A photograph on the wall might be a subject of interest. It might create an opportunity for stories or be used in a game. The different cues which the clowns picked up were used in order to build up the interaction; they were also used as ways of ensuring accept from the elderly. By paying close attention, the clowns found songs, games or stories which made the elderly laugh, cry or begin to

speak or sing along. The clowns focused on listening. One clown said that: a clown has to listen both to actual sounds, but also to energies and impulses (Interview, S). Listening or paying attention created a flow in the interactions and ensured that something took place. This careful listening also helped the clowns sense when their behavior was too loud, energetic or wild and when this kind of behavior was acceptable.

2.5.3 Awaiting

Awaiting means that the clown must slow down. This does not mean that everything moves in slow motion, but it means that the clowns must take pauses to allow residents to understand their actions. One clown said that she experienced that if she slapped her clown partner in the buttocks it could take the resident a minute to process before she would find it funny (Interview, I). Time thus, influenced their work. Sometimes the clowns would continue with an action for a long time without getting any reaction at first to see if a reaction would occur. They would also create pauses to let the elderly process what was happening. The clowns all mentioned this aspect as an obstacle or something to be aware of. The four hospital clowns saw this as the main difference between clowning with elderly and with children.

2.5.4 Being a person

A good clown is not just a character; it is part of the person who is the clown. One clown said that she had to base her clown on her inner clown; otherwise it would not be authentic (Interview, L). Another clown said he used himself and his personality: "*I use myself in my work and my whole understanding of things and my whole upbringing*" [*Jeg bruger mig selv i mit arbejde og hele min egen forståelse af ting og hele min opvækst*] (Interview, K). The artistic leader from DHK mentioned this as the most important demand they had for potential clowns in DHK (Interview, C).

2.6 Clowns in Forglemmigej

In this part I present three of the clowns in Forglemmigej. I do this to show how my informants differ from other clowns, and to make clear how they envision the clown figure. I describe how they look, their thoughts about clowns and clowning and how they see their job as clowns caring for elderly with dementia.

2.6.1 Frk. Æble

Frk. Æble, Sofia, is the youngest female clown in the group. She used a diploma education to become a clown and clowned on her own in different nursing homes for one and a half years before

founding Forglemmigej with the others. Frk. Æble wears a rather big, dull red nose which is attached with elastic band. She dresses in colorful stockings and old fashioned dresses. Her hair is gathered in a bun on top of her head or to one side and she uses scarves and curlers to decorate her hair. Sofia explained that it is not possible to talk in general about the clown figure since the figure differs depending on which function it serves (Interview, S). For her, there is thus a difference between the circus clown and the dementia clown. Frk. Æble was especially popular with the elderly men. She told me that she wished the nursing home staff would appreciate her professional competences as a clown more. She felt an urge to defy staff when they suggested that a specific resident was too fragile to meet the clowns (Ibid.). It was important for her that residents had a feeling of presence and being seen by her as a clown.

2.6.2 Fru Ballon

Fru Ballon, Maj, had worked in circuses before becoming a hospital clown. She had been a hospital clown for three years and told me that she felt that it had always been a part of her adult life. Fru Ballon mostly wore a light blue dress with small flowers. She wore green goggles on top of her hair together with hats, sponges and huge flowers. Her nose was rather small and attached with tape. Fru Ballon was very active and energetic. During visits she jumped on furniture and used washing brushes as baseball bats. Maj told me that she did not think there was a single thing her clown, Fru Ballon could do, which she, Maj would or could not do (Interview, M). She told me that her intention or life philosophy with clowning was that everybody is allowed to be here. She wanted to ensure that the elderly felt that they had the right to be humans and be accepted as they were (Ibid.). Maj admired the nursing home staff that cared in a loving way for residents with dementia.

2.6.3 Hr. Bønne

Hr. Bønne, Frank, had taken the hospital clown course some years ago, but he had never worked as a hospital clown. He was the newest member of Forglemmigej. His clown surprised me because it was more of a character compared to the other clowns. He used a standard uniform each time. Khaki colored shorts and shirt, and a large troupe helmet. He told me that he wanted a clown figure everyone would recognize. He always brought binoculars along as part of his costume. He used a nose with elastic band. Frank told me that he was not happy with noses. He thought it made him look silly. But he underlined that the nose made things easier because it clarified the purpose of his presence (Interview, F). He was calm during visits. The women adored him and I observed women blow him kisses, flirt and titter towards him. He told me, he found the elderly with dementia inspiring. Clowning with elderly was very meaningful to him, it gave him a purpose. He also said

that he felt that sometimes the elderly could see straight through him. He told me he experienced soul contact, between him and the elderly.

In this chapter I have unfolded the clown figure. I have shown that in order to be a care clown, a person must have artistic skills and be empathetic. I have provided four aspects which makes a clown a skilled dementia clown. In the next chapter I look at the clown as a liminal figure and a rule breaker.

Chapter 3 liminal care

Alma is sitting in the living room. She has just informed the clowns that she recently turned eighty years old. The two clowns, Fru Ballon and Fru Fryd have given her a balloon, which she and the clowns have played with. Suddenly the clowns are exhausted. Fru Fryd sits down in a chair, while Fru Ballon throws herself in the couch, places her feet on the table and smiles. Fru Fryd seems embarrassed by this and gestures to Fru Ballon. Fru Ballon looks at her, then she lies down in the couch and places her feet above her head, resting them against the wall. Suddenly Alma looks at Fru Ballon with a big smile and asks: “do you want to play”. Fru Ballon nods and smiles and Alma picks up a doll, which is lying on the couch, and hands it to her (Fieldnote, 28.09.2016).

So far I have stated that the clown is a supplement to nursing home care and that the figure serves multipurpose functions. The clown serves its own logic and violates cultural rules. In this chapter I look at how this liminal figure benefits residents with dementia. I begin by describing the position or role that residents with dementia occupy in the nursing homes. I then introduce the concept of carnival mode and show how clowns introduce carnival in the facilities. I use this to point out how the weird behavior of clowns, their breaking of rules and norms is part of the logic of clown-care.

3.1 Life in a nursing home

Life in a nursing home is a life built on routine. Residents are woken in the morning and caretakers help them get out of bed, shower, dress and eat breakfast. Then residents are seated in their private rooms or in the common living room until lunch. After lunch most residents take a nap. Then they wait for dinner and then they go to bed and sleep until the routine starts over. The routine is occasionally broken by different activities and visits.

Citron states that the hospitalization of patients is a liminoid position. Through hospitalization patients are stripped of their identity and moved from healthy to sick and eventually back to healthy. Patients are placed with people they do not necessarily know and might not have much in common with in the outside world. And finally, patients must surrender their bodies to medical staff and go through painful procedures and expose their bodies to strangers (Citron 2011: 253-254).

Residents in a nursing home share the position Citron describes. They are stripped of their identity when they are moved to a nursing home. Often patients with dementia have not chosen this move

themselves. This decision is taken by family members, doctors and the municipality. Residents will share space and meals with others, whom they have not chosen themselves. They are separated from their home and perhaps from a spouse they have lived with for many years.

Barbara Hornum builds on Arnold Van Gennep's three phases of rites de passage. These three phases are separation, margin or threshold and aggregation or incorporation (van Gennep 1960: 11). Hornum states that when residents change accommodation and move into a nursing home, they enter the phase of separation. They are separated from their previous social position and cultural condition (Hornum 1995: 152). Residents have to be reintegrated into a new role and position in the nursing home.

For many people with dementia the move from private home to nursing home results in confusion. They may not know where they are or understand why. Although residents have the possibility to bring furniture and personal belongings into the nursing home, these things will be removed as the resident enters later stages of dementia and needs health care equipment such as wheelchairs and ceiling lifts instead.

A nursing home is also a place with surveillance. Neil Henderson points out that due to the medicalization of long term care, nursing homes are places with high surveillance, task-oriented behavior and routines. This overlooks the psycho-social aspect of living in a nursing home and this devalues residents' humanity (Henderson, N. 1995: 38-39).

A nursing home is both the home for residents, and the work-space for caretakers. This results in a juggling between resident's privacy and consideration for the caretaker's job. Caretakers move in and out of resident's private space to do their job, which is to care for the elderly. During my fieldwork I experienced that doors into residents' rooms were rarely closed. Some places staff explained that this was a wish from the resident himself, other places I was told that the open door made it easier to check up on residents. Caretakers rarely knocked on doors when they entered in to check on or help a resident.

People with dementia do not necessarily understand that they are ill. They may fail to accept or remember that they are ill. This adds to their confusion. Residents are also affected by the disease in their communication skills. Steven Post points out that there is a tendency to assume that those who cannot communicate are of lesser value (Post 2006: 230). Residents may experience a loss of being heard, understood and they may experience being devalued. In order to keep residents safe and

perhaps also to keep them easier to handle for caretakers, behavior which puts the resident at risk, such as walking or situations which might over-stimulate the resident is discouraged. It lessens potential risks; however, it also keeps the resident rather passive. Opportunities to express themselves are limited.

Being a resident in a nursing home is a vulnerable, confusing position. It is a state with loss of memory, relationships and privacy. Residents are helpless and without control of their life-situation. Decisions concerning their life is often controlled or taken on their behalf by other people. They have a low status and a marginal position. Their everyday life is routine and they are made passive.

3.2 Carnival

Clowns are a different presence in the nursing home than daily caretakers. This is partly because they are only present in short periods of time, and then because they are clowns. Clowns are liminal beings. This means that they are in a position in between; they belong and yet do not belong in society as such. Liminality also involves a transition from one state to another (Turner 1967: 95). Clowns have traditionally been the figure of the carnival. During carnival the clown introduced triumphant laughter and played an important part in carnival rituals. I will use Bakhtin's concept of carnivalistic mode. I will define what carnivalistic means and show how the clowns introduce a this mode when they visit nursing homes.

Carnival is a period of triumphant laughter, joy, costumes and festivities. Originally they were religious festivals before Lent. Bakhtin states that carnival was a temporary liberation from the societal norms, truths and established orders. Hierarchical ranks, privileges and norms were suspended (Bakhtin 1984 [1965]: 7, 10). During carnival life was only subject to its own laws.

Bakhtin defines carnival laughter, the laughter during carnivals as a festive, yet ambivalent laughter (Ibid: 11-12, 20). The carnival laughter is laughed by all people, high as low status in society. It is a laughter which mocks order and rank, a triumphant laughter where people celebrate that power is overturned. During carnival this laughter was often directed at the king.

Carnival is a feast of becoming, change and renewal (Ibid: 10). It can thus be seen as a state of liminality, a transition from one stage to another. Carnivalistic mode is a period where parts of carnival are reintroduced. It is a period where laughter rules and power and social norms are

overturned. Carnivalistic mode is introduced during markets or during the last day of school in Denmark, where children in ninth grade dress up and make fun of their teachers.

Care clowns introduce the carnivalistic mode when they visit nursing homes or hospitals. Raviv shows how the medical clowns introduce the carnival laughter in the hospital. The laughter is shared by both patients, doctors, nurses and the clown. Patients laugh at the doctors, thereby they are empowered. The clown connects the serious world of disease and death with the carnival world of liberation and joy (Raviv 2014b: 599-602). The clowns introduce this carnivalistic mode and spirit with their colorful dresses and rebellious attitude. During their stay, the area is transformed to a place where everything can happen. I will now show how the clowns mark the carnivalistic period during their visit. Then I turn to what the effects of this carnivalistic mode have on the logic of clown-care.

3.3 Framework of carnival mode

Gregory Bateson made his theory about play when he observed two dogs fighting. He noticed that the dogs were not angry but playing. Bateson wondered how they knew the difference between a playful and an angry bite. Bateson explains that when the message *this is play* is invoked, it signals that things, actions and words spoken in this frame are not to be taken serious; they are to be understood as play (Bateson 1972: 184). When this message is clearly expressed, the receiver of the message can discriminate mood signs and spoken words as play. Bateson notes that although *this is play* is expressed, the feelings and expressions which are signaled in this framework are related with the real world (Ibid: 189,191). What is said through the meta-message should be interpreted differently from things said outside of the meta-message.

The clowns seem to mark *this is play* with their attributes. Although they do not dress in wild costumes, their old fashioned clothes are still different from staff uniforms. The clowns further make their costumes stick out by supplementing it with strange accessories. One clown used a wellington boot as a handbag, another wore a hat which crowed and a third used a sponge as a hat (Fieldnotes, August & September 2016). The colorful clothes and odd composition of clothing signals something out of the ordinary⁴. Often just one look at the clowns made residents crack up

⁴ Clowns are not the only figures who mark their differences with costumes. The white lab coat doctors use also signal difference. Where the colorful costume of clowns allows them to act out of order, the white lab coat signals power and status for the doctors

with laughter. The clowns further present the meta-message with their red nose. The nose signals to others that here comes a clown, and helps the clown act like a clown. According to Dream the nose helps a clown shake of normality (Dream 2014: 17). Some of the clowns did not particularly like wearing the nose, but they agreed that the nose helped mark their differentiation from others (Interview, F & L).

The clown's further structure their visits so there is a clear framework. When they arrive at the nursing homes they are not yet dressed. After greeting staff, they get dressed. When they have changed their outfit, they act and present themselves as clowns. After visits, when they evaluate the day with a staff member they take their nose off. This is a way of signaling the beginning and end of *this is play*. The clowns also make a clear frame around each individual meeting with an elderly. They greet the resident and thereby establish contact. Then they are together with the resident and when they leave, after ten seconds or five minutes, they say goodbye to the resident. This is both a way of structuring their visit and of marking *this is play*, so that from when they enter the room and until they say goodbye things might be out of the ordinary. Ida also told me that this clear frame was a way of making sure residents were not over-stimulated after the visit. This is thus also a way of ensuring their entrance into the nursing home again.

Moria Smith writes about humor and boundaries. She points out, that things, which are expressed in a humorous mode, breaks everyday norms of politeness and morality (Smith 2009: 152). Smith takes her departure in this expression of humor mode which resembles Bateson framework of *this is play*. If the humorous mode is not clearly expressed it might resolve in uncertainty about how to understand the message. When the mode is not accepted or agreed upon, people might react with *unlaughter*. Unlaughter is a response which signals this is not funny. It is not a simple lack of understanding of the joke or humor expressed, it signals disapproval of the message or action (Ibid: 155-156). The message of humorous mode or *this is play* must be clear so everybody understands how things should be interpreted. The sender of a humorous message must be prepared that his joke might not be accepted or approved.

The clowns are thus interested in clearly expressing that their actions are to be understood as *this is play*. However, the audience of the dementia clowns is, because of the dementia, different from a regular clown audience. Residents might not always respond with laughter. This is not necessarily unlaughter, showing that they do not approve of the humor. It might be because they have not understood it or because it has been too quickly done for them to grasp the humor. The clowns

therefore have to navigate carefully in the responses they receive. Was this understood? Was this too quickly done to be perceived or was this not funny at all? Sometimes the clowns did something which was met with unlaughter by residents. This was expressed directly or through body language. Often the other clown scolded her partner and they continued to interact with a resident, sometimes the interaction ended when a resident clearly expressed that the clowns or what the clowns did was not acceptable or funny.

Oda seemed a bit stressed when the clowns visited her. She told them that she had an upcoming exam which she had to prepare for. Frk. Æble began to blow up a balloon very loudly. Oda asked her to stop making so much noise. "I cannot concentrate" she said. Frk. Æble apologized but then she started to giggle and she began blowing the balloon again. Hr. Kanin immediately told her to stop, behave and be quiet. Then he found a piece of paper for Oda and helped her prepare for her exam (Fieldnote, 21.09.2016).

Frk. Æble's actions were met with unlaughter by Oda. Through Hr. Kanin's guidance she was able to realize this and to stop, so the interaction between Oda and the clowns could continue.

A clear marking of the humorous mode helps the clowns express that their actions are to be understood in a different reality mode. This, along with their liminality allows them to act out of order and break rules. With the communication of the meta-message *this is play* the clowns introduce the carnivalistic mode. They express that something out of order will happen and when it will end again. I will now show that through the introduction of carnival, things are changed, roles reversed and order broken.

3.4.1 Things are not as they seem

Clowns have the ability to see everything as new because they live in the here and now. For a clown all objects might be seen as something different from how they are normally perceived (Amoore & Hall 2013: 97). Roland de Graan, who has written about the relational abilities of clowns, states that using things differently from how they are usually employed is a result of the clown's curiosity (de Graan 2012: 62). The dementia clowns used different props. Most of the clowns used soap bubbles, balloons, and red sponge noses. Each clown also used specific props, Hendriks calls this the clown's personal kit (Hendriks 2012: 463). These were among others, stuffed animals, a tiny broom and dustpan, a rubber chicken and a tea strainer. These props were rarely used with their normal function. The broom was used to comb hair, the ukulele was used as a riffle and the rubber chicken was used as a security scanner and as a microphone. Hr. Bønne did not use many props, but he brought a fishing net on a stick as part of his costume. This net was used to catch things, such as the head of the observing anthropologist, or it was used as a transportation system or as a sort of bag.

The clowns did not only use their own props differently, they also transformed things in the nursing home.

Gerda took a careful look at Fru Fryd's shoes and commented that they were very pretty and that it was a butterfly on top of the shoe. Fru Fryd's shoes were white, pink and black with a large white flower on top. I could not see the butterfly. Fru Fryd smiled to Gerda and thanked her. Frk. Æble took the shoe off of Fru Fryd's foot and proclaimed that they had just found the shoe. Then she handed the shoe back to Fru Fryd who took the shoe and placed it at her ear and started to pretend it was a telephone. She made a ringing sound. Frk. Æble "picked up" the phone by grabbing the ukulele and placing it against her ear. The two clowns engaged in a conversation about Gerda through the telephones. Gerda laughed and helped Frk. Æble answer the questions Fru Fryd asked over the phone. Then Fru Fryd hung up after asking Frk. Æble to greet Gerda. Frk. Æble placed the ukulele on the table, turned to Gerda and said "I should greet you" (Fieldnote, 06.12.2016).

In the beginning of the visit things seemed to have their original function. This changed when the shoe was used as a telephone. The clowns changed the function of both shoe and ukulele and created a play frame in which their function shifted. People with dementia might not always use things as their normal function. As part of the disease they may forget the use of certain items or they may mistake them for other items. When Gerda said that there was a butterfly on the shoe it might have been because she thought the flower looked like a butterfly. It could also be, as a result of her dementia, that she mistook the meaning of butterfly for the meaning of the word flower. This did not matter to the clowns though. During a clown visit things are not as they seem, either because the clowns treat them differently or because the resident with dementia does.

The noses, which the clowns wore, were not simply just noses. Turner writes that the liminal person is defined by a set of symbols. He further shows how different symbols are used through the liminal phase (Turner 1967: 95, 96). The red nose as a symbol identifies the person who wears it as a clown. Louise Peacock suggests that the red nose signals an opportunity for humor and play (Peacock 2009: 145). However, the nose has further use. It masks the person wearing it; although it may be small, it changes the face. The nose signifies that something out of order is at stake and therefore the nose-bearer is allowed to act out of the ordinary. Laurel Butler comments that the nose not only grants the bearer permission to act out of the normal, it also makes people around the clown behave differently (Butler 2012: 68). This also happened in the nursing homes. I saw staff members jump and dance around cracking jokes with the clowns and each other. The staff did also joke when the clowns were not there, but they did act in a different manner when the clowns were there.

The clowns held a seminar for staff members at a nursing home before they started to make visits there. They conducted the seminar as clowns in full costume. During the seminar staff was invited to play a game. The game consisted of an imaginary ball which was tossed around in a circle. Each time it was

passed on it had to be to someone who had not previously had the ball. When a person received the ball she had to count, the first one to receive the ball said one, the next two etc. When a person made a mistake, they were spanked by the clowns with a ukulele. During the game staff members started to behave differently from their behavior when the seminar began. They laughed and made funny movements and wriggled their behinds before they were spanked (Fieldnote, 30.08.2016).

When the clowns made visits it was not only physical things which were changed. They used imagination too and invented delicious food, saw imaginary animals and gave invisible presents. Turner describes liminality as a state of reflection, where things are combined in new ways which make participants reflect. Bjørn Thomassen, who builds on Turner, states that during liminality participants come to question their own sensory apparatus (Turner 1967: 92, Thomassen 2014: 92). Especially during one clown visit, I came to question how I and the resident present had perceived things.

Kaj had admired how well shaved Hr. Kanin was. He told Frk. Æble that he needed to be shaved. Frk. Æble asked Hr. Kanin if he could do it and he agreed. He left the bedroom and made very loud noises. It sounded like he was turning on an old fashioned lawnmower. He came back into the room pushing the huge invisible shaver. His sounds had changed and now it sounded more like a huge chainsaw. He shaved Kaj with the invisible chainsaw shaver (Fieldnote, 12.09.2016).

In my field notes I made a comment to myself regarding this experience. I had clearly felt that we all agreed on this imagination, although I could not be sure. I described how I had felt that the shaving machine had changed shape and I wrote: *“This sounds crazy, how can you see an invisible shaver or chainsaw?”* I continued to write that I could not know if the clowns and Kaj felt the same and then I wrote: *“I clearly felt that we were looking carefully at the same thing agreeing on the imagination”* (Fieldnote, 12.09.2016).

Dementia might cause hallucinations and delusion (Lolk & Hørting 2011: 84, 85). A person with dementia might experience or see things which are not there. By accepting invisible things as real the clowns support the residents who experience hallucinations. Clowns and residents are able to understand and meet each other in imagination. This happens because clowns know that things are not as they seem and residents may experience things which others do not see. When staff members followed the clowns around, they too experienced situations where things were not as they seem and imaginary shavers or chainsaws suddenly occurred. Staff furthermore, experienced that things might change their use and that this was not necessarily a bad thing. Marcelo Bere states that through the clown’s perception of the world and of things, his audience might change their perception of the world (Bere 2013: 211). This might be the case through the liminal experience staff members share with the clowns and residents with dementia.

3.4.2 Roles and reversal

During the clown visit, the dementia clowns take lead of what is going to happen. Where staff is usually in charge of everything in the nursing home, during the clown visit they are given a more passive, onlooker role. During carnival, roles and rank are suspended (Bahktin 1984 [1965]: 10). Roles may also be reversed. During the clown visits I encountered, roles were not necessarily reversed, and yet there was a change which was close to reversal. Residents with dementia are normally treated as passive and their behavior is interpreted in terms of disease. During the clown visit the resident is the most important. In the small video, “Når Øyeblikket teller”, which is a movie about the work of the Norwegian dementia clown group, one clown describes the elderly and says: “*it is them who are Julia Roberts and Brad Pitt as we use to say*” (Davidsen 2013: 1:43-1:50). The elderly are seen as the stars. The role of resident is thus turned around from being unimportant and affected by the disease, to be important; the superstar of the encounter. This also happened with the Danish clown group.

Lydia is sitting in the hallway. She is very neatly dressed and she has a pearl necklace around her neck. Hr. Bønne walks over to her, bows and tells her that she looks very beautiful. He says that she looks like a queen. This makes Lydia smile. Hr. Bønne continues to tell her that she could do the New Year speech from her chair here in the hallway. She looks at him and says that she could probably easily do that if she got the papers. Hr. Bønne and Frk. Gul starts to address her as “the queen” [dronningen]. Then Frk. Gul suggests that they should sing a song. Hr. Bønne suggests it should be the national anthem. He asks the queen if she knows the song and she says “of course” then Hr. Bønne starts to sing and the queen and Frk. Gul join in. The clowns are standing while the queen is seated on her bench. When they reach the second part of the verse, the clowns seem to have trouble remembering the lyrics, but the queen leads them on (Fieldnote, 11.10.2016).

Lydia was treated and addressed as the Queen during the encounter. This is almost a reverse from her normal position. The role of staff is also changed. They often seemed less secure and sometimes actually nervous or uncomfortable participating in the visits. For me, the anthropologist, I never knew how a clown encounter would develop. I was involved in several visits quite suddenly and I always felt a bit of panic when it happened. Yet, because I followed the clowns in several nursing homes I became accustomed to the fact that I might be used as a prop or stand-in. In the nursing homes where the clowns only made one or two visits, caretakers were not always prepared for being involved and they did not always know what to do. Their role was not reversed but less secure than their normal role in the nursing home.

Asger, who was sitting in a wheelchair and the clowns, blew soap bubbles. Fru Ballon placed the mouth piece in front of Asger and he blew air into it and created bubbles. Then Fru Ballon moved over to the caretaker who was standing at the wall and placed the mouth piece in front of her. She blew air and created bubbles, but she seemed uncomfortable doing so. In the car on our way back, Maj commented, that this caretaker had not seemed like she enjoyed the spotlight she was suddenly placed in (Fieldnote, 29.08.2016).

Turner states that neophytes in a liminal phase are not classified, they are nameless, timeless and without social status. They are placed in a floating state of being (Turner 1967: 96, 98). During clown sessions, both residents and caretakers could be seen as neophytes. As mentioned, during liminality and carnival normal behavior is suspended. There are no rules for how to interact with others or of addressing people. When caretakers entered a resident's room accompanied by the clowns they did not have a clear purpose with being there, except to observe the visit. Their position was suddenly quite vague. Sometimes residents seemed disturbed by me and the caretakers' presence. When they shifted their attention to us, the clowns usually followed them and started staring at us. Sometimes residents asked who we were. During one visit, Åge turned his head and looked out in the living room area where I was standing with two caretakers. He looked at the clowns and asked: "*What are they, those cows standing outside?*" [*Hvad er det for nogle køer der står derude*] (Fieldnote, 21.08.2016).

How staff members were viewed by the residents during clown visits was changeable. The behavioral pattern, which usually structured daily life at the nursing home, was also different when the clowns were present. From helping with changing a pad or moving a resident from bed to wheelchair, the tasks of caretakers during clown visits consisted of everything between observing the encounter, blowing soap bubbles, and singing in a choir of false singers. The caretaker's role could thus, be seen as nameless, socially unstructured and unpredictable.

Through the clown visits reality was changed. Behaviors and acts which were previous odd or wrong, such as communicating by making humming sounds or singing falsely was suddenly changed to be okay. The clowns created situations which could offer residents a feeling of success.

The dementia clowns are the ones who introduce liminality to the nursing homes. During their visits they are the guides. They lead interaction, suggests games, act strangely and transgress rules and norms. Residents and caretakers are transformed through the visit. Turner states that through liminality, when structure is released, participants may experience *communitas*. *Communitas* is a spontaneous, transformative experience where a person discovers that he has something communal and shared with the others. Turner further describes that *communitas* appears as something magical and that it is a momentarily experience, not a permanent condition (Turner 1977 [1969]: 129, 138-140). During the clown visits, residents and caretakers may experience this feeling of togetherness, belonging and shared-ness with each other.

Giving residents and caretakers a feeling of *communitas*, gives residents a feeling of belongingness to a social group. It restates them as social beings in the group. This supports their personhood. Although I did not belong to staff, resident, or clown group, I experienced several emotional instances where I felt a belonging and fellowship with the others. This experience was especially strong when I, during a visit, participated in a joint, spontaneous choir.

Claudia, Svend, Emmy, and the clowns were seated around a kitchen table. They had been talking and Svend had just performed a song for the others. They decided to sing another song. Fru Fryd grabbed a rubber chicken from her bag and informed everybody that this was a microphone. She tested the microphone by counting into the chicken head a couple of times before she handed it to Svend. Svend suggested that everybody should sing along. Fru Fryd began to motion for staff members and the anthropologist to come closer. Frk. Æble suggested that we should sing “silent night” [glade jul] which Svend agreed on. Fru Fryd began to play on the ukulele and Svend, Emmy, Claudia, Frk. Æble, and I started to sing. Nobody sang the lyrics, everybody just sang different sounds. Slowly the caretakers who were standing around joined in. It sounded wonderful. I felt moved and had to focus on my job as an observer to fight back the tears which could have easily come. The yelling man, whom the clowns had visited a few minutes before, came into the kitchen and joined the choir by yelling two times. It actually fitted okay into the choir. Then he left again. We sang the song twice. Then Svend started to clap his hands and then everybody clapped (Fieldnote, 04.12.2016).

When the clowns were discussing the visits with a staff member Fru Fryd thanked the staff member for joining the choir. She said it had been a good experience for the residents to share with the staff. When caretakers are prepared to join in and share experiences, residents may experience a sense of togetherness or belonging with them. This choir was an incident where everybody could join in with their contribution. Svend, Emmy and Claudia joined in with different sounds, caretakers also joined in and the yelling man was, although only briefly, part of the choir with his yelling. Through the brief moments of singing caretakers and residents belonged together and had the singing in common.

Caretakers did not only share experiences with residents while the clowns were visiting. They were also sometimes able to see residents in a new light. Turner writes that while structure is a model for thinking and ordering the world, *communitas* has an existential quality. It involves the whole person in relation with other whole persons (Turner 1977 [1969]: 127). Through shared experiences the staff members appear as whole persons who experience residents as whole persons and not merely as dementia symptoms. Although *communitas* is only momentarily, it might, like liminality, have influences on relationships, roles, and order later on when structure is reestablished.

3.4.3 Rules and order

Clowns are known to defy social rules and norms. John Honigman has written about ritual clowns in 1941. He states that their function is to break the rules. The clown is a form of positive scapegoat

(Honigman 1941: 224). De Graan states that clowns question the order of society by not complying with rules (de Graan 2012: 43). Both scholars suggest that the clowns break rules for the benefit of society. Paul Bouissac writes that most rules that define norms in society are tacit. Most rules are common sense or good manners to people who live in those societies. According to him children and foreigners are allowed to make mistakes because they are not expected to know and understand these rules. Their mistakes are corrected through instruction or ridiculing (Bouissac 2015: 109, 110). However, systematically breaking rules is not accepted. If the norm is supposed to remain the norm, it must be unquestioned (Ibid: 110). People who have a dementia diagnosis are not always capable of following social and cultural rules.

When clowns break the rules of the nursing homes it can be viewed as a way of caring for the residents. They show that they share the confusion about societal rules with residents. In addition, when the clowns break social rules they position themselves as less smart. They allow residents to help them comply with rules. Patrick van den Boom, a care clown and clown educator told me that his clown is stupid because this makes the elderly feel a bit smarter, which he did not think they experienced often (Interview, P).

Fru Fryd was sitting on a bedpan chair she had picked up in Vita's bathroom. Vita was sitting in her chair and Frk. Æble was standing next to her. Then Fru Fryd began to drive the bedpan chair around while she yelled: "here comes the sausage wagon" [her kommer pølsevognen]. Vita laughed, a little embarrassed at first I think. Frk. Æble took out the bedpan and showed it to Vita. Vita told her to put it back in so Fru Fryd could pee. Fru Fryd asked her if she should pee now and Vita said "No" and laughed. Then Fru Fryd pushed the bedpan chair back into the bathroom (Fieldnote, 01.12.2016).

For some residents, a bedpan was the only toilet available. Either they had become afraid of the bathroom or they were not physically able to use it. Driving a bedpan chair around calling it a sausage wagon is therefore quite inappropriate. Some people with dementia have difficulties understanding how to use a bathroom. Old men, I was told, would often urinate in corners of their room. Not understanding how a bedpan chair was used or where it was inappropriate to pee is therefore behavior which many residents might have had experiences with. Vita helped the clowns navigate in how to use the chair and where to use it.

Hendriks gives an example of a dementia clown who, in an encounter with a resident, finds some breadcrumbs on the floor. The resident eats these breadcrumbs and the dementia clown follows her and eats them too (Hendriks 2016). It is a break of social customs to eat breadcrumbs of the floor. Hendriks describes how relatives often try to prevent their loved one from doing this kind of behavior, to try and make them act appropriately. He explains that being constantly corrected, for

not meeting standards has a crippling effect on people (Ibid.). The dementia clowns do not have expectations of this sort towards the residents.

Sofia told me that while she was clowning on her own she met a resident who crawled around on all fours. The resident started to bark like a dog. Sofia got down on the floor next to the woman and barked as well. They, resident and clown, then pretended to be dogs all the way from the living room area and down to the resident's room (Interview, S).

Carl and his wife were having coffee in his room when the clowns entered. Carl looked at Hr. Bønne and asked if he was Doctor Livingstone. Hr. Bønne replied that Doctor Livingstone was his uncle. He began to tell Carl about his travels on the seven seas and how he had visited all the continents. He told Carl and his wife that he had just been to Africa. Hr. Bønne asked Carl if he had ever been to Africa and he said no. Hr. Bønne suggested that next time they could go together. Then Carl said: "And bring more slaves to Denmark" [og tag nogle flere slaver med til Danmark]. Carl's wife seemed to be very embarrassed by this comment, but Fru Ballon said that the only slave Hr. Bønne had brought home this time was her (Fieldnote, 25.09.2016).

Pretending to be a dog and making comments on bringing slaves to Denmark is considered odd behavior. Inappropriate comments are often connected with frontal lobe dementia where a person is unable to filter comments and often gets quite inappropriate and aggressive. This disease is quite embarrassing for relatives to cope with, because they feel they have to apologize for the behavior. The clown on the contrary accepts all sorts of behavior and goes along with it.

Sometimes the clowns broke social rules just by entering the facility. Nursing homes are calm places. People talk and laugh, but they do so quietly. Furniture is not moved around, chairs are used to sit on, and helping equipment is there for a specific purpose. When the clowns entered they made noise. They played music instruments and talked loudly. They jumped on chairs, and walked on fences. They used walkers as racing cars and threw balloons and red noses around.

Hr. Kanin was always quite energetic but one day he was exceptionally energetic. He jumped on a fence, ran down the hallway yelling and then, he discovered a ceiling lift in a resident's room. The ceiling lift consists of a large grey hanger which hangs from the ceiling in a black elastic halter. It is used to move patients from the bed. The patient is placed in a blanket and the caretaker places the corners of the blanket on the hanger which is then turned into a form of large sling. Hr. Kanin asked the resident if he was allowed to do an acrobatic performance. The resident granted him permission. He then made the hanger come down from the ceiling. He placed his suspenders on each side of the hanger and started to run from wall to wall until he jumped and flew through the air hanging in his suspenders on the hanger (Fieldnote, 03.11.2016).

The breaking of rules is also a way of creating a trusting relationship with patients or residents. Pendzik and Raviv show how the medical clown quickly establishes bonds with a patient because of his disobedient behavior. By breaking the rules of the hospital or by disobeying the doctor, the

clown shows that he is on the patient's side (Pendzik & Raviv 2011: 271). Their noncompliance with rules also made the clowns function as a spokesperson for the residents.

The clowns were asked to visit the music café which the nursing home music therapist was in charge of. Approximately 80 residents, volunteers, nursing home staff and relatives were seated around tables. The music therapist walked around in the middle of the room and announced into the microphone which song they should sing. A pianist accompanied the songs. She played quite fast. It seemed like several people were not able to follow her pace. The clowns entered the café area and split up. Frk. Æble went to one side and Hr. Kanin to the other. He danced with some residents and helped others find the right page in the large song book. At one point he made a suggestion for the next song they should sing. After a couple of verses he announced quite loudly: "I think it is going rather fast" [Jeg synes det går vældig stærkt]. The pianist stopped and started again in a slower pace (Fieldnote, 21.09.2016).

With his rebellious attitude, Hr. Kanin protested against the fast pace and spoke for the elderly who were not able to follow.

Although rules may be changed or broken through the carnival period, there are still certain rules which apply. Although the clown is rebellious, this behavior can only exist as long as the rule-breaker understands the rules and when to break them (Warren & Spitzer 2014:21). One of the clowns explained to me that when a rule was broken, or a border was transgressed new borders and rules emerged. He explained that as a clown they took the responsibility for their rule breaking. Especially when they clowned with people who had dementia, because they were not always able to express when their personal boundary had been violated (Interview, K). The clowns are thus aware of rules and boundaries although it seems that they are constantly rebellious (See Houmøller 2016: 17-19).

By their introduction of carnival, clowns break existing rules and introduce new rules in the nursing homes. The clowns break the rules for fun and because this is their nature while residents with dementia break the rules, not by fault but because of the disease.

3.5 Carnival care

The carnivalistic mode that the clowns introduce during their visit is a part of the logic of clown-care. By breaking rules and acting odd, clowns create an opportunity for the elderly to be less passive than normally. The resident's specific form of communication is encouraged and lived out with the clowns. They gain opportunity to express themselves more freely than normally in the nursing home. The clown is non-judgmental and nothing is strange for a clown. If a resident chooses to crawl around on the floor and pretend to be a dog, this is what is appropriate for the clown too.

The breaking of rules and norms is caring in different ways. By breaking the rules, clowns show that they too may have trouble obeying social rules. The rule breaking also empowers the residents. Their chances of rebelling against the strict institutional order in the nursing home are limited, but when the clown rebels with or for them, they are empowered. This empowerment also happens when residents are given the opportunity to guide the clowns regarding appropriate behavior.

The clowns clearly show that they are the allies of the residents. Their focus is on the resident, how she acts, communicates, and perceives the world. When a clown goes along with a resident they create new rules of how to act in the world. Caretakers do not always understand the new rules or they are unable to communicate in the same way.

Being a liminal being the clown creates a transition for residents. During a visit, they experience *communitas* with caretakers and they gain an experience of harmony and happiness. These feelings may last after the clown has left. The clown visit is a break in the routine life; an opportunity to gain a recess for both caretakers and residents.

The carnivalistic mode gives caretakers an introduction to a different way of perceiving and understanding the world and the residents with dementia. The logic of clown-care thus provides the caretakers with new tools and ideas to their care. The logic of clown-care is exercised immediately through the visit, but it also has the potential to last longer if the caretakers are inspired and learn from the clown methods.

I have now presented how the clowns introduce carnival and how they act with residents in this liminal phase. I will now turn to the logic of clown-care.

Chapter 4 The logic of clown-care

"I am after the rationality, or rather the rationale, of the practices I am studying. Here the term 'logic' helps (...) It invites the exploration of what is appropriate or logical to do in some site or situation, and what is not. It seeks a local, fragile and yet pertinent coherence. This coherence is not necessarily obvious to the people involved (...) And yet, if we want to talk about it, we need to translate a logic into language" (Mol 2008: 9-10).

In this chapter I use Mol's enquiring mode to study the logic of clown-care. I follow words, actions and actors involved in the dementia clown-care in the nursing homes. This logic of clown-care did not follow a specific template for action, but through the different visits I observed, I was able to see coherence in the different actions. I could see how the clowns chose which actions were appropriate or logical to them. I will show how the clowns care through their special way of seeing, hearing, meeting, feeling and remembering. Furthermore, I show how the clowns care, by letting the elderly control and care for the clowns. By understanding and translating the different actions into a specific logic, it is possible to discuss it and contrast this logic with the logic of nursing home care.

4.1 To see

When I started my fieldwork, I saw the dementia clowns as an odd addition to nursing home institutions. I thought my upcoming thesis would be about clown-humor and entertainment. In the beginning of my fieldwork I thought I was supposed to study dementia-clowns in Norway. Therefore on the 5th of September, I gathered my belongings and took the ferry to Oslo. I did not have any concrete arrangements with my informants in Norway, nor did I know anybody. I stayed with a very heart-warm and friendly, although very busy, woman, her son, and their lovely dog. During the two weeks I spent in Norway I felt alone. I had no clue what was going to happen with my fieldwork and I did not have any friends to meet up with. Although I had practiced Norwegian, I had to concentrate to understand what people said. I spent hours taking the dog for a walk. I had never had a dog before, so there were many things, such as gathering dog poo, I was not sure how to do. Furthermore, I have bad sense of direction, so I managed to get completely lost in the forest nearby. I felt silly, embarrassed and ridiculous as I had to ask strangers for directions. I felt lonely, sad and in a way disconnected from my previous self. The happy, smiling, singing girl I used to be seemed far away from the nervous, disoriented, confused anthropologist, who was trying to figure out how to do fieldwork. Nobody seemed interested in me. Several times I felt like I was walking around amongst other people being invisible.

After two weeks in Norway I flew back to Denmark. Before going to Norway I had subleased my apartment. Therefore, I found myself in a city where I had lived for five years without a home to stay in. I moved in with my sister in her tiny dorm-room. I slept on a mattress on the floor. People at the dormitory kitchen talked with each other, but not with me. I was a stranger to them. If they talked to me, they were polite but disinterested. I was met as my sister's sister, not as me. I felt happy when I did fieldwork with the clowns, but here I also felt invisible and unimportant. As the observer I was supposed to keep in the distance, trying not to be noticed. I dressed in black or grey to attract as little attention as possible. This is quite far from the outgoing, joking, colorfully dressed woman I usually see myself as.

Then on the 7th of November I went to a nursing home with the two male clowns. They spent most of the car ride talking with each other. We arrived, they got dressed and started to clown. Then, when we were visiting Marius, an old man with dementia, Hr. Kanin, suddenly stood behind me and placed my ponytail on his head. He asked Marius and his clown partner about their opinion on his "borrowing hair". The clown partner laughed. I was in the spotlight, and I had no clue what was going to happen. Then Marius looked at us and said: "you are a cute couple" [I er da et sødt par]. And Hr. Kanin turned to me and looked me very intensely in the eyes and said: "yes, should we get married then" [ja igås, skal vi gifte os så]? Hr. Bønne then started to ask us if we would follow each other in sickness and health and then he married us. When he had announced our marriage, Hr. Kanin turned to me, looked me in the eyes and kissed my hand. In that moment, I felt I was being seen. I knew very well that this was a game. But as he looked me in the eyes and kissed my hand I felt like the most beautiful woman in the world. I felt I was the most important person in the room, and I felt so happy and special. Suddenly I felt that the different traits of my personality, which I felt had been overlooked during the last couple of months, were flourishing. This feeling of being special lasted for quite a while, and even now I can still recall the particular feeling I had in that moment.

It was not until a couple of weeks later I realized that this, being *seen*, was as much part of the clowns' contribution as humor and the crazy actions they performed were. I understood how important for human beings it is to be seen, and I found out that this was a vital aspect for the dementia clowns.

During my first period of fieldwork I felt: out of control with the situation, alone, helpless and invisible. These were also states or feelings I could see the elderly residents going through. I do not

claim to have had the exact same experiences and pains as a person with dementia might go through, but I do see how the loss of memory, abilities and sense of direction may affect a person. A dementia diagnosis is frightening for people because of the stigmatization attached to the disease (Behuniak 2011: 72). Losing one's ability to communicate and be understood results in frustration and pain. And as mentioned, people with dementia are often overlooked and ignored because of the disease. In autobiographies written by people with dementia the authors comment on the frustrations, anxieties and feelings they go through. Thomas DeBaggio, who has written about his experiences with having Alzheimer's disease, writes that Alzheimer turns the world into an *uncertain, frightening place* (Debaggio 2002: 135). Cary Henderson also writes about his experiences with dementia. Henderson mentions feeling stupid and alone because of the disease. He also states that he misses being important and that he feels that nobody loves him (Henderson, C. 1998: 19, 37, 74).

The dementia clowns have a way of seeing which is different from how we see other people. Their way of seeing is a way, which sees the person as a full social being. In my interviews the clowns made it clear that *seeing* is important. Maj described how she wanted to meet the residents with respect: *"it is important to respect them, in order to give, right? (...) The coolest is if I really succeed in seeing the person as it appears right now, stay where they are now and here, and that this person feels that: "I am completely accepted"* [det er vigtigt at respektere dem i hvert fald, for at kunne give noget for det første, ikke? Det fedeste det er hvis det lykkes mig for alvor at se det menneske som det er lige nu og her og at det menneske føler jeg er helt accepteret] (Interview, M). Kim told me that as a clown he had learned to pay attention to human mechanisms, which gave him information about how to interact with people. He also told me: *"not seeing [a person], is one of the worst things you can do. You kill a child if you do not see it"* [det der med ikke at se, er noget af det værste du kan gøre. Du slår et barn ihjel hvis du ikke ser det] (Interview, K). It was important for him, as for Maj, to really see the person.

Frank also wanted to make people feel seen. As Hr. Bønne, he had a special technique. He used his binoculars to establish contact with people in the hallway. He told me: *"sometimes I look at them with my binoculars to kind of underline that I have really, really caught sight of you"* [nogen gange kigger jeg også på dem med kikkerten for ligesom at understrege, at jeg har altså virkelig, virkelig fået øje på dig] (Interview, F).

Hendriks describes the clown's way of seeing as significant and respectful. He explains that the word respect has a double meaning, it means having regards for a person, and it is a specific way of looking to and upon people. Hendriks states that the clown's view honors people's presence, and that it offers the other, who is looked at, the opportunity to regain his footing in the world. The clown way of viewing sees the individual as a relational and embodied subject (Hendriks 2016). This specific way of looking attends to how the person is, supports the person and connects the person to others. Hendriks points out that the clown way of looking, is an engaged way of looking. The clown not only sees but also tries to incorporate the world of the other person (Ibid.). Thereby the clown attempts to understand how it is to be this particular person.

Dorte sits in a chair in the living room with a doll. She gently rocks the doll in her arms while she now and then addresses the doll with small noises. Fru Gul walks over to her. She admires the doll in Dorte's arms and tells Dorte how cute he is. Dorte smiles. Fru Gul gently touches the dolls face with a finger. A bit later Hr. Bønne joins the two women. He attempts to caress the doll as well, but Dorte tells him: "you cannot take him, he must stay here with auntie" [du må ikke tage ham, han skal blive her hos moster]. Fru Gul scolded him and said: "yes, he must stay with auntie" Field note, 03.11.2016).

Dorte treats the doll as if it was a baby. Whenever the clowns met Dorte during the two hour long visit, she had the doll in her arms. The doll is important to her. She caresses it, talks to it and protects it from Hr. Bønne. Fru Gul sees this and accepts it. With her remarks to Dorte about the baby she affirms her world. Where Dorte might be met by people who would see her as a silly old woman for playing with a doll, Fru Gul acts reassuring and accepting towards her.

The clown way of seeing is an engaged look, which discovers cues for games and subtle messages about the emotional state. It is also a look, which almost caresses the other person and encases them in attention.

4.2 To hear

During my fieldwork I noticed that individuals with dementia were rarely heard. This happened for instance during mealtime, where residents and caretakers were seated at the same table. The caretakers talked with each other. They did not ask questions or react much to the words or sounds the residents made. Several times while observing the clowns, I heard residents call out but nobody reacted. I heard and saw a woman cry out for help and she was ignored by the staff. People with dementia often lose their ability to speak, they forget words, use the wrong words or they are only capable of making sounds. Therefore communication with them is difficult. Anthea Innes and Andrea Capstick comment on the diagnostics of communication problems with dementia. They

point out that the diagnostic labels might encourage care staff to give up on communicating because “it is just part of the disease” (Innes & Capstick 2001: 137). They further note that a person is only able to communicate when he is responded to or heard (Ibid.).

One thing is to communicate with specific words and understand what they mean. Hendriks suggests that it is the expressed emotions, which are important. These emotions are experienced in the layer of feelings and not necessarily connected with the actual content of what is said (Hendriks 2012: 471). The dementia clowns in Forglemmigej both listened to the content and paid attention to the emotions expressed in the communication.

Tove is sitting in the couch between two caretakers. Three other residents are also seated in the living room. Hr. Bønne and Fru Gul walk towards the residents. Tove starts to smile and as the clowns move closer she starts to laugh loudly. The two clowns walk closer to her. Then Tove starts coughing and after coughing for a while, she tells the clowns that she has been waiting for medicine from the pharmacy, but they have not sent her the medicine. She seems to be very upset and angry with this. Hr. Bønne immediately takes his binoculars, places them in front of his eyes and looks out into the horizon. Fru Ballon joins him: she takes her hand over her eyes and spots into the horizon. She starts calling out for the medicine and Hr. Bønne joins her. They call “medicine” and “come with the medicine”. Tove starts laughing (Fieldnote, 11.10.2016).

The caretaker, Jane, who has followed the clowns around points them towards a woman sitting alone on a bench in the hallway. The two clowns slowly approach her. She is tearful and annoyed that no one has come to pick her up yet. She wants to go home. “They are waiting for me” she tells the clowns. And the clowns listen to her. “They are worried for me” [De er bekymrede for mig] she says. Fru Ballon looks at her, places her hand on the woman’s arm and says: “but they know that you are alright here” she tells her. This seems to reassure the woman (Fieldnote, 08.10.2016).

Both Tove and the worried woman who wants to go home express their frustration and anxiety verbally. In both cases the clowns reacted to the content of the spoken words and to the emotions expressed as well. They took both statements serious, but reacted in different ways. For Tove, they enlarged her frustrations and searched with her for the medicine. They exaggerated the search by using binoculars and yelling. With the other woman, the clowns took her grief and anxiety serious and they reassured her through words. Her message was heard and taken serious. Just as the clowns made an effort to see residents, they also made an effort to *hear* them.

While the clowns are talking with a male resident in a wheelchair, the nurse, Naja walks a bit further down the hall to bring Paula, the next resident, who the clowns are going to meet, out into the hall. I am standing in the hallway a couple of steps from the man in the wheelchair. I can see Naja and Paula. Naja tells Paula “there are someone here who have come to visit you” [der er nogen som er kommet for at besøge dig]. Paula said: “what is that lying there?” [hvad er det der ligger der]. Naja answers: “that is a mat”. “Help, it has come to kill me” [hjælp det er kommet for at slå mig ihjel] Paula cries out. “No, it is just a mat, look who is coming there” Naja points towards the clowns. Paula looks anxious and does not look in the direction Naja is pointing. “Help, get it away”. Hr. Kanin suddenly hears the voice and he says to his clown partner: “Come, there is somebody who needs help”. The clowns quickly say

goodbye to the man in the wheelchair and run towards Naja and Paula. Hr. Kanin looks at Paula and asks her: “how can we help you?” “remove the mat!” she says. Hr. Kanin takes his guitarlele,⁵ holds it as if it was a rifle and points it towards the doormat. “I will shoot it away” [Jeg skyder den væk] he says (Fieldnote, 20.09.2016).

Paula is frightened by the doormat, which she perceives as murderous. The nurse hears her anxiety, but does she listen, when she denies that the mat is dangerous? She seems more occupied with introducing the clowns. The clowns however, listen to Paula. They hear that she is in need of help, and they take it serious by offering to remove the mat by shooting it. It does not seem to matter that Hr. Kanin is killing the mat with a music instrument. What matters is that they hear her cry for help and come to her aid. The clowns seem to understand that Paula is not able to move beyond the mat and meet them before the mat is removed.

Clowns communicate in odd ways. They communicate with animal sounds, clown language or gibberish (Warren & Spitzer 2014: 8). Michael Bala, who has written about the psychological aspect of the clown, compares the clown with the fool and states that fools and clowns both speak the truth, though sometimes in a way that seems to make no sense (Bala 2010: 56). Clowns do not only speak in an odd manner. They are also capable of understanding non-sensical speech and foreign languages. De Graan comments that clowns have more options for relating with others than speaking the same language as them (de Graan 2012: 64). Hendriks further point out that clowns have the capacity to establish contact outside the scope of normal language (Hendriks 2012: 463). For a clown, the specific meaning of a word is not an obstacle for relating and understanding. Several times the clowns visited residents whom, they were told, often talked rubbish [sort snak]. This did not stop them from having conversations, which seemed to make sense for both resident and clowns.

Else is sitting in the hallway talking in rhymes and stomping her feet. Hr. Bønne and Hr. Kanin have made a song where they repeat her sayings and put them into melody. Then Else says: “yes, I think that too” [ja det synes jeg jo også da]. Hr. Bønne says yes to her. Then she continues: ”to which there has come such lovely habatijunauda” [hvortil der er kommet sådan nogle dejlige habatijunauda] “habatijunauda?” asked Hr. Bønne and Else said “yes” in a very certain voice. Then Hr. Bønne incorporated it into a song when he sang: ”she spoke of habatijunauda” (Fieldnote, 17.11.2016).

Inge was talking with Fru Gul and Fru Fryd when she suddenly turned her attention to me. I was standing in the hallway observing their interaction. Inge stared at me, and the two clowns turned and looked at me as well. “She has a kralifif” [hun har en kralifif]. Fru Gul carefully took my plaiting and said: “yes it is a kralifif here”. Inge nodded and turned her attention towards her door again (Fieldnote, 09.01.2017).

⁵ A music instrument, similar to a ukulele

Neither *habatijunauda* nor *kralifif* are words which exist in the Danish language. However, both Fru Gul and Hr. Bønne seem able to communicate despite of this. It was important for the clowns to understand the underlying message of the residents' statements. During a car ride Ida and Maj took turns saying something in gibberish to the other and then receiving a response in Danish from the other. After Ida had answered, Maj told her that it had felt really good being understood (Fieldnote, 19.09.2016).

The clowns listen to the elderly by acting on their words, communicating beyond the normal scope of language and by paying attention to the underlying emotions. They listen carefully. Where caretakers might expect that a resident's talk will not make sense, the clowns expect that they have a message and they attempt to understand it.

4.3 To meet what is

The clowns in Forglemmigej improvised every meeting. Frank noted to me that as clowns "*we do not perform, we step in*" [*vi optræder ikke, vi indtræder*] (Interview, F). He said that they stepped into the residents' world and stayed with them there. Line also said that as a clown they could follow residents into strange worlds (Interview, L). Kim said that: "*I have a feeling that we open for a room where the demented can have permission to be demented*" [*det er sådan min fornemmelse, at vi åbner for et rum hvor den demente kan få lov til at være dement*] (Interview, K). The clowns referred to this as *meeting the person where they are* [*at møde personen der hvor de er*]. This meant meeting them on their terms, with their particular mood, behavior, communication style and diagnosis.

Hendriks states that nothing is inappropriate or strange to a clown (Hendriks 2012: 462-463). This is certainly the case for the dementia clowns in Forglemmigej. They meet residents just as they are, without being judgmental of strange behavior or odd speech. Hendriks describes this way of meeting others as having an attuned body. A clown has a body, which is sensitive to the other person. This enables the clown to be moved by others and to be aware of how the other may experience things (Ibid: 467, 469).

Almine has taken Fru Gul by the hand and led her to a table. Almine is constantly saying "mmm mmm". Her voice goes up and down in pitch with the sounds. She sits down at the table and Fru Gul and Hr. Bønne both kneel down at the table end. They have started saying mmm with her. Now and then Almine moves her hand through the air, she moves her fingers and it looks as if she plays the piano. Fru Gul copies this movement. Now and then she slams her hand down on the table and Fru Gul also copies this. The sounds Almine made came in a very specific rhythm, it sounded almost like a chanting (Fieldnote, 06.10.2016).

By copying both Almine's movements and sounds, the clowns are able to meet her where she is. Although they might find it strange or they might have an urge to change the chanting, they do not change it because this is how she is, how she communicates right now. By mimicking her behavior the clowns gain new understanding of life and about themselves. This knowledge may help them tailor their care even better.

During a clown meeting Ida and Kim told the other clowns and me about an encounter they had recently had with an old man. When they arrived at the nursing home, they could hear him yell very angrily. He did that continuously while they were at the nursing home. Ida and Kim decided to visit him. They went into his room and he continued to yell. So both clowns began to yell as loud as they could with him. They slowly began to yell more quietly. In the end their yelling had become a whisper. Then the man looked at them, sighed and then he was quiet while they stayed with him for several minutes. Ida said that this man was probably constantly met with people who told him to be quiet or with well-meaning caretakers asking what was wrong. Both Kim and Ida said they felt he just wanted to be met and be heard (Fieldnote, 21.11.2016).

For staff at a nursing home, a man who is yelling most of the day, is probably seen as annoying, as an extra burden, or categorized, as Paterniti suggests, as troublesome (Paterniti 2003: 64). The clowns meet him where he is. They interpret his yelling as a way of communication, and they adopt it and participate in it with him. He is not met as troublesome, but with the prospect of companionship. Neither clowns nor caretakers can know for sure why residents act as they do. This is a condition for their work. They interpret residents' behavior. However, the clowns do not attempt to change the behavior, they go along with it. By meeting a person where he is, they make him feel like a person. Their goal is to make him feel respected and loved.

4.4 To meet the selves

It is generally accepted that one does not have a continuous "self". The person I was ten years ago is not the same as the person I am today. On the contrary the "I" is emergent and changes through meetings with the other (Borneman 2011: 43). Different meetings and situations make different "I's" emerge. When a woman meets a child in need the "I will help" may emerge, when she meets a handsome man the "I am flirting" may emerge. Sabat and Harre call these *the selves*. They state that a person may display different selves in different situations. Their understanding of selves could also be translated as roles. A person may display different roles during a day. Each role or 'self' provides the person with different aspects and benefits.⁶ It is thus beneficial for a person to be able to play out different selves. Sabat and Harre note that since the selves are socially constructed, the

⁶ See also Landy 1993 who in his work on drama therapy talks of roles and the necessity to play out different roles

performance of selves depends on the acceptance of others. If a person is not recognized or accepted by others as “I am helping”, the way they view and treat her will be affected (Sabat & Harre 1992: 446).

As already mentioned the position of a person with dementia is limited. During the day she has limited opportunities of displaying different selves. Moreover, building on Cohen’s thoughts about voice, and Taylor’s points about recognition and dementia, people with dementia are often not supported in presenting different selves. Sabat and Harre state that once a person has been positioned as helpless or confused, because of her dementia, people rarely recognize her as anything else than helpless or confused (Ibid: 454). Although a resident, in a nursing home attempts to present herself as “I am helping”, she is more likely to be viewed by others as “I am helpless”.

In the nursing home, I saw a tendency to deny that the self changes. I heard children say that they no longer had a mother although their mother was seated next to them. The mother with dementia is their mother and may feel as such, however her children do not completely accept this because her way of being a mother has changed because of her disease. Her opportunities to play out and be accepted as “I am a mother” are limited.

The dementia clowns meet the residents in the here and now. They accept the selves a resident displays. Although they play out one specific character, that of a clown, they tailor their character to the different needs of a resident. They may play the flirting clown, or they may play a very childish clown. This gives the elderly the opportunity to act out different roles, which can accompany the clown role. The clowns create an opportunity to invoke the resident’s sense of different selves or positions. They create situations which call for the “I am a flirting woman” or the position of “I am smart”. The resident gains the positive aspects of playing out different roles or selves.

Kjeld was lying in bed when the clowns arrived, but during their visit he has risen from bed to sit at the edge of the bed. Kjeld looks out into the living room for the third time during this visit. He stares at me, and the nurse who are observing him with the clowns. He asks Fru Ballon who those people are. This is the third time he asks this question. Fru Ballon tells him that it is his nurse, Gunhild, from Norway. Kjeld looks at her and says: “oh yes, I have been in Norway. The capital is Oslo, but it is also called Christiania” [åh ja, jeg har været i Norge. Hovedstaden hedder Oslo men bliver også kaldt Christiania]. Fru Ballon smiles and looks very interested. Then she asks: “So first it was called Christiania?” And Kjeld straightens himself, nods and says yes (Fieldnote, 21.08.2016).

Kjeld repeated himself throughout the whole visit, yet Fru Ballon acted as if it was new information. Her careful listening and her questions made the meeting look like a student asking questions to a teacher. When Kjeld straightened himself it also suggested that he felt important and

clever in that instance. Residents often repeat stories or questions and this is, as Paterniti describes, tiresome for health care staff (Paterniti 2003: 68). Having an interested listener might not be an experience the residents have often.

Viola was sitting in her chair in the room. Her room was covered with posters and pictures of the Austrian singer, Hansi Hinterseer. Hr. Bønne went over to her, took her hand, said hello and told her that she was very beautiful. She blushed, giggled and kept holding his hand. Frk. Gul walked over to them and stood for a while watching them before she greeted Viola and told her: "Hr. Bønne is a very handsome man" [er en meget flot mand] and Viola giggled and smiled. Hr. Bønne went to sit in the couch next to Viola's chair. Viola placed both her hands on his arm squeezed him and smiled. Frk. Gul stood next to Viola's chair and told Viola that Hr. Bønne was almost as handsome as Hansi Hinterseer. Viola looked at her and smiled and then she blew a kiss to Hr. Bønne (Fieldnote, 06.11.2016).

Courting or flirting with a resident was common for both male and female clowns. When the clowns flirted with a resident, I could see that many of the residents seemed to beam with pride and joy. While the male clowns often initiated the flirting by kissing the woman's hand or calling them beautiful, the female clowns were often the ones who were courted by the male residents. While Hr. Bønne initiated the flirting with Viola, Frk. Gul's actions assemble the gossiping between friends. Both roles of flirting male and girlfriend supported Violas feelings of being courted. Viola was not passive in this role, her squeezing Hr. Bønne's arm and blowing him kisses showed this. Grinberg et. al. show how medical clowns often use the role of courting lover to support female patients in hospitals. This facilitates the patient's perception of herself as a woman and a sexual being (Grinberg et. al. 2012: 46). Through flirting and playing the loving clown, the clowns show loving care for the residents and make them feel valuable, young and special.

Clowns have a special bond with their audience. Selena McMahan writes that the clown must always be aware of his audience and be prepared to respond in a surprising way (McMahan 2008: 19). Bala writes that the clown has the ability to take the emotional pulse of his audience (Bala 2010: 55). The clown is dependent on his audience and must react to responses from them. De Graan introduces the concept of *dialogic performance*. With dialogic he means that the clown listens to his audience and creates a dialog with them. Dialogic performance points to the clown's ability of being sensitive, aware and present in the moment. This way the clown constructs a relationship with the other, the audience, which is characterized by a minimal self-other differentiation (de Graan 2012: 78). Through the dialogic performance a special feeling of oneness is created. Although de Graan grants the audience part in the performance by being in dialog with the clown, his focus is mainly on the clown's ability to be aware and engage in this performance.

Thereby he, as Kontos et. al. show, overlooks what the other brings to the performance (Kontos et. al. 2015: 4). The uniqueness of the audience and their contribution is overlooked.

Kontos et. al. show that persons with dementia engage in clown play by initiating creative and playful engagements (Ibid: 15). They further introduce Hendriks' concept of *relational effect* which happens when it is unclear who the performer is and who the audience is (Kontos et. al. 2015: 9-10, Hendriks 2012: 470). This could occur when one clown engaged in a play with the resident and the other observed. Sometimes it was also unclear who started a game, the resident or the clown. Residents with dementia are not just passive receivers in the clown interactions. They add, suggest and interact with the clowns.

Frk. Æble and Hr. Kanin are visiting a group of men in a kitchen. They have been singing a song for the men. Suddenly Bo, who was sitting next to Frk. Æble says: "Could we say that she stays here and then you leave?" [Kan vi ikke sige at hun bliver her og så går du]. He looks at and talks to Hr. Kanin. Frk. Æble smiles, takes Bo's hand and walks over to his other side so she sits a bit further away from Hr. Kanin. Hr. Kanin nods and proceeds to walk away and asks: "For how long should I be gone?" [hvor længe skal jeg være væk] "All the time" [Hele tiden] Bo answers. "well that was long" [det var sørme længe] Hr. Kanin says. He takes another step away and asks: "When can I come back" "never in the whole world" [aldrig i hele verden] Bo answers. Frk. Æble is smiling and waves her hand to Hr. Kanin. Hr. Kanin proceeds to walk away from the happy couple. He looks very sad. Then he starts to sing a sad song of goodbye to Frk. Æble. Bo tells him: "You can come back when you have learned to sing!" [du kan komme tilbage når du har lært at synge]. Frk. Æble looks a bit worried and asks Bo: "Do you think I can do without him?" [tror du godt jeg kan undvære ham] "YES". He immediately says. She smiles and says "Yes, because now I have you" [Nåh ja, nu har jeg jo også dig] (Fieldnote, 23.09.2016).

By asking Hr. Kanin to leave, Bo presents himself as a courting man who wants to get rid of his opponent. He starts the game with his commentary question to the male clown. Frk. Æble accepts the premise to be the courted woman while Hr. Kanin takes the role of the defeated opponent. Both clowns follow Bo's lead, he is able to present a certain part of his personality, have control of the situation and start a game.

Not only did the clowns accept the different roles the residents play, they also often facilitated an opportunity for the nursing home staff to see the residents in a new light. Frank told me that the clowns had a special impact on the staff as well. Frank pointed out that meeting or seeing the residents in a new situation, not a situation of care, provided the staff with new insight. This could, he suggested later on, lead them to change their attitude towards the residents (Interview, F). One leader of a nursing home told me that she saw the residents in a new light. She referred to a particular male resident who enjoyed walking with the female clowns. She gave me her interpretation of their meeting: "*I think it is awesome to see a man who is long past eighty, he thinks he is twenty-one and has picked up the loveliest woman in the world, when he walks up the*

hallway” [*Jeg synes det er fedt at se en mand på snart langt op i firserne han synes han er 21 år og har scoret verdens skønneste kvinde når han går der op af gangen*] (Interview, B). Here the leader acknowledges a different side of this resident. She sees his flirting, self-secure role.

There were some residents which the staff wanted to shield from the clowns, or whom they wanted the clowns to be gentle towards. Through the clown interactions they suddenly saw that this shielding perhaps was unnecessary. This was especially clear with Margit, a tiny woman in the beginning of her eighties, who sat in a wheelchair. Before the clowns visited her, the caretaker Nanna, told the clowns to be calm and gentle with her.

The clowns entered into Margit’s room, after being told to be very gentle with her. Margit looked at them and smiled and Frk. Æble and Fru Fryd sat down next to her at the kitchen table. They were making small talk when Margit said that they should go for a ride. “Where to?” asked the clowns and Margit told them she had to go to her mom and dad. Frk. Æble took a grip around Fru Fryd’s chair and made noises and rocked the chair as if Fru Fryd was in a car. Margit looked at Fru Fryd and smiled. “Should we go?” Frk. Æble asked Margit and she said yes. “Where to?” “Germany” Margit answered. Frk. Æble started making loud sounds as a motorbike or car and pushed Margit’s wheelchair into the living room. Margit smiled. Fru Fryd followed the “car”. They pushed the wheelchair quite fast and pushed her halfway into the bedroom. “Where is Germany?” Frk. Æble asked. “In my bag” said Margit (Fieldnote, 04.10.2016).

The clowns disobeyed the order to be gentle, instead they pushed the wheelchair wildly around while they made loud sounds. Afterwards, Nanna told the clowns that it had been a good visit. In an interview she reflected on this episode.

N: Sometimes we also just have to try [nogen gange skal vi også bare prøve og turde prøve]

I: yes

N: I think this is good to remember. Because you can be a little too protective and you can be a little scared because you think “oh they are having a hard time” and we don’t want to make it harder for them [det synes jeg der er godt at have med. Fordi man kan godt blive sådan lidt for beskyttende man kan godt blive sådan lidt bange fordi man synes ”uh de har det svært” og vi vil ikke gøre det sværere for dem]

I: yes

N: but anyway, to live there has to be substance, understand me correctly, we need to feel that we are alive [men alligevel, for at vi skal leve skal der jo være indhold, altså forstå mig ret, vi skal mærke at vi er til] (Interview, N).

Through the clown visit Nanna saw that the wild behavior of the clowns did not harm the resident. Instead she experienced that it gave Margit a feeling of being alive, and added some joy to her life. This made her try to change her attitude towards residents in general.

4.5 To feel

Care clowns bring happiness and joy to patients in hospitals and nursing homes. However, the dementia clowns also, as Kontos et. al. show, allow for other feelings such as sadness to be expressed (Kontos et. al. 2015: 9). The clowns in Forglemmigej not only recognized these feelings, they also attempted to follow the resident into them. One clown said that he did not think it was important that a resident had to be happy. Instead he tried to acknowledge the feelings that were present and not asses [vurdere] these feelings (Interview, K). Two of the clowns commented that caretakers sometimes tried to correct a resident's feelings. Instead of acknowledging the feeling of sadness or anger, they tried to comfort and push the resident to be happy. The clowns thought that residents should be allowed to feel what they felt (Fieldnote, 25.08.2016).

The clowns attempted to share the emotional state that the residents were in. This was done by yelling with them, or by trying to understand why a resident was expressing a certain feeling. After being told that a particular resident was always angry, Line said: "*I would also be damned pissed if I did not have any legs*" [*Jeg ville fandeme også være sur hvis jeg ikke havde nogen ben*] (Fieldnote, 02.10.2016). Line understood his anger. Instead of being annoyed with it she found a reason for his behavior.

Nursing homes are referred to as "the last home" [den sidste bolig]. People rarely move to other places, they die in this home. Chatterjee writes that patients with dementia often sense the finality of moving to a nursing home and try to resist it in every possible way (Chatterjee 1998: 364). Residents may have emotions of grief, anxiety and perhaps anger of being moved to a nursing home. David Symons, who has studied elder-clowns across the world, also points out that there are many losses during a dementia course. There is a loss of sense of self/ role and being in the world (Symons 2012: 26). The dementia clowns allow residents to feel sad and feel this loss.

Signe suddenly said that she would soon be gone. Fru Fryd looked at her and listened to her carefully. "Then it is over, but then something else will happen" [så er det slut, men så sker der noget andet] she said. I felt my stomach clench and for a moment tears almost came to my eyes. I was not sure how the clowns would react. But Fru Fryd nodded and said "yes, then something else will happen" and Signe gave her a sad smile (Fieldnote, 04.12.2016).

It is often a tough experience hearing someone talk about their death, especially when it is imminent. I felt sad hearing Signe express these feelings. For a relative this expression of soon being gone might be painful to go through because it will result in a loss for them. Caretakers are also connected emotionally to the residents they care for. This might result in reluctance from caretakers and relatives to listen and talk about death with a resident. Signe seemed occupied with

her forthcoming death. When the clowns left her she also said that she was not sure she would see them again. The clowns accepted her talk about death. They acknowledged her point and comforted her by agreeing that something different would happen.

4.6 To remember

Even though the elderly with dementia have an impaired memory, this does not mean that they do not remember at all. Some remember things from their past, others have problems remembering the correct words and have a difficult time remembering names. Relatives remember the person with dementia as they used to be before they were affected by dementia. They mourn the loss of what has been.

The clowns do not have a memory of how the residents once were. However, they do remember them long after the visits are over. I heard many stories of particular residents that the clowns remembered and who, had come to matter for the clowns. One such story was of Kaja. I heard this story on my first day of observation while the clowns and I were driving to a nursing home.

Kaja lived in a nursing home where the clowns had done a longer course of visits when they started Forglemmigej. All the clowns had met Kaja and they were crazy about her. She had a deep and special sounding voice, and the clowns loved to imitate her. One day when the clowns were having a meeting, they started to imitate her voice again, but none of them could get it right. They just could not imitate her. A couple of weeks later, they were giving a speech at a conference about dementia. During the speech they showed a picture of Kaja. Afterwards a man approached them. He knew Kaja and told the clowns that she had recently passed away. When they heard the date they realized that she had died a day or two before their last meeting. The clowns said that they had felt this to be very moving, beautiful and weird. They connected her death with their inability to recall her voice (Fieldnote, 24.08.2016).

Although their relationship with Kaja only took place during several two-hour visits, she had become significant to them and they were sad to hear that she had passed away. Hr. Bønne became very fond of one resident, Solvej. He talked with her while she was lying in bed. When he left he kissed her hand and said “*goodbye beautiful*” [*farvel smukke*]. When we evaluated that visit, he said she had a special place in his heart (Fieldnote, 13.09.2016). He also mentioned her as someone special in his interview. In a way, Solvej had become a significant relationship he had had even though it only lasted for a few minutes.

The clowns care for residents by making them feel part of the society again. They treat them as persons, persons who they can flirt, joke and talk with. The clowns built on resident’s personhood by remembering them and cherishing those moments. While relatives remember what was lost,

clowns remember on a short-term basis. Their remembering treats residents as persons who are important enough to be remembered as they were in the meeting with the clowns.

The clowns also remembered the past with the elderly. Both their courting style and their songs were old fashioned. Clowns also triggered the resident's memories; some residents were able to remember the clowns from visit to visit.

Ib was in bed when the clowns entered his room. Fru Ballon took a kazoo from her bag and she started to play it. It sounded a little like a car-engine and she and Fru Fryd marched around the bedside while she played the kazoo. Ib got up from bed and he danced a short dance with the clowns. On his bedroom drawer was a red, heart-shaped balloon, which I recognized as the balloon the clowns had given him last time they visited. The balloon had lost quite some air since then. Fru Fryd pointed to the balloon and Ib said: "you gave me that last time you were here. It is six to seven weeks ago" [den gav I til mig sidst I var her. Det er 6 – 7 uger siden] (Fieldnote, 22.10.2016).

Just after the visit the caretaker told us that Ib had recently left the nursing home to search for his parents. When I checked my fieldnotes later that day, I could see that Ib had his facts straight. It had been eight weeks since the clowns had last visited him. Ib was not able to remember that his parents were dead, but he could remember the clowns and when their last visit took place. There was something about the clowns' costumes or their behavior, which made such an impact that they were remembered from time to time.

Although it did only occur once while I did my fieldwork, relatives were allowed to observe clown visits. The clowns told me that relatives were often a bit skeptical of clown visits beforehand. Some were anxious that the clowns would make fun of their demented parent. However, most relatives who observed the clown encounters found it very moving. The leader of a nursing home told me that she did not think that anyone, who had seen the clowns in action, would find them inappropriate (Fieldnote, 09.01.2017). Ida told me about one visit, which had made a huge impact on her.

Ida was clowning with a former colleague, Frk. Bi. They visited an old man at the same time as his wife and daughter were visiting. The clowns were very energetic and Frk. Bi made a balloon sword. The old man was very excited by this and Frk. Bi made yet another sword and the two of them engaged in a wild sword fight where they jumped in the furniture. Ida looked at the daughter and saw that she was crying. She immediately thought that she and Frk. Bi had overstepped an ethical boundary. After the visit she caught up with the daughter and asked her what had happened. The daughter told her that she was so happy. Seeing her father jumping around in furniture with a balloon sword had reminded her of her old father. He was always acting foolish and crazy (Interview, I).

The daughter was, through the clown's interaction, reminded about previous times with her father. Because of the cognitive impairments he did not have much in common with the father she used to know. But through the clown interaction she was able to see her "old" father in her father with

dementia. She did not only remember her father, she had the opportunity to recognize her father's personality, through the memories.

The clowns care for the residents by sharing memories with them. They also care enough for residents to remember them after their visit. Through the act of remembering clowns may bring residents and relatives closer to each other.

4.7 Control

As mentioned, life in a nursing home does not provide residents with much control. The clowns did not want to force their presence on persons who did not want them. They offered their visit to the residents. However, this offer of clown visit was handled differently by staff. The way the staff dealt with the offers was sometimes problematic

Sometimes caretakers told residents that the clowns were there and invited the clowns into residents' room without awaiting an answer from residents. Sometimes when the residents were asked if they wanted a visit it was not clear whether a resident understood the question. Perhaps residents refused a visit from a clown because they did not understand what a clown was. Or perhaps they did not want a visit. Sometimes a resident said 'no' when he meant 'yes'. Therefore, it was not always clear if residents felt forced to have a visit or if they accepted the offer freely. Even in the cases where residents refused a visit from the clowns this was not always accepted by caretakers. They would attempt to persuade the resident by telling them that the clowns were there especially for them, or by commenting on how funny the clowns looked.

The clowns were aware of their role as intruder on the residents' private space and of giving residents control of the situations. They would in different ways react and empower residents by letting them control the situation.

Bodil is sitting in her room at her table with a tray in front of her. It looks as if she has just finished eating her breakfast. There is a plate with bread crumbs and a glass of cordial on the tray. Marie, the caretaker walks into Bodil's room and says hello. The clowns follow her. Hr. Kanin looks at Bodil and asks her if it is okay that they enter. Bodil looks at him and says loudly: "Can he get out of here! [Kan han komme ud]. Frk. Æble walks over to the garden door, opens it and says: "You, get out!" [gå ud med dig] to him. Hr. Kanin walks out of the garden door and walks over to the window and looks in. He apologizes for just bumping into the room and asks if he can sing a serenade to Bodil. She accepts and he stands outside the window, strokes the guitarlele and begins to sing her a serenade (Fieldnote, 08.09.2016).

The caretaker Marie did not ask Bodil for permission for the clowns to enter. Asking for permission was thus a task which Hr. Kanin took on, which resulted in him being kicked out of the room. Hr.

Kanin accepted this, he did not know why he was thrown out and why Frk. Æble was allowed to stay, but he took the premise and attempted to make up for his rude behavior by singing a serenade to Bodil. During the next couple of minutes he was allowed to enter back into the room. Bodil was allowed to be in control of the situation. When she asked him to get out, he did. This would not have been the case if she had asked a caretaker to leave. Frk. Æble helped her control the situation by pushing Hr. Kanin out of the room.

The clowns also allowed residents to be in control by taking directives from them regarding behavior or how to move. Two of the clowns told me they had once been part of a fashion show. The female resident had instructed them how to walk and stand, and they had followed her directions. Maj also told me that during one visit a woman had looked at the clowns and told them their noses were no good. They had asked if they should take them off and she had said yes. She had allowed them into her room for two minutes to sing a song. Then they had to take their noses back on and leave (Fieldnotes, 20.09.2016 & Interview, M). The clowns never questioned an order from a resident.

The clowns met Vagn in the hallway. He sat in his wheelchair and they greeted him. After a while Hr. Kanin began to play music on his guitarlele. Frk. Æble stood close by Vagn, she smiled and made some singing sounds to him. Then Hr. Kanin began to sing as well. They sang for a short while until the man said: "that is wrong!" [Det er forkert]. Hr. Kanin immediately stopped and said: "yes it is". "It has to be in G-major" [den skal gå i G-dur] Vagn said. Hr. Kanin nodded and started to play a new tune. "Is this better" he asked. "Well, I do not know" Vagn answered. They all smiled at this (Fieldnote, 11.09.2016).

Whether the tune of the key was right did not matter, when Vagn said it was wrong, Hr. Kanin accepted this. Where residents normally are told what to do and when, they were now offered a position where they were in charge.

The clowns usually stated that they did not have an agenda with the meetings. They allowed for the resident's state of mind, ideas and health to shape the visit. The clowns all expressed that this was the hardest part of their job. Yet, sometimes they did seem to have an agenda. One clown told me, during an interview, that he had an agenda of playfulness (Interview, K). Sometimes the clowns were given information about a resident, which affected their interaction. A caretaker would perhaps tell the clowns that this resident had humor or liked to dance. This information sometimes made clowns overlook if this was what the resident wanted in that meeting. Maj told me how she had been informed that a specific man loved to dance. Instead of paying attention to his mood, she walked straight over to him and asked him to dance. It was not until he declined her offer that she

realized she had tried to force her own agenda on him (Interview, M). The clowns helped each other when their personal agenda seemed to overtake a meeting.

During a visit with Doris, she started walking across the room to where I was standing. She placed herself next to me and took my hand. While she walked towards me Hr. Kanin started to play the ukulele while he gently sang "ladidida". Hr. Bønne asked Doris if she wanted to dance. Doris did not hear what he said and said: "what?" Hr. Bønne repeated himself: "could one ask the lady to dance" [ku man byde fruen op til dans]. Doris said no. Hr. Bønne asked: "no? a little tiny dance? [nej, en lille bitte dans] and Doris again said no. "I will just stand here and dance a little then" [jeg står bare her og danser lidt så]. Hr. Bønne said. Hr. Kanin looked at him and said: "it was a no Hr. Bønne" [der blev sagt nej]. Hr. Bønne nodded and said "Oh that is right, we shall not do that then" [det er også rigtigt ja, det skal vi ikke så] (Fieldnote, 17.11.2016).

Hr. Bønne seemed so focused on dancing that he was unwilling to accept Doris no. But when Hr. Kanin reminded him of the no, he accepted it and allowed Doris to have control of her own body by refusing to dance.

Sometimes, as mentioned in my fieldwork report, the clowns overruled a resident's explicit wish for something. This was done when a clown felt certain that their refusal was not what they meant (Houmøller 2016: 17-19). Sometimes the clowns admitted that they failed to let the resident's agenda be the accepted agenda. But they attempted to let go of their own agenda and be controlled by residents. Letting go of control is a way of caring. This empowers residents and helps them express their personal wishes.

4.8 Caring

Care is not a one-way action; but something which goes back and forth between people. The clowns enable situations where residents have the opportunity to care for the clowns. Borneman states that in caring, the "I" addresses itself to other human beings with whom a relationship of reciprocity is established. According to him there is a possibility for reversal of roles, so that the person who cares for another is later cared for by that person (Borneman 2001: 43). Patch Adams states that care and love is not about control, but about giving and receiving (Adams 1998: 36). He too points to the double bond of care, it is both something a person gives and receives. The clowns transform the residents from the object of care, to the subject of care.

In the nursing home residents have limited possibilities to care for the staff. They cannot help them in the same way as the staff helps them. However, through clown visits the elderly are given the opportunity to care for the clowns by helping them.

The clowns were told that they should make an appearance in the common room and greet the residents there. There are four tables with people sitting around them and in the back of the room there is an empty table. Fru Ballon and Frk. Æble start to greet the people sitting around the tables. Fru Ballon walks over to the empty table and climbs on top of it. As she stands on the table she suddenly looks very nervous and says: "it is very high up here" [det er godt nok højt her oppe]. Frk. Æble notices her, rushes over to her and urges her to come down. Fru Ballon says that she cannot come down, she is afraid. Frk. Æble then walks over to a man sitting in a wheelchair and asks him if he can help her, but he says no. Then she walks over to another man who agrees to help her. They walk over to the table where Fru Ballon is standing shaking with anxiety of the height. The man and Frk. Æble holds Fru Ballon's hands and they help her to step down on a chair and then down on the floor. As Fru Ballon sets foot on the ground again everybody applauds. Fru Ballon hugs her rescuer (Fieldnote, 29.08.2016).

Although getting down from a table seems rather easy for adults, it proved impossible for this female clown. The man who helped her get down was given the opportunity to be very special; he was the one to rescue the clown. He cared for her by helping her. The clowns and especially Fru Ballon often made themselves helpless or vulnerable. By presenting themselves this way, they enacted situations, which could hopefully make caring subjects of "I will help" or "I will rescue" emerge.

Margalit states that caring is an attitude which suggests constant worry and apprehension about possible dangers (Margalit 2002: 36). He sees caring as a form of protection. Caretakers protected their residents from danger. They tried to shield residents who could be over-stimulated by impressions from the clowns. Staff also worried that residents would fall and hurt themselves. Residents, who could walk, were at times asked to move into a wheelchair so they would not fall. Sometimes this protection made the residents passive.

We were going down the hallway when a man in a wheelchair rolled towards us. "Good day" said Frk. Æble and the man raised himself from the wheelchair to a standing position. "You do not need to do that" [det behøver du altså ikke] said the nurse. The man continued to stand and took Frk. Æble's hand. The nurse and occupational therapist hurried to stand on each side of the wheelchair to support him if he got unsteady. He smiled at Frk. Æble and said: "You have to hold on tightly" [du skal holde godt fast]. Frk. Æble promised to do so with a big smile (Fieldnote, 10.09.2016).

This man was able to stand, although not very steady. It seemed important to him to greet Frk. Æble in a suitable way, by standing, however, staff encouraged him not to do so. Through the clown visits residents were given the opportunity to worry about and protect the clowns. Although some residents were severely impaired by dementia, they were still able to show their care and concern for the clowns. Taylor describes how her demented mother told her to lay down and rest after a busy day. Taylor states that even though she takes care of her mother now, her mother is still able to care in small, but important ways (Taylor 2010: 48). This was also the case with residents I met during my fieldwork.

Residents also helped the clowns take care of something else. During one visit, a rubber chicken played different roles. One resident started to stroke the chicken carefully, and one clown found a tiny cloth, which was placed over the chicken as a blanket. Then the resident and the clown looked fondly at the chicken. Frk. Æble presented her set of dentures to a female resident. The denture set was a windup toy which could move quite quickly. Frk. Æble told the woman that she had to keep an eye on it, otherwise it would disappear, and the woman promised to look after it (Fieldnote, 02.12.2016, 16.09.2016).

The residents did also show tender care for some staff members and in several nursing homes it was clear that staff and residents had a special bond. The clowns also acknowledged this. They commented that they could see this care from both residents and staff. The clowns helped some residents express their caring feelings for staff members by exaggerating or mimicking it. Mimicking was a special clown technique, a clown educator told me. Through mimicking a person's feelings or behavior, the clown could show that he had seen this person (Interview, C). Mimicking is also a way the clown subject addresses itself to the resident. People with dementia are often overheard, but when the clowns imitate their feelings or behavior, they may help others understand that this is important; this must be heard. The clowns are the mediators between residents and caretakers. Their liminal position in between, bridges the gap between caretakers and residents. By mimicking behavior, they amplify this and make reciprocity between residents and caretakers possible.

While the clowns visited Yrsa, a caretaker student was seated in the corner of the couch observing the conversation between Yrsa and clowns. Yrsa pointed to the student and told the clowns that she was wonderful and sweet [vidunderlig og sød]. Frk. Æble asked Yrsa "is it your girl?" and Yrsa said "yes". Fru Fryd opened her arms widely and walked over to the student and hugged her. The student blushed and giggled while she hugged Fru Fryd (Fieldnote, 10.12.2016).

Through hugging the student and asking if she was Yrsa's girl, the clowns embodied Yrsa's feelings and cared with her for the resident.

4.9 Comparing the two logics

Margalit states that care gives us a sense of belonging. It makes the other feel secure (Margalit 2003: 34). The clown-care is built on respect for the individual resident and attempts to give that person a feeling of belonging, accept and love. The care is not anonymous; it has a specific object of care. Neither clown nor resident can be replaced in that specific clown-care which is provided to the resident through a clown visit. In the logic of the nursing home care, both caretaker and

caregiver are replaceable. The nursing home care model is built on the premise that when staff is well trained, it does not matter who the caregiver is, and it should not matter who the care-receiver is either. However, people have different needs and it does matter who gives and who receives care. The logic of clown-care focuses on the small details which together make the framework for understanding the needs, wants and possibilities a particular resident has.

Nursing home care tends to be protective towards residents. They are shielded from taking risks, such as walking, and from things which might upset them. Clowns did protect residents, but they also allowed residents to take risks, such as the man who rose from his wheelchair to greet the clown. Residents in a nursing home are not expected to care for the staff that cares for them; the logic of nursing home care is a one-way care. In the logic of clown-care residents are not required to, but they have the opportunity to care for and about the clowns. The logic of clown-care is a two-way care. Nursing home care is built on care *for*; the staff attends to the physical needs of residents. The clowns care *about* the residents, their emotions, their stories and their selves. As Hendriks points out, dementia clowns help and support the residents' connection to the world (Hendriks 2016). They make them feel as persons belonging in the world.

Chapter 5 A clown's understanding of dementia

It is a sleepy afternoon at the nursing home. Otto, Ruth, Ella and two caretakers are drinking coffee in the kitchen. The caretakers are standing at the sink talking, while the three residents, who seem tired, are seated at the table. Fru Fryd walks over to Otto. She is dressed in a yellow sleeveless dress which stops just above her knees. She bends towards Otto with a big smile on her face and says: "Good day Otto". He smiles at her and says "Good day". Fru Fryd stands up again, winks at him and asks him what he thinks about her new dress. While she asks the question she turns around herself. Otto looks at her with a little smile and says: "it is damn fancy" [den er skide smart]. The two caretakers act very surprised, they start giggling and whispering surprised with each other. They do not seem to think that Otto would normally say those kinds of words (Fieldnote, 22.10.2016).

The dementia clowns in Forglemmigej have a different way of understanding dementia than caretakers and relatives do. Their understanding puts residents in a positive light. This understanding is an important part of their clown-care. In this chapter I discuss the impact of the clowns' understanding and look at what we can learn from the logic of clown-care. Clowns are becoming very popular in care-settings and I will discuss why this is the case. I begin this chapter by determining the differences in the type of relationship that clowns establish with residents compared with the relations which relatives and caretakers establish.

5.1 Clown relations vs. non-clown relations

So far I have shown how the logic of clown-care operates and what this care entails. While the clowns' way of meeting people may seem like a wonderful, openheartedly embrace of the resident this is only possible because the clown does not have an established relationship with the person beforehand. The clown lives in the here and now. There are no family-bonds, expectations or life-history between clown and resident. Although the clowns remember residents and the time spent with them, they do not mourn the loss of what has been. Hendriks points out that while caretakers and relatives try to hold on to the identity of the person with dementia, the clown is an outsider and lacks shared history. He is therefore able to meet the person anew (Hendriks 2016).

A wife or child of a person with dementia has a history with him. They have a set of expectations to how this relationship should be. They have known him before he was affected by the disease. The relative is embedded in feelings of loss and has to learn to cope with the new situation and with the disease. Taylor describes the concepts of '*stills*' and '*first*'. The '*stills*' are questions, asked by health care professionals about what her mother with dementia is still able to do. The '*firsts*' are the first time experiences with her mother; the first time her mother asked where her late husband was, or the first time she needed her daughter's help in the shower (Taylor 2010: 30-31). These were actions and situations which changed Taylor's relationship with her mother. It did not change the fact that her mother was her mother, but it affected their relationship. Residents with dementia as well as relatives need to figure out how to live with these changes. They have a past history and expectations to each other which makes it difficult, if not impossible, to live in the here and now and meet each other anew.

The caretakers cannot fully meet the residents as the clowns do simply because they need to take care of them. While the clown-care takes care of the person, and makes them feel like a person, caretakers in the nursing home take care of the physical body and keeps residents safe and alive. Staff has to provide food and medicine and change pads. This has to be done even when residents do not want to or do not understand the need for these actions. The nursing home staff has an agenda with their actions. They cannot accept when a resident resists medicine or does not want their pad changed. They do this care-job for the benefit of the resident.

Clowns on the other hand can accept a rejection from a resident. It is not a matter of life and death if they meet a resident or not. Even when the clowns meet a resident several times, they strive to meet him anew each time. The clowns in Forglemmigej were aware that their relationship with residents lacked expectations and agenda. One clown, Kim told me in an interview:

K: We do not have an emotional relation to the person we are sitting towards [vi har ikke en følelsesmæssig relation til det menneske vi sidder overfor]

I: no [nej]

K: And that gives a certain freedom in connection with (...) not being caught in, or how shall I phrase it weighed down by, if it for instance was my mother I was sitting towards who had dementia, then there would be plenty of things I would have difficulties doing, because we have a relationship, we have a relation and we have something which is called expectations, there is some sadness, and all these things, that I do not possess [og det giver en vis frihed i forhold til ikke at blive fanget i eller hvad skal man sige altså blive tynget af, hvis det nu var min mor jeg sad overfor der var dement, så ville der være en masse ting som jeg ville have svært ved og gøre fordi at, at vi har et forhold, vi har en relation vi har noget, der er noget der hedder forventninger, der er noget kedafthed og alle de der ting her som det har jeg jo ikke med mig]

I: mmm

K: Neither do I have an agenda saying that I need to make this person either eat a pill or take a shower or all these things, so in a way you can say that I come without other agendas than being there for the person who is there [jeg har heller ikke en dagsorden om at jeg skal få det menneske jeg står overfor til og enten at skulle spise en pille eller komme ud i bad eller alle de ting her så på den måde kan man sige at fordi at jeg kommer og ikke har andre dagsordner end at være der for det menneske der er der] (Interview, K).

Kim points out that his focus is meeting the person; he is freed from agendas and feelings, while a caretaker's or relatives' relation is affected by these things. The condition for the clown-care is that it acts in the present moment; free from expectations, agendas and losses.

5.2 Disease of loss

Dementia is a disease of losses, loss of memory, cognitive abilities, language, control etc. It results in loss of roles and understanding of one's own situation. It is also a disease with painful losses for relatives. Rikke, a nursing home leader described the loss as a slow loss, because: "*they will lose their father and mother several times*" [*De mister jo deres far og mor flere gange*] (Interview, R). I found that there was a tendency to focus more on how terrible the disease was for relatives than for the person with dementia. My grandmother told me about a couple, she knew, where the husband had dementia. He no longer recognized his wife. My grandmother focused on how terrible this disease was for his wife.

Birgitta Andersson and Agneta Ingberg write about Ingberg's course of dementia. Ingberg wrote the introduction, while Andersson took over writing the rest of the book as the disease made it impossible for Ingberg to do so. Ingberg states that she is tired of having the disease of the relatives: "*the relatives have their anxiety and their troubles, but as long as I am able, let me be sick!*" [*De pårørende har deres angst og deres vanskeligheder, men så længe jeg er habil, lad mig dog så få lov at være syg selv*] (Andersson 2007: 9). It is striking that there is such a focus on relatives in literature about dementia. Cohen describes stories about dementia as narratives of loss. He underlines that dementia is a social disease. A family is a social entity and when one part of that entity is affected, the rest of the social group is affected (Cohen 1998: 37, 49). The disease does affect the relatives, but one could say that all diseases affect the relatives of the diseased. Yet there is a tendency to focus more on the loss for relatives in connection with dementia compared to for instance relatives of a person with cancer.

Ingberg and Andersson states later on that relatives and the diseased person cannot be separated. They point out that relatives as well are affected by the disease (Anderson 2007: 76). Dementia

does make changes for both diseased and relatives and it affects their relationship with each other, but the tendency to leave the person with dementia out of the story is problematic. Pia Kontos and Gary Naglie point out that the common focus on loss of selfhood makes people treat persons with dementia as if they are unable to experience humiliation and pain (Kontos & Naglie 2007: 551). This is problematic for the respect towards people with dementia and this view and behavior is part of what Kitwood terms malignant social psychology (Kitwood 1997: 46).

When I spoke with caretakers about dementia they all focused on the losses and on how terrible the disease was. One caretaker said it quite frankly the first time I met her: “It is a shit-disease” [det er en lortesygdom] (Fieldnote, 02.09.2016). I did experience loss, sadness and despair in the nursing homes. The dementia clowns did not deny this. They told me several times that dementia was terrible. However, when they made clown visits they did not focus on the loss. They focused on the human being, not the disease. This was different from how I saw relatives and caretakers relate to and understand the disease.

5.3 Clowns understanding of dementia

The dementia clowns often told me positive things about residents with dementia. They said that they were inspiring and adorable. During a visit, Herla looked at Fru Ballon and out of the blue said: “*you have a lot more in your backpack than I have*” [du har meget mere i rygsækken end jeg]. Fru Ballon was moved by this, she felt that Herla had been able to see right through her. She and Hr. Bønne agreed that some residents were insightful and had a special wisdom (Fieldnote, 03.09.2016). Although I did hear caretakers express that they liked a resident or I saw them hug or smile to a resident, I never heard them express comments like this. The clowns have a way of understanding people which makes them valuable and which provides them with an opportunity to be understood differently than merely residents with dementia.

One of the clowns, Line explained how she understood dementia: “*it means that you are deprived many of your, what can I say, normal abilities, normal ways of being in the world as an adult*” [det vil jo sige at du bliver frataget mange af dine, hvad kan man sige, normale evner, normale måder at være i verden på som et voksent menneske]. Line focused on the change as something different from what is considered normal. Later she told me that people with dementia in a way came into an absurd or a surreal world. According to her this world was difficult to accommodate for relatives and caretakers. But the clown was able to be in this world (Interview, L). Line agreed that there

were losses and changes of personality. However, she still talked about a human being and focused on the difficulties others had of accepting these changes. In a way she suggests that people with dementia have difficulties acting in the normal way, and that relatives do not fully understand the situation that a person with dementia is facing. Cohen describes the familial body in India. This body consists of the different persons in the family. When a person in the family changes behavior because of a dementia disease, it affects not only how he is seen or treated, but how the whole family is seen and treated (Cohen 1998: 177). Relatives may therefore wish to keep their “familial body” as normal as possible by making the person with dementia act as normal as possible.

The clowns did not question this surreal or absurd world. They did not judge behavior. For a clown there is no normal way of acting, just new ways of being. The clowns know that the person they visit used to be something different, used to act in a “normal way”, but this does not matter for their meeting with this person. What matters is the here and now. This is a crucial contribution to dementia care. The clowns’ understanding of dementia and the logic of clown-care prove Davis wrong. While he states that dementia dissolves personhood, the logic of clown-care shows that this is not the case. Residents with dementia were able to share memories, care for others and express feelings during clown visits. Does this not prove that they are persons? From the viewpoint of the clowns and their understanding of dementia, one could question Davis’ perspective on dementia and personhood. Are people with dementia no longer persons or could it be that *we* are not capable of granting them this position in the way we treat them?

Clowns are in a privileged position because they have neither emotional bonds nor agenda when they meet a person. However, we can learn from the way they meet and understand people with dementia. It is possible to focus on what is, instead of what was. This does not mean that we deny or leave the “old person” behind; it means that we meet him where he is now. It is possible to look beyond the losses and see the present instead. When Taylor describes the ‘firsts’ of her mother’s disease she points out that not all ‘firsts’ have been bad. She describes some of the firsts, such as tucking her mother to sleep or walking hand in hand, as “*tender moments that I cherish*” (Taylor 2010: 31). A dementia disease is a “shit-disease” but it could be an easier disease to live with and in if there is a focus on the present circumstances instead of on the losses.

Opening up and meeting residents as they are without judging them by the “normal” standard creates an opportunity for active residents and for an acknowledging treatment of residents. It is a way of understanding people with dementia, which focuses on the fact that they are persons.

Besides from contributing to the understanding of dementia, I will now discuss how the clowns further supplement the official system of care in various ways.

5.4 Learning from the clowns

The clowns do not deny that relatives are affected by the disease but during visits they focus entirely on the resident and his needs. The clown-care they provide focuses on what it means to be human. It supports the person's feelings, expressions of different roles, self-esteem and it creates situations where residents are *seen* and able to be active. The clown-care concerns the whole being. Caretakers in the nursing home take care of the residents' physical needs. However, the clowns' understanding of dementia and their care shows that there is more to life than just having the physical needs covered. Roughly speaking caretakers in nursing homes help residents *survive*, the dementia clowns help them *live* as persons.

Caretakers do see residents as humans and yet their care sometimes neglects this aspect. Clowns can teach us to see residents with dementia as subjects and not simple objects of care. Care in a nursing home is anonymous, it does not matter who cares or who is cared for. The logic of clown-care states the opposite. It does matter because this care is between two persons. How they are, how they relate and how they see life is not standardized, it is dependent on context and personality.

The clowns focus on the present moment and not the past. This means that they care with the actions and communication style the resident presents. When they mimic behavior or hum along with a resident it is not to make fun of them. It is their way of addressing themselves to another person. They try, as Hendriks explains, to incorporate the world of the other; to approach the others' experience (Hendriks 2016). Clowns do not measure behavior against a 'normal' standard. We can learn openness from the clowns and learn to accept that people have different reactions and different ways of being in the world. For a clown this acceptance creates opportunities to meet without judgment and to relate in the present moment. For caretakers it could change the concept of troublesome residents into simply residents or persons. Not aiming at changing behavior but going along with behavior might make care-tasks easier in the long run.

Clowns are careful beings. They are full of care, but they are also cautious, thorough and alert. They care *fully* for the residents they meet, but they are also on the lookout for subtle changes in the resident's behavior. Most caretakers in the nursing homes also care fully for the residents. Their

way of caring is ungrateful. They care, even when residents resist the care, because staff knows that their actions will benefit residents, even though it is unwanted.

Hendriks shows how a dementia clown does not dare to walk across a tile-floor because she knows that some residents with dementia experience this floor as dangerous (Hendriks 2012: 463). The clowns in Forglemmigej were also aware that distance, objects and words might not mean the same thing for them as for the resident. This sensitivity made it easier to make changes when the situation required it. Most caretakers in nursing homes are excellent at caring, but they are restricted by low budgets, tight timeframes and a lack of knowledge about dementia. Careful care takes time. Care can be done quickly and efficient, but then it is not a careful care; it is a care which makes residents passive and which may fail to see attempts of communication or expression of personhood.

Although the clown is careful it is also daring. Clowns dare to crack a joke or do a weird action or they attempt something new even though they do not know how it will turn out. The clowns do not have a prepared performance. They try things. However, because they are careful, their actions are not harmful. On the contrary their actions might benefit residents. Caretakers need to forget routine. They could try to be in the here and now and sometimes it might be necessary for them to take risks. Clown visits might help caretakers take more risks. They should still be considerate, careful risks, but as several clown visits show there is no harm in making a daring attempt.

Just as the clowns see residents as persons they also see caretakers as persons. They are aware that their clown abilities and skills are different from the skills and abilities of caretakers. Caretakers are also aware of the differences. One caretaker told me that although she did not think staff should dress up as clowns, she still thought they should learn from the clowns. When staff was prepared for the clown visit things were easier for both staff and clowns. Britt, the leader of a nursing home said that the clowns and staff could make each other better (Fieldnotes, 26.10.2016, 21.10.2016). The clowns bring recess, inspiration and liminality to the nursing home. Caretakers should not aim at being clowns. This would not be possible, since they are not liminal beings. But they might try to be inspired by and learn from the clowns' approach.

5.5 A world in need of clowns

Clowns are becoming increasingly popular these years. DHK are currently expanding to several new fields. They have recently started to make clown visits in children's psychiatric wards, and they are preparing to start to visit children with autism. The worldwide organization Clowns

Without Borders⁷, which was founded in Barcelona in 1993, visits refugee camps, conflict zones and territories in situations of emergency. In 2016 they visited refugee camps in Haiti, Kenya and Lesvos to name a few places (cwb-international.org, clownswithoutborders.org). Raviv describes how he as a medical clown was used to treat patients with trauma during the war in Gaza from December 2008 until January 2009. He and his clown colleagues were summoned to the hospital along with nurses and doctors (Raviv 2012: 175).

The last couple of years DHK have had more than 100 applicants for their clown education. There is also an increased interest in finding one's own personal clown. Dream states that through the last decade the number of people enrolling in clown courses have grown (Dream 2014: 16). My informant Patrick, who teaches clown courses, also experiences an increased interest in clown courses (Private message, 21.04.2017). Why is there suddenly an increased interest in clowning and what does a clown in a refugee camp and a clown in a nursing home have in common?

Whether the clown works in a hospital or in a refugee camp the clown has a holistic way of approaching people. According to Raviv, the clown transforms the site where he acts (Raviv 2012: 173). A refugee camp is thus suddenly transformed from a site of despair to a place of laughter and fun. Peacock writes that play is a style of communication (Peacock 2009: 150). Through play, clowns are able to communicate with people who are traumatized by disease or war. This break allows patients to forget the traumatic experience for a while and it helps the patient to overcome the trauma.

There is a general agreement that human beings are more than our bodies and we have different needs. The medical world is realizing that there is more to curing and caring for people than treating their diseases and wounds. Both the expansion of DHK and Raviv's story of clowns treating traumatized patients during the war in Gaza, shows an increased interest in medical clowning. Patrick suggested that people are interested in clown courses because there is a general need in society to experience good things (Private message, 21.04.2017).

Peacock raises the concern that clowning might be over-stated. She points out, referring to Maslow's hierarchy of needs, that people cannot enjoy clowning if their basic needs are not met. Peacock also questions the transferability of clown-humor from one culture to another. She thinks that the money spent on sending clowns to refugee camps could have been spent on food or

⁷ Hereafter CWB

medicine instead. She states that clowning is not a panacea (Peacock 2009: 150-151). Although there seems to be some truth in Peacock's concerns regarding transferability of humor and the economic costs of sending clowns out, she seems to overlook an important factor.

Care clowns and CWB do not claim to be a panacea. They do not work on their own but aim at contributing to health and care with their abilities as clowns⁸. The clown contributes to health and care by paying attention to the whole person. Whether the clown acts in a nursing home or in a refugee camp the clown contributes by easing the spirit. Furthermore, the clown is able to *see* a person. This is something which is overlooked in refugee camps and in hospitals. The clowns are not to be understood as miracle makers who claim to be a universal cure; they are to be seen as an addition to health care, a liminal being, but a careful contribution to the existing system.

I suggest that the increased interest in clowns and clowning is a tendency to break with the general focus on money and strict timeframes in health care. It is a movement urging for a different understanding of what it means to be a person and what it means to care for others. Patrick recently told me: *"Seeing through the clown eyes we see much more, we see life, we see death. We let people be who they are and find their light, even if it might seem gone"* (Private message, 21.04.2017). The clown not only teaches us important things about being a human being or relating to other human beings. It teaches us new things about ourselves. It makes it possible to relate with people who are different from us. This ability, to understand ourselves differently and to meet the world and other people with new eyes, is an important contribution clowns add to the world.

⁸ Van Blerkom also states that it is irrelevant to discuss whether clowns have effect in themselves. She states that clowning enhances biomedicine. See Van Blerkom 1995

Chapter 6 Conclusion

To be a person one has to take initiatives, have memory, act carefully and controlled and one has to be able to communicate with others. For a person with dementia these tasks are difficult to act out. Because of the disease cognitive abilities are lost, communication and actions are changed and the ability to remember is impaired. This means that people with dementia are often treated as something in between a living and a socially dead person. They are spoken off as if they are already gone, and they are treated in a routine-based, standardized way. They are not cared for as subjects, but rather as objects of care.

The dementia clowns in Forglemmigej do not meet residents with dementia as objects. They meet them as subjects. Through the meetings and through the care the clowns provide residents are supported in being and feeling like a person. The dementia clowns provide a careful care to people with dementia. They are full of care for residents, and they are carefully tailoring their visits, communication and play to the individual person. While the care provided by the nursing home staff is anonymous, the clown-care is the opposite. In the logic of clown-care who we are matters intensely. By paying attention to the specific person, his way of communicating, his state of mind and his feelings, the clowns reintroduces him as a person in the nursing home. They connect the person to the world as a living being who belongs there.

The clown role is a liminal position. Clowns introduce a state of carnival and liminality and through their visit residents and caretakers may experience *communitas*. Being a liminal being, clowns change the normal standard of rules and behavior. This supports residents with dementia by making their break of social rules acceptable. The carnivalistic mode they introduce turns order in the nursing home upside down. Residents are empowered through the clown visits. In the logic of clown-care normal is annulled. Clowns live in the here and now; they do not evaluate residents against a specific standard. They accept what is here now as the new normal.

Clowns bring newness to the nursing homes. They bring new life, new ideas and they facilitate new meetings between residents and nursing home caretakers. This happens through the shared *communitas* experience and it happens when the clowns support residents' expressions of themselves as subjects. Caretakers are reminded to see what is here now and not what is lost through the disease.

The logic of clown-care does not claim to heal the world or the specific person. It operates as a supplement together with other logics of care. The clowns attempt to bring life, laughter and recess to nursing homes. And they try to inspire caretakers to learn from the clowns. Clowns are interested beings who attempt to meet others without judgment. As anthropologists do, clowns strive to learn from others and through their meetings learn more about themselves.

Clowns and their “logic of care” cannot only provide us with a different understanding of what it means to have dementia and to be a person. It also gives us a different perspective on care for people with dementia. This new understanding of dementia and care could also be useful in other areas. Clowns could provide us with a different way of meeting and understanding people with other psychiatric diagnosis. Through the eyes of the clown we could learn to meet them in the here and now and throw away our judgment and standardizations. The clowns teach us important things about ourselves and about what it is to be human. This knowledge might influence not only how we meet people but also how we structure care. What is a good “logic of care”? One which focuses on strict timeframes, money and routine? Or a careful care which makes patients and residents feel as persons again. A care which focuses on subjects and not just on tasks to be done.

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Appendix A



DEMENS CENTRUM AARHUS

AARHUS KOMMUNE 

DEMENS Gennem TIDEN

ANTIKKEN

Der er først i nyere tid kommet fokus på demens som en ikke-normal tilstand. Tidligere blev demens uløseligt forbundet med alderdom. Man mente, at det var en naturlig konsekvens af at blive gammel. Derfor talte man i mange år om **Dementia Senilis**.

Demens betyder på latin (*ade*) af *sind*. **Senil** kommer af det latinske *senex* der betyder *gammel mand*. Dette sås i det romerske senat, der udelukkende bestod af mænd over 60 år.



Aristoteles (384 f.kr. – 322 f.kr.) *Cicero (106 f.kr. – 43 f.kr.)*

Den græske filosof Aristoteles om ældre, formodentlig demente mennesker: *ondskabsfuldhed, mistro, smilighed, frygtsomhed, egoisme, skamløshed, at leve i erindringen, heftige vredesudbrud, hang til jammer.*

Den romerske filosof Cicero i 44 f.v.t.: "... sådan er det også med den gammelmandstålbelighed (*senilis stultitia*), man plejer at kalde *senilitet (deliratio)*; den rammer ikke alle gamle, men specielt de flygtige og ustabile (*senum levium est*)".

Demens har haft mange benævnelser gennem tiden:

Gammelmandstålbelighed	Senil ofsnidighed
Alderdomsløvsynd	Præsenil psykose
Tåbelighed	Forkalkning
Forykkethed	Gåen i barndommen
Alderdomssvækkelse	Senil Demens
Senilitetens sindssygdomme	Senilitet
	Præsenil

Gennem 1800-tallet blev alderdom en ofte anvendt medicinsk betegnelse for sygdom, og diagnosen senilitet dækkede nu over **mentalt forfald** i alderdommen.

Psykiateren Esquirol beskriver 1838 senil demens som en ikke-normal tilstand: "**Demens er en hjernefælde, almindeligvis kronisk og feberfri, karakteriseret ved svækket opfattelse, intelligens og viljesammenhængende tanker, bristende intellektuelle og moralske egenskaber er symptomer på denne lidelse.**"

1800-TALLET



Jean-Etienne D. Esquirol (1772 – 1840)



Alois Alzheimer (1864 – 1915)

I 1907 opdagede den tyske læge **Alois Alzheimers** nogle mikroskopiske forandringer i hjernebarken hos en midaldrende kvinde, **Auguste D.** der var død med svære demenssymptomer. Der kom nu opmærksomhed på, at demens ikke skyldes alderdom. Andre sygdomme der forårsager demens er bl.a. vaskulær demens, Levy Body, parkinsonisme, frontotemporel demens og Huntingtons Chorea.

Der manglede stadig retningslinjer og dermed enighed om, hvornår et menneske kan diagnosticeres med demens. Den franske psykiater **Poul Reiter** udtaler i 1954 om diagnosen senil demens, at det er "**en klinisk brokasse, indeholdende en mængde forskellige strandingsgods.**"

Tværsnit af hjerne, en rødd og en ryg hjerne (her Alzheimers sygdom)



1900 - 1970



Marie Curie (1867 – 1934)



Ronald Reagan (1911 – 2004)



Sugar Ray Robinson (1918 – 1966)



Margaret Thatcher (1925 – 2013)



Peter Falk (Columbo) (1927 – 2011)



Peter Szon (1936 – 1975)



Auguste Deter (1842 – 1906)

I midten af 1970'erne blev demens en del af WHO's officielle sygdomsklassifikationsystem ICD, og der kom mere ensretning indenfor området.

Det er dog først i løbet af 1990'erne at demens bliver mere og mere adskilt fra alderdom, da man i højere grad begynder at orntale det som **demens** i stedet for **senil demens**.

NUTIDEN



ICD-10 Demensriterier

I	1. Svækkelse af hukommelsen , især for nye data
	2. Svækkelse af andre kognitive funktioner (opmærksomhed, orientering, dømmekraft)
	Svækkelsegrad af demens (for udvælgning revideret)
	Lidt : Interferer med almindelige daglige aktiviteter
	Moderat : Patienten kan ikke klare sig uden hjælp fra andre
	Svær : Kontinuerlig pleje og overvågning nødvendig
II	Bevaret bevidsthedsklarhed i et omfang tilstrækkeligt til at bedømme kriterium I
III	Svækkelse af emotionel kontrol, motivation eller social adfærd med mindst ét af følgende symptomer:
	1. Emotionel labilitet
	a. Irritabilitet
	b. Apati
	c. Uoprettet social adfærd
IV	Varighed ≥ 6 måneder

Alle fire kriterier skal være opfyldt (1-IV) inden for 6-12 måneders observation af demens. Senil demens (diagnose) udelukkes for mindre end 1 måned.

MENNESKET MED DEMENS I 1800-1900-TALLET

1800 - 1950

Langt op i tiden havde hver enkelt overlæge sin klassifikationsmåde. Da man ikke havde en fælles definition af, hvad demens er, findes der ikke samlede optegnelser over antallet af mennesker der led af demens. Men i kraft af den forholdsvis lave levealder og gennem 1800-1900-tallet har der formodentlig ikke været mange mennesker med demens.

Der findes derfor heller ikke megen dokumentation for, hvor i samfundet mennesker med demens befandt sig. Man indrettede sig efter vilkårene. Det vi dog ved, er at nogle af de allermost syge har voldt store udfordringer for familie og omgivelser og har tilbragt længere tid på datidens sindssygeanstalter.



Vi formoder at mange har boet hos familier og således er blevet rummet i samfundet.
(Billede: Vejby-Risskov Lokalhistorisk samlng)



Således blev den syge svigermor rummet her, i bunden af svinstalden.
(Billede: Psykiatrisk Museum, Risskov)

1950 - 1970

Op gennem 1950'erne, 60'erne og 70'erne så man hyppigere indlæggelser af mennesker med demensproblematikker, herunder var mange langtidsanbragte. De var ofre for datidens **asyltanke**, og man nænede ikke at udskrive dem, når de blev indhentet af den fysiske alderdomsvækkelse. Flere har haft folke-registeradresse på eksempelvis sindssygeanstalterne **Jydske Asyl** i Risskov og **Skt. Hans** i Roskilde.

Virkeligheden på statsanstalterne var bl.a. 12-sengsstuer, ingen privat tøj, man fik udleveret to sæt tøj, sommertøj og vintertøj. Privatlivet bestod af et skab og et sengebord. Og behandlingen bestod af **sengeleje, kraftig medicinering og i nogle tilfælde fiksering.**

Johannes Nielsen om de lukkede afdelinger 67 og 68: **"Patienterne er hovedsageligt skizofrene, mani-depressive og senildemente, og de fleste er langtidsindlagte. En enkelt patient har været på afdelingen i 56 år".**



Jydske Asyl i Risskov
(Billede: Psykiatrisk Museum, Risskov)



8-sengstue
(Billede: Psykiatrisk Museum, Risskov)



Skt. Hans i Roskilde
(Billede: Psykiatrisk Museum, Risskov)

Stue for urolige patienter
(Billede: Psykiatrisk Museum, Risskov)




I slutningen af 80'erne kom der fokus på, at mennesker med demens fremover skulle behandles i lokalt regi
(Billede: Sygepsykiatrisk Museum, Falding)




1970 - 1990

I midten af 70'erne begynder billedet at vende. I forbindelse med at statsanstalterne overgår til amterne ophører asylfunktionen. Dels som følge af sparekrav, der skulle nedlægges sengepladser, og dels som følge af krav om øget kvalitet. Man gik nu i gang med at "genplacere" og inkludere de demente i samfundet på almindelige og psykiatriske plejehjem.

Samtidig med oprettelsen af gerontopsykiatrisk afdeling på Psykiatrisk Hospital i Risskov i 1987 udvikles distriktspsykiatrien i Århus Amt. Og da man i 1989 helt frarådede indlæggelse af mennesker med demens, kom der øget fokus på, at mennesker med demens fremover skulle behandles i hjemmet og på lokale plejehjem.




**DEMENS
CENTRUM
AARHUS**

AARHUS KOMMUNE 

NYE STRØMNINGER I DEMENSOMSORGEN

Som følge af tanken om **inklusion** af mennesker med demens i lokalsamfundet følger nye udfordringer. Demensomsorgen stemmer nemlig dårligt overens med en moderne ældrepolitik, hvor den ældre skal være aktiv og kritisk. Hvor omsorg er et tilbud, den ældre selv skal gøre krav på. Mennesker med demens stiller ikke krav om omsorg, de trænger til omsorg.

Der kommer derfor fokus på at mennesker med demenssygdomme kræver en specialiseret omsorg. Man opretter bl.a. uddannelse for demenskoordinatorer. Ligesom specialuddannelse af plejepersonale i kommunerne bliver derfor prioriteret.



Inklusion?

AARHUS ANTICORRUPTION

KURSUSBEVIS

AARHUS KOMMUNE

TEORIER OG TILGANGE

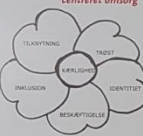
Personcenteret omsorg: Den demente behandles som en person med oplevelser, selvfølelse og rettigheder. Den demente er en aktiv samarbejdspartner.

Validering: Adfærd bærer mening, og værdien og gyldigheden af den dementes oplevelser anerkendes. Formålet er at øge selvfølelse og mindske stress.


Reminiscens: At styrke identiteten og følelsen af kontinuitet gennem vækkelse af minder.

Realitetsorientering: At orientere den demente i sin hverdag, tid, sted og egen situation

Tom Kitwoods model til Personcenteret omsorg



Reminiscens vækker minder



80'ERNE OG 90'ERNE

I 1980 indvies 48 boliger på Caritas for borgere med svære problemstillinger grundet demens og psykiske sygdomme. Senere følger flere andre specialiserede enheder.


I 1988 formulerer Århus Kommune sin første demenspolitik. Der erklæres "krig" mod demens.

I 1999 får lokalcenterne tovholdere på demensområdet, demensnæglepersonerne.


I 2003 oprettes Demens Cafeen som et sted hvor mennesker med demens i tidlig stadium og deres pårørende frit kan komme og møde ligesindede.

I 1995 etableres Hukommelsesklinikken ved Rigshospitalet og 2000 åbner Demensklinikken på Århus Kommunehospital. Dermed kommer mere fokus på korrekt udredning. Udredningen af demenssygdomme foregår i dag ved hjælp af kognitive tests, neurologiske og laboratorieundersøgelser og vurdering af funktionsevnen. Og sidst en eller flere typer scanning, der kan påvise strukturelle eller funktionelle forandringer i hjernen.

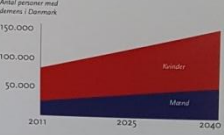
Caritas



Demens Cafeen



FREMTIDIGE UDFORDRINGER



2013: ca. 85.000 lider af demenssygdomme
2040: ca. 155.000 vil lide af demenssygdomme

For at løse de fremtidige udfordringer og målsætninger er der bl.a. stigende interesse for uddannelse af og omsorg for pårørende - "Care for the caregiver". Samt forskning i forebyggelse af demens og ikke mindst udvikling af hjælpemidler for mennesker med demens.

Politisk målsætning
"personer med demens får mulighed for at blive i eget hjem, så længe det ønskes, eller tilstanden gør det muligt"

Kilde: Samrådgangsforsøg for personer med demens, Region Midtjylland

LAD VIDEN UDFORDRE DEMENSEN!