Summary
For someone else. Decisional responsibilities in nursing home medicine.

The central question in this study is how to promote the interests of an elderly nursing home patient who is incompetent to decide for herself. The focus is on the medical decision making process in nursing home medicine. Decision making incompetence of the patient necessitates the involvement of a proxy decision maker, since the Dutch Medical Treatment Contract Act (WGBO) demands informed consent before treatment can take place (which implies proxy decision making in case of decisional incompetence). It is the proxy decision maker’s duty to look after the incompetent patient’s interests. It is the physician’s duty to fulfil all obligations towards the proxy decision maker, that otherwise he would have fulfilled towards the patient.

To decide what is in one’s own interest is no easy matter, even if one is fully capable to do the deciding oneself. Having to decide on behalf of someone else is even more complex. This is true when one has to decide on behalf of a child too young to be able to judge what is best for her; it is true when one has to decide on behalf of a person who has never been nor ever will be competent to decide for herself due to severe mental retardation; it is true when one has to decide on behalf of a person who has led her own competent life, but due to a degenerative illness like dementia is no longer able to decide for herself. Questions arise concerning the importance of former opinions and the value of formerly expressed choices. What is the value of opinions or preferences the incompetent patient expresses now; should these be taken seriously? Moreover, the involvement of the family member who acts as a proxy decision maker, may confuse the issue at hand and influence the weighing of pros and contras of medical treatment (e.g. because of emotions like anticipated bereavement).
Apart from informed (or proxy) consent what is needed for medical treatment is the medical decision about the correctness of treatment. Before medical treatment can be started the physician has to decide which treatment if any would form proper medical care for this particular patient with this particular problem. Points of reference are the professional medical standard, ideas concerning good care and the estimation of what is good for this individual patient. Especially when dealing with someone as vulnerable as an incompetent patient, it is the physician’s responsibility to keep the interests of the patient at the centre of attention. It is however not easy to decide how this responsibility compares with the authority of the proxy decision maker.

It is this range of issues that have lead to the phrasing of the following research question: “How can the interests of incompetent elderly nursing home patients be promoted and whose ultimate responsibility is this promotion of interests?”

Chapter 2: Method

In order to find and formulate answers to this research question, qualitative empirical research in the practice of nursing home care was combined with extensive literature research. The fieldwork research was done in three Dutch nursing homes by means of participant observation. The nursing homes were visited during a period of three to nine months. The groups subjected to observation were the nursing home physicians on the one hand, and more or less incompetent patients and their families on the other hand. Observation took place during rounds and during consultations between physicians and patients & families concerning medical treatment. Before, during and after the first phase of practical empirical research literature searches were done. After the first phase of empirical research groups of nursing home physicians were consulted on several occasions. At a later stage all three nursing homes were revisited. The aim was the exploration of the diversity and complexity of our questions within the practice of nursing home care, followed by a systematic reflection on the moral complexity of decision making processes in which a third party participates, next to the physician and the patient.

From the observed conversations and patient histories a set of cases was selected. These cases are described extensively in all their complexity; they offer a point of focus for the ethical reflection on the matter at hand.
Chapter 3: Competence

After a description of the clinical decision process, in order to clarify the moment of relevance of the patient’s (or proxy’s) consent to treatment, in chapter 3 the patient history of Mrs. De Jager is described. Her medication refusal is accepted by nursing home physician and family as fitting with her personality and not being contrary to good care. Neither the physician nor her family question her decisional competence. This raises the question whether Mrs. De Jager’s competence should have been examined more thoroughly, and if so, whether a judgement of her competence would have significantly influenced the final outcome.

There is a considerable quantity of literature concerning competence. The relevance of the question as such leads back to the dominance of the idea in Western culture that people should be allowed to make important decisions regarding themselves by themselves. This applies also to the health care setting. Only when doubts have risen concerning someone’s capacity to choose and weigh the consequences of the choice and when the intended action threatens to harm that person in a bad way, we are inclined to interfere and take the decision out of her hands. In principle decisional competence is judged independently of the outcome of the intended decision (competence should be judged by looking at the way in which the decision is reached and not in view of the oddity or deviation from the expected). Even so the oddity of a decision may give rise to doubting the competence of the person who decides. Criteria for decisional competence are generally agreed to be: 1. the ability to express a choice; 2. the ability to understand the relevant information; 3. the ability to assess the situation and weigh the probable consequences; 4. the ability to handle the relevant information and deliberation rationally. The emphasis in these criteria on cognitive capacities suggests that in nursing homes the majority of patients would most probably not qualify as competent. Even so it does not immediately mean that decisional incompetence renders the patient’s expressions of will or preferences irrelevant. Behavioural expressions may give a fair indication of the patient’s state of mind concerning medical treatment, and are the reality with which the caregivers have to deal. An incompetent patient is not necessarily a person without a will. The not-rationally motivated preference of a demented patient can be the expression of a deeply felt conviction of what she does and what she does not want to live through. In that sense the expression of a demented patient can be an important sign of what constitutes the patient’s interest.
Chapter 4: Interests

Generally a person may decide herself what she thinks is best for herself; when incompetent the decision making is taken out of her hands and done by someone else. This fact complicates matters considerably. For what is good for a person and how do we know? This problem is as old as the philosophical discipline of ethics. With the patient histories of Mrs. Van Huet and Mrs. Meijer in mind, in chapter 4 we explore several concepts that are related to ‘interest’: self-interest, quality of life, well-being, Good Life. We consider this via notions concerning people in general, then patients’ interests subsequently, ending up with the situation of incompetent patients in nursing home care. Ronald Dworkin’s ideas about critical interests and experiential interests prove to be illuminating. Critical interests are someone’s convictions about what helps to make life good in general, while experiential interests concern matters that make life enjoyable. The former represent critical judgments while the latter represent experiential preferences. According to Dworkin the critical interests deserve priority to the experiential interests; they should be regarded as decisive or at least indicative in the decision making process concerning the interests of an incompetent, formerly competent patient (for example someone suffering from dementia). This view is criticized by Agnieszka Jaworska, who states that demented people are still able to value activities and experiences in their lives. This means that they may still add to or adjust their set of critical interests, and that in the course of the disease (or possibly even with advancing years) the distinction between critical interests and experiential interests dissolves increasingly. Widely practiced methods to enhance the good life for demented patients fit in with these ideas. Concluding we may sat that in order to establish the interests of an incompetent elderly nursing home patient, the concept of well-being should be chosen as a point of reference. Well-being as a concept has a subjective component and emphasizes the necessity to aim at positive experiences. Having concluded, in the third chapter, that decisional incompetence does not necessarily have direct effects on the care or treatment actually given, this notion is supported by the subjective component of well-being as an aim of care. When in keeping with the experience of the patient herself, the aim to bring about a sense of well-being can help to choose the best course of action concerning medical treatment.

The notion of well-being may not be sufficient when defining good care for incompetent elderly nursing home patients. Sometimes the only thing one can aim at is avoiding an increase of suffering. Non-maleficence is still
the most important principle in medicine, the ultimate limit. Good medical care for incompetent patients in nursing home care should aim at the enhancement or at least preservation of well-being, based on the avoidance of (an increase in) suffering.

Chapter 5: Representation

Essentially human beings are social beings, they function in a social context. Relationships are an influential factor in a person's life, both outside and inside a nursing home (chapter 5). The involvement and familiarity with each other that is a result of this relationship, is exactly what qualifies a family member as a representative or proxy decision maker. Ideally the family member knows much about the patient's preferences and values when still competent. Besides, the familiarity with the patient enables the family member to interpret the signals the incompetent patient expresses now. The proxy decision maker thus places the personal perspective next to the medical perspective.

Being the proxy decision maker implies the duty to promote the interests of the incompetent patient. The history of Mrs. Verschoten and her daughters shows how a very strong involvement of family members can cause problems. However well-intended, the daughters damage the relationship between their mother and her professional caregivers. Something similar happens in the story of Mr. Molenaar, where mutual distrust and disagreement make an easy cooperation between wife and caregivers impossible.

Due to her familiarity with and knowledge of the patient, the family member who acts as proxy, can judge what the patient herself would have wanted. This is the usual view of promotion of interests: to make a substituted judgement. An advance directive is usually supposed to help determine the patient’s (former) will. But the former wishes of the person when competent, do not always coincide with the actual interests of the now incompetent patient. Dworkin claims that the advance directive expresses the person's critical interests. Because critical interests should take precedence over experiential interests, Dworkin states, the provisions in the advance directive should determine the course of action when the person has turned incompetent. Counterargument to this claim is the observed capacity of incompetent, demented patients to value (Jaworska). This implies that a person’s critical interests cannot be determined exhaustively in advance (by an advance directive). The actual experiences of the incompetent patient remain important: the incompetent patient is still subject to experiences (Dresser). The incompetent patient’s interests do not necessarily
coincide with her estimation of her life values earlier on.

The proxy decision maker has the morally complicated task to interpret
the patient’s interests. The proxy should so to say personate the patient’s
identity and personality, as much as possible in accordance with what the
patient shows to be or to have been. When due to the progression of ill-
ness this evidence decreases in frequency and explicitness, the proxy’s task
increases in importance. Even so the well-being of the patient remains the
central focus.

The fact that family members are intimately connected to each others,
whether they like it or not, may raise a problem. The involvement of a
family member may introduce other interests than just the patient’s in the
decision making process concerning the medical treatment of an incom-
petent nursing home patient. Professionals in nursing home care simply
cannot ignore the presence of members of the family in the daily course
of events, but they should also take into consideration the intricacy of the
various interests. In some way not only the needs of the patient but also
the needs of her loved ones are the nursing home physician’s concern. It is
the physician’s task to prevent the decision making process to assume the
characteristics of a battleground where the various interests fight for prec-
edence. Acknowledging the intricacy of patient and family relationships
and interests should result in commonly searching for the possibilities to
enhance the patient’s well-being, taking into consideration the fact that
this well-being may be strongly linked to the well-being of her loved ones.

Representation of the patient in terms of personating his identity and
personality, poses a problem when no close relative is available. In the
Netherlands several organisations have been founded to provide voluntary
workers as mentors for incompetent patients without next of kin. These
voluntary workers may function as participants in the decision making
process presenting an independent point of view, but they will never have
the intimate knowledge of the patient that is needed for a good represen-
tation. A family member is able to think in terms of the patient’s former
opinions and preferences, but a voluntary mentor can only try to find out
what is generally thought to be the best for a person in comparable circum-
stances (best interest standard).

Chapter 6: Responsibility
As soon as the patient is considered incompetent to decide for himself, a
third party is introduced to the decision making process. Central to chapter
6 is the question of the relationship between the patient’s own choices and
the physician’s judgement of what would be good medical care, and, more specifically, whether this relationship shifts when the patient does not speak for herself, but when her wishes are interpreted or represented by someone else, namely her proxy. After the patient histories of Mrs. Zeeman and Mrs. Van Dorp, various possibly relevant concepts and norms are studied. The concept of ‘proper care’ as presented in the Medical Treatment Contract Act (WGBO), and the norms concerning competence (as in qualification) in the Professions in Individual Health Care Act (wet BIG) are studied in search of provisions concerning decisional responsibility. The notions and regulations that were found turned out to be too general to be helpful. Norms and standards concerning tasks and responsibilities issued by the medical profession are not useful either, since they are mostly concerned with task descriptions and the definition of boundaries of responsibility (in comparison with other professions and specializations). The debate on professional autonomy offers help, especially Hilhorst’s argument that professional decisions cannot be determined by protocols or standards, since a weighing of individual factors is always needed. A medical decision is actor-specific: it always implies the personal involvement of the physician who acts. Good medical care cannot do without personal involvement, and this has consequences for the physician’s role in the decision making process.

Medical treatment is provided in the context of a relationship between care giver and care receiver. This means that a connection is formed that entails more than the delivery of services. In the tradition of ethics of care a distinction is made between several phases or elements in the process of care giving and care receiving. This distinction, combined with Van Heijst’s analysis of the connection between care giver and care receiver, shows how complex the relationship is between physician and patient, seen from a moral point of view, and how complex the process is of deciding in agreement with the interest of the patient. As an additional element Welie states the importance of mutual trust.

Evidently between physician and patient there is a relationship that cannot be defined easily. The modern trend to pose the patient as a customer (in the sense of: ‘who pays, decides’) falls short of the moral complexity of this relationship and of the moral complexity of medical treatment decisions. Medical treatment decisions demand an individual weighing per case. Also the physician is so involved in the treatment that he must be convinced that what he does is right. Within the boundaries of the professional standard of care, the physician must come to his own conclusion.
about what entails good medical care for this patient. This necessity to be able to morally justify what one does, is inherent to the nature of medical practice. Medical practice can be categorized along the lines of Hannah Arendt’s theory about labour, work and action. ‘Labour’ is repetitive, a routine, necessary to fulfil biological needs. ‘Work’ is aimed at production, at tangible results. ‘To act’ means to take initiative, to distinguish oneself, to express oneself in one’s uniqueness. ‘Action’ entails speech and deeds, and is the only activity that essentially takes place between people. A person who acts unveils himself, cannot help to show who he is. The characteristics of ‘action’ that Arendt distinguishes can be applied to the complexity of clinical medicine. The uniqueness of the sick individual, the uncertainty of the outcome, the necessity to find an answer to the question what would be best for this particular patient, the unfeasibility of forming a good doctor-patient relationship without investing something of oneself, the great risks that are involved, and the great interests of the patient that are at stake – all these factors underline the intrinsic morality of medical action. A physician is not a neutral actor. He is not just performing a task, but he himself is in the process of giving care. Thus he cannot avoid making his own decision about what good medical care implies in the case of this particular patient. Practicing medicine cannot do without interaction between physician and patient (and/or her proxy) since action cannot do without speech, and cannot do without both the involvement of the actor and of the other person who responds. Within this interaction it is not just the patient’s or proxy’s choice that decides what shall be done: the physician is obliged to make his own well-considered judgement of what is right to do.

**Chapter 7: Conclusion**

The final chapter of this study connects the most important findings. The voice of the patient is entitled to great moral weight, even when she is incompetent. She, in her actual situation with her own actual experiences, is the ultimate party concerned. It follows that medical treatment is characterized by the ultimate aim not to increase suffering; its end should be the enhancement of well-being. The potential tension between an advance directive and actual expressions points towards a fundamental ambivalence. The course of treatment and care for a person should be devised and carried out with an eye to the condition of the patient of that moment. But at the same time this person cannot be seen apart from who she was and the choices she made before. This fundamental tension is unavoidable, but it should encourage one to adhere to the norm of striving for well-being and avoiding the increase of suffering.
Involvement and familiarity with the incompetent patient is what qualifies a family member to act as a proxy decision maker; it enables her to place the personal perspective centrally during the decision making process for medical treatment. But this involvement may cause problems too. A patient’s interests cannot be regarded as an isolated phenomenon; attention should be paid to the interconnectedness of the patient and her social context. This applies to both competent and incompetent patients. Family members who know the patient are able to help determine what is good for her, because they are part of her life (as are her interests). The decisional possibilities of the proxy decision maker are limited by the objective interests of the patient (no increase of suffering; stabilization or enhancement of well-being). It is the responsibility of the physician to guard these limits, even more so in the case of an incompetent patient than of a competent one (since a competent patient may decide to harm herself while a proxy decision maker may not decide to do so on behalf of the incompetent patient). Moreover the physician has his own ideas about what constitutes good medical care for this particular patient. This professional responsibility is connected with the morally complex nature of medical practice.

Due to the nature of medical care the relationship between doctor and patient is characterized by a mutual moral involvement. The added presence of a third party who plays a larger role than just being a listener, does not disturb this relation but enlarges it. Physician and family should not regard each other as potentially opposing parties with potentially opposing interests, but as partners in the care for the incompetent patient. Good medical care is only feasible when family members, physician and patient do not form a triangle but a threesome. Only when the clinical and decisional process in nursing home care is understood in terms of the social embeddedness of a patient’s interests, justice is done to the moral complexity of the question ‘What is good for this person?’