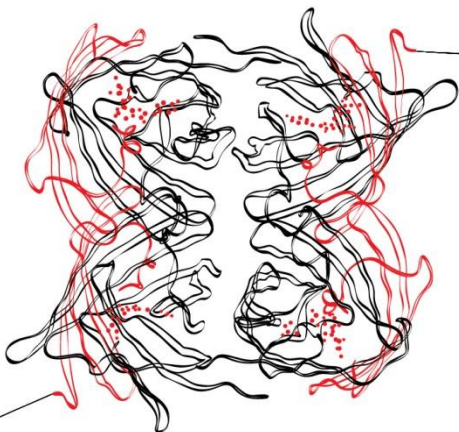
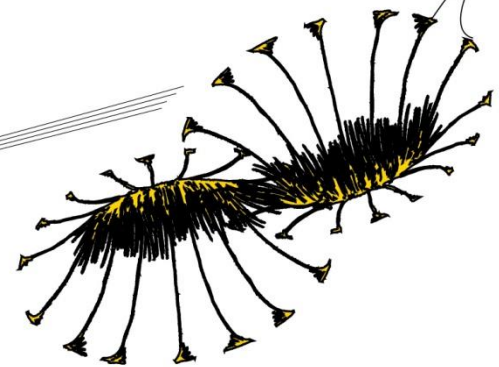




# Support needs of informal caregivers in the municipality of Hellendoorn

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Master Thesis



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## PREFACE

In front of you lays my master thesis. After having completed all the courses in the Health Sciences pre-master and master, this was the last obstacle I had to overcome to get a master's degree. And an obstacle it surely was. After a long and challenging period, I proudly present my thesis with the title: *Support needs of informal caregivers in the municipality of Hellendoorn*.

This research was performed at the municipality of Hellendoorn, and I would like to thank the municipality for providing me full cooperation necessary for this research. Special thanks go to Drs. Marieke van Crujningen, my supervisor from the municipality, who was always prepared to provide me guidance through this whole process.

Regarding my supervisors from the University of Twente, I firstly would like to thank Dr. H.G.M. Oosterwijk, for all the feedback sessions. I am very sorry, that I was not able to finish this thesis before his retirement started. I also would like to thank Dr. M. van Gerven – Haanpaa, my first supervisor, for her support and useful feedback on my thesis. In addition, I would like to thank Dr. M.M. Boere – Boonekamp, my second supervisor, for her willingness to step in at the last moment.

Furthermore, I would like to thank all the people who were willing to complete the questionnaire. Without them, a large part of this research could not have been carried out.

Finally, I would like to thank my family, friends, and Jacob for their support, advice and trust in me.

I hope you will enjoy reading this thesis.

Babet Nijhuis

Oldenzaal, June 13, 2018

## ABSTRACT

### Introduction

The percentage of informal caregivers in the Netherlands has risen in the last years, which is mainly caused by long-term care (LTC) reforms. These reforms were necessary because of the rise in healthcare expenditures. Before the reforms the responsibilities for LTC rested at state level, but since 2015 they have been shifted to municipal's level. The reforms resulted in new laws, which led to new principle. The main principle entails that professional care is only provided when the demand for care reaches beyond the possibilities of the persons' own network, thus it strongly leans on the abilities of informal caregivers. Providing informal care has become a cornerstone of the Dutch healthcare system, but it is hard to ignore that it may be a substantial burden for the informal caregivers. In the next decades the demand for informal care will rise, but the number of informal caregivers will approximately stay the same. So, the same amount of informal caregivers should be providing more informal care and it is very likely that this will lead to a substantial increase of burden on informal caregivers

### Objective

Given these trends, it is relevant to look into the possibilities of supporting informal caregivers, to prevent them from becoming overburdened. This research is done on behalf of the municipality of Hellendoorn, so it also aimed on the informal caregivers from this municipality. This research aims to investigate the factors that are relevant for the municipality, to organize support of informal caregivers in an effective way.

### Methods

This research used qualitative and quantitative methodologies. For the qualitative part, there has been done a desk research. For the quantitative part a survey, in the form of a questionnaire, has been executed. The population needed for the questionnaire, were the informal caregivers in the municipality of Hellendoorn. The questionnaire was available in a paper version and an online version. The data has been analysed with IBM SPSS Statistics 22.

### Results

The questionnaire had 187 responses that were usable for the analysis. The results show that the majority of the informal caregivers was female (70.6%). Regarding the burden of informal caregivers, a severe to very severe burden becomes less common with higher age. From the people with a moderate to very severe burden, 30% is not using any type of support. Regarding to the overall support need, the type of support that is most desired is information about national healthcare laws. After that, the most desired is practical support like cleaning, gardening etc. In third place comes the support with practical tasks that are care related.

### Conclusion

It was difficult to draw one straight line in the results, when it comes to combining needs with personal characteristics. The combination of work hours, care hours, relationship with the care receiver, involvement of other informal caregivers, personal issues etc., creates the need for support and which type of support is desired. Concluding, in order for the municipality of Hellendoorn to organize informal caregiver support in an effective way, they have to create a wide range of options that can be combined to a perfect fit for each individual.

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## 1 INTRODUCTION

According to the Public Health Service of Twente (GGD Twente), 1 in 6 inhabitants of Twente are providing informal care. In 2012 the percentage of informal caregivers was 12 percent and it has risen to 16 percent in 2016 (1). This increasing demand for informal care is mainly caused by the long-term care (LTC) reforms in the Netherlands, which were necessary because the ageing population and the increasing prosperity (that came with technological developments) led to a huge rise in healthcare expenditures.

Before 2015 the responsibilities for LTC rested at state level, but since 2015 they have been shifted to municipal's level. The core of the LTC reform entails that care for patients suffering from chronic diseases is basically provided close to the patient's social system; in the local environment. Institutionalization will be hold off as long as possible, care will be provided at home and the patient's social system has prime responsibility for the provision of care.

With the renewed Social Support Act (Wet maatschappelijke ondersteuning, Wmo) also came a new motto for professionals: professional care is provided *as light as possible – as intensive as necessary*. This principle entails that professional care is only provided when the demand for care reaches beyond the possibilities of the persons' own network. Self-reliance is the key in this new approach, thus it strongly leans on the abilities of informal caregivers.

Providing informal care has become a cornerstone of the Dutch healthcare system, but it is hard to ignore that it may be a substantial burden for the informal caregivers. Statistics Netherlands (CBS) regards someone an informal caregiver when the care provided lasts at least 3 months and is offered for at least 8 hours per week (2). This means a whole working day, and it can thus be a huge invasion in someone's life. According to Exel et al. (3), a large part of informal caregivers experience substantial burden from caregiving and have problems in maintaining their caregiving role in a responsible and sustainable way. Especially blinding in care activities in one's normal activities and role obligations. Here we can think of work and studies, but also one's social life, sports, friends and cultural activities.

GGD Twente expects a further rise of informal care demand, and based on its prognosis this will even rise with 55% in 2040, compared to 2012(4). The worrying thing about this prognosis is that the number of informal caregivers will approximately stay the same (4). According to this research, the same amount of informal caregivers should be providing more informal care and it is very likely that this will lead to a substantial increase of the pressure on informal caregivers. GGD reported that there are currently 28.000 overburdened informal caregivers in the region of Twente, and it goes without saying that this number will rise.

Given these trends, it is relevant to look into the possibilities of supporting informal caregivers, to prevent them from becoming overburdened. There are multiple ways to support informal caregivers. One way is to offer support in the form of respite care, which provides informal caregivers with a temporary rest from caregiving, while persons in need of care, continue to receive care. Other ways are emotional support, financial support and support in getting useful advice/information and education.

This thesis aims to investigate what kind of support informal caregivers desire in the municipality of Hellendoorn. This is a relatively small municipality in the region of Twente, in the province of Overijssel. The following research question is central in this thesis:

*“How can the municipality of Hellendoorn organize the support of informal caregivers in an effective way?”*

The regulatory environment for LTC has radically changed in recent years. Responsibility for LTC has been transferred to municipality level and this transfer was accompanied by budget cuts. Therefore, the first sub question to answer is:

1. *What is the regulatory environment for the design of supporting arrangements for informal caregivers?*

The step-wise transfer posed new questions for municipalities. There was no clear concept of what support-arrangements could entail. To organize informal caregiver support in an effective way, it is important to look at the current situations. Therefore, the second sub question is:

2. *What is the current organization of informal caregiver support in the municipality of Hellendoorn?*

If support is geared to local circumstances, it is important to know the need for support as it is by the informal caregivers. What are their concerns? What type of support do they desire from the municipality? Therefore, the third sub question is:

3. *What are the support needs of informal caregivers in the municipality of Hellendoorn?*

The first two question will be answered by doing desk research. The third question will be answered with a quantitative study by gaining data from questionnaires that are filled in by informal caregivers in the municipality of Hellendoorn.

This thesis is outlined as follows: Chapter two contains the theoretical framework. In Chapter 3, the methodology will be displayed. Subsequently, Chapter 4 will answer the first sub question about the regulatory environment, Chapter 5 the second sub question about the current organization and Chapter 6 the third sub question about the support needs of the informal caregivers. Chapter 7 gives the conclusion and in Chapter 8, the discussion can be found.



## 2 THEORETICAL FRAMEWORK

This chapter will provide a theoretical framework for this research. First the processes that are subject to the problem will be elaborated. After that the situation of informal caregivers will be described. At last the coping strategies that they can use, will be explained.

### 2.1 Underlying processes

According to the CPB Netherlands Bureau for Economic Policy Analysis (CPB) healthcare expenditures in the Netherlands have risen from 9% of the gross domestic product (GDP) to 14% of the GDP between 1972 and 2015 (5). What caused the healthcare expenditures to rise? There are multiple factors that contributed to this increase. Demographic change is to be seen as an important factor, especially when we look at how the age of the population influences the costs of healthcare. Furthermore, the increasing prosperity is also an important cause.

#### 2.1.1 Demographic change

Demographic changes in our society have led to the inevitable consequence of population ageing. Population ageing – the increasing share of older persons in the population – is a huge transformation that influences nearly all sectors of society. It already started before the twentieth century and was boosted by the post-World War II baby boom. People that are aged 60 years or over are the “older” persons and people aged 80 years or over are the “oldest-old”. Globally, the number of older persons is growing faster than the numbers of other people in any other age group and as a result, the share of older persons in the total population is increasing virtually everywhere (6). This global phenomenon of population ageing is caused by multiple factors like the drop in fertility rates, longer life expectancies and – especially – by the post-War baby boom generation which is shifting to the top of the age pyramid (7). See figures 1 and 2 for these population pyramids.

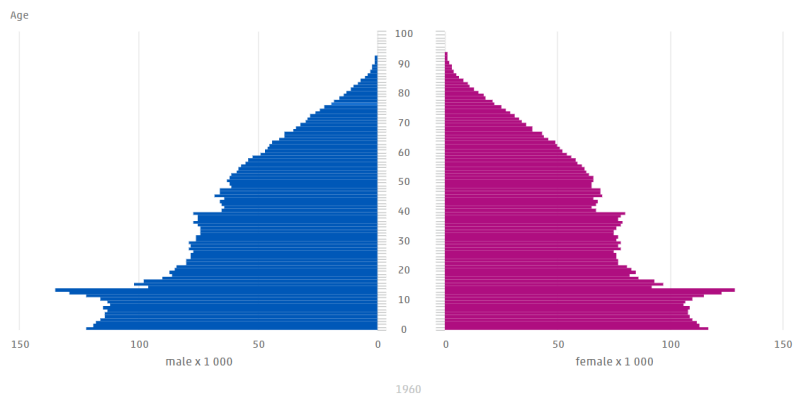


Figure 1 Age composition in the Netherlands 1960 (8)

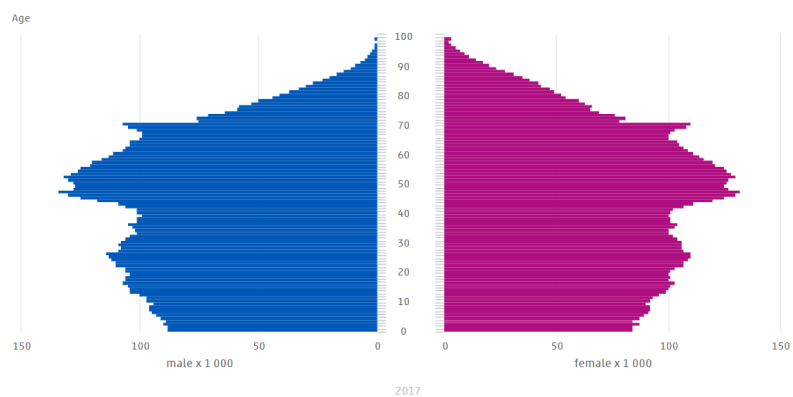


Figure 2 Age composition in the Netherlands 2017 (8)

Growth in the numbers and proportions of older persons puts pressure on health systems. Not only do people get older, they get older with more diseases. A study showed that 84% of patients 75 years or older had a chronic disease and 59% had more than one chronic disease (9). People with multiple chronic diseases (multimorbidity), are in need of more care and often need care from different disciplines. Therefore multimorbidity can be associated with an increase in costs and utilization of health services (10). RIVM has estimated that the average costs for healthcare is €5.500,- in the age category of 60-64. However, above the age of 75 we spend more than €10.000,- per inhabitant for both men and women. For people aged 95 and older, this increases to over €50.000,- for men and €60.000,- for women (see figure 3). So, the older the population, the higher the costs for healthcare.

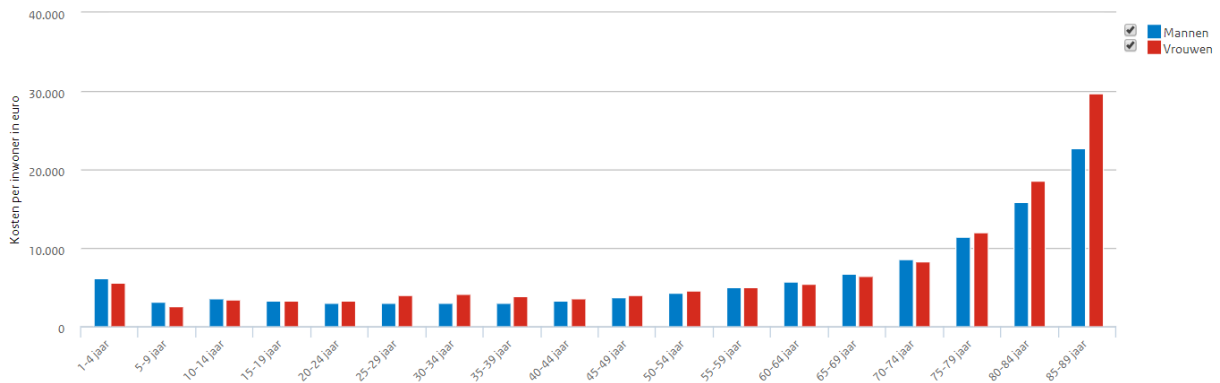


Figure 3 Healthcare expenditures per inhabitant by age (11)

### 2.1.2 Increasing prosperity

Another cause of rising healthcare expenditures is the increasing prosperity. As a society we are getting richer and when people have more money to spend, health is on top of the list on which to spend it on. According to the Ministry of Health, Welfare and Sport, increasing prosperity can be translated in two trends, that lead to rising healthcare expenditures (12).

Firstly, the society is changing. The increasing importance of healthcare means that we accept less discomfort and we have more explicit requirements for the care we receive. Think for instance about single rooms in hospitals instead of multi-person wards, and the extensive information we demand from health professionals. Furthermore, our lifestyle adapts with the changing society. Luxury foods are now within reach and the intake of foods often surpass the biological need for food. Diseases caused by obesity are much more common today than they used to be (12). In the same line of reasoning, people have developed a more inactive lifestyle and are not exercising sufficiently, which – again – leads to health problems. Next to the changing society, there is another reason for healthcare expenditures to rise, due to increasing prosperity.

The second trend is the growth of medical technology (12). Medical technology can prolong people's lives and a prosperous society means more money for technology and more investments in developing new medical technologies. Because of these developments we are able to treat more diseases and discomfort. However, the downside is that it causes a rise in healthcare costs.

### 2.1.3 Effects on health systems

Moreover, the increasing healthcare expenditures puts pressure on health systems as a whole. These systems must adapt to meet the growing demand for care, services and technologies to prevent and treat diseases that come with old age.

Until 2015 healthcare expenditures were (roughly) provided from two resources. On the one hand from insurance schemes and on the other hand from the Exceptional Medical Expenses Act (Algemene Wet Bijzondere Ziektekosten, AWBZ). The AWBZ was designed to cover a specific and limited number of expenses, but in practice all kind of ‘new expenses’ were covered by the AWBZ. Studies from the 1980’s and 1990’s made clear that the costs of the AWBZ were untenable.

After a long period of political discussion in the Netherlands, the great reform of LTC came into effect in 2015. Since then the aspects of the former AWBZ, have been placed with existing and new acts. This included the new Long-term Care Act (Wet langdurige zorg, Wlz), the Social Support Act (Wet maatschappelijke ondersteuning, Wmo), the Health Insurance Act (Zorgverzekeringswet, Zvw) and the new Youth Act (Jeugdwet) (13). Figure 4 provides an overview of these LTC changes (14).

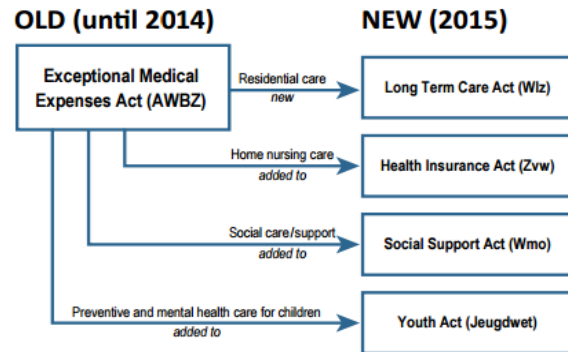


Figure 4 Changes in long-term care (14)

The Wmo and Youth Act were decentralized to the local level (municipalities) to keep it affordable, and also to organize it more efficiently, for which municipalities are in a better position because they are closer to the citizens (15). The principle of the Wmo is that people must first rely on their own network, for the provision of care, when in need of help. Self-reliance is key in this new approach; thus it strongly leans on the abilities of informal caregivers.

The next paragraph will elaborate on informal care and the burden that can come with being an informal caregiver.

## 2.2 Informal care

According to Oudijk et al. (16) informal care is described as ‘care that is provided to someone in need of help, by someone from their direct surroundings’. Parker (17) defines informal caregivers as ‘persons providing care for a disabled relative or friend at home, and who are unpaid’. Both definitions include a wide range of people who provide informal care like relatives, housemates, friends, acquaintances, colleagues, and neighbors, but they exclude professional support or organized voluntary work. The Social Cultural Plan bureau (SCP) in the Netherlands also uses this broad definition of informal care. However, the Central Bureau for Statistics (CBS) has a more specific definition and it has been aligned with the Municipal Health Services (GGD) and the National Institute for Public Health and the Environment (RIVM). They regard someone as an informal caregiver when the care provided lasts at least 3 months and is offered for at least 8 hours per week (2). Again, this person must not be a professional or an organized volunteer. The latter definition is quite dominant in current discussions regarding informal care.

The GGD Twente expects a rising demand for informal care, and according to their prognosis this demand will rise with 55% in 2040, compared to 2012. Worrying about this prognosis is that the number of informal caregivers stays approximately the same (4). See figure 5 for a graphic illustration of this prognosis. According to these numbers, the same amount of informal caregivers should be providing

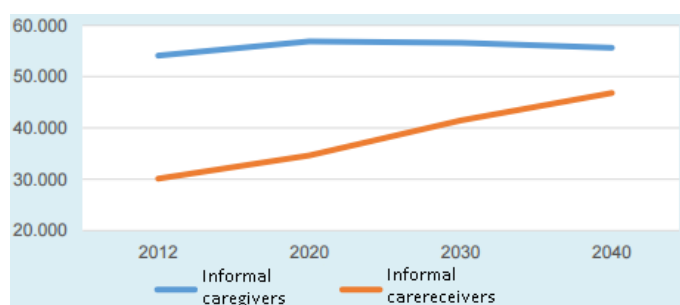


Figure 5 Prognosis supply and demand informal care 2012 – 2040 (4)

more informal care. It is very likely that this will lead to a substantial burden on informal caregivers, because being an informal caregiver can have a huge impact on someone's life.

Becoming an informal caregiver is a process that goes gradually. It often starts invisible, with tasks that can hardly be seen as a burden. Like going to doctors' appointments with your parents or putting the garbage-can outside. But the number of tasks increase slowly and suddenly they also need your help with groceries, cooking, cleaning, administrative tasks and often, medical tasks. When people think about their future, mostly they don't think of becoming an informal caregiver. Becoming an informal caregiver is something that happens to someone and the preparation for this role, will most often occur when they already obtained the role (18). Also, many informal caregivers feel that they have an obligation towards the person that they are providing care for. For example, children feel morally obliged to provide care for their parents, because their parents have invested so much in them., so often they won't say that it has become a huge impact on their personal life. It is no exception that informal caregivers have to give up important things in life, e.g. switch from full-time to part-time jobs, give up time that they normally spend on social contacts, sports and cultural activities.

This paragraph shows that the impact of being an informal caregiver may have severe consequences to the caregivers' personal life and that the burden on informal caregivers will increase. The next subparagraph will elaborate on how the burden can affect an informal caregiver's health.

### 2.2.1 Health effect of providing informal care

The former State Secretary of Health, Welfare and Sport, Martin van Rijn, indicates two sides of informal care: on the one hand it can have a positive effect on society (social cohesion) and on the people involved (feeling good about helping someone), but on the other hand it may be difficult to combine being an informal caregiver with your own life and it can lead to a substantial burden (19). Vitaliano et al. (20) state that caring for a family member is generally regarded as a chronically stressful process and that being an informal caregiver can be hazardous to one's health.

Schulz and Sherwood (21) differentiate between two types of health effects: *physical* health effects and *mental* health effects. They summarized the physical and mental health effects reported in the caregiving literature over the past three decades.

When it comes to physical effect, they found three relevant levels:

- global health-measures like chronic conditions, physical symptoms, health service use, medication and mortality;
- physiologic measures like antibodies and functional immune measures, stress hormone and neurotransmitter measures, cardiovascular measures and speed of wound healing;
- health habit self-reports like self-report on daily routines and self-report on healthcare.

Regarding mental health they found that outcome measures are:

- depression;
- anxiety;
- stress;
- subjective well-being;
- positive aspects of caregiving;
- self-efficacy.

Schulz and Sherwood argue that these outcomes are caused by primary and secondary stressors. Stressors are circumstances that most people find stressful and which causes the release of stress hormones (22).

Primary stressors are the impacts that caregiving has on one's personal life. For instance, providing care now and then is doable, but providing care every day may impact as a severe burden. Also, duration of care provision may have a similar impact. The same goes for the type of care that needs to be provided (does it involve particular skills or activities that are regarded intimate and "shameful"). The cognitive disabilities of the care receiver can also be regarded as a primary stressor (21). For example, it is much more of a burden to provide care to someone who is not capable to express pain or feelings or someone who gets angry really quickly, than to someone who is able to communicate with you about these things.

Secondary stressors are the impacts of providing informal care on the direct social system of the caregiver like finances and family conflict (21). If a caregiver needs to reduce working hours due to providing informal care, it may have financial consequences. Also, the healthcare costs may play a part. Furthermore, informal caregivers are often confronted with family conflict, because they are not able to meet the expectations that go with one's role in a family. Children may be disappointed, because their parents spend too much time on providing care, family dinners may be replaced by easy alternatives like fast-food, eating in front of the television etc.

Although there has been an increase on informal caregiver health research, there are not many attempts to create a theoretical model and bundle these researches. Vitaliano et al. (20) have made such an attempt which can be seen in figure 6. With this model, they depict the effect that exposure to stress can have on one's physiological responses. The model shows that it depends on one's vulnerability and resources how one deals with stress, and how exposure to stress actually may lead to psychological distress and risky health habits. The latter may lead to physiological responses that can translate into illness and even death.

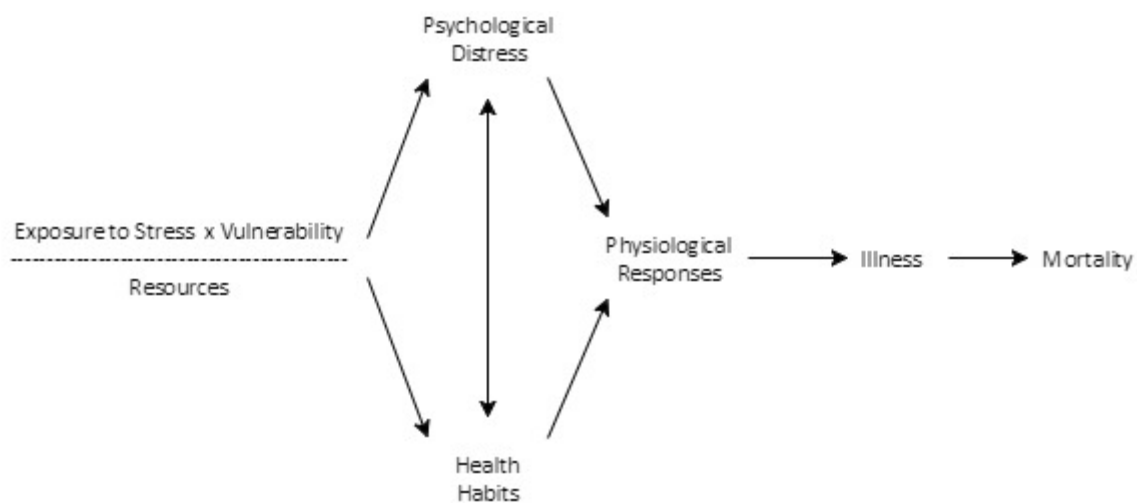


Figure 6 Theoretical model of stress and health/illness (20)

Stress – caused by both primary and secondary stressors – is generally used to describe the relationship between caregiving and health of the caregiver. Depending on the resources available; the new role of being an informal caregiver can come with a lot of stress. Stress is something that usually can be managed as long as it manifests itself below critical levels. Stress originates in very different ways depending on the characteristics of the caregiver, the recipient of care, their shared history, and the social, economic and cultural contexts within which they find themselves (23). Providing care for a parent who always has been warm and caring, may feel different in comparison to a parent who has been cold and harsh. But then again, it also depends on the personal capabilities of the caregiver. It is risky to define general statements; stress originates and is dealt with in many different ways.

## 2.3 Coping strategies

How a person relates to stress, can be described as a coping strategy. Coping strategies are the cognitive and behavioral efforts to handle demands that are perceived as burdensome or exceeding the resources of an individual (24). The objective of coping is to deal with problems or regulate the emotional response in stressful situations. Lazarus and Folkman (24) distinguish emotion-focused and problem-focused coping. Emotion-focused coping deals with managing emotions while problem-focused coping aims on resolving complications in a given situation. Another differentiation that can be made is between active (approach) and passive (avoidance) coping. Both of these approaches can be either behavioral or cognitive. When using an active coping strategy, one attempts to modify and solve problems, while the passive coping strategy is mainly about avoiding problems.

Moos and Schaefer (25) made an integrated classification scheme with two focus categories and two methods of coping strategies. The two categories for focus are approach and avoidance, and for method these categories are cognitive or behavioral. When combining these categories and methods you get four sets of coping responses: approach-behavioural, approach-cognitive, avoidance-behavioral and avoidance-cognitive. They characterized the four categories as can be seen in table 1 (25).

	<b>Behavioral</b>	<b>Cognitive</b>
<b>Approach</b>	Seeking guidance and support	Logical analysis, positive reappraisal, mental rehearsal of alternative actions and their consequences
<b>Avoidance</b>	Seeking alternative rewards, venting emotions and engaging in tension-reducing behaviors	Responses aimed at denying or minimizing the seriousness of a crisis or its consequences

Table 1 Moos and Schaefer's classification of coping strategies (25)

Seeking guidance and support will help people to deal with stress, as do logical analysis, positive reappraisal, mental rehearsal of alternative actions and their consequences. In these strategies people actively approach the problem zone and prepare their actions. But they may also hide from the problem, denying the severity of the problem and not face the consequences. They may also ignore the problem by drinking, (over-) eating or drug abuse.

Which coping strategy one uses in a stressful situation, depends on the capacities that people hold, how they react to stress and the severity of the stressors that apply to the situation. More severe stressors tend to elicit both more approach and more avoidance coping (26). The type of stressor and how it is appraised are also important. Folkman and Lazarus (24) found that middle-aged adults use problem-focused methods to manage work stressors and emotional-focused methods to manage health-related stressors. An observation of McCrae (27) was that individuals facing challenge used more problem-focused coping strategies, while individuals facing threat or loss were more like to use avoidance or emotion-focused strategies.

When stress is not managed well, it can lead to substantial burden on the caregiver. The next paragraph will elaborate more on this informal caregiver burden.

## 2.4 Informal caregiver burden

By most people it is considered 'normal' that one takes care of a close relative. But the fact that providing informal care can also come with a burden, is not often recognized. Grunfeld et al. (28) have also indicated this lack of recognition in their paper which followed advanced breast cancer patients

and their principal caregivers. Who are these caregivers and how does caregiving affect them? What is the influence of caregiving on their psychosocial, occupational and economic well-being? In their longitudinal study it was found that caregivers experienced substantial burden, anxiety and depression when it came to palliative and terminal illness. In addition to psychological morbidity, caregivers also experienced economic and occupational burdens. This indicates that there are unmet needs in the caregivers. But why do informal caregivers give no signals? Why do they muddle through even though it is on the expense of their own health and well-being? Grunfeld et al. (28) suggest in their paper that medical needs of informal caregivers are neglected because they are completely focused on their caregiving role. The research of Grunfeld et al. focused on advanced breast cancer patients. But what do we find on informal caregiver burden in other chronic diseases?

McCullagh et al. (29) executed a research on the determinants of caregiving burden and quality of life in caregivers of a stroke patients. They found that the burden of caregiving changes through the course of the disease. In the immediate aftermath of a stroke, there was a substantial level of anxiety in caregivers, but this decreased with time. However, there were no significant changes in patient's dependence or support levels, which suggests a response shift to normalization.

With an ageing population it is relevant to look into informal caregiver burden with patients that suffer from dementia. The course of dementia often follows a predictable pathway, and it is known to be a slow process of patients gradually fading away. Eters et al. (30) conducted a literature review on informal caregiver burden among dementia patient caregivers. They found that being an informal caregiver for someone that suffers from dementia, has negative effects on one's health. The impact of caregiving was influenced by many factors like gender, relationship to the patient and personal characteristics. They also address that female caregivers tend to report more emotion focused coping, while male caregivers reported more problem focused coping. Furthermore, Eters et al. (30) strongly advocate multicomponent interventions for caregivers with a tailor made approach. What goes for one person, does not work for another. A one size fits all may look well from the outside but does not lead to a decline of informal caregiver burden.

What can be learned from the studies mentioned above, is that the burden of informal caregiving may differ between disease groups. In the studies discussed so far, we learn that there may be various relations between variables. Age and depression for instance seem to be related, but not always in the same way. Burden of caregiving and quality of life can be related, but again in different ways. The studies also showed that regardless of the disease, being an informal caregiver often comes with a burden. As a result, many caregivers need support to maintain their care giving role. Substantially burdened caregivers, who remain without support, are at serious risk of burnout which potentially leads to the 'double boomerang' effect of one patient receiving informal care eventually leading to two patients being dependent on formal care. So, it is safe to say that there should be support for informal caregivers to avoid this double boomerang effect.

The next chapter will elaborate the methodology used in this research.

## 3 METHODOLOGY

This chapter will describe the steps and actions that were taken in this research in order to answer the main- and sub questions. It will describe the type of research, data collection, data analysis and data safety protection.

### 3.1 Type of research

This research is a mixed-method research. To answer the sub questions, it is in need of both qualitative and quantitative methodologies. By doing so, it is possible to fully address the research question. In the qualitative part, the first two sub questions will be answered. In the quantitative part, the third sub question will be answered.

### 3.2 Data collection

For the qualitative part, the first two sub questions, there has been done a desk research. These questions can be answered by using already existing information like laws and policies. To find these, the public website of the government has been used (31). For the quantitative part, the third sub question, a survey has been executed. A survey research in the form of a questionnaire was the most suitable method to acquire information about the preferences about the informal caregivers in the municipality of Hellendoorn. It comes with the opportunity to reach a large group of respondents and because there is no interviewer objectivity can be guaranteed. The questionnaire can be found in Appendix I.

#### 3.2.1 Population

The population needed for the questionnaire, were the informal caregivers in the municipality of Hellendoorn. Inclusion criteria were: informal caregivers who are providing care to someone who is an inhabitant of the municipality of Hellendoorn. So the informal caregivers could be living inside and outside the municipality of Hellendoorn. Furthermore, the informal caregivers needed to be older than eighteen years. Exclusion criteria were: care receivers outside the municipality of Hellendoorn and minor informal caregivers.

#### 3.2.2 Study procedure

First of all, the questionnaire had to be created. Because the respondents live in the Netherlands, it was decided to write the questionnaire in Dutch. After that, there has been thought of useful information to extract from the participants. Eventually this lead to the following four parts in the questionnaire:

Part 1: Pressure that is experienced by the informal caregiver

Part 2: Support need of the informal caregiver

Part 3: Knowledge of current support possibilities

Part 4: General questions

For the first part, pressure that is experienced by the informal caregiver, needed to be measured. There are various tools to do this, like the Caregiver Burden Scale, Caregiver Burden Inventory and the Burden Scale for Family Caregivers (BSFC). For this research a questionnaire was needed that would be suitable to all the informal caregivers of the municipality. Because the Caregiver Burden Scale only aims an care receivers with dementia (32), the choice has been made to not use this one. The Caregiver Burden Inventory was suitable for this research, but because of its length the 10-item short version of the Burden Scale for Family Caregivers (BSFC-s) has been used. This scale is developed to provide a measure of subjective burden, experienced by family caregivers. The BSFC-s is comprised of the 10



items with the highest discriminatory power from the 28-item original version (33). The choice has been made to use the BSFC-s, for various, mainly practical, reasons. First of all, the original version is very long with 28 items. This would have increased the likelihood that respondents would drop out early in the process and would not have returned a complete questionnaire. Furthermore, this research focusses mainly on the support need of informal caregivers. The burden is only a small part of the research and is needed to compare to other factors. Thus, it was not necessary to use the long version.

For the second and third part, there have been three meetings with the employees of Evenmens, an organization that focuses on supporting informal caregivers, and the policy officer of the municipality, who is responsible for informal care. In these meetings topics were discussed that would be most valuable to answer the third sub-question. This led to questions about; the support use, support need, knowledge of current support possibilities and general information.

The questionnaire was available on paper and online. The paper versions were spread through the contacts of Evenmens, given to home care organizations and to general practitioners. Furthermore, an email and a news item were created with a link to the online version of the questionnaire. The email was sent to the contacts of Evenmens and the news item was placed on the website of the municipality and in the local newspaper.

### 3.3 Data analysis

The digital responses from Qualtrics were extracted and converted to Excel on the 21<sup>st</sup> of August 2017. The paper responses were added manually to this data. The first part of the questionnaire consisted of ten questions about the experienced burden of informal caregivers and together, these ten questions led to one burden score. This score has been calculated in Excel and added as an extra column in the datafile. Then the Excel file was converted to a csv. file and imported in IBM SPSS Statistics 22. In SPSS various factors were combined with each other (mostly in crosstabs) in order to extract knowledge from the data. In the questionnaire there were three questions, that were multiple response questions (part 2 question 2, part 2 question 4 and part 4 question 10). Variable sets have been defined for these questions, in order to do multiple response analysis with them.

### 3.4 Data safety protection

The questionnaires were filled in anonymously, which makes it nearly impossible to identify the participants. The research data is stored at an external hard drive, which is stored at the home of the researcher, and thus is only accessible via the researcher. The questionnaires that were answered on paper, are also stored at the home of the researcher.

### 3.5 Permission ethical committee/informed consent

This research required a permission from the Ethical Committee of the faculty of Behavior, Management and Social Sciences (BMS) of the University of Twente. Permission has been granted under file number BCE17123. The participants of the questionnaire also signed an informed consent, which can be found on the second page of the questionnaire (Appendix I).

In the next chapter, the first sub question will be answered.

## 4 REGULATORY ENVIRONMENT FOR INFORMAL CAREGIVER SUPPORT

This chapter will answer the first sub question:

*What is the regulatory environment for the design of supporting arrangements for informal caregivers?*

Until the end of the 18<sup>th</sup> century there barely was any governmental involvement regarding to public health and welfare. Hygienic conditions were very poorly and care for the sick and poor was left to private initiatives. The unemployed, invalids, handicapped and elderly were seen as poor people and were left to the charity of others. The Ministry of Internal Affairs was responsible for public health as of 1801, but only as of 1854 they came with the Poor Law and in 1865 with laws regarding to professional practice of doctors and pharmacists and the State Supervision of Medicine. With this legislation the government aimed to end the epidemics that caused a lot of victims and the quackery that was much present due to poverty. The governmental involvement with public health flourished with the introduction of the Health Act (1956), the Health Insurance Act (1964) and the Exceptional Medical Expenses Act (AWBZ) (1968). The AWBZ had the objective to create a safety net for uninsurable risks and long-term care such as nursing for the chronically ill and the disabled. At the start the emphasis was mainly on residential care like nursing homes, psychiatric hospitals and homes for the handicapped. In the 80s and 90s of the twentieth century, the scope of the AWBZ was regularly expanded with additional arrangements like family care and social pedagogical services. However, with the expansion of services also came the concern about the desirability and sustainability of the AWBZ. Future prospects revealed that the ageing population would make the AWBZ untenable. There was also criticism on the imposed institutionalization and the lack of participation and freedom of choice for the individual citizens/patients. The access to AWBZ-funded care became more objective and strict in the 90s due to the introduction of the CIZ, centre for healthcare indications. From that moment onwards, access to AWBZ arrangements were put in the hands of the CIZ, that worked by uniform standards and criteria. However, this also led to concerns about the increasing bureaucracy and centralization. In the early years of the 21<sup>st</sup> century, the AWBZ has eventually been renovated through several changes.

First, in 2006 the Zvw has been introduced. This law replaces the old health insurance act (ziekenfondswet). The Zvw allows competition between health services, with the aim that competition would increase quality and lower prices. Although regulated and overseen by the government, the Zvw came with the introduction of market forces. Another aim was to create more room for consumers, providers and insurers to make their own choices. One of the key points of the Zvw is that everybody who is living or working in the Netherlands, is obliged to have a basic insurance. The insurers have an acceptance obligation, so they have to accept every person for a basic insurance regardless of their age, health or gender. The basic insurance in the Netherlands covers health risks like primary medical care (i.e. General Practitioners), hospital care, patient transport, pharmaceutical care, personal care and nursing via the district nurse, maternity care and paramedical care.

Second, in 2007 the Social Support Act (Wmo) has been introduced. This act made local governments responsible for social policies and it came with a new view on how to arrange healthcare. The act is based on the idea that citizens have to take responsibility of the care of themselves and their loved ones. Only if the care needs reach beyond the capabilities of the patients' family and support system, the local government will provide support. The Wmo has a different starting point than the traditional healthcare arrangements. Previously healthcare was focused on the problematic and the worrying. Now it aims to stimulate the abilities of citizens and make them aware of their 'own strength' and to connect them with possibilities, healthy social systems and networks. The central idea is that, because

municipality level is closest to the citizens, it is easier for them to realize these goals, which explains the decision to make local government responsible. At first in 2007, the main subject that was decentralized to municipalities, was domestic care. After 2011, the government aimed to bring an even more substantial part of the AWBZ under the responsibility of municipalities. This included personal care, day care and supervision. Next to the social support, there were also plans to decentralize youth care and labour reintegration. Parts of the AWBZ that were not transferred to the Wmo, became part of a new law called the long-term care law (Wlz). The implementation date of this operation was 1 January 2015. From this date onwards, the AWBZ expired, and the new Social Support Act, named Wmo 2015, came into effect.

The Wmo 2015 states that (34):

- Citizens carry their own responsibility for participating in society, and it is expected that they support each other with this
- Citizens that are not self-reliant or not able to participate in society, even with help from people in their near surroundings, should be able to appeal to government regulated support
- The governmental support of self-reliance and participation must be aimed at allowing citizens to stay in their own living environment as long as possible
- The municipal administration is responsible for social support
- The municipal administration is responsible for quality and continuity of the facilities

So, the Wmo aims at keeping people in their own living environment as long as possible, with the aid of people in their near surroundings, like family, friends and neighbours. Only if the aid and capacities of the social systems falls short, the municipality is obliged to offer additional social – and usually professional – support to make sure someone can stay at home. Access to classical arrangements like nursing homes are restricted by severe and strict indications.

In the Netherlands there are currently 380 municipalities (35). They all needed to develop their own policies regarding social support, following the legislation of Wmo 2015. Some municipalities choose to develop arrangements as a joint effort with other municipalities, but other fare on their own; developing specific arrangements that fit the profile of the local community.

The government is well aware that putting responsibility in the hand of citizens, may impose a severe burden for the patients' support system. Informal care puts pressure on the social system and it is not a given thing that social systems can cope with the challenges of informal care. This is especially the case when care is demanding and stretches over a long period of time. The government recognizes that, and therefore the Wmo 2015 also focuses on informal care in the following articles:

- Article 2.1.2 states that the policy should aim to enable informal caregivers and volunteers to perform their duties as good as possible
- Article 2.1.6 states that the city council is obliged to offer a yearly token of appreciation for informal caregivers
- Article 2.3.2 states that in case of a request for social support, there must be a survey with the citizen, and if possible, their informal caregiver. This survey should also look at the need for support of the informal caregiver.

So, these are the laws that municipalities have to take into account when developing their policies, when it comes to informal caregiver support. However, municipalities have the freedom to develop their own arrangement within the confines of the mentioned articles. The next chapter will focus on the municipality of Hellendoorn, what their policy says about informal caregiver support, and which arrangements are available.

## 5 CURRENT ORGANIZATION OF INFORMAL CAREGIVER SUPPORT IN THE MUNICIPALITY OF HELLENDOORN

This chapter will answer the second sub question:

*What is the current organization of informal caregiver support in the municipality of Hellendoorn?*

Hellendoorn is a municipality in the province of Overijssel in the Netherlands (figure 7) with a surface of 139 km<sup>2</sup> and 35808 inhabitants (35). The cores of the municipality are the villages Nijverdal, Hellendoorn, Haarle, Daarle, Daarlerveen and a few communities (36). Nijverdal is the biggest village of the municipality and it originated in 1836 with the arrival of the textile industry. The village rapidly grew from ±100 inhabitants to ±7000 inhabitants around WWII. In the 60's of the 19<sup>th</sup> century, the textile industry collapsed, but by then Nijverdal was a developed village. Nowadays it has ±25.000 inhabitants. In comparison, the other villages in the municipality have the following amount of inhabitants: Hellendoorn ±6.000, Haarle ±2.200, Daarle ±1.400 and Daarlerveen ±1.100. Haarle, Daarle and Daarlerveen are typical farmer settlements, with a largely agricultural population.



Figure 7 Location of the municipality of Hellendoorn within the province of Overijssel

All of the villages of the municipality of Hellendoorn have a strong sense of community. There are several community centers, and a lot of volunteers who are helping to keep these centers active and accessible. Solidarity – or as they call it in this region “noaberschap” (±neighbourship) – is of great importance in the municipality and there is a lot of social involvement.

Against this background, the municipality had to design its own policies in the framework of the Wmo. The framework memorandum Wmo 2015 – 2019 of the municipality states that it's essential to focus on the involvement of the citizens and to shift to a system where the own power of residents and their environment is optimally used (37). This is fully in line with the national policies.

The previous chapter outlined the regulatory environment under which the municipality has to organize their support for informal caregivers. The key points are that:

- the municipality should enable informal caregivers to perform their duties as good as possible
- they are obliged to offer a yearly token of appreciation for informal caregivers
- they should also look at the need for support of informal caregivers when carrying out a survey for social support.

Regarding to the second point, the municipality offers a yearly token of appreciation. Hellendoorn named it the “mantelzorgcompliment” (±informal care compliment) and every year they determine how much this will be. In 2017 informal caregivers could choose between €75,- or an arrangement from the local theater (ZINiN). To be eligible for the “mantelzorgcompliment” one has to live in the

municipality of Hellendoorn and has to provide informal care at least 3 months and at least eight hours per week. The municipality choose foundation Evenmens to coordinate the “mantelzorgercompliment” by providing them with the necessary funds. Informal caregivers can apply for the compliment at Evenmens, and after the foundation has approved the application, the informal caregiver gets the appreciation.

Evenmens is a foundation that aims on informal care since 1981 (38). By working closely with Wmo employees of the municipality and local welfare/care organizations they can connect supply and demand. Evenmens works in ten municipalities in the province of Overijssel, among which Hellendoorn. When an informal caregiver is in need of support, they can go to Evenmens to get in contact with an informal care consultant. They offer the following types of support:

- Attention, a listening ear
- Information about how to deal with the care receiver, or the illness they have
- Taking over arranging tasks
- Helping with filling out forms
- In case of a terminal illness, the deployment of a volunteer at night
- Organized themed meetings
- Fellowship courses
- Relaxing activities / day of informal care
- Providing information bulletins for informal caregivers
- Financial compensation (mantelzorgercompliment)
- Advise about respite care

All these types of support speak for themselves, except respite care. The next subparagraph will tell something more about respite care, to make this concept clear.

### 5.1 Respite care

The center of expertise for informal care describes respite care as ‘the temporary takeover of total care by professionals or volunteers, to unburden the informal caregiver, in the form of homecare, daycare, short-stay etc.’ (39).

The center of expertise for informal care created a pyramid for respite care (figure 8). This pyramid exists of three main layers: respite need, respite usage and respite effect. Between these layers are the ‘transition zones’. The terms mentioned in those lighter colored zones, are the characteristics of service which are marked as important by informal caregivers.

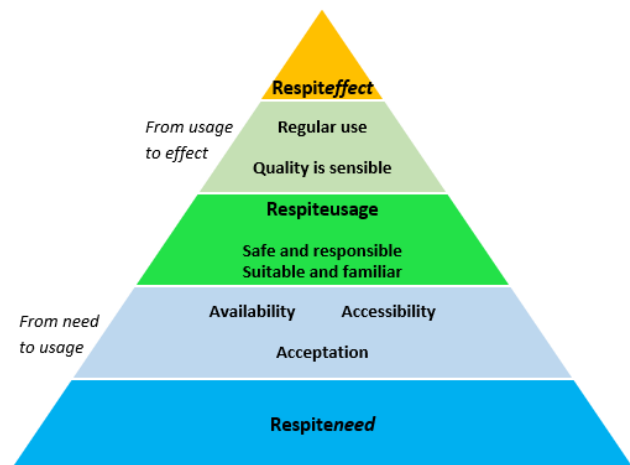


Figure 8 Respite care pyramid (39)

It occurs often that informal caregivers are completely focused on providing care, which makes them forget about themselves. When they reach out for help, it is mostly for information about the care receivers’ disease or the financial arrangements. In most cases, it is already too late when they realize that they also should care for themselves. To create that consciousness, it takes an outsider to ask

them: how are **you** doing? The first step in the usage of respite care is the awareness that the burden of providing informal care might be too high.

Once informal caregivers realize that they could use some support they have to take the next step: how do they get this support? There are three barriers that need to be taken which evolve around acceptance, availability, and accessibility. The acceptance of the informal caregiver is the first condition for effective respite care. It is often difficult for the informal caregiver and the care receiver to accept care from others. This process of acceptance takes time and only until the acceptance is there, it is possible to deepen in the possibilities. Furthermore, it is important that the respite care is available at the moment that the informal caregiver is in need of it and that it is accessible. When it comes to accessibility it is important that the information is understandable, that locations are physically accessible and that it is possible to finance the respite care. When all these conditions are met, the usage of the respite supply is the next phase in the pyramid.

When the informal caregiver and the care receiver accept the takeover of care and the supply is available and accessible, it is possible to start the respite care. To make the respite care successful it is important that it is safe and responsible. For an informal caregiver, it is important to know that the person they are taking care of is well cared for. The person who is going to provide the care should be competent and the care receiver should benefit from the respite care. Furthermore, it is important that the care is suitable and familiar. The care receiver should not get the feeling that he or she is 'dumped' with someone else. The care should fit with the preferences of the care receiver.

Just the usage of respite care does not guarantee effectiveness. It is also important to regularly use respite care, so that both caregiver and care receiver get used to let go of the informal care. This is more successful when there is good quality of care and the informal caregiver gets taken seriously by the care providers. Regular progress meetings and a good transfer of information are useful to achieve this.

When the phases of respite need, and respite supply are completed successfully, it leads to the top of the pyramid: respite effect. Informal caregivers can let go of the responsibility, which gives them some rest and the opportunity to engage in their everyday activities.

## 5.2 Summary

The municipality of Hellendoorn largely outsources the support of informal caregivers to Evenmens. Evenmens offers a wide range of supporting arrangements, and they have monthly meetings with the municipality's policy officer. There are short lines between the municipality and Evenmens, especially because they are housed in the same building.

When looking at the policies of the municipality of Hellendoorn, their Social Support decisions only states a few things about respite care. For unburdening the informal caregiver, they offer short-term stay. This short-term stay can be financed in two ways: a personal budget (persoonsgebonden budget, pgb) or care in kind (zorg in natura). With a pgb, the informal caregiver can purchase the care themselves, which can be useful in case the municipality doesn't have a contract with the desired caregiver. With care in kind, the municipality arranges everything, and the informal caregiver doesn't have to do anything, but to choose from a caregiver which is contracted by the municipality. Article 20 of the social support decision states that the pgb for short-term stay, provided by a professional, is €65,- per day. The pgb for short-term stay, provided by someone from the social network who isn't a professional, is €30,- per day. Article 21 states that the cost for short-term stay (zorg in natura) is €65,- per day (40).

So, except for short-term stay, the support of informal caregivers is outsourced to Evenmens.

## 6 RESULTS QUESTIONNAIRE

This chapter will answer the third and last sub question:

*What are the support needs of informal caregivers in the municipality of Hellendoorn?*

In the municipality of Hellendoorn a questionnaire has been spread to the informal caregivers. A lot of people luckily answered this questionnaire, which makes it possible to draw conclusions from their answers. Next to the general information of the respondents, which will be addressed in the first paragraph, there also were questions about the burden they experienced (paragraph 2), the support they are currently using (paragraph 3) and the support they need (paragraph 4).

The questionnaire was spread through the contacts of Evenmens, it was given to home care organizations and to general practitioners. Furthermore, a news item was created, which was placed on the website of the municipality and in the local newspaper. The response overview can be seen in table 2.

	Digital	Paper	Total
<b>Send</b>	x	285	x
<b>Received</b>	216	71	287
<b>Excluded</b>	93	7	100
<b>Total</b>	123	64	187

Table 2 Response overview

Because the people who received a paper questionnaire, also had the option to fill in the questionnaire online, the response rate cannot be calculated. The next paragraph will tell more about the general information of the participants.

**Note: Statistically significant relations are indicated in bold. For variables with the nominal measurement, the chi-squared test has been used. For variables with the scale measurement the bivariate Pearson Correlation has been used.**

### 6.1 General information

The fourth part of the questionnaire consisted of twelve questions about general information. These questions can chart the characteristics of the participants (table 3). As often seen in research about informal caregivers, the largest part of the participants was female (70.6%). The mean age of the caregivers was 61.2 years and in 48.7% of the cases, someone provided care to their partner. Furthermore 60.4% was living together with the person they provided care for.

In the theoretical part of this framework, a few definitions of informal care were given. It stated that the Central Bureau for statistics (CBS), the Municipal Health Services (GGD) and the National Institute for Public Health and the Environment (RIVM), agreed on the definition that they regard someone as

an informal caregiver when the care provided lasts at least 3 months and is offered for at least 8 hours per week. In the results of the questionnaire it is found that every single participant is offering informal care for more than 3 months, so that is in line with the definition. However, as can be seen in table 1, 24.1% of the participants offers informal care less than 8 hours per week. So, in the eyes of some important organizations in the Netherlands, almost a quarter of the participants, who regard themselves as informal caregiver, are not seen as such.

		M	SD	Number	Percent
<b>Age</b>		61.2	13.8		
<b>Sex</b>	Female			132	70.6
	Male			55	29.4
<b>Relationship</b>	Spouse			91	48.7
	Daughter/Son			30	16.0
	Parent			46	24.6
	Other			20	10.7
<b>Co-Residence</b>	Yes			113	60.4
	No			74	39.6
<b>Care hours (per week)</b>	Less than 4			9	4.8
	4 to 8			36	19.3
	8 to 12			39	20.9
	More than 12			103	55.1

Table 3 Characteristics of the participants

## 6.2 Burden of the informal caregivers

The first part of the questionnaire gained information about the burden of the informal caregivers, with the BSFC-s. This version consisted of 10 items, and the total score for these individual items was combined to one result. There were three categories for this combined result: non to mild burden (score from 0 to 14), moderate burden (score from 15 to 19) and severe to very severe burden (score from 20 – 30). Most of the participants (50.3%) experienced non to mild burden. A

		Non to mild	Moderate	Severe to very severe
		N (percent of cases)		
<b>Sex</b>	<b>Male</b>	26 (47.3)	16 (29.1)	13 (23.6)
	<b>Female</b>	68 (51.1)	40 (30.3)	24 (18.2)
	<b>Total</b>	94 (50.3)	56 (29.9)	37 (19.8)
<b>Age</b>	<b>20 – 39</b>	3 (33.3)	3 (33.3)	3 (33.3)
	<b>40 – 59</b>	40 (50.6)	22 (27.8)	17 (21.5)
	<b>60 – 79</b>	42 (51.2)	17 (21.5)	15 (18.3)
	<b>80 – 99</b>	9 (52.9)	15 (18.3)	2 (11.8)
	<b>Total</b>	94 (50.3)	56 (29.9)	37 (19.8)

Table 4 Burden by gender and age

moderate burden was experienced by 29.9% and severe to very severe burden by 19.8%. Table 4 shows the severity of burden that participants experience, divided in gender and in age. According to these results, 23.6% of the male informal caregivers experience a severe to very severe burden, while for the female informal caregivers this is 18.2%. Also, it can be seen that a severe to very severe burden becomes less common, with higher age. But when using the chi-squared test on these variables, there is no significant relation to be found. However, when using the total score BSFC-s and the age variable (both as a scale measurement variable), there can be found a significant correlation of **-0.12 (p<0.05)**. So that means there is a negative correlation between burden score and age. The higher the age, the lower the burden score. Note that this is a small correlation.

Some of the respondents, are also working, next to their informal caregiver tasks. There can be expected that this combination, is of influence on the severity of the burden that is present with the informal caregiver. Imagine someone having a part-time or full-time job. When they come home, they have to take care of their own family/household. When that is done, there is also a parent who needs help with the groceries, with cleaning and some administration. However, when combining the burden with the work hours, there is no significant association to be found (table 5). There is however a small bivariate association between burden and the amount of hours that an informal caregiver is providing the care. The more hours someone has to spend on informal care, the higher the burden. Furthermore, there was also no relation between the nature of the disease and the burden to be found.

## 6.3 Support use

The second part of the questionnaire extracted information about the current use of support. Currently, 112 out of the 187 respondents, are getting support. These 112 cases ticked a total of 172 boxes, so there are cases where people receive multiple types of support. Home care is the most used type of support. In 40.2% of the cases where there is support, they receive home care. This is to be expected, because people stay at home longer when they are in need of complex care. Since it is not always possible for an informal caregiver to perform complex care tasks, it is logical for them to get support from professional home care organisations. Next to home care, domestic help is also a frequent used support. In 38.4% of the cases, people are receiving support care. Table 5 gives an overview of the frequencies from support use.

Type of support used	N (percent of cases)
<b>Home care</b>	45 (40.2)
<b>Domestic help</b>	43 (38.4)
<b>Emotional support</b>	26 (23.2)
<b>Respite care</b>	20 (17.9)
<b>Providing information</b>	12 (10.7)
<b>Financial support</b>	5 (4.5)
<b>Other</b>	21 (18.8)
<b>Total</b>	172 (153.6)

Table 5 Support use

There are 112 people who are using support and there are 75 people who are not. From these 75 people who are not using support, there are 28 people with a moderate to very severe burden. In total there are 93 people with a moderate to very severe burden. So, 30% of the people with a moderate to



very severe burden, are not using any type of support. There has been analysed whether using support (yes or no) and burden are independent of one another. A significant relation was found ( $\chi^2 (2) = 7.84$ ,  $p = 0.02$ ).

When looking at the residential areas (table 6), it can be seen that home care and domestic help are also the most used support in all the areas. There are no huge differences between the residential areas and the support that is used at the moment.

Location	Use Support N	Homecare	Domestic help	Emotional support	Respite care	Providing information	Financial support	Other
N (percent of cases)								
Nijverdal Zuid	58	25 (43.1)	25 (43.1)	13 (14.4)	12 (20.7)	7 (12.1)	1 (1.7)	8 (13.8)
Hulsen etc.	24	8 (33.3)	9 (37.5)	6 (25.0)	5 (20.8)	2 (8.3)	1 (4.2)	4 (16.7)
Hellendoorn etc.	18	6 (33.3)	7 (38.9)	5 (27.8)	2 (11.1)	1 (5.6)	1 (5.6)	5 (16.7)
Haarle	5	3 (60.0)	1 (20.0)	1 (20.0)	0 (0)	0 (0)	0 (0)	2 (40.0)
Marle etc.	3	1 (33.3)	0 (0)	0 (0)	1 (33.3)	1 (33.3)	1 (33.3)	1 (33.3)
Overig	4	2 (50.0)	1 (25.0)	1 (25.0)	0 (0)	1 (25.0)	1 (25.0)	1 (25.0)
<b>Total</b>	<b>112</b>	<b>45 (40.2)</b>	<b>43 (38.4)</b>	<b>26 (23.2)</b>	<b>20 (17.9)</b>	<b>12 (10.7)</b>	<b>5 (4.5)</b>	<b>21 (18.8)</b>

Table 6 Support use by residential area

When looking at the used support compared to the gender (table 7), it can be seen that females tend to use more respite care and emotional support. Home care is used almost evenly by males and female. Males tend to use more domestic help (36.4% versus 17.4%). This is not very unexpected, since females (especially in earlier times) mostly take on the household tasks. So, when these females get an illness they can't perform these tasks anymore. Men who are not familiar with household tasks and are not able to learn this anymore, are then in need of domestic help. A significant relation was found between gender and domestic help ( $\chi^2 (1) = 7.87$ ,  $p = 0.005$ ).

Type of support used	Males	Females
N (percent of cases)		
Home care	12 (21.8)	33 (25.0)
Domestic help	<b>20 (36.4)</b>	<b>23 (17.4)</b>
Emotional support	4 (7.3)	22 (16.7)
Respite care	3 (5.5)	17 (12.9)
Information	2 (3.6)	10 (7.6)
Financial support	2 (3.6)	3 (2.3)
Other	5 (9.1)	16 (12.1)

Table 7 Support by gender

Looking at the age compared to the support use (table 8), it can be seen that the oldest category (80 – 99 years) uses the most home care and domestic care. This is a logical result, since they are of high age and probably with some physical limitations, which makes that they can't carry out these tasks themselves. People in age categories 40 – 59 and 80 – 99 make the most use of respite care. This can be explained because people in age category 40 – 59 are still working and are burdened more easily. People in age category 80 – 99 probably have their own limitations related to their age, which makes it difficult for them to provide care. People in the age category in between are mostly retired, so they have more time, and they are not physically limited as the highest age category, which makes them more able to take care of their loved ones. There were no significant relations.

Type of support used	20 – 39	40 – 59	60 – 79	80 – 99
N (percent of cases)				
Home care	0 (0.0)	17 (21.5)	22 (26.8)	6 (35.3)
Domestic help	0 (0.0)	17 (21.5)	20 (24.4)	6 (35.3)
Emotional support	1 (11.1)	11 (13.9)	13 (15.9)	1 (5.9)
Respite care	0 (0.0)	11 (13.9)	5 (6.1)	4 (23.5)
Information	1 (11.1)	4 (5.1)	7 (8.5)	0 (0.0)
Financial support	1 (11.1)	3 (3.8)	1 (1.2)	0 (0.0)
Other	2 (22.2)	15 (19.0)	3 (3.7)	1 (5.9)

Table 8 Support by age

## 6.4 Support need

The second part of the questionnaire also extracted information about the desired support. Currently, 69 out of the 187 respondents, is desiring (extra) support. These 69 cases ticked a total of 141 boxes, so there are cases where people desire multiple types of support. Information about healthcare laws are desired the most (50.7% of the cases in which they desire support). This is followed by practical support regarding work tasks (42.0%) like cleaning and garden maintenance and practical support regarding care tasks (37.7%) (table 9). There has been analysed whether being in need of support (yes or no) and burden are independent of one another. A significant relation was found ( $\chi^2 (2) = 26.99, p = 0.00$ ).

Type of support needed	N (percent of cases)
Advise (providing care)	14 (20.3)
Information (local support)	17 (24.6)
Information (laws)	35 (50.7)
Emotional support	16 (23.2)
Practical (care tasks)	26 (37.7)
Practical (work tasks)	29 (42.0)
Other	4 (5.8)
<b>Total</b>	<b>141 (204.3)</b>

Table 5 Support need

The most responses came from the areas Nijverdal Zuid, Hulsen & Nijverdal Noord, which is logical when looking at the number of inhabitants in these areas. When looking at the residential areas, it was to be expected that people in rural areas might be in need of less support, since there is more “neighbourship” and social involvement there. However, this conclusion cannot be drawn from the results in table 10. The desire for support is just as present in the rural areas (Hellendoorn etc., Haarle and Marle etc.) as in the other ones (Nijverdal Zuid and Hulsen etc.), but it is difficult to draw conclusions from this because there were no significant relations.

Location	Need support	Advise	Information about offer	Information about laws	Emotional support	Practical support care	Practical support work	Other
	N	N (percent of cases)						
Nijverdal Zuid	36	6 (16.7)	7 (19.4)	15 (41.7)	7 (19.4)	17 (47.2)	15 (41.7)	4 (11.1)
Hulsen etc.	10	2 (20.0)	2 (20.0)	7 (70.0)	2 (20.0)	1 (10.0)	4 (40.0)	0 (0)
Hellendoorn etc.	13	3 (23.1)	4 (30.8)	8 (61.5)	5 (38.5)	4 (30.8)	7 (53.8)	0 (0)
Haarle	3	1 (33.3)	1 (33.3)	1 (33.3)	2 (66.7)	2 (66.7)	2 (66.7)	0 (0)
Marle etc.	4	0 (0)	2 (50.0)	2 (50.0)	0 (0)	2 (50.0)	1 (25.0)	0 (0)
Overig	3	2 (66.7)	1 (33.3)	2 (66.7)	0 (0)	0 (0)	0 (0)	0 (0)
<b>Total</b>	<b>69</b>	<b>14 (20.3)</b>	<b>17 (24.6)</b>	<b>35 (50.7)</b>	<b>16 (23.2)</b>	<b>26 (37.7)</b>	<b>29 (42.0)</b>	<b>4 (5.8)</b>

Table 6 Support need by residential area

When looking at the needed support compared to the gender (table 11), females are more in need of emotional support than men, while men are more in need of practical support regarding care tasks. This corresponds to the stereotype of women in general being more caring and emotionally than men. Males are more in need of information about healthcare laws and support offer than females. They are evenly in need of practical support like cleaning and garden maintenance. There were no significant relations.

Type of support needed	Males	Females
	N (percent of cases)	
Advise (providing care)	5 (9.1)	9 (6.8)
Information (local support)	8 (14.5)	9 (6.8)
Information (laws)	15 (27.3)	20 (15.2)
Emotional support	3 (5.5)	13 (9.8)
Practical (care tasks)	10 (18.2)	16 (12.1)
Practical (work tasks)	9 (16.4)	20 (15.2)
Other	1 (1.8)	3 (2.3)

Table 11 Support need by gender

Looking at the age compared to the support need (table 12), it can be seen that people in the highest age category (80 – 99) are most in need of emotional support, practical support regarding care tasks and practical support like cleaning and garden maintenance. People in age category 40 – 59 are most curious about the national laws they have to deal with (Wmo 2015, Zvw, Wlz). Table 13 shows that the lowest age category, shows very few demands for support. This can be explained by the fact that there are not as much ill people in this category, and because the ill people in this age category often have multiple healthy relatives that can share the care burden.

Type of support needed	20 – 39	40 – 59	60 – 79	80 – 99
Advise (providing care)	1 (11.1)	8 (10.1)	5 (6.1)	0 (0.0)
Information (local support)	0 (0.0)	9 (11.4)	6 (7.3)	2 (11.8)
Information (laws)	1 (11.1)	20 (25.3)	10 (12.2)	4 (23.5)
Emotional support	0 (0.0)	7 (8.9)	6 (7.3)	3 (17.6)
Practical (care tasks)	1 (11.1)	9 (11.4)	11 (13.4)	5 (29.4)
Practical (work tasks)	2 (22.2)	14 (17.7)	9 (11.0)	4 (23.5)
Other	0 (0.0)	2 (2.5)	1 (1.2)	1 (5.9)

Table 12 Support need by age

## 6.5 Knowledge of the informal caregivers

The third part of the questionnaire asked questions about whether or not informal caregivers were already familiar with Evenmens and their current support possibilities. When looking at table 13, there can be seen that when the burden gets more severe, more people know Evenmens. However, when performing a chi-squared test this is not statistically significant.

	Non to mild	Moderate	Severe to very severe
Knows	72 (76.6)	46 (82.1)	31 (83.8)
Doesn't know	22 (23.4)	10 (17.9)	6 (16.2)

Table 13 Knowledge of Evenmens by burden

Furthermore, 62.0% of the participants say they know the way to support.

### 6.4.1 Open answers

The questionnaire also had the option for open answers if the pre-defined answers weren't sufficient enough. A recurring remark by nine people is that they think that there are too many cuts and that too much is asked of the informal caregiver. Another striking answer from three people is that they would like a better overview of all the options they have in the health care system. The informal caregivers tend to get lost in all the different laws (Wlz, Wmo 2015, Youth Act and Zvw), and indicate that this costs a large amount of time, which they can also spend on care.

There are also positive comments about Evenmens, which say that the organization is very helpful. And there are a few people who say that it used to be very normal to take care of your loved ones, and that they don't see it as a burden.

## 7 CONCLUSION

In this chapter the main question will be answered. The main question goes as following: *“How can the municipality of Hellendoorn organize support of informal caregivers in an effective way?”*. In order to answer this question, three sub-questions were composed.

Chapter 4 answers the first sub question: *“What is the regulatory environment for the design of supporting arrangements for informal caregivers?”*. The chapter shows that there have been a lot of changes in the last century, when it comes to the healthcare system in the Netherlands. A corner stone in the renewed healthcare system is the “own strength” of citizens. Together with the aid of people in their near surroundings, people should stay in their own living environment as long as possible. Only when the capacities of the social system fall short, the municipality will offer support. The government recognizes that this new system may impose a severe burden for the informal caregivers and therefore the Wmo 2015 states that the municipalities also must look at the need for support of the informal caregiver. But when it comes to developing a policy for this support, municipalities are free to develop their own arrangements so that it is suitable for the citizens.

Chapter 5 answers the second sub question: *“What is the current organization of informal caregiver support in the municipality of Hellendoorn?”*. In this chapter can be read that the municipality of Hellendoorn largely outsources the support of informal caregivers to Evenmens. Evenmens offers a wide range of supporting arrangements, and they have monthly meetings with the municipality’s policy officer. Via the Wmo-Consultant of the municipality, it is possible to indicate short-term stay, in which the care recipient will stay somewhere else (i.e. a nursing home) for a short time.

Chapter 6 answers the third, and most important, sub question: *“What are the support needs of informal caregivers in the municipality of Hellendoorn?”*. A lot of data was gained through a questionnaire, which gave large amount of information. There were a couple of outcomes that were to be expected, for example: the more hours of care, the greater the chance of a high burden score. Also, there were more women providing informal care. Regarding to the support need overall, the type of support that is most desired is information about national healthcare laws. After that, the most desired is practical support like cleaning, gardening etc. In third place comes the support with practical tasks that are care related. It was difficult to draw one straight line in the answers, when it comes to combining needs with personal characteristics. The combination of work hours, care hours, relationship with the care receiver, involvement of other informal caregivers, personal issues etc., creates the need for support and determines which type of support is desired.

Concluding, in order for the municipality of Hellendoorn to organize informal caregiver support in an effective way, they have to create a wide range of options that can be combined to a perfect fit for each individual.

## 8 DISCUSSION

This research has strengths and limitations, which will be discussed in the first paragraph of this chapter. The last second paragraph of this chapter will give recommendations for further research.

### 8.1 Findings and comparison with the literature

As can be read in the results chapter, 30% of the moderate to very severe burdened people are not using any type of support. This might seem very strange but the research of Exel et al. (41) also found that there are many caregivers that are in need of support, but do not ask for support. Grunfeld et al. (42) also found there is a lack of recognition in caregiver burden. Caregivers who are in need of support, but don't ask for it often find it very difficult to ask for help. They might feel like they are failing the person they are providing care for, or do not feel understood. This group of people is important for the municipality because this 30% is the group that could use support the most for their own benefit but also for the benefit of the healthcare system as a whole. By supporting these people, the double boomerang effect can be avoided, which would help in making the healthcare system maintainable.

Furthermore the literature already made it clear that being an informal caregiver is dealt with very differently by each person and that it is very dependent on the personal situation when people reach their limits (25). One person could have no problems with carrying out care related tasks like washing, while for another person this is something that they are not willing to do. But this person might be very good with policies, organizing, administration etc., while this is something that costs the first person a lot amount of time and thinking about doing that is already a burden. The answers to the questionnaire also reflect this picture because it is difficult to draw one straight line in the support needs. Because the support need is so dependent on the specific situation of a person, it is very important for the municipality that the support offer can be customized to the specific requirement of an individual.

The results chapter shows that there is a small significant correlation between burden score and age. Higher the age, the lower the burden score. This is remarkable because a research of the GGD Twente called 'Health Monitor', shows that the elderly people in the municipality of Hellendoorn are just as heavily burdened or overburdened as adults (43). This difference in results may be due to the use of the scale values for the calculation of the correlation.

### 8.2 Strength and limitations

A strength of this research is that it has a response rate of 187. With this amount of responses, it was possible to get a good view of the informal caregivers in Hellendoorn. Another strength is that Evenmens was involved in the construction of the questionnaire, so their expertise is also included in the process. Furthermore, by using a questionnaire, the respondents had a safe environment for completing the questionnaire. This ensured that there was a less chance of social desirable behavior.

A limitation of this study is bias in the research population. To distribute the questionnaire, multiple channels have been used. The questionnaire was given to general practitioners, homecare nurses and volunteer organization. There has also been a message on the website of the municipality and in the local paper. But the most paper versions were sent to the clients known by Evenmens. The people that are known by Evenmens, mostly already receive support. So, the informal caregivers that didn't receive a questionnaire are most likely informal caregivers who don't receive support. A second limitation is that it was not very clear in the questionnaire who received the support that was already present. Take domestic help for an example. If the care receiver and care giver are living together the domestic help is for their combined household, so this has no influence on the intention of the questionnaire. But when someone is not living together with the care receiver, the question can be

interpreted in two different ways: is the care receiver getting domestic help or is the care giver receiving domestic help? This should have been explained more extensive in the introduction of the questionnaire. At last, this research did not go further into the responses by for example taking interviews. Interviews could have helped to better understand the intrinsic motivations with regard to whether or not to use support.

### 8.3 Recommendations

It is recommended to the municipality that they create a flexible support system for informal caregivers that is able to bend with the needs of informal caregivers. This support system should have a wide range of options. It is also important to focus on the informal caregivers that are in need of help, but do not ask for it. This could be done by advertising, flyers, news items etc., but also by maintaining contacts with people who see the informal caregivers more often. At this point you could think of general practitioners and homecare nurses. Furthermore, the results chapter showed that there is a demand for more information about laws and legislation. When people have more knowledge about these things, it can be easier for them to find their way in the healthcare system. So, it can be useful to invest in creating clear overviews. At last, Evenmens is mostly well known to the informal caregivers, so its seems valuable to continue the co-operation with them.

There are also some recommendations for future research. This research has only focused on the informal caregivers and their needs. For the municipality it is also useful to get more insight in the economic aspect of informal caregiver support, so this could be an option for future research. It can also be valuable to look at other municipalities that are similar to Hellendoorn and compare the filling in of informal caregiver support. Finally, it can be useful to conduct a more qualitative research among the informal caregivers to gain better insight in the answers they gave in this quantitative research.

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## APPENDIX

### I Questionnaire

#### Vragenlijst voor mantelzorgers

U ontvangt deze vragenlijst omdat u iemand ondersteunt door mantelzorg te verlenen. Steeds meer inwoners van de gemeente Hellendoorn zijn mantelzorger en zetten zich vrijwillig in voor hun naaste. Dat is fijn voor degene die de zorg nodig heeft en verrijkend voor de mantelzorger, maar het vraagt ook wat. Naast de verrijking, kan het verlenen van mantelzorg ook een bepaalde druk met zich meebrengen. Deze druk kan zich uiten in fysieke en psychische klachten en om deze klachten te voorkomen is goede ondersteuning voor mantelzorgers wenselijk. Bij het creëren van goede ondersteuning is het achterhalen van de behoeftes van mantelzorgers erg belangrijk.

Mijn naam is Babet Nijhuis, en in het kader van mijn studie gezondheidswetenschappen aan de Universiteit Twente ben ik bezig met een afstudeeropdracht bij de gemeente Hellendoorn. Deze afstudeeropdracht richt zich op de druk die mantelzorgers ondervinden en de behoefte aan ondersteuning die zij hebben.

Om dit in kaart te brengen, heb ik deze vragenlijst opgesteld. Het invullen zal maximaal 10 minuten van uw tijd in beslag nemen. De vragenlijst bestaat uit vier onderdelen:

Deel 1: Druk die wordt ervaren door de mantelzorger

Deel 2: Behoefte aan ondersteuning

Deel 3: Bekendheid met ondersteuningsmogelijkheden

Deel 4: Algemene vragen

Op de volgende pagina vindt u eerst een standaardformulier waarmee u toestemming geeft voor het gebruik van uw antwoorden op de vragenlijst voor onderzoek.

Wilt u de vragenlijst invullen voor 9 juni?

Alvast bedankt voor uw moeite!

## Toestemmingsformulier

Deze vragenlijst richt zich op mantelzorgers in de gemeente Hellendoorn. De vragen gaan over eventuele druk die u ervaart en de behoefte aan ondersteuning die u heeft. Uw antwoorden zullen volledig anoniem en vertrouwelijk behandeld worden.

Uw deelname is geheel vrijwillig en anoniem. U kunt op ieder moment besluiten om uw deelname aan dit onderzoek te beëindigen, daarvoor hoeft u geen reden op te geven. Voor verdere informatie over dit onderzoek kunt u contact opnemen via:

E-mail: [b.nijhuis@hellendoorn.nl](mailto:b.nijhuis@hellendoorn.nl)

Telefoon: 0548-630633

Door onderstaand vakje aan te kruisen, stemt u geheel vrijwillig in met deelname aan dit onderzoek. U bent tenminste 18 jaar en u hebt het recht om op elk moment zonder opgaaf van reden de deelname aan dit onderzoek te beëindigen.

Ja, ik stem geheel vrijwillig in met deelname aan dit onderzoek.

## Deel 1: Druk die wordt ervaren door de mantelzorg

De volgende uitspraken gaan over uw situatie van de afgelopen 3 maanden. Kruis bij elke uitspraak de kolom aan (rechts ernaast), die voor u het meest passend is. Er is maar één antwoord mogelijk. Beantwoord alstublieft elke vraag.

	Klopt precies	Klopt overwegend	Klopt minder	Klopt niet
1. Ik ben minder tevreden met mijn leven door de mantelzorg werkzaamheden die ik uitvoer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Ik voel me vrijwel nooit lichamelijk uitgeput.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Ik heb vrijwel nooit het gevoel dat ik vrij wil zijn van mijn mantelzorg werkzaamheden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Ik voel mezelf soms niet meer echt als "ikzelf".	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Mijn levensstandaard is door de mantelzorg werkzaamheden niet achteruitgegaan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Mijn gezondheid is niet aangetast door mijn mantelzorg werkzaamheden.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. De mantelzorg werkzaamheden kosten mij niet veel van mijn eigen kracht.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Ik sta in dubio tussen de eisen van mijn omgeving en de eisen die door de mantelzorg werkzaamheden aan mij worden gesteld.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Ik maak me geen zorgen om mijn toekomst, ondanks de mantelzorg werkzaamheden die ik verleen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Mijn relaties met gezinsleden, familieleden, vrienden en kennissen lijden niet onder de mantelzorg werkzaamheden die ik verleen.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Dit is het einde van Deel 1. De vragenlijst gaat verder op de volgende pagina met Deel 2.

## Deel 2: Behoeftte aan ondersteuning

Dit deel van de vragenlijst gaat over de behoefte die u hebt aan ondersteuning. Kruis aan wat voor u van toepassing is. Indien er meerdere antwoorden mogelijk zijn, staat dit vermeld bij de vraag.

<p>1. Krijgt u momenteel ondersteuning bij uw mantelzorg werkzaamheden?</p>	<p><input type="checkbox"/> Ja <input type="checkbox"/> Nee</p>
<p>2. Indien ja, welke ondersteuning krijgt u? (Kruis aan wat van toepassing is. Er zijn meerdere antwoorden mogelijk)</p>	<p><input type="checkbox"/> Wijkverpleging  <input type="checkbox"/> Huishoudelijke hulp  <input type="checkbox"/> Tijdelijke overname van de zorg (opvang, begeleiding, respijtzorg)  <input type="checkbox"/> Informatie voorziening/advisering  <input type="checkbox"/> Emotionele ondersteuning (bijv. een luisterend oor)  <input type="checkbox"/> Financiële ondersteuning  <input type="checkbox"/> Anders namelijk:  <hr/>  <hr/>  <hr/>  <hr/></p>
<p>3. Hebt u behoefte aan (uitbreiding van) ondersteuning in relatie tot uw mantelzorg werkzaamheden?</p>	<p><input type="checkbox"/> Ja <input type="checkbox"/> Nee</p>
<p>Indien u met ja geantwoord heeft, ga verder met vraag 4. Indien u met nee geantwoord heeft, ga verder naar Deel 3 van de vragenlijst.</p>	
<p>4. Aan welke vorm van ondersteuning in relatie tot uw mantelzorg werkzaamheden hebt u behoefte? (Kruis aan wat van toepassing is. Er zijn meerdere antwoorden mogelijk)</p>	<p><input type="checkbox"/> Advisering over hoe ik om moet gaan met degene aan wie ik zorg verleen  <input type="checkbox"/> Informatie over het zorg-/hulpaanbod in de gemeente Hellendoorn  <input type="checkbox"/> Informatie over de wettelijke regelingen of vergoedingen die er zijn  <input type="checkbox"/> Emotionele ondersteuning (bijv. een luisterend oor)  <input type="checkbox"/> Praktische ondersteuning zoals opvang, begeleiding en tijdelijke overname van zorg  <input type="checkbox"/> Praktische ondersteuning zoals hulp bij klussen in en rond huis (schoonmaak, onderhoud, tuin etc.)  <input type="checkbox"/> Anders namelijk:  <hr/>  <hr/>  <hr/>  <hr/></p>

Dit is het einde van Deel 2. De vragenlijst gaat verder op de volgende pagina met Deel 3.

### Deel 3: Bekendheid met ondersteuningsmogelijkheden

Dit deel van de vragenlijst gaat over uw bekendheid met ondersteuningsmogelijkheden voor mantelzorgers in de gemeente Hellendoorn. Kruis aan wat voor u van toepassing is.

1. Bent u bekend met Stichting Evenmens? (Voorheen Stichting Vrijwillige Thuiszorg Overijssel (SVTO))	<input type="checkbox"/> Ja <input type="checkbox"/> Nee		
2. In de gemeente Hellendoorn zijn verschillende ondersteuningsmogelijkheden voor mantelzorgers. Kunt u aangeven of u bekend bent met onderstaande mogelijkheden en indien ja, of u er ook gebruik van maakt?			
	Ben ik bekend mee en maak ik gebruik van	Ben ik bekend mee, maar maak ik <b>geen</b> gebruik van	Ben ik niet bekend mee
a. Weet u van het bestaan af van het Alzheimercafé, waar mensen met dementie, hun naasten, professionals en belangstellenden samen komen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Bent u bekend met het mantelzorgcompliment <sup>1</sup> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Bent u bekend met het spreekuur dat wordt gehouden door de mantelzorgconsulenten van stichting Evenmens?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Bent u bekend met de mogelijkheid dat stichting Evenmens diverse regeltaken kan overnemen (kosteloos en zonder indicatie)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Bent u bekend met de inzet van zorgvrijwilligers die respijtzorg (tijdelijke overname van de mantelzorgtaken) kunnen verlenen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Indien u ondersteuning nodig hebt, weet u de weg naar deze ondersteuning dan te vinden, en zo ja, hoe?	<input type="checkbox"/> Ja, namelijk via: _____ _____ _____ _____ _____ <input type="checkbox"/> Nee		

Dit is het einde van Deel 3. De vragenlijst gaat verder op de volgende pagina met Deel 4.

<sup>1</sup> Het mantelzorgcompliment is een arrangement van ZINiN of een financiële vergoeding van €75 per jaar die wordt uitgereikt door stichting Evenmens en beschikbaar is gesteld door de gemeente Hellendoorn.

## Deel 4: Algemene vragen

Dit is het laatste deel van de vragenlijst. Dit deel bevat enkele algemene vragen. Kruis aan wat voor u van toepassing is of vul uw antwoorden in, in de daarvoor bestemde ruimte.

1. Wat is uw geslacht?	<input type="checkbox"/> Man <input type="checkbox"/> Vrouw
2. Wat is uw leeftijd?	_____ jaar
3. Wat is uw hoogst voltooide opleiding?	<input type="checkbox"/> Geen opleiding <input type="checkbox"/> Basisonderwijs <input type="checkbox"/> MAVO <input type="checkbox"/> VMBO <input type="checkbox"/> HAVO <input type="checkbox"/> VWO <input type="checkbox"/> MBO <input type="checkbox"/> HBO <input type="checkbox"/> Universiteit <input type="checkbox"/> Anders namelijk: _____
4. Bent u momenteel nog in loondienst?	<input type="checkbox"/> Ja, namelijk _____ uur per week <input type="checkbox"/> Nee
5. Wat is de relatie tot de persoon aan wie u mantelzorg verleent?	<input type="checkbox"/> Partner <input type="checkbox"/> Kind <input type="checkbox"/> Ouder <input type="checkbox"/> Anders namelijk: _____
6. Hoe lang verleent u al mantelzorg?	<input type="checkbox"/> Minder dan 3 maanden <input type="checkbox"/> Meer dan 3 maanden
7. Hoeveel uur per week verleent u gemiddeld mantelzorg?	<input type="checkbox"/> Minder dan 4 uur per week <input type="checkbox"/> 4 – 8 uur per week <input type="checkbox"/> 8 – 12 uur per week <input type="checkbox"/> Meer dan 12 uur per week
8. Woont u samen met degene aan wie u mantelzorg verleent?	<input type="checkbox"/> Ja <input type="checkbox"/> Nee
9. Van welke aard is de aandoening van degene aan wie u mantelzorg verleent?	<input type="checkbox"/> Psychische aard <input type="checkbox"/> Fysieke aard <input type="checkbox"/> Beide

<p>10. Wat is de aard van uw mantelzorg werkzaamheden? (Kruis aan wat van toepassing is. Er zijn meerdere antwoorden mogelijk)</p>	<p> <input type="checkbox"/> Huishoudelijk  <input type="checkbox"/> Fysiek (wassen, kleden etc.)  <input type="checkbox"/> Administratief  <input type="checkbox"/> Begeleiding  <input type="checkbox"/> Anders namelijk:  <hr/>  <hr/>  <hr/>  <hr/> </p>
<p>11. Zijn er naast u nog andere personen die mantelzorg verlenen aan de zorgvrager?</p>	<p> <input type="checkbox"/> Ja, namelijk _____ andere perso(o)n(en)  <input type="checkbox"/> Nee </p>
<p>12. In welk deel van de gemeente Hellendoorn bent u woonachtig?</p>	<p> <input type="checkbox"/> Marle, Daarle, Daarlerveen  <input type="checkbox"/> Hulsen, Nijverdal Noord (ten noorden van de grote straat)  <input type="checkbox"/> Nijverdal Zuid (ten zuiden van de grote straat)  <input type="checkbox"/> Haarle  <input type="checkbox"/> Hellendoorn, Hancate, Egede, Eelen &amp; Rhaan </p>
<p>Dit is het einde van de vragenlijst. Indien u nog toevoegingen of opmerkingen heeft, kunt u dat hieronder vermelden:</p> <hr/> <hr/> <hr/> <hr/> <hr/>	

Hartelijk dank voor het invullen van de vragenlijst!