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# YOU AND ME, TOGETHER WE ARE HUMAN

A reference framework for quality of life, housing  
and care for people with dementia





You and me, together we are HUMAN

A reference framework for quality of life, housing and care for people with dementia

*On the initiative of and with support from the Flemish Minister of Wellbeing, Public Health and Family,  
Jo Vandeurzen*

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# Table of contents

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Background of this publication	7
1. The broader context: quality of life, housing and care	11
Quality of life	11
Quality of care and housing	12
2. The model for quality dementia care	13
Building and using the model	13
The reference framework as a means for reflection	14
The core values	15
The central care relationship	17
Foundation 1. Societal and personal perception	18
Perception and stigmatisation	18
Frames versus counter-frames	18
“Forget dementia, remember the person”	19
Foundation 2. The normalisation principle	20
Make sure that normal can stay ‘normal’	20
The choice for normalisation in the organisation	21
Foundation 3. Independence in security	22
Finding the right balance	22
From deciding independently to substitute decisions	23
Foundation 4: Personalised care	24
The person comes first	24
Limitations and possibilities	24
The importance of a timely diagnosis and a proper follow-up	25
Foundation 5. The carers and relatives	27
On the SOFA	27
Foundation 6. The professional carers and volunteers	30
3. Applications in dementia care	33
Physical	34
Mealtime care	34
Prevention	35
Psychological	36
Challenging behaviour	36
Psycho-social support for people with dementia and their relatives	38
Level of independence	40
Documentation and care planning	40
Tools	41
Social relationships	42
Intimacy and sexuality	42
Volunteers for people with dementia	44
Environment	45
Architecture and interior design	45
Meaningful daytime activities	47

Culture	48
Social participation	49
Missing persons	50
Culture-sensitive care	53
Spirituality, religion and personal beliefs	54
Reminiscence	54
Existential and spiritual care	55
Advance care planning and palliative care	56
Advance Care Planning	56
Palliative care and end-of-life care	58
4. Sector-specific inspiration	59
Dementia-friendly home care	59
The role of social workers from health insurance funds	59
The role of the family care service	59
The role of the pharmacist	59
Dementia-friendly hospital	60
Pillar 1: a dementia-friendly environment	60
Pillar 2: a strong care team with dementia-specific expertise	61
Pillar 3: person-centred care from admission to discharge	61
Dementia-friendly housing	62
Intersectoral cooperation	63
5. Organisation-specific conditions	65
Bibliography	67



# Background of this publication

**Every day, thousands of formal carers and care facilities pursue high-quality care and support for people in need of care. More and more often people with dementia are becoming a part of this. At the time of publication, there are 132,000 people living with this condition in Flanders. The prediction is that this number will increase to more than 188,000 by 2035 (Steyaert, 2016).**

Most people with dementia still live at home, supported by home care facilities and home care support services. Others have moved to a service flat or a residential care centre. Sometimes they stay in a hospital temporarily. Wherever a person with dementia stays or lives, professional carers do everything they can to improve their quality of life and also that of their relatives. Person-centred, demand-driven and integrated care and support is what we strive for. Also society as a whole, supported by governmental policies, plays an important role. The Flemish government choose a care model, designed by the World Health Organisation, which is based on a conceptual framework that is people-centred and includes integrated health services. This framework focuses primarily on the perspective of people in need of care, their family, friends and the community (or communities) they are part of (Vlaamse Regering, 2016).

In Flanders, the Flemish Minister of Wellbeing, Public Health and Family is responsible for dementia care. Together with the Flanders Centre of Expertise on Dementia, the Flemish government has been working for years towards quality dementia care. Examples of their accomplishments include providing the financing of the reference person for dementia\* in residential care centres. In 2014, Flanders wrote the Transition plan for dementia, which describes the various responsibilities in care and guidance that are expected from different kinds of healthcare workers. Since then, the position of dementia aware professional has existed. In 2016, there was an updated Dementia plan, taking into account topics such as dementia prevention, balanced perception, culture-sensitive care and a dementia-friendly society.

The reference framework for the quality of life, housing and care for people with dementia works further on this and offers care facilities some foundations for quality of life, housing and care. Those who put this into practice are already a step closer to ensuring quality care and guidance. It was the Flemish government who, at the request of the network group Small-scale Normalised Living, decided to fund this project. Together with many care facilities, volunteers, carers and people with dementia, the Flanders Centre of Expertise on Dementia studied the question: what is quality of life, housing and care for people with dementia? Are the ideals being strived for really achievable? Which inspirational examples can we learn from? How can the different sectors help each other? And how can good care take shape in the workplace?

The result from this process is a model for quality of housing and care that can be adapted to all aspects of healthcare and welfare. The care relationship is at the core of the model, in which there are six foundations for quality care: the image of dementia, normalisation, independence in security, per-

\* A reference person for dementia is a professional counsellor who commits to increasing the quality of the guidance and the care for people with dementia and their surroundings. They are internal experts who advise other care providers concerning legal, judicial and financial questions, in the case of problematic pivotal moments in the care process and in complex situations in the dementia process. In order to fill the position they need to follow an 11-day training course.

sonalised care, the social network and family carers' involvement and the role of professional carers and volunteers.

The reference framework aims to inspire, inform, challenge, push boundaries and foster creativity so that people can feel good in any setting. It is a cross-sectoral publication, which focuses on home care facilities in the broad meaning of the term, on diverse kinds of housing for people with dementia and on hospitals. It concerns a framework for all actors that are involved in the care and support of people with dementia in one way or another.

In the Flemish publication, each chapter is illustrated with good practices that can inspire care facilities and formal carers. In this English summary we have excluded this. Though we do explain the key message in each chapter.

This reference framework is a vision text, for which the inspiration came from scientific resources on the quality of life and the quality of care, focus groups with professional carers, managers and family carers, interviews with people with dementia and family carers, expert discussions in Belgium or abroad as well as an analysis of what was happening in the field. It is also aligned with current guidelines from various professional groups. The reference framework is an **evidence-informed** document. It is therefore based on scientific literature but combined with insight from practice.

The authors

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### **The CASCADE project**

The CASCADE project, which is financed by the Interreg 2 Zeeën programme, includes ten partners from Belgium, the United Kingdom, France and the Netherlands who over the course of four years (2017-2021) are working together to develop an innovative and cost-efficient care model. This has primarily been based on the needs experienced by people with dementia and their carers. The reference framework for dementia has also played a big role in this. The foundations of good care were analysed and they were all integrated into the CASCADE model.

We asked dozens of people with dementia: what do you find important? What makes you happy? Their answers:





# 1. The broader context: quality of life, housing and care

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In this chapter, we provide a summary of the scientific literature regarding the quality of life, housing and care. You can ask for the references at [info@dementie.be](mailto:info@dementie.be).

## Quality of life

What one person considers a high quality of life may be completely different to what somebody else considers a high quality of life. Seeing the sea cheers Maria up, Arnold likes to sleep in till 9 o'clock every day and Olga likes to eat a bit of yoghurt before she goes to sleep. Being able to keep doing these small things could make the difference between living or letting life pass by for these people and then dementia does not necessarily come into the equation. The quality of life for people with a chronic condition like dementia does not necessarily have to decrease. For some people it increases, for others it decreases and for some others it remains more or less the same. Research shows that family members and formal carers often assume that the quality of life of people with dementia is much lower than what people with dementia themselves say it is. Family members and carers presumably base their opinion on the physical and cognitive issues that they see the person with dementia facing. This is the **disability paradox**: people who can adapt to changed circumstances and who add positive meaning to it, can still have a good quality of life. This includes people with dementia.

The World Health Organisation defines **quality of life** as

*'the individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment.'* (WHOQOL group, 1995)

In other words, it is a highly subjective concept that is influenced by many factors.

Research gives us an insight into the global topics on the quality of life of people with dementia (or in certain subgroups). These topics are not usually any different from those that people without dementia find important, in particular independence, the feeling of importance, having a support network, social relationships, self-reliance and having an adapted living environment (Lette et al., 2017). There are a lot of studies that reveal the factors which influence someone's quality of life. Positive factors include, among others, a good relationship with family carers, social interaction with the formal carers, being in a positive atmosphere, feeling healthy, a feeling of purpose, feeling heard and understood, feeling useful in the community, living in a homely environment, being able to keep engaging in their hobbies, the extent to which the building stimulates involvement and a feeling of homeliness, and/or being involved in daily activities. Factors which have a negative impact on the quality of life are for example, depression or symptoms of depression, anxiety, agitation or restlessness, feeling lonely or useless, feeling reliant on someone else ... Some of these factors are intrinsically linked to the care that the

homecare organisation, the residential care centre or the hospital provide. We can also move towards generic tools when it comes to the care for or the guidance of people with dementia. These tools are defined in chapters 3 and 4.

## Quality of care and housing

In short, we could argue that good care is care that contributes to someone's quality of life and sense of purpose. It is care that does its best to align itself with physical, psychological and social needs. It is also care that takes someone's philosophy of life and sense of purpose into account. The World Health Organisation is taking a stand for integrated, *evidence-informed*, gender- and culture-sensitive, person-centred care, in all settings where people with dementia live. They underline how important it is to support someone's independence and worth from the diagnosis right up to the end of life (World Health Organization, 2017).

A person-centred approach for people with dementia is not new. In 1997, Tom Kitwood put **person-centred care** on the map with his book, *Dementia reconsidered, the person comes first*. Kitwood sees people with dementia first and foremost as people, hence the name *person-centred care*. Respect and care, both for the person with dementia as well as for the person taking care of them are important pillars in his view on care. Kitwood emphasises how important it is to create an emotional bond. When the language disappears and it becomes more difficult to detect someone's emotions and desires, we fall back on reading body language. Providing sincere personal attention in that moment is the key to making contact with the inner living environment of someone with dementia. Kitwood was the first person to highlight the importance of the reactions of the people close to the person with dementia on their wellbeing. He called them person-enhancers and person-detractors. These later formed the basis for Dementia Care Mapping. The VIPS model by Dawn Brooker also builds on Kitwood's work.

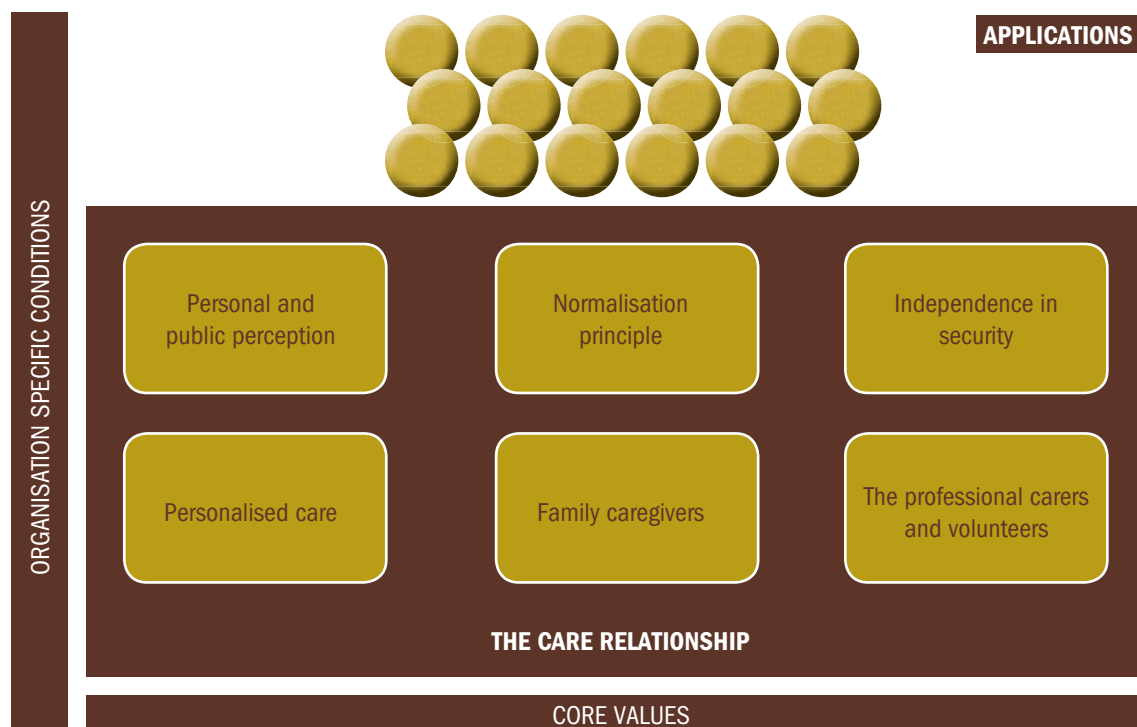
Another outlook in which the person's experience with dementia is the main focus, is the **Social Approach** by professor Anne-Mei The from the Netherlands. Based on hundreds of discussions with people living with dementia she concluded that the quality of someone's life is determined by the correlation between the condition itself (medical), the way in which someone with dementia copes (psychological) and the impact that the condition has on social relationships (social). The Social Approach to dementia assumes that you cannot prevent someone's pain from the disease and the resulting consequences, but that you can alleviate it with the right support. This mainly focuses on the psychological and social component of the quality of life.

Quality of life and a sense of purpose is very personal and this also includes the quality of care. In this project we address this with **person-centred care** or **personalised care**. Offering person-centred care to people with dementia, regardless of where they live or stay, is not a simple task. It requires, among other things, employees that are involved, a strong vision running through the organisation's veins, self-reflection and peer-to-peer coaching, getting the right people involved at the right time and the right place ... You can only achieve a high quality of life, care and housing when all staff are involved, play a role and feel personally responsible. Intrinsic motivation, a feeling of responsibility and team spirit are also important.

## 2. The model for quality dementia care

### Building and using the model

The model for quality care that we propose is made up of three horizontal layers, becoming more and more tangible as you go up: the core values form the basis of the model, the care relationship is the middle layer and the practical applications form the top layer.



The model starts from **core values**. They are not only an integral part of care, they also define the identity of the care facilities.

The **care relationship** is a central component of quality care and support. Quality care consists in six foundations that must all be present in order to consider it good care. *Perception*, whereby the person behind the condition always comes first. The *normalisation principle*, whereby 'keeping it as normal as possible' is the basic concept and social participation is key. *Independence in security*, whereby the person with dementia is supported in their independence but has a sense of security when necessary. *Personalised care*, whereby the formal carer and the informal carers together with the person with dementia look into what a quality of life and sense of purpose means to them. Good support and co-operation with *family carers and relatives*. *Professional carers and volunteers* who can use their knowledge and skills to offer quality care in all areas of life.

In this reference framework, we describe around twenty **applications** for these six foundations of care relationships. Please note, the applications themselves do not achieve any goals in itself. They are simply a way to put these six foundations of care relationships into practice.



A high quality of life, housing and care is only possible when all employees from the care facilities are aware of this. Also the **organisation-specific conditions**, such as vision, mission, leadership, organisation structure and culture are discussed in detail. The reference framework also pays close attention to some **sector-specific additions**.

### The reference framework as a source of inspiration

From the various chapters of the Flemish version of the reference framework, we have included some inspirational practices. In order to meet the constant evolution in the care sector, the Flanders Centre of Expertise on Dementia created an **online platform** where you can find more inspirational examples. Do you have your own initiative that you are proud of? Submit it to us so that we can put it on our website.

<https://www.dementie.be/referentiekader>

On the website there is also a **literature list** per topic with recommended and additional readings.



## The reference framework as a means for reflection

We think that it's important that care facilities take the time to stop and think about what is working and what is not working. In order to stimulate this reflection process, we translated the foundations and applications from this reference framework into objectives, with a **growth metre**. Every employee can evaluate the functioning of each separate area on it. Where does my organisation find itself in these objectives? Why have I given the organisation or department this score?

Red = completely do not agree

Orange = do not agree

Yellow = in between

Light green = agree

Green = completely agree



Put a group of people together who you will talk to about the foundation or applications. Ensure that there is **a wide variety of profiles**.

Ask all participants to add a stripe on the colour bar for each objective. Be **honest and self-critical**. Where a participant places their stripe for a specific objective, is subjective. Talk to each other about the 'score' that people gave and the reasoning behind the score. Discuss with the group ways that you could take a step towards the right on the growth meter. For example, how could you move from yellow to light green? Conclude on what is already going well and what could be improved for all the foundations and applications.

The objectives are drawn-up based on the perspectives of carers and care facilities: *'I ensure that people with dementia...'*. The wording of the objective invites you as a carer to think from the perspective of the person you are taking care of or supporting.



## The core values

The core values form the wide base on which the whole model is supported. When we talk about good care, we quickly look for values to explain why we (would) do something: human dignity, integrity, independence, security, striving for a high quality of life ... Ethical values are guiding parameters for the care itself and for the care policy (Denier & Dhaene, 2013). It is not surprising that a lot of the aforementioned values can be found in agreements and legislation.

In the reference framework for dementia we use the Axel Liégeois value framework as a reference. This includes ten core values, based on the historic evolution of the care perspective: care provision and protection of human dignity, independence, wellbeing and privacy, participation, justice and sustainability, trust and solidarity (Liégeois, 2009, 2017). The ten values give care facilities a wide and solid basis - and one language - in order to develop qualitative care. However, it is not a formula that can easily be adapted. In all situations where family carers, professional carers or our society are searching for the answer to what good care is, certain values are being respected or promoted, while other values are being threatened or violated.



# The central care relationship

Meaningful contacts and genuine connections are essential to achieving high quality care and a high quality of life. Employees only start to feel like they can really provide good care when they can develop a relationship with the person in need of care, when they can bond with them (Denier & Dhaene, 2013). This relationship allows the carer to align their actions with the needs of the care recipient: the carer sees the person with dementia as a person, as someone with a life story and a future. They are genuinely concerned about the person, they look for what could improve someone's quality of life and sense of purpose, they see what is important to that person at that point in time and what that person finds meaningful. The care relationship is an equal, **mutual relationship** and it is not only a transaction from carer to care recipient (Liégeois, 2009).

Based on literature, brainstorming, focus groups, interviews and numerous observation internships, we discovered six essential aspects in the care relationship.



## Foundation 1. Societal and personal perception

Unfortunately we cannot cure dementia yet. We have to learn how to deal with it. We can only do this if we change the image of dementia. Destigmatising dementia is one of the basic pillars of the Flemish Dementia Plan.

### Perception and stigmatisation

People with dementia are often confronted with preconceptions. People do not know what it means to have dementia and automatically think of all the nightmare scenarios, the clichés and the contact with their social network that crumbles. From our own research carried out in 2014, it seems that 75 per cent of Flemish people consider people with dementia as full-fledged individuals with feelings. However, 50 per cent do think that they lose their identity and personality.

In contrast to other conditions, we have established that the perception of dementia does not see the person as the main focus. When it comes to the main view on dementia, the person often disappears behind the condition. This dominant representation of dementia wins and the complex reality is lost. People are reduced to their condition. In addition, the disease is reduced to the later stages, while dementia usually evolves quite slowly and there can be many years between the diagnosis and the final stages. People with dementia also rarely get a say in it. They are usually only spoken about. Although we have seen a positive evolution in the past few years, there is still a real risk of the *self-fulfilling prophecy*: if we, and certainly the media, portray and engage with people with dementia as though they are completely dependent, isolated and helpless, we push them into this situation anyway.

### Frames versus counter-frames

By emphasising certain aspects of reality 'dementia' holds a certain meaning for people. With a modern term from communication science we're referring to '**framing**'. We can define 'frames' as frameworks for how we as a society see certain concepts, such as dementia. Frames offer a perspective, a specific view on reality, but by doing this, certain alternative perspectives fall outside our field of vision. When it comes to the perception of dementia, we can make out six dominant frames. They are illustrative tools to help put the way you talk about dementia into perspective. In the face of the six dominant frames we can also position six counter-frames: other ways to communicate, based on other views. They are not correct or wrong, but the communication on dementia will benefit from a balanced use of all the frames and counter-frames (Van Gorp & Vercruysse, 2012).

Frame 1: Losing your humanity

Counter-frame 1: Individuals remain individuals

Frame 2: A hostile intruder

Counter-frame 2: A foreign travel companion

Frame 3: Belief in science

Counter-frame 3: Ageing as a natural process

Frame 4: Fear of death

Counter-frame 4: Carpe Diem



Frame 5: Reversed roles

Counter-frame 5: Back to childhood

Frame 6: The suffering of loved ones

Counter-frame 6: An opportunity to care for people

## “Forget dementia, remember the person”

In order to turn person-centred care into a reality, we need to **continue making efforts to break through taboos** to resolve the stigma around dementia around the world. This starts with small things like the daily use of language at a macro level in society and at a micro level in care settings. People with dementia need to be used as a benchmark in all actions towards creating a dementia-friendly care setting that conveys the person-centred message of inclusion in all facets of their daily lives. Therefore, talk to them instead of about them. Or to summarise it in the words of the Flemish Dementia plan and the well-known Flemish destigmatisation campaign: ‘Forget dementia, remember the person’!

### Objectives:

I make sure that...

1. ... communication about dementia in care facilities is done in a **balanced and respectful way**.
2. ... we see somebody with dementia first and foremost **as an individual** and not as a collection of symptoms.



## Foundation 2. The normalisation principle

### Make sure that normal can stay 'normal'

Normalised living and housing means that people can live in as normal as possible and recognisable surroundings and that their lifestyle is based on the life that they have lead up till now. Normalisation therefore doesn't have anything to do with being 'normal'. It is more about things like: going to sleep when you feel like it, being able to go to the market weekly, baking a cake with eggs from the chickens in the garden, having a cosy and self-equipped room or simply the freedom to sit on the sofa for hours and not do anything. It seems most appropriate to implement the normalisation principle where people live: at home, in service flats or in the residential care centre.

People with dementia who still live **at home**, of course live in the most 'normalised' way. The workplace of the carer is also the house and home of the person in need of care. Nevertheless it is still a balancing act. Sometimes the rooms look more like hospital rooms with all the aids or security systems, which means that it is hardly normalised. If your organisation assists people with dementia living at home, ask yourself how you can keep the homely feeling despite the big or small procedures that need to be carried out. Also home care services try to tap into people's interests and hobbies. They do not only cook for, but mostly 'with', they choose how to spend the day according to their preferences, they do not open the front door straight away themselves but they let the person with dementia try it themselves first.



The **residential care centre** is a home away from home for those who live there. The person with dementia leaves their familiar home behind and moves in with different people who are in need of care. The residential centre becomes their new 'home'. The design of the residential care centre is an important element when it comes to normalisation: a familiar living room with a kitchen, cosy spaces, warm lighting, authentic furniture, a garden that you can enjoy when it's good weather ... In some residential care centres visitors and residents feel welcome straight away.

We want to convey normalisation in all aspects of housing and living, which means we also need to be critical about **professional clothing** in residential care centres. The advocates for professional clothing make the following arguments: it emphasises the professional identity, someone is easily recognisable as a carer and it is hygienic. Yet opponents ask questions on several aspects. Professional clothing subconsciously creates a hierarchy between carers and individuals in need of care, which increases the feeling of power.

A **hospital** is a place where people with dementia only stay for a short period of time. Therefore, the normalisation principle cannot be applied in the same way in this case. Nevertheless, there are still ways of increasing a feeling of home for people with dementia, so that the hospitalisation has a less negative impact on their health and wellbeing. You can make common areas and rooms feel more homely, for instance. Carers can take into account the habits of people with dementia as much as possible. Even when it comes to meal times you can increase the feeling of home, for example through the choice of tableware, by letting people choose their own meals from a buffet for example, by letting family members bring their own meal with them ...

Normalisation also means that people with dementia, possibly even with their family members, can **continue to take part in social life**.

## The choice for normalisation in the organisation

Choosing normalised housing and living, is a very deliberate decision. It means a substantial change in the culture of the whole organisation, for which all employees need to be involved. You completely change the perspective in your organisation from care to housing and living. Normalisation is a foundation of your outlook and translates itself into interior design, the daytime activities and the contact between carers and the person with dementia. Always talk about your normalisation outlook in detail with the person with dementia and their relatives. The employees also need to give it 100 per cent. It is essential that your choices are well-founded and that there is a lot of support for it so that people can live and work according to the same values.

### Objectives:

I ensure that people with dementia...

1. live in what are **cosy, homely and familiar** surroundings for them (interior design, furniture, objects ...).
2. ... have the opportunity to take part in what they consider **meaningful** daily activities.
3. ... **have a say** in how they want to **spend their day** (when they want to wake up, eat, go to sleep, what activities they want to do ...).
4. ... and their relatives **are aware of** the normalisation outlook (and of the consequences).

## Foundation 3. Independence in security

*'Nothing about us, without us.'* This slogan gave people with dementia a voice and increased the debate around participation in society. A call to respect their independence, in the broadest meaning of the term. People with dementia also have expectations and desires, about the past and about the future. They would like to continue making decisions about their own lives, also when dementia affects their cognitive abilities. Most people find it important that other people don't make decisions for them and that they are included in conversations that concern them.



### Finding the right balance

Independence is a right which is included in the European charter of rights and responsibilities of older people in need of long-term care and assistance (EUSTaCEA, 2010). You can also find various references to the topic of independence in the Patient Rights (2002) : the right to a free choice of care provider, the right to accept or refuse, the right to support from a confidential counsellor and the right to representation. The German Ethics Council describes the right to self-determination as the basis of human existence and therefore argues that this cannot disappear through a physical or psychological disease. It is an expression of human freedom that you do not want to be taken away from you (Deutscher Ethikrat, 2012). When you feel respected in your independence, you have the feeling that you're in control over what is happening around you. However, a breach of independence leads to behaviour that is difficult to manage (Rommel, Declercq, De Clercq, Van Audenhove, & Lammertyn, 1998). People rebel when their freedom is taken away from them. That's why care should be about **respecting and restoring independence** (De Vlaamse minister van welzijn, 2016). In the care relationship, carers look for the best way to put this into practice. And this is often the small things.

We need to put independence into perspective. People rarely make decisions all on their own in their lives. When making a big or a small step, they often check with friends, colleagues and family. There is always a social context which serves as a larger framework. Independence and self-determination are therefore not isolated principles. For all decisions, you **are connected to** other people.



As the dementia process progresses, it also increases vulnerability. People with dementia gradually struggle more with making their own decisions about their own health and their care, about the maintenance of their goods, about their estate ... Unfortunately, it sometimes becomes unrealistic to leave all decisions in their hands. Sometimes you need to protect someone from themselves and a safer approach is necessary. It is our duty to protect and **provide safety** if a situation is harmful or dangerous (Deutscher Ethikrat, 2012). The right amount of safety gives people a feeling of security and satisfaction. Not enough safety can lead to anxiety, a feeling of depression, stress and agitation (Rommel et al., 1998).

So it comes down to finding the right balance between independence and safety. How can you create the maximum space for someone's desires and expectations and at the same time take into account their vulnerability? (Koning Boudewijnstichting, 2015) Part of the answer - as always - starts with the experiences of people with dementia and their loved ones. What is meaningful for them? How do they experience the situation and what can we do to improve their quality of life?

## From deciding independently to substitute decisions

If the person with dementia still understands what they are being told and they can still weigh up various options before making a decision, then they can still go through the choice process in the same way as before they had dementia. Provided that communication is clear and calm. There are of course exceptions, whereby a designated legal representative is appointed early on in the dementia process (Deutscher Ethikrat, 2012). If the person with dementia is having a hard time making abstract decisions, it helps to give a clear image of what they are trying to make a decision on. The carer changes their way of communicating and pays attention to their body language.

If somebody cannot make a decision alone anymore, it does not mean that they can no longer be involved. The decision becomes a shared decision. Therefore, people with dementia should be able to trust the people close to them (Deutscher Ethikrat, 2012). Sometimes, the formal carer finds themselves in a situation where they need to make a decision for the person with dementia, a best interest decision. These kinds of decisions only happen if the person with dementia no longer has the cognitive ability to make decisions themselves or because the situation is so risky that it definitely needs to be handled with a safer approach. In this case, the formal carer is challenged to think from the person with dementia's perspective, as much as possible.

### Objectives:

I ensure that...

1. ... we consciously and creatively **stimulate** the **independence** of someone with dementia and that we **provide them safety** when necessary.
2. ... the person with dementia is always asked for their opinion and that they are **involved** in big or small decision processes. The way in which I do this is personalised and ties into their experience.
3. ... the person with dementia is first and foremost seen as an individual when others need to make a decision in their place.

## Foundation 4: Personalised care

### The person comes first

All residents in the residential care centre, all patients in the hospital and all clients in home care provide another interpretation of what a high quality of life and good care means. Each one always has their own character, their own values, a certain background, positive and painful life experiences, meaningful loved ones who were involved in a part of their lives, desires and expectations for the future. With these unique characteristics and with the vulnerability that dementia brings with it, the carer will work towards personalised care. Through the story of the person with dementia and their loved ones, the carer tries to work out what the diagnosis means for them, what their needs are, what is meaningful for them and what strengths they can build on. For people with dementia who can no longer express themselves verbally, the carer will have to rely more on the analysis of body language, non-verbal reactions and the behaviour of the person with dementia - right up to the last moment.

Personalised care is care that takes everything into account: the body, the social life, the mental aspect and the way in which people feel a sense of purpose. The carers see the person with dementia first and foremost as a PERSON and, as a result, view problems in the context of that person and their life story. I, you, together human.



### Limitations and possibilities

Personalised care is what care facilities are striving for. In family care, for example, we see more flexible hours in the morning and evening shifts, institutions offering smaller care packages to help people with their meals or to help them get ready in the morning to get to the adult day-care centre.

Start with a **'yes' culture** and do not create limitations until you are sure that there definitely are some: be creative and encourage your staff to do the same. Think in terms of possibilities rather than



limitations. Often carers choose to fall back on stereotypes or routine action in order to increase their own feeling of safety. Another obstacle for personalised care is structural care which only prioritizes efficiency and task orientation and therefore the personalised aspect is lost. Practice shows that the organisation's financial health and good care are compatible. The core values that we are advocating here, do not automatically mean additional costs for the organisation.

## The importance of a timely diagnosis and a proper follow-up

The first stage in a timely diagnosis is the detection phase. This is when we make a distinction between *case findings* on the one hand, whereby the doctor watches out for certain signs of dementia, regardless of the complaints that the patient has come to the appointment for, and, on the other hand, situations in which the family or patient makes an appointment because they are unsure about the patient's cognitive state and feel like there is just something not quite right. It sometimes takes a while before the person with cognitive issues or the family carers come forward to the doctor or specialist doctor to share their concerns. This is definitely the case with people in the early stages of dementia, when the changes start happening gradually, cognitive issues are not always obvious and they might not directly think of dementia (Janssens & de Vugt, 2014).

An important part of personalised care is getting a timely medical diagnosis, supplemented by a care diagnosis which carers can use to create a care plan and to follow up on the person with dementia (Schoenmakers & De Lepeleire, 2017). A **timely diagnosis** is important. This is a diagnosis just at the right time, in a stage of the disease that is manageable for the person with dementia and their family. Before, people spoke about an 'early diagnosis', as early as possible. This did not take into account the perspective of those involved.

The general practitioner plays a crucial role in the diagnosis, guidance and follow-up of the person with dementia and their loved ones. Doctors are the ones to initiate the procedure for the **diagnosis of the disease**. For the differential diagnosis and the medical imaging, it is advised that the general

practitioner refers them to a multidisciplinary team which includes a specialist doctor. The diagnosis of the disease is an integral part of the **care diagnosis**. In this phase, all the carers (professional assistants, volunteers, family and informal carers) assess what questions and care needs the person with dementia and their loved ones may have. This inventory should, over the course of the care, be regularly checked and adjusted so that the care can continue to be high quality (Schoenmakers & De Lepeleire, 2017).

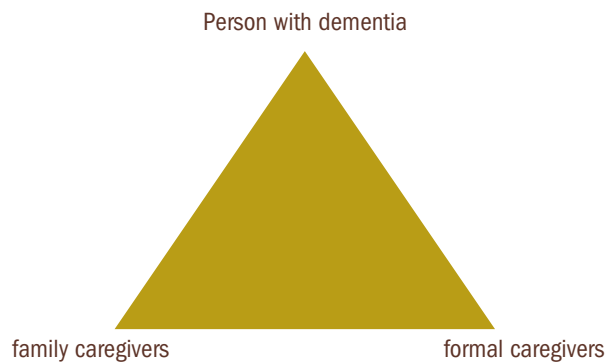
### Objectives:

I ensure that...

1. ... the care team get to know someone's **life story, personality and what aspects can improve their quality of life**. These elements are asked at the start of the care provision and are adjusted over the course of the care.
2. ... people with dementia **get care and support** that aligns with their desires and requirements (e.g. cultural habits and background) and those of other people that are important to them.
3. ... people with dementia who still live in their own familiar environment, have a **fixed point of contact** that closely follows the situation and is always available for questions.
4. ... the person with dementia gets **a care diagnosis as well as a medical diagnosis**, when they are ready for it.

## Foundation 5. The carers and relatives

In order to achieve good care, there are three crucial people: the person with dementia, the family carers and the professional caregivers. If they work together closely and honestly, we can consider it a **triangle of care**. In a triangle of care people start a *trialogue* with each other and everyone looks out for each other. Although everyone plays a role in this, it is usually the carer who takes the leading role by answering all the questions and talking about all the possibilities.



### On the SOFA

Sometimes the informal carer just needs advice or someone willing to listen. Sometimes they are the right-hand man in the care. Sometimes as a caregiver you get tips that help you take a step in the right direction. The role that family carers play, changes over time and they usually take up several roles at the same time. The Netherlands Informal Care Expertise Centre (*Expertisecentrum Mantelzorg uit Nederland*) carried out some research on these roles and brought them together in the SOFA model. Good co-operation with family carers takes into consideration the four roles they can play: fellow care provider, client, loved one and expert. All roles are linked to verbs, the starting letters of which form the word SOFA (Expertisecentrum Mantelzorg, 2016).

#### *Co-operation in the role of fellow care provider (Samenwerken)*

What can you do together to take care of or guide the person with dementia in the best way possible? How can you divide the tasks in a way that makes both the professional caregivers and the family carers feel stronger? In this part of the SOFA model the family carers are your partner in care. Particularly in the home situation, they are the ones who get the professionals involved in the care provision, and not the other way round. When you allow this change of perspective to happen, you will look at care in a different way. We step in when family carers and the person with dementia are confronted by their limitations. You can co-operate with family carers as fellow care providers through open and regular communication, a good division of tasks, whereby all parties can express their expectations, and by seeing the family carers as allies in care.

#### *Support in the role of fellow client (Ondersteunen)*

Although as a carer you are first and foremost focused on caring for the person with dementia, sometimes there can be other clients in the shadows: the family carers. They also have needs that you as a caregiver should try to respond to. So try to recognise signs of overburden, talk about it and refer them if necessary. Give them a pat on the back, a compliment and ask them how they are doing.



Foresee aftercare after the death of the person with dementia. Based on scientific literature (NICE, 2016), we advise supporting family carers, regardless of the setting, with the following: individual care assistance, psycho-education and patient groups that are adapted to the individual's needs, (referral to) telephone support, referral to internet sources and training on dementia.

### *Facilitating the role of the loved one (Faciliteren)*

A role of the informal carer that can never be ignored is that of the person concerned. They will always be the client's child, partner, friend... Give family carers the opportunity to talk to you about how much their role as a loved one has changed due to the care situation - if they want to, that is. What did they really enjoy doing together before the care situation? What needs do they have now? What new meaning can intimacy have now? How can the care provider or facilities help facilitate the original bond and connection? Making it possible for them to (partially) take up their role as a loved one again is an important task for professional carers and volunteers.

### *Consulting the informal carer as an expert (Afstemmen)*

Family carers usually know the person who they are caring for really well. They are the expert in this specific care situation and they can ensure that the care is more personalised and thus also often runs more efficiently (Hannan, Thompson, Worthington, & Rooney, 2013). They can provide valuable information about the life history or the small preferences of the person with dementia, they can 'translate' information in a personalised way, they can also have a calming effect in an atmosphere of anxiety and unrest. Sometimes they can be the first to notice behavioural changes or they can interpret them whereby the underlying cause can be handled. In other words: the family carers are essential partners.



**Objectives:**

I ensure that the family carers...

... as a fellow care provider...

1. ... are recognised. There is open communication, the expectations are clarified on both sides. The co-operation strengthens the capabilities of all parties involved (carers, family carers, person with dementia) and increases the quality of life of the person with dementia.

2. ... have a range of tasks that are **adapted** to their possibilities (capabilities-workload).

3. ... **are given information and skills** that are customised to the care situation.

... as a fellow client ...

1. ... are being asked about their **experiences or needs** and that the care or referral is adapted to this.

2. ... are informed about **respite care** (for people with dementia living at home) **and financial support options**.

3. ... have access to (or can be referred to) **psycho-education, information channels** over the telephone or online and **patient groups**.

...as a loved one...

1. ... get the necessary space to feel like a **partner, child or friend**... and not only a carer.

2. ... feel at home and welcome where the person with dementia is living. (only applicable for residential care centres)

... as an expert...

1. ... **are actively consulted and involved** as an expert and that their experience - as far as possible - is included into the care.

## Foundation 6. The professional carers and volunteers

In order to achieve a high quality of care, as an organisation, you need employees who can make full use of their **head, heart, hands and gut instinct**. Carers who take each other to a higher level both as an individual and as a team. Volunteers who provide support for the person with dementia and their family through small or big actions

Carers refer to conversations with people with dementia and their family carers as the key to good care, they have said this time and time again. **Friendliness, patience, tenderness, respect, empathy, authenticity, a sense of humour and creativity** are just a few of the characteristics they consider very valuable. These characteristics are necessary for dignified care that **takes into account** the things that the person with dementia and their family find important (Senden, Versluys, Piers, Grypdonck, & Van den Noortgate, 2014). This includes, among others, being there for someone in sadness or grief, in anxiety and uncertainty over the future. This way, real solidarity can arise, from person to person. In order to bring about this kind of solidarity, it is necessary to have a fixed group of carers responsible for the care.

**Taking the time to communicate with** the person with dementia, verbally and non-verbally, so that you can get to know them better, is often used as an example of providing good care (Stanyon, Griffiths, Thomas, & Gordon, 2016). It is also important to be there, not only as a professional, but also as a person, by sometimes doing something that isn't in your job description.



Besides the many psycho-social skills that the carers would have in an ideal world, **dementia-specific knowledge** is also very important. Carers need to know what dementia is, how they can handle challenging behaviour, what they need to pay attention to when communicating with people with dementia, what services and provisions can provide support and/or where family carers can ask questions. In specific contexts, it is also necessary to know what medication exists, how certain kinds of medication



interact with dementia and what is written in the guidelines, for example, the guideline for advance care planning and missing person protocol.

Volunteers also benefit from dementia-specific knowledge and skills. Make sure you also provide a framework through training and peer-to-peer-coaching.

When you offer care, you enter into a **partnership** with the person with dementia and their family. If the carer does this with respect and out of equality, then this can lead to a high quality of life and care. We also request a **critical, inquisitive attitude** from the carer.

We already expect a lot of formal carers and volunteers. They are ideally a **skilled companion** for the person with dementia and their loved ones. With their unique qualities as a person they will help them in a professional way and they will give them the care that best meets their needs. The knowledge and skill of the carers and building a caring relationship are both very important pillars (Harps-Timmerman, van der Cingel, Jukema, & Groen-van der Ven, 2009).

### Objectives:

I ensure that my employees and I...

1. ... provide **care that respects the client's dignity**.

2. ... have **dementia-specific knowledge and skills** and also continue to learn.

3. ... are **friendly, patient and respectful**.

4. ... feel **a real commitment** to people with dementia.

5. ... know what is **really meaningful** for the person with dementia and their loved ones.

6. ... are aware of our **position of power** and that we are careful with how we handle that position.

7. ... try to increase the quality of life and the sense of purpose of people with dementia through a **self-critical and inquisitive attitude**.

### An eye for informal care

In 2016, the Flanders Centre of Expertise on Dementia, together with Vonk3 from Thomas More University college, developed educational documents on the triangle of care under the name *An eye for informal care* (Oog voor mantelzorg) (Knaeps & Steyaert, 2016). This package aims to encourage carers to use a care triangle more in practice. The educational material consists of a series of thirteen cases (ten concerning outpatient care, three concerning residential care) in which they ask for the client's, informal carer's and counsellor's perspective. There are also guidelines explaining the care triangle and a scenario developed for the organisation of a training session.



## 3. Applications in dementia care

How can you as a care facility put these six foundations of good care to practice? In this chapter we talk about twenty possible applications. Each topic in this chapter is an application of the six foundations of good care and therefore can never be seen to stand alone.

The applications are clustered within the various **areas of life** as put forward by the **World Health Organisation**. Since the applications for *advance care planning & palliative care and end-of-life care* include all areas of life, as per definition, we made a separate section for this.



## Physical

### Mealtime care

The big daily meals mean a lot to most people. Not only for the tasty food, but also because it is an integral part of sociability, social contact and tradition. The broad meaning of food does not change when there is dementia. Meals and food have a big impact on someone's psychological and physical wellbeing. For people with dementia the experience of mealtimes and the mealtime events usually changes drastically. They have trouble doing the shopping or the cooking, there are changes to what they enjoy eating, changes in their behaviour during the meal, they may have trouble swallowing ...

A stressful or chaotic environment has a negative impact on how people with dementia experience mealtimes. Research shows that there are a number of people-orientated factors that make a meal feel 'right' and ensure that the person can really just enjoy their meal. It is a matter of offering choices and taking peoples' preferences into account, encouraging independence, respectful handling and facilitating social interaction (Reimer & Keller, 2009). Mealtimes are also a unique moment for carers to put **relational care** into practice. Through one-on-one contact there are many opportunities to make the mealtime a meaningful moment.

Besides the mealtime experience, nutrition and swallowing issues also play an important role. These issues are not a disease themselves, but usually they are a consequence of the condition.

The mealtime care and the approach to swallowing issues require a well-considered strategy. How can you ensure that people with dementia get the food they need and that they feel like eating? Just as always the answer lies in a combination of various aspects, whereby personalised care is the key concept. It is a matter of creating a feeling of involvement in mealtimes, ensuring that the space feels cosy, carefully choosing where someone with dementia sits, giving them enough time and choice of what to eat, professional guidance for nutrition and swallowing issues, promoting independence...

#### Objectives:

I ensure that...

1. ... the person with dementia gets **tasty, well-presented meals** that are customised to their nutritional needs (nutritional value, consistency ...).
2. ... the person with dementia can eat in a **pleasant environment**.
3. ... carers and I can keep an eye out in order to **prevent malnutrition and dehydration**, that we know about and understand **nutrition and swallowing issues**.
4. ... the person with dementia gets **personalised support and aids** for nutrition and swallowing issues.
5. ... the person with dementia can eat **what they want to when they want to**.
6. ... the person with dementia has **good dental hygiene**.

## Prevention

The twentieth century is known for a drastic increase in life expectancy, from the average of fifty years old to on average eighty years old. An extra thirty years of living in one century. It is generally well-known that the risk of dementia increases with age. What is not as well-known is that women have a higher risk of dementia than men of the same age. Unfortunately, age and gender are hard to change in order to lower the risk.

In recent years, more research has shown that there are also influential factors in our lifestyle that can have a substantial effect on the risk of dementia.

In 2017, Kay Decker's doctoral research about the LIBRA index came out (*lifestyle for brain health*) (Deckers, 2017). An important benchmark in the consensus is the commission 'on dementia prevention, intervention and care' from *The Lancet*, which published a report in the summer of 2017 with the following advice: 'Be ambitious about prevention.' (Livingston, Sommerlad, Orgeta, Costafreda, Huntley, Ames, Ballard, Banerjee, Burns, & Cohen-Mansfield, 2017). Up to 30 per cent of the future cases of dementia could be avoided by developing a healthier lifestyle when people are middle-aged (between the ages of 40 and 75). Once again, this refers to the classic lifestyle factors such as not smoking, sufficient physical activity, healthy eating, a healthy weight. **If it's good for the heart, it's good for the brain.** On the other hand, there are also a number of lifestyle factors that are specific to dementia, such as keeping cognitively active (and that is more than just solving sudoku or crosswords) and keeping socially active.

Carers and care institutions should be aware of the power of prevention, also for dementia, and they should find ways to make people between the ages of 40 and 75 aware of the importance of a healthy lifestyle.

### Objectives:

I ensure that people with or without dementia...

1. ... **are being encouraged to live a healthy lifestyle**, by for example, moving enough, healthy eating, staying socially active and doing cognitively challenging activities.



## Psychological

### Challenging behaviour\*

Shouting, tapping, wandering, not wanting to put on any other clothes, avoiding eating, hitting, collecting objects, wanting to 'escape', pacing ... These are just a few examples of behaviour that comes up with people with dementia over the course of the disease (Inspectie voor de Gezondheidszorg, 2015).

Within care facilities, carers need to consider how they can prevent and correctly respond to this challenging behaviour. Because the pharmacological approach to the behaviour often has more disadvantages than advantages, a **non-pharmacological approach** is always the first choice. That's why, as a care team, you continuously look for the needs underlying the behaviour. We are not just referring to the physical needs, but also - and above all - the psychological needs, as described by Kitwood in the flower model: identity, attachment, occupation, inclusion, comfort and love. The interaction with carers and family members can improve or undermine a person's wellbeing. Therefore, good basic care plays an important role in the experience and meets the most important physical and psychological basic needs of the person with dementia.

Try to avoid **provocative factors** when possible. There are people who react badly to certain carers, a smell, a sound ... There are also a few generally well-known provocative or undermining factors that are better to avoid like ignoring, accusing or misleading the person with dementia. Make sure that people feel at home, that they can move freely and they have the opportunity to withdraw themselves (Hoge Gezondheidsraad, 2016).

The Trimbos institute and Vilans summarise the approach to behaviour that is difficult to manage in a **step-by-step plan** (Inspectie voor de Gezondheidszorg, 2015).

1. Identify it in time
2. Do a thorough analysis of the behaviour
3. Talk about the behaviour in a multi-disciplinary team
4. Tackle the cause of the behaviour and not the behaviour itself
5. Opt for psycho-social intervention first
6. Only opt for psychiatric drugs if other means of intervention do not work
7. Get the family and family carers involved in the analysis and the approach
8. Always evaluate extra carefully before potentially ceasing to use psychiatric drugs

When it comes to certain kinds of behaviour that is difficult to manage, family, home carers or the residential care centre can reach their **limits**. If the behaviour requires temporary specialist support, it could be referred to a psychiatric department for people with dementia.

Prevention and a good approach to behaviour that is difficult to manage only works if all employees work towards the same vision. So work according to **a clear policy** about the use of psychiatric drugs and the use of non-pharmacological intervention. Make sure that the **outlook is well-known** and **carried out** by all employees (den Ouden & Schumacher). Education and training are therefore very important (Azermi, 2015; NICE, 2006; Pedersen, Andersen, Lugo, Andreassen, & Sütterlin, 2017; Yang, Lee, Chao, Hsu, & Wang, 2016). Make sure that carers can go to an expert like the dementia reference person or the regional dementia expertise centres, in complex situations.

\* Or responsive behaviours

**Objectives:**

I ensure that the person with dementia who displays challenging behaviour...

1. ... is surrounded by a team that can make **an analysis of the behaviour** (provocative, aggravating and influential factors).
2. ... gets treated with **the best approach** in order to decrease the behaviour or the unrest.
3. ... gets **as little antipsychotic medication** as possible and that carers are very mindful about the use of this medicine and the lowering of its doses.
4. ... is surrounded by carers that **are trained** in the prevention and the person-centred approach to behaviour that is difficult to manage.





## Psycho-social support for people with dementia and their relatives

When someone receives a diagnosis of dementia, it brings them and their family and friends into a period filled with lots of questions and emotions. People try to keep their lives on track while they are confronted with changes on a cognitive, physical and social level, among others. Lots of people do not know what to expect. Due to the progressive nature of the disease, people are also confronted with new challenges and all sorts of new questions arise. Psycho-social support for the person with dementia and their loved ones always looks different, depending on the needs that they experience in that moment. The informal carer and the person with dementia grow together through the disease process and see their roles as partner, child, employee, friend ... evolve.

Due to the diversity and evolution of the needs of people there needs to be a diverse approach to psycho-social support. In this way, people with dementia and their family members can opt for the help that suits them best at that period in time.



**People with dementia** who are struggling with the implications of the condition or who have questions, are asking for psycho-social support. A few of them get support from their peers, other people with dementia. This contact between patients has a positive emotional and social impact on them due to the fact that people can relate to each other, that they share experiences and that there is mutual support (Keyes et al., 2016). In that moment, they do not have a 'passive patient role' but they form an active group (Clare, Rowlands, & Quin, 2008).

The support and coaching of loved ones comes in many shapes and forms. Some initiatives are developed to suit **'the' informal carer (without taking a specific disease into account)**; however others are dementia-specific. Examples include the (Early-onset) Dementia Family Groups from the Alzheimer's League Flanders (*Alzheimer Liga Vlaanderen*), the meeting moments organised by the regional centres of expertise on dementia, the Dementia Cafes, info evenings, home-based counselling, online courses and guidance. In order to give family carers a bit of a push in the back to get started, various initiatives



have been developed both in Belgium and abroad that fall under the **psycho-education** category. For Flanders, Brussels and the Netherlands this is, among others, the psycho-education package called *Dementie en nu* (Dementia and now).

#### **Psycho-education package *Dementie en nu***

The Flanders Centre of Expertise on Dementia and the Alzheimer's League Flanders developed the psycho-education package *Dementie en nu*. Through all kinds of organisations, like the social work services from the health insurance funds, local service centres and memory clinics, the package is offered as a series of ten meetings, focused on family carers of people with dementia. Topics that come up in the meetings are: empathising with the experiences of people with dementia, dealing with care, behaviour, finances, safety; dealing and communicating with the person with dementia, their family and people close to them. Furthermore, the package addresses family carers' feelings and thoughts and balancing the amount they can bear and the workload and coping and a feeling of purpose.

Psycho-social support is part of the basic care. That means that all employees need to have listening skills so that they can listen to the person with dementia and their family carers. It means that they do not forgo the experience of loss and feelings of grief. They also need to know what support is on offer in the region so that they can refer to the appropriate support. Another possibility is organising psycho-education, contact between patients or other kinds of psycho-social support themselves.

#### **Objectives:**

I ensure that the person with dementia and their family carers...

1. ... can go straight to **any carer** with their story.

2. ... are aware of and referred to **psycho-education and peer support groups** in their area so that they can get the support that suits them best.

## Level of independence

### Documentation and care planning

A person-centred folder, regardless of the setting, describes who the person with dementia is as a person. It includes their past, their current experience and needs and their future prospects. A care facility that works on-site where someone lives should pay just as much attention to aspects of living and housing as they do to care. Care is also seen from a broad point of view: it is not only physical care, it includes the physical, psychological, social and existential care. In a good care folder there is also space for a care diagnosis in addition to the medical diagnosis, including an advance care plan. The folder is not made up from fixed practices, but leaves space for what the person with dementia and their loved ones experience and need at that time.

Personalised care requires a mindful approach, whereby the person with dementia is the main focus. If a difficult situation arises, you take action based on your observations, what the person with dementia has said and the possible underlying needs. These observations are combined by the team during a knowledge transfer, peer-to-peer coaching session or team meeting. Together you'll search for the approach that suits that specific person best. The outcome of this research will usually be written down in a care plan. A classical care plan is based on the symptoms observed and mostly contains aspects of physical care. As a consequence people miss the whole story, which can have many negative results for the person in need of care when it comes to dementia. In a **person-centred care plan**, however, this **holistic approach** is present. The personality, the life history and the current needs of the person in need of care are the starting point for setting up a care plan. This happens in conversations with the carers and if possible with the person with dementia. A person-centred approach is also necessary in hospitals in order to provide good quality care.

In the Flemish version of this document, we propose a person-centred anamnesis document. You can request this document at [info@dementie.be](mailto:info@dementie.be).

First of all, ensure that the care folder reflects the person with dementia as a person and that it takes their strengths as well as their needs into consideration. There should also be enough space to add person-centred information, such as someone's habits, rituals, life history, meaningful day-to-day activities ... Regardless of the setting, in any discussion there should always be room for all aspects of health and wellbeing (physical, psychological, social, existential, intimacy and sexuality ...) How you can increase someone's quality of life is the main focus. By structuring team discussions in this way, you ensure that a file does not become a dead letter.

#### Objectives:

I ensure that...

1. ... the person with dementia has a file that shows who they are in a **holistic and person-centred** way.
2. ... the person with dementia has a **customised and up-to-date care plan**, drawn up and discussed with themselves and their family carers.
3. ... the most important person-centred information is provided in case of a **transfer** to another care facility.

## Tools

When it comes to dementia, we think on the one hand of very **general tools and measures** that suit various kinds of situations and care needs that are not particularly dementia-specific. These include measures in the framework of preventing falls, safety and keeping mobile. There are also **tools that are specifically aimed at reducing the implications of dementia**. This does not refer to new or complicated things, but it does refer to writing up instructions on how to make coffee or how to use the television, for example. In addition, there are the 'real' tools, such as calendar clocks that also show the day and the month next to the time in order to avoid time disorientation. Or pill boxes that release the right medicine at the right time. **Robots** are still in a preliminary stage.

There is little systematic research available about the effectiveness of tools for dementia. This is the result of quick innovation in the sector and the versatility of dementia. We mustn't forget that the concept encompasses dozens of illnesses but also that the implications of the condition are very dependent on the individual and very diverse.

For every person with dementia, you need to check what tools and housing adjustments can improve the quality of life and what comes across as threatening or disturbing. Make room to learn how to use a tool and get used to it. Implementing tools for dementia is always a matter of customisation and it always requires continuous follow-up. Occupational therapists who are specialised in dementia care and/or care for the elderly can provide a lot of input.

When deciding whether to use a tool or not, don't forget to take the expected results, the purchase and maintenance costs all into account, but also some of the ethical principles. Tools should not be used, for instance, if it means that it will reduce contact with people. (Livingston, Sommerlad, Orgeta, Costafreda, Huntley, Ames, Ballard, Banerjee, Burns, Cohen-Mansfield, et al., 2017, p. 46) Decisions should always be **based on the quality of life of the person with dementia and their family carers**. So be wary of products that are presented with lots of enthusiasm and as if they have lots of results, for example memory games. Unfortunately, they do not slow down dementia (Max Planck Institute for Human Development & Stanford Center on Longevity, 2014).

### Objectives:

I ensure that the person with dementia...

1. ... is **informed and advised** about the tools that meet their needs and budget.



## Social relationships

### Intimacy and sexuality

Intimacy and sexuality are a part of life. They are a basic necessity, also for people with dementia. Intimacy is a kind of bond between two or more people. It is an important part of someone's quality of life. Intimacy and sexuality also appear at an older age. Although they are a part of life, these topics are not often taken into consideration in care facilities and they are carefully avoided by carers. Yet many carers are confronted by this on a daily basis: a couple that wants to sleep together, someone with dementia who gets undressed in public or wants to start a new relationship despite the fact their partner is still alive... One out of four carers do not know what to do when they are faced with similar situations (Van Houdenhove, Messelis, & Van Velthoven, 2016).

Some sexual or relational changes may come about with dementia: sexual apathy, erectile dysfunction, increased sexual activity ... A symptom that arises in 1 to 25 percent of the people with dementia, especially in men, is inappropriate sexual behaviour. It is important to understand this kind of behaviour within the framework of dementia problems. Be aware that not all behaviour that the family or carers find inappropriate is actually 'inappropriate'. Sometimes normal sexual behaviour from people with dementia is made to seem more abnormal and usually due to the diagnosis of dementia or the setting they are in (Zorgnet Vlaanderen, 2015).

For some people the sexuality increases or they become more comfortable because the inhibitions partly fall away due to the dementia. More often the sexuality and intimacy in the relationship decrease or disappear due to an increasing emotional imbalance of giving and taking (Hoogeveen & van Waarde, 2016; Zorgnet Vlaanderen, 2015). There are also ethical issues sometimes. What about in the case of advanced dementia, when someone can no longer give their explicit consent or refuse sexual approaches? What is important in this case is that neither the judicial capacity, nor being able

to consciously give approval is necessary for the approval of sexual actions. However if there is talk of coercion or harm or if the behaviour is affecting the living environment, the organisation needs to intervene (Zorgnet Vlaanderen, 2015).

For people with or without dementia there needs to be specific attention paid to people who are lesbian, homosexual, bisexual or transgender.

We recommend that organisations look at all behaviour and each question in the light of the unique needs of the person with dementia and their partner. The basis thereof is **a strong outlook and a clear policy** in the organisation. Topics such as privacy, intimacy, sexuality and sexual orientation should be open for discussion. Some carers assign someone for them to talk to, often the reference person for dementia, to discuss these topics with each client and to organise family evenings for this. Both in the residential care centres and hospitals, many people experience barriers to their intimacy and sexual experiences, like for example, the feeling that they don't have any privacy, the not-so-inviting surrounding and the negative attitude of carers or family members. A decent education for carers, in which taboos are broken down, is a good starting point for proper support.

### Objectives:

I ensure that...

1. ... care facilities have a **clear and positive** policy regarding intimacy and sexuality.
2. ... carers **are educated** on this topic and that they know the organisation's policy.
3. ... the person with dementia is supported when it comes to questions and issues regarding intimacy and sexuality. The organisation **pays attention to their experience of intimacy and sexuality**.
4. ... the **surroundings** where the person with dementia lives/stays make intimacy and sexuality possible.
5. ... the person with dementia **is protected** upon suspicion of coercion or harm through sexual activities or intimidation by other people who are in need of care, employees or third parties.

## Volunteers for people with dementia

Both in Flanders and abroad, volunteer organisations support meaningful daytime activities for people with dementia. Volunteer work and the buddy system are a great addition to the professional care for various aspects of housing and living. Working with volunteers should be a win-win-win situation: an added value for the volunteer, for the person with dementia and for the care facilities. Research on the added value of volunteers in dementia in the hospital is scarce, but a review concludes that there are signs that the person with dementia, their loved ones and the professional carers have all benefited from volunteer work (Hall, Brooke, Pendlebury, & Jackson, 2017).

Some volunteer work specifically focuses on people with **young onset dementia**, arguing that the needs of this target group are different to those of older people.

A specific example of volunteer work is the **buddy system**. Depending on the organisation, people with dementia are accompanied either individually or in a group by a buddy that knows them well. Sometimes family carers take part in the activities as well, whereby they get a bit of space to breathe and they get to know people who are in a similar situation.

Volunteers are part of your care facility and work according to your outlook, so they also deserve the necessary attention and guidance. That is why it is important that you have a **clear framework** for them to work on. Ensure there is a contact person that they can always go to and give them dementia-specific **training and peer-to-peer coaching**. Also give volunteers access to information that is relevant to them, like the approach to certain changes in behaviour, eating habits or a patient's life history. Some organisations offer an (online) platform where volunteers can exchange tips and information or ask questions, so they can support each other. Explicitly show them your **appreciation**.

Try not to structure the volunteer's work too much. It is namely because they are outside the team that they have more room for creativity and can respond to the needs of the people with dementia and their loved ones (Hall et al., 2017). Get to know what the volunteer's talents and interests are and use that as your starting point.

### Objectives:

I ensure that...

1. ...the person with dementia and their family carers **are informed** about what volunteer work is available to them and how it could improve their quality of life.

2. ... volunteers feel **welcome and valued** in care facilities.

3. ... volunteers are **trained and guided** in care for people with dementia.



## Environment

### Architecture and interior design

The environment that people live in or stay in has a big influence on their quality of life (Fleming, Good-enough, Low, Chenoweth, & Brodaty, 2016)[46]. This applies more to people with dementia whose cognitive abilities start deteriorating and who start to feel disorientated and displaced, and this is even in their own home sometimes. Architecture and interior design that is supportive for someone, where people feel free to and find easy to move around in, and where there is sensory comfort, is an added challenge for the care sector, for project developers and architecture companies.



The environment should first and foremost be **supportive for the person**. People should feel like they can keep in touch with who they are as a person and have the feeling that they matter (Stroobants & Verhaest, 2012). Such an environment is homely, it makes it possible to retrieve memories, it invites people to get actively involved and encourages social contact (Charras, Eynard, & Viatour, 2016). It also means that they can do meaningful daytime activities. In such an environment different activities are possible, supported and encouraged by the carers and loved ones. Those who enjoy playing music, maybe like to look through a stack of scores. Those who like to do housekeeping, would maybe like to hold a duster in their hand again. An environment with the right amount of suitable 'information' encourages people. However an environment that asks too much of them or does not encourage them enough, can lead to feelings of apathy, depression or agitation (Stroobants & Verhaest, 2012). Ensure that rooms and objects invite people to do activities. Design various places where contact or isolation is possible (Van Steenwinkel, Van Audenhove, & Heylighen, 2017). As a care facility, think about how you can facilitate both aspects in the design of the organisation. Research has conclusively proven the importance of outdoor spaces. So when constructing a new building or renovating ensure that there is an accessible and safe garden or terrace (Fleming et al., 2016; Stroobants & Verhaest, 2012). Avoid institutional elements as much as possible, like professional clothing and an infirmary (Charras et al., 2016). A hospital is obviously not a home for patients. Neverthe-



less, it is still recommended that the rooms are designed to feel as homely as possible. The more familiar it is, the easier it is for someone to feel more at ease and display less challenging behaviour.

An environment should support orientation. It is important that the surroundings are designed so that people can find their way around, for example by making the function of the room clear. So for example, in a kitchen you expect there to be hobs, hand towels, an extraction fan and a table. If people can have a clear overview of the room, it reduces the feeling of insecurity and anxiety. In an environment that is easy to navigate, people find their way quicker and can get back to the place they were looking for and they feel more in control of their life situation. Being confronted with barriers, however, like closed doors and shut-off areas, can lead to irritation or aggression.

Lots of people with dementia have difficulty with changes in visual acuity, contrast sensitivity and perception of movements. In addition, they are less familiar with sensory stimuli and have a greater chance of getting distracted. Therefore it is very important when designing a building that you take **the sensory comfort** into account. There is a lot of literature with tips on acoustics, changes to the design, and how you can discretely integrate safety elements.

We recommend that residential care centres let people with dementia live in small groups. Research shows that this has a number of positive effects, in comparison with classic, big-scale organised facilities. However, working small-scale goes beyond just the architectural aspect. Those who work with small groups without making it person-centred and normalised, are ignoring people's psycho-social needs and thus do not provide quality care. Small-scale is therefore a facilitating factor for **person-centred care**.

#### Objectives:

I ensure that the person with dementia...

1. ... has a **visual overview** of all the rooms in the house, the residential unit, the department, the day care centre for the elderly...
2. ... stays in rooms with a **clear function and demarcation**.
3. ... stays in an environment that **supports the person**: cosy, inviting, personalised and familiar.
4. ... has **freedom of movement** between their room and the communal spaces and also has access to an outdoor area. (in a residential setting)
5. ... can experience **a sensually comfortable environment** (visual, olfactory and acoustic).

## Meaningful daytime activities

Daytime activities can improve someone's quality of life, if it fits into their lives (Giebel, Challis, & Montaldi, 2014). In this chapter we are going to have a look at both organic and organised meaningful daytime activities and with some specific areas of concern for people with dementia.

According to an official report from the Flemish residential care centres, the time schedules and personal relationships are aspects that need to be worked on. The elderly give low scores when it comes to 'doing fun things together with other people' and 'maintaining good friendships'. They often can't pursue new skills or interests and there are not many pleasant things to do at the weekend (Agentschap Zorg en Gezondheid, 2017).

Firstly we advise care facilities to get started with **normal, day-to-day activities** that people with dementia can still do. This often refers to housekeeping, odd jobs or hobbies that they did before they got dementia. Studies among people with dementia have confirmed that it is not only good for their quality of life; it also makes them feel more able, they feel their own self-worth, they feel at home and there is a feeling of continuity in their lives (Davis, Byers, Nay, & Koch, 2009; Edvardsson, Petersson, Sjogren, Lindkvist, & Sandman, 2014; Fleming et al., 2016). Of course, there is also room for **organised activities**, however, on the condition that they are interesting for the people with dementia. Appeal to people's talents, do not underestimate their abilities and connect to their personal goals (Cornelis, Vanbosseghem, Desmet, & De Vriendt, 2016). The Flemish reference framework for dementia extensively describes how important contact with nature, with animals, with children, etc. is for people with dementia, but also how crucial it is that they keep moving.

Remember that opportunities and interests evolve throughout someone's life and that for some people it's not possible to keep doing the hobbies that they used to do. That's why the carer together with the person with dementia need to find ways to adapt activities. Sometimes people let go of previous hobbies and would rather see what's new on the horizon (Alzheimer Society Canada, 2014).

Meaningful daytime activities are a responsibility for everyone, regardless of their role or educational background. The living and housing supervisor should not be the sole person responsible for this. **All employees** should keep an eye out at aspects of living and housing and for the elements that are meaningful to someone. We advise that managers do not allow daily schedules to become too strict and that they give their employees more freedom to improve the life and housing of the person in need of care.

### Objectives:

I ensure that the person with dementia...

1. ... spends their day doing **meaningful, stimulating** and **relaxing** activities that are aligned with their interests, preferences and possibilities.
2. ... can continue to **play an important role** in the life of the person that they live with or spend time with.
3. ... can do these meaningful activities at **their own pace** (and not that of the organisation).
4. ... can also do meaningful activities at **the weekend, in the evening or on national holidays**.
5. ... is encouraged to do **physical activity**, within their possibilities.
6. ... gets plenty of opportunities to go **outside** and to enjoy nature.

## Culture

In this chapter we are going to look at the role of cultural heritage, visual arts, music and dance when providing care for people with dementia.

The cultural heritage sector has a lot of material that could be of interest to people with dementia, spread over a wide range of places like archives, museums, heritage libraries, heritage societies, heritage expertise centres and local heritage unions.

In art there is a variety of expressions and impressions through all kinds of art like painting, dance, word, music, sculpting, singing and writing. When it comes to experiencing art it is all about 'being in the moment', about what people feel and represent, without having to actively use their memory (Burnside, Knecht, Hopley, & Logsdon, 2017). Art allows people to express their thoughts and feelings, in other words their individuality (Killick & Allan, 1999).

We are seeing more and more long-term **collaborations arise between care and heritage organisations**, with products like reminiscence suitcases, film projects and exhibitions. Such an offer is a huge advantage, especially in the care for people with dementia. Since more and more cultural heritage organisations are making their collections digitally available, there is a lot of potential for creating a range customised to each person with dementia, regardless of where they live.

As their dementia progresses people continue to be creative and imaginative, so it shouldn't be a surprise that a lot of people with dementia also enjoy art. Both modern and classical art increase their quality of life (Camic, Tischler, & Pearman, 2014). Looking at art and holding objects (the so-called object handling) increases their wellbeing (Johnson, Culverwell, Hulbert, Robertson, & Camic, 2015) and interactive tours increase their social interaction and boost their mood (Droes, Hendriks, & Meiland). The art sector is very interested in the topic of dementia. The fact that **music** can have a positive effect on people with dementia has not only been proven through success stories but it is also strongly supported by studies. Music increases somebody's quality of life and their wellbeing (Young, Camic, & Tischler, 2016). Not only by listening (Särkämö et al., 2014; van der Vleuten, Visser, & Meeuwesen, 2012) but also by singing (Davidson & Fedele, 2011; Särkämö et al., 2014) and dancing (Guzmán García, Hughes, James, & Rochester, 2013) themselves. Music and dance are also great ways to connect with people with dementia.

We recommend care facilities enter into sustainable collaborations with artists, museums and cultural heritage organisations. Not just one-off projects but a fixed or recurring offer.

### Objectives:

I ensure that...

1. ... the person with dementia **has access to** various kinds of culture that suit their interests and talents.
2. ... the person with dementia is **actively stimulated** to express their talents in various art forms.
3. ... the person with dementia can do this both at **home** (or in a residential setting) and in the **community**.
4. ... the care facility actively looks for **sustainable partnerships** with art and cultural heritage organisations.



## Social participation

There should always be opportunities to take part in village life, city life and the broader surroundings, no matter where someone lives. Either **by getting the community involved** in the care facility or home situation or **by going outside**, outside the home or residency's walls. Either is possible in a dementia-friendly, age-friendly or caring community. Not only through dementia-specific initiatives but also by making the usual range accessible to people with dementia. There has not been a lot of research on this topic but scientists are becoming more interested in it [44].

In a **dementia-friendly community**, organisations join together to make the community more accessible for people with dementia: the regional centre of expertise on dementia, the care facilities, the Alzheimer's League Flanders, the local businesses, local authorities, the family carers unions, the heritage association, museums, schools, hobby clubs, public transport ... People with dementia should not be isolated because of their condition. This is an important responsibility for all care facilities.

**Tourism** for people with dementia is also progressing, because they also love going for day trips, a weekend away or even going somewhere far away on holiday. Various care facilities in Flanders are actively looking for ways for the person with dementia to travel if they see that the person needs it.

### Objectives:

I ensure that the person with dementia...

1. ... is **encouraged** to take part in community life, if they feel the need to. This can be where they live/stay and also in the neighbourhood, city and the wider surroundings.
2. ... will be **supported and guided** if necessary by family, volunteers and professional carers.

## Missing persons

In Flanders, around four people with dementia disappear every week. In their search for something to hold onto and safety they leave their home, the hospital, the residential care centre ... And they never find their way back. Often they are on their way to places that have played an important role in their lives or they take familiar routes. Out of a feeling of insecurity, they feel an urge to go home or to leave. These excursions by people with dementia are not always danger-free.

The topic of missing people is essentially finding the balance between supporting someone's independence and protecting their safety. When the person with dementia requires more physical activity or when there's a risk of wandering behaviour, the carer's task, together with the person with dementia and their loved ones, is to **open a dialogue** to discuss how they can approach it in a way that meets their needs at that point in time. For many people with dementia, filling in a preventative **missing person's form**, a document with personal information that can be used if they go missing, is a useful tool. The form includes the person's identity, a description of the person, whether the person has already gone missing before, the family and the informal carers' details, places where the person has lived and worked ... Preferably, the form would be filled in before someone actually goes missing, so that if necessary, the police and the carers can start looking for them in a structured way. In various places in Flanders, police zones, regional centres of expertise on dementia and care facilities join forces when somebody with dementia goes missing (Crabbé, Masselis, Vermeersch, & Verschraegen, 2016). A close collaboration and efficient communication ensure that someone can be found again reasonably quickly, before they are injured, or worse: before they have passed away.

### Objectives:

I ensure that...

1. ... we look at what the **underlying needs** are of the wandering behaviour. We choose, together with the person with dementia, the family and/or the neighbourhood, what the best approach is that still allows them to have a certain amount of freedom, independence and safety.
2. ... the person with dementia has a **missing person's form** that has already been filled in as much as possible and it is kept where they live or stay, if this approach seems appropriate for their situation.
3. ... the information is **transferred** across various sectors (for example when they go to a centre for a short stay, day care or if they go to the hospital).
4. ... the employees know **which steps** they need to take when someone goes missing.



## Freedom and restraint

In the past few years, many care facilities have focused on a restraint-free approach when it comes to the risk of falling and challenging behaviour. Besides scaling back on these freedom-limiting measures, the attention is also more focused on increasing the freedom that people with dementia have. Those who consciously work on freedom and restraint, proactively prioritise **independence and freedom of movement**, without forgetting about the **safety** of the person with dementia. Ensuring somebody's well-being is more than just avoiding physical injury. Being able to move freely, being able to decide where they are going themselves and being able to communicate with other people is often more important to people than the risk of falling. This is about prioritising the relational, psychological and moral dimensions of wellbeing (Gastmans & Milisen, 2006).

Meanwhile, it has become clear that physical restraint brings a lot of health risks with it and it doesn't prevent falls. If people are not restrained, the risk of serious injuries does not increase (Gulpers, 2013; Muñoz et al., 2016; Sze, Leng, & Lin, 2012; T. Talloen, Milisen, & Evers, 2003). It is therefore high time that this method is renounced.

The Belgian legislation (Royal Decree KB 9 March 2014) allows physical restraint but states that this can only be allowed in certain circumstances, namely in order to protect the person or others and only if there are clear medical grounds to do so. Restriction can therefore only be considered when there are no other options or less drastic measures available to achieve the same goal. Carers need to weigh up the interests of all of those involved. This balance is often more of an ethical matter than a pragmatic matter. What values and norms do you as a carer and as a person find important: dignity, independence, facilitating someone's general wellbeing or physical integrity, facilitating self-sufficiency ... (Gastmans & Milisen, 2006)?

Therefore when you decide whether or not to restrain, there is no standard solution. In all situations the multidisciplinary team needs to examine how they would cope with someone with dementia with a risk of falling or challenging behaviour. That way they are prioritising the person with dementia and they



are looking at the **needs underlying the behaviour**. They also analyse the environmental factors which could have an impact. Preventing restraint is, after all, a matter of combining a whole range of measures, whereby the rooms, the daytime activities, the way in which carers react, the number of stimuli, physical factors ... are all influential. A person-centred care plan can help a care team handle this.

We recommend that care facilities have a clear outlook on developing freedom and restriction of freedom and provide continuous training and peer-to-peer coaching for employees. It is also important that they invest enough in alternatives to restraint and they work on a policy in which carers are very careful about the use of physical restraints. A protocol on starting and scaling back on restraint could support this.

### Objectives:

I ensure that...

1. ... the person with dementia **gets as much freedom** as possible.
2. ... the carers' team first look for the **source** of someone's behaviour and for **alternatives** to physical and chemical restraint.
3. ... the care facilities have a **protocol** which is followed if restraint is still deemed appropriate.
4. ... there is an **outlook** on restraint in the care facility, in which chemical and physical restraint can still be started and scaled back on in a conscious manner.





## Culture-sensitive care

Our Western society is getting more colourful and diverse. This is enriching but it does make some things more challenging for carers. What is the key to successful culture-sensitive care and does it even exist at all?

Elements such as culture, ethnic background and socio-demographic characteristics influence how someone views a condition like dementia, and what aspects they find important when it comes to care. This has to do with, among others, someone's values, norms, beliefs, lifestyles and previous experiences with care. Western society, for instance, is very much focused on independence, while non-Western society is more focused on respect and honour (Willemsen & van Wezel, 2011). Some cultures look at dementia through biomedical glasses, as a pathology of the brain. Other cultures see dementia as part of getting older, as a psychiatric problem, as a religious or mystical experience, as a punishment for bad behaviour, as going crazy ... (Hinton, Franz, Yeo, & Levkoff, 2005). So from this perspective, it is not very surprising that dementia is still very taboo in some cultures. It is therefore important to inform people and raise awareness. It ensures that they can recognise the symptoms sooner and consider it a medical condition, that way they can get to the doctor quicker and are more up-to-date on what is on offer in terms of care and support in their area (Willemsen & van Wezel, 2011).

The care that care facilities now give, seems to be insufficient in relating to people with a migrant background. Do they need a 'different' kind of care? The answer is two-sided. Both people with and without a migrant background need personalised care: care that suits the customs, wishes and needs of the person with dementia. Culture and religion play an important role in the kind of care provided. People want to be treated respectfully, not only as a patient but also as a person (Degrie, Gastmans, Mahieu, de Casterlé, & Denier, 2017). That's why as a care facility you should take culture-specific needs of the person in need of care into account, without falling into stereotypes and over-culturalisation. Culture is still not a fixed standard package of norms and values (D. Talloen, 2007, 2008). That's why you need to look at it question by question and try to do this separately from its religiously charged nature.

### Objectives:

I ensure that...

1. ... the person with dementia has the **option to talk to** the carers about their outlook on care, their wishes and needs.
2. ... the person with dementia gets **care** that is **based on their cultural views**, wishes and needs.
3. ... we as a care facility take the time to think about our own values, opportunities and boundaries and based on this, we construct a **policy on culture-sensitive care**.

## Spirituality, religion and personal beliefs

### Reminiscence

Carers who know the life story of their clients, can find references in this that they can use to shape their care and support and it also helps them to understand someone's behaviour. Of course, you need to check if the preferences and habits from the past still reflect the person with dementia's current needs. People change throughout their lives and throughout their dementia.

When recent memories vanish, elements from the past can be grounding and soothing. Reminiscence or stimuli from memories is therefore a method that is commonly applied nowadays. For reminiscence people use triggers that bring up memories, like questions, stories, music, photos, newspaper cuttings, smells, tastes, objects ... (Kasl-Godley & Gatz, 2000). The carer ensures that the triggers are as personalised as possible and takes into account the phase of dementia in which the person finds themselves.

Reminiscence is best thought of as a broad concept, whereby you can integrate it both as an activity and in a more implicit way into the care and the living environment, for example during personal care and in the kitchen. Integrating reminiscence into daily life falls into an outlook on normalised living, as it is still based on those familiar stimuli, daytime activities, habits ... being a part of someone's life, just as before.

When you want to put people's life story (and their current wishes) to practice, this essentially means you need to provide **personalised care**. This usually requires care facilities to go through a culture change and therefore requires certain measures from management. You need to give carers the space to provide personalised care. Encourage them when they step away from the 'classic care pattern', at least if it has come from a conscious decision to strive for quality care for the person with dementia. In a residential care centre and in a home situation it is important that all direct carers know the person with dementia's life story. Even in a hospital, knowing about parts of their life story could help make the care more person-centred, whereby the wellbeing of the person with dementia increases.

#### Objectives:

I ensure that the person with dementia...

1. ... **gets the space to**, together with their loved ones, share their life story, their habits and rituals with the carers, if it will improve the care.
2. ... is surrounded by carers who are all **up-to-date** with the important elements of their life story - on the condition that they want to share these details.
3. ... experiences that **care is based on habits** and rituals from their lives as much as possible and at the same time it takes their current wishes and preferences into account.

## Existential and spiritual care

Those who are confronted with dementia, are always faced with the limitations that come with it. Questions like 'Who am I? What is happening to me here and now? What has made me who I am today? What choices played a role in this? What choices come up at the moment? What can I still hold on to now?' can all arise (RWS, 2017). For people with dementia, coping with the condition is often a recurring topic, as well as loneliness, not being able to function independently anymore, losing control, the change in identity, relationships and sometimes it leads to some people wanting to die. People are challenged to find purpose and meaning in this situation. A sense of purpose has a positive influence on the health of people and increases their quality of life and their psychological wellbeing (Kirby, Coleman, & Daley, 2004; Puchalski, Vitillo, Hull, & Reller, 2014). As a care facility, you have the important task of supporting people through this and referring them if necessary.

Everyone gives their life meaning in a different way. Some people find meaning in a worldview, others in their relationship with nature, in art, music or in their relationship with significant others (Vandevoorde, 2009). Research in Flanders shows that this is **still an important topic** for people with dementia and that many can continue to find meaning in their lives (Dewitte, Haekens, & Dezutter, 2017). Mostly health, family and personal relationships came up as important factors when it comes to giving their lives meaning (Dewitte, Schellekens, Vandenbulcke, & Dezutter, 2018). Some people with dementia find meaning in **religion**. The religious experience and the emotional and ritual aspect of believing stays with them for a long time (Mes, 2001). As a result, people can find meaning through believing long into the dementia process.

Including a sense of purpose in care is a shared responsibility of the whole care team. If an employee hears someone with dementia talking about the feeling that life has meaning or a lack of meaning, then it is their job to make the time to handle this with respect. The reference framework for dementia emphasises the importance of **education and training** for all employees so that they can recognise the existential pain of people and so that they can respond to it. If a carer or the person in need of care feels uncomfortable talking about a sense of purpose or if they have a question of a philosophical nature, it is often best if they are referred to a specialist, like the spiritual counsellor. It is important that existential care is structurally embedded into the care that is offered by the facility.

### Objectives:

I ensure that...

1. ... the person with dementia and their relatives **have the freedom of choice** to live according to their own ideology.
2. ... the person with dementia and their relatives **feel like they have enough freedom** to ask employees their questions on meaning or purpose.
3. ... the person with dementia and their relatives **know that** they can appeal to a **spiritual counsellor**.
4. ... **carers** recognise existential pain, they dare to talk about it and they can refer them to a carer who is specialised in spirituality.
5. ... **during discussions and in the personal file** there is explicit attention paid to the person with dementia's questions on the meaning of life.
6. ... **representatives** from various ideologies **gain access to** care facilities.

## Advance care planning and palliative care

### Advance Care Planning

Advance Care Planning (ACP) is ...

*'... a continuous and dynamic process of reflection and dialogue between the patient, their loved ones and carer(s) with the goal of clarifying the values and preferences of the patient in terms of their future care, which eventually allows future care goals or treatment possibilities to be spoken about and/or planned. This can facilitate decision-making at a later date if important decisions need to be made about care or treatment or if the patient is no longer in a state to express their desires.'* (Van Mechelen, Piers, Van den Eynde, & De Lepeleire, 2015)

Advance care planning is an adjustment process based on the values and preferences of the person with dementia. What someone considers quality care is therefore the main focus. If someone can no longer make a decision on a certain topic themselves, the previous path that they were on serves as a tool for their loved ones and the carers to make a choice at that moment from the person with dementia's perspective (Albers et al., 2016). Advance care planning is therefore more than just setting up a living will in writing. It is a process of ongoing dialogue and fine-tuning and a living will can also be a part of this process. In Flanders there is a lot going on in the area of advance care planning. In 2016, the Flemish Federation for Palliative Care (*Federatie Palliatieve Zorg Vlaanderen*) coordinated a group of experts to come up with the **directive for Advance Care Planning for People with Dementia** (Albers et al., 2016), which includes various areas of concern and recommendations.



Everyone has the right to be spoken to about advance care planning that is adapted to the knowledge of their condition and their cognitive ability ... Therefore as a care facility, you are responsible for getting **everyone** on a plan. However, the person in need of care is never obliged to accept this offer (Koning Boudewijnstichting, 2014).

Lead **various advance care planning discussions** over an extended period of time and talk about various topics, like values, how patients experience their lives here and now, the anxiety and concerns for the future and end of life, care goals, specific decisions on end of life and living wills (Albers et al., 2016). It is important that all carers can pick up signs for advance care planning and pass them on. Leading these discussions is normally done by caregivers that are trained to do so. From the start, they get the family carers and (future) legal representatives involved in this process.

It is best if for every transfer to another care setting a person with dementia's desires, care goals, care agreements, DNR/NTD\* documents, living wills and the contact details of the person's representative, doctor and care coordinator are all passed on as well. We recommend the use of a **standardised document for each care region**.

#### **Objectives:**

I ensure that...

1. ... the person with dementia or their representative knows what an advance care plan is and they **are informed** about what their own options are.
2. ... carers are **educated** with regards to an advance care plan and they know the *Advance Care Planning for People with Dementia* directive.
3. ... the person with dementia or their representative is **proactively approached** by carers and that they **proactively follow up** on them through advance care planning.
4. ... carers **across all settings** are up-to-date and communicate about desires and treatment goals (continuity of care) and that they also put them to practice.
5. ... the care facility has an **outlook on advance care planning**. A culture in which talking about the future is natural prevails.

\* Do not resuscitate – non-treatment decision

## Palliative care and end-of-life care

The approach to palliative care is holistic in nature and includes the needs of the person with dementia and their loved ones in various aspects of life. The care is focused on improving their quality of life, on an optimal wellbeing and it aims to prevent or relieve symptoms. Each person with dementia requires their own, different approach. Communication and sharing decisions is key. This also includes optimising symptom management, comfort care, setting care goals and pursuing advance care planning, continuity of care, psycho-social support and spiritual care, care for and involvement of the family, recognising the signs of an imminent death in time, an adequate prognosis, educating the care team and coping with societal and ethical topics.

Palliative care in Belgium is **a right**, established in the law on palliative care (14 June 2002, amended on 21 July 2016). Opinions differ when it comes to deciding **when someone should be considered palliative**. In Flanders, people opt for the use of the SPICT scale in order to identify a palliative patient.

In the Flemish reference framework for dementia we describe a few areas of concern for people with young onset dementia. We zoom into symptom management, pain management, spiritual care, end of life and after-care for family members.

It is the care facilities' responsibility to prioritise palliative care in the care and support process. **An outlook and ethical policy** on palliative care and end-of-life care that is well-known by all employees is a requirement. Make room for reflection, provide tools and a range of learning materials like trainings which employees can use to develop their own personal skills (Piers et al., 2016). If a care facility has both experts in palliative care and in dementia in-house, it is best that they work closely together, as both disciplines often overlap quite closely. Of course palliative care is not exclusively the domain of the reference person or the support team. All carers should be able to provide palliative care, within a multi-disciplinary team.

### Objectives:

I ensure that...

1. ... the person with dementia is assessed for palliative care **in a timely manner** (See SPICT).
2. ... the multi-disciplinary team make conscious choices which take the person with dementia's **well-being, care goals** and **comfort** into account.
3. ... there is **continuity in the care** (both within and across different settings) and good communication about the palliative care goals.
4. ... the person with dementia gets **holistic care/support** which takes their physical, psycho-emotional, social and existential needs into account.
5. ... the care facility has an **ethical policy on palliative care and end-of-life care**.
6. ... **family carers** are personally trained, informed and supported throughout the palliative process.

## 4. Sector-specific inspiration

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### Dementia-friendly home care

#### The role of social workers from health insurance funds

The core mission of social workers from health insurance funds is to guide and support the people in need of care (see the Flemish Residential Care Home Decree and the Dementia Transition Plan). They are also perfectly placed to take on the coordination of the care of people with dementia and their loved ones. Timely support and guidance throughout the process which respects the person with dementia's independence as much as possible and takes the weight off the family carers' workload, is now the health insurance fund's responsibility. That is why all health insurance funds in Flanders now focus on training their employees so that they can become dementia-competent basic carers. All families with a person with dementia can call upon a confidential counsellor that works as an advocate during the whole care process, from the moment that they feel like something just isn't right to moving to a residential care centre or to passing away.

#### The role of the family care service

Employees from a family care service often come for multiple hours a week to the home of the person who is in need of care. That's why they know their clients really well and they have a good overview of their psycho-social needs and strengths. Through the intense contact they build up a trust, which is an essential requirement for personalised care. Employees from a family care service do not usually work in a task-orientated way. They latch on to daily life and look at how they can support a person in need of care day-to-day so that they can keep living independently for as long as possible (Steyaert & Knaeps, 2016).

#### The role of the pharmacist

In the past few years we have seen a shift in the role that pharmacists play (Moors, 2017). Where the focus used to be on preparing and delivering medicines, the focus has moved towards providing guidance for the person in need of care when it comes to the use of medicines. For people with dementia, who often have decreased compliance and a higher risk of medication side effects, the pharmacist is an essential part of home care. They help to **optimise the use of medication, detect dementia in a timely manner and support family carers**. We advise that care facilities in home care start a sustainable collaboration with pharmacists or the pharmacist network which their clients are a part of.





## Dementia-friendly hospital

Year after year we see an increase in the number of hospitalisations of people with dementia (Van de Voorde et al., 2017). Since this kind of hospitalisation often has negative consequences for the person with dementia and their loved ones, there is a greater understanding worldwide that hospitalisation requires a specific approach in this case. In this chapter we describe the three pillars of a dementia-friendly approach in hospitals, based on examples from abroad and from scientific literature.

### *Pillar 1: a dementia-friendly environment*

The hospital's environment can have a big impact on the wellbeing of people with dementia. In a dementia-friendly environment, the patient is more self-sufficient, more involved in meaningful activities, eats and drinks more, presents less challenging behaviour and stress. There are also fewer incidents of falls and doctors prescribe less antipsychotic drugs. The chance of returning back home also increases (Waller & Masterson, 2015). The requested changes are usually not expensive. For example, it can refer to colour schemes, contrasts and signs.

Firstly, a hospital environment should be easy **to navigate in terms of time and space**. Calendars, analogue clocks, natural light and photos of the local area are all examples of this. A second feature is **familiarity**: design the rooms so that they can feel as homely and recognisable as possible and let people bring personal possessions with them. Ensure that people can **find their way around**. Provide accent colours, works of art, signs and landmarks. Provide books, games, snacks and rest areas... so that people can do meaningful daytime activities. Finally, ensure **'readability'**: organised rooms, discrete safety measures, balanced lighting... (The King's Fund, 2014).



### *Pillar 2: a strong care team with dementia-specific expertise*

All hospital employees, also those who work in a non-geriatric service, should have proper dementia-specific training (Alzheimer's Disease International, 2016; Borbasi, Jones, Lockwood, & Emden, 2006; Bourne, 2007; De Siún & Manning, 2010; Timmons et al., 2015) or they should be coached by colleagues with dementia-specific expertise. Caregivers' knowledge should extend beyond somatic topics like the kind of dementia or the various symptoms. A **psycho-social approach** based on the six foundations from the reference framework for dementia should be the main focus.

In Belgian hospitals an important role is set aside for the internal geriatric liaison (IGL). The IGL supports non-geriatric wards by evaluating the geriatric needs of elderly patients and by forming recommendations for the doctor and the nursing team from the services where the person is hospitalised (Deschodt et al., 2015). The IGL has a lot of geriatric expertise, which also includes a broad knowledge of dementia. Nevertheless, it is still advised that they regularly expand on this knowledge and keep it up-to-date. Given the variety of geriatric topics the internal liaison needs to have an in-depth knowledge of, it can also be worthwhile having a **reference person for dementia** in the team.

### *Pillar 3: person-centred care from admission to discharge*

In this pillar we recommend that hospitals work in a holistic and person-centred way. Collect enough person-centred information (What makes you feel anxious? What are your sleeping habits?). A person-centred approach saves formal carers a lot of time and energy during the admission and it prevents anxiety and stress for the person with dementia and their family carers.

We also advocate for the family carers to be seen as full-fledged partners in the care.



When a patient is admitted to hospital, the involvement of the informal carer is essential. Their experience and information have a positive effect on the stay, for all those involved. Support them throughout the whole admission and prepare them for the discharge to return home.

We emphasise the importance of avoiding unnecessary hospital admissions. If somebody is admitted anyway, it is important that unnecessary transfers are avoided and that the people with dementia are provided good guidance when moving departments or during a consultation. Dementia-competent volunteers can play an important role in this. In this chapter we also emphasise the importance of a proper policy regarding delirium, pain and malnutrition, seeing as the risk of this for people with dementia is clearly greater. Finally, we strive for a dementia-friendly emergency service, with quiet boxes and giving priority to people with dementia so that they can quickly be transferred to a ward. We also recommend letting the family carers into the operation area before anaesthesia and also in the recovery room.

## Dementia-friendly housing

Small-scale normalised living is a kind of housing where people with dementia co-house in a home and care environment that is as similar as possible to their home situation (Spruytte et al., 2009). In Flanders, the pioneers of small-scale normalised housing are Huis Perrekes in Geel-Oosterlo and the Bijster protected living project in Essen. In the past decades the number of small-scale houses for people with dementia has continued to increase. Small-scale is just one way of increasing the quality of life, housing and care. It is not a goal in itself seeing as it must go hand in hand with a strong outlook on care. For small-scale normalised living the principle is not what is useful or efficient but rather what the residents wants, requires or needs are (Spruytte et al., 2009).

There are **five working principles**. The goal is to create a housing environment that builds on the environment that the person with dementia is familiar with. (1) As normal, as ordinary as possible, recognisable and familiar housing, both inside and outside the home. (2) The care is offered in a personalised way. (3) The quality of life is very important. (4) The relationships are preserved or restored. (5) The care providers promote the independence of the residents when possible and ensure safety

and security when necessary. (6) To achieve the aforementioned principles, they opt for a small-scale approach (Spruytte et al., 2009).

Being **small-scale** is not enough for the small-scale normalised housing concept. It is a combination of architecture and working principles. We do recommend to work small-scaled, since it is easier to achieve the working principles of this reference framework.

For the professional carers, working with a small-scale normalised housing method means that they need to **distance themselves from the classic task differentiation**. \* In small-scale normalised living, everything happens around and involves the resident. Carers are not only there for hygienic care, they are also there for household chores.

## Intersectoral cooperation

Care and support requests are getting more and more complex and include more aspects of daily life: housekeeping, work-private-care balance, experiencing loss, getting older, administrative issues ... A lot of these aspects are more than just healthcare and fall more into the category of a social worker. In order to meet the needs of the current and future population of people with dementia, a cooperation between healthcare and welfare organisations is also necessary (SAR WGG, 2012). De-compartmentalisation and intersectoral cooperation are therefore very important.

In various domains we have seen positive evolutions with regards to cooperation across sectors: the search for the best way to share patients' data online, the increasing societal role that the residential care facilities play in the neighbourhood, the intergenerational housing concept which evolves along with the needs of those that live there, the intersectoral care paths and mentoring programmes, the dementia-specific networks in The Netherlands ...

Due to the socialisation of care and especially people's desire to keep living for as long as possible and as comfortably as possible in their own familiar environment, new kinds of care and housing are necessary. A **caring environment** can therefore become the organisation model of the future. In this kind of environment, both young and elderly people feel at home, neighbours know and help each other, there are places for meeting up and shops, there are plenty of green spaces and playgrounds, the traffic is safe, people in need of care and their family carers get the support they need, even if the care increases or changes. The housing and public spaces are adapted for the elderly and those in need of care (Bekaert et al., 2016; Vermeulen). In principle, an active caring neighbourhood focuses on everyone in the neighbourhood, but the concept of inclusion is crucial. The aim is therefore to enable the elderly or disabled to keep living at home for as long as possible and continue to have an active social life (Van Audenhove & Declercq, 2016). The power of this kind of initiative resides in its local character, whereby all members of a local network join forces to increase the wellbeing of the local residents and increase social cohesion: the neighbours, volunteers and family carers, businesses, medical care, services beyond the neighbourhood and the surrounding sectors like sport and the local social policy (Bekaert et al., 2016).

\* Each discipline has its own range of tasks in the care chain.





## 5. Organisation-specific conditions

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Person-centred and personalised care can only be a success if the whole care facility supports it. The same conditions that are important in care for people with dementia are also very important in human resources. This is just one of the organisational conditions for providing quality care and support. In the Flemish reference framework for dementia, we focus on topics like innovation, values in care, skill and talent management, learning and reflection, care for employees, management skills and the organisational structure, with additional inspirational practices.







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In Flanders, there are currently 132,000 people living with dementia. The prediction is that this number will increase to more than 188,000 by 2035. For every person with dementia, three family caregivers are involved.

Based on scientific research and together with many care facilities, volunteers, carers and people with dementia, the Flanders Centre of Expertise on Dementia studied the question: what is quality of life, housing and care for people with dementia? Are the ideals we aim for really achievable? Which inspirational examples can we learn from? How can the different sectors help each other? And how can good care take shape in daily practice? The result from this process is a reference framework for quality of life, housing and care for people with dementia. We present a model for quality that can be adapted to all aspects of healthcare and welfare. The care relationship is at the core of the model, in which there are six foundations for quality care: the image of dementia, normalisation, independence in security, personalised care, the social network and family carers' involvement and the role of professional carers and volunteers. This model formed the basis for the Interreg 2 seas CASCADE model.

*'You and me, together we are HUMAN'* aims to inspire, inform, challenge, push boundaries and foster creativity so that people can feel good in any setting. It is a cross-sectoral publication, which focuses on home care facilities in the broad meaning of the term, on diverse kinds of housing for people with dementia and on hospitals. It concerns a framework for all actors that are involved in the care and support of people with dementia in one way or another.

This publication is an English summary of the original Flemish publication *'Ik, jij, samen MENS. Een referentiekader voor kwaliteit van leven, wonen en zorg voor personen met dementie'*.