Continuity in Person-Centred Dementia Care during a Pandemic

A Guide to applying CASCADE Ways of Working

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Editorial

2020 will go down in our memories and history as the year of the coronavirus disease. Or possibly in variants such as the year of COVID or COVID-19 (the disease) or SARS-CoV-1 and SARS-CoV-2 (the virus). The term ‘corona’ is also used in the media and public discourse across Europe, as also referenced at places in this publication.

The COVID-19 pandemic affected our daily lives, work and our care for each other. It also affected the implementation of the CASCADE project and challenged all project partners to continue the best possible support for people with dementia.

This document stems from the shared commitment of all CASCADE partners to learn from each other, to see what works and to share good practice in dementia care in the Interreg Europe regions and all other EU countries.

Each country may have responded differently to the pandemic crisis but our experiences during this time are common. We aimed to produce a rich and pan-European document with authentic experiences, concrete tools and a clear vision supported and developed by CASCADE project partners.

We are also appealing to individuals and organisations with helpful insights and or good practices to share, to contact info@dementie.be We will include this information in a revised version of this publication that we hope to issue in Spring 2021.

We wish you all the best and an inspiring read.

CONTENT TABLE

Introduction

Dementia will have affected approximately 13.42 million people in Europe by 2030. Despite the growing number of people with dementia, the demand for good quality care and support is currently inappropriately met. The challenge is to provide sustainable person-centred programmes of care and support in local communities to enable people to stay in their own homes for as long as possible. The new coronavirus disease (COVID-19) introduced another layer of complexity to existent challenges in meeting the needs of people with dementia throughout condition progression. The Community Areas of Sustainable Care and Dementia Excellence in Europe (CASCADE) project partnership was set for full implementation of a collectively developed integrated approach to community dementia care prior to the onset of the COVID-19 pandemic. The majority of project activities came to a halt with an emphasis on keeping everyone safe from cross infection. Nevertheless, COVID-19 should not be an excuse for persistent experiences of suboptimal care but an opportunity to respond to the changing healthcare landscape and address overdue improvements in the care for people with dementia. This booklet offers guidance to applying CASCADE ways of working developed to promote and facilitate independence for people with dementia. The booklet constitutes of four parts incorporating stories from people directly involved in care and insights into continuous integrated dementia care in predicaments such as pandemics. Published literature mainly from the West complements Part 1, which presents an overview of the delivery and experiences of health and social care during the first wave of COVID-19. Part 2 outlines the CASCADE model including its core elements and how they work together to facilitate ongoing independence and engagement in meaningful activity. Part 3 of the booklet draws on possible infection control measures in a pandemic to describe opportunities for applying CASCADE ways of working to enable nonstop support for people with dementia. The last section, Part 4, is a reflection on challenges and ways of moving forward positively during and post-COVID-19 pandemic.

PART 1 How do people with dementia experience health and social care in a pandemic

The new coronavirus disease outbreak has possibly caused permanent changes to health and social care systems. Policy guidance at the onset of COVID-19 was quick and intuitive and in turn, impacted on population demographics differently. In Italy and America, for example, critical care in hospitals was rationed, excluding older people aged 80 plus and those with advanced dementia from ventilator support [1], [2]. Risks of contracting and spreading the virus are high among people with dementia due to the fact that the condition limits capacity to retain information and/or comply with safety precautions [3], [4]. Recent published evidence highlights that the COVID-19 pandemic has had grave effects on people with dementia ranging from decisions about their critical care to disruptions in routine monitoring and activities of daily living.

"The mother of this family went to a day care centre every day before corona. Father and mother still live at home, but there are relational problems and it this difficult for father to place mother's illness. Father's care for mother is difficult.

The daughter feels obliged to intervene and used to visit them every day after the day care centre closed. She would sometimes visit with the grandchildren, because it was not always possible to arrange care for them. It was a challenge for the daughter to organise daytime activities for the mother as an alternative to day care. Keeping mother stimulated was quite a challenge. In the end she succeeded with reminiscence: music from the past, smells from the past, certain substances that evoke memories".

A testimonial from the family care (Belgium)

The impact of society's response to COVID-19 on dementia care

The majority of people with a diagnosis of advanced dementia are in care homes while those with mild to moderate dementia are mostly at home in the community [5]. Care homes in Europe and America have so far contributed to more than half of the total COVID-19-related deaths reported in individual countries [6]. As the main focus of crisis management in dementia care entailed converting memory clinics into critical care spaces, relocating healthcare practitioners outside specialist practice and suspending routine monitoring and day care centres, it led to disintegration of the established dementia care pathways [7], [8].

"If you choose to work in the care sector, you know that it can happen that you end up in dangerous situations. That was clearly the case, there was a risk of infecting someone, or becoming infected yourself. All healthcare staff had to change their jobs, reorganise their normal work.

You got to know your colleagues much better, you quickly knew who you wanted to go to the front with"

Anonymous testimony (Belgium)

"I think the beauty of this is that everyone is committed to getting through this difficult period and helping patients as best as possible. I see this in every discipline within the organisation. Beautiful initiatives are emerging and there is a high degree of togetherness and appreciation among the staff"

Project Manager Housing & Technology (Netherlands)

“I have also experienced that we are all so focused on applying the measures as strictly and correctly as possible that we lose our focus on other things. For example, we were all working on one thing: “CORONA DOES NOT COME IN HERE”. Finally you turn on autopilot. Everyone has had to wake up a colleague that we should not lose our focus on the other matters. There was a shift where we focused on the virus, especially in the first few months. I have the impression that we are trying to restore this focus back to general working, but within COVID-19 measures as an extra point of attention. Today, I feel a recovery within our practice to provide good person centred care to our residents with dementia”

Occupational therapist (Belgium)

Person-to-person contact is inevitable for people with dementia with high dependence care needs and the structural setting in care homes, that usually involves use of common rooms, increases risks of spreading the virus [5]. Dividing up spaces creatively to separate infected from non-infected cohorts is unsettling for people with dementia placed in unfamiliar spaces without a familiar face [9], [5]. Personal protection equipment used to control the spread of COVID-19 not only frightens people with dementia, but also limits interpersonal reassurances to calm the resultant restlessness [8], [10].

"Why does everyone stay so far away from me? Am I being punished?"

A person with dementia (Belgium)

Behavioural responses to anxiety in dementia such as wandering undermine requirements for physical distancing [11]. The risk of using antipsychotics to calm the restless therefore heightens without adequate monitoring [9], [10], [12]. Some family caregivers in the community call on the assistance of formal carers due to rapid changes in care needs [13]. High stress levels among family caregivers arise from increased monitoring of the person living with dementia with neither support in the community nor respite [14].

Caregivers feel trapped in the quality of life of their person with dementia, including arranging practical matters on one hand, and complying with the necessary measures to protect themselves and their loved ones on the other. Both aspects are often difficult to reconcile, yet sometimes it is simply unclear what can and cannot be done [15].

"As a healthcare professional you want to help everywhere and jump in where necessary, but I'm also a carer for both mom and dad, and then you have to make choices. What do I want to take the risk, what am I committed to or not committed to? And whatever choice you make, you're left with a small sense of guilt, with despair. Am I doing the right thing now?"

Katrine, carer and care professional (Belgium)

"Vera, a woman with early onset dementia, was attending a day care centre five times a week. The centre closed at the beginning of the first lockdown. One of her children decided to take Vera into her home and take care of her, because living alone without extensive home care services was not possible for her mother. However, this daughter and her partner also have to work from home. Combining all that was not easy.

Previously, the contact between daughter and mother was not so frequent. Seeing her now every day and sometimes at night was very challenging and led to many questions about the future of her care. Also, practical questions about the here and now came up; for example, "can we go for half an hour walk with my mother on her arm? And how can we divide the burden of care among the children, taking into account the Corona measures?" Another daughter went to buy incontinence material for mother but was fined €250 for "non-essential travel" ((ed.) this is the fine in Belgium for breaking the corona measures). The uncertainty during this period, together with the decision to take mother into the house to surround her with the best possible care, placed a heavy burden on the daughter's family".

Anonymous testimony (Belgium)

"Patrick's mother lives in a residential care centre for about six months now. She is in her early 80s and has frontotemporal dementia, with many problems with day/night rhythm, increased risk of falling. His father stays at home alone and visits every day. Patrick and his partner (who works in the care sector) organise a weekly dinner or a walk and take care of the laundry.

The sudden lockdown of the residential care centres creates tension. His father is angry and afraid that Patrick's partner will be infected. Patrick wants to get his mother out of the residential care centre as soon as possible and take care of her at home. His partner holds back, as there is no hospital bed available, no home *care has been arranged, his own night's sleep will be affected, moving a person with dementia to a new environment causes anxiety. What's more, it's all hands on deck at work."*

Anonymous testimony (Belgium)

Feelings of isolation and loneliness are common experiences. Nonetheless, the times of joint clapping to celebrate the bravery of frontline health and care workers temporarily restored the community spirit [16].

Ongoing dementia care in the event of a crisis

Focusing on a crisis solemnly without considering holistic care pathways worsens the frailty of people with dementia [17]. Continued support for physical and emotional needs should be maintained to embrace the inherent personhood of people with dementia [5], [11].

"During the lockdown it was suddenly just basic care and the laundry and the pee. The warm care we were so striving for was repressed. But even without corona, warm care is a challenge. Just look at our digital files, which focus entirely on activities that can be ticked off, for elements of warm care or the life story of the person with dementia there is no place there. Surely there must be another way?"

Anonymous testimony of a dementia expert (Belgium)

“I feel I’m much more connected to the other disciplines. We can coordinate much better because the communication is much smoother and more direct. You can also respond much more to the acute needs of the residents.”

Physiotherapist (Belgium)

The effectiveness of some innovations for continued good dementia care and support in a crisis has been spontaneously tested. For example, window visits were challenging for older people who are hard of hearing and those that were unable to recognise loved ones following prolonged restrictions on frequent care home visits. The fast-paced uptake of telemedicine among health and care staff and people with dementia also presented with issues. Some people with dementia struggled with notion of virtual images as well as the technical knowhow of using electronic devices. Various healthcare staff were concerned that nonverbal cues vital in dementia care assessments could not be fully detected via virtual assessments yet in some cases, camera positioning contravened the person's privacy [2], [8], [18].

The impact of the COVID-19 on staff in residential care facilities

The COVID-19 crisis increased workloads in residential care facilities. Residential care staff had to deal with drastic changes in the care they provide to their residents including cancelling group activities and communal dining and restricting activities outside residents' rooms. More time and energy were devoted to performing COVID-19 related safety protocols amidst shortages in equipment, supplies as well as staffing levels. The safety of individuals and that of their families was a constant anxiety. Against this backdrop, CASCADE partners in Lille surveyed staff in residential care facilities for the elderly in France to evaluate burnout levels. Results surprisingly established a medium level burnout emphasising exhaustion, disengagement and feelings of being overstretched [19]. This result was deemed good news in view of the cumulative stressors but with accompanying caution against neglecting any level of health and social care staff burnout.

Key points

Lessons learned from natural disasters around the world point to the importance of being prepared with communication and practice (e.g., rescue & healthcare) protocols as well as psychosocial support [3]. Maintaining case management to coordinate holistic pathways integrating community and acute care is essential to make sure appropriate care and support are available at any level that need arises [5], [6]. Cognitive impairment particularly among older people requires timely follow up for more accurate diagnoses and condition management. The digital revolution witnessed including use of mobile texts, video messaging and online chat platforms is crucial for maintaining social networks and support for people with dementia [18]. Telecare comprising remote monitoring of temperature, gait, blood pressure and heart rhythms integrated with virtual communication and entertainment platforms would facilitate early intervention for better health outcomes for people with dementia [5].

The CASCADE ways of working present opportunities for continued good quality integrated dementia care during global or national crises. Good quality integrated care embodies established multidisciplinary dementia care teams, care coordination and seamless information flow [20]. Part illustrates the CASCADE approach to dementia care.

PART 2 The CASCADE Model

As the number of people with dementia is predicted to increase in the coming years, new and financially sustainable dementia care approaches that are widely applicable to different cultural/social settings are needed to avoid overwhelming health systems. A new holistic model of care for people of living with dementia (PLWD) was jointly developed under the CASCADE partnership comprising stakeholders from England, France, Belgium and the Netherlands. CASCADE is the acronym for Community Areas of Sustainable Care And Dementia Excellence in Europe. The rationale for the CASCADE model is that people with dementia (PLWD) require flexible support to maximise their independence, enabling them to respond to their changing needs at different points in time. The CASCADE model promotes a strength-based holistic person-centred approach for people with dementia in their community to optimise independence and quality of life. Dignity in care is an important concept in the model [21], [22].

Fundamentals of the CASCADE Model

The model has five fundaments that are the main tenets of the approach guiding all decision making. These fundaments are strengths based approach; holistic person cantered care in the community; safe environment for independent living; living life to the full; and positive public perceptions.

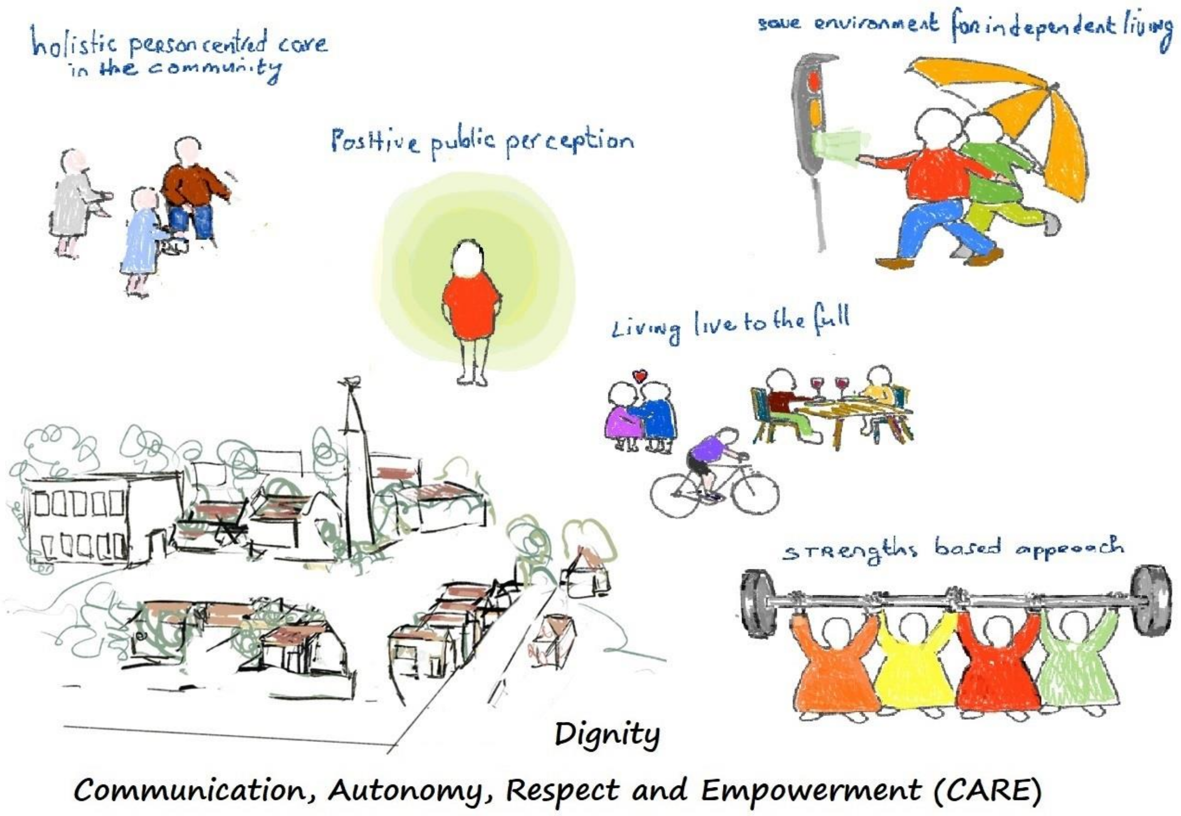


Figure 1 CASCADE model with the five fundamentals

Components of the Model

To translate the fundaments into actual practice there are six components of the model. The six components include: home; meaningful leisure activities; lifelong learning for everyone; supporting a person's journey through integrated working; technology; and sustainable business model.

Figure 2 The fundamentals and components of the CASCADE model

Inspiring example

An introduction and explanation of the model in a short video.

PART 3 Opportunities in practice

The CASCADE ways of working present opportunities to sustain good dementia care during a pandemic. This chapter incorporates input from CASCADE project partners to shares prospects for best practices. Piloting implementation of the model started before the COVID-19 period and continued during the pandemic in search for opportunities to continue good care for people with dementia. The opportunities are elaborated under the six components of the CASCADE model.

Home

Feeling at home wherever the person stays is an important part of good care. The first priority is to provide care in someone's own home if that is where they wish to live. Many changes took place due to the COVID-19 pandemic. People with dementia are confined at home without daytime activities and domestic help, causing the normal structure to disappear. Some guidelines for daytime activities recommend keeping regular telephone contact and investigating alternative forms of daytime activities that suit the home situation when it is not possible to go to day care centres.

At home in a care facility

According to the CASCADE model, the relationship between people with dementia and those close to them is central [22]. That is why it is important to involve loved ones of the person with dementia in care. When family visits a person with dementia, something is often taken along, such as magazines, news or a postcard. Delivering photos or belongings of loved ones to the care facility is nice for the person with dementia when visits are not possible or are restricted in time, number of visitors and place of the visit (e.g., large meeting room). Through these items, the people with dementia can experience recognition and familiarity. This is important because people with dementia can lose their grip on life [23]. Photos tell a story and the caregiver plays a major role in bringing memories back to life, which can also reduce loneliness. A desire for the parental home may also arise. In times of COVID-19, group activities in the care facility may disappear or change form with less contact in groups or with roommates. Placing furniture, a clock or photo frames in the room may help people with dementia to feel at home, especially when the item is positioned as it used to be. [24].

> *"overall, the homely environment has been wonderful for the patients. Their personal spaces are pleasant. Some personal effects and photos have made the rooms welcoming and familiar. The shared living room gives a sense of normality to their day" [Anonymous, UK].*

Picture 1 Home environment from Sanctuary Care (2020)

Inspiring example

Het Anker from AZ Sint-Maarten in Mechelen (BE)

Even in clinical settings such as geriatric wards of a hospital, it is possible to give people a homely feeling by changing the furniture of the daytime room, pictures on the wall and doors of individual rooms. The interior design may also encourage activity such as reading, playing and physical exercises.

The 'Virtual Hospital' and 'Virtual Care Home' of the Dementia Services Development Centre (Stirling) take you into the world of someone with dementia in an interactive way and show you how you can support recognition and orientation through minor interventions.

Looking for concrete tips to make a space dementia friendly? These checklists from The King's Fund will help you along the way at home, in residential homes and in the hospital.

Suggestions

for creating a recognisable and familiar living environment:

- Place furniture or other objects from the youth of the person with dementia in the living environment.
- Research by the knowledge centre Lifelong Learning in Music (2016) shows that music has great value for people with dementia. Familiar music can evoke a familiar feeling in the person. People with dementia recognise themselves in music and feel interconnected. Music can also be listened to independently, for example by using a music player. It is easy to operate for the person with dementia. Music from the past can be added using a USB cable. The music player can also be used well for different care recipients (OER, etc.). The Spotify app contains several playlists from the Alzheimer organisation, with many songs from the 1930s to the 1980s.
- As a caregiver, you can think of something to add to the house, for example painting the door in a special colour, or placing something recognisable next to the front door of the house for the person with dementia to recognise the home.
- For finding your way outdoors, there are also various tools available such as GPS tracking systems or special "walking tomtoms".
- The company Spectrum, partner with Elan, offers a guide for informal caregivers with suggestions for adapting existing homes for people with dementia. This guide mainly focuses on structuring the day, finding your way indoors but also outdoors.

Live with people with dementia

Caregivers can move in with residents for a longer period of time to minimise the risk of infection. People with dementia benefit from the same rhythms, activities and the same faces around them. Minimising the shift of services is an additional advantage offering people with dementia peace and regularity.

Inspiring example 👍

Fifteen employees lived with the residents in the Spanish care facility San Jerónimo.

It is also possible for a family member to move in where persons with dementia still live at home. A person with dementia can orient themselves better in daily living when fixed sequences and daily schedules are used [25]. People with dementia depend on others for both practical and emotional support. Living temporarily with a family member with dementia in the home situation provides 1-on-1 attention, good care and constant guidance. However, possibilities and limitations of the caregiver must be taken into account to avert the risk of overload [26]. That is why it is important to engage with the neighbourhood and community to offer the necessary support to prevent caregiver overload.

Explanation of the current situation

People with dementia living at home will follow the news. Sombre reports of COVID-19 can create feelings of fear and anxiety. There is a risk that the restless feeling will remain, but people will forget what caused this. Feelings of unrest can also be passed from a (informal) caregiver to the person with dementia. Thinking about what information can be shared with people with dementia and making sure you can share your concerns with others will not burden the person with dementia with anxiety. Living with sufficient relaxation and exercise, can ensure that the person with dementia continues to live calmly without anxiety.

Inspiring example 👍

Pharos (2020) has made a simple explanation about COVID-19 which can be consulted in various languages.

The lifelong learning component describes the learning ability of people with dementia. Activities can provide relaxation and fun when an explanation does not help. Activities as described in the meaningful leisure activities and technology components can kindle positive self-esteem [23].

Meaningful leisure activities

Currently, people with dementia sit at home all day or are bound to the residential care facility. People have limited or no access to residential care facilities due to COVID-19 regulations guidance. Residential care organisations and relatives are encouraged to keep in touch with residents to prevent loneliness. This means creative solutions must be devised for meaningful leisure activities. Implementing ideas might appeal to informal caregivers and residential care providers. When choosing an activity, people can look at someone's life experience, but people can also try something new and make new discoveries [27]. People with dementia can learn new things.

Inspiring example

The Dutch Alzheimer organisation has made an overview (in Dutch) of 100 activities that people with dementia can do independently or together. A distinction is made between useful, active, relaxing, challenging and outdoor activities. Many of these activities can be adapted to personal situations.

In Flanders, you can find a lot of inspiration on the website of Soulcenter

Also, active minds in the UK have created an app, called 'Support for Care' which care homes can use relating to activities. The app provides you with a number of activity suggestions that the person with dementia might like based on the details you input about the individual.

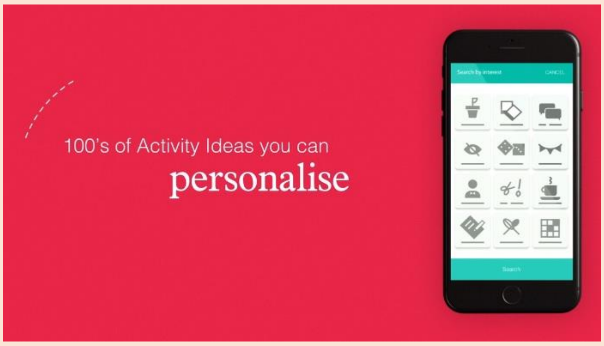


Image 1 Image from Active minds 'Support for care' app (2020)

Suggestions

for offering activities at a safe distance:

- Caregivers, family or friends can write letters or cards, make a special photo book or record messages or organise a call schedule.
- Family and friends can send a package containing puzzles (booklets), magazines, books and craft supplies.
- Something as simple as a window visit can also ensure social contact between family and the person with dementia.

to maintain daily structure:

- Write instructions on a paper using pictograms, pictures, colours and words. This clarifies step by step what the person has to do.
- Let the person perform their tasks step by step. If the person no longer knows what the next step should be, give some instructions. For example, after brushing your teeth, indicate the hairbrush.
- You can list activities for the day on a whiteboard. This overview gives structure to the day and therefore rests in the head of the person with dementia
- Make use of a day insight agenda, a paper agenda, designed with little incentive. Caregivers can use icon stickers to make it even clearer what the day is likely to be for the person with dementia.

"Here in Ten Kerselaere I use music therapy in an individual setting in a private music room, but I also play live music in the living room. In this way, I can make contact with everyone present in the room. Last week, I heard a woman who was playing cards at the other side of the house humming the last song I played on the piano. Music can fill the whole room and can appeal to anyone present.

Music has an implication on various domains that have impact on the quality of live. Music can provide relaxation when there is tension in group as well as within an individual. Music can facilitate communication, relationships and expression to meet physical, emotional, mental, social and cognitive needs. It can stimulate people to take initiative, to live their lives instead of being lived.

Music therapy can be significant for people with dementia because music is something of everyday and every time. Through music we can find another way to meet each other, to get in touch with the resident.

Getting out of isolation

A woman living with dementia, who has been sleeping the whole day, wakes up during a music therapy session in the living room. She starts singing and laughing. At that moment she is no longer isolated, but she is part of the group.

Music therapy is more than just making some music. There is a big difference between the music in music therapy and the music you play on CD of TV. This difference is the connection. At every moment I try to tailor the music to the atmosphere in the room, the resident I'm with and all of the other things I see and hear around me. Without this connection the music wouldn't be the same and there wouldn't be any possibility of therapy. I hope I have made my case in this short presentation. For me the value of music therapy lies in the possibility of having a medium where I can meet the person behind the dementia. "

Sofie Van Rompaey - music therapist in Ten Kerselaere, Emmaus (Belgium)

Lifelong learning for everyone

Lifelong learning is an important developmental aspect for all those involved in dementia care - healthcare professionals, family, informal caregivers and volunteers. Their learning is obtained from experiences of people with dementia and the environment where care is provided.

In this crisis, all these groups require additional training about how to meet the changing needs of people with dementia and their caregivers during the COVID-19 pandemic [22].

Also, lifelong learning can enable people with dementia to self-reliant and live at their home for a longer period. This will improve the quality of life [28]. Four forms of learning ae relevant for people with dementia: learn without mistakes, emotional learning, association learning and operant learning. People with dementia learn well through unconscious or automatic learning, in which the memory is used as little as possible. In this crisis that requires people with dementia to learn particular routines for their own protection from the virus, the following activities are important: performing daily activities themselves; operating a smartphone or tablet; dealing with their own frustration about the situation and learning a fixed walking route.

In the box, we present some suggested literature and tools that can help all groups to continue with their lifelong learning process.

Inspiring example 👍

An e-learning in Flanders about the impact of your mouth mask and protective clothing on the person with dementia. Tips for handling and communication. Developed by the Centre of Expertise on Dementia in Flanders and Sophia (regional centre of expertise on dementia, region Kortrijk), Televic Education and the support of Interreg2Seas CASCADE.

Nurses & Carers Netherlands (V&VN) (2020) has compiled an overview of relevant educational resources, training courses and knowledge squares around COVID-19. When caregivers acquire new knowledge about COVID-19, they have more insight into the clinical picture of COVID-19 and good care can be provided.

Also e-learning about dementia and COVID-19 are freely available in Flanders.

Forums and websites to share experiences

Alzheimer organisations have the forum "dementia and the coronavirus". On this forum, family members and (informal) caregivers can share knowledge and experiences and ask questions about COVID-19. Questions that are asked on the forum are: “I can't / shouldn't visit, how do I keep in touch?” And “Should I tell my neighbour what's going on?” The information on this forum is obtained from people close to the person with dementia. This allows them to learn from each other and apply this new knowledge to their neighbour with dementia. In this way experiences are shared, and people learn from each other.

In Belgium, the Flanders Centre of Expertise on Dementia, launched webpages with narratives and information for formal and informal caregivers at the beginning of the COVID-19 pandemic. Beside this, all Centres of Expertise on Dementia (regional and Flanders) jointly organise support and contact twice a week via videoconference. *The Alzheimer Liga Vlaanderen also gained this experience during the COVID-19 crisis. Its traditional family groups could no longer continue and temporarily had to go partly digital. For some caregivers this was a bridge too far. They were not digitally proficient enough or lacked proximity. For others, it was a unique opportunity to still participate in the family groups.*

Inspiring example

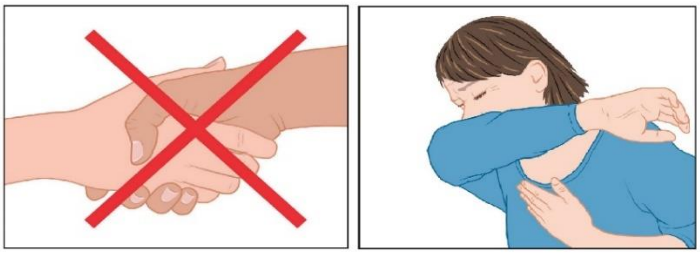
Alzheimer society UK has the website: Coronavirus support for people affected by dementia. Information about support at home, support in care homes and frequently asked questions can be found here.

"Needless to say, our family groups went offline, and we started online alternatives. Sometimes as a mirror image of the previously local groups, but also some at a Flemish level, regardless of location. We received signals from informal carers who thought the online version was an added value. They no longer had to arrange care for their partner with dementia, there were no traffic problems. So, we are definitely going to keep those online family groups, in addition to the regular groups, once they can return. In this way we will reach a previously relatively hidden target group".

Riet Pauwels, Alzheimer Liga Flanders

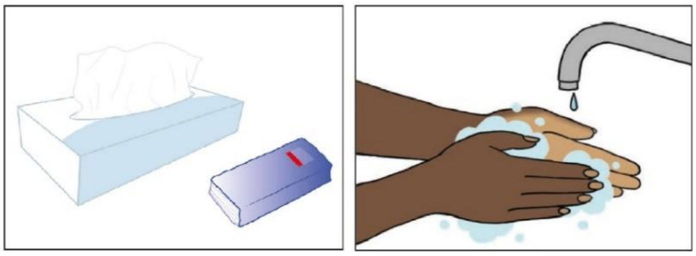
COVID-19 in simple language

Koraal Media [29] has made a Youtube Video (in Dutch) about COVID-19 in simple language in collaboration with "Language for all". In this video, text and clear images such as washing hands, explain what COVID-19 is and what can be done to prevent it from spreading. Also, Pharos [30] has developed information cards about the current advice regarding COVID-19. The information cards include clear images and additional text to show advice that should be followed:



Don't shake hands

Sneeze and cough into your elbow.



Use tissue paper when sneezing and blowing your nose

Wash your hands with soap several times a day. Wash well between your fingers too.

Image 2 Explanation cards Pharos [30]

In addition, Pharos has developed a clear poster about hygiene suggestions regarding COVID-19 in Dutch and English. The cards and poster can be used to teach people with dementia information about current advice. There is also a video about using a non-medical face mask effectively in Dutch and English.

Communication cards

Due to the symptoms or treatment of COVID-19, people can have difficulty speaking, because of shortness of breath. It is also more difficult for healthcare workers to make themselves understood because of the protective equipment. The protective equipment can also make the healthcare worker or informal caregiver unrecognisable to the person with dementia. All this can lead to ambiguity and unrest. The International Society for Augmentative and Alternative Communication - Netherlands and Flanders (ISAAC-NF) is committed to optimising communication options for people with communication disabilities. In the current situation, ISAAC-NF is developing communication cards for patients and healthcare providers in hospitals [31]. These cards contain the most common basic questions and statements for patients and caregivers. Using these cards can enable patients and caregivers to indicate what they want to say. Download the communication cards via the following website (*available in English and Dutch*). The use of pictures also helps people with dementia to express themselves. To make the healthcare worker or informal caregiver more recognisable, a photo of yourself can be placed on the protective clothing.

> *The masks hide our smiles where the resident with dementia shows restlessness. I have found this difficult for a while. You do your utmost to find a creative solution so that you can still offer that feeling of safety. But of course, we also experience funny reactions from residents who were not aware of any harm. I tried to be as playful as possible with all the protective equipment some residents also go along with it. An example of this is a resident who calls our protective clothing the new fashion. [Belgium]*

Supporting a person's journey through integrated working

Daily life has changed and the structure people with dementia were used to can be different, which can potentially result in restless behaviour. Focusing on the person and trying to understand the feeling and the emotion can enable effective and personal adjustments to be applied [32].

Advance care planning

Advance care planning is important in person centred care during COVID-19 [22], [33]. This discusses the wishes, preferences and goals of the patient, in order to prevent decisions being made on behalf of the person in question. Some of the choices discussed include whether or not to perform cardiopulmonary resuscitation or artificial respiration, admission to the ICU and the use of palliative care [34], [35]. It is important to have a conversation in good time, in which the person with dementia can still be actively involved [36]. This needs to be done as early as possible, considering the individual's condition progression, to make sure that people with dementia are able to vocalise their wishes through conversations with significant others.

Interdisciplinary work

When caring for people with dementia, it is important that different disciplines work together. Interprofessional collaboration is about providing care jointly, whereby the team looks at the person with dementia holistically (local multidisciplinary network, etc.). Many professional activities requiring physical contact could not be carried out during the COVID-19 crisis. People were no longer allowed to visit the hairdressers and nail technicians could not visit. In some cases, physiotherapists were stopped. It is therefore important to consider possibilities of how and where different disciplines can support each other during a crisis. Boundaries of the disciplines become blurred in interdisciplinary work, because people know each other's disciplines so well and through cooperation, they are partly involved in each other's field of activity [37]. In times of COVID-19, various disciplines can take on certain tasks from each other. For example, a nurse could take care of the nails of a person with dementia following instructions of the nail technician. An informal caregiver can consult with a physiotherapist using a tablet so that the person with dementia can continue exercising. A case manager who is the main point of contact in the care process of the person with dementia examines the support needed at any stage and coordinates providers to keep the care system integrated [38].

> *From a multidisciplinary point of view, we, as psychologists, have helped with daily care. We turned this emergency situation into an opportunity. We have strongly focused on the individual contact moments and activities with residents. Physical contact is so meaningful for our target group. We consciously opted for human care*
>
> *Eva Dries and Iris Machiels, psychologists from OPZC Rekem [Belgium]*

Loneliness

As a result of the visiting restrictions in residential care facilities, many elderly people can experience loneliness [39]. In the context of person centred care, it would be desirable for care providers to allow more time to be available to the person with dementia [40].

Inspiring example

At the website of V&VN there is more information (in Dutch) about extra support for clients during COVID-19. Digital contact is mentioned as an example, which is further elaborated in the technology component.

Picture 2 Picture from the website V&VN (2020)

In the first half year of the pandemic, carers of people living at home with dementia were faced with tough choices. Are we still going to visit our mother or father living alone, or do we choose to keep the risk of infection as low as possible? Informal caregivers of people in residential care facilities did not have that choice but they also had questions. Will we still be recognised if we do not visit for a long period of time? Will the care still be well organised? Many of the informal caregivers, next of kin or family members are also elderly and were shielding from COVID-19 infection risks. Contact and proximity had to be avoided, but alternatives were sought.

> *"Grandma, I put lipstick on your front door and put a kiss on it. Don't touch it, but it's a kiss for you!"*
>
> *Grandchildren of a grandmother with dementia [Belgium]*

Technology

Different support options for people living with dementia at home exist depending on the stage of the dementia.

Inspiring example

Vilans has classified the technologies according to the four stages of dementia:

mild memory loss, mild dementia, middle stage dementia and

advanced stage dementia.

Video calling

The CASCADE model of care underscores the value of the relationship between people with dementia and their loved ones [22]. Many caregivers were worried during COVID-19, wondering whether their loved ones with dementia would still recognise them after months without or with less physical and with other form of (digital) contact. In some cases, this turned out not to be the case, although it is unclear to what extent this could be due to the progress of dementia, or the frequency and manner of visitation [15]. Through video calling, contact can be made between loved ones and the person with dementia. Sources from the literature as well as individual experiences show that this provides pleasant moments and reduces loneliness [41]. Healthcare psychologist Maritza Allewijn confirms that people with advanced dementia also benefit from video calling [39]. When it is no longer possible to have a conversation, for example, you can listen to music together or the person with dementia can watch and listen when the formal caregiver talks to the loved ones. Video calling is an approachable way to make contact and can be done more often than visiting physically [42]. COVID- 19 will place greater emphasis on the possibilities for remote care and support. Online physiotherapy means that exercises are not forgotten and can be performed correctly to maintain the physical health of the person with dementia [43]. It is often thought that digital contact is impersonal, but talking from a familiar environment can offer peace of mind and generate more personal conversations [44].

Tablet

A tablet can also be used to view photos, listen to your own favourite music and play games. The use of a tablet can lead to an increased perception of quality of life and less isolation [45]. Reminiscing through music or photos can give a nice familiar feeling. Games and music stimulate physical activity, such as clapping along with songs and dancing. Movement stimulates the functioning of the body and the brain. In the time of COVID-19 crisis, this app can be a good daytime activity for people with dementia living at home.

Inspiring example

Reminiscing with the help of the 'My house of memories app'

When using the tablet, it is important that as few icons as possible are on the home screen. To make the tablet user-friendly for people with dementia, a "simple display" can be switched on. These tablets can also be operated remotely by loved ones, so that the person with dementia does not have to operate anything themselves.

Inspiring example

You can also opt for a special “simple tablet”, such as Memory Lane, Compaan, KOMP and the Seniors Tab.

Virtual Reality

Virtual Reality (VR) is a way of technology that allows someone to imagine themselves in a different world of experience [46]. This is in line with the fundaments of the CASCADE model, in which the person with dementia lives life as desired as much as possible. There must be room for curiosity and new discoveries in a recognisable living environment. Through the VR glasses, the user sees 3D images and has a 360-degree view. Sound and sensors are also used. For example, an air balloon ride can be made, a walk on the beach, a visit to an old Dutch fair or sailing with a canoe through the Grand Canyon. This can give people with dementia a calming feeling. It can also be a distraction for anxiety complaints due to COVID-19 related restrictions. Virtual Reality can stimulate the person with dementia to exercise, because they engage in activities attractive to them, for example, connecting to an exercise bike gives the user the feeling of cycling through nature [47]. Furthermore, VR can contribute to improving and maintaining cognitive functions [48].

Picture 3 Picture from the website Zorgplezier (2020)

Virtual informal caregiver

A virtual caregiver in the form of a screen or robot is encouraged for a caring and safe environment for independent living, which the CASCADE model promotes. A virtual caregiver can enable a person with dementia to maintain regularity and continue with activities of daily living (ADL). This can also limit home visits during times of COVID-19. The presence of a virtual caregiver breaks the silence and has a positive effect on feelings of loneliness [49].

Inspiring example

For example, Anne4Care can offer digital support in keeping a daily structure, taking medication and alerting to risks. Extra medication can be provided during medication intake by using a medication dispenser. "Anne" is a tablet that can communicate. Family members can also fill in a calendar remotely that expresses "Anne". For example, the person with dementia, but also their neighbour, is supported in a personal way.

Lifestyle monitoring

Lifestyle monitoring can be used not to reduce contact moments, but to gain insight into the activity pattern of the person living with dementia at home. Lifestyle monitoring is the use of a sensor network in common places in the home to monitor the person's movement 24/7. Sensors are placed in the living room, kitchen, bedroom, the toilet, in the bathroom and on the front and/or back door. Informal caregivers and healthcare professionals view the data via a website and/or a smartphone application. In the event of major changes in physical activity, a possible crisis is signalled early. In addition, lifestyle monitoring can send a notification if no movement is detected for a long time or if the person goes out the door at night [50].

Inspiring example

To get to know more about using different forms of technology for people with dementia, see the website of Vilans (in Dutch).

Or the Flemish website about assistive technology

The gap between the elderly and technology

The use of technology involves a generation gap, due to factors such as a lack of knowledge or apprehension among people with dementia. It is crucial to invest in user-friendly technology and clear instructions to reduce any resistance to technology. When the benefits are recognised, people will be more willing to apply technology. For example, 83% of the elderly indicated that they want to use healthcare technology if they can continue to live at home for longer [51]. Older people are willing to use technology when it is trustworthy, safe, easy to use and maintains their autonomy helping them in daily life.

But it was also clear that for many people with dementia this was not obvious. It is technology that they do not know from their childhood, and therefore sometimes seemed confusing.

Telephone contacts and zoom calls have been used. One of the patients (who has a diagnosis of dementia) has found the zoom calls difficult. Seeing her family out of context and then "they are gone" has caused her upset. Family have been encouraged to record video messages so these can be shown to the patient when she is alert, and replayed and talked about [UK]

Inspiring example

The Elderly Fund has the Welcome Online program. People with dementia can also be taught to make video calls, for which various online programs have also been made available.

The Alzheimer organisation has a platform where you can teach your loved one to video call, see the following website (in Dutch).

People with dementia often needed help when making video calls or using chat boxes, which meant that someone from the care staff was present during the call. Care staff occasionally found themselves in uncomfortable situations and heard things being said between the person with dementia and their digital visitor, which they preferred not to hear. Privacy and intimacy disappeared from the conversations. Organising a digital visit for this reason ceased to be an option [15].

Since visits were not possible for months on end, except in palliative situations, we put a lot of effort into digital communication, via video bells, social media and Whatsapp groups. Strict adherence to GDPR was not always possible. However, we did check whether it was respectful with every photograph, every video, every communication. Only then could it be done.

Erik Leus, Saint Joseph - residential care Emmaus (Belgium)

Sustainable business model

By deploying healthcare technology, customised care can be provided in a more efficient and effective manner. This can increase the well-being and independence of people with dementia, allowing them to continue living at home for longer [22], [51]. Using technology enhances contact between healthcare staff, loved ones and the person with dementia. In addition, the local community and existing infrastructures can be involved to support the person with dementia and also provide care more efficiently and effectively. It is anticipated that this will reduce the demand for professional care, resulting in cost savings [22].

Inspiring example

Myinlife app, with which family members and the person with dementia can be connected and agreements and tasks can be shared. The parties involved can indicate which activity they can help with.

Community volunteers

Connecting with different generations forms caring and accessible neighbourhoods, which prevents people from becoming isolated [52]. Young people could not do what they normally did in daily life, but they volunteered to support vulnerable elderly people in various ways during the COVID-19 crisis. For example, young people did and still do the shopping, write cards and or offer a listening ear by keeping in regular contact with vulnerable people. This brings people from different generations closer together and promotes understanding and appreciation between generations [52]. Other community initiatives include volunteers visiting the elderly every week at a safe distance with a surprise like a handwritten card or homemade soup.

Picture 4 Picture from an article by AT5 (2020)

Personal protective equipment

In the Netherlands informal caregivers can also receive free personal protective equipment (PPE) including surgical masks, protective goggles, examination gloves, aprons and disinfectant hand gel. Informal caregivers that are unable to keep a safe during care are entitled to a personal budget for PPE. Caregivers are required to contact a general practitioner or the Public Health Service if there is a suspicion of COVID-19 in the person with dementia.

Inspiring example

When the person with dementia actually has to be tested for COVID-19, the informal caregiver is entitled to a short-term PPE package. This can be collected free of charge from the pharmacy with an electronic prescription. If the test shows that the person with dementia actually has COVID-19, the informal caregiver is entitled to the longer-term PPE package. The National Institute for Health and Environment hosts a webpage with instructional films about the correct use of PPE for informal caregivers. These options enable informal caregivers to continue providing care when the person with dementia is suspected to have COVID-19 and reduce the demand for professional care leading to cost savings.

Technology and freedom

Sustainable care involves using technology to give the person with dementia as much freedom as possible. A form of home automation is a wristband with Global Positioning System (GPS). Living circles are used to determine the degree of freedom based on the stage of dementia, response to negative stimuli and mobility. This can vary between the house, the building, the garden and ultimately the neighbourhood. In circumstances of COVID-19, the living circle can be limited to the home and the garden. Wrist worn technology can also be used to communicate with the person and signal if the person has fallen. This can be attached to a belt or used as a key ring if the person does not want to wear anything on the wrist.

Inspiring example

, the Buurt Alert app

The sustainable business model component also encourages involving the local community and sharing knowledge [22]. The neighbourhood can be involved, for example with the help of an app. Residents in the neighbourhood that are registered users of the app participate in the well-being and safety of the person with dementia. In this way, people with dementia can be efficiently guided in maintaining independence and well-being.

Lifelong learning

By learning new actions or ways of thinking, care can be organised more effectively, whereby the person with dementia is more involved in the care process. This will make people with dementia more self-reliant. Caregivers can use the skills and characteristics of the person with dementia in the provision of care to match the wishes and needs of the person [22]. When informal carers and family share knowledge about people with dementia and COVID-19, the demand for professional care decreases, leading to cost savings. The free acquisition of this new knowledge contributes to the sustainability of the CASCADE model to provide care for people with dementia. Because people with dementia become more self-reliant and the informal caregivers can respond better to the needs of the person with dementia, the person with dementia can live longer in their own home if they wish.

Inspiring example

Free online (The Netherlands) training courses are available for people who have no or less experience with persons with dementia.

Also in Flanders there are two free online trainings available.

What is dementia

Changing behaviour and communication

PART 4 Thinking Forward

CASCADE is about living well with dementia in the community. Due to COVID-19, the community life in many European countries came to a standstill, and there are still a lot of restrictions which are likely to remain for some time. What does this mean for people with dementia and their loved ones?

We have all learnt a lot about the virus since the beginning of this pandemic. Personal Protective Equipment (PPE), a significant challenge for all residential care homes and services for dementia, is now more readily available in all countries. Several vital care issues we faced at the start of the first wave of the pandemic in March 2020 have now been addressed. Nonetheless, other important concerns remain a challenge in dementia care for people with dementia, their family carers and professionals.

Key questions arise in the search for a 'modus vivendi' in dealing with the pandemic. In some European countries and regions, such as the Netherlands and Flanders, a group of people from different stakeholder organisations in health care made a joint call to action to refocus on quality of life especially for those with a limited life perspective. All people have the right to decide for themselves what they consider to be quality of life. Even in a situation of dependence, people must have the choice and freedom to live the life they want to live. That also involves positive risk taking [53].

call in Flanders

manifesto in the Netherlands

In the fourth part of this document, we want to think forward and make some reflections. A crisis, such as the COVID-19 pandemic, accelerates innovations in healthcare and can be seen as a lever for implementing better dementia care. It brings sharply to the surface what is not working well and what really matters.

During the development of this booklet, CASCADE partners heard serious concerns from frontline staff, managers, networks in dementia care services and informal carers that the COVID-19 pandemic shifted the focus to somatic care and basic care. This essentially involved washing and nutrition without seeing the person as a whole, with other needs and desires. Safety takes precedence over quality of life, but 'care' is not only medical care. **Attention, social contact and involvement** are also at the heart of good care and service provision. This aspect **should be involved in discussions about the future organisation of care** [54].

Informal carers are extremely important partners in care. **Technology and remote consultation can support the continuation of care and dialogue** between people with dementia, informal carers and health and social care providers.

> "The months with COVID-19 measures have taught me that we, support workers, need physical encounters with clients. Our preference is for office appointments or home visits. COVID-19 forced us to an extreme exercise with other forms of contact and we found that for certain clients these forms of contact worked

better or just as well. It will be a challenge for the future to let our traditional preference for a meeting prevail less as a counsellor, but to offer a range of contact options to the person with dementia and their caregivers so that together we can make a choice for tailored assistance. Many tools have already been put in place to communicate about other possible forms of contact. Drawing up a simple visual step-by-step plan as an aid for people with dementia is still on the TO DO list!"

Staff member of social work department CM Limburg (Belgium)

At home and in residential and hospital care, carers give themselves 100% and even more in crisis situations. During the COVID-19 pandemic, they show tremendous resilience and are called heroes. Nevertheless, they are human beings without endless energy and capacities. The key question here is: "*Who cares for the carers? And how?*"

Caregivers get frustrated when they cannot meet their own ethical standards and uphold their professional pride. At a certain point, choices had to be made that were very difficult and could not really be supported. We heard the term "COVID-19 as a conscientious wretch" and maybe it is. Feelings of powerlessness have been very strong in the COVID- 19 crisis. In organisations where there was psychosocial support for the employees, this was strongly appreciated and experienced as necessary. Integrating regular ethical debriefing (even after the lockdown) also provides an answer to negative feelings of moral stress. Digital support via websites (e.g. *www.dezorgsamen.be*, www.actiz.nl, *www.dementie.be*) provides guidance.

Besides stories of alienation from one's own work and moral stress, we also heard messages about caregivers who regained awareness of their core motivation and rediscovered why they chose to care. This is caring for the most vulnerable in our society.

"Working in care, that's not just a job, hey, it's a vocation"

occupational therapist in a residential care centre (Belgium)

Other structural challenges that are coming to the fore during this crisis period are ageism, a deficit approach to dementia and negative public perception of residential care. Traditional media reported mainly about the negative side of the pandemic, the many deaths and the consequences of the restrictive measures. The nuance disappeared from the news coverage in the media.

> *"After 24 days in hospital, a journalist interviewed me about corona and my rehabilitation, and although 95% of the interview was about how well that rehabilitation went for me, only the 5% negative aspects were taken up in the newspaper".*
>
> *COVID-19 patient recovered during the first wave (Belgium)*

> *"The news media phoned us, asking how things were going in our residential care centre. After I told them it was going well, few infections, still plenty of good care, they told me they had enough of those stories, and started looking for something else. But unfortunately, I didn't see those other good stories in the media."*
>
> *A director of a residential care centre (Belgium)*

Prior to the COVID-19 crisis, residential care centres already had to contend with poor public perceptions that barely do justice to the good care provided. Unfortunately, this image has not improved in recent months.

> *“There is definitely an aspect of 'care home bashing', our facility has been in the local press and initially this was negative as they incorrectly quoted our figures of residents who died following COVID. In order to rectify this I carried out a telephone interview with one of the reporters with the aim of providing the human element of what has happened in care homes. This was printed online and in the local press, they also retracted the numbers originally quoted and gave the correct information.”*
>
> *A manager of a healthcare service (UK)*

This '*care home bashing*' (as this manager of a healthcare services aptly put it) carries the risk that moving to a residential care centre will be postponed even longer and opportunities will be missed to maintain quality of life in dementia. This is an additional reason to pay attention to home care services, which make it possible to live longer at home while maintaining quality of life. In addition, there are many residential care facilities that are able to realise a sense of home and embrace what matters to people who live in their facilities.

Florent and Cecile, 72nd wedding anniversary @ care home Mariawende in Beernem (Belgium). That must be celebrated, even in a pandemic.

A strength-based approach got snowed under during the pandemic. Values such as autonomy and involvement were compromised. This has an impact on the psychosocial well-being of residents in care homes and of people with dementia living at home. Emphasis was placed on their vulnerability and protection. Their voices were often not heard.

Participation in the care process and exercising one's own patient rights have always been important ethical issues for people with dementia. Advance care planning for people with dementia plays a crucial role here. It provides a handle on what needs to be done in certain situations according to the wishes of the individual.

Strict government measures and a strict isolation policy, sometimes motivated by fear, have sharpened **the ethical dilemma between security (infection prevention) and autonomy**. Changing the organisation of daily care and wearing of personal protective equipment can endanger the feeling of security that people with dementia desperately need. This is related to one of the fundamentals of CASCADE 'safe environment for independent living'. The search for a balance between safety (infection prevention) and quality of life needs to continue even in times of a pandemic. At end of life, family was sometimes not involved, for a dignified goodbye. The palliative care culture in which much has been invested in recent years has been pushed into the background. Palliative care took a completely different form in coronavirus times. Suddenly, touching and closeness became a problem, something that is at the heart of palliative care. Many caregivers asked themselves the question: how close can I get to someone; how can I be close and make them feel that I am there? Again, it is a trade-off between physical closeness and safety.

"As an expert, you can only really assess the situation properly when you go on the spot to see, hear, smell, feel,... how somebody is doing. Safety and proximity are possible. Starting a syringe pump, putting a patient upright in bed!! It is possible with the necessary protective equipment. And what's wrong with a pat on the back when you know this can be very meaningful to someone."

coordinator palliative care centre (Belgium)

But there were also other practices, where choices were guided by the search for an ethical balance between safety and human dignity.

> *"[we]…. took a very early view on the visiting of residents who were on an end-of-life pathway and this meant that following the completion of a very robust risk assessment and relevant documentation we were able to allow a family member to visit/to say their goodbyes. We have received comments from families on how much this was appreciated. We have a very robust process in place where visitors are greeted at the door, have all the risks explained to them, ask them pertinent COVID questions and get them to sign a visitor agreement. Each visit is booked like an appointment and the visitor is escorted whilst they are on the premises."*
>
> *a manager of a healthcare services (UK)*

In the search for the balance between safety and quality of life one takes calculated risks. This involves continuous evaluation of proportionality, health, safety and psychosocial wellbeing of the person and their relatives.

A number of instruments, which already existed before COVID-19 support ethical reflection. Websites like www.hetneon.nl (a Dutch network for ethical support) include many instruments. The development of ethical guidelines meets the need for value-driven decision-making. An example of this is the Flemish ethical compass for choices about visitation arrangements in times of COVID-19 that describes the steps of a care-ethical decision-making process [55].

The COVID-19 pandemic illuminated what is really important not only due to the limitations on crucial aspects of good dementia care, such as social contacts and involvement, but also through good and inspiring practices. In this booklet, we presented practical guidelines and tools following the CASCADE model. We have learned a lot through our collaboration in the Interreg 2Seas areas and want to close this booklet with a call to action:

- Coupled with excellent medical care, our key priorities for current and future organisation of dementia care should be focussed on sincere attention and presence, social contact and involvement of residents in their own care.
- We need to stay in dialogue with informal carers, offer them advice and suggestions on dementia care. Technology and remote consultation sources can help with this.
- We should show our sincere appreciation to frontline staff for the difficulties they are experiencing during the pandemic crisis; dealing with the crisis is a learning opportunity to reassess the principles and ethos of the health and social care, especially for people engaged in dementia care services.
- We should invest in moral and psychosocial support for both formal and informal carers who give the best of themselves in caring for the most vulnerable people in our society.
- Bringing stories about good dementia and what works in media is crucial in creating positive perception about living with dementia and caring for people with dementia.
- Human dignity needs to be in all circumstances, the starting point for care provision and policy.

- We should pay particular attention to the balance between safety and quality of living for residents in dementia care settings, to avoid over-medicalisation of the care we provide.
- Advance Care Planning and end-of-life care as a process of dialogue that values what really matters to people are essential elements in the care for people with dementia.

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