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Speaking out from the silence

Testimonials from the elderly care sector

Ad hoc commission for the assessment and
further implementation of Flemish corona policy

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The Spot

Je moet niet alleen, om de plek te bereiken,
thuis opstappen, maar ook uit manieren van kijken.
Er is niets te zien, en dat moet je zien
om alles bij het zeer oude te laten.

Er is hier. Er is tijd
om overmorgen iets te hebben achtergelaten.
Daar moet je vandaag voor zorgen.
Voor sterfelijkheid.

Herman de Coninck, Breast Stroke, 1994

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Speaking out from the silence

Foreword

In preparation for a debate on the Assessment and Further Implementation of Flemish Corona Policy, an ad hoc parliamentary committee was tasked with drawing up a social policy memorandum which, in addition to defining the problem, was to contain a long-term vision, while at the same time clarifying what was planned in this respect in the current parliamentary term. The ad hoc committee was also tasked with organising hearings with experts and representatives from the various sectors involved. On 26 & 29 June 2020 as well as in the morning of Friday, 3 July 2020, the ad hoc committee started hearing experts and representatives from the (residential) elderly care sector.

The Human Rights Chamber of the Flemish Ombudsman Agency contributed to the ad hoc committee's work, with the Agency's Dr. Annelies D'Espallier giving an introduction and presenting anonymised interviews conducted with elderly residents, carers and relatives earlier on 3 July 2020. The contribution explicitly focused on supplementing the testimonials cited below.

Presented below are a set of testimonials supporting that introduction and the audiovisual interview fragments, available on www.vlaamseombudsdienst.be.

A compendium of testimonials

Flanders and its population have been no exception, also being hit hard by Covid-19. The virus has left a trail of destruction in Flemish society, infecting and killing many, especially among vulnerable groups. It is now a well-recognised fact that residential care for the elderly, whether in the form of residential care homes or service flats, have been hit hard.

Covid-19 has had and still has a great effect on us, both individually and collectively. The virus is leading people to seek and find the best in themselves, to join forces for and with the group of residents, staff and families, even in the face of tough circumstances.

The Human Rights Chamber of the Flemish Ombudsman Agency has the task of investigating complaints, acting as an intermediary and making recommendations based on that work. With regard to the current situation in residential elderly care, these voices from the silence are part of this. These testimonials and audiovisual fragments constitute a collection of silent sounds and voices, telling of the suffering endured even today. Looking at the situation from different perspectives, these testimonials speak of the chaos and fear, of a situation where sturdy oars were needed to row the boat through the troubled waters, but where in many cases nothing but toothpicks were available.

The report was compiled using a qualitative research approach based on in-depth interviews. Though the focus is on testimonials and stories about possible bottlenecks exposed by the corona crisis in residential care homes (hereinafter often referred to as RCHs or care homes), possible positive aspects are also highlighted, both at an individual and relational level and at the level of society, charting various policy-relevant aspects. The full report contains a lot of information of great relevance not only for policymaking, but also for further developing care provision and research.

Without anonymisation, these voices from the silence, the interviewees featured in this compendium and the film fragments shown in the ad hoc committee meeting on 3 July 2020, would not have been able to reach the surface. These are voices which, in view of the age and health of those concerned, cannot be interviewed by the committee in Brussels in any other way. Furthermore, their anonymity means that each interviewee serves as a metaphor for a larger whole. Lastly, certain interviewees – relatives, volunteers but also staff and management – fear negative consequences if testifying publicly. They want to share their experiences and their perspectives, but can only do so freely and with peace of mind if they know that they are protected.

Other than generally practised, the Human Rights Chamber has opted this time to let the voices speak in an unadulterated manner: there has been no investigation of complaints, no truth finding, no search for arguments for and against. There is no finger-pointing, no wish to identify individual responsibilities. The voices are a naked testimony, intended to help build a better future

Between 23 and 29 June, the Flemish Ombudsman's Agency did what it always does: picking up and amplifying sounds. Even in the silence, a lot was said.

A total of 45 people were interviewed:

- 7 care home residents
- 17 relatives
- 21 professionals (technical staff, nurses, carers, physiotherapists, heads of departments, etc.) and volunteers

The associated video report was made in conjunction with the Flemish Parliament's Communications Department. We would like to explicitly extend our thanks to them, and especially to Dries De Koster who accompanied us.

Caught on the hop

This place will never be the same again

Chaos

Chaos is a keyword in the testimonials, a word used by each interviewee in each group. The Covid-19 wave swept rapidly across the country in spring 2020, catching everyone by surprise, as reported by several interviewees. Some even said that the word "chaos" was inadequate, preferring instead to speak of "war" or "all hell let loose". Various interviewees even raised the question of whether everything would ever get back to normal.

> *"We were completely out of control"* (director)

> *"For me it was a surreal and existential time. We tried to get through each day without further damage. For our residents, it was a question of pure survival. I knew people who were putting food in their pockets and cupboards because they thought rationing would be introduced because a war had broken out."* (staff member)

Chaos in care provision due to (too) rapidly changing staff, chaos in the way information trickled in and got circulated, chaos in the response of care staff and employees, chaos in the reactions of residents and family. One interviewee stated that he arrived as a temp worker in an RCH without having been informed beforehand that he would be assigned to a Covid department. He only stayed there a short time.

The reaction to this chaos was described by various interviewees as panic, driven by emotions rather than by well-considered decisions based on clear guidelines. Some feared that the guidelines, for example on protective equipment, were inspired more by the extent to which such equipment was available than by scientific evidence. There was talk of guidelines that were clearly inadequate, of others that were basically good but were introduced too late, for example that of not allowing visitors into care homes in March 2020. Interviewees reported taking the wrong measures due to changing guidelines and the sheer chaos. One technical employee had this to say:

> *"It was chaos. We were working in the same clothes, irrespective of whether the people were infected or non-infected. We usually worked in our own clothes. And I wasn't given any specific training either. And what I also don't understand is that, at a time when there was a ban on all non-essential visits to care homes, we were tasked with painting corridors. Was that essential work?*" (technical staff member)

One carer had this to say about the rules on wearing a mask: *"Some colleagues started wearing masks on their own initiative. But they were told that this was not allowed. But later on, this suddenly became a requirement."*

Chaos initially caused by a devastating virus, but – according to the interviewees – perpetuated in chaotic and ever-changing guidelines and sometimes in reactions towards residents and their families, according to staff testimonials.

"We were not allowed to tell the outside world whether we had any positive Covid cases so as not to blemish our reputation." (carer)

"To avoid panic, we initially only notified the immediate families of positive Covid cases, but not the relatives of other residents." (carer)

One relative had a similar tale to tell:

"The news of the first corona infection in the RCH was first communicated to the families of the residents concerned. Hours then passed without the news being communicated to the families of other residents in the same department. They only got the news via the social media." (a son)

Several relatives acknowledged the chaos and the difficult circumstances under which the RCHs tried to do their best, with one interviewee having this to say: *"Hats off to the staff".* But there was great and lasting unrest about what happened behind closed doors. Relatives were worried about their dear ones, inter alia no longer having any information over whether care and compassion remained sufficiently present, fearful of whether the circumstances were not just chaotic but also at times not compatible with human dignity. One relative reported that his mother had reported being hungry during window visits, while another testimonial of a carer confirmed that portions were being made smaller for the residents, so that staff could also eat that day. Other relatives reported parents having to stay sitting (too long) before a nappy was changed, or that they were washed too late and not in the best circumstances.

One carer confirmed the concerns to a certain extent: "*Not allowing visits meant that families were also protected from harrowing scenes and the way things were sometimes done"*. Elsewhere too, residents were whistled back by carers when they tried to leave their rooms or were tied to their wheelchairs so that they couldn't go anywhere – all of this the result of the uncertainty and panic accompanying the chaos.

A forgotten front, forgotten fighters

Various interviewees spoke of the burden they felt through being forgotten, criticising the fact that the difficulties in this sector were hardly or too late highlighted, meaning that appropriate reactions were also delayed. There was no real sense of urgency. Even at the end of June, many of the interviewees felt a lack of recognition and respect.

"All attention was focused on the hospitals. We found ourselves completely forgotten. As if everything was OK with us." (carer)

"*When things started getting bad, we were left high and dry. No politician ever came here."* (director)

One son had this to say: "*The elderly and the care homes in which they live were simply forgotten. It took thousands of deaths for the spotlight to be put on them."*

The fighters on this forgotten front, some in particular, were similarly forgotten. Technical staff tasked with building Covid wards stated, among other things, that they had to do so without tests and without protective equipment, despite moving between care homes. "*I worked without any protective equipment in four or five different homes over a period of two weeks*." And also: "*We were never tested. Management decided that the tests were not for us."*

What we had, what we lacked

Shortages of staff, knowledge, tests and equipment weighed on people. What staff felt lacked most was time. In combination, all these shortcomings made staff feel they did not meet the quality standards and that professional integrity took second place. The preconditions for high-quality care were just not present, resulting in various staff interviewees stating that they felt affected in their professional pride and sense of responsibility.

> *"I'm thinking about quitting, as I'm just not getting the resources to provide care as I feel it should be - whether for residents, their families or staff."* (head of a department)

People

> *"You go to work thinking 'who are we going to give up today?' Some you can save, but for others it's too late because you have to make choices when the pressure is on."* (nurse)

Many of the interviewees from the care sector reported that, even in normal circumstances, the water was up to their necks due to understaffing in combination with high staff turnover. Staff rotates more than the figures show: "*When I started working in the sector, 25 years ago, we would do a morning shift with eight workers. Now we're down to just three."*

One professional had this to say about the many deaths and how they led to staffing cuts. *"Only one member of staff could do night shifts, instead of two."*

Interviewees spoke of the consequences of staff shortages for residents:

> *"One resident had fallen over. He had to stay lying on the floor for one hour because the person on duty was unable to lift him up alone. She had to call for help to get the resident back into his bed." (a volunteer)*
>
> *One resident sat crying in the corridor, in nothing but her underpants. Her arm was in a plaster cast. 'I've been waiting so long for someone to help me get dressed. Nobody's got the time, and it'll soon be time for lunch.' I arrived just at the right moment."* (a volunteer)

Staff reported that staffing levels made it impossible to cope in a period where there were shortages of staff in many different places and at a time when extra hands were needed anyway. For instance, serving meals in individual rooms took a lot more time than when serving them centrally in a dining room. Separating positive Covid cases led to staff being unavailable to the remaining residents in several areas. One resident who recovered from Covid told how she was in awe of her carers who had to continually get into and out of their protective suits. This alone required extra time and effort.

In some cases, staff shortages were overcome by the use of helping hands from outside: "*Once home care staff came to work in our care home, things became manageable*." Similarly, helping hands from other sectors were noted and appreciated.

But these helping hands were not always available: "*You could supposedly get help from third parties. The Flemish Care & Health Agency (*Agentschap Zorg & Gezondheid*) offered this, but nothing much came of it. The lists had not been updated. We rang up 46 people, but no one was available because the outbreak in our home occurred quite late*." (member of staff)

In another case, one technical employee said that he had been furloughed after a while, despite seeing all the work needing to be done. "*Couldn't we have helped with meals or other things associated with care?*"

Even in the post-peak period when visitors were allowed back in, interviewees noted staff shortages: *"Occupational therapy and animation were no longer on offer, as these people now had to supervise the visits."* (a son)

One employee remarked that the director was barely coping: *"He was in the care home every day for weeks, despite having a family with small children at home. He would ask everyone how they were coping, but no one asked him. I tried to do so when I passed him in the corridor, but without much success. Residents were always bombarding him with questions."*

Training and know-how

Interviewees talked about the training and know-how they had and what they lacked. Know-how covered a number of different aspects. Little was known about the virus itself and the speed with which it would spread among residents. Similarly, there was little knowledge of the equipment to be used against the virus and to prevent infections. There were rules for putting on and taking off the protective clothing, but these were not generally known. For some care staff, any practice in handling preventive contamination measures dated back to their internships or vocational training.

In several places, the knowledge available was used to sensitise the entire home.

> *"We were fortunate to have just finished our hands-on care and reanimation training cycle."* (head of department)

Another carer reported that they had been able to prevent a lot of (extra) suffering because they were lucky to have had a nurse on the team who had worked in a hospital until recently.

Tests

Almost all staff interviewees expressed their incomprehension over the late and limited testing possibilities. Some reported going to their GP because they wanted a correct assessment allowing them to act (more) properly. Other interviewees reported having had additional tests conducted via their own networks. Both staff and family interviewees showed little understanding for the lack of synchronous testing in the various care homes, as well as how slowly this was done. Likewise, certain staff interviewees expressed their concern over the correct use of the tests.

According to the interviewees, the lack of tests meant that, in hindsight, a number of wrong decisions were made.

> *"There was no testing until you actually knew someone had it. But this resident's child had been positively tested. Thus alerted, we isolated her once she started showing symptoms. But up to that time, she had had her meals with everyone else, as usual.* (carer)

(Protective) equipment

A lot has since been said about the shortage of protective equipment. The interviewees were no exception in this respect, reporting *inter alia* the mandatory reuse and sharing of equipment. There were stories of boxes of protective equipment being 'overlooked' in the chaos and of staff concerns over the quality of such equipment.

> *"I was very scared, also in connection with the protective material. The packages felt quite rubbishy, especially when compared to what they wore in the hospital. I saw on TV that the parks department had better equipment – those white suits – to fight caterpillars than we had in our fight against Covid."* (carer)

> *"I wear glasses, so obviously I did not get protective glasses at the beginning."* (carer)

Interviewees reported that equipment was being stored under lock and key to keep track of supplies, but also to prevent hoarding by staff. The interviewee said that this made it seem as if there was a shortage and that it was a case of 'every man for himself'. Another interviewee said that masks had actually disappeared.

In the same vein, shortages of other equipment were discussed. For example, in some places there were just not enough carts to transport all the extra equipment.

All feelings mixed together

Love and fear

> "*My mother taught me to look to the skies and to see nature's beauty. The best present I ever got."* (a daughter)

Children spoke lovingly of a mother or father and about their fears, because they had handed over their parent(s) to a place which in hindsight they considered to be unsafe based on the figures. Fear and guilt were sometimes closely intertwined: *"He doesn't like sitting there. He only decided to go after I promised I would keep coming to visit him."* (a daughter)

Others spoke about their fears. Residents described the unrest that arose once it became clear that the virus would not be confined to China or Italy. They were afraid of becoming ill and afraid of contamination by other residents or care staff. Even today there is a degree of mistrust towards others suspected of being infected.

Care staff, their supervisors and management spoke of a feeling of fear of the virus, of each other, of becoming infected or of infecting others. *"I didn't feel safe. You also had this uneasy feeling that the mask would get damaged through continual use. I was afraid of infecting residents."* (nurse).

The appearance of the wards, with colour codes on the doors (green and red) and posters displaying 'contamination risk', created unrest and fear. Staff reported how, on starting a shift, they would anxiously check who was still there in their normal place and who had gone – temporarily or otherwise.

Those who had seen the virus in action described how difficult this was for patients and what effect this had on their own feeling of fear.

> *"Staff worked here with a feeling of having a gun pointed at their heads".* (director)

One employee spoke of the many different emotions experienced concurrently.

> *"In the first weeks, a colleague became ill, eventually dying from corona. That naturally had a major impact: fear combined with having no time to grieve and all the problems associated with learning how to work with all the new equipment and guidelines.* (member of staff)

Powerlessness and anger

Relatives in particular spoke of how their fear mutated into feelings of incomprehension, powerlessness and sometimes anger.

> *"There was nothing you could do. You just sat there watching your father or mother suffer. Compare it to a school. No parent would accept a school suddenly shutting its doors, keeping the children there and then telling parents that they could come and talk with them through the window but otherwise would have to remain outside."* (a son).

Relatives criticised, among other things, the interrupted or inadequate lines of communication with care home staff and management, the measures they considered too restrictive in the circumstances and/or because they missed having any say in the matter. Some wondered why volunteers were allowed back in at some point, but not them.

They spoke of a feeling that human dignity in care homes might not be the highest good, of their inability to do anything against what their loved ones were being subjected to, of the pain (and guilt) they felt after they themselves had urged their parents or relatives to enter a home. These relatives felt powerlessness and deep-seated anger at the injustice experienced.

> *"My mother is dying while still standing there at the window"* (a son)

Relatives were not the only ones with a feeling of powerlessness. Staff also spoke of their lack of control, almost despair. They felt themselves powerless in the face of this devastating virus, able to do so little against it. They felt themselves powerless in the face of so many sick people, so much suffering, and so many deaths:

> *"It was terrible seeing how a resident with corona had to suffer, struggling to breathe, gasping for air. For a moment I almost wanted to relieve him of his suffering, putting a pillow over his head. There was nothing we could do. We were totally powerless."* (member of staff)

Deep sadness

Many of the interviewees expressed their sadness: sadness about missing time together, about having to let go of their loved ones. Relatives who had lost a loved one would break down while telling their stories. They reported how difficult it was to find room for their sorrow, partly because of the postponement of the funeral until more people were allowed to attend.

> *"One resident was weighed down with grief. She showed me the obituary of her friend, a friendship that went back 80 years. She had attended all family celebrations, but hadn't been allowed to go to the funeral."*

Staff interviewees described their deep sorrow at deaths, especially when many occurred:

> *"We got on well with those residents, but we could not dwell on their deaths for long. Many were the tears that flowed. You also knew things were bad when someone had to be sent to hospital. Some were not even admitted and had to spend their final hours here."* (director)

> *"You felt sorrow about those you lost. Within just a short space of time, we lost quite a few. But there was nothing you could do. In other cases, you would go from great joy to deep sorrow. For example, someone came*

back from hospital. We all clapped because it seemed he had recovered. Two days later, he suddenly died as a result of corona. You start hoping, but then the people die." (member of staff)

"It was sad seeing the undertaker with his stretcher in the building. So much suffering in such a short space of time." (a volunteer)

And then there were those little things. One volunteer spoke of how sometimes cars with trailers drove back and forth all day. On those days, the belongings of those who had died were picked up, with their rooms cleared for new residents.

A feeling of guilt

Many interviewees reported feeling guilt – the guilt of families towards their loved ones for not being able to show the commitment they considered necessary. A similar feeling of guilt existed among the carers and other staff towards the residents and towards their own families. Staff off sick felt guilt towards their colleagues for not being at work. One director spoke of a certain feeling of guilt towards staff for sending them to the front so ill-prepared. But those infected also felt a sense of guilt towards the uninfected. And vice-versa.

"I was off sick and I felt guilty for possibly having spread the virus to residents, colleagues or at home. At the time, we couldn't do any testing at all to confirm anything." (head of department)

"We felt guilty, while at the same time we were constantly afraid of contracting the virus ourselves and not being able to provide care. We were working virtually around the clock. You might well ask: how did you manage? I've clocked up two months of overtime." (nurse)

Some stayed away from their families for long periods to avoid infecting them. One employee reported how difficult it was to put on a brave face during the day and then come home in the evening and take on her normal role in the family. Another spoke of the impact of working round the clock, separated from her family.

"It was really difficult during the peak period when the schools were shut. We made use of the school's emergency facilities. Our daughter was the only one there. That was hard, for her as well. She cried every day when I dropped her off. Not anything you like to do!" (member of staff)

Walking the tightrope between safety and compassion

Interviewees told stories demonstrating that caution and safety considerations weighed against quality standards in all care aspects. The weighing up, proportionality and balancing of these different values are human rights terms about which the Human Rights Chamber also wrote earlier in 2020, again in a corona context (see also: Corona addendum to the 2019 annual report of the Flemish Ombudsman Agency *Parl. St.* Vla. Parl. 2019- 2020, nr. 41/1-A).

Human dignity

Everyone concerned, whether relatives, frontline staff, management or volunteers, mentioned compassion and human dignity as the basic ingredients of good elderly care, in line with what is internationally regarded as being the core of the rights of older people. Pending a legally more binding UN convention on the rights of older people, the UN Principles for Older People (Principle 14, Resolution 46/91 of 16 December 1991) contain this passage:

> "Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives."

This same principle is reflected for example in Article 6, §1.1 of the Flemish Social Protection Decree of 18 May 2018:

> "Art. 6, §1, Flemish social protection contributes to integrating care and support and increasing self-reliance, taking as a starting point the needs, questions and aims of the person with care needs and his/her immediate environment and the desire for a certain quality of life. The Flemish social protection has the following goals:
>
> 1. Strengthening persons with care needs through letting them maintain or regain control over their own care and promoting their integration or reintegration into society as far as possible; (…)"

Yet all interviewees reported that human dignity had suffered. The virus, the shortages in all fields and the major disruption all weighed down on any humanitarianism.

> *"We are no different. Even here, our work is guided by figures. While that is obviously important, it means that people often take second place."*

Support

According to the interviewees, some residents needed additional attention. But it was difficult or not always possible to provide this due to staff shortages. *"Emotional support for (isolated) residents suffered. There was just no time for that. Any animation was limited to handing out books and magazines*." Residents spoke of how much they appreciated any extra minutes, telling of what it did for them when staff or the director dropped by to see why they had been silent for a few days. Several interviewees described having seen their carers working hard to keep giving them that feeling even during that difficult period. Relatives noticed this as well: "*The homes were obviously short of staff. You could see how stressful it was for some of them. But there were always those who kept smiling. That was really good".* (a daughter)

Human contact

Some staff interviewees reported having done everything to keep the virus out, though they recognised that this made them, the very ones providing warmth to the residents, potential virus carriers. They acknowledged how this weighed down and still weighs down on residents. One volunteer had this to say:

> *"I can well understand how difficult it was for staff, but the focus on safety cramped their style. The whole focus was on keeping the virus outside the home. This meant residents had to stay sitting in their rooms, in complete isolation. The care staff clearly had no training in how to deal with such a situation. The bar was set too high to keep the virus out, sometimes at the expense of residents' feelings."* (volunteer)

One interviewee from the group of residents spoke of noticing much loneliness around her, but that things had been tolerable for her because she had a partner nearby.

Organised and limited visits acted as an interim measure to successfully keep the virus out yet allow contact. However, such organised visits took place behind glass, sometimes behind bars, something that did not feel very human for many

relatives. They were not much good for residents with hearing problems or disorientated residents, who, together with the interviewed relative, yearned for that human touch. *"You couldn't call that contact. We were only allowed to see them once. Contact is something different."* Several relatives reported not being able to wait for things to get back to normal, as their mother or father had little time left. One daughter had this to say: *"My mother is 97 years old. We saw her for 20 minutes each time. I'm scared things will stay like this until she dies. I'm afraid we will have missed the chance to hold each other's hands."* (a daughter)

> *"And now she is not allowed to go out for a walk with her family because it is too hot, even though she is in her room all the time, tied to her wheelchair, sometimes with the curtains still closed."* (a son)
>
> *"Due to the strict procedures, the visit was very disappointing, not just because of the physical distance, but mainly because a staff member had to be there as a 'supervisor'. It ended up as a conversation with the staff member that was of no use to either my wife or her mother." (a son-in-law)*
>
> *"My mother is allowed to go out for a walk twice a day for 20 minutes, but she gets stressed. She constantly asks how long she has before she has to get back. We live just a few hundred metres down the road and I'm beginning to wonder whether she will ever be able to come and sit on our terrace again or whether we will have to visit her in her room."* (a son)

This call for more and genuine human contact sometimes clashed with the caution to which staff attached great importance, although almost all staff showed respect for the fact that the current solution had its shortcomings.

Care

Various interviewees reported corners being cut in the provision of care due to staff shortages or fears.

> *"Too little attention was paid to the human aspect of care. We chucked used nappies out into the corridors, picking them up later."* (nurse)
>
> *"I've heard things from residents such as: 'They'd forgotten I'd rang the bell' or 'I've been shouting out loud on the toilet here.'"* (a volunteer)

One son had this to say:

> *"Mother's mental condition deteriorated noticeably during the nine weeks quarantine. The approach taken was not that good as the focus was too much on confinement to counter the risk of infection and too little on a warm and high-quality care offering. There was no foot care and, after ten weeks of confinement, mother had to wait until 8 June for the hairdresser. Even now, on 25 June, still not everyone has had a haircut."* (a son)

Care staff spoke of the suffering they saw, leading them for example to take on hairdressing duties themselves: *"At a certain point we started cutting people's hair ourselves to spruce them up a little. After all, you're working in the care sector."*

Several staff members reported that residents with disorientation fears were sometimes sedated, something that staff had great difficulty accepting. After weeks of confinement, relatives, looking at the condition of their loved ones, noted that there had been much too little exercise and animation. Certain interviewees even stated that their father or mother had spent days tied to a

wheelchair.

> *"Just look at my mother. Within just a short space of time she has become a vegetable, slumped in her wheelchair. She doesn't recognise anyone anymore and she's no longer able to walk or speak.* (a son)

Meals

Meals are an inseparable feature of care. Children noticed that their father or mother had got very thin, while a volunteer reported seeing people who were not eating enough. *"When I offered to help the residents eat, the staff said that they could do that by themselves, but I always cleared away a full tray. But when I took the time to help a man eat, he ate well.* (a volunteer).

Interviewees also remarked on something else:

> *"They are getting their food on cardboard plates and in cardboard cups instead of a plate and glass, which is less pleasant to eat and drink, but otherwise we wouldn't have managed."* (carer)

One son saw dangers in this:

> "*Plastics cups are being used for hot drinks, but these can be dangerous for residents. It would have been just as possible to machine-wash a few extra dishes at a high temperature to make them bacteria-free. But that did not happen, perhaps because it was too labour-intensive and expensive."* (a son)

Dying in dignity

Terminal care is a further feature of elderly care. Here again, the virus and the reactions to it took their toll. People died alone, without their families at their bedsides. In panic moments, especially at the beginning of the wave, choices had to be made under pressure due to the chaos. For many interviewees, these were not always understandable or compassionate. This was hard on carers and they stated that they needed help, even now, so many weeks later.

> *"The resident never had any visitors, except after the palliative sedation had been administered: 2 people were allowed to stay for half an hour, but the resident had still not died. A body bag was already on the bed, so that the corpse could be quickly zipped up without risking further contamination. The resident knew she was alone and dying, and she felt very alone. For me, that was a very difficult moment."* (carer)

But it was not just the care staff who had problems with this. There were also the deceased residents, many of whom died alone. One employee had this to say: "*Dying people were crying out for their families, but no one was allowed in."* Then there were the families, shattered because they had not been able to say farewell to a father or mother, and who now had to live with the realisation that their parent had died without experiencing any warmth. This was especially true with regard to those who died without being clearly diagnosed as Covid-positive. Here again, incomprehension, anger and deep sorrow were expressed.

> "*When I finally managed to get to him, it was too late. No longer able to speak, he was about to die. He just managed to say 'cheers' when he heard me uncorking the bottle of champagne. That was all. That was how I had to let him go. It's something I'll never forget."* (a daughter)

> *"One story I'll never forget is that of a couple where the wife looked after*

her sick husband. When she got terminal cancer and was no longer able to look after her husband, they decided to come to this care home to spend their final days together. But then the lockdown came, and the prospect of not being able to receive any visitors, for example from her child, was just too much for her. The wife had to make that harrowing choice between her husband and child. She ended up spending her final days in hospital, while her husband remained in the care home. She felt unbelievably guilty about not having stayed with him right up to the end. She chose a day to die and on that day she was able to see her husband. Afterwards, the husband had to spend 14 days in quarantine because he had been in contact with the outside world. He thus had to spend 14 days sitting alone in his room without seeing his family, not even through the window. He had to go through this process of grief all alone." (a volunteer)

Confinement

Kept to their rooms

"We did our very best for residents. Quarantine didn't feel good, but what else could we do?" (nurse)

"It was really weird. It is just like practising for when she would no longer be with us." (a daughter)

Lockdown, quarantine, confinement – all of them measures intended to keep the virus out. Here again, the tightrope was walked between safety and humanitarianism. Confinement appears to have taken different forms, depending, inter alia, on the location and on the degree of infection. In shutting off care homes from the outside world, sometimes whole wards were locked down or in other cases people were isolated in their rooms. There were even cases where there were so many people sick that the decision was taken to isolate those not sick. According to interviewees, this led to incomprehension, and sometimes even resistance. In other places, those tested Covid-positive were isolated. Interviewees from family circles mainly questioned the intensity of confinement (for example, keeping people in their rooms) and its duration.

"My relative was finally allowed to leave her room after 16 weeks. But she had had so little exercise that she found walking very difficult. She is now allowed to walk in the grounds twice a day for 20 minutes, with the time strictly controlled. She is also now allowed to move around on the floor again." (a relative)

On the other hand, one resident reported that she had not noticed it: *"I spent a lot of time sitting out in the yard and speaking with my daughter on the phone. The weather was good."*

Almost all staff interviewees reported that they considered the confinement necessary, but that it took too long to balance it with the knowledge they had today about the virus and about how residents' well-being evolved. One interviewee put it this way: *"The confinement lasted much too long. We should never again isolate people that long."* (department head)

One volunteer noted what effect the end of confinement had on residents' well-being.

"*In my last week as a volunteer there, residents were allowed back into the dining room, though with sufficient distance between each other and at separate tables. You could see that that made a world of difference for*

them." (volunteer)

"Relaxing confinement, we let light back into their lives." (a volunteer)

Deterioration after confinement

The longer the lockdown lasted, the more I saw people wilting – like flowers without water."

Isolating the care home from the outside world and cancelling visits took their toll. Interviewees from all groups reported seeing a marked decline in many residents. "*They suddenly seemed a bit older*". Physically, people deteriorated a lot: "*People became stiffer and stumbled more. We put them on home trainers, but the physiotherapists were unable to follow this up*." Or again: *"The total lockdown was very disorientating".* Some interviewees spoke of a resident in isolation who stayed lying on his bed out of sheer misery and loneliness and stopped eating.

It appears to have been extremely difficult to properly explain the lockdown and/or the isolation. A number of staff interviewees remarked that residents with dementia experienced fewer difficulties because they did not really grasp what was happening, while others reported that the isolation was a major problem for such residents because they did not understand the situation and therefore became angry and sometimes even rampaged in their rooms. Some spoke of suicidal tendencies. Windows were kept shut for good reason. Several interviewees reported that residents with dementia were much more liable to be restrained.

"One resident had been tested positive, though without showing any symptoms. She was the only one who was still in a cognitively good state and it was hell for her to be 'locked up', especially because she still felt quite healthy." (nurse)

Locked doors and barriers

A lockdown sometimes had a clear physical dimension: a door that was locked or a chair placed between the different wards to prevent people wandering around.

"On leaving, I saw that other residents were sitting outside with barriers around their group. My heart bled because I knew my mother was crying. (a daughter)

"Some of the flats were locked. A neighbour of mine in his eighties had a dog. He had to let him out of the window in the evenings. Outside my door, the corridor was taped off and there were barriers. This meant that I was unable to use my wheelchair. You felt you were in prison. I then just cut the tape. (resident)

The word 'prison' was used quite often by the interviewees, even now after many of the measures had been relaxed:

"It really was a bit like a prison regime where detainees could receive visits in a specially equipped room, under the supervision of wardens, for a limited time. Residents were regularly allowed outside, albeit between four walls and behind barred gates." (a son)

Loneliness and appreciation for efforts

Several interviewees spoke of loneliness. One nurse spoke of a resident who had

given up and didn't want to leave her bed. Children spoke of the loneliness: "*Mother is not going to die of corona, she's going to die of loneliness".* Families and residents themselves remarked how much they missed human contacts.

> *"I used to drop by every day. I used to go and watch the news with him, but that suddenly stopped. I could then only see him through the window. But the window was shut, so we couldn't speak. And even then, we were the lucky ones. Relatives of people on the higher floors sometimes stood on the parking lot, shouting up and crying."* (a daughter)

One resident in a service flat reported how she missed her friends in the care home:

> *"I used to meet them every two weeks in the cafeteria for a coffee and a chat. We all very much looked forward to that. The joy of being together, especially for them because someone came from outside. Suddenly, that all stopped. I did give them a ring once, but this weekend I'll be visiting them for the first time again. I'm very much looking forward to that. I really missed seeing my friends." (*a resident)

The physical aspect of visits and contacts was completely ignored. One daughter spoke of her mother only really connecting through very close contact, a physical contact such as a hug or holding a hand. There was none of that the whole time. And the effect was very visible.

Many of the small, human gestures and moments came to a stop. Sharing a newspaper between residents, with that associated moment of passing it on, was for example replaced by personal subscriptions for those who could not do without a newspaper. The joint exercise sessions were replaced by much less frequent individual sessions with the physiotherapist insofar as there was room for such. The group moments at the table gave way to a life to a large extent (or completely) confined to one's room. One daughter had this to say about her mother having to stay in her room:

> *My mother spent a total of three-and-a-half months sitting alone in her room. Then there was a three-day pause, but then two new cases were discovered. She now can't get out of bed herself and is completely dependent on others. The window was also hardly ever opened. She was almost completely devoid of any outside air. She was in prison."* (a daughter)

Many appreciated the efforts made – by staff or by people from outside – to maintain contact between the world inside the care home and the outside world. That contact consisted, for example, of looking at photos together, chat windows, organised waving moments, or digital contact for those for whom that was an option. *"We worked with student volunteers as soon as possible. They came and chatted with residents. As far as possible, residents sat in groups of four, allowing them to have social contact*." One relative had this to say: *"My children cycled over and held up posters saying 'Did you sleep well?', 'Are you eating enough?'."* The staff of one care home spoke of the weekly concerts on the square outside the home. However, many of those involved spoke of too little and too limited contact serving as a substitute for real contact.

One volunteer told a very special story about compassion, resilience and assertiveness in the early days when the rules were not yet all too strict:

> *"One of the residents had a rope and hook brought to him, allowing him to pull up certain groceries that were not supposed to be left outside for a long time. This way he was able to put frozen scampi in his freezer. That*

same man also picked up crisps and chocolate, distributing them among the other residents. And each time he would write a little note." (volunteer)

During the most difficult period, many of family interviewees wanted (and still do) to see and speak to their relatives. For them, the visiting hours were just not long enough: *"Time is up so quickly, and then you have to wait a week".* It was also stated that the time was just too short for those concerned: "*The 20 minutes just flew by. They were already over before my mother actually got there*". Any contact that did take place was obviously made more difficult by the masks, shields, etc.: "*She's got hearing problems. With a plexiglass shield separating us, she doesn't understand a word."* One interviewee spoke of seeing his parent at a distance by the gate. While he was shouting out to his parent, other family members standing close by were doing the same for their relatives. There were RCHs which, for practical reasons, did not allow visitors to come on weekends, making things difficult for interviewees who could only visit on those days.

Residents who were ill were not allowed to have visitors. The disease hit the homes so severely that social contact became very difficult, regardless of any additional quarantine measures.

*"They tried to ring me up, but I couldn't hold my phone." (*resident)

Confinement in all aspects of life

"I kept my own child at arm's length until mid-May. You isolate yourself." (member of staff)

For the care staff themselves, this was also a lonely period, especially when the thoughts and suffering could not be shared with a partner even after a busy working day. Even so, many spoke of the support given to the group, for example via WhatsApp messages, or by the psychologists appointed by management or in team meetings. Some staff members made superhuman sacrifices, such as one carer who took her 4-month-old baby to her parents to avoid any infection. "*She didn't know when she would be able to hold her baby in her arms again*."

Searching, and sometimes finding

Understanding and being understood

Human interaction requires understanding and being understood, and apparently that often did not work in the difficult circumstances. Staff and family members spoke of how residents were moved to other wards to group them together, sometimes with the help of the fire brigade. They reported that residents did not understand this and that it was disorientating for them: "*All of a sudden, there were different people living in my street.*" Residents became so confused by the move that they were completely lost in their new rooms, not even finding the way to the toilet.

Many described how residents in many cases did not understand what was happening to them:

"*Despite everything we were doing, those residents did not always understand. Most of them also had dementia, making it very difficult for them to grasp what was happening to them. Two of them even became aggressive because they just didn't understand. We ended up having to sedate them, something which the carers found very hard to do."* (member of staff)

> *"When one of the residents was finally allowed to leave the corona ward and went out onto the terrace, he suddenly started crying. He was also suffering from dementia and thus it was very difficult for him to understand what was happening to him. We were just not able to put it across to him."* (nurse)

One resident described how another resident with symptoms just did not understand anything due to his age and circumstances and therefore went off for a coffee with his neighbours. That generated friction.

Finding someone to speak to

Communication was a core topic in the testimonials. Many staff members felt they had been left in the lurch through the ever-changing guidelines and the lack of what they described as a steady and sure hand. Staff who had been off duty for a few days sometimes struggled to keep abreast of guidelines that had since changed. Staff at all levels described how difficult it was to understand the rationality of these ever-changing guidelines and to constantly have to make adjustments within the RCH, also with regard to the residents. Some explicitly remarked that this also contributed to their feelings of guilt: *"Was what we did yesterday wrong?"* Good communication, especially at the peak of the crisis, seemed to have been difficult to achieve, in particular as it was something that could not be practised.

Many frontline interviewees remarked that they were heard by their management and that this had pleased them. For example, they reported that they could discuss clothing and where it should be washed: at home or at work. There was praise for management for watching over the condition of their staff and urging them to take time off. Some would have preferred to have seen the director or head nurse more often.

Residents spoke of news items which they got from staff and newsletters: *"The care home newsletter was positive. Though it mainly provided information on what was not allowed, I was glad to get some explanations."* A number of interviewees referred to the lack of an up-to-date website.

Adequate communication, but also sufficiently personal and down-to-earth communication, whether from the government or from the care home, seemed to have been the wish of many of the family members who testified. Among other things, they sought recognition of their fears, as well as reassurances, even though many understood that these were unpredictable times.

Several family interviewees felt very involved through good communication, though there were also other experiences. Those not receiving any reaction to questions or complaints were thoroughly displeased: *There was no point of contact. Nothing. At the start, I would always get an answer from the head nurse. But as time went by, I stopped getting any answers. That really annoyed me, especially I had asked some questions very politely."*

Interviewees found it particularly difficult when they received reactions which seemed like smokescreens:

> *"My mother spent 6 weeks confined to her room, without being tested. I was told that this was a government regulation, but I had the feeling that confinement was the easy solution."* (a child)

Various family interviewees reported noting a lack of compassion in the communications, even when the Covid wave was on the ebb. Many spoke of cold

reactions from staff, sometimes explaining this for themselves as being the result of high workloads, fatigue or fear. Some interviewees saw no other explanations than insensitivity.

One had this to say:

> *"I arrived too late for my scheduled visit due to a traffic jam. I couldn't help it, but the volunteer sent me away after just fifteen minutes. They were standing there with a stopwatch. I saw how weak my mother was. She was without energy and you could see in her eyes and face how upset she was. There was no time to stay. I was told to go. But I stayed put in my chair. My mother was taken away in her wheelchair like a prisoner while I fought like a lion to see her a little longer. Without success. I was really angry. I knew I was at fault. I had arrived too late. It was just a short visit to my mother, but there was so little understanding."* (a daughter)

Many relatives stated that they had not hesitated to call and email the home, asking questions and expressing concerns. They also remarked that they had often been very critical. One nurse confirmed that this happened frequently: "*Families tried to reach their relatives in the home. But when they were unsuccessful, they rang us up. We were getting so many calls that our care duties were impacted. We sometimes felt more like receptionists*." In the home where one of the interviewees worked, for this reason each ward was assigned a specific hour for calls. Elsewhere, the many calls soon proved to be a burden for all residents. According to the interviewees, the homes needed more staff for this, especially in times of crisis.

Many interviewees working closely with the residents, as well as management, stated that they had a lot of understanding for the criticism levied by the families, although they said that it was also sometimes harsh.

Families reported that there were moments when they felt like the enemies of the care home, despite everyone having the same goal: to provide the best possible care to the residents. Families missed true structural involvement, not just on paper but also in real life. *"I wanted to be involved so that I could better understand the way care was administered and be a partner of the home, for example interpreting what my mother wanted*." Or: *"We would like to be allies."* Some relatives had offered to work as volunteers but said that they had been turned down. Volunteers as well stated that there was more room for partnership between all sides.

The train speeds by

There is no button to press to get off it

Several of the aspects listed above relate to the following observation. A lockdown was announced for the RCHs, but no pause button was pressed. Residents, staff and volunteers were all shielded from threats from outside, but the threat came (and still comes) partly from within. All stakeholders have needs, even in times marked by an epidemic. While there is a need to protect health, there is also a need for respect and appreciation, for recognition and the successful exercise of care work. Staff have needs outside the RCH, with regard to their family and relatives who came under serious pressure. Residents need inter alia exercise, cognitive training, fresh air, good care, compassion and social and human contacts. Relatives need to give and share love and to keep in touch with their beloved ones, who they sometimes have to gently let go of – even without this pandemic.

A lockdown doesn't mean that there is no longer any room for these needs.

It is not yet over for us here.

> *""Everything is still too fresh, we just haven't had the time to reflect on what's happened. I have the feeling that we are still in the middle of it."* (director)

> *"As long as we can't go out for coffee and cakes, the crisis is not over."* (a daughter)

Many of the interviewees from among staff and residents stated that, with no end to the corona crisis in sight for them, the importance of recharging batteries was being evaluated in various areas, sometimes with a critical note.

> "*A poisonous blanket is hanging over the world. I ask myself, is that trip to the seaside really your biggest concern?* (resident)

Many staff members are fatigued. They've clocked up hours of overtime. Many have been ill and therefore suffer from residual fatigue. One staff interviewee said that she had applied for corona parental leave and was having difficulty getting it. Annual leave, scheduled in the summer months, had been provisionally approved. Various interviewees described that they had bags of overtime but that they would never be able to take the time off.

> *"Having to be available 24 hours a day numbs your mind and emotions. You don't sleep or don't sleep well, you get impatient due to fatigue. I've also lost 4 kg in weight, without having and great reserves to start with."* (member of staff)

Many interviewees from all groups still felt they were mentally in the first wave, or at least in the process of coming to terms with it. For many of them, it seems quite strange that everyone is already back to normal, out on the streets, sharing public transport, shaking everything off.

> *"The fear remains. When someone becomes ill, something that regularly happens in this population, you immediately think 'Oh no, not again'. This fear accompanies everyone all the time. It's a great burden. Everyone has been wounded. The wounds will heal, but the scars will be there forever."* (member of staff)

A turning point?

New ways of looking at things

The Covid wave in the first half of 2020 marks a turning point. Though the resident interviewees are well aware of their confrontation with death in their surroundings, they are now struggling. Recovering residents are trying to get back on their feet. Residents are coming together again, as far as possible in the communal rooms. Relatives also are responding positively to the proposed visiting times, perhaps cautiously embracing their parent(s), telling them what has happened in the meantime and proudly showing new (great) grandchildren. Care homes are remembering those who died and taking care of those recovering. Care staff are stocking up supplies, organising assessment and team meetings, licking their wounds.

Care staff interviewees felt that things which used to be quite normal, like eating together or group activities, are suddenly being questioned. An individual and collective grieving process is taking place, to a certain extent saying goodbye to

the world as it existed before.

People spoke of their need to find ways to put these bad times behind them and move on in life, remembering those who had to be left behind on the Covid battlefield and looking forward to what tomorrow has in store for them. They are searching for symbols and ways of doing things.

> *"We held a remembrance service for the residents we lost, giving both staff and residents the chance to say farewell and provide room for grief."* (director)

One staff member added: *"I noted that this was good for many residents because it allowed room for their grief."*

At the end of the day, everybody is looking forwards, in search of what tomorrow holds in store for them. A new way of life is emerging on the ruins left behind by this wave. And a new way of life requires a new way of looking at things, bolstered by the lessons to be drawn from what happened – for those prepared to listen. Various interviewees from all groups stated that they wanted to join hands to build this new way of life. Some of the aspects presented by the interviewees relate to this new way of looking at things, to their view of tomorrow.

Fragile hope in the face of fear

Among residents, staff and the other interviewees, hope was expressed. They hope that they will never come up against the virus again, a virus with which some of them had very close encounters. That is their greatest wish.

This hope is built on a degree of reassurance and expectation that things can be done better. Widespread testing and the availability of (better) protection equipment allow for hope that they will never again have to face the same problems.

We need hope in order to look to the future, but hope is also fragile. Several interviewees said that they were afraid of a second wave.

Some interviewees, to the extent possible or with an eye to the future, would rather be armed against the fear and protracted stress or unpredictability, for example through training. It is immediately noticeable from all the testimonials that Covid-19 often led to a feeling of powerlessness and inability to act, while training now often focused on decisiveness and action.

Armed against the virus

Looking forwards will also mean arming ourselves with knowledge and equipment against a new threat from outside. The interviewees from the care sector, whether staff or management, stated clearly that they now had a better understanding of the virus and what was required to keep it in check and fight it.

> *"We stand prepared, we have a plan. I have fears for those care homes which have not yet been through it. They'll have to be given all our procedures and can learn from the lessons we learned. Zorg & Gezondheid (*the Flemish Health and Care Agency*) can play an important role here."* (head of department)

Staff interviewees spoke of wanting to take the initiative locally, no longer wanting to have to kowtow to overall figures. At the same time, they hope for stronger governance and support from Zorg & Gezondheid.

Many added that equipment shortages were expected to be much less of a

problem, as the homes were now well stocked up. The fact that ample testing facilities are available also seems to have brought peace.

With regard to preparedness, relatives and volunteers also see the field of activities and recreation. The establishment of libraries, the creation of arts and crafts offerings or the development of platforms and digital communication channels offering a window on the outside world were mentioned by several interviewees as an additional element of preparedness, this time against loneliness.

The skin of a scar is stronger, but numb

> *"The situation is calmer now, but we have been left psychologically hurt."* (nurse)

Staff interviewees spoke of their traumata. Together with the residents, they spoke of their fears when looking at what was happening outside. For example, they spoke of their fear when they saw crowds on the street. Carers similarly spoke of their fear when using public transport, incurring additional risk. "*There are still small pockets of danger*."

Several interviewees spoke of how the camaraderie among frontline staff and in the digital world helped them pull through:

> *"There were days when we had 4 deaths among residents – people we had looked after for years. That's very difficult to come to terms with. Then it's good to have someone you can talk to." (*nurse)

These interviewees had different things to say about the support they received in this respect.

> *"We didn't get any coaching but were given an extra day of leave. That was quite disappointing"* (member of staff)

There were, however, many other interviewees who worked in places where management had noted a need for support, where peer-to-peer coaching, trauma counselling or other psychological assistance had been provided. Looking to the future, it might turn out that good support will be just as necessary for residents, and perhaps even for relatives.

Guidance and freedom

The measures taken in the care homes are being taken, as seen in the testimonials, with the goal of stemming the wave of infections. The search for the right balance was not always satisfactory. *"In my view, that's no life. I hope it never happens again.*" The search for the right balance between control – or guidance – and freedom, and sometimes also between safety and compassion, needs to be continued.

> *"I'm afraid that everything will start again. I find it difficult to go outside. There, we no longer have any control over how many people they see."* (carer)

One volunteer remarked how the search for safety had to be in balance with trust. *"A lot is possible in peak times with family volunteering, via for instance the Red Cross, but it requires trust to be placed in those people – trust that they will follow all precautions to avoid endangering residents and sometimes their own parents, siblings. Freedom and choices go hand in hand with responsibility.*

In these new times, the search is focused above all on guidance and freedom, on

safety and compassion. Both need to go hand in hand as far as possible and to the maximum extent. But this requires a new way of looking at things, taking full account of human dignity.

Recharging batteries

Many of the staff interviewees noticed widespread fatigue among staff, including themselves. They felt themselves strained and overburdened. There was talk of resignation, of being drained, of lacking creativity. Relatives as well noticed that at times that staff were performing their work more like robots. Many of the staff interviewees referred to the hours of overtime they had clocked up, and the lack of certainty about leave.

> "*If only I could take my overtime, do something relaxing. But I've not been given any leave in August. It's the same everywhere. I was taken on to compensate for my colleagues' overtime. We are now having to wait for the students in the summer.*" (member of staff)

Staff also reported that their directors, torn between their loyalty to their seniors and frontline staff, were drained and had less or no room to rest.

These weary troops need to recharge their batteries in order to be ready to provide the best care, a fact very obvious for many interviewees. Residents as well noticed the weariness.

Appreciation in all directions

> *"What we need now is hope, comfort, confirmation and appreciation."* (director)

Symbolically, many interviewees saw something in the daily applause which stood for appreciation and support. They really appreciated the donations from the outside world, such as meals and treats (cakes, muffins, sweets). But at the same time, it was noted that the applause was never more than a gesture. They missed any true appreciation in the form of more support (i.e. more staff), visible appreciation for what they had accomplished in the last few weeks and for the burdens they had had to put up with. Some of them had the feeling that others were trying to make them feel guilty for everything that had gone wrong in the homes and missed any attempt to banish such feelings.

The majority of staff were interviewed in late June, shortly after it was announced that, in contrast to hospital staff, they would not be benefiting from the €300 bonus for health workers. This was hard to accept: *"That feels really cruel."* Or also: "*All we want is recognition.*" Others would prefer structural improvements rather than a one-off bonus.

But appreciation was also sought by other groups of interviewees. Relatives who had shown great concern in this period for the circumstances in which their loved ones lived in the care homes also sought recognition and appreciation of their role. Several of them said that they explicitly wanted to help find ways to continue working with staff towards providing the best possible care for their loved ones. In some places, this was already happening. Relatives praised the way in which they were now being involved in discussing new visiting arrangements or preparing for a possible second wave.

For many, appreciation of their own role also consisted of participation and involvement. Families wanted to have a say, but there were also relatives who called for residents in particular to also have a say:

"In my mind, it would be good to hear residents who are able to / want to do so, and also families, on what needs to change." (a daughter)

Reform of elderly care

There is a lot of talk about reforming elderly care, for example in the 2019 annual report of the Flemish Ombudsman Agency as a result of a situation in 2019 regarding an attack on the interests of senior citizens. Even more fundamental than, for example, discussions about setting up a care reporting centre, Article 61 of the Residential Care Decree of 15 February 2019 already creates the (as yet) under-exploited possibility of reforming residential care.

Many of the interviewees from all groups were looking beyond a possible second wave, agreeing in essence that elderly care was in need of new forms and systems. On the basis of their experiences over the last few months, relatives often concluded that they themselves never wanted to have to make use of this form of elderly care.

"Let us humbly bow our heads in Flanders, asking questions as a society and seeking answers for better elderly care." (a son)

"We need to ask ourselves: what sort of care do we want when we get older? Could it not be provided otherwise" (family member)

"We all want to grow old, but we don't want to be patronised. We want to keep our dignity". (family member)

Staff and management also want to look at how they can do things differently, and above all better. One director saw room for improvements: *"Plus est en nous, plus est en eux, plus est en vous."* (director)

Time and professionalism proved to be key wishes:

"I would love to have enough time again for the people I work with. Time for a chat. The more time you have to sit down with people, the faster you notice if something is not right." (carer)

At the same time, many interviewees, looking back on this Covid wave, stated that, to be truly prepared for such a virus and at the same time to be able to provide high-quality elderly care, required work to be done very differently, for example on a much smaller scale.

Listen, listen, listen

In this report, we listened to people speaking out from the silence. Although many of these voices emerged from the silence, they remain silent voices, for example for health reasons or because of fear of negative consequences. The report reflects the experiences of ordinary people in unusual circumstances. The interviewees are obviously not the only voices in the silence. There are many voices which, as things stand, will never be heard, even though they also have a story to tell.

In this context, let us reflect on the following story. During a visit to an RCH in Limburg, the Flemish Ombudsman Agency met eight residents in the dining room. They all looked healthy and quite happy, chatting at their table. It was just not the place or time to suddenly broaden a conversation with one resident, putting questions to many more residents. Respect for the limits of our mandate called on us not to do this.

But an investigation conducted on a broader footing would also bring to light those voices that are even quieter than the ones heard today.

Listening constantly and effectively to the voices from the silence requires a local ear able to listen freely, for example outside of a care inspection assignment, however necessary, useful and valuable such an assignment undoubtedly is. And those who listen well and speak carefully can focus on better connecting people together, giving more scope to humanitarianism and human dignity.

As a compendium of testimonials, this report underlines the recommendation and offer of the Flemish Ombudsman Agency of 29 April 2020 in the Corona supplement of its 2019 Annual Report (cf. *Parl. St.* Vla.Parl. 2019-2020, nr. 41/1-A).

Some of the recorded voices from the silence would undoubtedly have been heard under the upcoming supervision mechanism provided for under the Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), published in New York on 18 December 2002. These voices are also set to help build a better tomorrow.

Our silent voice has been heard.

Finally, but perhaps most of all, the silent voices that were heard today were struck by the fact that they felt heard. Several interviewees expressed their sincere thanks for being able to share their experiences: *"Thank you very much for listening to me. I now have the feeling that the administration wants to hear us" (a daughter)*

The whole Flemish Ombudsman Agency team and in particular the interviewers Peter, Karin, Els, Nina, Chris, Viktor, Nele and Annelies, all specifically involved in this project, would like to thank all interviewees for sharing their stories.