

Home Marjorie, a care home for people with Huntington's Disease and other non-congenital brain disorders, Heist op den Berg, Belgium

Our Corona Story

This story is not meant to oppose Corona measures, but an attempt to clarify the effects of these measures on the lives of our residents.

In the middle of March, the spreading of the Corona virus in Belgium, created the necessity for the government to take precautions to protect the residents of care homes. Home Marjorie is normally an open house without visiting hours. Residents who are still able to take part in society are stimulated to do so. We provide them with the care and guidance they need but try to leave them in control of their lives as much as possible.

Corona changed the way we work enormously. This of course to protect the health of our residents and employees, but not without a myriad of effects on the overall well-being of residents.

In Home Marjorie we always try to balance individual interest with the interest of the group. For the first time this balance shifted sincerely in the interest of group safety.

Visitors

For two full months no visitors were allowed, except in extraordinary circumstances like a person being terminally ill.

This happened overnight without residents and families being prepared for this. We tried to alleviate the pain of the separation with video calls, postcards, e-mails,... But of course this doesn't replace live contact. Cognitively impaired clients had a hard time adjusting to things like Skype. In normal circumstances the visitor would often revert to physical contact to soothe their family member, but of course this was now impossible. Clients with problems communicating, had an even harder time than usual expressing themselves and being understood.

It was also hard for family members not to be able to see their loved one. They would have to rely blindly on us to take care of them and give them the attention they need.

In some cases the time spent without visits from family was exceptionally painful. Some examples. One family member of a resident who had recently lost his mother, was now banned from coming into Home Marjorie, the place his father lived. Another man, the husband of a resident, could not visit his wife, who then died unexpectedly. The last two months of her life, were spent without her beloved husband and children. A young man, son of a resident, celebrated his 18th birthday without seeing his sick father. A resident could not celebrate her 60th birthday with her family.

Since the 11th of May, visits are allowed but touching is still not recommended. Only two visitors can come at a time and they can only stay an hour. Mouth masks, social distancing and hand hygiene remain important during these visits. The visits bring more light in again, but the having to be careful

with physical contact is still hard. It feels weird that we can touch the residents to help them, but their family is encouraged to keep their distance. With cognitively or communicatively impaired people, it is hard making contact with them if you don't touch them. The mouth masks are also very limiting to non-verbal communications. Since the start of visits, we have been able to loosen measures, so that visitors can now go for walks with their family member and enjoy a less sterile contact.

There are however still limitations. A woman wants to see her husband and daughters together, but this is not yet allowed because only two visitors are allowed at the same time. A real birthday celebration isn't possible yet. But still we see how much every visit means to the resident and the visitor and how much of an improvement in life quality these visits are.

Limitations in accessibility of medical care

During lockdown people had to postpone non-urgent medical care. This could lead to an exacerbation of smaller problems. If they did get admitted to a hospital, they couldn't receive any visitors, which is hard on anyone but still harder on people who suffer cognitive decline and have a hard time understanding what is going on.

Day-care, part-time care, respite care, home care

People who normally went home every weekend or on a regular basis, could no longer do so. They had to choose between staying full-time in Home Marjorie and not seeing their family or staying with their family full-time and receiving (almost) no professional care until the crisis situation would change. And no one could tell them when this would be.

As of June, we have started letting people go back home and coming back in. This means that people have had to stay home or here full-time for 3 months. People coming back in after being home a long time will have to undergo COVID-testing and quarantine until the result is in. If the result is positive quarantine will last longer.

The people who came in for day-care a couple of days a week, were not allowed to do that anymore. Their families had to organise it so they could give full-time care at home. Our day-care clients missed coming in and having social interactions with peers. They felt isolated in lockdown with their family. Because we don't have a separate group for day-care clients, day-care is still not possible in Home Marjorie. The risks of a day-care client bringing a Corona infection in a residential group is still considered too high. This is taking a serious toll on families who relied on day-care to alleviate the burden of care.

Respite care is also only starting back up in July. In the lockdown months we had to cancel all short stays in Home Marjorie. These short stays are beneficial to both clients and their families. Family could take a rest and the client enjoyed the contacts and activities in Home Marjorie.

To see this in the right perspective, it is important to realize that a lot of people with Huntington's Disease in Flanders are on a waiting list for a budget from the government to be able to receive adequate (non-medical) care. Without these budgets one can only have a limited amount of days for day-care, respite care or home care.

One elderly gentleman with severe medical issues, taking care of his elderly wife with advanced Huntington's Disease, used his wife's limited days for respite care to keep his head above water. The lockdown has been especially hard on the couple, because also other services were not allowed to provide home care during this period. They were left to their own devices completely. Another man with Huntington's Disease and a mild mental disability lives alone. He wants to live in Home Marjorie full-time but doesn't have the budget for it. So, he lives for his little vacations in Home Marjorie where he doesn't have to be alone or fend for himself all the time.

We had some people in homecare as well which we could not tend to. These people are very pleased we have started coming to their homes again to help them organise their lives. During the period in which we weren't allowed to see them, we did keep in contact by other means to support them.

The limiting of a possible spread of COVID-19

When a resident had possible COVID-19 symptoms, he had to be quarantined in his room. In the beginning we had no tests so this confinement could take several days. Some residents with cognitive problems did not understand what was going on.

Most people with Huntington's Disease live a very structured life. They can get very anxious when restricted from carrying on with their routine. In Belgium an important part of dealing with Corona, is the strategy of working with "social bubbles". People should limit their contacts to certain groups of people. When a person is infected, the possible spread is then limited to this "bubble" and can be contained.

Because of COVID-19 and "working with bubbles" a lot of routines in Home Marjorie were disrupted. Some people had to switch therapists because their therapist could not come in their group anymore, because the therapist was assigned to a different bubble. The therapies were not in the therapy rooms but outside or in the patient's own room. The different groups in the house could not do activities together anymore. These may seem like small things, but for people with Huntington's Disease small changes can cause agitation and fear.

For some residents, we could also see some positive effects of the lockdown. Certain activities which they would do because they felt compelled to, but cost a lot of effort, were not allowed anymore. For example, someone who goes to town every day because he feels he should, even though he is too sick to do it, can be relieved to have a reason outside of himself not to do it anymore.

Restrictions in Activities and personal freedom

All of us were restricted in our activities during the lockdown, but people living in care facilities had even less freedom. Belgian people were allowed to go to essential shops and walk around for recreation. Residents of care homes were not allowed outside the property of the facility.

Therapists and care workers were very creative in finding new activities for residents, but residents who normally still had an active life in the community felt very limited in their freedom.

Some residents had trouble understanding why their rights were more limited than those of other civilians. One resident even went on hunger strike to protest the restriction of freedom.

Another difference with healthy individuals is the following. We all had things we looked forward that were cancelled due to COVID-19, but with some luck we will get new chances to take that trip,

go to that party, meet that friend ... But if you have a neurodegenerative disease, you may not be well enough to do the things next year that were cancelled this year.

For example, one resident was marrying one of our home-care clients this summer. They were planning a celebration with a large group of loved ones. No one can be sure that they will both be well enough to have this celebration next year.

Residents and personnel are happy that slowly life is becoming more normal again, but the pace is slower on the inside of a care facility than on the outside, while time on the inside is more precious and what is lost may truly be lost forever.

Afterword

By taking all of these precautions and probably with a good dose of luck, we have managed to avoid an outbreak of COVID-19 inside Home Marjorie. We hope to keep it this way. An outbreak would mean, apart from possible loss of life, a return to stricter measures and limitations of personal freedom, together with a higher focus on medical issues and the interests of the group.

Still we believe that the solidarity we have experienced inside of Home Marjorie and the support we have received from outside supporters, will have a positive influence on our future endeavours as a facility of care.

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