Karen Mogendorff

“There are many horrible diseases and conditions out there that do not get as much attention as Corona does now, not even close.”

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I am a Dutch social anthropologist, communication scientist and discursive psychologist living in Arnhem, the Netherlands. I specialize in projects with and for disabled people and in science communication. I have a special interest in reflexive ethnography and the uses of experience-based knowledge alongside scientific and practical knowledge. When relevant I use my own lived experience with lifelong physical impairments due to a congenital condition.

Currently, I am employed by an Academic Medical Centre in the Netherlands and by a Dutch patient organization. For both of my employers I focus on participation of ageing disabled people in clients in respectively medical research and e-learning. Additionally, I am an editor of a UK-based lifestyle magazine for and by disabled people named Disability Horizons.

27 February 2020

First confirmed case of Corona in the Netherlands; patient zero. A man in his fifties living in the province of Brabant. The sentiment is that Corona can still be contained in the Netherlands. Hygienic measures are advised, such as sneezing in one’s elbow and washing one’s hands regularly for 20 seconds.

In the week that follows more and more Corona patients are identified daily. Spring

break and Carnival get ´blamed´ for the Corona outbreak, partly because Corona cases are concentrated in the province of Brabant.

I have to admit, I am not sure why the Coronavirus garners so much attention from the media and government nationally and internationally. In press conferences and in the media generally it is stressed that most people will get the Coronavirus eventually, and that most of us will experience mild symptoms. It is also stressed that the elderly and already ill are particularly at risk (as it is with most diseases). The news is dominated by Corona. I have never witnessed something like this before.

I think it stands to reason to take precautions to minimize the chance of infection, particularly because you do not know whether you will get the mild or aggressive, possibly deadly form of Corona. But I am puzzled and also a bit irritated, if I am honest.

There are many horrible diseases and conditions out there that do not get as much attention as Corona does now, not even close. Think of AIDS, various forms of cancer, ALS and many more. Suddenly, illness – or at least one illness – is treated as a societal problem.

The argument I hear these days a lot is that the flu has killed more people each year than the Coronavirus. Which is true enough, I looked it up on www.worldometers.info.

9 March 2020

Handshake incident of the prime Minister Mark Rutte at a Corona press conference. Corona measures are expanded to include a ban on shaking hands. Rutte demonstrates that social habits are deeply ingrained by shaking hands with the chief Corona advisor of the RIVM at the press conference. The incident is picked up by the

media worldwide. We are also not supposed to hug and kiss people in greeting (which is customary in Brabant, in the South of the Netherlands).
The link with a video of the handshake incident:
https://www.euronews.com/2020/03/10/watch-dutch-pm-rutte-bans-handshaking-and-then-shakes-hands

Thursday 12 March 2020

In the afternoon I start to feel like crap. I wonder whether I am coming down with the flu or worse. I do not have a fever but I have a headache, feel tired and I am cold. I put extra clothes on but I do not seem to be able to get warm. I have a meeting in Houten Friday morning and decide to stay at home. I propose to meet online instead of meeting face-to-face. The two men I have an appointment with agree to a WhatsApp meeting.

Thursday evening 12 March

I feel a bit better. At the Corona press conference Thursday evening people in non-essential professions are strongly advised to work at home as much as possible. The importance of social distancing is stressed in order to minimize the spread of the Coronavirus. We are supposed to keep a distance of 1,5 metres to other people in order to ´flatten the curve´. It is now expected that the majority will eventually get ill, but that it is of paramount importance that we do not get ill simultaneously, otherwise our health system may implode. And not everyone will get the care that they need and deserve. I wonder about the last thing; it suggests that before COVID-19 pandemic everyone did get the care and treatment they deserved. And that is simply not true. For instance, part of the reason I do work at Erasmus Medical Centre is that the care for citizens with learning disabilities is lagging behind. They

do not always get the care they deserve.

Naturally, I do not want the health system to implode or to get ill – if it is avoidable, but they should be more honest about how the care system works and the inequalities in medicine and care, regardless whether there is a pandemic going on or not.
Many disabled citizens are concerned that they do not get the care they deserve if they end up at the IC – because of flawed assumptions about disability and health.

Events that involve more than 100 people are banned.

Friday 13 March 2020

First day that I do work at home due to Corona and have a WhatsApp meeting instead of a face-to-face meeting. Both of my employers decide today that everyone needs to work from home as much as possible. I hope I can do my job, because I am supposed to meet and talk to people a lot for my work.

In the evening a friend visits. Beforehand she asked whether I wanted to go through with our appointment, she had a bit of a cold. I say it is ok with me, we simply don't kiss and hug and keep some distance between us. I am not sure I can tell all my friends that I am doing this, opinions differ on what contact is still considered responsible and what contact is not.

We – the friend and I – planned to go out and eat at a restaurant but instead decided to eat at my place given all what is going on about Corona. The plan is to order some food but we decide to go get the food. As it turns out, the take away we selected has closed and we end up at the neighbouring snack bar. I feel a bit uncomfortable by this, although changes that someone at the snack bar has Corona are slim. It is fairly crowded and I do not like snack bars much to begin with. After we take the food, we

go back to my place.

Saturday 14 March 2020

I do go to the Basic-fit for my three-weekly workout. I have been exercising in a fitness club for at least once a week for over 20 years to avoid ´leg trouble´. As a teenager I had surgery that had adverse effects: surgery gave me a strongly atrophied right leg. Experience has taught me that if I do not exercise for several months, I will face overextension problems.
At the club they implemented social distancing by shutting down fitness equipment at regular intervals. It works fairly well except in the narrow corridor with the lockers, someone bumped into my backpack.

The latter I do find annoying, people that accidently bump into me trigger a strong startle response in me that often causes me to lose my balance. Not this particular instance, however.

I hope the social distancing rule of keeping apart 1,5 metres in public spaces will take hold and survive the Corona crisis. It would mean that I would fall down considerably less often.

Sunday 15 March 2020

I do get an odd email from my fitness club. They close until the 6th of April because they are a social club. Fitness I do not consider a social activity. It is something I do solely for the purpose of staying healthy and avoid overextension problems. The good thing about fitness is that you can easily adapt training programs to your own individual needs and limitations.

I have not watched the news all day, when I was on the News in the evening things became a bit clearer. All restaurants, bars, coffee shops and sport clubs are to close until the 6th of April. Shops are allowed to stay open.

Monday 16 March 2020

Today I was to chair a brainstorm session on client participation in Rotterdam. The session is cancelled. I hope I will be able to have the session because the GOUD consortium needs to do more with client participation but my impression is that many do not exactly know what it is to begin with.
This week many appointments are cancelled. My reservations with the Stayokay are cancelled. That is a first for me, an accommodation that calls you to cancel your reservations because they close until the 9th of April. No idea why until that date and not 6 April, but in the end it little matters. I hope I will get my money back in a timely fashion.

My employer at the Academic Medical Centre has decided that we must work at home. Social distancing – keep a distance to others of 1,5 metres is advised, not all employers though follow this route.

It is also the first day the schools are closed, at least until the 6th of April. Only parents who work in the so-called essential professions are allowed to bring their children to school and day care. For this reason, the schools were not closed immediately.

Wednesday 18 March 2020

My first day off (I work part time), I worry about the fact that I probably will not be able to train for a long time. And that is likely to negatively affect my functional walking ability. I have an Achilles tendon that works for less than 30%. If I do not

train at least once a week, I will develop after several months an overextended Achilles tendon. And that, in turn, will negatively impact on my walking ability.

I do surf the Internet to hire fitness equipment, but more people had the same idea. A complication is also that I cannot hire just any equipment, certain requirements need to be met to enable me to use it with my impairments.

Given that renting is not an option, I consider buying a cross trainer that allows me to keep my balance. The one I use at the Gym costs circa 8000 euro. That, I cannot afford, but I find something for several hundred euros that might be compatible with my impairments. I am not sure because it is not a type of cross trainer I have used before.

I ordered this two-in-one cross trainer, unfortunately it will only be delivered at the end of April. That is if I am lucky, deliveries tend to be delayed nowadays because online shopping has become most popular in times of Corona.

I also order weights for my ankles and wrists. I hope they help me to maintain muscle strength. These weights can be delivered in several days.

Thursday 19 March 2020

A long-time friend – this year we have known each other 25 years – visits to have breakfast together. We always meet in between our birthdays hers was 22th of February, mine will be 31th of March. We had a good time together although we had to change our plans a bit because of the Coronavirus, all restaurants and canteens are now closed after all. We also do not kiss and hug.

Saturday 21 March 2020

"There are many horrible diseases and conditions out there that do not get as much attention as Corona does now, not even close."
https://boasblogs.org/de/curarecoronadiaries/there-are-many-horrible-diseases-and-conditions-out-there/

My groceries are delivered by AH at my doorstep. They do not assist you anymore by carrying the groceries inside the kitchen due to the Coronavirus. It is for the protection of the AH employees and my own protection, they say. I do not mind much; I find it much more worrisome that online grocery shopping has become difficult. I order online groceries once in 2,5-3 weeks so I do not have to carry the groceries myself. Carrying groceries is more difficult for me given my balance disorder. Today was my 50th delivery.
Now, in times of Corona, people are stockpiling groceries and online shopping has become extremely popular. I cannot reserve a timeslot for my next delivery because everything is fully booked two or three weeks in advance.

The irony is that I probably will have to visit a supermarket more often due to Corona than before, although the government advises us to stay at home as much as possible and do only the necessary shopping.

For some reason, toilet paper is very popular. Stockpiling toilet paper is not a typical Dutch phenomenon.

The weather has been good, sunny. People go to the beaches in large numbers violating the advice to keep 1,5 metres distance between people. There is upset about this in the media, many people complain about it.

Sunday 22 March 2020

We all get a NL alert that admonishes us to practice social distancing and keep 1,5 metres in between people. It is expected that rules will get stricter.

I am not sure why staying at home for, so far, only a week, is apparently so difficult for many people. Probably that is because I am – as someone with a chronic condition – much more used to being confined to the house. A week is not difficult,

months on end might become problematic.

Personal lock-down in 1994

These days, I have to think back a lot about my personal ´lock-down´ in 1994. In January 1994 I had surgery that I was told was standard procedure. The surgery did not have the anticipated effects. It actually made my ankle more unstable, involved massive loss of muscle strength in my right leg and made me dependent on orthopaedic shoes. It did cost me my running ability. This surgery of, now, over 25 years ago is the reason I have to work-out at least once a week to avoid overextension problems.

I was confined to the house for months while I was recovering from surgery and tried to relearn walking again. For three months I did not leave the house at all and for almost six months I did not attend school. Luckily, I was allowed to do my school work at home, so I was not delayed in my studies.

All in all, the rehabilitation period in 1994 was a horrible time, I was afraid that I would not regain my walking ability especially because rehabilitation did not work out as hoped or expected. This time was depressing for other reasons as well, I will not discuss here in depth. I lost my appetite and did lose a lot of weight. My weight loss at some point became quite apparent and a health risk in itself. It still disturbs me that the rehabilitation specialist I was seeing at the time never said or did anything about it. He showed little interest in how I was doing. Basically, the only question he did ask every visit was: How are you doing at school?

One thing I learned from this period in 1994, is that it is not only important to cover the so-called essential things such as care and education, but that it is equally important to guarantee social contact. I practically had no contact with my classmates and teachers during my rehabilitation period in 1994. Back then, you did not have the Internet, WhatsApp, Skype, etc to stay in touch. Luckily, that is easier

nowadays, but still it is a concern. It is important to maintain or retain some normalcy in social relationships, I think.

Monday 23 March 2020

In the evening at the press conference extra Corona measures are announced. Individual people who do not respect the 1,5 meters distance rule in groups of three or more risk a fine of up to 400 euros for each offender, organizations or companies that violate the rule can get a fine of 4000 euros. Organizing events is forbidden until the 1 June 2020.
It is stressed that people should stay at home as much as possible and only get out for essential shopping.

I hope there will not come a total lockdown. Aside from the personal impact on people's lives there is now also some attention paid to the probable negative economic consequences of the Corona pandemic and the measures associated with it. I wonder whether in the end people in general will be harder hit by the economic crisis than Corona.

26 March 2020

Workwise, I think a lot about how to conduct real-time focus groups online now that face-to-face focus groups are out of the question. I am still recruiting experiential experts, luckily, so far, they are not deterred from participating. Still that leaves the question how to do things in a responsible manner. I am not sure what software I could best use, aside from actually conducting a real-life focus group.

Recently, I started using Zoom for work meetings but I am not really a fan of it.

As it turns out, my Internet connection is a bit unstable at times. Have to think about how to best solve this.

29 March 2020

I am finally assigned a new program manager. The last one is on sick leave since 13th of March due to a burnout. It is a beautiful day and I am thinking about what I can do for others during the Corona crisis. At work, the patient organization I work for, I proposed to start a dossier on Corona and cerebral palsy. In some ways, Corona impacts disabled people more than their non-disabled counterparts. In mainstream media hardly any attention is paid to this.

I will have to wait and see what the response will be.

30 March 2020

Another day at the office at home, or so it seems at first.
There is some discussion on triage and intensive care measures. For the first time, I read the proposed protocol. I am quite shocked by it; I have to digest this first. Something that greatly disturbs me is that people who cannot wash themselves will be refused at the IC unit, if code red will turn to code black. The latter means that the demand for IC beds will be greater than the beds that can be supplied.

Baked a cheesecake for tomorrow, 31 March is my birthday.

31 March 2020

Karen Mogendorff

Today I have a video call with my twin sister at 8.00 am to celebrate our 43th birthday. My twin sister Veronique is 7 minutes younger than me. My nephews aged between 7 and 12, sing for us. Last week I did send my twin sister my present for her and vice versa. We open our presents and talk a bit. Veronique has to leave at 8.30 am.

It sucks that I cannot hug my twin sister. My birthday is for me really ´Twins day´: the day we celebrate we came into this world together – which was a small miracle. We spend the first 8 weeks of our lives in hospital partly on the IC. Back then, the doctors were very pessimistic about our chances of survival: 15% chance we would make it, they estimated. 43 years later we are still alive and thrive.

I do not envy the premature babies that will be born during the Corona crisis. They might not be admitted to the IC if demand of IC beds exceeds their availability. The first patients who will be denied access, according to the IC protocol, are those who have a life expectancy of less than a year or patients who score high on the frailty index such as elderly patients, premature babies and people with disabilities.

After the video call with Veronique, I get ready for work and post a photograph of a slice of the cheesecake I baked yesterday on the work WhatsApp group. In response, I do get many birthday wishes. I decided to avoid Corona news for today and to focus on happier things; it is my birthday after all. Family members and friends call and app. Even my brother calls me. Normally, he only sends a message but does not actually call to congratulate me.

The Coronavirus measures mean that I have less contact with some people and more contact with others. I call my mother more frequently now – she just turned 70 last month. She is fine but she has a smoker's cough. Everyone is advised to stay at home as much as possible, but particularly people who are in an at-risk group or have symptoms of a flu or cold are expected to stay inside to minimize the chance of infection.

Coughing and sneezing have lost their innocence. This poses a problem for people who chronically cough or sneeze for a variety of reasons – such as being a long-term smoker or because of a pollen allergy.

Around dinner time I see that a time-slot for online grocery shopping has opened up (it was fully booked). I immediately reserve this time slot, if I wait until after dinner all time slots will again be sold out. It is a bit weird, but online grocery shopping has become something like ordering a coveted ticket for a concert.

Some plants I bought last week are delivered today, they should have been delivered last Friday. Luckily, the plants seem to be fine.

1 April 2020

It is my day off, but I do some work anyway. I have to rethink how to conduct focus groups. Obviously, I cannot do them face-to-face anymore. I have to do them online. Should I use Skype, Zoom or Google Teams? I have posted a question on Research Gate and I get a lot of responses.

It is not as simple a question as it seems. The devil is in the details. For one, whether you can record a meeting for instance depends on what version you use on what device. Eventually, after some testing, I conclude that Skye and Zoom do not work for my purposes.

I also work for a bit in the garden and get some belated birthday wishes. Late in the afternoon I have a Disability Horizons Zoom meeting. Since the Corona outbreak we meet biweekly. That is more often than before the Corona pandemic. In the UK disabled people self-isolate even more than disabled people in the Netherlands. The UK approach to Corona is a bit different, disabled citizen who are considered at high risk are supposed to self-isolate for at least 12 weeks.

Mail packages usually are delivered at my home at the end of the afternoon. Today the ´keep 1,5 meters distance´ buttons arrive. Two out of twenty are damaged. I plan to send the buttons together with some Easter wishes to family and friends.

Thursday 2 April 2020

I find out that the patient organization I work part time for uses Google Teams. I have not worked with Google Teams before and follow some YouTube tutorials and manage to get some other work done. The last several weeks meetings have frequently been cancelled or rescheduled.

I wonder whether I should respond to a rather disturbing column in the newspaper which comes across as ableist in relation to triage if hospitals are overwhelmed by COVID-19 patients.

Friday 3 April 2020

I am asked to do a workshop in October about ageing with a disability. I do find that quite uplifting. I do not know where we will be in October, but I find it positive that people try to look beyond the Corona crisis.

Corona measures are at least extended until end of April. According to the weather forecast we will have excellent Spring weather. In the media we are asked to stay at home as much as possible.

Saturday 4 April 2020

Karen Mogendorff

For the first time in 11 days I venture out to buy something and to go shopping. It feels weird.

Preview-Picture by Katharina Sabernig. She creates, knits and photographs medicinal objects to make medical content accessible to the senses (https://www.knitted-anatomy.at/).