Carescapes unsettled
COVID-19 and the reworking of ‘stable illnesses’ in welfare state Denmark
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On 11 March 2020, Denmark’s Prime Minister Mette Frederiksen addressed the nation through a televised press conference. Flanked by Health Minister Magnus Heunicke and infectious disease experts, she announced that Denmark would be going into lockdown. Images of overflowing hospital wards and overworked healthcare workers in Italy, and an expected spike in COVID-19 cases as people returned from skiing holidays in the Alps, prompted Frederiksen to be one of the first heads of state in Europe to send everyone home from work and school and to close national borders. Armed with a cardboard prop, Heunicke animated why ‘flattening the curve’ was necessary by contrasting the (by now) internationally recognisable red peak that inevitably bursts through a black dotted line representing national hospital capacity with the smoother green hill that remained within capacity (see Figure 17.1). For Denmark to remain green, strict stay-at-home measures, physical distancing, sneezing and coughing into elbows, and scrupulous hand hygiene were essential. Drawing on what was becoming clear from outbreaks in China, Italy and Spain, the prime minister emphasised that people living with a range of chronic conditions and older people were especially ‘at risk’ of hospitalisation and death from COVID-19. These groups were advised to self-isolate, while others would be allowed to leave their homes for shopping, pharmacy visits and outdoor leisure, albeit while adhering to strict physical distancing and hygiene requirements.
In the meantime, behind the scenes, the National Health Board was instructed to urgently devise a plan to ensure that Danish hospitals were ready for an influx of COVID-19 patients who might require intensive oxygen therapy and in some cases respiratory care. While time was of the essence, it was imperative to raise the dotted black line on the Health Minister’s ‘flatten the curve’ chart as high as possible in order to avoid overwhelming the healthcare system. The Prime Minister insisted that this was one of the most important objectives of Denmark’s national lockdown:

We need to prevent the collapse of our healthcare system. Should that happen, it would have consequences for everyone’s lives. … We are demonstrating our samfundssind [Danish; ‘social solidarity mentality’]. And we stand together in looking after those who are most vulnerable. Yes, in fact, we are standing together in caring for our society. … Right now we are seeing the value of the strong social contract that we Danes have with each other (Statsministeriet 2020a).¹

Two days later, on 13 March 2020, the National Board of Health drew up a ‘Memo on reduction of hospital activity in connection with COVID-19’ (Board of Health 2020), and sent it to all hospitals in the country.

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¹ Statsministeriet 2020a
Alongside plans for how to increase numbers of beds in intensive care units, hospitals were instructed to free up staff to look after an expected influx of hospitalised COVID-19 patients: ‘The Board of Health deems that this can be achieved by reducing outpatient activities in a number of clinical specialities [since] all forms of outpatient check-ups for patients with a stable illness can be postponed or redirected’ (Board of Health 2020, our emphasis). Likewise, diagnostic and treatment ‘guarantees’, which had been enshrined in law in 2002 to ensure that serious diseases were detected earlier and treatments commenced as quickly as possible, were suspended in order to reroute resources (see Manderson and Wahlberg 2020). In these ways, Denmark’s healthcare agenda was transformed overnight from a decades-long focus on chronic conditions to a focus on a singular infectious disease. While this exceptional focus on COVID-19 subsided during the summer with fewer confirmed cases, with winter approaching, by late 2020, doctors were warning that a ‘second wave’ influx of patients was leading to cancelled elective operations and fewer outpatient visits (Møller and Goos 2020).

In this chapter, we explore the ways in which COVID-19 unsettled not only Denmark’s universal, tax-funded healthcare system, but also the lives of those living with chronic medical conditions. Although fears of an overwhelmed hospital system never came close to materialising in spring 2020, and we have yet to see the full effects of Denmark’s ‘second wave’, the knock-on consequences of shifting resources and political attention to a single infectious disease has already and will continue to impact on the lives of those with chronic conditions, not least since, as the prime minister commented, Danes will have to ‘learn to live with the virus’ (Frederiksen 2020).

Chronic conditions emerged as the premiere focus of Danish healthcare policy from the early 2000s. We describe how a series of ‘carescapes’ (policies, services and programmes determined by nation-state, local government and employers, aimed at providing care for ‘deserving citizens’) coalesced and stabilised around some of the most prevalent chronic conditions within Denmark’s welfare state, in conjunction and at times in tension with various ‘caringscapes’ (forms of informal care carried out by family members and loved ones) (Bowlby and McKie 2019). Henriette Langstrup (2013, 1010) has argued that it is exactly through and around both formalised and informal forms of care that ‘chronic care infrastructures’ arise, encompassing the medications, knowledge and equipment that allow for the work required to manage disease over time and distribute it between various actors and locations. Within such infrastructures of chronic care, the emphasis has been on
encouraging and teaching patients to ‘live with’ their (multiple) medical condition(s) in order to ensure that they remain as independent as possible and able to lead ‘normal’ lives. Danish healthcare and interrelated eldercare has come to promote self-care and rehabilitation together with enabling treatment and support interventions under slogans like ‘help for self-help’ and ‘as long as possible in one’s own home’ (Kjellberg et al. 2011; Christensen 2020). At the same time, however, a string of reports from healthcare authorities in the past decade (most recently in September 2020) have drawn attention to glaring health inequalities in a welfare state that claims to provide universal healthcare for all: People with limited education experience more illness, suffer greater consequences from their illnesses, and die earlier than people with a higher education (Board of Health 2020). Reflecting this, in Denmark’s fourth largest city, Aalborg, people living in well-off neighbourhoods in the western part of the city live a staggering 13 years longer on average than those living just a few kilometres to the east (Board of Health 2020). Despite declared goals of universal access to and equal provision of high quality care to all citizens, socioeconomic inequalities continue to shape both ‘carescapes’ and ‘caringscapes’ in Denmark in ways that render chronic care infrastructures more or less accessible and relevant for those living with long-term conditions.

Only a few weeks into the national lockdown, general practitioners, cardiologists and oncologists began warning that the ‘massive corona-focus can cost lives’ (Nielsen 2020), as clinicians experienced a worrying fall in numbers of appointments and referrals. These numbers might well reflect the result of government officials’ appeal to Danes’ samfundssind, which for some meant ‘holding off’ on using the healthcare system for routine purposes (GP visits, dental care and outpatient check-ups), albeit others were wary of infection risks in hospital and clinic settings. Whatever the cause, healthcare providers felt a need to use national media outlets to appeal to the general public to not refrain from seeing a doctor if experiencing symptoms that could indicate any serious condition, not least since early detection was essential for the best possible outcomes.

But what of those already living with and managing a known chronic condition? In this chapter, we build on our long-term fieldwork engagements in Denmark, well before the COVID-19 pandemic, with families living with congenital heart defects, persons living with type 1 diabetes and ‘frail’ seniors. We explore the kinds of disruptions and concerns experienced by people living with medical conditions other than COVID-19 during Denmark’s national lockdown, calls to self-isolate and shifts of healthcare resources away from ‘stable illnesses’. In addition, we
explore how these families experienced receiving information and advice on being particularly ‘at risk’.

Over the past six years, though engaged in individual ethnographic projects, we have collectively explored how novel forms of chronic living have been taking shape in welfare state Denmark. Working together with the Danish Heart Foundation, Marie Svensson has carried out fieldwork among families living with congenital heart defects to gain insights into the everyday challenges they face in the years following the birth of a hjertebarn (heart-child) (Svensson et al. 2020). Based at the Steno Diabetes Center Copenhagen, Natasja Kingod has developed new forms of online–offline ethnography to explore how people living with type 1 diabetes use peer-to-peer online platforms – especially the Facebook groups function – to exchange experiences and tips with people who share the same diagnosis (Kingod 2018; Kingod and Cleal 2019; Kingod and Grabowski 2020). Sofie Rosenlund Lau has worked with home carers to examine how multimorbidity and resultant polypharmacy are managed in home settings through regular visits by healthcare professionals (Lau 2020). In addition, Ayo Wahlberg has been leading a five-year collaborative ethnographic study of chronic conditions, designed to characterise chronic living in the twenty-first century (Wahlberg 2018). While the pandemic continues to progress at time of writing (December 2020) with hospitals experiencing a second influx of COVID-19 patients and numerous restrictions currently being reimplemented in Denmark, our empirical insights were gathered in spring 2020 as COVID-19 disrupted the everyday lives of Danes for the first time.

The birth of ‘kronikere’ in Danish healthcare

In the 1980s and 1990s, Danish healthcare authorities were preoccupied with what was considered a somewhat embarrassing vital statistic: on average, Danes were living significantly shorter lives than citizens in neighbouring countries like Sweden or Norway (Juel and Kamper-Jørgensen 1989). In response to this anomaly, in 1992 then Health Minister Ester Larsen established a Life Expectancy Commission to investigate why ‘Danish life expectancy is not advancing as gainfully as in other countries’ (Ministry of Health 1994, 1). Two years later, their conclusion was clear: lifestyle – especially smoking – was to blame. Consequently, a series of public health initiatives were developed under a collective banner of KRAM (an acronym for the Danish words for diet, smoking, alcohol and exercise, which also means ‘hug’, an important part of pre-COVID-19 Danish sociality...
when meeting friends and family). Sine Knudsen and Peter Triantafillou have argued that these developments amounted to a ‘lifestylisation of the social’ in Denmark, leading to the consolidation of an extensive ‘lifestyle dispositive’ (2020, 3). Within such a dispositive, ‘although health and illness are the products of the sum of social and environmental influences, it is our lifestyle – made up by our consumption of tobacco, alcohol, accidents, physical exercise and diet – that constitutes the primary cause of … disease’ (Frandsen and Triantafillou 2011, 212). To address this, a series of initiatives targeting individual health behaviours (KRAM campaigns) were launched (Vallgårda 2011). By the turn of the millennium, healthcare officials had proclaimed success as life expectancy was again catching up with neighbouring countries, albeit unequally so, not least because Denmark’s record in diagnosing and effectively treating cancers continued to lag behind neighbouring welfare states (see Bergeron-Boucher et al. 2019). At the same time, as elsewhere in the world, increasing life expectancy had ushered in a new challenge – how to improve the lives of those who were now living with lifelong chronic conditions:

In recent years, average life expectancy has increased significantly more in Denmark than in those countries we normally compare ourselves to. … But health is not only about length of life. At least as important is quality of life. … We [must] focus much more than hitherto on both length and quality of life, not least quality of life in the years after working life when major diseases are more prevalent (Government of Denmark 2002, 6).

And so, alongside the ‘lifestylisation of the social’ in Denmark, we have over the past two decades witnessed what Ayo Wahlberg and Nikolas Rose have described as a governmentalisation of living ‘in the course of which the social and personal consequences of living with disease come to be an object of political concern, and made knowable, calculable and thereby amenable to various strategies of intervention’ (2015, 60). As a direct consequence of these more recent developments in Denmark’s universal, tax-financed healthcare system, the figure of the ‘kronikere’ (a Danish neologism used to designate those living with a chronic condition) has emerged as an object of concern (Wind and Vedsted 2008, 7–8) around whom chronic care infrastructures have coalesced. In Henriette Langstrup’s work on chronic care, such infrastructures are defined as ‘made up of various inconspicuous elements (medication, standards, control visits, doses, daily routines, sheets of article for registration and more) that tend to sink into the daily practices of patients and professionals’ (2013, 1010).
These chronic care infrastructures allow for what the Board of Health, in its COVID-19 instructions to hospitals, described as ‘patients with a stable illness’. Yet, as we consider below, describing people in this way unwarrantably overlooks the many forms of ‘illness work’ (Corbin and Strauss 1985, 1988) or ‘chronic homework’ (Mattingly et al. 2011) involved in keeping an illness stable, the costly resources that make chronic care infrastructures possible (not to mention extending these to people across the community), and the grave inequalities that can render such illness work more or less impossible ‘independently’. In what follows, we show how, by identifying those living with chronic medical conditions as particularly at risk and by asking them to self-isolate, Denmark’s efforts to control the COVID-19 pandemic amplified and highlighted the often laborious work involved in keeping illnesses ‘stable’, the challenging ways risk is negotiated by those already ill, and the often unrecognised efforts of individuals, families and ‘auxiliary’ care workers to (self-)manage chronic conditions. We now turn to three ethnographic descriptions of how families experienced their new-found and unsolicited status as ‘particularly at risk’ of COVID-19 and its complications.

**In and out of risk – living with a complex congenital heart defect in a pandemic**

‘I think the guidelines on what hjertebørn [heart-children] should do have been confusing and conflicting … one day almost isolate and the next day not at all’, Anita wrote in an email at the beginning of May 2020, when asked how her heart-child, 10-year-old Mikael, and the rest of the family, were coping during the COVID-19 pandemic. In Denmark, around 16,000 children and youth under 18 years live with a congenital heart defect (CHD) (Hjerteforeningen n.d.); worldwide, this is the most common major birth defect (Linde et al. 2011, 2241). CHDs encompass a broad spectrum of defects from ‘simple’ (without symptoms or need for treatment) to ‘complex’ and life-threatening (requiring surgery soon after birth coupled with lifelong follow up) (National Heart, Lung, and Blood Institute 2017). In Denmark today, as in other countries with well-resourced healthcare systems, even some of the most complex CHDs have been transformed into chronic conditions (Jacobsen et al. 2010, 40; Lüscher 2017, 2021).

However, as children with CHDs live longer, it is becoming increasingly clear that many live with risks of complications, deteriorations, further surgical interventions and reduced long-term survival compared to the background population (Larsen et al. 2017; Lüscher 2017, 2021).
For Anita and Mikael’s father, Ole, risks related to Mikael’s CHDs have been all too clear since his birth. Anita and Ole thought they had welcomed a healthy baby boy to the world, only to learn that Mikael had a complex CHD, needed surgery urgently and might not survive. Mikael has so far undergone three heart surgeries that have completely rebuilt his heart, but this is a temporary solution, and he may require a heart transplant in the future. The risks and high stakes of Mikael’s CHD have taken a detrimental toll on Ole, who has struggled with his mental health since the diagnosis, leaving it very much up to Anita to care for Mikael and his younger sister, Maja, as well as provide an income for the family.

Like most families living with CHDs in Denmark, Mikael’s family try to de-emphasise the risks of CHDs in their everyday lives. This is encouraged by healthcare providers who urge families to focus on the positives of the present rather than on their children as sick, limited and with a future full of risks. For Mikael’s family, living with his health risks is a routine aspect of everyday life. He is vaccinated against influenza and pneumonia and is kept at home if there is much illness in his school, and Mikael, according to his mother, pointed out to a classmate visiting for a playdate, ‘in this house, we sanitise our hands!’ The outbreak of COVID-19 accentuated such risks and moved them to the forefront of everyday life. It was, in fact, the hand sanitiser that made Anita aware that ‘there are actually people who are starting to panic’, as the pharmacy was unable to fulfil her routine order of hand sanitiser at the end of February. Fourteen days later, the Danish government announced a national lockdown, which was, as we noted above, to a large extent directed at so-called ‘vulnerable groups’ such as people with chronic conditions and the elderly.

In the following weeks, it became apparent to Anita that she needed to find out whether Mikael was ‘particularly vulnerable’, and especially whether he could return to school once the lockdown ended. This proved difficult, as it was for many parents. Calls to The Danish Heart Foundation’s ‘heart-line’ doubled during March–May 2020, and many sought peer advice on the Facebook page of the Foundation’s children’s club in the same period (around 50 posts with over 1,200 comments). In these early weeks of the pandemic, families came to rely on and expand their caringscapes, as priorities within the national healthcare system shifted towards COVID-19. At first, Mikael’s GP deemed him ‘at particular risk’, much like Anita had interpreted the general guidelines. However, things changed rapidly, and Anita ‘panicked when one day it was said [in the guidelines] by both the pediatric cardiologists and the Board of Health that he was at ‘particular risk’, and then the next day he wasn’t!’ More phone calls ensued, first unsuccessfully to Mikael’s current cardiologist,
and then to his former cardiologist, who agreed with the GP. However, Mikael's social worker decided that the decision on whether Anita would be granted compensation for lost earnings, so that she could home-school Mikael, had to be made by a medical consultant who did not know Mikael. As the family had previously experienced collaboration with municipal social workers as rather cumbersome, like many other Danish parents to disabled or chronically ill children (For Lige Vilkår 2019, 2), Anita was quite surprised when she was granted financial compensation.

Each month a new assessment arrives, and Mikael could suddenly fall out of risk in the eyes of the Danish welfare system. As sole provider, this would force Anita to assess whether Mikael's risk of infection from COVID-19 would outweigh the financial risks she to take unpaid leave from her job as a nursery teacher, which Anita felt made her ‘particularly exposed’ to infection. Coupled with stories of doctors’ experiences of complications from COVID-19 flooding the media, such as blood clots, she and Ole were left extremely confused and worried.

Yet, keeping Mikael at home was not without risks either. Anita had already been forced to defend to colleagues why Ole’s mental health problems meant that he could not home-school Mikael. Anita and Ole also had to leave conversations about the pandemic until moments where ‘small ears are not listening’, as Anita phrased it, because ‘it is just difficult for him, when it is something that makes him feel sick’. Mikael's check-ups, for example, would cause such unwanted attention to his heart defect every six months. Now, the reminders were daily. One and a half weeks into isolation, Mikael got sick – out of fear Anita thinks. While he vomited, he told her that he was scared. Unfortunately, Mikael's therapy sessions, originally initiated to help him deal with psychological and social problems at school, were also paused. Furthermore, the risks he had so far evaded concerning his ‘underlying’ CHD now surfaced. When he started therapy again after the lockdown, he told his mother bluntly on the way home that ‘you are super lucky that I have survived all of this [e.g. three heart surgeries], because there are not many who do!’ Home-schooling, however, relieved Mikael of long school days that often left him physically exhausted. He was also comfortable with less socialising, as his social interactions with peers after school were already limited due to exhaustion but also because he struggled with forging friendships. Yet, Anita realised while home-schooling Mikael, ‘he is fine with just sitting on his own. It’s not because there is anything wrong with that, but you can get a little weird by just being on your own’. So, although she feared the consequences were he to contract COVID-19, Anita realised that keeping Mikael at home was a ‘balancing act’. It involved ‘[keeping] several balls
in the air in terms of when you are doing the wrong or the right thing, and it is the kind of thing you can only know in the future'.

For Mikael’s family, this balancing act had to be done in the midst of a dramatic shaking up of the carescapes and chronic care infrastructures on which they normally leaned. Mikael’s current cardiologist was impossible to reach; previously routine precautions to avoid infections now caused panic (hand sanitiser) or proved impossible (staying home from school sporadically when there were bouts of influenza); the struggle for compensation for lost earnings was an everyday (uncertain) reality rather than a short-term solution during hospitalisations for surgery; therapy was paused when Mikael perhaps needed it more than ever; and guidelines on CHDs were constantly changing. Their situation exemplifies how depending on what struggles already surround the chronic condition, COVID-19 affects families differently. For this family, exacerbated social isolation, financial problems and mental health issues posed a particular risk that added to those related to Mikael’s physical health.

Many children with CHDs were, unlike Mikael, placed outside of risk groups, or were categorised as ‘at risk’ but still advised to attend kindergarten and school. However, for those ‘at risk’ isolated at home, the Danish government’s attempts to shield people with chronic conditions created a heavy extra burden of risk. Ina, mother of Julie, aged 15 and with a moderate CHD, reflected on the consequences of the COVID-19 pandemic, writing:

I don’t think that the fear will ever recede. … Now it is not just the congenital condition that is a risk, now there are also external risks that I cannot regulate or control. No matter how much I look after my child and keep distance, it can come to us and ruin an entire family. We cannot shut ourselves in for the rest of our lives, but how do we move on?

Navigating noise in online type 1 diabetes communities during COVID-19

As with congenital heart defects, uncertainty surrounding COVID-19 has been evident within several Danish Facebook communities for people living with type 1 diabetes. News about the unfolding pandemic made it to Danish television in early 2020 and gave rise to new communities on Facebook, where people shared their fears and concerns in the wake of
the global lockdown. To meet rising demand for information from the public, doctors created their own Facebook community to take the pressure off clinics and to provide reliable and evidence-based answers to the many questions on COVID-19 from the public. Offshoots within the larger patient-driven Danish online diabetes communities emerged around COVID-19 where interpretations of the government’s guidelines were shared and debated: are we at higher risk of contracting COVID-19? Do we experience more severe complications if infected by COVID-19? The flood of information from both news media and from peers within Facebook communities made it difficult for lay people to distinguish between health misunderstandings and facts.

With the rise of social media in the 2000s, and the opportunity to create interest groups on Facebook in 2010, the classical ‘field site’ has become ever more fragmented and its boundaries fluid (Hine 2015). At the same time, although they are a convenient 24/7 space to share important information, tips and knowledge on how to live with a chronic condition, online peer-to-peer communities have not replaced traditional ‘in real life’ conversations (Kingod et al. 2017; Borkman 1976). In times of uncertainty and despair when living with a chronic condition that involves complex self-care management regimes, mobile technologies are a valuable part of everyday chronic care infrastructures that enable patients to seek out peer knowledge through a single tap on their smartphone. Hence online caringscapes have come to supplement the support of loved ones through their offers of reciprocal informal care (Kingod 2020).

In Denmark, people living with diabetes co-create and tinker with different types of knowledge both from peers within communities on social media channels and from more conventional authoritative guidelines (Kingod 2018). Tinkering occurs to fit self-care technologies to bodies and medical guidelines to daily living with type 1 diabetes. With the complex chronic homework that goes into keeping type 1 diabetes ‘stable’, patients seek inspiration from peers online on how to interpret and adjust medical guidelines with the purpose of living a better life with the disease (see also Mattingly et al. 2011). This type of patient-to-patient knowledge is based on everyday embodied experiences that reach into all corners of daily life.

Lisa, mother to an 8-year-old daughter with type 1 diabetes, was confused by the initial authoritative statements in relation to COVID-19 risk for those living with type 1 diabetes. As she explained in a text-based conversation in a restricted Facebook community for mothers of children with type 1 diabetes:
I don't know if I should let her [daughter] go out at all. I talked to the Danish Diabetes Association and they told me that I should keep her at home and not send her to school. They even wrote that as a relative to a person with diabetes you can work from home to reduce the risk of catching the virus. But then I can see within other Facebook communities that there are great misunderstandings and differing understandings about these guidelines. First, the Ministry of Health said that people with diabetes were at high risk, then they changed it to people with poorly regulated blood sugar and then they were suddenly not at risk at all. Now the Diabetes Association has suggested my girl is at risk again. What should I believe in and do?!

Lisa is referring to contradictory information from Danish health authorities and other government spokespeople that flooded news channels and were recirculated on Facebook in the early weeks and months of the pandemic. Initial information placed people with diabetes in a category of ‘high risk’ in relation to catching COVID-19. While all citizens are at risk of contracting COVID-19, people with diabetes were given a double ‘at risk’ status, not only in relation to catching the virus but also to developing severe complications. For many people self-managing type 1 diabetes, being at health risk while immunologically and clinically vulnerable does not necessarily create feelings of being sick (see also Jauho 2019). Still, although the risks were unclear, many people with diabetes self-isolated at home during the first months as the pandemic spread. Lisa’s daughter has lived with type 1 diabetes for several years, and Lisa sees her as perfectly normal and capable of doing the same everyday life things as her friends. This is confirmed at quarterly check-ups at the clinic where her daughter receives her long-term blood sugar measurement, a haemoglobin A1c test that indicates her average blood sugar level over the past two to three months. Lisa uses this number as an indication of how well her daughter is managing her type 1 diabetes; for several years, this number has been within the ‘normal’ range.

Lisa is an active member of several Facebook communities. These have become an important part of her family’s caringscapes and have enabled her to emotionally cope with the heavy burden of receiving her daughter’s diagnosis years ago. She remembers that she was terrified and devastated, harbouring ‘forbidden feelings’ about her daughter as ‘broken and fragile’. By lurking in a larger community on Facebook and belonging to a smaller private group, she experienced support from like-minded mothers with children at the same age. For years, Lisa was a member of a closed community targeting the specific insulin pump brand her daughter
uses. She is also a member of a community that encourages and advises people on how to ‘hack’ their insulin pumps with complicated algorithms in order to fit the technologies to bodies and daily lives (Gavrila et al. 2019).

With the first cases of coronavirus, the government quickly closed institutions and schools; only grocery stores and pharmacies remained open. Lisa found a good rhythm in home-schooling her daughter, and she felt safe with the recommendation to distance her family from other people. When the government announced that primary schools would be the first institutions to re-open, Lisa felt unsure what to do. Confused about the different categories of risk in relation to diabetes, she joined a newly established Facebook community, 'My child should not be a guinea pig for COVID-19', which quickly gained more than 38,000 members. She checked the online activities of this community several times a day to receive support and guidance in her own decision-making processes about whether or not to send her child to school. Navigating an online sea of information was not easy, as posts turned into long threads with contradictory answers on governmental restrictions and guidelines. Online noise is a side effect of the bombardment of information on news and social media channels (whether contradictory or not) that people living with type 1 diabetes in Denmark must process, interpret and attune their lives to (Kingod and Cleal 2019). With the strength of aligned voices of parental fear, Lisa concluded that her daughter should stay home for another 14 days, so she could see whether the situation in Denmark had stabilised, with infections and hospitalisation rates declining. Lisa would lurk within the large community, and then discuss answers from this community with members in the closed group. Members of this smaller group have known each other for several years and they meet offline, and Lisa feels safest in expressing her concerns among peers that she knows and trusts. Lisa and peer mothers remain unconvinced about the safety of the situation. They keep themselves and each other updated online, share news feeds within the group, and discuss school and governmental guidelines. The category and presence of double risk will stay with them for a long time. Further, they have become increasingly exposed to the noise of massive amounts of health information. With changes in caringscapes and carescapes, in terms of the growing availability of peer-to-peer exchanges on social media between quarterly check-ups at the clinic and the shifting of resources towards COVID-19, many forms of type 1 diabetes care, formal and informal, moved online. Lisa and her peers were placed in yet another ‘at risk’ category – the uncertainty of how to evaluate health information they found online – and so she
devised a strategy of discussing it with other mothers in a smaller Facebook group.

**Cancelled appointments – disrupted social care among ‘frail’ seniors**

‘Up we go’, announced Wicky, the home care worker, as she raised Viggo’s elevation bed to her hip level. It was 8:15 a.m. on a cold Monday morning in February 2020 as news of a ‘mystery virus’ that had devastated Wuhan and since spread to Italy and Spain was making headlines in Denmark. Wicky was there to wake Viggo and help him get washed and dressed. Viggo contributed as best he could by taking off his shirt and following Wicky’s guidance. They chatted a bit during the work. ‘So, did your family visit this Friday?’ Wicky asked. ‘Yeah, my son was here. He brought fastelavnsboller [cream buns]’, Viggo recalled with a wide smile. ‘Haha, you should have seen the blood sugar’, he continued. Wicky laughed. She helped him get dressed and moved his 100 kg body to the wheelchair. Viggo was diagnosed with diabetes in 1991. Years of uncontrolled blood sugar had damaged the nerves in his feet, and eventually a wound on his heel resulted in untreatable gangrene. Four years ago, he lost the leg. He stayed for a short time at a rehabilitation centre, and had difficulty adapting after he returned home. His house was not fit for a wheelchair, and, despite daily home care visits, he was alone and had no one to help him on a regular basis. One morning, struggling to reach something on a shelf, he fell and broke his remaining leg. Afterwards, he was granted the penthouse senior apartment in a new multi-storey building and received more intensive home care.

Viggo had grown up, with four siblings, in a small apartment in a rough neighbourhood of southern Copenhagen. After primary school, he joined the Danish Railway Network and worked for 40 years as a train conductor. When he was diagnosed with diabetes, he was, in train terminology, ‘dropped off’, and took early retirement. Besides the diabetes, Viggo suffered from chronic pain and depression, and took medicines for raised blood pressure, raised cholesterol, oedema and vitamin deficiency. In total, to manage his various conditions, he took 17 pills per day.

During the last two decades, therefore, as with nine other interlocutors in a project on ‘frail’ elderly and medicines, Viggo intimately experienced health inequalities as someone from a particular socio-economic background living with a multitude of illnesses (Lau 2020). As a result of their ‘lifestyles’ through many decades, these elderly are aging
‘unhealthily’; when the COVID-19 pandemic struck, they were already at risk of functional decline and early death. These seniors are all dependent on help from a variety of social and healthcare institutions, including home care – a comprehensive, yet strictly standardised, carescape made possible by the Danish welfare state (Tufte and Dahl 2016) – and, due to high levels of multimorbidity, their daily living is primarily centred around and shaped by chronic homework (Mattingly et al. 2011). For Viggo, as for most seniors receiving daily home care services, every day looked more or less the same. A helper from the home care team woke him up in the morning. Twice a week, Monday and Thursday, he was provided an assisted shower. Afterwards, he ate his breakfast and drank his coffee while listening to the radio. At 10:00 a.m., the nurse called him, or dropped by to monitor his blood sugar and give him insulin injections. Afterwards, Viggo went on an outdoor trip; most days this included some kind of visit to a health clinic. Twice a week, he rolled himself down to the nursing clinic, where the pressure bandages on his leg were replaced. He went for regular checks at a diabetes clinic, an eye clinic and a foot therapist. Some trips included assisted transport, which required a lot of waiting time and often took the entire day. On other days, he brought himself across the parking lot to visit his general practitioner, the physiotherapy clinic or the pharmacy. In the afternoon, he often stopped at the grocery store at the ground level of his apartment building to buy bread, cold cuts and condiments for his breakfast and lunch. Dinner was provided by a private distributor commissioned by the welfare state, responsible for delivering microwaveable meals twice weekly. He ate most meals alone at home, but occasionally his daughter and her partner would drop in and prepare dinner, or his sister would take him out to eat at a local cafe. In the evening, Viggo called his children or sister and watched a movie while waiting, first for the nurse and his nightly insulin shot, then for the home care worker to help him back to bed.

In summing up these daily routines of chronic living that shaped his everyday life, Viggo’s caringscape seemed mainly connected to the chronic care infrastructures related to addressing his medical conditions and preventing decline. But it would be a great mistake not to include the social interactions embedded in these infrastructures: it was exactly these interactions which constituted enough enacted togetherness (Nyman et al. 2012) to create meaning in Viggo’s daily life, hence to keep a lurking social death at bay. Viggo thrived in the company of others and suffered in his homely solitude. To counteract feelings of loneliness, the radio or the TV was constantly turned on. Viggo used his phone frequently and, despite deteriorating sight and fine motor skills, used Facebook and other
social media. However, what counted most in ‘keeping up spirits’, as he framed it, were the daily trips out of the apartment. He always dressed up, even for the short strolls down to the nursing clinic. His hair was combed and he wore a fancy flat cap, giving him a slightly modern look. Viggo cared about his appearance. For some time, it had bothered him that he wore a slipper on his remaining foot, as it was almost impossible to find a nice and tidy shoe that would fit his oedematous ankle. He was full of joy the day the local shoe store finally brought him a tailored shoe. Appearance was important because Viggo used his outdoor trips to get in contact with other people. These trips meant so much to him, because, as he said, he needed the conversations with others to ‘feel alive’. The trips were pivotal to Viggo’s everyday life; they allowed social interactions and provided meaningfulness; when returning home in the afternoon, he felt he had accomplished something that day; he had seen and talked to other people.

For Viggo, the lockdown and self-isolation that came into force on 11 March 2020 dramatically altered these daily routines and disrupted his already confined social life. Viggo was, like other so-called vulnerable persons, told to stay at home as much as possible. Previously daily trips out of the apartment were reduced to a minimum, and instead substituted with more movies and, for Viggo, unhealthy solitude. Visits from family and friends were restricted. No more coffee chats or cream buns. His family kept away to minimise the risk of bringing the virus into his home, as an act of caring. Yet, for Viggo, the cancelled appointments changed the foundation not only of his chronic care work but, more essentially, of social care. As COVID-19 changed Viggo’s carescape in terms of the availability of clinical and social resources in his daily life, it automatically altered his caringscape and subsequently Viggo’s ability to care for himself.

Despite these efforts to keep Viggo out of harm’s way, on 23 March 2020 Viggo died from coronavirus infection and its complications.

Care interrupted

Three weeks into Denmark’s lockdown in late March, just as Viggo’s passing had added yet another COVID-19 casualty to the climbing daily mortality numbers published in newspapers and online media, Prime Minister Frederiksen held another of her regular press briefings, this time with a special message for those ‘vulnerable groups’ who had been advised to self-isolate: ‘It pains me to say this to our elderly and most vulnerable: you will need to adjust your lives against your risk of
contracting COVID-19. We are asking the weakest to be the strongest. This is a harsh message’ (Statsministeriet 2020b). While Denmark emerged out of its ‘first wave’ relatively unscathed when compared to Italy, Brazil and the United States, we have seen here through the experiences of Mikael, Lisa and Viggo, their families and the healthcare professionals on whom they rely, how COVID-19 has generated new forms of chronic homework, concern, worries and in Viggo’s case, his death. As we have shown, in the past two decades, Denmark’s healthcare system has come to be reconfigured around kronikere who lead lives with what the National Health Board calls ‘stable illnesses’. Yet, as the disruptions brought on by COVID-19 have shown, speaking of ‘stable illnesses’ belies the complex efforts that go into maintaining stability, and masks the genuine concerns that the pandemic brought as families struggled to come to grips with what it meant to be ‘particularly at risk’.

The navigation and interpretation of risk in relation to COVID-19 has become an extra burden for people with chronic conditions and their families. These families were already leading lives with many forms of risk related to their medical conditions and their socio-economic conditions, and COVID-19 added to already existing anxieties and difficulties. While the National Board of Health retracted its call for a massive rerouting of resources to address the pandemic, and COVID-19 units were closed down in a number of hospitals due to a lack of patients during the summer months, Denmark’s ‘second wave’ took hold towards the end of 2020, again leading doctors and nurses to warn of the knock-on consequences and necessary reprioritisations that rising hospitalisation rates entail. Likewise, the worries that a circulating novel coronavirus have generated for people living with (multiple) chronic conditions have not dissipated and will not do so any time soon.

Chronic conditions do not disappear because a pandemic arrives. While these ‘other’ conditions are (however provisionally) moved to the bottom of the healthcare agenda and prioritisation lists within healthcare systems, disrupted treatment and monitoring, calls for self-isolation and designating the chronically ill as ‘vulnerable groups’ who are ‘particularly at risk’, all serve to move ‘stable’ chronic conditions to the forefront of everyday life for patients and their families, much more so than in ‘non-pandemic’ times. The chronic care infrastructures, carescapes and caringscapes that had coalesced around people living with conditions like congenital heart defects, type 1 diabetes and multiple chronic conditions have been unsettled by a pandemic that has raised questions about how healthcare systems should be financed and organised in the coming years and decades, not least in the face of looming austerity. In the months and
years to come, we will learn how a communicable condition like COVID-19 has reshaped care- and caringscapes, hence complicated and unsettled the chronic care infrastructures and chronic homework routines aimed at keeping chronic conditions ‘stable’.

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Notes

1 Throughout this chapter, we have translated quotes from Danish politicians, policy papers and interlocutors, which originally appeared or were in Danish.
2 A December 2020 study from the Danish Cancer Association confirmed these fears, showing that there were 2,800 fewer cancer diagnoses from March to May 2020; an early indication of knock-on consequences when resources are shifted in such a massive way (Munch 2020).
3 Each project was ethically approved by relevant authorities nationally and at the University of Copenhagen.
4 Original in Danish: Mit barn skal ikke være forsøgskanin for covid-19.
5 For empirical insights from Viggo’s daily life and passing, see also Lau, Kristensen and Oxlund (2020).

References


Munch, Per. 2020. 'Formand for lægerne: “Folk bruger deres liv på at frygte corona, mens de får kæft”'. *Politiken*, 9 December 2020. https://politiken.dk/forbrugogliv/sundhedogmotion/art8027647/FORMAND-FOR-%C3%A6LGERNE-%C2%BBFolk-bruger-deres-liv-p%C3%A5-at-frygte-corona-mens-de-f%C3%A5r-kt%C3%A6f%2CAB/


