Re:visit
Humanities & Medicine in Dialogue

Long Covid as a Collective Experience: A Photo Essay

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Abstract

Although diseases manifest themselves in individual bodies, they usually have multiple, and often systemic, causes. They do not only affect one's immediate social environment, but whole cities and nations. The pandemic has demonstrated the extent of these interdependencies: a butterfly effect which makes clear that a virus, animals, humans and the environment cannot be thought of separately. And yet, this collective dimension of sickness and health is often pushed into the background. On various levels, Long Covid shows, just like the pandemic, that illness is a collective experience. The syndrome demonstrates the complexity, multidimensionality and the contradictory nature of the collective dimension of being sick and getting well; what it also demonstrates is that this collectivity can become a springboard for long-term transformation. This essay is one way of mobilizing the experience and knowledge of Long Covid patients to signal that we need to rethink our conceptions of illness and use them as a foundation for building new (health)care infrastructures that can hold us all. Whatever their possible shape, we should start discussing them now.

Keywords

Chronic illness, subjective experience, illness narrative, (in)visibility, patient activism

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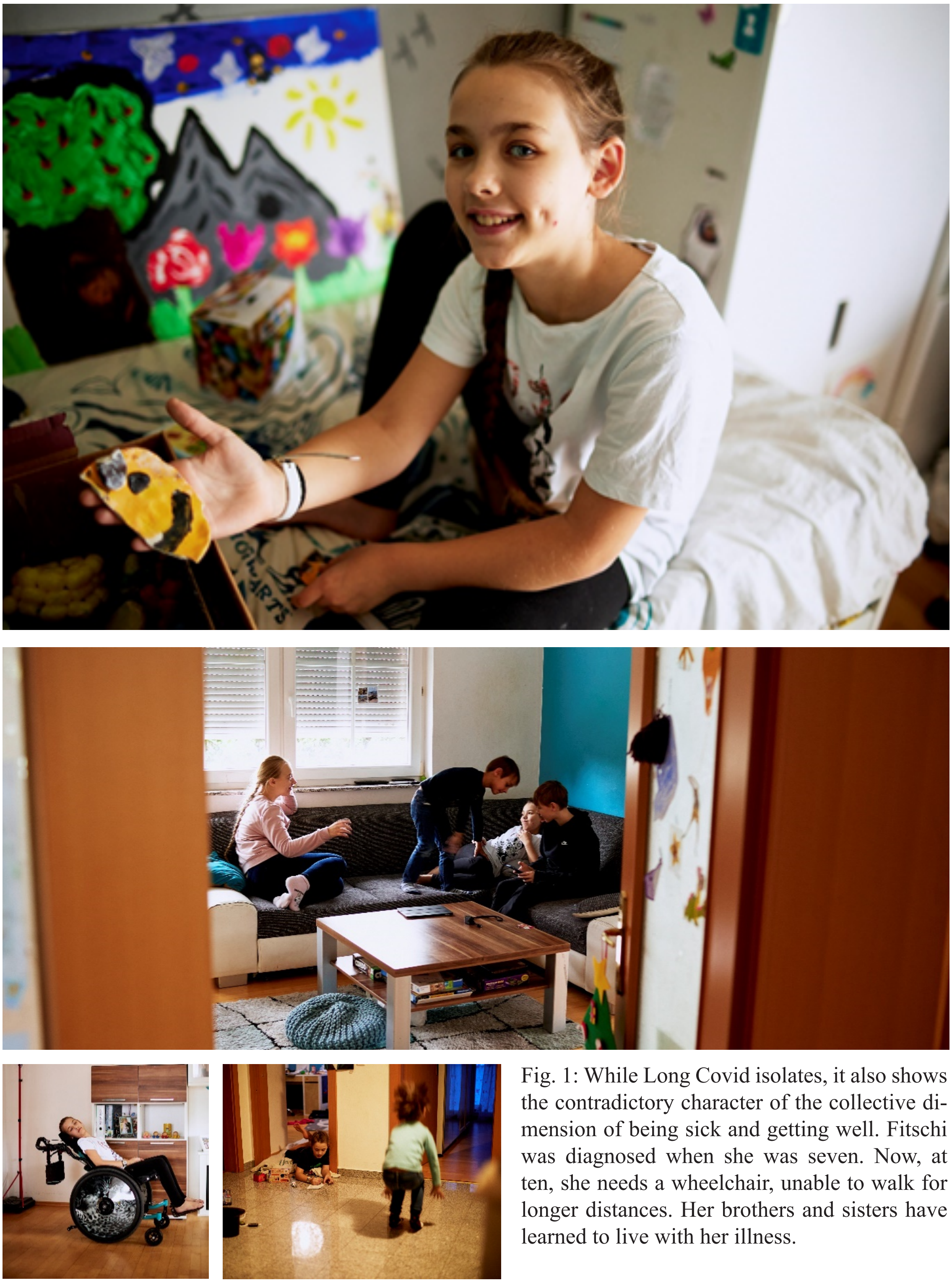

Fig. 1: While Long Covid isolates, it also shows the contradictory character of the collective dimension of being sick and getting well. Fitschi was diagnosed when she was seven. Now, at ten, she needs a wheelchair, unable to walk for longer distances. Her brothers and sisters have learned to live with her illness.

In our neoliberal systems, illness has become a problem of the individual. In a world in which self-optimization, effectiveness and productivity are valued as central to the regime of happiness, illness is something that must be eliminated and hidden.[1] Something that an individual must overcome as quickly as possible in order to meet the demands of a society determined by the free market. Being ill is equaled with inefficiency and social parasitism; it leads to monetary and market losses. Being ill is dodging social and economic responsibility. Being ill means being guilty: after all, the responsibility for prevention and protection against disease lies with the individual. In these contexts, getting well is a matter of personal accountability, regardless of whether and what resources and systemic solutions are available and accessible.[2]

And yet, in spite of these tendencies to frame illness as an individual problem, this, of course, rarely is the case. Illness constitutes a network of interdependencies and enmeshments. Although diseases manifest themselves in individual bodies, they usually have multiple, and often systemic, causes, which include poverty and social exclusion. They do not only affect one's immediate social environment, but whole cities and nations. The pandemic has demonstrated the extent of these interdependencies: a butterfly effect which makes clear that a virus, animals, humans and the environment cannot be thought of separately. This *collective* dimension of sickness and health is often pushed into the background these days. On various levels, however, Long Covid signals, just like the pandemic, that illness is a collective experience.

At first sight, Long Covid isolates the affected, slows them down and incapacitates them. The syndrome often forces them to cloister themselves in order to avoid external stimuli or to preserve their energy. This also means that they can no longer participate in social life or do so only to a limited extent. Other people literally become a threat to Long Covid sufferers. Any kind of emotional stimulation can hurt. At the same time, they grow dependent on the help and support of others – be it people, objects, or technologies. For instance, the social media, despite their problematic tendencies, have served as platforms for collective action and patient activism. Long Covid shows the complexity, multidi-

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[1] See Deborah Lupton: *Digitized Health Promotion: Personal Responsibility for Health in the Web 2.0 Era. Sydney Health &Society Group Working Paper No. 5.* Sydney 2013. https://ses.library.usyd.edu.au/handle/2123/9190 (15.9.2024); Matthew Sparke, Owain David Williams: Neoliberal disease: COVID-19, co-pathogenesis and global health insecurities. In: *Environment and Planning A: Economy and Space*, 54.1 (2022), 15-32. doi.org/10.1177/0308518X211048905.

[2] See Deborah Lupton: *The Imperative of Health: Public Health and the Regulated Body.* London 1995; Rose Galvin: Disturbing Notions of Chronic Illness and Individual Responsibility: Towards a Genealogy of Morals. In: *Health* 6.2 (2002), 107-137. doi:10.1177/136345930200600201.

mensionality and the contradictory nature of the collective dimension of being sick and getting well; what it also demonstrates is that this collectivity can become a springboard for long-term transformation.

Showing the Invisible: Co-creative Research Design

The complexities of this collective experience of being ill transpire from and lie at the core of the interviews with Long Covid patients. As part of the "Post-Covid-19 Care"[3] project funded by the University of Vienna and the Medical University of Vienna, our team interviewed 21 Long Covid patients in Austria. The semi-structured interviews were conducted between June and December 2023. The interviewees are volunteers who responded to a call we distributed via Long-Covid-Austria (https://longcovidaustria.at/) and the Arts for Health Austria association, an organization for the promotion of art interventions in the context of health and well-being (https://www.artsforhealthaustria.eu/). Seven of the interviewees agreed to participate in a photo sub-project. As part of the interviews, they worked with me, the project leader, and a professional photographer, Peter M. Mayr (https://www.petermayr.com/), to develop a visual language which would allow them to share their experiences of Long Covid with a wider audience.

In the interviews, we asked how the bodies of our interviewees had changed. How the disease had affected their everyday lives. How they had to adapt their lives, their daily routines, to accommodate these changes. What struggles had been part of their lives since then and what gave them hope and strength. As part of the photo elicitation process, we also showed our interview partners a number of images that have accompanied press articles about Long Covid. Generic photographs of fatigued individuals have often been used to represent the condition. This is problematic as it does not in any way represent the realities of living with the illness. Our interlocutors did not regard the images as good representations of what they had been going through. As a way of counteracting this tendency and bringing the everyday realities of the illness nearer to the public, we asked them to demonstrate what they would like the public to know about the transformations in their lives.

The photographs gathered here are snapshots of their illness experience. Clearly, preexistent knowledge, various selection processes as well as the patient's view of themselves, their situations and the press landscape have influenced the way they are portrayed here.

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[3] *Post-Covid-19 Care*. Post-Covid-19 Care - Interuniversity Cluster Medical Humanities (UW) and Health Economics (MUW), 2021. https://postcovidcare.univie.ac.at/ (28.8.2024).

Still, we would like the photographs to be considered as particular windows into the ‘parallel world’ of Long Covid that seldom comes to view in many of the media reports. We ask the reader to consider them as rapid, unfiltered recordings of lives transformed by the disease. We also ask the reader to take the time and see the people in them: the photographs here are not merely illustrations to the text; rather, they are an invitation to meet people who, on the face of it, might seem fine and recovered but who still struggle with an illness that we, as society, so very much want to forget. They offer the *patient perspective* that is so often missing in press reports. They are based on individual fates that may not be representative of Long Covid as a whole. These pictures need to be looked at together to highlight the multifacetedness of the illness that cannot be subsumed under a single image. I would like to thank our co-contributors for their openness, time, and energy. I would like to thank them for inviting us (and you) into their lives, which often came at the cost of their own health.[4]

While I have been involved in this project as a researcher, I strongly believe that it is my duty, in this role, to draw attention to extant social injustice and inequalities and, thereby, encourage change and transformation. One of my long-term goals has been to spotlight the ways in which we talk about and depict illness and shed light on the variety of stigmatizing practices that these representations invite. This essay is one way of mobilizing the experience and knowledge of Long Covid patients to signal that we need to rethink our conceptions of illness and use them as a foundation for building new (health) care infrastructures that can hold us all.

Threats to Relationships

Long Covid patients are physically and socially isolated. Because of that, human contact and intimacy are only possible to a limited extent. When every voice and every sound is distressing and every touch hurts, even the loved ones can turn from sources of support into threats. Patients hide from their siblings, children and partners. They protect themselves with eyemasks and earplugs, lie in darkened, closed rooms and hope that no one enters.

During the worst phase of her illness, Fitschi (10-years-old, fell ill with Covid-19 three years ago) reacted with seizures to sensorial overstimulation. Tanja (48, works in healthcare) could hardly speak on the phone, unable to leave her bed for five months. For Dini

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[4] The names of our interlocutors have been anonymised/pseudonymised. The verbatim passages have been adjusted slightly to facilitate the reading flow.

(30, once a teacher), the slightest touch became a full-body experience: “For a while, when someone touched me on the head, […] I felt it in my toes.” The physical changes brought about by Long Covid raise questions that most people rarely ask themselves in their everyday lives: How can you live and interact with others when every touch hurts? How can a partnership or family function if you have to spend most of your time in isolation? How do you maintain social networks when you don’t even have enough energy to make a phone call?

Fig. 2: Exhausted by the interview and the photo shoot, Fitschi lies to rest in the living room. Dini puts on her cooling mask when tired after our interview. She also wants to show us what she does against sensorial overstimulation. For Tanja it was important to demonstrate how she spend most of her time in the first five months of her illness.

Fig.3: Dini and Niklas have met after their Long Covid diagnosis. They understand the hurdles of each other’s illness but find it difficult to see the other suffer.

Illness strains every relationship. Paradoxically, the Long Covid diagnosis has brought together Dini and Niklas (25, student). As a couple, they understand each other’s problems. But, as Niklas reports, the reality for many Long Covid patients often looks different: “You read […] in the Long Covid Austria group that […] many relationships break up or marriages fall apart when one party falls ill. […] That many people are not lucky, that […] not even their partner or close family believes that they are ill." Excessive demands, communication problems, lack of energy and time, the burden of everyday life, which is made even heavier by health problems – all this nags on the substance of any relationship. When I ask Mathias, whose partner of Nadine was diagnosed with Long Covid, how he is doing, he says:

> How I'm doing is a very interesting question. Extremely stressed, actually overloaded, but there's just no alternative. The stress [... has] built up more and more over the last few months, because at some point you just can't manage everything anymore. The illness caught us in the middle of the move, in the middle of our training. [...] And of course there's no question that a relationship generally suffers as a result.

Weekend trips or holidays are hardly possible. "We used to love swimming, which is impossible in summer. Firstly, the heat is hard to tolerate and secondly, there are far too many people there […]." How do you provide relief to a strained relationship when every fathomable form of joint relaxation has a potential to make a bad situation worse?

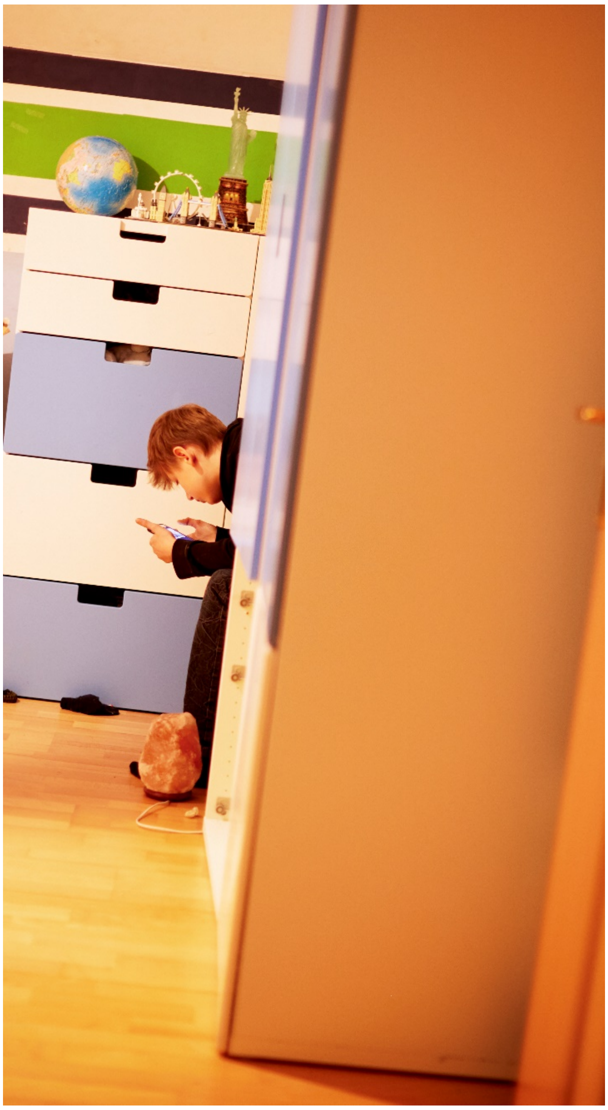
Fig. 4: Nadine R. and Mathias talk about the ways in which Nadine's diagnosis strains their relationship and that with their children who are at school during the interview.

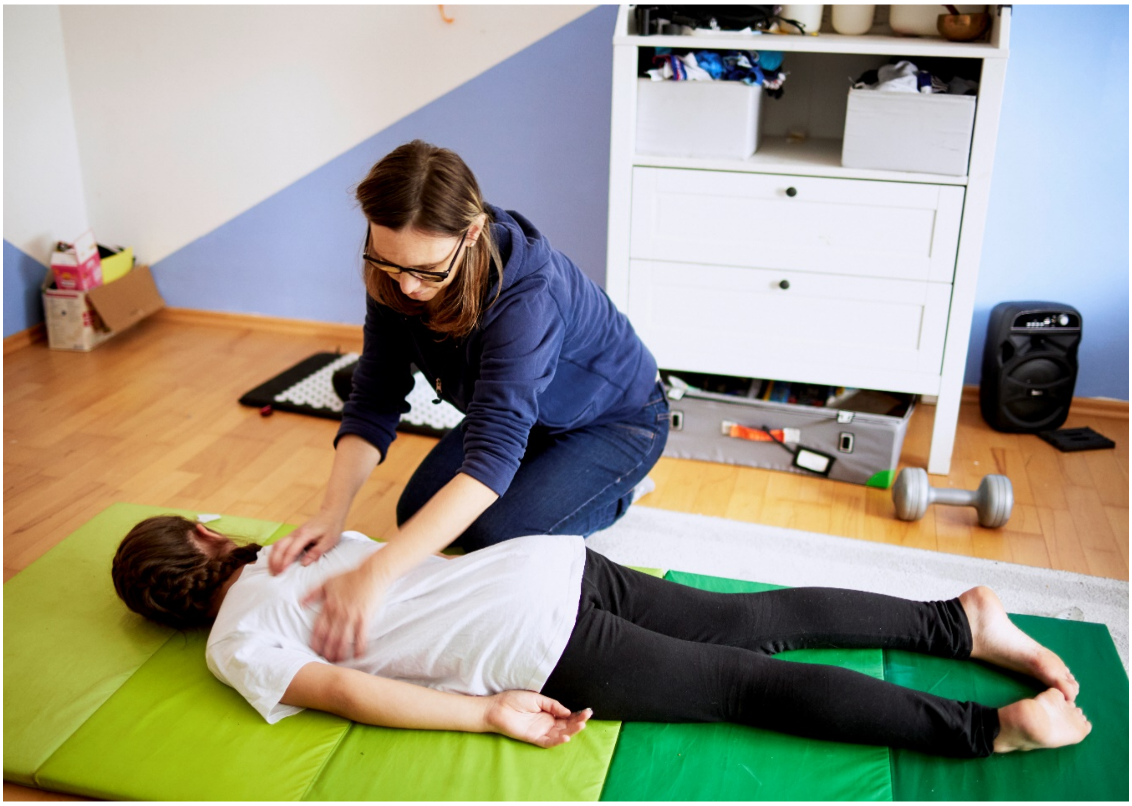
Parent-child relationships also suffer. Alix reports that her teenage children hardly seem to be aware of the extent of her suffering: "I think what's hard sometimes is when they say, 'What are you doing all day? Why haven't you cooked dinner?' Or something like that. And then I say: 'Because I don't feel like it. I just don't have the energy.'" A lack of understanding on the part of the children often goes hand in hand with worries about how their parents' illness will affect them in the short and long term. Nadine reflects on this:

> My children are sometimes plagued by anxiety and anger, which is normal to a certain extent as children develop. But you can tell [...], that there is sometimes a seriousness that is atypical for their age. There's a fear that if I fall ill with flu-like infections or Covid, I'll die. And these are fears that children shouldn't really have. And my job as a mother, the work I mainly do, is to support them emotionally, [...] we have conversations and talk a lot about their feelings [...]. But children also sometimes throw tantrums out of nowhere. And it's very difficult to keep your boundaries. Yes, I have aids such as [...] noise-reducing earplugs [and ...] my partner also helps a lot, but it is insanely difficult to manage [...] without the children carrying serious damage into puberty or into adulthood.

Sabine (42, healthcare worker), Fitschi's mother, also worries about her children. There is little left of the seven-year-old girl who once spent her time running around with her brother; now, every activity leaves her exhausted after the shortest possible periods of time. Sabine is proud that her three children help each other, but she wishes that they would not have to grow up so quickly. Valentin, the youngest, has accompanied Fitschi through her illness since he was four years old. Having to grow up quickly, being frightened, not understanding the changes – all this makes life more difficult for children and

Fig. 5: When we are there, Sabine is busy with making doctors' appointments, organizing her children's school days and driving them to their classes. She did not even have time to wash her hair, she tells us. Fitschis siblings have had to adapt to the new situation. The family turned one of the children's rooms into a space for her physical therapy.





worries parents. The effects that these developments will have both on the children and on their relationships are yet to be seen.

In addition to worries, frustrations arise on the part of close family members. Sabine spends her days taking care of the whole family while her husband, Harry, works abroad. She drives them to their classes, does grocery shopping, cooking, cleaning, helps them with their homework, goes to work: usual daily routines. With the difference that, on top of that, she is managing everything related to Fitschi's illness: doctors' appointments, therapies, rehabilitation treatments, school transportation, appeals to the ministry of health, interviews, anything to help her daughter. She uses the times when Fitschi is not home, the rare hours she spends at school or therapy sessions, to vacuum or blow-dry her hair because her daughter cannot stand these sounds. Sabine is repeatedly pushing herself to her limits.

There is not enough time. For her husband Harry, the little time he has with his children is very valuable, even if it is also very demanding:

> I'm glad that I've been here for three weeks now, for example, and that I've been able to spend more time with them again. [...] I like being a dad and I like being there for my children, [...]. But I haven't given up being an individual [...]. So I'm happy if I still manage to play a game of chess on the phone or read a book [...]. But that's it. Rare meetings with friends, hardly any with acquaintances. You get lonely. There's not much left to hold on to. [...] Somehow you have to grab yourself by the scruff of the neck and carry on. But yes, [...] it's tough.

Sabine adds that they have a very supportive social network. Still, she is concerned that even their friends and family may not comprehend the extent of the transformations their family has to face: "Our friends, I don't know if they fully understand, but at least they try to understand the situation and are also considerate. [...] I've always said that our door is always open [. . .]. Even if she [Fitschi] can only talk to her friend for an hour, it is a relief". And yet, Harry reports, their relatives do not seem to understand the issues that their daughter, Fitschi, has got to deal with. She

> doesn't leave a family celebration because she no longer wants to attend or because she doesn't enjoy it, but because she sometimes realizes that she can't stay there anymore [...]. Then she makes sure that she has peace and quiet, that the room is darkened, that the background noise is gone. And it's concerning

> for me that her closest relatives don't seem to understand this at all, [...] from time to time you get the feeling that we're just a nuisance, even for our relatives. I would even say, for the most part.

Long Covid isolates: physically, socially. It strains one's body and relationships. It introduces a veil of invisibility between the affected and the rest of the world. It forces the affected to insulate. With its vague symptomatology[5], it also introduces a level of incomprehensibility that impedes interhuman communication and makes it difficult for others to understand what Daniela terms as the Long Covid "parallel world".

Help despite Exhaustion

The subjective experience of Long Covid, however, is not only a lesson in isolation but also of support and solidarity: solidarity of partners, parents and siblings who are there for those affected despite the physical and psychological burdens that come with it; of a boyfriend who holds his partner's cup when her muscles give way; carries her to the toilet when she can't walk herself; helps her into her wheelchair; of brothers who play quietly when their sister is resting, who no longer go on family vacations because they are almost impossible to afford and an organizational feat almost impossible to master.

Cooking, organizing doctors' appointments and transportation, vacuuming and cleaning the apartment during the few hours that the ill are out: relatives do all this even though they should actually be resting themselves. Although their strength is limited, too. Because both Dini and Niklas have Long Covid, they understand each other's struggles. What helps, says Dini, is "that we don't have to spend so much time alone and [...] have similar everyday lives, similar daily routines." "And that we also have a lot of understanding for each other," adds Niklas. "If one of us has a bad time, then the other knows how bad it really is." Nevertheless, Dini divulges, it is also very painful to see the other person suffer.

Long Covid sufferers and their families would not make it without the support of others. Ellie's neighbors brought her food, did the shopping. Friends helped with the children because Daniela could no longer look after them on her own. When Fitschi had to go into rehab, her classmates gave her a box of notes. A drawing, a puzzle, one for every day of the entire five weeks. Fitschi shows us the box, picks out a few pieces of paper. Takes them

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[5] In the meantime, a center for post viral conditions is opening in Austria. This and other developments show, that the illness and the patients are being taken more seriously.

Fig. 6: Mathias tries to help Nadine however he can. While he does it willingly, it is often exhausting.

out of their envelopes. “Almost like a cross between an angel and a dragon,” I comment on one of the drawings, because Fitschi likes dragons: “I just think they’re cool,” she says, “and I think they’re cool to draw because, with dragons, it doesn’t matter what they look like. And you can draw them however you like,” she tells me a few minutes earlier.

Fig 7: The box with treasures given to Fitschi by her peers when she went to the rehabilitation center.

Tanja remembers how, in the beginning, her mother, sister and friend took care of the most important things: hospital, home, food.

> They did things for me, took care of doctor's appointments, collected medical reports, extended my sick leave, got medication, prescriptions, etc. [...] and the home help did my housework for me, so that things stayed somewhat tidy [...]. She would have also helped me with my personal hygiene, but I didn't want that. That felt uncomfortable [...] I don't think I could have done it without this help.

Tanja's friend got her eye masks and brought her a Discman so that she could listen to CDs when she was able to listen to music again.

The Discman seems almost as anachronistic as the willingness to help and the sacrifices that Long Covid sufferers and their families describe. Where profits, efficiency and self-optimization become ideals, there is little room for close-knit support systems and solidarity. The small and large gestures, help and attention that I have encountered during my conversations, give reasons to hope. It is not just people and human connections that are part of the support networks Long Covid patients rely on – it is also the material objects that help to alleviate their symptoms or are sources of distraction. Together, they are part of a multifaceted entanglement that has the potential to help Long Covid patients navigate a world that, for them, has been radically altered. And yet these close-knit, small-scale networks cannot shoulder the task on their own. Nor do they exist in isolation. They are embedded in larger systems of public health that require urgent transformation. What I suggest here is that we think of these small-scale entanglements as nodal points that can branch out and change these larger structures that we call public health and society as a whole.

Shared Knowledge

In spite of current scientific developments and the media presence of Long Covid, its possible short- and long-term consequences still seem not to have infiltrated public awareness.[6] This, however, is a prerequisite for (sustainable) medical and social restructuring to take place. Such changes are urgently needed. The activism around Long Covid began with the disease itself. It is the first disease, writes activist and sufferer Elisa Perego, that was created by patients on Twitter.[7] What she means by this is that those who continued to observe persistent symptoms after contracting Covid that could not be explained in any other way began to report on these on social media, share their experiences with

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[6] See Hannah E., Davis et al. Long COVID: Major Findings, Mechanisms and Recommendations. In: *Nature Reviews Microbiology* 21 (2023), 133-146. https://www.nature.com/articles/s41579-022-00846-2; Pia Kruckenhauser, Pia: „Was bedeutet es eigentlich, wenn man Long Covid hat? In: *DER STANDARD* (4 January 2024).
https://www.derstandard.at/story/3000000199252/was-bedeutet-es-eigentlich-wenn-man-long-covid-hat (24.9.2024).

[7] See Elisa Perego, Felicity Callard: Patient-Made Long Covid Changed COVID-19 (and the Production of Science, too): Analysis of Patients' Epistemic Contributions to a New Illness. In: *SocArXiv* (9 February 2021). https://osf.io/preprints/socarxiv/n8yp6 (18.9.2024).

others and collect them. At the same time, local lists of symptoms were created, which were then compared internationally. Long Covid sufferers passed on their experiential knowledge and thus also helped medical staff to gain insights into the then still unnamed, let alone, officially recognized, disease.[8]

Long Covid's clinical picture, as it is now described in scientific literature, mostly relies on patients' shared experience. Without this wealth of information, research would not have progressed as far as it has, nor would there be a growing public debate on the topic. The medical, social and political attention the disease has received is due mostly to patients coming together, sharing their experiences and communicating them to the outside world. Patient activism is not a new phenomenon, but digitalization has expanded and greatly accelerated the types of exchange.[9] This has enabled extensive networking, which, previously, only took place at a local level. Today, there are countless Long Covid groups (Long Covid SOS, Long Covid Europe). Some of the members are politically active, fueling public debate and working to raise awareness of the disease and institutional barriers. They also try to make their voices heard by the ministries in the hope that they can improve the care that, in many places, is still lacking and is otherwise rather patchy. Alexa Stephanou, co-founder of the Long Covid Austria group, did her utmost to make the discussion public in Austrian media. She also reached out to the Federal Ministry of Social Affairs, Health, Care and Consumer Protection in matters of work regulations.

Initially, however, online Long Covid communities were primarily used to gather information. Patients report that the early exchange with others showed them that there were many sufferers whose symptoms persisted. Today, online groups are still seen as platforms for exchanging information about the latest developments, possible treatments, medication and doctors. Sometimes, they also serve to give vent to the pent-up anger and frustration that often arises after visits to the doctor, the failure of therapies, meetings with experts or court hearings. Alix sees obtaining information as a duty she owes to herself: "And that I'm able to find the resources I need on the internet. But that's a state

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[8] For work on patients' subjective experience and its value, especially in the context of the pandemic and Long Covid, see especially: Sarah Atkinson et al.: Seeing the Value of Experiential Knowledge through Covid-19. In: *History and Philosophy of the Life Sciences* 43.3 (2021), 85. doi:10.1007/s40656-021-00438-y; Phillip H. Roth, Mariaclara Gadebusch-Bondio: The contested meaning of 'long COVID' – Patients, doctors, and the politics of subjective evidence. In: *Social science & medicine* 292 (2022), 114619 (1-8). doi.org:10.1016/j.socscimed.2021.114619 (24.9.2024).

[9] See Alan Petersen et al.: The Shifting Politics of Patient Activism: From Bio-Sociality to Bio-Digital Citizenship. In: *Health* 23.4 (2019), 478-494. doi.org:10.1177/1363459318815944 (24.9.2024).

of mind. It might take some time, but I'm determined to find answers. So, for instance, I wrote to all sorts of people mentioning possible treatments or the benefits of light therapy. And we had some very interesting conversations, and I just won't stop researching. I think that's just my duty to myself."

Daniela remembers how she tried to find out about the illness at the beginning, when many facts were still unclear to her,

> I called two friends who had gone through the same thing after catching Mononucleosis. Well, they had had Chronic Fatigue Syndrome, [...] they were both housebound for a year and bedridden for six months. And I was very lucky to know two people who had experienced the same and recovered again. Who managed to get out of it. Because when you read about it on social media, you get the feeling that it will be like that forever. That it will stay this way, and that makes you even more desperate [...].

What Ellie is referring to here has also been made clear by other interviewees: while online exchanges can be very helpful, it takes a certain degree of emotional distance and the ability to reflect to use these platforms and not be emotionally affected. The dissatisfaction and frustration that is sometimes channeled there can be difficult to process. The reports of the terrible fates of the many people, including the young, who have not recovered are frightening. For Niklas "a self-help group, where patients exchange information, [is] a double-edged sword [...] because everyone writes about what has helped them and then sometimes dubious therapies are shared there as well and alternative medical treatments. [...] Such a self-help group can help but can [...] also give false information." Despite this problem, which many of those affected are aware of, such groups are a place for solidarity. They show that even today there are still people who are willing to help others – anonymously and for free. One of our twenty-one interviewees talks about how another member of the group has helped them get access to an off-licence medication unavailable in Austria. They do not know, until today, who their benefactor was: a benefactor who committed criminal offence only to help them.

Community Action and Lessons Learned

Living with Long Covid relies on community action: our interviewees talk to us about people who help get off-licence drugs, who set up associations to raise awareness locally, nationally and internationally, and who raise funds for others and for research, who organize charity events and public campaigns to fight for themselves and for others. Niklas mentions that he is currently in the process of co-founding an association, "[p]recisely because it is so difficult to get social benefits and many people don't believe them or underestimate the severity of the symptoms." Nadine has an online account that she uses to share her experiences and encourage others. Although she is still very weak and is lying on the couch the whole time we are talking, she is active on social media because she feels a constant "urge for activism, my mini activism. [...] I opened an Instagram account in June or so,[10] where I just talk about my life or my thoughts [...] as a chronically ill person and social worker and mother [...] and try to draw attention to things. And last week, there was also a short report about me on TV. [...] Of course, that takes a lot of energy." This type of self-empowerment is pervasive amongst Long Covid patients. It is also important for Dini to participate in joint campaigns. She was unable to take part in the *NichtGenesen*-campaign[11] because she was too weak. *NichtGenesen* is an association of people suffering from Post Covid, ME/CFS and Post Vac and their relatives who are committed to research, recognition and care for their diseases. "I did take part in the ME/CFS demo on May 12, which took place in front of the parliament, where the shoes were standing. That's right, I sent shoes there and also a note, and I was there in person in a wheelchair. I was even interviewed." That was exhausting: she collapsed on site and had to be looked after by friends.

Although they often have little strength and even though they know they may suffer relapses, many Long Covid sufferers decide to talk about their experiences. They gradually try to improve the situation for themselves and for others. Even if this often means taking tiny steps. Ellie is happy because she has managed to get air purifiers for her child's school by talking to the school management: "We now have a 'clean air' working group." The fact that her actions can make a difference also empowers her. Nadine tells me: "my voice may not be anything big, but I feel like I'm a bit of a little grain of sand." She is happy that she is "doing something about the conditions; that the world is getting less hostile to disabled people; that it's becoming less hostile to women [...]."

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[10] Instagram.com/rien.nna.

[11] *NichtGenesen*, 2024. https://nichtgenesen.org/ (18.9.2024).

Fig. 8: Tanja’s Discman, Daniela’s air purifier, Nadine’s Instagram account or tiny presents for Sabine’s children exemplify the ways in which networks of dependence help in times of illness.

Networks of interdependencies do not only refer to the pandemic and the way that illnesses spread and take hold of the world and the popular imagination. Networks of interdependencies can also be seen in a positive light: as structures of support and sustainability that provide relief in straining times. From the couch, the bed and the mask that offer a hold in times of incapacitation, drawings of angel-dragons that are supposed to remind one of one's peers, and a Discman that makes isolation less frightening, to cooking, driving, cleaning, washing, choring, falling asleep from exhaustion, to calls for action and (mini) activism: all these belong to support networks that make life with Long Covid possible and bearable. But they are not enough. They should not be the only support that holds the burden of illness.

Long Covid patients have to make the most of their scarce resources. They are not the only ones. Many people *are* chronically ill. Many will become so in the coming years[12]. Wouldn't it be desirable to systematically restructure welfare- and healthcare systems with a view to these growing numbers and future generations? Isn't this one of the lessons Long Covid may teach us? This is a great challenge. And the call for structural change might sound almost like a call for revolution. The leap from the lives of individuals to structural challenges facing the healthcare system is huge and sounds rather utopian. What exactly would such a system look like? Would the development of a common vision be a first step towards a new normality with a welfare- and healthcare infrastructures that cater to the needs of the chronically ill?

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[12] See OECD: Chronic disease morbidity. In: *Health at a Glance 2019: OECD Indicators* Paris 2019, 78-79. doi.org:10.1787/5101558b-en (23.9.2024).