

# “You Think You’re Going to Get Better”: A Creative-Relational Inquiry Into Long Covid and Physical Activity

Qualitative Inquiry

1–8

© The Author(s) 2024




Article reuse guidelines:

[sagepub.com/journals-permissions](https://sagepub.com/journals-permissions)

DOI: 10.1177/10778004241234633

[journals.sagepub.com/home/qix](https://journals.sagepub.com/home/qix)

David Carless<sup>1</sup>, Jane Ormerod<sup>2</sup>, Kitrina Douglas<sup>3</sup>, Denise Kan<sup>4</sup>,  
Rachel Meach<sup>5</sup>, Lawrence D. Hayes<sup>1</sup>, Natalie Hilliard<sup>6</sup>, Joanne Ingram<sup>1</sup>,  
Jacqueline L. Mair<sup>7,8</sup>, Marie Mclaughlin<sup>9</sup>, Nilihan E. M. Sanal-Hayes<sup>10</sup>,  
and Nicholas F. Sculthorpe<sup>1</sup>

## Abstract

This creative-relational inquiry explores the lived experience of people suffering from Long Covid. Responding to calls for a publicly oriented qualitative inquiry, we collaborate across an extended project team to develop and share an accessible and engaging performance text which advocates for and supports those who live precariously as a result of contracting Long Covid. We offer our performance text as a resource to inform and guide personal, professional, public, and policy responses to Long Covid. We propose that creative-relational inquiries such as this beneficially extend understanding beyond what is possible through traditional evidence-based medicine alone.

## Keywords

arts-based research, evidence-based medicine, illness narratives, Long Covid, performance text, physical activity

## Introduction

At the start of their edited volume *Qualitative Inquiry in the Public Sphere*, Denzin and Giardina (2018) call for qualitative researchers to “take up research ‘outside the academy’ . . . to engage with concerns that align with activist-oriented scholarship, or at least that which centers social change as part and parcel of the research act” (p. 2). They acknowledge, however, the magnitude of challenge this task presents, particularly under current conditions which they suggest are characterized by “accountability metrics, extramural funding pressures, and the new managerialism rampant in administrative hierarchies of higher education” (p. 2).

Within this climate, Holman Jones (2017) proposes that critical qualitative inquiry might be constructively construed as “action and speech that creates a space between participants—between we, as a community of scholars, artists and teachers,” and between “we, as a privileged and ethically responsible assembly of human beings who must struggle to support other beings who are subject to precarity, inequality, and injustices” (p. 131). She invites us to consider our work as qualitative researchers “as a relation of the *freedom to speak* that enables us to act ethically (and equitably, supportively, persistently, and resistently) with and toward one another” (p. 131).

We take up these challenges in our current project, a pragmatic trial and narrative inquiry funded by the United Kingdom’s National Institute for Health and Care Research. This article focuses on the early stages of our narrative inquiry which explores the lived experience of people with Long Covid in Scotland. In keeping with Denzin and Giardina’s (2018) conception of public research as reach beyond the academy, we see our extended project team as including multidisciplinary researchers and academics, study participants, public involvement group members and

<sup>1</sup>University of the West of Scotland, South Lanarkshire, UK

<sup>2</sup>Long COVID Scotland, Aberdeen, UK

<sup>3</sup>University of West London, UK

<sup>4</sup>The University of Alabama, Tuscaloosa, USA

<sup>5</sup>Durham University, UK

<sup>6</sup>Physios for ME, London, UK

<sup>7</sup>Singapore-ETH Centre, Campus for Research Excellence and Technological Enterprise, Singapore

<sup>8</sup>National University of Singapore, Singapore

<sup>9</sup>University of Hull, UK

<sup>10</sup>University of Salford, UK

## Corresponding Author:

David Carless, Sport and Physical Activity Research Institute, University of the West of Scotland, Hamilton International Technology Park, South Lanarkshire G72 0LH, UK.

Email: [d.carless@hotmail.com](mailto:d.carless@hotmail.com)

stakeholders, and audiences for the research. To include, take seriously, and incorporate in a meaningful way experiences and perspectives from this diverse community, we build on recent work (e.g., Carless et al., 2024; de Andrade, 2022) utilizing the approach of creative-relational inquiry. Wyatt (2019) conceptualizes creative-relational inquiry as “inquiry that seeks not to ‘capture’ and hold still, but to find a way, through desire, to do justice to the fluidity of process” (p. 45). He proposes that it moves beyond common-sense understandings of creative (e.g., notions of making, of being artistic) to embrace “a radical, creative opening-up-to-what-may-be, an opening-up within an encounter [that] is not a confrontation with a thing but a relation that is sensed, rather than understood” (p. 45).

In this inquiry, we use collaborative storytelling—both oral and written—to share, explore, and co-produce accounts of the lived experience of Long Covid. Through our creative and relational collaboration, we offer a close-up, polyvocal story of Long Covid experience that aims to engage and inform practitioners, health professionals, and the public. Before sharing our creative-relational inquiry, we first provide a brief background concerning the context and development of Long Covid in the United Kingdom and Scotland since its genesis during the first Covid-19 lockdown in 2020.

## Long Covid in the United Kingdom

The term *Long Covid* has come to be accepted and widely used to describe the prolonged and debilitating symptoms which can follow Covid-19 infection (Greenhalgh, Sivan et al., 2022). In their study of patient experiences of Long Covid, Rushforth and colleagues (2021) report that participants described symptoms that can be “inconsistent and vague, affecting any or many body systems” and which come and go “without rhyme or reason” (p. 4). Participants described two particularly debilitating symptoms: cognitive blunting—or “brain fog” as some participants called it—and “exhaustion so profound they could barely move” (p. 4).

While the prevalence of Long Covid remains uncertain, it is significant. A 2022 report (Greenhalgh, Sivan et al., 2022) suggested that around 2 million people in the United Kingdom (approximately 3% of the population) were at the time suffering from Long Covid. Of these, more than 800,000 people experience symptoms that persist for more than a year and more than 400,000 still experience symptoms after 2 years. Figures suggest that by the middle of 2022, around 70% of the UK population had been infected with the Covid-19 virus and that between 4.2% and 5% of these went on to experience Long Covid (Office for National Statistics, 2022).

In Scotland specifically, around 187,000 are currently experiencing Long Covid, which equates to 3.5% of the population (COVID-19 Recovery Committee, n.d.). In our

recent cross-sectional survey, the most prevalent Long Covid symptoms in Scotland were post-exertional malaise, fatigue, cognitive impairment, breathlessness, headache, and sleep difficulties (McLaughlin et al., 2023a), broadly in line with the general consensus of the literature. Those living in a lower Scottish Index of Multiple Deprivation rated neighborhood were likely to report a greater number of symptoms, severity, and frequency of some symptoms. Vaccine status, age, sex, and smoking status had limited or no effect on symptoms. In the second part of our survey of people residing in Scotland, we documented the impact the disease and its symptoms have had on those living with the condition (McLaughlin et al., 2023b). People with Long Covid were often severely impacted in their ability to work and study. More than half of those surveyed changed their working hours and nearly 60% indicated that their work had been severely impacted by Long Covid. In summary, the unique characteristics—often including deprivation (Scottish Government, 2020)—of the Scottish population suggests that Long Covid has severe socioeconomic effects.

Despite the prevalence, severity, and consequences of the condition, Callard and Perego (2020) observe that Long Covid has only been acknowledged and accepted by the wider scientific community as a result of concerted patient efforts. Prior to this, there was widespread disbelief or suspicion of the existence of the condition, with reports of gaslighting and denial by health professionals (Rushforth et al., 2021). It is through online exchanges and social media that most people shared their illness stories, not with health professionals or physicians but with each other. And it is only through these communities that many were heard, witnessed, and able to receive confirmation and validation of their condition. As a result, Callard and Perego (2020) describe Long Covid as a patient-made condition—that is, “the first illness to be made through patients finding one another on Twitter and other social media” (p. 1).

Under these conditions, accounts of lived experience have been critical in guiding personal, professional, public, and policy responses to Long Covid. One person’s published story, for example, has provided solace for many patients and (through sharing with health professionals) influenced medical practice (see Callard & Perego, 2020; Garner, 2020). For Rushforth and colleagues (2021, p. 7), “Stories were (and continue to be) a crucial resource for long Covid sufferers to build awareness and mobilize action in others.” It is into this wider social, cultural, and political ecology that we insert our own creative-relational inquiry.

## “You Think You’re Going to Get Better”

### *A Researcher’s Voice: David’s Story*

Head out at first light to a small cove, near where I live. If I get there early, I’ll have it to myself. Branch off the coast path I’ve

walked so many times, squeezing between gorse and thistle. Two signs read: “Steep Cliff Path Ahead” and “Clothing Optional.” It’s rained overnight, the path is slippery, with a 200-foot drop to the rocks below. It’s worth the risk.

Ocean swimming has become my activity of choice these past couple of years as, one by one, other activities have been rendered impossible through the vagaries of health. No more running. No more weights. Currently, no surfing. At times, no yoga. Lately, I’ve not even been able to sit to meditate. Swimming in the North Atlantic is one thing I still get excited about. Each time I catch my first view of the ocean, I feel myself come alive. *I can’t wait to get in the water!* I’m reminded of the words of an Olympic swimmer Kitrina Douglas and I interviewed nearly 20 years ago: “When I see water, I have to get in it. When I smell a pool, I *have* to get in it. I’m sorry—it’s an obsession.”

This morning, I slip and slide down the cliff path, between ferns and boulders, grabbing for the rope considerate souls have installed to help others down to and back up from the cove. I tell myself to slow down, be careful, that I have time. I stop to look at the clear water beneath, the small waves breaking over golden sand as the tide recedes. There’s no-one around, just as I hoped.

Once on the beach I undress and stash my stuff. Goggles, trunks, swim hat, and stopwatch. The stopwatch is the most important item. Today, the water is 63 degrees Fahrenheit. About as warm as it gets in the United Kingdom, but still cold. I am OK in this temperature for half an hour. Forty minutes at most. Once I swim out from the cove, there’s nothing but ocean and towering cliffs. There’s no place to get out. I must get back to the cove before I’m too cold to swim.

Before entering the water, I survey the scene. Two rocky islands. A modest swell, light breeze from the northwest. A nose sticking out of the water, 300 feet offshore. One of the local locals: a gray seal. I wonder if it is the seal that I met last Sunday, the one that surfaced in front of me, eyeball to eyeball, just six feet away. We gazed at each other for a minute or two. She was all whiskers and snorting. I was all open mouthed and breath-holding. I said hello, asked her how she was doing. She didn’t answer. After a while, she dived, disappearing from view. Then, I felt her touch my foot. Moments later, I felt her brush against my leg. Slippery and slightly furry.

As I start to swim, I feel my body open and relax. I’ve come home. I feel like I am myself once more. Calm. At ease. Buoyant, supported by deep saltwater. I’m propelling my body effectively, free for now from pain, fear, distress, or exhaustion. I feel the undulating swell gently lift then release my body. Today, the water is clear enough to read my watch but deep enough that I can’t see the ocean floor. I am present. I am nowhere but here.

Back on the beach, I dry, dress, and pour a cup of hot tea from my flask. I’m shivering, need this to warm up. Pale

sunlight is just beginning to hit the beach. Barefoot, I stand, cup in hand, at the waterline. I notice now that I’ve brought my work with me: our Long Covid research. I don’t have my laptop. No network connection. No mobile phone. Not even a notebook or pen. But it is with me, nonetheless.

“It” is the first interview Rachel, our project’s qualitative research fellow, conducted. I read the transcript yesterday. “Read” is not the right word. I *lived* the transcript—dwelling, experiencing, and feeling between the words on my laptop screen. The words that hold the story Jane told of her life these past couple of years, of the time since she contracted Covid-19, just before the first lockdown hit. In some ways, her story overlaps with my own: I know some of the experiences she describes, too. In other ways, our stories differ, not least the magnitude of disability Jane has had to face. But I identify with Jane, nonetheless. Her story resonates in me.

I realize now, alone on the beach—tired, damp, and shivering—that this story is too important to leave out of our research. And, before me now—taking form somehow as I climbed down a cliff path, swum and floated in an ocean, shivered on a beach with a flask of tea—is the answer to the question of how to include it: through a creative-relational inquiry.

### *A Patient’s Voice: Jane’s Story*

You think you’re going to get better. You naturally think you’re going to get better when you have something like that. It was the middle of 2020 when I realized this wasn’t going to go away.

I remember the first day of lockdown so well. I was scared. *Scared*. Yeah. I can remember feeling unwell and thinking, “Well, I’ve got it.” There was no testing then. Having to isolate, being on my own in a bedroom for a couple of weeks. The night times were *so* awful—had a lot of tachycardia, chest pain. I thought I was going to die. I really did. But you can’t go and wake somebody up and say, “I think I’m going to die.” I remember how kind people were around here. I had somebody that would come and walk the dog for us and somebody that would fetch some shopping. People just banded together.

Once I got over that acute thing, I had a bit of a lull where I thought I was getting better and I could get out and have a walk. We’ve got a little garden, so I’d sit out in the garden. And I remember we just used to watch the news every evening. We stopped doing that actually ’cause it was, in terms of the figures, just going up and up and up. It didn’t help my state of mind.

A bad day, and there were a few of those in 2020, was when I was trying to juggle feeling absolutely awful physically and mentally, and trying to speak to a GP, not really getting anywhere, getting increasingly upset. When you finally do speak to them, it’s a waste of time in terms of

them taking onboard that I'm not getting any better. I need more investigations! It's like people don't believe you. What do they think? That I'm making it up? I had it said to me lots of times: "Have you thought about taking tablets for your anxiety?" I never took any tablets because anxiety wasn't causing my physical or mental symptoms. It was the fact that I had an illness that didn't seem to be getting any better.

It does take its toll on other people. To start with, my husband took care of me a lot. The family, they probably found it quite difficult to get their head around: "What is that?" "Why are you like that?" "Why are you not getting better?" We Facetimed a lot and they worried because there were days—and I still have them now—where I look absolutely crap. You can't get away from that. When people ask you how you feel, that continues to be a challenge. My little thing that I've got now is: "Well, today is not a bad day." That's what I say.

Post-exertional malaise? "Malaise" describes it totally. It's like a thing that comes upon you. It might start with feeling a bit sick, a bit shivery, like I can't control my legs. It's like someone's turned the battery down. I might have a headache come on. I might feel a bit breathless. It's like it's telling you: "Look if you don't lie down now, you're gonna collapse."

If you do too much, it makes your symptoms worse. Pre-Covid I could go at a hundred and ten miles an hour. I'd zip round doing housework, walk the dog, go to the shops, do some yoga. I might go out on my bike, do a bit of gardening. The pace would be fairly swift. Not a lot of sitting down. I've got to drive somewhere today, we're going up the coast for a couple of days, an hour's drive. I'll have a kick back from that. I'll have post-exertional malaise either tonight or tomorrow. Sometimes it might be just a fleeting thing, couple of hours, then it slackens off. It might come back a bit later. Sometimes it can last a whole week.

Don't have many days that my life is not touched by Covid. That's the big thing to get your head round, in terms of acceptance: making the best of what you can do and realizing there will be days when you can't do very much at all. Prior to Covid, as part of my role in the NHS, I had a reasonable grasp of what I needed to do to keep myself on the path of good living as it were. But when you've had the two and a half years I've had you're convinced that something else is gonna happen to you. So, trying to find strategies for when your mind starts wandering off and bringing it back. Managing your thinking. Managing your language as well. Little things, but quite big things.

I had huge problems with sleep and to some extent I can manage that now. I still use the Calm app if I can't sleep at night. And it just makes you feel a bit more control, it's like, "Well OK, it's not the end of the world if you can't sleep."

Yoga has been a godsend to me—it calms me down, helps me with my breathing and that helps me be in a better

place. I couldn't do it to the level that I used to. The first stretch that I do, I can tell if I'm gonna be able to proceed beyond five minutes. Sometimes I think, "No, not today" and leave it.

Counseling was really helpful. I would urge anybody to give it a go. After trying to tackle it three times with GPs, I couldn't stand it any longer and spoke to a nurse practitioner and she said, "Well this is not on, somebody needs to see you." It helped me a lot just to have somebody to talk to outside your own home.

The other thing was I got involved with Long Covid Scotland.<sup>1</sup> Before I joined, you're just swimming around in a muddy pond. There's nobody else in it. Or there were other people in it, but you couldn't find them. When I joined, I was like yeah, there definitely are people like me, and we've had a horrible experience and we're all in it together. It's trying to make something good out of something that's been absolutely grim. Both for me and for other people.

Those are the two things that have helped me the most: counseling and joining Long Covid Scotland. The other thing, the third thing I can't deny, is the support of my family and my husband. That's been . . . well, yeah.

The future? I try not to think "will it not get better" and just take every day as it comes. I'm not so reticent now about asking for help—medical help. If things are not so good, then you go and see somebody about it—bit by bit by bit. Symptom by symptom. Help them to understand what you're trying to do for yourself, so they get a bit more knowledge and experience in helping people with Long Covid.

You look back on it now and think, "God did that really happen?" But it did. We are where we are, and we did get through it. I think that's a big thing for everybody, especially for people who've lost people. I'm a pragmatist—I can see it's something that's not going to go away. It's like a bad smell and it's going to be around in various shapes and forms. Learning to live with it and learning to accept it is what it is, that's the way through for me. Just trying to everyday think, "Oh well, this is today, this is what we've got to deal with."

### *An Audience Response: Denise's Story*

I'm a registered social worker in British Columbia, Canada. At the same time, I'm pursuing my PhD in social work from the University of Alabama. I had been very careful because during the pandemic—2019 until 2021—I was working as a mental health clinician on the frontline. But I was diagnosed with Covid-19 in February. It became Long Covid. The doctor told me there's nothing they can do.

I still experience tiredness, foggy brain. My concentration's not as good as before. My memory isn't as good as before—when people tell me their name I turn around and I can't

remember. My self-confidence is affected too because I feel that I'm not capable. And my energy levels—I always feel fatigued. And the worst thing is its triggered anxiety as well.

I remember feeling hopeful as the “Narrative and Performance” panel at the International Congress of Qualitative Inquiry (ICQI) began at 9:30 a.m. on Friday, May 19, 2023. I was curious: *What is this?* The topic attracted me. Then when I heard your presentation—and I hear Jane's experience—that really touched me. I felt that—finally—somebody understands. Somebody is able to voice what has been going on. That kind of connection is very powerful. A lot of research has not talked about that—first-hand experience, using this creative, attractive, and powerful method to express what has been going on in a life. I found it very, very powerful.

It struck me how you, David, feel that you're still ill in the long term, but at the same time you are able to go back to nature. The description of the environment—the beach—that was very comforting. When you performed that, I had a picture of the seal scraping your leg as you swam. I love animals. Before the pandemic, I used to volunteer at the Vancouver Aquarium. So it brought back a lot of memories—to connect to nature and feel hope.

In a way, it is a privilege—you can still go swimming and you can still walk the coast path and climb the cliffs—compared to people with Long Covid who have had so many activities taken away from them. We can't be as active as we have been. But to me it is also a kind of freedom. It's giving me hope—that I *can* still do that. And nature, the ocean, is the only place you feel safe, right? You know how to swim, and you can enjoy that moment, forget about your pain. You were able to socialize with the seals! It's very beautiful actually to me, very beautiful, even though it's a privilege. It's an encouragement. A connection.

At that point in the performance, I felt sad. And angry. Because of some people's irresponsibility, no matter how careful I have been, I still got it. And now my life is totally changed. My perspective has also changed. It seems like my worldview has been changed as well. I don't feel safe anymore. Because of my past experience working as a mental health clinician in the frontline during the pandemic, I still remember that period of time. Very cautious. I had to wipe everything clean. I was *so* cautious. Social distancing, cleaning my hands very often. Then after work when I went back home, I changed my clothing, went into the shower right away. All these things. We were under huge pressure during the pandemic. In the southern United States, people are not very careful about this, they don't pay attention. And I got Covid. All these things still really trigger me to the extent that I don't trust people. I still try to maintain distance. I cannot be too close to people. It sometimes feels like I'm the only one experiencing Long Covid and people think I make a big deal of it.

I decided to approach you after your performance because I was excited—because I felt *finally* somebody can really help me to voice what has been going on in my life in the last few months. I also felt excited because of the creative way you expressed it. Very true. Very honorable. Very comforting. The connection was there. So, I also felt thankful that somebody can help me to voice out what has been going on in my life. I wanted to participate. I didn't know what would happen, but I told myself, OK, this may be my one and only opportunity, I want to reach out, I want to share how I feel. I also got inspired because no other professor has ever taught me this creative way.

There are many, many people suffering from long Covid, but they don't have the opportunity to share. You and your team, using this kind of approach, can really touch a lot of people's lives and empower people in our community. That is what I want to see.

### A Response Through Dialogue

*David:* It was a lot to share those three stories, all in one go. I hope that was OK, Jane?

*Jane:* It was fine. Well, I shouldn't say “fine.” But it was good. It's quite powerful, isn't it? It's the power of the link between those three very different people and very different circumstances. It's like a chain between them, isn't it? You're bound in some ways by Long Covid, aren't you? It's like a chain that's round your legs. But it also binds you to other people. And there's a strength in that, for the people concerned. Denise's point around being part of a community of people that have long Covid, but also from the research point of view. She is able to get something positive out of it in a number of ways. I think that's really powerful.

*David:* How was it for you hearing back your story in your own words?

*Jane:* Gosh, it's like, did I really say that? And I know I did. I suppose with the whole Long Covid thing, I can run it like it's a film in my head. And I still can three years later. I was listening to a podcast by somebody talking about her Long Covid journey. And one of the things she talked about was the trauma. At the time you realize it's absolutely bloody awful. But you don't realize it's a trauma until afterwards. I have enough knowledge of mental health to know that, yeah, for me it probably was a trauma. My reason for saying that is I think I kind of disregarded that. You like to think I've moved on from it. I've managed to get through the aftermath of it, I think, quite well. But it's still there in the background. I think you have to acknowledge it has been a trauma. And for many people it will carry on being. There's a role for health care and for public health policy around really taking on board the depth of that. You

know something being in place for people to help them to deal with it.

*David:* Part of the reason why we use these methods is that health care has become almost exclusively focused on evidence-based medicine (EBM). And it's a very narrowly defined form of evidence. It's really only evidence from clinical trials that is taken seriously. But in doing that, we've lost personal experience, any depth of understanding about an individual life. I've found with my own health problems that it's not that medical professionals haven't *wanted* to help, but they haven't *been able* to. I've had to follow various different paths to try to recover; making sense of it through reading, talking to different people, trying different things, and sometimes rejecting what a GP or specialist says. I understand now that most of the things I've found helpful *cannot* be evidenced through a randomized control trial. And because there is therefore no "credible" evidence for them, health professionals are not authorized to prescribe them.

*Jane:* I think you're totally right. I was a health professional. I was on that side of the fence for 40-odd years. What I've grappled with is, it's hard to describe, it's almost like, "Well, we know what's best for patients." And I say that with the awareness that there's a whole spectrum in Long Covid—from total dismissal and gaslighting at one end, to the other end where professionals are a lot more amenable to listening and taking on board what people say. And that does give me heart. Yesterday I was on a call with health professionals from the local Long Covid network. I was the only person with lived experience on the call. I was in the room but at no point in that meeting was I asked my opinion. I volunteered my opinion whether they wanted it or not. But I wasn't asked. It's not an intentional thing, it's just a way of working that's hard to change. And that is the balance of power in the relationship between health professionals and patients. Being involved in national strategy work around Long Covid, I witness that on a day-to-day basis. You think things have moved on a little bit, but I don't know if they have. It's not an intentional disregard. It's almost like, well, we'll just sail on like before cause we're a group of health professionals and now we've got people with lived experience in the group.

*David:* I'm sad to hear that it's still like that, Jane. It's like that in research too. Science is traditionally about being distanced, objective, and neutral. But that doesn't work if you're trying to understand personal and subjective experiences. So, for me, it's really important that we find ways of doing and publishing this kind of research alongside the science. We need stories as well. It's equally important to foreground rich accounts of lived experience so professionals, practitioners—and other patients—can learn from them.

*Jane:* I'm well aware it may not match up with what policymakers consider as evidence, but I think representing people's experience as part of this is crucial. It's especially crucial for a new condition like Long Covid, something we don't know much about. But we can learn so much from this way of dealing with the data; it's absolutely fantastic in terms of representing the real-life stories of people.

### *An Audience Response: Kitrina's Story*

One of my favorite books is *The Renewal of Generosity* by Arthur Frank. In it he writes,

Before and after fundamental medicine offers diagnoses, drugs, and surgeries to those who suffer, it should offer consolation. Consolation is a gift. Consolation comforts when loss occurs or is inevitable. This comfort may be one person's promise not to abandon another. Consolation may render loss more bearable by inviting some shift in belief about the point of living a life that includes suffering. Thus consolation implies a period of transition: a preparation for a time when the present suffering will have turned. Consolation promises that turning. To offer consolation is an act of generosity. (Frank, 2004, p. 2)

I was in the audience when you, David, performed this piece at ICQI. I remember being deeply moved. And I am moved again as I read it in written form, with the addition of Denise's testimony and Jane's reflections. What I think I experienced through the performance—and again through this text—is an act of generosity. Or, more precisely, a series of generous acts, offered through different voices. Multiple acts of generosity that unfold through relationships between persons involved in this project in diverse ways.

By that I mean two things. First, that this research has only been possible through the establishment of compassionate relationships. The relationship between Rachel and Jane (built during interview) made the telling of this harrowing tale possible. The relationship David developed with the text of Jane's interview; how by opening himself to it, making himself vulnerable through reflexively incorporating elements of his own illness experience, an innovative aesthetic representation of the "data" was realized. The relationship between Denise and the performance, enacted through sharing personal reflections on its resonance within her own life. And the relationships between the members of the research team, in reflecting on these rich, interwoven waves of personal testimony.

Second, it is apparent that this collection of voices—stories artfully curated in this form—act more powerfully *together*. Their power, meaning, and resonance are enhanced because they are in relationship with one another, side by side on the page. Jane commented on this, noting the

connections between the storytellers, bound together through their experiences of illness. It is through this togetherness that opportunities for consolation are made real. I heard echoes of consolation in responses from delegates at the ICQI performance, showing they learnt something new about Long Covid, about the brutal realities of this condition. Some reflected on how these insights connect to their own lives. I read powerful threads of consolation in Denise's response; both through hearing the story of a fellow Long Covid sufferer *and* through learning of—and experiencing—a way of doing research that brings hope and new possibilities. Consolation . . . made possible through generosity . . . enacted within caring relationships.

## Concluding Thoughts

Through this creative-relational inquiry we tell a different kind of story of and from our collaborative research project, a story that responds to Denzin and Giardina's (2018) call for publicly oriented qualitative inquiry. Our team comprises multidisciplinary researchers working with and for a range of stakeholders, including participants, public involvement group members, and audiences of the research. Using creative-relational inquiry has allowed us to collaboratively develop and share an accessible, engaging, and polyvocal performative text through which we take our place as part of an "ethically responsible assembly of human beings" committed to supporting others "subject to precarity, inequality, and injustices" (Holman Jones, 2017, p. 131).

Together, the diverse voices that comprise our inquiry constitute an innovative account of the early stages of our research study. Methodology is evoked in *David's Story*, while *Jane's Story* offers an in-depth personal testimony of one person's lived experiences of Long Covid, generated through narrative interview. Through *Denise's Story*, we trace the initial impact the research has made though foregrounding its meaning and value for one audience member also living with Long Covid. Through the dialogue between Jane and David, we pull back to offer personal reflections on the wider social, economic, and political issues that are developing around Long Covid and its treatment. Finally, through *Kitrina's Story*, we offer one theoretical interpretation of our creative-relational inquiry as an act of generosity within challenged and stretched health care environments.

"In the making of Long Covid," Callard and Perego (2020) write, "conventional hierarchies of evidence, and normative routes for scientific dissemination were frequently disrupted" (p. 3). The unprecedented chain of events that precipitated this disruption has prompted a paper provocatively titled, *Adapt or die: how the pandemic made the shift from EBM to EBM+ more urgent* (Greenhalgh, Fisman et al., 2022). In it, the authors—established and recognized proponents of EBM—conclude that it is "time to

bring in a wider range of evidence and a more pluralist approach to defining what counts as 'high-quality' evidence" (p. 253). They suggest these may include, for example, narrative accounts as well as new methodologies which address the complex systems within which health care is delivered in 21st century (which includes government, health service providers, and the public). Our creative-relational inquiry contributes a further rendering of what a more expansive conception of evidence-based medicine might look and feel like in future times.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work is independent research funded by the National Institute for Health and Care Research (NIHR) (Research Award COV-LT2-0010). The views expressed in this publication are those of the authors and not necessarily those of NIHR or the Department of Health and Social Care.

## ORCID iDs

David Carless  <https://orcid.org/0000-0003-1617-493X>

Kitrina Douglas  <https://orcid.org/0000-0003-1481-9642>

Lawrence D. Hayes  <https://orcid.org/0000-0002-6654-0072>

## Note

1. Long Covid Scotland is a volunteer-led charity run by people living with Long Covid on behalf of those living with Long Covid. The charity collectively advocates on employment and benefits, research, and local and national policy (<https://www.longcovid.scot>).

## References

- Callard, F., & Perego, E. (2020). How and why patients made Long Covid. *Social Science & Medicine*, 268, 113426. <https://doi.org/10.1016/j.socscimed.2020.113426>
- Carless, D., Douglas, K., Barnes, J., & Pineau, E. (2024). Sand in sculpture: Creatively rewilding ecologies of health. *Qualitative Inquiry*. <https://doi.org/10.1177/10778004241229786>
- COVID-19 Recovery Committee. (n.d.). *Long COVID*. <https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-covid19-recovery-committee/business-items/long-covid>
- de Andrade, M. (2022). *Public health, humanities and magical realism: A creative-relational approach to researching human experience*. Routledge.
- Denzin, N. K., & Giardina, M. D. (2018). *Qualitative inquiry in the public sphere*. Routledge.
- Frank, A. W. (2004). *The renewal of generosity: Illness, medicine and how to live*. University of Chicago Press.

- Garner, P. (2020). *For 7 weeks I have been through a roller coaster of ill health, extreme emotions, and utter exhaustion* [Blog]. *BMJ*. <https://blogs.bmj.com/bmj/2020/05/05/paul-garner-people-who-have-a-more-protracted-illness-need-help-to-understand-and-cope-with-the-constantly-shifting-bizarre-symptoms/?amp%3Bamp%3B>
- Greenhalgh, T., Fisman, D., Cane, D. J., Oliver, M., & Mcintyre, C. R. (2022). Adapt or die: How the pandemic made the shift from EBM to EBM+ more urgent. *BMJ Evidence-Based Medicine*, 27, 253–260. <https://doi.org/10.1136/bmjebm-2022-112046>
- Greenhalgh, T., Sivan, M., Delaney, B., Evans, R., & Milne, R. (2022). Long Covid—An update for primary care. *British Medical Journal*, 378, Article e072117. <https://doi.org/10.1136/bmj-2022-072117>
- Holman Jones, S. (2017). Assembling a we in critical qualitative inquiry. In N. K. Denzin & M. D. Giardina (eds.), *Qualitative inquiry in neoliberal times* (pp. 130–135). Routledge.
- McLaughlin, M., Cerexhe, C., Macdonald, E., Ingram, J., Sanal-Hayes, N. E. M., Hayes, L. D., Meach, R., Carless, D., & Sculthorpe, N. F. (2023a). A cross-sectional study of symptom prevalence, frequency, severity, and impact of Long-COVID in Scotland: Part I. *American Journal of Medicine*. Advance online publication. <https://doi.org/10.1016/j.amjmed.2023.07.004>
- McLaughlin, M., Cerexhe, C., Macdonald, E., Ingram, J., Sanal-Hayes, N. E. M., Hayes, L. D., Meach, R., Carless, D., & Sculthorpe, N. F. (2023b). A cross-sectional study of symptom prevalence, frequency, severity, and impact of Long-COVID in Scotland: Part II. *American Journal of Medicine*. Advance online publication. <https://doi.org/10.1016/j.amjmed.2023.07.009>
- Office for National Statistics. (2022). *Self-reported Long COVID after infection with the Omicron variant in the UK: 18 July 2022*. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/selfreportedlongcovidafterinfectionwiththeomicronvariant/18july2022#:~:text=%22Today%27s%20findings%20show%20that%20approximately,risk%20to%20the%20Delta%20variant>
- Rushforth, A., Ladds, E., Wieringa, S., Taylor, S., Husain, L., & Greenhalgh, T. (2021). Long Covid—The illness narratives. *Social Science & Medicine*, 286, 114326. <https://doi.org/10.1016/j.socscimed.2021.114326>
- Scottish Government. (2020). *Poverty and income inequality in Scotland 2016-19*. <https://www.gov.scot/publications/pov-erty-income-inequality-scotland-2016-19/pages/3/>
- Wyatt, J. (2019). *Therapy, stand-up, and the gesture of writing: Towards creative-relational inquiry*. Routledge.
- interdisciplinary arts-based and narrative research. He works at the University of the West of Scotland and is an honorary professor in the Centre for Creative Relational Inquiry at the University of Edinburgh.
- Jane Ormerod** is Chair of Long Covid Scotland. She is committed to enabling those with Long Covid to get prompt effective treatment and care.
- Kitrina Douglas**, PhD, is an award-winning researcher whose work spans the arts, humanities, and social sciences. She publishes her work as films, documentaries, poems, songs, stories, and musical theater, along with written publications in both academic journals, news media, film and multimedia.
- Denise Kan**, LMSW, RSW, is a licensed and registered social worker in New York, USA and British Columbia, Canada. She is pursuing her PhD in social work at the University of Alabama, USA, interweaving scholarship and practice to further contribute to communities in need.
- Rachel Meach**, PhD, is a research associate at Durham University. She has a PhD on the history of diabetes using oral history methodology. Her academic work centers around the use of narrative methods to understand the lived experience of chronic disease.
- Lawrence D. Hayes**, PhD, is an exercise physiologist by training who has published over 90 journal articles concerning physiology and other health-focused topics. He is co-I on several funding awards for research concerning Long COVID and ME/CFS.
- Natalie Hilliard** specialises in physiotherapy treatment and management for people with ME, post-viral illnesses and long covid.
- Joanne Ingram**, PhD, is a senior lecturer in psychology at the University of the West of Scotland. Her published work is in the field of cognition, particularly cognitive function, and language processing.
- Jacqueline L. Mair**, PhD, is a senior scientist in mobile health interventions with the Future Health Technologies program at the Singapore-ETH Centre, Core Director of Behavioural Health and Disease Prevention with the Centre for Digital Health Interventions at ETH Zurich, and Honorary Senior Research Fellow at the Saw Swee Hock School of Public Health at the National University of Singapore.
- Marie McLaughlin**, PhD, is a postdoctoral fellow at University of Hull and has several publications investigating Long COVID and ME/CFS.
- Nilihan E. M. Sanal-Hayes** is a lecturer in psychology at University of Salford and conducts research within Centre of Applied Research.
- Nicholas F. Sculthorpe** is a Professor in the Sport and Physical Activity Research Institute, University of the West of Scotland.

## Author Biographies

**David Carless**, PhD, is a researcher, writer, musician, and filmmaker. He has published numerous articles, chapters, and films on