Ars Medica

A Journal of Medicine,
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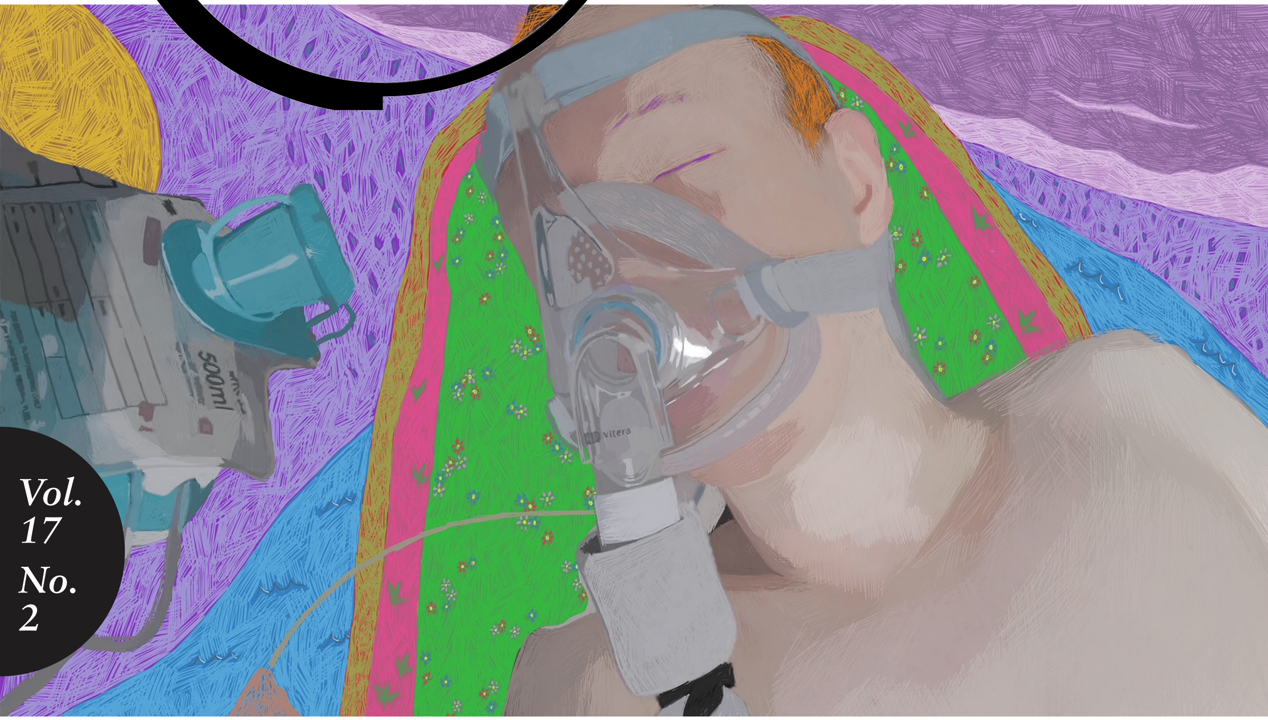

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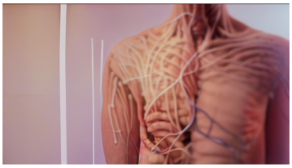
I want you to see the way I see you / Of Doing Illness
by Brad Necyk


I want you to see the way I see you


Of Doing Illness

Brad Necyk's artistic practice focuses on mental illness, empathy, consciousness, and flourishing. He completed a research-creation PhD at the University of Alberta, recipient of the Governor General's Gold Medal. He is a Postdoctoral Fellow at York University with VISTA and Cinema & Media Arts. He explains the front cover: "In the thick of it—illness—it's hard to see beauty, visions, illumination, and the rest. But often, it is the mud from which beautiful flowers grow." "Of Doing Illness" expresses that there is an art to doing illness. The patient becomes an expert, honing their craft, attuned to their illness's folds and fissures, ebbs, flows, and rhythms.

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Editorial

Frictions of Futurity, Curative Tensions, and Artistic Re-imaginings of Transplantation

Biomedicine is, broadly speaking, argued to aim toward futures shaped by a pervasive curative imaginary—that is, the disciplinary matrix, frameworks, and practices that orient toward cure and its proxies as the only rational possibility. Here, disability is uncontroversially and simultaneously a tragedy and a problem to be solved; medical intervention is not only desirable, it is imperative (Clare, 2017; Kafer, 2013). As a field of biomedicine, solid organ transplantation is a space in which curative futurities are particularly pronounced: health is offered through the twinned possibilities of technoscience and altruism; promise, transformation, and curative embodiments that are imagined to be free of disablement mark the field, practically as genre (Heinemann, 2020). However, because the contours of the curative imaginary are often part of the taken-for-granted aspects of daily routines and practices of transplantation, they are not easily captured for analysis or critical reflection (Abbey, 2011; Berkhout, Fritsch, Frankel, & Sheehan, 2022).

At the same time, transplant medicine is also a field marked by frictions: entanglements of self with other, graft with host; biomarkers, biopsies, devices, pills, and surgeries blur inside with outside. Hope and cure are paired, inevitably, with dying, chronicity, and the impossibility of being beyond illness (Heinemann, 2020). Temporal hauntings of before shape the afterward. Bodied absence (as with the removal of a failing organ) is juxtaposed with new presences that are themselves formed in absence and loss (McCormack, 2021). And in the day-to-day, commonplace struggles span this field. Whether through the investigations and assessments that enable listing, the interventions that arise while waiting for transplant, the many complications and complexities of medical regimens (and surveillance of the same) that occur in the aftermath of transplant, or the physical and emotional challenges of survivorship that arise farther out from the drama of surgery—time is borrowed and looped and experience lived in ways that undercut the seemingly straightforward and linear relationship between transplantation and cure. Insofar as articulating the complex personal costs of transplant rubs against cultural scripts of miracles and gratitude, relatively few come to witness how isolation, trauma, and affective messiness are also part of the scene, even if held out of frame.

As a site of deep ambivalence and tension with respect to futurity, where the possibility of having an “afterward” is an ever-shifting horizon, transplantation becomes a rich field for artistic engagement, exploring how binary logics of self/other, cure/harm, inside/outside, absence/presence structure biomedicine’s curative imaginary. Artistic practices offer novel ways to interrogate such bifurcations through counter-logics of sensation, affect, simultaneity, and multiplicity. Art reconfigures ways of knowing and sensing worlds (Rancière, 2006), providing opportunities for the emergence of new enactments within creative processes and artistic products (Borgdorff, Peters, & Pinch, 2020). Importantly, acts of breaking down, interrogating, resisting, queering, shifting, and complexifying binaries (including of beauty and ugliness) are significant, political aspects of disability aesthetics and disability art (Rice, Chandler, Rinaldi, Changfoot, Liddiard, Mykitiuk, & Mundel, 2017; White, 2017). If claiming crip is to imagine multiple futures where disability and non-normative bodyminds are desired differently and the social meanings attached to shifting abilities are understood as situated and intersectional (Fritsch, 2015; Kafer 2013; Schalk 2013), then artistic practices are an important location for cripping material-discursive worlds (Hamraie & Fritsch, 2019).

These are the tensions and desires that have driven the construction of this special issue of *Ars Medica*, "Frictions of Futurity, Curative Tensions, and Artistic Re-Imaginings of Transplantation." Each of the pieces within this issue, in their own way, invites a reimagining of the relationships between transplant technoscience, lived experiences that span the transplant process, aesthetics, and disability. Through generative tensions and juxtapositions (whether within a given piece or as the contributions are held/read/seen against one another), the collection explores how, as Donna McCormack, Lynne Zakhour, Richard Kahwagi, and Ingrid Young describe in the introduction to their image/text essay "Bodies on the Border," arts can express experiences that have been silenced or denied (McCormack et al., this issue). Artistic and creative making and doings are, in this way, onto-ethico-epistemological practices that are world-knowing and world-making (Barad, 2007). We have curated this issue so as to bring forward knowing/making in ways that resist erasures common to disabling practices and structures that surround transplantation.

Numerous themes cut across this special issue that help us understand how artistic works can offer affordances of crip spacetime in relation to transplantation. Complexity and the intertwining of life/death, hope/dread, absence/presence are foregrounded in each of the pieces within the special issue. The shifting and unstable cut between these binaries are especially palpable in the pieces that layer multiple artistic forms of engagement, such as image or film with prose. Multimodality mobilizes different sensorial engagements simultaneously, generating powerful emotional understandings within a convergence of different forms of signification (whether image, gesture, speech or inner stream of consciousness). Multimodal representations afford different kinds of meaning (Hull & Nelson, 2005); these different kinds of meanings are ones not easily spoken in clinical spaces or even in the domestic, private spaces of home, as showcased in Bibo and Brian Keeley's feature piece. Revisiting the emotional vortex and shared/individual trauma of Brian's transplant through diaries, collaborative film, and still image, "The Liquid Light," asks us to consider what is shared and what is held back, how do we cope, and what scars does that coping leave, in the midst of critical illness. These are questions that circulate throughout the Keeleys' works and the pieces of the special issue, just as they circulate and are relived in the daily lives of transplant recipients, donors, and carers.

Donna McCormack, Lynne Zakhour, Richard Kahwagi, and Ingrid Young's "Bodies on the Border," Dominic Quagliozzi's "Visceral Diary," and Tereza Crvenkovic's "Pain 21" similarly engage viewers/readers with the haunting aspects of transplant wounds, showing how the imbrication of life/death in transplantation are not merely whispers, or hints, or uncanny sensations—they are deeply bodied, material, and fleshy. By representing pain and loss in surprising ways, part of what becomes voiced are the myriad ways in which these experiences can be silenced through the public expectations of transplant recipients. The patronizing and cheeky phrasing of Quagliozzi's "Smile You're Alive," depicted through comic-style bubble letters, visually foregrounds the pain of this lighthearted erasure. Cheeky and playful form is also powerfully mobilized in Andrea Barrett's "Transplant Tarot Triptych," which draws attention to the ways that archetypes shape the field.

Form is central to the ways that artistic renderings create new knowledge in/of/about transplantation. Crvenkovic's opening letter finds resonance with the letters of Brian and Bibo Keeley. The formal qualities of these works—writing that takes the form of letters and diaries—invites the reader into what is otherwise private and interior;

the opposite of writing conventions such as the medical chart or even the expository essay. Form is also at the heart of Deirdre Hennings' "Life after Transplant (Contrapuntal)," which toys with separateness and blurring of voice and standpoint. The reader can move in a linear way to make sense of each opposing voice or attempt to cross the chasm on the page to read these together, reflecting the possibilities and the impossibility of knowing self/other, care giver/receiver—experimenting with different ways that these gulfs might be bridged or where silences still resound.

Silence is a compelling theme across many of the pieces, named explicitly in Alishia Hiebert's "The Silenced Side of Living Donation," while gestured to within the special issue's collection of poetry. The poetry within this collection provide a particularly powerful form of engagement with matters surrounding what it means to shift from living with one disease to another kind of medicalized existence that are not often spoken, by those giving or receiving care. To speak these truths would be to break the illusion of cure that transplant is built upon. And yet, artist practices are essential for opening experimental, expressive spaces that can offer partial truths and half-hidden realities. Revealing the half-hidden and questioning its meaning is on full display in Nancy Chong's "The Communicative Body," the politics of which resonate with spoken, unspoken, and speculative politics within "Justice & Borders," "Care as Violence," and "ReTool."

Jonathan Kawchuk's "Boundary Loss" engages an experimental sonic reflection on human-machine interfaces that are a hidden part of everyday transplant experience, resonating with descriptions offered in many of the issue's pieces. As a listening experience, "Boundary Loss" is difficult: it challenges an ugly/beautiful aesthetic binary, the blurring of which reveals a felt knowledge of transplantation as a field site that undermines the softness and comfort of transplant as a story of cure. "Dammar," "Primavera," and "Miracle Cures" bring us further into critical conversation with the common curative tropes of transplantation. Miracles, second chances, gratitude, and being willing to subject oneself to "whatever it takes" are repetitions and scripts that the artists' works challenge. "Dear Angelo," by L.J. Prance is titled in reference to what is miraculous about transplant and the idea of the donor as an "angel." At the same time, the piece offers ways of complexify the relationship to "the gift," by raising questions of the impossibility of speaking even the positive aspects of transplant as well as the difficulty voicing the shift in who one is and who one's kin might be.

This special fall issue of *Ars Medica* was conceptualized within the practices of the *Frictions of Futurity and Cure in Transplant Medicine* project, a multi-year, research-creation study that unabashedly sits at the convergence of crip technoscience, feminist science and technology studies, and arts-based research engaged with disability arts and artists. The impetus for the project and this special issue comes, in part, from an understanding that artistic practices can generate, as Natalie Loveless describes, “speculative frames through which to defamiliarize and reorganize the local” (Loveless, 2019, 101). This is art as micropolitics.

As you engage with the pieces of this special issue, consider how each of these might be part of a larger set of interventions that aim toward generating, revealing, naming, altering, and engaging with the multiplicity of frictions of futurity surrounding transplantation, persuading us to know differently and care differently (Loveless, 2019) so as to materialize liveability and thriving as political, creative acts.

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Suze Berkhout, Chloe Wong-Mersereau, &
Kelly Fritsch

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The Liquid Light

Bibo Keeley & Brian Keeley

DEAR BRIAN

Bibo Keeley

Dear Brian,
I have not written to you for the last few days because I have been unable to find any words to express what has been going on inside me. Instead, I will describe what happened.

Saturday. At 10.30 a.m. Nurse J. called to tell me they might have a donor heart for you. I have not been sleeping well for a long time, and I was exhausted and overwhelmed with so many different emotions that I wasn't as composed as I wanted to be. I hurriedly got out of bed, dressed, and rushed over to the Intensive Care Unit. I had to wait until your special pre-operation bed-bath was finished. Standing outside the ward door I started to cry. Dr S. came round the corner, and when she saw me, she gave me a hug. I tried to pull myself together, but as I entered your room, I still had tears in my eyes. So did you. I realised that we were both scared and I decided to be strong for you.

(See "BREATHE" by Brian and Bibo Keeley: https://www.youtube.com/watch?app=desktop&v=Kv2VtFtJOyk)

I told you that I was absolutely convinced that you would make it if your heart transplant were to go ahead. Everything would go well. I told you about the confidence others had shared with me, too—your aunt, your cousin, one our favourite nurses, and a friend back home. You appreciated that. Then I asked you what you were most scared of. You said, "That it's a life-or-death situation." I think what made it extra hard was that we had already been through the experience of our hopes being shattered after your transplant operation was stood down at the last minute two weeks ago.

You had been awake since 6:15a.m. and were so exhausted that you fell asleep a few times amidst all the preparation activity and the different people popping in to inform us about the procedure. Nurse J. made me a cup of tea with milk. The hot drink me made me feel less numb.

Later, we had some time to ourselves. I reminded you of the image that had come to my mind when I was sitting by your bed, right at the beginning, when you were in a coma. I had "seen" liquid light flowing through your body; a healing light, full of warmth, love, and energy. "I saw it, so it will happen," I said, "Your body will heal." The image seemed to give us both comfort. You told me how much you appreciated everything I had done for you and that I had stood by you all this time.

When it was time for you to be taken to the operating theatre, you said, "I am scared shitless." You wanted me to come with you. All the machines were still attached to you as they prepared to move you from ICU to the operating theatre.

They were looked after by different members of the team. There was a perfusionist, an anaesthetist, and the lovely doctor who had allowed our poodles to come and visit you. There were also two other members of staff we hadn't met before, nurse J. and me. You seemed anxious and said, "I didn't realize how many people were here to help."

I was only allowed to accompany you to the end of the ward, where the corridor leads to the operating theatre. You asked them to stop at the point where I had to go back. They did. You looked at me with a pained expression and said, "I love you. I will always love you." I kissed you on the mouth and said, "I love you, Brian." I whispered into your ear, reminding you to concentrate on your self-healing powers and the liquid light in your body. Then they took you away. I shouted after you "I love you!" Nurse J. put her arm around me, and we walked back to the ICU ward.

Your old room would have to be cleared, so I collected all your personal belongings. On the way out of the ward, I was introduced to the transplant coordinator. He told me that they had now assessed the donor heart in the other hospital, and it was still looking as if the transplant would go ahead. I think that was at about 12:30 p.m. From then on, he would keep me informed about the progress of the operation by telephone, and I would keep your mum, who was at home, updated by text and phone.

12:56 Brian in theatre now, getting prepared for op. Still looks like it's going ahead. Start of op. in two hours.

16:15 I phoned your mum with the following update: Chest opened up, all parts exposed, heart on its way, ETA 17:45.

18:10 New heart due to arrive within next 20 min.

I then sent the following text to many of our friends: Please create a lot of positive energy for Brian NOW + for the rest of the day + all weekend + all week! Thanks! (Heart transplant op. in progress.)

20:01 All well so far. New heart connected and already beating slowly. Now next phase starting: warming up and weaning off support machine.

22:25 Everything fine so far. Weaning process (off heart-lung support) starting now.

00:09 Brian is off heart-lung support. Heart appears to be beating fine at normal temperature. Now observation for 45 minutes before they close him up to see if any extra support needed.

At 02:00, I got a phone call from the intensive care unit. You had been back on the ward for half an hour and the surgeon wanted to see me for an update. I walked over from my hotel room to the ward. The surgeon told me that you were stable and that you didn't need extracorporeal membrane oxygenation (ECMO). They had expected that you would. The surgeon said that you now had a good strong heart. It all sounded so positive, but I didn't dare be overjoyed or relieved as I know by now that in ICU anything can happen at any time.

I was then allowed to see you, but only through the door of the adjacent room. You were sedated, with lots of tubes, cables, and lines attached to you, and there were several machines. Your face was yellowish, but you looked peaceful, which was reassuring. There was quite a bit of activity in the room with various doctors and nurses, so I didn't stay long. Back in the hotel, I phoned your mum. The call woke her up. She sounded startled, but I told her that everything was fine and looking positive and that I had seen you. She was relieved. Afterwards, I finally got some sleep.

I love you,
Bibo

COMING ROUND

Brian Keeley

I am gasping for air after frantically swimming back to the surface of some deep, dark water and suddenly breaking out into the fresh air. As I emerge into the light, I feel a hard tube getting pulled out of my throat through my mouth. I wake up coughing and choking at the same time. I am disorientated, but as things start to become clearer, I realise that I am on the other side of the surgery and recovering from the operation. This is a different room from the one I was in before. My mother and Bibo are here, and the nurses too. Apparently, everything went well.

I watch the choreography of people coming into my room, checking the monitors and the medications which are being administered to me intravenously, asking me questions and making small talk.

The clock on the wall says that an hour has passed since I last checked, but I am confused because the same procedure is repeating. The same nurse who came in an hour ago does so again and asks me the same questions. Other members of staff come in and repeat what has been done already, and in exactly the same order. I tell them all to stop because this has already happened, but they don't believe me. Then I notice that I know what they are going to say next, because they said the same thing previously. I continually protest that they are wasting time because I want to move forward. I feel overwhelmed by everyone in my room moving around and repeating things. I feel they are not helping me to move out of this continuous present. I point to the clock to prove that time is passing, and we are still repeating the same routines. A nurse comes in and says the same thing to me for a third time. I sink back into my pillow, knowing that I will have to lie here and watch another hour of the same repeated activity. This time I will be ready for them. I ask for a pen and paper so that I can write down what each person will say next, but I can't quite remember far back enough into the multiple conversations to transcribe what is going to be said. By the time I start to write something down, it has been said once again. It makes me want to shout: "See? I knew you were going to say that because you've said it already."

Sometimes, a whole day passes without a repeat and then I recognise one of the nurses saying and doing something they said and did much earlier in the day. I have to wait another full day before I can move on from the moment. All during these long sessions, I just hope that I can get through to the end of the day without a repeat. Maybe if I can get a good night's sleep, this time-loop will be broken. In the meantime, however, I am so frustrated. I know this is not right, and nobody believes me when I tell them that is actually happening. The operation has apparently been a success, but I wonder if I have become brain-damaged, and that's why my memory is all messed up. The thought of ending up like this makes me so despondent. All I want to do is to move on and get better.

The hallucinations began to fade as the effects of the anaesthetics slowly wore off, and after a few days the time-loops stopped without me even noticing.

What made me most aware of what I had actually been through was that I was now disconnected from the VAD (ventricular assist device). This was the whirring machine at my bedside, which had been pumping my blood for the previous 101 days. It was now gone, and there were no longer heavy tubes leading from it and buried into my chest. Instead, I could feel my new heart beating within me, all by itself. When I was left alone, I found myself staring at the display on the monitor which was mounted on a trolley to my left. Amid the array of information, one area on the screen held my gaze for long periods. A two-digit number would increase and decrease slightly, next to a flashing heart symbol. It was my heart-rate. My pulse.

I was still in the intensive care unit, and I knew that the first days after a heart transplant are the most risky. When I look back, however, I was more focused on the basic things like being able to eat and drink properly. The relief on the faces of Bibo and my mother gave me great strength. I also felt a huge sense of relief at this time. Despite the fact that I was very weak and in a lot of pain and discomfort, I dared to hope that I was in the early stages of beginning to return to the world.

SHARING TRAUMA

Bibo Keeley & Brian Keeley

Bibo: My contemporaneous account from 2013 was written in the form of diary letters to Brian when he was in intensive care. I wrote them not knowing if he would survive to read them. He had suffered a massive heart attack while we were on holiday in the Western Isles of Scotland. He was airlifted to a specialist hospital in Glasgow, where he went into cardiac arrest, and subsequently had a stroke and suffered kidney and respiratory failure. Brian was put into a coma, and he had a five percent chance of survival. I refused to accept his death as an option, and this had a strong influence on the way I supported him in the months that followed. It enabled me to bring a very different energy to Brian's bedside than if I had accepted the high likelihood that he might die.

Brian: When I began to emerge into a blurred and confused consciousness, I had no idea that I had been in a coma for several weeks. I could remember the terrifying pain of the heart attack, which had felt like my whole torso was being crushed in a vice, and I had flashback images of being in an ambulance: the bright orange of the paramedics' jackets, an oxygen mask approaching my face, the sound of velcro.

Very gradually, I began to be aware of my immediate surroundings. A VAD was taking over my heart function outside my body. I was on kidney dialysis, and a ventilator was supporting my breathing through a tracheostomy tube in my neck. This meant that I was unable to communicate verbally, so I could not share my thoughts. I had a profound sense of isolation and helplessness, and I was afraid that I would die without ever making it home with Bibo. I firmly believe that without Bibo's determined positivity and support throughout, I would not have survived.

Bibo: In my diaries, I wrote many things that I couldn't share with Brian at the time due to his fragile condition. I had had no preparation for the events that brought our lives to a standstill. During this time, I started to connect with the strength that lies in surrendering to the present moment, and from this grew my determination to try and manifest Brian's survival. At the same time, I felt scared, and I was exhausted.

Brian: After three months in intensive care, my lungs and kidneys had improved enough for me to be put on the urgent list for a heart transplant, and I received a new heart two weeks later. During the entire experience, I felt numb and somehow detached from real life. I had been confined to a bed, tethered to a myriad of machines and IV lines, unable to move, speak, eat, or drink. I was in constant pain and discomfort. After the transplant, I was so underweight and weak that I could not support my own weight, and I would slowly have to learn to walk again. One month after the transplant, I was discharged from the hospital and Bibo and I began the long road to recovery together.

In early 2014, when I was still recovering, I wrote an account of my experiences, an extract from that appears above, in which I was able to articulate the thoughts I could not share at the time. I knew that Bibo had written letters to me almost daily when I wasn't able to communicate, but neither of us would read each other's words until some years later. The two accounts show our experiences from two distinct perspectives, and in retrospect they offer some insight into the emotions and fears that we both experienced, and the differing ways in which we lived through precarious and unpredictable times.

Bibo: Our shared trauma is only one part of our continually evolving narrative—both as individuals and as artists—as we live a life that will always pivot around Brian's heart transplant: his lifelong dependence of medication just to stay alive, a heightened awareness of potential side effects, and other risks, which could lead to fatal complications, ongoing medical supervision and interventions, physical impairments, and the impact on our mental wellbeing.

AWARE (still image from film)

Brian: The pandemic has intensified the uncertainty and fear for me and others who are immunocompromised and more vulnerable to Covid. Despite the worldwide success of the vaccination programmes, there has been little, or no support offered (particularly in the U.K.) to the many for whom the vaccinations have no effect, and who have been simply left behind. After six vaccinations by the end of 2022, a test showed that I had developed no antibodies, so I still feel that I need to live life as if I had never been vaccinated at all.

Brian and Bibo: As a practising artist-duo, we take a number of approaches to expressing the shared narratives of our trauma, emotions, memory, and the subconscious, all of which are rooted in lived experience. Our collaborative work in recent years has largely been produced in the isolation that Covid shielding, and our continued sense of vulnerability, necessitates. It is multilayered and multidisciplinary, interweaving autobiographical elements with themes around compassion, mindfulness, and environmental issues.

AWARE (still image from film)

Our film *Aware* (2022) explores our experience of the uncertainties of living during the Covid pandemic, and the sense of detachment we felt from the rest of society at a time when the precautions designed to protect the most vulnerable were being phased out. The film raises questions of belonging and not belonging, inclusion and exclusion, and being unwillingly "transplanted" into a frightening reality that requires new coping strategies. In our short film *Breathe* (2021), we merge the individual and the universal through references to breathing, fear, and death. Nightmarish memories of Brian's struggle to come off the ventilator and to be able to breathe again are juxtaposed with imagery of Bibo singing and screaming underwater. This underwater imagery represents the time when Bibo would go swimming in the pool of the hotel she stayed in during Brian’s long critical illness, Bibo would swim up and down for long periods, singing and screaming underwater as a way of releasing her emotions. The surrounding natural setting points to aspects of rootedness, isolation, and perhaps friction.

AWARE (still image from film)

About the Artists

Bibo Keeley is a visual artist in Scotland whose work incorporates sculpture, film, performance, sound/voice and photography. Her themes include autobiographical trauma and ecological concerns. Email: b.keeley@rgu.ac.uk

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Bodies on the Border: Between Ableist Cures, Nationalist Hostilities, and Deadly Futures

Donna McCormack, Lynne Zakhour,
Richard Kahwagi, & Ingrid Young

Introduction

This series of images emerges from a collaboration between academics and artists focused on organ transplantation and chronic illness. The images are part of the ongoing work of Capturing Chronic Illness, a project founded by U.K. based medical humanities academics Donna McCormack (University of Strathclyde, U.K.) and Ingrid Young (University of Edinburgh, U.K.) to explore how arts may engage with health, illness, and non-normative embodiments that exceed dominant narratives. In this project, we seek to address, through arts, how to listen to silenced or denied experiences, particularly of queer health and illness.

The exchange that produced the images is based directly on McCormack's project, Transplant Imaginaries, which analyses fictional texts (novels and films) to explore biotechnological and anticolonial embodiments and relationalities in representations of transplantation. Building on McCormack's extensive work, we sought to create a set of texts—visual and written—that capture and reflect the key ideas and themes in transplant imaginaries. Our collaborative process was based on original text written by McCormack, and illustrations by Beirut based artist Lynne Zakhour created in response to the text. From the outset, Young and designer Richard Kahwagi joined conversations with McCormack and Zakhour to reflect on and shape the images. This co-production resulted in the first edition of our zine, Bloody Chronix.

The following three images explore transplant medicine beyond a curative imaginary. They point to key issues, which are rarely discussed or even acknowledged in the clinic, but may be discussed in memoirs by recipients and in fiction. These images, then, push us to reconsider how organ transplantation necessarily demands we pay attention to those embodied stories of living with the dead, crossing borders, and how care—even that deemed "lifesaving"—may be violent.

Hauntings

Image description: Dead woman with red hair lying down with mouth open. A brownish-red tree grows out of her torso. Flowers sprouting organs grow out of her breast, mouth, nose, and eye.

Haunting captures the presence of the dead other of which some organ recipients speak. This may convey a changing sense of self, as well as a sense of non-linear time where the history of the dead donor intersects with that of the recipient. Additionally, death may be constantly present as that which structures daily life when one's life expectancy is reduced, and also as that which has made life possible through the dead donor.

Justice & Borders

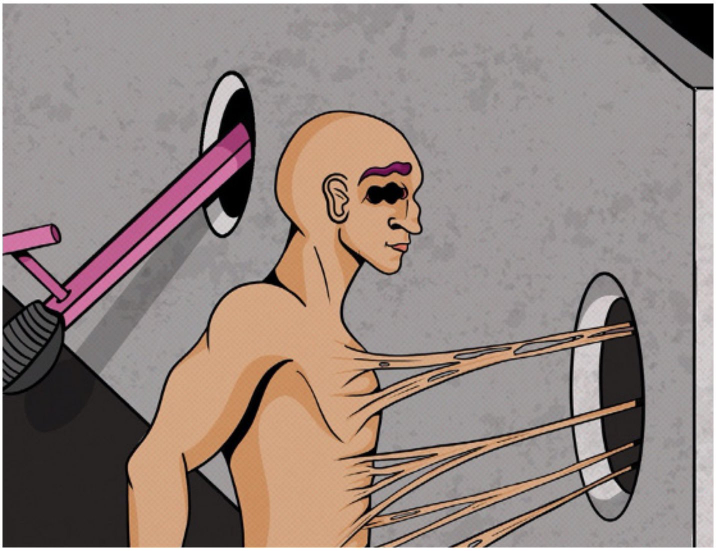

Image description: A gender non-specific person crossing a border through a small circle cut out of a grey concrete wall. Divided by the wall, the person is cut in half but still attached by long sinews of flesh. On the right-hand side of the wall, the person's insides are on show in vibrant pink and red, and in the background is barbed wire. This half person is bleeding as their other half remains on the other side of the wall.

How do organs cross borders, and which borders may be crossed to save lives? Large numbers of migrants continue to be killed or die from government policies that refuse entry across national boundaries. Crossing the body's border in transplantation is seen as a necessary intervention to delay death. How do we decide who lives and who dies, and what is justice if biotechnologies are used to save some lives as we watch others die?

Care as Violence

Image description: On the left-hand side is the torso of a Black woman with a white face emerging from the belly. This face has bright purple hair and is smoking. On the right-hand side is the torso of a white woman with a Black face emerging from the belly. This Black person's hand is holding a drink. Both faces have no eyes, and there are random eyes in drinks, pierced through nipples and on necklaces.

Transplantation, whilst offering the hope of continued life and perhaps even a cure, may tie recipients to regimes of care that are restrictive, invasive, and distressing. Furthermore, the possibility of speaking of what is happening in one's body post-transplantation may be denied and as such comes to be lived as a form of violence. Here, the donors emerge from the recipient as a way of voicing what may be silenced.

About the Artists

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Visceral Diary Drawings

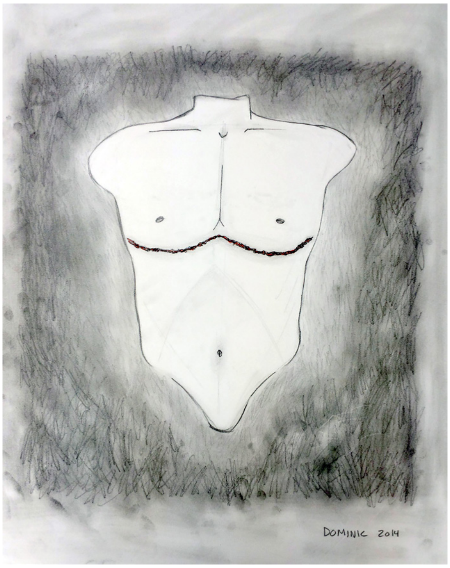
Dominic Quagliozzi

These drawings are intuitive diary entries capturing my physical and emotional states during my double lung transplant journey. They mark moments in time on the transplant waiting list with lung failure, meditations on what receiving the transplant might be like, and documenting the realities of post-transplant life. Some of these drawings were made in real time during hospitalizations.

I am Support Devices, 2014

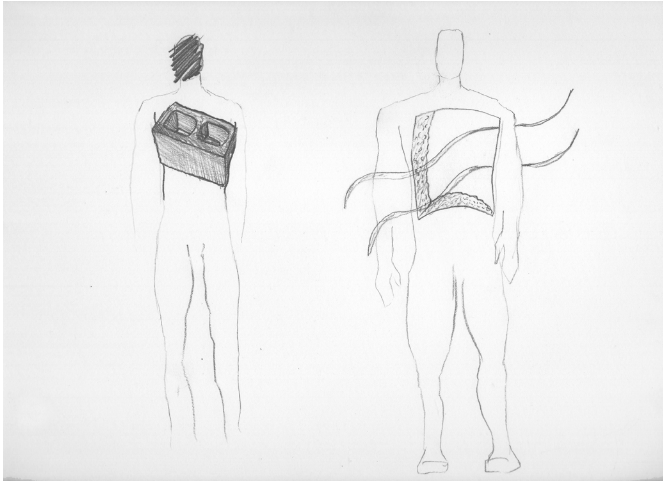
Pre-transplant

Lung Transplant Fantasy, 2014



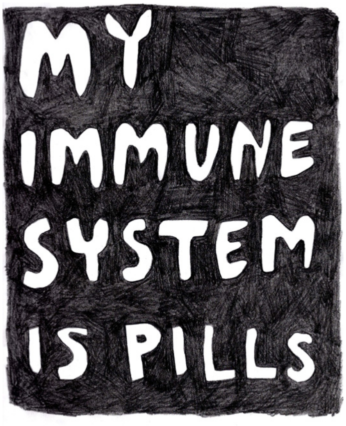
Pre-transplant

Cinder Block Chest and Breeze, 2015



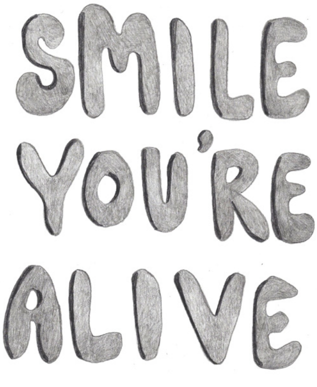
One-month post-transplant

My Immune System is Pills, 2015



Three-months post-transplant

Smile You're Alive, 2017



Two-years post-transplant

About the Artist

Dominic Quagliozzi is a visual artist living and working in Massachusetts, US. He makes work about his lived experience with chronic illness and being a lung transplant recipient. ArtistDominic.com. Instagram: ArtistDominic Email: Dominic.Quagliozzi@gmail.com

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Fragments of Futurity, Reflections on Transplant Sustainability / Transplant Tarot Triptych: Cards and Descriptions

Andrea Barrett

Fragments of Futurity, Reflections on Transplant Sustainability

I have survived over twenty years since my heart transplant. Most heart transplant recipients cannot say this. This truth is never far from my mind. When making life decisions, when deciding how to spend my time, even further compressed by chronic illness and a high need for rest—more and more, as time passes and I become host to an ever-shrinking numerical statistic in terms of longevity, and I witness the increasing global crises as an immunosuppressed person—the question of long-term sustainability of transplantation for my body, for all human bodies, becomes an ever-louder scream reverberating in my mind.

Sustainability as a concept evokes the environment: our planet, our home, our natural world. However, this is only one dimension. Sustainability encompasses all dimensions of existence, and their capacity to keep on keeping on. I have begun and had to pause many a research project on transplantation: my ill health has gotten in the way. Below are some fragments of future research areas I hope I develop the health to conduct. Or that someone, somewhere, will be able to undertake.

When considering calculating a mathematical formula of the overall, interconnected global benefits and harms that the advanced technology of transplant medicine brings the world, we do not know yet which way the scales of justice will weigh in. We have to sit with the weight of uncertainty, with curiosity and hope, until more extensive research has been conducted.

Environmental sustainability

Another twelve hours, another set of medicines. This has been my last twenty years, and, I must hope, my next twenty, for I am not even 30 years old yet. I often procrastinate taking them for a few moments. In these moments, fiddling with the empty blister pack shells ubiquitously used as pill packaging in much of Europe and many places around the world, I often flit between thoughts connected to them.

Today's thoughts: blister packs are not typically recyclable. They go to landfill. My country, like all "developed" countries, pays "developing" countries to take our landfill. However, developing countries don't have the infrastructure to dispose of the waste safely. Environmental pollution harms health. This waste, including my pill packaging, is harming, even killing, people elsewhere. I put the empty blister packs down. Others are paying a heavy price for my staying alive. The pills are already out their packaging: it's time to do my daily duty.

Unfortunately, the very medicine that has the lofty goal of remedying pain, suffering, and otherwise fatal bodily damage, is contained within a shell which, once discarded, gives rise to the very diseases that the medicines aspire to cure. This chain of interconnections between pill packaging and global health trade-offs, spans vast distances. The implications from cause to effect are not immediately noticeable. Once noticed, however, they cannot be forgotten: the very medicines that make possible the transmutation of organ failure, in organ transplant recipients, are also creating organ failure elsewhere. The spectacle of progress and advancement is revealed as a reality of exchanging one problem for another: the cycle of life's maladies, even with technological intervention, seems to continue, on and on, as an infinite unsolvable problem.

Currently, organ transplantation depends upon the health harms its pollution causes to exist. Transplantation, including materials associated with surgery and life support machinery, also depends on broader contributions to environmental pollution and climate warming. Yes, my life was saved. Millions of people have had their lives and loves saved by transplants. But if the cost, at least in part, is making the world more unsafe, if it has meant harming the planet and its other inhabitants, then its environmental sustainability is in question.

Ironically, the pollution the transplant field engenders is making the world more inhospitable to transplant recipients, who are more vulnerable to the impact of increasing temperatures than most and will be the first to be impacted as the climate crisis escalates.

Physical sustainability

After winning the medical lottery by being allocated a transplanted organ, a patient's failing organ is replaced with a functional one, at a cost. The bodily cost is the sacrifice of the normative functioning of one's immune system. In technical terms, the immune system of transplant recipients is disabled by immunosuppressants. This disabled immune system means an altered reality for the transplant recipient: they, we, I, have been disabled.

Transplant medicine creates disabled people. It is a controversial statement, but one which needs wider consideration. A caveat: we transplant recipients were already at the stage of disability when we needed an organ transplant. It is not transplantation that transforms someone from able-bodied to disabled, but rather it performs the magic of ending one kind of disability by enacting another kind of disability. The law of substitution is in play: an organ is substituted, at expense of an immune system, which then will need substitutive intervention at a later date, be it through increased vaccination, monoclonal antibody infusions (immune cell transplants), et cetera.

Transplantation shows that disability can be a treatment *and* that treatment can disable, but also be the kind of disability offering sufficient potentialities that it is simultaneously a disability aid, too. Transplantation crosses object boundaries and polarities of existence, being both supportive aid (enabling) *and* new disability (disabling) all in one.

As a child who avidly read, I clung to a compelling metaphor to make sense of the challenge of living with a disabled immune system. When I was grappling with what transplant medicines meant for me soon after my transplant, just before my eighth birthday, having been taken through the long list of complications associated with immunosuppressants, the literary metaphor of "drinking unicorn's blood … and forever living a cursed life, a half life" (Rowling, 1997) was imprinted in my mind, as a way of making sense of transplant life.

Twenty years later, as an adult, I would argue this may well be factually true, too. Not the cursed part, or at least not without the nuance of it simultaneously being a blessing, but rather the aspect of halved life expectancy. Reading up on the statistics of transplant life expectancy has led me to the discovery that transplant life expectancy is half that of the average of an untransplanted person; thus, the notion of "half life" may be interpreted literally, too.

Now, how did I work this out? The maximum years of survival post-transplant for many transplant recipients (hearts, lungs, etc.) is about 40 years (Anon, 2022a, 2022b; Graham, Watson, Barley, et al., 2022; Shaffer, 2023), and the maximum for kidney transplants is about 50 years (Anon, 2020; Matas, Gillingham, Humar, et al., 2008; McKrimmon, 2022). These statistics are true only in exceptional (minority) cases. With the human capacity to live beyond 100 years—likewise, in exceptional cases (Smith, 1997)—the maths suggests that as transplant medicine currently exists, the human body can only sustain transplant grafts (and transplant medications) for half the human life expectancy.

For those who receive a transplant in middle age, this limitation is arguably negligible. For those who receive a transplant before the age of 40, it brings genuine concerns about physical sustainability for achieving a full and long life. This concern is particularly significant for child recipients. Recent data aggregation across the UK spanning long-term multi-decade outcomes by NHS Blood & Transplant (Hogg, 2023), indicates mortality is not nearly as stark in child recipients compared to adult recipients, but it by no means matches a lifetime trajectory equitable to the non-transplant population. Ultimately: the litmus test for physical sustainability of organ transplants ought to be from the vantage point of babies who receive a transplant. As transplant medicine currently stands, for babies who receive transplants, the metaphors of transplantation as gift of life, second chance at life, and rebirth, need scrutinising.

Societal sustainability

I have never been very good at telling a "good" transplant story in a public forum. A "good" transplant story goes from disability to ability and focuses on restitution narratives. Whilst this has sometimes been true in the ebb and flow of health attendant to my experiences with chronic illness (aka immunodisability), these stories have always felt incomplete and fundamentally lacking in integrity. Transplantation, being one of the few medical interventions that depends intensely on good PR and social approval, means that my inability to tell a good transplant story makes me a bad transplant patient.

The societal view on transplants feeds into whether individual families of brain-dead patients in hospitals decide to donate their loved ones' organs. This means that the public need to remain on side for transplantation to be a sustainable option for treating organ failure. The scarcity of sufficient organs for those on the transplant waiting list, means that the PR from organisations that desire to raise awareness about the need for an increase in donations, is caught in a holding pattern of emphasising only the positive aspects of donating organs and transplant life. This, in turn, means that there is a gap between the perception and reality amongst most people in society.

It also means that society currently is unprepared to digest a more nuanced narrative. To a general public that prizes health and stories of recovery, attaching narratives associated with chronic illness and disability to transplantation, is a massive shock to the system. There is a sense of stability and hope, in the consistency of the A to B narrative of organ failure, then transplant, then no organ failure. Stability and hope are both essential traits needed for sustainability. There is the danger that, as narratives exploring transplant life and transplant medications—from more "negative" (realistic) perspectives—gradually enter society, there will be a pendulum swing of regard. The already scarce supply of donor organs could be reduced even further, or even dry up completely.

The key root of this danger is the pre-existing societal problem of ableism. If society continues down an ableist path, the revelations of the blunt realities may be a threat to the societal sustainability of organ transplantation.

What is ableism? Ableism occurs when the standard of ableness is expected as the default in life, and those who are disabled are expected to conform to this standard to be included in society. Those who cannot conform are expected by society not to exist in able-bodied spaces. Ableism taken to its most extreme conclusion becomes everyday eugenics, where nonconformity to being abled means death.

As a result, people feel they cannot share certain facets of transplant life and the harsh realities of transplant medicine because it could potentially reduce the pool of organ donors. What it boils down to is the ableist belief that if transplant medicine as it currently stands qualifies transplant recipients as disabled, perhaps transplantation is bad overall, and people are better off dead than disabled. The danger of societal unsustainability of transplantation rests with the continuation of the not-infrequent ableist societal belief that chronically ill disabled people should want to prefer death, rather than gladly choosing to elect into a new life of (immuno)disability.

Transplant sustainability depends on the success of disability justice to overcome ableism as a prevailing outlook and to overcome health supremacy eugenics as its praxis. The continuation and advancement of transplant medicine in our time of global crisis depends upon a societal embrace of disability accessibility and effective challenge to the rise of health supremacy, a form of health fascism that has been on the rise since the start of the pandemic in 2020. Disability accessibility in society from transplant recipients' point of view means bridging the equity gap from immunodisability and an associated health condition point of view: development and availability of monoclonal antibodies, use of (improved) face masks, and widespread installation of HEPA-grade air filtration, to name but a few.

Logistical/financial sustainability

The dimensions of logistical and financial sustainability are highly under-researched. It is typically the domain of health insurance companies and health funding bodies; raw data is hard to come by and, when funded by those with a vested interest in promoting organ transplantation, weighted towards encouraging the outcome of increasing donations, rather than a comprehensive account of the situation as it currently stands.

Organ transplantation depends on a complex infrastructure: technology, enough skilled staff, and enough space in hospitals for transplant recipients and donors. Wherever there are bed shortages, or reductions in available hospital beds, there will be a *de facto* reduction in transplants that can be performed. All those who campaign for increased hospital capacity are supporting the logistical sustainability of transplantation. Currently, hospitals around the world are facing staffing shortages in healthcare. From my vantage point of attending national and international transplant healthcare meetings in my role as patient advocate, I have heard that these shortages are already hitting transplant centres and are projected to increase if logistical changes are not implemented to enable more staffing and more bed space. Improving both financial and logistical sustainability is essential for transplantation to fully expand to developing countries that is needed if transplantation is to embody the values of disability justice, which includes intersectional equity, across continents and nations.

Psychological sustainability

Whilst I truly believe that having a mental health condition is a disability and not anything to be ashamed of or at all a reflection of the person's personality or character … for some reason I pride myself in having successfully avoided getting formally diagnosed with a mental illness. Yes, sure, I see a psychologist and my record says a tendency towards anxiety. And yes, I see a separate department for neurodivergency. When it comes down to it, this pride is rooted in how I can tell my transplant team that I am of sound mental health: nothing to declare. This originates from a place of primal survivalism; were I ever to need another organ transplant—a genuine probability—having nothing to mentally declare would be an advantage to me. People are sometimes denied the opportunity to even be put on the transplant waiting list on the basis of mental illnesses, indeed even for being neurodivergent. Proportional to how any psychological difference gets earmarked as a potential weakness, any avoidance of having certain psychological labels added to one's medical records can bring with it certain advantages and privileges.

Psychologically, in parallel with the normalised restitution narrative, transplant patient behaviour is being directed by primary protector selves: the mask of the Clinic Self. To be clear, this particular mask is performative. The mask of the Clinic Self is what the "good patient" wears, predominantly to the transplant clinic, but also in society and at home.

The Clinic Self presents the superficial front that everything is fine, conforming with the popular story that the transplant has fixed the problem, that the patient is now living life to the full and is very much in the moment. The future will unfold the same as that of someone who is not a transplant recipient, in trust and faith of the transplant team and the institution of transplantation. The mask's voice says: "I will not speak a negative word, for doing so is ungrateful to the donor and the doctors may not want to treat me if I need their help again, and I may die." The Clinic Self does not speak of new comorbidities without restitution framing.

The lived experience of transplantation contains feelings, emotions, and thoughts that are constellated within "selves" separate to the Clinic Self and counter-clinical narratives. Since the Clinic Self censors all other selves within and also within other people, it is difficult for the voices of the other selves to be able to speak.

There exists a hierarchy around what is considered "reality" or "truth." This hierarchy gives rise to the Clinic Self unconsciously perpetuating:

normalised toxic positivity, medical gaslighting, internalized gaslighting, ableism, and internalised ableism. Other rationalised forms of physical and psychological violence as means to the end of preserving the restitution narrative in relation to transplantation. Inevitable cognitive-somatic dissonance creates significant baseline stress within transplant participants which, in my view, contributes to a lowered quality of life and lowered length of life. More extensive research needs to be conducted; the results of which will hopefully either dismiss or verify these theories.

My hope is that by expanding the selves which are allowed and creating safe spaces for the clinical self (and by extension the clinic and clinicians) to enter into dialogue with other psychological selves through other institutions, such as art organisations and participant-led support networks, a rich assemblage of multivocal narratives would be able to coexist, thus creating a greater psychological wellbeing.

Psychological sustainability is interconnected deeply with physical sustainability. However, I believe that it is far more complex than the commonly touted “think positive and you’ll stay healthy” ideas floating around. Health is homeostasis and psychological distress is unresolved stress. Instead of focusing only on the positive, the negative needs to be tackled directly in a way that resolves the distress, or at least lessens it. It is true that for some, positive mindsets may be sufficient for reducing distress. I suspect this relief is short lived, as it soon only reinforces low level alienation from the self and others.

Spiritual sustainability

Organ transplantation brings with it the potential for greater connection to the universe at large, an awareness of the precariousness of life, and the realization that one can no longer consider oneself as just an individual: we transplant recipients have become hybrid, forever tethered to connection with the flesh of another, and to the twenty-first century, via advanced pharmaceuticals, and to medical institutions. The ever-present closeness to illness that living immunocompromised brings, gives rise to increased stark consideration of what is truly important.

Transplant recipients carry the burden of extra layers of intensity of reality. We are in a position where we often contend with topics important to being human: loss, uncertainty of life, proximity to death, the questions of living a good life. We do so with our bodies as the crucible of philosophical debates. Our bodies are the embodiment of a very specific spiritual understanding of the world: that the mind is severable from the flesh. The interchangeability of body parts, sacrificing one system for another. We hold the experience of margin of error of a certain kind of philosophy in our bodies every day. That doing so is possible, is one of the many paradoxes that the paradise of transplantation brings.

Spiritual sustainability of transplantation requires resilience in holding space for contradictory ideas and feelings in one's mind and spirit at once. The capacity to hold space for paradox, both individually and collectively, is essential. Embracing the spiritual principle of paradox by society is necessary for sustainability under the intensifying crucible of increasing pressures of the world. We need to do our part to co-create a world that can appreciate the value of paradox and not just value it but desires it; a society that seeks it out and nurtures it and wants to build it up. A world resistant to paradox will inevitably be hostile to organ transplantation and organ transplant recipients.

Choose a transplant, choose life, choose paradox.

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Transplant Tarot Triptych: Cards and Descriptions

The following three cards and their descriptions are the initial few of a projected full deck of transplant-themed tarot cards. The artistic medium was a combination of back fineliner on paper with digital colourisation. Here, the first three cards, are laid out one by one; when cut out and placed side-by-side (L to R, in order) their geometry combined is greater than the sum of the parts alone.

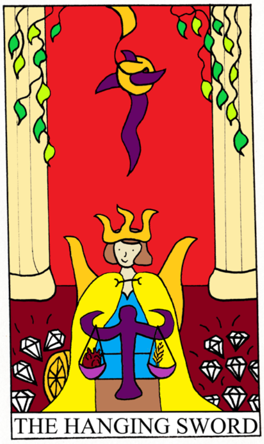
The Surgeon

The Surgeon is the archetype of a modern Prometheus. Wielding the scalpel, wearing ritual robes, and creating transformation via the mimetic tools of the physical dimension: oxygen, blood, organs, electrical impulses; these can all be substituted. The Surgeon is the master of the atomic world, capable of deftly working amidst the balance of life and death. The hourglass of finitude hangs above. Paradoxically, the Surgeon uses the amplification of fragmentation to create greater unity within a person: the human self is divided into separable, interchangeable organs, the immune system is made the altar's sacrifice; for generating

a new kind of human order. Transformation at this scale comes at a cost: maintaining equilibrium is a never-ending battle. Sustaining the finite is an infinite battle. Chained to the operating table, the Surgeon must carry on replacing organs for all eternity, transplant after transplant. The end is not in sight. From donor to recipients. Donor to recipients. Donor-Recipient. Donor. Recipient. Cutting and stitching. Cutting and stitching. First, second, third transplants. Never enough transplants can be done, surgeries are always needed. Transplant after transplant, the Surgeon carries on. Rinse and repeat. And all the while, an Eagle—the Eagle that destroys organs that the surgeon uses to regenerate others—is poised and ready to swoop in to devour the organ—as soon as the patient leaves the hospital. And where the Eagle can, it will swoop in even before the patient leaves. And then the Surgeon must step in again. With the delivery of immunosuppressants, a transplanted organ can last anything from fifteen seconds or fifteen years, or less, or beyond. The science of transplant medicine can be an unpredictable art. This allows wonder to remain. The Surgeon has the strength and determination to keep on keeping on. This archetype is the force encompassing both the power and limitations that mastery of the physical realm brings. The problem is the solution, the solution is the problem, round and round the cycle of transplant life turns. Physical substitution of transplantation can lead to needing more transplants: sometimes of the same organ, other times another organ (often the kidneys due to their vulnerability to damage by immunosuppressants), sometimes immune cells to compensate for suppressed immune systems; all of which solve issues arising out of transplant medicine itself. For transplantation can sometimes set the stage for next challenges, which transplant medicine can then, once again, solve … for a while. The Surgeon is the archetype of all authorities that make organ transplant physical reality. As such, physical existence is the start and the end of the domain of the Surgeon.

The Hanging Sword

The Hanging Sword, short for the full name *The Hanging Sword of Damocles*, is the ever-present dread-doom that accompanies being a transplant recipient with a critically engaged understanding of transplantation's complexity. Transplantation is not just the transfer of organs but also its requisite immunosuppression. It is the paradoxical experience of having both extraordinary privilege and living with extraordinary peril. Heavy is the crown, plentiful are the jewels, high are the stakes, precariously thin is the thread, upon which the sword hangs. It is the archetype of gravity: the force pulling us to earth, to rock solid reality,

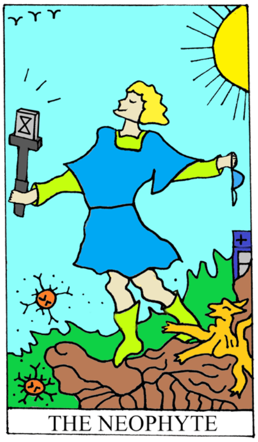


to seriousness, into graves. All other archetypes can be subsumed by the weighty power of this archetype. Transplant recipients must live with both the possibility and actuality of a great many life-threatening complications, due to the immune system being disabled, and with the uncertainty when they may strike. It is the sinking feeling in the back of one's mind. If one looks beyond the initial persona of privilege, where one's existence is as though a monarch on a throne, to the bigger picture, one can see that proportional to the excess privilege, there is also excess potential peril. The scales of justice are constantly being weighed up. The sparkling diamonds in the throne room are covered in the blood of all the transplant recipients that came before and who have already been hit by the falling sword. A second chance at the gift of life comes bound up with additional lottery entries into the grim reaper's list of who is next for the gift of death. The presiding judge, holding the scales of justice, comes in the spirit of the ancient Egyptian goddess Maat: on one side, there is a heart; on the other, there is a feather. The classical myth tells how in traditional ancient Egyptian death rites, the test for progression to heaven rather than hell, on the way to the Underworld, is whether the heart can be lighter than a feather. With transplant life, transplanted organs must match the levity of a single feather, for the recipient to remain spared the fall of the hanging sword perched directly above.

Bound up with gravity is its polar opposite, levity. Both are core forces in the universe. Whereas gravity is the force pulling down, levity can mean going up or moving sideways. Levity is a form of levitation. It is pliability, adaptability, a weightlessness—associated with the etheric realm. The Hanging Sword is always there, ready to fall. In order to be able to have a Mona Lisa smile whilst the sword could fall at any point, one must either learn to fly up and repair the weakened threads or learn to move sideways. The first option may one day be achieved by pharmaceutical innovation. The latter is a more immediate option. Thankfully, the throne is poised to transform into a wheelchair: one of its two wheels is visible (if one knows to look). The wheelchair is a disability aid, and the option of a moving throne alludes to the possibility of all kinds of disability aids being employed to enable moving out of the path of various falling swords. By embracing a more nuanced understanding of disability and including transplantation within its realm, at least sometimes, and putting theory into praxis with a new approach to the vulnerability of transplant recipients, there can be better responsiveness in relation to real dangers and complications that transplant life can bring. The proactivity of a moving chair rather than a fixed throne allows greater success against injury and fatality from falling swords. Full acceptance of what is, and proportionate proactivity, gives rise to the possibility of sustaining a deeper, more substantial, lightness to being. The lesson of the archetype of the Hanging Sword is that the force of gravity can only be kept at bay with equanimous levity.

The Neophyte

The Neophyte, from the Latin for "newly planted," is the archetype of the newly initiated into the gift of life that is given via organ transplantation. Every participant in the process of transplantation can be a Neophyte. Typically, this lens or perspective is centred to that of the organ recipient. With overt mirroring to the Fool card in the traditional Tarot deck, the Neophyte holds a selfie stick and dangles a face mask in place of the wanderer's travel accoutrements. The sun is shining and we're on top of the world. The Neophyte is determined to relay the best of life back to the universe (via social media). Where the Fool, with his trusty dog nipping at his heels, wears a harlequin's tunic, the Neophyte wears a hospital gown and medical compression socks. Instead of a dog, there is a clawed supernatural creature growling a warning at the crumbling cliff edge up ahead and the virus particles floating in the air. In the distance, to the left, there are three birds, eagles, flying towards the Neophyte; to the right, a hospital exists on sturdier ground. The Neophyte is both the exhilarating, enlivening force of the happy ending, with its attendant gratitude and spirit of adventure, and simultaneously the wider context that a happy ending is only the beginning of another far greater adventure, with proportionally greater peril too. The lesson of this archetype is that looking away from



what is in front of you and subscribing to a "positivity only or else!" mindset can, paradoxically, set people up to encounter more issues than taking in what's there in the moment and responding accordingly. Being transfixed by the brightness of the sun (reflected back in one's technological intermediary) and looking away from danger doesn't make the negatives vanish. Wanting to exclusively see the bright reflection of the sun can lead to blind spots to approaching danger, which can lead to one's premature end. There is a beauty in this way of shining brightly, but for a shorter time. Its bleached white sweetness can also leave an artificial saccharine aftertaste. It is the shiny, bloodless PR image of transplantation. Every transplant participant has the potential to remain in or, at times, slip into the Neophyte archetype, even with years of lived experience with transplantation and its ups and downs. One embodies the spirit of the newly planted when one is caught up in the moment, the past and future out of mind, in a world of pretence of normalcy, losing oneself in meeting the all-too-human need for belonging in the world—amongst the non-transplanted—or simply a moment of being careless, not thinking of possible consequences. The present moment gifts us the luxury of simplicity and novelty. For a while, only giving validity to the correspondingly high proximity to the light can serve very well as a coping mechanism for the proportionate excess of darkness. But light cannot exist within the dark. An excess of brightness, without corresponding darkness, can be just as treacherous as only darkness. Without the interplay between light and dark, the light loses its sparkle.

The Neophyte is fundamental to transplant life. Indeed, the archetype can often be seen as the end goal of transplantation and the sign of success by clinicians and society alike. It is only the most surface persona, the public face, but sometimes making a positive persona one's whole identity can be enough. After all, life is short, so let's put complexity to the side. Let's focus on the new and the now. I'm doing fine, you are too, right? Everything's amazing. Best make the most of this very moment!

Acknowledgements

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Pain 21

Tereza Crvenković

To whom it may concern,

There is [sic] significant disability related to previous disseminated herpes zoster encephalitis with associated major stroke and residual right upper thoracic postherpetic neuralgia … Her infection resulted from extreme immunosuppression in an attempt to salvage a failing renal transplant … Because of the initial generalised zoster infection during her extreme immunosuppression, her post-herpetic neuralgic pain has been amplified.

— Dr R., neurologist

* * *

"This is about average for an immunosuppressed person." Dr F., my greying, blue-eyed, nephrologist surveys the peeling, hanging, weeping flesh on my shoulder and arm, facial expression cold, bland, fixed.

Under his orders, I remain at home for 10 days, watch the virus eat away at my body, fester, blister, ooze. See the external world pass through my bedroom in splintered shards: sun-stapled carpet; spliced wall shadows; darkness speckled white.

I tremble, whimper from the pain, swing between helplessness and terror, succumb to sleep only when exhaustion decides "enough."

Now in the ER, angry, crimson fire flares up through the thick opioid haze in my head, burns in my belly.

What, this? Average? Why do ER nurses and doctors come in to gawp at "the worst" herpes zoster outbreak they've ever seen?

With his one comment, my specialist shunts the extremity of this outbreak including my pain, my suffering, my fear, into the bottomless, faceless, nameless abyss of the immunosuppressed.

Dr F. tacitly reinforces that this savage outbreak, which would otherwise be an exception, is the norm, is part of the expectation for immunosuppressed people and organ transplant recipients like me to endure.

But how can human experience, human suffering, be categorised as above average for some and about average for others? Isn't our human need for compassion, care and empathy in horrific circumstances the same across the board?

Dr F. rattles off a treatment plan. I listen to his well-practiced medical parlance, realise that the hard, callous mask is part of his polished physician's persona, worn when faced with his own medical misjudgements.

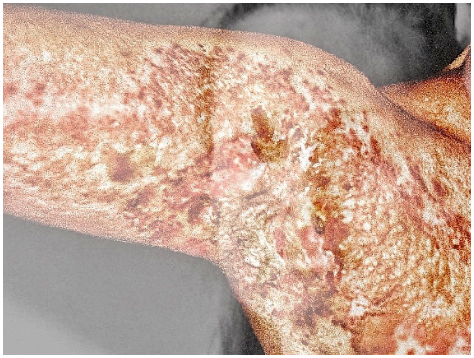
His words shrink; his coldness pushes me into free fall and my humanity tumbles through the cracks.

In the end, Dr F. prescribes a hefty, round-the-clock opioid cocktail, but no antivirals.

"Antivirals could damage your kidney further. Besides it's too late to start."

A few months later, I almost lose my life because of this.

About Average



* * *

“What’s she doing here? She’ll put everybody at risk.” My move from the ER to a ward where the majority of patients are immunosuppressed has been ill-considered. The shingles virus is highly contagious and potentially life-threatening to the most vulnerable. The ward manager and staff debate my condition, within earshot.

I look over at their frown-frozen brows, the fixed, gunfire-glare of their eyes. Fear punctuates the air with little black dots. She, she, she. I’m an outcast, yet have no control over the virus or its possession of my body.

On my way to a chest x-ray, a porter, with long white hair and a beard like Santa’s, yells at me when I tell him that the shingles virus has caused my pneumonia. His fear is palpable: his face blazes red as he pushes me into a dim corner of the corridor and walks away.

* * *

Two months after my herpes zoster outbreak I have a major brain haemorrhage, a direct result of the infection left to simmer in my spinal fluid.

I'm unable to sit, stand or walk; my left side is paralysed, my body withered. The injury to the nerves in my right shoulder, arm, and hand from the herpes zoster virus is severe.

And then the pain: unbearable, soul-destroying; without beginning, without end.

I plead for death for the first time in my life.

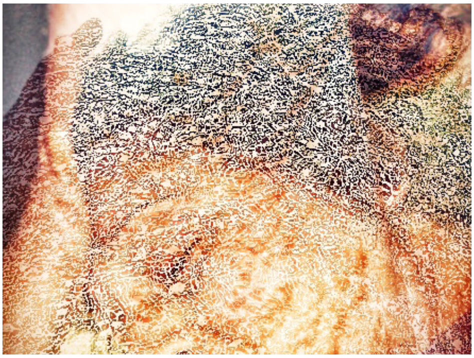
* * *

Wooden walking pattern, clumsy gait, stooped posture, balance unhinged.

After eight weeks in rehab, I return home, scarred, forever changed. Deficiencies from the stroke and the extreme nerve pain collide. My right shoulder—in a bid to alleviate the burden of the pain—sits hitched up towards my ear.

Pain slices through every moment, swamps my senses, drags me into its deepest, most secret recesses. My life is now a revolving door of excruciating sensations.

The Scream



At times, I feel as though I've been stabbed; subjected to electric shock; had acid thrown on my right shoulder, across my chest, along the underside of my arm and armpit. My skin feels burnt, scalded, singed, roasted, baked, charred.

At times, it feels raw, scabbed over, dry, ready to crack; it throbs, vibrates, bubbles, crawls, grips, prickles, pinches, itches. Throughout the day and night, pressure radiates from my shoulder, builds, then explodes into intense spasms for minutes at a time. During these agonising moments, my right arm and hand—even the right side of my lip—tremble and twitch.

21 shades of pain and counting.

* * *

The pain breathes its own life, beats its own rhythm. I whimper, I cry. Sometimes, all I can do is scream.

The spasms from my damaged nerves are so bad, so terrifying, so all-consuming, I feel as if I'm going to die. My flesh, my blood, my humanity are unable to contain the burden of my distress and remain silent: shrill shrieks fly from my mouth, out from my bedroom window toward the rows of houses and apartment blocks on the neighbouring hills, out into the amphitheatre of surrounding "spectators."

During one of these episodes, I experience a sharp reminder that my voice transgresses the expectation, the requirement, reinforced so clearly by my nephrologist, of silence, to swallow my suffering: a voice in the neighbourhood shrieks right back at me.

In that moment, I acknowledge that my shrieks are disturbing, annoying, boring. But I'm beyond caring about what people might think. My shrieks contain an innate sense of loss, a recognition that my existence as a pain-free body is gone. The pain has thrust me into a roiling, dark void of desperation unknown to the uninitiated.

If the able-bodied voice belonging to the human being behind the taunt felt this vile pain extinguish their life as they know it, they wouldn't be able to contain their suffering either.

Yet there's something else in the shrieking, primal vocalization of my pain.

Sometimes I imagine these buildings as much more than homes with people in them. In my mind, the buildings form a solid, fortress-like boundary around me.

During my worst moments, when I feel the reach of death in my pain, the fortress provides a force field, a sense of protection, safety, solace; offers to absorb and contain the extremities of my pain.

It can't get worse, won't get worse, I reason, because the fortress denies expansion of the pain into the eternity of the skies beyond.

* * *

The nerve damage has affected my fine motor skills: my left, stroke-affected hand is weak; my right, dominant hand is weak and numb. I have to re-learn how to brush my hair, use chopsticks, hold a pen. My handwriting is an illegible mess of scratches.

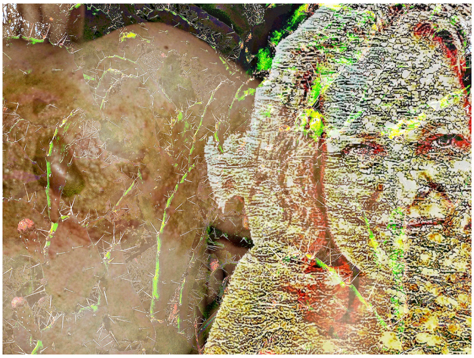
As my pain and life progress in tandem, there are specific rules and regulations for me to follow. In order to re-enter the outer, able-bodied social world, my crying, wounded, shrieking body has to appear pain-free. In spite of everything, my existence has to appear seamless, "normal."

* * *

The stroke-pain narrative is etched on my body, yet there's a tacit understanding that pain-talk is off-limits. The bland, "I have severe chronic pain," is permissible. Anything more is unpalatable, might attract a "whinger" label, which would minimise the seriousness of my daily battles.

So, I adopt a pain-free mask, pretend my body isn't hurt, that I'm just like other people. Behind every word, every smile, every laugh, though, there is the piercing, internal scream of my pain.

Let's Pretend



* * *

Several months after my discharge from rehab, my sister organizes coffee with an old friend. I look forward to seeing her: a desire to share my big, life-changing story burns inside. When we sit down, she barely looks at me, turns her dark, glossy head of hair towards my sister, talks of her new job, new boots, travel plans.

Being invisible is excruciating. When I get home, I collapse on the small sofa in the kitchen and sob for hours.

In the end, my desire to humanise the brutality of the pain, talk about my grief and loss from the stroke, express my gratitude in being able to walk again, to breathe, to be alive, burns out.

In order to get back to my bigger life, I swallow my big story and listen to stories about the lives of others.

* * *

"You're such a brave girl;" "You're so strong."

I am not.

And yet I am.

I've been fed the stoic acceptance narrative since the age of five, when I was first diagnosed with chronic kidney failure. No matter how painful or intrusive the procedure, I learned how to wear a mask, fool others, make my bravery believable. Perhaps this is why I readily assume the pain-free mask in public.

Underneath the smooth, masked surface, my inner landscape has supported floods of sadness, despair, rage, wild fear, emptiness. Yet in amongst all of this: courage.

Now I ache for the physically strong, pain-free transplant woman I was before all of this happened. I'm angry and afraid and grieve her passing.

* * *

"You'll never get back to where you were."

Behind his rigid desk, Dr F. attempts to hammer the stoic acceptance narrative into place. Again.

His comment deepens my anger and mistrust.

I know more about myself than you ever will.

I'm not a statistic, a line, a squiggle. I'm a human being with every right to believe in my recovery. I may not get back to where I was, but the core of my humanity will never bend to expected long-term outcomes or succumb to hopelessness.

From the smoke and ash, I vow to harness the indestructible inner strength that will always be mine, commit to work with my pain and my disability.

For the first time ever, I consciously choose the acceptance narrative, not as a mask, but as an ally.

* * *

I acquaint myself with the abilities within my disability, discover how to live with my altered body. I learn to use public transport, then drive; attend yoga classes again; paint; write; cook; complete a postgraduate degree. After my first kidney transplant fails, I manage to cannulate my left arm and place myself on home dialysis, until I undergo a second kidney transplant.

Although the stroke and pain have both affected my balance and mobility, I can now walk.

How did I manage to do all of this? How do I continue? I'll never know.

I won't pretend. Living in a body fettered to severe pain is hell.

All I know is that with each day, I try to follow the light that lives inside me towards a fuller life—in whatever form possible. Hope is stronger than anything, even pain itself.

* * *

Sometimes I look down at the motley scars on my chest and right shoulder where the virus branded my flesh. I see a mess of irregular shapes and textures, bleached, criss-crossed lines, craters, pits.

Sometimes though, mesh-like patterns emerge, and I see a mass of faded links, chainmail, a suit of armour.

My life-death battle with the virus follows me like a shadow wherever I go. When I choose to step inside the shadow, there is a web of dark and light.

Grief and loss will always sit in a small box inside me. Moments when the box swings open, when the grief seeks me out and scoops me up into its cloak, will haunt me forever.

Yet now, with my pain-sharpened nervous system, the lifeworld is a cut diamond: facets flash, shine fuller, brighter, than ever before. I can taste solid gold sunlight, smell eternity in fragrant jasmine, feel cold water in the splash of a baby whale.

I am a warrior. I live in pain, but I live.

* * *

Postscript

Breathe in, breathe out.

Sometimes at the end of my yoga practice, when I lie on the floor in *Savasana* (corpse pose), the pain in my shoulder slips into silent, eternal nothingness, shapeshifts into a small black star, a pin-sized pulsar, a tiny thorn, a soft touch, a little pinch.

I know when I lift myself from the floor the scalding, wave-like spasms will resume. But this short pause, this alternative reality, this echo of my life before my existence as a pain-body, offers solace.

Maybe my pain is really just an asterisk marking a memory. Maybe it’s just a blotch surrounded by a system of botched signals in my brain.

And really, that’s all it is.

All, yet everything.

About the Author

Tereza Crvenković is multidisciplinary artist whose creative practice explores her lived experience of 2 x kidney transplants (1992; 2017), a major stroke (2009), chronic pain, and disability. Email: tereza.crvenkovic@gmail.com

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The Communicative Body's Call for Prospective Organ Donors: Montefiore Health System's *Live and Let Live* Digital Platform

Nancy Chong

Nini Skye is an eight-year-old child in Far Rockaway, and she needs a kidney transplant. Her best chance of survival is to find a living donor who would be willing to donate a kidney. In the two-minute film released through *Live and Let Live*, a digital platform by Montefiore Health System (2021), viewers are introduced to Nini's family and friends, invited to witness some of her deepest passions, such as drumming, and told of her aspirations of becoming a chef when she grows up. Against the backdrop of archival footage of Nini's childhood and candid video recordings of her daily life, periodic interruptions of a black background with typed text intrudes the narrative of Nini's dreams and desires. Through this effect, the film advertises an untraditional "product" to viewers—a chance to save a life, by donating an organ to someone who they have never met.

Like Nini, more than 100,000 people are on the national transplant waiting list for a liver or kidney, and about 20 percent of those are in need to find a living donor (U.S. Department of Health & Human Services, 2021). Often times, patients waiting for an organ transplant take grassroots means to expand their chances of finding a living donor by renting billboard spaces or crowdfunding within their networks. This requires a lot of time and effort. To allay the challenges of finding a donor, Montefiore Health System launched *Live and Let Live* to provide a digital presence for patients to build out intensely personal ad campaigns to reach a wider network of potential donors beyond their personal circles of connection. Other patients' stories listed on the platform follow a similar narrative format to Nini's story. Viewers are taken through the story of patients' lives by introducing their families, homes, hobbies, and dreams—connecting patients to viewers who may have experienced similar circumstances. By taking a closer look at Nini's narrative, I will demonstrate how *Live and Let Live* idealizes what sociologist Arthur Frank calls "the communicative body" (Frank, 1995), transforming personal stories of patients in need of an organ transplant into persuasive marketing campaigns that "sell" prospective donors the idea that they can potentially save the life of a stranger.

According to Frank, the communicative body is not only an ideal body type, but an *idealized* one (p. 48). The communicative body provides the ethical ideal as it accepts contingency and is fully associated with the self. At its core, the communicative body is dyadic and produces the desire to receive assurance through storytelling with others, which "crystallize the body's ethical dimension" (Frank p. 49) as it recognizes that other bodies can relate to the suffering as being shared. Throughout Nini's story, viewers witness her deep desire to continue to live. She elaborates on the many goals she dreams of accomplishing and the people she hopes to be there for, saying things such as, “I want to be here for my mom, Alba,” and “I want to get really good at music.” The video ends with her simple request, “Can you help me?” and later, her ultimate desire, “I want to live.” Viewers witness Nini playing the drums, kissing a picture of a tiger, playing with her best friend, and spending time with her mother and father on the beach. Viewers also hear her voice, and the voices of other important people in her life, stitching a narrative that inherently involves the viewer into Nini’s life through her testimony. Now that viewers are invested in Nini’s future, they face with the great responsibility her request for a kidney donation. It is through Nini’s communicative body that the viewer’s body becomes aligned to hers and is led into a communion of her dyadic desire. This presents a reminder to the viewer that Nini’s body does not belong to herself alone, but is constructed in relation to the viewer’s body. Nini’s communicative body sets a dyadic relationship with a body outside of hers and by offering it in a highly personal and visible medium, she creates the space for “reciprocity that is storytelling … offer[ing] herself as a guide to the other’s self-formation” (Frank, p.17). Although she is still a child, Nini’s dyadic body represents “an ethical *choice* to place [her]self in a different relationship to others” (Frank, p. 37) because her communicative body calls viewers to sacrifice for another. By virtue of the video format, there are multiple times Nini looks straight into the camera, directing her gaze to the positionality of the viewer, which deepens her story as coming to be human in relation to the viewer. Who wouldn't want to donate a kidney so that Nini can live? Nini's story reclaims and redefines the need for "living for the Other" (p. 15) that Frank argues has been sufficiently lost in modernist culture. Thus, Nini as teller, and the viewer (and, hopefully, a potential donor) as listener, enter the space of the story for one another and redefine what the responsibility of living for others means.

Nini's communicative body recursively creates itself as one that chooses which actions it desires to bring into being. She lists the reasons for why she wants to live in the video, and it is this reclaiming of interruption brought on by her illness, and acceptance of her body's contingency, that allows for her desires to reach others. Frank describes that "only the communicative body can reclaim interruption because only it associates with its own contingent vulnerability. The communicative body makes this contingency the condition of its desire, reaching toward others who share this vulnerability" (p. 165). The dual senses of Nini's body gaining self-reflection and making itself real in action can only be achieved through the communicative body—because it makes her story a compelling one for potential donors. In fact, her story has more than 11 million views already, and is Montefiore Health System's most watched video on YouTube.

However, a perfect story does not exist. Even the idea of placing more weight on an ideal body type, such as a communicative body, marginalizes other types of bodies and narratives that may not fully possess the privileged medium of storytelling.

Upon further research, I found out that Nini's story is fictitious. Although the details have not been specified other than that her story "is based on an amalgamation of real Montefiore patients' stories" (Gianatasio, 2021) and that Nini is not sick, her film was a pilot ad to launch the *Live and Let Live* platform. With no disclosure that Nini's story was invented by the advertising agency that created the platform, the stories of real people who need organ transplants are undermined. Under Nini's video, there are many comments by people who wish they could donate their kidney so that Nini could live. What would happen if they found out that her story was not real?

In addition, the video prioritizes patients who are willing and able to advertise themselves in this highly public way. Guided by prompts, patients can include as many details about their personal lives and relationships as they are willing to share, along with images and audio, which the platform will transform into a heartfelt film (Beer, 2021). I find this very dangerous. The repetitive narrative arc that the *Live and Let Live* platform crafts and replicates through each video is not only disrespectfully simplistic, it also reduces an illness story into a linear narrative form. Patients' stories should not conform to a template structure that is filled out in a Mad Libs-esque way. Otherwise, it creates a "social rhetoric of illness" (Frank, p. 21) that affects how others tell their stories and also shapes the mediation that happens when editorial forces come into play. The formulaic nature of a cut and paste template may help to circulate the stories of patients who seek organ transplants quickly and persuasively, but they uphold and embed the common metaphors of renewal and "gift-of-life" language that dominates the transplant industry. *Live and Let Live* should trust that their patients are educated and capable of making meaning of their own stories.

While the story advertised through Nini's video is fabricated, it still offers a testimony that entangles others in what they witness when they receive her account. This forms a "reciprocity of witnessing [that] requires not one communicative body but a relationship of communicative bodies" (Frank. p. 282) between the teller and listener, as well as teller and story. Nini, as the main protagonist of the narrative constructed in the video, adds other individuals—the viewers—to her understanding of her illness and expands the nature of her testimony by placing her story on the greater continuum of other patients' stories through the community that now exists on the *Live and Let Live* platform. Although finding out that Nini's story is fictitious undermines the dyadic relationship set up between the teller and viewer, perhaps there is still potential for an ethical demand of real people who are sick and in need of an organ transplant on the *Live and Let Live* platform. Other bodies may commune with their pain if they explore the expansive nature of their testimonies by not limiting what they share to respond to the platform's cookie-cutter prompts, designed to generate a good story. That way, patients are seen for what their bodies testify to and are a witness to their story as well as the stories of others. In contrast to how the platform's name—*Live and*

Let Live—places more power in the hands of the organ donor to decide whose life is worth saving, let us instead ask ourselves: "What is my relationship, as a body, to other persons who are also bodies? How does our shared corporeality affect who we are, not only to each other, but more specifically *for* each other?" (Frank, p. 35). Only then can the bodies of the teller and listener be joined in their shared vulnerability and orchestrate a communication of recognition that opens the space of the story for the other.

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ReTool Transplants 有限责任公司

Keith ‘Doc’ Raymond

Liselle slammed her fist into the counter. She looked up at her husband as they both stared at the holographic image, and said, “Even with donor-derived cell-free DNA percentages near zero, your chance of rejection is high and your life expectancy is only fourteen years.”

“Unacceptable!” he answered, leaning over her shoulder in disgust, a drop of spittle collecting on his lower lip. “I didn’t build an empire just so my heart could stop me before I fulfill my twenty-year plan.”

Claude’s phone chirped, announcing a text message from UNOS, ‘“Match is available. Acknowledge acceptance, then proceed to Branson Deaconess Medical Center. Time limited offer. You have twenty minutes to accept.”’

“Don’t pass up this opportunity, Love.”

“With these stats? They only want me because I can pay for the anti-rejection drugs. You saw the report in the Times. UNOS is prioritizing those with the ability to pay. Insurance companies have defaulted on transplant patients’ medications because of monthly costs. It’s a double scandal suppressed by the corporations.”

“We have ah … eighteen minutes to decide.”

“Find me an alternative. Where’s that useless kid of ours? Natches?!”

Natches' head appeared in front of the holographic stats they were just reading. A cloud of images floated around his head, "Wot, Pops?"

"Your father wants you to troll the Dark Net for transplant services."

"That's old school, Mom. Got to dig deeper. Black Web sits two layers down. Wait, is this entrapment? I'm not down for being set up. Sick of being grounded."

"Serious, son. Natches, work your magic. No retribution, and an allowance bonus if you pull something up quick," Claude said. He looked out at the gray sky from their chateau outside Paris, praying for a better alternative.

Natches rubbed his hands together greedily. Then his fingers were flying up and around his face as the cloud of images and data changed rapidly. His parents stared in wonder at the speed with which he worked. Gelled turquoise hair seemed to spark at the ends. His facial tattoos illuminated, then darkened.

A girl's head, then another boy's, appeared in the floating image, their expressions changing as they added their dexterity to the web dive. Six fingers manipulating virtual space, checking and rejecting sites. There was a moment of pure white out, then several flashes, then they were back at it.

"Here, check it," the girl with silver hair and red cat's eyes paused. The three of them directed their eyes up and to the right. Six eyes read a script in saccades going back and forth, tracking down.

"This'll work," Natches barked. "Check it, Parental units." Natches seemed to throw the screen at his parents. The image ballooned open in front of Claude and Liselle's faces.

Ironically, their parental controls slashed across the website, forbidding entry. Liselle had to allow the viewing that their kid clearly somehow circumvented.

ReTool Transplants. Beneath the banner flashed a second banner in red: Illegal, Dangerous, Expensive, yet Effective.

What followed was a load of disclaimers, arrest risks, and limited liability conditions in multiple languages. Then came a great deal of information, most of which required a sub-specialty in transplant medicine to fully appreciate. Liselle kept nodding. Clearly, she did most of the research, familiarizing herself with the details of the heart transplant her husband needed. Claude didn't bother, too busy with building his construction empire.

She turned to her husband with three minutes to spare. "If their claims and success rates are reliable, you need to do this. ReTool is transplanting just about everything, including limbs."

Claude's face ran through a series of micro-expressions reflecting the inner workings of his mind. Then he said, "Fourteen years isn't long enough to do what's needed. Let's go with ReTool."

She pinged the contact link, opening a video channel to an attractive young Chinese woman. She began speaking in Cantonese, then seeing the western faces switched seamlessly to English. "Mr. and Mrs. Laurent, greetings …" the woman's eyes drifted down and to the left. “Good. You are pre-approved for a transplant. When can we expect you, and who will be the recipient?”

“I need a new heart,” Claude answered, both he and his wife surprised at the speed of the financial clearance. “As soon as possible.”

“Very good. I have you booked first class on a suborbital shuttle. Visas will await you both on arrival at the international terminal in Guangzhou. You can use your own transport, of course, but we believe this will be the fastest route.”

“That’s acceptable,” Liselle answered, after nodding to Claude.

“Will your son, or any servants, be accompanying you?”

Natches shook his head wildly, juddering the data cloud around his head.

“No, just us,” Liselle answered.

“Thank you for contacting ReTool Transplants. We have updated your account, and we will see you soon.”

UNOS texted, demanding an answer. Deaconess texted, reporting Claude’s bed allocation. He responded to both simultaneously, “Thank you, but no thank you.”

“Party at the Mansion!” cried Natches.

“Not if you plan to spend the rest of your college education in cryosleep!” Claude barked.

“Aww, Dad.”

* * *

A Hongqi L5 with a V12 internal combustion engine burbled beside the sidewalk, waiting for them at Arrivals. ReTool personnel met Claude and

Liselle at the ramp (no sign) and escorted them through Immigration. The chauffeur loaded their bags into the limousine trunk. The woman they had spoken with on the vid link was their escort. In the electric vehicle age, the Hongqi drew stares both of wonder and derision.

They had expected to be taken to a high-tech high-rise facility in downtown Guangzhou, but to their surprise, they were driven out of town and into the countryside. Liselle anxiously watched out the window as rice fields passed. Paved highway became dirt road, moving them from the bright future back into a living past, as oxen drove plows through mud. Someone set them up—Natches?

While passing through a village, they stopped at a storefront, a country market selling fresh fruits and vegetables. Everything was labeled in Mandarin except a small wooden sign in English, ReTool Transplants, nailed at the side of the door frame. The store owner bowed to the young Chinese woman, who led the couple through a beaded curtain into the back.

Claude and Liselle saw their imminent end, as a meat cutter with a bloody apron slammed a cleaver into a cutting board.

"Sorry for the theatrics," said the woman, clicking the implant at her temple. A portion of the wooden floor lifted, and a gleaming elevator rose. Doors opened automatically. The three of them stepped in. "The entire practice in underground to preserve sterility and security."

As they descended, they saw floors of labs, operating theaters, clinics, rehab, and patient rooms. Ten stories down, the elevator stopped, letting them out at a thickly carpeted corridor. Classic paintings decorated the walls. They stopped by a numbered room; the woman tapped her implant, and the door opened on a luxury suite.

“Your accommodations. A technician will be by shortly to collect a bone marrow sample, Mr. Laurent. I’ll let you settle in. We’ll unpack your bags shortly. Check your closets then. Ciao for now.”

“Please lie on your stomach, Mr. Laurent. This will only take a minute. You’ll feel a pinch.”

Claude dreaded the bone marrow biopsy. He already reviewed the technique online. Needles, drills, and a grunting tech suctioning white goo, while the patient squirmed. His terror, only worsened, when the tech rolled in an instrument that looked like a drill press.

“The pinch is the local anesthetic, Mr. Laurent.”

Claude winced in preparation, but it was a hot spray aimed at his back that became instantly cool, then numb. The tech handed Liselle a set of purple tinted goggles saying, “You’ll need them.” Then he donned a pair himself. A moment later, there was a fireworks display, and then a twenty-five ml glass tube filled with bone marrow.

The tech disappeared through the suite door, taking the ‘drill press’ with him a moment later.

“You okay?” Liselle asked.

“Never better.” The high-tech anesthetic was already wearing off and there was no residual tenderness.

A knock at the door, and a silver-service supper rolled in. The waiters lifted domes off serving platters and filled dinner plates with confit de canard, long leaf spinach, and spiced yams. The wine already decanted was a vintage Beaujolais. Not your usual pre-op meal.

"While you eat, we will provide a holo-vid of the procedure. It should not spoil your appetite. In what language would you prefer to watch it?"

"French," they said together.

"At the end you can sign consent, virtually."

Welcome to Retool Transplants. We have collected your bone marrow cells and will retool them into induced pluripotent stem cells (iPS). Or what you think of as stem cells. Using CRISPR cas9 technology, we insert transcription factors (Oct-4, Sox2, c-Myc, KLF4, and nanog) into them to enable the transition.

We then select the targeted embryological sequences you require. We replicate these cells and select introns to differentiate them into the organ you need. Your replacement limbs or organs come from your DNA.

How can we transplant your new ReTool within days? We literally print them using 3D printer technology. Your DNA acts as the template, and by adding assembled proteins, adipose, and other tissues, we construct and print it in an environment so sterile, the machine must detect the site for transplant before even we can access the printer contents.

Your heart, Mr. Laurent, is already beating. While it is only a collection of cells, within a few days, you will be ready for surgery. Therefore, we will start your pre-op regimen immediately. Your surgeon is Ren Kato, the great grandson of Tomoaki Kato, who first successfully transplanted multiple organs into human subjects.

I know you will have questions and Xiaoping will stop by to answer them. While this presentation is highly technical, we have simplified it so you can appreciate what is happening while you wait. Besides the procedure, you will receive all needed therapies. What you won't need when you leave are any medications. Please sign your consent now. Merci beaucoup.

The video displayed all the areas of ReTool Transplants, including the surgical theater, labs, and therapy levels. What was paramount in their mind was why the procedure was illegal. Everything seemed so legitimate.

When Xiaoping entered, she answered the question without prompting. "No animal testing. No government approval. There were early failures, and many transplant deaths occurred. Please believe we are long past those tragic days. Now, the procedure is so expensive it is not available to Chinese citizens, including those of the Party. It is why we only advertise on the Black Web. It requires a level of expertise in cybernetics only the one-percenters with skills can access."

After answering a series of additional questions, both common and rare from the Laurent's, Xiaoping met their expectations, and showed them Claude's agenda for their stay. It was intensive, and Liselle played an integral part. If anything, her activities were even more intense than Claude's. Xiaoping then left them to get over their jet lag.

The virtual bay window lit up beside their emperor-sized bed, allowing them programmable landscapes to view. Though the suite was large, the window helped them not feel claustrophobic. Claude sat down and poured himself a cognac. An overhead announcement interrupted his sips. “Enjoy, Mr. Laurent, this will be your last alcohol while you are here. Post procedure, you’ll feel so good, you may not want another drink for the rest of your life.”

“Unlikely,” he muttered, as Liselle clapped him on the shoulder.

His face, pale from poor circulation, unnerved her. They had decided on the procedure in the nick of time. His deterioration was rapid, and she wondered if she would ever see him play tennis, go deep sea fishing, or even dance again. She’d be happy with one of those, or even just playing catch with Natches.

* * *

Three days later, Dr. Kato informed the Laurents’ that the new heart was ready, and the procedure would begin in the morning. Claude conducted business while he waited in his hospital suite, and during that time, he earned sufficient funds to pay for the surgery, although it was not his intention. Meanwhile, Liselle was busy, despite all her hand wringing.

In the morning, an attractive Chinese nurse placed an IV line and did Claude’s skin prep before transporters transferred him to a gurney. They rolled him through a back hallway. To this point, his surgical experience was as he predicted. Then everything changed.

They pushed him into an airlock; the door sealed behind him with positive pressure. Tongs on a frame emerged from the wall and embraced his body, then the gurney dropped through the floor, and the room sealed. He then was "sterilized" using several sprays, additional shaving, all followed by ultrasonic and ultraviolet light treatments.

As he was rolled into the surgical theater, Claude was surprised by the lack of personnel. Four surgical robots closed in on him positioning themselves around him. Claude could see Dr. Kato outside the room on the other side of the glass. Laurent stared apprehensively at a heart, his new heart, suspended in a plexiglass column, floating in a transparent solution, already beating and pumping blood.

The tongs that suspended him lowered him onto the bed, which was painfully cold. Almost immediately, a robot approached and administered a sedative. The tension eased from his body and his concerns floated away. His body temperature was lowered into the hypothermic range.

"We will perform the entire procedure at high speed," Dr. Kato said through an overhead speaker. "Perhaps you noticed the lack of bypass equipment." Claude hadn't. "Once your chest is opened, we will remove your old heart and transplant your new heart within six minutes while you are under general anesthesia. I will be with you throughout the surgery."

Claude wasn't sure how the transplant surgeon could *be* with him while outside the room. But he no longer cared, as they added a second sedative to his IV. Claude felt the endotracheal tube pass through his vocal cords, then nothing more.

While he slept, a scanner passed over his chest, identifying tissue layers and the sternum beneath. A precision laser cut between the cells rather than through them. Layer by layer, down through the bone, the incision deepened. Clamps gently retracted and opened his thoracic cavity.

The new heart rolled into position above his chest, then the robots clamped all the major vessels to both the old heart and the transplant at the same locations. Ramping up power, the robots removed the old heart at a speed that was hard for the eye to follow. They implanted the new one, which seemed small compared to the old heart, but far healthier.

All the vessels were re-approximated, and tissue glue made from Claude's serum applied to the cut edges. It was a molecular glue, stronger than the surrounding tissue, containing a matrix and endodermal growth factors to allow new cells to migrate into and grow in place of the glue. It would dissolve and reabsorb over six weeks.

When the robots removed the clamps, his circulation recommenced with his new heart. It took longer to explain than the actual surgery. Dr. Kato checked the patient's parameters.

He carefully assessed pulmonary pressure, ejection fraction, tissue oxygenation, and other variables. Satisfied, he ordered the robots to close. They used the same tissue glue instead of sutures.

When the machines pulled back, the seam in Claude's chest was barely visible. The bots titrated off the anesthesia and removed his endotracheal tube. While warming him, transporters transferred him back to his suite. Dr. Kato followed the patient, along with a recovery room nurse who would observe Claude. Dr. Kato would patiently answer Liselle's questions while they waited for Claude's first words.

For the first time in years, Claude's cheeks were flush and healthy. While he recovered, they took tissue samples from the old heart, which they stored in the lab. Like the wooden model cast made from the client's foot for a custom made shoe, they stored his DNA for his next transplant, when needed.

"So, when can we leave?" Liselle asked.

"After about two weeks of cardiac rehab. It is much shorter than traditional rehab post transplant because the tissue trauma is far less. It is more about adjusting than strengthening. The body needs time to catch up with the new heart."

"Will he be on any medication at discharge?"

Kato looked over his medication list through his augmented reality glasses, smiled, and said, "No."

"Nothing?"

"He won't need any of these anymore."

"No anti-rejection meds?"

"It is his own retooled heart. There's nothing *to* reject."

After a pause, Liselle asked, "How can all this be illegal? It is so far ahead of anything we have seen."

"Most of this is experimental. It isn't approved and it's unlikely to get approval in our lifetime."

"But why?"

"It would dismantle an entire dysfunctional industry. Billions of dollars and thousands of jobs would be lost. UNOS would be gone. Not to mention the illegal organ trade. There is too much at stake. Too much invested to see the technology and medicine we are practicing here to be adopted."

"How can *that* be right?"

* * *

"Best million euros I ever spent," Claude said, as he signed the non-disclosure agreement. He wanted to tell all his friends about this transplant program, but the Laurents were sworn to secrecy. They'd have to find out about the program on their own.

"They'd need someone like my son to take them below the Dark Net into the Black Web. I'm going to have to buy that kid a new car once we get back to Paris. If he and his friends haven't destroyed the house."

* * *

Basking in the afterglow of the first sex they'd had in a while, Liselle grinned at her husband. Biting into her croissant, she looked at the back page of the morning newspaper he was reading. There was a small article about an illegal transplant clinic raided by the Chinese government. She gasped when she read they had killed a Dr. Kato during the raid.

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The Silenced Side of Living Donation Evaluating the Measures of Success in Living Organ Donation

Alisha Hiebert

I am the oldest of four in a family forged through adoption. Growing up my siblings and I experienced a typical relationship that could be summed up with the sentiment, "I'd give up an organ for you but don't touch the TV remote."

I am the only one in my family with Glycogen Storage Disease, the genetic condition hallmarked by the cruel inability to convert glycogen into glucose, and the very thing that resulted in my need for a transplant. When the time came that a new liver seemed like the best viable option, my doctors recommended we first look at living donors. Both of my parents eagerly hopped in line to get tested, and due to various circumstances, neither was a match. More donors, not related, were tested on my behalf, each one denied. The longer I waited, the more my body deteriorated, and my condition worsened. My biological brother, who was in college at the time, came forward and offered to get tested. I was in the parking lot of the hardware store when my phone rang, the transplant coordinator confirming what I already knew in my bones to be true. He was an ideal match, and our shared surgery date was scheduled for the middle of August.

I was concerned for my own survival, but my big sister instincts also kicked in and I was equally concerned for him. He was young, physically fit, an ideal candidate in every medical sense. It was these very things that made me nervous. I knew if something happened to him, the guilt would eat me alive. Leading up to the surgery, my medical team reiterated the risks until the numbers were almost meaningless. Their reassurances were little comfort: they wouldn't do the surgery if they didn't feel it was safe; if my body rejected the organ, my brother wouldn't be to blame; I wasn't to blame if something went wrong in his surgery. He was four years younger than me. Even if there was no talking him out of it, it had always been my job to protect him. Now here he was, undergoing major surgery because of me.

The morning of our surgeries, he went into the operating room before me. A few hours after his surgery had already begun and before mine was scheduled to commence, I was taken back to pre-op, to wait among the rows of stretchers bearing people waiting to be moved into the operating theatres. Huge double doors led to the outer part of the hospital where our family waited. Every time the doors separating the OR waiting area and the rest of the hospital swung open, despite knowing his body already boasted the mark of a surgeon's scalpel, I hoped to see him. I was alone for this part, and so was he, but I wanted to be alone together. We were about to embark on a journey no one else would ever understand, and all I wanted was his hand to hold along the way.

The surgery did not go according to plan. I would learn later, from perusing medical records and asking doctors who flocked to my bedside to marvel at this medical unravelling, that in the middle of my surgery, my brother had unexpected complications. Surgeons hopped from one room to the next, trying to stabilize both of us. I hadn't even left the OR for the first time when doctors were already speculating that I would need a second transplant. In the days I spent sedated, intubated, fighting for my life, my brother was fighting for his, in his own way. My parents entered every parent's worst nightmare, crossing the hallways of the ICU, going from the bedside of their son to the bedside of their daughter.

Before my eyes even opened, I knew. I knew the liver inside my body didn't belong to my brother. It was unfamiliar and not at all familial. When the words were finally spoken, when my mother told me that I had received a second transplant, she led with the words "Jacob is fine."

In that moment, I would have traded the entire world to make sure he was okay. My own survival was secondary; the need to make sure he was alright pervasive. Jacob—the baby I used to dress up, the child who I pushed down the stairs for playing with my toys, the one who grew up and became this funny, wise man I consider one of my best friends—an entire life flashed before my eyes. It wasn't mine, but his.

Due to hospital regulations during Covid-19, the first time I was able to see him was weeks later, when I was finally released from the hospital. As I crossed the street towards my rented apartment across from the transplant centre, I saw my brother and began sobbing. There are no words for the way I exhaled when I finally saw that he was safe.

It has been two years since both of our lives changed forever. My second transplant from a deceased donor is considered successful thus far, and my brother is studying abroad for his final year of college. In terms of statistics, we are a mostly successful story.

Except there are nights when I can't sleep, when the only thing I can feel is intense guilt for what I put him through. The flashbacks of what it cost to survive are so vivid they threaten to steal the air from my lungs. And I know he'd do it all again. I can't help but think, though, that we can no longer quantify success as the sheer survival of two people. We both live with trauma and scars that won't go away, haunted by what ifs and what should have been. We are the side of living donation that isn't talked about.

When it gets quiet, when the calendar pages turn to August and I walk the familiar hospital hallways, when I think of this transplant journey and the places it has taken me, I think of him. Not for giving me part of his liver, but for the ways in which we walked through hell. The bond we share is one no one will ever understand, and if I had to go there with anyone, I'm really glad it was with him.

Hey J, I love you. Forever and always, your big sister.

About the Author

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Dammar

Mark Zimmerman

There were nights when the land of Gorkha District would flood with moonlight and the Himalaya, tall and silent, their broadsides aglow, seem to drift above the undulant hills. Nights when a boy could walk over long, rough trails and not be afraid.

In the summer of 1969, when Dammar turned seven, he began to notice he couldn't see well after sunset. He told his parents, but perhaps they were too busy with matters they could understand—keeping a farm going and putting rice on four children's plates. They waited for Dammar to get better, but within a month, he was blind.

I didn't choose Dammar as a friend. I've always looked back, somewhat bemused, at how events led me to grow close to a blind Nepali man. In 1987, when I worked at his village's hospital in Amp Pipal, Dammar would wander into the church, usually late, sit down, and begin playing his flute (intermittently in tune with the hymn).

A few years later, after I was posted to work in a hospital in the capital city Kathmandu, Dr. Helen Huston in Amp Pipal arranged for Dammar to move to a social service center in Kathmandu. There, they taught him to weave woolen carpets. Helen wrote to me saying, "If you can spare time in your very busy schedule, could you go visit Dammar? He has no one to pray with out there." I began to meet Dammar and his blind friends in their five-coloured house in Nakipot, two miles outside the city.

He used an old, straight tree branch as a walking stick, holding it like a shepherd's staff and bouncing it back and forth on the ground in front of him. With a little practice, he was soon able to walk by himself on narrow, heavily trafficked city roads all the way to Patan Hospital. Every Saturday morning at ten, he'd turn up outside the hospital gate and we'd walk together to Patan Church.

Dammar taught me a few things about faith. Several times, we'd hiked together back to his village. There—where the trail climbs 2,500 feet up crazy rock staircases, runs along the narrow rims of flooded rice paddies, clings to cliff edges, and leaps from mud to stone to tree root—Dammar was dependent on a friend. I had to take his hand, which felt remarkably sensitive, and lead him. He needed to be told to step short or long or very long. If my words misled him, he could easily miss a target rock and plunge his foot into a channel of muddy water. But he was easy to guide. He didn't ask me to tell him what was coming further along the trail. Chatting away in a lilting voice, he usually just held on and patiently trusted. On a good day, we'd make the climb in three and a half hours, a reasonable rate for a seeing person.

Dammar seemed happy at the social center. His circle of friends had grown compared to that of his days of sitting idly on his father's front porch, and if he wasn't the most productive of carpet makers, at least he had something to busy himself. He lived there for three years.

During Dammar's last year there, the center's director, a Catholic father from America, learned Dammar attended church. Feeling strongly that his social work in a strict Hindu kingdom might be threatened by Christian conversion, the director gave Dammar a choice: quit attending church or leave the center. I tried to persuade the father not to take such a drastic step, but he was unyielding. His ultimatum created a dilemma. Dammar didn't want to return home, where he'd already felt himself becoming an unwanted burden. Still, he didn't think long about his decision. Within a few days, he'd left the center and returned to Amp Pipal. He said, "This is the only way if I'm to walk with the Lord Jesus."

Some years passed. Although I'd kept loose tabs on Dammar through friends, I'd not seen him for a long time. Then one Saturday evening in February 1995, while I was treating patients in the ER, the watchman led him into the patient waiting area. Dammar recognized my voice, turned his face upward in his patented, beaming smile, and reached his hand out, eager for my touch. The day's journey? He'd walked with a nephew down the hill to Turture, had a quick snack there, came alone on a minibus to Dhumre. There, he hitched a ride in a private van to Mugling (where the police made trouble, saying, "Blind people shouldn't be out on the roads like this!"), given them the slip and got on a bus to

Kathmandu (only vomited twice), taken an auto rickshaw to the center of town, and finally a taxi to the hospital (driver may have overcharged).

“It’s good to be here, Dr. Mark. I hope to stay for about two weeks.”

“Great, Dammar. Can you wait here while I see some patients?”

Dammar got acquainted with the big town, shuttling himself from one group of friends to another. In between, he stayed in my apartment’s guest room. Two weeks became two months (“Why leave so soon?” he asked me several times when I’d explored his departure plans.) It always seemed when I was most busy with patients, the hospital operator would page me to say “Your blind friend is waiting for you out in the courtyard.” Different people approached Dammar differently—some warmly, some distantly, but all very curious. As he and I stood talking over some mundane matter, a crowd would circle to gape and listen.

One night, we had a big meal of *daal bhaat* at the Hungry Treat Restaurant and Lodge, whose sign advised, “Treat Hungryness & Be Healthy.” Then we went across the street to have some ice cream. It was Dammar’s second time ever eating this dessert, so he wasn’t too graceful with the tiny wooden spoon in the paper cup. A few dabs and slurps and Dammar finally just put his lips down into the cup to suck up the ice cream. One of the young waiters sauntered up and pointed at his walking stick.

“Hey, what’s this, bro?! You can’t see at all?!”

“Huhm,” without missing a lick, “can’t see.”

"Since when? Since birth?"

"Since six or seven years old."

"So what, the eyes just went like that?"

"Just went."

Neither the waiter nor Dammar regarded this line of questioning as rude. Dammar had been through it a thousand times before. A few minutes later, two other waiters joined the first over by the ice cream counter, and they repeated the same dialogue among themselves.

I encouraged Dammar to spend some time with his uncle on the west side of Kathmandu, an area called Kapurdaada. Since there are no street signs or house numbers in Kathmandu, we rode around on my bicycle trying to find the place, me carrying Dammar's stick across my handle bars and Dammar balancing behind on the book rack. Picture a tall white guy pedaling unsteadily on the back streets of the town, taking directions from his blind passenger, both searching for a house neither of them had ever seen.

I thought Dammar was going to go back to Amp Pipal after visiting his uncle, but I later learned he'd stayed another week. During that time, one of the girls in the house, a shy sprite of eighteen named Bhagawati, had suggested they take Dammar to the government eye hospital in town. If they'd asked me beforehand, I probably would have said, "No, his eyes have already been checked over several times and nothing can be done," but I hadn't been there to ask. As it turned out, the National Eye Hospital was closed that day due to a strike and the taxi driver suggested they try the new eye institute beside the Pashupati temple. That night, they phoned me and convinced me to come along with them the next day.

Tilganga Eye Institute had recently been established by Nepali ophthalmologist Dr. Sankuk Ruit, with the assistance of his friends in Australia. Tilganga was a state-of-the-art institution for Southeast Asia, with a production unit for intra-ocular lenses and a cornea bank, at that time stocked with corneas from the U.S.

Dammar was ushered through the crowded rooms—a little roughly I thought, but it was good not to have to wait. His right eye was beyond repair, they said. While the front part of the left was badly damaged, probably by a deficiency of vitamin A, the ultrasound of the back chamber, where the retina lies, was normal. We were soon back in front of Dr. Ruit, who was saying to me in rapid-fire English, "We can't be too optimistic. Your friend has a 20 percent chance of regaining useful vision. We'll put him on the list for a corneal transplant and an intra-ocular lens implant. It will all be free. We expect a shipment of corneas within a month and will call you as soon as they arrive."

In the busy hallway outside, I related this news to Dammar's two nieces. The three of us had to hold back tears. Dammar seemed unmoved. Maybe he was wiser and saw it as a long shot. Or maybe he was uncertain about whether his life would really be better in a visible world. That night, among a group of his village friends, he didn't say a word about his visit to Tilganga. The next day, when I coaxed Dammar to imagine what he would do if he could see, he seemed confused by the question and then said, “I suppose I’d plant the crops on my own land, and serve God by helping less fortunate people.”

***

A man from the eye institute called me on a Tuesday. He’d just received a fax saying a package of human corneas was being sent from Baltimore, Maryland. Could I bring my friend Dammar to the hospital on Thursday afternoon, the day the plane would land in Kathmandu?

We waited among a group of patients and their relatives. Dammar’s two nieces read my magazines. A nurse had instructed us to put antibiotic drops into Dammar’s left eye each hour throughout the afternoon; Dammar usually asked after 40 minutes if it wasn’t time for the next application. At about four o’clock a male nurse I knew hurried past carrying a large box, tapped it, and said, “Doctor Mark, the eyes have arrived.”

I looked out the window at a vine wrapped around a post and climbing towards the roof, extending tendrils bearing violet flowers. Two women walked away from the hospital with a gentle sway that caused their shoulders to brush. Monsoon clouds swirled above a row of trees whose leaves glistened in the breeze of an approaching storm.

Dammar was case #1, slated to be handled by the director, Dr. Ruit, at 8 p.m. Afforded VIP status, I watched from the library, which was separated from the OR by a plate-glass window. A nurse led Dammar to the operating table and equipment was swung over his face.

Suddenly, an eye filled the closed-circuit TV screen in front of me, a misshapen globe covered sloppily by a white-tissue omelet and surmounted by a tangle of hungry blood vessels. I sat transfixed. A huge tube descended, sized up the curvature several times, and then sliced deeply into it. Thick vitreous humor welled up and mingled with rivulets of blood. In two minutes, the uneven landscape had, cut into it, a precise circle opening into a black hole. It took half an hour more to cover the space with an American cornea and secure it with 12 sutures of thread finer than human hair. Dammar emerged from the operating room wearing a tight bandage and went home with his two nieces, who would be able to provide the daylong, post-operative care I could not.

The realization Dammar had not miraculously regained his vision dawned on us over several weeks. Two days after the operation, the girls called me to say that when Dammar peeked out from under the bandage nothing seemed different. Later they reported that, at his first revisit to the eye institute, he'd perceived only a little more light than before the operation.

When he came to stay with me, I immediately took off his patch. I found he turned his head away from a bright beam of light. He could differentiate the colors of books that I held in front of him. Sometimes he could catch a stick as I passed it in front of his face. New light was getting into his eye. When he got up and walked to the bathroom, however, he bumped into chairs and groped along walls the same as before. We repeatedly practiced the simple vision maneuvers, but I wondered if I was encouraging progress or just deluding us both.

Dammar stayed in town one more month so he could be rechecked by the eye doctors. When he was with me, he spent his time listening to the cassette tapes I'd laid out for him or washing his clothes more times than needed. One morning, as I walked back from a friend's house, I noticed a figure on my flat roof, silhouetted against the clouds. It was Dammar. He must have gone up to hang laundry to dry. He stood near the railing, staring up into the morning sky, passing his hand back and forth in front of his face.

On one of his last nights in Kathmandu, Dammar and I were having dinner together in my apartment. He'd left the tape player running and Doc Watson's rendition of 'The Wabash Cannonball' was booming from the next room.

"That's the blind American, isn't it?"

"Yeah, that right. Do you like him?"

"He's good. Dr. Mark, I'll never see again, will I?"

"What kind of talk is that, Dammar? The eye doctor told you your vision might continue to improve for six months after the surgery. Why lose faith so quickly?"

"Sorry. You're right."

***

At 6:30 in the morning, we wandered the bus park among revving engines and billows of exhaust, searching for an auto-rickshaw going to the west side of Kathmandu. As we climbed in, whom should we find inside but Dammar's distant aunt, her brother, and her son. They, too, were returning to Dammar's village. We were all surprised. They expressed curiosity about Dammar's operation, but didn't appear at all interested in helping him. At the crossroads, we all got out of the rickshaw, and they walked away and boarded a different bus than we did.

A government bus took five hours to carry Dammar and me to Dhumre, along the 100-mile road that followed the Trisuli and Marsyangdi Rivers. The third leg of our journey took us to Turture on a dilapidated local bus. The only empty seats were in the very back, so I led Dammar clumsily down the aisle, which was crammed with cases, backpacks, and a folded-up baby carriage. Everyone stared at us. A man said loudly, "Who would bring someone like *that* on a journey?!" All the windows were closed to keep out dust, so it was sweltering inside. The bus crossed a briskly-flowing stream and lurched onward. Several times it seemed as if it might tip over as a wheel slid into a deep fissure in the muddy road. I understood why Dammar had skipped lunch.

By the time we started walking, only three hours of daylight remained, which was barely enough time in the best of conditions, and I didn't even remember the path well. In the town of Taadi Pokhari we came abreast of a group of men who were sitting out in front of a row of stores chatting. One of them greeted me. It was Ganesh Shrestha, a shopkeeper from Dammar's village. He was a clever businessman, a man who'd had enough money to build a local temple to the Hindu god Ganesh. I wasn't expecting him to jump up from his friends and offer to make the trip with the two of us, but he did just that.

The first half of the hike meandered through meadows bordering rice paddies; the second half was a steep climb. Dammar was walking totally in blind mode, ignoring any light that might be entering his eye. I held his arm as I picked my way along the hard trail. My patience was beginning to flag, but Ganesh continued to encourage Dammar. "That's it, Dammar, step short! Very good!

"Soon you'll be back walking this path on your own.

"Hey, that's not your fault, bro. If you stumble, we're to blame."

Ahead, two mountains formed a semicircular ridge; Dammar's village clung to the western side of this forested half bowl. It was getting dark and Ganesh had taken on the difficult job of guiding Dammar for the last hour of the climb. The thick jungle smelled of dank earth. On the banks of the trail, lightning worms glowed among the ferns. Overhead, the sky was gradually adding layers of darkness and the stones on the path were now barely visible. I plodded on, carefully feeling for each foothold, as Ganesh came up behind me with Dammar. Cliffs dropped off to our left. The trail slid clear of the forest, and the lights of the hospital complex, like a sprawling, grounded spaceship, leapt into view and then disappeared as the trees thickened again. The clackety-thud of its distant generator competed with the chorus of crickets.

At Dammar's sister's house, the family, who were considered poor in a notably poor town, laid out a splendid dinner for us. Sitting on a woven straw mat on the floor, we ate with our hands—rice, black lentil soup, vegetable curry, meat curry, and two types of spicy chutney. Before I could refuse her, Dammar's sister had opened a bottle of Fanta for me. It had probably cost her more than the whole meal.

Every so often, a villager poked his head through the doorway, face flickering in the light of the kerosene "lamp"—a wick dunked in a bottle. Each person asked the same question: "Can you see now, Dammar?"

Between bites of food, he patiently explained yet again. "Not really. It's about the same. But the doctor said it might continue to improve for up to six months after the surgery." Dammar's brother-in-law added his advice that eating spinach and other colourful vegetables would surely increase his chances of recovery.

After dinner, I led Dammar out in front of the house. A full moon had just risen above the ridge, freeing itself from the trees high above us. A perfect circle cut from the black velvet night, its light filled the courtyard where we stood, both of us in turn spilling cold water from a brass urn onto the other's hands to wash away the clinging grains of rice.

About the Author

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Miracle Cures

Anna Krentz

You take the pieces of your syringe from the bottom of a drained pot, air dried after a boil for sterilization, the glass singeing your fingers. Scrubbing your hands, you settle near the back window at a table so clustered with bottles and cloths it could stand in for a pharmacy. You fit the pieces of the syringe together, piston into cylinder into needle. Right arm before lunch, so left arm now. The scent of alcohol slaps as you paint a circle on your meagre bicep, then over the cap of the insulin bottle. You withdraw the metal wire from the needle, draw fifteen units of air into the syringe, stab the point through the sterilized rubber. Invert the bottle, push in the air, trade for liquid. Pinch skin from your arm into a plateau, drive the needle into that funny, loose space just under the surface. Piston pushed slowly, silvery needle emerging backwards, bit by bit. Cotton pressed against the prickpoint, already vanishing.

* * *

It’s 1923, and you’re an eighteen-year-old with diabetes, just over fifteen months past having only days to live. Fifteen months past your first injection of the breakthrough drug insulin, discovered in your own hometown. A miracle cure, the papers have called it. You know it’s not a cure.

* * *

It’s also 2019, and you’re a thirty-two-year-old with cystic fibrosis, nearing your first year post double-lung transplant. One year ago, your lung function was 19 percent and you gasped for breath wheeling your IV pole to the bathroom, high-flow oxygen freezing and drying your nose. At your last appointment, your lung function was 120 percent. You can go weeks without coughing.

* * *

You’re writing your experience through historical fiction, because that’s what you’ve always done. The first successful double-lung transplant for cystic fibrosis was done at the Toronto General Hospital in 1988. So was yours, thirty years later. But you’ve found your emotional resonance in the 1920s. Still revolving around the Toronto General.

* * *

You’ve reached the point of starting to catch yourself sometimes not feeling constant gratitude, but also not yet past the bewilderment of being alive at all. Especially when feeling the most content, walking for hours beneath another season of flaming leaves you once were unsure you’d see again, the sense might arise that it isn’t real, that it’s only delusion from a hospital bed.

* * *

Even when the present solidifies, the future wavers. You hope for it, plan for it, can’t quite believe in it. Taking up your old passions and ambitions feels audacious, committing to years you might not have. Your treatment is so new, still a work in progress, that it’s hard to know. It’s only been a year and a half since a person *could* live on insulin, in 1923. Just over thirty years with a double transplant, in 2023. How long is possible?

* * *

There’s a freedom to the new spaces you find yourself in, the ones you’d never experienced when you were sick. There are corners that don’t remind you of pauses you needed to take, as your lungs or legs struggled. Stairs you never tried to avoid, water fountains you never had to tear yourself away from.

* * *

New people don’t pity you, or worry you’ll infect them. Nothing external gives it away. Scars beneath your clothes, medications administered out of sight. You’re lucky to be young, older people say. You haven’t yet had to deal with constant prescriptions and tests, medical appointments, and chronic pains.

* * *

In 1923, doctors advise you not to tell anyone, to talk about it as little as possible. To develop character, to avoid anxiety, to stay cheerful. And to keep your feet clean.

* * *

Discipline still holds the day. Insulin might be a priceless gift, the doctors drill, but there can be no exchange for rigorous control elsewhere in your life. Decades before most of your peers know what a calorie is, you can rattle off exactly how many grams of fat, protein, and carbohydrates you're allotted per day, how any regular food breaks down, the weight of a pat of butter or cup of oatmeal. Each week presents a mathematical exercise, dividing food values by meals, subdividing by meat and side dish and the occasional treat of saccharine and agar-agar. You can't eat a thing that hasn't been weighed except black coffee, broth, and the wateriest of vegetables.

You avoid eating out, dodge explanations of your odd, diet-constricted meals. You seek solitude to close your eyes and suck a candy at the first dizzying touch of hypoglycemia, savouring the rare sensation of sweet as you wait for your shaking to still.

* * *

You're healthy now, or close, but catch the slightest sniffle and you'd never know it. Confinement to bed, food cut, insulin increased. Hourly instructions to check your temperature. Don't shed your blankets, don't forget to test your most recent urine; we want to see nothing but blue in the test tube. But observe for any signs of insulin shock, with that extra dose. Drink your tea before it gets cold. A fresh broth will be ready soon. Rest, let's not have any stress. Enough handkerchiefs? Don't make that face.

You know that not long ago even a cold was alarming. The smattering of germs that a normal person would hardly feel could have shattered the minimal carbohydrate tolerance you retained, shot you down in a spiral of acidosis. Back then you didn't come out of coma.

And maybe the awareness is hard to shake. You hear of soldiers, otherwise perfectly normal, who hear a backfire or a champagne cork pop and dive for cover. You get so used to being on guard, to thinking maybe this is it, even when you're pretending to yourself and everyone else you've never had that thought at all.

The familiarity can get to you. The backrest of piled pillows, the pyjamas in the sunlight, the deluge of black tea and broth.

You might think it's better to push yourself than be coddled. You're used to pushing yourself. But to your loved ones, you still exist only in two states: healthy or dying. No in between recognized.

"We have to be careful," they say.

"We." Isn't it *my* illness? *My* body that doesn't work? Did *we* inject ourselves three times a day and intimately know the sugar of *our* urine? Was it *us* who starved ourselves?

Would *we* die in a diabetic coma?

* * *

A person cured of illness walks free from hospital. The recovered consumptive says farewell forever to the sanitorium. Freed of your inflamed appendix, you might never face a hospital admission again.

You haven't been an inpatient since you were first sent home with the insulin, drilled in dosages and sterilization methods, fitting together syringe components as automatically as a soldier with his rifle. It has been almost a year and a half.

But they've put the diabetes clinic in the hospital, so every couple of months you report in, dread settling as you pass through the hospital gate. With their regimented lines of tall windows, the buildings loom like skyscrapers. Warm brown brick does nothing to reduce the severity. The white veils and aprons of nurses flicker across the grounds like ghosts.

You have to visit the outpatient pavilion only, not the front lines of the wards. Still, whatever else you try to think about, the speckled terrazzo of the floor and the enamel-like gloss of the walls crowd with memories you'd rather flee. That certain snap of shoes on a hospital floor; those notes hit by the wheels of medical furniture; that bleach scent in the corridors, evocative as the smell of fried food at the fair.

Only a check-up. All is going well. A long while since the last appointment that wielded a devastating blow. Almost no chance of facing sentence to these antiseptic cells. Almost.

Your eye catches on the other young patients. You can feel close to each other, veterans of the same battles, comrades-in-arms. All the same, like a soldier, you learn it's best not actually to get close, solidarity without attachment. Well wishes are given in silence, and in the abstract.

* * *

The topic arises sometimes, among strangers, among friends. The Nobel Prize for Medicine, in 1923, the first ever awarded to a Canadian. You pretend you hadn't heard the announcement, even if you already clipped the article. You let your friend explain it to you. "That whole diabetes cure."

"It's not a cure." A reflex.

"No? I thought it was."

Why had you said that? How could you not?

You try to explain as if you barely know. A family friend, that's all. They didn't die. Because of the insulin. They live with it. That's all you know.

Should you have said nothing?

Should you have said more?

What would your new friend say, if you confessed?

I'm sorry. How awful. How lucky.

You'd be the someone he knew, talking to others about insulin, the diabetic in that narrative of suffering and redemption. Little brave deserving victim.

You're never going to tell him.

* * *

You count eight drops into the test tube, then pour out the rest and flush it away. One teaspoon of Benedict's solution. Over the alcohol lamp the potion bubbles. Three minutes, remove, cool.

Say you dropped the tube into the tub to shatter on the enamel. Hurled the bottle of Benedict's solution out the second-floor window. Passed your morning urine without a thought.

The diabetic should avoid emotional upset, the doctors dictate. Stress is nearly as dangerous to the diabetic as it is to the man with a weak heart. Simple as that, modify your emotions just as you modify your diet. Prescription with "life of calm" next to the insulin.

Slight precipitate clouds the test tube. Colour somewhere between tan and olive. Shades like fabric options. Only the slightest trace of sugar, but there shouldn't be any. By noon you're bound to be feeling low and that shouldn't be, either.

Downstairs to the next round of bottles. How easily that glass syringe would break under your heel …

Be cheerful, write the doctors in the patient guides. Cheerful, and thankful the disease is not of a hopeless character. Be cheerful, and keep your feet clean.

* * *

All goes well until it doesn't. You nick your foot on a piece of glass and can't risk attending that night's dance. You want to pretend it'd be fine. Except what if it does get infected? What if it doesn't heal? What if your blood sugar shoots out of control? Maybe insulin can stop working. Maybe your foot could die and they'd have to cut it off. You could be back to starvation. The thirst could return, and the pain, and the bleakness, acidosis, blindness. And it would be your fault.

You stay home.

* * *

You wake one hazy morning to worried faces and wracked muscles. Orange juice forced into your mouth, burning your bitten tongue. "You were having convulsions," they say.

Hurried to the hospital, movements and thoughts submerged in molasses. Your body aches as if every limb was stretched out to the limit and let go to snap back.

The doctor interrogates. Determined that your fault must be somewhere.

If you're responsible enough. If you control yourself enough. If you steer your chariot's steeds, Diet, Insulin, Exercise. You crashed; you let the reins slip.

No one says this to you, except you.

* * *

Most of the time you feel normal. You'd say normal; would others? Impossible to imagine how other people feel, unreliant on the mercy of their blood, straight lines of energy and awareness, heads always set securely on their shoulders, feeling sick only when they've eaten bad food.

* * *

Sometimes you wake with dreamt scraps of the hospital still clinging, tense with the expectations of needles, the hushed conferral of parents and doctors. Wheeled beds on linoleum floors, ward smells of starch and alcohol and urine. Whimpers of starved children, the sharp skid of metal on metal as a curtain draws abruptly shut.

* * *

Sometimes you're put back in the hospital.

Walking the designated hallway, you imagine yourself growing weaker, every fought-for ounce of fat and muscle melting away until you become once again the teenaged wraith haunting these halls. Nondescript doors and alcoves stand out as landmarks, remembered waypoints from treks around the floor made arduous by wasted legs. That wide marble window-sill, leant upon with gratitude, a lookout from where to watch pigeons gather on the flat roofs. The jerky hand of the dial above the elevator. The trapdoor in the ceiling that beckons exploration, but probably leads only to pipes and wiring. You remember each detail like a long-serving prisoner would remember his jail.

You fall into the rhythms of the hospital day as if you never left. Delivery of breakfast, delivery of lunch, delivery of dinner. Eggs, bacon, bran, cream, bacon, boiled vegetables. Injection of insulin, withdrawal of blood. Weight, temperature, repeat.

Your friend visits you in the hospital. You tell him you're a diabetic. He tells you he has epilepsy. You become best friends.

* * *

Soon, sooner than it once was, you're home. Back in clothes again. Sterilizing your own syringes again. Back to a space you can call your own and close the door on. A few doses shifted. Little else.

Celebratory brew of cocoa shells. Quiet rest in your own bed, peace from constant footsteps and rubber wheels, the cacophony of coughs and weak protests and urgent murmurs. Coffee that is coffee and not hot water dyed brown.

* * *

You believed once that character could hold the day. If only you could be strict enough with yourself, disciplined enough, cheerful enough, never turn away and never let your hands slip from the reins. In the end, triumph, through sheer force of character.

No one ever said triumph. That was all you. The metaphor was the charioteer, not the chariot race. Races have an end. Insulin might now be a third horse, but there is no finish line. Only endurance. But that's a thing you can do. You can endure.

* * *

You, with your diabetes and insulin, in 1923.

* * *

You, with your cystic fibrosis and transplant, in 2023.

About the author

Anna Krentz is an archivist and writer, five-year post-double lung transplant. She currently lives in St. Andrews, New Brunswick.
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Primavera

Michael Diamond

April is the cruellest month, breeding
Lilacs out of the dead land, mixing
Memory and desire, stirring
Dull roots with spring rain.
— T. S. Eliot, The Wasteland[1]

She was a wraith, a walking ghost, condemned to wander the face of the planet hungry for air. In her early 30s, she floated in, veiled in the diaphanous attire of a teenage waif, her consciousness thinly attached. A Quattrocento nymph sorely in need of a warm West Wind. Is it fair to call it depression, the condition of a person wasted to the point of standing at death's door? Depression, strictly speaking, the reason she sought treatment, is a diagnostic category that applies to the living. Neither living nor dead, she occupied that tenuous space between the two, the breath of life a mere suggestion on her lips. Once she had dwelt among the living in a well-to-do neighborhood of the city, two doting parents and an adoring older, though vexed, stepsister. The girl had run with a pack of party girls and had risked the occasional romance of youth. The frailty of her body could not hold her back. She drank in life with a preternatural gusto that seemed as if it might outstrip her death sentence. Now she was silently saying goodbye to all that. The condition of her flesh had reasserted its dominion.

Cystic fibrosis is an autosomal recessive disorder whose silent gene is present in one out of every twenty-five persons of Northern European ancestry. Dorothy Hansine Andersen, judged most unladylike by her American medical peers, named the condition in 1938[2] based on the gross pathology of the affected pancreas. However, it was lung disease that killed the girl, that kills most CFers. Ironically, it was lung disease that killed Dr. Andersen at 61 after a life of hiking, canoeing and carpentry. But the disease that afflicted the girl had entered the awareness of physicians as early as the 18th century in Germany and Switzerland with the clinical admonition, "Woe to the child who tastes salty from a kiss on the brow, for he is cursed and soon must die."[3]

Death by the age of fifty awaits the afflicted in even the wealthiest countries. More often it comes sooner. A temporary lifting of the curse has been conjured by multidisciplinary clinics overseeing diet and the use of digestive enzymes, proactive treatment of airway infections, wise deployment of ergonomic breathing and energy conservation techniques, and regular visits for pulmonary physical therapy. A handful of orphan drugs have helped a few patients as has oxygen therapy and occasional surgical intervention. Gene therapy has so far proved disappointing.

Shortly after her first psychiatric consultation, the girl's number came up, a warm wind from the West. Pittsburgh to be precise. In essence, she won the lottery for double lung transplantation and was whisked away to the city of dreams-come-true. It worked for a while. Her post-op course was a rough go, typical for such big surgeries, for which only a few lucky CFers qualify at all. The required immunosuppressive therapy is a bear for patients, both in terms of the requisite strict adherence to protocol and medication, and a plethora of side effects. All of these strictures faded from view when the girl made her triumphal return home, the once wilting nymph now in full flower. Her family and friends were ecstatic. She was Lazarus back from the dead, very much alive. Maybe a bit of Job as well as Lazarus, the unreality of redemption from extreme loss.

The girl returned to the vagaries of youthful existence in all its ecstasies and sorrows, in all its inconsistencies and surprises. All told, she was granted a two-year reprieve, two years to fly outside the cage of her inevitably fatal illness. Then the door slammed shut again. The graft did not hold. The girl was buried amidst great mourning and bewilderment, the conundrum of her living and her dying hermetically sealed against further interrogation. Her stepsister, who had lived in the shadow of her sister's illness most of her life, took up the mantle of depression herself and wore it unceasingly for the ensuing several years. The girl's flight into health cut short by a zealous immune system, she returned to the breath from whence she came, no more to walk the narrow strand between Venus and Mercury, first blush, and transit.

Notes

1. Eliot, T.S. 1922. The wasteland. *The Criterion*, 1.
2. Andersen, D.H. 1938. Cystic fibrosis of the pancreas and its relation to celiac disease. *Am J Dis Child*, *56*, 344–399.
3. Yu E. & Sharma, S. 2022, August 8. Cystic Fibrosis. In *StatPearls* [Internet]. Treasure Island (FL): StatPearls Publishing.

About the Author

Michael Diamond is a psychiatrist in private practice in Potomac, Maryland. He has published fiction, verse, translation, and creative non-fiction in literary and medical venues. Email: michaeldiamondmd@gmail.com.

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Dear Angelo

L.J. Prance
Edited by Fraser Allen Best

Dear Angelo is one of many stories of my transplant trip. I like to think of it as a conversation I may have had with my donor: https://vimeo.com/867980072?share=copy

I chose the name “Angelo” as both a metaphor and a homage to a friend—Dhanyavaad.

About the Actor

Larry Prance is an actor currently living and working in Toronto.
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Artist Interview
Boundary Loss

Jonathan Kawchuk & Suze Berkhout

Click to play audio

In this interview, Jonathan and Suze discuss their research-creation collaboration within the *Frictions of Futurity and Cure in Transplant Medicine* project. As a sensory ethnography of solid organ transplant based in Toronto, Canada, the Frictions project uses different artistic practices to explore sensory experiences in transplantation, which are often excluded as being relevant sources of knowledge for the field. Jonathan joined the research team over the course of a weekend, facilitating sound walks and sonic immersion in transplant-related clinical areas. Jonathan recorded using a mix of regular microphones and microphones that record inaudible electromagnetic signals from machinery and convert the signals into sounds we can hear. His field recordings have been developed into a soundscape and the recordings and our exploration of them have contributed to the body of research that the Frictions project works with.

November 12, 2022: Day of Recording

Suze: Jonathan, you recorded in a number of different spaces in the hospital where transplant patients and family members transit: acute care spaces like the hospital wards and the intensive care unit, but also everyday spaces like the hallways, the elevator lobby, and the visitor’s atrium. Any reflections?

Jonathan: I was prepared technically to go into the experience, but being gowned up next to people suffering, people who might not make it, it was pretty heavy. From the standpoint of recording, it's a weird mix. It's not nice. It's actively brutal, it's mundane, then there are some positive [sound] experiences, all together. The mundane sounds, I think those were the most hopeful part of all of it. [It's like], I'll take boring over precarious. In a lot of ways, it's what I imagine it's like for people in the hospital.

Suze: What other ways do the sonic qualities in the recordings reflect something about the experiences within the space, do you think?

Jonathan: The hospital environment is really distressing. [I mean], people are dying; you should be anxious and distressed. The sonic environment is also stark, sterile. The sound experience in the hospital isn't going to reveal a truth that is easier to handle than that, because it's not easy to handle. The essence of the thing is difficult.

There was a way that recording captured this. The sounds of dialysis—it's a boring thing that takes forever. But it's also transhuman and a miracle. The electromagnetic recordings—it's electrical hail and droning, but then you'd hit two droning things next to each other that are a fifth apart and suddenly it's sonorous, pleasant.

Suze: What did doing the work of field recording reveal for you? Any surprises?

Jonathan: The hospital can be a magic place where magic happens, or it can have so much mistrust and pain. It was surprising to go into everyone's room. I was thinking, "Why is he letting me do [this recording]?" But what's happening to him is, so many people are already doing weird stuff anyway, so it's like, "Sure. Do whatever measurements you want." If you have only a tiny bit of energy for self-advocacy, where do you aim? How you figure out what you push at is very hard, I think.

* * *

September 6, 2023: Listening to the Soundscape
Suze: What was the sketching process like, to create the soundscape?

Jonathan: It was interesting. It was about finding a structure, thinking about timing, the narrative arc. It's a mix of electromagnetic [sounds] and actual open air. Together they give depth to one another.

Suze: It's quite something to listen to. It's hard to hear. There are definitely parts that are uncomfortable and unexpected.

Jonathan: It's all unpleasant, even the non-electronic sounds. They make a harsh soundscape.

Suze: I remember when we were recording that you had reflected on how, sonically, the hospital is very sterile. I think I have a sense of that here.

Jonathan: And how do you work with that? There's no sense of new life. The soundscape doesn't give you a sense of what is living. But it has this almost amniotic feel, like you're in a critical, sterile place, waiting to go through the sliding doors.

Suze: Any sense of time, tempo, flow, or temporality that you had when you worked on creating this?

Jonathan: There isn't much in the recordings or the soundscape that gives you a sense of time. There's a stasis that is sonically present. Everything is regulated, monitored, static. It felt like I wouldn't know what time of day it was, sonically.

Suze: I think that's often what it's like when you've been in an acute care hospital setting for any amount of time, too.

Jonathan: I'm surprised with it. "Happy with it," is a hard thing to say. It's a hard listen. But it captures something about disorientation, feeling both overwhelming and underwhelming, and hidden layers. There's this internal, dream-like quality and the unfamiliar—although it's not spontaneous. It's not what you'd expect. The microphone, in recording, sometimes is called the "prosthetic ear." But these tools [like the microphone] only kind of represent what you might be hearing. This is like the transhumanist version, with the electromagnetic signals especially, which speaks, in a way, to what it means and what goes into people getting new organs.

About the Sound Artist

Jonathan Kawchuk is an award-winning wildlife recordist, composer, vocalist, and sound artist. In his artistic work, Kawchuk attempts to capture the resonances of natural surroundings and explore the recursive, interactive, and relational aspects of sound in the field. He has scored many films, including Memento Mori, for which he was nominated for a 2017 Alberta Film and Television Award in the category of Best Original Musical Score. Email: jonathan.kawchuk@gmail.com

About the Interviewer

Suze Berkhout is an Assistant Professor in the Department of Psychiatry and an affiliate of the Institute for the History and Philosophy of Science and Technology at the University of Toronto. She is an early career clinician-investigator and practicing psychiatrist. Her program of research in feminist Science and Technology Studies (STS) utilizes ethnographic, narrative and arts-based methods to explore social and cultural issues impacting access and navigation through health care systems. Suze is also an Editor at *Ars Medica*. Email: suze.berkhout@uhn.ca

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What Comes After Transplantation

Deirdre Hennings

Life after Transplant

Inspired by Tyehimba Jess

Tetchy at the wheel, you blare the horn
as you yell expletives
goaded by GVHD, after an SUV cuts us off

disgusted by my dawdling, fed up with
side effects (eyes stinging, mouth enflamed)
Why can't I see you need some fun?

Finally at the Director's Guild
squinting at *Variety*, don't look at me so
for an apology you know you won't get—

I cringe when the car peels out
I'd rather not be here
you're so moody again, so often angry now—

whatever I'd promised, long forgotten—and
worse, I resent agreeing to see such a silly film
like *Diary of a Teenage Girl*.

In the lobby I see old Max, never
glum, always a wink, never an excuse—
some joke—but when lights decline, I find you.

* * *

At home, mollified by the film, you're calmer
when a tiny puffball hops in the elevator, spins,
bumps your sore leg, you totter and shriek,

stagger to our door and spit
You should have stopped it! I almost fell!
You pitch your body on our bed,

cry out your terror of never walking again,
your career over,
no way to help you do what you do best.

I'm finally able to smile at such cuteness
dancing in delight! But when the Pekinese jumps
I shrink as you scream

in front of a stranger,
as if I could control a 3-month-old puppy,
as if I am to blame for all hurt,

as if I could prevent another disaster
I feel chained
no way out except going it alone.

You sob when another thought strikes:
Sex gone too? No more
“You’re macho man, put my ass to sleep?” or
not yet, not now. No waiting ‘til Shavuot,
see if God notices! You must fix
what’s broken:

you limp to the living room,
put on a record
we hug and sway to Bernstein’s lyrics:

We’ll do the best we know.
We’ll build our house and chop our wood
and make our garden grow.

Can’t afford to move, not in LA,
can’t start over. Not as if
I’ll meet another wunderkind like you
to encourage me, help me, love me
so much. Instead, I choose to rub
your heart, then

I go to the kitchen to start dinner,
grateful to see you smile
and I think of the old Ruth Etting song:

I wanna be loved by you
just you and nobody else but you
I wanna be loved by you alone

Note: Contrapuntal poems offer two opposing voices presented in mirror images of one another, to be read left column first, then right column, then reading both voices together across the page.

Immunocompromised

You’re more susceptible than a newborn;
one sniffle and you’re back in the ER.

So, I must wear a mask 24/7 in the house
Lysol each faucet after every touch,
come trotting like a servant
no matter how tired
sleep separately
watch fear
crater
us

yet keep up our spirits by acting
as if I am quite at home.

But I *am*
at home. *You*
are still here, still
make me squeal in delight
our smiles melting irascibility,
your attempts to stem your outbursts
my balm in Gilead, your body my hot box
against the cold, your shining eyes the guidewire I need

to keep walking this line as I whistle
through the bars of our new cage.

The Premiere

He can barely hobble
hip so painful (dying bone
caused by too much prednisone)
that surgery is days away. How
can he convince the world tonight
that he still has his old bounce?
His film shot months ago
when movement was no problem.
Now he can barely
get out of a car.

My arm supports him as we mince
past churning search lights
toward laughing crowds of people half our age
who flounce as if life is truly wonderful
and so it becomes:
everything about him lengthens—gait, height, smile—
as we stroll down the red carpet, cool,
ebullient as cameras flash.

He walks into the great domed movie palace
escorting *me* now, past so many knees, to my seat.
Later at dinner, I watch him work the room
gliding from producer to matinee idol,
drink in hand
laughing
steady
tall.

Next morning, his desk
chair is in the hall, abandoned
where he left it trying not to fall
just to get to bed.

Love, Tripwired

Only thirty days of him
taking prednisone
and I’m hollow
as an empty tin can.

Mere eating goads him to fury
and anything I try only gets me stung.
You can’t fight fair or reason with a wasp.

Is the only way to save myself to leave?
I start to research a new apartment.

Wait. In better days he listened,
made me laugh, loved me full.
That man was here just days ago. Surely
with luck he might return?

So I steel myself
coerce myself to   blink
past his latest ravings   beat
down my rising gorge   believe
a better change comes if I can just   be
like Lawrence of Arabia,
his finger in the candle:
            Of course it hurts.
The trick is—somehow—
not to mind it.

Caregiving

Is being buried alive by your sandstorm what worries me
so—

or the emptiness
once your wind is gone, the sand is still?

About the Poet

Deirdre Hennings' poems appear in Yale's *The Perch*, *Litro/UK*, *Healing Muse*, others. Email: deirdrehennings@gmail.com

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Altered Routes / SAFEWATER

Dixie Partridge

Altered Routes

Awaiting Diagnosis

Late afternoon you turn off the path,
downhill riverside;
push through thick grasses and willow.
Fine filaments glint in the breeze

before sundown: sheer creation,
ongoing, without the need of anyone.
Tops of trees on the other side
light up like hammered gold.

Morning's rain has crisped all edges
and colors: more shades of green
than you've noticed in months,
lemon-lime to olive to jade.

The quiet denseness here is out of sight
of town walks and streets,
a dimension desired and slipped into
with that aching sense of the momentary.

With dusk come fading variegations
of light, the river placid over steep undertow,
and a longing deep as marrow
for such moments to be enough.

There's a faint thrum of insects that stops
when you stop. It's as though
only movement is acceptable,
but you don't want to move on

from faint healing offered
in the ongoing lap and lave of water
against this narrow shore.

SAFEWATER

Before Transplant

when days grate
like the scraping of boats tied too close
to the pier

when sound and sight
nag: the dark cumulus of someone
else's dreams

intricate of plot, of whys, of why nots
of throbbing races foreign to sailing
and a finish

that's never there

the lonely self, looking
for solace, finally
turns inward

beyond loneliness
drawing in the sails
it spins slowly

out into the harbor
heedless of breeze
absorbed only in reflections

of the sky's last light

About the Poet

Dixie Partridge, native of Wyoming, spent most of her adult life living along Columbia River in Washington State. She is the recipient of the U.S. national Eileen Barnes award. Email: pearanttree@gmail.com

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A Field of Trilliums

Lori-Anne Noyahr

At a glance
you might be sleeping
beneath the blue-striped
blanket, your chest heaving
though only to the whirr
of the ventilator,
delivering breath
without life.

Your mother kisses
the curls at your cheek,
releases your hand.
Take care of my baby
she says, although
she knows that
you are gone.

We transfer
from bed, to table,
gently unfolding coils
of adrenaline
at your neck,
gathering around
this vessel that once
contained you,
to whisper thanks.

And yet,
my heart is unaffected
while the oximeter
still counts heartbeats,
while the tube at your lips
mists, twelve times a minute
and the red hills of your pulse
grow steeper on the screen,
as I quicken the flow
of liquid from the
clicking pumps.

The surgeon's gloves
glow bright under hot lights,
fingers working deftly
as I await the metal grate
of the final clamp locking.

Only when
the off-switch thuds
and the respirator
bellows collapse
is the illusion,
broken.

I can do nothing to
reverse your slumber.

I cannot tap your arm
to wake you, nor can I
liberate a raspy voice
from your throat.

Instead, I search beyond
the white walls,
the halo lights,
calling your name only
in my head, my heart
suddenly filling

with the grief
of those who love you

and the relief
of those you rescue.

About the Poet

Lori-Anne Noyahr is an anesthesiologist in Toronto. Her poetry explores themes of medicine, family, and community. Email: dr.la.noyahr@gmail.com.

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Faceless

Kayla Ashley Simms

On the 3rd floor, a faceless stranger:

How is your pain today?

Behind the curtain,
a face I never see.
Nor do we exchange names,
not once.
For names matter
only to those who arrive
with trays,
bedpans,
12 o'clock pills,
and shifts,
endlessly changing.

Faceless, they answer their own question:

Today's been a good day for me.

I know that means
they will soon depart,
from this place.

How old are you?

Behind my curtain,
I wonder if my voice

gives any clue
as to the colour of my skin
or to the depth of my incision.

I look down upon it,
peeling at the fraying bandage
suddenly, exposed.

Digressing, they continue
with a portrayal
of the friends they long for
and the one who never visits.

Are you still there?

Faceless, I wonder if they believe
I have actually gone from this place.

Bewildered, I close my eyes;
certain I never will.

About the Poet

Kayla Ashley Simms is a psychiatrist and lecturer at Queensway Carleton Hospital and University of Ottawa. Email: ksimms@uottawa.ca

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Hope In Spite Of

Austin Lam

They say your
Liver
Damaged and impaired
You ask, “Like me?”

Whispered in your mind’s eye
Vivid imaginings of
Dancing in a forest of
Overgrown roses

Bleeding with every turn
Dance, Dance, Dance!
They yell, they yell, they yell
You comply, hugged by prickled arms

Screams and shouts
Whistling in the wind
Waves inside the cranium
“What six months?” You ask

Would the *officium mori* be preferable
You ask, to no one
Living with one disease
To be afflicted by another

It was never just you
Help offered and taken away

Siphoning the devil's concoction
Sweet and bitter aroma, crawling through your skin

Medusa's face, rearing herself
Turning you to stone.
Forest of Gulliverian
Height roses

Sweet to scent
Salt-metal taste to mouth
With blood drawn from your
Twirling body.

Confused beauty in
Miasma of death
Emanating from
Cavity caressed by booze

Do you dare see
Escape out of this forest!
What hope? What reason to live?
Depends on the liver. Said James.

About the Poet

Austin Lam is a second-year Psychiatry resident in the Research Track at the University of British Columbia. Email: austinl5@mail.ubc.ca

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The Transplant

Larry Kuhar

I am sleeping awake, wandering woods
as a hum encroaches in the gloaming.

A tall tree, I overlook the valley,
breathing life into this liminal space.

My exhaust competes with a thrumming jet
thirty-three thousand feet over this peak

carrying the donated piece of me
I have not met and do not yet discern.

I have been rooted here for six decades,
a proud rosary of circles carved deep

telling my story of searching for light.
But today I am uprooting myself —

leaving a counterintuitive hole
in the ground where many others before

lay silent fallen by storm and the saw —
to have one of my xylem rings replaced

annulling time told in concentric curls.
Through the terminal glass I see myself

boarding the 767's arc
away from life and land I know so well.

The gate agent tells me the flight is full.
Asks me to remove dead boughs to save space.

I cast brown limbs into a silver can
wobble to my seat impaired by wet sap

dripping from exposed holes as if a wind
mimicking a dieback ripped them from form.

I am the only tree on this transport
who does not know if it will root again.

I will not feel turbulence encountered
just before we circle around red streaks.

What I will see will not be remembered
until I feel the hard jolt of touchdown

and only then my old roots will tell me
if my trunk accepts its new replaced ring.

About the Poet

Larry Kuhar a professor and writer who publishes poetry and has had a play produced. Email: lawrence.kuhar@wilkes.edu

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