



FVU READ

In Between

By Celestine Fraser

I'm in bed, watching Jameisha Prescod's film *I'll Still Be Here When You Return* on my laptop.

For seven minutes, my surroundings seem to recede. I enter a kind of tunnel. There are tears in my eyes.

And yet there is enough space between Jameisha's words, and enough ambiguity in the visuals, for my thoughts, still, to wander; for the film of my own life to play in parallel in my mind.

I'm transported eight years back, to the first time we met.

In this space

It's December 2018, and I'm producing [ill, actually](#), a BBC/ BFI documentary about disabled identity and the internet. Jameisha is one of our three contributors.

Our crew, cameras and lighting equipment are squeezed into their bedroom.

At some point, our director says "Ok, action!". We shoot b-roll of Jameisha in bed, their grey duvet, light streaming through the gauze curtain. Then it's time for their talking-head interview.

"On a bad day," says Jameisha, "I don't do almost anything. I sometimes feel like I'm levitating in the bed. It just feels like I'm not on this planet sometimes, with how tired I am."

Later, in the edit, I think how these same words could have come out of my own mouth.

Where my body and the universe begin and end

I leave the shoot after lunch, because of my body. I feel anger at my body. I feel anger at other people.

Even though I'm the producer, and the documentary was my idea, and it's ironic because the film was commissioned because it's about disability, this is the only one of four shoots I can attend. To have enough energy for the others, I would need to stay overnight in a hotel, and we don't have the budget for that.

I think of Jameisha, too: of how exhausting it must be for them, shooting over one long day. But we only have the budget for that.

As the day's adrenaline dissolves, fatigue descends. Heading home in an Uber, I stare through the window at South London streets, flashing in technicolour. My throat tightens.

I want, so badly, to be in the middle of things.

I want to live furiously, to cartwheel over rooftops, to collide with other people and launch fireworks at a vast open sky.



Sometimes it feels like I've slept my entire life

Six months later, and I'm in my childhood bed again. I'd forgotten how it felt to be this ill.

The days are long and all the same. I pass the time by scrolling, and saving screenshots to my camera roll as evidence of my time on Earth.

In the day I drown in fatigue, and at night I levitate with insomnia. I fall asleep only with drowsy antihistamines.

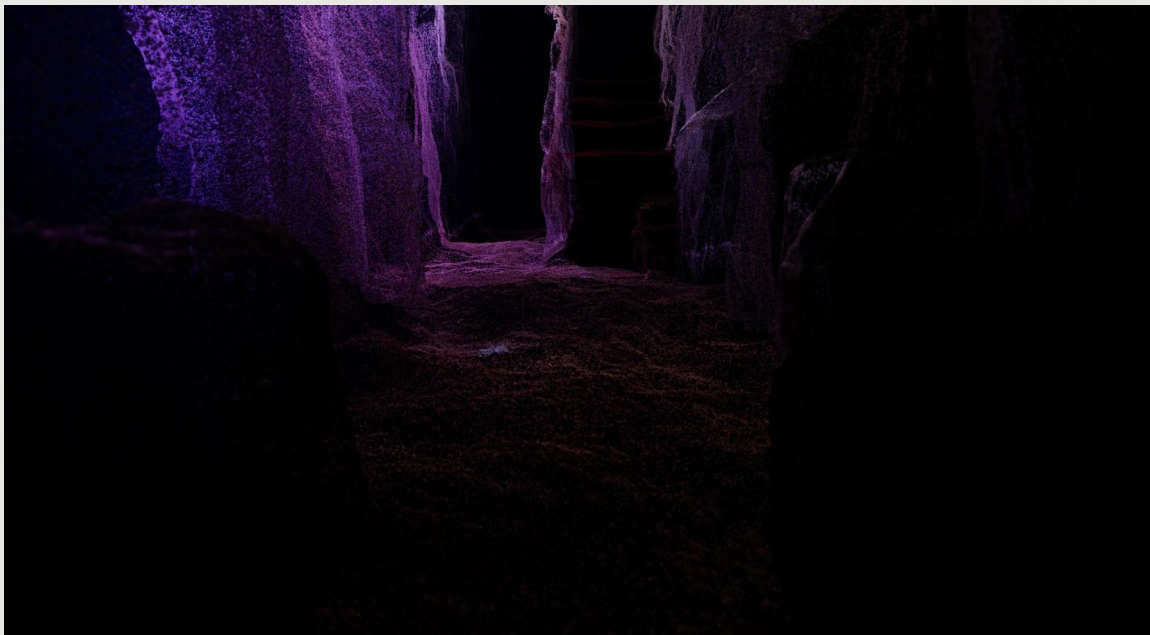
I make myself laugh at the idea of one day having a daughter and calling her Promethazine. It would be funny. Our names would rhyme.

The space between sleeping and wakefulness

My GP is concerned about the long-term effects of my daily use of antihistamines. Something about dementia and the blood-brain barrier. She refers me to an NHS sleep clinic, and eight months later I start a program called CBT-I.

We meet once a week on Zoom. If we weren't all so tired, it would be hilarious: a strange cross-section of society, alike only in our inability to perform the most basic of human functions.

We learn about 'sleep compression', are taught meditation, and one week our homework is to keep our eyes open for an entire night. It's torture, but it works: it takes so much concentration to keep your eyes open, all your other thoughts seem to go quiet. I fall asleep.



I've been scared of falling asleep

On the CBT-I program, we're taught not to nap. They tell us napping makes insomnia worse. I try to stop napping. I start to associate napping with a deterioration in my health.

One afternoon, I lie down on top of the covers, telling myself that it's just for a few minutes – I won't, I won't fall asleep. But as my body grows weary, and I'm losing the fight, I become convinced that this is the end: my god, it's really happening, I'm dying.

I'm kicking and screaming, all the way down.

The so-called real world

Three years pass in a blur like this. And then finally, one August: light.

I find a new doctor; start some new meds. I leave a painful relationship; return to myself. I begin 'pain reprocessing therapy', and realise how afraid I'd become of my symptoms; of all sensation; how in the attempt to avoid pain, I'd been exiled from pleasure.

After years of shielding and solitary confinement, I begin a slow process of re-entry.

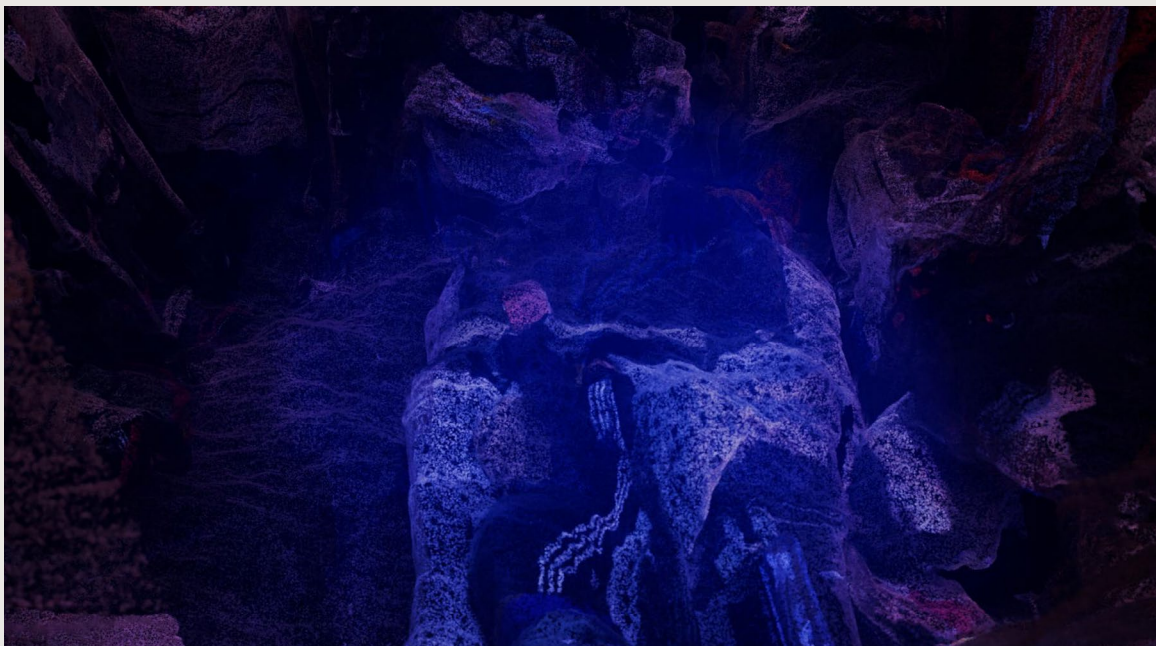
I'm outraged to learn that while I was away, the world had the audacity to keep spinning on its axis. Topshop has closed, the lids on bottled water have changed, and Big Ben has been undressed from its scaffolding.

I am a tourist on this planet.

I embarrass myself, in a group of friends, by not knowing how to use a QR code.

I try to pay for a book, and the cashier laughs, pointing out that I'm using an old £10 note; the new ones are laminated, they have been for several years now.

Wherever I go, people ask me where I'm from. They don't believe I was born here: "No but I swear you've got a bit of an accent?"



A tiny space

After a year of freelancing and living at my mum's, I've saved enough money and made enough progress in my recovery to spend a month in Paris. I rent a tiny studio with a loft bed under wooden beams.

I am, of course, still ill. But I am also alone, in Paris, and not even thirty, buzzing with the kind of freedom I spent a decade dreaming about.

In my second week, I go for coffee with a girl from a dating app. She has green eyes and dimples, and when she smiles my stomach takes flight. We say hello, do la bise. As she sits down, she says: *Je te trouve très jolie*.

That night, I can't sleep. There is too much on my mind. I try to distract myself from the memory of her face with the hum of the electric fan.

There's a moment in time

We meet again a few days later, on a bench by the Seine.

Emboldened by beer, we begin, tentatively, to play with each other's fingers. We argue about which one of us is taller, then she kisses me with a fearlessness that gives me courage of my own.

My legs don't even hurt as we walk, giggling, through the Marais, back to my studio. We set up a picnic under the open window, in the amber glow of streetlights. At some point she spots my mobility scooter, folded in the corner of the room. She asks me what it is. Nervously, I tell her that I was ill for a long time; that I still am, I suppose, sometimes.

There is only softness in her eyes.

We surrender to the sofa, and as she climbs on top of me, everything is sensation, and I am nowhere but here, and now.



In my dreams

Later that week, she takes me to see Monet's Water Lilies in her favourite museum.

There's a long queue to get in, so I pull up a nearby plastic chair.

An employee from the museum marches over and tells me I'm not allowed to sit in a chair in the queue. I tell him the queue is long and I can't stand, I have a disability.

He laughs, and says lots more people will have disabilities after they trip over my chair. We are arguing. I am raising my voice. I remember I am on a date. I feel like I'm going to cry. She stands in the queue for both of us. I sit where I am told, fifty metres away. I feel like a dog.

After the museum, we go back for dinner at hers, a new build in the suburbs, where she lives with her three best friends.

That night, for the first time in years, I sleep in another person's bed.

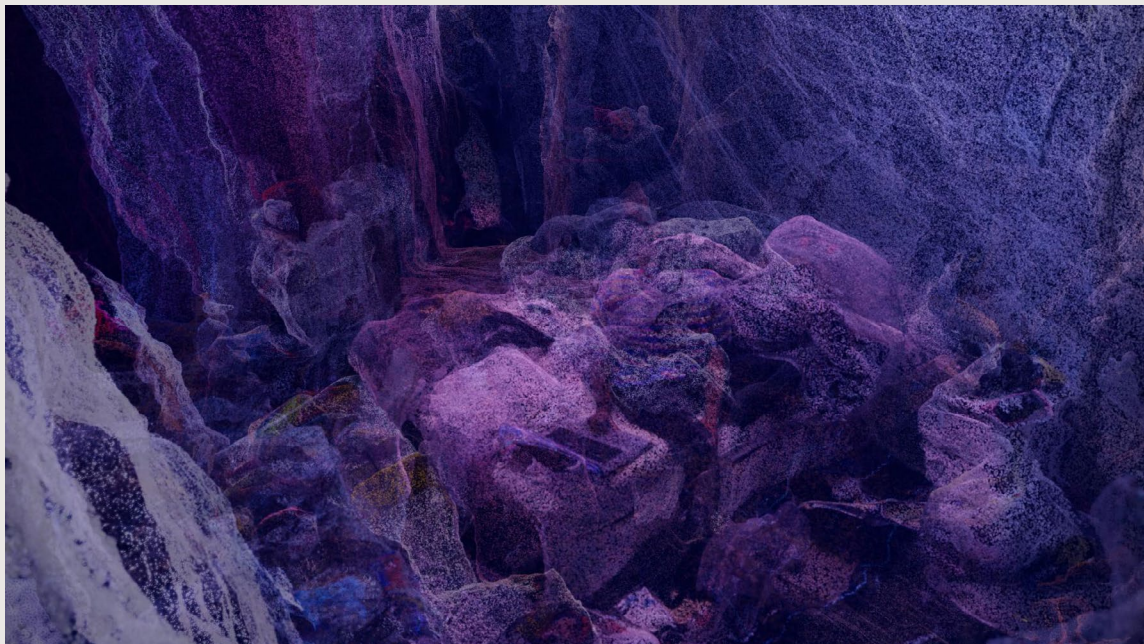
Anything is possible

She sleeps soundly, an angel in an oversized t-shirt, waking every couple of hours just to reach for my hand. I spend the night being eaten alive by mosquitoes. I get three hours of sleep, and wake to a guilty, open window, and swallows shrieking over rooftops of the urban skyline.

When she wakes up, she's fidgety, with a new and anxious energy. I put on the white linen shirt I used last night as a shield, and see that it's stained with blood – the mosquitoes', mixed with mine. She keeps coughing. *C'est juste un petit rhûme*, she reassures me, as we kiss, a bit abruptly, goodbye.

Nauseous with exhaustion, and struggling to walk, I can barely keep my eyes open on the metro journey home. I don't yet know that I will never see her again, or that in a few days' time I will test positive for COVID-19, or that the fatigue will come back and months of relapse will confirm my deepest fear: that connection has a cost.

For now, there is only the memory of last night, and words ringing, like a refrain: I'm alive, I'm alive, I'm alive.



What we've always known

Eight years have passed since we filmed Jameisha in their bedroom.

It feels strange that we met for the first time in their room, and that years later we meet again, in a way, in mine. It feels strange that it's only because of illness that we even met at all. It feels strange, and miraculous, that through art we can reach each other.

As the soundtrack soars, bittersweet but hopeful, Jameisha concludes:

"So maybe my bed is a gateway. And maybe pain is a portal."

The hairs on my arm stand to attention.

I close my laptop.

I'm overcome by a feeling of completion, like I've returned from a very long journey, and am so happy to be home.

I've travelled to this in-between

These days, when I meet someone new and they ask, "So where are you from?", I'm never quite sure how to answer them.

How do I explain the way I lived; where I've been?

I can already picture their awkwardness, apologies, the pity in their furrowed brow. How would I tell them that in those ten years of stillness, I saw distant galaxies; stepped foot on other planets; that I travelled round the universe twice?

They were only making small talk.

So I smile, and simply say, "I'm from London. But I was away for some time."

Celestine Fraser is a writer, editor and filmmaker. She has worked with the BBC, BFI and VICE, and with charities and independent media. She writes about disability, access and queerness, including for her newsletter [Body Babble](#).

In Between by Celestine Fraser has been commissioned by Film and Video Umbrella to accompany *I'll Still Be Here When You Return* (2026) by Jameisha Prescod.

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