

# By My Bed

Catalogue

Wednesday 15 June to Saturday 25 June 2022

EMERGING  
WRITERS'  
FESTIVAL



ARTS ACCESS VICTORIA

Published 2022

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W: [artsaccess.com.au](http://artsaccess.com.au)

E: [info@artsaccess.com.au](mailto:info@artsaccess.com.au)

P: 03 9699 8299 (voice only)

P: 0477 860 955 (text or voice)



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W: [emergingwritersfestival.org.au](http://emergingwritersfestival.org.au)

E: [info@emergingwritersfestival.org.au](mailto:info@emergingwritersfestival.org.au)

P: 03 9094 7809 (voice only)

By My Bed is a partnership with Emerging Writers' Festival and Arts Access Victoria with support from:



# By My Bed

What are the objects that make up your world?

In *By My Bed* – on display at No Vacancy gallery for the duration of the 2022 Emerging Writers' Festival, and online – Disabled Artists with lived experience of disability, chronic pain, and chronic illness answer the question, 'What are the objects that make up your world?' by sharing photographs of their bedsides.

Alongside the photographs, find the artists' musings about the body, accessibility, care, community ... and the order, mess and tenderness that can accumulate by their beds.

Explore works by **Jase Cordova, Mali Hermans, Jessica Knight, Tori Hobbs, Elena Macdonald, Jo Newman, N.S. Sibanda, Michelle Roger** and **Hannah Turner**.

Audio descriptions can be accessed by scanning the QR code below, or visiting [artsaccess.com.au/by-my-bed](https://artsaccess.com.au/by-my-bed).



# Transient Spaces: Black Disabled Bedside

**Elena Macdonald**



I have always found bedsidess in the crip, black disabled world, to be transient spaces, spread across endless locations. My photograph represents this confusion of location, and lack of permanence. When invited to take part in this exhibition, I struggle to decide how best to represent my 'bedside'. One location did not seem right; because it is not the reality for myself, and those of many black disabled kin I know.

Not all bedsidess provide sites of rest and regeneration; some (many) are simply sites of survival and grief, of trauma. It is impossible to present all this within one photograph without overloading and losing meaning and balance; whilst there is pain and trauma-rooted 'bedsidess', I have also managed to build pieces of safety and cocooning; of a space that is all my own, tenuous 'accessibility'. So I present these collections of images to you, in a way that best represents my spaces.

This collation of my spaces, my sites of healing and violence will not perhaps be intelligible to all who view it – and that is intentional. My focus, as always, is to my kin and community, and it is to their centre, from the margins, that I 'speak'. I will explain some of the collage here; but what remains unintelligible is intentional, and a discomfort to be embraced.

The central, background image of flowers on a hospital bedside comes from a recent admission. Flowers play a central part in many of my bedsidess because of the ways they soothe and ground me; bring some

part of Country and lightness into what can often be an unending confinement to the indoors, whether by medical necessity, or the limitations of my body/mind. The flowers can often 'mask' the more oppressive reminders of the medical walls within which I am incarcerated, and so I return to them again and again.

The books and journals point to another critical part of the power and promise of my bedside-spaces: reading and thinking more generally. I will always have a journal close by to make sense of whatever thoughts make their way through my fogged and illness-hazy mind. These writings form the foundations of work when I have capacity to do so; when I am no longer so restricted to the bedside-space. The muddling through this thought builds up capacity in the community work I undertake with black disabled kin, and in the continual conversations we have, throughout all stages of our bodies' limits.

The final two images at the top present a more concrete, practical reality of my bedside spaces: the medications and medical supplies and medical devices I rely on for my survival, and which are inescapable. They become the background, daily routine in my bedside existences. Including them was important, because to present only the gentle and caring aspects of my bed-sides would be to misrepresent the unavoidable reality of crib bed-sides: their clutter, messiness, and dysfunctionality. This is represented here in part by my IV

pole, with its enteral nutrition bag and line, fed through a pump. What is mundane and joyous to me (the key to my survival, and quality of life) remains, all the same, messy and complicated. To the left is my extensive medication basket, and all the necessary medical supplies required to make my taking medications possible.

And so there they are – the transient crib bedside.

**Elena Macdonald** is of the Paredarerme Nation, a 'Tasmanian Aboriginal' traditional Nation located on the east coast of Trouwunna/lutruwita. They work as community organiser both within their own community and within the disability justice space, organising to envision a better future and centre Indigenous disabled peoples within community spaces. Elena writes and studies between Naarm and Trouwunna.

# By My Bed

## Hannah Turner



There is decay beside me. An unwavering smell of death coming from somewhere, although whether it is the decomposing flowers or my unwashed hair, I do not know. Perhaps it is me, emitting a stench that will finally give some visibility to the way I feel – rotten inside.

Maybe it is that writing on sickness causes such decay. There would be no career of mine if not for debilitating illness, pain, suffering. Tethered to bed, I tweet my achievements, my work successes. Every article I produce racks up likes, comments, emails from strangers applauding me, thanking me for doing such work.

Bed is where I am worker but then patient, prisoner. Here I perfectly arrange myself so the faded grey headboard could in fact be a sofa, so my greasy hair, creased pyjama shirt appear as a slick bun, office casual. I file an article on my sex life then Zoom a specialist in Barcelona, I take down the bun, allow the messy hair to assure the doctor, yes I am sick, I need help but no I am not a slob, this isn't my bed, yes I work, no I am not depressed.

I log back online. People write to say they feel understood, seen, acknowledged, more thank you's, shedding light, explaining the truth, saying it how it is.

Is it really how it is if this persona of me, of sickness but success, is built online for the consumption of others? The Internet is voyeurism, first and foremost. Countering success with surgery scars and hospital



gowns is a futile attempt to reconcile the seemingly ever more disparate parts that make up this one body. Some might say oversharing is not possible online, more celebration to show the real you, the authenticity, the bits to stop it being a highlight reel. The reality of sickness. But mostly those watching are afraid of becoming just like you.

This opportunity to write this is the product of those personas, which one exactly is hard to place. Perhaps the jarring of the two is acknowledged as useful but what good does that do if the well people observing it, sending the congratulations and adoration do nothing more to further progress for sickos like me in reality. After all the internet's existence is not a bodily one. I announced this show from a hospital ward, accompanying the program artwork with a tearful, morphine high selfie. You all said I was brave.

With every piece of work comes a tightening of the tether between sickness and me. I am now nothing without it. The successes are shaded by the reality of chronic pain. Days in bed, on repeat, end on end, twenty four, or sometimes forty eight hours pass by without much more than bathroom breaks and meals on trays. What is the use in a career if daily existence is a fight you're always losing? There is necessity in jobs, misplaced pride in contributing to something that might, but likely won't, make some kind of change, an undeniable egotism involved in choices to make public

contributions, to create something that can be consumed and commented on in real time (or internet's time).

When the battery dies and stories you write are quickly forgotten, you are left rotting in bed, only your body to keep you afloat.

**Hannah Turner** is a 26-year-old writer living with complex chronic illnesses. Her writing focuses on disability and pop culture. She writes creative non-fiction and features journalism. Her words have appeared in Refinery29, Glamour, Mashable and Digital Spy. She lives between Amsterdam and London, and is currently studying an MA in education policy. Sometimes she swims in very cold water; she is often stranded in bed for days at a time. She is always very tired.

# By My Bed

## Mali Hermans



Grief has always structured my experience of disability, blurring the boundaries between this world and the next. Not only do I grieve the loss of my disabled loved ones and kin, but I mourn my own loss of movement and access to the people and places I find life-giving. As my disabled body struggles more frequently, and as fatigue and pain increasingly dictate my every day, I find myself confined to bed. Working, imagining, dreaming, crying, grieving. My bed has had to make room for this all.

Despite what this world demands of disabled and chronically ill people, and what able-bodied people might expect to consume from *By My Bed*, I guard this space and the objects beside it – the objects that make up my shrinking world – with love and protection, resisting the vulnerability I am so often coerced into. Whenever I seek care, whether through doctors, hospitals, workplaces, universities, the NDIS, or even my friends, I find myself forced into exposing the most intimate parts of my body and mind, undermining my own humanity to prove I'm disabled enough to gain the support I need to survive.

As I learn to resist this world's coercion and practice autonomy, I refuse to make vulnerable my place of rest and create work that places my body and the aids I use to care for it on display, existing only for an abled audience hungry for aesthetics of sickness they can reassuringly situate themselves in contrast to. After all, the pink bed cart I so often pull towards me, carrying



heat packs, medications, salves and braces, makes up only one small part of my world.

The objects I find guiding me through heightened grief, fatigue, and pain on the days I spend in bed are rarely those found in my bed cart. Instead, they are letters of love and solidarity from my Blak and queer disabled kin, devices that grant me access to online spaces and communities, and books, like *Feminism. Abolition. Now* as pictured, helping me envision worlds beyond the violence we endure.

Like the worlds these books and letters evoke, place too sustains me through sickness and isolation. As I continue to come to terms with living a smaller life, I recognise that much of my grief is bound up in place; in having limited mobility to visit Country, or ground myself through bush walks, swimming and birdwatching in the places I yearn for. Yet still, as I mourn reduced movement and mobility, I continue to find ways to be surrounded by place.

I rely on a small blue speaker sitting on my bedside, almost constantly turned on, filling my room with stories and music. Often, I find myself listening to Wiradjuri poet Jazz Money's Dreamy sleep story *Bilabang*, and from my room, am transported to the banks of the Marrambidya Bila (Murrumbidgee River). Carried by bila, the same water flowing through this image, I find different ways to move, to rest, to travel and to be – even from bed.

**Mali Hermans** (she/they) is a disabled and neurodivergent Koori and European woman living in Meanjin/Brisbane. Mali is a community organiser, worker and writer deeply invested in disability justice and abolitionist work, committed to challenging ableism and the many oppressive systems and institutions it remains embedded within through grassroots mutual aid work with the Disability Justice Network.

Mali has had work published in *Overland* and the *Guardian* among others, and has appeared at events such as the Sydney Writers' Festival and Emerging Writers' Festival.

# By My Bed

## Jessica Knight



'If you can't take the pills!' The doctor said as I sobbed.

'We can't give you a new kidney.'

My meds keep my father's kidney sitting happily inside me. I couldn't swallow pills as a child.

Now, I buy Nippy's Iced Chocolate Milk in bulk and swallow a handful of meds every morning and night.

These little rituals are imperative.

Some days the setting up another week of medication feels huge. I can barely face the mere thought.

The opening of numerous boxes, the popping of pills from blister packs.

My instinct says don't bother, give it up and see what happens.

Sometimes my instincts are the enemy.

'Want me to do it this week?'

Magic words of love.

The machine is new. It helps keep my tiny lungs keep kicking.

'Do you wake up in the middle of the night gasping for breath?'

'Yes. I thought it was panic attacks.'

'I won't use the machine. It's unsexy and ugly. I would rather die.' I sob in the ICU.

Sometimes my instincts are the enemy.

My nurse rubs my back soothingly.

My lungs had been storing poison inside my chest for over a year. I sleep badly and woke up with a sluggish mind and heavy body. It

felt like I was trudging through the swamp of sadness, the mud slowly swallowing me, there was no luck dragon coming to whisk me away. The agonising headaches greeted me every time I woke up.

The first night I used it I didn't sleep much. I lay there in my hospital bed with a respiratory nurse coming in and out to check on the machine and me. She would stroke my forehead and squeeze my hand. 'I'm scared to go to sleep.'

She promises I will be ok.

In the morning I remove the mask. I didn't tear it off in an angry tantrum in the night. My head feels clear like I slept deep and proper. I dreamed.

No headache pounding at the back of my skull.

Oh great. The fucking thing works.

A medical object helps a human object function.

The first morning at home again I couldn't even spoon porridge into my mouth, so overcome with grief regarding my own body and how it had betrayed me in a new and scary way. Now bedtime was not free of medical intervention.

How can I make this beautiful? Perhaps it's not in how the machine looks. The beauty is in what it allows to happen: breathing in and out, soft and consistent taking in the good and breathing out the bad so it doesn't collect and conspire to destroy me.

During the day I keep the machine under my

bed and out of sight. I'm separating the day version of myself from the night version. A little bit of self-delusion never hurt anyone.

I had no intention of ever sharing these particular details. Then I was invited to be a part of this small coven of chronically ill slash disabled creative witches.

I struggled to get the courage to show the objects that sustain my life and allow me to continue to exist as a living breathing thing. What's the point of ensuring I sleep to dream, keep breathing, if I don't embrace the less tangible things: reading, writing and take creative risks, that give my waking life joy, make it beautiful.

Give it meaning.

**Jessica Knight** is a writer based in Naarm. In 2021 she was a recipient of an Accelerate: Create grant from Arts Access Victoria to work on her first book. She was highly commended for her application to the Wheeler Centre's 2021 The Next Chapter programme. Her piece about growing up with inoperable cataracts was published in *Growing Up Disabled In Australia* (Black Inc. Books, 2021).

# I've Decided to Make Everything Really Easy for Myself

**N.S. Sibanda**



Peer pressure has already mapped out the appropriate performative self-deprecation in penance

For my refusal to grind myself against the four walls around me

For buying what I want because I can't afford what I need

For ignoring the carefully curated cudgel of your concern

For disregarding the barely disguised disgust behind the guise of guidance:

To tend to the infrastructure while I wither

To let my rooms knead me, fold me in on myself, stretch out the fraying edges of my time until I can't expand or rise

To put my pills in organised piles to rifle through and then re-organise

To put my sunglasses into the cupboard with the other sunglasses so when my eyes pick up every glimmer of light as a searing supernova and I need my sunglasses I have to go to the cupboard with the other sunglasses which is hard to do when I can barely see because I need sunglasses

To put my headphones away even though ... you know

To eat in the kitchen instead of in bed  
because suffering and morality are  
synonyms and how will I know my spine  
will feel like I'm being spaghettified when I  
haven't even tried

I prefer to peer over the rolling hills of my  
soft pillow,

Survey the skyline of nearly everything I  
need within arms reach

And live



# By My Bed

**Jase Cordova**



You can tell a lot about a person by what their bedside looks like. My bedside is a lot like me; messy and chaotic, with no real order to it. It's littered with half-finished projects, books, and cups I haven't had the energy to take to the kitchen yet. It's a place where my phone lays to charge, and where things gather to be dealt with later (much, much later). My bed is my desk, and my bedside is my filing cabinet, dining table, rubbish bin, and medicine cabinet. It's a mountain of both the necessary and the forgotten. Though I've grown to accept that this is how things are, I'm embarrassed by my bedside.

I feel similarly about myself.

I feel like humans shouldn't need this much help to simply exist, and I slip into moments where I wonder if the effort is even worth it. I know life isn't easy for most people, but I feel like I'm building on shaky foundations and whatever I construct could never withstand what others could.

My body is doing its best. Since childhood it's tried to protect me, tensing itself at every movement. It wound itself up tight for so long that now everything hurts. I thank my body for trying, but sometimes I'm still angry. And I'm tired.

I'm tired of coffee with friends being cut short because I can't sit longer than an hour without being in pain. I'm tired of crying out after simply attempting to roll over in bed. I'm tired of missing out on experiences, of being judged by strangers, of taking

accidental naps for three hours a day. I long to be regular-person exhausted.

Every day I dutifully take my medication to give me the clear mind and tolerant body I need to get through the day, but sometimes I pause. I wonder if I even need them anymore, if all of this was temporary and while I was waiting, I got better.

Of course this is ridiculous. I find this out once the withdrawal symptoms have gone away and I'm back inside my body, living uncomfortably in this place my mind has created and having to again return to my doctor with my tail between my legs.

I dream of floating through my days undetected, a background character that you don't even notice unless you're talking to them, but using a mobility aid as a person under 60 is like carrying around a flashing neon sign that says "I'm different". Sometimes I think the sign says something else when I'm not looking, like "I am using this stick to make fun of old people", or "I just want attention". So sometimes I stop using this too.

After years of my body being this way I am still learning. I am still convincing myself that having supports is not weakness, or showy, nor does it mean I'm any less of a human.

Most days I manage, but every day is a reminder that everything hurts.

**Jase Cordova** is a writer, editor, and podcaster residing in Meanjin. Jase has had poetry and essays featured in literary mags worldwide and has previously written articles for Disney.

When not writing Jase can be found elbow-deep in audio files editing their podcast, *Do You Still Like Me?*, making art with needle and thread, and being annoying on Twitter. They are at constant war with their mind and their body.

# By My Bed

## Tori Hobbs



For a long time, my bedside was all I knew. Everyday as a child, I'd stand with my hands on my hips, examining each inch of my world. Corner by corner, surface by surface. I'd meticulously wipe and scrub every spot clean. A ritual I'd complete when it felt like too much to bear. I'd let the ringing in my ears build, as if it was filling the whole room, the outside noise wouldn't dare to creep in. I'd create a fortress in my bedroom, lovingly arranged and rearranged. And then I'd tear it all down and re-built it from the foundations up, all over again. Every time I created this new world, I'd notice the heat on my face melting away, turning itself into a blanket to envelope me. The ringing in my ears fizzled out, quietening itself. Some days the world beyond my bedside didn't exist.

Disability forced me to become intimately acquainted with my bedside in a way I'd never been before. My bedside became all I knew. The glitter lamp I'd inherited from my childhood bedroom, its books, snow globes, frames and toys were still lovingly arranged, nearly a thousand kilometres away from where they'd once been.

Over the following months, I'd study the texturing of our unit's popcorn ceiling. Corner by corner, surface by surface. The imperfections burned into my brain. The smell of the mould on our window frame, the flaky, peeling paint on the wooden windowsill. The familiar feeling of anxiety would return except this time, with no energy to quieten it. My bedroom, once neat and organised, would become a mess of

empty foil pill cartridges. Half drunk cups of sparkling water. The previous night's discarded hot water bottle. Snotty tissues. Self help books. Machines and creams.

The world that had once been so open to me was forced closed, and I endeavoured to enter it in a different way. I sought a new world through my phone, I trawled through every app I had, seeking the community that I knew was out there, that I knew was waiting. I carved out a space where I could create those impenetrable bonds. The digital world became my primary form of community. One of the first places I would go for comfort. My phone was a conduit, an invisible bridge connecting two worlds.

From my bedside, I've seen the cycle of grief, pain and punishment that has followed me throughout my life. I've also been lucky enough to create and enter new worlds from between heat packs, fuzzy blankets and faded sheets. From my bedside, I step into a world built on the foundations of empathy and care. Unconditional love and understanding. One where you're respected and embraced, regardless of who you are and what you do with the life you're given. From my bedside I am able to enter a world where every inch of me is wholly accepted. Where there are people who are willing to sit with me, to hold me, to help me find solace and safety in this world I've created. To help me tear it down and rebuild. Corner by corner, surface by surface

**Tori Hobbs** (they/them) is a queer, disabled Burgher writer and care worker living on Ngunnawal/Ngunawal and Ngambri land. Tori focusses their energy on providing care, mutual aid, advocacy and support to multiply marginalised disabled people in their community through their paid work and their work with the Disability Justice Network. Tori hopes to invest their personal and professional experiences of ableism, care work, disability justice and its intersections into all that they do.

# This is Where I Slept

**Jo Newman**



I played a lot of video games while I was bedridden. Mostly survival horror. I'd start off playing them as intended – gathering supplies, crafting tools and shelter, hunting monsters and going on gritty adventures. But eventually it would get too hard, or I'd get bored, and that's when I'd turn on admin cheats and really get into it.

I spent most of those 18 months building cute little cottages, rearing virtual animals, and tending digital gardens. If I was feeling adventurous I'd take my avatar for a long walk through the visually stunning environments that some game designer far away had thought up.

Most days it was a struggle to walk down the hall to the bathroom, but digitally I could visit snow-capped mountains, tropical islands, and expansive, shimmering deserts.

My bedside at that time was my whole world. It was cluttered, overfull, confused. Game controllers, meds, water, chuck bucket, books, notepads, fidget toys, more meds, heat packs and tissues and snacks ... It was claustrophobic. Four walls closing in. So I'd turn to the virtual mountains, and try to breathe.

I write in the past tense, as if it's over, but it's not. Not really. I'm always on the edge. I've swapped digital making for analogue (which I enjoy much more), but I still spend most of my time in bed. I call it 'housebound' now instead of 'bedridden', a sign of hope more than realism.

But I don't mind being in my bedroom now.



I don't mind being in bed. Because there are moments outside of bed, too. Mornings in the living room with a crochet project and a coffee. Dining room permanently set up as a sewing space. Chuck bucket back in the laundry, where it belongs, instead of living by my bed.

Still cluttered, yes, but not overfull, confused. Not claustrophobic. I can walk down the hallway and out the back door, and breathe.

**Jo Newman** is a chronically ill Yamatji writer from Boorloo (Perth). They've been writing since childhood, but have the attention span of a gnat, so they mostly write short memoir and flash fiction. When they're not reading or writing, you can find Jo napping with their dog and cat, or re-watching their fave horror movies on Netflix.

# Inverted

**Michelle Roger**



A little piece here.  
 A little piece there.  
 My day broken into unconnected activities.  
 Partial activities.  
 Things started and discarded.  
 Only to be picked up an hour or two later  
 and tossed aside once more.

I try  
 To piece together my day.  
 To find continuity, creativity.  
 To account for all the time that has passed.  
 Only to come up short.  
 Because  
 Tired fractured thoughts  
 Equal tired fractured activities.  
 Punctuated only by pills and potions.  
 Tinctures and tisanes.  
 Gathered from bedside tables.  
 In inverted universes of soft cotton and  
 flannelette.

The weariness of activities undertaken on  
 the days prior.  
 The necessary accounting of the weariness  
 of days to come.  
 The weariness of pain.  
 The weariness of the drugs used to take the  
 edge off the pain.  
 The weariness of existing  
 In this body.  
 When the wanting and the doing of the  
 creating are warring.

Not the creation I imagined.  
 Not the one before.  
 That one still seeps in to berate me on the  
 dark days when the self I've built seems  
 more tenuous, more fleeting.

Instead  
 This one  
 Inverted, reassembled, reimagined.  
 Like all aspects of me and mine.  
  
 So I start to type and stop.  
 I plan and forget before the idea drips from  
 neuron to neuron, to arm to finger to ...  
  
 My default position,  
 Supine on my bed.  
 Propped just right.  
 Down to the exact millimetre and exact  
 angle.  
 To manage the pain.  
 And the blood pressure.  
 And the nausea.  
 And...  
  
 And where the heart is wild it must be filled  
 and controlled in equal measure.  
 Look right to the light and the whimsy.  
 The practicality and necessity.  
 Pop the pill and wash it down with a  
 jellybean chaser.  
 Place the mouse on my chest and watch it  
 beat.  
 Sending its secrets to faraway places.  
 Rub sweet creams on old scars and tender  
 flesh.  
  
 Pick up the notebook.  
 And find my pen.  
 The pen that is right.  
 The only one that lets the words flow.  
  
 Scattered amongst telehealth, and exercise  
 and admin, and relief and renewal through  
 connection and mindlessly scrolling.

To sit next to the bottomless lolly jars  
 And heart monitors  
 Ceramic chickens  
 Memories of better days  
 And outside places  
 Cut crystal holds water  
 Collections of battered pill boxes hold  
 functioning.  
 And empty silver squares  
 Whose contents  
 Measure the day, the health, the  
 productivity.  
 A kaleidoscope of small silver butterflies  
 unfurling to give me time.  
 Breath.  
 Being.  
  
 I flick through the channels on the television.  
 I'm not watching.  
 Or listening.  
 No details emerge.  
 Yet I know.  
 The idea scattered amongst the other  
 scattered pieces internal and external.  
 Forms.  
  
 Pop the dosette box once more.  
 Afternoons are peach and orange.  
  
 Reopen my lap top  
 Tap on keys.  
 And write down the snippets.  
 Of which this is one.  
  
 And piece together my day.  
 The minutes.  
 The hours.  
  
 And me.

**Michelle Roger** is a writer, photographer and artist. Her work has appeared in *The Victorian Writer* and *Kill Your Darlings* and online for Writers Victoria and ABC RampUp. Michelle received a Write-ability Fellowship in 2014, has been a panellist and performer at the Emerging Writers' Festival, Digital Writers' Festival and Latrobe Literary Festival. She has performed at several Writers Victoria salons. As her health changed, Michelle has focussed on the use of social media platforms such as Instagram to combine photography and short written elements, with focus on memoir and an exploration of her life as a disabled woman.