

Independent researcher

Heather Taylor Johnson

Semantics

Biographical note:

Heather Taylor Johnson is a novelist, poet and independent researcher, with a PhD in Creative Writing from the University of Adelaide, a subject she has taught at Flinders University. Heather's fourth book of poetry is published by Five Island Press and her second novel by UQP. She is currently working on a collection of lyrical essays on illness narrative, specifically researching where illness and art intersect, through the works of Vincent Van Gogh who, it was discovered in the 1990s, had Meniere's disease and not epilepsy, as was long assumed. Meniere's disease is a chronic illness stemming from faulty mechanisms of the inner ear and something Heather, too, has. In 2015, she gave a paper on why poetry is suited to illness narratives (soon to be published by Inter-disciplinary Press) and she is currently editing the poetry anthology *The Fractured Self: Poetry of Chronic Illness and Pain*. She is the poetry editor for *Transnational Literature*. She is also an American Australian.

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Creative writing – Lyric essay – Poetry – Illness narrative

The personal issue of telling stories about illness is to give voice to the body, so that the changed body can become once again familiar in these stories (Frank 1995).

1.

Let's talk about needles, their steely eyes and sharp tongues. In an earthy smelling white room full of glass jars, Chelsea sticks the first one in the top of my head. Next, she moves to behind my ears, the backs of my hands, the tops of my feet. 'This will take a lot of sessions. Maybe six over the next four weeks.' Because I am sick. Because I have been sick for years. So I come back, again and again, because the only thing I have to lose is my health. At this point in my illness, there is a second baby, Sunny, who needs me, as I need him. I am desperate. I swallow two cups of steaming crap every day, the raunchy herbs in the glass jars that smelled up Chelsea's workspace and now my home. I want to spit them back out, splatter their goodness all over the kitchen and, finally, belch.

Session one, session two, session three, and then: Chelsea's needles and cups of crap are working. For the first time in the five years, I've owned this illness (this illness has owned me) something is finally working. I feel like she understands my body, like she *hears* me. Odd because she doesn't encourage talk beyond our 'how are you' routine. She's busy. There are other rooms with other people; there are many more needles.

How are you?

Better. I didn't have a major attack this week.

That's good.

I'm still too dizzy to drive though. Public transport is killing me.

How's the ear?

Pretty loud.

When the needles go in, my breath slows. My body spreads beneath itself. I am ice on a hot day, relishing the melt. When she leaves me in my warm puddle, I imagine other conversations.

How are you?

Better. Shit.

Tell me about the better and then the shit.

I haven't had a major attack this week but yesterday I went to uni and had a panic attack at the top of the stairs because I swear they started moving. I held onto the railing with one hand and a friend held me strong on the other side. I wanted to cry the whole way down.

You can't take the elevator?

I'd puke all over it.

Sounds horrible, Heather. And how's the ear?

Still loud and sensitive. I flinch when my child whispers in it. I screamed last night when he kissed me on it, it freaked me out that badly. I scared him and it made me want to cry. Again.

You should cry. Crying is good. Like needles, it moves the bad energy on.

Chelsea's needles and cups of crap work so well I want to tell my doctor about them. My thought process is frenzied and noble: *If I told him he could tell his next patient who would then tell her family and each person in her family might tell their own friends whose 'mother-in-law has it', whose 'friend's daughter has it', whose 'neighbour from Port Augusta, Mr So-and-So had it, and boy was he sick, nothing could help him'* and everyone will then know that Chinese medicine can help Meniere's disease. So I tell my doctor I feel better and it's because of acupuncture. I tell him about the cups of crap and the steely-eyed needles and my slow-motion crawl from a moveable darkness, but he cuts me off with laughter and a shake of the head. Apparently it's funny that Chelsea's helping me where he never could. Apparently 'There is nothing we can do for you,' was supposed to be enough. Apparently, Chelsea and I have got it all wrong: he is a specialist, and needles are for sewing.

Illness will heave itself onto your neck and drag you down,
so rise. Consent to your body because it is lurching. Lurch with it.
Become mirrors for that body, snapping animals. Look for a pattern
in what you chose to become as well as in the toilet bowl of your days.
Sew you a heavily quilted thing though your thread may be thin.
Choose fabric wisely. Sew illness to your arms first, give them layers;
they'll want the extra weight to grow bicep-strong so that they may fight
off further illnesses. Know that frays at the edges of fabric are good.
They are scars your children will one day touch, and wonder over.

Now that I'm better I stay away from Chelsea. I write all the time, trying to fit new letters before and after my name, like *Dr* and *PhD*. I write about mothers: my own and myself. Now that I'm better I like my baby more. He makes me smile more. He grows because I know how to love him and look after him, no longer caught up in the drama that was me. Sunny. He's so strong I don't ever want him to break.

My illness comes back. It is [*w*]hat *I fear and respect most* (Maxwell 2007). I want to see Chelsea, though she's moved to the hills, almost an hour away. The hills, those rolling slopes, those winding roads, for almost an hour, would maybe-probably kill me. So I see Ute, who is down the flat road from where I live. I have a new baby now. A daughter. I am terrified of what my illness will do to me. To her. Ute asks me my symptoms and I list them off like artillery: I have vertigo (I have a bomb); I have nausea (I have grenades); I have fullness in my left ear (I have an endless supply of machine guns and some tear gas, too). I want to tell her more than this, but I know this is the drill (*Occasionally it is interesting to think about the outburst if you would just cry out – / To know what you'll sound like is worth noting –*) (Rankine 2014). She's quick. She hurts. She says, 'There,' when it's over. 'There. Now you feel better'. I ask her for a follow up, which she says I won't need. 'I've needed follow-ups in the past', I say. She smiles tightly and tells me what I owe her.

the listener was not listening to what was said (or did not hear what was said)

the listener heard what was said, but was so engrossed in interpreting a previous utterance that no immediate further processing of the current utterance was possible

the listener heard what was said but did not understand what the utterance (or some part of the utterance) meant, for instance did not know the meaning of one of the words

the listener understood the words of the utterance and parsed it correctly but could not interpret 'the thin meaning' in the current context and was waiting for more information before trying to respond

the listener understood the utterance in the current context of information but was unable or unwilling to produce an appropriate response (Brown 1995).

On the way home I'm confused at a right turn, decide it is no longer safe to drive. I know my illness is settling in like rain often does in May, and I know now, as I know in May, that it will be a long winter.

I have never been so sick in my life. I want Chelsea and her cups of steaming crap like my newborns wanted my dripping nipple. I don't care what snake's back I have to crawl along to get to her, I only know I must get to her. My husband drives me almost an hour to the hills, through the hills, and I can't stop groaning, retching, thinking about death. When I walk to her door, only fourteen steps from the car, it takes me almost an hour again. Chelsea is my saviour but the drive is my undoing. I've lost weight. My face is grey. The sound of her four-year-old's voice is shrill and spins me so far out I cannot stand. Her needles, their steely eyes and sharp tongues, pierce so deeply into the stink of me I think it's going to work, but the ride home fills the tiny gaps left by the needles, negating everything but the illness. On my fifth visit she tells me not to come back, it's counterproductive, and gives me Carol's card. 'I think she can help you.'

My bed is my new lover, devouring me day and night and rocking me to a nauseous sleep. I fuck it for weeks, only rising to show my family I exist, if only for ten minutes. If only as a shadow. There are three children and a husband who don't know who I am. I don't know who I am if I am anything other than this. I believe my dog might know me.

Carol gives me needles like they are drugs (they are drugs). Carol asks me if I was a car-sick child (I was a car-sick child); if I was a morning-sick mother-to-be (I was a morning-sick mother-to-be); if I suffered migraines in a previous life (How does she know this? – Oh the stories I tell her). She asks me about my family. Do I miss America and how often do I go back. My writing. My sleeping patterns. If I am social, what I do for fun, how I deal with those things when I'm sick. I speak of minor traumas and major ones; I speak of passion and longing and things that shit me off. *Language knows a 'subject', not a 'person'* (Barthes 1977). We need someone to listen so that the person can be seen, and so for months, I am Carol's teacher and she is my shrink, as well a constant source of needles, and when I'm better she tells me to never stop seeing her. Needles are preventative and I should use them to keep my illness in check, maybe even keep it away, like soap keeps bugs away and scissors keep dead ends away. Like regular brushing – though there is never a guarantee – should keep away a root canal. I believe in hygiene so I make follow-up appointments catering to my need. Her cups of crap have been made into tiny resin pellets I swallow by the handful.

Let's talk about needles,
their steely eyes and sharp tongues.
Staked in, they are pre-language; trembling,
they are deconstructive. *Needle what?*
Needle pierce you where you've been:

on opposite magnetic poles in Cessna aeroplanes upside
down on a balance beam in love experimental insecure
at loud concerts underwater in verse on drugs sucking in
the toilet bowl and spitting sickness out in it, then,
making up stories for the unknown dead:

this needle brought that woman out of her grave
this needle erupted in a violent pinch
this needle nearly put me to sleep
this is the needle I pray to
and this one shines its light on me.

2.

Carol's told me where to massage Sunny. Where his pressure points are. The second toes are important because the feet and their appendages are monstrous highways that abhor traffic. Down the inside of his shinbone, up the outside, because this area, oddly, is linked to the gut, and Sunny's gut is wrong. I remember how to do it by thinking, 'down and out' because that's what Sunny is. There is a ball bearing I can stick to him, between the halfway points of his bellybutton (that place that proves he is mine) and the meeting point of his ribcage (that place like bird skeleton). I do this. His specialist has given him new medicine. It's all too early to tell what works. If anything works at all.

I want to talk about words, about the heft of them and their imprints. Without words we have only our bodies, but when our bodies break down, what happens to the words? Barthes might say when we depend on words, we, as the authors of our own stories, die. I say: in the heat of it, the bile of it, the fiery non-escape of illness, words fail where we thrive, ridiculously. I aim for the moan and the animal groan, use simple words like 'oh' and 'god', sometimes stringing them together, so meaningless in the dry mouth of an atheist. 'I'm so sick', I say. 'I hate this', as if there's any potency, because what does 'hate' really mean? What is 'sick'? How much is 'so'? *Language intrudes itself between the sufferer and the listener, creating a distance from the felt experience* (Conway 2007). I should do better. I'm a poet.

But the word just flew out the window even though the window's closed. I can see it in the leaves of the drooping bough. I can see it falling, landing on the rain-soaked grass, shaking itself free of earthen specks and the clinging cold even though its skin is unaccounted for (where is the poet who will make it bold?). The word is haughty, laughing; it was never mine.

Down the hill. The word's among rubble, resting like a ten cent coin primed for pocketing, like a hitchhiker waiting for a ride out of town. It's looking fine as a wine with a seven-year dust on one side of its thick green glass. It's a drunken thing, a fickle one-night stand. Gone so fast, my tongue never knew to savour its taste or to call it by a name.

For a year Sunny's been ill. Nasty Bolivian bug invaded his perfect innards and exacerbated a glitch within his slippery-tight body. Ten years old and he wakes to vomit. He loses any small meal his shrinking stomach accepts. He vomits when he's active. He vomits when he's excited. He vomits when he's anxious or afraid. *All we have in this world is the body. Where the body begins, the poem begins, always with the senses* (Hilda Raz, qtd. in Bugeja 1997). 'I just threw up,' he says, and continues what he's doing. For Sunny, words have always been straightforward; his dyslexia demands simplicity, verbal expression a challenge. His frail body gives him away, but only to those who know him best. To others, he is a tree-climber, a ruler of his own world with the blueprints in a sketch pad to prove it. He gets on with things. He's always practical.

Sunny Sunny, your body keeps rolling though it wants to crash.
The night time of your gut harbours insomniacs trying to get out,
the moon leading you down the hallway and past the kitchen table
(you hate) and into the bathroom (you also hate) where the sink waits,
the drain waits, for water to wash it away.

Still, you're the rug in front of the fireplace, only a little singed.
You're the badass Lego Supertronic Speedmaster SSS
with one miscoloured piece (the last S is for Sunny).
When the room's gone dark, you are the light bulb
stuck in its packaging, dreaming of vision, busting to get out.

So bile burns in you, then out of you, like hatred singing arias.
I love that you hear pop music. I love that you wear tap shoes.
I hold you all day, like time, because you are my clock.
A tattered hammock; lie on me. Let's sway to our own singing,
to that song by Katrina and the Waves.

Years ago, when I told the doctor (who was a specialist) about my illness, he seemed to think he already knew. 'Meniere's disease is a disorder of the inner ear that causes episodes in which you feel as if you're spinning (vertigo), and you have fluctuating hearing loss with a progressive, ultimately permanent loss of hearing, ringing in the ear (tinnitus), and sometimes a feeling of fullness or pressure in your ear' (Mayo Clinic Staff 2015). So he has defined Meniere's disease beautifully after telling me, 'You have Meniere's disease', but who is the 'you' he's referring to? What about the traces of my life? Leaving my family in America left a heavy trail of isolation. Trying to do a graduate degree while coping with chronic illness left sloppy, sticky footprints I didn't know how to clean. I was a skydiver then, sensing that particular identity was coming – had to come – to an end, and I was in denial. I was falling in love with my housemate and it was confusing. When I tried to tell the doctor all of this, all of me, he didn't want to know. But the body knows. These things, every adverse thing, every

complex thing, lives in the body, clogging it and turning it against a natural, healthy flow. Needles touch me there.

Carol once told me that it's all about semantics. That Western doctors choose to treat the disease while Eastern doctors choose to treat the symptoms, and that ultimately their refusal to think that they're doing the same thing is really only a problem of language: one uses a single word (or two or three strung together) and one uses multiple words. In my case it is Meniere's disease (Western) versus vertigo, nausea and a fullness in the ear (Eastern). 'I have Meniere's disease' – *we must know much more than the analysis of this sentence on each linguistic level. We must also know the reference and meaning of the morphemes or words of which it is composed; naturally, grammar cannot be expected to be of much help here* (Chomsky 1957). And so it is the 'I' that I am interested in. 'I' as in 'the body'. 'I' as in 'some people with Meniere's disease only experience it as a minor nuisance that comes and goes for days at a time, while others experience it as debilitating, lasting for weeks or months'. In this case, the patients who have the same-named disease should undergo different treatment when visiting their doctors: one reason narrative is so important. The disease needs a story to go with it. Isn't it vital to tell the doctor that it is impossible to rest because you might be a single parent with little support? Isn't it essential the doctor knows that you become depressed when you're sick or suffer severe anxiety? This 'baggage' we carry around with us is, in fact, the 'I' as much as it is the symptoms of our illnesses, the extra words we bring to what is represented by the randomness of the letters that spell out the name of our disease. Words are important. Words matter.

How was your day?

It was great!

Did you throw up?

Oh, about four or six times. And twice before breakfast.

What had you been doing at school before you threw up?

Well, one time I was running across the oval and one time I was having lunch and the other times I was just doing my work.

Was it hard work?

No, it was fine. Well, I didn't much like the reading.

Did you make it to the toilet on time?

In class I either swallowed it or yeah, I made it to the toilet on time. Outside no one saw me. I just went 'blah'. (Insert throwing-up motion.) I hate it when people see me throw up, Mum. It makes me wish I never went to school that morning. No one's going to want to be my friend.

I'm so sorry for you, Sunny. Throwing up at school must make you really nervous. It probably makes you want to throw up! But people will always want to be your friend because you're funny and clever and kind. So is that one of the reasons you had a good day? Because no one saw you throw up?

One reason.

What was another?

I got to play the guitar.

*Well that would make it a good day.
It did! I had a great day. (Insert hug)*

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Research statement

Research background

When encouraging doctors to personally engage in their patients' stories as a means to better treat them, Arthur Kleinman writes:

The facial expression, tone of voice, posture, body movements, gait, and, especially, the eyes expose the emotional turmoil that is so much a part of the long-term experience of chronic illness. The manner in which difficult sentiments – anger, despair, guilt, worry – are expressed and dealt with also reveals how the sick persona [is] handling the illness (1988).

I consider the written body of work as symbolic of the corporeal body: facial expression is formatting; tone of voice is lack of punctuation; body movements are section breaks; gait perhaps the length of paragraph or stanza, and so on.

Research contribution

'Semantics' is a representation of illness narrative while also a plea for understanding *through* illness narrative. The work is meant to politicise the patient (the author) as well as those in what Arthur Frank refers to as the 'remission society' (1995), and do so in an innovative way, exploring words as cross-genre. Just as there are many sides to illness, there should be many ways to express it.

Research significance

This work builds on the practice of life writing by blending illness narrative forms to create a hybrid of genre, emotion and instruction. While working with stanza-formed poetry alongside lyric essay, the work also melds the two genres together to form a third: prose-poetic essay. Therefore, while stressing the importance of words as an argument for illness narrative within the medical practice, the author is experimenting with words in an attempt to express her illness narrative in a way significant to her.

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