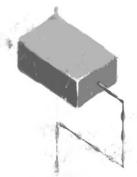


START AT BELONGING



Poems by Tara Coleman & Illustrations by Sam McLauglan

Published by Tara Coleman and Sam McLaughlan

www.creativedialogues.co.nz

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Introduction

Welcome to *Start at Belonging*; This book is the result of an evolving creative dialogue between poetry and illustration, between words and images, between illness and understanding, and between artistic practice and Parkinson's. It grew from a series of in-depth conversations we – Tara and Sam – shared about living with young-onset Parkinson's disease and about the challenges of communicating that experience to others.

On the following pages you will find seven illustrations and poems in dialogue. These dialogues represent our individual and shared creative process in response to the question: *How can shared creativity help communicate the experience of illness?* This question has shaped our work, our conversations, and our understanding of Parkinson's and chronic illness—not just as something that happens to a body, but as something that exists in relationships, in language, and in the ways we seek and offer understanding. After each dialogue, we provide reflections and offer a series of questions to prompt your own creative response.

We invite you to play around with creative dialogues in your own projects and personal life. This book pairs with our website, where you will find space for further exploration. You can also share your own creative dialogues by visiting our website here:

www.creativedialogues.co.nz

At its heart, this book is a collaborative autoethnography—a collection of personal stories and reflections that reveal both individual experiences and shared meanings of illness within culture. By exploring these different scales – the individual and personal, and the societal and cultural – our collaborative process opens up a space for emotionally layered, nuanced, and experience-close dialogue. We invite you to step into this dialogue with us, to explore the ways illness can be mapped, visualised, and expressed—and, perhaps, to find new ways of articulating your own experiences.

Who is this book for?

This book is for everyone! Our hope is that each dialogue included will resonate with readers in multiple ways and facilitate continued conversation and greater understanding of what it means to live with illness - and how we can better understand and include those who do.

If you are a person with Parkinson's or another chronic illness, we hope this book inspires your own creative expression and supports you to communicate your perspectives and experiences. It can be difficult to articulate what illness means, but doing so can be therapeutic and can help you connect with yourself and with others.

If you are a researcher and/or artist, we hope this book will motivate further experimentation with creative strategies and collaborations that enable personal and emotionally resonant accounts of illness.

For health practitioners, caregivers, and friends and family of those living with chronic illness, we hope our work inspires you to consider art-based strategies as therapeutic and enabling for those you care for, and for your own wellbeing.

Introducing Sam

Sam is an illustrator and graphic designer. He see's illustration as a key form of communication in his work as an educator and as an artist.

A note from Sam:

"To be in the dark with forces listening as you are short of words - words that would bring light to see...It has been a privilege to bring my experience as an artist, illustrator, and graphic designer to such a breathtaking project and explore the illuminating power of creative dialogue. These works reflect the space between us; they are an act of pulling the illness experiences of others closer, to translate their osculating orbits and the tides that push and pull."

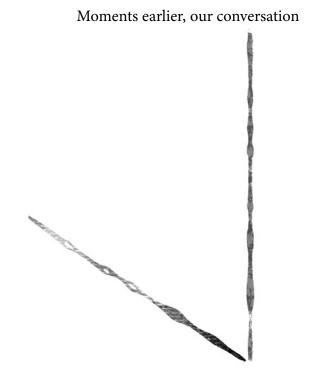
Introducing Tara

Tara is a researcher-poet, lecturer and health advocate working in the community to enable others to share their stories of illness. She also lives with young-onset Parkinson's.

A note from Tara:

"Undertaking this project has convinced me that creativity is a super power – creativity empowers a sense of agency through self-expression and is deeply therapeutic, slaying even the wildest anxiety and fears. Working creatively and in collaboration with others is also a powerful connector, not just of people, but of ideas, perspectives, practices, and places. It has been rewarding and a great privilege to be able to explore creative collaboration as a personal and collective force for empowerment.







can I tell you about my neurology appointment

the gravity of my body forces at odds beneath my skin

we were wrong it wasn't a pinched nerve

discoveries dipped in dark ink dissolving certainties

I am a solar system fragmenting

liquid dreams words boxed scattering

you sat silently for the longest time

tangled pieces shifting ground if we untether – will we be free or out of control?

I'm an open-minded person
I love travelling
even though I've hardly been anywhere
but travel is such a beautiful thing
to talk about
well, I used to think so

now I look at unfamiliar landscapes I'm meant to want but since they told me I'm ill the unboundedness of travelling

being taken so far forward in this whirring body who would I be when I got there? Isn't that terrifying?

constellating memories words not my own interpretation watery decorating stone along my border

when you think of a life with Parkinson's is it a river of moments headed to the sea?

travel can have such a nice feel especially if by water like the time we took the ferry bubbling white above blue

when you hear the word "Parkinson's" do you question how dark the night could be?

we reached an island's edge weightless waves at shoreline ministering sounds

when you see the mask of Parkinson's in the mirror can you find the familiar face?

we watched a fellow traveller disembark passed down steps toted across a watery vault many hands passing limbs and bags when you hear the words incurable and progressive does it burn your tomorrows?

on the mainland we saw the traveller bent and slow still in pain but no less amidst the jostle

when you imagine your place in the universe do we still come from the same cosmic beginnings?

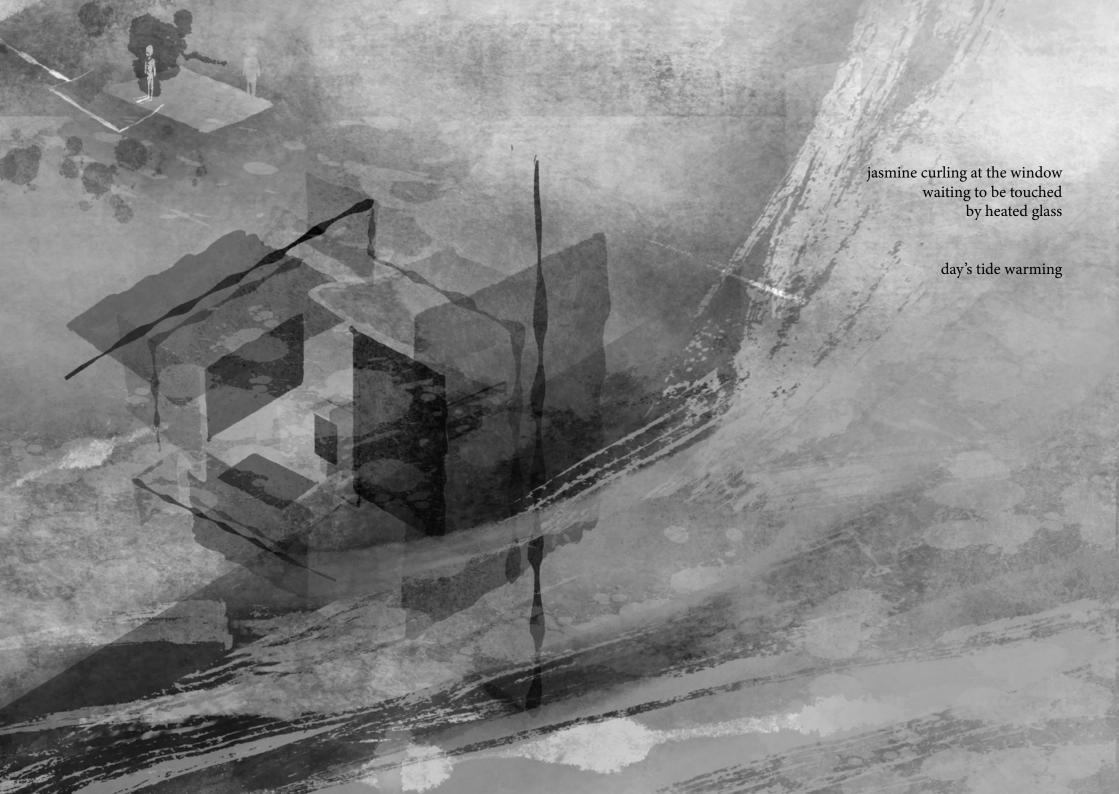
as we passed by, we called see you next time and I thought of you – you deserve islands, and mainlands too



Dialogue II

At my desk all morning, pen in hand





my white page a register of absence words dissolved edges syllables of ghosts, disoriented by their own shifting forms

which markings will explain the crumbling shoreline of my body a collage grey or dripping black ink along a rippling spine

we are all running out of time

if I'm honest, I hide plotlines in the mists white-tipped secret twists, pulsing songs hiding behind names architecture bruised landscapes emptying

ask what the story is my answer will float through open walls fogged ruins deconstructing more than flesh

my words will ribbon sea-salted air blurring atmosphere painting memories pale

we are all running to find what happens in the end

if we pause here, can you feel the story a rift between dimensions differently observed unequally loved, waiting to be told in a different language



waking early
hot in ice-packed morning
fists hard bone, rubbing
internal organs rumbling
flexed in tension
like absence regretted

or that inner warning calling insects and animals to pause, as if revived by innate power though lives hang on thin planes of air

my coffee settles a fine mist as I rock my chair watching passers-by swing their arms effortlessly feet at equal distances walking as they should I remember my old ways

the soft grasses along the path between the house and fields dotted frangipani and palm where we played with our children laughing prisms of light pushing swings

but to tell this story, would mean recalling the glue of medicines losing stick breath abandoning bedrooms whole houses streets and communities left gasping

we are all running out of air



is any story ever stable isn't the beauty in the shifting character of words cube-like and suspended in mid-collapse paper pressed with damp ink

but I am an edge tearing

maybe it's not you I am writing as jasmine warms at my window attention caught in glass perhaps a reflection of a corridor of selves weaving in and out of mist

but I am disappearing

what can't be denied are these muscles twisting against their own foundations a hollowing architecture taking place inside me, yet the story could be scaffolding

but I am built from weathered bone

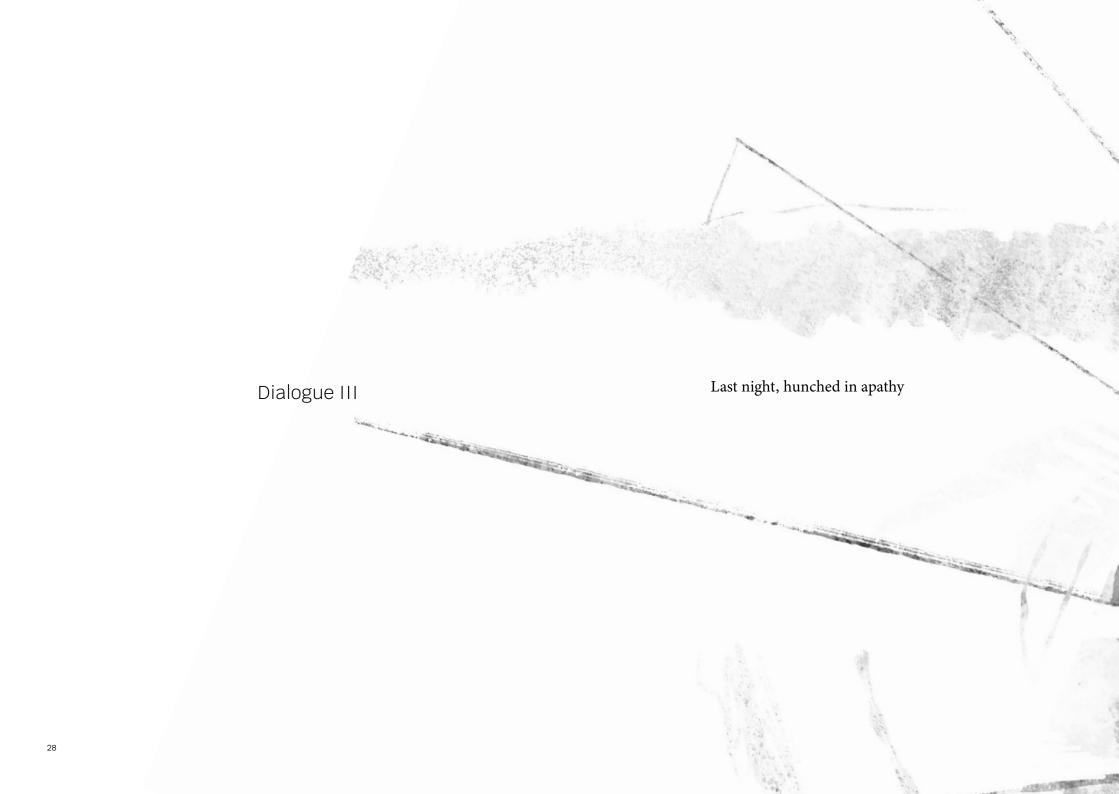
you rest a dragging foot beneath a seat of concrete take a wreath fixed with wire and moss lay it at the base of a monument weave through wind circling fleshy patterns grief caught at your skin in tattoo greens and blues

if I was stronger
I'd invite you to tea
ask if you'd like to share what only we know
within bodies dried early
but I forget the tea and the question

offering instead an amphitheatre-self dome-shaped arena of clay and water maybe that's ok since we are a couple of actors

that's how you remind me of stories like weather and skin or mist and paper playing variously on many stages pendulous and platformed, or light of step

ask again what the story is this time my answer will be untethering letting mist-dampened words fly smiling as I invite you to lunch to talk about anything but weather





ascent or descent
was the question
but still I was unsure
couldn't find a clear trajectory
couldn't feel
anything I wanted
where I wanted to be

resignedly, I grabbed shoes tossed air with affirmations looked in the mirror sternly you have to keep moving keep ahead of apathy's arms don't let illness amass power don't become stone

by mid-morning, I was on my way

wandering a lane staggering a hillside I was a bit shaky on my pins but I made it, and the reward was bubbling tips of snow the most beautiful scene a bright quiet

sure, it was cold, steep utterly demanding but there I was – me travelling through the landscape enjoying it I even met others along the way can you believe it some people waved others stopped to chat or sat where I'd just sat by the time I made it back I was part of the place a spirited landscape an island in an archipelago of joy

in the last light of the evening

thinking about what I enjoyed the most of course – it was the people they woke each day in the same uncertainty had to find strength had to get up and keep on we were alike in so many ways I wasn't alone

upon waking, I found myself hunched in apathy again

squinting through ambiguous panes unsure and wondering is it worth even bothering to move then – snap! I remembered faces nods and smiles my community my people

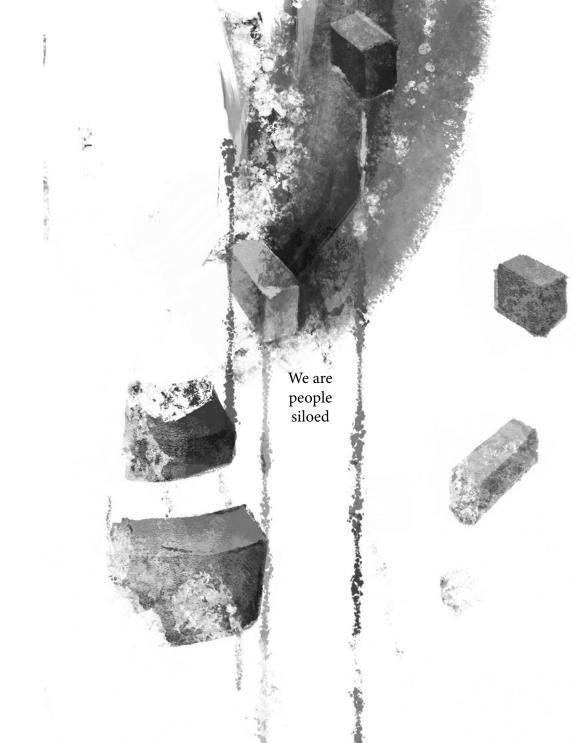
the joy of gritted teeth being together stretching past struggles

because the question isn't which way or up or down the question is an act

step forward in any direction in joy

in community find shifting light that is humanity

where you belong



Dialogue IV



the health of the nation depends on the quality of primary health care

> we are unable to find a GP to enrol with our daughter is sick

we are people with Parkinson's we need access to patient-centred, integrated care

limited knowledge of how Parkinson's is experienced there are misconceptions especially in young-onset

we are a lack of primary healthcare staff - people devalued and overlooked people left without basics

> a splintering maze-like landscape

> > we are people with chronic illness, without regular checks

we are people with Parkinson's we need the unseen things

primary care fragmented access and quality of care not in place for everyone reactive care is the usual

we are now facing gaps opening, risks unfolding people who feel wronged

different relationships some near, some far

> complex issues are managed inadequately due to absence of disease-specific expertise many different gatekeepers

we are the social contract between the government and citizen under strain no response when we stand to be heard

all trying to navigate

finding fissures instead of the expected doors

we are people with Parkinson's

We are people with Parkinson's

there is little coordination between disciplinary areas funding criteria don't help integrated care is a struggle

we are trust in the system eroded, persistent cutting of services, underfunding the only sure thing, a storm

> lines that fray steps erased worlds slowed voices thinned

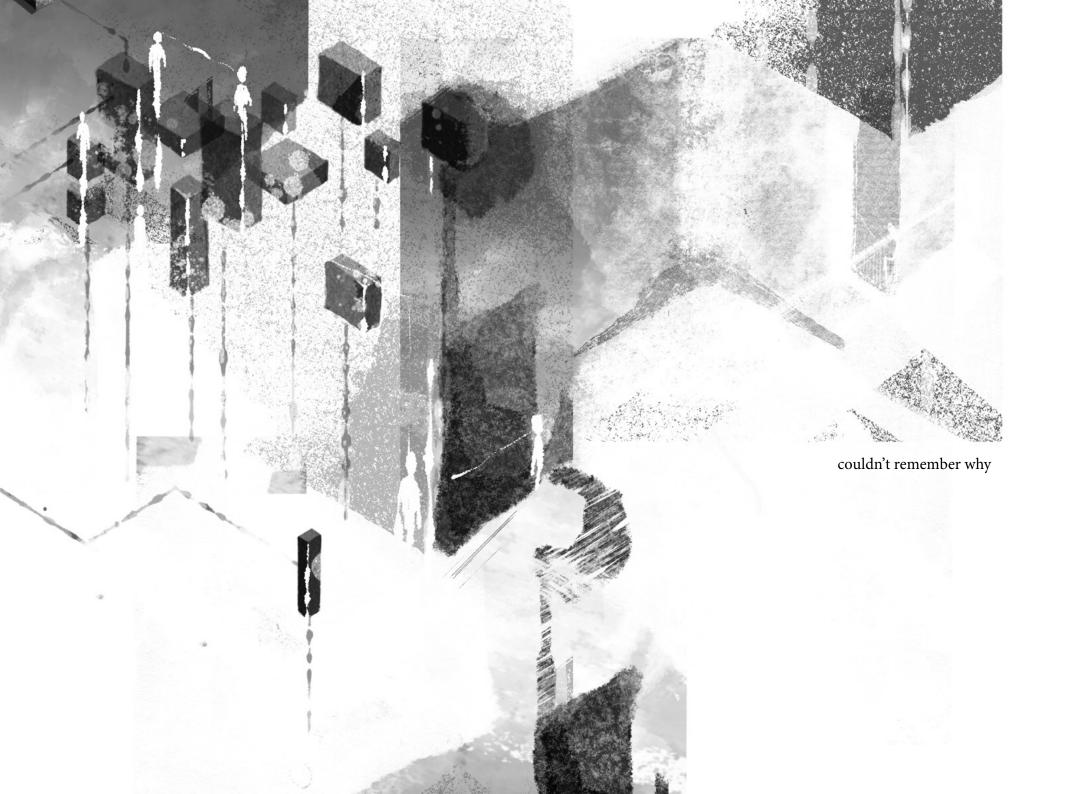
we are a ticking time bomb for public health

we are people with Parkinson's we need to stay well the shock waves of our degeneration are far-reaching

our treatment plans focus on the disease rather than people who live with illness

Dialogue V

He woke disoriented, anxious



it came to him slowly he was between places

his feet were aching and swollen there hadn't been space to lay his treasures

he hadn't been feeling quite right for a while, didn't recognise himself

it was causing all kinds of trouble in his relationships

in fact, it was the one thing his wife had yelled when she opened the door and asked him to leave

said he was no longer the same man she married he was an apathetic scarecrow sitting frozen on the couch

he thought, she's right and something that felt important coiled tightly in his chest

years later, her description took on a different meaning as he listened to a neurologist explain early Parkinson's the bag slung around their shoulders seemed to be stopping their arm swing

they made a mental note to grab the backpack instead

the one from their holiday in Fiji that first trip when they'd felt strangely slow

when it had become clear they were suffering exhaustion probably from their recent break-up

kindly, their sister had arranged another week at the resort they spent the time resting in the sun and sleeping

in the end though, staying at the resort for longer hadn't changed much

their energy never picked up despite a self-care routine

eventually their tiredness would become crippling and one day in the middle of the night they would awake

feeling as if a switch had been flicked inside their body which would from that moment on hum and shake

he was excited about the day ahead he was illustrating an interesting new project

it was all about early Parkinson's disease he had been studying what he could find on the subject

there wasn't much on how it felt to live with the condition but he had been working with the lead on the project

she had early Parkinson's and they had talked for hours while he drew and she made notes for her poems

he was surprised at how much information he had digested even so, he wondered if he could claim any real knowledge

he didn't live with the disease himself, after all that did worry him

but his worry would be set aside when the work was finished and he could see his story

of collaboration, of being a well person willing to listen willing to make space for those not yet acknowledged

inspiring others to do the same that meant a lot

to offer support to people facing obstacles to be more aware of all kinds of chronic illnesses

that mattered he was sure of that

she always looked forward to the end of the day when everyone was asleep and she checked the day's writing

she enjoyed tracing movement in the project looking over its shapes and sounds

she found the cube shape in the illustrations reassuring at times, even calming

yet, sometimes the repeating squares were darkly ominous casting shadows or becoming shadows themselves

reminding her how the world could be so different suddenly sky and ground could be indistinct

things of great presence could suddenly be absent

or change again and again the world was never still

sometimes I wake in the night / wondering is the world / breaking apart am I falling / where am I really me too, I can be perfectly happy as I tuck / into bed then I wake trying / to find my footing only to realise

I'm without foundations / for me it's a feeling of being / between / neither here or there disorientated caught in a dissolving / reality yes it's like I can't tell what is / sky

or ground reality / shifts my step forward becomes a step / back you know what stands / out to me though when we get together talking / candidly

we can decide on what it all means



agreed, we can give it / weight or let it float weightlessly box it up and pack / it away or keep / the box open and share

the important thing is we are not / victims we are not waiting / for drifting stone or the ground to choose / a timber we are not spilled / ink splattering

we are multidirectional
never one way
facing everything at once
transforming uncertainty
at the far edges
squeezed in-between
a remarkable feat
of strength
resilience



Dialogue VI



a landscape half remembered a city hesitant familiar and incomplete write down medications and dose keep good records

return echoes in ghostly corners muscle memory takes over play brain games spell backwards while skipping

"welcome to the jungle we've got fun and games"

knowing is temporary subject to revision bricks, wood, concrete tar seal certainty is rare

all we can know is one stone to step from a tiny ripple in a sea of unknowing

"be sure to wear some flowers in your hair"

I am a place in half-light small figures gathering along my inner paths veins streaked white across my landscape trying to hold together I am a room of echoes dissolving textures pieces aligning versions of myself confronting normative ideas slaying ableism

"if I can make it there, I'll make it anywhere"

start at belonging to arrive at wellbeing this is not the place but I exist my walls flickering

moonlight on water trees thickening shadows I am a silhouette against the sky the path forming in the dark tomorrow

> "our city is the bomb if your city makin' pay throw up a finger if you feel the same way"

illness changes us we live in this world and others



Dialogue VII





move in inky gravity solid and melting I can be lost or returning

her eyes were behind / boxed frames
I could feel them / squinting
she'd take a while to settle / into talk / I thought –
I was wrong /she talked for hours / I learned she was funny
as she bent into her bag / grabbing pills / she smiled
total confidence / as she swallowed

have you ever hidden your diagnosis or avoided sharing it?

one limb can move slower a string-suspended cube I am one string snapping

fragility can be dependent on how much weight I can tolerate

he'd wanted to tell / his story it made him / sad sometimes yes, he was lonely / too but always generous / with his time loved by all / though he didn't know it

where do you feel most comfortable and welcome?

mapping the unseen testing the landscape for fog, for dreams for building

an internal world population of one what secrets do these cubes hold will they box me in

she was a person of great / reputation in the community / giving to those struggling yet, she remained reserved / cool playing things / close to her chest

how do you manage work when symptoms are their worst?

curving a timeline light and shadow obscuring revealing

re-writing scenes letting go everything held or falling again

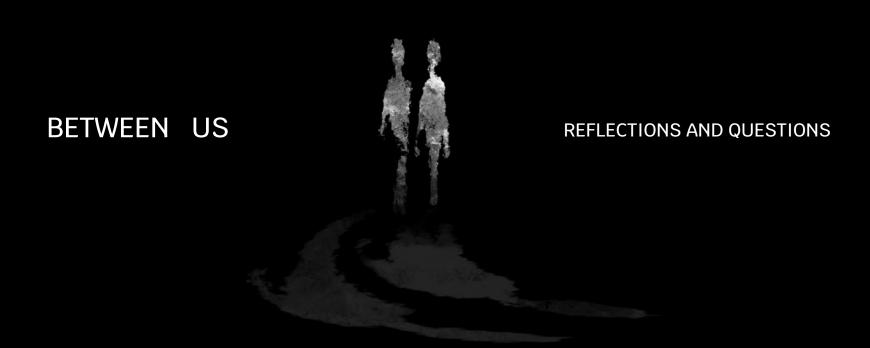
yes, he was very sad / sometimes but adamant that stuff / was small in the context of days / filled with people he loved / not to mention / his work in the community / and his painting

have you ever been excluded because you have Parkinson's?

an elegy of selves ghosts restless inward facing surviving

will you be the witness telling a story as it falls like a river







DIALOGUE I, REFLECTIONS:

Sam

Entering into a conversation with anyone, on a subject that is unknown to you, is like standing in a vast darkness. I felt that this isolation (a beginning) was a place we all find ourselves in at some point, and wanted to communicate a sense of inertia. However, there are ways to move through the emptiness and I considered what this might be like for someone who is confronted with a diagnosis.

Space seemed like an appropriate theme, it evokes alienation, but the stars give a sense of light, a place to reach. The pulsing lines are a reflection of messaging, of muscle, of connection. To me this image relates to circumstances where we have to stand up, look out and search for a way to step out.

QUESTION PROMPTS:

- What emotions or ideas stood out in this dialogue?
- How does the combination of poetry and illustration shape your understanding of the themes in this dialogue? Consider how the words and images interact—are they complementary, contrasting, or even contradictory?
- What role does uncertainty or ambiguity play in this piece?
- How do you relate this dialogue to your own experiences with communication, illness, identity, or uncertainty?
- How might poetry and illustration help express emotions or experiences that are difficult to articulate in everyday conversations?

DIALOGUE II, REFLECTIONS:

Tara

This poem emerged from conversations with Sam about the loss and grief that can accompany degenerative illness. As we exchanged fragments of illustrations and poems, two vivid but seemingly unrelated memories surfaced—one of my cousin crying at a funeral, and another of a ferry ride with a friend.

By placing these memories side by side, shuffling them, and playing with fragmentation, I realised that linking experiences of grief and travel could create a complex picture of grief as both a personal and collective experience. The poem then became a kind of memorial—something I could hold closely for comfort or share as a way of connecting with others.

QUESTION PROMPTS:

- How do the illustration and poem work together to shape your understanding of the story? Were there moments where they seemed to align or diverge?
- What role does instability play in this piece? Consider dissolving words, shifting memories, and crumbling architecture—how does imagery influence your sense of meaning or certainty?
- The poem explores the tension between presence and absence. How did that theme resonate with you? How does the idea of an 'untethered' story connect to the way we communicate personal experience?
- Do you think the poem suggests that stories can ever be fully told, or are they always fragmentary and shifting?
- Did any lines or images connect with your own experiences of loss, memory, or identity?



Sam

The conundrum of any system is to cater to needs, as an educator, I have a sense of the challenge that presents. Any system needs firm ground (the cuboids) to function from, but this security leaves little room for dealing with the complexities of public health. The grid-like image here represents both existing linear systems and directions. It is both compass-like and net-like, it guides you and snares you.

For the traveler it is both enabling and disabling. I wanted to reflect these ideas in the imagery. The figure at the top of the page, with its reaching shadow, is reflective of the cover. It is my attempt at trying to share my understanding of what it might be like to have a condition that you are keeping up with as it reaches and takes you to an emotional state you haven't been to before.

QUESTION PROMPTS:

- How does the speaker's perspective on movement change throughout the poem? Have you experienced moments where action felt more important than direction?
- The dialogue explores the challenge of moving forward despite apathy and illness. What are some obstacles—internal or external—that have shaped your own journey?
- The imagery shifts between personal experience and landscape. How do you interpret the idea of the speaker becoming "a spirited landscape"?
- The dialogue suggests that community is found in shared struggles and simple gestures. How do you see connection and isolation represented in both the poem and the illustration?
- The final stanza shifts away from direction and instead emphasizes the act of stepping forward. How does this message resonate with your own experiences of uncertainty or perseverance?

DIALOGUE IV, REFLECTIONS:

Tara

When I revisit this poem, I am reminded of how poorly Parkinson's is understood, even within healthcare. Misconceptions about early Parkinson's in particular, create barriers that impact quality of life for people with Parkinson's and their families.

I was intrigued by Sam's use of cubes and boxes. They prompted me to consider what is confined, transported, or contained. The imagery also evoked the way we navigate healthcare systems, performing different roles in different spaces. I wanted direct language to convey urgency and reflect the repeating motion of the cubes. The phrase "we are people with Parkinson's" is deliberately repeated—I'll leave it to readers to interpret why.

QUESTION PROMPTS:

- How does the imagery of waiting and isolation resonate with your experiences of healthcare or other institutional systems?
- Which images, lines, or phrases stood out as particularly powerful or unsettling? Why?
- How do the repeated references to "people with Parkinson's" shape your understanding of the challenges faced by thi community?
- What emotions do the images of silos, shadows, and crammed bodies evoke?
- How do you interpret the 'ticking time bomb' imagery in relation to the broader healthcare crisis?



DIALOGUE V, REFLECTIONS:

Sam

Navigating is a strong theme for me in these illustrations, as I continue to orient myself and create a metaphorical map of others' experiences.

This image came to me, as a way of representing transitions, to and from the health system, to and from the workplace, its myriad of textures look to make the architectural spaces hard for the reader to grasp, in the same way that some spaces in our communities must be challenging to those with illness.

As with the other illustrations, the figures are ghostly, this is to remind us that many people feel unseen, find it hard to connect to the present and are searching to feel safe in place.

QUESTION PROMPTS:

- How does the imagery of cubes and repeating squares shape your understanding of chronic illness?
- What emotions do the fragmented narratives evoke as they shift between different voices in the poem?
- Did the contrast between the personal experiences and the illustrator's perspective change how you view art as a tool for communicating illness?
- How do themes of disorientation, identity loss, and resilience resonate with your own experiences?
- What does the concept of being "multidirectional" mean to you, and how might it apply to your own life?

DIALOGUE VI, REFLECTIONS:

Tara

Sam's imagery made me think deeply about the extent to which we can ever truly return to ourselves after a challenging illness experience. With Parkinson's, a difficult experience might be a new symptom, the worsening of an old one, or simply the exhaustion of the long game. We return changed—but we do return.

I wanted this poem to capture the disorienting experience of continually adjusting to an altering self. The rhythm is intended to be chaotic yet meditative, reflecting change as both a mental and spiritual practice. The inclusion of song lyrics marks the poem as cultural—but I'll leave the question of 'why' open for interpretation.

QUESTION PROMPTS:

- How does the imagery of "a landscape half remembered" resonate with your experiences of disorientation or change?
- What emotions arise when you read about the idea that "knowing is temporary, subject to revision"? How does this concept relate to your life?
- Which lines or images stand out to you the most? Why?
- How do the song lyrics woven into the poem influence your understanding of the piece? Do they evoke any memories or feelings?
- The poem blends external landscapes with internal experiences. How do you interpret the "small figures gathering along my inner paths"?

DIALOGUE VII, REFLECTIONS:

Tara

Since this is the final poem, it felt fitting to reflect on the act of storytelling itself. Before I do so, I have just one question for readers:

How has storytelling in this book shaped your understanding of people with Parkinson's/chronic illnesses, and of yourself?

I have enjoyed the multidimensional imagery Sam has brought to this project since it has allowed exploration of different spaces and places – the "in-between," "internal worlds," and "the unseen, yet mapped." In my academic work, I have long been interested in the interdependencies of physical and emotional landscapes and their impacts on experiences like isolation, community, and self-image. What stands out to me is the power and possibility of bearing witness to illness, change and resilience 'taking place.'

Now there is only one thing left for me to do, and that is – invite you to try the exercise on the follwing page and get your own creative dialogue going, and perhaps share it with us via our website:

www.creativedialogues.co.nz

EXERCISE; BEGINNING A CREATIVE DIALOGUE

Part One

You and your research partner will each create small artworks to introduce yourselves. If you already know each other well, use this exercise to share something about yourself your partner doesn't know.

Choose any artform you are comfortable with or interested in. If you're unsure, consider sketching ideas, jotting down words, or journaling to get started. Again, remember the quality of the artwork is not the focus at this stage—the emphasis is on deepening conversation and connection.

Examples of Artforms You Might Use:

- Photovoice and photography
- Writing and performing plays
- Videography
- Artwork and exhibitions
- Creative writing and poetry
- Journaling
- Mixed-method collage
- · Anything goes!

Part Two

Once both artworks are completed, meet in person or online with notebooks and pens at the ready. Share your introductions and take time to absorb your partner's work—let your eyes wander over their artwork and simply observe.

After a few minutes, jot down the first things that catch your attention. Let your mind drift and note any words, images, or ideas that stand out—without trying to analyse them yet.

Next, focus on emotions. As you look again at the artwork, still not overthinking, write brief descriptions of any feelings it evokes.

Pause and discuss your first impressions and emotions with your partner before returning to your notes to expand your reflections, expressing your emotions in detail. Record any questions that arise in conversation with your partner or your own thoughts.

Respond to your partner's introduction in real-time. Use your notebook to sketch words or images that stand out to you. Remember, the quality of the art remains secondary—the goal is to communicate in a way that allows each of you to feel seen and understood. Swap sketches when done and discuss what you've learned.

Discuss your impressions of the exercise with your partner and how it may work or be challenging when enacted with research participants or another group you are thinking of working with.

We hope you enjoyed this introductory exercise and this book! Visit our website (www.creativedialogues.co.nz) for additional exercises.



NOTES

