

## **The Longview** Journal 2023

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#### Dear Reader:

#### Welcome to the Longview,

The Longview Journal is an annual student-run, peer-reviewed, inter-disciplinary, creative arts journal focused on the humanities in healthcare. With this collection of creative works describing the unique experiences of students and faculty, we hope to angle a creative lens towards contemporary healthcare. The Longview was established in 2014 by a group of medical students at the University of Calgary. For the first time, the journal welcomed submissions from outside the field of healthcare. Our aim is to create and foster an interdisciplinary space where health and humanities come together, supported and united.

Our mission is to see the journal grow, better encompassing the many viewpoints of the different positions in healthcare.

I would like to thank our faculty mentor, Dr. Tom Rosenal, for his support of this project. I would also like to thank the Longview editorial team for their dedication in promoting the Longview, reviewing the submissions, and working to create the final project. Finally – thank you to everyone who submitted to the journal and to everyone who supports health humanities. I hope you enjoy reading and reflecting on these works.

#### Longview Editorial team, 2023/2024



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# **Table of Contents**

How Time Gives	Carolyn Stephens	p.1
What I do Know	Priya Khalsa	р.3
Baggage of Assumptions	Stacy de Lima	p. 6
Witnessing	Valerie Cates	p.8
This New Reality	Alisha Ebrahim	p.11
Reflections on Dignified Care	Xiao Yang Fang	p.14
Sentinel	Breanne Summer Gordulic	: p.20
Primrose & Thistles	Valerie Cates	p.22
In Memory of	Chelsea Barlow	p.24
Kept Hidden	Tarannum Rahnuma	p.27
latrogenic Stigma of Mental Illness Among Medical Learners	Simran Sandhu	p.28

## How Time Gives

And through your eyes I see black and white And through mine I try to show you color But time has taken your eyes, And the agility with which you dance, And has traded your world for four walls, Given you silence disquised as peace, A longing for the old days -When you were teacher, provider, supporter, problem solver... The old days come back in waves, Memories that ebb and flow and name you the hero, at least sometimes The old days come back in your faith, And though you no longer read the words, They are present in your mind, and keep your soul alive. Time, so generous with years But is a two-edged sword- for it gives, and will take away Time ultimately wins, And has taken much But it cannot take your smile, It cannot take your voice, Nor the way you have changed lives Nor the spark in your eye It cannot steal the memories we have of you And so, you will live on in our time, and In black and white, and In color.

The poem was inspired by my 95-year-old grandmother Dorothy Stephens who lives in Jamaica. I lived with her for 13 years and during that time saw how her function and daily routine changed. Her vision deteriorated (she had her left eye removed), her gait slowed, and she had less and less control over her life and decisions. In Jamaica, it is a part of our culture to care for older adults in the family at home, and so my grandmother lives in the home that she raised her family in. She has a live-in caregiver that helps her with her ADLs and her children take care of her iADLS. Four years ago, she was diagnosed with heart failure and has since become frailer. I look at all that time has given to her; the opportunity to grow old, see her children grow up, contribute to the lives of her grandchildren and meet her great grandchildren. Time has allowed her to see so many milestones and life-changing events such as the Rastafarian Movement, the Great Depression, and the independence of Jamaica. Through her we have those stories, and her view of the world then. I refer to her vision in black and white because the social context in her younger days did not tolerate diversity in thought and expression. Growing up in that social atmosphere, and raising your family with the same values, it is difficult to change and accommodate concepts that seem commonplace today. We all need grace, so I meet her in her world; and in so doing she gets a glimpse of mine. Grace for each other in healthcare can be such a powerful tool in broadening our capacity for compassion and understanding.

**Poet:** Carolyn Stephens **School:** Cumming School of Medicine, University of Calgary

### What I Do Know

I have yet to meet you, but I already know that you are dying. You have non-small cell lung cancer. We studied lung cancers earlier this year, but that knowledge has long been washed away by the unyielding, torrential pour of information that is medical school. Still, I know from my preceptor's hushed tone and tactful phrasing that your prognosis is not good, your tumour inoperable.

I enter the room with two brisk knocks, a half turn to close the door, a smile that I know is visible through my mask. Already, I am nervous. I do not know what I can offer you. I am unsure if I have the right information, the right words to care for you properly. I know that you have come for a prescription refill, but I do not know what for.

"Codeine. It's for the pain in the side of my ribs. It's always there, and it's keeping me from sleeping."

I nod in response. I am careful to keep my posture relaxed, one leg crossed casually over the other as I mentally rifle through my repertoire of knowledge, searching for the next question to ask. My brain is slow to load, weighed down by the gravity of your diagnosis and my fear of saying the wrong thing. I wonder briefly about the potential for opioid abuse, and whether I should inquire into your usage. Then I wonder, at what point would I even be concerned for misuse? Maybe I should try to get a better sense of your pain...

Instead, I settle for asking how long you have been taking codeine and whether it is helping your pain and sleep. I ask if you have had a discussion with your oncologist about the risks and benefits of codeine, and how to use it safely. Really, that is all I need to know.

You tell me that it is helping your symptoms. A brief pause. "My physical symptoms."

Unknowingly, you've thrown me a buoy. I grasp on to this new direction with the relief of a stranded swimmer. What about your mental and social well-being? I ask about how you've been doing, and whether you have family and friends to help you cope.

"Oh yeah...I mean, I've got my partner and my two kids at home. My kids don't know yet but they can tell something is up. My partner is wonderful, but I think she's having a hard time accepting this whole thing." You laugh wryly. "She's still in the googling phase."

We talk about some options for counselling. Some people find strength in the solidarity of support groups, while others prefer individual counselling. I even offer both as an option for your partner.

You deliberate carefully, lips pressed together. "I think a counsellor might be helpful for me. I'm not sure if my partner is there yet, though. She still believes there's a way for me to get better."

I hear the weight of your partner's impossible hopes. The exhaustion of maintaining a façade just to keep your children from teetering off the precipice of innocence too soon. Your strength, while admirable, raises my concern. I ask about your hopes for the future.

"I want to make it to Christmas...and to just have a really nice time with my family." You look at me. "I want to know that my family will manage after I'm gone...My partner is a stay-at-home mom, and I'm the breadwinner. And I'm self-employed."

The overhead lights reflect brightly in your eyes, but the wetness has yet to spill over. I worry that I have pressed too hard, but instead you seem grateful to have been granted an opportunity to share your innermost hopes, to trust someone with this piece of you. It feels more precious than anything I have ever held.

I thank you for sharing with me.

This is a safe space. You are not alone. I promise to you that we will take care of your family together. That is when you know you have been heard, and the tears finally fall.

We discuss the financial and legal supports that social workers can provide, and I give my word that I will send the referral immediately, in addition to setting up counselling sessions for you. I offer to set up sessions for your partner too, so that everything is in place when they are ready. I tell you that my door will always be open to your family, for as long as they need. By the end, you are a new person – a rare flower unfurled in the moonless night. You thank me for a lovely, lovely visit, and tell me that this all feels much more manageable to you. That you feel better than you thought you could.

Later, I will think about the care that I am able to provide and what I have to offer as a medical student. It is easy to get lost in what I do not know, paralyzed by the pressure to perform. I am neither an oncologist nor a pain specialist. I am not a counsellor or a social worker. I do not know all the medicine, but what I do know is how to offer comfort. How to make you feel supported in this solitary journey, so that you know you are not alone. How to listen to your spoken words and the spaces in between, and to give you my full attention so that your fears, hopes, and desires are heard. How to give you space for vulnerability, for contemplation, for decisions so that we can move forward together.

At the end of the day, the medicine that we all seek is that of our own humanity.

The next time that I enter a patient room, I pause with my hand on the door and remember this encounter – the first time that I felt like a doctor. I may not know all the medicine, but I do know how to be human.

Author: Simran Sandhu School: Cumming School of Medicine, University of Calgary

### Baggage of Assumptions



This piece reflects how I feel about the way I instinctively view others of different ages. It shows the same man at different ages/stages who are all carrying their personal belongings with them. The size of the containers holding their belongings correlate with how much "baggage" we reflexively assume one has as they age, and the design of the container reflects our perceptions of those ages as well. The child's belongings are held in a birthday present box which is light and fun, the middle-aged man's belongings are held in a moving box representing him still trying to establish and find himself, and the elderly man's belongings are held in a piece of luggage which although allows for travel is still represents taking those belongings to a more permanent place to stay compared to the other two. When opening the containers, you see a picture of a tree at different stages of growth which contradicts the outward appearance of the males in the painted image. First you see a tree that is equal in height to its root dimensions representing stability, grounding, and experience. The middle-aged man is carrying a tree that is slowly dying but still exhibits a vast root system. Finally, the elderly man is carrying a tree that has just been planted and is starting to take form. This art piece to me represents how we may assume the experiences one is carrying with them. But this can be very detrimental to making real connections with those we are caring for because we don't know what roots were laid for them in childhood or adulthood and how that changes the way they perceive and interact with the world. It comes back to the common phrase of "kids will be kids" which often permits certain behaviours or actions due to someone being younger implying naivete as the justification for the faux pas. This type of forgiveness is not often afforded to the elderly as they "should know better" but the knowledge that they have is all based on the exposure, teaching, and guidance that they have been afforded throughout their life. I want to keep challenging my beliefs of what "baggage" people carry with them, and limit the assumptions I make about how people should and should not act based on their age.

Artist: Stacy de Lima School: Cumming School of Medicine, University of Calgary

## Witnessing

People with chronic illness travel a vast border country', I once heard it phrased; Perpetually lost, seeking refuge in an unknown, unforgiving land; Their friends and families pressing noses so close against the glass, Following the same path, Unable to break through; an invisible barrier that holds us hostage. Helplessly hoping. Helplessly watching. Carrying unseen loads. Unable to smooth salves on blistered, tired soles, Only to offer tears of solidarity in times of drought through barricaded windows.

I wrote this poem about something hard to hear. When I first encountered the words, "the chronically ill are like those trapped at a frontier, wandering confused in a poorly known border area" by Arthur Kleinman in his book The Illness Narratives, my brain tingled with a series of thoughts, emotions, and memories that left all remaining synapses paralyzed. That's him. That's me. My partner is that wanderer and I am that individual pressing flesh and bones into glass, watching him struggle to find any path out of this purgatory borderland called chronic back pain. Though it is not my pain, I feel it all the same.

Since 2017, we have struggled to adapt and make sense of the endless chaos story we find ourselves in – a sinister fairy-tale of fate. Each moment of seemingly unprovoked frustration, I am his primary witness. Each ache, each night of lost sleep, each moment something else he loves – a dinner, an adventure, a friend, a hobby, a job, a celebration – slips through his fingertips, I am here. Though he has always been an emotional person, the back injury, the break, became a hotbed for emotions to bubble out with fury at the slightest shift in pressure.

I know from my graduate research that back pain is a leading cause of disability worldwide. I know that it costs more money than nearly any other type of illness. I know that finding a cure for back pain can be as convoluted and twisted as the anatomy itself. In the spine clinic, I see how chronic pain patients struggle with opioid dependency, and how opioids can perpetuate a cycle of pain and disability. I hear their stores of disappointment when despite the surgery, they feel no better. Yet, with all I know, it's different when someone you love is in the middle of that pain.

As a caregiver, I've tried endlessly to show him I am here. To knock as loud as I can on that impenetrable glass hoping to provide some form of comfort through witnessing. At the same time, I have grieved in silence. Grieved for those simpler times, a time where pain wasn't peering from the peripheries of our life, waiting to make itself known at the most inopportune times. Silent so as not to take away from his pain or remind him of his grief. As a caregiver, you become a constant reminder: a reminder to your loved one to keep going, to stand up straight, to do the prescribed exercises, to go to the appointments, to hold off on that cigarette that gives a moment of comfort in endless moments of pain. We are constant reminders of not only how difficult things are, but also how easy things once were.

I wish I could say his spine break was a fantastical story arising from adventure and novelty. Unfortunately, as for most injuries, it was not. It was simply a standard spring day in Calgary that gave rise to a slippery night. That fateful morning became the start of the story we told ourselves to make sense of chaos. A way to cope and contextualize, to give order to randomness. He slipped, fell, and fumbled his way up two flights of stairs into our front entrance, wheezing and sobbing in the process. As my 5'4 frame lifted his 6'5 body onto the living room couch, I knew something was wrong, but I lacked the training to see the signs of a spine injury. All I saw was signs of shock.

"Take him to Emerg if it gets worse," the 811 nurse coldly advised, no doubt hearing the same story from other worried callers all morning.

Though it never got worse, it never got better either.

For months, we waited – watching his spine curve over, wiping away tears, waiting for relief that seemingly never came. Months later, an unrelated X-ray revealed the bony fracture that sent splinters into our normal everyday life. However, by that point the physical injury had healed, and all that remained was a story to try and make sense of the remaining psychological injury. It became a story we told ourselves, our families, our friends, and whoever would listen. The tricky thing about pain stories, though, is that we all have one. Despite being one of the most common human experiences, pain is one of the most difficult, personal, and isolating things we will inevitably encounter. I will never be able to understand the entirety of my partner's pain – both physical and emotional. Yet, I, and everyone else reading this, each have our own pain story that frames how we ingest and respond to the pain stories of others. Unfortunately, when someone is lost in their pain, we share our stories to sympathize, and the act of sharing often isolates the person further.

**Poet:** Valerie Cates **School:** Medical Science, Faculty of Graduate Studies, University of Calgary

## The New Reality

Every day I look up and I think about how I got here, and why this here is even mine to have.

Coming home exhausted, but feeling as though no time has passed, a January chinook wind, not what you expected but exactly what you needed, thatthat kind of day seems to drown out all of the tears in the elevator, Advil before breakfast, honey I'm home-alone kinds of moments that normally would tear through the day but instead just leave micro-aggressive thumbprints, reminding me that each day of good is something to cling to.

Fading into thoughts of curious eyes and windy conversations makes those days fly by with a hop in their step, landing in a place softer than where they began.

A place where I forget the eyes that pierce, the eyes that glaze over, and the eyes that deceive, irises sharing more than words ever can, serving me divorce papers to severe the tie between what I thought and what I knew, what I filled in and what you created, giving me a chance to finally breathe as the curious eyes fill my horizon and all the rest disperse.

I've learned to love the storm as much as its calm eye, and to find moments that gently linger, teaching me how to appreciate my sharp edges, the ones that used to grate but have since found a place where they fit, a place where there is room for my soft soul alongside my stoic mind, neither cast aside because in this place, we all have a role to play.

The splendid drama of it all, the high highs and low lows, you and I feels like soaring above the rest, I've been given permission to sing and so my lungs have chosen a harmony that describes why every day shines and while not all that glistens is gold, all that glistens is a gift in its own.

**Poet:** Alisha Ebrahim **School:** Cumming School of Medicine, University of Calgary

### Reflections on Dignified Care

Grandma fell around 6am. She called out to my mom who came running from the other room and found her on the floor beside her bed. Mom lifted grandma back onto the bed and examined her to see if she might have broken anything. What mom didn't realize was that grandma had lost control over her left arm and leg, and that she was rapidly losing control over her speech.

All of this was taking place while I was mid-flight to Beijing. I was only supposed to be in China for a few days. It was going to be an exhausting trip, but I was eager to see my family. My uncle was going to pick me up, and all of us were going to have Peking duck together. Instead, mom and uncle had taken grandma to the hospital.

EKGs were done. Blood was drawn. CT scans were made. A message was left on my phone. "Grandma fell this morning. Can't pick you up. Take a cab home, we'll see you later." Hours pass until mom finally calls. They were still in hospital and weren't coming home that night. My orders were simple, "figure out dinner. Go to sleep. Try to come by tomorrow."

I ask how grandma is doing. "They did more CT scans, they think it's 脑梗" "What's that?" "I don't know how to say it in English, can you Google it?" I do, and then I freeze. "Cerebral infarction, commonly known as stroke."

My heart drops and immediately I go into a frenzy of Internet searches, trying to bury my fears with web-knowledge on symptoms, causes, and treatments. I text my brother-in-law in Italy who is a doctor, "how can we tell the difference between ischemic and hemorrhagic stroke?"

It's Saturday afternoon in Italy but he texts back almost immediately. We go back and forth about some details, and I send him all of grandma's symptoms and all the tests they've done so far. I ask a million questions. My brother-in-law is very rational. He walks me through some basic answers and tells me not to panic. But I am panicking.

I wander hazily over to grandma's room. I imagine her body on the floor that morning. I imagine her sleeping in her bed. I walk over to the kitchen where we had cooked together just this past summer. There were dirty dishes in the sink. There was fresh soy milk that my mom must have made in the morning but had no time to drink. This is not how I imagined today to turn out. We were supposed to have Peking duck...

#### In hospital

When I got to hospital early next morning, grandma called out to me. I rushed into the small curtained-off space where she lay on a temporary bed and we "chatted". By that I mean I said a whole bunch of things, and she slurred some things in return. I could identify a few garbled words here and there, but most of it was guesswork.



Grandma was a writer and former principal. She played the piano, was an incredible Chinese watercolor painter and taught Taichi for 50 years. She enjoyed playing Mahjong and always beat us at the game. Her body and mind had been agile – until yesterday. How frustrating it must be for her to try and form words, only to hear the distorted sounds that come out and to see the puzzled looks on our faces.

#### So we developed a different way to communicate.

For yes, *bat your eyes*. For no, *shake your head*. If you're hungry or thirsty, *stick out your tongue*. If you're uncomfortable, *make a sound*.

We stayed in that small, curtained space for about 10 hours. I instinctively took pictures of grandma's IV bags and other details of our little space. I remember thinking how ugly and boring the walls and ceilings were. How bright the lights. How uncomfortable the chairs. And a strong but inexplicable need to document it all.

Grandma was in and out of consciousness, but mom and I never left her side. Occasionally rubbing grandma's legs and feet, occasionally feeding her drops of water, occasionally changing her diaper. Most of the time, holding her hand.



At some point I Interlaced our fingers and hummed one of her favorite piano tunes. "You remember that grandma?" A small squeeze. Her fingers tapped with mine. Out of rhythm, but tapping nonetheless.

I kept thinking that I should tell grandma that I love her. But somehow it felt morbid, like something you say to someone in their last moments. And I didn't want to jinx it. I didn't want to signal to her that I was ready to say goodbye. Because I wasn't.

Around 6pm, a bed became available in another hospital and an ambulance transported us across the city. We scanned a QR code to pay for the ride. Grandma's medical bills were accumulating rapidly – so many receipts, so many reports, so many documents to keep track of.

The moment we arrived at the new hospital, grandma

grandma was wheeled out of sight, and mom and I were left processing through security and registration. While mom filled out the paperwork, I was swarmed by doctors and paramedics.

"What's her condition?" "What's the diagnosis?" "When did you first notice symptoms?"

"What meds has she been given, how much, and what times". "What IV fluids has she had, which ones, and at what time". And on it went.

I stumbled on the details of her procedures. "I'm not sure what she was given...they all had these long names. They must be written somewhere". I fumbled for my phone and showed some of the pictures I had of her IV bags. Then, as I dig through the growing pile of reports and prescriptions, the paramedic lets out a sarcastic chuckle. As if he were saying, "how can you not know these things?"

In that moment, all the stress and lack of sleep caught up to me and tears came rolling down. I realize I hadn't cried yet since I learned of the stroke. And it wasn't seeing grandma in such a sorry state, or the knowledge that she probably



didn't have very much time left, or the anticipation of grief. All that would come later. **No, what** made me cry was the helplessness in meeting the demands of the medical team. The doctor softened a bit. "It's OK. I'm sure the reports have everything we need to know".

Then we learn that the bed that was promised was no longer available, so grandma would have to stay the night in the hallway of the ER, where family members are not allowed. The doctor told us to "sign this paper so you can go home". Her tone implied that she was relieving us of a burden, but mom and I were incredulous.

"Wait, what? We can't be with her? Can we at least talk to her and let her know?" "No. Not if you stay in this hospital." "Then let's get her to a different hospital."

Finally, a bed was found in a different hospital. The fourth hospital grandma would be transferred to in the last 36 hours. It was a "shabby hospital", a "level 3". But they allowed us to be together, and that's all that mattered. When grandma was finally wheeled out, it felt like we had rescued her. I thought about the irony of it all.

That night, mom and I slept in a hallway on hard make-shift beds. Despite the melatonin pill I took, I lay wide awake and listened to the sounds of the hospital. From one of the rooms came a gargling sound, followed by the hurried footsteps of doctors and nurses.

The squeaky stap-stap of their sneakers distinct from the muted shuffles that indicated the slower footsteps of slipper-wearing patients. Something was done, some words were exchanged, then all was quiet again. Apart from the rhythmic beeping of monitors. Always the beeping of monitors.

Reflecting on events of the day made me aware that **hospitals are focused on symptoms, not humans**. Bodily functions are measured and managed. Heart rate, blood pressure, oxygen levels. Some machines are used to pump in calories, medicine, air. Others to suck out phlegm, saliva, blood. Mom and I filled our survey after survey with grandma's demographics, and conditions measured on Likert scales; but none about who she really was. It felt as if she were being reduced to numbers and diagnoses.

Over the next few days, nurses would come in to draw blood unannounced, and care aides would pump





powdered mixtures up grandma's nose. All was done expertly and methodically, but I found myself often having to advocate for grandma's basic respect. "Wait, please tell her first what you'll be doing, explain the procedure and what it's for."

Or, when doctors walked in while grandma was uncovered, "please wait a moment while we change her, give her some privacy". I was surprised, no, annoyed, that all this needed to be explained. **That grandma was still a human, not just a body.** That even though she couldn't move or speak, she still ought to be treated with dignity.

Grandma had ischemic stroke and brain hemorrhage, treatments of which contradicted one another. Blood thinners would aggravate the hemorrhage and blood clotting would worsen the artery blockages caused by

the stroke. The doctors had recommended no treatment beyond oxygen and basic IV fluids for hydration. Anything else would be too risky. But if they didn't treat grandma, her stroke symptoms would likely worsen and she may never again regain her mobility or speech, or even the ability to eat. She would live, perhaps, but be forever bedbound.

Having always taken pride in her independence, my mom and uncle knew with absolute certainty that grandma did not want to live in a vegetative state. They weighed the pros and cons of stroke treatment and were willing to take the risks. But the doctors wouldn't do it. "We understand that you care about her quality of life, but our priority is to keep her alive. We can't treat her even if we wanted to. It would be illegal to go against medical opinion." And so we waited.

Grandma resisted in her own way. With the little control she had left on her right hand, she kept pushing off the blood oxygen sensor.



But every time she managed to wriggle free, the machine would start to beep and someone would come to clip it back on. Eventually, I took off the sensor and clipped it on my own finger. Ever since she got to hospital, grandma had been poked, prodded, scanned and restrained. What she needed now was not to know whether she had 87% or 93% oxygenated blood, but to be left in peace. To experience the little freedom and comfort that she had left.

#### Epilogue

Grandma passed away three days later. At 92, she had had a rich and full life. Yet for the next few days, all we could speak about were hypotheticals. What we could have, would have, should have done, not done, or done differently. All the what ifs and the if onlys. There are no words to process grief.

Notwithstanding the immense gratitude I feel towards all the doctors, nurses, and care aides that have helped my grandma, I was troubled by the medical system that pressured them to prioritize protocols and efficiencies over empathy and dignity. Reflecting back, the doctors and nurses were matter-of-fact, doing what they needed to do to keep grandma alive.

I had wished for them to have cared about her mind as much as they had for her body. It may not have prolonged her life, but it would have filled her last days with more tenderness and choice. What gives me solace is that I got to kiss grandma goodbye, and to tell her that I love her. Always have, always will.



At grandma's funeral, we finally had Peking duck.

#### Author: Dr. Xiao Yang Fang School: Community Health Sciences, University of Calgary

About the author:

Dr. Xiao Yang Fang is a postdoctoral researcher in the department of Community Health Sciences working on the Radical Mental Health Doula (RMHD) project. This is a community-based model of support that was co-developed with people with lived experiences of mental health challenges and that is currently being piloted in community. The central tenets of the RMHD model are to uphold the rights and dignities of people who are seeking and receiving mental health support.

## Sentinel



A television waits in the middle of a wheat field on a warm summer evening, the sentinel. Walking into a patient's hospital room, it often feels like the television is the patient's most reliable connection to the outside, providing surveillance of events and experiences of the world, standing guard day and night. This feeling for me is heightened when the patient is near the end of life and their hospital bed is now the extent of their physical reach. Each encounter in their room feels still, isolated from the energy of the rapidly changing outside world.

Bullrushes, resilient plants able to withstand drought and floods, line the start of the path into the field. The patients I have met near the end of life or critically ill are mighty beyond appearances and my preconceptions, with fortitude to endure procedures, medications, and isolation.

My first time guiding a patient into palliative care, was my own sentinel. Each visit brought intrusive thoughts confronting me with what my end of life may look like, and the creation of a mental list of choices for myself. Every patient I meet and care for brings more clarity to both my own purpose in medicine and my eventual end. A vibrant setting sun in this piece is my reminder that the passage of time is out of our control, but our choices in how we experience this transition should be celebrated.

Artist: Breanne Summer Gordulic School: Cumming School of Medicine, University of Calgary

## Primrose & Thistles

He wanders through his memories; Unstuck in time, but here all the same. We surround him, each feeling our own emotions for the proprietor of our last name.

His words drift to sunshine; The expansive prairies; his home; some distant dreamy days. He wanders back to now: A hospital bed enveloped by his family's tearful gaze.

Heartache saturates his sterile room; We absorb his final hours, ingest his final thoughts. Unable to hold the pain, she wilts: A tired primrose in dry Irish moss.

He held himself like thistles; In sickness, he remains the same. Despite all the tubes, he smiles: He remembers us and the people we became.

His gratitude runs deep; Nourishing our dry soil with tenderness and relief. His eyes close and he concedes: "I think I need some sleep."

He welcomes us to stay; To swaddle him in love and warmth. We oblige. His shallow breaths breathing peace Into our weeping hearts.

Time floats on and we soak up what we can. But, eventually the primrose fades, And I hold her withered hand. For as much as he means to me, He's everything to her. "Goodbye, my sweetheart. I'll see you tomorrow." A whisper left unheard.

This text is a reflective assignment written in August 2022, for the "Neurosciences and Aging" Course (i.e., Course 5) of the Medicine Program at the University of Calgary. It has been adapted for submission to the Longview Journal.

**Poet:** Valerie Cates **School:** Medical Science, Faculty of Graduate Studies, University of Calgary

### In Memory of...

The past four weeks have been personally challenging and unexpectedly relevant to the Geriatric and Palliative Care topics of the "Neurosciences and Aging" Course. I have been procrastinating the reflective assignment because it not only means acknowledging my grandfather's passing, but accepting the reality that his physical presence is gone. Even more sad is realizing my grandmother is a widow – it is uncomfortable writing that word, and I can feel the lump in my throat tightening. My grandparents were married for over sixty-five years. They met when she was fifteen. He died the afternoon of August 22, and that morning, Grandma said she finally realized she was losing her partner. A heaviness in my chest grows when I remember her comment.

Grandma took care of Papa his entire life, and I imagine there will be an emptiness and a sense of loss; not only grief surrounding the loss, but also losing a sense of purpose. They lived an active life with their three children while stationed in Germany. Life was filled with travel and connecting with people. Papa worked as an airplane mechanic in the Canadian Air Force and boxed in his spare time. Upon their retirement, they started a ranch, bed and breakfast, and campsite called Hidden Lake Ranch, which was ten minutes east of Vermilion, Alberta. They both loved meeting new people and riding horses. His favorite horses were Echo and Nugget, and he enjoyed going to the local college, wearing his cowboy hat, to practice "cutting" with the students. As he aged, he adapted his environment to suit his physical abilities: building a smaller home with all necessities on one level, using fences to get on his horse, riding the quad "side-saddle" (with Grandma holding him on), and hiring a contractor to install a stair lift when he could not climb the stairs. Grandma was critical in maximizing his independence and ensuring his dignity.

Two or three years ago, his kidney function deteriorated, and he declined dialysis. Thankfully, the Course 4 "Nephrology" content addressed the issue of dialysis and older adults, and I recognized that it would not improve his prognosis. Consequently, I embraced the opportunity to build stronger connections with my grandparents. My son, Louis, was born in December 2019, and his innocence and development were gifts that helped strengthen our family bond and brought laughter to the household. We spent last Christmas Eve and Day with Grandma and Papa, and when Papa started using a four-wheeled walker, Louis rushed over to sit on the seat, excitedly exclaiming he was, "riding a seahorse!"

Life in my grandparents' household was difficult over the previous month. His health gradually declined, and she was sleeping poorly because, as his primary caregiver, she was providing round-the-clock care. Papa's last living sibling, Gloria, had dementia and was dying, and although he was not medically stable for long distance travel, he insisted on driving the five hours to Calgary to be with his little sister. There were seven children in his family, and his parents immigrated to Canada from Ireland in the early 1900s. Grandma recently told me that he did not want to be the last remaining sibling, and he and his sister shared a special bond. It made sense for him to see his sister, even if it meant a faster decline of his health. Through the support of his wife and daughter, Papa made it to Calgary to say good-bye to his sister, who, miraculously, recognized her brother and reached for his hand.

It seems like a bitter-sweet plot for a tear-jerking movie: While in Calgary, Papa started coughing blood and was transported to the Peter Lougheed Centre. He was admitted, but somehow my grandparents convinced the doctors to discharge him to his home-town hospital. On the way home, his blood work results returned positive for MRSA, and they were told to immediately drive to an ER. Upon arrival to the Vermilion Hospital, he was delirious with fluctuating consciousness. I visited him with my son and studied for a medical school exam beside his hospital bed to give Grandma a few hours respite. On the day we left, Papa was more alert and only ever said Louis's name when "Little Fuzzy" was present. Louis found a stethoscope and listened to Papa's leg, proudly saying, "I'm going to fix Papa."

That was the last time we saw and hugged Papa. The palliative care team assessed him the following Monday, and his comfort seemed to be their top priority. Grandma confided that it was a relief to be in a small-town hospital where they knew the staff, including a nurse who was one of their godchildren. It is impossible to avoid crying when I remember Papa, but it is important to reflect on what I learned from my grandparents' relationship and life experiences. I am emotionally exhausted from translating my memories into writing, but I will summarize my insights:

- Planning for the future is essential to live the way you want in your older years, but it is equally important to "live in the present," explore the world, and maintain social connections throughout all stages of life.

- Being a caregiver is hard. Even when the direct caregiving duties are ultimately over, the caregiver might feel mixed emotions, such as loneliness, relief, and loss.

- It is possible to maintain your dignity and do the things you enjoy in advanced stages of disease. However, it requires a committed, loving support-person to make that happen when the person's physi cal and cognitive abilities are declining.

- Everyone has a story, and older adults are no exception. Experiences, memories, goals, hopes and emotions contribute to the person imme diately in front of you.

His memorial is Saturday, September 3.

In Memory of my Papa, Frank Gannon

Author: Chelsea Barlow School: Cumming School of Medicine, University of Calgary

## Kept Hidden



My piece aims to capture the lived experiences of those with chronic pain, which affects approximately 1 in 5 Canadians. Through my research and interactions with chronic pain patients, I have come to recognize that the daily struggle of managing chronic pain can make even the simplest tasks challenging. This is particularly true in social situations, where individuals may feel pressured to conceal their symptoms to avoid being stigmatized or perceived as a burden. My painting depicts the emotional and physical toll of masking pain in social settings, particularly during happy occasions such as celebrations.

Through "Kept Hidden", I hope to foster greater empathy and understanding of the experiences of those living with chronic pain. I believe that by raising awareness and encouraging dialogue, we can create a more supportive and inclusive society that recognizes the challenges faced by those living with pain.

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### latrogenic Stigma of Mental Illness Among Medical Learners

Before medical school, I worked at a father focused parenting center that provides services for racialized families who are involved with Children's Aid Services (CAS). Although there are no formal gender, race or income requirements, the organization primarily serves low-income black parents and their children. My role involved supervising and documenting access visits and co-facilitating a parenting group for fathers with domestic violence concerns. Families were referred to the agency via a self-referral process or through CAS if their worker felt they could benefit from culturally informed services. The families served primarily high-risk families; reunification planning was rare. The family I worked with most frequently consists of a young mother in her early twenties, her biological 8-year-old daughter and 4-year-old son, and the son's father who is in his forties. The son and daughter had recently been placed in the same foster care home.

CAS' referral form noted the mother's personality and learning disorder as risk factors. There were ongoing concerns pertaining to domestic violence and the children witnessing sexual violence. Previously, CAS noted concerns about her impulsivity and inability to make decisions in line with her children's best interests.

The strengths perspective was useful in assessing the family. Despite the significant history of trauma in the mother's past, she was loving and attentive when she was with her children. The children were eager to see their parents when they arrived for visits. They looked forward to sharing news about their week with me. Though they missed their mother, they were accustomed to having a primary caregiver, and eventually warmed up to their foster mother.

I describe this case to illustrate an important point. Regardless of the circumstances, losing one's child is heartbreaking and life-altering. The clinical notes by health care and social work professionals were used to substantiate CAS' decision to remove parental rights in court. CAS' lawyers successfully argued that the children should be Crown Wards.

Even when these rigid inalterable decisions are in the best interests of the children, as health care professionals, we must ensure that we approach patients without bias and that we remain objective in both oral and written communication. Judges give great weight to physician expert evidence to make life-altering

decisions regarding custody in family law and sentencing in criminal law.

Though health care providers will encounter challenging patients in all settings, biases and stigma tend to most often challenge our communication with patients involved with the criminal justice and child welfare systems. When we work with high-risk patients and their families, particularly in paediatrics and psychiatry, it's easy to gravitate to the labels, weaknesses, mistakes and losses. I have come across this issue many times in medicine; one incident was unforgettable and especially detrimental to patient care.

It was a Friday evening in my first year of medical school. My friend, a 1st year resident in a non-psychiatry specialty, had invited me to a games' night event at her home. I arrived late to find 6 other residents playing a game I had never heard of before. I introduced myself and sat on the corner of the only couch in the living room. I had met 3 of the residents on a prior occasion.

Shortly after dinner arrived, the residents started talking about the ubiquitous effects of residency stress. I listened quietly, trying not to let my ignorance show. One of the residents, A, proceeded to complain about her last off-service rotation, which was psychiatry. She said that Cluster B patients are a waste of a doctor's time. Since they threaten suicide so much, why don't they just do it already? Another resident agreed with her.

When the evening ended, I cried, wishing I had spoken up for the patients I didn't know. I thought about that family I worked with years ago, specifically the connection the children had to their mom and their strengths in the face of unimaginable trauma.

My friend defended A, explaining that as a medical student, I didn't understand how difficult it was. Perhaps it was a combination of frustration, the alcohol, complacency and lack of protest that led to her comments. The reason didn't matter. I still think about this evening months later and wonder how we can reduce stigma amongst physicians.

As I approach clerkship and my psychiatry electives, I reflect on the importance of learner and physician education; being aware of one's biases; and burn-out support in residency. I've seen many moments of good in medicine and in my previous career working with vulnerable populations, but this wasn't one of them. This was a moment of weakness, a learning opportunity that calls for us to do better. Patients living with mental illness, any illness, deserve our advocacy and support even when they are not in the room. On one hand, their patients never heard these harmful comments but on the other hand, these comments reflect physicians' attitudes towards specific diagnoses which in turn, create barriers to building trust and empathizing with patients. Speaking about patients in this way to learners can have long-lasting tragic consequences such as passing down stigma-laden labels and normalizing inappropriate language and uncompassionate attitudes.

Many of us pay lip service to remaining unbiased but how can we secure lasting change in the fight against stigma and discrimination? More attention needs to be paid to the issue of iatrogenic stigma of mental illness among medical learners. Patient advocacy and communication are critical aspects of the medical profession - stigma precludes the development of both skills. As medical programs plan curriculum reform, they should incorporate stigma reduction earlier in training - at the medical student level.

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