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BLOOM BLOG

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'I feel very humbled, now that I'm a patient'

By Louise Kinross

Helen Donnelly is Holland Bloorview's beloved Dr. Flap—a therapeutic clown in a trademark aviator hat with goggles, a white medical coat and a red nose. Helen came to Holland Bloorview in 2007 to work with Ricky, the clown we knew as Jamie Burnett, who has since died.

This is how BLOOM described the duo in 2012: *They created a kind of magic that bounced like a ball between the clowns and the child and the child and the clowns. Sometimes the magic moved back and forth through the blinks of the eyes alone, sometimes through silly body movements and sounds. Sometimes it was a child conducting the taps of drum brushes on a wheelchair tray or commanding the clowns to perform outlandish antics. Sometimes it was an elaborate story the child told and the clowns acted out. Other times it was a dance to the strums of a red ukulele.*

In June of 2019, Helen was diagnosed with multiple myeloma, an incurable cancer of the plasma cells. She had two stem cell transplants with high dose chemotherapy in hopes of extending her life by a couple of years. But because of her genetic makeup, her body rejected the treatments and she didn't go into remission. She's now part of a clinical trial with an experimental treatment. We talked about her changing role from clinician to patient.

BLOOM: What was it like to receive a diagnosis when for years you've been on the giving side of care?

Helen Donnelly: At that time I was in so much pain and I was so anemic and fatigued that the first thing that occurred to me was 'Well, at least we have an answer.' Then in stages it occurred to me: 'Oh, this is cancer. Oh, this is cancer. Oh, it's an incurable cancer. Oh. Oh.' The news sort of set into me in stages, and then maybe a couple of months later I recognized the fact that I've now transitioned from clinical provider to patient and yeah, it's a very, very thoughtful time. Because for 15 years I was the one giving care and I was the one tending to the psychosocial wellbeing of all of my clients and suddenly here I was a patient now, with a disability, and the roles have totally reversed. It was a very humbling time, in the early days of my illness.

BLOOM: What are the qualities you most value in clinicians who have treated you?

Helen Donnelly: I'm really lucky to be overseen at Princess Margaret Hospital. There's something very special about that building. My partner Neil and I always say it has to be something in the way they hire. Every single person, without exception, has been incredibly empathetic, gentle, kind, and patient. There's not one time—even when I was in urgent care a couple of times—not one instant when I felt rushed or spoken down to. I don't know how they do it, because it's an extraordinary thing to consistently give that kind of care.

There was an extreme example where I was just coming out of giving blood, and I had another couple of hours to wait for my next appointment. My partner and I were sitting on a bench in the hallway, and I went to get up, and I couldn't get up. I had no strength, no energy to stand, which was really scary. I

was very dizzy and lightheaded and I sat back down again and my partner was looking around. There was a woman who was part of the cleaning staff who saw that I was in a certain amount of distress, and she called a code blue and the team was there in two minutes and I was in urgent care within three minutes. It's that kind of attention to detail, from everybody, no matter what position they hold, that makes you feel so cared for there.

BLOOM: What parts of cancer care have you found lacking?

Helen Donnelly: Because I'm a clinician, and because I know health care maybe a bit more than the average person, I wanted everything. I set myself up with a social worker, with psychiatry, for all kinds of things, and I'm glad I did, but the one thing I would say is lacking is around mental health.

There hasn't been a huge follow-up or curiosity about how I'm doing with my mental health, with how I'm doing psychosocially with my disease. I had a preliminary session with the psychiatrist in the early days. I met with her and she was lovely, but it was only an hour and she said 'Yeah, it's obvious you're very anxious but I wouldn't classify you as depressed, keep up with the self-care regime you're doing. I'm around if you need me.' But there hasn't been a follow-up, so I've had to do a lot of that heavy lifting on my own.

I'm doing what I can. I'm now reaching out in the community for a gestalt therapist. I had to start my own cancer care support group, because the ones that exist, unfortunately, didn't mesh with my sensibilities. I'm an atheist and I uphold modern medicine. In the ones I tried there was a lot of talk about prayer and alternative medicine, which I don't support. It made me very uncomfortable. I thought what I want doesn't exist, so why don't I build it? So now there's a weekly Monday night support group on Zoom that I started and we're in our fourth week and we have seven members. It's wonderful. We're really supportive of each other and we have a lot in common. The focus is where it should be, on emotional support, not about advice giving.

BLOOM: Yes, I think there's a bit of a similarity between advice people give when you have an illness and advice they give when you or your child has a disability. It's astounding what people will suggest.

Helen Donnelly: I've been very vocal about not wanting unsolicited advice, and that I'm in charge of my own care.

I've thought a lot about parents like you, and the other families at Holland Bloorview, and how much you've all had to endure over the years in terms of unsolicited advice. I find it so tricky myself.

The people who give me advice are friends of mine on Facebook. They're not all close friends, but some of them are. It's hard to find the wording—I have to be gracious but firm.

I have friends currently who are struggling with a cancer diagnosis, and I know the first instinct I have is 'How can I help?' I have to examine the wording of what I say, and the timing of it, and I've had to train myself to say 'I'm here, whenever you need me. If you just want to chat, or someone to yell at, I'm your person.' That's what I need.

I made a conscious decision from the very beginning to make my plight very public on Facebook. That was for me to process what was happening out loud. I thought if this ends up helping other people process their own diagnoses, then great.

I had a couple of friends who private messaged me and said you've helped debunk a lot of the mystery about cancer, so thank you. It's certainly helped me to be able to process out loud and to reach out to my friends. It's really helped my mental health. I read every single comment and I embrace every single emoticon. It's something that really lifts my spirits. I'm so glad that I chose to do that from the beginning.

BLOOM: It's interesting that you say the one thing missing in cancer care is patient mental health and emotional support. I have heard the same thing from friends who are patients in different parts of the country. It's a huge gap.

Helen Donnelly: I am baffled as to why mental health is not something that's constantly being attended to. My oncologist will say 'Call me anytime' and that's great. But I don't know why talking to me about my self-care supports, or asking if I feel I need a bit more help with my mental health, isn't a standard question. It's the same with my palliative care team. It's a new relationship, and they're lovely, but I don't remember us talking about mental health. They'll talk to me about my pain, and about the medications, and they might say 'Is there anything else you want to talk about?' It would be better if they were specific about mental health.

What has been the greatest challenge?

Helen Donnelly: Accepting that my life is now severely threatened. My prognosis is likely less than a year, and I'm 52, so coming to that realization that I'm now facing the end of my life at 52 is angering. I'm grieving the loss of my life and of my career. I would say I'm at the height of my career, and to be cut down now is a really big challenge. It's really hard to get my head around it.

I've had to make this massive adjustment from anticipating all the projects that I intended to do in the next two to five years, to just taking those off the plate. Instead, I'm now wrapping up my life. I'm now into legacy-making, and there's a huge amount of stress to do with that, as you can imagine.

There are a lot of things I need to do. A lot of mentoring has to happen, a lot of lesson plans need to be gifted to colleagues. It's endless and my chore list is very long, and when you're not given a specific date, it's really hard to plan your time. So every day I feel like I'm racing the clock.

I'm trying not to let that overshadow the joy of living. Neil and I made a decision that we wouldn't let stress take over the last months of my life. We wanted to find something to be grateful for every day, and something joyous to do. And that strategy has worked overall. But certainly I'm struggling with the reality of it all. It's unbelievable to me.

On the other hand, I've lived a very charmed life in terms of being incredibly healthy, and having a life of joy and laughter, literally. I've been so lucky.

I'm grateful for this clinical trial I'm part of that has so far kept my myeloma cells at bay. Only about 100 Canadians are on this new drug that I'm on, and I'm one of 14 at Princess Margaret that are on it. I feel very lucky and fortunate to have qualified for this amazing new drug.

I'm currently out of pain and my appetite is back. The only challenge is that it does damage your eyesight, but hopefully it will restore itself. That's a small price to pay for gaining some months and maybe even more than a couple of months. And to be out of pain is so wonderful.

BLOOM: What do you and Neil do to find joy in every day?

Helen Donnelly: The two of us are really connected to nature and we're most happy when we're outside getting fresh air and hiking or bird watching. We live in Dundas, Ontario, which is a small town outside Hamilton, and our immediate neighbourhood is filled with cats. We love cats, so we'll go for our catwalk and we'll see and pet about five cats. Wandering around, petting cats, bird watching and taking in some fresh air really helps both of us.

Every day I prioritize those things that will give me joy. These days it's art-making. I do one piece of art a day that I complete. They take about three hours and it's time for myself to get lost in something creative. They're abstract and colourful, so they cheer me up. The bonus is I'm doing them for friends and in turn they're contributing to **[Red Nose Remedy](#)**, my non-profit. They are commissioned works, so I think about my friend as I'm creating a piece for them.

I do that in the early part of the afternoon, and then by 4 or 5 Neil and I will go out for a walk or a hike. That's for our mental health, and for my physical health, to keep me walking. Then after that we'll have an early supper and that's when I dive into my to-do list. I try to work for three to four hours a night on what might be a priority for that day. I have to chip away at this mountain of jobs and try to manage my stress.

BLOOM: So you have the strength to do three or four hours of work?

Helen Donnelly: Yes, I have lots of energy. I'll take some breaks. People in our neighbourhood and our friends have been very kind. They've brought a lot of treats and homemade goodies. So I'll wander down and pick up a scone and then dive back into work. I feel good at the end of the day when I've ticked something off my list.

BLOOM: Has your illness, and receiving care, given you any new insights into how we can better support children and families?

Helen Donnelly: A lot, so many. I'm no longer a therapeutic clown, but back when I was working, it's impossible to put yourself in someone's shoes. You do what you can to try to look for signs of connection, for what we call success. Am I going at a good pace for this client? Are me and my partner too overwhelming, or are we just right? There are so many things to think about when you're working with a client in real-time.

The one big thing that occurred to me, especially when my 'chemo brain' was really present—meaning I was having trouble with word searching and I wasn't able to respond right away, and in general my rhythm was much slower—was that we need to slow down. It occurred to me that this is something I need to share with my clown colleagues.

I would be in a meeting with my hematologist, and I would have all of these things before me—a notebook that I'd write everything down in, and I'd have my questions and I'd write down the answers. But everything they were saying came to me at a rapid pace, and I would have to ask them to slow down or to repeat what they said. Before COVID-19, Neil was allowed to attend the meetings and that was really helpful because he was able to say 'Helen, did you hear what he just said? Did you get that down?'

That was a big, big lesson to be thinking about my former clients. I hope I wasn't going at a rapid pace to the point that they weren't enjoying themselves during our visits. To really slow everything down was a big, big lesson for me.

BLOOM: I guess clinicians always feel they don't have enough time, that someone else is going to be waiting.

Helen Donnelly: The irony of that is that if a clinician has to repeat themselves, then they're actually doubling their time. If you checked yourself, and went at a slower pace, you only have to say things once.

Something that I'm proud of that we did as clowns, after introducing ourselves to a new client, we would hover at the doorway and not say a thing and wait for them to bring anything up. It's something that any clinician could learn to do. It might make you feel awkward at first. It's a very foreign thing to be silent. But I encourage everyone to try it—to just stop everything and just be open and wait and see what happens spontaneously.

Because there were often times when I had things on my mind and because of the chemo and the stress, if they were doing a lot of talking, I couldn't hear my own thoughts, and I couldn't get organized.

If you give your clients just a couple of breaths, and allow them to centre themselves and search their thoughts, that's a very precious time where you can learn so much.

That was a really big eye-opener for me. I remember thinking to myself 'Oh man. I hope I was the kind of clinician when I was working that I didn't talk over clients, or make them feel rushed. I'm sure I erred all the time, but I just hope I had more successes than failures.

BLOOM: I think slowness allows for gentleness in a clinical visit. But I'm not sure if clinicians would understand the degree to which you may need to slow down.

Helen Donnelly: I'm rethinking some of the assumptions we made as clowns. For example, when we went to the brain injury rehab unit, we would slow everything down by about a third. We knew, when we turned left to go to BIRT, to look and breathe and slow everything down. I'm now rethinking the decision to only do that on BIRT. Because say I was on the SODR unit, where there were clients with cancer that would have 'chemo brain,' or clients who were non-verbal. There's a part of me that's thinking just slow everything down for everybody. And then go at the pace of the client, once you're sure that they're driving a rhythm.

BLOOM: As a culture, do we need to change how we think or talk about cancer? I'm thinking about a lot of myths about what causes cancer. I'm also thinking about people I've known, who have had end-stage cancer, and yet people still say to them: 'Keep fighting.'

Helen Donnelly: Yes, there are two things I want to say about that. There's a lot of misinformation about cancer that captures people's imagination, and makes them feel bold to express, or to mimic, the factoids which are false. One common one is that sugar causes cancer. That's a really big one. It's absolutely false.

What cancer sites say is that prior to getting a diagnosis of cancer, everyone should have a balanced diet. Obesity could lead to heart issues and cancer down the road. But it's the obesity piece, not the sugar piece, that causes the problem. I've been the target of friends who are trying to be helpful who are a bit horrified that I love chocolates, and who suggest that as a cancer patient undergoing treatment that maybe I'm not looking after myself as well as I could be, because I eat chocolate. That's really hard to take. There is a mountain of cancer misinformation and anti-science factoids. Those are really tough for someone like me who loves science.

I reject the fighting metaphor. I have an equal amount of friends with cancer who uphold that warrior, fighting metaphor, who find it helpful. And just as many who reject it. For me, I don't see it as a fair fight, as a fair opponent. There's nothing fair about it. When someone dies and I see on Facebook that they 'lost the battle' to cancer, I say they weren't losers. To call someone a loser because they weren't able to overcome cancer I find so insulting and so demoralizing. Hopefully the sentiment is that they led a very good life and in spite of the challenges at the end of it, let's celebrate what was so amazing about this person.

BLOOM: Yes, during the pandemic, there have been many obituaries that say so-and-so 'succumbed' to COVID, as if it was a choice. There is no choice!

Helen Donnelly: That magical thinking runs rampant in our society, there's no escaping it. Our society can't seem to say, with any comfort, 'She died of cancer.' They have to say 'She passed away.' It drives me bonkers.

BLOOM: As if it's not honourable to die. Over the years, I've come to think that much more in life is unpredictable and random than we would like to believe. I remember thinking that when Jamie Burnett got sick. There was no rhyme or reason why someone like Jamie should get sick. Just like there was no reason why my son should be born with a fluke genetic change. I've read some books about how, as humans, we cling to the idea that there is always a cause-and-effect story to explain each event, when in fact, there often isn't. I've found the idea of randomness to be freeing.

Helen Donnelly: Absolutely. Why would babies be born with cancer? Something I want to plug is a great book I'm reading now called [Do You Believe In Magic? Vitamins, Supplements and All Things Natural](#).

BLOOM: For families and co-workers who may want to support you, can you explain Red Nose Remedy?

Helen Donnelly: This is a therapeutic clowning service that serves all of Ontario and beyond, now that Zoom is working for us. We're a non-profit therapeutic clowning company, and all eight clowns are graduates of my school at George Brown College. Go to [Red Nose Remedy](#) and you can read all about us and how you can get involved.

BLOOM: Is there anything else that we haven't discussed that you'd like to talk about?

Helen Donnelly: Mostly I feel very humbled, now that I'm a patient. When I reflect on my career serving in health care for 15 years, being a patient really does give me pause. I feel like I have a greater connection with those memories now that I'm going through my own life-threatening moment or reality. It is humbling and it's a learning experience. It's the one part of my illness that I don't regret. I feel like I'm still learning, which makes you feel very alive. I miss everyone so much at Holland Bloorview. Just tell everyone that you bump into that you talked to Helen today.

You can read more about Helen in this [2017 interview](#) she did with BLOOM.





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