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To cite this article: Laboni Das & Sathyaraj Venkatesan (2023): Of comics and dementia: an interview with Nigel Baines, Rebecca Roher, and Liza Futerman, Journal of Graphic Novels and Comics, DOI: [10.1080/21504857.2023.2190145](https://doi.org/10.1080/21504857.2023.2190145)

To link to this article: <https://doi.org/10.1080/21504857.2023.2190145>



Published online: 12 Mar 2023.



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Of comics and dementia: an interview with Nigel Baines, Rebecca Roher, and Liza Futerman

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ABSTRACT

Dementia is often represented as both a terrifying illness and a social threat. Graphic medicine is a burgeoning comics genre dealing with the experience of dementia through physical, and emotional issues. Through the medium of comics, graphic memoirs tease out how dementia operates formally and thematically. In this email interview, three graphic memoirists, Nigel Baines (author of *Afloat*), Rebecca Roher (author of *Bird in a Cage*) and Liza Futerman (author of *Keeper of the Clouds*), reflect on their nuanced understanding of dementia, their experience as caregivers, the challenges of dementia caregiving, and the potential of graphic medicine to convey such issues. The interview is divided into two sections: in Part I, titled *Of Comics and Dementia*, the authors respond to common questions related to dementia, personhood, dementia care, and graphic memoirs, among others, and in Part II, titled *Tragedy not deep and sharp if it can be shared with friends: The Power of Storytelling*, each of the authors responds to questions related to their respective dementia comics

ARTICLE HISTORY

Received 7 September 2022
Accepted 8 March 2023

KEYWORDS

Personhood; self; dementia;
graphic medicine; comics

1. Nigel Baines

Nigel Baines is an illustrator, writer and designer based in Hertfordshire in Southern England. In 2019 he completed a two-year Masters with a Distinction in Authorial Illustration at Falmouth University. Some of his works have earned him awards, such as *Spud Goes Green* which won 2005 Blue Peter Best Book of Facts, *Yuck's Rotten Joke* was chosen as a 2009 World Book Day book, *Do Igloos Have Loos?* has won 2010 Blue Peter Best Book of Facts. In 2019, he spoke at the Worcester Illustration Symposium on the role of Graphic Medicine. He is currently working on a book *A Tricky Kind of Magic* set to be published with Hachette in January 2023.

2. Rebecca Roher

Rebecca Roher is a cartoonist and educator in Toronto. Her first graphic novel, *Bird in a Cage*, was published with Conundrum Press in 2017 and won the Doug Wright Award for the best book at Toronto Comics Arts Festival. Her comic, *Mom Body*, went viral in

2015 and was nominated for an Ignatz Award for the best webcomic at the Small Press Expo. Roher is a contributor to *The Nib*, *Taddle Creek Magazine*, *CBC Arts* and *Bitch Media* among other publications. She has received numerous grants from the Canada Council for the Arts, Ontario Arts Council, Nova Scotia Community Culture and Heritage and the Toronto Arts Council. Roher is currently working on a graphic novel based on interviews with near-hundred year-olds about ageing and longevity, set to be published with Drawn and Quarterly in 2023.

3. Liza Futerman

Liza Futerman (MA, MSt) is a mixed-abilities contact improvisation instructor, a bodywork practitioner and a facilitator of community online grief and celebration of life circles. Liza is a social entrepreneur who works at the intersection between education, healthcare and arts. Her most recent children's book for adults (in Hebrew), *Don't Forget Your Heart* (Illustrated by Lena Simonovich of Simsisters studios), speaks about the fragile state of being heartbroken and the delicate routine one can cultivate to live through loss, grief and bereavement. Liza's first graphic medicine short memoir, *Keeper of the Clouds* (illustrated by Evi Tampold), was published with Tampold Publishing in Canada in 2016. She is currently working on a sequel graphic medicine memoir titled *Alzheimer's vs Cancer: A Love Story*, a visual narrative about a mixed-abilities dance instructor living with PTSD.

3.1. Part 1: of comics and dementia

1. While writing your book, why did you choose comics over the traditional form of book writing? What aspects of comics did you find most apposite to communicate your experiences? How long did you take to complete your memoir?

Nigel Baines (NB): I was doing Masters in Authorial Illustration, where my visual research took me to the graphic narrative. The fit with my passion for word/image combinations was ideal. *Afloat* was my final project, and it made sense for it to be my first foray into graphic literature. I started planning in late January 2019, and the book went to print in July 2019. It was quite an intense process.

Rebecca Roher (RR): I have always been interested in the power of visual storytelling and the ways that images and symbols can contain and communicate meaning. Particularly with this book [*Bird in a Cage*], I was trying to distil my own memories and the stories I heard about my grandmother, which are clear in my mind as visual images. I wanted to record those images in my own hand as I imagine them in my mind's eye to allow the reader into my experience, using a light pencil line to capture a sense of hazy memory. This story was compelling to me in the ways that it was both tragic and funny, and comics were the perfect way to balance those opposing forces, to evoke empathy from readers, and to face this difficult subject matter with levity.

It took me about three years to complete the book. I had completed the first 20 pages as a stand-alone comic in 2014 when I was a Masters student at the Center for Cartoon Studies in Vermont in the US. My grandmother, who suffered from early onset dementia resulting from a brain injury, started to go into decline that February. I went home to be with her and my family as she was dying. At the time, I was already thinking about turning the comic into a longer graphic novel, so I journaled throughout the experience and did research about her life. After I graduated, Conundrum Press offered to publish the book and I started working on the longer graphic novel. It was published in 2017 and won the Doug Wright Award at the Toronto Comics Arts Festival that year.

Liza Futerman (LF): Initially I wrote *Keeper of the Clouds* as a testimony of ‘a day in a life’ sort of thing. It took me 4 or 5 hours of organic writing and editing. I didn’t plan to write it when I did. It was a couple of days before my mother’s 60th birthday and I wasn’t thinking about the date that much. Only when I finalised the first draft and signed it with a date did I realise it was my way to express and communicate the mix of grief, gratitude and joy I was feeling as my mother’s birthday was approaching.

As you note later in your questions, *Keeper* didn’t start as a comic. In fact, shortly before *Keeper of the Clouds* appeared in its graphic medicine book form by Tampold Publishing it was first published as a peer reviewed article in the Humanities section of Canadian Medical Association Journal (CMAJ). The article was accompanied by a single photograph I took of 2 pigeons sitting on a wire. My mother’s poetic landscape as described in *Keeper* has travelled with me for quite some time and took various forms in my artistic endeavours.

In 2016, at the time the article appeared in CMAJ, Evi Tampold (the illustrator) and I were already deeply engaged in the collaborative process of creating the comics version of *Keeper*. Evi and I met at a Graphic Medicine panel at the University of Toronto while I was still a PhD student there. It was November or December of 2015, so shortly after I wrote the first draft of *Keeper*. While waiting in line to speak to the panellists, Evi and her mother, Carol Nash, introduced me to a graphic medicine memoir Evi wrote when she was 16. *The Hallway Closet* illustrates Evi’s experiences with ADHD when she was a child and tells about how her mother’s attention and creativity helps her cope. Once I saw Evi’s illustrations I knew I wanted to work with her and transform *Keeper* into a graphic medicine memoir.

I’m a big fan of picture books and of comics in general and specifically of graphic medicine novels. I also remember feeling strongly about reaching as many people as possible with the story, simply because it offers a glimpse for how to communicate and rebuild relationships between individuals living with dementia and their loved ones. I find that knowledge translation mediums such as comics can engage individuals of diverse age groups. In many ways, I was waiting for an opportunity to create my own graphic memoir to reach out to younger generations who might not care much about dementia and other age-related conditions. When the opportunity showed itself I invited both Evi and Carol for a home cooked meal to discuss the possibility of working together. Evi was 17 when we met and *Keeper* became her final project for the democratic high school she attended at the time. We were working organically and intuitively over

a period of 9 months. After 9 months *Keeper of the Clouds* was published in its comics form.

2. Do you think visual narration enables discussion of the embodied experiences of a caregiver more effectively than verbal/prose narratives? If yes, is it because of your involvement with the medium as a cartoonist/illustrator/artist?

NB: The magic of graphic narrative is the ability to ‘show’ rather than ‘tell’. Human experiences are complex in that they belong wholly to us. They are trapped within us. Words like ‘belief’ or ‘joy’ or ‘pain’ mean as many different things as there are people to speak them. In that sense sometimes it is better to show a visual representation of an experience and let the reader interpret it through their own experience.

RR: Images have a direct and effective ability to contain and communicate emotion in a way that can transcend language. Drawn facial expressions, which can capture the entire breadth of human emotion with the subtle angle of an eyebrow or lip, can evoke empathy in the reader and promote a deeper understanding of another’s experience. Capturing the struggles of caregivers in visual narration can help put the reader in an empathetic state, so they understand the difficulty of caregiving. It’s heavy to face and think about these struggles, but friendly drawings can help invite the reader in to face difficult subject matter they might otherwise want to avoid engaging with.

LF: I believe that the combination between images and words has a very powerful effect, mostly because we might notice the dissonance between the words and the illustrations thus forming a visceral emotional and sensory response to that which is being narrated. The sensory response, of course, is not always pleasant or comfortable, but it is human, and it has a lingering effect that allows us to empathise with the characters and feel connected to a human experience that is larger than one’s personal tragedy.

3. What technical devices do you deploy while working with your narratives/illustrations? Tell us about any artists/writers who inspired or influenced your style of drawing/writing?

NB: There are many influences. Tom Gauld, the economy of line and using the contrast between big and small. Benoit Jacques for angry and vibrant line work, but they are just two of many influences. As I had a tight deadline, I needed to work quickly. I do much of my illustration in Photoshop with a large Wacom drawing screen, which is ideal.

RR: The ways characters are facing and looking at tells a lot about their intentions, interests and relationships. I use text, eye direction, movement and dark areas to help lead the eye in the direction it is meant to go. I used to do everything in traditional media – pencil on paper, watercolours and gouache – but now I do most things digitally on Procreate. My knowledge of traditional media has definitely informed the way

I approach digital work. I draw inspiration from my heroes, such as Eleanor Davis, Lynda Barry, Roz Chast, Quentin Blake, Jules Fieffer, Sempé, among so many others. I love a loose and lively style that feels sketched in a moment, and the effectiveness of simple lines.

LF: My most efficient technical device is writing or reading. Both actions tend to inspire me and help me understand myself better. If writing doesn't come easy I turn to stream of consciousness or to somatic writing techniques to inspire the process. The difference between these two devices is in the source of inspiration: While stream of consciousness focuses on the way thoughts travel through words, somatic writing practices highlight the ways in which the body's sensorial experience can be verbalised and integrated through writing. I'd say that each of these strategies can serve a different purpose. For example, if the source of the 'writing block' seems to be a result of overthinking I'd suggest trying somatic writing. It might sound counter intuitive. The reason why I suggest going to the somatic practice rather than the stream of consciousness in this case is to bypass the narratives that the conscious and unconscious minds forms thus creating the writing blockage. On the contrary, when I'm in emotional turmoil or experiencing physical pain or fatigue I'd rather resort to stream of consciousness – thus offering my sensory experience some rest and delving into a practice that allows me to reach deeper than the standard narrative lines that I keep in my mind. Sometimes I'd alternate between the two and improvise with whatever comes.

At the time *Keeper* was written I remember reading and re-reading Sarah Leavitt's *Tangles: A Story about Alzheimer's, My Mother and Me*. I was deeply engaged with the plot and the storytelling as it described so vividly my personal experiences with my mother and her Alzheimer's. I don't remember myself thinking 'ooh I should tell my story too' rather, it was more like: 'ooh I want to reread this story and dive deeper into it'. I think that the comics genre is fantastic for telling many different stories and sharing multiple sporadic memories that in prose oftentimes can be misunderstood without the proper storyline. In comics these can come alive given the meticulously drawn frames.

4. In the present age, society privileges responsible, independent and able-bodied individuals and believes that 'loss of memory' is 'loss of self'. How do you respond to this social perception/cultural logic?

NB: This is a very interesting question. The West assigns great importance to the unique self at the expense of the communal self. We have somehow got to a point where we measure everything, including human usefulness. That is a grave error. The other interesting point is whether there is indeed a unique self or whether we are simply complex story-making machines. Even so, the loss of the ability to recall the story should not have an impact on who we are, but sadly, it does; society discards those who do not fit the mould.

RR: It's a shame that we essentially dispose of the elderly so readily because they are no longer able-bodied and need more support. This is a symptom of society's capitalist-

leaning values, which prioritise individualism, youth and profits over people. People who are not able-bodied can still contribute to society, and we should be more active in finding ways for them to do that. Memory loss cannot take away who a person is or what they have done. Their past has already affected the outcomes of the present and nothing can ever take that away. A person, even without their memory, still is a 'self' who experiences each day moment to moment.

LF: This question has been a major one in the PhD project that I've discontinued after writing *Keeper of the Clouds*. If you were to ask me the same question in 2016 I'd probably have a very clear thesis to offer. I've even written a spoken word poem in Hebrew about it, translated it and performed it at a TEDx talk entitled 'The Art of Living ... with Dementia'. But since then, a lot has changed in my life and so I'd like to reflect on this question from a new stand point while sharing with you some of the shifts that led to my current take on this issue. 10 months after *Keeper* was published my mother's condition has drastically deteriorated and from a state of 'not remembering' she went into a coma, following which I've started having anxiety attacks and later on a full blown arsenal of symptoms that were diagnosed as Complex Post Traumatic Stress Disorder (cPTSD). This was what led to me quitting my PhD and return to Israel, to be closer to my parents and to take care of myself and this whole new self that I was not familiar with. From a responsible, independent and able-bodied individual who cares for her mother and advocates for individuals living with dementia as valuable members of society that ask society to reassess its take on value, responsibility, independence and ableism, I could no longer recognise myself. On the surface, I was abled-bodied, young and capable. But the anxiety attacks and the depression episodes made my thoughts foggy and my memory a blur. I could no longer read or write, nor could I have an intellectual conversation, I was burned out and constantly overwhelmed and I couldn't keep my affairs in order. Ironically, as I was fighting the stigma against people living with dementia, the stigma on mental health issues was very pertinent in my mind, which prevented me from seeking help for a long time. It was only in 2019, 2 years after returning to Israel that I agreed to seek help and visit a psychiatrist who diagnosed me with cPTSD. It was a huge relief to have this title. Yet, I couldn't accept my new self for a long time. Even today, 6 years after the symptoms have appeared, I tend to fall into a state of forgetfulness. Forgetting not only who I am but also what I've been through. In these moments I tend to privilege my former self and other individuals who appear to be responsible, independent and able-bodied, blaming and shaming myself for not keeping up. Much like the saying 'when the student is ready the teacher will appear' - When I realised I could seek help to cope with the internalised stigma that intensified the symptoms of cPTSD, I became aware of a therapeutic practice called Somatic Experiencing (SE). SE focuses on the sensations that appear in the body and force us into fight, flight, freeze response - the very response that makes us feel entirely helpless and more importantly, choice-less. SE was developed by Peter A. Levine to treat trauma with the help of focused attention to our bodies. What I found most curious and boggling as I was getting treatment in and learning about SE was that while the popular discourse around dementia speaks about individuals living with dementia as 'empty shells' due to the said loss of memory, Levine refers to individuals who have lost their connection to their

body as ‘empty shells.’ I find this label problematic, no matter which condition or collection of symptoms we attach it to. I think that the categorisation and alienation of individuals because they are struggling with big changes in their lives is an unnecessary burden that we, as a society, should take extra care to avoid.

5. Your work on dementia is often associated with the emerging field of graphic medicine. How aware were you of this field while making the narrative? Would you comment on the community’s influence on your work?

NB: Before starting my Masters I had no awareness at all. As soon as I started researching and reading, I came across it on so many occasions. It became a significant focal point for all my research and work. Seeing what was being done, for example, at Penn State University in the US, filled me with hope for the future.

RR: I was aware of Graphic Medicine while working on this book and was encouraged by the existence of a community interested in the power of visual storytelling to help distill and disseminate important healthcare information. While I was making the book, I was hoping that it would encourage empathy for the elderly in general and help prepare families for end-of-life care. I didn’t realise it might also help doctors become more empathetic towards elderly patients and encourage more humane treatment until a medical school in Colorado had me as a guest lecturer to talk about my book.

Since making the book, I have worked with doctors and medical organisations to create comics stories and visual aids to use in teaching their patients about what’s going on with their bodies and what their options are for treatment, mostly surrounding reproductive health. It gives me great pride to think that my artwork is being used to empower people with information that could be used to make their life better or easier.

LF: Well, simply put, unless the life changing panel, at the University of Toronto, where Evi and I met, *Keeper of the Clouds* would have not existed in its current form. I’d say this is quite something.

6. How important, do you think, are memoirs in reclaiming the identity of the dementia-afflicted individual against the stereotypes prevalent in popular media?

NB: Very important. In the UK, there is now a much more open discussion about dementia; books about the experiences of younger sufferers are being published. This is vital as it moves the narrative into a wider arena beyond simply age related.

RR: Memoirs have a powerful ability to memories accessible to those who can no longer remember. This can provide a sense of self by reminding them of where they came from, what they have been through, and ultimately, who they are. Memoirs can provide a deep sense of comfort by reminding them about their identity, to help them find grounding in themselves and their present experience.

Documenting the life history of a person with dementia can also help inform their caregivers of their life stories, filling out the picture of who they are, and reminding caregivers of the humanity of those with dementia. This can encourage improvements in the care and treatment of those with dementia.

LF: I think that it's crucial to have the personal stories to counter the stereotypes and stigma. I speak about it elaborately when I tell about John Wood's Time Travel Cards.

7. What are the challenges of being a dementia caregiver? What suggestions do you have for people caring for a loved one with dementia?

NB: You only have to look at the faces of those caring for someone with dementia. The pain writes itself all over their faces. You are thrown into the situation of child-minding someone who is child-minded, managing their fears and anxiety, and dealing with all the perils of finance, systems, and bureaucracy. My best advice is that you have to add another patient to that list. Yourself. You must allow yourself some space and time to earn some distance. You need a support network, and you need to know that you will never feel you have done enough, but in all likelihood, you did everything you could.

RR: I think the major challenge for being a dementia caregiver is frustration at being asked the same questions over and over again. It can also feel very lonely as oftentimes the burden of support falls on one person alone. My other grandmother suffers from Alzheimer's and I asked her caregiver what advice she would have for people caring for loved ones with dementia. Her main advice is patience. You need to have it if you are going to be able to cope. I used to try to have conversations with my other grandmother, but since her short term memory is gone, she would always ask the same questions and it never went anywhere. Now, we do activities. She loves colour and arranging objects. We play with children's toys, like lego, that engage us in the moment. It's a great way to spend quality time together. My grandmother's caregiver also thinks of activities to do every day to try to keep my grandmother's mind sharp, like quizzing her on numbers, colours and spelling.

LF: This is such a tough question and every time I try to answer it I think myself inadequate giving any advice on this subject matter despite my lived experience.

There are endless challenges in being a dementia caregiver. I speak about some of them in my other responses. But I think that the challenges that emerge are very much context dependent. That is, different people experience different challenges. As a poet, a linguist and literary critic, and just as a person who is uber attentive to words and phrasings, I get frustrated with the popular discourse around dementia in Israeli, Russian and English speaking cultures. So everything to do with policy papers around dementia was a huge challenge for me as a family caregiver. I'd constantly get offended on my mother's behalf. It was infuriating. Since my mother passed away and I took some distance from the direct engagement with the field of discourse analysis and dementia

in particular, and also since I've matured I'm being more patient (or at least trying to be) and more tolerant towards words that are being misplaced. I feel that the popular discourse about dementia and Alzheimer's makes it appear as if there is a set amount of challenges, but it's truly complex, and oftentimes the challenges emerge not from the illness itself but from the bureaucracy around the illness. For example, with my mother's case, she was only 58 at the time of her diagnosis so it was actually a struggle to get her the care she needed because of her age. Every family has their own struggles, some are similar, others are unique.

Given that there is no one size fits all formula in this conundrum, the best suggestion I have for the sake of the interview is to take it day by day, moment by moment. Slowing down is good. I'd also recommend finding out what you love to and make time and space for it, if you need a companion that will help you commit to it, find a companion, if the companion can't commit, find another one. In other words, find your people. It's a journey like no other and it's full of surprises. Oh, and another thing, don't try to fix anything, maybe it's not broken, maybe it's just the way it supposed to be. You'll have to develop your sense of trust, it's not an easy task but it's doable. Finally, breath. (this last one is the hardest to implement).

8. Drawing/writing about illness experiences is perceived by many as a cathartic process. Was there anything cathartic about telling your story? If so, why? If not, why not?

NB: Another interesting question. Most people assume it was cathartic for me, but on the surface, it was not. When I started, it was a year since Mum had died. In one way, I had dealt with all the emotions. Also, I sort of had to distance myself from everything as I did it. I wanted it to work as a narrative, I didn't want it to be a personal confession that would not help other people. I'm used to working to deadlines and have worked in publishing for years, so it just became a project with a deadline and narrative threads that needed work on. As time passed, I realised there was a cathartic element to it, though. Perhaps it is no more than feeling as though there was sense to it all, a narrative, even if one I imposed on it.

RR: It was definitely cathartic to document my grandmother's story. It helped me come to terms with the tragedies of her life. I also found comfort knowing that the memories of her life and our family history would not be forgotten after she was gone.

LF: Every time I agree to share my story feels cathartic. This interview included. This is why it took me so long to write-up the answers to these questions. I think that the cathartic part about writing, for me, is in sharing the story with my friends, family and larger communities. In some ways then writing is a means to an end. On the other hand, writing itself is therapeutic for me. It gives me pleasure to write. It's fun. Fun in the most profound sense of lived experience. I do believe that having fun and enjoying our time on earth is a necessity for a meaningful life. And writing is a meaningful activity for me. However, when it lacks a community of readers – by the way sometimes having one

reader who can offer a thoughtful reflection can feel like a sustainable community – the writing might be experienced as meaningless and the cathartic experience might be forgotten. Other times, I find it meaningful to write for my eyes only and it can be cathartic and therapeutic. I guess that what I'm trying to say is that there's no straightforward answer to this question. It really depends on many variables including my state of mind, my needs at a given moment and my relationships with myself and others as well as my relationship with the writing I produce.

9. What are your upcoming graphic narrative projects? What issues and themes would you like to address in your future work? Do you plan to write/draw more on dementia and dementia care? If so, why?

NB: I signed a two-book deal with Hachette, the large children's publisher, two years ago. My first book, *A Tricky Kind of Magic*, is coming out in January 2023. It is about a boy who cannot deal with his father's loss and believes he can still find him. So there is a link there – stories about our humanity – and they are all things I want to explore more. Fear, joy, loss, being human. The second book is in synopsis mode at the moment and features a girl who has a grandfather with dementia, so I am interested to see where that story goes.

RR: I am working on another book about the elderly, although not specifically about dementia. The graphic novel is a compilation of short comics based on interviews with near-hundred-year-olds from around the world called, *One Hundred Year-old Wisdom*. It profiles their lives, advice and secrets to long life. Since it's based on first-hand interviews, most of the interview subjects I spoke to had their memories relatively intact, but I hope it also promotes empathy for the elderly and helps people learn how to age well. The book will be published with Drawn and Quarterly and is set to come out in 2024. There is a young adult graphic novel I would like to work on which is an adaptation of a friends' memoir about the death of her brother, and the canoe trip we went on to discover the truth about how he died. I would still be tackling themes of death, grieving and catharsis.

LF: In January of 2022 I collaborated with a Toronto-based artist and together we've created a short illustrated narrative about a miscarriage told from a first-person narrative voice.

In the future I'm interested in sharing a graphic medicine story about a dance instructor living with cPTSD and dancing in a mixed-abilities dance ensemble. I'd like to make it into a novel length journal with illustrations and photographs. I'd like to discuss topics such as shame, regret, the value of arts for healing, memory and forgetfulness, identity and body politics, gender, sexuality, parenthood, friendship and romantic relationships. Dementia would probably figure into the story in one way or another but it won't be the focus of this story. I've written up the first chapter of this narrative back in October 2020, when my mom was still alive and when my dad was getting treatment for

his liver cancer. It's current working title is: 'Cancer versus Alzheimer's: a love story'. I'm currently looking for a publishing house and an illustrator to collaborate with so if you hear of one feel free to connect/introduce us.

Part II: "Tragedy not deep and sharp if it can be shared with friends": The Power of storytelling

NIGEL BAINES

1. How might *Afloat* influence the medical, artistic and caregiving communities?

The most moving moments are when people have said it made them feel less alone, that someone else understood what they were experiencing. That is the power of graphic memoirs. You step into the pictures in a way you do not always do with words. We are behind in the UK, but the use of graphic narratives in books and advertising is growing, and the health sector is one where it would be hugely valuable.

2. In your memoir, *Afloat*, you have described an episode where your teacher took you to a 100-mile trek on a record-breaking hot summer day (Baines 2019, 96–7). With a small bottle of pop, you can only think of hydrating yourself by drinking water from the filthy slime-covered canal, which we believe is an interesting comparison with your difficulty in discovering a care system for your mother. Do you agree? If yes, then was this comparison consciously intended while writing the book?

That is such an interesting and astute observation. It was not a conscious decision at all. It just felt like a light-hearted moment to break the narrative. But perhaps I was unconsciously aware of something, which is why the memory stuck with me. The canal at that time was uncared for, full of slime, and became a place to discard things you did not need. So yes, that makes total sense. It makes me want to explore that more.

3. Your family story became the basis of the graphic novel *Afloat*. Compared to your other works/illustrations, *Afloat* is also different in terms of its theme and style. What difference has *Afloat* achieved in terms of its publication and reception?

I have been very moved by some of the comments I have received. It has been featured in a couple of journals, I have done some talks and interviews, and last month it was published as *Mom Don't Sink* by Guyoydang Publishers in South Korea. I want to revisit it and see if I can make it a bit more universal. The storytelling is very Anglo-centric, and I might like to balance that out.

4. MK Czerwiec, popularly known as 'comic nurse', in the *Graphic Medicine Manifesto*, claims that creating comics on illness doesn't require professional training. Do you think professional training is a prerequisite for artists?

No, not really. Truth and honesty are more important. In fact, sometimes, a naïve drawing style can really highlight the sense of personal experience. Allie Brosh is a perfect example of this. So MK is correct, it is a very democratic form, and that is where I can see it being useful in patient/medical practitioner dialogues where experiences can be shared and understood without getting lost in the language. Having said that, though, I think a grounding in storytelling techniques and the techniques of the form are useful. Scott McCloud's book is ideal for the latter, and there are many books on narrative. Having drawing or visual training helps in giving you extra tools to play with. You know how and when to pan the camera out, to go close up to use space and silence. And yet there are

many films, such as *Blair Witch* being the first, that were shot as handheld, had very little cinematography, yet still told an excellent story.

REBECCA ROHER

1. *Bird in a Cage* does not entertain the traditional concept of 'gutter'. Interestingly, the panels are borderless, or are 'uncaged' throughout the narrative. Could you please comment on the artistic intention behind using 'borderless panels' and what it adds to the narrative?

The borderless panels are both an aesthetic and thematic choice. I've never felt at home with the rigidity of panel borders and prefer a page to flow loosely between images. With a story like this, I am trying to capture a sense of memory and memory loss, so the edgeless panels feel appropriate.

2. Compared to your other works/illustrations, *Bird in a Cage* is different in terms of its theme and style. While several of your works are bright using watercolour, the memoir is monochromatic and a pencil drawing. Why so?

I drew the book in pencil because of its ephemeral quality. The fact that pencil can be smudged and erased felt aesthetically appropriate in dealing with the theme of memory loss. Monochrome also felt right with the theme of faded memory. I have done many short comics in watercolour, but a longer book would have taken me exponentially longer. As it was my first full-length graphic novel, which is already a huge undertaking, I wanted to keep it achievable by keeping the artwork more simple.

3. The cover page portrays a sharp, strong-willed and independent woman, Grandma Wylie, as 'caged'. Again, on page 9, we see the grandmother trapped in the bottle (see Figure 1). Why did you choose to name the work, as *Bird in a Cage*? And how such illustrations are in sync with the narrative?

I chose the title, *Bird in a Cage*, because of the connection of birds and song. As we learn in the story, Grandma Wylie loved singing, and the family tradition of the 'Sing Song' was a constant throughout her life. There is a powerful moment in the story where



Figure 1. Roher, R. (2016). *Bird in a Cage*. p 9.

songs from her childhood help reconnect her to a sense of self. Trapped in her own body by her dementia and stuck in a home, she was unable to be her true, lively, active and capable self. The image, to me, is the perfect metaphor for her story.

4. You are also an educator. What role do comics play in your career as an educator? Do you teach comics?

I do teach comics! I have taught in libraries, artist residencies, elementary schools and universities. I developed a comics course for third-year undergraduates at Nova Scotia College of Art and Design in Halifax, Nova Scotia, Canada, and taught it for the first time last fall. Creating comics helps develop an incredible combination of skills – research, writing, storytelling, composition, drawing, graphic design and digital media, just to name a few – and can be used as a lens to apply knowledge in almost any subject. Teaching is a wonderful balance with my studio practice, which can often feel lonely. I get so much energy and from working with people who are passionate about comics and visual storytelling.

LIZA FUTERMAN

1. In *Keeper of the Clouds*, you propose how we can use improvisation strategies to communicate and connect with people living with dementia and altered states of consciousness meaningfully. How did your mother's dementia illuminate altered ways of your thinking?

My mother's dementia clarified to me that if I want to keep having a meaningful relationship with my mother I must learn new ways of relating to her and to myself. It's easier said done, and it's easier to practice when it's not our parents, when it is, however, it touches us in all the places that our wounded inner children have not yet accepted the proper healing. In many ways I am the artist I am today due to my mother's dementia. Before her diagnosis in 2014, while I could still actively deny that there was something that requested our attention, I kept on researching art. I studied linguistics and used it to offer literary and cultural criticism, I then studied visual culture and history of art and used my knowledge of literary and cultural criticism to explore performance, comics and photography. However, once my mom's diagnosis was sat in April of 2014 I felt I could no longer ignore what was happening with my mother, with our family and with me, as an extension of this family. At that stage it was clear to me that for me to meaningfully relate to my mother I'd have to embody the art that I was researching. The first action that I took once the diagnosis was sat was to enrol into improvisation sessions and into a writing workshop with the Israeli author Eshkol Nevo and the Israeli poet Orit Gidali – who published a children's book about Alzheimer's in 2018. The book is called *People Touched the Moon*.

At the improvisation sessions I learned how to respond intuitively and playfully to situations that could otherwise baffle me and inhibit my actions. At the writing workshop I'd write about my grandmother's funeral, about my crumbling marriage and about my fantasy of having a healthy mother. The writing sessions were more like a therapy for me, while the Improv lessons were like a training that prepared me to be a caregiver who can work with the bewildering situations as raw materials for creative and revealing moments that would bring me closer to my mother and to our family. During my PhD I worked with Dr. Pia Kontos whose PhD dissertation was on elder clowning – a form of therapeutic clowning practice that was developed in order to work with individuals living with dementia. Later, when I came back to Israel in 2017 I turned to dance and

fortunately discovered mixed-abilities contact improvisation. At some point I came to realise that elder clowning and mixed – abilities contact improvisation dance have a lot in common and bringing these two practices together could benefit the individuals living with dementia and their care circles (family and professional). I ended up running a 3-months-long pilot of a practice I called ‘contact clown’ at the nursing home my mother was hospitalised in. I quit after 3 months because of an incessant struggle with depression but I never stopped believing in the value of this practice for the quality of care of dementia patients and their care circles. Today, having established a sustainable community of contact clown practitioners, I’m happy to offer a contact- clown course as a training in long term care facilities. The target audience for this course are care professionals who wish to enrich their tool kit and care practices as well as family members and individuals living with dementia and other life-altering conditions who are interested in enriching their relationships through dance, play and humour. I don’t know if I would be working in this field was it not for my mother’s Alzheimer’s. Probably not, but then again . . . who knows.

2. *Keeper of the Clouds* has several instances where the characters’ facial expressions and bodily gestures are intensely presented. Similarly, there are instances where the zine zooms into the characters’ faces and eyes (see Figures 2). What are their stylistic implications?

My Masters of Studies in History of Art & Visual Culture at Oxford explored *MAUS* by Art Spiegelman. While I was researching the function of still photographs and performative elements of the graphic novel genre, I came across the idea that comics is often perceived as closest form to film. One way to look at it is soap operas where you have the camera zooming in on the face of a character to intensify their emotion and in some ways to manipulate the audience’s gaze and emotional landscape, as if to say, hey I know you can be looking on all kinds of things right now and feeling a myriad of emotions, but you should look at this very thing right now because we want you to empathise with this character and what they are going through right now. The Figures you chose were carefully crafted and discussed elaborately with Evi Tampold. [Figure 2](#) was to symbolise time – an abstract concept that is usually represented by time measuring devices such as sand dials, clocks and watches. Time is one of those things that is hard to



Figure 2. Futerman, L. (2016). *Keeper of the Clouds*. p 5.

grasp when we are kids. When I was a 5-year-old, I was waiting for my mom to come sit with me before I fall asleep and she would tell me she's going to come in 5 minutes. I remember asking her time and again if the 5 minutes were up yet. This inability to orient ourselves in time can be very prominent when engaging with people living with dementia. It was the case with my mother. Evi and I didn't want to use the usual methods to symbolise time, because we felt that we wanted to defamiliarise time for ourselves and for our readers. In a way we wanted to experience time as an empty signifier. After a long discussion about the philosophical implications of time in a capitalistic and material culture, Evi came up with this image which for me was very powerful. What makes this image so strong for me is first of all the fact that it's unclear whose eyes these are: the mother's, the daughter's or possibly the reader's. Therefore, it's unclear who should we empathise with. This void opens up space for interpretation. Unlike the zoom in in a soap opera that tells us who to empathise with, this particular close up creates confusion and misunderstanding, thus evoking within the readers the emotions that caregivers and individuals living with dementia experience in their relationships. I find that I'm being interpretive of the images now that I'm reading them again, which challenges and fascinates me. Every engagement with this text reveals something new to me, since this text is mine and not mine – nature of collaborative work, isn't it? The digitalised format of the numbers that figure in the eyes remind us that in today's rapidly developing technological environment, people living with dementia and Alzheimer's were born in an analogue generation. There are so many layers to this frame. For instance, it evokes also the 00:00 of a bomb that is about to blow up, while at the same time these are the numbers that would appear on a stopwatch at the onset of a race. I can think of many more associations that come up with this image that figure prominently in popular cartoons and comic strips, each of these can lead us to a slightly or radically different interpretation of the narrative that is being formed due to the word-image connection. What is most evident to me though, as a mixed-abilities dance instructor and a somatic learner and educator is the fact that time is set in one's eyes. It is embodied. Engrained in our bodies. When reading the image along with the text and in light of what we know about dementia and time, this instance in the visual narrative begs the question: If time is embodied, that is, if we can feel time in our body, why do we need a time-measuring devices? My answer to this question is as follows: We each have our time. As much as our bodies are different, each person's perception of time is unique and deeply personal. It leans on social, cultural, spiritual, physical and mental factors. Time is elastic. It can be stretched or condensed, depending on whether we are having fun or feeling pain. Time can be on our side and we can run out of it. There are so many metaphors that help us understand and sometimes misunderstand our relationship. In capitalistic, goal-oriented societies the time-measuring devices function as a technology that unifies time. One size fits all kind of paradigm. The multiverse that opens up with Alzheimer's invites us to rethink our relationship to time.

3. *Keeper of the Clouds* was originally created as an essay but it later transitioned into a visual narrative. Is it because you think graphic memoirs can afford marginalised voices than the mainstream discourse on dementia? If yes, in what creative ways?

I find that narratives that are told by individuals who live with a particular illness, not only dementia for that matter, introduce the voices of the so called afflicted. In

medicine and in mental health cases we usually hear stories about an illness or about patients something that distances and dehumanises individuals who live with the condition. Telling a story from a standpoint of a family caregiver or of the person who lives with the symptoms allows a more nuanced glance on life. The other benefit of creating graphic medicine stories is that it inspires more individuals to express their voices and add more intimate perspectives to the dominant distancing discourse that is fraught with stigma and this ongoing narrative of devastation and tragedy. One example I have to offer is that of John Wood. John reached out to me in 2016 after reading *Keeper of the Clouds* and told me that he is an artist and a father to a 6-year old boy. John told me he started losing his memory a few years back and as an artist he decided to use his art to communicate with people whenever he forgets his words. He created Time Traveler Cards that would explain to his companions how he felt and ended up presenting his work at the Greater Michigan Dementia Creative Arts Exhibition at the Charles Schridde Gallery in December 2016 – January 2017. He told me that after reading *Keeper* he was inspired to write his own graphic medicine narrative. What I think is so unique about John's work is that his Time Travel Cards were already a graphic medicine narrative, just not in a book form, and of course, unlike books, these cards, can function as a companion to anyone who struggles with memory issues to express how they feel and invite others to help those who are struggling to feel seen, heard and empathised with. I actually have been carrying these cards with me ever since I got them from John. They are quite helpful when I get overwhelmed or experience any other symptoms related to cPTSD.

4. Graphic medicine is an emerging genre of pathographies using comics. There are several critically acclaimed dementia narratives such as Dana Walrath's *Alicheimer's: Alzheimer's Through the Looking Glass*, Tom Batuik's *Roses in December: A Story of Love and Alzheimer's*, and Paco Roca's *Wrinkles*. Are you familiar with any of these writers or their works?

I'm familiar with Dana Walrath's *Alicheimer's: Alzheimer's Through the Looking Glass*. I was getting ready to write an article about it after reading it. I remember it made a very strong impression on me with its gentle and beautiful storytelling. Before leaving to Israel in 2017 I gifted my copy with my notes to one of my PhD supervisors, Dr. Pia Kontos, whose work in the field of dementia care through arts has enriched my life and my world view. I strongly recommend the play *Cracked: New Light on Dementia* as well as her writing on embodied selfhood in Alzheimer's disease. *Wrinkles* I didn't get to read but I did see the animated film and was deeply touched by it. I haven't heard of Tom Batuik's story before. I hope to get hold of both these texts when time is right.

Disclosure statement

No potential conflict of interest was reported by the authors.

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