

How to Grieve with Barriers

The last time I felt so weightless was when I was freezing my t-ts off by Southbank. My interview prep session was cancelled because of the snow. I called my Mum whilst looking at the building where it was meant to be. I told her that this must be a sign, I didn't know if I wanted to interview for this PR agency because they have alcohol accounts and didn't tell me if I could just work on the arts ones. (Lol at Muslim dilemmas). She told me to focus on one thing at a time, and since my day was now clear, to come to her hospital appointment as a distraction. Enticed by the offer of free coffee and how nice it would be to just walk from the river to Warren Street, I agree to go.

When I look at this photo, that's what I wish I could only remember about that day. I grew up a lot after that afternoon.



Thursday 1st March 2018

That personal development started because I was in the same room as my Mum when she heard

“Mrs Begum, you have a tumour.”

I didn't know what to do. I kept looking at Mum, just observing how she was taking it. I couldn't cry because she hadn't. It would be selfish. So I kept quiet as my internal voice went rogue. *What does this mean Aksana? Is she not going to be okay? Fuck, what if she dies? Oh my God, oh my God...Allah, please...please...I need her, I...really need her. J-just breathe a little...breathe.* I inhaled and my mind conjured the image of my family, a happy picture ripped by a dive into hypotheticals I didn't want to turn real...*We need Mum. Stop being selfish. What's Mum feeling? I don't know what I'm feeling. Is this sadness - rage - anxiety? This is painful. This feels primal. I want to let out a fucking scream. How isn't Mum screaming? I want to scream. But there are people outside of this room and I don't wanna scare the shit out of them, especially if they get bad news too-*

"Does this mean that I will die?"

Mum's quiet words were seconds after the Doctor's. They clanged. My running motorway of thoughts halted. Once she said it, she looked so vulnerable. That's something you hope to never see with your parents, or at least not for a very long time.

We cried.

I realised that the primal thing I was feeling was heartbreak.

In between as we gathered ourselves, the Doctor and Nurse patiently answered our questions. I took the lead because I'm the eldest. I knew that if I were Mum, everything would be tinnitus. So I sat there, Mum being a mum by wiping my tears, and me being her daughter, holding hands, trying to understand. From what caused it, whether it was benign or malign, had it metastasised, what stage, if it were operable, the treatment plan. All of it. I don't know if I were scraping those questions from what I learnt from GCSE Biology, or books, or from what I had heard from others. But it grounded me in this new reality, the one where Mum has cancer.

From that day, and in the months to come, I learnt what it means when you're given awful news...you become both intolerant of bullshit and a desperate optimist. You see, one in two people will develop cancer in their lifetime. We got bad news. Mum was unlucky.

I just prayed that one day, we would be the ones leaving the hospital with a smile instead of clutching papers as we solemnly walked to the bus stop.

I learnt that trying times means deciding what is a good use of your energy and headspace. I had to be a carer with the rest of my family. I cancelled that interview, put my job hunt on hold, decided to not go for a masters, and worked with my family to focus on Mum and help out. This makes me unusual if you read museum job adverts. Being in my position unveiled the snobbery of this field. Heck - one job interview, I was asked why I never had a full time permanent role. I couldn't emotionally and financially invest in museums when there are bigger things. There's a

lot of people who think that way too, and I completely get it. What would the world of museums offer people like me?

Throughout my Mum's treatment, I went between London and Coventry (where I lived at the time). My impression of the rail announcement lady got good. I racked up enough Nectar points to get free coffee at Café Nero regularly. My time management improved massively and I made sure to spend quality time with my friends and family. I became that person who constantly tells people that I love and appreciate them too. (See, positives!)

This was not without challenges. I was depressed but couldn't rest. It wasn't an option when you have bills to pay and people to look after. So you just take things one day at a time. I'm not so good at thinking long term because of the impact of cancer. I stupidly, naturally compared myself to others who were killing it in the sector. But I always composed myself, remembered that museums could wait. I couldn't pause the time I had with my Mum.

I don't regret it.

Mum is thankfully, Alhamdulillah, okay now. We are lucky.

When things started to look up, I left my post in a recruitment company and started getting paid roles in heritage. (Big up the learning team at the London Transport Museum for having faith in me and tapping me in).

I was navigating the sector "properly" as I couldn't when Mum was ill. I did it - and still do - not only with the baggage that comes with being a working class woman of colour, but with the experience of someone who has family responsibilities too. I do however, acknowledge the privileges that come with

- being South Asian
- being able bodied
- being straight
- having the ability to code switch
- can work between two regions
- live with my partner, and
- having a support network too.

Unfortunately, Wednesday 10th October 2018 happened. It made what we went through with Mum seem like a loose rehearsal for what was to come.

My thoughts on the West Midlands are formed on how my requests for accommodation were not taken seriously as it wasn't just about my Mum. This time around, my grandmother,

"Mrs Bibi has terminal cancer."

Hearing this statement by another Doctor, in the same room as my Nani's kids (Mum included), it felt like déjà vu. I was technically once removed from the epicentre. Compared to Mum's situation where there were options, with Nani we could only have pain management and make her feel "comfortable." That one in two stat? That day we were part of the 50% who got the worst of the worst news.

With my Mum, there was hope; Nani was irrefutably dying.

This was going to hurt. Nani is the only grandparent I grew up with. She was going to be my first personal death. I knew that I was going to be grieving before actually grieving. I wasn't familiar with this process. I was scared.

My personal challenges felt heavier because whilst London institutions have the resources and culture to understand that you don't need to be a parent to ask for accommodations, the West Midlands can do better. How can organisations support people like me and those without my privileges?

By the time 2019 had started, I was transparent to those I worked with and at job interviews about my Nani's health. It didn't protect me. From my lived experience the past year,

- I learnt that if a job requires "resilience", you should run. If it's tough at home, it shouldn't be at work.
- I received five pages of feedback from an internal role on why I wasn't a suitable candidate. I can handle constructive criticism, but five pages makes you unprofessional.
- I was told that I expected too much to be asked "how are you?" from a busy team as a conversation starter. I mean, it's not like I'd asked for their life story.
- I was refused flexible working after telling my former manager that I was scared to take public transport after dissociating and almost fell down the stairs at New Street Station.
- I learnt that some people perform allyship, will quote Reni Eddo Lodge and loudly admire Akala, but won't hold power accountable when they have a chance. They're either scared or have other things they consider as more important than your wellbeing. It's cultural neoliberalism y'all. It's why the arts value past activism; they will programme around safe topics, but not a lot of people will be nice to people around them.
- I was told that "remote working is earned, not given" by someone who went on to chair a panel on diversity in the arts.
- In less than 24 hours of Nani's burial, I was WhatsApped about handover without being asked how I was.

But 2019 was also the year I learnt about the true value of community. I was really lucky that I had my loved ones look after me. 2019 was also the year I learnt that

- Cancer, or rather death, is so common but it's not spoken about. Your colleagues will not know how to manage you as you try and figure it out. But what can be helped is if they can have accommodating policies and structures in place. If they don't, it is just risky because it all depends on their personalities. It's even more risky if you haven't known

them for a while. So if you freelance and are in a financial position to, try not to take on new clients.

- If you ask, people will try and help. I had people who took time out of their day to check in on me at work. I tweeted about what to do when navigating palliative care, and there were so many kind people who messaged publicly, and privately. My friends in the sector, some of those I worked with, and Museum Detox really looked out for me. I received advice on how to manage professional relationships whilst going through bereavement. If it were not for them, I would have given up on this sector. I will never ever forget their kindness.
- If you need to cry, cry. Anticipatory grief (grieving for someone before their death) will have you become blunt and you might become a mess in ways you wouldn't expect.
 - If you have a support network/live with others, be honest. In the months to come as you focus heavily on the inevitable, you'll become subjectively crap with making decisions that aren't to do with life or death. I lost a lot of weight because there were days when I wasn't motivated to cook. I am so lucky to have a partner who looked after our home so I would have one less thing to worry about. And my lovely friends checked in virtually and met with me when I had the energy.
 - Your emails may be a bit to the point and less flower-y. I was reprimanded for this. (I hate how feminine women have to sound on emails just to give a good impression). You might not be good at phone calls because your voice will crack when you have to be so positive (this sucks in a front of house role). You will, however, know what your boundaries are and I have never stood up for myself more because of this. This is terrifying when you're in a junior position.
 - It's oddly freeing to cry without caring. I have cried in the loos, on a few trains, and a particular favourite was the post-work Nando's at Grand Central (made my chicken salty). It's not worth it being emotionally constipated.
- To logistically get my stuff together
 - If you need help with managing your mental health, please speak to your GP. You may need to take medical leave because of your mental health.
 - The NHS offers cancer support to directly related family members. Nurses are able to write notes to confirm to your employer that you have attended appointments. It may take a while to get talking therapy. So try and get on a waiting list as soon as you can so that you don't wait longer than you have to.
 - Take mental health days. You bloody well deserve it.
 - Leave work at the time you're meant to, your manager won't pay for your funeral. It helps when you're going through it because you will go into survival mode, and start compartmentalising your stress. Your situation will be a health check on your organisation as it will question them on what areas they need to improve in too.
 - Financially, if you are in a position to, try and save as much as you can. This applies to both the salaried and self employed. You do not know when you can return to work, so it's good to have a buffer as you might eat into your annual leave, and go into unpaid leave, and whatever is left from your rainy day pot.

There may be administrative errors to your pay slip because of time taken off. And freelancers, if you have invoices to send, you can schedule them to go on certain dates. The last thing you want to do is negotiate finances when you should be healing.

- Have a strategy in place so you know what would immediately happen when you tell your colleagues that your loved one has died. Do you phone in? Do you send an email or just text your manager? Will your manager let your team know? Who will take over your responsibilities when you return? Can you go from full-time to reduced hours? Can you work remotely? Etc. Ask those questions.
- Keep a list of what gets done and what hasn't been done so that when you do take time off, people know their boundaries. I especially changed my freelance email's out of office for this.

Aksana is on a break Re: [REDACTED]



me 16 Oct 2019

to [REDACTED]

Hi there,

I hope you're well.

For my wellbeing, I'm currently on a break from work to be with family after a recent death.

I hope you can understand that at this difficult time I am reducing screentime for my mental health. I won't be around to make timely responses to work-related queries. If you have my mobile number, please do not use it to ask me questions about projects.

Have a good day, and I hope you tell your loved ones you appreciate them.

All the best,
Aksana.

- If you are salaried,
 - Ask if you want people to know about your situation, whether you want to communicate it, or ask your manager to. This is because your relationship with

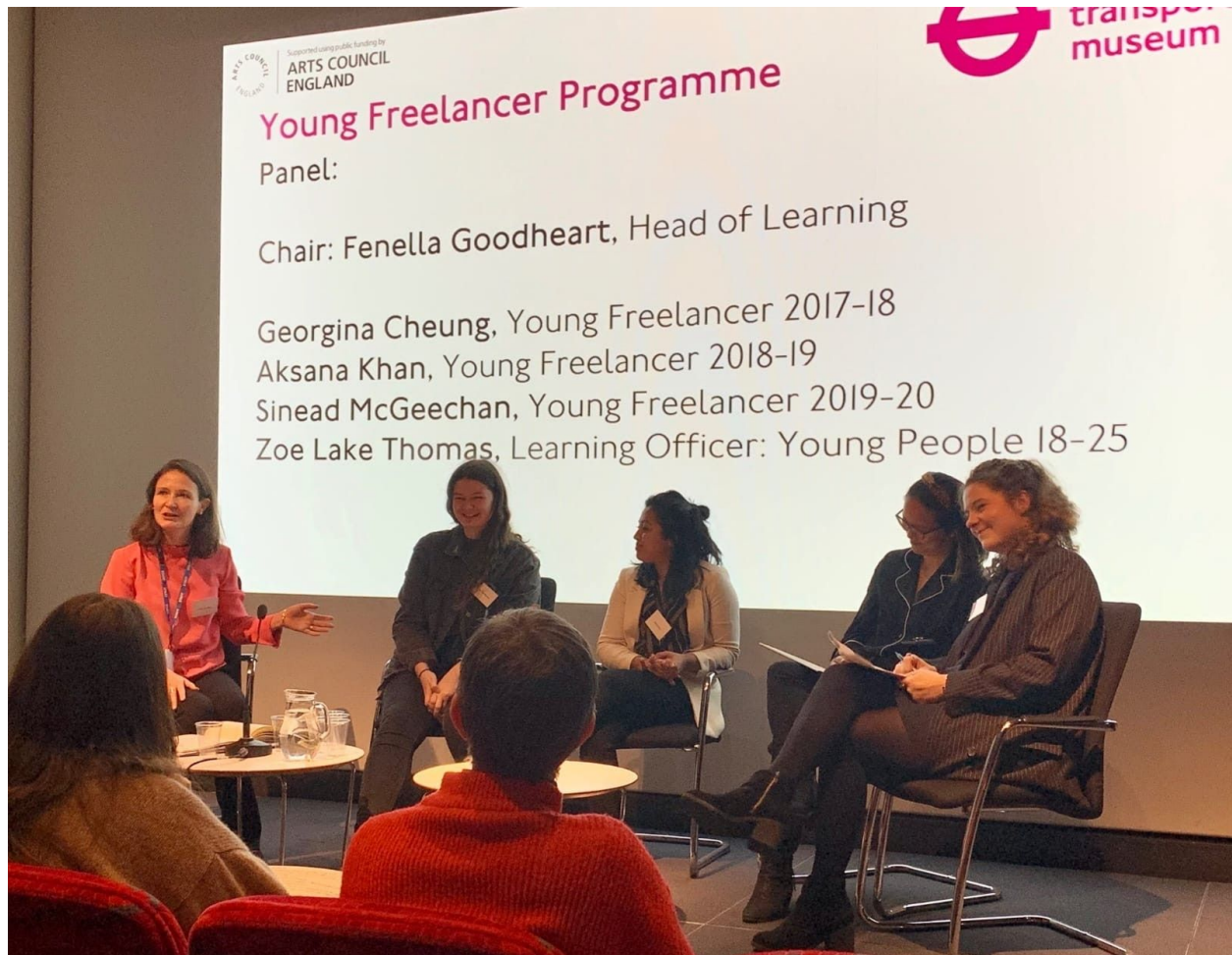
your manager and colleagues will impact your long term future in the organisation.

- Check your policies. The death of a grandparent may not be included in a bereavement policy. Organisations are not legally required to have a bereavement policy, so death is classed under compassionate leave and this varies from place to place. The cognitive dissonance was underlined when my Nani died, my (white) partner was technically offered more leave than I was. The UK legislation on bereavement is wild. From anecdotes from my friends and family members in non-arts careers, corporations win in this area.
- Be in a union. Any queries you have, there should be a written record. If you have a challenging work situation, ask for a rep or someone you trust to come with you for support. I do not have experience of this but I wish I had.
- If you're someone who has no idea what to do with your colleague who is going through bereavement, and you see them every day
 - Don't expect them to perform at your level. For more information, please refer to these [Acas guidelines](#).
 - Don't ask them about work in their personal time and especially through their social media. Social media is not the same as emails.
 - Respect how they have said they want you to acknowledge their loss when their loved ones die.
 - If they haven't said anything, don't email your condolences to their work email. If you were in their position, is that what you want to see when you return to work and check your inbox for the first time? If you don't feel particularly close to them or have their number, a staff condolence card helps. If you have their number, text them. Don't expect a reply either but it takes seconds to say "I heard the news about your ___ and I'm so sorry. We'll be here to support you."
 - Since it's 2020 and it needs to be spelt out, it is really weird if you previously spent time joshing around, and then say nothing to them in person. It's also weird to lurk on their social media too. These things matter because pain is magnified when people don't acknowledge it and it would help with managing relationships as well.

This is not an exhaustive list and these are things I've learnt personally. I am sure that others would be able to provide more insight, but I've written this because I couldn't find any museum staff resource on bereavement. It was quite haunting that the only thing I could find on death were museum events for dementia carers, the occasional Macmillan cake day, and articles on the repatriation of remains. The arts are comfortable with death if it's a skeleton on display, not when it's someone grieving in your office.

Currently, I am still processing a world without my Nani. I have my good and bad days. I took about a month off of work and my professional commitments before slowly easing myself in.

My first gig back was when I was invited to speak at the Kids In Museums' Young Freelancers panel. It was surreal to say to a room of people, that I found my way working with the London Transport Museum because of the "c word."



Tuesday 12th November 2019

I spoke my truth in part because sometimes the museum sector needs to be read. But I spoke it mainly to assure any of the young people in the audience, that I struggle with my mental health sometimes, and it is going to be okay.

But if I could sum up how I navigated the arts, cancer, and bereavement in the past two years, it would be that 'best practice' starts with being kind to those around you. You cannot think you're doing a public service if you're not looking after the people you work with. It's why it is so disingenuous and disappointing when the arts and especially gatekeepers, support and fund organisations without a bereavement policy, programmes for young people as participants without supporting young professionals, and not accommodate and safeguard their health and wellbeing when they go from volunteer to intern to staff. It is reckless, especially for young people of colour. It gives the dehumanising message that

- “We only want you if your personal life doesn't affect the project GANTT.”
- “We want your lived experiences if it is in line with our strategy.”
- “We want to talk about past trauma, not the kind you’re going through because we can’t profit from it.”

So if we can’t change the structures that make it hard to ensure compassion, then it’s on you as an individual.

Your integrity cannot exist without being kind.

So please, for the sake of all of the young people we work with, let’s start there.

By Aksana Khan

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