

ISSUE ONE March 2021

navigating uncertain times & life disruption

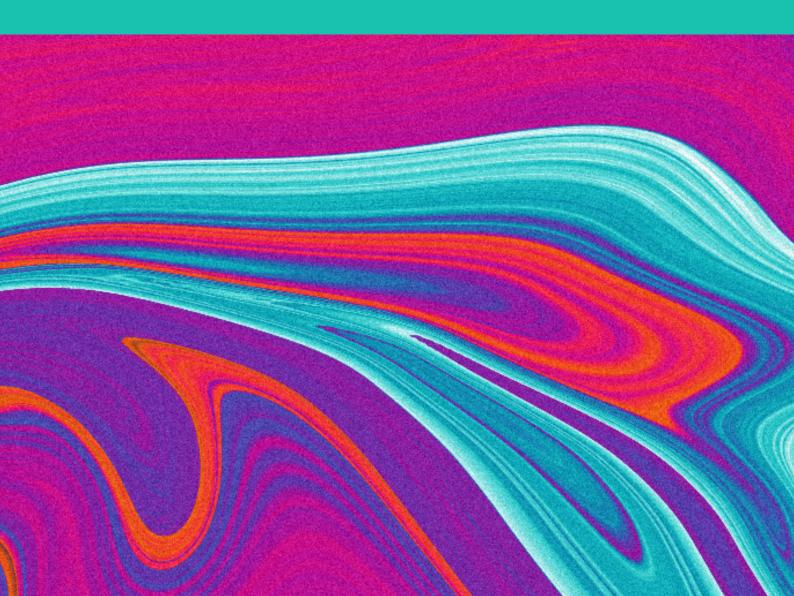


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www.lelan.org.au

LELAN acknowledges the traditional custodians of country throughout South Australia. We value their cultures, identities and continued connection to country, waters, kin and communities. We pay our respect to Elders past, present and emerging.

> We acknowledge the lives and work of people with lived/living experience, as well as our supporters and allies, who shoulder us up and who we shoulder up as we act to strengthen the voice, influence and leadership of lived experience in South Australia.



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POETRY & WRITING

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Circumstances come together, only to fall apart moments or months later. And then, in a flash, we must rise up and regain our footing. In the rearview mirror, I now see so clearly what escaped me then: It's not that the ground underneath me was suddenly shifting; it's that it is never still.

That's part of the work of my journey getting comfortable with life's groundlessness.





to LELAN's first online zine showcasing the contributions of people with lived experience of mental distress, social issues or injustice (as well as our supporters and allies).

Nelcome

We hear frequently from the lived experience community that they would like a platform where their stories and lives can be shared with others. Always with the recognition that how people share and contribute could look different (e.g. writing, spoken word, art or craft).

The theme for this inaugural issue is navigating uncertain times & life disruption. For many people with a lived experience of distress, the COVID pandemic hasn't been our first time of getting through tough times. Our past experiences may even offer helpful tips, tricks and tools for others to connect with and benefit from.

With this in mind we invited people to share their experiences with uncertainty and disruption with us. The result is the following online mag, full of art, poetry, writing, craft, the occasional interview and lived experience resources.

We hope you enjoy!



I wanted a perfect ending. Now I've learned, the hard way, that some poems don't rhyme, and some stories don't have a clear beginning, middle, and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next.

Delicious Ambiguity.

- GILDA RADNER

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RUNNING, RAGGED

Rushing through life get it done while I can, while the world still spins around me and I can suffice without a white cane scared of the encroaching darkness, change. Racing towards a finish line without a ribbon; nothing in this life is a given the unknowns, my suspicions. Small was this sorrow now growing, gaining pulling taking, digging deep, hollowing out happiness, draining me of these yet undiscovered moments, unformed memories. - Bethany Cody

3.1. ~

CAN WE MAKE A TRADE

I'd trade these endless afternoons for a life-full of Winter's light on your unborn face, a future with him holding you. But I am as of yet undeserving. In this space, at this snail's pace I'm still learning not to dwell on my down days, sinking feet first into the suck. - Bethany Cody

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THE TSUNAMI

The events leading up to a Tsunami begin with an Earthquake, a shaking, a shift in the Earth's tectonic plates, the ground shifting under our feet, what we believe to be solid shifting beneath us. My father's illness also began with a trembling, a literal shaking, but I failed to predict the tidal wave due to follow.

The first thing I did was ignore reality. I played it down, "it's just a tremor, just an itsy bitsy Earthquake", and pushed it out of my mind. I watched as Dad worked around it, avoiding the steps at the front of house to go round the back door. I watched as he leant on others for support. I watched as he took things slower. As we all learnt to take things slower, in a world forever telling us to go faster.

The water of the wave loomed closer, lapping at our feet, as I watched my Dad begin using a cane.

I watched as he struggled to breathe, an infection in his lungs had pulled him under, under the waves. I watched as he caught his breath again, but forgot my name. I watched as he remembered it again, and things were calm once more- for a time. But the tsunami was coming.

My mind seemed to have just only had one thought during this time: What's next- what's next- what's next-

A wild churning panic that never switched off, an uneasy feeling that I couldn't shake. Throughout this period, I wanted not just to watch, but to know. As Dad became sicker again, I wanted to know what lay around every corner and what would lay in front of me as I hesitated before stepping into his hospital room week after week, wondering what challenges we would have to face that day.

I felt as though I was drowning in uncertainties and fear. This was the tsunami. This was the dread, the panic, the tumbling, the debris of how our lives used to be surrounding us. My family, people I had known my whole life, felt almost unrecognisable to me as we each struggled to deal with the deluge.

F. P. YI

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I was surviving, but I was missing something important. While I was consumed with knowing what may come next, I frequently overlooked all the tiny opportunities right in front of me to find joy, peace and laughter. To find grounding and certainty of a different kind. Listening to music, sitting in the sunshine or doing the crossword with my Dad for example. All these moments were, for the most part ,lost to me, drowned out by the crowd of anxieties blaring in my mind. Drowned by the salty water of the tsunami.

Then, one day, I caught one. A special moment. Unlike the tsunami,

which threatened to drown me, this was more like catching a gentle wave into shore- it was exhilarating and rare and beautiful. It started with

a shaking of Dad's arm, growing more and more insistent , as he couldn't find words to speak and every time I failed to guess what he needed, the frustration grew. I finally caught on when his other arm began to rise from the armrest and I understood. He wanted a hug.

The magical moment, the glimpse of power and peace I experienced is indescribable. Certainty. We were there, in the present, and we were connected. For days afterwards, for the life of me I couldn't work out why I had always been so concerned with what was going to happen next. Why I let the tsunami pull me under. Whatever would happen, would happen. We had this moment. And so, as the surge of emotion died, as the hug ended, as I sailed into shore and planted my feet on the ground, I knew I could carry this feeling wherever I went. Whatever waves came my way.

- Cat Morgan

about the author

I'm Cat. I am a human being with curly hair and a love of many things, including writing. I also have lived experience of living with mental distress. The piece I have written is about finding small moments of gratitude and grounding amongst uncertainty. It can be a hard thing to do, but is absolutely worth it, even if you can only manage it sometimes. I hope if you are ever struck by a (metaphorical) tsunami like I did, you survive it well.

TT. P.YL

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UNTITLED

I think of all the effort, the times I tried so hard, To avoid being a stereotype, "A teen mum" To avoid the father being "Him".

And now I curse my body,

For not doing what it's mean to As if it is some sort of punishment.

- Anonymous

DEAR UBER DRIVER

Idle Chatter in the backseat of your car, making a U-turn out of the street of my childhood home thank you for acknowledging the sacrifice, the exclusion, the dark mass, dissolution, the intrusion on my central vision keeping me off the road. You called me brave where most days I don't; afraid of what I'll lose before I've even lost it a rite of passage, independence, little birds venturing from their nest. - Bethany Cody

IT JUST TAKES ONE

I've walked the walk and fought the storms and pain was my best friend, Confusion, mind games and no self worth is what brought me to the end The life I lived and thought I knew had left me on my knees, Cause pouring love into the dark is something no one sees I feel no shame for believing good exists within us all but not all hearts are quite as pure and that is where we fall To make a stand and share your scars as open as they feel will lead you out the path of pain into time that only heals If I can now enlist my heart to use this pain for good I'll hold the hand of all that fear feeling lost and misunderstood As it JUST TAKES ONE to know your hurt believing in your dreams that will walk the walk when life gets hard and nothings as it seems

- Sandy

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Sea and and

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IN THE MEANTIME a nonfiction memoir

If you look at me, you can't see it. There will come a time when I will see nothing at all.

My journey with vision loss has been gradual. In 2018 during a routine eye exam with our local optometrist an abnormality was found and I was referred to a specialist, the same doctor my father was seeing for glaucoma. After a series of strange new eye tests and a referral to yet another specialist I was diagnosed with a degenerative eye disease, retinitis pigmentosa. I was told there is no cure, the rate of degeneration varies from person to person and I am likely patient zero as to the best of our knowledge no one in our family has the disease.

For years I struggled with my night vision, finding it difficult to adjust to dim lighting and walking at night, feeling like I was stepping into the abyss, never sure of where my feet would fall. Years of quiet concern pushed to the side, fuelled by my greatest fear, going blind, eventually led to making the appointment and later, my diagnosis.

In the same year I met my soulmate. He is the biggest reason I continue to look for the positives in life and have not allowed depression to consume me, or regress back to self- harm, which I struggled with in high school. His support means that although the knowledge that I'm going blind crosses my mind multiple times a day - inescapable reminders, hyper aware of my blind spots, the TV-static shimmering of the world around me - I'm able to find meaningful distractions, a break from reality, happiness.

The concerns I have for my future aren't unique. I worry about bringing a child into the world with limited capabilities for looking after them, let alone myself, burdening my partner and missing out on the milestones. I worry about my capacity to work and contribute in society, accessing the disability pension as well as continuing my creative writing career and how my creative process will be impacted. I worry about losing my individuality and being unable to express myself with makeup and fashion. Currently I feel like an outlier in the blind community because I'm not classed as legally blind and am able to function quite autonomously. I feel like I don't quite belong in either worlds, sighted or unsighted

was recommended by my specialist to stop pursuing my driver's license because night driving would endanger myself and others. I recall a conversation with an Uber driver, an older man who once lived in my street, where I was asked about my license. After slight hesitation I boldly admitted to my condition and was told that I was brave for choosing not to drive when so many people my age were eagerly getting their license, a rite of passage. It was a bittersweet compliment, one that acknowledged the sacrifices that come with the loss of independence.

J. P. YI

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Some days I go back and forth about sharing my experience with vision loss publicly, privately, whether it should be something I do to help accept it myself or help others understand what it's really like. There are a few people I know who share updates about their life with disability on social media and while I admire them for being so open and honest, I struggled to replicate these feelings about my own experiences. There are days I aspire to be more like them, loud and open and unapologetic. Other days I want to retreat, pretend, deny.

I believe there is such a thing as toxic positivity, where we overshare our plight and try to twist it into something positive, something to be happy about or thankful for and although this is healing and liberating for some, I feel it can invalidate other's struggles, coming across as disingenuous and emotionally draining.

I am fortunate that since my diagnosis I have retained a fairly unchanged level of sight. My first pair of glasses came earlier this year (I've needed them for a few years) and was a revelation. They help me enjoy what I can still see of the world while I'm able.

In the meantime I try to take each day as it comes, to be thankful when I wake in the morning and see the framed painting of an autumnal landscape on our bedroom wall, my partner's sunbathed face. I've learned to enjoy the little things and keep a busy mind, to not indulge myself in wondering about the what-if's. It's a daily struggle. The next step is to take a genetic test and despite my reluctance to uncover the timeline of my sight's deterioration, I believe my partner and I will navigate the results to the best of our ability with the support of my specialist, family, friends and the wellbeing of our future in mind.

- Bethany Cody

about the author

Bethany Cody is an Adelaide based writer of short stories, flash fiction and poetry. She has received awards in the 2018, 2019 and 2020 Campbelltown Literary Awards and was highly commended in the 2020 Shire of Mundaring Poetry Competition. Her poetry and short stories feature in anthologies published by Truth Serum Press and Pure Slush Books. In 2018 she was diagnosed with a degenerative eye disease and incorporates aspects of her lived experience with vision loss into her creative works.

J. P. YL

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ROSE TINTED GLASSES

Change and uncertainty are constants in our life.

It comes down to a matter of perspective. Whether we view this from rosetinted glasses or whether we do the complete opposite. In my perspective, a life without change...

a life without uncertainty...

it'd be too mundane for my hyperactive and chaotic mind.

I'd question whether I'd be learning...

Whether I'd be challenged...

Whether I'd be growing as a human being.

Whether I'd even be contributing anything to the universe that we live in. I guess what I'm trying to say is that perhaps, a global pandemic is what I needed to throw me off guard, to turn my world upside down, and to come out of it with new ways of thinking, living and breathing.

I am one of few who saw this global pandemic through rose-tinted glasses with a hint of privilege - a privilege to be navigating change and uncertainty from the most stable position in society...

with a roof over my head...

with a steady income... and with loved ones who open their arms and surround me with empathy, love and care.

COVID has allowed me to experience things I never thought I'd experience in my 23 years of living.

The global pandemic exposed me to my own vulnerabilities and complexities when it came to my mental health.

COVID forced me into leadership positions - which I never thought I'd thrive in and encouraged me to conceptualise myself as a leader and provided with a vision of how I want to lead in the future. It enabled me to find my existence as an advocate and allowed me to recognise the role, voice and platform I have to shed light on the injustices experienced on the day-to-day.

Most importantly, it directed my focus onto the simple things in life and fostered a greater appreciation for things I previously took for granted, such as nature, quality time and connection.

Perhaps, as a society, we need to put on our rose-tinted glasses...

IT TOT

Look past the grey hues that have come into our line of vision in the past year... and see what colour COVID has brought us as a society.

- anonymous

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AUTOBIOGRAPHY IN FIVE SHORT CHAPTERS

Ι.

I walk down the street. There is a deep hole in the sidewalk. I fall in. I am lost. I am helpless. It isn't my fault. It takes forever to find a way out.

11.

I walk down the same street. There is a deep hole in the sidewalk. I still don't see it. I fall in again. I can't believe I am in the same place. It isn't my fault. It still takes a long time to get out.

|||.

I walk down the same street. There is a deep hole in the sidewalk. I see it there, I still fall in. It's habit. It's my fault. I know where I am. I get out immediately.

IV.

I walk down the same street. There is a deep hole in the sidewalk. I walk around it.

V. I walk down a different street.

- PORTIA NELSON



Hope - Hope in the face of difficulty. Hope in the face of uncertainty.

The audacity of hope!

- BARACK OBAMA

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'ENTANGLED' - AJ

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ALL DATE

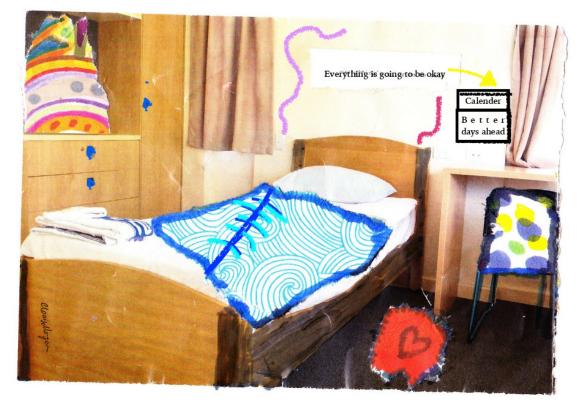
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'IN THE WIND' - AJ

UNTITLED PHOTO





A colourful makeover of psych ward room

Sometimes the little details of where we are just as important as why we're there and who we're with... for me personally, a splash of colour makes all the difference...

'A COLOURFUL MAKEOVER'

ASI'N YA

~

- Cat Morgan

about

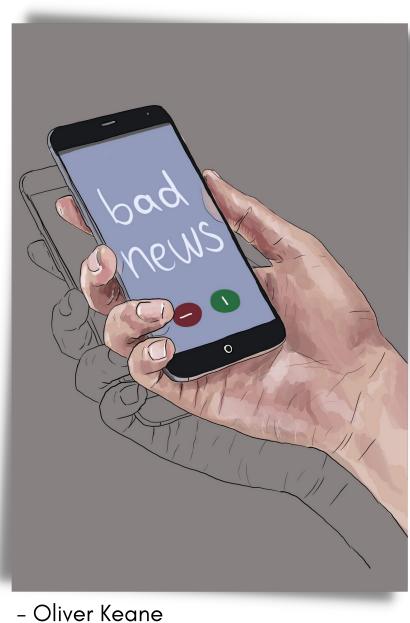
I'm Cat, occasionally I dabble in collage! I also have lived experience of mental distress. This piece is a collage in which I have reimagined a psych ward room by adding some colour and a cheerful quote! I do think that our environments, and the relative cheerfulness of them, can make all the difference to how we feel.

The Last Time I Wrote Poetry

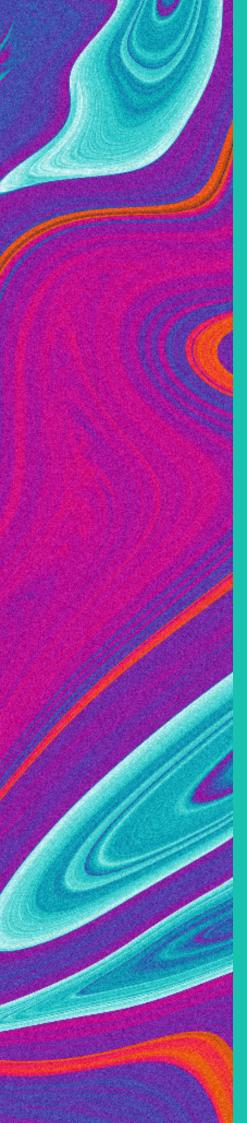
Easter 2012, Group crafts on the ward Making paper baskets. I packed my bags, Never wanting another admission, Was I cured now?

I sat on my hands the whole 600 km drive, The sun beating down, April was unusually hot For 7 hours my brain told me, "You're going to grab the wheel" "You're going to grab the wheel"

- anonymous



- Oliver Keane olskie_



You may not control all the events that happen to you, but you can decide not to be reduced by them.

- MAYA ANGELOU,

LETTER TO MY DAUGHTER

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CHRIS SMALL ART

While in shutdown I received a commission from someone who wanted to spend money on a painting so her internal space was somewhere that was easier to be in. She gave me total freedom and trusted to paint whatever I wanted in my particular style. It freed me up and gave me a focus of something 'to do'. I was able to get 'lost' in colour, which meant I felt stimulated and calmed throughout the day.

I spent time 'connecting' in my heart and spirit with the person I was painting for who was experiencing struggles with suicidal feelings at the time.

I regularly updated her with the work and sent videos of me working on it, so the painting felt like a moment in time of our relating to each other and connecting on a level that went beyond language.

It sits in her lounge room and she says she sees more and more in it each time she looks at it. This gives me great feelings of pleasure and warmth and that I have been able to perhaps pass this into her heart for moments of the same.

Art can deeply connect us as humans, going beyond needing words to frame our experiences and moments and feelings. It just is an expression of spirit and 'me'. Painting got me through COVID- and my painting also helped others through COVID.

You can go and look at my work at the Fleurieu Arthouse in the Main St McLaren Vale (operates out of the Hardys Tintara Winery site) .

I am also planning on starting to run art workshops that are mindful in nature, using the process of my way of painting to reconnect with passion for being alive.

I would like to work with community workers through art as a medium to disrupt the way systems we work in interrupt our human connection to the people we work with. I want to reignite our passion for the work we are doing and bring us back to being radical and productively disruptive in our work. A space to facilitate remembering what we need to remember. I am also looking at taking this further out from workers, but my experience of worker burnout in these systems is something I am passionate about.

I am still working on what this looks like but if you would be interested let me know via chrissmallart@gmail because I would like to find out what the interest is out there.



@chris_small_art
www.chrissmallart.com



THE WOMAN WITH 1,000 an interview

HEARTS

an interview with Michelle Casserly of Port Lincoln

What was happening for me when COVID hit

It felt like when COVID hit that everyone around me was dealing with some really big emotional stuff – including me. I had been feeling burnt out at work, I was having anxiety attacks, and I realised "I need to change things."

How I handled it

Every Summer, I swim with my friend down at the shark net – and we have done that every year for quite a few years. I've always been a Summer swimmer, but every year I said to myself "One day I will get a wetsuit and swim through Winter." Last year, when Covid hit I had just been in hospital and I said to my friend – "This is the year. I think we're gonna need to keep swimming". We always have a mini debrief before we get in the water, and then we say we are gonna wash it off in the water. At the time I was unable to work due to illness, and was waiting for Jobseeker to come through, my daughter was paying the rent and for food. My friend was down to her last bit of money but offered to take a leap of faith, spending it on two wetsuits – one for each of us – which was very generous.

Why swimming was important

I think for us the benefit was that all we had to focus on was getting to the water each day. It could be lockdown, raining, windy, or freezing in the middle of winter but we would motivate each other to go swimming and have a mini check in each day. One of the things I loved about it the most was that I was not a particularly adventurous person, so it was kind of fun, feeling brave. People would actually say to me "You're so brave", and at first, I would be giggling because I didn't believe them but eventually their words sunk in.

#1000hearts

#1000hearts is a global kindness project that was started by Sarah De Jonge in Hobart, Tasmania in 2016. She is a counsellor and noticed that in the week between appointments her clients were quite sad and upset. So she started stitching felt hearts, to give her clients between sessions as a little support they could carry through the week. It then became a kindness project – kind to ourselves, kind to others and kind to the environment. She encourages us (the Heartists) to use natural products when making the hearts. Her mission is to change the world, one heart at a time.

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Y J.F.

How I got involved

I became a "Heartist" in 2018 after seeing a Facebook post. I loved the concept of it – that you could do something so little and simple and bring someone some care or kindness or joy. Some of the stories that I hear from people when I give them a heart are really moving. I think the most help actually has been for me. Since Covid it has had a profound effect on me, when everything felt out of control, and the world was scary it gave me purpose. It was that idea that you can't control all the big stuff but you can control little things that you do. I would be swimming in the morning, and stitching hearts during the day.

What I do with #1000hearts

I have been taking hearts that I made to people in the community – pharmacy workers and other workers who were "essential" during Covid. I also took hearts to the women's shelter and Centacare – for workers, people receiving counselling and new foster kids coming in. I gave hearts to everyday people as well – I would always have one or two hearts in my pocket so if I saw Mums with kids crying or someone who seemed a little sad, I could give them a heart. It kind of became a mission for me, where I forgot about what was going on in the world and thought about who I could bless with a heart each day.

Michelle is running free Heart & Chat sessions with a local counsellor during Salt Festival in April at Port Lincoln. For more info visit: <u>www.saltfestival.com.au</u>

If you would like to learn more about #1000hearts visit:<u>www.1000hearts.com.au</u>



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5 WAYS TO WELLBEING

The Five Ways to Wellbeing were originally developed by the New Economics Foundation (NEF) in the UK. They offer evidence supported actions for nurturing individual and community wellbeing. Below we share insights and examples from people with lived experience. These are the tips, tricks and tools that help us get through uncertain times.

CONNECT

staying connected with family and friends via video call platforms is excellent, but don't feel pressured to agree to every planned call / accept every invite my lifeline is my animals .. i find walking my dog and getting smiles from passersby helps to stop the void with social disconnection connecting with friends over games online

connecting with triends over games online check in with others. check in with yourself





BE ACTIVE

meditation, swimming, walking, podcasts, movies, art, colouring, poetry moderate exercise (walking, gardening) creativity (cooking, writing, making, designing, gardening) grounding myself in nature is my biggest go to - bush time or just being outside in fresh air walking is good for my mind

i remind myself to get some sunshine



taking one day at a time, hour by hour. being careful not to make big decisions when in a state of distress at the end of the day noting things i am thankful for relaxation/meditation music is very calming and can help settle anxiety. i also find it helps me to focus and concentrate gratitude, enjoying stillness and quiet, reflection and meditation

day by day. breath by breath being aware and protecting personal boundaries unapologetically





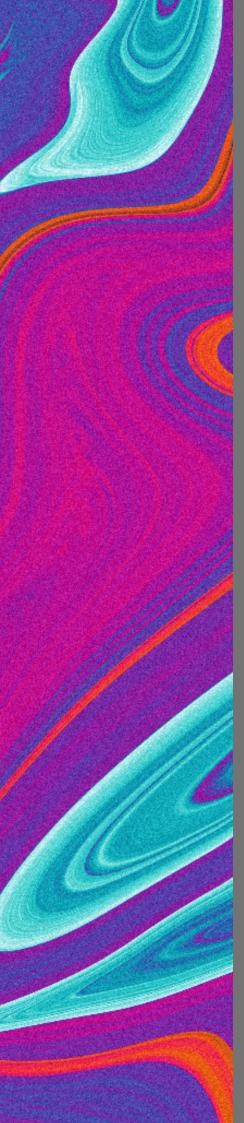
break up your day in small blocks of time. i like to do blocks of 30 minutes but you could do 15 (sometimes i do when i am struggling) .. don't be too hard on yourself about 'what' you get done in that time but instead appreciate your ability to work on that activity for the time you put aside for it making smaller changes

adapting to rapid changes and reminding myself to radically accept rather than resist this new reality

GIVE

nurturing self so there is energy and to nurture other kindness to ourselves and others support the poor and brave talk to others. be open and compassionate

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There is so much about my fate that I cannot control, but other things do

fall under the jurisdiction. I can decide how I spend my time, whom I interact with, whom I share my body and life and money and energy with. I can select what I can read and eat and study. I can choose how I'm going to regard unfortunate circumstances in my life-whether I will see them as curses or opportunities. I can choose my words and the tone of voice in which I speak to others. And most of all, I can choose my thoughts.

- ELIZABETH GILBERT

RESOURCES

for and by the lived experience community



Mad in America - YouTube video www.youtube.com/watch?v=vedR8LP8V-A

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The Courage to Live with Radical Uncertainty - TED Talk www.ted.com/talks/shekinah_elmore_the_courage_to_live _with_radical_uncertainty



ReAwaken: Connection - Compassion -Meaningful Action - Free eBook www.reawakenaustralia.com.au/ebook





Connection & Cuppa with LELAN - Every 2nd and 4th Thursday of the Month at 1pm us02web.zoom.us/j/85715879942

RESOURCES

recommended by the LELAN community





thanks for reading ISSUE ONE of UNHEARD we are now taking submissions for ISSUE TWO UNHEARD: Stories of Activation

we want to hear about **what activated you** when and why did you start to share your lived experience story? was it someone or something? was it to change your own story or for systems change?

for many of us, there is a shift that happens in our lives when we start to feel that burning or an awakening that leads us to activism these are the stories we want to highlight in ISSUE TWO

submissions for ISSUE TWO close Friday May 14th, submit your ideas via <u>www.surveymonkey.com/r/LMG87QV</u> <u>or email them to info@lelan.org.au</u>

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