

Lived wisdom on panic, worry and isolation: stories to support the community amid the COVID-19 crisis, from mental health service users, survivors and ex-patients.

Why This Document Exists

Some of us were thinking during this period of global concern with COVID-19 about the idea of knowledges earned through difficult experiences that might be useful to lend to others. We considered how the mental health consumer/survivor/ex-patient (c/s/x) community doesn't often have the chance to share the hard won expertise learned through traversing challenging life experiences with folks in other contexts where it might be useful.

Many of the experiences commonly navigated by folks who have had some experiences with mental distress mirror some of what's going on around COVID-19, experiences that might be called panic or worry, which for many in the world may be new. These characters seem to be present in most media descriptions of the public right now as well as increasing instances of strongly enforced isolation. The latter many of us who have had contact with mental health services have experienced along a spectrum from discrimination induced lack of social contact to full on compulsory treatment, these are very different to what's going on for folks self isolating.

So we called out for contributions of special knowledges around these things from our c/s/x community. This document contains the wisdom of thirty people's experience with panic worry and isolation. We've been pretty moved by people's contributions, they're really generous and rich descriptions of experience and skills. There is such a sense of care and wanting people to know they can get through in the words that were shared, we hope you find a snippet or two of these words educational, validating, inspiring or maybe a little comforting.

On what Panic and Worry can invite into our lives

It can get in the way of connecting with what is important to us

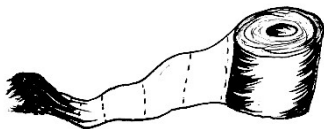
*I've had many times in my life where I felt afraid. Whether it's a mild worry or an all-out panic, I find fear gets in the way of living. If I'm scared, it means I don't feel safe. And really, **being safe** is pretty high priority.*

Panic gets in the way of the kinds of relationships that I'd like, sometimes it from the things that are really important to me.



It can be pretty scary!

Pretty awful, terrifying and hectic.

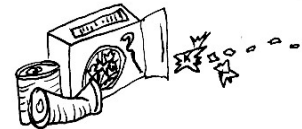


Covid-19 does feel pretty scary to me. Not in the sense of needing to panic buy. Actually panic-buying makes me scared. But thinking about all the lives lost and still to be lost, and feeling scared about how some people are behaving towards each other. I'm a bit scared of going to the supermarket, it doesn't feel like a safe place anymore.

Inviting sadness along with it...

If I'm fearful for a long time, I start to feel sad and despairing as well.

[It feels] Bleak. Sad. Apologetic. Feelings of frailty, impending doom, no good end in sight. Inability to support or help others.



We can become stuck, immobilised or frozen

Fear makes me want to hide away from others, it makes me more hesitant, and less confident, and kind of frozen.



When I've been really worried or faced panic, I suddenly feel all alone with it, sucked into a vortex, and then I freeze with the thoughts of what awful things could happen.

Immobilising. I couldn't do what I ordinarily could do like go for a walk. My heart raced and my heart pounded going outside onto the street. I couldn't stay in confined spaces for long, I remember needing time outside to get fresh air but I couldn't be around people

Being immobilised by fear or anxiety, PTSD, worry and loneliness, leading to depression. Being unable to have support. Panic leading to lack of trust, self isolation, loss of jobs and friends, being misunderstood, betrayed by people close. Feeling suicidal, self harming, wanting to abuse drink or drunks, trying to self medicate.

It can make up stories about the future and our capabilities

Sometimes I don't notice when panic rises up, it tells me that it is the absolute truth of the situation, it's somehow able to disguise that it is greatly exaggerating things or making up stories about what "will happen".

My mind runs concerns over and over, they grow into big problems! But if I can't do this, I can't do that, and then I can't do that either...it's a snowball rolling down a hill, gathering more snow, becoming a snow boulder, becoming an avalanche.



It can have a lot of bodily effects!

Immobilising. Frightening. Racing thoughts. Fizzy body. Pacing nowhere but everywhere. Painful.



what made it so hard was being alone with it spinning in my head, making me so tense and overwhelmed, I couldn't think straight.

It was overwhelming, felt like I would die, my heart would burst/stop and I would wet myself... nothing seemed to make it better

I felt overwhelmed and could not think straight

it was horrible. i was the living dead. but it ended.

Awful. My body was shivering, heart palpitating, not enough oxygen, too much oxygen, restless, I felt nauseous, had migraine for weeks, terrible dreams and sleep paralysis. Vomiting and severe anxiety attacks where I would collapse where I was and be very dizzy with numbness.

My throat swells and until recently I could not differentiate between asthma and anxiety. I get scared.

[I felt] Disassociative.

It was really scary, I felt pain in my chest like I was having a heart attack. I was Hearing Voices that told me I was going to die, which made it all so much worse because I started to believe them.

Like sinking into a deep hole. Feeling out of control with zero help or understanding.

Overwhelming and overthinking [felt] numbing

On what we have known to be useful when facing Worry or Panic

Reflecting on what makes me feel safe

When I notice feelings of worry or panic, I check in about what I am scared of, and what I need to feel safe.

If I'm in panic mode, I need to be able to call on my inner resources, focus on stopping, making things still, whatever feels right for that time, whether it's meditative, walking, drawing, music. We each need to have our own reserve of these ways to calm.

Hold tight to any feeling that is known to be good.

Sharing the experience with others

Sometimes I find talking to a trusted mate is great to help put things in perspective and reduce my fear.

Ring friends.

My tip is trying to get a hold of someone who is able to help plant my feet on the ground..

Worry is reduced if I can pull myself away from my own head and talk out my concerns with someone, a person who cares and will listen all the way through, a person who can smile, offer reassurance, relate, and offer some steps to help me sort out all that I'm fretting over.

Be with trusted people and avoid arseholes.

What helped was when I found a way of being listened to, where all feelings were welcome.

Keep in touch with other people, remember that the best that we can hope for in this life is to be the narrator of our own story.

Reaching out to like minded people. Spending time with animals.



Knowing it comes and goes



Remembering that it passes like a wave and delaying action on anything important when I can think panic might be around is how I get through with minimal effects. This too will pass.

Don't approach cliffs, real or metaphoric where it's only one step over the precipice. Cos there's no backward step.

Ride the wave think like a canoeist on moving water - as long as I move slower or faster than the water I will be ok.



It does pass, and I joined a peer support group to learn that panic attacks and debilitating anxiety can come in waves, can be situational, are often unpredictable in terms of when, where and for how long. But, that feelings are just feelings and can no more harm me than my shadow. So I learned to accept, name my experience and then keep moving through it.

Acknowledging things are hard and you aren't overreacting

Sometimes there have been pretty good reasons to feel scared, so then it's more about making some changes in my life.

Taking action on injustice that makes us feel scared

Increasingly over the years, I find I'm less interested in accepting things that are not OK, and I find getting politically active is a great way to tackle my fears, by trying to help create a world that is safer for all of us.

I'm turning my energy to things like #TheKindnessEpidemic, because it reminds me of all that's good in humanity, and to using the little political power I have as a citizen, to help hold our governments to account.

Take up some sort of cause for yourself. If you're sick, try to help others who may be affected as you are.

Considering crisis as opportunity

Think about the possibilities a crisis can also deliver - for more kindness and for a slowing down of life, notwithstanding the suffering that such a crisis produces - I don't wish to diminish this.

Specific skills

counting, I find this calming (personally I like repeats of four).

focus on the little, manageable things and most importantly, on supporting each other.

Get enough or at least some sleep. Don't drink to intoxication.

Suspend sense making for affect regulating. Focus on the physical sensations via breath work, mindful based activity. Slow down. Move with purpose. Compare perceptions with reality.

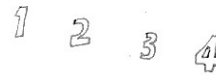
Just focusing on my breathing and what I can deal with now at this moment.

Dogs.

God.

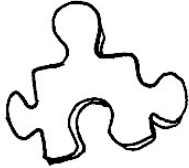
faith.

Focus on something you are interested in.



Focus on one thing at a time, tell myself to worry about that IF it happens

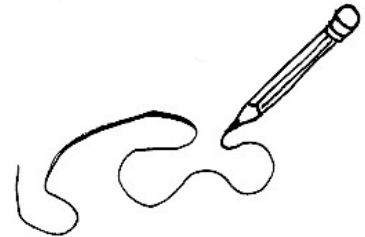
Switch off all non essential social media. I enjoy gardening so I go in my garden. My cats and dog are my best medicine. I see my psychologist weekly. Try to eat healthy.



I know I have to ground myself in the present and distract myself from my thoughts. I listen to music, have a bath or shower. I also find drawing or colouring in helps. I play candy crush or online games, or do puzzles. Walking or doing something physical helps me to.

Cutting conversations short, and walking and nature were so very helpful in a) giving me something to focus on, rather than my fear and body reactions, and b) it was free as looking at clouds was something I could and can do wherever I am. (and sometimes I may Google Images of clouds if it's not possible to go outside)

Find your focuses. Whether it's a pet, work, a project, helping others. Be creative, make artwork, learn a craft, write, start a hobby. Get outside in nature, swim in the sea, walk in the woods, dog walking, nature photography. All these things can be done alone and help focus on something else, other than the panic that starts when other people are around, or when demands are placed on you. If you can, exercise, meditate, walk, stretch, move your body. Eat healthy.



On getting through periods of isolation

Connecting to the importance of being isolated right now

I was forcibly isolated in psychiatric services, and frankly it was terrifying for me. I don't feel that way about the need to isolate for Covid19, in fact I don't think I would mind if we are all required to isolate ourselves at home. I'm not sure why it feels different. In both cases, the choice is not in my hands, so it can't just be that. Maybe it feels different because being isolated in a mental health service felt both unnecessary and abusive. It certainly didn't keep anyone safe, if anything it caused harm. But, I think isolating ourselves because of Covid19 is a sensible step. It may help to keep all of us safer, especially many people with vulnerabilities like disability or age, and that seems pretty damned reasonable.

Think of the greater good - how my behaviour will be most helpful to others.

Being grateful

Cherishing the slowness and the quietness. Bringing myself into myself. I am tired of noise, light and business in any case!

being isolated in my own home is a safe space for me - I have my adored cat, Angus, my art materials, my books, and my favourite pillow. Of course, not everyone has a safe space at home, or even a home...

Being isolated can suck! When I have been forced to be in hospital I would sleep or make art as it was the only thing I could do to pass the time. Luckily in COVID isolation, we might the chance to indulge in things you otherwise wouldn't get to do but enjoy. I might even watch my favourite movie that I like to watch over and over again, for me it is The Blues Brothers, my favourite part is all of it, what's there not to love, the singing, the dancing... ah!

See the good in it. Time to be with self for repair. Get sunlight.

Increasing feelings of agency and choice

The worst bit about it is the fact that someone is telling you that you can or can't do something. Finding ways to feel like you have control over what you do in these times can be counter-affirming, like deciding when you sleep or eat, organising objects or furniture or making something like art or food. I wonder info folks in COVID isolation might find trying something like this helpful.

Remind self to do something with what one can control and not worry about what one has no control over.

Staying connected in inventive ways

Depending on what forced your isolation, you can reduce impact. If it's cause was losing friends, family that supported you, find online community. That really helped me. We had commonalities. Always have somebody to contact tomorrow, also, because completely cutting yourself off from others will slowly make you feel like you no longer exist. And you do.

I would look up 'listening partnerships' online, or words to that effect, and find ways to join a support group or similar where you get to vent and feel seen and heard. There are more and more groups springing up and they make a difference in helping you breathe and think of the next most rational step.
xxx

Remember it doesn't last forever and keep up the social glue that holds us together.



Develop a network of other people you may know who have self isolated and make up word games that can be played on line.



Talk over phone to people you like. Use messenger if you don't feel up to talking.

Stay connected. Phone calls, social media, emailing or Skype. Enjoy this time with yourself, or family, like a holiday!

The internet is a saviour with online movies, kindle books, audacity, social media, Letterboxd, blogs and self help sites, as well as Online learning and education.

Keep making plans

When you are winding down for the day, think of what you want to do tomorrow. Even if it's just one good thing, that's one thing that will motivate you to get going, out of bed, when you wake up.

Make doable and sensible plans. Don't call in strife or unhelpful people. Do some jobs but do some stuff that's more likely to be enjoyable and not risky or dangerous. Know that the tough parts will pass. Reminisce good times.

Make a list of a mix of things needed/wanted to do. Include fresh air - garden or open window gazing. Remind self of pleasures.

Look upon it as a holiday and think about the things you say "oh I wish I had time to do that" especially in the home. Keep busy.

Plan some fun things for the day, as well as planning important tasks, make a schedule for the day. Imagine your on a holiday, resting in a spa. Schedule in your day some nice meals, exercise, a good movie, maybe decide to tackle all those things you were meaning to get to, like tidying up a cupboard, learning a new language, reading some educational books, or getting lost in some classic literature.

Stay in touch with your interests

If you had interests you let go when occupied out in the world, renew them, a bit at a time, a little every day.



Ideas for what you might enjoy getting up to!

Drawing, music, connecting with others through social media, cooking, cleaning

Have nice things you like to eat. Garden, tidy cupboards etc. keep busy doing what you like. Late at night when people are asleep and you feel crap look at funny pictures or videos. Even if you don't feel like it or can't settle. It will help you settle and have a real laugh. You'll feel better and be ok.

curated social media connection. baths. dog.



Distraction, reading, internet and movies, just binge watching your favourite tv series (comedies are good).



Phone calls, do the gardening.

Document your journey. You'll see how it changed you, how you grew.



Purposeful Movement within the house like painting walls.

Hobbies, studying online, connecting online with people, volunteering, doing jigsaw puzzles, playing guitar, gardening, journaling, helping others in need, cooking new dishes, and spring cleaning doing those jobs I don't always get to. Initially forced isolation from those I love was so very hard, but over time I've noticed it gets easier, and can even have benefits. I have more time to do what I want when I want to do it and that feels good.

Good books, movies, music.

Learn new crafts, upcycle things in my house, like old clothes, or cutting up magazine and making decoupage furniture.

Going for drives, taking pictures, and have start writing a book.

Writing, knitting, making Jewellery, photography, digital art, making clothes, decoupage, cooking and baking, reading, meditation, yoga, stretching, walking, swimming in the sea, spinning yarn, making notes.



These are some of the insider knowledges from a selection of people who wanted the world to know them. We hope that by reading these things you might feel less alone in your worry and isolation experiences. Some of us visit these experiences regularly and we have your back in getting through what might be new to some. Maybe you have knowledges of your own to share with your communities, we would encourage you to do so! Maybe you could record the things that are helping you through right now, we never know when we or others could stand to lean on that wisdom.

If you would like to respond in any way to this project you can email : 91312@protonmail.com

