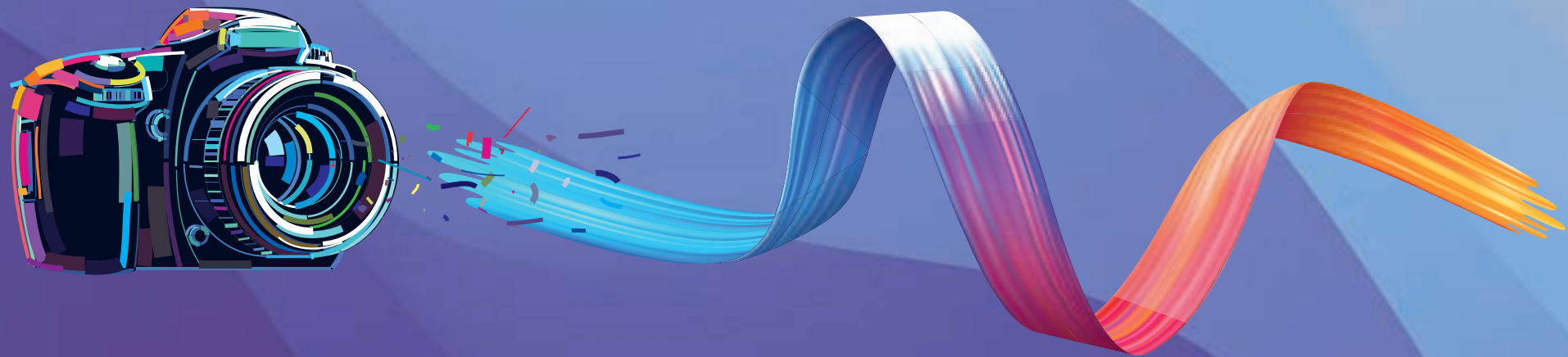


With Us, For Us
Lived Experience Project Group



Living with Trauma

Storytelling through Photography and Artwork



Our reality of living with trauma.
Published in 2023 All content With Us, For Us, VOX, SRN and the individual contributors.

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Background to With Us, For Us Project

Scottish Recovery Network and VOX Scotland were commissioned by Healthcare Improvement Scotland to support the work of the Personality Disorder Improvement Programme by engaging with people with lived experience to inform the final programme recommendations. The programme of engagement provided an opportunity for people living with trauma and/or who have been given a diagnosis of personality disorder to share their experiences and what supports their recovery and wellbeing. In particular there was a focus on their experiences of services and their ideas for improving services.

Scottish Recovery Network, VOX Scotland, and us, the Lived Experience Project Group are developing a suite of resources in line with the findings of this report. The resources will aim to address some of the issues around stigma and discrimination, as well as provide support for services to develop best practice including this: **'Our reality of living with trauma'** resource.

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Scottish Recovery Network promotes and supports mental health recovery.

Our vision is:

Together we can make Scotland a place where people expect mental health recovery and are supported at all stages of their recovery journey.

Our mission is to bring people, services and organisations across sectors together to create a mental health system powered by lived experience which supports everyone's recovery journey. Collaboration and lived experience are central to our work.



Our Website: <http://www.scottishrecovery.net/>
Email us: info@scottishrecovery.net

VOX Scotland is a national membership organisation, open to all people in Scotland with lived experience of mental health difficulties.

VOX Scotland works to ensure that people with lived experience can shape Scotland's laws, influence service design and delivery, promote a better understanding of mental illness in wider society and advance the general interests of people living with mental health issues.



Our Website: <http://www.voxscotland.org.uk/>
Email us: info@voxscotland.org.uk

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Why

did we want to develop our 'Living with Trauma' booklet?

”

Our ambition was to be able to communicate more effectively with professionals and the wider community what it's like – no more cliches!

”

It's about encouraging people to see the picture and put their own meaning to them, it's not always obvious.

”

Each picture can mean something different to people, to us it means something important. Everybody's different, including our perceptions.

”

Having mental illness and trauma is hard and an everyday struggle, but if I can use my struggles to help others get the care and understanding they need and deserve then it will at least bring something positive, however small.

”

As someone with 2 degrees in journalism, this is a new way of creating a story and sharing an experience with a fresh perspective.

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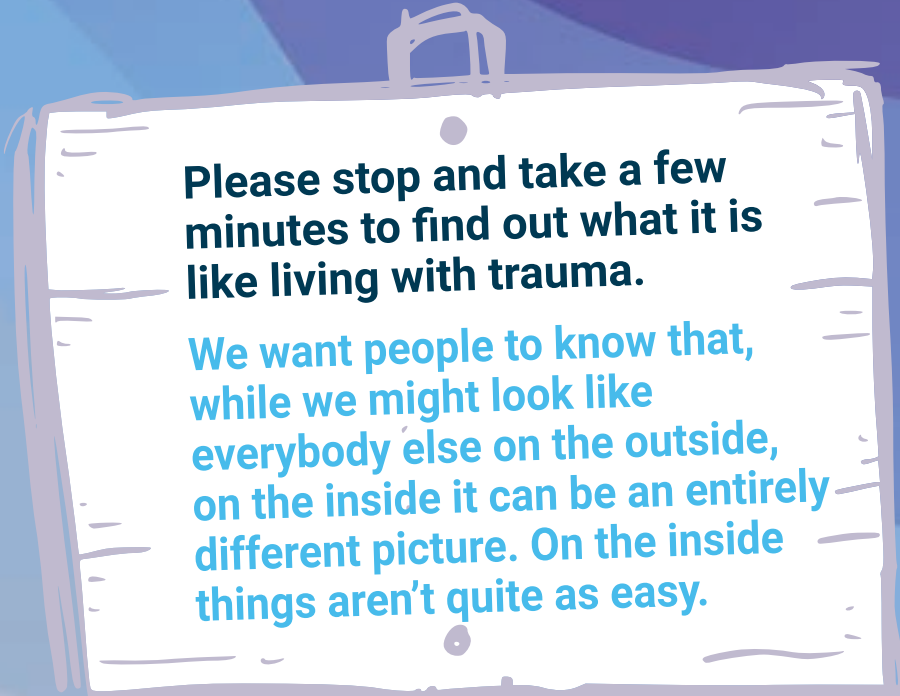
How

did we develop our 'Living with Trauma' booklet?

Over a two month period, the Lived Experience Project Group who are based around Scotland, participated in regular photographic storytelling workshops during February and March 2023 online via Zoom in addition to previously attending 'PhotoVoice' 1 day training earlier in September 2022. We were invited to capture our own photographs and captions and encouraged to explore ways to share our own powerful insights and experiences. In this co-production approach, we had control and choice over which photographs articulated our experiences as we would like them to be understood.

We hope our Living with Trauma booklet will contribute to the wider With Us, For Us project and the powerful captions and photographs will provide insight and a starting point for further engagement

We recognise that recovery is hard work and in this context we feel that it's important to have peer support and to develop our learning from each other. In creating this booklet, we have looked to our own experiences of: how does it really feel?



Please stop and take a few minutes to find out what it is like living with trauma.

We want people to know that, while we might look like everybody else on the outside, on the inside it can be an entirely different picture. On the inside things aren't quite as easy.

Our Message

We, The With Us, For Us Lived Experience' Project Group (LEPG) were interested in sharing our creative skills to have a voice through photography.

This booklet visually illustrates, in our own words, the reality of living with trauma.

What we would like to communicate:

- » This is our interpretation and our way of sharing and hopefully enlightening others.
- » This is our everyday, this is what it's like, this is capturing our voices.
- » We understand that everyone's experience of trauma is different but here is some insight into ours to share.

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The wave and the night rainbow

The night can be lonely, frightening and I can feel vulnerable, it's a time where I question life, my purpose. It's where the trauma's fester, they become heightened and then come crashing down, ready to rise back up again.

But when I'm confronted by a wave of colour rolling through the night, I am challenged. I didn't realise these two things could exist together, the powerful crashing waves of the darkest night meeting their match in the colour of an inexplicable night rainbow.

All of a sudden I realise that the darkness has colours and textures, they're reflected in the radiance of the colours.

Night traumas are still there, they rise and fall, but so too is the light of the rainbow, in all its colourful reassurance and comfort. I could paint with these colours and make it through the night.

My friend Susan painted this stunning piece of art, she called it - "Night Wave, The light shines brighter in the dark of night."

Permission for use granted by the artist: Susan Card



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Peer Support

These 3 women became friends through COVID. None knew each other before they connected through shared interests on social media. This led to friendships. Then traveling 100s of miles to meet up together.

They represent strength and weakness, becoming friends while stumbling across how to support one another. Sharing everyday life, crafting together and crying together. Together they learned to crochet, paint watercolours and shop online, at the same time they shared their struggles and traumas.

Creating a genuine place of kindness and compassion.

It's authentic 'peer support,' to use the jargon, its people coming together to get through this life, daring to be vulnerable, and always making space to laugh and be yourself.

Peer support is vital to me, as someone constantly living with the effects of trauma and relentless mental illnesses, I wish I could find peers in my town too.



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Snowberry amongst the thicket

As I dared to step out the door of my home today, I captured a few remaining snowberries that are alive, not perfect but still living.

I had anxiety about going out before COVID, now that anxiety is debilitating, I struggle to leave the house for anything. My struggles stem from trauma, they are terrifying fear, smothering guilt and bleak loneliness.

I want to leave the house, I want to enjoy a coffee with a friend. I long to take my young nephew out for adventures. I want to live. But I feel isolated and cut off.

But if these little berries can survive the hedge trimmers and the harshness of winter, perhaps I can try to poke my head out of isolation and see what I can see. As I try, as I dare to ask for help, please don't stigmatise me, appreciate me as a whole, don't only look at my labels and roll your eyes. I need some help please, to be met with kindness and compassion, a hand held out in support.



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The Christmas blanket

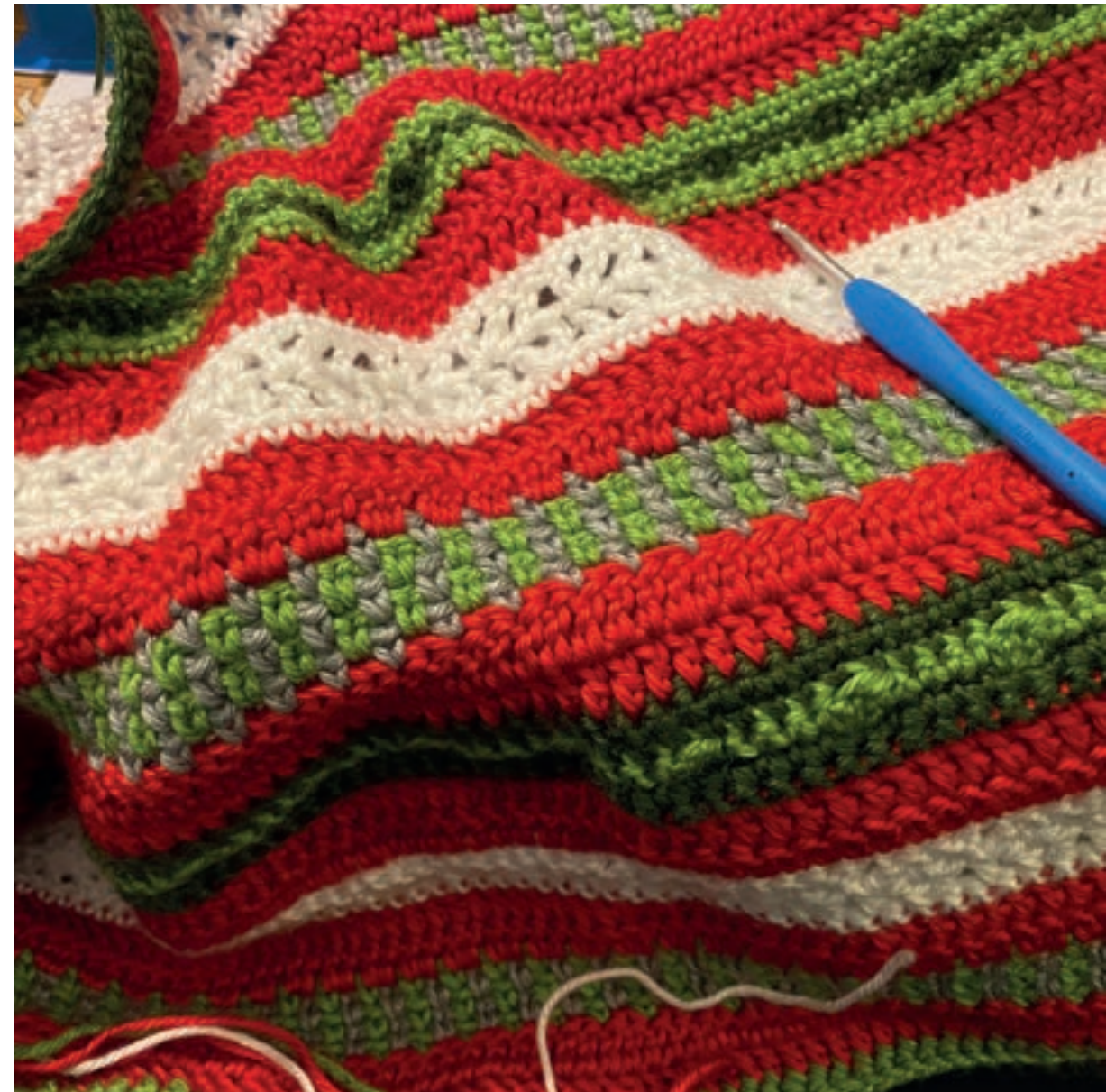
I started it in October, it's now February.

Will the cycle ever end, the pattern goes on for pages, and repeats .. coming back to the same pattern again and again.

Sometimes I despair that life is going on and I have little control, it goes round and round in cycles of trauma responses, struggling through flashbacks, disassociation and anxieties. Dredging through a life affected by trauma can be a hard slog. Even harder when you try to be apparently competent.

Then I remember to look at the beautiful colours and the warmth of the yarn and I pick it up for as long as I can persevere again. I may spend time hiding away, everything is a threat and I feel guilt for not taking part in all that life has out there. Then one day I have the energy and courage to engage. And I see that I can find enjoyment for a time.

Hoping the blanket will be finished and ready to bring comfort by NEXT Christmas.



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The Reality of Living with Trauma

I can't speak for everyone living with trauma, but I can share my experience of what it is like.

One of the first words I would use to describe it is frozen. Frozen through fear. Frozen when the memories and flashbacks strike. Frozen in time. Frozen in a mind that is that of a much younger, child me while by body and life is existing in an adult world. Frozen in an existence where I can see the people and the world around me moving on, advancing, growing up and succeeding while my life has remained small and full of fear and struggle as I desperately try to find a way through and cling on to hope that it won't always feel this way.

Many people would not look at me and know about these daily struggles. On the surface I, mostly, function and appear fairly composed. But trauma doesn't have a specific look and what you don't see is the effort and difficulty that goes in to trying to appear 'normal,' or the way every day I try to suppress the memories, fears, depression, anxiety and suicidal thoughts and mask my ASD in order to get by in a world that feels overwhelming, scary and at times, just too much for me to cope with.



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Like the swan on the lake looking calm and serene, you can't see how much she has to work to stay afloat, or how dirty the water below is, or how strong the currents below really are and how quickly they can pull you under.

And much like the water, the currents change. Some days can be better than others. In fact, for me, my mood and struggles can swing greatly just throughout the course of a single day which makes the experience even more difficult to cope with as I don't feel in control of my emotional state. It isn't always easy to know what triggers my mood and destructive thoughts to change so quickly, sometimes it may just be one thing that triggers a memory to a time where I felt, and was, unsafe, other times it is the culmination of experiences or thoughts over a day or a few days that, much like the ripples on the water, intensify and grow bigger until they feel, to me, like a tsunami and I am swept below the surface. When that happens, when I feel like I am drowning, not just with the trauma but of the feeling of not belonging in this world. I just want it all to stop and often feel like my life isn't worth living. Unfortunately, that is when the daily suicidal and self-destructive thoughts are more likely to turn into plans and actions as I am filled with self-hate, a belief that I am a bad person and that I am not made for this world and I just cannot cope with this existence anymore.

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Sometimes, myself and people who have similar struggles are met with negative judgements and misunderstandings when we have these experiences of intense emotions or self-destructive behaviours. Some people regard it as immature or attention-seeking, but for me that couldn't be further from the truth – at those moments I want nothing more than to disappear, stop the feelings and not be noticed - and those judgements hurt and add to the already high levels of emotional turmoil and self-hate that I experience.

However, for people like me, it doesn't have to be all bad. There is still hope if people can learn to understand and we can get the right support to allow us to manage - or fully overcome - the struggles and start living a life that isn't ruled by trauma and mental illness. It won't be a quick fix trying to undo the years of negative beliefs, thoughts, and memories, but rather a slow thaw. By slowly but surely creating and adding positive ripples to the water - appropriate treatment, understanding, time and help to build confidence and add meaningful components to our lives – we can move from that frozen state described above to one where we can have a hopeful and fulfilling life, potentially alongside ongoing mental illness, and not a life merely filled by mental illness and hopelessness alone.

Yes, living with trauma and enduring mental illness is hard and a struggle to fully explain - the above words barely even scratch the surface. However, maybe they can help just to shed even the slightest bit of understanding and potentially more importantly, help to convey some hope that with the right approaches, there is hope and a much brighter path ahead for people living with mental illness.

I express my feelings through song
“Music was my first love,
and it will be my last” (John Miles).

“Here we go,
here we go
round the world”

Opening words of Live Aid,
(Status Quo)

*I was actually there,
best concert ever.*

*Co production
at its finest;
84,999 + me + global tv.*

”



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**“I’m still
standing”**

(Elton John)

Although I have good days
and bad days, I keep going.



“All is quiet”

(Susan Cattaneo)

Cruden Bay Beach, not as quiet as it looks

All is peaceful on the outside, but underneath
my stomach is churning.

Cruden Bay beach, looks peaceful, but
underneath it is the pipeline bringing ashore all
the North Sea oil, churning away 24/7.



“The Long and Winding Road”

(The Beatles)

Windy and hot

I hate the heat, living with trauma,
never ending, times of self hate.



“Knocking on the green door”

(Shakin’ Stevens)

What colour am I today?

What label am I going to get?



“The Northern Lights of old Aberdeen, sorry Cairo”

Nightmare to me, to others...

The Mental Health system, many pathways,
which has the right light for me?

How it feels when working through mental
health issues.



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Faces

I used to struggle to identify as a person who had experienced trauma. Trauma was always presented to me with a capital 'T' – as if it were a checklist of things a person might have experienced that would somehow justify their struggles. Someone once rattled this list off to me, appearing increasingly frustrated when I answered 'No' to each one, their response loaded with the implication that if I hadn't experienced these big T traumas, there couldn't possibly be anything wrong.

At the time, I internalised this as a belief that my struggles made no sense and I was therefore inherently flawed. These days, however, I understand that a person can experience trauma not only through these big 'T' events, but through a series of small 't's throughout their journey.

I understand, now, that the everyday encounters a person has with the world can teach them that it is a dangerous place where they do not belong; that even these "minor" experiences can train – as Van der Kolk puts it – "the alarm bell of the emotional brain" to remain on high alert; and that this emotional siren can be responsible for many of the symptoms associated with poor mental health.

When we talk about trauma, I wish more people would remember the small 't's as well.

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Mountain

When people took my experiences and put them into a personality disorder box, the box came firmly packaged with a set of assumptions about who I was and how I experienced the world. It didn't matter that the box never really fit or that the things inside it made no sense to me; this became the only way that I was seen. I was no longer an individual person with my own identity – people saw the diagnosis and assumed they knew everything they needed to know about me.

I encountered some well-meaning people throughout my journey: people who were sincere in their desire to help, but blinkered by the label given to me. Often, it felt like being lost up a mountain with someone trying to help from beyond a sea of cloud. They were trying their best to help me navigate my way back down, but they couldn't actually see what I saw from their place beneath the cloud. They were guessing and assuming based on mountains they'd encountered before – the route 'must' look like this; the terrain 'probably' feels like that – but my mountain had its own unique trail with its own distinct view and their guesswork attempts at helping only further disoriented me. It was a painful experience – getting my hopes up that help was here, only to end up all the more lost.

What I needed was for them to put aside their assumptions and to climb up through the cloud. I needed them to get alongside me – to walk in my shoes and see the world from my point of view – in order to help me find the safest route back down.

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Snowdrops

Snowdrops have always felt like symbols of hope to me. After the cold and the dark of a winter that seemed like it would never end, snowdrops are the first to poke their heads up through seemingly - barren land – the first signs that things are changing and spring is about to come.

It felt like a cold, dark winter in my mind for a long time. It was difficult to believe there would ever be snowdrops on my recovery journey, but I found them eventually -
– little indicators that things might change; that better days might come for me.

My snowdrops sprouted up through a third sector support service who looked at me not as a label or a level of risk, but simply as me – a whole person, with opinions and interests and hopes and dreams, all of which they nurtured within me. My snowdrops grew further with long-term therapy, delivered by a professional who disregarded labels, helped me piece together my story, and shifted between modalities according to what I might need. My snowdrops blossomed in abundance through peer support – both connecting and finding solace through people with similar experiences to me; and then taking on a supportive role of my own, finding meaning and purpose to the winter of my past.

I have high hopes that, one day, our understanding of trauma and the things labelled “personality disorder” will shift in such a way that peoples winters need not be so long; that their springtime arrives more quickly; that there are snowdrops everywhere we look, varied and abundant in the things that offer hope.

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**Reflect
on these
questions**

**What's
it like to
live with
trauma**



**How
would
you feel**



*Try taking
a photograph
to show
something
about your
day-to-day life
that people
may not
know about.*

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Our thanks

go to Scottish Recovery Network and VOX Scotland for support to co-produce this booklet and to each other for offering and providing peer support to make this happen.

We also thank PhotoVoice in introducing us to a powerful and creative way of communicating our experiences.

**We hope that the individual photos and captions in this booklet illustrate:
"This is what it feels like."**

**PhotoVoice is a UK based non-profit organisation which promotes the ethical use of photography for positive social change.
www.photovoice.org.uk**