



RECOGNITION & THANKS

This work was gathered and produced in Tarntanyangga, which belongs to the Kaurna people of the Kaurna nation.

Thank you to our contributors Gus, Red Sky, Little Cat Trauma, Shannon, Tim and Maggie Bell. We offer thanks also to the Office of the Mental Health Commissioner for South Australia who supported this work through a small grant.

LELAN recognises the lives and work of people with lived experience, particularly those that passionately, intentionally, and skilfully use their lived experience for change. It matters.

This zine discusses topics including mental distress, suicidal ideation, suicide attempts, and death by suicide. It also shares key advocacy messages and actions we can individually and collectively take to improve things.

Medical Disclaimer: This zine is not intended to be substituted for professional medical advice. If you are considering starting, changing, or stopping medications, or making decisions regarding your treatment and support, please reach out to your team and seek input tailored to your circumstances and needs..



EDITOR'S NOTE

Many Australians could reasonably understand and expect what being prescribed an antidepressant involves.

Almost none of us know what can happen when we increase, decrease, or stop these medications after long term use.

Withdrawal effects can be long-lasting and debilitating.

Reducing and discontinuing antidepressants, also known as deprescribing, is not yet well understood by the medical community.

Many folks changing or ending their use of these medications are left to find out for themselves what side effects they may experience and how to taper from them.

In this zine, we have gathered the stories, art, and lived experiences of people who have been through this.

The zine has been part of the Antidepressant Withdrawal and Deprescribing Project in Australia. Our goal is to foster an open dialogue about the challenges surrounding antidepressant prescribing and deprescribing, and to advocate for vital improvements to information, supports and services for those seeking to reduce or discontinue them.

THE **AUSTRALIAN** PERSPECTIVE

South Australian-based researchers from the Critical and Ethical Mental Health Research Group at the University of Adelaide are leading research on antidepressant withdrawal experiences.

Researchers surveyed 555 Australians who attempted to, or were currently attempting to, cease antidepressant use.

They focused on prescription, withdrawal characteristics, and experiences with healthcare systems.

While their research is still in the process of being published, LELAN has gained permission to report the following statistics and findings.

almost

of people surveyed were first prescribed antidepressants under the age of 25

45% withdrawal symptoms were intolerable

just over

have been taking antidepressants for 10 vears

were unable to get informed advice on how to safely and easily stop antidepressants

40%

said they had not been able to stop antidepressants despite wanting to stop

40%

were told they could stop antidepressants in a few days or weeks without problems

were told by their doctor that their 34% withdrawal symptoms were a return of their underlying condition

WHAT NEEDS TO HAPPEN?

When asked what needs to happen to improve healthcare experiences, survey respondents suggested the following:

More **education** for prescribers on withdrawal effects and how to taper safely.

More **information** about the risks of withdrawal effects.

More available **alternatives** to antidepressants for treatment of depression, anxiety and insomnia.

Easier availability of **smaller doses** of antidepressants.



Online peer support groups and websites were identified as most helpful.





This is who I am, here and now. I checked my phone, rifled through my address book, and scoured my email contacts. In a rush, with my eyes clouded by uncertainty and anger, I searched... through friends and acquaintances, desperately seeking a silent embrace. An embrace that would ask no questions about my tears, offer no judgments, give no advice, or attempt to console me. I found myself alone, in the middle of nowhere...

Gus Hibberd wrote this tribute to his friend, Ed White, who was very much loved and respected in the withdrawal community. After all Ed had done for the withdrawal community, he was unable to endure the withdrawal effects from Efexor any longer and tragically, on the 13th of October 2021, ended his life.

> GOOD RIDDANCE EFEXOR, YOU RULE ME NO MORE, YOU MADE ME PAY FOR ENDLESS DAYS AND MANY MORE. I KNOW WHY SOLDIERS DON'T SPEAK ABOUT WAR, AND I KNOW OTHERS HAVE SUFFERED, MUCH MUCH MORE. TRULY DEVASTATING, UNSPEAKABLE THINGS. THINGS NO ONE SHOULD ENDURE, FROM STOPPING "MEDICINES". WE DON'T SPEAK OF IT TOO MUCH, TO THOSE WHO DON'T KNOW, IT MEANS DIGGING TOO DEEP, IN THE HOLE WE KEEP CLOSED. IN THIS TERRIBLE STATE, OUR EYES BECOME TRULY OPEN, NOW THEY'RE OPEN WE REALISE, THERE AREN'T MANY WE CAN COUNT ON. THE SLEEPING BEAR, HE'S STILL THERE, WE DON'T WANT TO WAKE HIM, IT'S BEST TO AVOID THINGS MOST STIMULATING. THE KINDNESS FROM STRANGERS, IT CAN MAKE US STRONG, GIVING US THE WILL, TO HIDE WHAT'S GOING ON, AND FIND A WAY TO CARRY ON. UNTIL THE LIGHT STARTS TO SHINE. IT BRINGS US BACK FROM THAT WAR. FROM THAT KINDNESS OF STRANGERS, WE START TO GROW CLAWS. LIKE THOSE BURIED DEEP, TWISTING OUR BONES, SHARP, LIKE HIS WHO HOLD US THERE. BUT A DIFFERENT REASON FOR. THERE'S NO USE TRYING TO FIGHT THE ONE WHO CAN'T BE FOUGHT. FOR YOU MY GOOD FRIEND, I WISH I'D DONE MORE. WE SLOWLY CLIMB OUR WAY OUT, UP THOSE PITCH BLACKENED WALLS. IMPOSSIBLE TO FORGET, THE WAY IT TORE, THROUGH OUR BRAINS AND BODIES, TOO OFTEN MISDIAGNOSED, AND NEVER FELT BEFORE. IT BURNS EVERYTHING, THE HOTTEST VOLCANO IN HELL.

> > I KNOW I'VE NEVER FELT SO UNWELL.

BUT I'M READY FOR IT NOW, IF WHEN I DIE I GO TO HELL..

I KNOW THE PAIN YOU FELT, BECAUSE I FELT IT TOO,

I MANAGED TO MAKE IT THROUGH, SO I HAD FAITH IN YOU.

BUT I'M NOT YOU AND YOU'RE NOT ME. WHY THIS DID I FAIL TO SEE?

YOUR KINDNESS WOULD'VE SURROUNDED YOU, BUT I JUST COULDN'T SEE.

IN TIMES OF PAIN, FRIENDS ARE MEANT TO BE THERE.

MAYBE YOU THOUGHT I DIDN'T CARE? AND I BET YOU WERE SO SCARED.

YOU LEARNT SO MUCH THE FIRST TIME ROUND, NOW YOU WERE PREPARED.

I KNOW HOW STRONG HIS GRIP IS THOUGH AND SHOULD'VE SHOWN MORE CARE.

WE GET TAKEN SO FAR AWAY WHERE NO ONE HEARS US PRAY,

LEFT THERE ALONE, TO ENDURE, UNTIL IT SLOWLY FADES.

NO ONE CAN SAY HOW LONG IT TAKES, TO LEAVE THAT DARKEST PLACE,

PRISONERS IN OUR BODIES AND BRAINS UNTIL IT SLOWLY FADES.

IF ONLY I'D MESSAGED MID WEEK, SO I REALLY KNEW, JUST HOW MUCH

THAT DESPERATE PLACE WAS AFFECTING YOU

YOU SAID I WAS VERY STRONG, TO'VE MADE IT THROUGH,

WHY WASN'T THAT MY CUE, TO REACH OUT FOR YOU?

WHEN IT RUNG I WAS STILL EXCITED, TO FINALLY SPEAK TO YOU,

BUT WHEN IT WASN'T YOU, I KNEW.

I PRAYED FOR A MINUTE, FOR IT TO BE UNTRUE, BUT DEEP DOWN INSIDE, I KNEW.

I DON'T KNOW HOW SHE KEPT IT TOGETHER AS SHE BROKE IT DOWN,

YOUR HUSBAND, A FATHER, WAS NO LONGER AROUND.

"OH FUCK!! I'M SO SORRY,"

IT'S SO HARD FROM 37.5.

WE'D RATHER HIM HERE ON SOMETHING, THAN NO LONGER ALIVE.

DESPERATELY SEARCHING TO BE EXEMPT FROM AN INJECTION,

I DIDN'T THINK TO ASK THE CAT LADY

FOR AN EXTENSION OF KINDNESS FOR OUR STRUGGLING FRIEND.

YOU'D HAVE FOUND THE STRENGTH, FOR YOUR CLAWS TO GROW,

SO IN TIME YOU COULD SHOW YOURSELF YOU COULD MEND.

FILLED WITH FEAR FROM WHAT THEY'D ALREADY SAID,

THE TRUTH BULLET HAD LODGED, TOO DEEP IN MY HEAD.

FOR THAT OUTSIDE HELP, I WISH I HAD PLED.

KNOW HOW IT IS FOR THE RED FLOWER WHO LOST HER GEM,

WE BOTH NOW WILL NEVER GET TO MEET WITH OUR DEAR FRIENDS.

WE TOLD EACH OTHER ABOUT IT. I THINK WE BOTH TOLD THEM.

BUT NOW OUR CHANCE ON EARTH IS GONE, TO MEET WITH OUR DEAR FRIENDS.

IT WASN'T MEANT TO BE THIS WAY, I WISHED FOR US TO MEET ONE DAY,

NOW YOU'RE IN THAT BLESSED PLACE.

BUT IT'S SO FAR AWAY.

I WISH I'D FOUND THE RIGHT WORDS TO SAY, WE MAY STILL MEET ONE DAY.

I'LL THINK OF YOU WITH YOUR WINGS EACH DAY,

LIKE THOSE ANGELS SENT TO HELP FROM ABOVE.

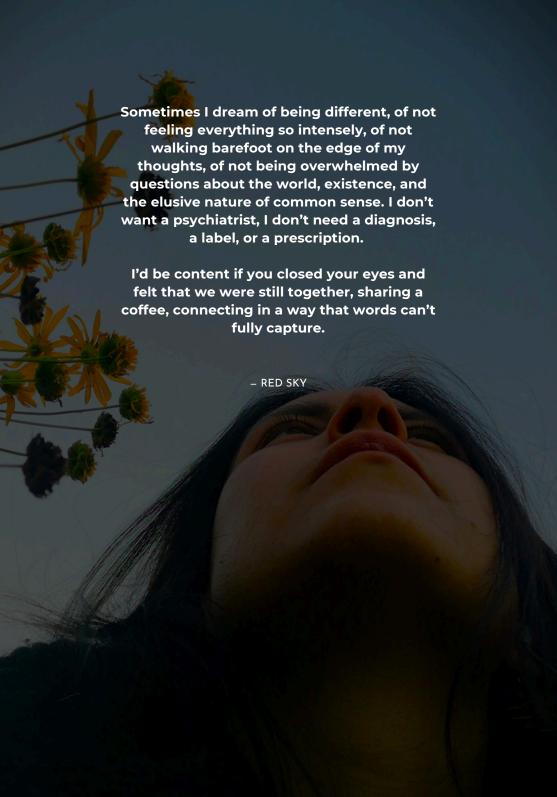
FLYING FREE FROM ALL THAT PAIN.

IT'S OFTEN SAID THERE'S AN IMBALANCE. BUT IT'S NEVER BEEN PROVEN, I WONDER IF YOU WOULD EVER USE THESE DRUGS ON YOUR OWN CHILDREN? THERE'D BE NO SURPRISE IF YOU DID, YOU BELIEVE IN THEM SO MUCH, IF THIS HAPPENED TO YOUR OWN KIDS, WOULD YOU STILL HAVE THAT TRUST? THIS THOUGHT FILLS ME WITH DISGUST, WAIT A MINUTE WHILE I GO THROW UP. I'LL ALWAYS PROTECT MY LITTLE LIGHT FROM THIS INCREDIBLE EVIL, AN EVIL THAT EVEN CONTROLS THE MINDS OF OUR MEDICAL PEOPLE. AN UNSTOPPABLE NEED TO KEEP YOU SAFE FROM THIS MOST OF EVILS. THE ONE THAT'S PEDDLED BY ALL OF OUR BLINDED MEDICAL PEOPLE. ARE THEY BLIND OR IS IT SOMETHING ELSE? ABOUT THIS I OFTEN WONDER. TO ME YOU'RE ALL JUST BITCHES OF BIG PHARMA AND ALL ITS DOLLARS. AND WHEN THE BLIND OUTWEIGH THE UNBLIND, BUT AT LEAST 20 TO 1, MOST OF US HAVE NO CHANCE TO WELCOME THE LIGHT'S RETURN FROM THE SUN. I'M "BRAINWASHED" BY THIS PAINFUL TRUTH, A TRUTH I HOPE NEVER HAPPENS TO YOU. IF IT EVER DID. YOU'D KNOW IT'S TRUE AND YOU'D BE "BRAINWASHED" TOO.

YOU'VE GIVEN ME A PURPOSE, THAT I NEVER HAD BEFORE.
GOOD RIDDANCE EFEXOR, YOU RULE ME NO MORE.

- GUS







ADVOCACY: FOR DEPRESCRIBING ANTI-DEPRESSANTS USING HYPERBOLIC TAPERING AND PERSON-CENTRED APPROACHES

How much soft-soap is needed? If I pleaded

for connection, Would you abandon your tower, of ivoried objections and descend, where humans meet humans?

If "do no harm" has become Blinders creating "see no harm", and if speaking of harm is repellent,

then.... Where. Do. We. Start?

There <u>is</u> harm.
Harm <u>is done</u>.
Yesterday.
Today. And tomorrow
There is disruption and sorrow.
Lives are taken,
Life paths broken.
Yet anger spoken
is frowned upon!

A crowd is told Speak soft, be gentle Be ever-so careful. Remember, remember, It is considered essential That any criticism raised be made as suggestion....

I say:

All this begs the question...
Within this system, where exactly does fragility lie?

I say:

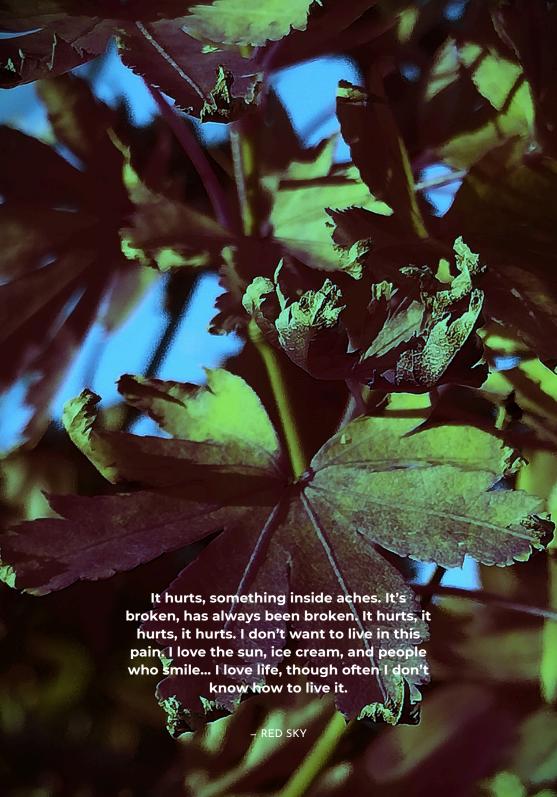
Watch us, hear us
feel our resilience.
We tip-toe quietly
against "expert" status.
We log our adversities,
Our knowledge, our expertise,
we lay case upon case
as foundations for change.

In ceaseless advocacy. We will continue to say: "Here are the harms".



What helped is peer support.

There's still not a person in this world who helped me, like the people who had experienced that level of injury from a fast reduction.

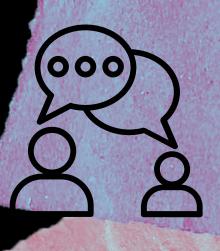




TATTOO MAGAZINE PICTURE ON A RAT TRAP-COLLAGE.

Maggie Bell

This is how I feel. Trapped and the total frustration while trying to advocate for myself. It's beyond exhausting.



'Stop the Silence': Recognise Antidepressant Withdrawal

It's time to acknowledge that antidepressant withdrawal is real, widespread, and needs urgent attention.

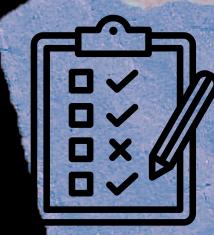
The whole story about antidepressants must be told so that people can make informed choices when considering, starting or stopping these medications.

'Well-intended Harm is Still Harm'

Many prescribers, despite good intentions, unknowingly cause harm by not being informed or educated on antidepressants, their side effects and consequences, and what safe withdrawal and tapering are.

We must educate to break this cycle of harm.





'End the Prescribe-and-Forget Cycle'

Prescribers are quick to prescribe yet forget to provide people with relevant information to make informed decisions and forget to follow up or review regularly.

We call for a mandate that all prescribers have a more comprehensive approach rather than making it a flick and tick.



Education for All:
Equip Prescribers, Empower People

Prescribers need updated education and training on antidepressant prescribing and deprescribing management.

People deserve access to reliable information and tools to safely taper, ensuring informed choices and empowered decisions at every stage.

'Australia's Next Silent Epidemic':
What Will You Do?

Antidepressant withdrawal is Australia's next silent epidemic.

People must be held accountable.

Will you stand by, or will you help bring it to light and be part of the solution?



The Responsibility to Care Means Something

Whether you're a prescriber, medical or allied health practitioner, policymaker, this issue demands attention and action.



FRUSTRATION SEEKING HELP. PERSON SHOOTING THEIR HEAD OFF.

Maggie Bell

I'm particularly interested in the use of art as a creative way of healing and using art for Artivism and starting conversations around community education.

This piece reflects my total frustration at seeking services (including doctors). It's how I feel a lot of the time.



AN URGENT CALL FOR CHANGE

LELAN co-created a series of advocacy messages with people with lived experiences of antidepressant withdrawal.

During this process, people identified three main audiences and accompanying advocacy strategies to target and influence change.

For medical practitioners and prescribers:

advocacy must be done through education, training, and professional development as well as fostering dialogue between people with lived experience and prescribers to address disconnects in realities.

For politicians and decision makers: it is crucial to build bipartisan support, humanise the issue, and use data to inspire action. We also know from our own experiences, and what is emerging in the United Kingdom, that making antidepressant withdrawal relatable evokes genuine policy change.

For the media: visual story-telling and sharing the faces and voices of those most affected is essential.

The media are also a tool to rapidly share the problem and drive solutions.

There are also roles for key allies to drive meaningful change...

Akathisia

It is constant.

Gnawing,

Aching,

Cold and bitter;

An interminable battle against my ceaseless self.

Why me?

My bones

Rotting inside my restless, painful form.

Everything is grinding.

It is against me,

I am against me,

I am my body's adversary.

Little Cat Trauma, 2024.



These resources are not a substitute for professional medical advice. They have been shared by people with lived experience and found to be helpful or valuable. If you are considering starting, changing, or stopping medications, or making any decisions regarding your treatment and support, please reach out to your team and seek input tailored to your circumstances and needs.

Academic Papers:

These papers, co-authored with members of online peer groups, explore antidepressant withdrawal.

- White et. al. (2021): Investigates the role of Facebook groups in managing and raising awareness of antidepressant withdrawal, questioning whether social media is filling the gap left by health services.
- <u>Read et. al. (2024)</u>: Presents recommendations from 708 patients regarding antidepressant withdrawal support services.

Documentaries & Video Media:

- <u>The Happy Pill</u>: Follows a woman's 10-year journey through the mental health system and medication withdrawal. (Norwegian with English subtitles).
- The Project: A lived experience perspective on antidepressant withdrawal, calling for more understanding from health professionals and highlighting the role of online peer groups.
- <u>Video Series by Dr. Mark Horowitz</u>: Covers key topics on antidepressant withdrawal and personal experiences.
- <u>Angus Hibberd's Prose</u>: A heartfelt dedication to a friend going through antidepressant withdrawal. Content warning: Contains strong language, mentions of suicide, and criticism of prescribers.

Websites:

• <u>Mad in America</u>: Offers drug withdrawal resources, including guides, educational courses, research studies, and personal stories. Disclaimer: US-based website.

Online Peer Support Groups:

- <u>Surviving Antidepressants</u>: A peer support website for psychiatric medication tapering and withdrawal.
- <u>Surviving Antidepressants Facebook Group</u>: Online peer group, accompanying the Surviving Antidepressant websites, with real-time sharing of information, resources, and individual/group peer support.
- <u>BenzoBuddies</u>: A peer forum dedicated to benzodiazepine withdrawal support.

