OUR voice

LAUNCH ISSUE | October 2016

INTERVIEWS ON LIVED EXPERIENCE FROM MULTIPLE PERSPECTIVES

person with lived experience - Jay Close
South Australia’s first Mental Health Commissioner - Chris Burns

POETRY & WRITING BY PEOPLE WITH LIVED EXPERIENCE FROM MULTIPLE PERSPECTIVES

the astonishing magnitude of stigma
what does recovery mean
tips for talking to children & young people
supporting recovery in practice

a magazine on the lived experience of mental health issues by South Australians for South Australians
our voice was imagined and edited by Ellie Hodges (2016)

Reading this magazine may bring up some things for you. If you would like more support reach out to helpful people in your life or seek additional supports. Speak with a peer, your GP or another health professional. Other sources of information and support may be:

- lifeline - 13 1 14
- SANE Australia - sane.org or 1800 18 SANE (7263)
- (for young people) Headspace - headspace.org.au or 1800 650 890
- (for eating disorders & body image) Butterfly Foundation - thebutterflyfoundation.org.au or 1800 33 4673
- South Australian Mental Health Triage - 13 14 65
- South Australian Mental Health options - online information

The views expressed in this publication are those of the author for that piece only and do not mean that everyone who is featured or involved with our voice agree.
The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.

Elisabeth Kübler-Ross
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SO MUCH BELIEF, SUPPORT & CONTRIBUTION

THANKYOU

our voice started as a random idea one winter’s night. Now here we are with it a reality that has only been made possible by each and every contributor and person who responded to a short survey seeking guidance on what to include. Thankyou.

This year I have been amazingly supported and cheered on by other people who are speaking up and making a difference for people with lived experience of mental health issues. Thankyou.

Other colleagues, and friends have been believers and supporters too which has enabled me to see this project through. Thankyou.

And to my husband - Shaun, and our little people. Always and forever thankyou.
Anonymous

My soul is naked and bare
quivering, shaking unprotected
acclimatizing to the light and the air
once locked away so tightly
behind a fortress of walls and fear
the walls have come down
but the fear remains
they were my protectors
now they are my prison
separation from connection and trust
with the walls crumbling down
the fear comes and goes
revealing it’s self as a protector
who stumbles on his sword
no longer needed
no longer useful
the fear pulsates like butterfly wings
so very heavy on my heart
I hold the fear so gently and tenderly
no anger
no hatred
simply compassion
simply gratitude
I hear you
I feel you
thank you
you have protected me for many years
come back for a visit
but do not stay
I release you

the intruder

Val Smith (2015)

From out of nowhere
a violent storm
erupts
rips our lives
apart

the black dog slinks
away

loved ones pick up
pieces
move on
after she left

J V Birch

She sits with a gin and tonic
precisely alone
with its pockets of sound
opposite

She studies its stillness
knows how something so big
can be so quietly there.

She imagines it breathing
treetops travelling heartbeat.

difference between

J V Birch

I stride ahead
all angles, edge and mission.

You are where I want to be
in the fullness of here

arm in arm with it
like the lost couple of us.

I can never still myself
to take breaths that matter

the kind to flood your insides
not just pond skate the lip.

And when I begin
I see you stop and reach

the space I once filled.

self-help

J V Birch

She plugs gaps with cotton wool
when holes take root
prevents cracks from creeping to edges.

She picks strands of sunlight
singing in shadows
to take home in bone china vases.

She cups shells over ears
to drown voices
filling mouths with saltwater silence.

She forgets what these pills
used to help her with
strings them up into bracelets and necklace.
bully for you!
Guilio Bortolozzo

Do you think you have nothing to offer?
Use self-talk which is negative and untrue
And you don't think you amount to much?
Then I have just the thing for you!

Bully for you, bully for you
I have a bully for you!

I look for people to victimise
My admiring buddies think I'm great
I like to see fear in your eyes
You deserve to suffer mate!

Bully for you, bully for you
I'm the bully for you.

I will persist, never let up
I don't consider how you feel
My life's work is to see you suffer
You don't matter, you're no big deal!

Bully for you, bully for you
I'm the bully for you!

We control our thoughts
We are what we perceive
We can choose to be powerless victims
Until we change what we believe

Victim for you, victim for you
Will I be the victim for you?

I'm a worthwhile person!
I have qualities unique to me
We are all different from each other
That makes us the same you see?
No, I will not allow you to bully
You don’t have my permission you see
I will not be your sporting obsession
You are not the bully for me!

Bully for me, bully for me.
You are not the bully for me.

The cloak of silence
is the bully’s best friend
So speak out, everybody
It’s the cloak that’s specially tailored
For you and for me!

depression
Bronnie Leibhardt

Depression
Emotional
Perplexed
Restricted
Emptiness
Suicidal
Sadness
Isolated
Overwhelmed
Neurasthenia

junction
Bronnie Leibhardt

Junction is where we meet
Up and down emotions
Nice to meet some friends
Chatting to one another
Teaching us how to cope
Interacting group sessions open arms of understanding
New beginnings to wellness.
through fire and ice

Vesna

Today the sun bakes the city.
Everyone heads for shade, content with their coolness.
A mother bites her lip over and over.
Torment envelopes her like hot lava.
Her son is homeless but there is more...
Her son is also an addict.

His addiction is ICE the scourge upon Australia –
the plague.
A plague so bad that nothing remains...
Not even her son, for he is gone.
Lost is the little boy whose hand fit snugly into hers.
Gone is the safe bed, the little fluffy Ted, the stories
And the dreams of when I grow up.
Replaced by lies and desperation.
Fingers now gripping onto life’s window ledge
And a mother’s hands cannot help.
Who can help?

The abyss grows larger, the grip is weakening.
If only she could take him back in time,
Back to the little boy,
Wide eyed and in love with the world... and with her.
She swears she would do it better,
She would watch him like a hawk.
He would not go off the rails,
He would not veer off the straight path.

But here we are at the end of an Australian Summer.
She knows it will be hotter tomorrow
And hotter again the following day.
There is no respite from this heat.
There is no respite for her son, homeless within it.
There is no respite from her torment.
Guilt envelopes her, she has coolness.
She has food, she has a bed.
She has worked hard for those things but now she cannot enjoy them.
For she is in the lava.

She wonders why they call it ice.
For everything it touches... it cooks?
People, families, jobs, futures, young people, life itself.
It blisters with its intensity.
It inflames.
It is insatiable and uncontrollable,
Leaving in its path pure hot embers like a bushfire,
Blackened and charred.

She prays for a cool misty rain,
Because from the rain new life can once again shoot.
Even a weed, held in contempt,
Can break through the blackness and reach for the sun.
Ever so carefully, positioning itself,
With one carefully placed leaf reaching up at a time.
The promise of growth is strong within its DNA.
The knockers will not want the weed to grow,
For it may spoil the beautiful garden.
They may want to kill it, remove it.
Or simply ignore it for as long as possible.
But the weed will prevail, for it is strong
And it has a purpose – Life.
It knows not that it is spoiling the garden.
Nor does it care.
It reaches for the sun.
And so the mother can relate to this purpose,
For she gave her son life.
She watched him grow towards the sun,
Back in a time when life had purpose.

She bites her lip again, hard.
Hoping the pain will somehow
Ease the inner torment and the intense
outer heat.
It cannot do either,
But it slows the freight train in her head
For just a moment.
Long enough for her to realise
It’s actually not her fault!

The sun is in summer,
She cannot hold back the sun,
To ease the conditions of her homeless young man.
In fact she cannot do any one thing - to stop anything.
Not today - nor tomorrow.
She knows this already because she has tried everything
At least five times over,
From every direction and in every season.
She could not stop him from growing up
And choosing his own path.

She prays for a cool misty rain and bites her lip again.
A single droplet of blood emerges
And falls like mist onto her work desk.
She replies to another email and a customer is on hold.
Life continues on.
From the haze, the customer was in fact her son.
Begging for money, crying for help.
The window ledge is now empty.
And his grip had given way long ago.
The sun bakes the city
And the next day will be hotter.
NO change is in sight.
a photo of a photo of a photo

Alysha Herrmann

I have loved ones who are hurting.
Everyone does.
I have loved ones who are hurting themselves.
Too many people do.
When you love someone who is hurting themselves, it’s hard to look at them. To be with them. To see them.

Someone very, very dear to me is hurting.
Has been hurting for a long time.
Is hurting themselves.
Is hurting me.
When I sit with them and talk, I want to run away, retreat, leave, shout at them to SHUT UP. It takes all the patience in me, all the patience I don’t have to be there with them. To sit with them. To see them.

I found a stray photo of them in amongst old photo albums early last year. Real, physical photo albums with real, physical photographs printed on glossy paper. A novelty. The photo is of a younger them, smiling cheekily into the camera with two dimples prominent on either cheek. I looked at that photo for a really long time.

And then I cried.
For a really long time.
I cried for all the distance and time separating that tiny human in the photo from the angry, grown-up, hurting human I know now. I cried for me, and all the ways I don’t really have the energy to keep watching them hurt themselves. I cried for both of us, for all the lost things, the forgotten things, the promised things.
And I cried because no matter how hard it is to watch someone you love hurt themselves, it’s harder and hurts more to not have them anymore. I cried with the fierce joy of having them still here when we’ve lost so many others.

I cried. And cried. And cried.
And cried.
And then I placed that photograph gently back into my photo album.
They are no longer a dimpled child.
They are an angry hurting adult.
I can’t untangle the past that’s brought us here. I don’t even know where to start.
But I can sit.
I can listen.
I can see.
I can swallow my impatience and fill my skin with the radiance of loving them enough to wait.
I can be myself with them. Just that.
Emma Willoughby

There is an elephant in the room. A warm, kind and compassionate animal. She listens whilst we argue about how to fix ‘it’. She hears our calls for change, to be heard, to be visible. She hears our rage at things that diminish us - promising care, but delivering nightmares. She mourns our struggle with distress, lunacy, illness, unhappiness. She delights when we take risks of vulnerability and connection. She’s been sitting patiently for years whilst we talk. Today we noticed her and she smiled. We asked her what to do. She replied simply: ‘What would love do?’
waking up the dead

Jay Close (2012)

Prod me, poke me
I won’t feel a thing
I hear the music
But it won’t make me sing

What is this I feel?
Could it be pain?
Something I’d buried
Again and again

I am happy in my misery
I feel nothing at all
People talk to me
But I don’t hear their call

Never before have the roses
Smelled so sweet
The grass so soft
As it sweeps beneath my feet

Please don’t take them
My life, my drug
Just let me be
In this hole I have dug

The tears on my face
They taste like salt
I cannot see
But it’s nobody’s fault

I try to cry, I can’t
I’m a shell
Numbness is my Heaven
And my Hell

I hear it now, the laughter
It’s bliss
Everyone is smiling
Not a moment do I miss

Then the fog inside me
It clears
The pain of the rain-clouds
Suddenly disappears

A warmth inside me rises
The love, the sun
And I see everything
And everyone

It’s like magic
A magic potion
I pull out the cork
And I’m flooded with emotion

Emotions they cut
Both ways, like a knife
But without them
I would have no life
An old Cherokee is teaching his grandson about life. 'A fight is going on inside me', he said to the boy.

'It is a terrible fight and it is between two wolves. One is evil—he is anger, envy, sorrow, regret, greed, arrogance, self-pity, guilt, resentment, inferiority, lies, false pride, superiority, and ego'. He continued, 'The other is good—he is joy, peace, love, hope, serenity, humility, kindness, benevolence, empathy, generosity, truth, compassion, and faith. The same fight is going on inside you—and inside every other person, too'.

The grandson thought about it for a minute and then asked his grandfather, 'Which wolf will win?'

The old Cherokee simply replied, 'The one you feed'.
interview ::
the lived experience perspective
with Jay Close

Tell us a little about your lived experience.

I have lived with depression and social anxiety disorder for most of my life. Early in my life it stopped me from trying new things as it meant taking social risks which terrified me, so I avoided social situations whenever I could. Unfortunately this strategy further worsened my social isolation and my feelings of worthlessness and depression deepened.

What was challenging about your experience?

My social anxiety made it hard for me to make friends, form deeper connections with people. I was bullied throughout high school, so I grew up believing I wasn't worthy of true friends, girlfriends. I've always had a good relationship with my family, but struggled with anyone not close to the family or strangers, who with time, could have been potential friends if I'd given them a chance.

If you sought help what was that like?

I sought help at 19 years old and went to see a psychiatrist in Adelaide (I'd moved up to Adelaide from Mount Gambier to study at uni). I was nervous sitting in the waiting room, not sure what to expect. I was diagnosed with depression and social anxiety disorder, which finally gave me a label for all the feelings and sensations my body had gone through as a teenager.

What really helped you in the midst of the worst of your experiences?

Understanding that I was not my illness, it was just a part of me, helped me get through the tough times.
What do you do now to look after yourself?

Writing about my experiences is very therapeutic for me. I'm a reflective person by nature, so I feel the best when I'm reflecting and thinking deeply (if at times I over think stuff!)

I'm currently in the process of my writing a book about my lived experiences of social anxiety disorder and depression. It's been very rewarding and at times confronting to revisit memories and feelings.

I also love books about psychology as I'm constantly fascinated at how the brain works (for us and against us).

What has been good/useful/revealing about your experiences?

It was only by hitting rock bottom did I realise how strong a person I was. For many years I'd been labeling myself as weak and pathetic because I let people tease me, belittle me, and worry what people were thinking about me, but I realised (finally) that I was actually strong because I didn’t react to drama. I realised compassion and empathy (traits not valued by a lot of teenage boys) are actually traits of strong people, the quietly confident ones like myself who cruise along in the background.

What is your take on recovery and living with/beyond mental health issues?

While antidepressants were part and parcel of recovery, it was really a small part of mine. I'd been in and out of work my whole life, on and off Centrelink. The past 5 years of my life have been the most balanced. I'm finally doing a job I love, working in disability services, helping people to get the most out of their lives.

My job has become my identity, so turning up for work has become apart of my mental health maintenance. At times working in disability services is challenging and does test my ability to manage my stress levels, most of the time it is cathartic and therapeutic.

By helping others I helped myself. I hardly recognise the person I was 5 years ago. I'm so relaxed and laidback as if I'd always been this way (though of course I haven't)

Recovery is as individual as the person with the lived experience. My flavour of depression may be different to another.

Why do you choose to write about your experiences?

Writing is so powerful. Ever since I was a child I have been fascinated by the written word. We might say more than 1,000 words a day, but how many of those sentences are profound, insightful? How many of those sentences stay in our mind? How much of what we actually say is just small-talk?

I feel writing captures the more important sentences in our life. When something is written down we tend to remember it better, can truly take the time to absorb its meaning. Writing is powerful because you write about your feelings in an unguarded manner (unlike work situations where you have to be careful about what you say).

Any advice, recommendation or final thought you would offer to someone who is experiencing mental health issues now?

I would recommend finding a GP/psychiatrist you feel comfortable with. Shop around. If a GP writes you up for antidepressants on your first visit, you should be skeptical. In my opinion, antidepressants should be a last resort, not the first plan of action. Sadly, GP’s hand out antidepressants like lollies.

I was obligated to see a psychiatrist every two weeks after a mental health issue and found the experience disappointing. All she offered was to write me up for medication, then adjust the dose.
It was almost as if I was just another client, another number. **Finally after about 2 years of this humiliating experience I was then given the option to stop going. I was so relieved I’d finally been given a choice. I’d had enough of being treated like a lab chimp, as a chemical imbalance, not a human.**

I still took my medication as advised, but at least I didn’t have to put up with my unhelpful psychiatrist. Instead I found my own way. I hit the library and Internet hard and uncovered some wonderful resources which talked about mental health in a compassionate and insightful manner. I’d discovered a more holistic approach to my mental health. They focused on what is important to us, not to the antidepressant drug industry, which has a turnover of more than a billion dollars a year just in antidepressant sales alone. I’m not saying medication doesn’t have a role in recovery, it does, but not to the tune of one billion dollars a year. In summary, if you need medication there’s nothing wrong with that, but don’t limit yourself by buying into a psychiatrist’s limited knowledge of you.

You know yourself better than anyone else. In the end go with your gut feeling. I had to work hard to find these resources, but it was worth it. Just because something’s not mainstream, doesn’t mean it doesn’t have value.

I’m currently writing a book about my mental health experiences in the hope that I can inspire people with lived experience of mental illness to be themselves and not feel they have to conform to society’s standards, that there is help and information out there (beyond medication), you just have to dig around.

**Recovery is very individual. Find your own way and you will find that strength you thought you never had. Good luck!**

Any great resources you found particularly helpful and want to share with others?

I’m a bit biased regarding resources - I love books so I try and read anything interesting about the brain, philosophy, etc., but SANE Australia, Beyondblue and Headspace have great websites. I think there are more organisations around, but these three have simple to understand information and offer wider advice than my GP/psychiatrist ever did.

Other good websites are: youth beyondblue, psychcentral, anxiety network and mind Australia.

**Some books:**

*Artificial Happiness* by Doctor Ronald W. Dworkin, M.D. (absolutely brilliant!)

*The Art of Happiness* by His Holiness, the Dalai Lama and Howard C. Cutler, M.D.

*Emotional Intelligence* by Daniel Goleman, (an alternative measurement of a person’s worth)

*The Art of Happiness in a Troubled World* by the Dalai Lama and Howard C. Cutler, M.D.,

*Free Thinking* by Stephanie Dowrick,

*Flourish* by Martin Seligman, (modern psychology)

*Happy* by Tony Wellington,

*Happier* by Tal Zac-Shahar,

*The Power of Now* by Eckhart Tolle,

*Dying of Embarrassment* by Barbara G. Markway, C. Alec Pollard, Teresa Flynn, Cheryl N. Carmin.

*Positive Psychology – The Science of Happiness and Flourishing* by William C. Compton and Edward Hoffman,

*Depression – The Way Out Of Your Prison* by Dorothy Rowe,

*The Shyness and Social Anxiety Workbook for Teens* by Jennifer Shannon,

*Power Over Panic* by Bronwyn Fox,

*Living fully with Shyness and Social Anxiety* by Erika B. Hilliard,

*Being Wrong* by Kathryln Schulz,

*The Ant and The Ferrari* by Dr. Kerry Spackman,

*True To Our Feelings* by Robert C. Solomon,

*The Highly Sensitive Person* by Elaine N. Aron,
interview ::
the clinician (with lived experience) perspective
with Matt Ball

Tell us a little about your lived experience.

When I was 21 years old I had recently returned to the UK from Australia and I found myself somewhat transient. I had begun to experience some alternative states of mind in Australia. This became more pronounced when in the UK, I also became depressed and was using street drugs as something of an attempt to function. I visited a GP at the advice of a friend and the GP handed me a piece of paper and time to present to a psychiatric hospital.

I spent the next 18 months in and out of hospital, hearing voices, fearful for my safety and wellbeing and depressed. Having attempted to take my own life, I found myself in the cycle of admissions, prescribed multiple psychotropic medication (that did not provide relief), hopelessness, and labeled as psychotic and seeing very little future.

I then spent 18 months living in a housing community for people with mental health problems – mostly with psychosis, was in weekly therapy and came off all the medications in what became the journey of personal recovery and understanding.

How are you using your lived experience in your life and now and/or to support others?

I work as a mental health nurse and therapist. I consider that the experience of being in an altered state and having lived with my peers and friends, and understood mental distress and psychosis as an everyday experience that we all lived with, contributes to my hope in peoples futures and understanding not of mental distress and psychosis as a hopeless illness but one part of a person’s life that may well go on to be a creative aspect of defining who they are.
What is it about lived experience perspectives and drawing on your own in various ways that keeps you in it and passionate?

I think that the lived experience provides an equal or potentially more valuable understanding of the experiences individuals can live with and work through, than a hypothetical understanding that often, at its origin unintentionally, defines people as a label. Seeing experiences through the lens of lived experiences can reduce the burden of the risk view and in doing so provides opportunity to see the uniqueness of each and any individual, or each experiences as representative of the story of the individual journey that forms the person’s life.

What is easy or enjoyable about how you are using and sharing your lived experience or being a support to others having a voice around lived experience?

It is authentic and does not have the restrictions of a prescribed understanding. Using this sense can often facilitate a space where others can begin to make sense of their experience through their own perspectives. Seeing individuals grow in empowerment and hope as a response to the shackles of others definitions being removed is an awesome privilege. Witnessing the process of emancipation of individuals in reflection to the use of lived experience stories creates hope for much wider social change.

What is challenging or difficult about how you are using and sharing your lived experience or being a support to others having a voice around lived experience?

In my role as a professional, the use of lived experience can be threatening and be seen to be subversive, without ‘evidence’ and can create fear in other professionals as their sense of autonomy and power in ‘understanding’ or being the ‘expert’ can be overwhelming and lead to (often unconscious) attacks or expressions of the persons vulnerability towards the professional with a lived experience.

An obvious response is for professional colleagues to see a sense of disloyalty by me to my colleagues, a sort of ‘crossing the line/boundaries’ of ‘colluding’ or ‘splitting’.

Again these are likely to be the response of a person who feels (needlessly) threatened and the response is often in the form of an attack from the professional who does not talk to the lived experience perspective and in some way senses the lived experience perspective as challenging their authority or sense of having the answers.

What do you think most people seeking support are looking for from someone who is open about their own lived experiences?

A sense of hope, a belief that they as an individual are ‘okay’ and not beyond help. Some sense of not being alone and that they can connect with a future and their dreams, that the immediacy of the distress might just not be for ever.

What really helped you in the midst of the worst of your experiences and how does that relate to the support you offer others or the voice you have about lived experience?

I found great support from a chaplain at the hospital. Although not a lived experience of mental distress, the ‘lived experience’ of his deep connection with finding meaning, relating and finding love and compassion for self and others was extraordinarily important to me. I do not identify as having the same spiritual beliefs as the chaplain, but I will forever value his integrity and sharing of the human journey that is both mental distress and a spiritual path.

There was no such thing as lived experience workers when I was in the system, so the lived experience of being with others in communities (such as the housing community) gave a sense of not being alone – this is available and often not acknowledge in psych wards and other settings around the world. The community and
Conviviality between people with mental distress is a potentially vital and under acknowledged reality in the journey of many individuals.

I am also extremely grateful to family and a few friends that walked alongside me and I think gave a sense of hope and potential for a future, despite the horrible sense that a future may not exist for me at the time.

Do you think your experiences and role offers something different than other workers, support people or clinicians?

I am both a clinician and a person with a lived experience. I think the lived experience offers something different, but I also take the view that many clinicians and workers have various aspects of their journey that constitute valuable lived experience that can be of so much value in the journey of being a supporter alongside a person with mental distress.

Often the lived experience of clinicians is not something that is safe for an individual to discuss. We might choose to be mindful that just as a person in mental distress does not share each and every aspect of the journey overtly so this is true of workers and both the individual in distress and the worker may well be very skillful in using the experience without overt articulation.

It may be for valid, skilful and healthy self nurture that they chose not to be overt in expressing their lived experience. But non explicitly expressed lived experience can still be ‘felt’ by the other and provide the same value.

How do you look after yourself in all you do and with your own lived experience?

I have aspects of my life that are about other things. For me my family (wife and children, and wider family and friends) are an important focus in developing and maintaining a sense of being a whole person, unique but connected, able to love and be loved...and to have a lot of fun and silliness.

I also have reflective space with other peers to consider the ongoing journey. I seek and take advice from people with more skill and background in sharing their lived experience such as colleagues and friends in the Lived Experience work force and supervision groups.
What has been good/useful/revealing about your experience as a clinician open about their own lived experiences?

I have found that I have become a resource of a different kind. I have also found that I have been given alternative opportunities such as presenting at conferences, writing in book chapters, being referred people that would otherwise not have been referred. I feel enormous value in the experiences I went through having new layers of value and meaning when individuals experience something important about their own journey through reflection and spending time with me, a clinician with a lived experience.

What do you wish you had known earlier about being open about your lived experiences and being a part of the movement?

Perhaps I could have used the experience earlier on in my work life; how to respond to some of the many challenges that are thrown at me by ‘colleagues’ from different disciplines, how to make decisions about which invitation to work with and how to understand the motivations of others in ‘using’ the lived experience in my life.

What do you wish others knew about being a clinician with lived experience and supporting others to have a voice?

That collectively accepting others with lived experience may well lead to new understanding and less oppression. That lived experience practitioners are legitimate and should not be patronised or dismissed as in some way lacking in knowledge or boundaries. And that clinicians with lived experience are not a threat but a potential positive.

What is your take on recovery and living with/beyond mental health issues?

Recovery is a vital conceptualisation that a person can go on to live a life they choose and that the often restrictive diagnostic labels should not define a person. However recovery can also be used crudely as jargon or a hiding ground for covert attempts to return someone to a way living their life that is more sanitary for others.

Recovery at its best can be a language of individuals being full citizens, emancipated and empowered people that can and will define their own journey. At its worst it is language that is misused as a façade by which individuals in mental distress lose their rights and freedoms.

Why do you choose to have such an active role in advocating, speaking up and supporting others?

Because I cannot know the experience of another without the individual speaking, being heard and having the privilege to walk along side a person contributes not only to a persons sense of worth, but also to them connecting to who they want to be.

Any great resources you know of and want to share with others?

Endless youtube clips, hearing voices networks (esp Australia), Mad in America website

Any advice, recommendations or final thoughts you would offer someone experiencing mental health issues now?

Find a way to define your own experience, your own journey and your own sense of who you are. Do not be defined by others, be soft and strong not hard and weak. Be the wonderful person you are.
Tell us a little about your lived experience.

I have lived with mental illness for 35 years. I have had OCD since the age of 13 and whilst the symptoms disappeared in my late teens they returned after the birth of my first child at the age of 26 whilst living in a domestic violence relationship.

I then experienced extreme anxiety, PTSD and acute depression as well. In one year I spent more time in hospital than out and I had to give up my job as a dental therapist due to medication side effects. I gave up wanting to live any more as I did not know how. I was later told that my family was informed that it was believed the only way I would live was to be in an institution.

In 1992 I married an amazing man who was my neighbor and we moved to Mt Gambier. He helped connect me with a wonderful GP and mental health nurse who took time to get to know who I used to be, recognize my strengths and stay in there for the long haul. It wasn't smooth sailing with many setbacks but slowly my recovery journey began!

How are you using your lived experience to support others?

I experienced many of the difficulties faced by consumers residing in both metropolitan and particularly regional areas and hold a passion for using my lived experience to inform future planning, design and delivery of services to ensure that the journey for current and future consumers is made as smooth as possible to enable optimal recovery outcomes.

I am currently employed at the Carer Wellness Centre, providing support to families living with mental illness. I am also casually employed by the Mental Health Coordinating Council of Australia to provide training and assessment in the Cert IV Mental Health Peer Work and soon to be delivering the course here in SA.

I commenced advocating locally in Mount Gambier and then became a member of the inaugural SA Mental Health Taskforce. I then became a consumer representative on the South Australian State-wide Mental Health Clinical Networks for 6 years, South Australian Social Inclusion Consumer Advisory Group and Nationally on the ATAPS Expert Advisory Group, FaHCSIA Targeted Community Care programs evaluation Committee, and National Frameworks in Mental Health Consumer Reference Group.

I am currently a member of the Australian Commission on National Safety and Quality in Health Care Mental Health Reference Group and the General Practice Mental Health Standards Collaboration. I am also a member of Mental Health Australia’s Consumer and Carer Register, an Ambassador for Beyond Blue and Blue Voices member.
What is it about peer work that keeps you in it and passionate?

I have been fortunate to have been well educated, have good communication skills and a high degree of literacy. Through my illness I lost the ability to advocate for myself and as a consequence have now developed a strong passion to use my skills to advocate for better outcomes for all individuals living with mental illness. My passion drives me to ensure that we have mental health systems that provide quality consumer centred, holistic coordinated care in an attempt that individuals may have the opportunity to live full and meaningful lives that I myself, had the good fortune to achieve.

I went to a “perspectives” conference around 2007 and heard Shery Mead speak about peer work and from that moment on I was determined that the knowledge and wisdom from the pain and suffering I had endured, could be used in a positive way to help others.

I know that people living with mental illness value working with someone who can connect with what “it feels like” and hold hope. I am told on a daily basis that I make such a difference in a person’s life. I feel honored and privileged to be able to walk alongside another person, to be trusted and to see a future when sometimes they cannot see it.

I am determined to bring more peer work to SA.

You have been a peer worker for both those with lived experience and for carers. What is unique to each group and also similarities? How do these influence the support you offer?

I came to my current role at the Carer Wellness Centre having worked as a consumer peer specialist in the P HaMs program in both regional and metropolitan South Australia. So I came to the role with: an understanding of mental health issues from both a learned and lived experience of 30 plus years; a passion for making a difference; knowledge of working in a rural community; a knowledge of services; a good understanding of the Recovery model and of Trauma Informed Practice; and some advocacy skills having advocated at a local, state and national level.

My challenge was that I did not know what it was like to be a carer so I met with carers and asked them. Carers were telling me that they: find their role really challenging and are often dealing with crisis; feel like they are walking on “egg shells”; struggle to get services to support the person they are caring for; have no hope that anything will ever change; want to know more about the illness their loved one has been diagnosed with; feel socially isolated and have no freedom; themselves were experiencing anxiety and depression and poor physical health but are unable to go out to seek assistance; and they feel unable to talk to the person they care for about the issues.

I feel uncomfortable talking with carers about the people they care for without them present so I explain to the carer that having a conversation with the person they care for is essential if we are going to find suitable services that may help and that being involved in an open dialogue would greatly assist in working together.

I share that I have a lived experience and that I am happy for them to tell the person they care for. In 95% of cases the Caree agree to the meeting. Initially we meet either in their home or at a place out in the community and chat a little about my lived experience, just enough to break the ice. I then used Wellness Recovery Action Plans as a tool to open up the discussion further, to create a support team around their health and wellbeing and plan early intervention strategies to help prevent crisis. In this way I am able to build the support team around the family using services in the community.

The difference for me in working with carers is that I do not come from a lived experience perspective but there are many things in common that I can use such as empathy, understanding, hope, listening and problem solving.
What is easy or enjoyable about your peer work role?

It is a real privilege to be able to assist families at an incredibly vulnerable time. By supporting whole families, it is really rewarding as we are building a team of support where each person understands each other better and people do not journey alone.

As I grow in knowledge I find my role easier as I gain more skills. Every day is challenging but I love problem solving and advocating for others rights. It is so rewarding and the mutuality and reciprocity of the role means that I am better at maintaining my wellbeing also

I enjoy knowing that my experience has been for a reason to be able to help others.

What is challenging or difficult about your peer work role?

Some of the challenges are the: constantly changing service criteria and service environment; inconsistencies in service provision and entry criteria; and inequality of service provisions in metropolitan and regional areas as well as across the nation.

Working in my previous role with management who did not truly understand the role of the peer worker or have policies and procedures that were trauma informed was difficult. Also there can be a lack of understanding of the peer worker role in the mental health sector overall.

What do you think most people seeking support, carer or those with lived experience, are looking for from a peer worker?

Empathy and understanding. Hope. Assistance to navigate the sector and find appropriate services. Support to identify their strengths to increase self-esteem, connect with their community and find a sense of purpose.

How do you use or draw on your own experiences in your peer work role?

I draw on what it feels like to be living with mental illness to connect to another person. I can meet them where they are at and draw on my experience of how I got “through” those times to give others hope.

Coming from a trauma background myself, I am very aware of trauma informed practice and respect their choice and self direction and level of disclosure. I do not “tell my story” but use small parts of my journey where appropriate to intentionally provide hope.

I look at what services were helpful and what referrals may be appropriate.

What really helped you in the midst of the worst of your experiences and how that relates to the support you offer others?

What really helped was the strength, love and support of people around me and my children. It also helped knowing that I had not always been like this.

Just breathing and taking one minute at a time was helpful and knowing that I have survived influences the support I offer others.

Do you think your experiences and role as a peer worker offer something different than other workers, support people or clinicians?

I believe that every person is an individual and as such an expert in their own recovery journey. My approach is that: I do not do things to people; I do not have a time limit that people have to meet: I hold hope; I work in a relationship of trust,
mutuality and reciprocity; I don’t expect people to work to what I want; I tailor myself to the individual and their needs; I never give up; there is no judgment or expectation; and I work from a trauma informed perspective.

How do you look after yourself as a peer worker and with your own lived experience?

I debrief and network with other peer workers and surround myself with positive people. I walk, eat well, drink water and practice mindfulness and I have a wellness plan shared with my GP that reminds me of what I need to do for self-care.

What has been good/useful/revealing about your experience as a peer worker?

Peer work has maintained my wellbeing and given me a sense of purpose. Through this work I have realised how little management of organisations really understand the role of the peer worker and the amount of stigma that exists in mental health services. There is a lack of willingness for organisations to work collaboratively to achieve better consumer and carer outcomes and we have a long way to go in developing recovery orientated services.

What do you wish you had known earlier about peer work?

Not to have so much trust in organisations to understand my role and that building the peer workforce would be such a work in progress as we are so behind other states and nations.

Also to have a better understanding of Trauma informed practice and to know that many organisations do not work from this perspective so that I would not have been mistreated and triggered and experienced unnecessary retraumatisation.

What do you wish others knew about peer work?

For people to understand that peer work is a unique way of working using a specific skill set. Learned and lived experience equals real knowledge!

Peer workers are an essential component of the mental health workforce and can often connect with individuals at the lowest times in people’s lives. Peer workers change and save lives! Peer workers should not be used in tokenistic ways.

Peer workers are actually very resilient people as they have learned to be through their journey. They are not weak and more likely “to get sick”

What is your take on recovery and living with/beyond mental health issues?

If I had to live my life over again as much as it was unjust and awful I would do it all over again if it meant I could reach this point in my life and be able to advocate for others. Recovery is nonlinear but from my own experience my recovery now is reaching for the sky. I have never felt such wisdom and appreciation for life itself.
I believe that anything is possible if you have hope.

**Why do you choose to have such an active role in advocating, speaking up and supporting others?**

I have personally experienced the stigma of having a mental illness and the injustice of being judged as having no hope. I have been persecuted in the judicial system in relation to parenting skills because of having a mental illness and had to fight for the custody of my daughter. I have been detained, restrained and given ECT against my will and my family was told to “give up”.

**I have also witnessed others being treated in in-human ways and therefore will stand up with all I have, to ensure that everyone is respected, understood, treated with dignity and has their human rights upheld.**

**Any great resources you know of and want to share with others?**

The Certificate IV in Peer work is soon to be coming to SA. For me it is the culmination of a great deal of aspiration and hard work and my passion is that we will grow the peer workforce to the point that every individual living with mental illness will have the opportunity to work with a peer worker.

There are many great resources but the Mental Health Coalition SA has been tasked with developing the Lived Experience Workforce and would be a great place to start!
interview ::
South Australia’s first
Mental Health Commissioner

with Commissioner Chris Burns

Tell me what your role is at the Mental Health Commission.

The Commission was set up by this government as a result of a promise it made before the last election.

The important thing about the Commission is that it is independent of the Department of Health and it’s the first time we have had an agency like this for mental health.

The importance is that I can now go across the whole of government So I can reach out to education, police, corrections and we can make this a whole of community issue and a whole of government issue and a whole of life issue.

The Commission has been tasked with producing a State Mental Health Plan for 5 years from 2016/17 through to 2020/21 and we will do that but, more importantly, we have to take that holistic look at mental health in the State and come up with a plan that addresses all the other issues that haven’t been addressed in the past. By necessity the only way to do that, which is the essential to everything we do, is the voice of lived experience.

I know very well that the lived experience community has been consulted many many times and maybe not listened to all that often. My undertaking is to not reinvent the wheel because there has been a lot of consultation, studies, reviews, reports and recommendations that have either been acted and failed, acted and not gone any further or not acted upon. We will get all of that information and go back to the community and say ‘this is what we think you said, has it changed?’ and if that is what you mean then we will go back and work out how we are going to address it. When we think we have an outline of what might address the issue we will come back to the community and say, ‘you said that this was the situation we think this might be a part of the solution, is this consistent with what you were thinking?’ If it is yes, well we go on. If it is no, then we rethink and we reframe the plan.

The end objective is to have a plan that everyone owns. That everyone feels they contributed to. That everyone feels it is achievable. It can’t be pie in the sky. And it can’t demand a budget that’s not achievable. It is going to mean that some things will
have to be rationalised and will require us to use ingenuity. We are going to have to come up with innovation. We can’t just keep looking at things the old way. And it can’t be a moving the deck chairs exercise.

The perspective I’ve gained in the time I have had is that the discussion and discourse around mental health in SA at the moment is ‘do we have enough acute beds and how many hours are people spending in emergency departments?’ My perspective is that if that is the start point of the discussion you are at the end of the book. That the discussion and the book starts right at the very beginning. At the prevention, the early intervention and the education. Equipping people to know and understand and deal with mental health.

We went from an initial role to drive the reform of the mental health services in SA. That’s what we were told and it took us about 2 weeks to work out we couldn’t ever do that. It presumes that the core of the problem is that there is a problem with mental health services. We’ve turned it around now.

We think that the role of the Commission is to strengthen the mental wellbeing of South Australians in order to maximise the state’s mental wealth.

It means that this is what we are going to do to achieve this. It says that it is meant to be positive. We haven’t used the world health or illness, but wellbeing and wealth. And that says it is not all an illness and that it is not all health, it’s about community and the education side of it. It is about having an informed community, be it emergency services, police, ambulance, corrections and people in government that are as aware of mental health as they are about physical health. I want to know that if someone comes up saying ‘I am feeling really down’ that I know how to deal with it. That’s what I am trying to do. That’s what I think we should be doing.

How do you feel about your task?

Some days I wake up thinking what have I got myself into. But at the end of every day I think ‘yeah … ok, this is achievable’.

There is a lot of work but there are a lot of great people out there doing a lot of great stuff. A lot of passionate and very compassionate people who are giving more than the norm under some extraordinary circumstances.

What are the keys to getting there?

That we be realistic and we make sure everything we do is achievable. That it is clearly defined and that they have milestones and key performance indicator’s for each thing. Someone is already writing up the evaluation plan for the plan so that at every step of the way you can ask, ‘Is that really achievable?’, ‘Is it affordable?’ and ‘will it achieve the effect that you want?’ Now, if you can tick those you can say ‘ok let’s keep on going’. But there is no point having pie in the sky notions that we will reform the world and there will be no more need for acute beds or no more appearances in emergency departments because that isn’t going to happen.

It’s about reality. It’s about being pragmatic. It’s about being rational. The only way you can do that is to listen to everybody. You can’t afford to just hear the view of the clinician. You can’t only hear the position of lived experience, but they are probably in the best position.

Before you said that it is not about reinventing the wheel but there is room for innovation. How do you do both things at once?

Reinventing the wheel is about the consultation. I don’t want to start from the start. We have to do the courtesy of those who have been consulted
before and listen to what they said. We need to look at all the recommendations and what wasn’t enacted and why it wasn’t enacted and look at how can we enact it. Rather than cast that all aside and saying we know what we’re doing and starting again with a fresh piece of paper.

They will only feel safe to talk to me if they are confident that I am going to react to what they say. Experience tells me you can’t have a plan that doesn’t address the issues of lived experience. That’s what my background tells me. And I’m not a clinician.

On innovation. A lot of people confuse invention with innovation. A lot of people confuse ingenuity with innovation. Innovation is about taking an idea or a notion all the way through to it being commercially viable. If you have an idea it is the start of an invention and an invention is no good if it just sits there. It needs to be broadly out there and used. That’s innovation. You have to see good ideas through to being useful and employable.

Do you think that not being a clinician is a good thing?

I think it is a very good thing. I don’t have that medical perspective on it. It hasn’t been my whole life. It has been a little part of my life. I have got some lived experience through the military and through veterans and PTSD. I come with a fresh set of eyes and come at it from a strategic perspective. That’s one of the first things that struck me when I first came into this. Hang on, why are we only looking at this from the perspective of acute beds and time spent in emergency?

Everyone, if you say mental health or mental illness everyone always says Hindmarsh Square Department of Health and everyone believes the only solution is government dollars. It’s not. It’s all of us. It’s all of our dollars. And if we are smart up front and invest up front we won’t have to worry about acute beds. The way around it is knowing where the core of the problem is.

And being two months into the job where do you think that is?

If you address it early enough. You are not going to eliminate it but you have to minimise the demand at the end of the chain before it becomes an issue. You have to be prepared for it. There has been a focus on the acute side. And with stepping up and stepping down efforts being the focus it has meant that over time gaps have formed between steps and indeed over time some of the steps have gone and as one step goes missing it becomes like a big ravine and people disappear within it.

What is the point of listening to people with lived experience? There has been a lot of talk for a long time about the importance of participation yet it has been tokenistic on many levels. How do people know that it is safe to talk to you?

That’s a good question.

The first part of why listen to them? I will tell you from my military experience, experience is the best and only true educator. If you want to understand how to fight a battle you talk to someone who has been in battle. You can read about it as much as you like but when you see a person and you monitor their emotion and you can see what was the peak point for them and you can tell by the tone of their voice and their demeanour. So you do it because you need to have personal engagement with them and particularly people with passion and who really believe in something. They give the message to you in the non-verbal. That’s why I believe in talking to people with a lived experience and not reading a book.
I get tied up on terminology. To me stepping up is from one to one to one. But if you describe it as ramping then it suggests a smooth path up and a smooth path out. People now think I have to go from this step to that step and you get blocked. We have to work out things of transition where at any time you can ramp up and you can ramp down again and you don’t have to get to that acute phase.

One of the strongest things I have picked up on over the last two months and am really keen on is the role of the Peer Worker. Particularly the lived experience peer worker who can sit there and say, ‘hey I’ve been through it. This is what you may go through and I’ll be there to help you through’. That is as important as the clinical side.

How will the plan facilitate the relationship between Peer Worker and clinicians because the relationship is a bit contested at times?

It is but I’ve found there are a core group of clinicians who believe in and support the peer worker role. Its working with them and telling the story. That’s part of the stigma to me. It’s education and telling the story. It’s the good news story saying what we have done and what we are doing.

As the Commissioner, how do you account for all the different knowledge and the nuances of different funding arrangements and divisions in approach?

That’s what has crept into the culture. The hard science and the social science. And everyone wants to keep their funding. Hard science is concerned that if you give money to social science it will come out of their pocket. But I think that is because the whole argument has been centred around health and clinicians and this is the whole thing about discussion around mental health and mental illness is ‘oh that’s the Department of Health’. If you expand it to the broader whole of community and whole of government you will get different voices and you will start to address the culture. It’s not health having to do it all.

What will make you feel like you have done a good job as Commissioner?

There will be a lot of measurable things that come with the plan and when we start meeting them and succeeding. When I see resilience and wellbeing being taught in schools. When I see an industry focus on managing mental health as much as physical health. There is no end point or finite day when we pop the champagne. This is multi-generational. I don’t want to reinvent the wheel but I do want to turn the ship. Not around, but alter the course. Take it more towards a positive acceptance by everyone and understanding that mental health isn’t the boogie man everyone thinks it is. You don’t have to be scared just because someone is saying they are thinking of self-harming. We should be able to say, ‘gee that’s tough, let’s talk about it’ and then know where to go for help after that. To know what the next steps are.

How do you address stigma and discrimination?

Education; always education and from the earliest days. Make it a mandatory part of the curriculum. I think that stigma is better than it used to be. We are going down the right course but we still have a long way to go. We need to get the media talking about things other than acute and ED beds.
Funding for the Commission is for two years. What then?

The risk is that if you just leave it to the Commission to do the plan and then close the Commission the plan will fail. Once you have a plan you have to execute it and you have to oversee it. Someone has to be monitoring that. And hopefully the plan will be seen for what it is and not just a Department of Health plan but a whole of government plan and they will have to have the Commission there to continue to oversee it. The plan can’t be a document that sits on the desk. It has to be dynamic because as you implement it you need to monitor and evaluate it and fine tune it or ramp things up to maximise the effect.

I hope that the Commission stays on and is then given the responsibility of maintaining the mental wellbeing of South Australians and we see our mental wealth grow.

In doing your role what do you need to be aware or conscious of?

To be conscious of that gap between hard and social science, the perceived gaps between people with lived experience and clinicians. The political nuances. Breaking down the stigma. And being realistic.

We are not going to turn the ship in a minute. It is going to be slow and we will hit the bottom a couple of times on the way around but maintaining that positive focus. Tell the story. Tell a good story and be prepared to admit when we don’t quite get things right.

It is having faith that in the end the plan will be better for South Australians and better for people with lived experience.

What is your message for people with lived experience?

Don’t be afraid to talk to us. Be open and honest with us. We will listen, but we will be realistic. We won’t give you false hope. We will do it slowly. We are in this for the long run. It is all about mental wellbeing and maximising the mental wealth for the whole state.

Anything else?

We have got to break down the ‘we’ and ‘they’. We have to work together on this. We won’t succeed if we don’t. There isn’t any other way.

3 words to sum up.

Let’s make it four. Listen to lived experience. That’s what we have to do.

We can only understand if we listen to lived experience. And that’s not a whimsical thought that came to me in the last two months. That’s my life experience. You only learn from people who have experienced it.
Courage doesn't always roar. Sometimes courage is the little voice at the end of the day that says 'I'll try again tomorrow'.

[Mary Anne Radmacher]
a parent's experience of navigating the SA Health system

Fiona Dale

I am writing this article to illustrate the complexities of the SA Health system for a family with a child who has an eating disorder. I hope that by sharing our experiences I will assist other families to navigate and advocate within the system for better outcomes. Eating Disorders are bound up in incredible stigma which stifles many from sharing their experiences.

In October 2014 my 15 year old daughter was diagnosed with anorexia by our local GP after an unexplained decline in her weight. She was referred to the Statewide Eating Disorder Service (SEDS) for an appointment with a psychiatrist.

In early December 2014 my daughter had her first appointment with the SEDS psychiatrist. I remember this date vividly as it was the most isolating and frightening experience I have had as a parent.

My daughter was taken into a room with the psychiatrist, I was not involved, I sat in the waiting room crying. In the last five minutes of the appointment I was called into the room where I was told my daughter had anorexia and would need to return to SEDS for weekly appointments with the psychiatrist and to be weighed. At no point was I asked my opinion, given any information, or provided with support.

We left shattered and cried in the car together, I was grappling with the diagnosis, asking my daughter a range of questions from “is it because you want to look like other girls?”; “has someone hurt you?” etc. as I was trying to understand why this was happening and what I could do to help my daughter get better. At that stage my knowledge of eating disorders was minimal, although I did have a friend who died of anorexia in the 1980’s when medical treatment and understanding was very limited.

We continued to make the trek to SEDS weekly and the lack of inclusion or acknowledgement of my valuable role as a parent continued to be ignored. I continued to sit in the waiting room occasionally crying, and at other times angry and frustrated. On the second visit my daughter was given a prescription for antidepressants, which I diligently filled and which she refused to take. I am not a parent who condones medicating children and young people, but, I was grasping at straws. What can I do to stop this? What have I done wrong? Why has this happened to my intelligent, creative, beautiful daughter? I had tried to raise both my daughters without stereotypical images of women’s bodies – no fashion
magazines, no watching music videos (sexualisation of women), no calling things ‘fat’ or ‘thin’, positive reinforcement at all times around eating, never dieting myself and ALWAYS supporting and guiding with unconditional love.

On one occasion at SEDS a woman came out to the waiting room, sat down next to my daughter and commenced describing a study they were undertaking and presented her with a clip board of papers to sign to be part of a research study. My daughter was not in a sound frame of mind to read and understand the information due to the starvation mode she was living. but, she diligently signed the forms. As the researcher stood up to leave I interrupted to say I was N’s mother and would like to know what she was signing up to. “But N is 16 so she is able to sign for herself” as she is considered a ‘young person’ in the health system”. I insisted on information being provided and was only given the consent form N had signed. This experience further dis-empowered my already vulnerable ‘voice’ in the care of my daughter.

I recently read in the Southern Health News, June 2006 that SEDS ‘provides assessment, care and information for people living with an eating disorder or where an eating disorder is developing, their families and carers. Education and support is also available.’ This was definitely not our experience. On one visit I saw a woman come out into the waiting area from a room with ‘Manager’ on the door so I asked to speak with her. I started to cry so she took me into a room. I told her how I was feeling and that I did not know what to do, I asked for information, resources etc. She left and came back with photocopies of book covers telling me I should buy them to read. I asked if I could borrow the books as I did not have any income at that time due to my caring role, I was told ‘no, perhaps try the library’.

At no time was I provided with an overview of the treatment options, care plan or what was available to us as consumers of SEDS.

Our last visit to SEDS was early February 2015, on the psychiatrist’s advice we drove straight to the Flinders Medical Centre (FMC) Emergency Department and N was admitted within five hours to the Paediatric ward (only over 18 year olds receive treatment in the specialised Weight Disorder Unit). She had lost almost 13 kilograms under the care of the SEDS psychiatrist (in under 8 weeks). The paediatric nurse told me that she was the most critical child on the ward.

So our journey with the FMC Paediatric ward started that night. N was stripped down in front of me and put in a hospital gown (the first time I had seen her body in many months, I silently sobbed), a nasogastric feeding tube inserted with much distress, heart monitor and total bed rest ordered. I was told to go home at which point I broke down and said I could not leave N, let alone drive safely. I was told it was not standard practice for parents to stay with patients, I argued that I would not leave as my daughter had never been in hospital and I felt she needed my support. At no time was I given support, empathy or information. I slept on a chair by my daughter’s bed not sure that she would live through the night as I was told that due to her extreme emaciated state her organs were shutting down. I had to ask where I could get a towel to wash my face, if I could make a cup of tea or where I could buy some food.

A range of nurses attended to N with varying levels of care and understanding. The one I remember most stood at the end of the bed and lectured me on how ‘this will be the hardest time of your parenting life. You thought toddlers were bad, well let me tell you this will be worse’. I was given a book to read and told implicitly in front of my daughter ‘your daughter almost died, you need to be strong’, ‘eating disorders have the highest incidence of mortality of any mental health issue’ and ‘you are responsible for keeping your daughter alive’.

I was also implicitly told that they were not trained in treating eating disorders, were not funded to care for patients with eating disorders and had very little time to spare for ‘this type of stuff’.

 Needless to say I did not feel relieved that N was in the Paediatric ward or hopeful of a positive outcome, but, I did still carry hope that she would realise the seriousness of this and change her eating habits. I was in for a huge learning curve!
I attended care meetings where I was once again lectured on how seriously sick my child was, how recovery was challenging and that I was pivotal to the success of N’s recovery process in the Maudsley Method. At these meetings I felt as if I was guilty as a parent and responsible for my daughter’s condition. The fragmented SA Health system started to be revealed, from no involvement at SEDS to total responsibility for purchasing, preparing, cooking, feeding and keeping my daughter alive through the Maudsley Method.

I did not need to be told repeatedly how gravely ill she was, I had seen the progression of the condition and felt powerless in a health system that did not utilise the expertise of a parent’s knowledge of their child, their motivations, their history and needs.

I went home and started to do what I knew best - research, ordering and reading any book I could find to inform and prepare myself for the journey ahead. I felt relieved that at last I could do something towards helping my child to heal. N was discharged ten days after admission into my care with only Paediatric appointments in her discharge plan. We were to find and pay for private psychology appointments which she has been attending fortnightly for 14 months at $210 per visit (a Mental Health Care Plan only subsidises 10 appointments per calendar year).

We diligently attended the Paediatric Outpatients appointments weekly where my daughter was taken into a room, stripped down, weighed and a urine sample taken. At no time was it discussed with me what the purpose or aim of these visits were, what the treatment plan/care plan was or what I could do to assist my daughter’s recovery. My daughter does not want to know her weight as it distresses her, on every visit to the outpatient clinic I had to restate this to ensure the nursing staff did not let her see the scales or the file, and on one occasion the nurse came out of the weighing room and announced loudly to the waiting room ‘N is 52kgs’. I was so annoyed and distressed and let them know. This was a breach of confidentiality and insensitive to her medical condition. The Paediatrician spent five minutes with us each visit, reviewed the weight chart, asked N questions that she wouldn’t answer and made no other suggestions.

At no time did any of the SA Health staff let me know about the greatest resource in SA the charitable organisation Eating Disorder Association of SA (EDASA) which has since folded due to lack of funding. I discovered EDASA online and attended an amazing carer’s workshop that provided information, caring, connecting to other parents, resources from their extensive library and group opportunities for my daughter. I rang EDASA on several occasions for support and advice as they worked with empathy and lived experience. EDASA staff were also crucial in referring us to a specialist private psychologist practice that worked within the Maudsley methodology of Family Therapy. This psychologist has been our lifeline to support, guidance and inclusive practice that has enabled our family to work together as a team and support N’s recovery.

It is now 18 mths since N was discharged from FMC and I have been successful in getting her back to ‘healthy weight’ which was the focus of the hospital’s perspective. The ongoing mental health issues of extreme anxiety, depression and obsessive behaviours are the greatest challenge. At no time in our SA Health experience were we informed that eating disorders are a chronic mental health condition and what the treatment options were, the focus was always on BMI and returning to healthy weight.

Throughout our journey of the health system I was made to feel as if I had allowed this insidious condition to take over my daughter’s (and our) life. The impression was that it was the child’s choice to starve themselves. My daughter told me she would lay in her hospital bed and hear the nurses at the nurses station discussing loudly “Oh, I have the eating disorders tonight” she said to me ‘I am not an eating disorder Mum. I am a person!’ N’s psychologist feels that she potentially has Posttraumatic Stress Disorder from her hospitalisation, it is reported that several patients may have PTSD as a result of their experience of Flinders PTSD Medical Centre admissions.
My greatest frustration is that the international evidence reports that currently the most effective intervention for an Eating Disorder is the Maudsley Method. Unfortunately, we spent valuable time attending SEDS, to see ‘experts’ and in that time my daughter declined almost to her death. This situation could have been avoided if the SA Health system was consistent in its approach to person-centred care of Eating Disorders and informed by international evidence based treatment across all interventions.

What is vitally needed are services and interventions to support families and carers, ranging from dedicated and tailored workshops as well as coaching and strategies to reduce stress and distress for families caring for a person with an eating disorder. I am a lucky parent as I have over 20 years experience working in the community service sector, Social Science and Early Childhood qualifications and a dynamic understanding of mental health issues. I am incredibly concerned for parents who enter into this mind field with limited knowledge and understanding. Although, when faced with a child experiencing a life threatening condition I often felt powerless and voiceless, that is why I am speaking up!

If you are a carer or family member for a person with an eating disorder you play a significant role in their treatment and recovery. The active support of the family and care-giver is a core practice principle in the National Framework for Eating Disorders and is essential for a person-centred and family inclusive approach. This approach is sensitive to the needs of individuals and treatment must reflect this. Therefore, the role of the family and carer becomes more important as they work in partnership with multi-disciplinary treatment teams and assist in the implementation of individual care plans. ‘Families and Carers as Integral Members of the Team’, The National Eating Disorders Collaboration, April 2015.

For information and support go to –
the Butterfly Foundation or call 1800 33 4673
(Monday – Friday 8am – 9pm)

If you are a parent navigating the system and would like to talk with me please contact Ellie Hodges, ellie@elliehodges.com, and she will pass on your contact details to me.
THE IRONY IS THAT WE attempt to disown our DIFFICULT STORIES to appear more whole or more ACCEPTABLE, but our WHoleness — even our wholeheartedness — ACTUALLY DEPENDS ON THE INTEGRATION OF all of our EXPERIENCES, including the falls.

[Brene Brown]
the not so ugly truth about depression

Jay Close

Depression. We’re told to fear it, medicate it, conceal it, fight it, eradicate it, as if it’s the worst thing in the world. The Oxford Dictionary defines depression as “feelings of severe despondency and dejection.” A dangerously simplistic definition that implies that there is only one flavour of depression, one experience.

Some cultures don’t even have a specific word for depression. It’s not that they don’t feel sad, it’s more that they see sadness as a part of who they are, not a separate entity.

I prefer to see depression as “a sunken place or hollow on a surface.” I see this as a more accurate description of depression. It implies that it can be repaired, that we’re human. We’re not built to be rigid, inanimate objects. We are made up of 60% water, fluid like our thoughts.

Depression, or melancholia as it was once known, has been studied for hundreds of years but it’s only fairly recently in the 1970’s that a deeper understanding of depression came about. I’ve been there many times, depression, that scary void between happiness and sadness, where emotions go to die. Unable to give and receive love, despite the love that exists around you. You look at people you love and you smile, but it’s just a mask you wear because the truth is so scary. You don’t feel anything, you’re a robot.

Some people may require medication to find their feelings again, but finding a way through on your own can be a tremendous source of strength and a unique opportunity to learn. We often learn the most when our backs are against the wall.

I learned that I was going about it all wrong. You don’t fight depression, it’s a part of you, it’s your compass, your natural alarm system.

We’re so used to medicating pain, that we forget the value of pain. Pain is uncomfortable for a reason. It tells us to stop and take notice. Sometimes you’ve got to hit rock-bottom before you get better. Sometimes you never know how strong you are until being strong is the only choice you have.

I remember my first depression, a depression in my heart, gouged by the wheels of life. Trapped in my body by my thoughts, my heart in a strait jacket. But over time I learned that the tension in my chest and muscles, the lack of energy and appetite for life was not me being punished, but simply the resistance of my mind to follow my heart.

It was then I found the beauty in depression, the diamond in the rough. It had been helping me all along, but I’d only just started noticing. Depression slowed down time so I could process properly what I was going through, see the all the light, not just the dark. Change is painful, but it can also be the start of something better.

The truth is sometimes it is time not medication that is needed, it’s listening not talking that is required.
Should we be afraid of mental illness?

Sarah K Reece

Being a peer worker in mental health I’m often caught in a certain tension between the reality of my own experiences, and the ‘party line’ I often feel a certain pressure to toe. One of the areas this occurs in is the many current efforts to reduce the stigma associated with mental illness.

A couple of years ago I listened to a presentation about research and psychosis that was very interesting. After the talk, I asked the presenter what I, as a ‘consumer’ could do to help. He told me that research indicated that stigma reduction campaigns that relied on increased education actually often backfired. Giving people more information about the nature of experiences such as psychosis sometimes just gave people more information about something they were already really frightened of. What did help was humanising these experiences. Putting a face to these conditions helped people to see that we are still human, that we are deserving of care and dignity, and there is so much more to us than ‘illness’. This conversation was one of the motivations for my passion for peer work.

get right, because you are trying to sum up a huge concept and idea into a phrase. This is like trying to communicate advanced physics concepts through haiku. It takes rare talent!

I get where this idea is coming from.

I just find it difficult to subscribe to.

I live in a funny corner of the world where most of my personal networks are peopled with people who experience, or support someone who experiences, a mental illness. In my world, issues are the norm. This is cool, I prefer it. I fit in, I get the people, we speak our own shorthand language, complain about sleep deprivation, are sensitive about touch, navigate life with a painful awareness of our own vulnerabilities. I get that the idea of telling people not to be scared is what I’m trying to communicate when I give mental health talks and say – so, guess what, I have multiple personalities and none of them are axe murderers! It’s what I’m trying to say when I give talks about voice hearing and try to get across the message that we are not some strange, terrifying, alien species; we are regular folk, who happen to hear voices. What we’re all trying to say with messages like this is that common myths about violence, insanity, psychopathy, do us harm. They’re needless and harmful fears. They alienate and damage whole groups of our communities, leaving them alone with their demons, without help or comfort. Mental illness is nothing to be afraid of.

Here’s the other side though, I know what it’s like to be suicidal, constantly, deeply, permanently thinking of death. I know what it’s like to be afraid of myself. I know the shame of waking up and finding fresh self harm wounds. I know the misery of panic attacks, of ‘ugly days’, of ‘non-food’ days. I care deeply for others who battle things like this. I’ve been the full time carer of someone who spent 6 months in hospital in a state of intense emotional distress and a constant drive to die. I’ve cared for friends who cut, or starve, who hate themselves, who experience paralyzing depressions, horrific trauma stress, chronic nightmares. To tell you the truth, ‘mental illness’ our strange, impersonal term for so much hurt and suffering, scares the hell out of me. I don’t want it, and I don’t wish it on any of the wonderful people I care about. Watching people you love suffer, watching the cycles, the decent into their own personal hell, it’s terrifying, and it’s painful.
Here’s the thing, the people are nothing to be afraid of. They’re still people. If they were assholes before, I doubt that a mental illness has improved matters. If they were decent people, in many cases it makes them difficult to live with, but not dangerous. There’s nothing to fear from them. There’s much to fear for them. And even there — there’s hope.

There’s paths through these things. There’s ways to reduce their impact, to limit their capacity to destroy lives. People change, grow, heal. It’s not a life sentence. Mental illness isn’t the grave of all our dreams for our lives.

But people suffer. And people die. You can’t work in this field and not be aware of it. The situations some families are living in is horrifying. When we paint a rosy image, when we put photos of calm, happy, beautiful people on our banners and pamphlets and say — mental illness is nothing to be afraid of, we deny the reality of a lot of people who are suffering terribly. Their pain is devastating and it is something to be afraid of. Not the kind of fear that paralyses, the kind that makes us speak up about better resources. The kind that makes us research our options, get help early and get good help, look after ourselves, stay connected with our mates, fight stigma and discrimination, count our blessings.

People are suffering, and people are dying. I think it’s okay to be afraid of this. I think that in the face of this fear, we chose to act and live with courage.
why don't we talk about it?

Shaun Hodges

We all know a story such as this - a young person takes their own life. The funeral, as is always the case with younger people, is packed. There are so many people there, so many good friends from all facets of their life, and everyone just couldn't believe that this has happened. **By all accounts there were no obvious signs, no idea that they were struggling with mental health issues.** Comments are made along the lines of 'with all these friends here, why couldn't they say something? Why didn't they seek help?' A good question indeed and one that is frequently asked at the wrong end of tragic events such as this.

Even in describing what happened, it is skirted around. Rather than being told what occurred, and suicide named and brought into the light, it is instead a 'tragic accident dealing with issues'. And that, in a nutshell, encapsulates so much that has gone wrong.

**The stigma around mental health is pretty much ingrained in our culture and society.** The non-reporting of suicide or talking openly about it are clear examples of this, like it is somehow going to give people ideas that they hadn't considered. If we don't talk about it, perhaps nobody else will think of it. Instead, the silence and secrecy is more isolating for those who are struggling.

Why is there shame in discussing or acknowledging mental health struggles?

This is in complete contrast to physical health, where there are facts and figures bandied around all the time, with different lifestyles and diets being touted as reducing in this or helping with that. Again, reinforcing that its ok to have potential 'general' health issues, but we can't talk about mental health.

**Mulling over this did get me to thinking - when was the first time you ever had a talk around mental health? When was the first time you ever had a proper discussion around this?**
To be honest, I have no recollection at all. Parents and care givers will always ask if you are feeling sick, and if there are any issues these are regularly checked on. Schools will look at sexual health and information, career prospects and direction as well as general education on a number of fields. But where is the discussion around mental health? Again - silence.

At this point I will state that this doesn’t mean there aren’t support networks within the school system, or teachers who are genuinely on the lookout for things and will act upon them. **But where is the education? Where is the validation for people to be made to be ok to talk about ‘feelings’?** Why isn’t there proper education about mental health from a very young age?

**Feelings! This word in itself is a bit of an over simplification.** Too often this means happy or sad. Happy - good. Sad - bad. If you are sad, we need to make you happy again. And yet, as adults we know that there is a huge grey area in the middle between these two ends of the spectrum. In boiling things down to being good and bad, happy and sad, this is again invalidating the fact that in amongst this, there might be a mix and confusion of emotions and thoughts running parallel to each other. Making sense of this in a developing mind and body would surely be a good time to discuss this.

Social media is putting an interesting spin on this too. While people can be ‘connected’ to hundreds or thousands of people wherever they are, this is entirely (well, somewhat) superficial. For many people it’s all about just being super happy and displaying a facade of beauty, sexuality and contentment. Ok, so I acknowledge this is perhaps over simplifying things too, but it does have a degree of truth to it. **To have a number telling you how many friends or followers you have, yet nobody to talk to about how things really are and everyone showing how amazing their life is ... it’s not an ideal mix.**

Posts around ‘support’ of mental health and suicide are also, in my opinion, entirely demeaning and devaluing. To put up a copy and pasted status about ‘the black dog’ as some kind of support or understanding is frankly hollow and meaningless. If you really care (and I am not suggesting people that post such things don’t) then **how about using your own words? How about reaching out to people you care about? How about stopping and making some time to catch up with anyone you know might have been having a tough time lately?**

Figures are always good to look at, so let’s consider this. **Suicide took the lives of 3 027 Australians in 2015** (ABS, 2016). Given this is the ‘end state’ of mental health issues, the extreme result if you like, how many more do you think contemplated or attempted suicide over that time? The number would be truly frightening.

Hospitalisation due to self-harm rates provide a bit more of an indication about the extent of the problem we are facing – and that figure for 2013-2014 was 33 956 (AIHW, 2016). **Nearly 34 000 were people hospitalised for self-harm.** So again, how many didn’t attend hospital? How many perhaps weren’t recorded as self-harm?

Yet again I point out - silence is what we get from the media and broader society. Silence is what we are coerced into maintaining.

Let us compare it to road safety. This is drilled into us over and over and over again. You can barely go through a set of ads without a road safety message being shown, and this is not without good reason. Deaths from traffic accidents in Australia in 2015 was 1209. Working in this industry, so to speak, I also would guarantee that a number of those were self-inflicted, or strongly influenced by mental health issues. **A life is a life, sure, and the loss is no greater either way. However, attempts at trying to improve and prevent the situations are vastly different.**

But so many people drive – it’s important that we are safe! Well, yes. But we all have complicated lives, with so many influencing factors and issues
to deal with. Every person needs to look after their own mental health, whatever they are doing and whatever their age (ok, babies and toddlers may be exempt). But the way these two things are approached just demonstrate the massive hole into which so many people fall.

Mental health as a term is also something that could be, and should be redefined. Physical health is about being even more healthy, getting fit, going to the gym, eating well so your selfies look better on Instagram. Mental health on the other hand is something that people only worry about when it’s not ok. Isn’t that really starting at the wrong end of things? Just as you can exercise your body and look after it, you can do the same with your mind.

I know even for someone who has pretty good insight into these things, it’s really hard to bring up issues of mental health, even with the person you are closest too. Through being the partner of a person who struggled with anorexia, and who continues to live with the ongoing effects of PTSD, there were many years of significant impacts to be dealt with. Just as an example there were weeks and weeks (and weeks) of time spent in Flinders Medical Centre – unaffectionately renamed to Hotel Flinders by us.

It’s all a bit of a blur now, and it’s hard to believe sometimes that this was so consuming of our life for such a significant amount of time.

This silence extended beyond telling others about what was happening though. Before it got to the point of hospitalisation, even in observing what was happening to my wife through this, there was a very long period of silence before I said something. I let it get really bad, the weight loss extreme, before I made a strong point of saying enough was enough, and actually bringing it into focus.

Why? Why when I knew for so long that things were going in completely the wrong direction did I not do something?

I don’t have a good answer for this, other than it shows another way the stigma around mental health and illness imposes itself. It demonstrates how powerful it is, when people who are (I would say) otherwise intelligent and good communicators can sit in silence watching things unravel. Luckily, eventually something did happen, conversations were had, and things were commenced to make it right. It took time though, it wasn’t always easy and whilst the silence was no longer between us it was still pervasive around us.

I have learnt from my own experience that it’s much better to ask a question, or say something, and (maybe) be wrong than to sit in silence. There is no solace in saying after the fact “I knew there was something wrong”. The regret of not saying something – that just may have helped in someone’s darkest hour – may sit with you forever.

So what is the answer to this?

Well, as is usually the case, education would be a great place to start. Education from an early age too, before the stigma and barriers have been built. Young people are extremely receptive to new concepts and ideas, they are a blank slate to be shaped and crafted to fit into the world.

Let’s start early to build understanding, resilience and acceptance of mental health as something to be aware of, both in a positive and negative sense. Parents, schools and care givers owe them this to give them tools to fall back on.
when things do get difficult. Nobody ever (I assume) sits down and tells people we are not allowed to talk about our feelings - and yet that is what our societal norms create.

Also, there is no point in just hoping they never have to deal with difficult times - because that is frankly ridiculous. Depression and anxiety, grief and loss, severe mental health issues and traumatic life events know no bounds. They cross all social boundaries and cross into all levels of wealth and entitlement.

For most people who will be reading this, and for myself too, the most we can do is simply to just try our best. Try our best to be on the lookout for signs that our friends, family and colleagues may be struggling, and then to put a genuine hand of support out for those who may need it. Try our best to build understanding in young people that we may have contact with. Try our best to ask for help too, should the need be there. In short, try our best to positively influence those around us, and in doing so, challenge this stigma around mental health.
Mental Health Stigma & How We Must / Can Do Better

Stigma against mental illness is common
It’s impact is serious

Stigma stops people asking for help and getting the treatment and support they need. It makes it more difficult to find somewhere decent to live in a flat, a mortgage, or even a partner. People may feel difficult or even impossible to keep friends, feel good about yourself, or even to feel that life is worth living. Stigma is a major barrier to recovery.

Results of a 2016 SANE study on levels of stigma experienced by people living with a mental illness.

Common Elements of Stigma
1. perceptions that a person is ‘weak, not sick’
2. perceived dangerousness
3. beliefs that a person is responsible and can control his/her condition
4. feelings of guilt, shame and embarrassment
5. a reluctance to disclose a diagnosis, due to concerns about discrimination and harassment
6. a desire for social distance

Components of Stigma
- knowledge: ignorance or misinformation, keeps us afraid of or suspicious
- attitudes: prejudice, because they’re dangerous, I’ll avoid them
- behaviour: discrimination, because they’re dangerous, I’ll avoid them

Types of Stigma
- personal/public stigma: people with depression should be kept out of our community
- perceived stigma: I would be able to snap out of my depression
- self-stigma: people with mental illness feel bad about themselves
- structural stigma: someone’s mental illness makes it more difficult to find work, housing, etc.

A Mental Health Council of Australia study in 2011 found that people living with a mental illness report similar levels of stigma from health professionals as from the general community.
Funding inequities between physical and mental illnesses are international

Stigma-Reduction Approaches

Educational approaches
- This includes information resources which challenge inaccurate stereotypes and replace them with factual information.
- May be more effective for adolescents.

Contact approaches
- This includes interpersonal contact with people with mental health issues.
- Most effective way with adults.
- Must be targeted, local, repetitive, and continuous contact.

Picture This Recommendations

SANE surveyed 5,000 people, the majority who had a lived experience with mental health issues. These recommendations were developed to assist in fair and accurate visual portrayals of mental illness.

Hidden adversity
Human experience
Non-violent
Search words
Diversity of experience

StigmaWatch
Find something that contributes to mental health stigma. SPEAK UP! Ignite a media storm and make a difference in society.

The astonishing magnitude of stigma

Click on any of the images to access an uncut version of the infographic.
I’m still me

I may be experiencing a mental illness... but I’m Still Me!

A mental health problem should not define who we are.

The I’m Still Me anti-stigma promotion encourages us to treat each other kindly and not define people by their experience of mental illness.

Brought to you by the South Australian Mental Health Commission

Government of South Australia
SA Mental Health Commission

samentalhealthcommission.com.au
1 in 5
South Australians will be affected by mental illness in any given year.
5 in 5
South Australians can help.

Given how common mental illness is, it’s likely we, or someone we know, is living with a mental illness. It’s important then to make sure we treat each other – and ourselves – kindly and not define people by their experience of mental illness. We are much more than that.

Labelling people can cause exclusion and discrimination or ‘stigma’ which can stop people seeking help.

Support and acceptance from family, friends and the community can make all the difference.

The I’m Still Me anti-stigma promotion encourages us to treat ourselves and each other kindly and challenges negative stereotypes of mental illness.

Visit our website: samentalhealthcommission.com.au/imstillme to view a video of people sharing their ideas of what it means to “still be me” and live well with mental illness.

Numbers to call for help, support and advice:

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what does recovery mean

Sarah K Reece

Like any field, Mental Health has its own language and uses certain words in specific ways. If you’re new to the field, this can be confusing and frustrating. If you’re currently on the fringes of the Mental Health field, you will probably have heard the word recovery banded about a bit, with no one ever really explaining what it means. **In the general culture, to have recovered from something means you’re completely better, cured.** The recovery model uses the word in a different way, to mean that people with Mental illnesses still have something to offer, still have rights, and can still live meaningful lives – whether they get completely better, live with and manage their condition, or remain very unwell. The recovery model was moving away from some of the issues with the medical model. Like anything, some people like it and some don’t. I like the model itself a lot, but the way it is implemented can leave something to be desired. Unfortunately, I don’t think we’re ever going to find models that are so perfectly designed we can’t screw them up.

**What is a recovery focused service supposed to look like?** There’s some great ideas and articles about this out there. I like the work of Marianne Farkas, who in her article *The vision of recovery today: what it is and what it means for services*, published in World Psychiatry, 2007 sums up the recovery approach into four main values.

**person orientation**

This means not seeing people just as ‘sick’ or mentally ill, but recognising that outside of that role, they are whole people with many different characteristics. This is very important to me, whenever I have a new worker of some kind of in my life, the relationship begins very role-bound. As quickly as I can, I move towards a relationship that has two unique people in it, rather than a ‘service provider’ and ‘service user’. By that I don’t mean that it becomes inappropriate or unprofessional. Rather, that I am seen as more than just ‘someone with a mental illness’ and we move away from that unpleasant dynamic of needing help and having no answers, and them having all the answers and needing no help. I’m always more comfortable when there are two humans in the room!

**person involvement**

Person involvement means including me in all stages of services, how they are planned, created and delivered. **The ‘patient’ role favoured by the medical model is a very passive one; I as the patient go in for treatment and hopefully come away cured. My job is to turn up on time and follow instructions. In mental health this passivity is painfully destructive.** Firstly, selling the idea to people that someone else can fix your mental illness is cruel. Recovering from a mental illness is an active affair! No one can pluck it out of you. The more you engage, the more you learn about your situation, and develop awareness of what works for you, what makes you worse, what keeps you stable and well, the better the outcome often is. That doesn’t mean doing this alone! But a passive patient in mental health can give no useful information to the people who work with them. The service providers are ‘flying blind’ and reduced to guesswork about what the person needs and what approach might work. Collaboration, where you are in the driver’s seat as much as possible, and their role is support you, encourage you, help keep you safe, and help you access resources, that is about recovery.
This means having choices! You have the right to choose one service over another, to refuse services that you don’t like, and to be allowed opinions about your own care. The medical model doesn’t just invite a passive approach; it often requires it and punishes any other response. People are assessed on the basis of their ‘treatment compliance’, how submissive and agreeable they are. Being labeled as ‘non-compliant’ can cause you major problems with getting help, doctors may refuse to treat you or hospitals to admit you, you may have problems with Centrelink, and the public health system is not geared towards choice – staff rotate on their own rosters and you don’t have much power to request to stay with someone you got along with. In fact trying to access the same person can be interpreted as attempting to ‘manipulate’ the system and be another ‘non-compliant’ act, even though most of us understand that good rapport is important and changing service providers regularly is very stressful and tends to result in fragmented care. **Choice is about understanding that people are different**; there are ‘horses for courses’ and allowing people to settle with providers and approaches that work for them.

**Hope**

Sadly, this is an easy value to lose. Those who constantly work with the most unwell, disadvantaged people can lose sight of hope. Carers or staff can begin to think of all people with mental illnesses as being profoundly disabled.Discouragement sets in, and people with illnesses start to be set up for failure, being told things like ‘schizophrenia is a degenerative disease, you’re only going to get worse’, ‘it’s very unlikely you’ll ever be able to work again’, ‘you’re a hopeless case’. Despair and frustration characterise the conversation between service providers and users, and the level of animosity can become very deep and very entrenched.

Hope isn’t supposed to be naivety, but an awareness that things can change for all of us. The most profoundly unwell person still has growth potential.

Likewise, those of us who are doing great have the potential for illness. Current roles of ‘well’ and ‘sick’ are not permanent; they may even be exchanged over time.

This awareness helps us to interact in a more humble and respectful manner. People can remain stuck and overwhelmed for many years before something clicks inside. I know people who’ve spent many years in hospital and been told they would never recover who are now living independently. **Things can change,** **roles can change,** and service provision should always be about nurturing that potential for growth, not making the environment so hostile and depressed that it has little chance of taking root.
I'm pretty keen on all these ideas and I'd love to see more of all of them in our services. **In my experience,** we're using the terms but not always understanding just how profound the power shift is supposed to be.

There's still a long way to go in improving the quality of mental health services and developing systems that are designed to be flexible, adaptive and responsive to individual needs.

At the moment we often have systems that are limited and restricted, with some awesome people struggling to work within them. **Getting your degree – or diagnosis, can be like being invited to a war.** You're given your uniform and told what side you're on, and from that point forwards everything is 'them' and 'us', and no one is rewarded for seeing the other point of view. There is a better way, and I think recovery values are part of this.
a balanced life

Lisa

I'm glad I got an eating disorder.

I emerged from it with a keen understanding of the ways women’s power is diminished by so much attention to weight, shape, size and beauty. I’m determined to live differently. Liberation at an early age from fears, doubts and unhealthy activities that waste people’s energy—sometimes their whole lives—seems a small sacrifice. I love the place I have come to.

I am grateful for my body, for its many strengths and capabilities. I accept all of it and now find the idea of trying to ‘perfect’ it a terrible waste of my time. Food and cooking is a joy. I eat now for nourishment, pleasure, health and celebration.

Once you’ve been through years of body dilemmas and punishing improvement, it’s such a relief to slowly, gradually, expand your options and find out that nothing terrible happens. The opposite. Freedom. Spontaneity. Joy.

Being who I am is easier without the food and body rules that never kept me safe anyway. I have embraced who I’m comfortable being: a straight woman who—at least most of the time—doesn’t feel very girlie. I like trousers and men’s pyjamas. I hate makeup, high heels and similar adornments that just get in the way of living, as far as I can see. I’m fine being the only woman in the room with sensible shoes and undyed hair.

I wonder if others might like to try it too.

So how did I get here? It’s hard to say exactly how one changes from a life of mental rigidity and disorder to something freer, lighter and more comfy to live in. But it had much to do with the concept of balance.

Eating disorders are about extremes in thinking and behaviour: often disorientingly regular shifts from famine to feast and back again. With my face over a public toilet, I finally realised that extreme wasn’t working for me. A step towards the middle, the centre—towards balance—was needed.

Quickly, seemingly magically, something shifted. The extremes started to drop away. As I forwent food restriction, so binging wasn’t needed.

Simplistic? Yes. There was also much reading of self-help books, attending feminist body-image groups and seeing a supportive Counsellor. There were life transitions to make. But balance was the key to a life in which food and my body have taken their proper joyful place.
5 keys to my recovery from anorexia ::

Ellie Hodges

Knowing that I have successfully recovered and reclaimed my life from an eating disorder people often ask me how I did it.

At times I find myself reflecting on this also. I try to figure out what the key was; so that I can wrap up my experience better for myself and to share my learnings so that others may inform their own path away from that struggle.

In reality, there is no magic answer.

There is no formula to be defined and repeated over by other people. Another thing is that I do not have complete clarity about my journey of recovery from anorexia or how reclaiming my life was made possible.

What I do know is that there were many little things that added up over time and some other big things that held my hope and me together enough to get through and move beyond anorexia. Many built on other things that were happening and in isolation may not have had the impact that they did. Whilst I do remember clear decision points and lightbulb moments there are so many more that now escape me.

Here are five keys that have been critical to my recovery. They are skills and ways of being that continue to evolve and continue to be nurtured even today.

1. Taking Charge of MY Recovery Journey:

For a lot of my years living with an eating disorder, even when I seemed more committed to holding on to it than fighting, I still had the desire for a life free of it. Progress was easily halted by fear and uncertainty and seeking answers external to myself.

After some time it became clear that who and what was involved in my ‘treatment’ was not what I needed. Early on it was easy to disregard these reservations and stay in the turmoil. Whilst I knew what was not working and what would not work I was not sure what would work. It was incredibly difficult to work that out and get into a position where I was willing to trust myself and advocate for that. It didn’t help that people were questioning my decisions and reasoning, assuming that I was being ‘non-compliant’ or siding with my eating disorder.

In recovery circles they say that at some point you have to take charge of your own recovery. When I did that, with no desire to justify my actions to others for their sake, things shifted. I had tried different treatment options. I researched others. I thought long and hard about what I was willing and unwilling to do and my reasoning behind it. I reflected on the ideas I had of what I thought would be helpful to me at that time. I checked-in with my husband. I used my knowledge of the helping professions and the therapy process.

I backed myself. And I took action.

2. Letting the ‘Right for Me’ People In:

Once I determined what was no longer working for me I had the task of finding people with understandings and practices that aligned with my own. They had to be willing to believe in me and have the capacity to stick it out; over time and without distraction.
After research around my core issues I found someone who online seemed to fit the bill. At the first session I was able to articulate some of what I had previously found unhelpful so that our partnership could then proceed. And the thing is, in the 18 or so months I saw that person outside of getting an understanding of my eating disorder experience and history we never spoke directly about it.

That is what I knew I needed.

My earlier experiences had shown me that when the focus became about food and weight and eating disorder behaviours therapeutic benefit ceased. This was my ‘right for me’ person and an approach that was right for me. I know that this is not what would be best for everyone.

Once I found this ‘right for me’ person and the right approach for me I was then able to confidently drop other treatments and people knowing it was for the right reasons and best for my recovery. They were a great addition to the strategies and supports that had been put in place at home by my husband and I.

Over time more and more people have become ‘right for me’ and serve different purposes. Common to all however is their trust and belief in me, their partnership and ‘real’ approach and the space that opens up between us. They enable me to explore all aspects of myself and by validating my experiences they validate me. My opening. My vulnerability. My connection. My transformation.

3. Surrender - In All of its (Bitter) SWEET Glory:

Once the relationship was built with my ‘right for me’ people they were able to challenge and invite me into new understandings of myself and ways of being in the world.

An absolute therapeutic turning point for me is one that in the therapy room did not stand out. However the ripple effects were enormous.

Whilst exploring a particular topic I was asked ‘why don’t you just surrender?’ Pleadingly. Matter of factly. At the time it didn’t make much sense. In the week following though it did and I wrote a poem titled iSurrender .

That was the moment that I was able to speak my past, present and future in an integrated way; with clarity and resolve. It was a release and an opening to possibility; a foundation for forging ahead.

I now have surrendered in Sanskrit tattooed on my foot with the warrior pose from yoga – when I feel strong and connected to myself. A visual reminder of my surrender and the strength to continue on, with every step I take.

My surrender is not about giving in or loss. It is a deep acceptance for all of myself. My pain. My grief. My survival. My decision to continue _ for me.

4. Finding my Voice and Speaking my Truth:

Through recovery I have been able to find my voice and speak my truth. This came with time and has changed in the way it manifests.

Initially I had to learn to be my own advocate in regards to the care I was being provided and accessing. I then gave words to my experience so that I could make sense of my world and myself. Further along I have been able to find a voice and share my experience more broadly so that others may benefit whether through validation, knowing they are not alone or for ideas on what they could do for themselves.
I speak with integrity and authenticity. I benefit from my lived experience both personally and professionally.

5. Love & Compassion:

Love has been present throughout, and has been integral to, my recovery. It is beyond the romantic type. It is richer and deeper than that and flows further. The love that has been important is an undercurrent that exists around and within me.

Over time I have had to learn to open myself to love. To allow myself to be loved. To be loving of others in and of themselves. To open myself to liking, accepting and having compassion for myself and my life. To loving myself. Not just my experience and struggles but of me as a person. To ALL of me; mind, body and spirit. In my own right. As I am.

All of this together represents parts of my lived experience of recovery from anorexia and (re)claiming my life more broadly. It has been easy but it has absolutely been worth it!
my 6 keys for living well with PTSD

Ellie Hodges

We often hear about PTSD in the media in relation to veterans and horrific events. Less spoken about is the PTSD that people live with as a result of childhood sexual abuse and living situations. It’s this latter group that I fall into and that I speak from; as someone who lives with chronic PTSD and as someone who supports many others who have experienced trauma in their lives.

For me to say that I live with PTSD is a new thing. To live with it isn’t.

Anorexia had been my go-to solution for masking and managing it. I had also tried over-working and other destructive ways. As I gave up these things and became more ‘comfortable’ with, or at least not avoiding, my experiences I became able to talk about struggling with anxiety and experiencing trauma. True in themselves, yet not a full representation of my experience with them. More acceptable and palatable to others yet not adding to the conversation that needs to be had about PTSD and childhood experiences. The one where there is space for stories of people living well and thriving despite.

The following keys are how I live well and what I help the people I work with to discover for themselves, no matter what our history is and no matter what the effects are in our lives now. They may be helpful to you or someone you love, they are not a guarantee.

1. I educated myself and the person closest to me.

I have always worked in the area of trauma and been interested in its effects and overcoming. Even though I have always been well aware of my own struggles and history it was not until 2010 that I read myself into the words and interventions and started to apply them to myself. I searched out the papers and chapters that felt right for me and studied everything in the context of myself, forgetting about how it related to work or the people I supported. In the early stages I was reading things that are now becoming more mainstream but by comparing and checking my lived experience to it I learnt more about my experience and why and how to help myself.

Reading and becoming more acquainted with what I had experienced and was experiencing made it possible to know that through addressing them I would recover from anorexia and reclaim my life back. It also led me to seek specialised support for trauma with someone who also had experience with eating disorders. The primary focus for my therapy changed and that was a major shift for everything. In my way and in my time I became more articulate and able to share what was most relevant with my husband. To increase his awareness of my experience, to help me be supported in managing and to also disclose in a roundabout way what I had been trying to cope with on my own and that remained largely unspoken between us for 16 freaking years.

Being able to speak about PTSD directly and what was going on internally for me has opened space for behaviour change and a reduction in my symptoms. Naming it directly also helped with understanding and deopathologising it. Rather than me being a horrible person to be around I became someone finding my way after some awful experiences and choosing to no longer engage in destructive behaviour. 2012-2014 were extremely hard years as I, we, worked this out.
Before 2011 my experience framed as PTSD had gone largely unacknowledged by professionals involved in my care. My new therapist did not shy away and opened space for us to talk about dissociation and avoidance that became key moments toward validation and healing. At that time I wrote a poem to describe my experience and relationship with dissociation. Before then I had never shared with anyone that symptom and how it impacted my life. I could finally talk about it all with no shame, no judgement and complete acceptance of me as a person.

2. I stopped avoiding my situation and moved toward acceptance.

Another turning point came when I stopped avoiding myself, my body and my experiences; when I stopped consuming my head space and time with an eating disorder, busyness, too much work and hurting myself.

I had to stop living in denial and struggle and give myself a chance to cope rather than living in the belief I had no capacity or skill to address my issues without being sent over the edge.

I had to sit with my fear and not let it take more from me than it already had done; I didn’t have much more to give anyway. I had to move beyond intentional numbing of myself, believing that things shouldn’t be how they were and cease being pissed off about where things were at because it was getting me nowhere. I had to believe there were solutions and I had to be gentle with myself.

All of these things needed to happen but I had to titrate my exposure and sitting with it all. If I didn’t I would have overwhelmed myself and been worse off. Moving towards acceptance was a long process and in the early stages was very difficult and misunderstood.

I accept that I will live with PTSD in some way for the rest of my life, my version is chronic. With that said it doesn’t mean that it has major impacts on my life, most people would never know this about me, but it is something that I have to be aware of and consider.

I don’t embrace and would never choose what living with PTSD means for me but I can accept and live with it now. I no longer struggle with it. I no longer fight it. I no longer try to remove it from my life. Taking these steps have been big contributors in helping me manage and live well. Before I accepted what is and allowed it to be I had to stop trying to defeat it because the reality was I was only defeating myself.

3. I found a way to make sense of my experience for myself.

With the help of my therapist I came to name, understand and acknowledge my experiences and symptoms. I got to know ‘my system’, my physiology and brain, and came to see it as me but also separate to me and not what I need to identify myself by. What I was going through and trying with all my might to push aside was not about there being something fundamentally wrong, bad or crazy about me but brain and bodily reactions that made complete sense given everything. When I realised this I became able to work with it and start living better bit by small bit.
By working with the effects of my experiences and how they continued to show up in my life I started to know how to help myself and when I could not help myself I at least started to not make things worse. **Mindfulness approaches have been critical to me living well and is taking on a bigger role in my life the more that I practice.** In the early days I did need to approach mindfulness with caution as it sometimes sent my system into overload and was not helpful, even when others said it should have been. **Through trial and error and persistence I came to know my own version of PTSD and how to manage and bear it.** Critically I learnt to trust myself and believe in abilities to withstand my emotions and my experiences. Very difficult to do but so worthwhile.

**Medication has played a role in helping my system settle down more when I haven’t been able to do it alone.** This is an ongoing lesson in acceptance for me. I hate taking medication of any kind; I rarely finish a full dose of antibiotics when prescribed. The struggle is not because of what the medication is for; it is because of medication full stop. **I breathe and I know my reality.** The fact for me is it helps and I am now committed to doing what works and living my best.

4. **I made room for the full experience of PTSD and healing from trauma.**

As I came to know more about my system and the physiology of PTSD other aspects of my self came to the forefront and had to be dealt with. Some taking on priority and importance at different stages. **I had the stories of myself and my experiences to contend with.** Stories of being at fault. Stories of being bad. Stories of something being damaged and disgusting within me forever. There were also the feelings associated with those stories. Shame. Guilt. Bewilderment and questioning. Where ‘why me?’ twisted into being ‘of course me’ and had me waiting for the next thing to happen and condemn me further. And there was the final big elephant in the room of my body. The thing that had let me down and was the bane of my existence. The thing that I denied most. That I did not inhabit. I didn’t trust it or care that it existed and I definitely had not wanted to feel it. **I had to manage the ebb and flow of grief related to my experiences and the impacts on my life that remain.**

In making room for these things I had to get to know myself more and integrate all of it together. To be a person with a body and with experiences that had shaped me. I had to have a space, and the therapy room and my therapist became that space, where I could acknowledge and then own all I had been through so that I could then acknowledge and then own all of me.

**In remembering and accepting my experience I came to honour myself. All that has shaped me to this point made sense. It became ok and in that becoming ok, in a non-ok way, I became ok.**

When I became ok what felt possible changed and opened my life up immensely. My limits are my possibilities. I have a body and I inhabit it. I embody who I have been and who I am becoming. **I have a choice in how I make sense of my self and my life as well as what I create.** I don’t deny or hide any of it from myself. I pace myself and continue to address these in various ways even now. I am growth focused and reach new depths as my understanding, acceptance and healing occurs. I live with PTSD but I have emerged out of the shadows. I live beyond and am no longer bound by it.
5. I worked on my sense of safety.

Safety, or lack thereof – in both a real and a felt sense – have been huge parts of what I have had to work on and is the thing that endures the most. When I feel unsafe my body tells me that I am unsafe, my system goes into overdrive very quickly and is slow to return to my normal. Anorexia had been my way to create safety for myself and was how I became ‘ok’ which in itself over time was actually a very unsafe and un-ok approach.

I know what environments and circumstance affect my system and I have things in place to minimise or counter their impact. Sometimes it is music tempo. Sometimes it is the vibe of a space or person. Sometimes it is overstimulation. Sometimes I just feel exhausted and need to respond to that. All things that I can manipulate to help myself most of the time and that I can be checking-in with myself about. Sometimes baths are ok and sometimes they are not. Sometimes yoga is ok and sometimes it is not. Sometimes hugs are ok and other times they are not. I now know to take charge on this for my own wellbeing even when it is hard to communicate this to other people. It has also meant that at particular times, and occasionally for extended periods, sexual contact with my husband has not occurred. My system needed time to settle and I needed to put clear and firm boundaries in place to do that. No one else will and I would not have helped myself as much as I have if I didn’t.

6. I started to do what I needed to do for me!

Once I discovered and started implementing the five keys above I knew myself more and started to live in alignment with that, even when it went against what was recommended by some professionals.

I know what balance looks like to me and I have found it – most of the time. I know my non-negotiables. I know what helps me and what does not. I know my values and what and who is most important to me. I know my worth and what I stand for. I know what I need to do to be well.

There is no more diminishing myself or putting others perceived need above my own. Professionals. There is no more diminishing myself or putting others perceived need above my own.

I have learnt that when you heal what is beneath PTSD it changes everything and that it works both ways. Doing the above things heals and healing what is beneath supported me to do those things. PTSD does not define me and it will not stop me.
People in recovery know three very important things: 1) the ways in which mental health systems currently help people; 2) ways in which mental health systems currently fail and harm people; and 3) ways in which mental health systems could be better at educating, engaging, and supporting people and their loved ones in their own recovery journeys.

If we can invite, value, and benefit from their accumulated wisdom, ideas, and energy, we might be able to create together a system that is more accessible, respectful, and responsive to all those in need—whether or not they choose to join, or to become invested in helping to further improve, the system that cared for them.

[Larry Davidson]
landing in a place of hope

Julia McMillan

There are few things more scary or rewarding than leaping from safety to the unknown. All those 3am awakenings. You know the kind – when your body seems to be blissfully sleeping but your brain shakes it awake with an insistent murmur, gradually escalating to a consistent nagging which brings you to that pseudo-awake status where your brain can really take over and provide you with every negative reason why you should never, ever, ever leave the comfort of a known role and leap with cheerful abandon into a role which couldn’t possibly provide any satisfaction but rather, plunge you into the darkest of dark places: uncertainty.

After many 3am awakenings and sparring sessions with my less positive (aka scared witless) side, I made the very brave (and very scary) decision to accept a secondment to a role with the new SA Mental Health Commission. Some aspects of the decision weren’t difficult at all – several familiar faces beamed their welcome as I walked cautiously to my new and very unfamiliar desk, and for those welcoming smiles, I was extremely grateful.

But oh, the unknowns... Just how was I to embark upon a Stakeholder and Community Engagement Plan which would ultimately inform a brand new Commissioner as he worked towards the development of a 5 year mental health plan for South Australia?

And who was this new Commissioner, anyway? My heart plummeted as I heard the goss – this guy had no background in mental health. He came from the military, and more recently, the defence sector. Good Lord, I thought, what are the odds he’ll bang on about PTSD in the vain hope that we won’t notice his total lack of understanding of lived experience, about the public, private and NGO mental health sectors, about the neverending stigma and the sense of ‘otherness’ which people who experience mental illness, and their families and friends, understand only too well?

I figured I’d give it a go, this new job, with this new guy and this new team in this new Mental Health Commission. And if it wasn’t a good fit for me, I thought, I’d bolt back to the safety of my substantive role.

And this is the good thing about risk taking. Sometimes, it actually works out pretty well. This new guy, this bloke with the military and defence background? Turns out he does know a bit about PTSD.

But he is also very clear that he comes to his new role with a blank slate, and (to quote him) “with two ears and one mouth, so that I hear twice as much as I say.”

And that’s a good thing: this Chris Burns, CSC, Commissioner guy comes with no agendas, no biases. He is intelligent, strategic, and sharp as a tack. It’s clear that he’s a leader, and a good one at that. I must admit, I half expected I might need to salute him, or that he might bark orders at me as I came to work each morning. But nothing could be further from the truth.
He is humble. He is kind. He’s actually pretty funny. He’s also interested – oh, so interested in hearing people’s stories. He’s rarely in the office to bark orders (even if he wanted to, which I know he doesn’t) because he’s out there, in the community, at gatherings, in meetings, talking one-on-one with people who want to tell him about their experiences in the mental health system - the good the bad, and the ugly.

He smiles and enjoys hearing the good stories, and he remembers them. Sometimes he writes them down in his little black notebook. He is deeply concerned by the bad and the ugly stories – and they are also recorded in his book in his scrawly writing.

He has a memory like an elephant, and the tenacity of a Jack Russell Terrier – if he believes in something, he won’t let go until it’s achieved. He has an excellent track record – he was instrumental in securing SA’s role in building ships and submarines into the future.

And if you think that has no relevance to mental health, perhaps consider the way in which he did it. He talked to people – leaders and managers and workers at the coal face, to communities and politicians until they realised that building ships and submarines in SA was a “no brainer”.

And that’s what we need for mental health. Someone who understands that mental health is everyone’s business.

So as it turns out, when I took my leap into the unknown, I landed in a place of hope. I don’t want to be all Pollyanna about this, but I really do feel that the Commissioner, and his trusty team at the Commission, will deliver the very best mental health plan for South Australia that it possibly can. And the Commissioner is adamant that he can’t do it alone.

So he’ll continue to meet with people (with his little black notebook in hand), and he’ll be encouraging you to get involved. Not in a happy-clappy, Kum-bah-ya way (not that there’s anything wrong with folk songs. Or guitars.) But rather, by contributing your thoughts, your ideas, your stories in any way you can – via the SA Mental Health Commission’s Facebook page or website, or (shortly) the yourSAy website.

Or, if you’re not keen on the internet, there’ll be lots of other opportunities to have your say, and to get involved. Keep your eyes and ears open for those opportunities, which began on World Mental Health Day, Monday, 10 October, continuing into 2017.

Take a step into the unknown and have your say. It might just turn out pretty well!
tips for talking to children and young people - or anyone for that matter - about mental health

Ellie Hodges

I don’t believe that it is ever too early to start talking about mental health or that there are people we shouldn’t be talking about it with. Children and young people are perceptive. They notice anyway.

We need to have these conversations early to: minimise worry they have for themselves or people they care about; prevent the transfer of misinformation, myths and stereotypes; normalise and encourage seeking support for themselves or people they look out for; and decrease the chance of internalised stigma adding to their experience.

These tips will assist you to start the conversation about mental health and keep it going:

-> Be honest
-> Stick to the facts
-> Keep it hopeful and reality based; people do recover, heal and live well despite
-> Be informed yourself, yet don’t think you need to know a lot or be an expert first
-> Don’t make it too heavy or too jargony
-> Talk, don’t lecture
-> Seize the moment, embed it into other conversation’s as opportunities arise
-> Match your approach to who you are talking to – their age and maturity, their needs and concerns, their experience and knowledge, their character and circumstances, etc
-> Get the balance right. Say enough so they know but not too much that they become overwhelmed
-> The first conversation should not be the last. It needs to be ongoing
-> Normalise the ebb and flow of life and our mental wellbeing. Don’t make it just about mental illness
-> Use physical health metaphors to help explain things. Just like our physical health everyone has mental health and can do things to make themselves ‘fitter’. Talk about strategies for feeling good – sleep, food, exercise, talking about how we are feeling and going with things. Model these yourself
-> Let them know it’s ok to get help
-> Answer questions or concerns they have
-> Offer reassurance
-> Check-in and observe their response
-> Access more resources and supports if you need or they want, including professional help
when you or someone close has a mental health issue

If you are wondering if you should talk about your own or someone else’s mental health issue the answer is yes!

Follow all of the previous suggestions plus:

-> Be comfortable and clear on what you are willing to share and what you are not. What are the key things you want them to know?

-> Ask a friend, support worker or partner to support you

-> Reassure them more specifically – that you or the person don’t love them less, that it is not their fault that you or the other person is unwell, that they did not cause the illness, that they cannot make you or the person better, that you or the person are doing what you/they can to get help, etc

-> Ask about their experience and what they notice. What are they worried about?

-> Talk about what they can do for themselves

-> Remind that the person you are speaking about is more than the illness

-> Check-in whether they want to talk to someone themselves or what they want to know more about (and follow through)

Talking to children and young people about mental health starts with helping them identify, articulate and express feelings. As they get older you can speak more specifically about particular challenges that people face and how they can build their own mental fitness. It’s about providing a language around mental health and wellbeing so that the experiences can be made sense of.

It is essential that children and young people hear that people can and do live well despite mental health issues and that help is available.
a real example with children

We have a five year old daughter, we talk to her about ‘physical / body health’ and ‘brain / feeling health’ and she gets it.

In the lead up to putting this magazine together I asked if she would like to draw a picture of what brain / feeling health means for her. She asked if she could ask her friends at school to do it too.

Her incredible Teacher, SH, thought this was a great idea. Together our daughter and her Teacher spoke to the Reception Class about brain / feeling health and everyone drew a picture.

The pictures were all different, many choosing light and bright feelings and imagery whilst others were quirkier and darker exploring other emotions and imagery. This was absolute evidence that this class of five and six year olds can take these ideas on and make sense of them.

The recent Adelaide storms prevented permission processes being finalised in time to include all of the drawings. Below, however, is the one that Munch drew.

As a validation of this process the morning after Munch and SH spoke to the class another parent spoke to me about Munch’s sharing and how his daughter had talked to him the night before about it. He said that they had been trying to work out how to talk more about that stuff themselves. It made an impact and the ripple of talking about mental health has started.

a resource for young people

In 2014 I was involved in delivering a four session program to Year 8-9 students and to start the conversation about mental health.

A facilitation guide was developed and two sessions held for Teacher’s and other school personnel. They learned about the background to the program, were able to ask questions about mental health to increase their understanding and provided with the opportunity to experience some of the exercises themselves all with the goal of then being able to deliver the sessions in their schools themselves.

Young people, schools and staff involved in the project all reported that the program was useful. It was also endorsed by the South Australian Department of Education and Child Development as an important resilience building tool.

The Starting the Conversation: Talking with Young People about Mental Health and Wellness (Facilitator’s Manual) can be accessed by clicking the title.
when 'I' is replaced with 'we', even 'illness' becomes 'wellness'

[Malcolm X]
supporting recovery practice ::
the self-righting star

Ellie Hodges

Helen Glover is a practitioner and consultant with a lived experience of mental health issues and developed the Self-Righting Star.

The Self-Righting Star acknowledges that recovery is complex and multi-dimensional and that people live between shifts in experience that look like polar opposites but are actually much more related and closer in effort and process than is often recognised.

People negotiate their lives and recovery between the seeming polarities, not at either end.

When practitioners nurture the movement between the polarities toward the space for self-righting - of hope not despair, of ability to respond and take control not the inability to take control, of connectedness not disconnectedness, of discovery not alienation and of an active sense of self not a passive sense of self - they provide a recovery enabling environment.

In her article, Recovery Lifelong Learning Empowerment & Social Inclusion (2012), Glover provides a list for practitioner’s and services to reflect on their practice and question how recovery enabling they are. These questions are below:

(For the questions with reversed after them these are aspects that people and services should be aiming not to do).

HOPE - DESPAIR

Does my practice infer a permanency of illness or distress? (reversed)
Have I enquired as to what is important to the person?
Have I enquired as to the hopes and dreams a person has?
Have I been curious about the exceptions to their distress?
Have I been curious as to how the illness experience does not stop a person achieving?
ACTIVE SENSE OF SELF - PASSIVE SENSE OF SELF

Have I looked for the initiative that a person is utilising to meet their needs?
Am I assuming that a person is totally stuck and without initiative? (reversed)
Have I been curious as to how a person is meeting his/her own needs?
Does my support or intervention inadvertently stop the ‘self righting’ of the person? (reversed)
Does my support or intervention invite someone’s awareness of their active self (for example: determination, courage, stubbornness, and so on)?
Does a person know more about themselves as their own change agent as a result of my intervention or support?
Does a person know more about ‘others’ as being their change agent through the support I / we provide? (reversed)

PERSONAL CONTROL & RESPONSIBILITY - OTHERS’ CONTROL & RESPONSIBILITY

Have I enquired as to what gets in the way of a person being able to maintain control?
Does the intervention or care I provide infer to the person that they are not in control? (reversed)
Have I been curious as to what the person remains in control of, despite the distress that they are experiencing?
Am I upholding a client’s choice alone without negotiating support? (reversed)
Have I negotiated the support with the person and their family?
Is there a clear indication of when the current level of support will no longer be required? Does the person have the same understanding?

DISCOVERY - ALIENATION

Have I checked for self-meaning?
Have I interpreted the situation and provided an external meaning? (reversed)
Am I directing the care based on my knowledge of the person’s illness? (reversed)
Am I endeavouring to encourage self-direction?
Have I limited my assessment to a ‘medical’ explanatory model alone?
Do the processes that I use privilege my understanding alone? (for example: documentation, reviews, assessments, care planning) (reversed)
Have the processes I utilised meant that the person I am working with knows the same information as I do?
Have I enquired as to what the person has discovered about what works and what does not work for them?
Does the intervention or support I provide support a learning environment for the client?
Because of the support I offer, can I articulate what I am learning from the client?

CONNECTEDNESS - DISCONNECTEDNESS

Does the environment of support that I / we provide require a person to participate through their illness identity? (reversed)
Does the support or environment that I / we create help someone to connect with their citizenship (with same roles, expectations, responsibilities/rights and opportunities as everyone else)?
Does the support or intervention provided reinforce a sense of reciprocity for the person? (reversed)
Does the support or intervention help connect a person with a sense of contribution to other relationships and / or community?
Is there a dominance of illness-saturated environments within the support structures that I provide (for example: drop in centres, groups, centre based-support)? (reversed)
Have I considered how other people without a mental illness/support service would access the community before I create a ‘service’ response?
Have I enquired as to ‘what gets in the way’ for a person to access the community before providing access through a mental health service response?
Does the support I offer connect a person to relationships that are not paid?
Does the support or intervention that I / we provide potentially connect a person to relationships beyond those who experience a mental illness?
supportive strategy :: belly breathing

Ellie Hodges

With any strategy it is important to listen to yourself and notice the response that you have to it. Only do what serves you and if you find a practice unsettling, stop and try again another time.

-> Position yourself comfortably.

-> Place one hand palm down on your chest and the other palm down on your belly.

-> Pay attention to your breath and notice if you are naturally breathing into your belly, your chest or both. You determine this by observing which hand is moving the most. Don’t try and change your breathing pattern or try to force it. Just notice and observe.

-> Know that deep relaxed breathing takes place in the belly. If you are breathing more in your chest lower your focus to your belly.

-> Deliberately draw air into the bottom of your lungs on the inhale. Your belly should expand and extend out. On the exhale your abdominal pressure will release and, with minimal effort, your belly will slowly pull in. Your chest should remain still.

-> Take your time and experience at least three full inhalations and exhalations of belly breathing.

-> Continue as long as you wish.

-> If belly breathing is new to you what did you notice in your body as your breathing lowered into your belly? What are the lingering effects of belly breathing for you?

-> If you found belly breathing helpful or like it could be useful how can you incorporate this into your life or remind yourself to practice?

And for a bit of fun, watch this clip to belly breathe with Elmo.
Lived Experience Resource :: TED Talks

confessions of a depressed comic

Kevin Breel

a tale of mental illness, from the inside

Elyn Saks

because that’s the sickness, that’s the struggle, that’s depression, and depression isn’t chicken pox. You don’t beat it once and it’s gone forever. It’s something you live with. It’s something you live in. It’s the roommate you can’t kick out. It’s the voice you can’t ignore. It’s the feelings you can’t seem to escape, the scariest part is that after a while, you become numb to it. It becomes normal for you, and what you really fear the most isn’t the suffering inside of you. It’s the stigma inside of others, it’s the shame, it’s the embarrassment, it’s the disapproving look on a friend’s face, it’s the whispers in the hallway that you’re weak, it’s the comments that you’re crazy. That’s what keeps you from getting help. That’s what makes you hold it in and hide it. It’s the stigma. So you hold it in and you hide it, and you hold it in and you hide it, and even though it’s keeping you in bed every day and it’s making your life feel empty no matter how much you try and fill it, you hide it, because the stigma in our society around depression is very real. It’s very real, and if you think that it isn’t, ask yourself this: Would you rather make your next Facebook status say you’re having a tough time getting out of bed because you hurt your back or you’re having a tough time getting out of bed every morning because you’re depressed?

During the next year, I would spend five months in a psychiatric hospital. At times, I spent up to 20 hours in mechanical restraints, arms tied, arms and legs tied down, arms and legs tied down with a net tied tightly across my chest. I never struck anyone. I never harmed anyone. I never made any direct threats. If you’ve never been restrained yourself, you may have a benign image of the experience. There’s nothing benign about it. …

While I was preparing to write my student note for the Yale Law Journal on mechanical restraints, I consulted an eminent law professor who was also a psychiatrist, and said surely he would agree that restraints must be degrading, painful and frightening. He looked at me in a knowing way, and said, “Elyn, you don’t really understand: These people are psychotic. They’re different from me and you. They wouldn’t experience restraints as we would.” I didn’t have the courage to tell him in that moment that, no, we’re not that different from him. We don’t like to be strapped down to a bed and left to suffer for hours any more than he would. In fact, until very recently, and I’m sure some people still hold it as a view, that restraints help psychiatric patients feel safe. I’ve never met a psychiatric patient who agreed with that view.
**The voices in my head**

Eleanor Longden

Fourteen minutes is not enough time to fully credit those good and generous people who fought with me and for me and who waited to welcome me back from that agonized, lonely place. But together, they forged a blend of courage, creativity, integrity, and an unshakeable belief that my shattered self could become healed and whole. I used to say that these people saved me, but what I now know is they did something even more important in that they empowered me to save myself, and crucially, they helped me to understand something which I’d always suspected: that my voices were a meaningful response to traumatic life events, particularly childhood events, and as such were not my enemies but a source of insight into solvable emotional problems. ...

And likewise, for survivors of distress and adversity, that we remember we don’t have to live our lives forever defined by the damaging things that have happened to us. We are unique. We are irreplaceable. What lies within us can never be truly colonized, contorted, or taken away. The light never goes out. **As a very wonderful doctor once said to me, “Don’t tell me what other people have told you about yourself. Tell me about you.”**

**Depression, the secret we share**

Andrew Solomon

The opposite of depression is not happiness, but vitality. And it was vitality that seemed to seep away from me in that moment. Everything there was to do seemed like too much work. ...

And so I began to feel myself doing less and thinking less and feeling less. It was a kind of nullity. ...

So now people say, “You take these happy pills, and do you feel happy?” And I don’t. But I don’t feel sad about having to eat lunch, and I don’t feel sad about my answering machine, and I don’t feel sad about taking a shower. I feel more, in fact. I think, because I can feel sadness without nullity. ...

well, what is the conclusion? How did those people who have better lives even with bigger depression manage to get through? What is the mechanism of resilience?

And what I came up with over time was that the people who deny their experience, and say, “I was depressed a long time ago. I never want to think about it again, I’m not going to look at it and I’m just going to get on with my life,” ironically, those are the people who are most enslaved by what they have. **Shutting out the depression strengthens it. While you hide from it, it grows. And the people who do better are the ones who are able to tolerate the fact that they have this condition. Those who can tolerate their depression are the ones who achieve resilience.**
I pose these questions to you: What would you do if your family member, friend or loved one was suicidal? What would you say? Would you know what to say? In my experience, it’s not just the talking that you do, but the listening. Listen to understand. Don’t argue, blame, or tell the person you know how they feel, because you probably don’t. By just being there, you may just be the turning point that they need. If you think someone is suicidal, don’t be afraid to confront them and ask the question. One way of asking them the question is like this: “Others in similar circumstances have thought about ending their life; have you had these thoughts?” Confronting the person head-on may just save their life and be the turning point for them. Some other signs to look for: hopelessness, believing that things are terrible and never going to get better; helplessness, believing that there is nothing that you can do about it; recent social withdrawal; and a loss of interest in life.

For so long in the beginning I mistook my cause for moral crusade. I felt very angry about uncaring managers and greedy doctors and I wanted to restore the right values in healthcare, but every time I demonized those I was trying to influence I just created resistance. We had to remind ourselves that non-judgment is a critical part of compassion. Eventually I let go of my anger. That’s really hard for social activists because we are driven by a sense of moral outrage. But on the days I remember not to judge and criticize, the more people start listening. ...

We finally spotted a profound pattern. We noticed that all of the strategies that didn’t work involved separation, and all of the strategies that do work involve connection. When we declare the moral righteousness of our position and judge others we stand apart. When we try to persuade we create resistance. When we proclaim ourselves to be the experts we call others ignorant. When we turn our gifts and talents into business products we separate buyer from seller. When we always fight against what is wrong we draw up the battle lines. Every action that separates us defeats our purpose of building a better world, but every action that connects us has the power to transform.
our voice is a digital magazine raising the volume on the lived experience of mental health in South Australia. It launched during Mental Health Week 2016 and is a quarterly publication.

our voice is by South Australians for South Australians and aims to be broadly representative of the diversity of experiences and perspectives of living with mental health issues. It is by and for people who have struggled, carers and supporters, workers and interested community members.

Mental health touches us all and it is important we talk about it.

more information at ourvoicesa.org
- the role of self-compassion in recovery
- making sense of our experiences
- raising our voice for mental health advocacy
+ interviews
+ contributions from the lived experience community

If you would like to contribute writing, artwork or photography, a resource list, a supportive strategy, be interviewed or make suggestions about future content email ellie on info@elliehodges.com.

our voice website coming soon: ourvoice52.org
OUR voice

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