

Lived Experience

Co-design of Illawarra Shoalhaven Safe Space

Feedback Loop 1



Roses in the Ocean
stemming the tide of suicide

Acknowledgement of Country

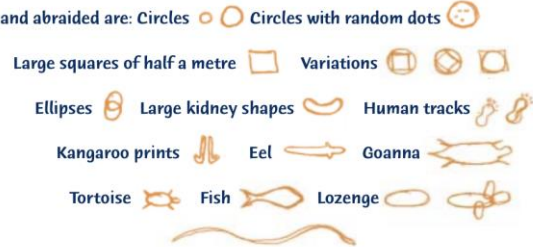
Patterns

Patterns can reflect a number of things:
The totem of the clan/ band, the family or the individual.



Symbols

The main symbols used in the Dharawal area that were painted or pecked



We acknowledge the Dharawal people of the Illawarra Shoalhaven region, pay our respects to their elders past, present and emerging.



http://www.lesbursill.com/site/PDFs/Dharawal_4Sep.pdf



Acknowledgement of Lived Experience



We acknowledge those who have considered ending your life, and those who have attempted to do so.

We acknowledge your courage and tenacity to carry and move through the immense pain.

We acknowledge those who care for loved ones through suicidal crisis.

We acknowledge the fear and helplessness you experience, and your endless endeavors

to empower them to live.

We acknowledge those bereaved through suicide.

May your immeasurable loss define a legacy and a mission to discover healing and a new purpose.

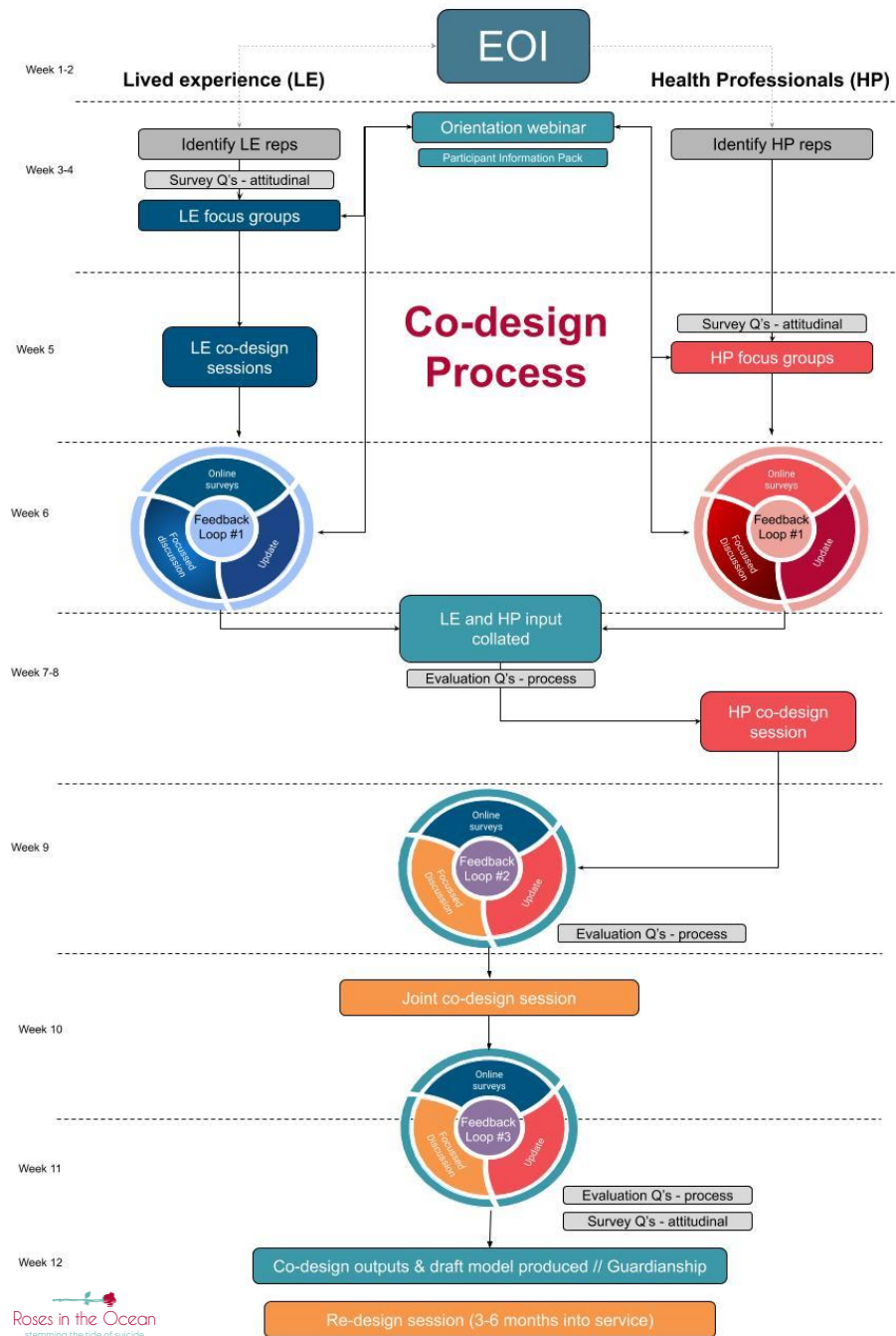
We acknowledge all the magnificent lives we have lost to suicide and those who are struggling with life today.

Everyone's lived experience is unique.

Everyone's lived experience is valuable.

Everyone's live experience can make a difference.





Process so far

- [Orientation Webinar](#)
- [Information Pack](#)
- [NSW Ministry of Health Guidance Document](#)
- LE Focus Conversations – groups of 3
- HP Focus Conversations – groups of 3
- LE Session 1A – 2 hours
- LE Session 1B – 2 hours

Purpose of Feedback Loop 1

- Provide context of the co-design process
- Make sure we have captured what has been shared during the co-design round 1
- Gather broader views and experiences
- Explore what is missing
- Help prepare for round 2 of the co-design process

Feelings, Needs, Ideas

- We walked through the experience of a person seeking help through ED (and for Health Professionals, the experience of supporting someone through the process) and explored their feelings, the reasons why they felt that way and what needs they had at each stage:

finding, arriving, checking in, waiting, treatment, leaving

- The following slides highlight the key points of discussion and feedback from the first phase of co-design
- Everything that was shared in the conversations has been captured with the most common themes shown here

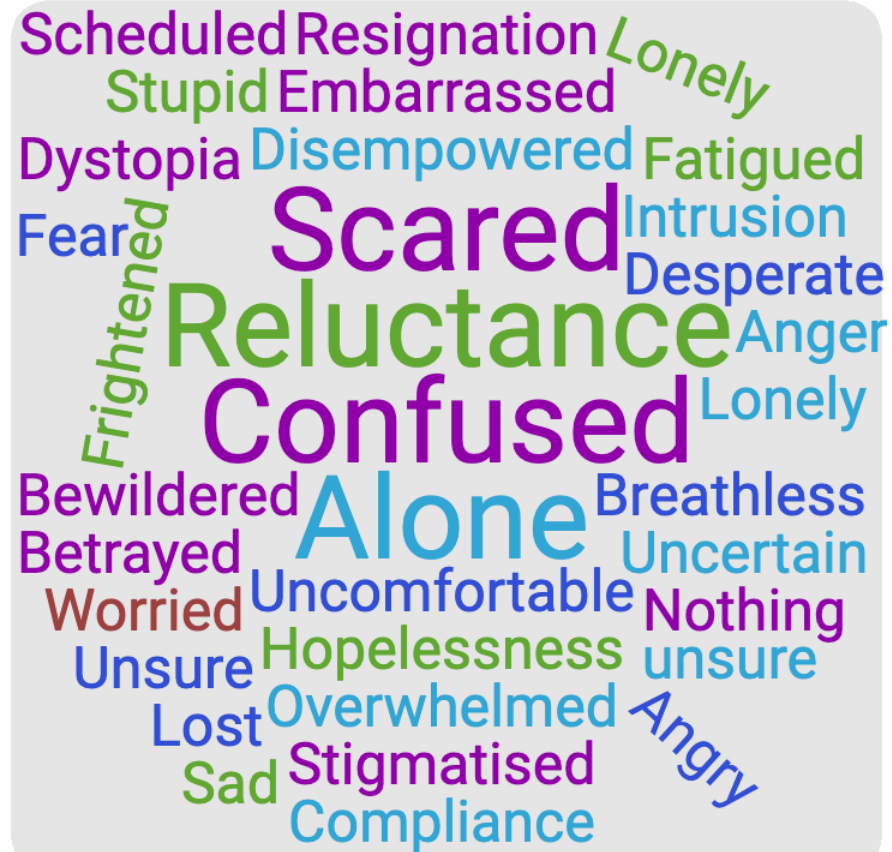


Understanding your experience



Finding

Feelings

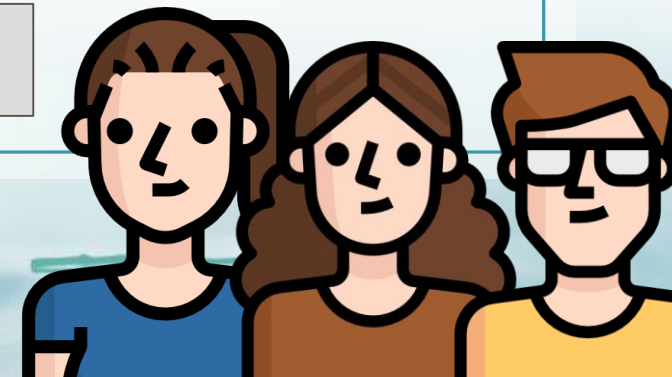


Why were you feeling this way?

“Convincing friend to go and then getting there is like the amazing race”

“Its like I was following a magnificent script and then they throw you the same old thing time and time again, Ambulance and police rock up, you sit in the seat and it all happens, its surreal, you know what's going to happen”

Scared I would be arrested for committing a crime.



Arrival

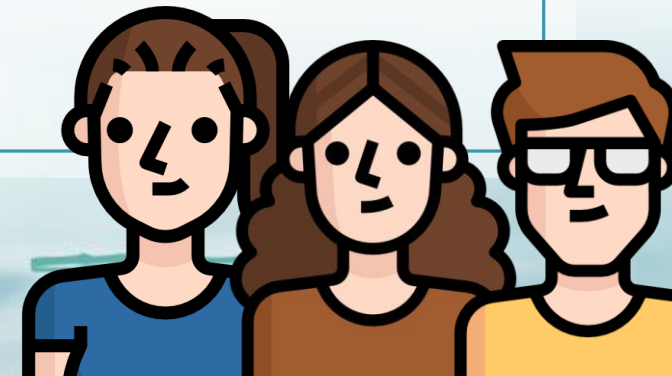
Feelings

Tired Questioning
Offended Resignation Chastised
Reluctance Disturbed Relief
Scared **Relieved** Stupid
Guilty **Confused**
Hopeless **Alone** Angry Powerless Safe
Concern Worried **Confusion**
trusted Shocked Burden
Angry Overwhelmed
Disorientation
Resented
Blamed

Why were you feeling this way?

“Other people start writing your life down as soon as you arrive and you know it's not true what they're writing but you're locked into that system with grand human emotions being viewed through narrow constrained and ultimately fiction through clinical lenses, whole journey based on that fiction”

“I felt relieved because I had a small bubble of hope that maybe I would find support, and then realised I was being treated like an imbecilic child and that quickly turned into growing concern for my safety.”



Checking in

Feelings



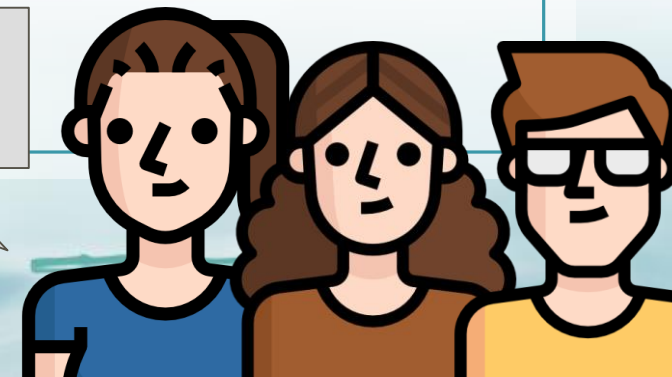
Why were you feeling this way?

“There must be a better way to treat people with different needs. I wasn't bleeding, I hadn't stopped breathing, I wasn't having a heart attack, but my life was at just as high a risk as those that were triaged”

“Everyone's watching”

“Felt insignificant nobody understands”

“Lots of private questions in a public space”



Waiting

Feelings



Why were you feeling this way?

“Still hopeful I might find someone to support the process, wondering if all the gatekeepers were just the silly ones so keeping calm and waiting for someone with knowledge to support.”

“Feel like I shouldn't be here and everyone is judging me.”

“Unable to communicate my needs as nobody was listening”



Treatment

Feelings

fury Self-blame Blind
Relief Depression
Trapped Discredited Sadness
Abusive Disconnected Labelled
Stressful Insignificant Confusion
Lack confidence
Conflicted **Judged** Reluctance
Confused Isolation
Lacking Dehumanising Ignored Lack
Safer Controlling Blamed
Numb Humiliating Alone
trust Lion's Den supportive Loss
Unwelcome

Why were you feeling this way?

“Infuriated that there are so many people with kind hearts involved but they are a little skewed because everyone seemed to focus on sedating my physicality, and then leaving me to myself and own devices for the rest of my life”

“I learnt early on that I am the expert in my mental health, I was angered as I was not asked what I thought I needed”

“How can these people help my friend when they've only just met them?”



Leaving

Feelings

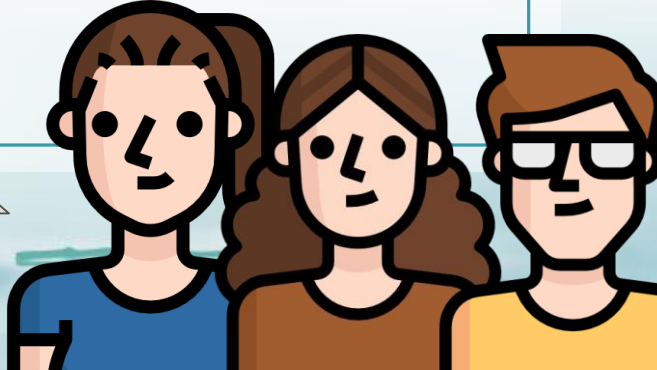


Why were you feeling this way?

“Lack of support and clear advice around the discharge process. Suddenness of discharge concerning. No time for recovery from hospital - back to school, work. I had to liaise with school, work out how that would look without advocacy to assist us. Convincing my son he was ready to go back to school and re engage.”

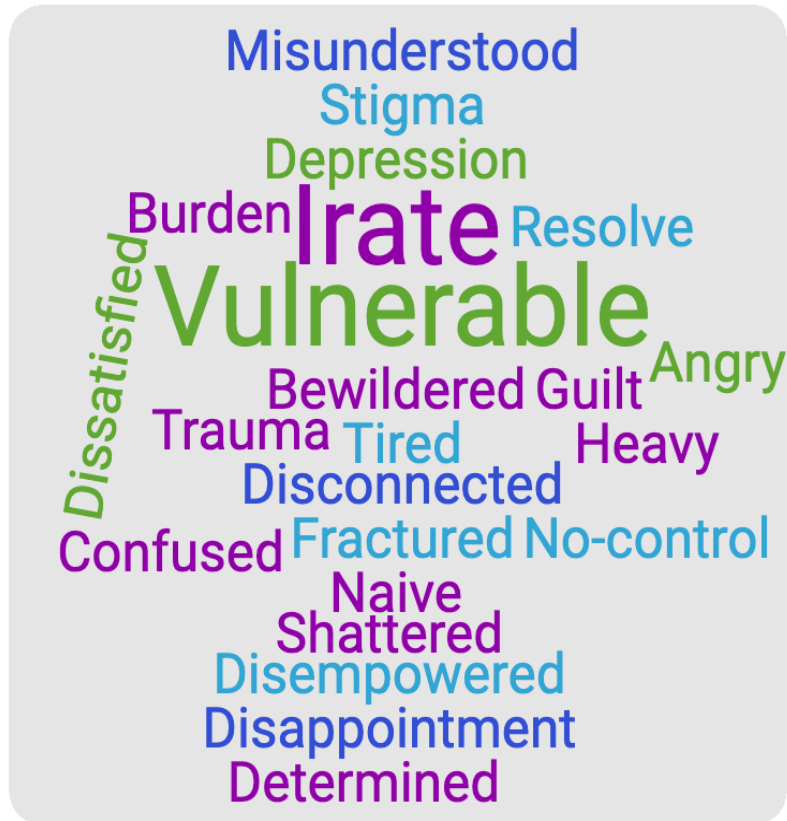
“it's rarely over when you leave the ED”

“I don't feel safe I have nowhere to go or no support”



Generally

Feelings

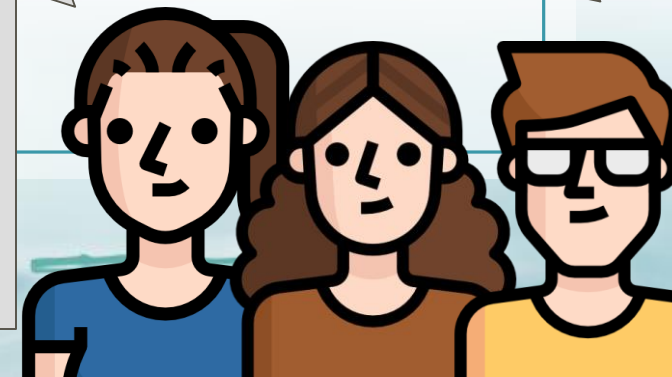


Why were you feeling this way?

“It was like 10% of me stayed in the ED and the process, but 90% had to leave. I was physically there but -my spiritual self was gone because I told it to go away because it wasn't going to cope. I split myself because I needed to protect myself. Showing emotions wasn't going to help me get out.”

“I felt blind fury, and annoyance beyond that that no one cared about my mental, emotional and spiritual tortured state and they just focused on sedating me and propping me upright so I could mimic a human in seated silence.”

“Traumatised as care was imposed upon me”



Have not accessed ED or would never consider

“I wouldn't go back in the current circumstances but I would like to say that with changes underway I'd like to think it could be a safe place for me to go and embrace at another time. I need to feel assured that there is a recognition that when people are vulnerable they are the experts in their experience, and that people with lived experience are there to help them”

I haven't accessed supports via emergency departments because it has never occurred to me to do that. Why would a person considering killing themselves go to a place dedicated to saving the lives of people who are accidentally or inadvertently experiencing life-threatening situations?

“At the moment it is not a safe place for me but I'd like to look forward to a time when things are different. There is an inequity of power in the hospital. Others with physical needs are prioritised above my need - and yet my life is just as important and just as at risk - people need to be asked what they want and what they need.”

“There are many people who care but their hands are tied by the system - time, resources, policies. They get burnt out and become victim of the system itself”



What needs should our safe
space need to meet?



Needs

Practical Connection

- Food, drinks, warmth
- Access to the outdoors
- Safe environment
- Quality TV, magazines and entertainment
- Time and space
- Space for private conversations
- Administrative support

Emotional Connection

- Being in good company
- Being heard, eye contact
- Communal areas to connect with others
- Meaningful activities (art, craft, exercise)
- Empathetic staff
- Welcomed, hosted and respected
- Connection with skilled staff



Needs

Information Connection

- Process information (what's next?)
- Guidance on transition / exit (maintaining own health and where to access services)
- Information on what a person in crisis is feeling (for carer)

Other

- Mental health support
- Confidence in workers
- Avenues for creativity
- Human rights respected
- Autonomy as a person
- Expert in own journey





Co-designing our safe space



Values

- Equality
- Connection
- Respect – unique individuals, 'being'with'
- Autonomy
- Co-passionate support
- Freedom – self reflection, insight, choice, own decisions
- Nurturing – empathy, kindness, love, fun
- Transparency
- Integrity
- Humility
- Authenticity
- Dignity
- Trust
- Non-judgmental
- Inclusion
- Team
- Acceptance
- Mutuality – kindness, spirit of mate-ship
- Ambiguity – observe holistic space
- Curiosity
- Deep listening
- Facilitated choice
- Unquestionable right to be here
- Flexible
- Welcoming



Principles

1. This is our place . . . Our place is YOUR place
2. We will welcome you as you are in a spirit of mutuality, unquestionable belonging and respectful acceptance
3. We will walk together amidst the freedom of autonomy, self reflection and choice.
4. We will offer co-passionate sharing of every person's journey
5. XXXXX
6. XXXXX



Your IDEAS to design your safe space

- Not on hospital grounds, and not in hospital
- Central & accessible, safe to access
- Totally opposite to ED
- NON-clinical
- Lived Exp of suicide Peer Support workforce
- Management of service NOT by clinician
- Collaboration & integration with health system when we need it
- Soft furnishing, nice lighting, prints on wall,
- Welcomed to space when you arrive
- Seamless way to feel information into another place the person needs to access
- Opening times – to be discussed
- Oriented into the safe space by welcoming
- Essential kitchen table for tea coffee scones
- Computer if someone needs to access it, phone chargers
- Something to do. Colouring, self guided activities,
- Freedom to interact or not – on your terms
- Option to go for a walk with peer worker
- Simple way to collect info – give person or family member a book they could start writing, drawing their story in so they don't have to keep sharing – author their own story or co-authored with a LE Peer worker and family members



Your IDEAS to design your safe space

- Mural walls
- Artwork that changes with sunlight
- Resident dog
- Imagery in information pack
- Physical space – no reception desk but a kitchen table, look like you're walking into a kitchen space. Welcoming. Real pot plants.
- Seating set up really important – coffee tables next, diagonal facing chairs, a corner bean bag with sensory; group casual space; no direct focus on TV in central area
- Colour of walls really important – not white and not super bright
- Consider aesthetics and functionally
- Kitchen – able to bake fresh baked goods
- Techniques to help people feel grounded – sensory modulation
- Peers with a lived experience of suicidality
- Clinical manager should be non-medical – social worker/psychologist - ideally with their own lived experience



Over to you . . .

Webinar Q&A Feedback Loop 1 Survey

<https://www.surveymonkey.com/r/ISSS-feedback-loop-1>

Opportunity to provide your ideas and answer questions through the survey
(open from today to May 26th)



Next steps

- Feedback Loop 1 – live webinar, survey questions and review documents
<https://www.surveymonkey.com/r/ISSS-feedback-loop-1>
- Health Professional Session 2 (provided with LE outputs)
- Feedback Loop 2 - live webinar, survey questions and review documents
- Joint stakeholders Session 3
- Feedback Loop 3 - live webinar, survey questions and review documents

