

Lived Experience of Suicide Language and Imagery Guide Includes supporting papers



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Introduction

In recent years there has been much greater focus on communications guidelines for people working within, and communicating about, suicide prevention. The National Communications Charter and MindFrame Media Guidelines are two excellent points of reference to guide safe and responsible communications about suicide.

However, we need to go even further and be even more attuned to the potential impact language and imagery can have on those who read, hear and see our communications. Both have the ability to evoke strong emotions and memories, and will be experienced differently based on an individual's experiences.

Roses in the Ocean takes a lived experience informed lens to everything we do, including language and imagery. We are continuously seeking input on, discussing and exploring the evolution of language within the context of suicide, and provide training on the use of imagery through our Critical Lens workshop, components of which form the basis of this document.

Language

"I remember the first time someone explained why the phrase 'committed suicide' hurt them so much. This distinguished gentleman, who would become a friend, broke down in tears as he described how the term accused his beautiful daughter who had taken her own life, of committing a crime and a sin. It broke his heart to think that anyone could judge his daughter like that. I recall thinking, regardless of what I felt when I heard the phrase, the fact that it brought so much pain to others, was all the reason I needed to help change the language used."

"When I first heard in the co-design about visitors to the local safe space being referred to as guests, I thought to myself – this actually sounds like somewhere I could go and be treated with dignity and respect as a human being."

Why language matters

For people or communities with a lived experience of suicide, language has the power to wound or heal, disenfranchise or empower, defeat or motivate.

Language isn't just a communication tool, a passive device for conveying information. It isn't just a mirror of who we are; it actively shapes our reality.

Language communicates our social and cultural norms and therefore influences attitudes which in turn impacts how people are treated. Because of the history of stigma and discrimination around the topic of suicide, the language we use when talking about it matters.

Stigmatising language can reinforce prejudice and promote discrimination. The language used by a service can determine whether someone will seek help or not. Clinical language which pathologises people's emotional pain and distress can be retraumatising to people who have had hurtful and harmful experiences within the mental health system when seeking support for a suicidal crisis. This is especially important for people and communities whose experiences of stigma, prejudice and discrimination are compounded in relation to suicide such as First Nations people and people who identify as LGBTIQ+.

It is equally important to understand that when we communicate about suicide in an open and honest, non-judgemental and compassionate way, we can contribute to transforming the destructive narratives around suicide that have shaped people's past experiences into helpful and healing ones. Respectful and inclusive language that acknowledges and honours the diversity of people's experiences, identities and bodies can also help to heal past hurt and trauma for people who are sexually or gender diverse, or people living with disabilities.

Glossary of terms

TERM	DEFINITION	
Lived experience of suicide	In 2014, Roses in the Ocean developed the now nationally adopted definition of lived experience of suicide as 'having experienced suicidal thoughts; survived a suicide attempt; cared for someone through suicidal crisis; or been bereaved by suicide'. In recognition that this non-Indigenous definition does not capture the unique cultural dimensions of suicide for First Nations people, an Aboriginal and Torres Strait Islander definition of Lived Experience was developed in 2020. See: <u>https://www.blackdoginstitute.org.au/education-services/aboriginal-and-torres-strait-islander- network/</u>	
Suicidality	Often used interchangeably with 'suicide ideation' to mean someone's experience of thoughts of suicide, especially used when these thoughts are 'chronic' or 'persistent' in nature.	
Suicidal / suicide crisis	Refers to someone seriously contemplating ending their life and/or planning to do so.	
Suicide attempt	Suicide attempt - it is extremely difficult to actually define what a suicide attempt is, as it is an intimately personal experience. Many people who have made an attempt on their life reflect that what they were seeking was to escape the unbearable pain or 'psyche-ache' they were experiencing.	
Self-harm	It is important to distinguish a suicide attempt from self-harm (sometimes known as 'non-suicidal self-injury') which is a deliberate act of harming oneself but without intent to die but rather an avenue to releive emotional pain. It is also important to note that this type of self-harm is often dismissed as 'manipulative' or 'attention seeking', but is a sign of intense emotional distress (often as a result of complex trauma) and in itself a risk factor in suicide.	
Suicidal / suicide ideation	An unnecessary clinical term that can be better said in plain language. This term remains widely used however, and there are many different views about it. Better described as 'A person who experiences thoughts of suicide'.	

TERM	DEFINITION	
Bereaved / Bereavement	In general usage this term refers to someone being 'deprived of a close relation or friend through their death'. In the context of suicide, lived experience of bereavement refers to someone who has lost a loved one/significant person with whom they have a very close personal relationship with. It is very important to understand the difference between being bereaved through suicide and being impacted by suicide through a person's line of work or a more distant connection - for example, a clinician who has a client/patient die by suicide. Whilst there is no denying this has a deep impact on the clinician, this is not equivalent to a family member where the impact extends far beyond the much deeper immediate loss, spans generations and extended networks, and re-emerges at numerous touchpoints throughout their lifespan. Different support is required for people who are blindsided by the death of their loved one and those who find themselves having to transition from a carer role to that of someone bereaved. Those who have cared for, lost and then find themselves caring for another loved one in crisis, need different support again. As the bereaved experience other life challenges, their loss and pain often re-surfaces requiring yet another layer of support. It is also important to understand and recognise that within Aboriginal and Torres Strait Islander communities, and Defence and Veteran communities, a death by suicide is experienced at a deep emotional and cultural leve (often referred as 'tribal grief') by many within the structure of these extended family cultures.	
Consumer	This is a term used within the mental health sector referring to someone who has an experience of living with a mental illness and who may have had direct experience with public mental health services (either voluntarily or involuntarily) or who has not received or been denied services that they have sought.	
Carer	In the context of mental health, 'carer' has traditionally been associated with someone who is providing unpaid care to a mental health consumer. This term is less commonly used in the lived experience of suicide sector; more typically people who support loved ones are referred as those who 'care for' or 'love and care for'. It is important to note that not all people who support people living with mental ill-health identify with the term 'carer' and will identify themselves in terms of the relationship they have to the person they are supporting (for example, 'friend' or 'partner'). This is also the case in the context of suicide prevention.	

Glossary of terms

TERM	DEFINITION
Lived experience perspective	An understanding of suicide based on having experienced suicidal thoughts, lived through a suicidal crisis and/ or suicide attempt, cared for someone through these experiences, or who has been bereaved by suicide. The perspectives of people with lived experience are seen as important because they are the experts by experience of what does and doesn't work about the current way people are supported, as well as how to improve supports and people's experiences of these supports.
Lived experience workforce	This is an umbrella term that refers to anyone with a lived experience of suicide who provide their insights and expertise to suicide prevention activity. This 'workforce' spans the spectrum of people who share their stories in public contexts, people who provide 'light touch' volunteer peer support, advocates sitting on committees and advisory groups, as well as paid specialist suicide prevention (SP) Peer Workers. It should be noted that the term is being increasingly used to describe the mental health consumer and carer workforce that was previously known as the mental health consumer and carer peer workforce.
Lived experience informed	Indicates that all aspects of an organisation or service (suicide prevention specific or mainstream) has been informed by the lived experience of suicide. It means that people have looked through the lens of lived experience and applied LE Engagement Principles, best practice, existing and emerging evidence.
Engagement	This refers to both the methods and actions taken to involve people with lived experience in service and systems improvement initiatives, spanning the spectrum of participation from consultation to co-production.
Meaningful inclusion	This term is also often used in suicide prevention rather than 'participation' to refer processes by which people with lived experience are engaged by commissioning agencies and organisations to contribute their expertise to system and service improvement initiatives in a way that is genuine and consistent with best practice co-design/co-production principles.

TERM	DEFINITION	
Co-design	A process whereby traditional experts work in equal partnership with experts by experience (people with lived experience) to 'design' a service or service improvement. The core co-design principle of power sharing is especially significant in the context of suicide prevention where people with lived experience have been disempowered by their experiences of stigma and discrimination and unhelpful responses within the clinical system.	
Co-production	While co-design is an essential component of co-production, co-production is a more involved process where people with lived experience equally collaborate, or lead, a major piece of work (eg: research project) from inception to evaluation of outcomes.	
Tokenism	Sometimes known as 'box ticking', tokenism refers to when people with lived experience are engaged to contribute to a suicide prevention activity, but their contributions are not taken on board or taken seriously.	

Language guide

Language is often attributed to fueling the stigma, prejudice and fear that we still experience surrounding suicide. This in turn can prevent people from seeking help, and indeed reaching out to help others too.

It is widely accepted that the inappropriate use of language when describing suicide and discussion of method, can have a significant impact on people who have a lived experience of suicide, and other members of the community, especially those experiencing emotional distress and/or suicidal crisis. When people are particularly vulnerable with thoughts or plans for suicide, the wrong language and/or discussion about method can have devastating effects.

For this reason, we must ensure that when talking about suicide in any situation where we do not know the audience and their personal situations, we do not describe how someone took their life, nor do we discuss specific details about a suicide attempt including means and location.

Similarly, we need to ensure we are not 'too afraid' to talk about suicide as a community, while respecting and understanding the risks in certain situations.

Don't say	Do say	Why?
'committed' or 'commit suicide'	'died by suicide' or 'ended his/her/their own life'	To avoid association between suicide and 'crime' or 'sin' that may alienate some people.
'unsuccessful suicide'	'non-fatal' or 'made an attempt on his/her/ their life'	To avoid presenting suicide as a desired outcome or glamourising a suicide attempt.
'successful suicide'	'took their own life', 'died by suicide' or 'ended their own life'	To avoid presenting suicide as a desired outcome.
'suicide epidemic'	'concerning rates of suicide'	To avoid sensationalism and inaccuracy.
'mental patient', 'nutter', 'lunatic', 'psycho', 'schizo', 'deranged', 'mad'	A person is 'living with' or 'has a diagnosis of' mental illness.	Certain language sensationalises mental illness and reinforces stigma.
victim', 'suffering from' or 'affected with' a mental illness	A person is 'being treated for', or 'someone with a mental illness'.	Terminology that suggests a lack of quality of life for people with mental illness.
A person is 'a schizophrenic', 'an anorexic'	A person 'has a diagnosis of' or 'is being treated for'	Labelling a person by their mental illness.
'crazed', 'deranged', 'mad', 'psychotic'	The person's behaviour was unusual or erratic.	Descriptions of behaviour that imply existence of mental illness or are inaccurate.
'happy pills', 'shrinks', 'mental institution'	Antidepressants, psychiatrists or psychologists, mental health hospital.	Colloquialisms about treatment can undermine people's willingness to seek help.
'psychotic dog', using 'schizophrenic' to denote duality such as 'schizophrenic economy'.	Reword any sentence that uses psychiatric or media terminology incorrectly or out of context.	Terminology used out of context adds to misunderstanding and trivialises mental illness.

Extracts taken from: Everymind <u>https://everymind.org.au/suicide-prevention/understanding-suicide/role-of-language-and-stigma</u>

Language guide continued....

Whilst we understand that no one intentionally uses language, phrases and conversation to bring distress to others, we do need to be very aware of the conversations we have. At every opportunity, it is important that we improve the suicide literacy of the community including the use of non-stigmatising and safe language when discussing suicide.



Further guidelines regarding terminology and discussion of mental health in the media can be accessed through the MindFrame website:

https://mindframe.org.au/suicide/communicatingabout-suicide

ALSO READ: Why we shouldn't use the 'C' word, by Susan Beaton, Dr Peter Forster and Dr Myf Maple. Published in InPsych February 2013. Available online at: <u>https://www. psychology.org.au/publications/inpsych/2013/february/ beaton</u>

Conversations Matter

For a more in-depth guide to discussing suicide visit **Conversations Matter**, a practical online resource to support and effective community discussions about suicide at <u>www.conversationsmatter.com.au</u>.



To encourage safe discussions about suicide Roses in the Ocean is a proud signatory to the @LifeinMindAU #CommsCharter. Working together with unified messages can reduce stigma & empower people to get support. To sign, visit: www.lifeinmind.org.au/the-charter



Alternative language table extracts taken from: Everymind <u>https://everymind.org.au/suicide-</u> <u>prevention/understanding-suicide/</u> <u>role-of-language-and-stigma</u>

Other language

There are some very common words and phrases that have been used for decades that, when used with an audience gathered for the purpose of talking about suicide, do cause distress to some people. Whilst we need to be sensible about how much we sanitise our language, when working with groups of people with lived experience of suicide it is important we consider their impact especially in how they relate to suicide method. Other language that may cause distress to people depending on their experiences.

Replace	Some suggestions to consider
'trigger' 'triggering'	This term can be distressing for people bereaved by suicide where someone died by firearm. An alternative expression may be - 'causes an emotional response'.
'hanging around' 'hang in there' 'hang about'	References to this method of suicide can be distressing for people bereaved by suicide where someone died by hanging. Some alternative expressions may be - 'spending time' / 'you can do this' / 'just wait a moment'.
'Suicide is a permanent solution to a temporary problem.'	This commonly used phrase could be percevied as either a protective factor (if a person's problem is indeed temporary, eg a relationship breakdown is something that someone can move through and go on to meet someone new in time), or it could be a risky statement (eg if a person is suffering chronic pain, or an enduring mental illness a permanent solution could be quite appealing to them).
'We have to stop parking the ambulance at the bottom of the cliff.'	A very distressing statement for anyone bereaved through a suicide where someone died by falling from a height. It is also dangerous as it speaks to a suicide method directly.

Biomedical language

Some of the biomedical language we have heard that is challenging people is listed below in Table 1. To continue to support the ongoing development of language we have also drawn on valuable work from the New South Wales Mental Health Coordinating Council, in particular their recently published second edition of Recovery Oriented Language Guide (Mental Health Coordinating Council, 2018).

Table 1

DISEMPOWERING LANGUAGE	EMPOWERING OR PREFERRED LANGUAGE*	WHAT IS THE PROBLEM WITH THIS LANGUAGE
Assertive outreach	Proactive Outreach	Has power overtones – assertive implies forcing someone.
Non-compliant	Declined a service, wanting to explore other options	The word compliant is problematic - it implies a need for someone to relinquish their (human) rights.
Treatment resistant	The person has unmet needs or challenges that need to be resolved	The word resistant is deficit focused and implies a person is unable to be helped rather than seeing this as an opportunity to uncover why the person is not engaging – what is their unmet need or what needs resolving or alternately what is it about the treatment on offer that is not what the person wants or perhaps feels they need?

* For example: Trauma informed, culturally competent & strengths-based language

WHAT IS THE PROBLEM WITH THIS LANGUAGE
Fails to acknowledge a person's behaviour is often a response to their needs not (yet) being met.
It reflects judgement about culturally acceptable and unacceptable ways of seeking help. It is a term that is generally used to shame females for seeking help in ways that males tend to be culturally raised not to use.
When used in the context of suicide, it reinforces the myth that people who speak up about thoughts of suicide are not serious and are just being 'manipulative', which is a truly dangerous myth.
Unusual beliefs help normalise a person's experience, and challenges already stigmatising language often associated with people who are experiencing extreme mental distress.
'Psychotic' is sanist language. It is based on the premise that people who have a different experience of reality must have something wrong with them and that reality is defined by the majority. Again, it is a concept that reflects cultural acceptability. It is culturally acceptable to incorporate a God whose presence is 'felt' into a person's reality, but a person is 'sick' and 'unstable' if they claim the existence of anything else that other people can't see.
This word labels and negatively stigmatises a group of people (Link & Phelan, 2006). It falsely labels people as simply one-dimensional beings which diminishes the whole person and is not strengths-based language. It also ignores the fact that as humans we are the sum of many different public and privately held identities and belong to many groups in society.
An unnecessary clinical term that can be better said in plain language. This term remains widely used however, and there are many different views about it.

There is also a second body of language which is emerging during our facilitation of the co-design of Alternatives to ED: Safe Spaces. This language is service specific and relates to the words and phrases people with lived experience of suicide are sharing with us that they would like used in these non-clinical alternatives. This language and suggested alternatives are listed in Table 2.

Table 2

DISEMPOWERING LANGUAGE	EMPOWERING OR PREFERRED LANGUAGE (trauma informed, culturally competent & strengths-based language)
Patient	Guest, visitor.
Facility	Safe space, safe haven, place, safe haven cafe.
Referral	Warm connection, offer ideas, options, pathway, invitation, support.
Exclusion criteria	Safety boundaries, mutual expectations, appropriateness, aim of the service, is this the best place for the person?
De-escalation	Addressing the person's need in that moment, conversation, relationship building, empathy, connection, calming, grounding, reducing distress, positive engagement.
Risk management	Working with someone to stay safe, dignity of risk, recovery plan, keeping well.
Recovery	Journey, discovery, healing, resilience, strengths, positivity, hopefulness.
Triage	Welcome, wellness check, prioritisation, what is important now, planning, talking, listening.
Assessment	Discussion, what is needed right now, listening to full story, collaborating, understanding.

Tonality guide

All communications are to be warm, respectful, polite, professional, and to the point, no matter the platform or forum (written, verbal, digital or print).

Every effort should be made to ensure that language used in written communication is easy to read and understand by the general community.

Be mindful that, although you may use abbreviations in your daily vocabulary, your audience may not have heard them used before. Be sure to write abbreviations in full, initially, in the document and explain anything that is being raised for the first time.

Try not to use unnecessary jargon when the audience is not familiar with the subject.

Always think about who will be reading your words and the impact they will have on them.

3

Practical tips

Provide clear communication

While it is vital that people with lived experience of suicide are given every opportunity to speak their truth and be heard, the process of sharing their experiences may bring with it a possibility of reliving emotionally painful and traumatic experiences either directly or through listening to others.

To reduce the likelihood of this happening, safe and appropriate language must be consistently used (see previous pages) and there needs to be clear communication prior to active engagement of the topics that are likely to be discussed.

Use plain English

Not only can clinical language be potentially re-traumatising, the use of technical language by traditional experts can also serve to further disempower people with lived experience and make them feel excluded from, or unable to fully participate, in conversations. It is therefore vital that common and plain English is used in all communications with people with lived experience. This includes the limiting of technical terms and explaining acronyms or complex concepts.

It is equally important to consider the unique literacy needs of people from culturally and linguistically diverse backgrounds and people living with intellectual disabilities.

Utilise available lived experience expertise

When generating communications of any type within the suicide/suicide prevention context, always arrange for the language and imagery to be reviewed by a number of people with lived experience of suicide. It is important that these people bring a range of lived experiences, as people will be tuned in to notice different aspects of the content depending on their specific lived experience, the nature of method used in an attempt or death, and the circumstances of how others have related to their experiences.

If you do not have access to this valuable resource internally Roses in the Ocean is always happy to review content for you.

Remain open to listening and learning

Language is constantly evolving so being open to listening, learning and respecting the change shows respect and humility. Everyone's perspectives are drawn from their particular lived experience of suicide influenced by internal paradigms, external societal judgements, the specific circumstances of the experience and much more.

Fundamentally the language we choose to use is just that, a choice, and at all times the overriding determinant for this choice needs to be 'do no harm', and then the practical aspect of considering how the language chosen will encourage (or discourage) a person to engage with the conversation, resource, service.

O2 Imagery

Introduction

Use of imagery is very important in the context of suicide prevention. We need to be particularly tuned in to the potential impact of various imagery on people with a lived experience of suicide and others experiencing emotional distress or feeling vulnerable at any given time.

Strict guidelines need to be followed when choosing or creating imagery for the purpose of use in areas such as presentations, social media, newsletters, workshop materials, etc.

Roses in the Ocean can provide guidance and recommendations to external organisations regarding appropriate use of imagery.

The following pages highlight some key considerations when choosing or creating imagery.

Use of imagery

Use of imagery can be highly emotive and powerful when chosen and used thoughtfully, responsibly and with purpose. Viewing imagery through the lens of lived experience is imperative and takes practice. There are many perspectives (lenses) through which we must consider the impact of an image before we can determine if it is appropriate or not.

We need to avoid any imagery that may cause distress to others, being sensitive to the wide range of experiences that people have. Different people will see or interpret images differently, so we need to take an objective and lived experience informed view. It is a useful exercise to share with a number of people for consensus.

Images that could be perceived to relate to a suicide method are to be avoided.

If in any doubt, don't use the image.

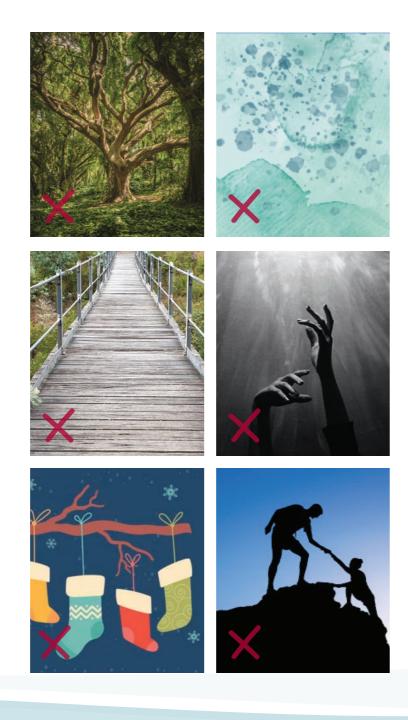


Images to avoid

Be objective when selecting imagery. Avoid imagery that may cause emotional distress. Certain images include trees, bridges, cliffs, trains, perspectives looking down from heights.

Anything that may be seen as a noose or rope, or anything that hangs. Also be aware of shapes made in patterns, these can create loops or look like rope. Some watercolour patterns, for example, can look like blood splatter.

It is also important to consider how an image portrays the help seeker and the provider of support and the power balance or imbalance depicted in the image.



How to be critical about content

'Rescue' (*language*) - we don't need rescuing, we need support.

'Fight' (*language*) - it shouldn't be a fight, it should be support.

'They can't rescue you if they don't know you need it' (*language*) - This statement puts an expectation on the person struggling to reach out when in need with no responsibility anywhere else to notice and reach in to the person. It suggests the onus is totally on the person in need. People with lived experience understand how hard it can be to reach out for help. The message in this advertisement is not helpful.

Hands (*imagery*) - the hand in need is depicted as being small/weak, while the 'rescuing' hand is large depicting strength. This is a blatant visual expression of power imbalance and does not acknowledge the immense strength and resilience people in emotional distress/crisis demonstrate and the strength it takes to be the one to reach out and ask for help.

Falling (*imagery*) - it could be perceived that the person in need is potentially falling.



How to be critical about content continued....

'Contagious' (*language*) - the use of this term is incorrect and is inciting fear, in the reader. It is also highly stigmatising.

'Committed' (*language*) - Stigmatising term that causes many people (suicide attempt survivors and people bereaved through suicide) great distress.

'We found that exposure to suicide predicts suicidality' (*language*) - this is a broad sweeping comment without context that could be misleading.

The location, clothing (hoodie), head in hands, darkly lit (*imagery*) - all are stereotypically stigmatising.

Women's Weekly

Suicide can be 'contagious' among young people

MAY 22, 2013 10:00AM



Suicide can be "contagious", especially among young people, a new study has found.

Canadian researchers found teenagers who had a friend who had committed suicide were five times more likely to have suicidal thoughts themselves.

The effect — known as the "suicide contagion" — was most pronounced in 12 and 13-year-olds and the increased risk lasts for two or more years.

"We found that exposure to suicide predicts suicidality," study leader Dr Ian Colman, Canada Research Chair in Mental Health Epidemiology and Assistant Professor of the University of Ottawa said.

"This was true for all age groups, although exposure to suicide increased the risk most dramatically in the youngest age group, when baseline suicidality was relatively low." How to be critical about content continued....

'100% Preventable' (*language*) - this statement is not true and has a strong impact on people who are bereaved through suicide insinuating they could have and should have prevented the death. We know many people bereaved through suicide carry guilt, shame and blame as part of the complex grief they experience and this statement has the potential to compound these feelings.

'Speak Up Reach Out' (*language*) - Onus once again on the person needing support instead of others having responsibility and opportunity to reach in and offer support.

Placement and size of hands (*imagery*) - the hand reaching out with palm facing up to offer support is larger and masculine looking, while the hand reaching in is smaller and appears childlike or feminine. We need to consider what message this sends regarding power imbalances, role of men needing to be the strong supporting role all the time. This hand imagery is better than the one on the previous page but still needs improving.



OS Lived Experience Acknowledgement

One way to show that your organisation values lived experience is through a formal acknowledgement at the commencement of events, meetings, presentations, workshops and so on. This will demonstrate respect for those participating who will or have already generously shared their lived experience of suicide insights, and to those more broadly in community for whom we serve. For events, meetings, and workshops it is ideal for a person with lived experience to deliver the Acknowledgment of Lived Experience of Suicide. For single presentations, the presenter will make the Acknowledgment.

Depending on the occasion, the Acknowledgement of Lived Experience will acknowledge the range of Lived Experience of suicide and the role Lived Experience is playing in the context of the gathering. Here are some examples of a non-Indigenous Acknowledgements:

Acknowledgement examples

SHORT VERSION:

I would like to acknowledge people with a lived experience of suicide. Those who have experienced suicidal thoughts; survived a suicide attempt; cared for someone through suicidal crisis; or been bereaved by suicide.

MEDIUM VERSION:

I would like to acknowledge people with a lived experience of suicide. Those who have experienced suicidal thoughts; survived a suicide attempt; cared for someone through suicidal crisis; or been bereaved by suicide. I'd like to acknowledge their courage and strength in sharing their wisdom and the impact it has on our work to save lives.

I would also like to acknowledge those who are impacted by suicide in community or through their line of work.

LONG VERSION:

At Roses in the Ocean, we acknowledge those of you 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 of you who care for loved ones through suicidal crisis. . . we acknowledge the fear and helplessness you experience, and your endless endeavours to empower them to live.

We acknowledge those of you bereaved through suicide... we acknowledge your immeasurable loss, the life that was lived, and the complex and often confusing emotions that accompany the ever-present ache. May your loss define a legacy and a mission to discover healing and new purpose.

We acknowledge all the lives we have lost to suicide and those in our wider community who are struggling with life today.

Everyone's lived experience is unique.

Everyone's lived experience is valuable.

Everyone's lived experience matters.

04 Papers

Supporting papers

Following are a set of papers that have been developed at Roses in the Ocean based on language.



DISCUSSION PAPER:

Invitation to an open conversation about language

STRATEGIC ISSUES PAPER:

Roses in the Ocean responsibility over use of language in workshops

POSTER IASP WORLD CONGRESS 2021:

Presented at IASP World Congress 2021 by Roses in the Ocean Lived Experience Advisory Group: *It's what and how you say it: safe language use in suicide prevention*



INVITATION TO AN OPEN CONVERSATION ABOUT LANGUAGE

Key Words: SP Peer Work, strength based, lived experience, stigma, non-clinical alternatives

Thursday September 10th was World Suicide Prevention Day (WSPD). WSPD was originally started by esteemed suicidology researcher and psychiatrist Professor Diego De Leo in 2003 with a view to it being a day when key suicide prevention research was released. At its inception it was never intended to be a worldwide awareness raising day. Since that time however, the International Association of Suicide Prevention (IASP) and the World Health Organisation (WHO) have continued to lead the promotion of this global day as one of recognition to shine a light on suicide prevention. The theme this year is Working Together to Prevent Suicide. Every year countless activities and events are held around the world in big and small communities alike.

Roses in the Ocean is an Australian national lived experience of suicide organisation. Ordinarily, in any other normal year, our organisation is involved in a number of activities and events for WSPD including hosting an annual community event in Brisbane city's Queen Street Mall. However, we know, 2020 is no ordinary year, COVID19 has made sure of that! Public events and large gatherings (even if they are to shine a light on the important issue of suicide prevention) cannot and should not be happening, no matter how important the issue is. That said, as an organisation we continue to work towards reducing the emotional pain that suicide brings to many people across Australia. One way we are choosing to do that this year is to encourage open and compassionate conversations about some of the language used when discussing suicide and particularly in relation to the language used in the newly emerging non-clinical alternative to care for people and their loved ones experience emotional distress relation to suicide.

In Australia, social change relating to caring for people in suicidal crisis is rapidly occurring. For starters, the suicide prevention peer workforce (SPPeer Workforce) is developing as a new workforce as is noted in (Hawgood et al., 2020). Roses in the Ocean is playing a role in the development of this new workforce in partnership with other organisations in New South Wales. We are also leading the co-design for new Alternative to ED: safe spaces that are being operationalised across all 15 of the Local Health Districts in NSW. This ground breaking whole of state project is funded under the New South Wales government's Strategic Framework for Suicide Prevention in N.S.W 2018-23 (NSW, 2018) as part of the Towards Zero Suicide Initiative. Click here to learn more about the <u>Towards Zero Suicides Initiatives</u> and the whole-of-state approach by New South Wales.

These new alternatives to ED for non-clinical and SP peer-run safe spaces and blended workforce aftercare services represent seismic shifts in suicide prevention with New South Wales leading the way in terms of innovation and genuine models of non-clinical care for those experiencing emotional distress and suicide attempts. With this amount of co-occurring activity, it is not surprising that there are some inevitable growing pains. One such challenge which has also come to the fore during our work in leading the state's co-design workshops with local communities with both lived experience people and health staff relates to the desire by many to change the language (including some of the clinical language) used in these new non-clinical alternatives.

We acknowledge some language used within conventional clinical services will remain relevant providing it is well-supported by those accessing these services and based on sound evidence for continuing its use. We have heard from the many people contributing in co-design workshops that



much of the language that comes from a traditionally biomedical model of psychiatric treatment and systems needs to change. We have heard that this language can be problematic, stigmatising and harmful to people who live with suicidal thoughts, experiences of suicide attempts, mental health struggles, and including those who have traumatic experience of our current medical health care system. In an article by Carpiniello and Bernado the authors highlight this point by stating out 'stigma displayed toward suicide may result in severe consequences for people who have attempted suicide or who have been bereaved by suicide' (Carpiniello & Pinna, 2017). We also know there are some words that have been around for eons and have become standardised, seemingly harmless in relation to suicide prevention health care. We believe (having listened to those with direct lived experience) that just because certain words, phrases and clinical terms are well ingrained in clinically operated health care does not justify their continued use in non-clinical peer led or co-led services.

Some of the biomedical language we have heard that is challenging people is listed below in Table 1. To continue to support the ongoing development of language we have also drawn on valuable work from the New South Wales Mental Health Coordinating Council, in particular their recently published second edition of Recovery Oriented Language Guide (Mental Health Coordinating Council, 2018).

Table 1

DISEMPOWERING LANGUAGE	EMPOWERING OR PREFERRED LANGUAGE*	WHAT IS THE PROBLEM WITH THIS LANGUAGE
Assertive outreach	Responsive Outreach	Has power overtones - assertive implies forcing someone.
Non-compliant	Declined a service, wanting to explore other options	The word compliant is problematic - it implies a need for someone to relinquish their (human) rights.
Treatment resistant	The person has unmet needs or challenges that need to be resolved	The word resistant is deficit focused and implies a person is unable to be helped rather than seeing this as an opportunity to uncover why the person is not engaging – what is their unmet need or what needs resolving or alternately what is it about the treatment on offer that is not what the person wants or perhaps feels they need?
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* For example: Trauma informed, culturally competent & strengths-based language



Manipulative behaviourA person expressing unner needs, extreme help- seeking behaviourFails to admowledge a person's behaviour is often a response to their needs not (yet) being met. It reflects judgement about culturally acceptable and unacceptable ways of seeking help. It is a term that is generally used to shame females for seeking help in ways that males tend to be culturally raised not to use.PsychoticUnusual beliefs and experiencesWhen used in the context of suicide, it reinforces the myth that people who speak up about thoughts of suicide are not serious and are just being "manipulative", which is a truly dangerous myth.PsychoticUnusual beliefs and experience, and challenges already stigmatising language often associated with people who are experience and challenges already stigmatising language often associated with people who are experience and challenges already stigmatising language often associated with people who are experience of reality must have something wrong with them and that reflects cultural acceptability. It is a currently acceptable to incorporate a God Whose presence is field" into a person's reality, but a person is 'sick' and 'unstable' if they claim the existence of anything else that other people can't see.Suicide AttemptersA person with a lived attempt OR a person who has made a suicide attemptThis word labels and negatively stigmatises a group of people (Link & Pholan, 2006). It falsely labels people and privately held identities and belong to many groups in society.Suicide ideationA person who experiences thoughts of suicideAn unnecessary clinical term that can be better said in phain language. This term remains widely used however, and there are many different yee	DISEMPOWERING LANGUAGE	EMPOWERING OR PREFERRED LANGUAGE*	WHAT IS THE PROBLEM WITH THIS LANGUAGE
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	Suicide ideation	experiences thoughts of	said in plain language. This term remains widely used however, and there are many different



There is also a second body of language which is emerging during our facilitation of the co-design of Alternatives to ED: Safe Spaces. This language is service specific and relates to the words and phrases people with lived experience of suicide are sharing with us that they would like used in these non-clinical alternatives. This language and suggested alternatives are listed in Table 2.

Table 2

DISEMPOWERING LANGUAGE	EMPOWERING OR PREFERRED LANGUAGE (trauma informed, culturally competent & strengths-based language)
Patient	Person, participant, guest, visitor, attendee.
Facility	Space, building, location, haven, place, locale, venue, centre, safe space, hub, service, cafe.
Referral	Link, recommend, connect, offer ideas, options, pathway, invitation, support.
Exclusion criteria	Safety boundaries, mutual expectations, appropriateness, aim of the service, is this the best place for the person?
De-escalation	Addressing the person's need in that moment, conversation, relationship building, empathy, connection, calming, grounding, reducing distress, positive engagement.
Risk management	Safety plan, working with someone to stay safe, dignity of risk, recovery plan, keeping well.
Recovery	Journey, discovery, healing, resilience, strengths, positivity, hopefulness.
Triage	Welcome, wellness check, prioritisation, what is important now, planning, talking, listening.
Assessment	Discussion, what is needed right now, listening to full story, collaborating, understanding.

As we continue to openly invite discussion on new language, we acknowledge that the suicide prevention sector has been leading the way in terms of sound evidence in support of appropriate, safe and non-stigmatising language when discussing suicide. In (Beaton et al., 2013) for example, the authors argue language associated with suicide needs to help create an environment that is conducive to people talking openly about their lived experience of suicide. Similarly, a related argument relating to stigma is noted in (Rimkeviciene et al., 2015).

For the most part language moves with the times. However sometimes language needs revisiting; and we believe now is an opportune time to further evolve language, especially as the suicide prevention peer workforce and non-clinical and aftercare alternatives emerge.



We also know that to bring about meaningful change of any kind it requires all those involved to be working together to bring about sustainable change. It is only through open, respectful and compassionate discussions about language that we can continue to evolve and shift where necessary the language used in these new settings. This open dialogue includes having these very same discussions with all stakeholders; including the people with lived experience of suicide, health professionals and organisational leaders collaborating in these new non-clinical alternatives to care. There is too much at stake here for us not to find ways to collaborate as a sector and help bring into being a more recovery oriented and strengths-based language when discussing and supporting people with a lived experience of suicide.

For Roses in the Ocean and our lived experience collective across Australia, it feels as if a brave new world for those experiencing suicide related emotional pain and those caring for them is finally dawning here in Australia. For all of us seeking to shift the language used in places where suicide prevention care is provided including these new non-clinical models rolling out in Australia, now is the time to be a little more kind, a little more tolerant to those who hold differing views. We need to find ways to discuss shifting and co-creating some of this new suicide prevention language with curiosity, openness and simply a shared desire to help make the world a better place for those living with and supporting those living with emotional pain, thoughts of suicide and suicide attempts and bereavement.

Our hearts and minds are open.

We invite you to do the same and come and share your views with us about how we can continue to keep working together to improve the language used in suicide prevention care settings, including in the new non-clinical alternatives.

An open conversation from Roses in the Ocean to you . . .



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STRATEGIC ISSUES PAPER



ROSES IN THE OCEAN RESPONSIBILITY OVER USE OF LANGUAGE IN WORKSHOPS

SUMMARY

Being sensitive to language in suicide prevention is important. Roses in the Ocean workshops cover this in an appropriate manner. Some considerations for the way facilitators lead this discussion are outlined below and include empowering participants to be sensitive to not only the needs of others but also their own perception and emotional reaction to language.

By focusing on individual perception rather than creating a list of "do not speak" words, we ensure that the reality of suicide is not glossed over and that participants do not lose confidence for fear of saying the wrong thing. It also bolsters their ability to be effective suicide prevention advocates.

BACKGROUND

Within Roses in the Ocean workshops, participants have a discussion over the impact of language used to describe suicide on others. Despite this, some participants still use language that can cause distress or does not meet Mindframe guidelines. This issue is regularly discussed at the operational level at Roses in the Ocean.

The Roses in the Ocean Lived Experience Advisory Group (LEAG) define safe language according to the Mindframe media guidelines. The Roses in the Ocean LEAG also extend this to apply to the depth that a participant goes to in telling their story. It is important to recognise that some things do not need to be included in a story.

It is recognised that Australia is ahead of many other countries in employing safe language and that international reporting that does not adhere to our standards will continue to occur. It is also recognised that many words that are used in the mental health and suicide prevention sector are not being used appropriately in the community, e.g. when people say they are "triggered" to by something that they don't like.

SOLUTION

The Roses in the Ocean LEAG believe that safe language is important in order to not cause other people distress. In promoting this safe language, it is also important not to "smooth over" the reality of suicide and its impacts. In this, the LEAG use the example of supermarket meat and how it is so far removed from its source. Over sanitising our language may run the risk of not demonstrating the truth about suicide. We need to be clear about the purpose of restricting language use and the context in which the language is used, e.g. it is imperative we don't speak in detail about method in the media but there may need to be discussion of talk of method when advocating for change related to the specific method (i.e., we need to restrict access to XYZ).

The discussion on language at Roses in the Ocean workshops should be around being sensitive to the perception of the person perceiving the story. This shifts the focus from a specific list of words that are not appropriate, and puts the emphasis on being considerate to others. Perception is a very personal experience and it is not realistic for participants to expect that there is a way to talk about suicide that will not provoke an emotional response in others.



Further to this, if we instill a sense of panic about saying the wrong thing in participants, the panic may become exhausting and participants may lose confidence as a speaker/advocate. There is value in empowering participants to understand their own reaction to language and to find strategies to process and respond to any use of unsafe language. Learning how to manage our own reaction to being involved/surrounded by suicide prevention activities and stories is an essential part of the recovery pathway and better equips people with a lived experience of suicide to be involved in suicide prevention activities.

Additionally, when we are overly sensitive about language, the message that is sent is that people with a lived experience of suicide are fragile and at risk because of words spoken/written. It is much more important to recognise and celebrate the strength that people with a lived experience possess. By taking an approach that favours self-insight and self-regulation, Roses in the Ocean workshops will put responsibility back on participants to take responsibility for their own responses and emotional regulation rather than taking a protectionist approach, wrapping them in 'cotton wool'.

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IT'S WHAT AND HOW YOU SAY IT: SAFE LANGUAGE USE IN SUICIDE PREVENTION

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"Safe suicide messages not only help heal and give hope to those listening but to those who find the courage to talk. And when people are heard, they can start to heal and that is why feeling safe is so important."

- Imbi, Lived Experience Collective

INTRODUCTION

Evidence-based guidelines such as the national Mindframe guidelines for the discussion, reporting and publication of content, which references suicide and self-harm¹ highlight the importance of steering away from stigmatising and unsafe language in the media. Studies have demonstrated that sharing certain details of suicide behaviour or death in a public domain increase the risk of further suicide behaviour and distress², generally using correlations between public reports and rates of suicide behaviour. There has been little published research that draws on the perspectives of those with a lived experience and this is a key piece missing.

FROM EVIDENCE-BASED TO LIVED EXPERIENCE-BASED

Conversations about suicide are not always on a high-profile public stage. Conversations happen in organisations, committees, yarning circles and one on one. They can involve many people, few or even just two. They occur in public, in private and sometimes in unconventional settings like over email or online chat environments. They also sometimes involve highly charged emotion, misunderstood or misrepresented meaning and confusion. Drawing on the wisdom of lived experience, the Roses in the Ocean Lived Experience Advisory Committee have developed the following model for considering the construction of safe messages in discussions about suicide and suicide behaviour.

AUDIENCE

When thinking about how to talk about suicide experiences, we must carefully consider who we are talking to, how they feel about the topic and whether or not they have safe places in which to process our suicide messages. We do this by remaining open to others needs and having a dialogue about boundaries in all our conversations.

"Hearing the particular method my son used to take his life takes me straight back to that shit place. We don't need to hear the how's."

- Melanie, Lived Experience Collective

DELIVERY

How you speak your messages to others influences they way they are perceived and the impact they have on the audience. When messages are delivered with sensitivity and in earnest, a one-way delivery becomes a twoway dialogue.

"A message of pain and struggle, loss and grief can be communicated without graphics, our emotional expression can paint a wonderful picture."

- Jenny, Lived Experience Collective



CONTEXT

Your suicide prevention messages will have differing levels of impact depending on where they are shared. When you tell your story, is the listener in a public, vulnerable place? Are they surrounded by people who care and can help them understand your message? We need to consider where our messages are or will be shared.



"Context is key. The language you use when talking one-on-one to a counsellor might be different than you use when talking to an audience where you don't know what others experience might be. Choosing your words carefully is an act of kindness."

- Jo, Lived Experience Collective

LANGUAGE IS EVER CHANGING

Through all these lenses, those with a lived experience tell us that language is constantly changing. We have seen words like "lived" and "living experience" rise in use and evolve in meaning. Words like "triggered" are used to describe feelings of being moved by unpleasant things while those with a lived experience may find this word distressingly closely associated with suicide method. In this way, we need to be continually reevaluating our language use through a two-way dialogue with the people we speak to, in the places where we speak and in an open and learning style.

CONCLUSIONS

Speaking about suicide is hard enough, we don't want to make it harder to share by being specific and prescriptive about the words that are and aren't ok to use. We also don't want to gloss over or avoid the harsh reality of the suicide experience. By negotiating and discussing appropriate ways of sharing safe suicide messages, we empower ourselves and others to speak openly and safely about suicide. You will say things that hurt people, make them cry and move them in a deeply emotional way. That is what lived experience tells us of suicide. But by having an open dialogue about what is right and wrong, we can negotiate these deep and sometimes unpleasant feelings and become more connected and understanding about the experiences of others.

"Ensuring political correctness can sometimes prevent us from talking openly about difficult things. Talking about suicide is no different. We need to be able to talk about suicide without the fear of saying the "wrong thing" whilst being mindful and respectful of others." - Lindy, Lived Experience Collective

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Lived Experience of Suicide Language and Imagery Guide v1.2

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Includes supporting papers v1.2

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