Submission
No 59

INQUIRY INTO PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NEW SOUTH WALES

Organisation: Western PTSD Support

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Western PTSD Support
Clinical Advisory Board

Submission to the NSW Legislative Council Standing Committee on Social Issues inquiry into the prevalence, causes and impacts of loneliness in NSW

Western PTSD Support Clinical Advisory Board

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Summary

This document is a submission to the NSW Legislative Council Standing Committee on Social Issues' inquiry into loneliness. It was prepared by Western PTSD Support, a monthly support group for first responders, veterans, and other individuals with PTSD. The submission argues that PTSD is a significant contributor to loneliness, drawing upon the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria for PTSD alongside the lived and living experience of group participants. The submission then explores the impact of the lack of access to effective treatment for PTSD in rural areas and the challenges individuals face in navigating the Workers' Compensation system, highlighting how these factors exacerbate loneliness and social isolation, and calls for funding, incentivisation strategies and improved compliance with existing practice standards in order to ameliorate the devastating impact of loneliness on rural people living with PTSD.

Background

On 10th July 2024, The Hon Rose Jackson, MLC, Minister for Mental Health, referred the terms of reference for an inquiry into the prevalence, causes, and impacts of loneliness in New South Wales to the NSW Legislative Assembly Standing Committee into Social Issues. This document is a formal submission to that inquiry.

Western PTSD Support is a monthly support group which meets in Orange, NSW. The group has existed under various structures for approximately five years, and primarily provides social support to people who have experienced trauma in the course of their employment, and who have received a diagnosis of posttraumatic stress disorder (PTSD). The group is attended by first responders, veterans, drivers of heavy vehicles, health care workers and others who have been exposed to traumatic events in the course of their work. Participants attend from across the Central West, including from Bathurst, Dubbo, Parkes, Cowra and Molong. The group is currently under the auspices of Lifeline Central West and is overseen by an advisory committee consisting of consumers and mental health professionals, with a clinical advisory board as subset to this. The clinical advisory board has prepared this document for submission.

The format of the group is generally a round-circle discussion during which members share their experiences over the previous month with each other, sharing both the symptoms and experiences that have been troubling, as well as their positive experiences, treatment gains and achievements. Group norms encourage participants not to share the specific details of the traumatic events they have experienced, but to focus instead on ongoing impacts and reflections on their day to day lives. The group has been facilitated variously by mental health professionals and lived experience peer workers. Loneliness is a universally acknowledged experience of the participants of the group, and this submission is being lodged in recognition of the group's membership of a cohort for whom the subjective sense of being disconnected and isolated from loved ones and the population in general is a part of daily existence.

PTSD and Loneliness

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) sets out the criteria by which a diagnosis of post-traumatic stress disorder can be applied to the collection of symptoms experienced by a person in the wake of having been exposed to "actual or threatened death, serious injury or sexual violence" (Criterion A). Criteria B through E specify categories of symptoms including intrusive symptoms, avoidance behaviours, alterations in thoughts and mood, and arousal/reactivity, all of which contribute directly or indirectly to both objective social isolation and withdrawal, and the subjective sense of being separate from one's family and community that is understood by the term "loneliness".

Criterion B – the presence of intrusion symptoms – probably represents the most recognised symptom cluster of PTSD, and includes nightmares, flashbacks, dissociative states, and intrusive thoughts. People who experience these symptoms speak of having a sense of their bodies and minds being overtaken in ways that are out of their control, where they are often reliving the worst moments of their lives in sharp sensory detail, with accompanying physiological arousal. These experiences are so aversive that many who experience them start to reduce their social activity outside their homes in order to minimise the risk of such experiences occurring in a public place or where there is no possibility of easy egress. Group members also speak of the difficulty in explaining these occurrences to concerned loved ones, which increases their sense of disconnection and isolation.

Criterion C is the symptom category which may be most closely linked to social isolation and consequent loneliness. Avoidance behaviours as described by the DSM-5 fall into two categories; avoidance of external stimuli associated with the traumatic event, and avoidance of internal thoughts, feelings and memories associated with the event. In relation to loneliness, these symptoms are reported to impact group members in two main ways. Firstly, many of the group members are first responders who have worked in their local communities for many years and have experienced multiple, significant traumatic events at many sites. Hence a simple trip to the supermarket or into town to see a doctor may involve an overwhelming number of related stimuli and the associated avoidant behaviours may require an almost complete withdrawal from social activity. Secondly, the nature of avoidance as a coping strategy is that it is generally very effective in the short term at reducing psychological distress, which increases the likelihood of the strategy being utilised again in future, generating a self-perpetuating cycle of avoidance that leads directly to increasing social and behavioural isolation. Over time, this gives rise to a sense of impossibility for the person being able to confront their distress and avoidance in order to engage in any activity that might reduce the impact of loneliness on their lives and wellbeing.

Criterion D describes the collection of symptoms encompassing negative alterations in thought and mood. A number of the exemplars in this category are directly related to a person's thoughts about themselves, others, and their place in the world, and can therefore be understood to be directly contributing to a set of unhelpful beliefs and assumptions that shape social avoidance and disconnection from others (e.g. "persistent and exaggerated negative beliefs or expectations about oneself, others, or the world…", "persistent, distorted cognitions… that lead the individual to blame themselves or others…", "markedly diminished interest or participation in significant activities…", "feelings of detachment or estrangement from others..", and "persistent inability to experience

positive emotions.") It therefore becomes clear, that in the absence of effective treatment, individuals whose behaviours are shaped by a set of beliefs which have been distorted by their experiences of trauma and leave them perpetually feeling unsafe in the context of relationships with others are almost guaranteed to endorse feelings of loneliness. Members of the group speak frequently and eloquently about how they frequently feel alone, even in the context of their intimate family relationships and friendships, and often report that the only time they feel heard or understood is when they attend the group each month and share in the experiences of their fellow group members. Several group members speak of the group being "life saving" for this reason.

The last criterion describing the symptoms of PTSD in the DSM-5 is criterion E – "marked alteration in arousal and reactivity associated with the traumatic event." Some of these alterations may include "irritable behaviour and angry outbursts", "reckless or self-destructive behaviour" and "hypervigilance." Anger is a frequently acknowledged emotion amongst group members and although they are often able to recognise that their angry outbursts are often out of proportion to the provocation, they nevertheless feel that their responses are out of their control to regulate. Some group members note that this has led to increased social withdrawal in an attempt to prevent such outbursts, whilst others describe histories of broken relationships, high-risk behaviours resulting in injury or contact with the criminal justice system, or simply an ongoing feeling of being a threat to the safety of those around them - even those that they love. Group members have also described the emotional and energetic toll of hypervigilance - that their attention is so focused on the perception and avoidance of threat that they have no capacity to attend to other cues which may indicate safety, security or a partner's bid for connection.

The DSM-5 Criteria for PTSD establish the symptoms which cluster together to define the disorder and differentiate it from other types of psychological distress or psychiatric illness. The four criteria described are necessary for a diagnosis and all contribute differently to an individual's subjective experience of loneliness – whether that is by changing a person's perception of the world as a safe place, of others or themselves as trustworthy, by contributing to avoidance behaviours or by causing physiological arousal that results in behaviours that alienate them from their loved ones. Hence it can be argued that PTSD is to some degree unique in its capacity to contribute to a deep sense of being cut off from human connection.

Experiences of treatment-seeking for PTSD and impact on loneliness

The cohort of people diagnosed with PTSD who attend the Orange PTSD Support Group and who are represented in this submission live in rural communities which in many cases are characterised by a lack of easy access to evidence-based, trauma-informed treatment for PTSD, in either inpatient or community settings. It should also be noted that many of the group participants, having sustained a psychological injury in the course of their employment, have experienced their attempts to access appropriate diagnosis and treatment through the functions of the Worker's Compensation system. Both of these factors, via different mechanisms, contribute to the maintenance and exacerbation of distressing symptoms of PTSD, and hence to the ongoing social isolation and loneliness experienced by those living with the disorder.

Research has found that rural Australians who live with mental illness are at almost three times the risk of premature death when compared to the rest of the population, and that the causes of this increased risk include poor access to mental health services and mental health workforce shortages,

in addition to poorer health outcomes for rural Australians in general. Workforce shortages are demonstrated by a 2018 Australian Institute of Health and Welfare study which found that there were 34.5 psychologists and 4.9 psychiatrists per 100 000 population in outer regional areas, compared with 77.5 and 13.3 respectively in major cities. This research aligns with the lived experience of the group, who report experiences such as; not being listened to by health professionals, being given inappropriate or ineffective treatment by mental health professionals, spending long periods of time on waiting lists, not being able to access sufficient numbers of sessions under Medicare, and having to travel long distances in order to access appropriate inpatient PTSD programs. Group members also report being advised by mental health professionals that their PTSD will be a lifetime diagnosis, and that symptom management is the best that they can expect, leading to a widespread belief that effective treatments for PTSD do not exist and that recovery is impossible. Under these circumstances, group members often cease their efforts to access psychological treatment and instead may spend many years managing symptoms with medication and behavioural strategies which support a level of functioning but do not engender recovery. As noted above, the self-perpetuating nature of avoidant strategies and the negative cognitions with regard to self and others mean that under these circumstances, loneliness frequently becomes a constant state of being.

Attempts to navigate the Workers Compensation system in order to access appropriate income support, compensation and treatment are without a doubt one of the most frequently reported significant stressors that group members experience. Despite SIRA's NSW Guidelines and Practice Standards for the management of psychological injury claims, group members routinely describe interactions with insurers which cause them significant distress and in fact, often contribute to exacerbations in PTSD symptom intensity which can last days or weeks. Members report that rather than feeling treated with empathy and with their own needs as central to the process, (as prescribed by the Standards), they are often made to feel as though they are malingerers, with their motives questioned and their own lived experience undermined by case managers. Group members report that they almost always feel as though the needs of the insurer and the employer are paramount in the process, and many members strongly believe that the long-term goal of insurers is to place so many obstacles in the path of workers that they give up, or die. This is particularly challenging for the group of participants who have spent their working lives in the service of others, and whose personal values are often aligned with altruism and self-sacrifice, and gives rise to the possibility of moral injury. Group members describe being spoken to condescendingly, feeling frequently harassed by phone calls and demands for meetings and appointments, and being denied access to treatments that have been recommended by their treating professionals. Although the Standards state "early, empathic engagement with the worker has been shown to have a significant impact on recovery…", group members almost universally report experiencing the opposite, which has the impact of increasing feelings of shame, which leads to increased social withdrawal and a reinforcement of feelings of loneliness.

Trauma-informed practice is an approach applicable to all areas of health service provision and which necessitates a deep understanding of the dynamics of trauma responses, not only as they apply to PTSD but to all who may have experienced traumatic events. It is a practice which focuses on creating psychological safety and empowering consumers to move toward recovery, rather than symptom management, and which strives to prevent re-traumatisation which can occur in institutions through experiences of shame, disempowerment, and betrayal of trust. The deep integration of trauma-informed principles at all levels of engagement in the public health and

workers compensation systems would go a long way toward ameliorating many of the systemic factors contributing to loneliness amongst people living with PTSD in rural NSW.

Recommendations

As the custodian of the mental health and workers compensation systems within the state, the NSW Government can make significant changes which would ameliorate the impact of loneliness on rural people with PTSD by;

1. Increasing funding for community-based programs which incorporate mental health lived experience expertise as fundamental to their operating model in order to improve access to spaces where those living with PTSD can feel connected and understood by their peers.
2. Improving incentives for mental health professionals, particularly those trained in evidence-based trauma-focussed interventions, to provide services in rural areas, in order to reduce the impact of the symptoms of PTSD and resolve some of the contributing factors to loneliness.
3. Require all Workers Compensation insurers to demonstrate that they meet standards of trauma-informed practice on a regular basis (i.e. They demonstrate behaviours that create safety, trustworthiness, choice, collaboration and empowerment for their consumers.)
4. Review preventative programs in place for existing NSW Government employees who are at risk for PTSD as a result of their occupation, including police, firemen and women, paramedics and health care workers, and strengthen access to psychological and peer support services prior to the onset of disordered mental health.

The Clinical Advisory Board and Western PTSD Support as a whole, sincerely hope that this inquiry consider the above submission to be a clinically accurate assessment, supported by the lived and living experience of our group participants, of the situation relevant to those in regional NSW who live with a PTSD diagnosis, and act on the recommendations presented.

Signatures

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