

I AM ALS presents Veterans with ALS and Suicidal Ideation: A Community Created Intervention

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Background:

I AM ALS is a community-led US non-profit that revolutionizes ALS advocacy. People living with and impacted by ALS self-organize into community teams, such as the Veterans Affairs Community Team (Veterans Team). This team meets once a week to raise awareness for veteran-specific ALS issues, help connect veterans with resources and advocate to improve the lives of people living with and impacted by ALS through advocacy.

In "Suicide among Veterans with Amyotrophic Lateral Sclerosis"¹ (2021), Emily Lund, PhD writes the risk of suicidal ideation tends to be highest following the initial diagnosis of ALS, and the risk of death by suicide is 3.98 times higher for veterans with an ALS diagnosis when compared to veteran counterparts who do not have an ALS diagnosis (Lund). Upon reading this article, the I AM ALS Veterans Team decided to create and collect mental health resources and build a social media campaign that raised awareness of mental health and suicidal ideation and connected people to resources.

Objective:

The I AM ALS Veterans Team sought to create a campaign that raised awareness of and reduced stigma around mental health and suicidal ideation and connected people to resources in any effort to improve the lives of those living with ALS and reduce the number of people who die by suicide.

Methods:

The I AM ALS Veterans Team conducted a literature review of articles addressing the intersections of ALS, suicidal ideation and/or veterans in an effort to learn best practices for addressing suicidal ideation, as well as gaining an understanding of the most important mental health issues facing veterans living with ALS. The literature reviewed informed the creation of a dynamic multiplatform social media campaign and the creation of Mental Health Among Veterans with ALS [webpage](https://iamals.org/get-help/mental-health-among-veterans-with-als) on I AM ALS' website:
<https://iamals.org/get-help/mental-health-among-veterans-with-als>

The I AM ALS Veterans Team worked thoughtfully and diligently on every piece of this campaign. Members created informed and vulnerable content based on their research, making sure every piece of content they produced met those needs. They shared their own stories of pain, grief and sadness to create relatable content for an audience who also may be struggling. They did not shy away from the darker parts of this content.

Beyond letting the content speak for itself, team members diversified the types of content they used, even introducing two completely new formats to I AM ALS' social media platforms: images with voiceover and scripted text conversations. Images with a voiceover were created by attaching an audio file that a community member recorded to an image of them alongside the text they or their assistive technology verbalized. The scripted text conversations were a series of images that mimicked a text exchange between two people living with ALS and one of them struggling with mental health. Both types of new formats performed extremely well.

Results:

This impactful social campaign ran across four different platforms -- Twitter, Facebook, Instagram and LinkedIn -- for 17 days, from September 4-30, 2021. The 85 total posts sent out reached 182K+ users driving 8K+ engagements and 3K+ users to mental health resources.

One resource in particular developed through the leadership of the Veterans Team was housed on I AM ALS' website focused on Mental Health Among Veterans with ALS. Since launching on September 5th, 2021, 193 people have accessed this resource 328 times. Of the people who visited the page, 154 (77%) were new website users.

Through this campaign, the Veterans Team was able to reach new audiences, provide curated and critical content to support other's mental health, share their own stories for viewers to relate and connect and show up for a community of veterans impacted by ALS.

Discussion:

The success of this campaign provides insight into best practices ALS organizations and advocates could use to address sensitive topics within the community. By combining research with the lived experiences of people living with and impacted by ALS, the Veterans Team created a vulnerable, honest, compelling and engaging campaign. The success of this campaign tells us mental health is a salient topic that needs to be addressed for people living with and impacted by ALS.

By creating a campaign that mixed resource sharing and personal stories, having varying content (text conversations, voiceover graphics, etc.) and featuring members of the community, the campaign kept social media users engaged and made a topic rarely discussed in the community top of mind.

Conclusion:

An extraordinary amount of time within the ALS landscape is spent talking about the physical impact of ALS. This campaign demonstrated the psychological impact of ALS is extraordinarily important and should be addressed by ALS organizations and advocates. The I AM ALS Veterans Affairs Community Team will continue to expand upon this initial campaign to further its goals of connecting veterans with ALS to the mental health resources they need.

References:

1. Lund EM, Hostetter TA, Forser JE, et al. Suicide among veterans with amyotrophic lateral sclerosis. *Muscle & Nerve*. 2021:1-5