

# 100 Poems from People Affected by ALS

### **Overview**

"This message is so simple yet it gets forgotten. The people living with the condition are the experts." - Michael J Fox, actor, advocate for Parkinson's Disease.

100 Poems from People Affected by ALS will be a collection of poems from people with a lived experience of ALS. It will bring together poetry from people living with the disease, their loved ones, as well as medical practitioners and researchers dedicated to the ALS community.

The collection aims to capture the diverse perspectives, deep insights, and authentic emotions of those navigating life with ALS. By offering an unfiltered portrayal of their experiences, the collection seeks to foster understanding, empathy, and awareness.

All profits from the book will be dedicated to ALS research and patient care initiatives, contributing to the ongoing fight against this challenging condition.

## **Goals**

- 1. **Empower ALS Patients**: Offer a platform for individuals affected by ALS to creatively express and share their experiences through poetry.
- 2. Raise Awareness: Increase public understanding and awareness of ALS.
- 3. **Support Research and Treatment**: Generate funds to support scientific research and initiatives aimed at treating ALS.

## **Guidelines**

There is no rigid framework or set criteria that submissions must adhere to for 100 Poems from People Affected by ALS. Poetry is a versatile and expansive form of expression that doesn't necessarily need to rhyme or conform to any specific structure or traditional rules.

Poems can be free verse, lacking a set rhythm or rhyme scheme, or they can adhere to classical forms like sonnets or haikus. They can be as short as a single line or as long as a short essay. The essence of poetry lies in its ability to convey emotions, ideas, and experiences in a unique, authentic and impactful way.

The lack of strict guidelines allows for innovation and personal expression, making 100 *Poems from People Affected by ALS* a truly inclusive and dynamic collection.

#### **Word Count**

Submissions can be as short as a single sentence, or up to four hundred words.

## Making a Submission

To submit a poem, email it to <a href="mailto:pkellycontact@gmail.com">pkellycontact@gmail.com</a>

Include a byline and if you wish, a brief description of your relationship to ALS. For example, "By John Doe, 58, England. Diagnosed with bulbar ALS in 2021." Or, "By Jane Doe, 58, England. The loving wife of John Doe."

# **Stages**

#### I. Collection Process

The first stage involves raising awareness globally among individuals affected by ALS and inviting them to contribute their poems. The goal is to gather submissions from a diverse range of contributors, ensuring a rich and varied collection of voices and experiences.

# II. Finalising the Collection

Once a sufficient number of submissions have been collected, the focus shifts to formatting the collection and securing necessary permissions from the contributors. This stage ensures that all contributions are properly organized and legally cleared for publication.

## III. Selecting Publishing Route

In this stage, potential publishers will be identified and engaged in negotiations. A decision will be made whether to publish the collection through a traditional publishing house or to pursue independent publication. Each option will be carefully evaluated based on factors such as distribution reach, financial viability, and creative control.

## IV. Distributing Financial Proceeds

A thorough selection process will be conducted to determine which ALS research and patient care organizations will receive the financial proceeds from the book. Arrangements will be made to ensure transparency and accountability in the

handling of all financial elements, guaranteeing that funds are directed to impactful initiatives.

# V. Strategic Book Launch Event and Media Campaign

The final stage involves planning and executing a strategic book launch event and media campaign. Efforts will be focused on coordinating the publication timeline, generating maximum publicity, and creating buzz around the release. This will include engaging with media outlets, leveraging social media platforms, and organizing events to promote the book and its cause.

## **About the Editor**

Paul Kelly was diagnosed with ALS in 2015, at the age of 23. With a background in media and communications, and a strong academic foundation in literature, Paul is a passionate advocate for ALS research and patient welfare. He resides in Tasmania, Australia.



## **Further Information**

For more information about 100 Poems from People Affected by ALS, get in touch via email: <a href="mailto:pkellycontact@gmail.com">pkellycontact@gmail.com</a>