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Stop Requested: A Collection of ALS Poetry

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Stop Requested: A Collection of ALS Poetry

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Introduction: This project aims to use poetry to convey the lessons, challenges, and experiences encountered by patients in the Jefferson Weinberg ALS Center diagnosed with Amyotrophic Lateral Sclerosis (ALS). This will not only allow for individual patients to freely discuss, reminisce, and reflect on their journey with this disease, but distributing the collection to our community will aid in a better understanding of ALS patients, serve to humanize ALS, and deepen the empathic bond between community members and patients. Additionally, it will create an environment in which both myself and physicians can reflect on the human experience and how disease affects a patient holistically.

Methods: A questionnaire was drafted and used to guide conversations with patients about their experiences living with ALS. After the interview, the conversation was analyzed for themes and a first draft of a poem inspired by their story was created. Edits were obtained from advisors and peers, and poems were then organized into a final collection, to be printed and distributed to clinic patients and the Jefferson community.

Results: This project resulted in a printed collection of poetry titled *Stop Requested: A Collection of ALS Poetry*. The final product is to be distributed to each patient at the Jefferson Weinberg ALS Center and more broadly to the ALS and Jefferson communities. This collection details intimate accounts of confusion, suffering, fight, hope, and change that ALS patients experience during their disease progression.

Discussion: By using poetry to portray the human experience specific to ALS, this collection helps to connect patients to each other, providers to patients, and community members to patients. The experiences outlined in this collection help to build compassion within the medical field and community for those experiencing ALS and offers a unique perspective of the spectrum of suffering, and triumph in neurodegenerative disease.