BACKGROUND
To complement the clinical and therapeutic knowledge about symptoms, prognosis, and social implications of ALS, health research and care need to develop methods that capture and communicate the unique individual impact on daily living with the disease.

OBJECTIVES
To explore how stories can communicate experiences of daily living with ALS and compensate the progressive loss of ability to speak.

METHODS
Twenty-four interviews at home with six people diagnosed with ALS were transformed into narrative journalistic stories. A formal readership was selected by the participant among his or her most significant health professionals. Topics of stories were categorized and selected themes analysed and interpreted.

RESULTS
The stories communicated daily living with ALS as a continuous process of creating a new normality of everyday life. The stories also revealed conflicting views about information about disease and prognosis. The approach used provided an understanding that informed individual healthcare professionals’ engagement with the patient.

DISCUSSION
The narrative journalistic story enhances communication about daily living with ALS by offering a mode of sharing experiences that compensate the progressive loss of communicative abilities. The story can sustain meaning in living with ALS and support patients to appreciate a day-to-day life which is not just a waiting for death.

CONCLUSION
Narrative journalistic storytelling is a relevant method for the study of patient experiences in ALS. It maintains or restores communication as the ability to speak deteriorates, and it may enhance patient involvement. The approach can be used over time to get an in-depth understanding that informs individual healthcare professionals’ engagement with the patient.

REFERENCES

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THE COMPLETE STORIES
Being ill and oneself: Six stories about living with Amyotrophic Lateral Sclerosis can be obtained upon request to the corresponding author.

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