Questionnaire for people living with ALS and their carers: Share your experience!

Why participate?

Your contribution will help us…

- **Identify gaps** in care and support
- Capture the **lived experiences and needs** of patients and carers
- Improve and harmonise ALS care across Europe

Who can take part?

- **People living with ALS**
  You can respond on behalf of a patient or a patient community
- **Family members or carers** supporting a person living with ALS
- In all European countries (EU or non-EU)

Scan this QR code to access the questionnaire!

Anonymous and voluntary

Available in 32 languages

Deadline: 30 April 2026

Your voice matters

Feel free to share this with others who may be concerned!

This initiative is led by the European Reference Network for Rare Neuromuscular Diseases (ERN EURO-NMD), within the framework of the JARDIN Joint Action (Task 6.2)

European Reference Network
for rare or low prevalence complex diseases
Network Neuromuscular Diseases (ERN EURO-NMD)

JARDIN

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https://ern-euro-nmd.eu/breaking-news/questionnaire-for-people-living-with-als-and-their-carers-share-your-experience/