

# THE LIFE WITH AMYOTROPHIC LATERAL SCLEROSIS: SOCIOECONOMIC IMPACT OF THE DISEASE ON PATIENTS AND THEIR CAREGIVERS IN THE CZECH REPUBLIC

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## Background

Amyotrophic lateral sclerosis (ALS) is a rare, progressive neurodegenerative disease characterized by degeneration of cortical, bulbar, and spinal motor neurons. These neurons degenerate rapidly and eventually die, leading to muscle weakness and difficulties with speech, swallowing, and limb movement. As the disease progresses, the respiratory muscles become affected, resulting in shortness of breath and ultimately death. Most patients die within two to five years from the onset of weakness, primarily due to respiratory failure. The global prevalence of ALS is estimated at 4.5 cases per 100,000 people, with an annual incidence of 1.75 cases per 100,000 people. In Czechia, there are approximately 600 patients living with ALS. (1,2).

The complex nature of the disease not only results in a physical burden for patients but also affects the quality of life of both patients and their caregivers. As the disease progresses, the demands of patient care increase, which is associated with a growing economic burden for patients and their families. In addition, due to progressive functional impairment, patients experience high disease-related absenteeism from work, leading to a loss of income. (3).

## Objectives

The objective of the study was to collect local data on the socioeconomic burden of ALS on patients and their caregivers, as well as on society, the health insurance system, and the social support system, to describe the overall burden of ALS in Czechia.

## Methods

A cross-sectional questionnaire survey was conducted to collect local Czech data on the socioeconomic impact of ALS on patients and their caregivers. Data were collected between March 12 and March 30, 2025, in cooperation with the patient association ALSA.

We collected demographic and clinical data for both patients and caregivers, as well as data on healthcare resource use, out-of-pocket expenses, social transfer costs, and responses to validated questionnaires: WPAI (Work Productivity and Activity Impairment), EQ-5D-5L, and for caregivers, the Zarit Burden Interview (ZBI).

For the EQ-5D-5L questionnaires, the UK value set (tariff tables) was used to evaluate utility values (4,5).

Costs due to loss of productivity were assessed using the human capital approach. For retired patients and caregivers, productivity loss was not calculated.

The gross wage used for cost calculations was based on the Wages and Labour Costs statistics published by the Czech Statistical Office (CZSO) as of Q4/2024, which were the most recent available data (6). The average monthly gross wage was CZK 49,229 (€1,969). Employer contributions amounted to 33.8% (9.0% for health insurance and 24.8% for social insurance), resulting in an average total cost per employee ("super-gross" wage) of CZK 65,868 (€2,634), including all contributions.

The "super-gross" wage reflects the total cost of an employee from the perspective of the employer and the state, encompassing all taxes paid to the state as well as the net wage.

To estimate productivity loss costs, we used the Work Impairment (WI) measure from the WPAI questionnaire. These costs were calculated for the entire cohort of patients and caregivers based on mean "super-gross" wage and WI scores. The resulting values were then proportionally averaged per patient and per caregiver. All costs were converted from Czech Crowns (CZK) to euros (€) using the average March 2025 exchange rate of 25.003 CZK/€ (7).

## Results

A total of 53 patients and 55 caregivers completed the survey. The mean age of patients was 57.6 years, and the majority of patients were male (70%). The average age at symptom onset was 52.7 years, and the average age at ALS diagnosis was 53.8 years. The overall proportion of working patients was 17%. For the working cohort, the mean age was 54.1 years. The mean age of primary caregivers was 52.2 years; 80% were female, and none of them were diagnosed with ALS. The proportion of working caregivers was 44%, with a mean age of 49.5 years (Table 1).

Demographic characteristics (Min-Max)	Patients (n=53)	Caregivers (n=55)
Mean age	57.6 (33-84)	52.2 (21-88)
Mean age at symptom onset	52.7 (29-70)	-
Mean age at diagnosis	53.8 (30-74)	-
Mean age – working subgroup **	54.1 (38-67)	49.5 (30-69)
Sex (number, % female)	16 (30%)	44 (80%)
Quality of life (Min-Max)	Patients (n=53)	Caregivers (n=55)
EQ-5D-5L	0.104 (-0.510-0.906)	0.756 (0.223-1.0)
VAS	42.1 (1-90)	67.5 (0-100)
Employment status (no. of answers, % of patients)	Patients (n=61)*	Caregivers (n=58)*
Full-time	8 (15%)	15 (27%)
Part-time	3 (6%)	8 (15%)
Freelance contract	1 (2%)	3 (5%)
Casual contract	2 (4%)	1 (2%)
Disability pension	32 (60%)	3 (5%)
Pension	10 (19%)	13 (24%)
Maternity leave	0 (0%)	2 (4%)
Unemployed	5 (9%)	13 (24%)

\*Patients were able to select multiple answers.

\*\*Working subgroup: n=9 for patients, n=24 for caregivers.

In relation to ALS, 81% of patients used their own car for transportation to medical appointments. The mean monthly transportation cost calculated for the entire cohort (N = 53) was €52 per patient. Additionally, 11% of patients reported using public transport (train, bus, etc.), with a mean monthly cost of €3 per patient. Patients paid an average of €18 per month for prescribed medicines and €113 for over-the-counter medicines, vitamins, and other supplements. On average, patients also spent €116 per month on assistive devices (e.g., wheelchair, orthosis), €62 on physiotherapy and logopedic therapy, €38 on assistant and household services, and €6 on spa treatments, €34 on special dietary modifications and €25 on other costs. Overall, the average monthly out-of-pocket cost per patient was €467 (Table 2).

Transportation costs (n=53)	Mean cost per month
Transport with own car	€51.9
Transport other than car - train, bus, taxi	€2.6
Drug costs (n=53)	
Prescription drugs	€18.2
Over-the-counter drugs/supplements/vitamins	€113.0
Other costs (n=53)	
Assistive devices	€116.0
Physiotherapy and logopedic therapy	€62.2
Assistant and housekeeping services etc.	€38.2
Spa treatments	€6.4
Special dietary modification	€33.7
Other costs	€24.9
Total costs	€467.1

Disability pension level (n=53)	Patients (%)
None	21 (40%)
Total number of patients on disability pension	32 (60%)
1st level	1 (2%)
2nd level	4 (8%)
3rd level	27 (51%)
Social security costs in patients (n=53)	Mean costs per patient/month
Care allowance	€499.3
Disability pension	€479.8
Mobility allowance	€13.0
Housing allowance	€4.0
Sickness allowance	€6.3
Child allowance	€1.1

Disability pensions were received by 60% of patients. Among them, 27 patients were classified in the third degree of disability, 4 in the second degree, and 1 in the first degree. The average monthly disability pension reported by these patients was €480 per patient (N = 53). Additional reported social security benefits included a care allowance averaging €499 per patient/month, a mobility allowance of €13 per patient/month, and other benefits averaging €11 per patient/month (Table 3).

The unemployment rates observed in the study were significantly higher than those in the general Czech population – 9% among ALS patients and 24% among their caregivers, compared to 2.7% for the general population in February 2025 (8). This disparity highlights an additional work productivity loss, likely due to the excessive caregiving demands associated with ALS and disease progression of the patients.

According to the WPAI questionnaire, only 17% of patients were employed, with an overall productivity loss of 40%. This included 3% absenteeism (time missed from work) and 38% presenteeism (reduced productivity while working). Additionally, all patients experienced 74% (mean) impairment in regular daily activities (Table 4). Although 44% of caregivers reported working in the main survey, only 40% of caregivers reported working in WPAI questionnaire (two working caregivers did not successfully complete a part of WPAI questionnaire related to work, presumably due to misunderstanding). The main survey provided more consistent and complete data for employment status; thus, 44% employment rate was used for further calculations. Caregivers who completed work-related part of WPAI reported overall productivity loss of 48%, absenteeism of 25%, and presenteeism of 39%. The degree of reduction in regular daily activities among all caregivers was 59% (Table 5).

WPAI in patients	%
Absenteeism (N=9)	3%
Presenteeism (N=9)	38%
Work impairment (N=9)	40%
Activity impairment (N=53)	74%

WPAI in caregivers	%
Absenteeism (N=22*)	25%
Presenteeism (N=22*)	39%
Work impairment (N=22*)	48%
Activity impairment (N=55)	59%

\*Two working caregivers did not complete part of the WPAI questionnaire related to work.

MiToS classification	Number of patients in cohort*	Productivity cost/cohort
Stage 0	91	€996,109
Stage 1	272	€3,330,702
Stage 2	147	€1,365,922
Stage 3	45	€696,680
Stage 4	45	€1,002,074
Total cost for whole cohort		€7,391,486
Total cost per one patient		€12,319

\*The analysis assumes a population of 600 ALS patients in the Czechia; patient counts were rounded to whole numbers.

Table 6 presents the mean annual productivity loss costs in the ALS patient cohort, estimated at €7,391,486, with a mean cost per patient of €12,319. Similarly, Table 7 shows the mean annual productivity loss costs in the caregiver cohort, estimated at €9,286,474, with a mean cost per caregiver of €15,477.

	Proportion of caregivers in the study	Number of caregivers in cohort*	Productivity costs/caregiver	Productivity costs/cohort
Employed	44%	262	€15,174	€3,972,897
Disability pension	5%	33	€19,705	€644,906
Unemployment	24%	142	€28,057	€3,978,932
Pension	24%	142	-	-
Maternity leave	4%	22	€31,613	€689,739
Total costs per the whole cohort	100%	600	-	€9,286,474
Total costs per one caregiver	-	-	-	€15,477

\*One caregiver per patient was assumed.

To assess functional disease progression in patients, we used the MiToS (Milano-Torino staging) system, which classifies patients based on the loss of key motor functions such as speech, swallowing, mobility, and respiratory capacity. In our cohort, 15% of patients were in stage 0 (no functional loss), 45% in stage 1 (loss of one function), 25% in stage 2 (loss of two functions), 8% in stage 3 (loss of three functions), and 8% in stage 4 (loss of four functions) (Table 8).

MiToS classification	n (%)	EQ-5D-5L	VAS	Monthly costs		
				Societal	Work impairment	Out of pocket
Stage 0	8 (15%)	0.532	59.75	€1,330	€917	€351
Stage 1	24 (45%)	0.113	45.75	€1,917	€1,022	€335
Stage 2	13 (25%)	0.015	36.23	€1,421	€773	€560
Stage 3	4 (8%)	-0.199	34.50	€1,303	€1,282	€274
Stage 4	4 (8%)	-0.212	12.00	€1,803	€1,844	€788

Health-related quality of life was assessed using the EQ-5D-5L questionnaire and the visual analogue scale (VAS). The average EQ-5D-5L utility score among patients was 0.104, with a mean VAS score of 42.1 (Table 1). Table 8 summarizes the distribution of patients across MiToS stages, along with corresponding health-related quality of life measured by EQ-5D-5L and VAS scores. For each stage, the table also summarizes average monthly social security system costs, productivity loss costs and out-of-pocket expenses. When stratified by MiToS stage, average utility scores ranged from 0.53 in stage 0 to -0.212 in stage 4, showing a clear decline with disease progression. Similarly, average VAS scores decreased from 59.75 in stage 0 to 12 in stage 4 (Table 8). Caregivers reported an average utility score of 0.756 and a VAS score of 67.5, reflecting the psychosocial and emotional burden experienced by informal caregivers of ALS patients (Table 1).

Caregiver burden was assessed using the Zarit Burden Interview. The average score among the caregiver cohort (N = 55) was 38.4 points, corresponding to a moderate to severe burden. For comparison, caregivers of patients with advanced cancer typically score around 23.3 points (9), indicating that caring for ALS patients imposes a significantly higher physical and psychological burden.

## Conclusions

**Our study provides local data on the socioeconomic burden experienced by ALS patients and their caregivers in Czechia. The findings demonstrate that ALS significantly affects not only patients' quality of life and economic stability, but also the psychological well-being of caregivers. The average yearly productivity loss was €12,319 per patient and €15,477 per caregiver, representing a substantial societal burden. Caregiver burden scores were notably higher than those reported for other serious conditions, such as advanced cancer. Importantly, the study indicates a clear association between disease progression and reduced quality of life, as reflected in lower EQ-5D-5L and VAS scores across advancing MiToS stages. While cost data suggest a general trend toward increasing economic burden as the disease progresses, the pattern is not strictly linear. These results highlight the urgent need for targeted support for ALS patients and their caregivers within both the healthcare and social support systems.**

## References

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