

Historically first web portal about personal assistance in the Slovak republic

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Who we are:

The Organisation of muscular dystrophics in the Slovak republic, is a specific patient's organisation, which already 25 years connects people with neuromuscular diseases as Duchene muscular dystrophy or spinal muscular atrophy.

What we do:

The activities are divided into two groups systemic oriented and personal oriented. Both of them help to increase the quality of patient's life and inclusion into the society. The main activity of the organisation is consulting in the field of specialised social care and support of the personal assistance.

Our objective:

The main objective of the organisation is to advocate for the patients with rare neuromuscular diseases and to spread further positive example how to handle the disease. We provide expertise as well as humanity.

Personal assistance:

In the year 2018 it is 20 years since personal assistance was introduced as for social help for disabled people in the Slovak republic. Personal assistance is a supportive tool, which helps people with health impairment to live relatively independent life. It helps to create own space within the family, school or work. On the other hand, it creates more space for the family to spend it with disabled in a normal daily life.

Our 2 agencies of personal assistance:

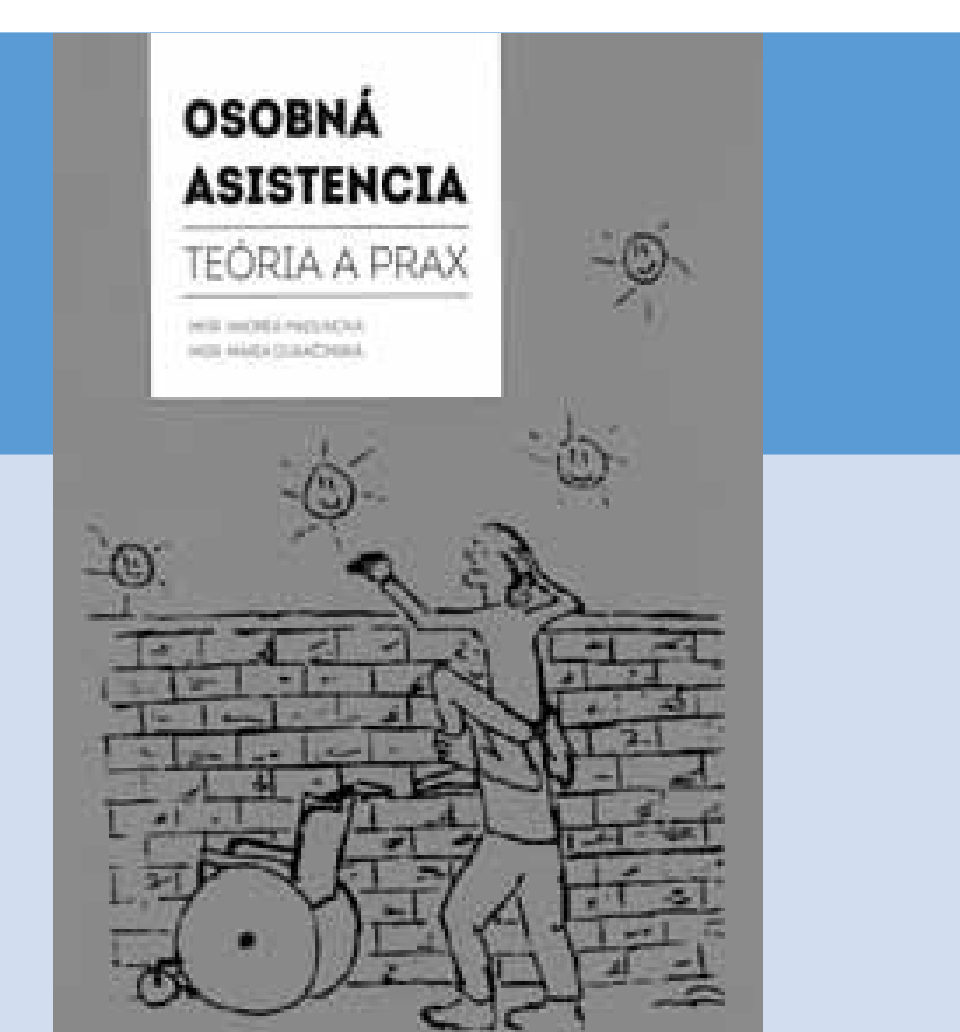
This agencies provide personal assistants. The agencies are also involved in increasing the awareness about the independent life of disabled and the importance of personal assistants. They manage the databases of client as well as potential personal assistants. They help personal assistants with administration of their profession. In conflicts between clients and personal assistants they could act as mediators. Personal agencies are in direct contact with the clients and help them to find solutions tailored to their individual needs.

How do we increase the awareness about the importance of the personal assistance:

documentary movie about the personal assistance

- "I assist, therefore I am"
- <https://www.youtube.com/watch?v=lksCDHu3uIc>

a brochure about personal assistance.



web portal about personal assistance
<https://www.osobnaasistencia.sk/>

- The web portal is for disabled people, their families and potential personal assistants. Its main aim is to increase awareness about the philosophy of independent life. It helps to answer questions about personal assistance and motivates for further interest.



Further activities to increase patient's quality of life

Campaign „Belasý motýľ“

- „increases awareness and collects financial sources for co-payment for medical devices <http://www.belasymotyl.sk> 280 421.57 for 518 neuromuscular patients

summer camps for children young adults and adult with neuromuscular disorders

- Every summer we organise 6 summer camps, for different target groups differentiating in age and orientation as sportive/ creative

journal

- Quarterly a journal about our activities and news in the field of neuromuscular disorders The audience is members, neurologist a social workers

sports, for disabled people

- Our members are golden Paralympic winners from Rio de Janeiro 2016 in boccia

systemic issues

- in cooperation with healthcare providers, academy and legislatures to improve the level of health care in the Slovak republic.

