

ADVISORY SERVICES FOR CAREGIVERS OF STROKE SURVIVORS



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CEREBRUM – ABOUT US

- Association of Individuals after Brain Injury
- Founded in 2007
- Located in Prague, Czech Republic
- 3 main pillars of activity
 1. information support for stroke survivors and their families
 2. cooperation with specialists from the field of Neurology / Neurosurgery
 3. aim for legislation change through dealing and communicating with local politicians – goal is comprehensive aftercare for stroke survivors

Approximately 300 clients / year – 30 000 stroke cases / year

HOW WE CAME TO
IDENTIFY THIS AS A
PROBLEM IN OUR
COUNTRY

Reason for founding this NGO – stroke survivor relative aiming to create an organization which would provide information to stroke survivors and caregivers

Nonexistence of an information hub for stroke survivors and their families in the Czech Republic

300 Cerebrum clients vs. 30 000 stroke victims = problem in information resources = imbalance of people seeking information versus statistical number of stroke cases in the Czech Republic/year

Feedback from Cerebrum clients on our informational wealth and resources they received from us

FINDING FUNDS FOR THE PROJECT

- Project is fully funded by European funds – EU – European Social Fund – European Social Employment
- 24-month project length
- Project started in September 2019
- 1 full time and 8 part-time employees involved in the project :
3 advisors, 1 peer, 1 psychologist, 1 occupational therapist,
1 leisure therapeutic activity coordinator



Evropská unie
Evropský sociální fond
Operační program Zaměstnanost

HOW THE PROJECT WORKS

- 4 advisory offices in health care institutions in Prague (communication with social workers, therapists, and seldom, with doctors)
- Aim is to disseminate our contact details to patients who are being discharged
- It takes about 1-2 months for a caregiver to really contact us (after realization of feeling lost in the system)
- Advisor's role is to clarify the core issue the caregiver needs to solve (the final core issue is far different from the original request)
- Preferred communication is via e-mail
- We often identify that a caregiver is in need of a psychological support for her/himself (we provide counselling with a psychologist – free service)
- The moment we realize the caregiver is in need of a psychological support – this is a crucial moment of this project (oxygen mask on the plane)

HOW WE MEASURE SUCCESS



Regular use of questioners and feedback forms (before knowing Cerebrum and after knowing Cerebrum)



We process Request database to create Frequently Asked Questions manual



We take every feedback very seriously

PROJECT ACHIEVEMENTS

Our participation in a holistic approach to caregivers in the Czech Republic, which has been happening in the last two years

Building a communication bridge between caregivers and hospital personnel for after-care treatment after discharge from hospital

Supporting caregivers in cooperation with doctors regarding long-term treatment process (where and how), to understand what is going on now and what will happen next, what social support they are entitled to receive from the state

Providing contacts for regional rehabilitation services close to patient's home

PRACTICAL TIPS FOR THE CAREGIVERS

- Caregivers of patients in acute state – provide information about who to talk to, where to obtain information, what institutions to contact in order to receive support from the state
- Provide caregiver with information what happens with patient in acute state, what to do next, what to ask a doctor to better understand patient's health condition
- Create and maintain a list of rehabilitation institutes in the country (incl. conditions of the treatment)
- Information and links for aftercare and home care services in individual regions of the country
- Make the caregiver a priority – our motto (oxygen mask on the plane)
- Key moment – response to the caregiver asap – their queries are very important to us, we pride in being active listeners (half work is done by active listening and being there for the caregiver)
- If there is no solution for a query – collect such queries and use them as a base for the System change
- Build Peer to Peer program – use caregivers and their experience to share with others

FUTURE OF THE PROJECT AND ITS AMBITIONS

Seeking funds to continue this project (after February 2022)

Create an online community for caregivers – moderated by Cerebrum

Participate in the project of the Alliance for Individualized Support in the Czech Republic (project for long-term caregivers with all spectrum of diagnosis)

The natural step is for the caregiver to contact CEREBRUM to realize that he/she is not alone in this dire situation

We want to be the light accompanying the caregiver on the way through the tunnel for him/her to reach the light at the end of the tunnel

THANK YOU FOR ATTENTION

Cerebrum – Association of Individuals after Brain Injury

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