MENTAL HEALTH CARE AS A VITAL PART IN THE HOLISTIC CARE FOR PATIENTS AND FAMILIES WITH RARE DISEASES

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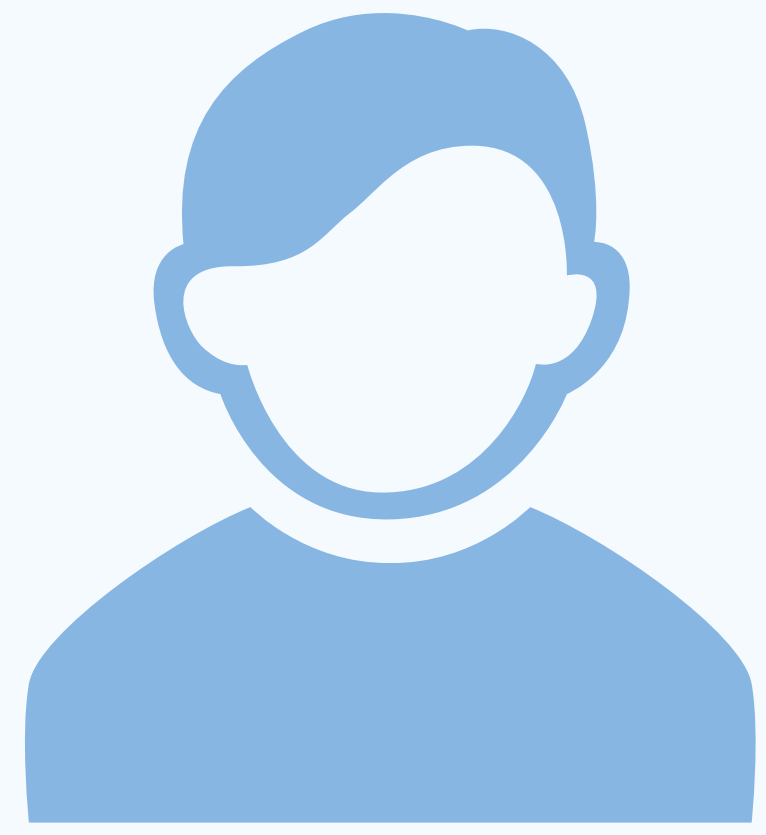
LIFE WITH CHALLENGES has a successful helpline for over 5 years now. The free psychological support was implemented in 2019 and in 2020 it continues to grow as a network of psychologists and psychotherapists.

Mental healthcare and psychological wellbeing are recognized as a vital part of the holistic care, which was until now lacking in the support of the patients with rare diseases in the Republic of North Macedonia. We focused not only on the patients but also on their immediate family members, who are also severely psychologically affected and experience severe psychological stress, trauma and sudden change in the family dynamics and every day functioning.



Lack of medical diagnostic procedures and treatment

Anxiety disorders

Depression

Chronic stress

Social isolation

Diagnostic mistakes

Delays in diagnosis

Family dysfunction and divorce

RARE DISEASE PATIENT

Why Family-Systemic psychotherapy approach is important?

Illness in one family member affects and changes the whole family dynamic and all family members. It's a challenge for the family as it is as the sick individual. Apart from accepting the illness and adapting, also sexual and other dysfunctions in the marriage within the families with a rare patient are common. This is why we used Family-Systemic psychotherapy approach, which proved to be extremely beneficial.

What psychological services we offered:

- Psychological counselling
- Individual, Couples and Family-systemic psychotherapy
- Psychoeducation
- Psychodiagnostic evaluation

The psycho-diagnostic evaluation and psychological testing, were very useful and contributed to the early detection of psychopathology in these individuals, timely treatment and good prognosis for their mental health.

The 12th Annual
International Experience Exchange with Patient Organisations
18 - 19 March 2020, Berlin, Germany

RARE DISEASES ARE CHRONIC CONDITIONS

depression

feeling different

intensive existential fear

feeling insecure

anxiety

general exhaustion

low confidence

desperation

negative body image

lost of hope

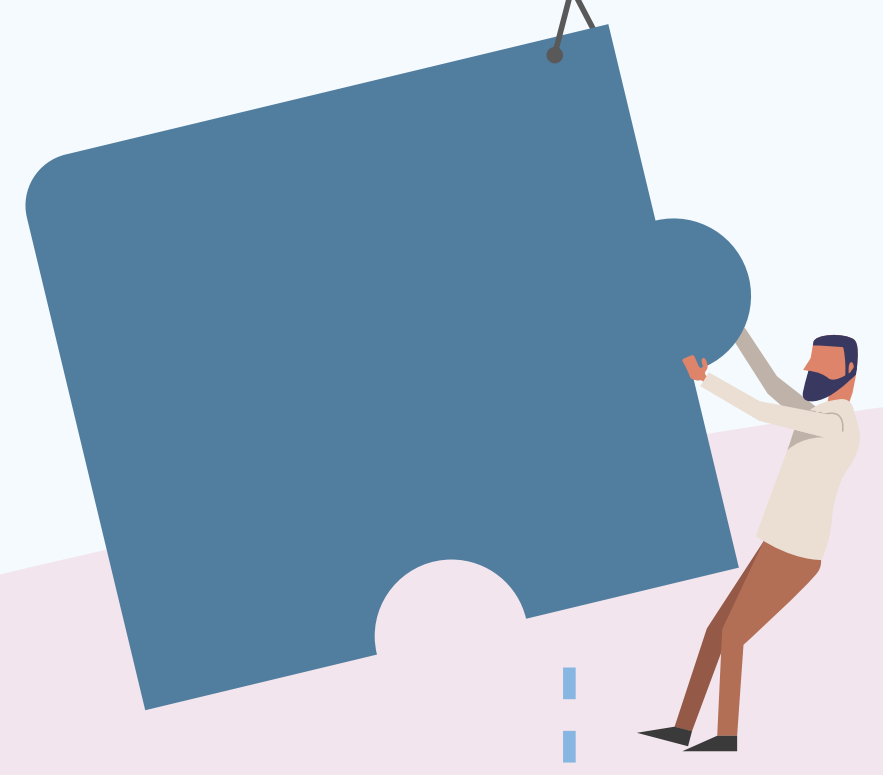
severe deterioration of mental health

OUTCOMES:

The implementation of **free psychological support** and treatment within the other services provided by the Association LIFE WITH CHALLENGES, encompassed an important aspect which was identified as important need for these patients. Around 40 patients with their families received psychological support for 2019, and the number is constantly growing due to the recommendations and positive feedback.

The psychological care services were recognized and accepted as a service of paramount importance for prevention and treatment regarding mental health and overall wellbeing. The outcomes that we noticed in the patients are:

- Anxiety reduction
- Improvement in the mood and will
- Better stress resilience and coping mechanisms
- Better life activity and day organization
- Increased feeling of control over their condition
- Better quality of life and wellbeing
- Facing and accepting their illness
- Better socialization and openness in interpersonal relationships
- Improved family dynamics and reorganization
- A strengthened feeling of self-worth
- Empowered patients and caregivers
- Decreased feeling of stigma and marginalization



Founded 2009 with a mission to provide better quality of life of patients and families with rare diseases. It represents over 100 rare diseases, >500 members (patients, families, volunteers, healthcare professionals).

Founded 2017 by MSc. Ivana Hadjivanova with goal to offer psychological care and support, prevention and treatment of mental health in children, youth and adults.

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FUTURE STEPS:

- Psychotherapy group for support of family members of patients with rare diseases, especially parents of children with rare disease
- Other professional trainings and continual education for the team of psychologists who is working with this patients
- Group supervision for the team of psychologists
- Professional trainings for school psychologists, pedagogue and teachers, which will offer psycho-education for basic interventions, sensibilisation, knowledge and tools for early detection of mental health disorders and deterioration in children with rare diseases and disabilities in the schools, and help for better integration
- We will continue with education of other psychologists and psychotherapists in our country and furthermore in the region where needed

Helpline for rare diseases:

- Over 400 phone calls and over 70 face to face meetings
- Communication through social media and e-mails
- 5 educational meetings organized and participation in over 10 conferences and meetings
- Exchange of information about clinical trials.
- Connected over 20 families with rare diseases
- Creation of a website with information about rare diseases in Macedonian and Serbian language
- Cooperation on regional level and International level (EURORDIS, IGA, IAPO, MDS, MPS, IPA …)
- Support to patients and families to establish their own patient organization (FAP, SMA, MS)