Holistic psycho-social support for people living with a rare disease and their family members

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ALAN – Maladies Rares Luxembourg
What is a Rare Disease?
OVER 6000 distinct rare diseases

Each one affects fewer than 1 IN 2000 PEOPLE

No cure for the vast majority of diseases and few treatments available

All together, an estimated 30 MILLION PEOPLE are living with a rare disease in Europe

They are geographically scattered and often isolated

Expertise, knowledge, information on diseases and their consequences are scarce and difficult to access

Few experts, geographically scattered
Research is fragmented
The impact of rare diseases on daily life and well-being
Solve-RD project, EURORDIS initiated the Community Engagement Task Force
Serious care burden for PLWRD & carers

65% have to visit different health, social and local services in a short period of time.

67% feel that these services communicate badly between each other.

7 in 10 do not feel well informed about their rights.

7 in 10 find that organising care is time-consuming; 6 in 10 find it hard to manage.
85% of people living with rare diseases report that their condition affects their physical and mental health.

RARE BAROMETER SURVEY 2017

#RAREDISEASEDAY
RAREDISEASEDAY.ORG

29 FEB 2024
Psycho-social support

Reduces stress, burden and isolation among PLWRD & care givers

General aims of psycho-social support

- Overcome their care burden and to secure the services and support that they require
- Achieve a quality of life on an equal footing with other citizens
- Participate in society and in the job market to their highest potential
- Fully realise their fundamental human rights
ALAN’s consultation service
Objectives

- Improve mental health & emotional wellbeing
- Facilitate social inclusion
- Reduce stress in daily life
Pathway

Request via Infoline

First consultation with psychologist & social worker

Co-creation of support plan
Pathway

Request via Infoline

First consultation with psychologist & social worker

Co-creation of support plan

Psychological consultation (if requested)

Case management: coordination of care & support
Pathway

1. Request via Infoline
2. Psychological consultation (if requested)
3. First consultation with psychologist & social worker
4. Case management: coordination of care & support
5. Co-creation of support plan
6. Evaluation of support plan
7. Decision continuation of support
Challenges

- Coordination within the team
- Inclusion criteria
- Prioritization of requests
- Cultural differences
- Staying up to date
- Navigate the system
Countering these challenges

Communication

- Weekly team meetings
- Custom-made, secure database
- Documenting all interventions

Team support

- Intervisions between team members
- Monthly supervisions with external expert
- Continuous training
- Caring leadership

Team attitude

- Respect & empathy
- Cooperation & trust
- Focus on patient goals
Countering these challenges

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Breaking down conventional barriers

☑ Service is **free of charge**
☑ **Multilingual** (important in Luxembourg)
☑ **Respect** for different cultural backgrounds and believe systems
☑ **Patient-centered** and **needs based** approach
☑ **Accessible** office space
☑ **Staff specialized in rare diseases**
☑ Good **visibility** and reputation
Reach of our Service

Luxembourg

2,586 km²
The National Plan on rare diseases allowed us to:

- Create the National Rare Disease Infoline
- Hire more staff
- Further professionalize
- Increase our visibility
Number of requests for support

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<th>Year</th>
<th>New requests</th>
<th>Ongoing requests</th>
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<td>2023</td>
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Reach of our Service in 2023

- 140 Psycho-social consultations
- 114 Social consultations
- 901 Psychological consultations
- 115 Interdisciplinary meetings
- 31 Accompanied medical visits
- 11 Other
Practicalities & Transferability

- 5 social workers & 3 psychologists
- Personal office space
- 2 consultation rooms
- Access free building
- 2 company cars
- Training budget
Contact

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