

How to go about setting up a Helpline for RD - a need in Greece

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Helplines for RD

A Helpline is amongst the “Information Services” which are essential to support patients with rare diseases, along with their families.

Patients with RD all share common problems, irrespective of specific symptoms

1. Loneliness & anxiety
2. They often lack of information about their disease
3. There are often problems related to diagnosis & treatment
4. They have difficulties finding and accessing practical information

The current situation in Greece

The unofficial “Helpline” is currently supported by basically ONE person in the Greek Alliance for Rare Diseases

This strongly limits a wider capability to respond to the needs of patients and their families with RD in Greece.

Number calls per week varies from a just 1-2 to many (>20), especially if there has been some media exposure eg Rare Disease Day

[approximately 300-500 calls per year]

The current situation in Greece

- Generally, sources of information are limited
- Internet use is limited, especially in rural areas/communities
- Mass media (newspapers, TV) play a basic role as a source for information, either about
 - the existence of the Greek Alliance or other patient organizations
 - some of the rare diseases themselves

The current situation in Greece

The support from public services is minimal to non-existent.

Greek patients with RD usually do not have

- easy access to information about their disease
- clear rights with respect to state social contributions, public amenities or accessibility to medications
- There is an absence of psychological support, both within the health system and outside

The current situation in Greece

First-time callers to the Greek Alliance are usually

- Lost, shy, ashamed.
- In need of reassurance, empathy, psychological support
- In search of information about their disease and suitable clinicians/clinics.
- They are often misunderstood by clinicians
- They are often undiagnosed (misdiagnosed)
- They are ignorant of their rights and social-state support with respect to e.g. schooling, medication (each ministry has different list of rare diseases which they include for special rights!!!)

Aspects to address when setting up a helpline

Have an in-depth practical understanding of the range of considerations that need to be taken into account when setting up a helpline.

PERSONNEL

- Skills
- Training

MONITORING

INFRASTRUCTURE

- Technical “Hardware”

Personnel (professionals & volunteers)

Skills

- Helpline staff should be trained in how to listen and respond

Limitation in Greece:

General lack of professionals and volunteers to operate the Helpline (there is not a tradition of volunteers as in many other European countries)

Core Helpline Skills includes:

- Listen & respond with empathy to the caller & ensure that their problem is clearly understood.
- Try to release tension & sense their feelings.
- Provide information slowly, to analyse how the person is reacting.
- Put information into simple terms.
- Do not necessarily give all the information available; More information can lead to new uncertainties
- Propose another call, a follow-up, leaving more time to check with specialised experts.

Core Helpline Skills

- Ensure confidentiality
- Be aware of strategies for ending calls, including those that are abusive.
- Be aware of the limits of the helpline service.

Methods for Training on Core Helpline Skills

- Collective sessions with a teacher
- Double-listening and call follow-up training
- When no specific training is organised, volunteers, parents and operators usually share their experiences as a minimum.

The latter would be the situation in Greece

Advanced Helpline Skills

- How to take care of basic symptoms/side effects of treatments.
- For more specialist requests, operators should know when to refer to healthcare professionals, who prefer to receive written materials.
- Psycho-sociological expertise and education for support and counseling of patients and families.

Methods for training Advanced Skills

- To provide training with social workers and medical advisors.
- Some enquiry lines recruit social workers with psycho-sociological expertise and education.
- Others recruit volunteers from the organisation and train on-the-job.

Helpline evaluation and monitoring

Monitoring and evaluation is important

- The appropriate roles of helpline volunteers must be defined.
- The motivation & background of helpline staff/volunteers must be evaluated before & during recruitment by the rest of the team & through self-evaluation.
- As enquirers can call several times for the same question, different people may respond. It is therefore important to co-ordinate responses.
- For migrants or travellers (language line services): over-the-phone translation exists in some countries but this service is expensive.

Technical requirements and equipment for Helplines

- Telephone line and exchange
- Personal computers (to record callers details etc)
- Answering machines

Before acquiring /purchasing equipment:

- Analogue or ISDN line?
- What do I need to think about when buying an answering machine for my helpline?
- How do I monitor calls (What about confidentiality issues?)

It is imperative to establish a comprehensive
Helpline for RD in Greece

However, a helpline in Greece is just one of
the needs of patients with RD that need to
be addressed!!