

MODULE PARENTS AND EXPERTS

ACTIVITY 1. TWO FACES OF A DIAGNOSIS

- **TIME:** 30m.
- **RESOURCES:** Poster.
- **LANGUAGES:** ENG / SPA.

DESCRIPTION:

It often takes years for families to receive the correct diagnosis of a neuromuscular disease. The road to diagnosis is an odyssey filled with tests, different specialists, uncertainty and anguish. This poster aims to illustrate this journey to diagnosis and to do so in such a way that the family's part and the specialist's part can be seen simultaneously, in order to generate more empathy.

OBJECTIVES:

- To guide affected families through the 4 basic steps that a patient in search of a diagnosis must follow in order to get a diagnosis. It also aims to place patient organisations as the central axis on which to rely during this process, as they serve both as a support for families and as a link with health professionals.
- To generate empathy in the experts' environment, so that they can see at a glance the situation that families have to live with a child who has a disease of this type.

LESSON OVERVIEW:

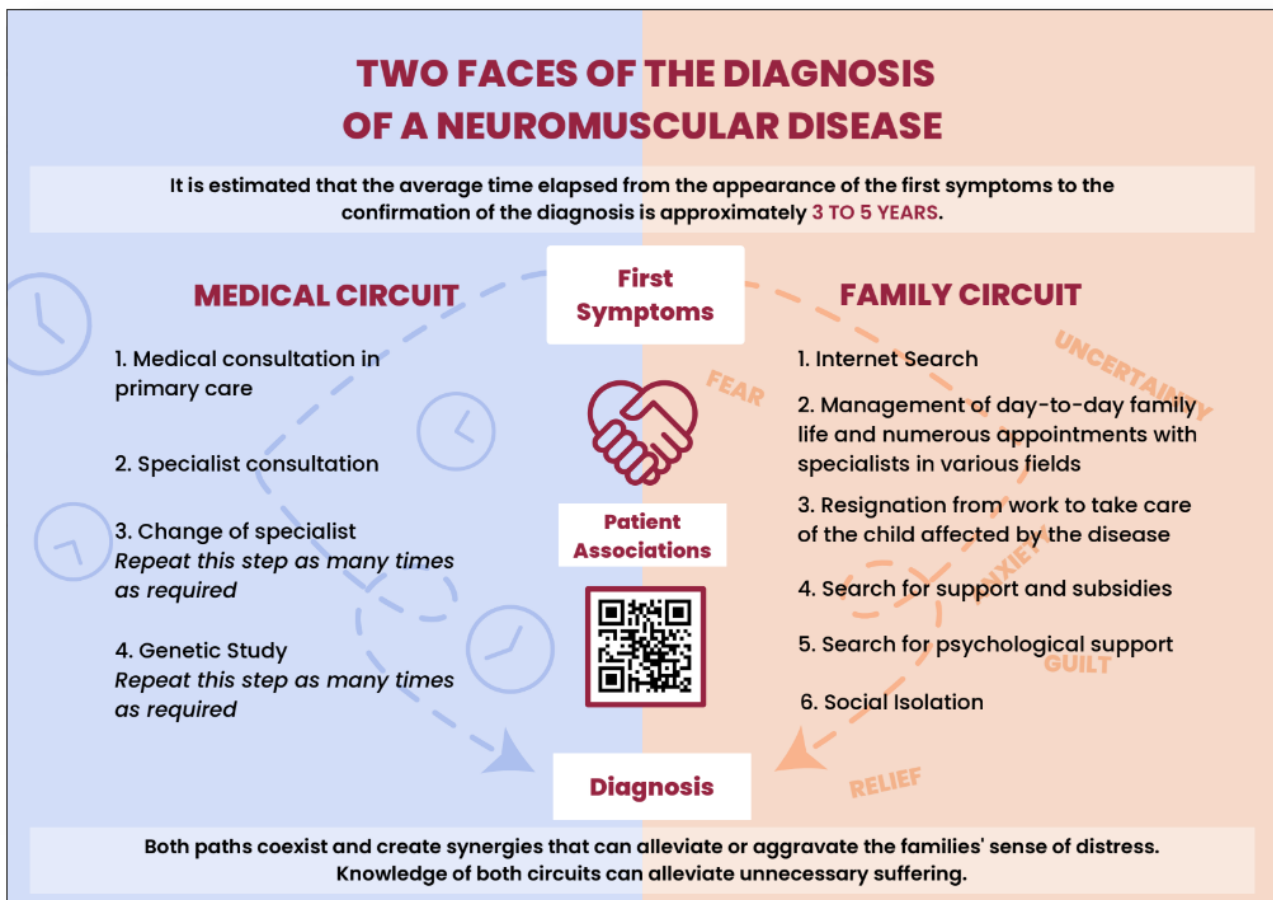
Infographics of the process to make it more accessible, simple and easy to understand.

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RESOURCES:

- POSTER.



TWO FACES OF THE DIAGNOSIS OF A NEUROMUSCULAR DISEASE

It is estimated that the average time elapsed from the appearance of the first symptoms to the confirmation of the diagnosis is approximately **3 TO 5 YEARS**.

MEDICAL CIRCUIT

1. Medical consultation in primary care
2. Specialist consultation
3. Change of specialist
Repeat this step as many times as required
4. Genetic Study
Repeat this step as many times as required

**First
Symptoms**



**Patient
Associations**



Diagnosis

FAMILY CIRCUIT

1. Internet Search
2. Management of day-to-day family life and numerous appointments with specialists in various fields
3. Resignation from work to take care of the child affected by the disease
4. Search for support and subsidies
5. Search for psychological support
6. Social Isolation

FEAR

UNCERTAINTY

ANXIETY

GUILT

RELIEF

Both paths coexist and create synergies that can alleviate or aggravate the families' sense of distress. Knowledge of both circuits can alleviate unnecessary suffering.