

## MODULE PARENTS AND EXPERTS

### ACTIVITY 2. HOW TO COMMUNICATE A DIAGNOSIS? / HOW TO REACT TO A DIAGNOSIS?

- **TIME:** 30m.
- **RESOURCES:** List of tips.
- **LANGUAGES:** ENG / SPA.

#### **DESCRIPTION:**

Both giving and receiving the diagnosis of a child with a rare disease can be challenging and difficult. On the side of parents that receive this news, it can be a shock, a relief to finally having found a diagnosis, a source of suffering... Multiple emotions collide, which might make that moment difficult to manage. It is important that professionals communicating the diagnosis do it in a manner that facilitates assimilation of the situation and eliminates unnecessary suffering.

On the other hand, confronting such a challenging situation might also require that parents receive the necessary assistance, tools and information to be able to carry on in the most positive way possible. This will be a source of resources both for parents and professionals.

#### **OBJECTIVES:**

- Educate professionals on how to communicate a rare disease diagnosis.
- Reduce suffering from parents receiving the diagnosis.

### **LESSON OVERVIEW:**

Provide this information in a format that makes it easy and quick to understand. It would be handed to families in the doctor's office. IT would have previously been handed to doctors and explained, to ensure that they are prepared to communicate the diagnosis of a rare disease to the family in the best possible way.

## How to communicate a diagnosis of a rare disease?



- **Prepare yourself before approaching the family:**

Prior to communicating the diagnosis, inform yourself thoroughly on the disease in question and how it affects children. Crucial information you will need to research is: symptoms, prognosis and available treatment options. Making sure you are well prepared will allow you to provide concise answers to the parents' questions.

- **Practice active listening:**

Parents want their questions and worries to be heard. Look them in the eyes and listen calmly letting them share their feelings and worries. Let them express themselves without interrupting them.

- **Use language that is as easy to comprehend as possible:**

Whenever possible, use simple language to convey topics rather than complex medical jargon.

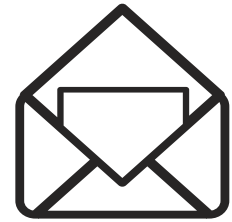
- **Deliver information gradually:**

Providing all information at once, might imply a huge shock and saturation of emotions for the parents listening to it. Therefore it is recommended to gradually provide the information about the disease and its implications in the life of the child and the family. Rare diseases are often complex, as well as the medical jargon, therefore staging the delivery of the information facilitates its processing.

- **Provide information additional resources and support:**

Once the diagnosis is found and communicated to the family, it is also the moment to provide information on the resources available. For instance, patients' organizations on rare disease, governmental resources, medical experts, etc.

## How to receive a diagnosis of a rare disease?



- **Allow yourself to experience and process the feelings that arise:**

Feelings of despair, rage, grief, or confusion are normal. It's important to identify and accept these emotions rather than repressing them.

- **Look for support:**

Seek out people who can offer you emotional support and understanding, such as family members, close friends, or support groups. Being able to express your sentiments to those who have gone through similar things can be reassuring.

- **Ask questions:**

Learn more about the disease: Ask all questions that generate uncertainty to you. Knowing more can give you more confidence and make you more prepared to make wise choices.

- **Focus on the present:**

While worrying about the future is normal, try to keep your attention on the here and now. Focus on giving your child the greatest care and assistance possible right now.

- **Your child is much more than their diagnosis:**

Celebrate their individuality, uniqueness, abilities, and accomplishments.

- **Take care of yourself:**

Caring for a child with a rare disease can be physically and emotionally demanding. Make time for self-care, seek professional help if needed, and don't hesitate to lean on others for assistance.