

"To get to a diagnosis of acromegaly has an important impact for the patient and involves a great change of life. It may take as long as 8 to 15 years to have a correct diagnosis, and the patient often must go through several professionals to find those who see "the big picture".

It must be taken into account that acromegaly causes significant physical changes: growth of hands and feet, growth of the jaw and tongue, decreased muscle strength (fatigue), joint pain, decreased peripheral vision (vision in "tunnel"), headache, sweating, thickening of the skin, increased unintentional weight, etc. As you can see, these are all symptoms that affect the quality of life in an important way and, the more delay there is in the diagnosis, the greater will be the impact which lowers the possibility of restoring a good quality of life. As many of the changes are facial, the impact they have on women is greater still.

For the patient it is not easy to accept the disease and adapt to the changes it implies. They go through a period of adjustment, which can be divided into several phases. The first will be that of uncertainty and confusion. This disease is framed within an uncommon pathology and, as such, little is known so it is likely that the patient has never heard of it. In this stage it is important to have the support of qualified staff (specialists and patient support groups) that can help to keep the patient calm. The second phase will be feeling overwhelmed; having information about the disease and its treatment alternatives, contemplating the possible consequences -- of course this will help make the picture clearer but can lead to anxiety. The third stage is that of denial, opposition and/or insulation where the patient appears to have difficulty accepting the diagnosis. The time needed from diagnosis to acceptance of the disease will vary from patient to patient. The fourth stage will be rage that, well-managed, will provide the energy needed to confront the disease and take the necessary decisions. The fifth stage will be sadness, which, when well-managed can allow the patient to adapt to the new situation and give them the time to think and consider the future with serenity. By the end of this process, the patient has managed to accept the changes caused by the disease and continue with their lives.

There is no default timeframe to carry out this process, and it can vary from days to months, depending on each person (each patient is a "world"). Counting on the support of comprehensive specialists and associations of patients helps tremendously to make this process short and productive.

There are so many questions that arise when the patient receives the medical diagnosis of acromegaly, because it is thought to be “rare” and little known. Ultimately, the best thing to do is to refer them for a consultation to a specialist who can help them alleviate their doubts.

A patient support group, not only helps patients cope with the impact of knowing about this rare disease, but patients are able to speak with others who have gone through the same process, learn from their previous experiences, and are able to speak "the same language". In the very least, it is a way to provide information about access to the right treatments, team of specialists and the coverage by the right health care providers.

Of course, as a corollary, an essential element to overcome the diagnosis and face the proper treatment in the best way, is to always keep a positive attitude. This will help a lot in the success of treatment as well as reducing the impact of the stress of the change of life that acromegaly implies."

- Sandra Mesri, Advocacy Group, Argentina