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Rheumatological diseases: patients waiting for a diagnosis even for seven years



Waking up with a pain that prevents you from doing even simple gestures such as getting dressed or going shopping. A pain that together with other symptoms takes you to the doctor, but that no one can give a name to. It can take years before a diagnosis is made. It happens in Italy to one in ten people who suffer from one of the rheumatological diseases. We are talking about 5.4 million people who live for years waiting to receive an accurate diagnosis. Only 18% of patients were able to name their disease within the first three months of the onset of symptoms. A delay that limits the life of entire families and which also translates into a cost for the community.

How much does the diagnostic delay cost

The 'family' of rheumatological diseases is very broad, but they all share a diagnostic delay. "Late diagnoses even affect 1 million Italians – he says **Gian Domenico Sebastiani**, president of the Italian Society of Rheumatology (Sir). "Patients wait up to 7 years to find out they have psoriatic arthritis or fibromyalgia, 5 for ankylosing spondylitis, 3 for systemic sclerosis and 2 for rheumatoid arthritis. These are too long times, which cause a worsening of the symptoms and make recovery and treatment more difficult".

The impact on people's lives and on the community

Living with a rheumatological disease can be very frustrating. "Many pathologies present difficulties and pains that make it difficult to carry out daily activities: studies show that 57% of rheumatological patients need help in everyday life", underlines **Ennio Lubrano of Scorpaniello**, Vice President Sir. But the community also pays a price. For example, in Italy rheumatoid arthritis costs the community over 3 billion euros every year, between direct and indirect costs. It is one of the most feared and painful rheumatological diseases, with remission possible in about 50% of cases provided that the diagnosis is early and can allow rapid therapeutic intervention.

Effective therapies and updating of doctors

However, unfortunately this is not the case and these patients go on, day after day, with disabling symptoms, with joint damage and consequent disabilities. There are complications that can even be fatal, such as those affecting the lungs and heart. "Today, drugs make it possible to stop the progression of pathologies, with a good recovery of functionality and a satisfactory recovery of one's professional and personal life: however, this requires timely intervention, starting from the first symptoms", continues Sebastiani. In the last twenty years, progress in research has made it possible to offer innovative therapeutic solutions, with fewer side effects and a reduced impact on daily habits. "Unfortunately – adds the president of SIR – the identification of the disease is not always simple, because the symptoms are often attributable to other pathologies. This is why it is essential to invest in updates and training for all specialists, from general practitioners to rheumatologists themselves, who must also be able to take care of patients with less common characteristics".

The importance of adherence to therapies

Naturally, patients also have to do their part. If early diagnosis is the first step in achieving healing or stabilization of symptoms, in fact, adherence to therapies is essential to allow the achievement of a good quality of life and prevent worsening. "In the post Covid – they add **Silvia Tonolo** president of Anmar, National Association of Rheumatological Patients, e **Roberto Messina**, Senior President Italy FederAnziani – there has been a greater discontinuity in care: the main cause is the long waiting lists for specialist visits. Patients, once they notice an improvement in symptoms and are unable to get in touch with the rheumatologist, increasingly decide to stop treatment".

Fear of adverse reactions

This causes, first of all, the worsening of the disease, with the reappearance of pain, secondly, serious difficulties for the doctor in defining an effective personalized therapy. "Another triggering factor – continues Tonolo – is the fear of possible adverse reactions. As an association we try to provide information to the sick, urging them to have a greater knowledge of the therapies, not to take independent initiatives and to wait for the doctor's advice, but it is essential that the institutions act as leaders, because non-adherence in chronic pathologies can lead even to death."

Information campaigns

To raise awareness among doctors, institutions and patients, we need to talk more about these diseases. "It is necessary to provide correct information so that patients do not underestimate pain and to offer general practitioners the tools suitable for recognizing rheumatological disease and referring the person to a specialist", declares Sebastiani. "Like SIR – adds Lubrano di Scorpaniello – we carry out continuous dissemination activities both towards clinicians and towards citizens, so that on the one hand they can develop awareness of the importance of contacting their own doctor, on the other, quickly recognizing the symptoms and refer the patient to a specialist who can quickly place him in a treatment programme. In 2021 we launched the 'Early Diagnosis' campaign, which with the distribution of 200,000 brochures, social activities and refresher courses aimed at pharmacists, has allowed us to reach millions of patients and caregivers. Today we continue with talk shows and video clips that allow us to maintain a dialogue with them and to respond to doubts and perplexities".