

# LYMPHOEDEMA MANAGEMENT IN SPAIN

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In the 1980s, as a result of the work of a group of vascular surgeons, including Dr Azcona and Dr Jimenez-Cossio who founded the Club of Lymphology (a group of doctors interested in the study of lymphatics and lymphoedema) and Dr Samaniego, who was the first to perform venous-lymphatic anastomoses in Spain, lymphoedema began to be more widely discussed in Spain. At the same time, a doctor who specialised in rehabilitation, Margarita Serra from Valencia, developed swelling in her lower limb and went to the Földi Klinik in Hinterzarten, Germany to receive decongestive treatment. She subsequently became interested in this therapy and was the first to explore and study conservative treatment for lymphoedema in Spain, and started up an outpatient clinic affiliated to the Rehabilitation Department of Hospital La Fe in Valencia. She published two books and gave numerous conferences and talks, educating doctors involved in rehabilitation, physiotherapists and vascular surgeons about lymphoedema. Her invaluable work helped to raise awareness in lymphoedema which, until then, had been a relatively neglected condition in the country (Serra, 1994; Serra, 1997).

The medical specialty of physical medicine and rehabilitation aims to improve and restore functional ability and quality of life to patients with physical disabilities. It includes diagnosis, prevention and treatment

of many different and specific areas such as spinal cord injuries, neurorehabilitation, cardiopulmonary rehabilitation, prostheses and orthoses, children's rehabilitation, speech therapy, traumathologic orthopaedic surgery and lymphoedema (American Academy of Physical Medicine and Rehabilitation, [www.aapmr.org](http://www.aapmr.org)). Working alongside physiotherapists,

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the specialty treats the whole person, not just the chronic condition, and thus is well placed to treat patients with lymphoedema. In Spain, vascular surgeons have traditionally dealt with cardiac and arterial surgical techniques, the lymphatics have never been their focus of attention.

However in recent years, the number of physiatrists or rehabilitation specialists and vascular surgeons showing an interest in lymphoedema has increased, as can be seen in the rise of scientific literature about lymphoedema. The organisation of symposiums discussing lymphoedema at national scientific meetings, the presentation of papers at conferences about lymphoedema reflect that things are changing and that the condition is beginning to be recognised.

## Training in lymphoedema management and treatment

The University School of Physiotherapy in Valencia offers various degrees. These three-year courses differ in the amount of time given to training in lymphoedema management and treatment, some include 40 hours while others just a few hours. Thus, some physiotherapists have only touched on lymphoedema during their training, while others will have studied it in depth, being introduced to manual lymphatic drainage (MLD) and receiving practical training at a lymphoedema unit. Training in the management and treatment of lymphoedema can also be undertaken at postgraduate level, with a masters degree being offered by the University School of Physiotherapy ([www.uv.es/efisio/](http://www.uv.es/efisio/)). With the increasing demand and interest in this area, other courses have become available throughout Spain in private institutions or public universities.

Medical students receive minimal training in lymphoedema when studying breast cancer during the fourth year of their six-year training. Thus, newly-qualified doctors are unfamiliar with the condition and are surprised if they discover a lymphoedema unit in their hospital and the work that is done there, although these are still very few in number throughout the country.

Since 2007 and the late modifications of the law in 2008 (*ORDEN SCO/846/2008, de 14 de marzo, por la que se aprueba y publica el programa formativo de la especialidad de Medicina Física y Rehabilitación, BOE 77, de 29 de marzo de 2008*), students studying physical medicine

and rehabilitation receive one month's training in lymphoedema during their second year. There are no postgraduate courses in lymphoedema management for doctors.

### Diagnosis of lymphoedema

As there are few specialist lymphoedema units in Spain, management of these patients often falls to specialists in rehabilitation, whose knowledge depends on their personal interest in this field.

The clinical management of patients with upper and lower limb lymphoedema is different. Upper limb lymphoedema is a well-known sequellae of breast cancer treatment. Oncologists, radiotherapists, breast surgeons are aware of it and send their patients to specialist units in the early stages of the disease to get a precise diagnosis, be taught preventive strategies for lymphoedema or, if necessary, to receive treatment. For example, the lymphoedema unit in the author's hospital has been invited to join the hospital's breast cancer unit to work together and share knowledge to improve the care of these patients. Staff in the breast cancer unit recognise that the work of the lymphoedema unit can help to alleviate their workload.

For patients with lower limb lymphoedema the story is completely different. In the author's experience they often present at specialist lymphoedema units more than 13 years after the onset of symptoms (Forner Cordero et al, 2006), during which time they may have visited many doctors and private clinics without any result — perhaps even travelling to other cities, and if they have got a diagnosis, it is only 'lymphoedema', without any further explanation. They are often told that they are obese, even when their body mass index (BMI) is quite normal. Some have received intravenous fluids for three days in order to lose weight, without any result. Others have been admitted to hospital with a false diagnosis of venous thrombosis and have been treated with anticoagulant drugs

when they reported high fever, and local and progressive erythema in the lymphoedematous limb, typical signs of lymphangitis. When diagnosed, they are frequently told that they must learn to live with the condition because there is no cure.

Thus, patients in Spain who manage to attend one of the few specialist lymphoedema units are grateful and relieved to receive a precise diagnosis and information about lymphoedema.

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If well treated, their limb volume can be reduced, complications can be minimised, lymphangitis attacks become less frequent, and they learn how to self-care and wear adequate compression garments. This possibly incurs less costs to the healthcare system as the number of complications are reduced, resulting in less treatment.

### Decongestive treatment

Throughout Spain there is a lack of consensus about treatment. MLD is performed in some hospitals, but many of the therapists do not have special training in lymphoedema. Most hospitals use intermittent pneumatic compression (IPC) pumps to treat patients with lymphoedema, but many of these are monochambered and can damage the lymphatic vessels. Moreover, many beauty salons apply pressotherapy without medical or physiotherapist support, and do not use compression bandaging, the most evidence-based therapy for the treatment of lymphoedema (Badger et al, 2004; Lymphoedema Framework, 2006; Partsch et al, 2008). This lack

of expertise can be seen by the long waiting lists at the few public health centres that provide lymphoedema treatment in Spain.

### Compression garments for maintenance therapy

As a result of the absence of any internationally agreed consensus for garment style and compression level (Clark and Krimmel, 2006), throughout Spain the availability and reimbursement by the public healthcare system of garments is different. In some areas patients receive one garment every six months, and in others, one per year. With temperatures reaching 29–30°C in the summer months, this can cause great discomfort. The situation tends to be that patients wear a wide range of products, depending on availability rather than accurate prescription, and all too often the optimal garment is not worn (Forner-Cordero et al, 2008).

In the author's opinion, those involved in prescribing, measuring and fitting garments in Spain all need more training. Yet, this is still not happening in most centres that treat lymphoedema. Doctors, usually oncologists, prescribe a garment and the orthopaedic technician, with little or no expertise, decides which one will fit best. No one checks if the garment fits correctly. With the same code in the prescription form you can get a standard circular-knitted sleeve or a made-to-measure flat-knitted sleeve, depending on the orthopaedic store. Compliance is also a problem and, due to lack of education, patients frequently refuse this important aspect of lymphoedema treatment (Forner-Cordero et al, 2007).

### Patient complaints

One of the main complaints from patients with lymphoedema in Spain is the number of years that they have been going to different doctors without a correct diagnosis. When some kind of diagnosis is finally reached, it is often incomplete and little information is given. The most disturbing fact for the patient is underestimating the consequences of the disease, treating lymphoedema as

a simple aesthetic problem, inherited from family, making the patient believe that he/she is exaggerating the symptoms and complaining, when in reality the disease is progressing.

Once diagnosed, the lack of curative treatment strategies or drugs for lymphoedema is distressing, leading some patients to deny their condition and refuse any prescribed therapy. When they are finally ready to accept that they have the condition and start to actively look for treatment, the lack of trained staff and specialist centres, together with the expensive therapies and lack of psychological support, are further difficulties encountered. Furthermore, delays in recognising the disability can cause discrimination for those in employment, as no allowances or ergonomic adaptation of the workplace are made. This can result in people having to give up their jobs, leading to further economic hardships. All these grievances could and should be reduced to relieve the suffering of patients with lymphoedema in Spain.

### Associations

As far as the author is aware there are at least seven patient associations in the different regions of Spain with more than 500 members. AMAL (Asociación Madrileña de Afectados de Linfedemas) from Madrid and ADELPRISE (Asociación de Afectados por Linfedema Primario y Secundario) from Vitoria were the first and are the most active associations in Spain. In other regions, ADPLA (Asociación de Pacientes de Linfedemas de Aragón), AGL (Asociación Galega de Linfedema), LIMFACAT (Asociació Catalana D'Afectats de Linfedema) and ADELPRISE-Sevilla (Asociación de

Personas Afectadas por Linfedema Primario y Secundario) are working to give information to patients. One of the most recently founded associations is ACVEL (Asociación Comunidad Valenciana Enfermos de Linfedema), which is increasing in numbers.

These associations provide information about lymphoedema, organise workshops on self-care and support patients. All this is positive for patients, but the number of people registered in one or another association is still relatively small compared to the number of patients diagnosed with lymphoedema, and considering the inadequate provision of lymphoedema care in the country.

### Forum

The existence of the online forum of patients with lymphoedema ([www.med-foren.de/](http://www.med-foren.de/)) since 2005 has helped to spread information among patients in the Spanish language, to answer their questions and help them with their decisions and alleviate their fears.

We need lymphoedema units where specialists in rehabilitation, physiotherapists, occupational therapists and psychologists all get involved, working together and undertaking research in order to manage patients with lymphoedema more effectively. Something has to be done in Spain to improve knowledge about lymphoedema among patients, politicians and healthcare professionals. **JL**

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WHY NOT WRITE ABOUT THE CARE AND MANAGEMENT OF PATIENTS SUFFERING FROM LYMPHOEDEMA IN YOUR COUNTRY, AND SHARE YOUR EXPERIENCES WITH OTHERS WORKING IN THIS FIELD WORLDWIDE.

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