

LYMPHOEDEMA ASSOCIATION OF AUSTRALIA

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The Lymphoedema Association of Australia (LAA) was founded in 1982 by Drs John and Judith Casley-Smith. The society includes patients, practitioners, allied healthcare professionals, carers and partners. The stated philosophy has been that this association was 'formed to help each and every one of you'. The LAA previously ran lymphoedema treatment training sessions for both patients and healthcare professionals, but with the untimely death of Dr John Casley-Smith in 1997 and the illness of Judith Casley-Smith in 2003, classes of the Casley-Smith method are no longer taught in South Australia, but the website still continues.

Key words

Lymphoedema education
Awareness promotion
Patients
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Web resource

Dr John Casley-Smith was one of the most eminent lymphologists in Australia. He literally lived at his internationally known Electron Microscope Unit, which was based at the University of Adelaide. From the late 1960s through to the 1990s he was an active member of the national (Australian) and international lymphology community, a founding member of the International Society of Lymphology (ISL) and was involved in the establishment of basic care and treatment programmes for patients, which were practicable and possible in the South East Asian and Indian regions.

Given his international involvement and perspective, and knowing that in many instances we were just 're-inventing the wheel' rather than moving forward, John Casley-Smith spent

much of his time looking at how the treatment of those with lymphoedema could be improved. Even in Australia, he saw many significant, unsolved issues in the way in which lymphoedema was being identified, managed and treated. Interestingly, his approach was to examine and compare ultra-structural changes between the normal and lymphoedematous tissues, and to

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compare these with further changes in the tissues of those who had good treatment outcomes versus those who had poor, or even negative outcomes. His concerns about the poor and often inaccurate knowledge, as well as poorly targeted treatment of lymphoedema, combined with his experiences with pleading patients who had heard about his work and sought treatment, led to the formation of a group of clinical and scientific researchers and students. Working under his mentorship and guidance, they helped to find answers

for some of the frustrating problems facing not only the patients, but also the medical and allied healthcare communities.

Being particularly affronted by the lack of knowledge and concern for this group of patients, and the frequent comments from GPs and specialists that, 'lymphoedema does not exist in my clinic', or, 'it's only a swelling – they should learn to live with it', as well as comments from patients, such as, 'do I have to go through the rest of my life like this', and 'what a disfigurement — how can I hide this' and 'help', Drs John and Judy Casley-Smith founded the Lymphoedema Association of Australia (LAA) in 1982.

The first meeting of the LAA was held in a lecture theatre of the R A Fisher laboratories in the Department of Zoology, University of Adelaide. It was well advertised and was attended by about 25 patients, students and healthcare professionals. The initial meetings were often quite 'spicy', with feelings of frustration being expressed by patients and healthcare professionals alike. At least, however, the meetings provided a focus on the condition: a focus for future change and an initial reference point for those in South Australia and, later, across Australia and the rest of the world.

Although the LAA did not have funds to financially encourage research

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in the area, honours and doctorate students were offered strong and friendly mentoring (often over a glass of home-made apple cider) in any type of research into the lymphatic system or the consequences of its failure.

John Casley-Smith was an excellent lobbyist and within a short time he had gained the support and patronage of the Governor of South Australia, Sir Walter Crocker. Along with this came the formalisation of the Lymphoedema Association of Australia (LAA) in the form of a constitution. The major objects of the association were: 'To promote the treatment, education and welfare of patients suffering with lymphoedema', 'to encourage and support research projects relating to lymphoedema and the prevention, control or cure of these and related diseases', and to 'found, encourage or contribute to scholarships, fellowships or travel grants'.

John Casley-Smith was continuously frustrated by the fact that neither lymphology nor lymphoedema (recognition or treatment) were included in any medical, nursing, physiotherapy or other allied healthcare courses. He and the LAA worked hard to try to improve this deficiency. To this day, there is still a poor representation of any lymphatic-related module in taught courses. However, there are signs of requests for improvement in awareness of the lymphatic system and of the impact of its dysfunction from general practitioners and specialist groups in medical and allied healthcare professional courses. While John Casley-Smith recognised the competing areas of knowledge, he knew that awareness of the lymphatic system was crucial in view of its role as a 'sewerage system' and its impact not only on lymphatic diseases and disorders, but also on vascular and immune system-related ones.

The LAA and other national and international leaders in lymphology and phlebology are now working together to evidence the need for further curriculum depth and detail into the

lymphatics and their functioning in health and disorder/disease.

Role of the LAA

The LAA considers itself a mixed society of patients, practitioners, allied healthcare professionals, carers, partners, etc. There are no restrictions as to who can apply and be accepted for membership, and all interested parties receive equal representation. From its inception, the LAA also

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welcomed overseas members. Up to one-third of its members in the late 1990s were from outside Australia, attesting not only to the need, but also to the excellent communication and information dissemination network that the LAA established, even in the early days of computer-based communication and networking.

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Education and training

There are a number of significant areas where the LAA has made a national and international difference. Firstly, the LAA was involved with the establishment of an education and training programme for anyone interested, including patients, their partners or carers, and healthcare professionals. The training programmes were generally of a two-week duration and run by John and Judy Casley-Smith. They attracted professionals and patients from around the world. Rightly or wrongly, there were some critical comments about the issues related to mixing patients and healthcare professionals, given their wide variation in knowledge base and understandings of anatomy, physiology and pathophysiology. However, it seemed that the first periods of theory provided in the programme brought all to a similar level of understanding in

preparation for the intensive practical sessions that followed. All of these workshops were conducted in the Casley-Smith family residence.

A measure of the success of these sessions is evidenced by the enduring use of the term 'Casley-Smith method' of lymphatic massage and treatment, as well as the fact that schools teaching this technique are still running in the UK, Israel, the US and other places around Australia. These teachings have remained, although with some variations to the original strategies resulting from the extended knowledge base.

Website

As well as running courses, John and Judy Casley-Smith were heavily involved in the development of one of the first comprehensive websites providing advice to patients and healthcare professionals about aspects of lymphoedema, from diagnosis to treatment. The information given was based on the research-based evidence from the expansive and wide-ranging work of John and his students. It was continuously updated with the latest Australian and international research — with, of course, a slight favouring of the Casley-Smith views and understanding of things.

The website was revered by patients and practitioners and received up to 160 hits per day, particularly as it provided information about those who had received the Casley-Smith training around the world (approximately over 250 individuals). This information was freely available, ensuring that patients got the best treatment from educated and trained professionals. The site also contained valuable information about garments, garment suppliers and other useful hints and suggestions about managing the problem of lymphoedema.

Newsletter

Alongside the website, the LAA provided a comprehensive, quarterly newsletter which was sent out to all members. Like the website, these newsletters covered new directions and findings in lymphoedema research,

and regularly contained articles about recent congress outcomes and special comment from other international experts. For those with lymphoedema, or who wanted information about it, these newsletters were a rich resource (and really the only resource in the early days) of evidence-based information — although John would always give his personal view and invite critical comment. His views and comments in the newsletter, on the website and at international congresses were sometimes controversial, sometimes questionable, but they always made us think and question and, thus, helped advance knowledge immensely.

The widely distributed newsletters (the circulation in the 1990s was over 3,000) were also used as a means of gaining information from the large number of patients who received them. In particular, one questionnaire designed by Judith Casley-Smith explored the nature of the financial, psychological and physical problems faced by those with lymphoedema. The data obtained from this questionnaire was key in making the plight of those with lymphoedema and the burdens they faced known to the medical, government and grant-furnishing bodies around Australia and the world. These surveys provided the proof needed for change, and change certainly followed both in terms of improved recognition and funding for this group of clients. It was still not ideal, but the knowledge and the facts were now out there for everyone to see. In particular, the National Health and Medical Research Council (NHMRC) and the Australian Research Committee (ARC) and a number of other research groups, including private drug and manufacturing companies (Shaper and Brümmer; Germany, then Hoffman-La Roche [Ciba-Geigy group]) and others, such as the Army, began to award grants to enable the application of knowledge to patient care.

What was of particular significance was that John Casley-Smith was a prolific publisher of his findings, spending many nights on his computer with his favourite pipe, apple cider or a good brandy and writing up what he had found based on

his surveys and wide-ranging research work. While John (together with his wife Judy) wrote over 500 papers in a range of journals, the ones in the author's opinion that made the most difference were, 'How the lymphatic system works' in the *Journal of Lymphology* published in 1968 and a later one in the *New England Journal of Medicine*, of which he was extremely proud entitled, 'Treatment of lymphoedema of the arms and legs with benzopyrones' in 1993. This was perhaps the first time that lymphoedema and its treatment had been acknowledged in such a high level journal.

The LAA today

Unfortunately, John Casley-Smith died in 1997 in Paris, a shock to all who knew him. He was always the consummate gentleman, he loved disputes and challenges, and everything he did was done with flair, charm and panache. None of the members of the LAA have ever forgotten him.

Upon the death of her husband, the LAA, training and newsletters were taken over by Judith Casley-Smith with the same degree of fervour, enthusiasm and dedication. Judith worked tirelessly to improve the website and to make it relevant to anyone, regardless of their location in the world, with additional updated information on experts, garment services and trained therapists worldwide, so that patients could always get advice, contact a therapist and have their issues and problems rapidly and professionally dealt with.

Throughout 2008 the website is being upgraded. While it will no longer be interactive, providing advice to patients and professionals via return email, it will still direct questions and queries to the appropriate persons. As well as summaries of recent literature, reviews undertaken by staff at the Lymphoedema Assessment Clinic in Adelaide will also be posted from time to time to inform and educate practitioners and patients, one of the strong wishes of John Casley-Smith.

The website re-design is being managed by Professor Neil Piller. The goals of the restructured LAA during

Key points

- ▶▶ Key to the LAA are education for patients and professionals.
- ▶▶ The LAA website provides freely available information about the lymphatics, lymphoedema and its treatments and problems, with good links to other information sources.
- ▶▶ The LAA site is dedicated to Dr John Casley-Smith in memory of his significant contribution to lymphology and lymphoedema, and how his work has resulted in more positive outcomes for lymphoedema patients worldwide.

2008–2009 are primarily related to the provision of freely available information about the lymphatics, lymphoedema and its treatments and problems, with good links to other information sources. Its aim is to inform and educate and provide a balanced presentation of our collective knowledge in a form from which most can understand and benefit. JL

Dedication

This article is dedicated to Dr John Casley-Smith, one of the founders of modern lymphology, a true gentleman, friend and mentor, without whom many of us would never have embarked on a path of discovery in the world of lymphatics and lymphoedema to learn how we can make a difference.

Web address of the Lymphoedema Association of Australia

www.lymphoedema.org.au

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