

National Institute for Health and Care Excellence

IP1893 Lymphovenous anastomosis at the time of axillary/inguinal lymph node dissection for the prevention of secondary lymphoedema

IPAC date: 8th February 2024

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response
1.	Consultee 1 Patient	3.4	<p>I am a patient who has had LVA surgery to my left leg following a radical hysterectomy for cervical cancer. It is very hard to succinctly describe the effect that lymphoedema has had on my life. The psychological impact has been huge and all consuming. I have been treated for depression and it is only very recently that I have been able to look at my body in the mirror. There is such a sense of loss. I am faced with a life long condition affecting every aspect of my life. My ability to stand for long periods for work or recreation was affected. I couldn't sit comfortably in restaurants or the cinema as I needed to elevate my leg. I couldn't stand chatting for long periods. I cant travel long distances comfortably on the train, in the car, in a plane. I can't camp anymore for risk of getting bitten. My son lives in [REDACTED] and I don't know how I will tolerate a long flight without being able to elevate my leg. Warm weather is unbearable and I can't wear shorts in public as I am self-conscious and I have to wear a stocking in all temperatures and I mustn't get insect bites for fear of cellulitis. I have a wardrobe of clothes that I can't wear and have to reinvent myself somehow over time. My LVA surgery has helped me considerably. The swelling in my foot and ankle has reduced and I can continue to wear my normal shoes. This was so important as I have a collection of Doc Martens and it meant I could retain that bit of me. I am lucky to be able to wear "off the peg" loose-fitting trousers to disguise my leg but many people cannot. The surgery has had only limited success in terms of volume reduction as I had waited too long before arranging it and my lymphatics were already damaged within a year. However, my leg felt immediately more</p>	<p>Please respond to all comments</p> <p>Thank you for your comment. The Committee very much welcomes hearing from patients who have undergone lymphovenous anastomosis procedure. They considered these experiences and views in their deliberations.</p>

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			comfortable and the tissues are softer. it has enabled me to stand more comfortably and this means I am not thinking of it constantly and feel more positive about the future. The surgery has helped me psychologically and enables me to manage the swelling more easily. I am writing this as the impact of lymphoedema on a person's quality of life goes largely unrecognised and, if there is a way of preventing it, then I really hope that this becomes more freely available in the future. The current services for lymphoedema in the NHS are very patchy and I personally have had to fund much of my self-care. There are very limited resources available to me. There has to be a better way of managing this condition going forward as more people are surviving cancer. I hopefully have many years ahead of me but I worry about how my lymphoedema will progress and the quality of the life that has been saved.	
2.	Consultee 2 NHS Clinician		I have read the guidance and agree with it. Please record my response.	Thank you for your comment.

"Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees."