

Lymphoedema education for a Breast Cancer Support Group: an overview of the programme and its delivery

Jane Board

Key words

Empowerment, Lymphoedema, Prevention, Prudent, Self-management

Jane Board is Lymphoedema Consultant Nurse Practitioner, Lymphoedema Specialist Services Ltd, UK

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Abstract

This article summarises an education programme delivered to a breast cancer support group who had, or were at risk of, developing lymphoedema as a consequence of their treatment. The programme's objectives of empowering the group members with education and self-management techniques to prevent and/or control lymphoedema are described in this article. Quantitative and qualitative feedback from the attendees is included, in conjunction with the difficulties in obtaining it. Despite the limited responses, the author concludes by making recommendations for practice.

This article reports on a programme of lymphoedema education undertaken in 2019 by Lymphoedema Specialist Services Ltd (LSS) for 'The 1066 Pink Ladies' (PL); a support group with 56 members who were undergoing or had completed treatment for breast cancer. People who have undergone treatment for breast cancer (surgery, lymph node removal and radiotherapy) are known to be at risk of developing lymphoedema in the treated breast area and/or ipsilateral arm and hand. LSS wanted to empower the members of PL in self-supportive management (Miller, 2020) that would empower them with the knowledge to reduce the risks of developing lymphoedema. Alternatively, if a lymphoedema was already present, the confidence to control the symptoms, and prevent complications such as infection/cellulitis (British Lymphology Society and Lymphoedema Support Network, 2016).

The report commences with the background and factors instigating the programme of lymphoedema education. It describes the actions undertaken by the two staff members of LSS and the organisers of the PL to determine the objectives and logistical delivery for the

support group, and the programme of audit to measure success. The article goes on to methodically summarise the four sessions of education and report on the quantitative and qualitative feedback obtained from the PL members who attended each session. It concludes by discussing the factors impacting on the logistics of the lymphoedema programme of delivery and recommendations for future practice.

LSS is a small, independent company, and a specialist health provider of lymphoedema care. Between 2011–2019, LSS was a holder of a collaborative NHS contract for lymphoedema treatment for sufferers residing across large parts of East Sussex. In line with national standards of referral, the contract meant sufferers of lymphoedema were seen when a lymphoedema was established. LSS became known to the PL during this time because some of the members were receiving NHS funded lymphoedema treatment from LSS. The request for education from the PL to LSS was two-fold and arose during the final year of the company's NHS contract:

1. The PL members with an established lymphoedema were wanting to further the knowledge obtained during their

NHS-funded treatment appointments with LSS.

2. The PL members without lymphoedema and at risk of its development were seeking explicit information and practical advice to prevent the condition from occurring.

LSS were excited by the request. Their new, independent status from a busy NHS contract provided the capacity to organise and deliver an education programme surrounding the prevention and early detection of lymphoedema. In doing so, this enables LSS to transit from an impairment-based approach of lymphoedema care (Stout et al, 2012) and uphold the prudent healthcare ethos of the NHS long term plan (NHS, 2019).

Initiation

The initiation of the education programme was a partnership approach. The organisers of the PL applied and achieved a support grant from Macmillan, while LSS formulated a framework for lymphoedema education. In response to the PL's advertising, on October 10, 2018, LSS attended a scheduled meeting with the organisers and support group members.

Practice development

LSS's objective was to determine the needs of the group through open discussion and incorporate the findings in the programme of lymphoedema education. In consideration of the two PL member cohorts, the following requests and information was reported:

- A concern about lymphoedema: what is it? what can we do to prevent it?
- Explicit, written literature: the current, nationally produced leaflets are too generic
- A need for knowledge and skills to prevent and/or detect lymphoedema early
- A need to be empowered with knowledge and skills to manage an established lymphoedema
- Specific requests for practical information surrounding lymphatic massage, care of the skin, exercise and reducing the risks of developing lymphoedema.

LSS designed the programme to capture the educational needs identified, and its delivery in accordance with the PL'S meetings. Four teaching sessions were arranged over a period of 5 months (*Table 1*) and were to be delivered during the PL meetings on Wednesday evenings: 1900-2100hrs. Each of the sessions commenced with a theoretical aspect, prior to a practical component to support the learning. Organisation of the programme involved the formulation of PowerPoint presentations, the design and printing of literature (handouts) to support the sessions and the purchase of pertinent items for each PL attendee to keep, as a practical component of the teaching e.g. squeeze balls and emollient cream.

The overall objective was to educate and empower each PL member who attended with the knowledge and practical skills to:

- Prevent and/or detect lymphoedema early
- Self-manage to control and/or reduce an established lymphoedema
- To know who to contact in the event of a clinical need

LSS also designed a programme of audit to measure the success of the programme, assist future teaching by LSS and enable credible reporting to Macmillan, the provider of the support grant.

The series of documents were designed to achieve quantitative and qualitative data/feedback from the PL members

Table 1. The programme of lymphoedema education.		
Date	Topic	Objectives
April 10, 2019 Session no. 1	Exercise and Movement: 'For the good of your lymphatic system'	To understand the impact of movement and activity on the lymph system To enable confidence with daily living Practical: To be instructed in specific forms of exercise and movement
May 8, 2019 Session no. 2	Skin care and the prevention of cellulitis	To understand the role of the skin in relation to the lymphatic system. To understand cellulitis and the precautions to take to prevent its development. To know what to do should it occur Practical: Demonstration of emollients and how to apply
August 14, 2019 Session no. 3	Bioimpedance and fluid measurement in the tissues	To gain an understanding of bioimpedance and the measurement of tissue fluid. Practical: To receive an individual measurement session (subject to your consent)
September 11, 2019 Session no. 4	Self-lymphatic Drainage (SLD)	To understand the rationale of SLD and the benefits to the lymphatic system. Practical: To participate in a group session for practical instruction to self-manage (arms only, subject to your consent and in the absence of clinical contraindications)

who attended each teaching session. Documentation was provided at the start of each session, which PL member attendees were asked to complete prior to leaving. To encourage completion and enhance the retrievability of findings, questions were kept brief and wherever possible, replicated.

Pre-education questionnaire

To determine how the group felt about lymphoedema, members were asked to complete a questionnaire prior to the first session. The questionnaire consisted of two questions. Question 1 was 'Does the development (or worsening of an existing) lymphoedema concern you? It utilised a

tick box, with 'medium concern' receiving the highest amount of answers ($n=6$), followed by 'high concern' ($n=5$), 'extreme concern' ($n=4$) and 'mild concern' was ticked by one person. Question 2 was 'Why is this?' enabling the PL member to answer in free text format. Sixteen completed responses were obtained (*Table 2*).

The sessions

Session 1: Exercise and Movement: for the good of your lymphatic system

The key objective was to demonstrate that exercise and mobility stimulates the movement of lymph fluid through lymph vessels.

Table 2. Reasons for answers to 'Does the development (or worsening of an existing) lymphoedema concern you?'

Because I'm worried about the possible impact of lymphoedema and having to go back to hospital, feel I've left that behind a bit
 Don't know much about it. (2)
 Development would be something else to worry about. There is no cure I understand.
 It is extremely painful. I wouldn't want it to get worse.
 Getting good care from lymphoedema specialists.
 Don't know how to prevent or if I will get this.
 Because my Mum had it.
 I haven't had it or got it but interested to learn about it.
 Because I have seen very severe lymphoedema and I would hate to have this problem.
 Limitations on the life that could be led, appearance.

Session 2: Skincare and the prevention of cellulitis

The key objective was to inform of the signs and symptoms of cellulitis and the need to take prompt action in the event of development.

An explanation involved a PowerPoint presentation, with a dedicated leaflet surrounding cellulitis and prevention for members to take home. The practical session involved the classification of an emollient, with specific examination and sampling of lotions and creams e.g. Diprobase, E45.

Fifteen completed feedback forms were obtained (Figures 2a and 2b).

Session 3: Bioimpedance and fluid measurement in the tissues

The key objectives during this session were:

1. To demonstrate how a LymphScanner can measure tissue fluid.
2. The measurement of body muscle, fat and water mass with the use of bioimpedance scales.

The session was practical, with each PL member attendee measured individually, in a private room. A member of LSS staff measured, while the other explained the results and their meaning. The measurements were recorded as a benchmark on a personalised sheet for participants to take home.

13 attendees, only 2 feedback forms were obtained.

Session 4: Self-Lymphatic Drainage (SLD)

The key objective was to provide members with a self-treatment to assist in preventing lymphoedema or as a control in the presence of lymphoedema.

A PowerPoint presentation, with supporting handouts provided an explanation of the technique and its rationale. Each attendee exposed their swollen or 'at risk' arm to facilitate practice of the technique (PL members had been informed in advance and verbal consent was given from all attendees).

Follow-up session

By the fourth session (September 2019), LSS perceived the programme of education to be a success. However, time constraints appeared to prevent members from asking questions. The request for a follow-up session was, therefore, made by LSS to the

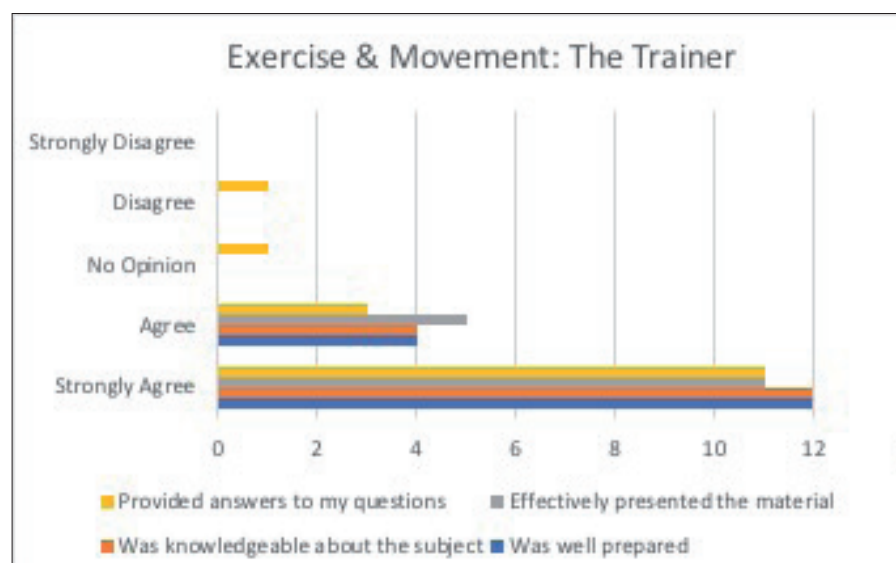


Figure 1a: Feedback on the trainer for the 'Exercise and movement' session.

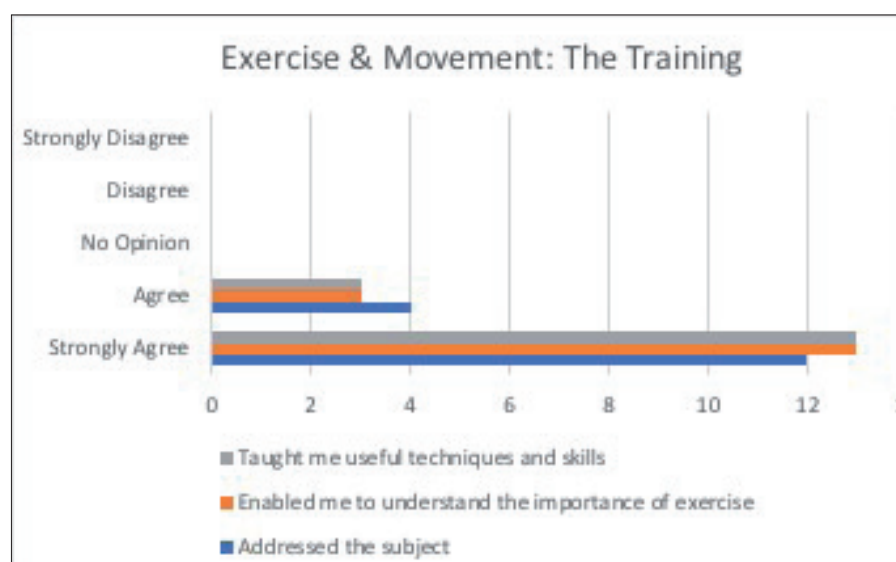


Figure 1b: Feedback on the training for the 'Exercise and movement' session.

A PowerPoint presentation and supporting literature explained the mechanical workings of the lymphatic system in relation to body movement. Squeezy balls were issued to each PL

member attendee to enhance the impact of the exercise regimen, with members encouraged to continue the practice at home. Sixteen completed feedback forms were obtained (Figures 1a and 1b).

Practice development

PL to enable:

- A comprehensive question and answer session
- The obtaining of post education feedback
- The potential for further education sessions
- What could LSS have done better?

The follow-up meeting (session no: 5) occurred on November 13, 2019. To enhance reliability, the 2 questions asked in the pre-education questionnaire were repeated. An additional, question (no: 3) was asked to determine the number of attendees at each session.

Nine completed post-education questionnaires were obtained. To the question 'Does the development (or worsening of an existing) lymphoedema still concern you?', the most popular answer was 'medium concern' ($n=4$), followed by 'mild concern' ($n=3$) and 'high concern' ($n=2$) (Table 3).

Out of the nine members of the follow-up session, five attended all four education sessions, two attended three sessions and two attended one session.

Discussion

The results of the written feedback from the PL members identified an increase in their knowledge in lymphoedema and the risks and strategies of self-management to prevent and control the condition. The limitation of the programme was time management, with all four sessions running over their allocated time. Factors impacting on time included the extent of questions from the PL members and the need to leave the rooms rented by PL at 2100hrs; in accordance with the terms and conditions of their rental agreement. Some PL members also reported LSS's theoretical (PowerPoint) section taking over 50% of the allocated time, thereby shortening the practical component of the session.

Significant to LSS, was the difficulty in obtaining completed feedback forms at the end of each teaching session because of the extent of discussion from the PL members, and the rush to clear up and vacate the building in time for its closure. Obtaining a full quota of feedback forms was compounded by PL members non-attendance at some sessions, and for a variety of reasons e.g. unwellness from the effects of cancer treatment, holidays, and the dark and wet evening of the November meeting.

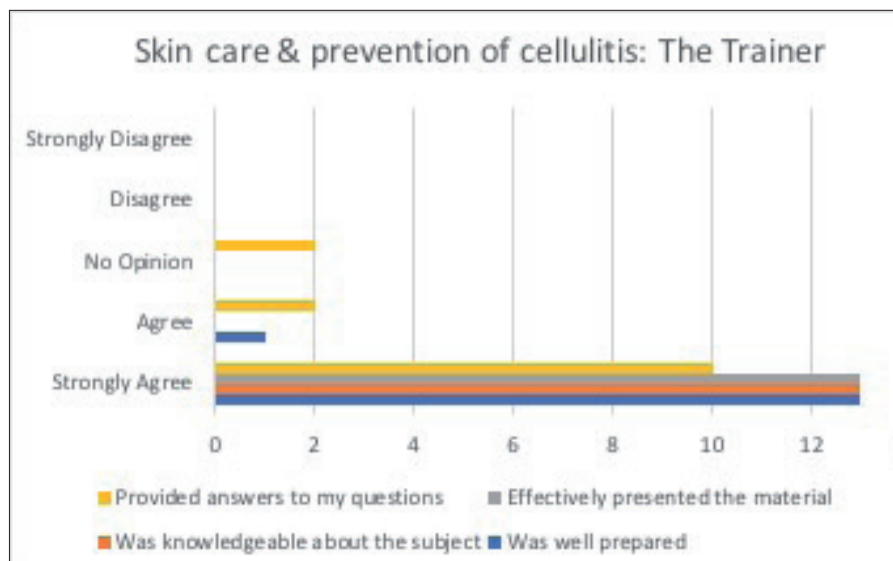


Figure 2a: Feedback on the trainer for the 'Skin care & prevention of cellulitis' session.

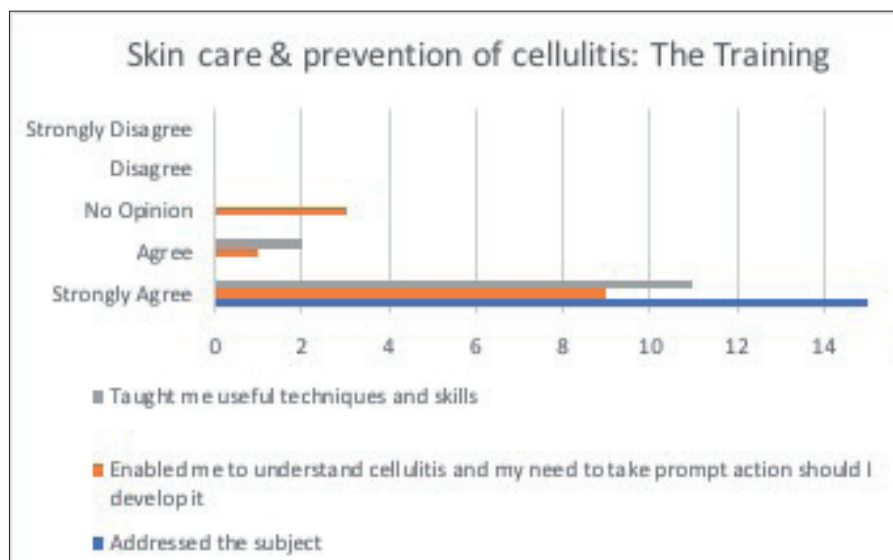


Figure 2b: Feedback on the training for the 'Skin care & prevention of cellulitis' session.

In respect of patient confidentiality, LSS was not informed by the PL of the cancer status of their members who attended the teaching programme. However, most of the PL members openly vocalised their cancer state and treatment experience during the teaching sessions. Reflection on the experience demonstrated LSS's sharing of an enhanced depth of education and explicit information with the PL members in addressing issues such as body image, fatigue and general wellbeing; pertinent to individual clinical circumstance.

In response to the feedback, LSS have been invited by the PL to provide further lymphoedema education sessions. LSS are to meet with the PL organisers to explore other topics that have been identified by the PL members for teaching in relation

to lymphoedema. LSS also plan to discuss time management, and ways to remove the hurried approach when delivering information. For example, a shortening of the theoretical component by LSS, or the undertaking of a daytime session to prevent a rushed completion on a mid-week evening.

A request was also made by the PL members for LSS's publication of the literature supporting the teaching programme and interactive teaching via social media. LSS view these requests as positive feedback and will explore their viability.

Recommendations for practice

The quantitative and qualitative feedback from the PL members indicates the benefit

Table 3. Reasons for answers to ‘Does the development (or worsening of an existing) lymphoedema still concern you?’

(mild) = I am worried it will get worse. Four sessions attended
(mild) = no comment. One session attended
(mild) = just aware that this is still a possibility after many years since treatment. Four sessions attended
(medium) = seems to be under control. I know help is available. Four sessions attended
(medium) = ongoing concern as a result of treatment and lack of information from the NHS, understandably due to funds/time. Four sessions attended
(medium) = unfortunately missed sessions due to having chemo so don't know much about it. One session attended
(medium) = feel much more informed to look for signs of worsening and more in control of the SLD. Four sessions attended
(high) = because I understand it to be a progressive condition. Three sessions attended
(high) = don't want it to disrupt present lifestyle i.e. doing/playing sport. Three sessions attended

of lymphoedema education to people at risk of developing lymphoedema, or those where the condition is established.

During the group discussion, the following recommendations were made by the attendees:

- More practical tools to prevent lymphoedema
- More practical tools to manage lymphoedema
- FAQ sheet/information leaflet pertinent to breast cancer-related lymphoedema
- Algorithm of what to do and when explicit - generalised
- Interactive social media support, e.g. SLD videos
- Refresher sessions

• Practical workshops

While the exercise is a very small sample, it does support the national drive with lymphoedema for risk reduction, early diagnosis, intervention and supported self-management through the empowering of individuals (The National Lymphoedema Partnership, 2019).

LSS, therefore, supports the delivery of programmes of education that empowers people with knowledge to reduce the risk of the development of lymphoedema, and self-management strategies to control established lymphoedema.

LSS also recommends establishing a programme of audit from which to measure the clinical effectiveness of the teaching in reducing the risks associated with

lymphoedema. Benchmarking key clinical characteristics of each attendee in relation to lymphoedema at the commencement of the teaching programme (e.g. the presence of lymphoedema and episodes of cellulitis) would help to monitor the impact and effectiveness of the education. However, LSS recognises the issues of staff capacity, data security and patient consent, which pose threats to the undertaking of this work.

Finally, Lymphoedema Specialist Services Ltd wishes to thank the organisers of ‘The 1066 Pink Ladies’ for their commissioning of lymphoedema education, through a support grant provided by Macmillan. It was (and we hope will continue to be) a pleasure to work in partnership with the support group.

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