## Lymphoedema

<table>
<thead>
<tr>
<th>Type of protocol</th>
<th>Supported Self-Management</th>
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<tr>
<td><strong>Purpose</strong></td>
<td>The Lymphoedema protocol was developed by Louise Shakespeare, Advanced Lymphoedema Nurse, with the aim of supporting patients to self-manage their Lymphoedema.</td>
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| **Protocol overview:** | The protocol consists of:  
- Information about the causes and management of lymphoedema  
- Symptoms monitor |
| **Anticipated Outcomes** | The aims of the protocol are to help embed use of techniques which assist with the management of lymphoedema.  
The anticipated outcomes of using the protocol are that:  
- Patients will have improved understanding of lymphoedema, awareness of the importance of skin care and knowledge of the symptoms of cellulitis  
- Patients will use the self-management techniques  
Hence:  
- The progression of their lymphoedema will be minimised  
- A reduction in the incidence of cellulitis and of hospital admissions |
| **Corresponding national outputs and outcomes** | Achievement of these outcomes would contribute towards:  
- **Personal responsibility** *(NHW outcome)* – by assisting patients to take responsibility for their own health by self-managing  
- **Quality of life** *(NHW outcome)* – by contributing to better management of the patient’s health condition  
- **Cost effective** *(NHW outcome)* – by reducing repeat hospital admissions  
- **Better adherence** *(HMHM output)* – by reinforcing health information and advice and encouraging use of management techniques  
- **Increase in self-management / condition control** *(HMHM output)* – by actively using techniques which assist management of the condition  
- **Reduced hospital admissions** *(HMHM output)* - by contributing to a reduction in the number of patients requiring another hospital admission |
| **Pathway** | Thus far use of Florence has been an addition, which has enhanced the existing patient pathway once patients are referred to the lymphoedema service. |
| **Enrolment process** | All newly diagnosed lymphoedema patients referred to the lymphoedema service are offered the opportunity to enrol on Florence. |
| **Development and deployment** | **Take up** |
| Developed: Nov’16 to Dec’16 |
| First patient signed up: Jan’17 |
| Patients to date: 18 |
| Uptake of the protocol has been slow, but steady since January’17 |

### Lymphoedema

![Graph showing Lymphoedema take up from Jan 17 to Mar 18](image-url)
## Lymphoedema

| Timescale and costs | Duration of protocol = 5 months  
|                     | Average cost per patient per month = £0.63  
|                     | Average overall cost per patient = £3.31 |

| Monitoring | While using the protocol patients were asked 2 monitoring questions:  
|           | - Thinking about the last 7 days, how many days did you wear your compression garment(s)?  
|           | - On a scale of 0 (not at all) to 5 (a great deal), please rate how much your lymphoedema symptoms are currently affecting your life.  
|           | All 10 patients who have completed use of the protocol responded to these questions on most of the occasions they were asked  
|           | • Garments – 39 responses received – a response rate of 88% - with an average response of 5 (i.e. patients have worn their compression garments 5 times)  
|           | • Symptoms – 33 responses received – a response rate of 92% - with an average response of 3  
|           | • Symptoms responses did not show any clear downward trend |

| Objective evaluation | Evidence from patients, who were asked at review appointments, indicates that:  
|                      | • None of the people who have used the Florence protocol have been admitted to hospital with cellulitis or had any worsening of their swelling |

| Patients’ views | Responses from 7 patients, out of 10 sent the text message survey (response rate = 70%) – a good response rate  
|                 | • 100% would recommend Florence to other people in their circumstances  
|                 | • 83% felt the text messages from Flo had helped them cope with their lymphoedema (n=6) |

| Text message survey | Responses from 4 patients, out of 5 sent the questionnaire (response rate = 80%)  
|                     | • 100% of the patients who responded agreed that Florence was easy to understand  
|                     | • 75% agreed Florence had helped them understand and manage their own health and had enjoyed using Florence  
|                     | • 50 % had found Florence was helpful and supportive |

| Paper Questionnaire A | Responses from 4 patients, out of 5 sent the questionnaire (response rate = 80%)  
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| Paper Questionnaire B | So far no responses from the 5 patients sent this questionnaire. |

| Free text responses about Florence | Like: Helpful for some information (P.1)  
|                                   | Like: You can get up to date information from correct sources, makes it much easier to read about your condition (p.3)  
|                                   | Dislike: The service is impersonal, I would rather talk to a human being (P.1)  
|                                   | Suggested changes: I find at the moment for me, there would be nothing to change as service is fine (P.3) |
## Lymphoedema

### Case study

The lymphoedema in Mrs A’s right arm developed during her radiotherapy. Although her lymphoedema is mild, she is very self-conscious about her hand as she feels that this is particularly noticeable and she is very anxious to prevent this becoming worse. She enrolled for Florence following her initial assessment.

Mrs A has found the information provided by Florence has reinforced the initial information from the clinic, helping her understand her lymphatic system and the rationale for the advice offered.

Florence has also helped her develop a routine for managing the lymphoedema in particular the Simple Lymphatic Drainage (SLD) video has improved her confidence in carrying this out on a regular basis.

### Clinicians’ views

The clinician’s views:

- Some patients have not answered the monitoring questions or provided the same response each time
- Three patients who I’ve had the opportunity to ask have said the messages are useful, and have been good reminders
- Flo has provided a means to reinforce the information offered at the initial assessment. It also enables the remote monitoring of the effect of initial management of lymphoedema symptoms from the patients’ perspective.

### Informal feedback

- The number of patients enrolled on the Lymphoedema protocol has so far been low and these have all been enrolled by the lead clinician
- Finding the most effective way of offering Florence to patients to maximise take-up has required some trial and error
- Florence is not suitable for some lymphoedema patients, due to the complexity of their condition (for example, the role of obesity)
- Breast cancer nurses have been encouraged to refer people to Florence, but so far have not done so
- It is a challenge to motivate people with longstanding lymphovenous and/or obesity related lymphoedema to participate in self-management. When asked specifically about their lack of interest in enrolling, this seemed to relate to a disinterest in learning more about the condition
- Feedback from some patients suggested that they found the number of monitoring questions intrusive, so the number has been reduced in the current version of the protocol

### Assessment

Challenges have included:

- The patients who have been enrolled on Florence have engaged well with the protocol and are generally positive about Florence.
- Patients have provided good evidence about wearing their compression garments, on average wearing them 5 times per week, with a range between 0 and 7 times.
- Results so far suggest that Flo is contributing to patients’ understanding of their condition and assisting them to develop self care strategies.
- None of the patients using Flo have experienced cellulitis since enrolling and none had attended GP for specific lymphoedema problems. Whilst this suggests a cost saving for the health board, longer term data is required to confirm this.
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<table>
<thead>
<tr>
<th>Future:</th>
<th>Proposals include:</th>
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<tr>
<td></td>
<td>• Continue using Florence to support patients with lymphoedema</td>
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<tr>
<td></td>
<td>• Continue to liaise with other clinicians who could be offering Florence, to encourage them to do so</td>
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