

Delivering a prudent lymphoedema service

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What is lymphoedema?

Lymphoedema is a chronic swelling caused by lymphatic system failure. It mainly occurs when the lymphatic system is damaged by surgery, tumour, radiotherapy, trauma or infection. It can also occur as a result of a congenitally determined lymphatic abnormality. It is chronic and incurable and requires lifelong management. Lymphoedema can affect people of all ages and can occur in any part of the body. It affects people physically, psychologically and socially, having a significant impact on quality of life and the ability to undertake the normal activities of daily living.



Ms A explains what living with lymphoedema is like:

“Having lymphoedema has been a massive drain on my life. I am only 38 and am a single parent with two young children. Two years ago I was diagnosed with breast cancer; I had a mastectomy with the lymph nodes removed from underneath my arm followed by chemotherapy and radiotherapy. My arm started to swell two weeks after my operation. Due to the swelling in my hand and arm I have had to change my life completely. I have to wear a compression sleeve every day, which has stopped me from being a highly-skilled dental nurse to sitting in an office for far less money.”

“As a family, the choices we now make are all related to the swelling in my arm - will it make my arm worse? The clothes I wear; the activities I do are all focused on my arm. It rules my life. The cruellest thought ever is that I have to live like this with a swollen arm and compression garments for another 40 years. I can get over breast cancer but I can't get over lymphoedema. A cure will mean a life for me and my two children.”

The services

Until recently, there was a wide variation in the organisation and delivery of lymphoedema services across Wales. Some health boards had commissioned full lymphoedema services; others offered cancer-only services and certain areas did not provide any at all. Clinics ranged from lone practitioners to small teams and waiting and treatment times varied as well as treatment options. This diversity was not a result of patient need and was not patient centred.

Most people with lymphoedema went undiagnosed and untreated for long periods of time as a consequence of the poor level of knowledge of this disease among both health professionals and the public.

In 2009, the Welsh Government published its lymphoedema strategy, which set out clear aims to enable access for all lymphoedema patients to the appropriate services at the right place, right time and with the right person, regardless of whether their lymphoedema was related to cancer.

In 2011, the government invested £1m to implement the strategy. With the limited funding available, our focus centred on ensuring we maximised the impact of the investment by identifying opportunities to improve the service for the population of Wales. This included setting up an All-Wales Lymphoedema Network board to maintain a strategic oversight of the strategy for lymphoedema in Wales.

The network board developed a national lymphoedema service development programme to promote a consistent, standardised approach to care, supported by robust, evidence based protocols and procedures. This has enabled each health board to develop dedicated lymphoedema services with specialists, practitioners and assistants and provided the facility for all lymphoedema patients to be able to access assessment and treatment.

What makes the services prudent?

People have asked why lymphoedema services are being highlighted as an example of prudent healthcare in Wales and the answer is simple - limited funding was available, therefore our focus centred on ensuring we maximised the impact of the investment by identifying opportunities to improve the service for people across Wales. The remainder of this paper shows how the lymphoedema service embodies the main prudent healthcare principles.

1. Equity-based care - treating greatest need first

The lymphoedema services provided by the seven health boards in Wales follow the same referral criteria and assesses every patient using the same data set. By adopting a standardised approach based on clinical need, waiting times have been

substantially reduced. The original waiting time target for new lymphoedema patients was 24 weeks and within three years we have reduced this to 18 weeks; it will reduce further to 14 weeks by April 2015 - 86% of the health boards are currently meeting the 14-week target.

The All-Wales Lymphoedema Network has also developed criteria to ensure patients are prioritised:

- Palliative patients are seen within two weeks of referral;
- Urgent patients are seen within four weeks of referral;
- Urgent is classed as head and neck oedema genital oedema, chronic breast swelling, two or more episodes of cellulitis in the past year requiring IV antibiotics, acute lymphorrhoea (leaking) and children and young people under 18.

2. Do no harm

Compression garments are the mainstay of treatment for lymphoedema patients as they help support and reduce swelling. Since March 2006, these garments have been available on prescription via the WP10. The WP10 is a process where patients can receive medication or a compression garment via a prescription from their GP to take to a pharmacist for it to be dispensed.

Following complaints from patients the wrong garments were being issued, the national lymphoedema service development programme carried out an audit at Abertawe Bro Morgannwg University Health Board, which highlighted that 50% of compression garment prescriptions were being dispensed incorrectly. Some of the garments issued caused harm - for example a made-to-measure garment was ordered and a ready-to-wear garment was issued, which was four times too small for the patient. Some garments were the wrong shape or style, which actually caused swelling to be pushed into the hand or thigh region. In addition, the average time for a patient to receive a garment was 42 days.

Through communication and collaboration with the All-Wales Medicine Management Committee and Community Pharmacy Wales, the programme set up a project to reduce waste, harm and variation, which included critically appraising the existing processes and systems and implementing simple changes, educating staff, and auditing the revised approach.

The introduction of a communication recommendation sheet, which is faxed from the lymphoedema specialist to the pharmacy when a patient has been seen has reduced the time a patient has to wait for a garment from 42 days to 10 days and reduced the number of garments wrongly dispensed from 50% to 5%. Improved communication and sharing of pertinent knowledge to the right people at the right time has made a significant improvement to patients' care and treatment. The steps taken as part of this project have now been applied across Wales.

In addition, through communication with CPW, we have established that many of the prescriptions were being dispensed via wholesalers in England and pharmacies had to pay prior to delivery. This has now changed with all scripts being dispensed in Wales and all community pharmacies have 31 days to pay after invoicing. This has improved sustainability within Welsh community pharmacies and better streamlining of financial management

3. Do the minimum appropriate to achieve the desired outcomes

In Europe, the normal lymphoedema service care model consists of three weeks of intensive daily manual lymphatic drainage and multi-layered bandaging, which significantly reduces the size and improves the shape of the oedematous limb, followed by the use of a compression garment. This has a major impact on normal quality of life, including family and work life, as the patient has to attend hospital daily for at least two hours. In NHS Wales, we have changed the service model by issuing a compression garment first and, if the desired outcome is not achieved, we then offer intensive therapy. This approach provides a good outcome for patients for minimum clinical intervention.

4. Choose the most prudent care, openly with the patient

Working closely with patients, openly discussing the options available, ensures they are empowered to make informed decisions about their health with professional guidance. Every patient referred to the All Wales Lymphoedema Network is taught to self manage. Self management includes the basics of healthy eating, exercise, skin care and daily washing. Every health board has healthy living days, expert patients groups and standardised all-Wales lymphoedema leaflets.

5. Co-production in action – Setting My Agenda

A co-production pilot – Setting My Agenda - was introduced in Abertawe Bro Morgannwg University Health Board in 2013 - each patient attending the clinic received a form to record what they wanted to achieve from their appointment and any issues they wanted to discuss. The pilot received positive feedback from patients, as they felt more in control, with treatment addressing their concerns. The results highlighted that 95% of patients did not know their body mass index (BMI); 50% were two stone off their weight estimate; 75% had a BMI of more than 25. Overall, 54% of patients reported their appointment improved using the Setting My Agenda approach; 43% of patients reported the same level of satisfaction with their appointment and 3% of patients provided negative feedback. This has now been rolled out across Wales.

6. Consistently applying evidence-based medicine in practice

In 2013, the all-Wales lymphoedema compression garment contract was launched – it came into force on October 1, 2014. The project involved working alongside Procurement Wales and the Surgical Materials Testing Laboratory Wales (SMTL) to ensure the best product, best outcome and the best price for all compression garments issued in Wales was achieved.

A specification and tender was developed and nine manufacturers responded and submitted products against 15 lots. The evaluation process was rigid and facilitated joint working with stakeholders and clinicians in establishing a pass or fail for the lots being considered. All successful items were sent to SMTL for testing. The SMTL process is unique in Wales as no other country has independently tested products against each another.

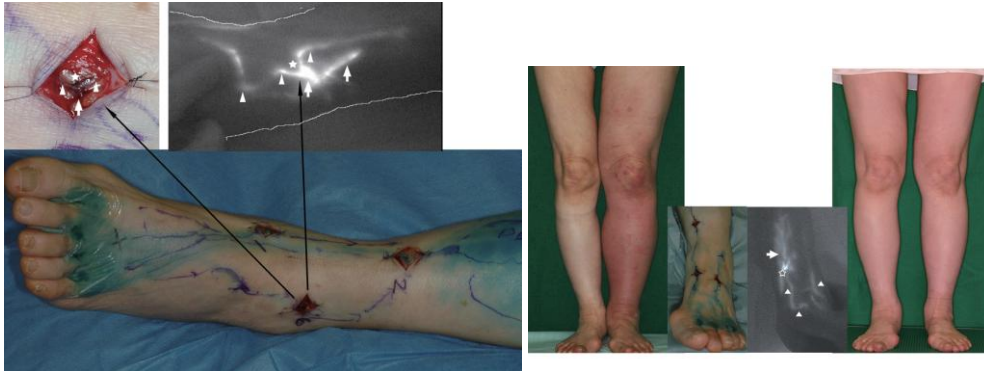
Ensuring value for money was a key benefit criterion for this project and by using a reverse auction - manufacturers had to outbid each other to gain the business - has ensured financial benefits of more than £80,000 for NHS Wales.

During the testing process, serious concerns were raised about some of the compression garments available on prescription. These included negative gradients, wrong pressures and CE marks not being adhered to. Consequently, only half of the contract has been awarded; part two of the contract will start in March 2015.

As a result of this work we can be now be confident NHS Wales is using compression garments which provide the best clinical outcomes for patients.

7. Cutting edge practice - Lymphatic Venous Anastomosis (LVA) and the curing lymphoedema programme

Lymphoedema has always been a chronic incurable condition, however new evidence suggests a potential cure is available. In Japan and Europe, a super-microsurgical technique, which joins the defunct lymphatics to a functioning vein, has resulted in a 96% reduction in cellulitis episodes and 70% of patients have stopped utilising compression garments (Basta MN, Gao LL and WU LC (2014). This is revolutionary for many patients and clinicians and we are fortunate that Abertawe Bro Morgannwg University Health Board has a trained super-microsurgeon who can perform this surgical technique. The only other hospital offering this surgery in the UK is the Royal Marsden.



(Maegawa J, Yabuki Y, Tomoeda H, Hosono M, Yasumura K,(2012)

The curing lymphoedema programme, supported by the NHS Programme Management Unit, has received a £250,000 Health Technology and Telehealth Fund award to support the implementation of this life-changing surgery. A business case has been developed and the project has an NHS Wales chief executive sponsor. Working collaboratively with the Welsh Health Specialised Services Committee (WHSSC), an evidence and service specification document has been produced, together with a detailed benefits analysis. The programme is hoping to secure funding from WHSSC and is recommending that 42 patients a year receive this surgery from April 2015.

Potential patients will be scanned by members of the national lymphoedema team on the Tenovus mobile unit. If a patient is suitable for surgery, they will be referred to Abertawe Bro Morgannwg University Health Board.

This day surgery could realise significant qualitative and quantitative benefits. The referral criteria are strict to ensure patients and NHS Wales receive the maximum possible benefit. A 96% reduction in the number of cellulitis episodes for lymphoedema patients which need hospital admissions is significant, as are the longer-term benefits of curing and discharging chronic patients.

8. Co-create health with the public, patients and partners

Lymphoedema services have always worked collaboratively with Macmillan Cancer Support; collaboration with Tenovus has seen the development of the Tenovus mobile lymphoedema clinic, which travels across Wales providing a clinic base in rugby stadiums, markets, shopping villages and supermarkets. Patients have said this unit makes it easier to attend clinic as they can park directly outside, reduces time off work and travel.



Summary

Significant changes and benefits have been realised and achieved in a very short time and the lymphoedema service development programme is eager to ensure services for people in Wales are world class. This vision is dependent on the continued commitment of the staff working in lymphoedema services across Wales to ensure the best outcomes for patients.

Our impatience for progress will see a number of developments in the next 12 months, including:

- A Delphi study with Swansea University about the economic impact of the lymphoedema services in Wales;
- Working with Macmillan Cancer Support to create a new national innovations lymphoedema specialist to scope paediatric services and assess the impact of the curing lymphoedema programme with breast cancer patients;
- The accreditation and standardisation of all lymphoedema education courses across Wales;
- The development of a cancer rehabilitation minimum care pathway in collaboration with Breast Cancer Care.

References

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