

# Dispelling the myths of Lindsay Leg Clubs®

**The Lindsay Leg Club® model is an alternative to traditional leg ulcer clinics. Within the Lindsay Leg Clubs, people with lower leg problems become members of a Club they themselves own with their care delivered within the Club by NHS staff. A randomised controlled trial demonstrated higher healing rates and an improved quality of life for clients receiving care with this method of service delivery compared to traditional care models (Edwards et al, 2009). This social model of care is available through 20 Lindsay Leg Clubs within the UK and has, sadly, been subject to a raft of misconceptions. The purpose of this debate is to answer some of the most common myths surrounding the Lindsay Leg Clubs, and so perhaps help healthcare professionals and potential Lindsay Leg Club members to see the value of this model as a component within the NHS's delivery of safe, effective lower leg care.**

**TY**

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**Myth or reality — Leg Clubs® are no better than NHS leg ulcer clinics?**

**CM:** This question reflects a lack of understanding of what makes the Leg Club® model unique compared to a standard NHS clinic. Firstly, the standard of clinical care can and should be excellent in both settings (Leg Clubs and NHS clinics). This depends on the experience, training and supervision of staff. If this is not of a high quality, care will be poor irrespective of where it is being provided.

The Leg Club model is unique in the way in which it views patients as partners in the care they receive and as experts in their own condition. It embraces the significant issues of isolation, loneliness and the ability to empower patients through knowledge of their condition and its treatment, with a very direct involvement in care. The Leg Club model is far more than simply the provision of leg care, although this is paramount, but rather a social model that seeks to address the myriad of issues these patients face. Being able to share care together and support each other is for many patients a very helpful model. Research is clear that leg ulcer patients are socially isolated and have a reduced quality of life (Moffatt et al, 2004). The Leg Club model addresses these issues.

A second important aspect of the model is viewing patients as partners in care and allowing them to make decisions and take control. This is sometimes hard for professionals to relinquish and can lead to tension and labelling of patients as poorly concordant. The Leg Club model is

not just about treatment, but also has a strong focus on preventative care and prevention of deterioration and complications. When it is working well, it is a wonderful partnership between healthcare professionals and patients and is at the heart of current NHS reforms, where patient satisfaction and feedback are key drivers of the quality agenda (Darzi, 2009).

**Why cannot anyone start up a Leg Club along similar lines, and why do you have to sign up to the Lindsay Leg Club® Foundation model?**

**CM:** It is imperative that anyone thinking of starting a Leg Club understands the methodology and standards required for this undertaking. It helps to protect the ethos and methods that have been so carefully developed by Ellie Lindsay and the Lindsay Leg Club Foundation over many years. Poorly developed Leg Clubs would damage the work of the Lindsay Leg Club Foundation. Signing up to the Foundation ensures that new clubs are supported through their endeavours and provides new knowledge through a greater understanding of the work involved in a Leg Club. Lack of understanding and knowledge are the single most important threat to the work of the Lindsay Leg Club Foundation, as it is crucial that those involved with setting up Leg Clubs, do so with due diligence and support.

**Is the Leg Club model a profit making private organisation that uses NHS staff?**

**AM:** The Leg Club is a registered charity (Charity registered number

**CM:** *The Leg Club model is unique in the way in which it views patients as partners in the care they receive and as experts in their own condition.*

**AM:** *There is no evidence that infection is higher in the Leg Clubs than in other community or hospital-based locations.*

111259). It is a 'not for profit' organisation that exists to promote and support the implementation of the Lindsay Leg Club model through dissemination, education and monitoring quality assurance. Apart from the cost of nurses, treatment and dressings, and an annual audit (currently being considered), there are no costs to the commissioner or healthcare provider.

**If the Leg Clubs are so good, why is there a poor uptake across the UK even with the support of a randomised controlled trial?**

**AM:** There are currently 21 Leg Clubs in the UK and others in the embryonic stage of development. One of the challenges of the Lindsay Leg Club Foundation is to continually engage all of those responsible for the provision of leg ulcer care and demonstrate the positive outcomes of the Leg Clubs in terms of improved healing rates, cost-effectiveness, and improved quality of life. Arguably, the greatest challenge is to convince healthcare commissioners and primary care trusts (PCTs) that a social model of care, based in a non-traditional community setting, can provide an excellent service with improved health outcomes. There may be a misconception that persists of the fear of an increase in rates of cross-infection. There is no evidence that infection is higher in the Leg Clubs than in other community or hospital-based locations. Health and safety and infection control is a primary consideration within the Leg Club model. It is clearly covered by documented guidelines and risk assessments based on the Standard

Infection Control Precautions (SICPs, Health Protection Scotland (HPS], 2009).

The Lindsay Leg Club Foundation needs to strive to disseminate these messages widely, despite the support of the evidence from a randomised controlled trial (Edwards et al, 2007). Clearly, in the current climate of financial austerity, it is incumbent upon those responsible for commissioning leg ulcer care services to carefully examine different types of services and make the decisions on the best available evidence. The Lindsay Leg Club Foundation welcomes the opportunity for such scrutiny.

**Why is the NHS suspicious of the Lindsay Leg Club Foundation?**

**AM:** The NHS is based on a traditional model of health care, where care is provided in the hospital, community centre, or GP practice. Any attempt to move from the model will inevitably arouse suspicion and concern. The development of District Diabetes Centres in the 1980s and 1990s attracted similar suspicion from the NHS, in that the centres were designed to move away from the traditional clinic environment. The rationale for the change was as a result of the poor standards of education and diabetes control observed in the clinics, where the large number of attenders, short consultation times, lack of continuity and prolonged waiting times contributed to poor results. The move to an environment of a dedicated centre was considered more

conducive for people with diabetes to engage with education programmes and receive more comprehensive diabetes care (Day and Spathis, 1988).

Likewise, Leg Clubs are a move away from the traditional model, and have similar difficulties that the diabetes clinics used to experience, to a model of care that embraces the concept of empowerment with the patient being at the centre of care, actively engaged in their treatment and management planning. This approach contributes to the positive outcomes that can be achieved by members of Leg Clubs. Radical change is often perceived as a major threat, and it is the responsibility of all those involved with the Lindsay Leg Club Foundation to enter dialogue with key personnel who can facilitate the change to the Leg Club model, to reduce the threat, and get them on board to accept the benefits of Leg Clubs.

**How can you prevent cross-infection in a church hall setting?**

**JSH:** The core principles of infection control and sound clinical practice apply regardless of environment. Guidance has been given to Leg Clubs by a consultant advisor, relating to infection prevention and control (Kingsley, 2009).

Guidance provided to each Leg Club is based on the Standard Infection Control Precautions (HPS, 2009), with the emphasis of a 'work safe at all times' system, irrespective of knowledge of carriage of pathogens by the patient.

To ensure that Leg Club venues offer a suitable environment for the provision of health care, an infection control assessment is made by the local infection control nurse before opening a new Leg Club, with consideration given to the statements in the document *Infection Control in the Built Environment* (NHS Estates, 2001).

Replicating the facilities of a medical environment is unlikely to be possible in most social venues. However, as when nursing patients in their own homes, it is important that methods of working adapt to the environment to ensure that control of infection principles are not compromised.

Leg Clubs are run in many non-medical environments, such as village/community centres, church halls or meeting rooms. Strict adherence to guidelines around environment/setting, professional staff and behaviour of patients need to be followed (Kingsley, 2009):

#### Environment/setting

Although not purpose built, it is imperative that the following facilities are available:

- ▶▶ Clinical work should be undertaken in an area floored with washable, non-jointed vinyl
- ▶▶ Appropriate hand washing and drying facilities
- ▶▶ Toilets
- ▶▶ Running tap
- ▶▶ Area for disposal of water following leg washing. There need to be a sufficient number of toilets to dedicate one to the discharge of waste water when the Leg Club is in operation (Kingsley, 2009)

- ▶▶ Appropriate coloured or double bags for the disposal of dressings
- ▶▶ Work surfaces that can be wiped down. Screens that are wipeable rather than being made of material
- ▶▶ Seating that is wipeable, softer furnishings should be avoided
- ▶▶ Plastic sheets to cover the floor below chairs where patients sit for treatment
- ▶▶ Facility to store equipment used.

#### Professional staff

The professional staff at Leg Clubs should:

- ▶▶ Be educated in infection prevention and control and educate patients accordingly
- ▶▶ Have access to personal protective equipment, i.e. aprons, gloves supplied from stock
- ▶▶ Assess the patient and consider the risk of, or any infection present
- ▶▶ Space people well
- ▶▶ Follow strict hand-washing procedures
- ▶▶ Limit time for wound exposure
- ▶▶ Dispose of dressings according to local guideline with appropriate bags
- ▶▶ Use sterile dressings and store appropriately.

#### Patients and their behaviour

Patients play a pivotal role in their care, and are encouraged to become involved in all aspects of their treatment, including:

- ▶▶ Personal and hand hygiene
- ▶▶ Awareness of infection prevention and control
- ▶▶ Bringing dressings/bandages to appointments and being aware of non-interference with dressings/bandages.

#### Are Leg Clubs a model for mobile wealthy individuals, excluding those who are housebound?

**JSH:** The Leg Club is a service committed to the well being of people of all ages, regardless of socioeconomic status. The direct costs of care delivery are funded through primary care organisations. Leg Clubs are self-funded through money raised by volunteers within the community to cover running costs and equipment. Members are encouraged to become fully involved.

There is an increasing question about those who are housebound but many individuals who have previously been considered housebound are, indeed, able to attend Leg Clubs.

To address issues of restrictive mobility, transport may be available through Dial a Ride, Red Cross or volunteers. However, this will depend on the arrangements made between the local Leg Club team and the community. It is this aspect of Leg Clubs that enables many 'housebound' individuals to experience the benefits of treatment, in an inclusive, supportive environment.

Frequently, the nursing team from a Leg Club will provide the service to the totally immobilised housebound patient.

Importantly, a robust care pathway should be followed wherever the patient has the service delivered, irrespective of any social class.

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### How much did it cost for you to set up a Leg Club?

**JG:** It is impossible to give an exact figure to the cost of setting up a Leg Club because it depends on many different factors. However, I can give an outline as to what needs to be covered in the lead up to opening a new Leg Club.

I strongly believe that time is the most expensive commodity in setting up a Leg Club, and the amount of time needed is as much as it takes. Before embarking on the 'nuts and bolts' of setting up a Leg Club, the whole team who will be facilitating the club need to be fully on board and understand the aims of the Leg Club and how it can help to improve the quality of care provided. This may well involve visiting other Leg Clubs, talking to those who run clubs and even perhaps attending the annual Leg Club conference.

Further, identifying and talking to other stakeholders will ensure that you have their support and that they also understand the principles behind the model, and have reassurance that the service is not being reduced but, in fact, potentially enhanced by incorporating a social aspect to care. In this period of informing others, it is also important to make contact with local interest groups such as the Lions or Women's Institute (WI), or others. These groups can potentially help with the provision of volunteers, or with fundraising or even giving donations to the initial set up funds. They can also give support with the practical issues of setting up bank accounts or keeping simple accounts.

Time is spent looking for your venue; this is mainly down to local knowledge. It helps if you can access a hall/meeting place that is already familiar to your potential service users. It needs to be checked by your local health and safety officer to ensure it meets regulations, i.e. clinical waste disposal and toilet/hand washing facilities.

Contact with companies who sponsor the Leg Club foundation can be fruitful in donating raffle prizes or supplies of tea and coffee.

Those who produce hosiery are able to supply samples of their products, and aids to fitting, which are helpful when your members are ready for this stage of their care. When the club is open, having them out as a display allows members to get familiar with the look and feel of these essential products.

Once you have your venue and the support of your local stakeholders, the holding of a public awareness morning can easily become a simple fundraiser event. This will probably give you the necessary funds to pay for the first month of the venue's rent.

Most equipment is already at hand within the district nursing team and effective time management ensures that it is at the venue at the right time.

The Lindsey Leg Club Foundation has a strong set of infection control guidelines (Kingsley, 2009). For most, it will involve the purchase of a plastic carpet protector which can be cleaned after each attending member has

received their care. Seating also needs to be washable, as well as the tables used to store consumables.

Having been up and running for a year with accounts to show, a Leg Club can apply for lottery grants to cover the cost of such things as transport. Local voluntary organisations and the local authority should also be approached.

### In the current financial climate, will Leg Clubs result in redundancies for tissue viability nurses (TVNs)?

**JG:** The Leg Club ethos is to provide care in the community on a collective model and, as such, fits well into current Government thinking about the delivery of care closer to the home. By using familiar halls/community centres, those attending are comfortable in their surroundings and perhaps more receptive to the advice and support offered.

The role of the clinical nurse specialist has developed in response to social, technological and political changes that have impacted upon the delivery of health care.

Back in 1999, a wide ranging review of district nursing, *First Assessment* (Audit Commission for Local Authorities and the National Health Service in England and Wales, 1999), expressed the need for nurse specialists to assist in improving practice and as givers of advice.

By supporting Leg Clubs, tissue viability nurses (TVNs) are in an ideal position to fulfil many of the

components of their role, including:

- ▶▶ Expert practice
- ▶▶ Professional leadership and consultancy
- ▶▶ Education and training
- ▶▶ Practice and service development.

Further, by working alongside the general nurse, the potential of the negative element to nurse specialisation, that nursing care has the potential to become fragmented, thus compromising the continuity and accountability of patient care, is negated.

Leg Clubs are an opportunity for tissue viability nurse specialists to assist in the development of skills which, in turn, impacts on improving standards. Tissue viability nurses often express difficulty in getting nurses to attend training. Leg Clubs provide access to these nurses with real patients to discuss care and treatment options. Effective and appropriate use of wound care products can also be discussed, and improved knowledge of products can lead to cost reductions. By working alongside the general nurse, the credibility of the skills of the tissue viability nurses is assured, making their teaching more effective as they have been seen to work in 'the real' world. Overall, attending Leg Clubs is both a cost and clinically-effective use of the specialist nurse's time.

Audit results of Leg Clubs suggest that they show improved healing rates in lower limb leg ulceration. However, this need not alarm tissue viability nurses that their jobs are on the line, as there are many other complex wounds needing their expertise.

### Is it possible for my leg problems to be treated as confidential in such a communal setting?

**MRF:** The Leg Club Guidelines require Leg Club practitioners to 'explain the collective treatment regimen to new members, and to ensure that provision is available for individual treatment' should it be required or requested.

So, 'yes', if you so choose. However, a member may benefit more if they join in the 'collective treatment'. Some of the relevant Leg Club objectives may help to answer this question more fully:

- ▶▶ To meet the social needs of isolated members by providing a mechanism for social interaction and peer support
- ▶▶ Rebuild members self-esteem and self-respect by destigmatising their condition
- ▶▶ Facilitate an informal support network
- ▶▶ Provide an informal forum for health promotion and education.

My experience is that most members with leg ulcers and other lower leg limb problems feel very alone, self-conscious and isolated about their situation when they arrive at a Leg Club. The benefits of mixing with others with the same condition gives a feeling of 'we are all in this together', and talk and interaction follows naturally. So, I always encourage members to join in with everyone else during refreshments and the club atmosphere while waiting for, or resting after treatment. They hear continuous stories of how ulcers are healed by those receiving post ulcer care and progress checks, and this

positive feedback inspires members to become stakeholders in their own treatment in a social and family setting.

### How does attending a Leg Club differ from attending a GP surgery?

**MRF:** The environment of a GP surgery is necessarily formal and by appointment. Surgery nurses normally have a high volume of patients passing through as quickly as possible, requiring many different treatments. There is normally no specialisation in leg ulcer treatment, or the availability of the special equipment used in Leg Clubs. The Leg Club environment could not be more different, typically being held in community centres, church halls, under scrupulously clean conditions. No appointments are required. Patients 'drop in' to the weekly Leg Club meeting, or are driven from their homes to the venue by volunteers. Once at the Leg Club, they are considered as members, not patients. Refreshments are provided by volunteers and 'chat' takes place between members in a social setting. Members are welcomed on arrival by a volunteer and when it is time for their treatment, they are called forward to be looked after by NHS nurses.

The nurses who work in the Leg Club are district nurses, staff nurses, practice nurses and student nurses receiving training. Treating so many members in the same place at the same time, cuts down on the nurse's travelling time and expense — a huge saving for the NHS — and enables them to also enjoy the social aspect while treating members. The

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atmosphere is friendly and informal and time is given by nurses who are experienced in leg ulcer treatment. During conversation, nurses are also able to encourage members to adopt a 'well leg' regimen, so that they actually understand how to participate in their own care to get well as quickly as possible.

Doppler equipment allows the testing of member's leg circulation and suggests the type of compression bandaging required to optimise the healing of leg ulcers.

### Why do people continue to attend Leg Clubs once they have healed?

**MRF:** Most people who attend Leg Clubs do so after their GP surgeries have failed to heal their leg problem, so they are desperate. With Doppler testing and treatment as per the Leg Club Model, 70% of patients are healed and are immensely grateful (Clark, 2010). Their social needs have been met in the warm and supportive environment of the Leg Club where they have enjoyed empathy and peer support from others, and their self-esteem and self-respect has been enhanced enormously. Many wish to help others and still enjoy going back to the Leg Club to tell members their story, enjoy the tea and biscuits, and inspire those not yet healed to carry on with the treatment. Cured members also choose to return for periodic checks to receive advice about how to prevent further problems with their legs, and to make sure that their legs remain in a satisfactory condition.

If you had suffered from ulcers for 10–15 years, as many of the Leg Club members have, and a Leg Club cured what you thought was incurable, painful and preventing you from going out or socialising, maybe you would want to go back and help others and say, 'yes, you can get better'.

### Conclusion

The future growth and development of the Lindsay Leg Club model depends in large part upon the acceptance of Leg Clubs within the wider National Health Service. The Lindsay Leg Club Foundation must help this process of acceptance by removing perceived barriers both to the creation of new Leg Clubs and the safe running of established Leg Clubs. Hopefully the comments offered here by patrons, Leg Club clinicians and members will help to dispel common myths surrounding the Lindsay Leg Clubs. Any clinician interested in the Leg Club model is most welcome to contact the Lindsay Leg Club Foundation to find out about their nearest Leg Club, where members and staff alike will warmly welcome visits so that you can see firsthand how well the model works in today's Health Service. **WUK**

**MC**

*The Lindsay Leg Club® Foundation is a 'not for profit' organisation committed to the well-being of people of all ages experiencing leg-related problems. The Lindsay Leg Club Foundation is an umbrella organisation that exists to promote and support the implementation of the Leg Club® model and monitor adherence to its defined standards.*

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