THE LEG ULCER CHARITY IS A UK REGISTERED CHARITY
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ABOUT 500,000 PEOPLE IN THE UK HAVE RECURRENT LEG ULCERS

Not only are ulcers uncomfortable, sometimes painful and always annoying, they often prevent patients from leading a normal work or social life. Furthermore when family, friends and other carers are included, this horrible condition affects millions of people every year in the UK.

How sad it is to find out that the majority of these leg ulcers could be cured. Not “healed” by dressings and bandages that only temporarily get rid of the ulcers for them to come back again. But cured for good.

Over the last 20 years, research has led us to improved understanding of leg ulcers and what causes them - and more importantly how to cure them. Using this research, it is now possible to permanently cure most leg ulcers, totally changing patients lives as well as the lives of their family and friends.

For many reasons, the vast majority of patients are not ever given the opportunity of a cure, despite the cure being cheaper than continual dressings and bandaging. If patients with leg ulcers are properly investigated and treated, the majority should be permanently cured. If healthcare professionals are not going to offer this, patients and their advocates need to know what to ask for.

The Leg Ulcer Charity has been set up to empower patients, their families and their carers to understand their condition and to know what to ask for to get a cure if possible - and if not, to find out why not.
Empowerment
The first priority is to empower patients, their families and carers to understand that their leg ulcers may be curable and to help them ask for the correct investigations and treatment. This website is the first concrete element of that empowerment and as funds increase, this will be improved and made more interactive helping more people get the information, investigations and chance of cure that they deserve.

Research
The Leg Ulcer Charity is already sponsoring a Ph.D. student through the University of Surrey to look at the consequences of having a leg ulcer and the patient and the people around them. The project will also then measure the impact of curing those leg ulcers that are curable. The research student, Pippa Tollow (see profile below) started in October 2013 and should complete her Ph.D. in summer 2017. Other research projects will be started as donations and funds allow.

Education
The Leg Ulcer Charity is working towards providing educational days for doctors and nurses involved in the treatment of patients with leg ulcers or those who wish to enter this exciting field. In addition, as funding allows, we hope to be to introduce new techniques into the UK to be able to cure the more difficult ulcers particularly those involving the deep veins.

Treatment
Finally our ultimate aim will be to raise enough money to be able to provide assistance to patients with leg ulcers who are curable but who are unable to find a cure local to themselves. Clearly the Leg Ulcer Charity will need to have grown considerably before this becomes reality but when we are able to achieve this, having achieved the three points before this, we will then have become the charity that we wish to become.
WHAT ARE LEG ULCERS?

Leg ulcers are areas of the lower leg, ankle or foot where the skin has broken down and the underlying tissue is exposed. Some people refer to these as “open sores”.

In normal healthy people, the skin covers the whole of the surface of the body protecting the insides away from the outside environment. When the skin is ever broken, such as in a graze or cut, in normal healthy people a scab is formed and new skin grows underneath the scab healing the wound.

In patients with leg ulcers, something has gone wrong with this natural process and the wound does not heal. As such, it remains open. This open ulcer, which can be regarded as a chronic open wound or open sore, can get infected and can ooze a lot of fluid.

Ulcers can be big or small, painful or not painful, smelly or not smelly, wet or dry. There are a great many different appearances of ulcers when looked at on the surface and this has resulted in a lot of confusion particularly in nurses and dermatologists who only look at the surface.

Apart from checking that there is nothing a very abnormal with the leg ulcer, such as a rare skin cancer growing in it, there is very little of use that can be found just from looking at the surface of the leg ulcer. Certainly, it is impossible to tell which are curable or incurable from looking at the surface alone.

To understand leg ulcers, and to cure them, what they look like on the surface is virtually irrelevant. What is needed is to understand the underlying cause and then use specialist ultrasound investigations to identify the underlying cause and to direct treatment are to cure the ulcer.
WHAT IS THE UNDERLYING CAUSE OF LEG ULCERS?

The commonest underlying cause of leg ulcers is problems with the veins (a venous ulcer). The second commonest cause is problems with the arteries (an arterial ulcer).

Venous ulcers and arterial ulcers account for almost all leg ulcers. There are other causes but these are uncommon compared to these main two causes. Although arterial ulcers are less common than venous ulcers, they are the most important to diagnose. Firstly, they can often be treated by opening the arteries using an angioplasty balloon or stent, or sometimes a bypass graft.

Secondly, arterial ulcers are a very bad sign showing that the leg does not have enough blood supply to keep it alive. If this is the case, and a blood supply cannot be restored, gangrene is a possibility. Therefore it is important to know if a leg ulcer is arterial first (see the section on “What sort of leg ulcer do I have?”).

Once you know you do not have an arterial leg ulcer, then the chances are you had a venous leg ulcer.

The good news about having a venous leg ulcer is that if you are mobile and able to walk by yourself, you have a very high chance of being curable.

A good hint as to whether you have a venous leg ulcer or not is whether you are being treated by compression bandages or compression stockings. These make arterial ulcers worse but make venous ulcers better in the very short term. Unfortunately, although compression bandages and compression stockings they can help “heal” a venous leg ulcer in the short term, they do not cure it as they do not cure the underlying vein problem.

There are two main causes for venous leg ulcers - the commonest is “hidden varicose veins” (also called superficial venous reflux or chronic venous insufficiency - CVI) and the other less common is due to deep vein problems.

The good news for people with leg ulcers is that “hidden varicose veins” are easy to diagnose with a duplex ultrasound scan and can be completely cured with local anaesthetic endovenous techniques. In the majority of people, curing these “hidden varicose veins” results in the leg ulcer being permanently cured.

Deep vein problems are much harder to treat as the deep veins can either be blocked or can have lost the valves causing deep vein reflux. Although some of these can be cured, not all can be. Fortunately, the vast majority of venous leg ulcers are due to “hidden varicose veins” and so are curable.
WHAT SHOULD I DO ABOUT MY LEG ULCER?

ARE YOU ABLE TO WALK EASILY?

If the patient is not able to walk easily, then many of the treatments for leg ulcers are even less effective or ineffective. If however the leg ulcer is very painful even at rest, there might be some advantage in trying to treat it may lead to remove the pain. However this would require individual assessment by a specialist doctor.

Provided the patient is able to walk easily than the following guide can be followed in most cases:

SUSPECTED ARTERIAL LEG ULCER

If an arterial leg ulcer is suspected, then it is essential that the arteries are investigated to find out what treatment is optimal. A simple Doppler pressure test at the ankle is not sufficient. If such a test is performed, it is often inaccurate and frequently says the pressure is better than it actually is. In addition, it never says whether an ulcer is curable or not.

There are several ways that are acceptable to investigate the arteries in a patient with an arterial leg ulcer. Colour flow duplex ultrasound scan of the arteries is very useful as it not only shows the arteries and any narrowings and blockages, but can also be used for the veins. However it is often difficult to see the arteries deep in the pelvis and so some vascular surgeons do not favour this. Arteriogram (injecting contrast and taking x-rays) and MRI can both be used with relative accuracy to find narrowed or blocked vessels. No test for arteries is 100% accurate and many vascular surgeons favour having at least two different techniques to be certain.

Without at least one of these imaging techniques being performed by a specialist vascular surgeon, no patient should ever accept that they have an incurable arterial ulcer.
Most people with leg ulcers will have a venous leg ulcer and so should follow this advice.

The presence or absence of visible varicose veins is irrelevant. Many patients with arterial leg ulcers incidentally have visible varicose veins and many patients with venous leg ulcers have “hidden varicose veins” that cannot be seen on the surface.

A previous history of deep vein thrombosis (DVT) is interesting but irrelevant unless the patient has had a scan and damage to the deep veins has been proven. Most patients with previous deep vein thrombosis recover without any damage the deep veins and so telling patients they are incurable just because they have had a previous deep vein thrombosis is wrong.

In previous decades, a “venous flare” or little blue veins around the ankle was thought to indicate damage to the deep veins as was deep brown staining of the lower leg. In the past many doctors and nurses have erroneously told patients with these signs that they have incurable venous leg ulcers. This has now shown to be completely incorrect as most people with these signs actually have “hidden varicose veins” (also called superficial venous reflux or chronic venous incompetence) causing them which are of course completely curable.

As such - No patient should ever accept an opinion from a doctor or nurse as to whether their venous leg ulcer is curable or not unless they have had a colour flow duplex ultrasound scan performed in a specialist clinic or by a venous specialist.

If any patient is treated with compression bandaging or compression stockings and has not had a venous duplex ultrasound scan performed by a venous unit specialised in vein disease and diagnosis, then there is a very high chance that they are missing out on a chance of being given curative endovenous treatment. It is exactly this situation that the Leg Ulcer Charity is targeting first as this is both the simplest group of patients to cure but also the largest group of patients that are currently being mistreated and prevented from getting a cure.

A venous duplex ultrasound scan, when performed by a specialist vein unit, should be able to pick up deep vein problems as well. If the superficial veins are normal, in other words the duplex ultrasound scan has shown there are no “hidden varicose veins” then unless a clear diagnosis is made of another cause, the patient should either be referred or seek specialist investigations and opinions as to whether there is deep vein obstruction or deep-vein reflux.

As noted above, this advice should cover about 90% of people but can only be given in general terms. Individuals may vary and will need to seek medical advice on their own particular circumstances. However the principles as outlined above are clear and, if the patient has not had the appropriate investigations, they cannot be told with any honesty or accuracy that they are incurable and need only dressings and bandages.

As the Leg Ulcer Charity grows we aim to improve this guidance and make it more specific as donations allow us to do appropriate research.
HOW ARE LEG ULCERS CURED?

The basic principle of curing a leg ulcer is very simple. It is to find out the underlying cause of the leg ulcer and to correct it. Providing it can be corrected, the body will heal itself as it would do in a normal and healthy person.

Without doubt exercise, physiotherapy, diet (particularly high protein, vitamin C and zinc) will help the healing process.

Ulcer dressings do not heal ulcers unless they have some active growth factor or biological ingredient, but they can make the environment of the ulcer surface more friendly towards healing. However that is useless if the underlying problem hasn’t been corrected.

Compression bandages or compression stockings increase the pressure inside the lower leg that can reduce blood refluxing down “hidden varicose veins” and also reduce swelling of the lower legs. Once again this can help temporary healing but as soon as the compression is removed, the same process starts again and the ulcer recurs. Of course if it is an arterial ulcer, the compression makes the ulcer worse and more painful.

If the ulcer turns out to be incurable by endovenous surgery or arterial surgery, then of course the above factors are all that are available. However as none of these cure leg ulcers but only can hope to “heal” them in the very short term with the virtual certainty that they will come back again, then patients, carers, family as well as doctors and nurses really should be absolutely certain that someone is incurable before sentencing them to a lifetime of dressings and compression bandages.
CURING VENOUS ULCERS DUE TO “HIDDEN VARICOSE VEINS” - THE COMMONEST CAUSE OF LEG ULCERS

The majority of venous leg ulcers are due to “hidden varicose veins” (also called superficial venous reflux or chronic venous incompetence). Unfortunately these cannot be seen on the surface and so if a specialised duplex ultrasound scan has not been performed, doctors and nurses may be unaware that “hidden varicose veins” are present.

In these cases, the duplex ultrasound scan shows which of the veins have lost their valves and are allowing blood to fall the wrong way down the “hidden varicose veins”. This backward flow of blood is called “venous reflux” and when it hits the veins at the bottom of the leg, the resulting inflammation causes the skin damage. Over the years, the inflammation and progressive skin damage causes swelling followed by red skin stains, sometimes with venous eczema, followed by brown stains and finally leg ulceration.

Although steroid creams may make any venous eczema feel better, and support stockings and dressings may temporarily reduce the reflux by pushing hard on the outside, none of these factors are a cure.

Once the venous duplex ultrasound scan has identified which veins have lost their valves and are allowing venous reflux, venous specialists can close these “hidden varicose veins” under local anaesthetic using combinations of endovenous laser, radiofrequency ablation, foam sclerotherapy, phlebectomy and perforator vein closure (TRLOP). There are also some new endovenous techniques coming out that might be useful in some patients.

All of these techniques are pinhole procedures and none require a general anaesthetic or sedation. In skilled hands they rarely fail.

Once the venous reflux has been stopped, ulcer healing usually follows within 3 to 6 months provided the patient is walking well and the ulcer isn’t perpetuated by constant dressing. In the majority of people who have had treatment, nature’s own dressing - the scab - is as effective if not more effective than any dressing that is bought from a company.

Compression might be needed if there is still swelling at the ankle or in the short term after foam sclerotherapy but the aim is to try and get the patient out of all compression. There are a proportion of patients who do get a complete cure but due to persistent swelling, often from lymphoedema, will need to wear graduated compression stockings whenever they are up and around. Usually these can be below knee and worn as socks.
CURING VENOUS LEG ULCERS DUE TO DEEP VEIN PROBLEMS ARE - A MUCH LESS COMMON CONDITION

Patients who have either blocked deep veins, reflux in the deep veins or both present a more challenging situation.

However, a large number - if not the majority - of patients who have been told that they have “damaged deep veins” or “blocked deep veins” actually have only “hidden varicose veins” and so are curable. The reason for this is that doctors and nurses traditionally have told anyone who has had a deep vein thrombosis (DVT) in the past that their deep veins will be damaged and that they are incurable.

Research has shown this not to be the case and the majority of patients who have had only one deep vein thrombosis (DVT) which has been treated, end up having normal deep veins. As such there are an awful lot of people in the UK who have been told that they are incurable who are in fact curable.

Therefore do not accept that your ulcer is incurable due to you having deep vein problems unless you have had an expert duplex ultrasound scan that has proven beyond a shadow of a doubt that only your deep veins are causing the ulcer.

If you have had a duplex ultrasound scan and probably another scan to confirm it such as an MRI or venogram, and your deep veins have been shown to be the problem, then there is a lot of research suggesting that you might still be curable.

Although only just coming to the UK, elsewhere in the world and particularly in the United States of America, blocked veins or narrowed veins can be assessed using a specialised investigation called IVUS (intra vascular ultrasound) and the blocked or narrowed veins can be opened up by inserting a expandable metal tube called a “stent”. The results from this have been excellent.

It is one of the aims of this charity to try to raise enough money to increase the research into this sort of cure and make it available to more patients in the UK.

CURING ARTERIAL LEG ULCERS

As noted earlier in this website, arterial ulcers account for approximately one in 10 leg ulcers. The cure for these is to find where the arteries are blocked and to either open up the blockages using balloon angioplasty or arterial stents or even bypass grafts.

Arterial leg ulcers are well catered for in the National Health Service and most vascular surgeons are specialist in arteries not veins. As such although the Leg Ulcer Charity provides information about arterial leg ulcers, particularly empowering patients and carers to try to get a diagnosis, we are not involved in research and treatment of them which is already well supplied in the UK.
ABOUT US

TRUSTEES

Prof Mark Whiteley
Prof Mark Whiteley is an internationally recognised specialist in venous disease and the founder of the Leg Ulcer Charity. Mark set up the Leg Ulcer Charity with a view to empowering patients and their carers to insist on the right investigations and treatments, and to fund further research to improve the care of leg ulcers even further.

Mr Barrie Price
Barrie Price is a well-known Consultant Vascular Surgeon who has for many years specialised in the treatment of venous disorders which includes in its remit, venous ulcers. The Leg Ulcer Charity aims to inform patients, educate those who treat them and develop ways of doing things better through solid, well thought out research. These are matters that Barrie Price is happy to be involved with.

Bryn Edwards
Bryn Edwards is a chartered accountant and during his career he has worked in most parts of the World. He has considerable empathy for the sufferers and would like to support a charity which is dedicated to research to enable a cure to be found for leg ulcers.

Dr Ian Clapp
Ian is retired, having worked the major part of his career for Investment Banks in the City. He feels that anything that can be done to combat such suffering must be worthwhile and his involvement with the charity enables him to give a little bit back to those people who continue to suffer from the same hardship today.

Philippa Tollow
Philippa completed her undergraduate degree in Applied Psychology and Sociology at the University of Surrey in 2012, and she was awarded my MSc in Health Psychology from the University in 2013. As part of her undergraduate degree she spent a year in the industry, working within the South Thames Cleft Service at Guys’ and St Thomas’s NHS Foundation Trust, and it was here that she developed an interest in the interaction between psychology, health, and illness.

RESEARCH
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Leg Ulcer Charity
“Empowering patients and carers to search for a cure”