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**'The Lived Leg Ulcer Experience'**

**Qualitative Data Report**

Commissioned by Primary Care Unit, Midland Health Board

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## AIMS OF STUDY

- To investigate the quality of life of the patient with a leg ulcer, attending the community leg ulcer clinics in the Midland Health Board.
- To ascertain if patients who have attended the community leg ulcer clinics are satisfied with the service provided.

## OBJECTIVES

- To review the literature in relation to quality of life and leg ulcer sin order to highlight issues which may be relevant to this group of patients.
- To develop a research methodology suitable for this patient group in order to allow patients to explore other quality of life issues which may be relevant to their situation.
- To explore the patient's perception of the service provided.

## LITERATURE REVIEW

A literature review forms one of the main aforementioned objectives of the study.

- To review the literature in relation to quality of life and leg ulcers in order to highlight issues which may be relevant to this group of patients

The information for this section of the report is the same literature review used in Belton, Maura, Quality of Life and Patient Satisfaction of clients attending Leg Ulcer Clinic in the Laois/Offaly Community Care area

(Extra Mural Diploma Course in Communications Studies at Athlone Institute of Technology, 2000)

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## "Quality of Life and Patient Satisfaction of Patients attending Community Care Area Leg Ulcer Clinic in Laois/Offaly"

### LITERATURE REVIEW

#### LEG ULCERATION

##### Definition.

*"A leg ulcer is defined as an open wound in the skin below the knee, present for four weeks or more".*

*(British Association of Dermatology).*

1% - 1.5% of the population suffer from leg ulceration. The majority of leg ulcers (85%) are found in the elderly and they decrease their quality of life.

Leg ulcers are a predominantly female problem (Ratio male female 1:2)

#### COMMUNITY LEG ULCER CLINIC

##### Definition.

A community leg ulcer clinic is a nurse led clinic where clients who suffer from leg ulceration are assessed and treated.

There are many such clinics in the U.K and Ireland, including five clinics in the Midland Health Board area.

These clinics are known to make effective use of community nurses time and improve healing rates.

The literature states that the distribution of ulceration is not related to social class, but that those in lower social classes are likely to suffer ulceration of a greater duration.

In a study conducted by Phillips (1992), 73 clients were interviewed. 65% complained of severe pain. 40% were troubled by discharge and swelling and over 80% had problems with mobility.

Hyland et al (1994), produced a self report quality of life questionnaire for patients with leg ulcers. It was completed by fifty clients. The researchers concluded that pain, sleep disturbance and mobility impairment were major factors affecting quality of life.

The majority of patients had severe pain.

The financial impact of patients interviewed appeared to be substantial in terms of job loss, time lost from work and expenses for dressings and medications.

The psychological impact of leg ulceration was considerable. Emotions reported included fear, social isolation, anger, depression and negative emotions and more mobility problems. Older patients seemed to be able to cope better with limitations and disabilities.

Male patients appeared to complain more about pain, and as they were generally the breadwinners, they were more likely to be angry and frustrated with their situation.

In a study conducted by Harmer et al (1994) thirty seven per cent of those interviewed felt that pain was the worst thing about their leg ulcer. Restriction in mobility also had major influence on their quality of life. Over 39%, were worried about healing.

In another study, Callum et al, examined and interviewed 600 patients with chronic venous ulceration. 42% reported that the leg ulcer interfered with their work and leisure activities, moderately or severely and 10% said it affected their mobility.

In a study by Lindholm et al (1992), the Nottingham Health Profile (NHP) was used to assess disease influence on six areas of daily life, mainly:

- pain
- physical
- mobility
- sleep
- energy
- emotional reactions
- social isolation.

Standard questionnaires were distributed to patients with chronic leg ulcers of varying aetiologies. Complete data was obtained from 125 patients.

Males had highest scores for pain, emotional reactions, social isolation and physical mobility.

For women, the impact of leg ulcer disease seems much less marked.

The duration of the leg ulcer didn't seem to influence the quality of life in any aspect other than pain.

Hildegard, Charles 1995, considered that the psychological effects of ulceration in patients quality of life were not well documented. He conducted an investigation which focused on the quality of life experienced by people with ulceration for many years.

There were five themes identified under the heading of physical effects.

Pain was one dominating physical factor for his interviewee.

Sleeplessness was next and caused major exhaustion and worry.

Impaired mobility was the third theme.

The interviewees said that the treatment for their ulcers often produced intolerable side effects and that the nurse would not listen to them.

They also said that the health worker did not explain what treatments they were using or what

they were doing to the patients.

The psychological effects were hopelessness, helplessness and control.

In the social effects category, effects on the patients working lives and human interaction were

the two main themes to emerge.

In conclusion, the interviewees demonstrated that patients with chronic leg ulcers suffered negative effects in the physical, psychological and social areas of their lives.

Pain, the lack of effective health and a reduced quality of life permeated their lives.

Research conducted by the Vascular Surgical Service in the Venous Ulcer Clinic at Charing Cross Hospital, Riverside Health Authority, showed that research - based assessment and treatment of chronic venous ulcers substantially improves ulcer healing rates.

Leg ulceration was identified as being a community problem and following a successful pilot study in a group practice, a project in Riverside Health Authority evaluated the effect of community leg ulcer clinics.

This was followed by the development of community leg ulcer clinics. They were staffed by community nurses and supported by specialist nurses from Charing Cross Hospital.

Research indicates that given the necessary training and resources, nurses are capable of achieving healing rates comparable with those in a hospital clinic.

Nurses have a responsibility to provide the most effective research - based care for their patients.

"All clinical practice should be founded on up to date information and research funding".

*(Department of Health Strategy for Nursing 1989)*

Traditionally, most people with leg ulcers are treated in the community by district nurses, visiting each patient in their home. A study investigated quality of life issues of patients from the Riverside Ulcer Project.

The patients were interviewed using a standard questionnaire, and then re interviewed after twelve weeks of compression bandaging to observe changes.

The results showed significant reductions in anxiety, depression, cognition and hostility after twelve weeks.

There was also a significant reduction in pain. Reductions in depression and hostility were related to complete healing, indicating its importance in improving general well-being.

The reduction in pain was dramatic which was mainly due to the fact that the ulcers of half of the patients were completely healed.

Mobility was also improved following healing.

There was also an improvement in the social aspect, as the ulcers were no longer malodorous

The results showed that patients had an improved sense of well-being even when their ulcer was not healed.

This may be because of the effect of treatment, the attitude of the nursing staff and the

continued healing of most ulcers or a combination of all of these factors.

#### PATIENT SATISFACTION.

The Riverside project assessed the degree of patient satisfaction with the service. Twelve weeks after commencing treatment the patients completed a questionnaire, the results of which indicated a high level of satisfaction with the service.

#### CONCLUSION.

The implementation of community leg ulcer clinics has improved quality of life and patient satisfaction of the clients who attend them.

The nurses who run the leg ulcer clinics receive special training and the patients' treatment is research-based.

This also helps the nurses to have better job satisfaction as they themselves are no longer working in isolation. They have the skills and the knowledge to treat what was looked upon as a "Cinderella" area.

## RESEARCH METHODOLOGY

*For any investigation, the selection of an appropriate research design is crucial in enabling you to arrive at valid findings, comparisons and conclusions.....the strength of an empirical investigation is primarily evaluated in the light of the research design adopted. When selecting a research design it is important that it is valid, workable and manageable.*

Kumar, R Research methodology: a step by step guide for beginners (1999)

### SELECTION OF DESIGN

Since the main purpose of this study is to identify quality of life issues and patient satisfaction with the service provided a qualitative approach was deemed to be the most appropriate and information yielding. In order to assess the lived leg ulcer experience a focus group methodology was used. Focus groups are group discussions, which involve usually 6-10 people. They were used to stimulate ideas and explore people's health experience of the lived leg ulcer experience and generate a range of views on that topic. These groups also give respondents a chance to share that experience with each other. Essentially this approach aims to gain an in-depth knowledge of that experience to complement existing Health Board data on prevalence and healing rates. (Brennan, Carmel et al Audit Report of the Midland Health Board Primary Care Leg Ulcer Clinic Project 1998-99)

### ASSEMBLING GROUPS FOR FOCUS GROUPS SESSIONS

Individuals with healed ulcers were invited to attend by the relevant Public Health Nurse. It was hoped originally to run additional groups in Mullingar (Co. Westmeath) and Mountrath (Co. Laois). The group in Mullingar was assembled but only 3 participants arrived on the day the focus group session was to be run. Of these three one member had an unhealed ulcer. It was not possible to run the Mountrath group due to the time-constants on the study. Generally a rule of thumb when running focus groups is to stop groups once similar types of answers emerge through the group discussion. This happened in both the Longford and Athlone focus groups implying that the small number of focus groups conducted was actually sufficient for the requirements of the study.

### PROFILE OF PARTICIPANTS IN FOCUS GROUPS

All participants in the Longford focus group were male while there was a mix of male/female in the Athlone focus group.

### FORMAT OF FOCUS GROUP DISCUSSIONS

The focus group discussion followed a focus group discussion guide. In some cases questions were pre-empted in discussion.

### FOCUS GROUP ANALYSIS

1. Tapes were fully transcribed in order to capture the richness of the data. Transcription involved adding in non-verbal data including pauses.
2. Transcripts were coded.
3. Codes were transformed into themes.
4. Focus group themes are written up under subject areas as illustrative data.

### VALIDATION OF THEMES EMERGING FROM FOCUS GROUP ANALYSIS

#### (RIGOUR IN QUALITATIVE RESEARCH)

The ultimate validation of themes emerging from focus group analysis is similarity of themes emerging from other groups and definite corollaries established between different data sets. In this case the two different data sets are the two focus groups, Athlone and Longford. The data was coded and prepared by a researcher and the findings validated by the group facilitator.

### RESEARCHER ROLE IN THE SURVEY PROCESS

The focus group sessions were co-facilitated by Public Health Research Officer and the data coded and compiled onto a report format by another Public Health Researcher. In a sense the Researcher role in the process is the assimilation of data. The survey process itself actually reflects participant's willingness and enthusiasm to become involved. In both groups under direction of the facilitator discussion was lively and very information yielding.

### LIMITATIONS OF STUDY

Since this work targeted healed leg ulcer patients view of the services is retrospective rather than present moment. This in a sense gives an overview of the whole leg ulcer healing process enacted at the Clinics. However, since all participants have a healed leg ulcer their views of the service will be naturally favourable. A further study among patients in the process of actually attending and having an immediate leg ulcer experience may be very information yielding and complement the findings in this small study.

## FINDINGS

### INTRODUCTION

Focus groups as already stated were conducted in this topic area in order to assess the lived leg ulcer experience. The themes identified below are those, which emerged from the focus groups transcript analysis. Excerpts to identify validity of identified themes are included. This was necessary to show the groups linguistic frameworks on the topic of the lived leg ulcer experience and how discussion facilitated demonstration of a salient point. They are also reflective of questions used in the focus group discussion guide.

### LENGTH OF TIME TO HAVE A LEG ULCER PRIOR TO COMING TO LEG ULCER CLINIC

In the Longford group participants had only a very recent history of having leg ulcers whereas in the Athlone group participants had ulcers for a longer length of time.

*Ms M. - It was nearly a year it was a long time before I heard about here, a long time before I was told about it the nurses etc., the doctor never suggested it, Ann Dwyer she's a receptionist in doctor O' Mally's, she was talking about it because of her mother was very bad with ulcers*

*Health Board Facilitator How about anyone else? ..... how long? .....*

*Ms M Word of mouth*

*Mr. J - I was suffering from various ulcers for a long long time before I consulted the clinic, now you see when you have varicose veins in your legs if their not broken out don't worry you know..... but my ankle now I'll just show it to you now if you don't mind you see, see I was often used to liftin' heavy things...I usually wear stockings just didn't wear them today.....anyhow I had trouble with them for a long time But only I had a pain in my legs and that but as I say when the various veins burst out but if I got a knock on that you see they would open up and then that's now I had terrible trouble before I came to the clinic because I was putting ointment and stuff on it and this that and the other, and the doctor was telling me this and telling me that, but it would heal but it would take a long time to heal you know*

*Health Board Facilitator So would it be true to say you have all had the ulcer for a while before you came into the clinic*

*Mr. S - I would be different in that I never suffered from ulcers until one occasion about four ...three years ago I went out I was given out mass cards or something like that I was given out these mass cards I went down to this particular house and there was a dog there and he bit me It was the first time in my life a dog ever bit me and it turned into an ulcer now if you can appreciate I am a diabetic - insulin dependent and I have bad circulation in my legs as you can see you know and this was the leg I was bitten on now .....back here some where (indicating where on leg) but am I never bothered with anything I just got a few wipes when I went home, but it turned into an ulcer and am I need not tell you I went straight over to my GP and he said you can claim below in the hospital you know and that he said do you know X (Public Health Nurse), I said of course I know her she goes next door and that she lives beside me well that's how I started.*

*Mr. J - Someone told me about the clinic you see down there Mrs Y actually do you know Mrs Y (other group members say Yeah Yeah)....she goes down there. I mentioned it to my own doctor and he said of course you can go down there if you want to you know so I went down there to Nurse X and they done wonders for me you know I haven't had a break out now.... not since I was here now... and I have a bad ankle and all you know now if I watch that I wear a sock you see also given to me by the Midland Health eh.....Nurse X and if I ware a sock on that and take care of it and don't get a knock on it I'm as right as rain but it's when I get a knock on it and it burst's again it's terrible hard to keep you know*

(Athlone Focus Group)

Ms. M - I'd have had it a few weeks maybe, I went to the doctor twice and then he referred me to the clinic so about three weeks I suppose I was probably with the doctor twice before I went to the Clinic and I think I was one of the first....when they started up ...they only started up ...and they told me I was one of the first to come to their Clinic anyway

Ms S - I had mine since June, and I was attending causality and they sent me to the clinic I think I was there just as Patricia was nearly finished

Ms. G - I was just a few weeks with Dr. Y and I was on antibiotics and then he referred me

Ms. M - Mine happened the week after my daughters wedding and I went to a.... my own doctor was away I was coming down from the west and my sister in law is a public health nurse from the west so she dressed it for me, he told me what to do naturally because she would be attending people who had ulcers 'n' all the rest so she told me to go to my old doctor when I go back and she put whatever dressings they would put on it I can't think of the name now on them but then my man was away so I went to Dr. X (local G.P.) and he referred me to the ulcer clinic I never knew it existed.

Ms. M It had only just started.

(Longford Focus Group)

### REFERRAL PROCEDURES TO LEG ULCER CLINIC

The transcription excerpts shown above also indicate 'word of mouth' and G.P. as being the two sources of initial communication about leg ulcer clinics. In this case 'word of mouth' is very powerful as patients with leg ulcers can actually hear first hand or know of improvement in leg ulcer healing rate and definite success of the leg ulcer clinics. The G.P. is also a trusted source of knowledge.

### QUALITY OF LIFE ISSUES WITH A LEG ULCER

#### Physical

#### Pain

In all groups all respondents identified pain as being a dominant influence in their life during the course of the ulcer.

Ms M - Don't talk about pain morning noon and night for a year and a half one was bad then the other one got burst. Then the dressing 'd get stuck

Health Board Facilitator Was the pain worse at any particular time of the day?

Mr. S What I use to feel now not interrupting you was that at ....eh.....night in bed I couldn't sleep. I could not sleep with the pain of it.

Ms M Nurse X gave me a yoke that would lift up the blankets that would lift up the clothes for me cause I had old-fashioned blankets I wouldn't throw them out cause they are of sentimental value. And she gave me this thing to raise up the blankets ....It didn't make up any difference a devil a bit

Health Board Facilitator If you were to describe the effect that the pain had on your life.....did it limit you?

No one replies for a moment

Mr. S Well when you are not sleeping you're next day you see...any day that you don't have a good nights sleep it's very distractin' you know. You could be in bad humour or.....you know what I mean your concentration we'll say is lax

Health Board Facilitator I was just saying to everyone about the effect that pain would have on your life and Mr. J was saying about him in particular that if he didn't have a good nights sleep it would have a big impact on the day after. How does everyone else feel about that?

Mr S(b) - It would have all right, the pain at night-time seem to be the worst time for pain.....the heat of the bed would have an effect on it as well. I found that I use to take Solpadine's nearly every night as a painkiller. I found that aspirin or Panodol weren't able to help it (Yeah Yeah from other group members). I would have had

to take the Solpadine nearly every night and if I woke up four hours afterwards the pain'd be back and you'd have to take another

(Athlone Focus Group)

Ms. M(b) – Very hard to cope when you have pain especially in your leg you know

Yeah Yeah from other group members

and then you feel you should be restin' and doin' nothin' and you can't do cause you have to do a certain amount you know you couldn't enjoy anything or you couldn't go out or even to shop like going into to Tesco to get your messages with the pain it's unbelievable isn't it?

Um Um from other group members

Ms. S – It kept me awake the whole Christmas like that was a whole 6 months after it started like that was the first actual bad thing that was really sore and painful really throbbing horrible pain the whole of Christmas

Ms. G – The pain is unbearable but I think I possibly had an infection in mine that I was on antibiotics twice and there fore that went on for three to four weeks..... the pain..... just drives you scatty and then your on pain killers and they don't always agree with the tummy and all the rest and.....

(Longford Focus Group)

In all groups there was definite consensus on the dominant negative influence which ongoing pain can have on one's life. This pain was related by all in the groups to loss of sleep

### Loss of Sleep

This loss of sleep was seen to impinge on 'normal everyday activities which in itself imposed a limitation on participants in their every day lives.

Mr. S – I was often awake at night if it wasn't the ulcer it was something else, I go off in the day time and sit in the car and I'd be gone.....I have no concentration now whatsoever I use to be a great reader but now I can't even read for 5 minutes I'd fall asleep or the book would fall out of my hand or somethin' else.....but eh.....I put pain behind me I never took painkillers you know or.....what do you call them?.....anything that would make you sleep or anything like that as a matter of fact one Friday morning I arrived here and I got a terrible pain in me chest which was not my heart I was being treated for an infection that came out of the blue so I went down to the emergency in Ballinasloe I spent a week down there and I was pumped with antibiotics. I never saw anythin' like it four times a day a huge big needle and that was it. I couldn't lie down. I had suffered that for a fortnight before I decided I would go down and then I coughed and coughed and every time I coughed the pain would come out through my ears

Health Board Facilitator Are you saying then that you would normally be a poor sleeper?

Mr S I am normally a poor sleeper I would have to get up a couple of times during the night about two would be the most but I'd go back to sleep just like that. Nine thirty would be the latest and I'm up at six because I have to get an injection then I have my breakfast at half six or quartet past seven or that and that would be it

(Athlone Focus Group)

Ms. S Forget about it there's no sleep.....

Ms. M(a) – That's one of the things I found the hardest cause I run a pub, so I have no choice in that my son helps but you can't ask him to stand for what is it 16 hours a day its not being mean I couldn't just get someone to fill in for a few hours, we had a lady and she died sadly there of cancer. Everything seemed to happen at the one time. My daughter got married and this woman had cancer and she was only 40 and I had the ulcer and all I could do was continue leg ulcer as best I could but what I didn't know was until the end, now it wasn't their fault, but you know that chart that they give you I didn't receive that until the end and I didn't realise how vital it was to keep your legs elevated when I could. Someone said if you're only going to the bathroom going to the loo. If you could even spare 5 minutes in the bathroom to put your legs up along the wall it'd make a big difference to you. I don't know if ye find these things.

Ms. P – When you're very busy it is hard to do that and you guilty if you then if you d lie down

Ms. G – I had a case that I had one leg up but the other had to be kept down because I had a blocked artery and I couldn't get it up and ended up straggled and in the end I put the two feet up

(Longford Focus Group)

There is a very strong suggestion in the Longford group of trying to continue a typical day i.e. work in the context of pain and no sleep.

### Other Physical Symptoms Identified

#### *Itch*

This physical symptom associated with leg ulcers was identified but did not invoke the same discussion as pain and loss of sleep did.

Ms. P – You'll have the itch anyway once you have veins you'll have the itch

Ms. G Terrible

Ms. S Really it's horrible. It wouldn't start rightly until you'd lie down at night the heat of the bed used to drive me mad

(Longford Focus Group)

This was not developed further by group members or discussed in any length by the Athlone group which may be an indication that pain and loss of sleep are the overriding symptoms with a leg ulcer and obviously the most intrusive in one's life. Other symptoms such as itch are present but the intrusion on 'normal' everyday life is more secondary.

Ms M(b) And the itch is something terrible as well it was when I was actually having the bath it was bandaging. I had an ulcer for a year and a half. it got better as time went on. It was worse at the beginning and it eased off

(Athlone Focus Group)

### SWELLING

Swelling emerged as a symptom of ulcers only with prompting from the group facilitator in the Athlone Focus Group. There was no group consensus on this as being a pervasive symptom associated with having a leg ulcer but like with itch was seen in a more secondary way.

Health Board Facilitator *What about swelling of the actual leg? Did that occur with many of you?.....*

Mr. J – my ankle use to swell up just the ankle now

Ms M(b) – no I didn't have any swelling. I got an ulcer a which I didn't hit or anything it just came and the doctor dressed it and I asked to be sent to Tullamore and it was in Tullamore that they told me about the hospital here (Athlone)

(Athlone Focus Group)

### AIDES TO LIFE WITH LEG ULCER

Again both groups document elastic stockings as being an invaluable assistance with regard to support to leg when one has a leg ulcer. However it was also evident that easy availability of these outside of Clinics was an issue of concern for participants.

Ms. M(b) – Mine was on my ankle my inner ankle. I wear the elastic stockings now. What I also find is that when you go into the chemist they mightn't just have your size or.....I dunno maybe I'm just unlucky. It'd be great if you could how will I say it? Eh.....

Ms S The ones I had in the Clinic I found were fantastic. You can't but them in town

Ms. M(a) That's it

Ms. S They get them in Dublin

Ms. P. Did they not measure you here for the proper size Ms. S?

Ms. M(a) They did yeah

Ms. G But you only get the one pair and one pair is no good to you

Ms. M(a) That's right, that's right

Ms. P Yeah yeah

Ms G I bought a pair up in Schools or whatever you call them and they are not the same

Ms. M(a) They are not the same at all

Ms. G They are not the same quality. Them is the good ones.

Ms. P They only last 6 months.

(Longford Focus Group)

Ms. M(a) – I would come down one week and I would be improved and the next week and I'd be gone back that was my way, it'd never be the same any two weeks made me feel rotten, very bad, I was attending a year and a half two years. Nurse X had to fly up to Dr. O's a few times for me because I had a clot and had to go to Tullamore. The stockings were always really hard to put on because I fell and broke my shoulder and I couldn't get them on. My legs get tired of the stockings

Health Board Facilitator Anyone else with the stockings?

Ms M(b) – Summer and winter I leave them on all the time they gave great support.

Ms M(a) But you'd take them off going to bed

Ms M(b) Oh Yes but first thing in the mornin' I'd put them on again

Mr. S(a) My problem is getting' them on in the mornin'

Yeah Yeah from other group members

Ms M(b) You'd be afraid you'd catch them on a nail

Mr. S(b) They give you great support there's no doubt about it

Yeah Yeah from other group members

(Athlone Focus Group)

### LACK OF PHYSICAL MOBILITY

Impaired physical mobility was observed in both focus group sessions.

Ms M(a) No I wasn't able to go out I had neighbours comin' in to me. I wasn't bale to get around I was a year a year and a bit sit done feet up from the bed to the chair. I found it an awful change cause I used to go out every mornin'

Mr. J – when the ladies done my leg up there was never any problem when they started they dressed it and that was it, leave it on for the week until I came back the following Wednesday, I had never any problem like that maybe I would get a bit tired or that but once I'd rest meself for an hour or so I'd be as right as rain again.

Certainly they gave me great relief I'd say after three visits here the pain went out of my leg I was attending here about six months eventually it healed up and I don't know I never had a problem since I still had a pain in my leg but it didn't have anything to do with the ulcer. I think it's my hip

(Athlone Focus Group)

Health Board Facilitator You mentioned about getting around – you know your mobility when you actually had the leg ulcer were you able did it inhibit you in anyway in performing your day to day activities

Ms. M(a) Well it did really. I had to do it against me will and wishes. You had no choice in the matter because.....

Ms. G – I invested in a walking stick and it gave me tremendous help if you could go for a little bit just out the road and people'd say Oh G., G. what happened you?. You couldn't understand but to lean on the stick you were

*kinda propelled forward and meant you could take another step I use to walk out to the clinic it was a marvellous help. I just used it for a few of weeks it was great to lean on it now I didn't use it around the house only outside and also it was a protection it kept anyone away from my leg but it was a great help walking .....the walking stick*  
(Longford Focus Group)

Both of these excerpts show great adjustment by participants to life with leg ulcer and that regular activity is inhibited to a greater or lesser degree depending on the approach of participants to life with a leg ulcer.

This is also emphasised in the discussion in the Longford group regarding daily activities such as washing.

*Ms.M(a) – The other thing is the shower was very hard to.....*

*Ms.P Oh stop!*

*Ms.M(a) Thanks to Ms. M(b) I was only spongin' meself.*

*Ms.M(b) I had got it it's a thing to cover bandages 'n' that. They got one for me at the Clinic they bought one for me, it comes right up, it comes in over your whole leg and comes up to there it doesn't let the water in it costs about £15 or that but was fantastic wasn't it*

*Ms.M(a) It was but that was the only one they had that's the only one they had like*

*Ms.M(b) – you couldn't get another one*

*Ms.M(a) – I want to mention about that for about three months not even in the bath standin' but actually sitting on the side of the bath washing yourself from the wash hand basin and drying use to take nearly an hour at this stage you were jaded just jaded because you were afraid to go into the shower and I did ask them about that.*

(Longford Focus Group)

*Ms. M(b) – Not being able to get into the bath was terrible*

*Ms. M(a) One leg in and one leg out*

*Ms. P you feel so awful and you feel so dirty it's terrible*

(Longford Focus Group)

### SOCIAL INTERACTION WITH A LEG ULCER

Again in both focus groups there is a definite sense of adapting to situations as they arise in the context of life with a leg ulcer. There was some suggestion in the group of avoiding situations where one might get 'a bang on the ulcer' and a sense of limitations that having an ulcer may impose i.e. getting comfortable shoes suitable for a formal occasion. However there is an overwhelming sense in both groups of 'personal adaptability' i.e. participants being aware of limitations that leg ulcer can impose, minimising risk and if deemed possible then for the participant the relevant social interaction is engaged in.

*Ms. G – Well you are always conscious that you wouldn't get knocked 'n' that*

*Ms. P – You were limited alright to where you could go, if you thought about it all right but I'm not a person to be going out but I did go once to the cathedral to that that wonderful concert that was on, and what I brought a thick cushion and people thought I was going to sit on the cushion but I put my foot up on it and it was marvellous and I could keep it up like that for the two hours and it was great because I don't think I would have survived that concert ...which but it was magnificent without having the leg propped a bit*

*Ms. M(a)– What your saying about social life if your going to a wedding or anything and you'd have this big bandage on and you couldn't get a shoe to fit you particularly where it was on my ankle my leg was twice the size as normal there was about three bandages on it*

(Longford Focus Group)

Mr. S(a) *I do they hovering now at home*

Ms M(b) *Good man I could do with the ironing being done*

Laughter in group

Mr. S(a) *My wife is a ciatog and I couldn't be looking at her.*

Laughter in group

Mr. S(a) *Apart from that I do it and I think you know that the least knock I get I have to stop because of the dangers of the other complaints that I have but eh.....I had no bother it never caused me a thought when you think about these things that's when it is likely to happen.*

Ms M(b) *That's right you'll surely hit the end of the bed or the corner*

Mr. S(a) *I've no feelin' down that end at all. I have to watch my feet very single day of my life and that's when I see the cuts 'n' that at the moment I've only one plaster on me and I think it's nearly healed. The danger is if you neglect them they could turn ulcerous and you can't afford to have that*

(Athlone Focus Group)

In both groups certain situations were seen to be particularly hazardous with a leg ulcer.

A leg ulcer was seen to be contributory to social isolation by some group participants but not by all. This would suggest that peoples level of 'personal adaptability' is reflective of their own definition of illness and appropriate behaviour in the 'sick-role'. A larger study would be required to resolve this unequivocally.

Ms M(b) – *I felt very isolated I didn't go out at all. I missed goin' to Mass every mornin'.....I lived alone too. I wouldn't stay now with them grandchildren...I'm terrified but it's all watch Granny's Legs, watch Granny's legs. (Laughing in group). With that as well Granny's legs aren't goin' to get better so I avoid that I go down for the day and I come back in the evenin'.*

Mr J *I think your own temperament has a lot to do with it to as S said you just have to get up and go on with it*

Mr. S(a) – *I would say this now and not speaking for meself but next door to me there's a lady next door to me you know and I have to bring her down she's 85 or 86 this months I'm not sure she lives alone and she has two legs and from there down (points out area on won body) was a massive ulcer and they've healed up but she wouldn't come home this time because what would she come home for she doesn't want them back again.*

(Laughing in group) *but she does not....she's up cock crow in the mornin' and she goes to bed at all hours and it doesn't inhibit her in any way. The reason why is that she doesn't even think about it.*

(Athlone Focus Group)

Health Board Facilitator *Some people have said when they have their leg ulcer that they have felt isolated Would anyone here have had that experience*

No response from group

Health Board Facilitator *In terms of not being able to go out or being stuck to safe areas or areas that you felt safe in*

Ms M(a) *You had to do it you just had to do it*

Ms. G *Well you have to be extra careful.*

Ms. P. *I think it becomes automatic to avoid all these things. Well when Y (granddaughter) is dancing on the floor she's 8 now, she kicked me by accident, although I never actually told her so if she comes dancing near me I say to her Y go over there and dance because she's forever.....and she's always moaning I'm never allowed to dance near you anymore you know*

Ms. G – *Well you are always conscious that you wouldn't get knocked 'n' that*

(Longford Focus Group)

Both of these discussions also hint at children playing being a particular hazard for those with leg ulcers

## OPTIMISM WHEN ATTENDING CLINIC FIRST

Optimism about the clinic was demonstrated in the Athlone Focus Group discussion mainly because of word of mouth and a strong successive previous history of dealing with leg ulcers.

**Mr. S(a)** *Well When I heard about the clinic first I heard a fair bit about it for 2 or 3 people who had been here that it was the last word. Now I was optimistic all right and I couldn't understand how they could heal it in such a short time but after two visits I got great relief and to tell you the truth I still don't understand it it's there now and I have to look after it of course but once as I keep doing that with the advice I got here from the nurses.*

**Mr. J** *- I certainly agree with that and to say that I had consolation in coming and I felt too that you have support and that's the great consolation that you have support, they put you at ease as well as doing the job.*

(Athlone Focus Group)

## TREATMENT CHANGE ON ATTENDANCE AT LEG ULCER CLINICS AND PATIENT SATISFACTION WITH THIS CHANGE

These discussion excerpts really follow on from the previous topic of optimism when attending the Clinic first. In both groups the treatment at Clinic was seen to be very effective/successful (proved by healing of ulcer in all cases) and delivered in a friendly and efficient manner. This delivery of service is seen to be very important to leg ulcer sufferers as it provides consolation and a support network. The consolation received and the support network established are coping mechanisms for life with leg ulcer.

**Ms M(b)** *- It was always going to be good because there was no treatment there. The doctor never dressed my leg. I didn't know about any of ye but he never dressed my leg*

**Mr. S(b)** *Never done any for me even when I was down in Portiuncula I had bit of a black-out and when I pointed out the varicose they just nodded their heads and passed by and never even put a dressing on it for me. (Comment refers to care before attendance at Leg Ulcer Clinic)*

**Ms M(b)** *- Here in the clinic they will try different things like if it is not healing they'll change to something else I found in Tullamore it was one thing all the time whether it was healing or not*

**Mr. S(b)** *- That's what I liked about this I concur absolutely with S and J there's no disagreement on that the nurses were first class but it didn't matter which nurse'd come to you they were all the same you know and if this ointment wasn't working they'd switch to another, no bother absolutely no bother and what's more if I may say this if I may say this they would give you what ever was left in the tube, and they would tell you if you have occasion to change this now let us know because I have to watch my legs every week every day having to do it and they'd give me this .....I forge what the hell they call it .....*

Member in group says Gel

.....and that worked for me mighty

**Mr. S(b)** *- They were so professional, we hadn't been used to that doctor to hospital doctor to hospital they were so professional I mean you I felt a great level of care*

**Ms M(b)** *They knew their job*

**Mr. S(a)** *It was great for someone to do something for you which you didn't get from the doctor like you'd be with him and you felt you were just the patient but with the nurses here you'd have great confidence in them I knew from the third time when that I came down here that it was going to heal I never had any.....I knew how it was to put a dressing on my own leg and that's how far it went two or three times a week even when I was working now I don't have to dress it at all because once I can wear my stockings, watch me legs in the have a bath or have a shower or that. That's what you call the power of positive thinking*

(Athlone Focus Group)

**Ms. M(b)** *- It was much better*

**Ms. P** *You're in one pace where there's only really half attention to another place where they really care*

Ms. S Concentratin' on your ulcer 'n' that

Ms. P – Your not just one of a number your you. You could talk to the nurses it's more easy to talk to them than to the doctor

Yeah yea in agreement from other group members

(Longford Focus Group)

### TREATMENT AT CLINIC AND PERCEPTION OF LIFE WITH LEG ULCER AS BEING A TEMPORARY TIME RATHER THAN PERMANENT

Treatment at the Leg Ulcer Clinics gave patients hope that improvement was imminent giving an understanding that life with a leg ulcer was temporary rather than permanent.

Mr. S(a) – *Once I came here and I knew who the nurse were I didn't mind, Ah well I have a positive approach to life in every respect and I wouldn't say that it would bother me one bit, it wouldn't, to be quite honest with ya.*

*That's the truth*

Health Board Facilitator *How about anyone else?*

Mr. J – *After my second or third visit now I was fully consoled I wasn't worried I knew what it was going to be like. I could see it and I could feel it*

Mr. S(b) *I found that after seven or eight months going through it and not seeing any light at the end of the rainbow, when I came even after my second or third visit I could see an improvement and I had the confidence that it was on the way and it was going to happen*

(Athlone Focus Group)

### ROUTINE OF WEEKLY CLINIC VISITS

The routine of weekly visits was not seen to be an imposition on participant's lives as improvements in the leg ulcer were easily noted and the leg ulcer clinic as viewed as being very specialised.

Health Board Facilitator *And did you find having to come every week was it normally every week?*

Yes Yes from group members

Mr. S(a) – *I couldn't understand why I couldn't heal it myself It was costing me a fortune buying ointments and stuff and still I couldn't make any difference on it and when I came down to the clinic, I was amazed I couldn't understand it that after 3 weeks it was healing up and it must be about 1'2 months now since I finished up.....maybe not now but I'd say it was....., like S says there I got great healing and they were very very good and everything was good after.*

(Athlone Focus Group)

Ms. M(a) – *your morning was gone anyway hut you were so (emphasis in speech in original) grateful they are so good*

Ms. G – *Oh they are marvellous (emphasis in speech in original)*

Ms. M (a) *They were lovely lovely (emphasis) I knew I was right you didn't have to touch it for a week and you came back next week and gave it over to them*

Ms. S - *I brought my mother in a couple of times when she was coming because she's on holiday and she's in a wheel chair and when I was coming in to town I would bring her and she had ulcers years and years ago and she couldn't believe they bandaged it up and cleaned it up and everything.*

(Longford Focus Group)

## PATIENT SATISFACTION WITH LEVEL OF EXPLANATION OF TREATMENT RECEIVED

Patient Satisfaction with level of explanation of treatment and actual treatment received at the leg ulcer clinic was very strongly expressed at the focus group sessions. Satisfaction with level of explanation of treatment received centres around a clear explanation at the beginning of treatment and the personal treatment received. Patient satisfaction with actual treatment centres on issues such as regular assessment of ulcer, flexible course of treatment, and reports being kept of treatment as it progresses.

*Ms M(a) With the doctors you have too much to talk about there's too many patients and you're just another Mr. S(b) - your a number in the doctors and that's it*

*Health Board Facilitator Was the treatment explained at the beginning like what was going to happen with regard to the treatment of the ulcer when you came in first*

*Ms(a) Yeah it's be assess from one week to the other to see if it had advance a bit or gone back the way or forward*

*Mr. J - yes I though it was explained pretty well, I had eczema around the area of the ulcer and that was bad and the nurses told me I should go to the doctor and he would give me treatment for it as well as anti - biotic he would give me ointment for it they did explain that it was eczema they kept using it until it cleared up*

(Athlone Focus Group)

*Ms. S - they tell you that they'll dress it and they'll try compression and various things you know*

*Ms. P - The first thing I had done was they put a machine on it they do this to find out if you are suitable for compression I was a good hour and a half*

*Ms. S - yes it was explained My leg was that bad that mornin' that do you know when they take your blood pressure that had to put a band on your leg that couldn't put it on mine it was so tender*

*Ms. G - I didn't have the compression test because I had the ultra sound done so I couldn't have the test*

*Ms. P - It was a learning process*

*Ms. G - They did everything to the best of their ability it was all new to them as well*

*Ms. M(b) - No you wouldn't feel because you could say anything to them they didn't have loads of time but they listened to you anyway*

*Ms. G - And they also took notes on what you wanted and how you were getting on they kept a file on how you progressed*

(Longford Focus Group)

## SUGGESTIONS FOR IMPROVEMENTS OF LEG ULCER CLINIC SERVICE TO PATIENTS

Since the level of satisfaction with the Leg Ulcer Clinic was very high suggestions for improvements was very low. The main area of concern in the Athlone focus group was filling a bucket each time for each patient and in the Longford Clinic small working area for Clinic.

*Mr. S(a) The only thing I'd say about that is I use to pity the nurses they had to fill every bucket out of .....that thing you know the way they used to do it*

*Ms M(a) never approved of the bucket*

*Mr. S(a) the bucket was the only way that they could get you r foot down into it and the water'd come up around, each bucket had to be filled out of the hand basin, Nurse X told me that they were goin' into this new extension and that they would have a place there I was saying if people could walk in and I'm only sayin' this now .....and eh.....emerge their feet down into a bath that would be a big help*

(Athlone Focus Group)

*Ms. G The rooms were very small, having to be moved from room to room*

(Longford Focus Group)

## CONCLUSION (SUMMARY OF ISSUES RAISED THROUGH DISCUSSION)

In all cases ulcer healing was the final outcome of the leg ulcer clinics. Focus group discussion identified that the experience of living with a leg ulcer was a very pervasive one in all group participants lives. This pervasiveness is reflected in on-going pain and loss of sleep. Constant itch and swelling was also identified as being present but not in such an intrusive way in participants lives.

Both groups saw elastic stockings as being an invaluable assistance for mobility with regard to leg ulcer support. However, ready availability was raised as an issue of concern to participants. Mobility was affected to a greater and lesser degree in the group participant's lives. Personal washing was identified as being a particular problem with a leg ulcer. One of the most crucial observations to emerge out of the analysis of the focus group discussions is that people's level of adaptability is reflective of their own perception of the 'sick role' and resultant appropriate behaviour.

The treatment at the Leg Ulcer Clinics was obviously very effective for participants, as there was a 100% healing rate among all participants. Through the operations of the leg ulcer clinics great consolation was received by participants as to the prospect of full healing of their ulcer. This as well as a support network established through patient and nurse interaction provided a coping mechanism for dealing with life with a leg ulcer.

Patient satisfaction was very evident with the level of explanation received prior to treatment and treatment received.

The only suggestion for improvement mentioned in the Longford focus group discussion was an alternative to the bucket system used there and more space in the Athlone leg ulcer clinic.