

**THE PROGRAM OF APPLIANCES FOR DISABLED  
PEOPLE (PADP)**

**Organisation:** Hunter Lymphoedema Support Group

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Partially Confidential

## **HUNTER LYMPHOEDEMA SUPPORT GROUP**

CHARITY NO. CFN 17609 - ABN 35 587 399172

With having worked and helped a lot of lymphoedema sufferers the last three years I would like to speak on their behalf.

To try and have a normal life after going through cancer operations and treatments is hard enough, then suddenly develop something like lymphoedema can come as a huge shock and hard to cope with.

Like all disabilities there are different degrees as it is with lymphoedema, but what is the same is the fact that it cost a lot of money to be able to combat this disability. It is very sad and hard to describe the way some of these people have to live their lives as they cannot afford to have the proper treatment. A lot of these people are also house bound as they have their lymphoedema in the legs and are so bad they cannot get around.

One of the important thing that would help all lymphoedema sufferers is to get help through PADP for their compression garments.

Each person is different with their lymphoedema, some need sleeves and gloves, some need just knee high stockings, some need thigh high stockings, and some have to have special made garments (greater cost) but it all comes down to the same problem as to how can we afford to have what is required.

Earlier this year I was told I had cancer and had to have a radical hysterectomy including removal of lymph nodes from the abdomen. I had to have 4 lots of radiation. After that I developed lymphoedema in the legs and need compression stockings at a cost of \$70 plus per pair and a frame to put the stockings on at a cost of \$50. I am 67 and on the age pension, and I am now also aware of having to have other treatments like lymphatic massages and other things to help me so I can still be able to get around. This has been a real shock to me.

I was diagnosed with cervical cancer in 1973. Admitted to Newcastle Hospital for radium, insert per vagina. Returned 6 weeks later for hysterectomy. Sent to Jean Colvin Hospital for 6-8 weeks Cobalt Therapy. I was diagnosed with lymphoedema in 2001 in left leg. I need Compression stockings at Approx \$90 per pair at least 4 times per year. I also need massage treatment once per month at \$75. As I am on a pension this is hard to keep up each year but I need the garments so I can walk around. I belong to the Hunter Lymphoedema Support Group.

I developed breast cancer and had to have my left breast removed December 2002, and in July 2003 I developed lymphoedema.

I need to wear compression sleeves every day which one of these sleeves cost anywhere from \$80 plus depending what grade I need and where they are ordered from. The minimum I should have is four. With the cost of the sleeves plus massages at least every month (should be at least twice per month) at a cost of \$80 and the creams we have to use for our lymphoedema and oils and body washes these extra cost are around \$250 per year. To get compensated for our garments would help ease the burden of the cost to my family.

Two years ago I developed breast cancer, I had lumpectomy – lymph nodes removed and had to have radiation and chemo. After the treatment I developed lymphoedema which causes great pain and discomfort. I have to wear a sleeve and have regular lymphatic drainage treatments. I find it very hard to keep having the treatment I need as the cost is ongoing. Sleeves should be purchased at least every 3 to 4 months and as you should have to every time I can only afford one at a cost of \$80, which is \$320 per year, and the lymphatic massage are \$80 per massage. There are also other cost I have to outlay to try and have a certain quality of life.

It would most definitely help me to be able to afford extra sleeves to help keep the lymphoedema under control.

I am a member of the Hunter Lymphoedema Support Group.

I have had lymphoedema for seven years and it has been a struggle from day one to try and live a normal life. I have the lymphoedema from the waist down and therefore have to have specially made compression garments made to measure. The cost of these specially made garments are round \$1200 per pair and each time I have to have two made at a time as you have to put a different pair on each day and they are too thick to dry over night as they cannot be hung out side to dry. The correct time you should renew these garments are every 3-4 months, I use to but now it is impossible as the cost is too much as there are other cost involved in keeping my lymphoedema under control.

To be able to get some help with the purchase of my compression garments to keep my lymphoedema and all with lymphoedema would mean a lot to all sufferers and their families.