Submission No 33

THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Name:

Ms Joy Ryder

Date received:

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Submission for costs for lympoedema clients:

From: joy ryder

Sent: Monday, 1 September 2008 11:14 PM

Subject: re costs for lympoedema clients

Thank you for the opportunity to write on behalf of my many lymphoedema clients both primary and secondary, many of which have already endured much through surgery, radiation and chemotherapy due to melanomas, breast cancer, prostrate cancer, cervical cancer and non hodgkins lymphoma. Lymphoedema is not curable but can be managed if the clients are educated properly, something that is lacking in the medical area at the moment.

They need to be aware of diet (specific to lymphoedema), exercise (specific to Lymphoedem) massage (specifice to lymphoedema) compression garments (that can be extremely expensive) and even more so if the condition worsens which it will if left untreated. Elevation is also important at the right height and therefore other appliances may need to be purchased. Skincare products are essential to stop tissues from being fibrotic and to avoid infections such as cellulitis, which can lead to antibiotic treatment or even hospitalisation causing more pain and anguish for the lymphoedema sufferer.

Heat is another problem area as the lymphoedema limb must avoid heat at any time making this very difficult in summer, extra sun protection is required, also insect bites and scratches need to be dealt with immediately as this can also bring on cellulitis. Most of my clients can not afford the right compression garments due to the costs, they need approximately four pairs a year depending on the severity of their condition and unfortunately they will only get worse.

I have one particular client that sleeps in a lift chair, due to her condition as she can not get in and out of a bed she is in her 70 s, her husband has Alzheimer's is in a nursing home, she has no family, a truly sad case, but this is what happens when lymphoedema is not picked up soon enough and the right treatment is not given early enough. This is just one of my cases there are many more some are even more sad than that as they are younger with small families, some have lymphoedema and are going through secondary cancer treatment with radical surgery of second breast all of which can be very costly both emotionally, physically and financially and in some cases can lead to depression causing even more strain and anguish.

Shayne Connell and I met at a cancer council meeting some time ago with regards to lymphoedema post cancer I have a diploma of lymphatic drainage and work with the N.S.W Lymphoedema Support Group in the Hunter region and I believe we can make a difference to many lives with more awareness both with the government bodies, medical profession and the community at large.

Thank you for taking the time to read this letter. Regards, $\ensuremath{\mathsf{Joy-Anne}}$ Ryder.