Submission No. 1299

(Better support for carers)

AOC. 27/1/09

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Catherine

Thursday, 8 January 2009

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To: Committee, FCHY (REPS)

Hi, I got this web address and email from the carers newsletter and would like to put forth a suggestion that would help carers.

My son has Cystic Fibrosis and requires extra heating and cooling but I could not get a concession on my gas/electricity because the health care card is in his name.

TRU energy were going to allow me too but DHS knocked it back. I have several letters that were written back and forth about this and it was very frustrating.

Martina from CFV helped me write the attached letter but we didn't get anywhere. It would be very helpful if we could get this concession.

Cheers, Catherine

12 June, 2008

To whom it may concern,

This morning I spoke with "Glen" in the sales department of TRU Energy regarding a client of ours whose son has the life threatening condition, Cystic Fibrosis. As explained to Glen on the phone, I asked if our client, Mrs Catherine

was able to add a health care card concession to her account which is in her 3 yr old son Jakes' name as she is a primary carer and receives carer allowance for her son who has cystic fibrosis. Glen spoke with a supervisor who said that this was allowed to occur and to get to contact TRU energy with her concession details. This information was then passed on to

As you may know, cystic fibrosis is a genetic condition which affects the respiratory and digestive system. Lung infections, caused by bugs such as a common cold, among other things, are a genuine concern and a life shortening issue. It is essential, therefore, to have the heating on constantly in the house in winter, to prevent Jake contracting a cold or flu bug and, in the summer, for air conditioning to prevent him losing large amounts of sweat and salt (another common problem for people with CF) through overheating. This of course, as I am sure you understand, makes for an extremely high electricity and gas bill.

As costs for CF medications and other essential treatments is extremely high, I would appreciate you adding the concessional discount to account (both electricity and gas) as was agreed to by Glen when he spoke with his supervisor this morning. When I spoke with Glen this morning he did not make any notes of this conversation as he did not access account because I was ringing on behalf of her.

If you have any questions please do not hesitate to contact me Please advise myself or as soon as possible about the outcome of this request. Please note, she has not had trouble with her water company applying this concession. To apply the concession immediately the concession card number is

We thank you for your understanding in this matter and look forward to the application of this concession to her account.

Sincerely,

Martina Community Support Worker