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From: Wingett Carole [mailto:C.Wingett@rbht.nhs.uk]

Sent: 09 December 2011 14:36

To: DWP PIP assessment

Subject: Cystic Fibrosis team, Royal Brompton Hospital

I have some comments from our Cystic Fibrosis Team in respect of the Daily Living Activities and their application to cystic fibrosis patients.

Activity 1 – Cystic Fibrosis affects the lungs and digestive system and patients are often too breathless to lift saucepans and prepare food. Those with CF need to eat good quality nutritious meals and need to eat 150% more calories than those without CF. Meals therefore need to be cooked conventionally as the dietary requirements cannot be achieved with a microwave. Would descriptors F and G apply if this were the case? Another issue is that it might also not be possible to use a cooker because of the use of oxygen and someone else would have to cook for them.

Activity 2 – We were wondering if the descriptors would apply to those CF patients who need encouragement to eat. Food is seen as part of their treatment for many CF patients and not a pleasurable activity. CF patients often have no appetite and the effort to eat can be tiring.

Activity 6 – Those with respiratory conditions find bending down to dress the lower half of the body causes breathlessness and therefore we were not sure why the score was less than for the upper body.

Activity 11 – We would like some clarification in respect of the assessment of mobility. Cystic Fibrosis patients are mostly young and do not wish to use a wheelchair. They tend to struggle to walk because of breathlessness and only walk a short distance before stopping and resting. Walking would tend to involve a lot of stops and rests. Which descriptors would apply if they were only able to walk up to 50 metres before they had to stop but could carry on after a rest?

Regards

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