



MANCHESTER ADULT CYSTIC FIBROSIS CENTRE

University Hospital of South Manchester



NHS Foundation Trust

The Manchester Adult Cystic Fibrosis Centre, Wythenshawe Hospital, Southmoor Road, Manchester M23 9LT  
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Tel: 0161 291 2154 Secretary to Professor Webb and Dr Jones  
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PIP Assessment Development Team Department for Work and Pensions  
2nd floor, Caxton House  
Tothill Street  
London  
SW1H 9NA

Date: 18/7/2013

Dear Sir/Madam

Re: Consultation on the PIP assessment 'moving around' activity

On behalf of the Manchester Adult Cystic Fibrosis Centre, I have enclosed a detailed copy of concerns regarding the impact of the proposed change to the eligibility criteria for the enhanced rate of the mobility component of PIP on our patients.

I hope you will give due consideration to these concerns in making the final decision to this matter.

Yours Sincerely

Professor Kevin Webb

Clinical Director







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To whom it may concern

PIP Assessment

Department for Work and Pensions

**Consultation on the PIP 'Moving around' Criteria:**

On behalf of patients with a diagnosis of Cystic Fibrosis who attend The Manchester Adult Cystic Fibrosis Centre at Wythenshawe Hospital, Manchester, we would like to raise our concerns about the impact of the proposed change to the eligibility criteria for the enhanced rate of the Mobility Component of PIP.

**Health**

Cystic Fibrosis (CF) is a progressive life shortening illness which mainly affects the respiratory system but can also impact on the normal functioning of the liver, pancreas and digestive system. In addition to the constant daily battle to combat ever present bacterial chest infections, via nebulisers and inhalers, most young people with CF are prone to regular episodes of acute chest infection and symptoms can include increased mucus in the airways and lungs, chest tightness and or pain, violent and frequent coughing episodes, breathlessness on minimal exertion, general fatigue and significant loss of appetite with an associated dramatic loss in weight. CF symptoms can often be unpredictable and variable in nature.

**Mobility limitations**

The people that we work with are young adults, a few of whom have children of their own. We feel that the reduction of the eligibility for 'assistance to enable independent mobility' from 50 metres to 20 metres will have a significant detrimental affect on our patients' lives. Since 20 metres is a very short distance it would certainly exclude some of our patients who have significant mobility limitations in the 20m-50m range.



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## **Employment**

Despite the complications of CF disease, advancement in treatment now offers most of our young patients the opportunity to participate in every day activities like attending higher education, finding work and having families of their own. This possibility has been embraced warmly by our young patients because they are keen to achieve, to contribute to society, and to lead a more normal life not too dominated by deteriorating health. These wider life opportunities and increased independence are however only possible because of :-

- a) More effective antibiotics
- b) Quicker treatment times using smaller and more portable equipment eg nebulisers
- c) Considerable assistance from carers to do treatment at the start of the day
- d) DLA Mobility Component and the use of a Motability car

We would argue that d) is as important as the other factors listed in helping young people with CF to secure and succeed in employment. Having a Mobility car via DLA – Mobility Component offered CF patients the financial means to meet transport costs, especially in relation to the cost of Insurance which, for young people generally, is a barrier to transport choice and work opportunities. In addition having such transport has markedly improved our patients' Quality of Life as it gives them choice to access friends, family, cinema etc.

It is also worth noting that the late Sir Alf Morris, who was a Wythenshawe MP (and the force behind the introduction of DLA through Parliament many years ago), regarded the option for disabled/chronically sick people to be able to access amenities ( including employment) as one of the main thrusts of the legislation. This goal appears to have been lost in the change to PIP.

Those who would no longer qualify under the new PIP criteria are likely to experience difficulties accessing higher level education, employment and health care. They will struggle with tasks that they were independent with previously, such as going shopping and participating in the wider community by being able to access social activities and visiting family and friends. In some cases we feel that without the higher rate of the mobility component of PIP the government are condemning some CF individuals to being virtually housebound. This new proposal under PIP does little to help disabled people to fulfil the social contract of being part of society and contributing by working, volunteering or being part of their community.



One of the biggest fears our patients are expressing is in relation to the risks of isolation and loneliness, of being housebound, since for most of us contact with family and friends depends on being able to go out. Research on the impact of the Motability car scheme by Oxford Economics in 2010 concluded: "... by enabling people to visit family and friends more frequently, Motability increased its customers' wellbeing by the monetary equivalent of up to £3.2bn in 2009".

Recent research has shown that chronic isolation does real physical damage, affecting health and wellbeing and reducing life expectancy. An international study has found that involuntary loneliness carries a higher mortality risk than air pollution or obesity. Under PIP, many people will inevitably face loneliness and isolation and, according to the available evidence, deteriorating mental and physical health and a shorter life expectancy.

### **Public Transport**

For many of our patients public transport is not going to be a viable solution to enable independent mobility. CF patients have difficulties accessing public transport for a number of reasons:-

- Some patients are extremely self conscious of the frequent and often violent coughing episodes that they experience and the need to expectorate sputum. Even in hospital they prefer to do this privately.
- Their walking ability is variably limited by breathlessness (sometimes to the point where they are housebound during episodes of acute chest infection).
- They are limited in their capacity to stand to wait for public transport because of exhaustion and in some by arthritic type joint pain.
- They are anxious about close contact for more than a few minutes with members of the community some of whom may be harbouring viral/bacterial infections to which they are particularly susceptible
- A small number of patients with CF related arthritis will be unable to safely and regularly manage to climb a bus's steps.





- Those who live more than 20 m from a bus stop cannot be certain that they will be well enough to walk that distance regularly, especially at the end of a trip out.
- Public transport provision can be inaccessible or very poor in some areas, with those in rural areas being most affected.
- Some patients are only mobile with oxygen but would not risk a bus journey in case a bus was cancelled and they ran out of oxygen.
- Patients in hospital for long periods because of the need for intensive medication and physiotherapy, psychologically, at intervals, need a break from the Ward – this they can do by driving home for a couple of hours to then return to hospital mentally refreshed. This escape option for many would be impossible without a Motability vehicle.
- Most of our patients live outside of the Manchester area and have to travel long distance to our regional centre – this is often the case nationwide for those who have CF because they need to access the specialist centres for their treatment. Not having a car would mean that it would be more difficult for them to attend their outpatients clinic appointments. In addition there are the cost implications to consider – at present those on high rate Mobility, but without Motability cars are just about able to meet the cost of taxis to travel independently to hospital. It doesn't appear fair or just that they should be disadvantaged in accessing all other amenities by virtue of this un-researched ad-hoc change in the eligibility criteria.

In addition patients often attend the Out-patient Clinic or are admitted to the Ward in a very poor state of health, having been driven to hospital by carers who act as named drivers of their Motability car. When the new CF Centre was rebuilt at Wythenshawe Hospital in 2009 it was essential that there was a 'dedicated' patient car park as some patients had over the years driven home unseen because they couldn't walk from the main car-park to the CF Centre (~50-100m).

In conclusion we would suggest that the original distance criteria of 50m be re-instated- it is a universally recognised measure of disability in the UK. The proposed criteria change to 20m –for what appear to be superficial cost saving reasons – are likely to have a negative impact on the health and well-being of our CF community with a long-term cost impact



which could be significantly more as a consequence of the effects on employment, and both mental and physical health.

Professor Kevin Webb

Clinical Director

