

WELFARE REFORM COMMITTEE

THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND

WRITTEN SUBMISSION FROM THE BUTTERFLY TRUST

The Butterfly Trust, on behalf of the Cystic Fibrosis community throughout Scotland, is responding to the call for evidence.

As an organisation we frequently help clients with applications for PIP, DLA, ESA etc., through reconsiderations and representing them at Appeal Tribunals. Our specialist knowledge of the condition Cystic Fibrosis plus our long experience of various disability benefits have ensured a very good success rate and, to date, we have not lost a single Appeal. We were part of the consultation process when DWP were preparing for the move to PIP and made our views known at the time.

There are positive aspects to the PIP form, with its associated points system, which make it much more focussed and easier for us to advise clients on the information required. However the time scale allowed for return of completed forms is quite unrealistic, especially for vulnerable people struggling with a health condition and who ask for our help. The return date is based on the date the DWP letter was written, but often it is not received until 7-9 days after that date thereby adding to the pressure on the individual.

The change in the criteria for the mobility component is, perhaps, more contentious and there are many concerns about the potential to lose their motability car and the concomitant loss of independence. As regards the 20 metre walking 'test' there are two points to make of relevance to Cystic Fibrosis sufferers:-

1. The use of public transport is often not an option because the condition can cause severe breathlessness, exhaustion and pain, and many are limited in their capacity to stand (and wait for public transport).
2. The use of public transport is, in many cases, not recommended because it involves close and prolonged contact with others who may be harbouring viral/bacterial infections to which they are particularly susceptible.

The one Mobility area in PIP where we have had a problem to date concerns the section on "ability to plan, follow and undertake a journey", and we are awaiting a reconsideration decision on that. However we are aware this is currently subject to two very different decisions reached by two upper tribunal judges (on 17 and 23 June 2015) and await a resolution.

One final negative view on the process. We frequently attend the medical 'face to face' assessments with our clients and we believe the assessment report is being given an unduly high weighting, in the decision process, in comparison with the other evidence the decision maker receives (the PIP form, statements from specialist medical professionals, supporting letter from social support organisations etc.).

The move to PIP is seen by some as rather more stringent and 'unfair' but, to date, we are not generally having problems with that benefit process. Nor do we have problems with DLA or ESA. The people we represent are being awarded a fair rate, with our help. However some parents are not aware of our services when their child is first diagnosed with the condition, and we are writing to others in the Scottish Government to try and ensure we are

embedded in the process early on. As far as the future delivery of social services in Scotland is concerned, we would urge that our organisation is integrated into relevant processes/protocols to ensure that parents of newly-diagnosed babies know about our services so that they can use them, whenever needed, from the very earliest opportunity.

I hope that this can be included in your deliberations.

Dr Miles Tew
Chairman of Trustees
The Butterfly Trust (SC 033174)