



THE SOCIAL SECURITY COMMISSIONERS

*Commissioner's Case No: GD/LA/2188/2001*

SOCIAL SECURITY CONTRIBUTIONS AND BENEFITS ACT 1992  
SOCIAL SECURITY ADMINISTRATION ACT 1992  
SOCIAL SECURITY ACT 1998

APPEAL FROM THE APPEAL TRIBUNAL  
UPON A QUESTION OF LAW

COMMISSIONER: J.P. POWELL

1. This is an appeal by the claimant, with my leave, against the decision of the Stockport appeal tribunal ("the appeal tribunal") given on 16<sup>th</sup> February 2001. For the reasons which I give, that decision is erroneous in point of law. I therefore allow the appeal and set it aside.

2. In exercise of the powers conferred on me by section 14(8)(a)(ii) of the Social Security Act 1998, I make the findings which I do below and give the decision which I consider appropriate in the light of them. My decision is that the claimant is entitled to the middle rate of the care component for the period from 24<sup>th</sup> November 2000 to 23<sup>rd</sup> November 2005, inclusive of both dates.

3. The issue in this appeal is whether or not the claimant satisfies the statutory conditions set out in section 72(1) of the Social Security Contributions and Benefits Act 1992, for an award of the middle rate of the care component of a disability living allowance. He is already in receipt of the lower rate of that component.

4. The claimant is a small boy. He was born on 24<sup>th</sup> November 1995. His father has been appointed to represent him in this matter. For simplicity, I shall simply refer to the "claimant" although, because of his age, all decisions and actions are taken or carried out by his appointee. The claimant has the misfortune to suffer from phenylketonuria – sometimes referred to as PKU. It may be helpful if I set out the relevant entry in the Oxford Concise Medical Dictionary.

Phenylketonuria *n*, an inherited defect of protein metabolism causing an excess of the amino acid phenylalanine in the blood, which damages the nervous system and leads to severe mental retardation. Screening of newborn infants by testing a blood sample for phenylalanine (see Gurthrie test) enables the condition to be detected soon enough for dietary treatment to prevent any brain damage: the baby's diet contains proteins from which phenylalanine has been removed. The gene responsible for phenylketonuria is recessive so that a child is affected only if both parents are carriers of the defective gene.

Pages 52 and 53 of the papers are a copy of a letter dated 10<sup>th</sup> October 1996, written by the Chief Dietician of the Willink Biochemical Genetic Unit, which is part of the University of Manchester School of Medicine. That letter describes a very strict dietary regime which, at least when the letter was written, was backed up by "weekly blood tests, and regular hospital visits to review his blood levels, advise on dietary change and check on his growth and development".

5. On 7th November 1997, a disability appeal tribunal sitting at Manchester awarded the claimant the middle rate of the care component for the period from 24th May 1997 to 23rd November 2000. The relevant decision notice will be found at page 65 of the papers. On 19th July 2000, the claimant applied to renew that award from and including 24th November 2000. On 26th July 2000, a decision maker decided that he was not entitled to either component of a disability living allowance from and including 24th November 2000. See pages 103 to 105 of the papers. A second decision maker reconsidered that decision but did not revise it.

6. The claimant appealed and his appeal came before the appeal tribunal on 16th February 2001. That was an oral hearing which the claimant's father attended on his son's behalf. He made it plain to the appeal tribunal that what the claimant as seeking was the middle rate of the care component and that the mobility component was not in issue. The evidence before the appeal tribunal did not refer to the mobility component. For that reason, and because there is no suggestion of any inability to walk, I shall confine myself to the care component. In the event, the claimant's appeal succeeded in part. The appeal tribunal awarded the claimant the lowest rate of the care component for the period from 24th November 2000 to 23rd November 2005. This was on the grounds that the claimant required attention for a significant portion of a day and that his needs were in excess of those normally required by children of his age. That is, the appeal tribunal were of the view that section 72(6) of the Social Security Contributions and Benefits Act 1992 was satisfied. The appeal tribunal declined to award the claimant the middle rate of the care component.

7. The appeal tribunal's findings and reasons are set out in the statement of facts and reasons which appears at pages 116 to 120 of the papers. This is a long and careful decision and the chairman is to be commended for the amount of time and trouble which she spent writing it. The appeal tribunal accepted the evidence adduced on behalf of the claimant and made it plain that there was no evidential

conflict which it had to resolve. After recording that the tribunal was being asked to award the middle rate care of the care component, the statement goes on to say:

... [The claimant's father] asked us to consider both the appellant's requirement for attention with his bodily functions during the day and his need for supervision during the day, to prevent him from eating anything which is outside the strict dietary programme imposed because of his PKU.

We understood that eating prohibited foods, or eating foods which are allowed but either above or below the amount calculated in the exchanges has potentially serious consequences and that if this is not or cannot be rectified by adjusting subsequent exchanges the result is irreversible brain damage. There is no antidote, no emergency treatment equivalent to sugar for a hypoglycaemic attack or antihistamine for an allergy reaction.

As I understand its decision, the tribunal approached the appeal on the basis that that description of the claimant's dietary needs was correct.

8. In the part of its decision which appears at page 118 of the papers, the appeal tribunal decided that the claimant did not require continual supervision throughout the day in order to avoid the risk of danger to himself or others. It is a lengthy passage, and I mean no disrespect to the appeal tribunal by not quoting it. It is also a closely and carefully reasoned passage. Nevertheless, despite the care which has obviously gone into drafting them, the tribunal's reasons are, in my judgement, flawed. For example, it is said that even if the claimant does eat something which he should not, steps can be taken to avoid harm by adjusting his diet on the following days. However, it is necessary to supervise what the claimant eats in order to know whether he has eaten something he should not and how much and when he did so. Further, any adjustments made in the following days must be carefully monitored both during and between meals. I am, therefore, of the view that, despite the care with which its decision is constructed, the appeal tribunal erred in law in relation to the continual supervision test. I therefore allow the appeal.

9. I consider that this is a case where it is expedient that I should exercise the powers conferred on me by section 14(8)(a)(ii) of the Social Security Act 1998, and make appropriate findings of fact and give the decision I consider appropriate in the light of them. That being so, I find as a fact that as the claimant

suffers from phenylketonuria exceptional care needs to be taken with his diet. He must be supervised closely so that he eats exactly the right amount of the right things at the right times. Indeed, the amounts which he eats have to be carefully calculated. Further, great care must be taken to see that he does not eat even very small amounts of foods which he should not eat. If he does eat something which he should not, this must be noted and remedial action taken. Such action will often involve adjusting what he eats at the next meal or subsequent meals. I find as a fact that, because of those strict dietary requirements, the claimant requires continual supervision throughout the day in order to avoid substantial danger to himself. Of course, all children of the claimant's age require continual supervision. However, the claimant, because of his condition and the need to ensure that there is rigid adherence to his diet, requires a greater level of supervision than other children of his age. Section 72(6) is, therefore, satisfied. Putting it simply, it must be extremely difficult and involve a lot of supervision to ensure that the claimant does not eat a sweet or a biscuit or a packet of crisps when he should not.

10. It follows that the claimant is entitled to the middle rate of the care component. The appeal tribunal awarded the lower rate of that component for five years. I award the middle rate for the same period of five years. That is, from 24th November 2000 to 23rd November 2005 inclusive of both dates.

11. The claimant will be 10 on 24th November 2005. By then conditions will have changed. If he applies to renew the award, a fresh decision will have to be made. That decision will depend on the facts and evidence put before the decision maker in 2005. It may, for example, be harder or easier to satisfy section 72(6). The claimant's dietary needs may, but not necessarily will, have become easier. Much may happen. If a decision has to be made in 2005, it must be made on the facts prevailing at that time. I merely say this. It is in the interests of children who suffer from serious medical conditions that they learn how to manage their own care as early as possible so that they can lead independent lives. For example, the diabetic child who learns to give his or her own injections and carry out tests with a small blood monitor – something many children of eight or nine can do – can stay overnight with friends, go on school trips or holidays and do many other things that a diabetic child who is not able to inject himself or do a simple blood test cannot do. In saying this I express no views, one way or another, as to the future in relation to the claimant. The award which I have just made is no indication of the nature of any

future award or whether one should be made. Any future award will depend on the facts at the relevant time.

(Signed) J.P. Powell  
Commissioner

Dated: 11<sup>th</sup> February 2002