

## Rules for Renal Dialysis

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### Introduction

1. This chapter is relevant to individuals applying for, and individuals receiving Child Disability Payment (CDP) who report a change in their condition. It describes rules of entitlement for the care component of CDP that apply to people receiving renal dialysis due to a disability or a health condition<sup>1</sup>.

*1 CDP regs, reg. 16(1)*

2. CDP is made up of the care component and the mobility component. Each of these components is awarded at a different rate. Rates describe a set amount of money at which the disability allowance is paid to the individual. There are three rates of the CDP care component: the lowest, middle, and highest rate [LINK TO DETERMINATIONS CHAPTER].

3. Individuals receiving particular types of renal dialysis may qualify for the CDP care component under the rules for renal dialysis. If the individual qualifies for the care component under the special rules for renal dialysis then they do not need to meet the usual rules for the care component.

4. Undergoing renal dialysis does not automatically entitle individuals to the higher or lower CDP mobility component. They can receive the higher or lower CDP rate of the mobility component if they satisfy the criteria for the mobility component.

5. Dialysis is a procedure to remove waste products and excess fluid from the blood when the kidneys stop working properly. It often involves diverting blood to a machine to be cleaned and can be performed at home or in hospital. There are two types of dialysis:

- haemodialysis is carried out on average three times a week. Each treatment takes approximately four hours
- peritoneal Dialysis is carried out daily for most children and young people. It takes 10-12 hours over night.

### Eligibility

6. An individual receiving renal dialysis is entitled to the care component of CDP if they:

- receive renal dialysis at least twice a week<sup>1</sup>
- meet the other entitlement criteria, such as age, residence and presence
- meet the backwards and forwards test.

*1 CDP regs, reg. 16(1)*

7. An individual is entitled to the care component if:

- their type of dialysis makes it necessary for another person to be present or to supervise<sup>1</sup> during set-up or the dialysis period
- they need another person to be present during dialysis to help with their bodily functions or to supervise the individual in order to avoid substantial danger to them<sup>2</sup>.

*1 CDP regs, reg. 16(2)(a)*

*2 CDP regs, reg. 16(2)(b)*

8. See the CDP Care Component Definitions chapter [ADD LINK TO CARE COMPONENT DEFINITIONS CHAPTER] for definitions of the following terms:

- supervision
- bodily functions
- substantial danger.

9. There are special rules for individuals who are terminally ill. These are set out in the Special Rules for Terminal Illness chapter [Add LINK TO SRTI CHAPTER].

10. There are special rules for individuals who are over 18 and whose entitlement for Personal Independence Payment (PIP) has not yet been determined by age 18. Please refer to the CDP individuals aged 16 to 18 chapter for more information [LINK].

11. To be entitled to the care component, individuals need to fulfil the backwards and forward test.

### **Attendance or supervision required during dialysis**

12. There are individuals who receive a type of dialysis that makes it necessary for another person to be present or supervising during set-up or the dialysis period. The case manager should assume that an individual applying for, or receiving, CDP has a need for attendance or supervision in relation to renal dialysis without requiring any further supporting information.

#### **Example: an individual requires supervision during dialysis**

Nine year old Julija receives haemodialysis treatment in her local hospital in Glasgow every Monday, Wednesday and Friday. She is accompanied by her

parents. At the time of her CDP application she has had her kidney condition for four months and therefore satisfies the backwards test. The dialysis normally takes up to four hours. A nurse sets up the dialysis and makes sure Julija is comfortable. Most days, the nurse also checks vital signs and how Julija is coping several times during treatment. After the dialysis is completed the nurse turns off the machine and help Julija get up. Julija is entitled to the middle rate of the care component due to her dialysis. The case manager does not need ask Julija's parents to demonstrate that they or the nurse are present during her treatment to make that decision.

## Day and night criteria

13. CDP individuals who receive dialysis during:
- either the day or night are entitled to the middle rate care component<sup>1</sup>
  - both the day and night are entitled to the highest rate care component<sup>2</sup>.

*1 CDP regs, reg. 16(3)*

*2 CDP regs, reg. 16(4)*

14. Day and night must be considered relative to the routine of the household where the individual lives<sup>1</sup>. This is likely to be different for each individual.

*1 CDP regs, reg. 11(6)(a)*

15. For CDP, this generally involves considering when the parents or carers get up and go to bed, rather than the individual's bed times. If the individual's parents or carers either

- stay up to provide attention
- get up to supervise the individual

when they would normally have already gone to bed if they did not have to care for the individual, this counts as night-time care.

### **Example: an individual's dialysis satisfies the day criterion**

Nina, 5 years old, starts her haemodialysis when she goes to bed around 7pm. Her parents set up the dialysis and stay with her until she is asleep. The haemodialysis lasts approximately four hours.

They then check in with her from time to time until the dialysis has ended, which generally is around 11pm. Afterwards, they:

- help Nina use the bathroom if she needs it. She tends to feel dizzy after dialysis and could hurt herself without support
- disconnect the tubes and clean the dialysis machine which takes them about 30 minutes
- go to bed around 12.15am.

In this case, only the day criterion is satisfied as Nina's parents prepare and supervise the dialysis before they normally go to bed.

Their night-time routine therefore isn't impacted by their daughter's treatment.

**Example: an individual's dialysis satisfies the night criterion**

Sonia, who is 10 years old, used to receive haemodialysis during the day in her local hospital. This however

- led to her regularly missing school
- required her grandmother, who is her carer, to drive for over an hour to and from the hospital.

Sonia has therefore started receiving haemodialysis at home every night, starting around 8.30pm. This means that Sonia has to go to bed earlier than before. Her grandmother, who has been trained to assist her by the hospital:

- sets up the dialysis once Sonia is in bed
- stays with her until Sonia is asleep, which normally takes 30 minutes
- checks on her during the dialysis which takes approximately four hours
- has to clean and put away the machine and tend to Sonia once the dialysis has finished.

Therefore, she has had to change her sleeping pattern from her usual bedtime at 9pm to approximately 1.30am. The case manager decides that Sonia's dialysis satisfies the night criterion, as:

- the individual's carer would normally go to bed at 9pm
- the majority of the care takes place after the household's bedtime.

## **Dialysis and other needs**

16. An individual receiving renal dialysis who also has needs due to other conditions is entitled to the middle rate of the CDP care component in both these cases:

- They receive renal dialysis during the day and satisfy the middle rate of the care component criteria due to their other daytime needs
- They receive renal dialysis during the night and satisfy the middle care rate of the care component criteria due to their other night-time needs

17. An individual is entitled to the highest rate care component of CDP if they receive renal analysis during the:

- day and also satisfy the night criterion due to other needs
- night and also satisfy the day criterion due to other needs.

**Example: an individual has other needs in addition to undergoing dialysis**

Alistair is 7 years old and undergoes daily peritoneal dialysis during the day due to kidney disease. Alastair was also diagnosed with Acute Lymphoblastic Leukaemia at age 5. Alastair received the highest rate of the care component because he required day and night care. At night his parents had to regularly:

- help him change his sleeping position
- stop and clean up regular nose bleeds
- help him with toileting needs when he had diarrhoea
- soothing him when he was in pain.

Following treatment, Alistair has made a complete recovery from Acute Lymphoblastic Leukaemia. He no longer requires care overnight or during the day for his Acute Lymphoblastic Leukaemia. However, he continues to receive care for his dialysis during the day. The case manager therefore concludes that Alastair should receive the middle rate of the care component from now on.

**Where the dialysis takes place**

18. The individual will satisfy the rules on renal dialysis for the care component whether they receive dialysis in a National Health Service or private hospital, or at home.