

Benefits.

How they Enable Patients.

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Little Hearts Matter





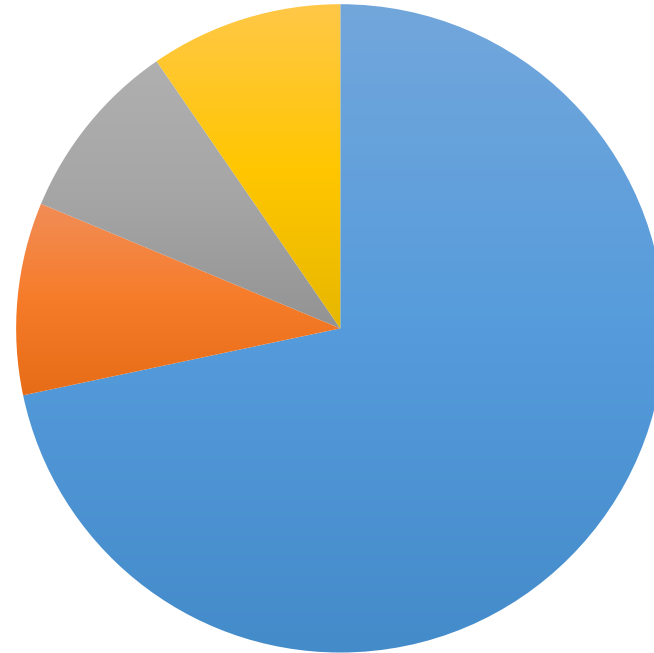
Benefits

The 2024 Little Hearts Matter DLA and PIP Survey

- 226 respondents
- All regions of the country were represented
- All age groups were represented
- All single ventricle conditions were represented.



Benefit Awards



- Received benefit on first application
- Received the benefit after Mandatory reconsideration



“Degrading, you're made to feel like you are scrounging, there absolutely no communication between face to face assessment and award letter which is immensely stressful”.

“How

“It is a nightmare. Every time we apply it ends up going to tribunal. Last time they upset my son by telling him, he was preventing himself from getting better by using his wheelchair on bad or long days like going out for the day. This completely shattered him; it has been difficult getting him to accept he needs to on occasions.”

“Anything your child can't do. Highlights the difficulties more.”

“Very time consuming, painful to complete in one go. Very difficult to continue with.”

“Extremely time consuming. It raised my anxiety considerably going over all the traumatic events of his life as I filled in the form. It was incredibly repetitive and the anxiety I'd get it wrong was extreme.”



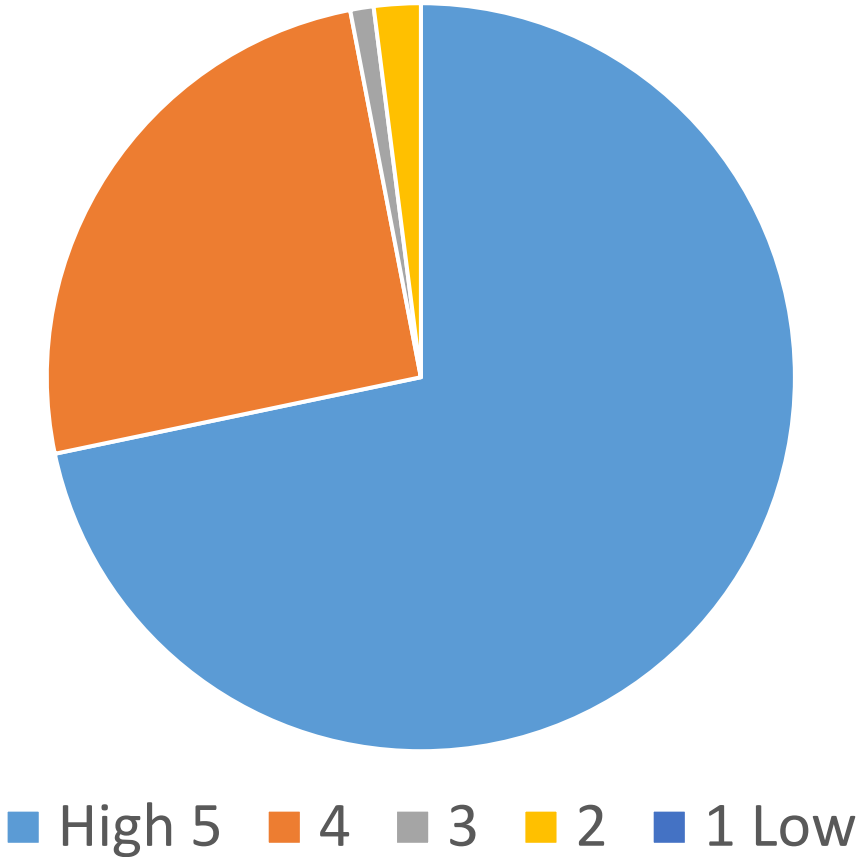


“It takes me weeks of mental preparation to get ready to face all that information again, never mind physically write it out. It affects your mental health so negatively having to talk about the mortality of your child, and knowing they'll never be better. Lifelong conditions should be awarded for life.”

“Talking about your worst day hurts the soul. It is very triggering.”



Stress created when applying for or appealing benefits.



DLA and PIP are enabling benefits.

- They are not means tested.
- You can be in work and still receive the benefit.
- The award is measured against heart healthy peers.
- Parents can not always take all of the added care load.
- Mobility is an essential for adolescents and adults as they fall behind the abilities of their peers.
- Isolation is a problem for adolescents and adults who are unable to gain any independence.



“My wheels are my lifeline. Without mobility allowance, I would struggle to get around. Only being able to work part time this has ensured I can access work and not just have half a life.”

“Having PIP and having a Motability car has made my life easier and more independent for me. Public transport would of made it harder for me to go out as I would get tired easy with all the extra travel I would of had to do.”



“PIP has meant that I am able to get a car through Motability, which has meant I can remain as independent as possible as public transport isn't accessible where I live. It means I can still go out for the day without the travel tiring me in the way public transport does!”



“Difficult because they ask for so much information, and the letters they want from the cardiologist do not describe them against healthy children, only their own past.”

DLA and PIP assessors are measuring an applicants needs needs against their heart healthy peers.



DLA and PIP Medical Evidence

www.gov.uk/government/publications/medical-guidance-for-dla-decision-makers-child-cases-staff-guide#:~:text=This%20guide%20for%20staff



Supporting medical evidence can make a crucial difference to the success of certain benefit related claims or appeals, for example Employment Support Allowance (ESA) and Personal Independence Payment (PIP) or Disability Living Allowance (DLA).



Providing independent evidence.

Use the outpatient letter.

- Re phrase the opening paragraph.
- Explanation of medical pathway.
- Include a greater explanation of exercise tolerance and reduced energy levels. (mention the spoon theory)
- Overarching explanation of disabilities.
- Concerns within education or employment.
- Mental Health, isolation, fears for the future.
- Aspirations



The next step

We would be grateful for your comments.

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Thank you.

