



## Little Hearts Matter PIP and DLA Survey Results.

Little Hearts Matter is a national charity that works with children, adolescents and SVH adults, and their families, affected by single ventricle heart disease, half a working heart.

The aims of the charity are to reduce the fear and isolation created by this life-changing diagnosis and to empower the charity's members to understand their heart conditions and the lifestyle challenges that they bring, allowing them to live their life to its full potential.

### **Introduction**

Single ventricle heart disease is a non-correctable congenital heart defect. Although survival rates have improved, the conditions create a variety of disabilities. Access to disability benefits enable children and adults with half a heart to gain supportive care and added mobility support.

The allowances enable young people to aspire, to gain from their education, to join in with normal life and ultimately to live as independently as their heart condition will allow.

Little Hearts Matter has worked with families for 30 years working to help them cope with their diagnosis, but also to help them access the support that allows them to live their life as fully as their disability allows.

Accessing benefits has been reported as a major struggle for families with many families unable to successfully gain the care and mobility support that is needed to support their child to gain their full potential.

### **Survey Aims**

The 2024 DLA and PIP survey aimed to gain up-to-date information from anyone travelling the single ventricle treatment pathway about their access to childhood Disability Living Allowance or adulthood Personal Independence Payment.



## Methodology

The Little Hearts Matter team created a survey seeking information on access to disability benefits from both parents of children with SVH and adults with half a working heart.

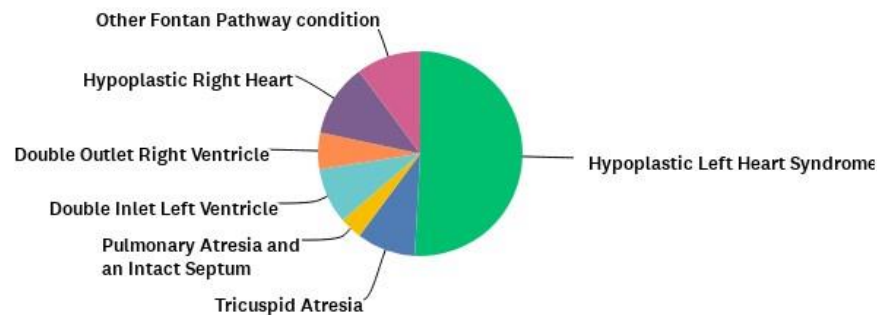
Over eight quantitative and qualitative questions, those surveyed answered questions about their access to benefits and the challenges and stress they felt as they applied or had to appeal.

The survey was distributed via social media, both the charity's and other 3<sup>rd</sup> sector organisations. It was also disseminated at the charity's national Single Ventricle Heart conference.

## Results

The survey collected 226 responses.

### Q1 What is yours or your child's heart condition?

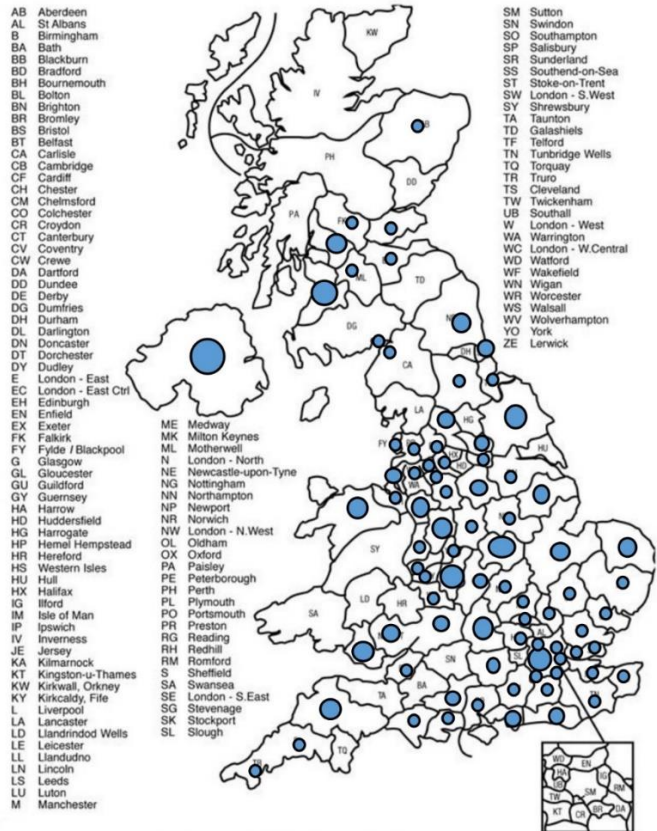




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## Q2 Where are you based in the UK?

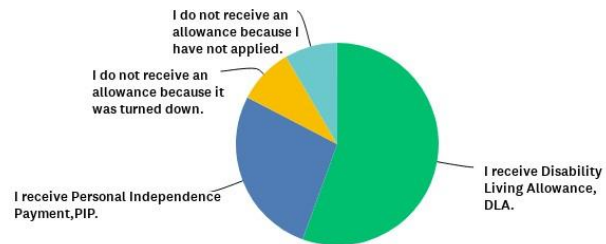
### UK Postcode Map



The coloured dots represent a response with larger dots representing a larger number of responses in a given postcode.

### What allowance did you receive on your last application?

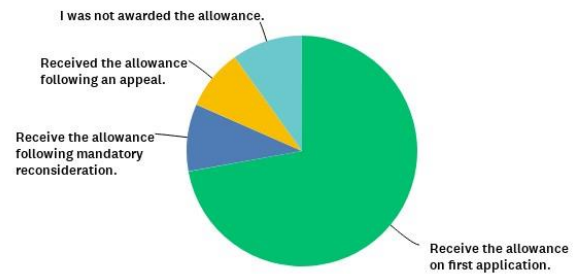
Q3 Do you receive:-



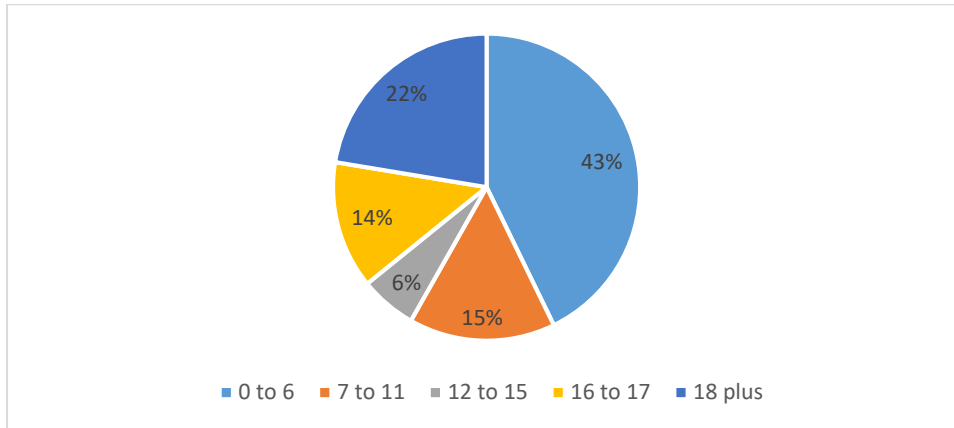
### Q4

### What was the result of your last application?

Q4 When you last applied for an allowance did you?



**At what age was the last benefit application made?**





Q6

Please tell us what applying for DLA/PIP is like?

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will extremely makes feel answer well last experience able applying exhausting son  
look understand straightforward better everything Horrendous awarded detail many  
time consuming full much years fill face lot work application long process  
things long winded process families condition upsetting make  
quite know emotional feel easy need possible long awful  
time worst day child help stressful draining form  
one go stress difficult give life told questions way s every  
takes worry hard heart conditions days assessment complete different  
Hard work information heart explain bad found PIP also complete forms  
write really fight evidence put think tiring repetitive parent filling form limitations  
trying hospital renewal appeal always compared support live



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“Daunting. It’s not only time consuming but find our kids are often overlooked as many of our disabilities and challenges are silent and not physical. It also takes a very long time to hear back.”

“Horrendous. Trying to pull together all the documentation and evidence and go through the mental anguish of going through day-to-day life and the limitations affecting my child.”

“Horrible. You feel like you’re being judged and people telling you that your child doesn’t need it when these people have no medical experience.”

“It is challenging as you have to consider things from a worse day. It is an art form to negotiate the form, and to find the right answer. It is difficult for one’s mental health too. The appeal process is demanding and without support extremely difficult.”

“Really difficult — to pull together all paperwork, to complete forms properly, to make sure my daughter was understood.”

“I started the process again but didn’t have the mental energy to go through the appeals process.”

“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.”

“Heartbreaking. Writing down everything your child can't do. Comparing them to their peers highlights the difficulties more.”



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“Very time consuming, painful and overwhelming. Not possible to complete in one go. Very easy just to give up and not continue with.”

“Stressful, long. Emotional remembering our daughter's limitations and some of her toughest moments in her life.”

“A nightmare. No one understands what single ventricle heart defects look like. You then have to go through an appeal which then is a huge undertaking when you're trying to balance work, your heart health and being able to live your life.”

“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.”

### **Q7 – Do you have anything else to add?**

“These people who assess your child or young adult haven't got a clue about the heart conditions and complex issues they have.”

“It frustrates me that the mobility aspect is based on how far they can walk - he can walk, but he gets tired and managed it by balancing our days accordingly.”

“The face-to-face assessors aren't trained for rare diseases they tend to tar us with the brush as acquired heart disease.”

“I believe congenital heart conditions that impact on daily life, such as single ventricle conditions, should be an automatic acceptance for DLA/PIP - people with these conditions shouldn't have to prove they need support any more than someone who can't see or can't walk - their disabilities might be invisible to the average person





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but they impact the person in so many life-affecting and life-limiting ways that having to 'prove' that you/your child is disabled should simply be known by the people who assess the applications. Having to 'prove' it is deeply traumatic, as if the disabled person and their families aren't already going through enough.”

“We need these children to be granted it for life not to keep applying.”

“Additional information being provided to the DLA that could get HLHS recognised as lifelong condition.”

“I feel a disability is heart condition not ADHD , a child with that is on the highest than a child who has a heart condition. Something isn't right with the process.”

“Knowing I have to do this every 6 years for the rest of my life is daunting. My condition will never get better, we're essentially in heart failure. This should be considered and lifetime awards should be looked into because we're going to get worse, not better.”

“That where a condition is palliated then unless there is significant change (e.g. worsening of condition) then the benefit is life long and doesn't have to be applied for every year as it is just too stressful.”

“They need to understand more about the condition and that it isn't something that can be cured.”

## Summary of Findings

**The survey reached people from across the whole of the UK and included responses representing all age groups. Of the people surveyed almost 30% of the children and adults with a single ventricle heart were refused their benefits on initial application. Just under 10% of applicants are never awarded the benefit.**



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## Conclusion

The overwhelming response has highlighted issues of stress, frustration and anxiety when; completing the benefits forms, waiting for the DWP decision, appealing a decision or ultimate denial of the award.

Concerns of discrimination have been raised about how some conditions are recognised, understood and easily achieve benefits but single ventricle conditions do not.

The survey results suggest that because single ventricle heart disease is not understood, confused with acquired heart disease and invisible, assessors do not understand the disabilities it creates.

## Recommendations and forward actions

- Improve DWP assessor information relating to an understanding of Univentricular hearts and long-term disability.
- Engage with medical teams to make their DLA and PIP work easier.
- Member and friends of LHM call to action – Government Poll – calling for recognition that Univentricular Congenital Heart Disease is a long-term incurable condition that requires benefit support for life.
- Draw from the personal quotes and stories about the need for DLA or PIP and the stress of the application and appeal process.
- Further support anyone on the Fontan pathway's ability to apply, successfully, for DLA and/or PIP.
- To create a simple poll that measures the stress levels of people applying for DLA and/or PIP. *See results below.*

## Phase 2 Survey: Assess the stress of benefit application.

Following the results set out above, LHM contacted LHM members, parent and SVH adults to seek their thoughts on the stress created by the application process.

The poll consisted of one question:

On a scale of one to five (1 as lowest and 5 as the highest) how stressful is completing DLA and/or PIP applications?

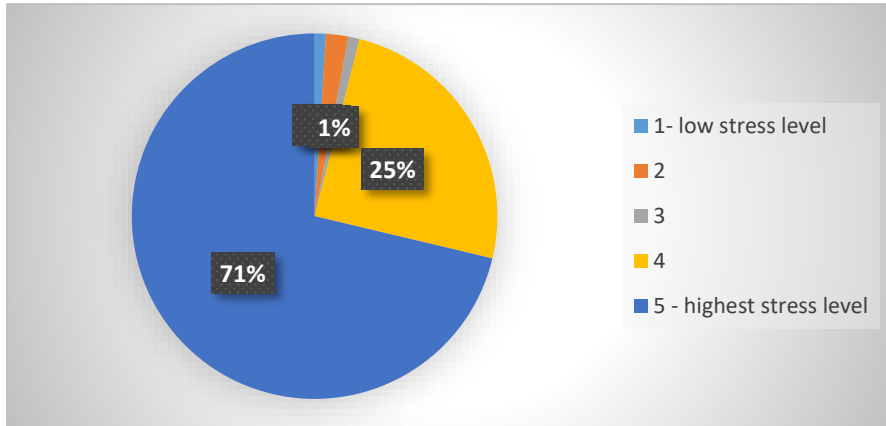
### Parent group



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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.

Responses were gained from 184 parents of children with single ventricle heart disease.



Clearly parents applying or appealing Disability Living Allowance suffer extensive stress levels.

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

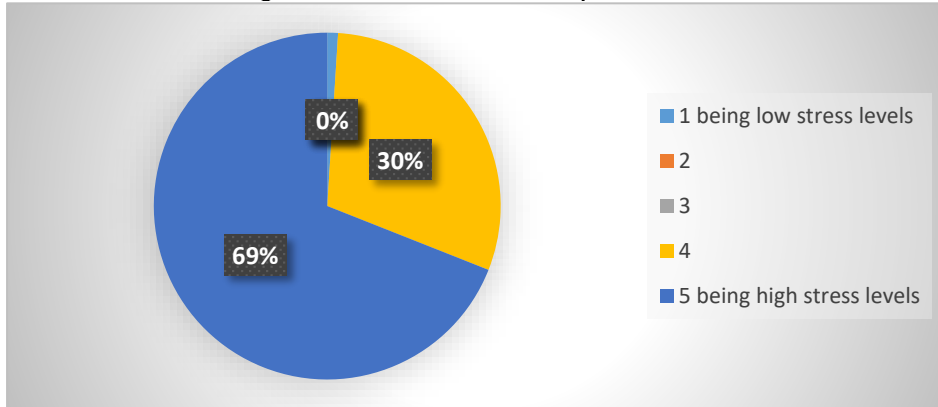
“My daughter is nearly 6 and I still haven't applied because I can't face it 😭😞”

SVH Adults



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23 adults with single ventricle hearts responded to the same stress-related poll.



### **Conclusion to the stress-related poll**

The results of the follow-on poll to assess the individual stress levels experienced by people applying for or appealing for disability benefit support clearly show that the experience of completing applications and appealing Department of Work and Pensions decisions leads to very high levels of stress.

### **Recommendations for future action**

Little Hearts Matter will take the results of Phase two of the survey and add the findings to the information gathered during Phase one. The information collected will be used as the basis of an appeal to Government to understand the needs of children and adults with single ventricle heart disease and to inform and shape the approach from medical teams supporting the medical care needed by anyone with a single ventricle heart condition.

For further information on this research contact Suzie Hutchinson RGN RSCN MBE, Head of Service, Little Hearts Matter  
01214558982 [suzie@lhm.org.uk](mailto:suzie@lhm.org.uk)