



## 25<sup>th</sup> Anniversary Membership Survey – Creating a Better Future.

In its 25<sup>th</sup> Anniversary year Little Hearts Matter sought to review how the needs of its membership may have changed over the past 25 years and where their greatest challenges were moving forward.

Abstract:

### History of the treatment of complex single ventricle heart disease

25 years ago the treatment for most right sided single ventricle conditions was established but the mortality rates through treatment were extremely high. The treatment of left sided conditions like Hypoplastic Left Heart Syndrome was in its infancy. 25 years ago patients were given an 80% mortality rate if they had a diagnosis of HLHS.

Antenatal diagnosis was improving but sporadic around the country and termination rates were very high because the risks of treatment were so great.

25 years on, the treatment of all single ventricle heart conditions is offered as a standard treatment. Outcomes have changed now patients are given a 70% survival rate with 62% of children reaching the age of 5.

In 2019 the survival rates have improved but the conditions have not been cured. The surgery the children receive is palliative; they still only have half a working heart. Long term disability, in varying degrees, is the lifetime path for these children, teenagers and adults with transplant for many being the only opportunity of reaching adulthood.

### The aims of the study

The study set out to gain the insights of teenagers and adults, and their parents, living with a single ventricle heart condition.

- The challenges they face every day.
- The challenges that they see in the future.
- What they feel would help them to reach their full potential.

### Survey group

The survey was aimed at teenagers with a single ventricle heart, adults with a single ventricle heart and parents of anyone with a single ventricle heart over the age of 13.

### Dissemination

Links to the survey were sent out through Little Hearts Matter internal and external social media forums and LinkedIn and linked through The Somerville Foundation's adult congenital heart charity, social media links.

### **Response rate and general dynamic**

#### Response Rate

The charity had 81 responses:

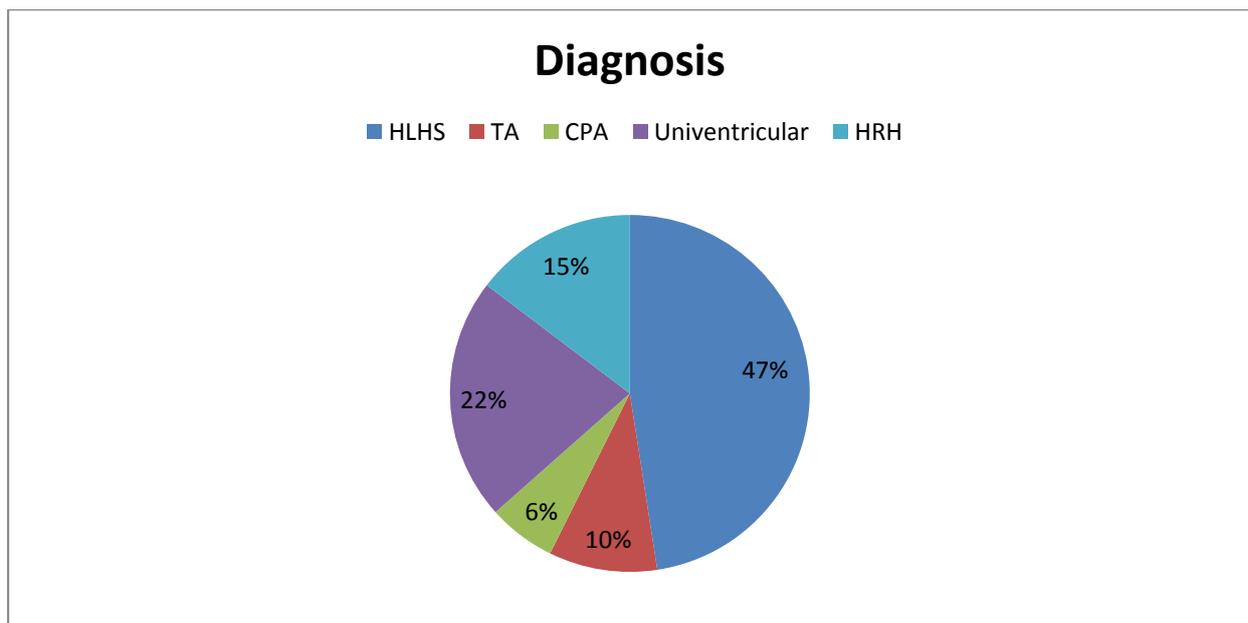
Teenagers – 21

Adults – 29

Parents of Teenagers – 31. (Most highlighted that they were completing the survey with their teenage or adult member to help them contribute to the survey).

#### The diagnosis

The diagnosis breakdown shows the greatest number of respondents had Hypoplastic Left Heart Syndrome, the most complex of the single ventricle heart conditions.

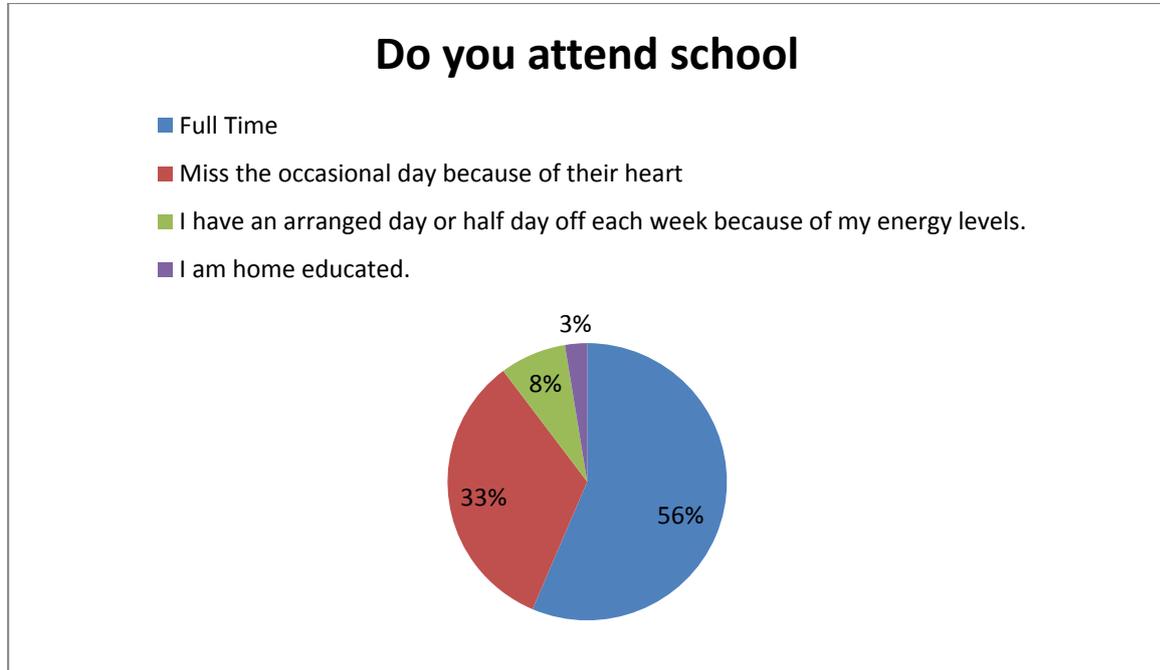


#### Do the respondents receive any benefit?

- 45 respondents receive either PIP or DLA.
- 21 respondents state that do not receive any allowance.
- 5 respondents receive Employment Support Allowance.
- 3 respondents receive education support.

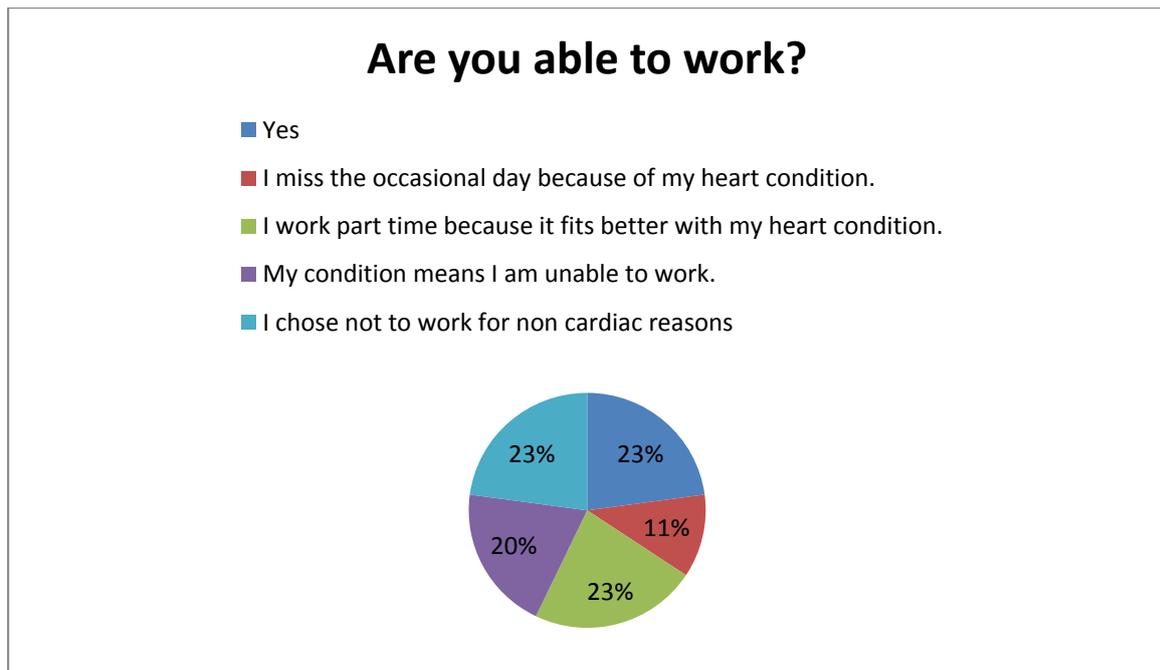
If you are at school, are you able to attend full time?

These results are for the respondents still in education = 39 respondents



If you work are you able to attend full time?

35 respondents talked about being in work.



### Analysis of Basic Dynamic Data

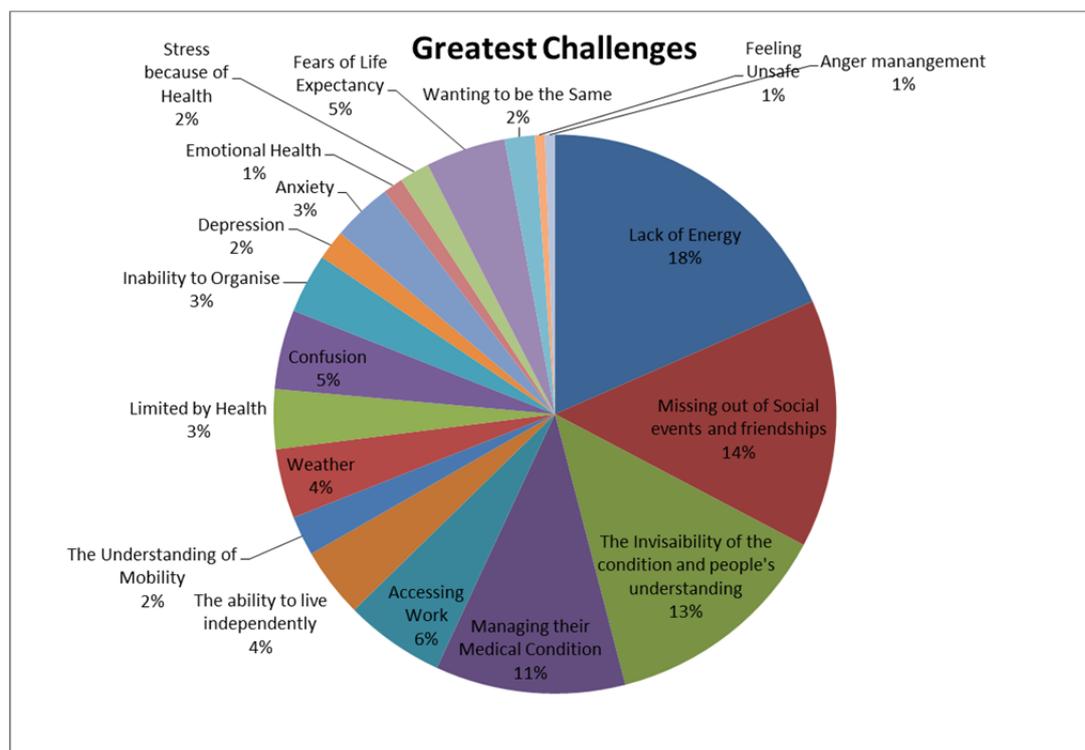
The data shows that teenagers and adults with all of the different types of single ventricle heart condition are represented in the study.

A majority of them have Hypoplastic Left Heart Syndrome which may be a reflection of the history of the charity. On the inception of the charity in 1994 the organisation only offered services to people affected by HLHS. In 2004 the charity broadened its reach to all single ventricle heart conditions. Therefore a majority of the older cohort of members has HLHS.

It is clear that a majority of them are in receipt of State Benefit and that maintaining full time work or education is a challenge.

The second part of the survey specifically looks at the types of disability or challenge experiences by the respondents.

**Q. The respondents were asked to name their three greatest challenges.**



As can be seen by the results a broad spectrum of challenges are experienced.

The challenges can be broken down into specific areas.

- **Lack of Energy**

Having less energy than their peers goes hand in hand with having a non correctable single ventricle heart condition. The circulation is driven by one, not two, heart pumps which requires more energy. The energy deficit is compounded by the fact that many of the

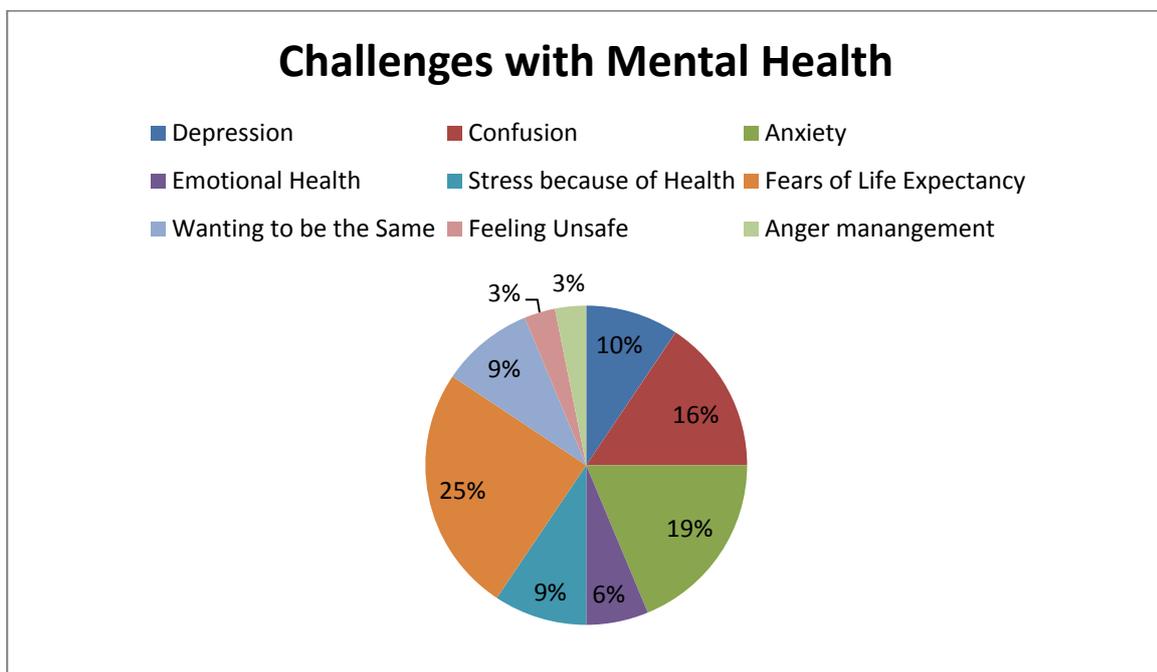
children or adults living with half a heart are slightly cyanotic which restricts the amount of circulating oxygen available to create energy

*“The issues would all be manageable if there was an end date to them or if there was a chance I would get better, but they’re made harder when you realise that it’s a reality of having a terminal condition” 23 year old adult with HLHS.*

- **25% of respondents said that their mental health was affected by their diagnosis.**

57% of respondents raised issues about their mental health.

This can be further broken down into subsections of mental health



**Q. Does having Congenital Heart Disease make you feel anxious?**

- **72.2 % of respondents said yes**
- **27.8% said no**

**Q. Does your condition leave you feeling isolated from normal life**

46 respondents said that their condition gets in the way of them achieving the same as their friends. With:

- 47% of respondents said they were left out of activity
- 22% said they were never left out
- 30% said they were sometimes left out

Respondents also raised issues around their ability to live independently.

**Although concerns were raised by all age groups about how their condition affects their inclusion the teenage group specifically raised the wish to appear normal and to fit in. They did not want to let their condition define them.**

*“I hate being referred to as a CHD hero or a heart warrior - because I am just me. My heart doesn’t define me at all, I prefer to think about all the things I CAN do rather than the very few things I can’t.”*

- **Manage their medical condition**

A concern raised by teenager’s parents is their inability to manage their medical condition.

Adults raised concerns about their inability to truly understand their condition and therefore adequately interact with their medical teams.

- **A lack of understanding from family and professionals about the effects of the condition.**

The respondents raised issues around the invisible condition and a lack of understanding from their friends and extended family. They also raise frustration that medical, educational and social service/service providers lack insight into their condition.

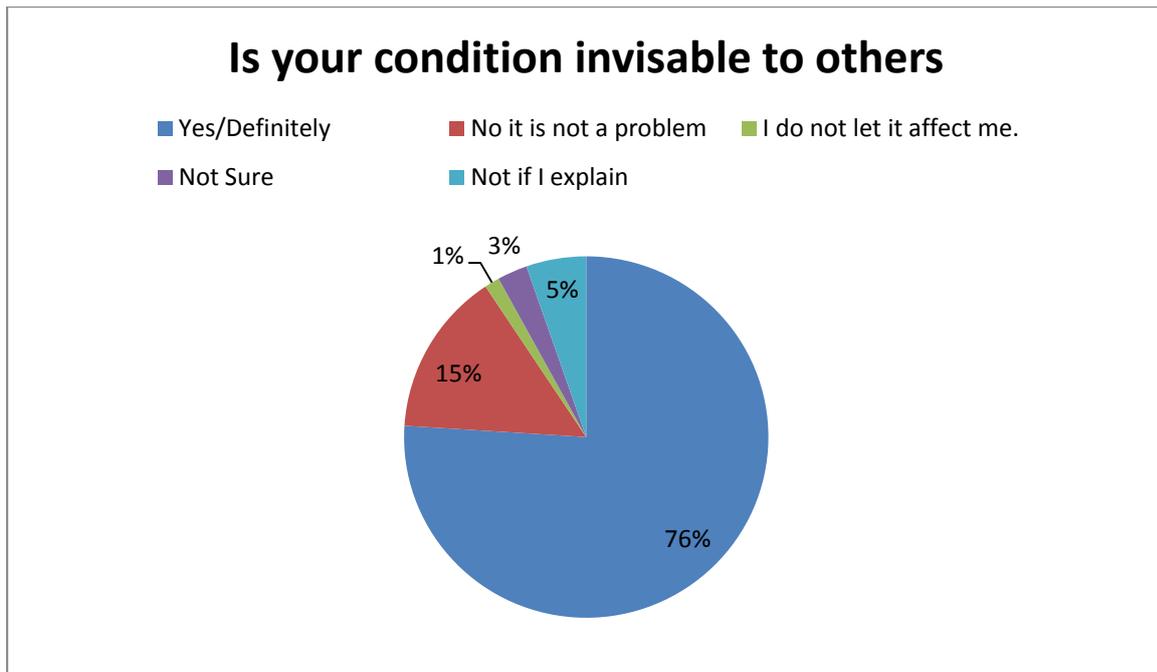
*“Yes definitely it builds tension as I get angry when people lack understanding no matter how much I try to educate them they think I pretend”*

*“Not everyone believes me.*

*If I’m blue they comment on it. Having a wheelchair means I can’t get to places independently. Can’t even get round shops.”*

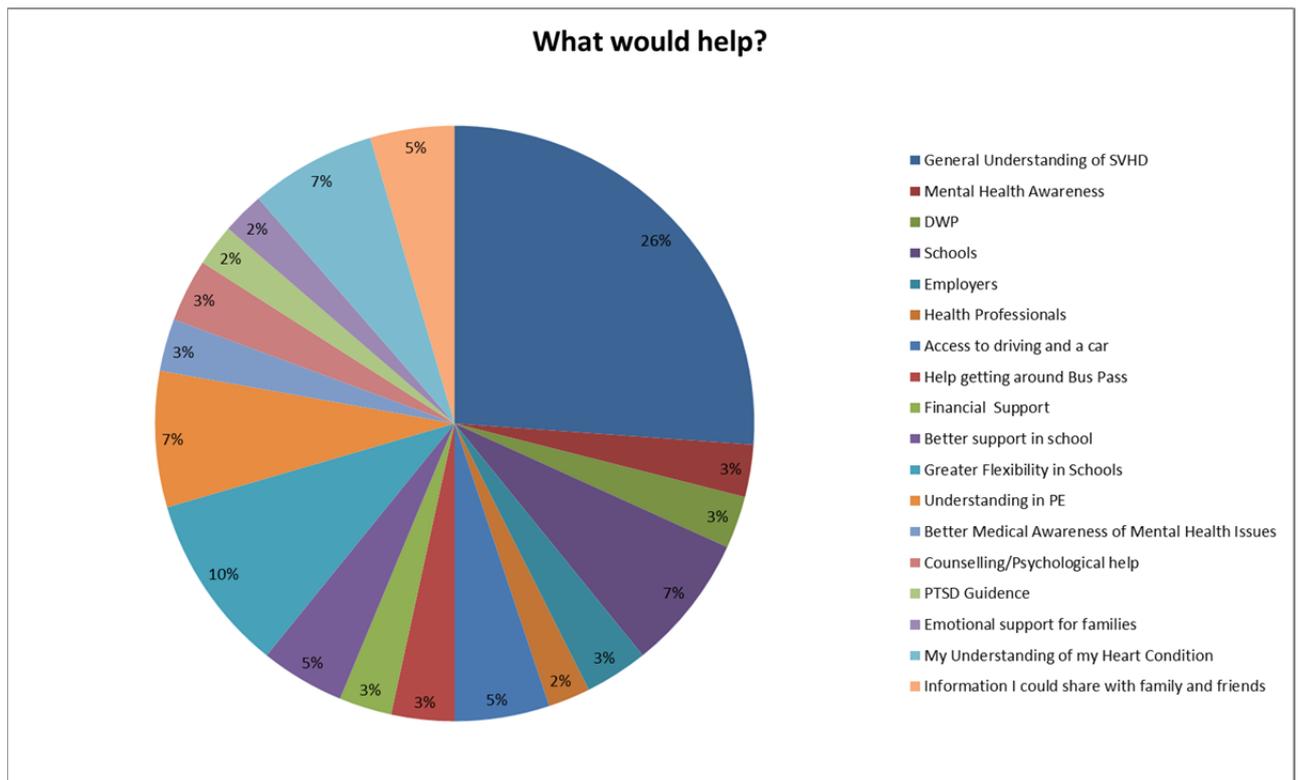
This is further confirmed by the answers to the next survey question.

**Q . Do you think that having a heart condition that can't be seen affects the way that your teachers, tutors, staff at work, family and friends understand your heart problem and any restrictions it may create?**



**Q. Tell us three things that you think would help you to achieve the things you find important? For example help with getting around, better support in school, people understanding your energy restrictions.**

Having gained the voice of teenagers and adults to identify and describe their challenges LHM asked them to name three key things that they felt could be done to help them navigate those challenges to give them a better quality of life.



- **All responding groups asked equally that their quality of life could be improved if people had a better understanding of their condition.**

All respondents, teenagers, adults and parents asked for a greater awareness and understanding of their condition.

What would help ... *“People understanding .....Be me for a day”*

- Generally throughout society.
- Within Schools, colleges and Universities.
- Department of Work and Pensions relating to Disability Benefits
- Better awareness with employers.
- Better awareness within the health services. This normally related to local services or the recognition of issues with mental health.

This was further supported by 5% of respondents asking for better written information that they could give to friends and family to explain their condition.

*“More understanding of invisible illness by society in general.”*

- **Mobility**

Lack of energy was raised as a challenge to achieving independence by 25% of respondents earlier in the survey. They raised the need to create a better understanding both generally and specifically with the Department of work and pensions to ensure they had better access to mobility support in the form of DLA or PIP Mobility Allowance and

better education authority support to gain transport access to schools, colleges or Universities.

Many respondents mentioned the need to drive. They suggested that it would allow them a modicum of independence as using public transport sapped their reduced energy levels and they did not like having to rely on friends and family for every trip.

*"A priority has to be getting my mobility car back".*

### **Better understanding and support in schools/further education and with employers.**

22 % of respondents were seeking an improvement in the understanding of their condition and the support available from teachers and school/further education staff and a greater understanding with employers

*" Teachers at school always say I lack concentration. They don't think about the tiredness."*

This was further described by 4 Parents, 7 teenagers and 2 adults as the need for greater flexibility within schools or employment.

7% of respondents wanted there to be a better understanding of the heart conditions with PE teachers.

*"Let me show you what I can do not just what I can't. Just ten mins of PE is amazing instead of just watching"*

- **Better Personal Understanding of the heart condition.**

A number of adults and teenagers expressed the need to understand their condition and its treatment better. This is in line with information coming from health professionals that teenagers making the transition between children's and adult health services do not understand their condition.

This was further supported by the request for written information that explained conditions and treatments.

*"I would like a better understanding of my diagnosis and to feel more comfortable to ask my cardiologist questions - so I can better explain it to others."*

- **Mental Health support**

A number of respondents wanted to see a greater recognition and the support with mental health issues, highlighting PTSD.

#### Counselling/Psychological support.

Adults highlighted the need for counselling or psychology provision. Teenagers did not suggest it but 4 parents suggested that counselling support should be available for their teenage children.

*"We need mental health support in our heart clinics."*

## **Little Hearts Matter's Analysis and Comment of the Challenges faced by teenagers and adults with single ventricle hearts.**

The responses gained from members of all ages have highlighted a series of challenges faced by the majority of those living with half a working heart.

Although the number of respondents represents only 13% of the adult and teenage membership, the comments made are consistent within each group of respondents and with what is known, more anecdotally, by the charity as it works with members on a day to day basis.

Following a full analysis of the data collected, Little Hearts Matter has highlighted three key areas for further comment.

### **Lack of Energy**

It is not within the gift of Little Hearts Matter to improve the energy levels of anyone with a single ventricle heart. An energy deficit, of varying degrees, is part of the long term disability created when you have one ventricle doing the job of two.

The fact that their energy deficit is very high on the young members' agenda and that it leads to frustration, lack of achievement and exclusion is a clear indication that as individuals they need more understanding of their condition, the effects it has on their every day life and aspirations, and the ways to maximise the potential of their hearts.

### **Mental Health**

A quantifiable number of respondents highlighted a growing problem with their mental health. It may be that this is a problem that has never manifested itself before because many of the young people with a single ventricle heart did not live into their teens or adulthood.

Medically and societally there is an increased recognition that mental health issues are prevalent in adolescents and adults with a long term health condition. *Ref 2*

The members' response to questions about anxiety levels and frustrations are clearly an indication that mental health concerns are common in a large number of respondents.

The need for better recognition of mental health issues in the complex CHD community is clearly a priority as is swift treatment and ongoing support.

## **Conclusion**

The 25<sup>th</sup> Anniversary Survey has confirmed the growing needs of our young members and the charity will expand its services to reflect the needs identified.

Two marked areas have been highlighted:

1. The challenges of living with a single ventricle heart.
2. The lack of general and statutory service awareness of the needs of young people with single ventricle heart disease

### **The Challenges of Living with a Single Ventricle Heart.**

Little Hearts Matter currently works with 618 teenagers and young adults living with a single ventricle heart condition.

Their condition is non correctable and although they each have a different prognosis the longevity of their heart function is in question for every one of them, all of them have a significantly reduced life expectancy.

*“The issues would all be manageable if there was an end date to them or if there was a chance I would get better, but they’re made harder when you realise that it’s a reality of having a terminal condition.” Andrew age 23*

The energy deficit created for young people with one working ventricle, heart pump can be further evidenced here

- Most teenagers run at a 100% energy level at rest and are able to increase that to 500% on activity. Young people with a single ventricle heart run on a normal level of between 50% and 75% which can only rise to 200% when active. If they use up all of their restricted energy stores very rapidly they have to compromise on further activity. *Ref 3*
- We know that up to 36% of them have an educational deficit; for some this has led to a diagnosis, for others, it just creates added challenges in school. *Ref 4*
- Many of them express fears for their future and suffer with PTSD, anxiety and depression. Mental health issues are raised in small children, needle or hospital phobias, night terrors and discussions about death are common in children under the age of 10. *Ref 1 and 2*

### **Little Hearts Matter response to the challenges of living with a single ventricle heart.**

**It is clear from the results of the survey and the intelligence gained from working with young members that the Little Hearts Matter team need to continue to build a robust support and information service for teenagers both before and after the transition from children’s to adult services.**

**The immediate focus will be the mental health of the young members and their access to statutory services.**

### **Lack of statutory body awareness of the needs of the LHM membership.**

Every respondent mentioned a lack of understanding as a challenge to their ability to achieve either within school, work or generally with their independence.

They also highlighted a lack of understanding within groups of friends and family which they feel contributes to their feelings of isolation and exclusion which also affects the mental health of the respondents.

*“People having more knowledge and understanding.”*

*“Having people in my direct circle of friends who 100% understand a CHD and terminal prognosis”.*

### **A Lack of General Awareness**

The one surprising result to come from the survey was that every respondent prioritised raising a greater awareness of their condition, and the challenges that it brings, within general arenas.

Young members feel that building a greater general awareness will allow for a greater awareness within the statutory services that they rely on for their healthcare, their education or workplace support and the benefit provision that supports their desire to live as independently as possible.

It is true that complex congenital heart disease is an unseen disability. The scars are hidden.

It is also true that the general public think of Congenital Heart Disease as a curable problem, holes in the heart can be mended, or something that you do not survive.

When young members explain their heart condition as living with half a working heart, it is met with incredulity. Shouldn't you be dead or how are you alive.

It is only relatively recently that the survival of children with complex heart conditions has meant that there are a substantial number of teenagers and adults living with a single ventricle heart.

### **Little Hearts Matters response to the lack of awareness.**

**It is clear from the survey that members are asking the charity to work to raise a greater awareness of their needs, throughout their life.**

**In Little Hearts Matter's 25<sup>th</sup> Anniversary year we will work to raise a greater awareness of the life limiting, life affecting heart condition that all of our teenage and adults members live with.**

**Why would society understand when no one has asked them to or explained why they should.**

**Our Campaign – My life with Half a Heart ...Only Half understood.**

**25 years ago so few children lived with half a heart that society, healthcare, education and social care teams did not have to understand what life with half a heart might mean.**

**25 years on it is time for them to get a better understanding so that children do not have to lose out in school or adults struggle to be understood at work. So that health services really support their needs wherever they live and benefit providers do not expect every family to have to fight for every grant or allowance they need.**

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