



Big Hearts Matter LHM's Youth Newsletter

Issue 28
Spring 2016

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Starting 2016 with a Bang!



Laura

We've had a really great start to 2016 so far, we're settled into the new office, we've had a couple of good events already, and got loads booked in the diary for the rest of the year! What have we got planned?

- ♥ Open Day, 16th April, Birmingham
- ♥ Family Get Together, 14th May, Cardiff
- ♥ Activity Weekend. 29th July, Lancashire
- ♥ Activity Weekend, 12th August, Surrey

We also have some more family events planned for this year in places like Ireland, Cornwall/Devon, and Leicester so keep your eyes peeled for more information on those!

If you'd like any more information on the events that we've got coming up, you can get in touch with me laura@lhm.org.uk

Youth Activity Weekends



Youth Leader Laura is really excited to announce we will be running 2 activity weekends this year for our 11-13 year old youth members; one in Lancashire on 29th July and one in Surrey on 12th August. **Interested? Read on to find out what sort of things you'll get up to!**

- ♥ Meet other young people like you
- ♥ Do fun activities like archery, canoeing, abseiling... the list goes on!
- ♥ Learn more about your heart condition
- ♥ Have fun ☺

Sound like something you'd like to do? Make sure you get your parents to get in touch with Laura to put your name down as we have limited spaces and they will be allocated on a first come first served basis.

Aged 14+? Don't worry, we're planning something for you too! The last few years we noticed our 14+s didn't seem that keen on an activity weekend, so we're looking at doing something special for you.

Want to put your name down for the activity weekend? Just get your parents to email laura@lhm.org.uk with your name, age, and which weekend you'd like to come to.

Half Dress Down Day



On the 15th July we're asking people to get involved for our half dress down day. It'd be great if you could get your schools/colleges involved too, and even get your parents and their workplace to take part!

You can wear your uniform on one half and then some PJs on the other if you want to go casual, or maybe you've got a cool fancy dress outfit you can wear half of? There's so many options to choose from, and you can do whatever you like!

We have posters available if you'd like to get involved so just get in touch with the LHM office to get them.

All you have to donate is £1 to take part. Why not ask your school/college to get involved?

Your Questions Answered—Sleep and Sleepovers

We get a lot of questions here at Little Hearts Matter HQ, and we thought it would be good for us to share our answers to them. *Please remember that all our answers are general, and that you should always talk to your doctor because they know about your specific heart condition.*



Question: If I stay up late is there a certain time I should be in bed? Also when I have sleepovers everyone stays up really late e.g. midnight - Can I do this?

Answer: Sleep is very, very important if you only have half a heart because it gives your body a chance to rest but it also gives it a chance to fill up on oxygen in each cell so that you have a reasonable amount of energy the next day. If you have a heart condition and don't have enough



It is a good idea to have 9 or 10 hours sleep a night.

sleep you run on empty which is not much fun. It is a good idea to have 9 or 10 hours sleep a night. If you choose to go on a sleepover, half-terms and holidays are best so you have time to catch up on sleep. It is all about balance - tough I know but you want to get the most out of everyday.

For more information on sleep and why it's important when you have half a heart, check out our sleep article from Issue 26 (not got a copy? Just get in touch to request one!)

Have a question of your own? You can send it straight to Laura (laura@lhm.org.uk) who will try and find you an answer. Our new website will be launching too in the next few months which will not only have a separate youth area for our Zippers (that's you!) but will also have special questions area where you can see other questions that have been asked, as well as ask your own. Exciting, right? So keep you eyes peeled for the changes coming to www.lhm.org.uk!

“Drama Group Has Upped My Confidence”

One of our young members, Lucy (Tricuspid Atresia, 11) wrote a lovely email to Youth Leader Laura to talk about her life and what she's gone through so far, including how joining a drama group has helped her confidence and a nice message to her Mom.

I was born with **Tricuspid Atresia**, a heart disease where my right ventricle is missing. I had a very tough time when I was a baby. I was born in Leeds hospital and they fitted a BT Shunt when I was two months old. I was so poorly and in April when I was 4 months old, the doctors at Leeds said they couldn't do anything so I was ambulated to The Freeman hospital in Newcastle.

John Sullivan, one of the doctors there, said that they could operate on me. Then they did my second operation called a Glenn. After that I had Guillain-Barré Syndrome which caused me to not be able to walk or anything; I was totally paralysed. I was seriously ill. Then I had my Fontan when I was three and that went well.

When I am older I will need a heart transplant that I some times worry about. Now, life is still difficult because I have got a restricted lung condition, I'm asthmatic so I need inhalers. I don't go to school very often because I have chronic migraines but I love it there and have many friends.

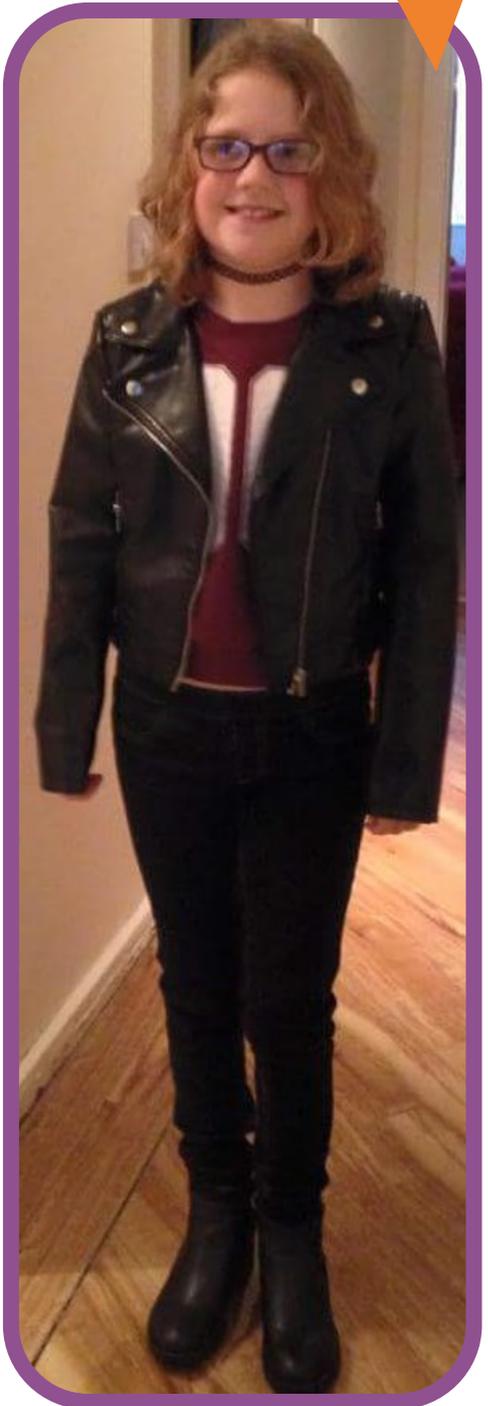
I have also joined a drama group called Identity Theatre that has upped my confidence and has got me to do lots of shows to the public.

I have horrendous migraines which make my life even worse, when it doesn't have to be. I'm also on a lot of medication what are sildenafil, frusemide, aspirin, gabapentin and spironolactone which I don't really like taking every day but I have to.

Sometimes I have absences that makes me unresponsive so my mum has to wave her hand in front of my face. I love my mum very much, and to go through horrific times that she has had to go through is terrible. **I really appreciate her she is an amazing woman.**

What a brilliant story, thank-you for sharing with us, Lucy!

Want to write a story for our newsletter too and share your heart journey? Maybe you've had similar experiences to Lucy? Or maybe you've taken up a really great hobby that you can even though you have half a heart? Whatever it is, I want to hear from you, so just get in touch with Laura (laura@lhm.org.uk) to send your story that will get featured in the next newsletter.



Some More Psychological Therapies

By Dr Liza Morton



In our last two issues, we published articles about the emotional challenges of growing up with a heart condition, and what psychology can offer people living with a congenital heart condition. This is the third article in the series, written by Dr Liza Morton for The Somerville Foundation. *Missed the last two articles? Get in touch with us at LHM to get a copy of the last two newsletters!*



In Part 1 we explored some of the unique emotional challenges that might arise from living with a heart condition from birth. These included feeling different, living with hidden symptoms, feeling out of control, enduring traumatic experiences, missing out and feeling unsafe.



In Part 2 we considered what psychology can offer us, exploring Self Help, Emotional Support, Person Centered Counselling and Cognitive Behavioural Therapy (CBT) as possible sources of psychological support.

We noted that although not everyone who is born with a heart condition would need this support there is no harm in being aware of these options and deciding for ourselves, especially since a holistic account of living with CHD (congenital heart disease) might offer better physical and emotional health and a better quality of life.



Interpersonal Psychotherapy (IPT)



IPT focuses on reducing mood problems by developing a more supportive social circle. Early sessions review the key people in your life. Therapy focuses on one of four areas; an Interpersonal Dispute (such as an argument with someone who is important to you), a Role Transition (like moving house), a Grief or Loss and Interpersonal Sensitivities (general problems with making and keeping relationships). These four focus areas could be appropriate depending on the trigger for your current mood difficulties. A focus on Interpersonal Disputes might

help if you are having problems navigating the medical system or if you are being bullied. Role Transitions might benefit you during the move from childhood to adult care, adapting to having a cardiac medical device fitted, enduring surgery or having a heart transplant. Role Transitions could also be useful if you are recovering from post-traumatic stress disorder (PTSD). A focus on Grief or Loss may help following the loss of a peer, a further loss of health or not being able to have children. Interpersonal Sensitivities is generally considered useful if you have a limited social network. The goal of IPT is to improve your social skills and increase your social network and it is perhaps more appropriate when you suffer from health problems since it connects life events to emotions. IPT is advocated in NICE (National Institute for Health and Clinical Excellence) guidelines and is offered by some Chartered Psychologists and some other therapists both privately and within the NHS.



Body Psychotherapy



Recent approaches within psychology offer a more holistic account of human experience than previous approaches. During a threatening situation the body reacts by preparing to defend itself through its fight, flight or freeze response. Sometimes even though the threat is gone the body is left stuck in this mode which can cause a number of physical and psychological symptoms including sleep disturbance, panic attacks, exhaustion, feeling unsafe, flashbacks and nightmares. This is known as post-traumatic stress. Body psychotherapy is an integrated method of psychotherapy that addresses thoughts, emotions and bodily sensations. The aim of therapy is to help you manage

your anxiety, establish feelings of safety and process traumatic experiences. This kind of therapy could be useful if you are suffering from post-traumatic stress as a result of medical trauma.

The Human Givens

The Human Givens approach is based on the idea that we each have a basic set of needs (such as security, attention, autonomy, emotional intimacy, status, meaning and purpose) and if they are not met then we feel emotional distress (see the Human Givens Institute www.hgi.org.uk). This approach works to help you adjust your life so that all these needs are being met with the aim of reducing psychological distress.



Finding the right therapist



The quality of the therapeutic relationship is at least as important as the therapeutic method. Therefore, finding the right fit with a therapist that you feel comfortable and safe with is as important as finding the type of therapy that you feel would help you the most.

How to access help

Referral to a Clinical or Counselling Psychologist, CBT Therapist or Counsellor in the NHS should be done via your GP or another doctor such as your cardiologist. Therapists typically charge between £35-70 per hourly session for private work and your GP may also be able to advise therapists who do private work locally. The British Association for Behavioural and Cognitive Psychotherapies (www.babcp.com) lists accredited private CBT therapists.



 Living with a heart condition from birth can present many challenges. It is normal to have an emotional reaction to these adverse life events. However, there is not always the opportunity to deal with difficult emotions when you are also having to cope with serious medical problems. For some these emotions can develop into periods of low mood or anxiety. Emotional Support, Self-Help, Counselling and Psychological therapies can offer the chance to process and manage these emotions leaving us free to make the most of our present and future. There are many different types of help available and different approaches will suit different people. **In part 4 we will consider 'The Good News' by looking at how living with a heart condition from birth can also have a positive impact on our emotional and psychological wellbeing.**



About the Author: Dr Liza Morton, born with Complete Congenital Heart Block, was recently fitted with her 9th cardiac pacemaker. She has also had an ASD repaired by Open Heart Surgery. Liza, a volunteer for The Somerville Foundation, is a Trainee Counselling Psychologist. She has studied Psychology for many years, an interest that was driven by her wish to understand how her heart condition and extensive medical history had shaped her. As part of her training she has undergone therapy with both a Counselling Psychologist and a Body Psychotherapist, work she feels has helped her process the difficult aspects of living with a heart condition from birth.

If you have been affected by any of the issues in this article, please know that **this is normal** and that you can get in touch with us here at **Little Hearts Matter** (info@lhm.org.uk, 0121 455 8982). You can also get in touch with **MIND** who are a national charity with lots of information on mental health, the different conditions, and diagnoses. Their website (www.mind.org.uk) has leaflets, information, and a shop for publications/books and self-help material. They also run a helpline (0300 123 3393)



If you would like more information on emotional and mental health issues of living with Congenital Heart Disease, or to talk through an emotional or mental health issue, you can contact Anne Crump (anne@thesf.org.uk), who is the Mental Health Support Worker with The Somerville Foundation. The Somerville Foundation also have a selection of articles and resources designed to help with coping with the emotional and mental health issues of living with Congenital Heart Disease. These can all be found on their website: www.thesf.org.uk/help-advice/managing-your-heart-condition/emotional-health

One in five people can experience depression at some time in their life. Someone with a congenital heart condition might, at times, face additional challenges that can affect their mood, such as: changes in symptoms experienced, feeling different from others, deterioration in health, possible physical limits on exercise and activities, waiting for and recovery from surgery, bereavement, and concerns about the future and life expectancy issues. Getting down and feeling low can be a normal reaction to these events, as can the experience of other feelings like anxiety and anger. Depression is when low feelings continue for a longer period of time and become more intense, so that they start to interfere with daily life.

If you need help now because of feeling desperate, despairing or suicidal, please contact The Samaritans 08457 90 90 90 which is available 24 hours a day.

Write for Us!

Have you got a good story about life with half a heart that you think other people like you would enjoy? Got some tips or tricks about life with half a heart? Maybe you've read a good book or seen a good film recently that you want to tell other people about?



Whatever it is, I would LOVE to hear from you—if you fancy writing something for the newsletter or blog (or both!) then please get in touch with me.

It doesn't matter if you're not the best writer or speller, we just need more of our young members to write for us!

Stay
CONNECTED



Like our Facebook page to get involved with our other young members: [LHMzippers](#)



Follow us: [@LHMzippers](#)



Check out our blog for stories, tips, updates, the odd funny photo, and more: [zipperzone.tumblr.com](#)



If you have any stories for our blog or other social media sites, please email them to laura@lhm.org.uk



We always love to hear what you're doing, so keep your messages and posts coming in!

Spring Word Search

Can you find all the spring flowers in this word search?

O	F	V	G	C	U	D	B	Y	L	I	L
D	S	L	L	E	B	E	U	L	B	C	A
A	S	V	I	O	L	E	T	S	T	G	D
F	P	O	P	P	Y	C	T	T	J	T	Y
F	O	R	G	E	T	M	E	N	O	T	S
O	R	I	N	Y	X	C	R	O	C	U	S
D	D	S	U	S	S	I	C	R	A	N	L
I	W	R	S	P	I	L	U	T	F	W	I
L	O	J	X	O	L	H	P	Z	Z	C	P
S	N	Q	D	D	P	G	S	I	R	I	P
D	S	N	H	T	N	I	C	A	Y	H	E
P	K	O	M	E	Z	D	A	W	I	P	R

- ♥ Bluebells
- ♥ Buttercups
- ♥ Crocus
- ♥ Daffodils
- ♥ Forget Me Nots
- ♥ Hyacinth
- ♥ Iris
- ♥ Lady's Slipper
- ♥ Lily
- ♥ Narcissus
- ♥ Phlox
- ♥ Poppy
- ♥ Snowdrops
- ♥ Tulips
- ♥ Violets



The Silly

Q: Why is the letter A like a flower?

A: A bee comes after it!

Q: What flowers grow on faces?

A: Tulips!

Q: What do you get when you pour water down a rabbit hole?

A: A hot cross bunny!

Think you're funnier than Laura? Email your jokes to laura@lhm.org.uk!