



The magazine of the  
Grown Up Congenital Heart  
Patients Association  
Issue 65 // SUMMER 2011

# GUCH NEWS

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## NATIONAL PATIENT CONFERENCE DETAILS ANNOUNCED!

We are thrilled to announce that the 2011 Annual National Patient Conference will be held in the Welsh capital city of Cardiff. With an extensive programme of presentations and workshops for all GUCHs, and their friends and family, there is bound to be something for everyone. This is a fantastic opportunity to meet fellow patients and families from across the UK, as well as to meet the GUCH PA staff and GUCH medical professionals.

For those wishing to stay the night at the conference hotel, there will also be an excursion on Sunday morning to Cardiff Castle where you can explore the lavish and opulent interiors, and get a sense of Cardiff's rich heritage.

To register an interest for the conference email: [conference@guch.org.uk](mailto:conference@guch.org.uk) or call 01473 252007.

Following last year's success working with the Children's Heart Federation to run a Youth Conference for Brighthearts (GUCHs aged 13-24), we will again be teaming up to deliver a separate event with a special programme exclusively for our younger members. For more information see page 9.

*Our conferences are friendly, relaxed, informative and enjoyable. Join us this year in Cardiff!*



*Images re-produced with kind permission.  
With thanks to Mike Hocking for some of these photos.*

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## EDITOR'S WELCOME



Hello,

As I write this, the sun is shining and the sky is bright blue – it's fantastic to be able to say “hello summer” and I hope you're enjoying the recent pleasant weather.

Summer for some people can be problematic though, and not everybody can feel comfortable in the sun. Remember to stock up on the high factor sun creams if you're sensitive and take things easy in the heat.

GUCH PA has been its usual hive of activity over the last months – we've been busy with our young people's events (see page 9) and planning our Hythe social weekend for July 1st–3rd (see page 11). We have produced brand new cards to promote our confidential helpline, and these are now freely available at GUCH units across the UK. We hope this will encourage more patients and their families to reach out and approach us for support.

We are very pleased to announce details for our two conferences this year, taking place in October. Check out all the details on the front page, or if you're 13-24, take a peek at page 9 for our exclusive youth conference! We're really looking forward to seeing as many of you there as possible, so don't miss out, reserve your places now!

This issue is absolutely packed full with some really exciting stories and informative articles, as well updates from the organisation that we hope you'll find both interesting and useful. Our eyes have certainly been opened to the needs and extreme lack of support available to many carers out there, and thanks to Sarah Barker's article on page 14 hopefully many of you who are caring can connect with support available. Do get in touch and let us know your stories – we are always really keen to hear from our members and to help if we are able to.

For those of you off on summer holidays – enjoy and take care, and for those holidaying at home (a “staycation”!) – fingers crossed for the weather!

*Victoria*

P.s: The next deadline for submissions is 1st August 2011.



Grown Up Congenital Heart Patients Association  
Registered Charity No 1138088

The long awaited proposals from the Safe and Sustainable review have been published regarding the future of children's cardiac surgery centres.

There are four main options, although other possibilities may still be considered.

The proposals focus on children's surgery only, but will have a significant effect on where GUCH surgery will be carried out. The surgeons who operate on GUCHs are the same as those that operate on children, and therefore if children's surgery ceases at a centre, it is most likely that GUCH surgery will also cease.

The principle behind the changes is very important. It is believed that by reducing the number of centres, the number of surgeons at each centre will be higher and the number of procedures higher too. This, it is said, will concentrate expertise; and as the name of the process suggests, surgery will be safer and more sustainable. The same argument can be made for GUCH surgery.

In theory, GUCH PA should support this principle, and we would do so already if the proposals had taken into account GUCH services and the possible impact on them, which they have not.

GUCH PA is therefore going to submit a response to the consultation process. We are at the moment considering what the implications are of the loss of each of the centres under threat, so we can try to make sure the best GUCH centres remain.

The proposals can be seen online at:  
[http://www.specialisedservices.nhs.uk/safe\\_sustainable/public-consultation-2011](http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011)

The four options are:

**Option A – seven surgical centres**

Freeman Hospital, Newcastle  
Alder Hey Children's Hospital, Liverpool  
Glenfield Hospital, Leicester  
Birmingham Children's Hospital  
Bristol Royal Hospital for Children  
2 centres in London

**Option B – seven surgical centres**

Freeman Hospital, Newcastle  
Alder Hey Children's Hospital, Liverpool  
Birmingham Children's Hospital

## SAFE & SUSTAINABLE – PROPOSALS TO REDUCE THE NUMBER OF CHILDREN'S CARDIAC SURGICAL CENTRES

Bristol Royal Hospital for Children  
Southampton General Hospital  
2 centres in London

**Option C – six surgical centres**

Freeman Hospital, Newcastle  
Alder Hey Children's Hospital, Liverpool  
Birmingham Children's Hospital  
Bristol Royal Hospital for Children  
2 centres in London

**Option D – six surgical centres**

Leeds General Infirmary  
Alder Hey Children's Hospital, Liverpool  
Birmingham Children's Hospital  
Bristol Royal Hospital for Children  
2 centres in London

**London – The preferred two London centres in the four options are:**

Evelina Children's Hospital  
Great Ormond Street Hospital for Children

Birmingham, Bristol, Liverpool (Manchester for GUCH) and two London centres are included in all options. Those which are under consideration are Newcastle, Leeds, Southampton and Leicester. Two of the options have six centres and two have seven centres.

We have no preference other than obtaining the best national service. We believe that people want the best surgery that they can get, and they are willing to travel for it when necessary. We must ensure that we retain the best. There are obviously going to be concerns amongst people who go to the centres which cease surgery, but some such changes are unavoidable. GUCH PA must therefore focus on trying to save the most valuable centres.

*Michael Cumper, GUCH PA Chairman of Trustees*

*Editor's note: Just before going to print it was announced that there would also be a review of specialist service providers for grown-ups with congenital heart disease (GUCH). Read the statement and find out more about the proposed process here: [www.specialisedservices.nhs.uk/info/guch](http://www.specialisedservices.nhs.uk/info/guch)*

# VOLUNTEERING OPPORTUNITIES

## TELEPHONE HELPLINE ADVISOR

Can you provide a friendly listening ear to those in need? Could you remain professional and impartial under pressure? Are you able to give constructive advice and provide proactive support to callers across on range of health and emotional care issues?

If the answer is yes, then why not apply to become a helpline advisor?

Our helpline is an in-demand service providing emotional support and practical information to GUCH patients, their friends, families and healthcare professionals.

## WRITE FOR GUCH NEWS!

Do you have a real passion for writing? A talent for telling a tale? Is there an issue you'd love to research, or do you have a story you want to share?

GUCH News is the quarterly magazine from GUCH PA, covering all the latest news, info and member stories from the world of congenital hearts. We are always looking for constructive, relevant member input and are happy to discuss ways you could get involved, both short term and long term. Check out past issues here: [www.guch.org.uk/experiences/gnbi](http://www.guch.org.uk/experiences/gnbi)

## FUNDRAISERS

Got a whacky way to be sponsored? Want to climb a mountain or host a coffee morning? There are so many ways to have fun whilst fundraising for GUCH PA - if you're interested, then get in touch with us today for more tips, ideas and support.

**REQUEST OUR FUNDRAISING PACK**

## GET IN TOUCH!

To apply for any of the above roles, or to discuss other ways you can get involved with us as a volunteer, please contact Volunteer Manager Victoria Goldsmith on [victoria@guch.org.uk](mailto:victoria@guch.org.uk) or phone 0207 4220630.



## NATIONAL DIRECTOR'S UPDATE

There has been some fantastic feedback from the Thriller theatre trip and the Into the Hoods event, both targeted at younger patients. I am particularly looking forward to seeing many of you again and meeting new faces at our GUCH weekend, which this year will be held in Hythe on the coast in Kent. Additionally, having listened to some of your ideas, I am in the process of looking at opportunities and planning events for older patients. I believe that our events are enormously important. They provide an opportunity for patients to meet together, share experiences and support one another. They also give us the opportunity to listen and learn and find out how we can best support you!

I am really keen to find out how to ensure that our events are welcoming to everyone and to this end we have a survey on our website [www.guch.org.uk](http://www.guch.org.uk). Please complete this as it will be very helpful for our planning. It would also be good to know what prevents you from attending our events. If you haven't been before, why not? Are there steps we can take to help you attend? Have you any ideas for new venues/different types of trips etc? As always, we welcome your ideas and feedback as we constantly look to improve our services for patients.

*Very best wishes  
John Richardson  
National Director*

A big thank you to everyone who took part in our recent survey. In total there were 120 responses, 84% of whom were by people born with a heart condition.

## FEEDBACK FROM THE RECENT ONLINE EMOTIONAL AND MENTAL HEALTH SURVEY

The results and suggestions were really informative and helpful, giving us a very clear idea of what you need from GUCH PA.

The materials that will be developed first are those that scored highest in the poll, which include:

- How to cope with anxiety and worry
- How to cope with depression and feeling down
- Coping with surgery and invasive medical procedures
- Living with ongoing symptoms.
- Dealing with deterioration in health
- Life expectancy issues

There is some information already on the GUCH website and links to other organisations on some of these topics but the idea will be to bring this together and expand what's available. The information will be in PDF form so that it can be viewed online, downloaded or printed off and posted to people. It was noted that many of you were also interested in videos, workshops and further articles in GUCH News on different emotional health issues.

Our aim is to include self-help strategies and other resources that can be a support for you, as well to try and connect the information directly to your different experiences relating to congenital heart conditions. Some of you said you would value examples of

personal experiences and how others have dealt with situations and what helped. We will certainly try to include this, so please be in touch if you think you could contribute by writing a short paragraph or giving a quote or suggestion on any of the topics above. It would also be great to hear from you if you would like to help us draft any of the new resources.

Don't forget that you are welcome to contact me if you would like more information or to talk through any emotional or mental health concern.

*Anne Crump*  
Mental Health Support Worker  
[guchmh@googlemail.com](mailto:guchmh@googlemail.com)  
020 8240 1165



### ANNUAL NATIONAL PATIENT CONFERENCE

Relax in beautiful Cardiff, make new friends and learn about issues that affect you as a GUCH patient – join us for our annual national patient conference happening on October 22nd–23rd. Contact the office for more details and to book

### ARE YOU AGED 13-24?

We are running a special event exclusively for our younger members and YOU are invited! Join us in Cardiff for an action packed weekend that will help you learn more about growing up with a heart condition. There will be plenty of time to chat to other members and make friends, as well as have a lot of fun! See page 9 for more details.

# LIVING WITH SCIMITAR SYNDROME

For years Rosemary Stone felt unwell, but neither she nor her doctors could identify the problem. Having finally been diagnosed with both a congenital heart condition and lung condition, she speaks to GUCH News about living with Scimitar Syndrome.

## WHAT IS SCIMITAR SYNDROME?

It is a rare congenital heart defect (CHD) characterised by either Partial (PAPVR) or Total (TAPVR) Anomalous (abnormal) Pulmonary Venous Return (return of blood from the lungs to the heart).

The syndrome gets its name from the curved shape formed by the pulmonary vein. On a chest radiograph, the vein is said to look like a scimitar, a curved sword originating in the Middle East. The pulmonary vein may be abnormally connected to the inferior vena cava (a vein leading to the right side of the heart), sending already oxygen-rich blood into the chamber that sends blood to the lungs. Because this is an inefficient way for the heart to work, the heart can become enlarged and weakened. Untreated, this CHD can lead to dyspnoea (breathlessness), irregular heart beats, high blood pressure in lungs pulmonary, and heart failure. The affected lung and pulmonary vein tend to be smaller than usual and the heart is located on the right side of the chest instead of the left (called Dextrocardia / Dextroposition)

## NOT BEING ABLE TO PUT MY FINGER ON IT...

As I was born with this condition, my body had naturally adapted to it without me being aware, the only time I noticed that I was different to other people was on exertion. I would struggle when it came to running, cycling and swimming; even walking home from school. Trying to keep up with other people's walking pace was a nightmare because I just could not keep up!

I now look back over my life and this has always been a regular pattern. I have spent my entire life going to and fro to the doctors explaining the symptoms which would be:

- Always feeling tired, poor sleep, chronic fatigue.
- Always feeling cold, especially my hands and feet, tingling in the bottom of my feet.
- Light-headedness, headaches, dizziness, fainting, palpitations.
- No energy, being wheezy. It feels as though my life support batteries have been removed.

- Breathlessness and not getting my second breath.

The doctors said it was either asthma or panic attacks. I knew this was not so because the inhalers did not work. I told them this, but again they did not listen, so in the end I just gave up.

## HOW I CAME TO BE DIAGNOSED

It was purely by chance that my work colleague noticed that my lips had turned a bluish/purple colour and I had lost colour in my face. I was totally unaware of this myself and none of my family or friends had ever remarked about my lips. So in January 2009, I went to see a doctor who actually sat and listened to my concerns.

I went for a CT pulmonary angiogram in May 2009 which revealed significant Scimitar Syndrome with partial abnormal return of blood from the right lung into a vein leading to the wrong side of the heart. There was also a single large pulmonary vein draining into the left atrium along with evidence of the heart being on the wrong side. In June 2010, I went to have intensive pulmonary tests requested by the cardiologist in Birmingham, as it showed that my breathlessness was coming more from my lungs. It revealed that, more than likely, I was born with fixed small airways disease, and to prove that I did not have asthma, I went on a three week course of steroids which did not open up my airways at all, and my peak flow was still showing a poor reading.

The cardiologist felt, seeing that the shunt was small, that I did not warrant the corrective surgery. I was somewhat relieved, as any heart surgery is worrying. The only concern I have is my heart valves, as they are under a lot of pressure, and so are my lungs.

## LIVING WITH SCIMITAR SYNDROME

If I overdo things then suddenly without warning I will come over very tired. I will slow right down to what ever I am doing and just go and sit down quietly or lie down and sleep. After a couple of hours it will pass. I still won't be 100% but I will feel a lot better.



*Rosemary is really keen to know other people with Scimitar Syndrome*

My employers have been accommodating to my needs and have made necessary adjustments as I cannot engage stairs or any inclines. I am one of the Housekeeping team, which is a demanding role and it takes up all of my energy. Often I am too shattered to do any of my cardio and pulmonary exercises when I get home, so all I do is rest up ready for work the next day and at the weekends.

I know many people advise staying away from the internet because of all the incorrect information out there, but for me, I have found my own research to be very helpful. I have a heart condition and a congenital lung condition and both are quite rare. Because of this, it can be hard to find answers. Apparently the severity of Scimitar Syndrome varies considerably. Some people have it and are entirely unaware, or have it diagnosed but a doctor determines that the effects are so minor that no action needs to be taken. In other cases, the defect causes health problems or puts the heart in danger, in which case surgery may be recommended to address the problem.

I have drawn support from being a member of GUCH PA, and have especially found GUCH News to be a source of reassurance and helpful information. I love to read the real life heart stories from other members. You know you are not alone which in itself is a comforting relief.

*Rosemary Stone*

*Editor's note: Do you have Scimitar Syndrome? Get in touch and let us know, we'd love to hear from you.*

## ARE YOU A GUCH WHO HAS BEEN CO-DIAGNOSED WITH PAH/PH (PULMONARY ARTERIAL HYPERTENSION)?

GUCH PA is working with a number of other groups and organisations on a project looking at the current service for co-diagnosed patients, and any areas in which it could be improved. We are in the early stages of this work, but hope to have a patient feedback survey to send out to co-diagnosed GUCH/PAH patients within the next few months. The project leader at GUCH PA is Beth Greenaway, who is compiling a confidential list of interested patients who will have the opportunity to give their valuable input.

If you already filled in the form about the project which was available at the GUCH PA annual conference last September in Manchester you do not need to register again, although it is not a problem if you choose to do so.

Please contact Beth at [BethPAHproject@guch.org.uk](mailto:BethPAHproject@guch.org.uk) if you have any questions, want to register your interest in taking part, or want to be kept up to date with the project.

## GET CONNECTED!

[www.guch.org.uk](http://www.guch.org.uk)

[www.facebook.com/guchfb](http://www.facebook.com/guchfb)

[www.twitter.com/guchpa](http://www.twitter.com/guchpa)

facebook

twitter

## GET CONNECTED!

The words all heart patients dread. When I got told this, it came as quite a shock. I was very well and didn't expect it at all.

I had many worries upon hearing these words; would I be in lots of pain afterwards? How long would recovery take? Would I ever recover to full health? - and even (though I thought it unlikely) would I ever wake up?

It is now three months since I had a successful pulmonary valve replacement and I am relieved that it is over and that I am fully recovered! Knowing how uncertain and daunting it is to be waiting for surgery, here are some things that I found helpful for anyone who may face this in the future:

#### Contacting people who have been through a similar experience.

Although everyone's experience differs slightly, I felt much better prepared after hearing other people's stories. I felt less anxious hearing some positive stories and got some helpful hints beforehand.

#### Treating myself

From the day I got my date to the day of the operation was a nerve wracking time. I dealt with it by keeping myself busy getting ready for hospital and doing lots of nice things like going to the cinema, catching up with friends, going out for meals etc.

#### Pre-meds

These were offered either the night before or in the morning before being taken to theatre. I had them the night before, had a good night's sleep and awoke feeling relatively calm considering it was the day of my surgery!

#### Large pyjamas

Open heart surgery involves breaking the breast bone. Although I didn't find the pain too bad (of course I had lots of good pain relief in hospital), I did find it very uncomfortable. Lots of my movements were restricted at first and getting dressed was difficult. Large pyjamas with buttons down the front made it a lot easier!

## "I'M AFRAID YOU NEED AN OPERATION..."

#### Communication chain

All my friends and family wanted to know how I was doing, so I arranged for my parents to contact 3 friends and my grandmothers, who then passed updates onto other friends and family.

#### Remembering that each day gets a little bit easier

I wasn't very good at this in the beginning. I remember feeling terrible on the third day. I felt more tired and uncomfortable than I had previously imagined I would. I thought it would take me forever to recover and I felt quite angry about this. However, the next day I felt a bit better and the next day I felt better still. If I could, I would go back and tell myself on the third day that before long I would be feeling better.



*Rosie is now enjoying being back at University following her surgery earlier this year*

Finally, I would say that open heart surgery is a big procedure but by taking each bit as it comes, it is more manageable (lots of chocolate and presents from friends and family helps too!). Although I hope I never have to have this surgery again I have had a positive experience. I have made friends along the way and feel like I have undertaken a great personal achievement.

*Rosie Edwards*

## ARE YOU AGED 13-24?

### JOIN GUCH AND THE CHILDREN'S HEART FEDERATION FOR OUR SECOND YOUTH CONFERENCE

Make new friends and make a difference

**WHEN:** 22nd-23rd October

**WHERE:** Cardiff

**WHY:** We'll be running an exclusive young persons' conference, packed with information and advice about growing up and living life with a heart condition, as well as having lots of fun overnight and during the fun activity on the Sunday!

If you would like to book a place or find out more please contact the Brighthearts team at the Children's Heart Federation: [brighthearts@chfed.org.uk](mailto:brighthearts@chfed.org.uk) or 0207 422 0630

We would be keen to talk to young people who want an active role in the planning of this conference – get in touch!



Last year's conference was a huge success and enjoyed by all - be part of it in 2011!

"I feel more confident in managing my heart condition at university"

Hassid, aged 21

"I loved making new friends and learning more about issues that are beginning to become important now that I am a teenager" Kerry aged 17

"Everyone was really friendly, and it helped me a lot to talk about my heart condition and learn about other people's stories too"

George, aged 16

"Some people had the same heart condition as me, so I learnt I'm not the only one" Laura aged 14

\*Quotes from feedback following 2010 Young Person's conference. Names have been changed to protect privacy.

Did you know that there are around 50,000 doctors in the NHS working towards a higher qualification? These doctors all play a crucial role in the NHS and without them it would not be able to carry on.

Joining the NHS straight after university, doctors then begin their long journey to become GPs, consultants or speciality doctors. Over the years, they will learn from formal education and gain experience by treating patients.

If you have been to hospital, the chances are that you will have been treated or spoken to by a trainee doctor; however, it is very hard to know what stage in their career they are at. A doctor's training path is a mystery to many people, and there are a number of different titles which they will appear under. For example, the term 'speciality' doctor has only recently been introduced and it replaces names such as staff grade, clinical medical officer and hospital practitioner. To confuse you even more, these original names are still used in some places.

After a doctor's degree is over they move onto the Foundation Doctor two year programme. This will see them work in different medical specialities under the supervision of senior doctors. When they have completed their first year of the programme, they are added to the GMC Register. This register controls and regulates who can practise as a doctor. A doctor must be on it in order to practise in the UK, and it also has the power to revoke or restrict a doctor's registration.

When doctors have successfully completed the second year, they are awarded the Foundation Achievement of Competence document. During these years, a doctor's typical title will be junior or foundation doctor including F1 or F2.

The next step on a doctor's journey is to decide whether to enter a specialist area of medicine such as surgery or psychiatry, or train as a GP. When they enter into this phase, they become Speciality Registrars, and their titles here become things such as SpR1, SpR2, SpR3, etc or StR1, 2 3, etc where the number shows their years spent in speciality training. These titles all seem a bit confusing, but the doctors themselves receive guidance on how they should introduce themselves and explain their level of training to you.

## HOW DO YOU KNOW WHO IS TREATING YOU??



Each Speciality Registrar will spend 3 to 8 years, depending on speciality, completing this training to become either a GP or a consultant. During these years they will work in an area, such as obstetrics or surgery or anaesthetics, and will now look after patients and perform procedures under supervision. As they progress through their training, they will gain more experience, knowledge and competence.

Some doctors do not complete speciality training but can still work as Speciality doctors. They will have a wide range of experience and have at least four years of postgraduate training. Don't be alarmed, as in many cases Speciality doctors are senior doctors, however they will also be supervised and a consultant will have overall care of the patient.

When Speciality Registrars successfully complete their training, they can go out into the world and apply to become a GP or a consultant. A consultant is a doctor who is responsible for your care and is also responsible for all the other doctors you see on his or her behalf. Consultants are on the GMC's Specialist Register and have completed all necessary steps in their training to work unsupervised as specialists. Even after all of these years, a doctor's learning life never stops as they have to keep on top of all the latest procedures and practices.

What is fascinating is that, as a patient, you can easily get involved in their training. Whether filling in feedback forms at hospitals and GP surgeries, or being a patient representative on committees and in decision making, you can get involved in a doctor's journey of training all the way through. Talk to your local medical Royal College to get more information on how your experiences can help give doctors just that little bit more information. You can also contact the Department of Health for information on local authority engagement groups.

*Tamsyn Jones*

*This article has drawn on sources from the Academy of Medical Royal Colleges and the General Medical Council's "A Guide to Training Doctors".*



**THANK  
YOU**

Thank you so much  
to **George and Molly  
Carr** for their extremely  
**generous donation of £500,**  
in memory of their daughter  
**Elizabeth.**

## **WE'RE OFF TO HYTHE TO BE BESIDE THE SEASIDE... BESIDE THE SEA!**

**We'll be packing our sun creams and sandals and heading off to the beautiful coastal town of Hythe in Kent for our annual social weekend away on the 1st–3rd July.**

**Our annual social weekends are a fantastic way to make new friends, meet other families and enjoy an affordable weekend away.**

**We have a very limited number of places still available, so if you fancy joining us, get in touch today on 01473 252007 or email [admin@guch.org.uk](mailto:admin@guch.org.uk)**

## **LETTER TO THE EDITOR**

Dear Editor,

I am a heart patient and use Ring and Ride. Our buses are going to be cut down due to the cost of running them. I have many friends who rely on this service and wouldn't be able to make social outings if the cuts go ahead. I won't go on public transport due to suffering panic attacks since having my purse stolen two years ago. If any readers use Ring and Ride, I urge them to write to the papers etc. This is a service which users cannot do without.

Yours faithfully

Julia Knight

*Editor's note: Ring and Ride is a door-to-door public transport service for people of all ages who find it difficult to use ordinary public transport. It is operational in many parts of the UK - contact your local council to find out more.*

Until recently I didn't realise how, over time, a seemingly small concern can escalate into a major problem and really damage your health.

Like most people with a CHD, I have always felt the need to prove myself to others to show that I am just as capable in the workplace as they are. So when I got a job in a public sector post, I believed I had finally achieved my goals and had proved the sceptics wrong. However, during my five years there, I suffered bullying at the hands of my boss. With her snide remarks and discriminating put-downs, my life became hell. Knowing that I was deaf in one ear, she would stand the wrong side of me and then accuse me of not listening. Comments like that got harder to ignore. Little by little, she wore me down and inevitably, I brought my problems home. Practically every night my partner would have to listen to me complain about work. Sometimes I would wait until he fell asleep and then I would cry and hope he didn't wake up and see me in tears.

Soon panic attacks set in and I became reluctant to go to work. I took lots of time off sick and it didn't go unnoticed. As I wasn't my boss's only victim, our whole team reported her behaviour to one of the Heads of Department, but nothing was done. Eventually I went to see my union representative. This was really upsetting for me because, again, I felt like I was the one that had to prove how good I was and that I had the right to hold down my job. The rep listened to my concerns and my manager and I had to have a meeting with an independent person to discuss my allegations. Fortunately, I had kept a diary of every incident and she was made to apologise and agree she would be more respectful. Although I accepted her apology, I was really disappointed as I felt that she got nothing more than a slap on the wrist, and that the problem was just swept under the carpet.

Things seemed better for a while, but then she started the bullying again. At the time, I was going through some tests for my leaking heart valves so I really didn't have the energy to go through an official complaint again. This time I couldn't cope and I became withdrawn. I lost weight rapidly and ended up in hospital with chest pains and a racing heart. As I lay in the hospital bed I made a conscious decision to quit my job. I handed in my notice and did what I never wanted to do in my life – sign up for Jobseeker's Allowance.

I was so ashamed of myself for letting the bully win. It had taken me years to get where I was and I had thrown it all away. I stopped wearing make-up, exercising, going out and having fun. I became isolated by avoiding family and friends. I came to be scared of my own body and for the first time in my life, I felt frightened about my CHD, even though the doctors told me nothing was wrong. I was agoraphobic and wouldn't leave the house; even to get a pint of milk. I relied on my partner and my best friend to fetch things for me, then I hated it myself for it.

This was probably the closest I ever came to a complete breakdown, but luckily for me my GP arranged for some counselling sessions. Incredibly, I only had to wait a few weeks for the first meeting.

I am not embarrassed to say it now, but at the time I didn't realise how much emotional baggage I had been carrying, and for how long I had been carrying it, from the resentment of my physically abusive father, to the heartache of not having my own children, to living with my disabilities. Everything came out and I felt much better for it.

Thanks to some fantastic people, I gradually got emotionally and mentally stronger, and in just under a year I was back to my normal self and even had a new job.

I now work for the Department for Work and Pensions in a demanding call centre. However, instead of feeling the need to prove myself, I know I am good at my job, and I know this because our team leaders and managers often tell us. My employers have made reasonable adjustments to accommodate my needs. Amongst other things, I have fixed working hours that enable me to be at work at my most productive times, and they understand that sometimes I do get tired so might not always be at my best by the end of the week. I feel valued and respected and that's all I have ever wanted.

*Amanda Davies*

## RUNNING A MARATHON FOR GUCH PA

We'd love to extend huge congratulations to Corinne Ellison for her amazing achievement of running the London marathon for us, just 10 months after heart surgery. Completing the mammoth 26 miles in just 4 hours 12 minutes, Corinne has raised £366 so far – and counting!

Speaking to GUCH News not long after flying over the finish line, Corinne told us:

"I made the decision to fundraise for GUCH, despite being lucky enough to have a ballot place for the marathon. I was overwhelmed with the response I had to this and have so far raised £366 for GUCH!

On the lead up to the big day, I had a blip with shin splints. I took the physio's advice, rested and eased back on running for the last four weeks. This psychologically, was a hurdle in my training but after deferring last year before I had my heart surgery, I was utterly determined to get to the start line.

The race itself was hot, full of atmosphere and certainly a physical challenge. At low points, I took myself back to my hospital bed, reminding myself of how long I had wanted to be here.

Near the end, this fire inside enabled me to pick up my pace and finish strongly – something I have never done! The feeling at the end was of extreme satisfaction, pride and relief. Ten months after heart surgery, I had achieved my dream of running the London marathon again. It doesn't get any better than that.

I hope others are inspired to take up the challenge of running, whatever their ability. Having a race to focus on has kept me going during difficult times and I am so grateful for that."

Corinne – you are certainly a big inspiration to us! Congratulations!

*Corinne wrote a feature about her late diagnosis and her passion for sport in our last issue, available online to read at [www.guch.org.uk](http://www.guch.org.uk)*



*Corinne hopes to inspire other heart patients to take up exercise*

**THANK YOU**

## HELPING HEARTS BY CELEBRATING SUNFLOWERS!



With the sun shining and summer taking shape, GUCH member Steve Rogers and his team at Natwest took the opportunity to raise money for GUCH PA by holding a Sunflower competition.

Raising a really impressive £160, it is with warm thanks that we congratulate Stephen and his team.

**Carers UK estimates that 1 in 8 UK adults are carers. With many not being formally recognized or supported, Sarah Barker profiles one family unit struggling to cope, and investigates sources of care for carers.**

Helen is 45. Her husband, 51-year-old Michael, was born with a complex congenital heart condition. He has had three operations and is currently awaiting a valve replacement. His condition has become more debilitating as he has got older. He took early retirement as work had become increasingly difficult as his stamina and energy declined. Helen and Michael have three children; two grown up, who live away from home, and 15-year-old Ellie. Michael needs regular care as he has reduced mobility and day-to-day tasks are difficult due to his constant tiredness.

Helen suffers from diabetes, a spinal injury and depression. She takes anti-depressants, suffers mood swings and is constantly worried and exhausted.

Helen would like more help but is not sure what is available and does not know what questions she should be asking. Michael does not like having strangers in the home providing care. Helen and Michael therefore rely on relatives and friends to help with care arrangements. They have a roster system with people taking turns to cover the care arrangements. Some relatives live too far away to travel daily and so have to stay overnight when it is their turn, despite having their own families to consider.

Since Michael stopped working, the household has suffered financially. Although social services have assessed Michael's needs, Helen is not sure if he is receiving all financial benefits available and finds it difficult to find out what benefits they might be entitled to. Helen's manager recently suggested that she ask social services about the Carers' Assessment which is also available from social services. Helen had not been told about this before. When she enquired about the Carers' Assessment the person she spoke to had not heard of it. Her manager put Helen in touch with Carers UK and gave her a copy of a leaflet that provides details of the Carers' Assessment.

Helen works full-time. She has found combining full-time employment with her caring role and her

own health problems difficult. She feels that she is constantly trying to "juggle" her commitments. She considered giving up work altogether but realised that she needs to work, not only financially, but also to give her something to focus on. She finds it difficult to concentrate at work and her frequent absences have affected her performance. Her manager has helped by providing details of organisations that can provide help and support. However, although her manager has allowed her paid time off, Helen has found it difficult to find time to contact the organisations, as she still has to try to do her job. Her manager has also adjusted her workload and suggested changing her working pattern. However, any reduction in her hours would cause further financial pressure. Helen worries that she will be unable to continue working.

Helen used to enjoy sewing and cooking but feels guilty when she dedicates time to herself. She feels angry and frustrated that life is passing her by and that she is not really "living".

Ellie spends her holidays at home helping her dad instead of being out with her friends. Her mum likes her to come straight home after school so that someone is with Michael when other carers have gone home, before Helen gets back from work. Ellie has not told her friends about her home situation, as she does not want to be different. She finds it difficult to concentrate at school and is worried about her GCSEs. She would like to go to university but worries about leaving her mum and dad.

Helen and Ellie do not see themselves as "carers" and feel that looking after Michael is part of family life. They do not like to complain and feel guilty about having a life outside the home when Michael has no choice.

Michael does not know what he would do without Helen and Ellie, as he constantly tells them. Although he finds it hard when they go to school and work, he also worries that they have given up their own lives to look after him.

## Issues Affecting Carers and Sources of Help

The story of Helen and her family, based on a real carer and her family, is typical of some people living with a long-term health condition or disability. Typical factors include:

- Carer's own health. Depression, anxiety, stress and other mental illnesses are particularly common. Also common are muscular-skeletal injuries through the continual strain of lifting or assisting a relative with limited mobility.
- Emotional difficulties such as guilt, anger and frustration.
- Financial difficulties from the carer and / or person cared for having to reduce or give up work and additional costs associated with the illness or disability.
- Wanting / needing more help, but not knowing what is available or how to access it.
- Work-related issues due to trying to combine work and caring.
- Not having a life outside caring.

It is important that carers tell social services, their GP and their employer that they are providing care.

The Employment Act 2010 provides protection for carers through the inclusion of Associative Discrimination. This means that carers must not be treated less favourably than other employees. This could include flexible or alternative working patterns, including home working. Some employers have signed up to the Working Families and Employers for Carers scheme, undertaking to recognise and provide support to staff who are carers. Some employers provide specific networks or support groups and make other provisions for carers. For instance, the Civil Service Benevolent Fund can arrange to complete a "carer's passport" for civil service staff.

The Carer's Passport identifies how the carer is affected by their caring role and provides advice to the carer's manager, aiming to help the carer to maintain a healthy work-life balance.

*Sarah Barker*

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NOT ALONE...**

**Contact our  
FREEPHONE  
HELPLINE  
service for advice,  
information,  
or if you just need  
someone to listen...**

**0800 854 759**

**Got Questions?**

- Insurance?
- Money worries?
- Concerns about the future?
- Need to talk?

We offer practical help and advice to anyone born with a heart condition, their friends, family, colleagues and carers.

Call us. We care.  
**0800 854 759**



**A moving extract from GUCH patient Max Compton's new beautifully bold heart transplant journal, *A Change of Heart*.**

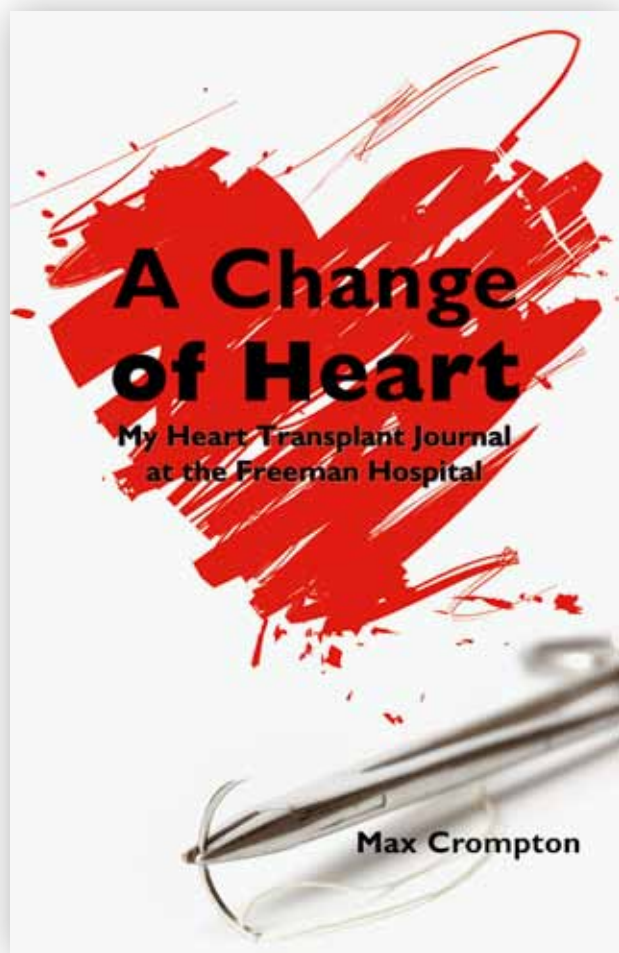
You know, sometimes I feel quite guilty. I feel a little ashamed of myself with some of my thoughts about my heart. I berate it in my mind sometimes, sometimes I swear at it – I even can, every now and again, feel repulsed by it – when I replay some of the words doctors have used to describe it... 'a big bag full of blood, not really doing anything' and 'ventricle like a balloon, blown up and up, with the heart wall stretching and thinning' and the worst one of all, 'it's like a ticking time bomb and no one knows when it will go off.'

I feel let down by my heart, disabled by my heart and even tormented by it. I used to think, when I had my aggressive palpitations, that my heart was almost teasing me, almost laughing at me, at how it is terrorising my life. I sort of thought of it as a kind of villain – a vindictive evil that dominates me sometimes – sometimes to the point when I would – although I only did this a few times – thump my chest to try to hurt it. Shameful, but that's what I've done sometimes, when I'm in a rapid atrial flutter, or on a really, really tired day.

I have created a monster in my mind and called it my heart – and I have attributed all of my faults, all of my fears, all of my personal insecurities and frailties to its make-up. I have created a terror and one which, most importantly – and here's the thing – I can hate and I can blame.

I have packed together every ill and limitation and problem I have, wrapped it in a black cloak, giving it a sunken, sallow face and staked it down to the beating muscle in my chest cavity. And this is why I now feel so guilty and ashamed – for at the end, I realise, I am wrong. Everything is not how it seemed.

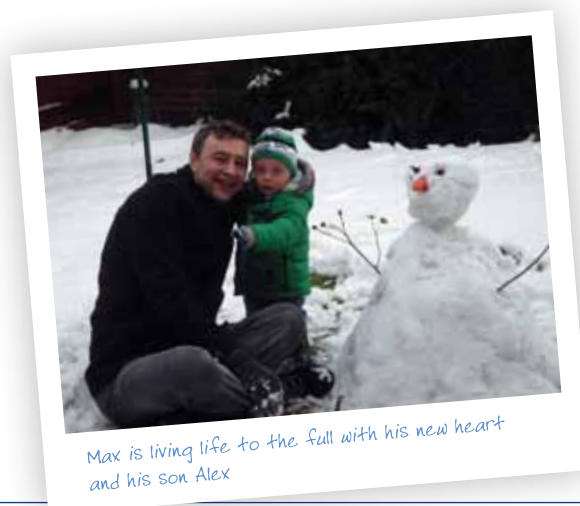
I have written previously about how poorly my heart is and how unbelievable it is that I am so well. And really, when you think about it, this miraculous health and amazing quality of life is all my heart's glory. Even though systolic function is measured at only 15%, it still fills me with life. Even though the right ventricle is massively volume loaded, it still fills me with life. Even though my atrial rhythm disturbances further decrease efficiency and my valve lets blood go the wrong way, it still fills me with life. My heart



has got me here today and has done so despite its problems and its bad luck. It has constantly worked tirelessly for me, when it could have given up long ago – but still, it beats on.

So, I suppose, now, at the end of our time together, I really need to say just two things – sorry and thank you. God Bless. I can't think of anything else to say, I just hope that when I move onto my new life, my old heart remains with me in virtue, if not in person.

**We have 3 copies of Max's brutally honest, deeply engaging "A Change of Heart" to give away. For your chance to win, see Page 19.**



I am 25 years old and as a young adult with a congenital heart defect I'm never sure whether or not to declare myself as 'disabled'.

## DISABLED OR NOT DISABLED?

As a child I was unwell and underwent a series of operations for my condition (Tricuspid Atresia), and though there have been some complications as I've grown up, I have largely enjoyed good health. My condition has never prevented me from doing the things I've set my sights on- whether that be taking a gap year and teaching English in Malaysia, leaving home for university or taking up paid work as a mentor and support worker. It's simply been the case of making some reasonable adjustments, and being of a mindset where my condition does not dictate my life.

But does my heart defect mean I'm disabled? For a start, I am required to go to the hospital more frequently than most, have regular INR tests and may find it more difficult to work in physical labour, for example as a builder, or work in highly stressful environments, like the police. However, I realise that other people with heart conditions may be able to work in these jobs and be perfectly fine – we are all different! I also have to take medication indefinitely, and then of course there are the social ramifications. If I tell someone about my condition, be that a friend or colleague, I'm met with uncertainty about what is wrong with me or told not to 'overdo it.' Of course everyone views their heart condition differently, but for me, I've always felt it's made me different from everyone else my age – probably because my health has always been on the agenda and as I was growing up, learning new things, like riding a bike or swimming, were delayed. So my condition has set its own personal challenges in terms of how I view myself. Does this constitute a disability?

Recently, I have been unwell and did consider applying for disability benefits on being diagnosed with arrhythmia. I have never claimed for anything in the past, and was worried about being labeled 'Disabled' and 'unfit for work' - as I personally believe work can be good for you and I want to work. Although at times we'd all rather not work and perhaps enjoy being Lottery winners, work gives you a purpose, a sense of belonging and worth, and if you're lucky, some

extra funds to treat yourself. For me, I don't want my 'disability' (if that's what you'd call it) to influence if and when I am given work, but I am compelled to inform employers of my condition. I'm beginning to resent the label 'disability' or 'condition', for fear in the future of not being able to secure a competitive mortgage (or one at all), or not being able to get insurance, or any of those financial necessities. Of course, there are those that will campaign on my behalf for these things, but that doesn't stop me from sometimes feeling different or simply frustrated.

Though one thing is for certain, whether 'disabled' or not, I aim to live a full life and be challenged. Half a heart does not mean half a life.

*Harry Ludlam*

*Editor's note: Do you, like Harry, feel confused about the issue of "disability" labelling? What does the word, and its implications, mean to you?*



Hello! I would like to tell you all a little bit about the Children's Heartbeat Trust (formerly known as Heartbeat).



We are a Northern Irish charity working to provide emotional and practical support for those affected by heart disease in children in Northern Ireland. Established in 1982 as a parent support organisation, this is still our central aim and we provide this support in a number of ways.

The charity maintains 4-bedroom accommodation above Clark Clinic (the centre for paediatric cardiology in Northern Ireland) in the Royal Belfast Hospital for Sick Children. This allows parents to stay at the hospital in comfortable surroundings, in what can be a traumatic time for both the child and the parent. This accommodation is especially invaluable to parents who would otherwise have to travel long distances daily to and from the hospital.

We also organise local parent-led support groups which meet right across Northern Ireland to provide community support to families of children with heart disease. Through regular meetings, parents have the opportunity to meet others experiencing similar issues and problems and share their concerns, thoughts and triumphs!

Central to our work is the provision of up-to-date and accurate information on the services offered in Northern Ireland, and what help and support parents and families can access. We deliver this information in a variety of ways; via our website, parent support groups, specialist information evenings, quarterly 'Heartbeats' magazine, e-bulletins and leaflets.

As we are all aware, there is a growing population of teenagers with heart disease and the charity also works alongside our paediatric and congenital cardiac liaison nurses in support of a new nurse-led transition service called 'rheartz'. The area of GUCH care and provision in Northern Ireland is one that we will be closely following and doing our utmost to ensure that teenagers and GUCHs in Northern Ireland are receiving the same treatment and support as offered across the rest of the UK.

We are lucky to enjoy a close relationship with the clinicians in Clark Clinic, funding medical equipment and supporting new initiatives such as the innovative 'Heartbeat Suite' a tele-medicine centre which uses real-time interactive video communications and imaging services to link paediatric cardiologists directly to the homes and parents of children with serious heart conditions throughout Northern Ireland.

Currently we are partnering with three other local children's charities to raise £2,000,000 for the 'Children's MRI Scanner Appeal'. The Royal Belfast Hospital for Sick Children is the only children's hospital in the UK without this facility and it is envisaged that cardiac MRI would account for at least 20% of the scanner's use. It is an essential service in order to ensure that children with heart disease in Northern Ireland receive the best care and treatment possible.

So, there you go – we are busy over here! If you would like to receive our 'Heartbeats' magazine or e-bulletins, please email your details to [sarah@childrensheartbeattrust.org](mailto:sarah@childrensheartbeattrust.org). Also check out our website at [www.childrensheartbeattrust.org](http://www.childrensheartbeattrust.org) and our Facebook page to keep up to date on all that's going on here in Northern Ireland.

Thanks!  
*Sarah Quinlan*  
*Executive Officer, Children's Heartbeat Trust.*



*The Children's Heartbeat Trust offers fun family days out and festive treats for its members*

# SPOT THE FIVE DIFFERENCES AND BE IN WITH A CHANCE OF WINNING ONE OF THREE SIGNED BOOKS!

We have three copies to give away of Max Crompton's moving collection of transplant journals, *A Change of Heart*, as featured on page 16.

A true, inspiring and brutally honest read written by a GUCH patient. Join Max on the his admission day at the Freeman hospital, and journey with him as he receives his change of heart...

To be in with a chance of winning, simply tell us the five differences between the two images below.

Email your answers, along with your name, full postal address and contact number to: [victoria@guch.org.uk](mailto:victoria@guch.org.uk). Alternatively, pop your answers in the post and send them to our head office.

The winner will be announced in the next issue.



*If you're not lucky enough to win our competition, you can still get hold of your own copy at [www.amazon.co.uk](http://www.amazon.co.uk). Published by Jumble House and usually available for £9.99, all monies from sales will go directly to the Freeman Hospital, Newcastle.*



**CONGRATULATIONS!**


CONGRATULATIONS TO  
ISSUE 64'S WINNER  
LYNNE MCEVOY FROM  
CAMBRIDGE, WHO BAGS  
THE BATH SET AND CHOCS!

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HELP AND  
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**Got Questions?**

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- Need to talk?

We offer practical help and advice to anyone born with a heart condition, their friends, family, colleagues and carers.

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## GUCH PA NOTICEBOARD

Spend some time online with us – GUCH PA has an extensive website, a range of message boards for all ages, Twitter and Facebook. Don't miss out, visit [www.guch.org.uk](http://www.guch.org.uk)

Want to receive your own copy of GUCH News hot off the press or straight to your inbox? Contact the office to register your details today.

Fancy fundraising for us? Get in touch for hints, tips and support. Thank you!

**THE DEADLINE FOR  
SUBMITTING ARTICLES FOR  
OUR NEXT ISSUE IS MONDAY  
1ST AUGUST 2011**

Join us in Cardiff for our annual patient conference - make friends, get informed and stay up to date with all the GUCH news! See the front page for more details or contact the office.

Explore our website, chat on our message boards, keep up to date with all the info online at:  
[www.guch.org.uk](http://www.guch.org.uk)

Support GUCH PA as you shop - at no extra cost!

[www.easyfundraising.org.uk/](http://www.easyfundraising.org.uk/)

Access loads of your favourite high street stores through this easy to use site and shop securely.

Want to get involved? Write an article for a future issue? Contact the editor at [victoria@guch.org.uk](mailto:victoria@guch.org.uk) to discuss your ideas!

Don't forget to give us feedback - what would you like to see in GUCH News? Get in touch!