South Wales and South West
Congenital Heart Disease Network

Autumn 2021
Issue 10

Newsletter

Inside this edition

Clinical Director's Introduction

This is one of my favourite times of the year, bringing with it a kaleidoscope of colour as the autumn leaves start to fall and nature prepares for a period of winter dormancy.

Our latest newsletter brings with it a similar multitude of change with articles introducing new members to our core network and clinical teams across the region. We are, however, far from slowing down for the winter months ahead! Like all of you we "battle" with ever changing national guidelines, the advice on vaccinations as well as the effect of displaced seasonal respiratory infections normally seen in the winter to our summer months. That said, we are gradually seeing light at the end of this very long pandemic tunnel with the gradual restoration of clinical services.

My own reflection is the effect that this pandemic has brought upon our young children, teenagers and young adults who have had their most informative years of learning and experiences disrupted by COVID-19. This has been mirrored by a rise in mental health and wellbeing issues in many. It's great to hear, in this edition, from Hannah Mustard and Amy Woodham who have joined our psychology teams to help support those in need.

I remain very proud of our community network that has grown and thrived despite the challenges we've all endured.

Engaging with, and learning from, our patients and partner charitable organisations remains a key goal for our network. As you flick through the pages I hope you agree.

Dr Andy Tometzki
Network Clinical Director

Your South Wales and the South West Congenital Heart Disease Network is here to support CHD patients of all ages throughout their cardiac journey, as well as their families/carers and the staff who are involved in CHD care across your network.

Your network connects all of the hospitals, services, staff, and patient/family representatives from across South Wales and the South West of England. Together we aim to deliver the highest quality care and experience for our patients.

The network is also part of a national group of congenital heart networks that work together.

Network Team Key Contacts

Clinical Director: Dr Andrew Tometzki
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Lead Psychologist: Ness Garratt
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COVID-19: CHD Support

COVID-19 has affected us all, bringing much change for individuals, for staff working in the NHS and for patients and families affected by congenital heart disease. Services have had to think differently as to how best to deliver care safely, trying to meet patient need while balancing the risks of COVID exposure against the risks of delayed care.

Urgent and emergency services continued to a large extent throughout the pandemic but the capacity to provide elective services was heavily reduced across the country. Adult CHD services were significantly impacted by a high demand for intensive care beds during peaks of the outbreak, but all hospital services were affected by infection control and distancing measures, which reduced the number of operations and procedures that could be completed in a theatre session and patients that could be seen in a clinic. This has caused waiting lists to expand across the NHS, with CHD services no exception.

NHS staff are acutely aware of how difficult it has been for CHD patients during this time. Rising to this challenge has meant clinical teams working together even more closely, making use of improved teleconferencing and telemedicine technology to continue to provide care from a distance where they have not been able to do so in person. Waiting lists are reviewed by consultants to ensure that it is safe to delay appointments, scans or treatment for a certain period, so that the limited capacity available is prioritised effectively and safely. Staff across the region have given up evenings and weekends to put on additional clinics and sessions to help reduce the backlog of patients still needing to be seen. Unfortunately, there is still some way to go.

The SWSW CHD Network is **enormously grateful** to staff for their hard work and focus, and to patients for their patience and understanding, during this tremendously challenging time.

We recognise that these delays can be a source of worry for patients. Cardiac nurse specialist teams have been available throughout to answer clinical queries from patients and families, while administrative teams have supported with queries about appointments.

For further useful resources, visit the COVID-19 pages on our network website: www.swswchd.co.uk

Meet John, our network manager

We were delighted to welcome John to the team in June 2021 as the new CHD Network Manager for South Wales and the South West.

"I was pleased to join the network team in June this year, moving across from the children's hospital management team in Bristol. My interactions with members so far has highlighted the fantastic passion and dedication of individuals and teams across the region who are determined to make CHD care in the South West and South Wales the best it can be.

My own priority for the next year is to keep the momentum and continue the great work that has already begun, while making the most of new ideas and new ways of working open to us.

Our work-plan for 2021/22 is ambitious, but it needs to be if we want to tackle the big challenges facing CHD services.

After the lessons of 2020, we recognise we may also need to be flexible in our priorities to respond to the unpredictable, ensuring that the health and wellbeing of our patients and services comes first. All this will not be easy, but this network is well-placed to deliver this valuable work."

Find out more about John on our website: www.swswchd.co.uk/en/page/who-we-are

South Wales and South West
Congenital Heart Disease Network

Find out more at: **http://www.swswchd.co.uk**

Follow us on twitter: **@CHDNetworkSWSW**

Respiratory Syncytial Virus (RSV): the facts

Situation

Parents and carers are encouraged to know the signs of respiratory illnesses in young children. Respiratory illnesses, including respiratory syncytial virus (RSV), which can cause a cough or cold, are very common in young children and are seen every year.

RSV is a common seasonal winter virus, which causes mild respiratory infection in adults and children, but it can be severe in infants who are at increased risk of acute lower respiratory tract infection.

RSV is the most common cause of bronchiolitis in children aged under two years.

Assessment

The signs of RSV can include:

- A high temperature of 37.8°C or above (fever)
- A dry and persistent cough
- Difficulty feeding
- Rapid or noisy breathing (wheezing)

Most cases of bronchiolitis are not serious and clear up within two to three weeks, but you should contact your GP or call NHS 111 if you are worried about your child or your child:

- has taken less than half their usual amount during the last two or three feeds, or they have had a dry nappy for 12 hours or more
- has a persistent high temperature of 37.8C or above
- seems very tired or irritable

Dial 999 for an ambulance if:

- Your baby is having difficulty breathing
- Your baby's tongue or lips are blue
- There are long pauses in your baby's breathing

Further information can be found at; https://www.gov.uk/government/news/health-chiefs-issue-warning-as-childhood-respiratory-infections-rise-ahead-of-winter

Background

Last winter, the restrictions in place to reduce the spread of COVID-19, kept these other viruses at bay and there were far fewer infections in younger people. Around the world there has been evidence of unseasonal outbreaks of these infections.

As restrictions ease and people mix more, an increase in respiratory illnesses in children is being seen, with cases higher than usual for this time of year compared to a typical season, and further increases expected over the winter months.

For most children, these illnesses are not serious and they will soon recover following rest and plenty of fluids. For other children though, those under two years old, those born prematurely or those who have certain heart conditions, or are on long-term ventilation, it can be more serious.

Congenital cardiac patients deemed at higher risk, who meet the national criteria for a medicine, palivizumab, to prevent RSV, may be contacted and offered the monthly injection, during the RSV season (until early spring).

Recommendation

Prevention of RSV:

- Good hand hygiene; washing hands with soap and water for 20 seconds
- Cover coughs and squeezes with tissues, throwing the tissues in the bin and re-washing hands
- Avoid touching face with unwashed hands
- Clean and disinfect frequently touched surfaces, e.g. door handles

Those patients at high risk and who fulfil the national criteria will be offered the palivizumab injection, but will be contacted regarding this.

Quality Improvement QR code project

By Abhishek Oswal, ST2 Paediatrics, Severn School of Paediatrics &
Wendy McCay, ST7 Paediatrics and SPIN Cardiology, Severn School of Paediatrics

For professionals working with families of children with congenital heart disease, a commonly-faced challenge is finding appropriate resources to help improve patients' understanding of their condition. For this reason and in view of the COVID-19 pandemic and the increasing drive to reduce reliance on paper resources, we have designed posters based on QR codes which link to British Heart Foundation leaflets.

We have made multiple versions of these posters, linking to leaflets for parents and leaflets for patients themselves. We plan to make these posters available across all hospitals in the region and to collect feedback on these posters as they are rolled out.

From the responses of an initial survey completed by senior clinicians and nurses across the South Wales and South West CHD Network, we feel these posters could be utilised in a number of ways. These include, but are not limited to, having the QR code posters displayed in:

- Outpatient departments for parents to access freely
- In clinic rooms for parents to be directed to by clinicians
- Having individual codes on patient clinic letters, particularly when lesions are newly diagnosed.

Here is a sample – to use the QR code:

1. Open your device's camera or download a free QR code reader
2. Point your camera at the QR code
3. The link should open as a pop-up!

Try it on the code to the left to visit the network hospitals page.

Did you know the network website contains a large range of online leaflets and resources?

This one tells patients about the importance of healthy teeth when undergoing congenital cardiac interventional procedures and why it is especially important for people with a congenital heart condition to maintain good dental health

https://www.swswchd.co.uk/image/page/Dental%20information%20for%20cardiology%20procedures%20%20June-2021.pdf

Website homepage refresh!

ANNOUNCEMENT: View our coronavirus page for the latest updates and guidance on Covid-19.

Welcome to the Congenital Heart Disease Network
South Wales and South West

We proudly support over 6,500 children and 8,000 adults with a congenital heart condition.

Babies and Children

When your baby or child is diagnosed with a

Teenagers/Young People

Adults

When you are diagnosed with a cardiac

Have you seen the new rolling photo banner on the network website homepage?

We are updating the photos on the network website, social media and our network publications. As part of this, this summer we held a couple of professional photo shoots to take new photos of our heart heroes of all ages on their CHD journey and some of the staff who provide their care. We are grateful to those who consented to take part.

Would you like to feature as a CHD network representative for our region? We welcome high-quality photos!

New advances: Patent ductus arteriosus (PDA) closure in neonates

By Dr Francisco Gonzalez Barlatay, Consultant Paediatric Cardiologist at the Bristol Royal Hospital for Children

The background – what happened and how?

The ductus arteriosus is a blood vessel connecting the pulmonary artery and the aorta, which exists in a typical fetal heart but usually closes shortly after birth. If this connection remains open it is known as a patent ductus arteriosus (PDA) and typically results in a continuous left-to-right shunt, meaning that oxygen-rich blood is diverted back into the lungs instead of circulating around the body.

Presence of a PDA beyond the first week of life occurs in as many as 50% of premature babies and in more than 80% of severely premature, extremely low birth weight infants (weighing less than 1kg/2.2lbs at birth). Persistence of a hemodynamically significant PDA in these children has been associated with an increased risk of developing necrotizing enterocolitis, chronic respiratory disease, pulmonary haemorrhage, intraventricular haemorrhage, and death.

Traditional treatment options for haemodynamically significant PDA closure in a premature infant include medical management or surgical ligation, which requires the surgeon to open the chest from the side to directly ligate (tie-up) the vessel.

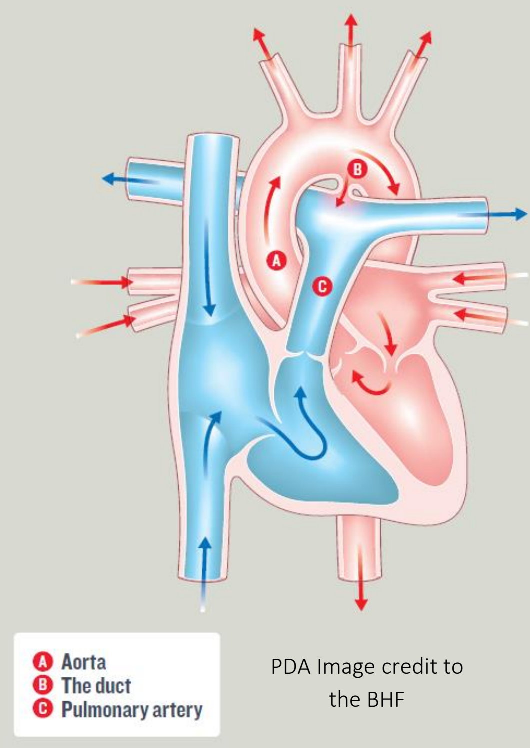
A new approach?

The standard approach in larger infants, children and adults is transcatheter device closure of PDA. This is a keyhole procedure where a catheter (thin tube) is inserted into a blood vessel in the groin and threaded up to the heart, allowing a closure device to be placed without needing to open the chest.

Historically, transcatheter closure of PDA has not been performed routinely in very small infants (under 2kg) but recently a growing body of clinical evidence has emerged suggesting that transcatheter closure of PDA can be performed safely and effectively in premature infants as small as 700g and potentially even smaller.

A single arm, prospective, multicentre, non-randomized study was performed to evaluate the Amplatzer Piccolo Occluder (Abbott Structural Heart, Plymouth, MN; previously approved for patients weighing over 6kg) to treat PDA in patients weighing 700g or more.

From June 2017 to February 2019, 200 patients were enrolled at nine centres, with 100 patients weighing less than or equal to 2kg. This study demonstrated that this intervention is safe and effective and led to FDA approval in January 2019 becoming the first device approved for PDA closure in patients weighing 700g or more. It also obtained a CE-mark in Europe in September 2019.



PDA Image credit to the BHF

Scan this QR code with your phone to find out more about PDA in this British Heart Foundation (BHF) leaflet.

Continued… PDA closure in Neonates

What happened next?

In November 2019, a group of paediatric interventional cardiologists from the Bristol Royal Hospital for Children (Dr Demitris Taliotis, Dr Andy Tometzki and Dr Francisco Gonzalez Barlatay) along with NICU clinical lead (Dr Anoo Jain) attended the first European PremiClose event in Paris with a view to considering starting a programme in Bristol.

Our first PDA patient under 3kg was a patient from Truro who weighed approximately 2.5kg and received a successful transcatheter intervention using the Amplatzer Piccolo Occluder. For that patient, we contacted colleagues from Paris and London who had more experience with this device. However, the next occasion did not happen until 2021 and was a smaller baby (1.5kg).

We decided to formally start a programme along with our neonatal unit at St Michael's Hospital in Bristol and for this we brought a proctor from London, Professor Alain Fraisse who is the UK colleague with most experience in this area.

This case was followed by two other patients (1.3 and 1.4 kg babies) also with the presence of Prof Fraisse. Bristol Royal Hospital for Children is now in the process of becoming a designated independent centre for this intervention.

What impact will this have on our care of patients going forward and what benefits will it bring?

We are able to offer a less invasive approach for a significant problem in neonatal patients that will allow these babies to have earlier extubation, recovery times and discharge times.

Who needs to be recognised/ thanked:

The Bristol Royal Hospital for Children Paediatric Cardiac team (cardiology and cardiac surgery), the Paediatric Cardiac Anaesthetics team and the NICU team that supported the change in practice.

tiny tickers
a better start for tiny hearts

Tiny Tickers are delighted to launch their new free, virtual peer-support sessions. Let's find out more from Katy Lawson, Head of Communication:

"Our virtual peer-support groups provide a safe and non-judgemental space for heart parents to connect and share their journeys together.

We are delighted that with the support of our funders, and generosity of our supporters, we are able to support more families going through the unthinkable.

We encourage heart parents to sign up for one of our six-week parent or parent-to-be groups, or attend a drop-in session. Led by a qualified facilitator, all sessions are free and take place online.

Visit the Tiny Tickers website to find out more: https://www.tinytickers.org/support-info/virtual-peer-support-groups/

Heart parent, Emma, shares:

"Taking part in the parent-to-be virtual support group gave us huge levels of support before our baby was born. After our diagnosis, it provided a platform for us to meet other parents experiencing the same worries and emotions, reminding us we were not alone.

We are all still in regular contact and continue to support each other through our children's surgery and aftercare."

Education and training

One of the network objectives is to support and promote training and education opportunities for our healthcare professionals. During the COVID-19 pandemic, the network has been able to deliver a variety of programmes of education and training online.

Link nurse events

Jess Hughes, Network Lead Nurse, hosted monthly virtual 'meet and greet' drop-in sessions in 2021 for adult and paediatric nurses working with CHD patients (also known as link nurses) across South Wales and the South West to join if they could.

The aim was to better understand the peripheral link nurse successes and challenges, and how the network can help to shape the role and improve the service delivered to CHD patients. These have been really useful sessions and are running throughout the autumn too. Any preference of topics for discussion is always welcome.

Following feedback that the general preference is for bite-size training and education sessions, a virtual education forum for the CHD link nurses was held on 22 June 2021 as a half-day event instead of a full day. This was very well attended and the topics discussed included complex end-of-life care and psychology support, incorporating related case studies.

2021 Paediatric Cardiology Nursing webinar series, delivered by nurses for nurses

Well done to the Bristol Royal Hospital for Children Clinical Nurse Specialist team for delivering a series of six live and interactive teaching webinars over the year.

The webinar content was based on a survey carried out across the network to establish what people wanted from the online webinars. These were really well received with great feedback. The webinars covered:

- ✓ Normal heart, fetal circulation, PDA, ASD,VSD, AVSD
- ✓ Rhythm and arrhythmias
- ✓ Prostin, TGA, coarctation, AS, PS and Fallots
- ✓ Univentricular hearts and anticoagulation
- ✓ The patient pathway
- ✓ Cardiac failure and common cardiac medications

The webinars have also been recorded and are published on the paediatric nurses page on the network NHS Future Platform. Health professionals can register to access these with their NHS email by emailing: SWalesSWCHD-manager@future.nhs.uk

> "A great illustration of how training can be delivered online"

Photo taken before the COVID-19 pandemic

Thank you to those involved

2021 South West Paediatric Cardiology Education Forum (summer)

This regional event was held virtually on 9 July, with fantastic presentations from consultants in Bristol, Taunton, and Cardiff. Topics included universal saturation screening, and early management of the duct-dependent newborn.

Cardiac Physiologist Forum

Daniel Meiring, Bristol Fetal and Paediatric Cardiac Physiology Service Manager, and the network team hosted the quarterly virtual forum for cardiac physiologists from across South Wales and the South West, on 15 June and 21 September.

This is a fantastic opportunity to share good practice and knowledge, work collaboratively, develop project ideas and discuss challenges. The next virtual meet is planned for 14 December 2021.

2021 Welsh Paediatric Cardiovascular Education Forum (autumn)

This event held on 1 October was also open to all across the network. The theme was acquired heart disease, and topics covered included COVID-19 and the heart; myocarditis and pericarditis; and pacemakers for paediatrics.

Details of training and education events can be found on the network website. A number of specialist training events, including fetal cardiology, national and international meetings, are also publicised there.

What's coming up regionally?

- Fetal webinar series
- ACHD study day, 19 October 2021
- Level 1 & 2 Clinical Nurse Specialist Day, November 2021
- Physiologist virtual meet, 14 December 2021
- PEC education forum, 21 January 2022
- Psychology network day, February 2022

News from the psychology team

By Hannah Mustard, Adult CHD Clinical Psychologist, Bristol Heart Institute

It has been a pleasure to join the congenital heart service in Bristol and to also attend the CHD network meetings and learn about the exciting work people across the South Wales and the Southwest are involved with.

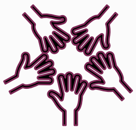
A project that I am currently working on is designing handouts for patients on topics such as coping while in hospital and managing procedural anxiety.

We are also designing psychological skills training packages for staff across the network, which we hope to offer in bitesize remote training sessions in future. These will focus on issues faced by non-psychologists working in congenital heart care such as working with adults who are experiencing low mood or anxiety connected to their condition, health anxiety and anxiety when facing medical procedures (that could impact on their engagement with the procedure).

In paediatric cardiology, Josie Steel, Clinical Psychologist, at the Bristol Royal Hospital for Children, is designing a similar package for staff working with children and their families.

The paediatric psychology team is running a webinar series in the autumn 2021 following the pilot event last year. These will be live events that parents can attend with a question and answer session at the end of a short presentation by the team. Topics include:

- ♥ Preparing for coming in to hospital
- ♥ Managing the impact for parents
- ♥ Supporting siblings
- ♥ Plus a new webinar around mindfulness and using this approach during hospital admissions.



The plan is that the recordings will also be available on the network website so that network clinicians can signpost parents to the resource following the live event – we welcome feedback from the teams.

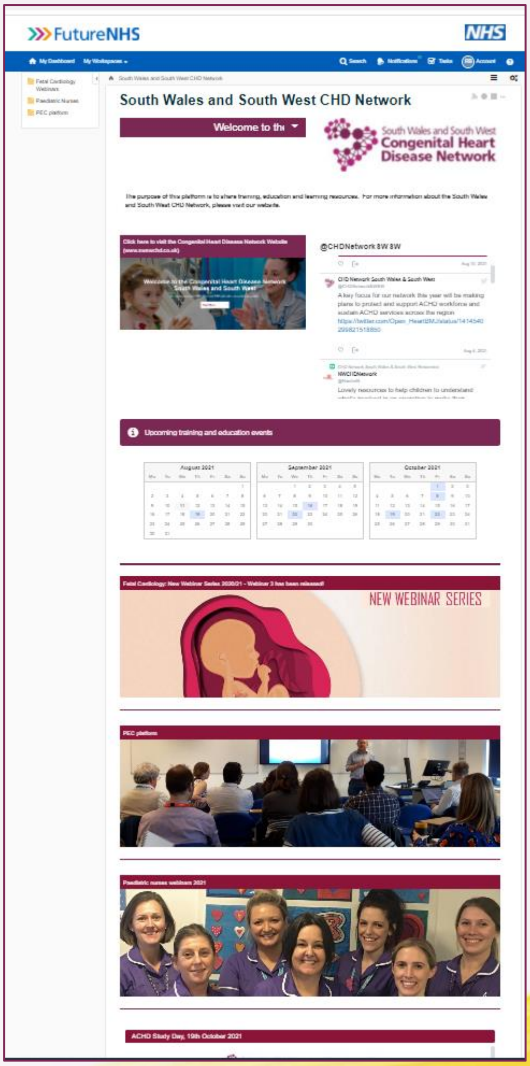
This is a resource we hope to expand to a range of different topics that may support children and families in the future. It is my hope to develop a similar set of film resources suitable for the Adult Congenital Heart Disease service over the next few months.

SWSW CHD Network NHS Future Platform

This platform for healthcare professionals is currently home to the:

- Fetal cardiology webinar series
- Paediatric cardiology nursing webinar series
- PEC platform

If you think a professionals education page would be useful for your team/staff group please do let us know.



South Wales and South West CHD Network

The purpose of this platform is to share training, education and learning resources. For more information about the South Wales and South West CHD Network, please visit our website.

Click here to visit the Congenital Heart Disease Network Website (www.swswchd.co.uk)

CHD Network South Wales & South West

A key focus for our network this year will be making plans to protect and support ACHD workforce and sustain ACHD services across the region https://twitter.com/Open_HeartBMJ/status/1414540299821518850

NWCHDNetwork

Lovely resources to help children to understand

Fetal Cardiology: New Webinar Series 2020/21 - Webinar 3 has been released!

New CHD competencies development package for cardiac nurses/link nurses with an interest in cardiology

Background

In response to national requests from level 1, 2 and 3 nurses and cardiologists, a CHD development package of cardiac competencies has been developed for cardiac nurse/link nurses with an interest in cardiology who work mainly in the level 3 centres.

The competencies provide standard learning and development objectives for all nurses supporting level 3 clinics, so a clear baseline for knowledge and skills can be understood across the CHD network. It can also be used as a way of evidencing progress which can be used for revalidation and appraisal purposes.

The competencies were a joint piece of work between the Leeds CHD Network and the South Wales and South West CHD Network lead nurses, and have been circulated to the network nurses and board members for comments and feedback, as well as nationally at the national network of CHD networks lead nurse meeting and with the British Adult Congenital Cardiac Nurse Association.

The competencies are underpinned by the NHS England CHD standards and specifications (2016) and comprise of sections which include clinical knowledge, support, and communication with staff members in the CHD Network.

It is suggested that the competencies will take 12 months to complete and would require support from the local manager/matron, in collaboration with a Level 1 centre clinical nurse specialist and the lead nurse for the CHD Network.

Implementation across the network

The competencies development package will be launched in Autumn 2021.

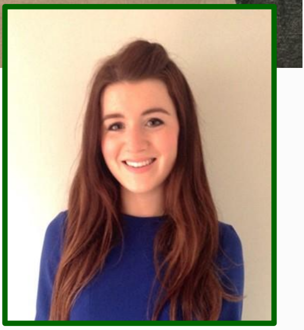
They will be sent to nurses, nurse managers, medical teams, and service managers to support Level 3 nurses in achieving them. They will be advised of the process for support and sign off.

Nurses working on the competencies will be linked with a CNS or other relevant professional who will support their completion. Evaluation forms will be sent to nurses as they complete the competencies 12 months after commencing them.

For more information, please contact
Jessica.Hughes@uhbw.nhs.uk

What does level 1, 2 and 3 mean? Congenital heart disease is a specialist service so different types of care are provided in different ways across the hospitals in the network. In the South Wales and South West region there are three levels of CHD centres (hospitals) where services are provided. The role of the network is to be a bridge between them. Most hospitals provide both adult and paediatric CHD care.

Level 1 care: Specialist CHD surgical centre (Bristol).
Level 2 care: Specialist CHD centre (Cardiff).
Level 3 care: Local CHD centres (local hospitals across South Wales and the South West).



Dr Amy Woodham

Clinical Psychologist for the
Paediatric Cardiology Service

Tell us a little about your background

I qualified in 2020 from the University of Oxford. During my training I worked in a general paediatrics psychology team and child and adolescent mental health services, gaining experience working with children, adolescents and families with a range of physical and mental health conditions.

I joined the Paediatric Cardiology team at the Bristol Royal Hospital for Children in May 2021. The role of a clinical psychologist in the team is very varied which I really enjoy. We provide psychological support to young people, siblings and parents along all of the pathways.

Some of the common issues and concerns our service supports includes preparing for procedures such as blood tests, cannulas, cardiac catheter and/or surgery, coping with being in hospital and behavioural changes, adjusting to having a cardiac condition, support around body image and feelings about surgical scars, as well as providing staff consultation and training. We offer support on the cardiac ward (Dolphin) and paediatric intensive care, as well as on an outpatient basis in face-to-face appointments, virtual video-call clinics and on the telephone.

What are your interests?

I really enjoy working with young people and families to collaboratively identify what really matters to them in their life (their values), what might be getting in the way of connecting more to these (such as particular worries, or practical considerations such as being in hospital or treatment regimes) and finding ways of doing more of what matters to them, in spite of the difficulties they are experiencing.

My research interests include what a good transition between child and adult health services looks like, and the experiences of adolescents and young adults during this time, as well as adolescents' understanding of health diagnoses and the impact of this on self-management, talking to important people in their life and relationships with health professionals.

I look forward to supporting with more service development and research within my role.

What do you enjoy doing outside of work?

I enjoy being with my family and friends, playing tennis, boxing and going to the coast.

There are a number of changes in the teams across the network to update you on:

Welcome to the network Dr Nadia Hajiani, new consultant in paediatric cardiology in Cardiff. Dr Alan Pateman has taken over as clinical lead (since September) for the paediatric cardiology service in Cardiff.

Welcome to Katrina Spielmann and Claire Ormson, two new ACHD clinical nurse specialists in Cardiff.

We would also like to welcome Becky Mirams, new paediatric cardiac link nurse in Taunton, and cardiac link nurses Sharon Russell, community children's nurse in North Devon, and Kate Scobie, community children's nurse in Exeter.

At the Bristol Royal Hospital for Children, Jane Hetheringron handed over her role as the matron for cardiology and neurosciences, to Helene Craddock in August 2021. Alistair Hustig has also joined the team as the new cardiac anaesthetist. We also bid farewell to Dean Barry, cardiac CNS team administrator.

At the Bristol Heart Institute, we said goodbye to Caryl Evans, long-standing adult clinical nurse specialist, and welcomed Rachel Wyatt.

At Torbay and South Devon NHS Foundation Trust, we bid farewell to Gina Skipworth, service manager for paediatric CHD and welcome April Hopkins and Simon Dunn. We also say goodbye to Gaynor Sattar, service manager for adult CHD, and welcome Michelle Baker.

Introducing
Dr Georgia Spentzou

Consultant Paediatric Cardiologist
and Electrophysiologist at the
Bristol Royal Hospital for Children

I was very excited to be appointed as a paediatric cardiologist and electrophysiologist at the Bristol Royal Hospital for Children in September 2020. It's great to bring my experience to the care of babies and children with congenital heart disease or a heart rhythm abnormality.

Background and training

- I trained in paediatric cardiology at the Royal Brompton Hospital in London, Birmingham Children's Hospital and the Royal Hospital for Children in Glasgow.
- I then undertook extensive training in electrophysiology and cardiac devices in children at the Royal Hospital for Children and in adults at the Golden Jubilee National Hospital in Glasgow.
- Following this, I completed a fellowship in paediatric electrophysiology at the world-renowned Royal Children's Hospital in Melbourne.

Life outside of work

Outside of work I enjoy spending time with my husband and our young son and I'm often in the kitchen cooking something new for them. I love outdoor activities. I particularly enjoy swimming in the sea having grown up in Greece.

I'm enjoying exploring what Bristol has to offer and the surrounding countryside.

Interests

My main passions are the:

- Diagnosis and treatment of arrhythmia with invasive electrophysiology studies and ablation
- Management of children with an inherited arrhythmia
- Care of patients with a pacemaker or an implantable cardiac defibrillator.

In the CHD network, consultants from Bristol visit hospitals around the South West to support the local teams and patients.

Dr Spentzou regularly visits the Royal Cornwall Hospital to do a paediatric CHD clinic.

Did you know you can find more clinician profiles on your local hospital page on the CHD network website? https://www.swswchd.co.uk/en/map

Winner of the National Congenital Cardiac Nurses Association Best Poster Prize, 2021

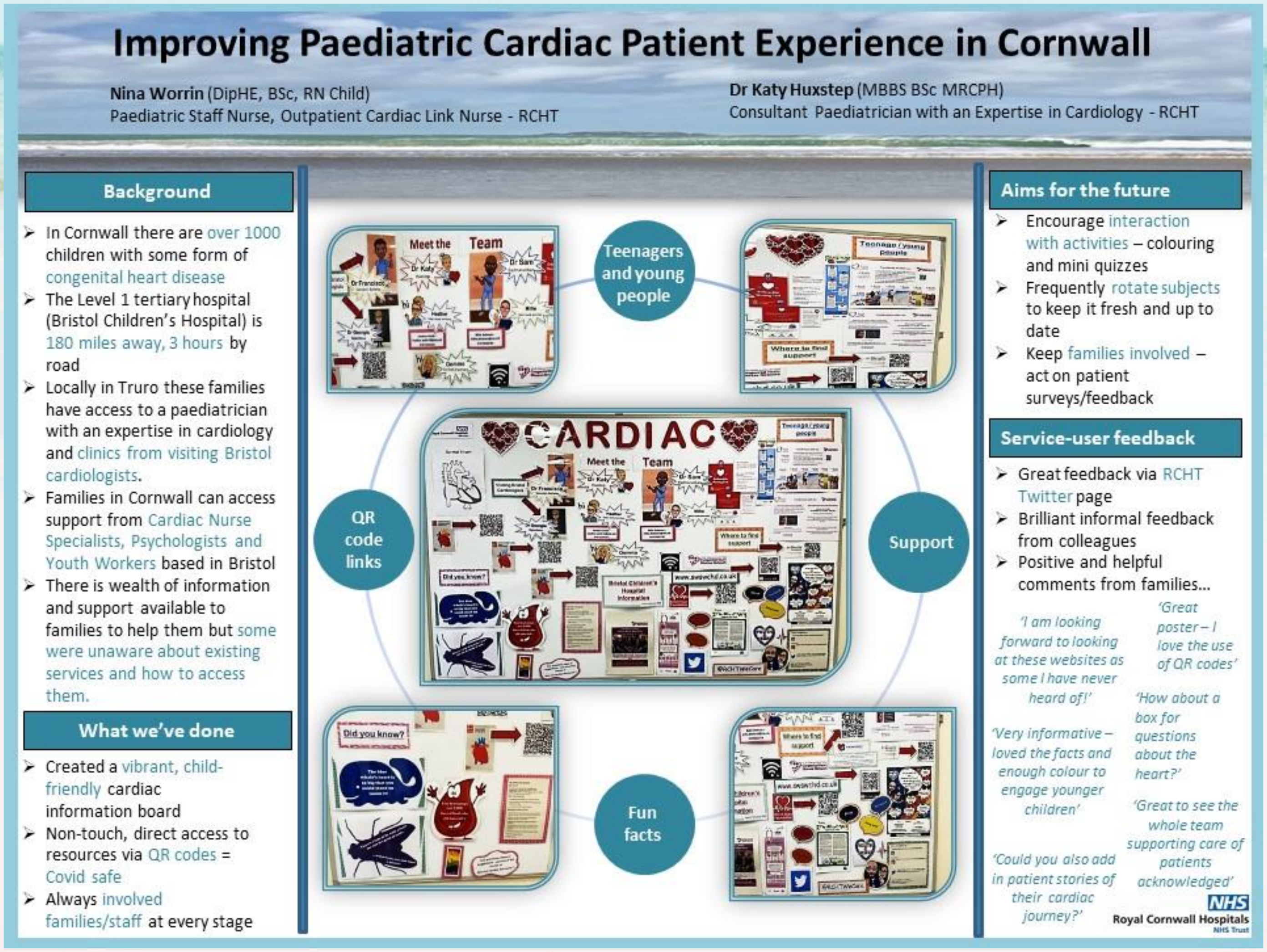
By Nina Worrin, Outpatient Cardiac Link Nurse, Royal Cornwall Hospital

After promoting our new outpatient cardiac information board on social media and in the CHD network spring 2021 newsletter, we received **some really positive feedback** from around the country and abroad. This included an invitation to **present it as a poster at the Congenital Cardiac Nurses Association (CCNA) conference** on 10 June 2021.

We were very excited to have been asked to do this, and thought this would be a fantastic opportunity to highlight and promote the work we are doing in Cornwall to **help families of children with congenital heart disease.**

This is the first poster presentation I have ever taken part in – this coupled with the fact that it was all presented virtually was new to me, so to end up being **awarded the 'best poster'** was amazing, and completely unexpected!

We have also had a **great response from patients and their families**. We added some of these comments into the poster and I feel this brings the poster to life. It has meant so much to us to be able to involve families and they have **offered us some brilliant ideas for the future, not just for the board but for the service as a whole!**



Improving Paediatric Cardiac Patient Experience in Cornwall

Nina Worrin (DipHE, BSc, RN Child)
Paediatric Staff Nurse, Outpatient Cardiac Link Nurse - RCHT

Dr Katy Huxstep (MBBS BSc MRCPH)
Consultant Paediatrician with an Expertise in Cardiology - RCHT

Background

- In Cornwall there are over 1000 children with some form of congenital heart disease
- The Level 1 tertiary hospital (Bristol Children's Hospital) is 180 miles away, 3 hours by road
- Locally in Truro these families have access to a paediatrician with an expertise in cardiology and clinics from visiting Bristol cardiologists.
- Families in Cornwall can access support from Cardiac Nurse Specialists, Psychologists and Youth Workers based in Bristol
- There is wealth of information and support available to families to help them but some were unaware about existing services and how to access them.

What we've done

- Created a vibrant, child-friendly cardiac information board
- Non-touch, direct access to resources via QR codes = Covid safe
- Always involved families/staff at every stage

Teenagers and young people

QR code links

Support

Fun facts

Aims for the future

- Encourage interaction with activities – colouring and mini quizzes
- Frequently rotate subjects to keep it fresh and up to date
- Keep families involved – act on patient surveys/feedback

Service-user feedback

- Great feedback via RCHT Twitter page
- Brilliant informal feedback from colleagues
- Positive and helpful comments from families…

'I am looking forward to looking at these websites as some I have never heard of!'

'Very informative – loved the facts and enough colour to engage younger children'

'Could you also add in patient stories of their cardiac journey?'

'Great poster – I love the use of QR codes'

'How about a box for questions about the heart?'

'Great to see the whole team supporting care of patients acknowledged'

NHS
Royal Cornwall Hospitals
NHS Trust

Network update

By John Mills, Congenital Heart Disease Network Manager, South Wales and South West

Since our last newsletter, the SWSW CHD Network has said goodbye to Cat McElvaney who has done a fabulous job as our network manager for almost three years – we thank Cat for all her support and wish her the very best of luck.

The network team has continued to support COVID recovery efforts in the region and has hosted a range of virtual education events and webinars for nurses, cardiac physiologists and paediatricians to name a few. We continue to promote clinical learning and collaboration between cardiac teams across the region.

Focused work has begun in preparation for the assessment of CHD standards in Wales, and to ensure a sustainable workforce for adult CHD services. We work closely with patient representatives and encourage feedback on all the work we do. So please do get in touch – we would love to hear from you!

Meet our new Network Board Chair

In June 2021 we were delighted to welcome Dr Dirk Wilson as our new chair of the Network Board. Many of you will recognise Dr Wilson as a consultant paediatric cardiologist in Cardiff.

“I have been a consultant paediatric cardiologist in Cardiff since 1999. Since that time I have also provided input into the adult congenital heart disease service in South Wales. One of my main accomplishments has been to play a part in establishing the Transition Service in South Wales.

Having worked closely with the Bristol team for two decades, I am also aware of the challenges and achievements of the paediatric and adult congenital services across the South West. I have been supportive of the South Wales and South West CHD Network since its inception.

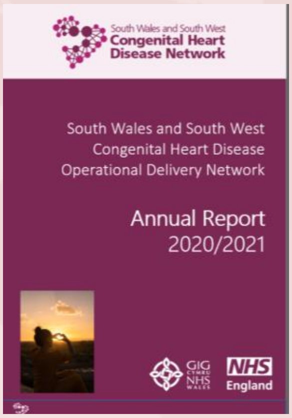
I am pleased to take on the role of network board chair. I have had senior clinical management roles within Cardiff and Vale Local Health Board and have been chair of governors in my children’s primary school, so I hope I can run a meeting successfully!

As health professionals, we do what we do to improve the wellbeing of our patients. One of my aims in the network board chair role is to ensure we listen to our patients and help to change things for the better.”

Find out more about Dr Wilson on the network website:
https://www.swswchd.co.uk/en/staff/30

To keep up-to-date with network news and our publications please follow us on twitter.

CHD Network 2020/21 – Read all about it!



South Wales and South West
Congenital Heart
Disease Network

South Wales and South West
Congenital Heart Disease
Operational Delivery Network

Annual Report
2020/2021

GIG CYMRU NHS WALES
NHS England

The Congenital Heart Disease Network Annual report for 2020/21 has been published.

Find out about the key achievements and challenges for the network in its fifth year of operation, and the key priorities for future years.

Thank you to all the network members who have contributed to this fantastic update on progress this past year. Please visit our network website (www.swswchd.co.uk) to read it in full.

Network dates for your diary!

Key network meetings:

7 December 2021: Network Board

Network Clinical Governance Group

9 March 2022: Network Board

CHD Standards & Audit in Wales

By Andrea Richards, Specialised Services Senior Planning Manager, Welsh Health Specialised Services Committee.

The CHD National Standards published by NHS England in 2016 provide a specialist framework of care for people and their families affected with congenital heart disease. The standards cover the whole pathway for CHD patients, including fetal, paediatric and adult services, and includes specifications for level 1, level 2 and level 3 centres. To date, these have not been formally adopted in Wales, although centres do strive hard to meet these standards.

See page 8 for a brief guide on level 1, 2, and 3 centres

The recent investment in both paediatric and adult CHD services in Wales is intended to support centres in meeting these standards. Recently the Welsh Health Specialised Services Committee (WHSSC) has consulted on a CHD Service specification based on the NHS England standards and service specification document. This enables the CHD standards for the Level 2 centre in Cardiff to be formally adopted.

Further work is being undertaken in regards to the local centres with the aim of enabling the CHD standards for the local level 3 centres to be adopted.

WHSSC on behalf of the local CHD centres have been working with both the South Wales and South West CHD Network and the North West, North Wales and Isle of Man CHD Network to develop a national standards audit strategy and self-assessment process to assess the Welsh centres within their boundaries against the national standards.

The aim of the self-assessment process is to understand how centres are delivering the standards. It provides the opportunity for CHD centres to highlight areas that are working well, identify any gaps or concerns, and request any support. Over the forthcoming months, WHSSC will continue to work closely with both CHD networks in supporting the level 3 centres self-assessment process, and finding solutions.

WHSSC will also develop a national service specification on behalf of the local health boards, which will then enable the standards to be adopted

Did you know… Another key component of the CHD standards was the establishment of CHD networks to cover different geographic boundaries across the UK. The UK group of CHD networks meet regularly to share updates, provide support, and escalate issues – during the pandemic virtual meetings have been held regularly chaired by Dr Andy Tometzki (Clinical Director) and Michael Wilson (NHS England Programme Director).

What is WHSSC?

Welsh Health Specialised Services Committee (WHSSC) is a joint committee of the seven local health boards (LHBs) in Wales. The joint committee brings LHBs in Wales together to plan specialised services fort the population of Wales.
.

WHSSC's strategic aim is on behalf of the LHBs to ensure there is equitable access to safe, effective and sustainable specialist services for the people of Wales as close to patients' homes as possible within available resources. All of this work is undertaken with ongoing engagement with patients, service users and professionals.

The Cardiac Commissioning Team and Children's Commissioning Team at WHSSC is made up of: Andrea Richards, Specialised Services Senior Planning Manager; Kimberley Meringolo, Specialised Services Assistant Planning Manager and Dr Helen Fardy, Associate Medical Director for Cardiac Services and Children's Services, with support from IT and finance colleagues.

The team is currently working with colleagues at the University Hospital of Wales in Cardiff and the South Wales and South West CHD network, to ensure that there is equitable access to safe, effective and sustainable CHD services across Wales.

It was a great achievement to have secured two business cases last year releasing c. £790k to enhance ACHD services in Wales, and c. £388k for paediatric CHD services. This includes an increase in the number of CHD consultants, nurse specialists, physiologists, and psychology staff.

Supporting your mental health for children and families

By Dr Vanessa Garratt, Network Consultant Lead Psychologist

With the remarkable treatments and healthcare teams we have today, 95% of children with congenital heart disease reach adulthood.

For young people and families, adjusting to the managing a cardiac condition, comes alongside the normal stages of growing up. It is normal for this journey to be associated with a full range of emotions – both positive and negative and is it often described as a rollercoaster as it contains many ups and downs through diagnosis, surgery/intervention, times of decision making and hospital stays.

Many families develop resilience as they build upon their existing coping strategies and learn new ways of coping. However, it is normal to experience times of increased stress or worry. These might come a few weeks or months after a surgery or time in hospital. You may have the strength in the moment to manage each day but as you begin to process the event it can feel harder to cope at times.

We know that there can be an impact on parent to child, sibling and partner relationships and everyone's experiences will be different. Therefore, talking together about the impact of a heart condition can be an important first step for all members of the family as you may all have different questions.

Below are some ideas and resources that you may find helpful. These can help to remind you of your existing coping strategies and/or provide you with some new ideas.

Information and support

It can help to think about what information you need and seek social and emotional support from family and friends and your medical teams.

- You can contact your child's cardiac clinical nurse specialist when you have questions about your child's care or need further information.

  Bristol Children's Cardiac Clinical Nurse Specialist team:
  0117 342 8578

  Cardiff Children's Cardiac Clinical Nurse Specialist team:
  029 2074 4749

  Our psychology webinar on coming into hospital and wellbeing toolkits can help you with ideas and top tips to support your child, yourselves and siblings: www.swswchd.co.uk/en/page/wellbeing-toolkits

- It can be helpful to hear about the experience of other families by contacting local and national charities and support groups www.swswchd.co.uk/en/page/charities

- The British Heart Foundation has information and resources for young people about various cardiac conditions. www.bhf.co.uk

Continued… Supporting your mental health for children and families

Relationships

You may be worried about your relationship with your child or their siblings as it is also not uncommon for this to impact on your confidence around parenting. You are not alone if you sometimes feel guilt for having to prioritise your time and energy into caring for your child with a heart condition. You may also feel there is an impact on your own relationship with your partner because of social, financial or emotional stressors.

- Our psychology team has produced a webinar and toolkit on how to support siblings of a child with a heart condition. These share information on some of the common experiences of families in a similar situation, and advice and ideas around this. www.swswchd.co.uk/en/page/getting-support-parent

- The 'Youngsibs' website is aimed at children and young people who have a sibling who has a disability. Whilst the information relates to disability, the website has helpful resources and information. www.youngsibs.org.uk
- Some parents can find relationship counselling and support through local services and organisations helpful, for example, Relate. www.relate.org.uk
- You may also find it helpful to talk to other parents through support groups, such as Heart Heroes.

Looking after yourselves

As a parent or carer of a child with a heart condition, it is really important that you also take time for your own wellbeing. As the saying goes, 'you can't pour from an empty cup' and in order to be there and support others, you need to also recognise and take care of your own needs.

You can link into support group cafes and events to gain support from others, for example Heart Heroes and Heart Families South West as these can help you feel less alone and learn about ways that others have managed these challenges. Find out more on the network website www.swswchd.co.uk/charities

- Our psychology webinar on managing the impact of having a child with a heart condition for parents, can help you to find out about some strategies and ways of coping that other families have found helpful.
- Our toolkits and digibooks also have advice and tips on this topic: https://www.swswchd.co.uk/en/page/getting-support-parent
- You may find it helpful to talk about how you are feeling to family and friends who you trust.

It is normal to experience low mood and anxiety in relation to challenging times in your life. However, it is important that if these symptoms are ongoing, start to affect your day-to-day life, or you feel that you are not coping, you seek help.

Speak to your GP to find out what mental health support options are available to you. Your cardiac nurse specialist will also be able to let you know about options for support around the impact of your child's heart condition and treatment.

If you are in crisis and/or feel unable to keep yourself safe, please call 999 or attend A&E. For services that provide a listening ear in times of need: Samaritans: call 116 123. Shout: text 85258

Arrhythmia Alliance
www.heartrhythmalliance.org

DefibsSaveLives.org

By Trudie Lobban MBE, Founder and CEO, Arrhythmia Alliance

When footballer Christian Eriksen suffered a sudden cardiac arrest on the pitch during Denmark's opening Euro 2020 match, the world watched in shock. It didn't take a miracle to save Eriksen – just a small piece of equipment called an automated external defibrillator. Erikson was then taken to hospital to recover.

What is an Automated External Defibrillator (AED)?

An automated external defibrillator (AED), or defib, is a life-saving piece of equipment that significantly improves the chances of survival after an out-of-hospital sudden cardiac arrest (SCA) — from 9% with CPR alone to more than 50% with CPR plus an AED.

It gives a high energy electric shock to the heart of someone who is in cardiac arrest. After phoning 999 and starting CPR, using a defibrillator is the next important step in saving someone's life.

However, defibs can only save lives if people have access to them. For this reason, Arrhythmia Alliance calls for AEDs to be as commonplace as fire extinguishers and smoke alarms, and for AEDs to be accessible 24/7.

What is a Sudden Cardiac Arrest?

A sudden cardiac arrest (SCA) is not a heart attack, but both are medical emergencies. A SCA is when the heart stops completely because of a fatal arrhythmia (heart rhythm disorder), whereas a heart attack is when the blood supply to the heart is blocked.

While risk factors for SCA, such as congenital heart disease, have been identified, understanding exactly who is at risk of an SCA is extremely difficult.

For example, footballer Christian Eriksen had no known risk factors for SCA prior to his SCA during Euro 2020 — he was seemingly an extremely fit young man who had undergone rigorous medical tests. Therefore, we must assume that anyone of any age or gender can have a SCA at any time, and we must ensure we are able to help them if they do.

Key to that is providing prompt access to an automated external defibrillator — there is no time to wait for the paramedics. After a SCA, the chances of survival decrease by 10% with every minute without treatment. Indeed, the reason that Eriksen survived is because his medical team used an AED on the pitch within minutes of his collapse.

CPR ALONE = 9% CHANCE OF SURVIVAL

CPR + AED = OVER 50% CHANCE OF SURVIVAL

What about training?

You do not need training on how to use an AED as the machine provides clear instructions and, importantly, will only work if it detects a fatal arrhythmia — it will not let you shock someone whose heart has a non-fatal rhythm..

Arrhythmia Alliance's Defibs Save Lives campaign has long provided placement of AEDs, that are accessible 24/7, in communities.

But of course, there is no value in having an accessible AED if you do not know where it is, so Arrhythmia Alliance is calling for everyone to find their nearest AED and register them on to the national database (https://www.heartrhythmalliance.org/aa/uk/locate-your-nearest-aed)

Emergency call-handlers can then use this database to direct people to their nearest AED.

For more information, visit:
www.DefibsSaveLives.org

Frankie's story

By Frankie Carlin, Patient Representative

I've been a cardiac patient all my life, having been born with various issues, including problems with my aortic valve.

In the last 20 years, I have had two open heart surgeries – the most recent a Ross procedure in February 2017 in Bristol, which was particularly brutal. It was very complex and recuperation was even harder as it was a "re-do". I had to undergo many procedures before and after both surgeries.

The mental health repercussions from both operations and procedures were far harder than I anticipated. As a freelance stage/floor manager and part-time lecturer with a busy family life, I am used to being in control of both my work and home life. So the total lack of control I felt during my hospital stays was a real shock. Although I have had wonderful care from the NHS, experiences like being called by my bed number instead of my name and the loss of dignity I felt when unable to do things for myself were hard to process. I had gone from being a capable person who could cope with most eventualities to someone who needed help just to sit up in bed!

I don't think that the feeling of total vulnerability ever fully leaves. It is always in my thoughts – as I'm sure it is with many heart patients – and has really taken its emotional toll over the years. I read a quote recently that really resonated with me: "Just because your patients are resilient doesn't mean that they aren't suffering… Resilience is often out of necessity and doesn't mean that someone is OK". This was so true for me – we carry on putting a brave face as we really have no other choice. We may look like we're resilient, especially as we start to heal physically, but I know that for me that's when I started to struggle mentally – and it felt like there was nowhere for me to turn.

I was so grateful to have received all the medical interventions that were keeping me alive that I didn't want to cause a fuss about my emotional wellbeing. However, I now realise that they go hand-in-hand and patients need to be treated in a holistic way. I know I'm not alone in saying that I have often struggled mentally with the enormity and the brutal nature of the operations. Although the cardiac nurses in Cardiff were fantastic support, I felt that psychological therapy would have helped enormously before, during and after the healing process both physically and mentally.

Through getting involved in the network, I and the other patient reps have been able to suggest counselling throughout a patient's journey. I have been a huge advocate for cardiac patients being treated holistically, and I hope that sharing my story will help to highlight why this is so important.

Supporting patients & families

Supporting our patients and their loved ones through their congenital heart condition and journey is very important to the network.

On the network website you will find information on the range of support available to you.

https://www.swswchd.co.uk/en/page/getting-support

There are a number of types of support available and different services you can access, depending on how much support you need at a given time.

Psychology support

The Bristol-based Lifespan Cardiac Psychology Health Service is here to support children, young people and adults in coping and managing with a heart condition.

You can ask your network cardiologist and cardiac nurse specialist to refer you to the service. Once you have been referred and the team feel that they are the right service for you, you will be sent a letter with more details about the service and how it works.

A virtual psychology service is now on offer, so patients can join via video or telephone.

Alternatively, the team can meet patients if they prefer to come into hospital or are an inpatient on their site.

Find out more on the network website :

https://www.swswchd.co.uk/en/page/how-do-i-access-cardiac-psychology-services

Charity updates

To find about more about the work charities are doing to support patients with CHD and their families, please visit the charities webpage on the network website (www.swswchd.co.uk)

‘Demystifying the network’ social media campaign

To raise awareness of the CHD network, what it is/does, and to signpost patients/families to support resources available on the network website, a social media group consisting of the network team, patient representatives and charity support group representatives, pioneered a new series of Facebook posts called ‘demystifying the network.’

These were launched and piloted during a Bristol Royal Hospital for Children Facebook network takeover week at the end of May 2021 and posted on Twitter too. These were re-posted by the support groups on their social media pages.

Do you have a department or support group social media page you would like to share these on? We would welcome your feedback too.

The first six posts:

1. Have you heard of the South Wales and South West Congenital Heart Disease (CHD) Network?
2. Have you met the Network Core team?
3. How do you find your local CHD team?
4. How do I find out about my or my loved one’s journey of care?
5. How do I access support?
6. How do I find out about other patient stories?

South Wales and South West Congenital Heart Disease Network

NHS University Hospitals Bristol and Weston NHS Foundation Trust

Getting the support you need

ADULT SUPPORT

PARENT SUPPORT

YOUNG PEOPLE SUPPORT

CHILD SUPPORT

Find out more at: http://www.swswchd.co.uk Follow us on @CHDNetworkSWSW

Want to know more?

The network website is for patients, families and clinicians.

We have information on:

- Patient leaflets
- Getting support
- Hospitals and clinicians across the network
- Patient stories
- Patient pathways
- Clinical information
- Network meetings and training events
- Research.

Scan this code with your phone to visit the network website

Thank you for reading!

If you have any stories or ideas you would like to share for the next edition in **spring 2022**, please contact Rachel.Burrows2@uhbw.nhs.uk

We welcome:

- Patient/family/staff/team stories
- Clinical news/updates
- Events
- Network related issues
- Anything else you think might be relevant!

The newsletter will be published twice a year.

Sign up for free

Join our mailing list today to receive the SWSW CHD Network newsletter directly to your inbox.
Send your email address to Rachel.Burrows2@uhbw.nhs.uk requesting our newsletter