

Youth Worker for Adult Congenital Heart Disease

Xander Cook – Youth@Heart



My Background



Attended De Montfort University 2010-2013 to study BA (Hons) Youth & Community Development.



First post graduation job with LPW December 2013 – August 2015 in the South team.

Seconded to '*Choices College*' August 2015. College Closed April 2016, moved to North team.



TUPE to CYN (June 2018) after change of council tender.



Over the Wall Camps #mischiefandmagic 2007-present.

Youth@Heart

Who and Why

Aims

Fundraising

Youth Worker Post

The Future

Youth Work in Hospitals

'Youth Work is a distinct educational process adapted across a variety of settings to support a young person's personal, social and educational development' (NYA <https://nya.org.uk/careers-youth-work/what-is-youth-work/>)



TCT Youth Support Co-Ordinator roles.
TCT opened its first unit in 1990



Nottingham have an NHS Youth Service now in its 22nd year! - <http://www.nuhyouthservice.org.uk/>



Attended the Health Based Youth Worker's Conference in 2019 and again in 2020



@HBYWG

Cardiac Charity Youth Work



Little Hearts Matter - Youth Worker runs closed Facebook groups, evening text support and provides events/activities for service users.



British Heart Foundation - Run Teen Heart (13-18) and One Beat (18-30) groups

Lots of useful information on the website about lesions, risk factors and lifestyle

A screenshot of a website page titled "Transitioning to adult care". The page has a breadcrumb trail at the top: "Home > Information & support > Support > Children and Young people > Understanding my condition > Transitioning to adult care". On the right side, there are social media sharing icons for Print, LinkedIn, Twitter, Email, and Facebook. Below the title, there is a section "UNDERSTANDING MY CONDITION" with a sub-section "Transitioning to adult care". The main text explains that transition is the move from child to adult care and provides information on what it is and how to prepare. At the bottom, there is a video player for "Transition: Your Journey" and a list of key points: "Exercise will have a positive effect on your overall health" and "Understand your limits and how far you can push yourself".

Referral Criteria Agreed

Introducing Referral Criteria

- Agreed with Charity and the Clinical Team at BHI
- Discussed with Psychologist to avoid overlap and clarify role boundaries
- Referrals can be made via email (NHS), telephone or face to face discussion, via CNS

Referral Criteria

- Young people who are preparing for a procedure or surgery
- Inpatient Support, young people who are going to be on wards, HDU and CICU
- Education, Employment, Finance and Housing
- Lifestyle Support
- Someone to talk to or listen to them about issues relating to cardiac condition
- Mental Health

1 - Referral Criteria

Young people who are preparing for a procedure or surgery

- Outlining role and offer of support
- Meeting YP in Pre-Op Assessment
- Being available for YP before coming into BHI (for non medical queries)
- Signpost referral to additional ACHD Psychology support if appropriate

2 - Referral Criteria

Inpatient Support, young people who are going to be on wards, HDU and CICU

- Reintroduce offer of support and time to talk
- Using the Rescue Rucksack
- 1:1 chats about life, the universe and everything
- Helping friends/family have a break from bedside support

**DON'T
PANIC**



2 - Referral Criteria Feedback

"Couldn't remember if your in today but I just wanted to thank you for all the support you gave me while I was in hospital.

you had made it a lot more easier for me to cope in here just by play a few games. I most likely won't be here tomorrow so I thought I would leave you this text.

Thank you for taking my mind off of things and I wish you all the best." 19 years Fontans

3 - Referral Criteria

Education, Employment, Finance and Housing

- Education, absence, deadlines, finance, advocating to school, college or University
- Employment, apprenticeships, FT/PT jobs
- Finance, support with benefits, accessing funds PIP, JSA, Universal Credit (<https://www.gov.uk/browse/benefits>)
- Housing support and advice

4 - Referral Criteria

Lifestyle Support

- Drinking, smoking, recreational drugs
- Exercise, diet, dentist, Endocarditis
- Signposting to charity websites e.g. BHF/Somerville, smoking cessation, FRANK and CNS team
- Involvement in YP clinics

5 - Referral Criteria

Young people who need someone to talk to or listen to them about issues relating to cardiac condition

- Neutral (not family or HCP)/Non-biased
- "*Elephant in the room*" is dealt with e.g. EOL
- Clarifying understanding of condition and facilitating improved communication with medical team e.g. jargon busting

6 - Referral Criteria

Mental Health

- Low Mood
- Risk taking behaviour e.g. medication compliance
- DNA to clinics
- Using Mind Journal



6 - Referral Criteria Feedback

"I've really struggled with my mental health since I was 13 years old, I've never had a way of being able to express myself or tell people how I am feeling, I never really got on with therapy or talking to people about it.

I've had the journal for a few weeks now and it has been a massive help. Everyday you're given new tasks to complete and it really does make you think. I think overall this book has been a massive success at helping me find ways of dealing with my mental health.

For the past few weeks I've been positive at work and always try as hard as I can, I feel that if I didn't have that book available to me, I would've really struggled at work. I'd like to thank everyone from Youth at Heart for helping me these last few months as I struggle with my mental and physical health. Xander has been excellent" 19 years Hypoplast Fontan

Other Examples of Support

- Games of Uno and cards in CICU and on the ward
- Supported a young person with learning difficulties while having their blood taken
- Ran a bowling trip for 3 young people, 2 of these came to a recent transition event at BHI
- Purchased a takeaway for an inpatient, refusing to eat hospital meals
- Closed Facebook groups started for CHD patients, parents and siblings – www.facebook.com/atyouthheart

How to refer...

Ping me an email

Xander.cook@nhs.net

Xander.cook@uhbristol.nhs.uk

Call me if a 16-24 year old is on the ward

07832 668907

Or via the CNS teams



SUPPORT FOR YOUNG PEOPLE

ARE YOU AGED 16-24?

DO YOU HAVE A
CONGENITAL HEART DISEASE
DIAGNOSIS?

I can help with...

- Support if you are an inpatient on the ward
- Support for outpatient clinics
- Preparation for procedures/surgery
- Listening and lifestyle support
- Signposting to other services
- Events and activities

Contact Xander on
07832 668907

xander@youthatheart.co.uk
www.facebook.com/xander.heart.18



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CHARITY COMMISSION NO:1158249

Fill in your contact details below
and tick the boxes that relate to you

Name: _____

I have CHD

I am between 16-19

I am between 20-24

I am a friend/partner of someone with CHD

I am the parent of someone with CHD

My contact details are:

Mob: _____

Home: _____

Email: _____



HOW TO GET IN TOUCH
THE CHARITY
contactus@youthatheart.co.uk

01452 690830



@styoutheart



@youthatheart22



@youthatheart22

Working partnership with



SUPPORT
FOR YOUNG
PEOPLE

Aged 16-24

Introducing
The Adult Congenital
Heart Disease
Youth Worker

Registered Charity: 1158249

Communicating role to CHD Network

- Intro piece went out in the Autumn 2019 Newsletter
- Business cards, leaflets and posters to go out to peripheral clinics, on wards and letter into young people packs
- Youth Work page on SWSW CHD and Youth@Heart websites
- 2020 plans to engage with peripheral clinics

Social Events/Activities

First event in November 2019 – Bowling at The Lanes Bristol

Initial offer was to young people who attended a transition evening from BRHC

January 2020 - written to 18 Pulmonary Hypertension young people to offer spaces to an event in Bristol for March/April

Organise future events in other areas of the South West and South Wales region



Plans for 2020

- Attend Peripheral Clinics
- Grow Facebook groups
- Increase awareness of role / draft competencies for future post
- Write article for BJCN and Somerville Newsletter
- Organise more events/activities
- Review referral criteria

Thank you!

Please like, follow, share, tweet us!



@atyourheart



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[linkedin.com/company/youthatheart/](https://www.linkedin.com/company/youthatheart/)