# Youth Worker for Adult Congenital Heart Disease

Xander Cook – Youth@Heart





# My Background

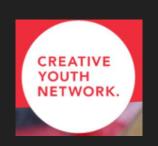


Attended De Montfort University 2010-2013 to study BA (Hons) Youth & Community Development.



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





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 <a href="https://nya.org.uk/careers-youth-work/">https://nya.org.uk/careers-youth-work/</a>)



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



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



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

# Cardiac Charity Youth Work

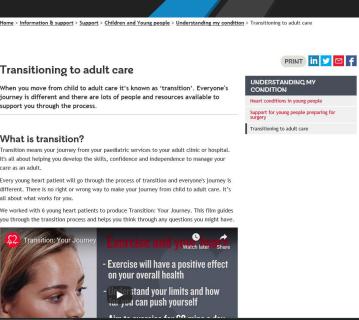


Little Hearts Matter - Youth Worker runs closed Facebook groups, evening text support and provides events/activities for service users.



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



# 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

- 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

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

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



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





# 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

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 (<a href="https://www.gov.uk/browse/benefits">https://www.gov.uk/browse/benefits</a>)
- Housing support and advice

#### 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

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

#### 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



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 CH	D 🗌
I am the parent of someone with CHD	
My contact details are:	
Mob:	
Home:	
Email:	
This Course A. Jean.	





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!

**f** @atyouthheart





