



Dear

I am writing to introduce myself. My name is Xander and I am the new Youth Worker for Adult Congenital Heart Disease. I am working for the charity **Youth@Heart** (www.youthatheart.co.uk) and working in partnership with the team at the Bristol Heart Institute and the South Wales and South West Congenital Heart Disease Network.

I have been a Youth Worker for 12 years, working in youth club settings and most recently in Bristol supporting young people on a 1 to 1 basis. I have also volunteered for the charity, *Over the Wall*, who run camps for young people with serious illnesses, and their siblings. These experiences have inspired me to work with young people who have health challenges.

Why am I writing to you?

I would like to find out what help and support you feel I could give, as the ACHD youth worker, to you, your family and friends.

Thoughts so far are:

- Offer you support if you are an inpatient on the ward, at an outpatient clinic appointment and preparation for procedures/surgery.
- Being someone, you can speak to about your condition, education, employment, lifestyle challenges. If I can't help, I will try to put you in touch with someone else who can.
- Run events and activities across the South Wales and South West region offering the opportunity for you to meet others with CHD, but also try new things.
- Create closed Facebook groups to allow you to meet peers with CHD, to discuss things that are important to you and to share experiences of your condition. There will also be closed groups for parents, siblings and partners.

I am not medically trained so any specific medical questions will need to be raised with your Doctor or call the Clinical Nurse Specialists (0117 3426599).

If you have any further ideas or thoughts, please get in touch.

Kind regards,

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