

'Going it alone'

Your family/carer will be welcome to sit in with you for your clinic appointment. For part of your appointment you will be offered the opportunity to be seen on your own as there



may be issues which you would like to discuss in private.

This is an important step and could just be for a few minutes at first, but gradually builds up over time to be for most of the appointment. This helps everyone focus on the most important person – you!

This can be hard for your parents too and we'll also support them!

Writing down any questions or worries you may have before coming can be helpful.

Follow up

It's important to remember when you are due to be seen again whether it is in a few months or a few years. If you do not receive an appointment letter in time please telephone the consultant's secretary (the contact details are on the back page of this leaflet).

Even if you are feeling well it is important to keep your appointments so we can deal with any changes if they happen. Sometimes it might be difficult if you are at university or travelling but we can make arrangements to see you on your return or during holiday periods.

Being admitted

If in the future you need to stay in hospital because of your heart you will stay on one of our cardiology wards. The staff are very friendly and caring. Where possible we will try and make sure you are in a private cubicle or on a ward with the same sex.

You are allowed to bring in iPads and/or mobile phones but they will need to be put on quiet mode. Most hospitals in Wales have access to free Wi-Fi.

Parking

Most hospitals in Wales have free parking apart from the University Hospital of Wales ("Heath Hospital", Cardiff) and Glangwili (Carmarthen). Please contact these hospitals for further information on parking/other travel options.



Useful Contacts:

Elizabeth Corris (ACHD secretary): 029 20743892

Ann Jermyn (Transition Nurse): 02920748046

Bethan/Sarah (ACHD Nurses): 029 2074 4580

Cardiology Outpatient Department: 029 2074 3266

New Appointments: 02920 744 3619

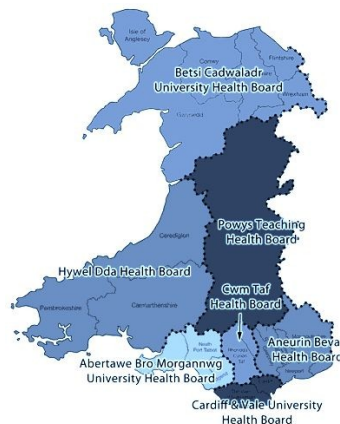
Useful Websites:

www.thesf.org.uk

www.bhf.org.uk

We are building and developing new clinics for ACHD patients across South Wales; aiming to bring care closer to their homes. Clinics will be held in:

- University Hospital of Wales, (Cardiff & Vale)
- Ysbyty Cwm Rhondda (Cwm Taf)
- Prince Charles Hospital (Cwm Taf)
- Singleton Hospital (Abertawe Bro Morgannwg)
- Neath Port Talbot (Abertawe Bro Morgannwg)
- Princess of Wales Hospital (Abertawe Bro Morgannwg)
- Glangwili Hospital (Hywel Dda)
- Withybush General Hospital (Hywel Dda)
- Ysbyty Ystrad Fawr (Aneurin Bevan)



Young person's guide to Transition and the Adult Congenital Heart Disease (ACHD) Service.



Eloy Jarrell
13-10-16



What is transition?

At the moment your hospital care is from a Paediatric (Children’s) Congenital Heart Disease Team. As you grow older, we need to think about your care being provided by a team who looks after adults.

“Transition” is the process of talking about and preparing you for this move to an adult service.

When do I have to move to an adult service?

Most young people will move to an adult service when they reach 16 years of age. We know if we plan early then young people feel much better prepared for moving. Talking to your doctor, specialist nurse or parents can help to ensure you feel prepared and ready.

The Adult Congenital Heart Disease team!



The adult team are looking forward to meeting you, along with your parents/carer when the time comes for your care to be transferred to the adult service in Wales.

Our team consists of doctors, nurses and physiologists. We work together to provide care for adults (people aged 16 years and over) with Congenital Heart Disease across Wales. We work alongside other health care teams to improve your overall care.

We are based in the University Hospital of Wales and also attend clinics in other hospitals in South and West Wales. Your consultant and specialist nurse will talk with you about choosing where you can have your follow up adult care so that it may be closer to your home. (Locations of these clinics are at the back of this leaflet).



How you may feel

You may feel nervous or excited about coming to the adult clinic. This is completely normal. We have set up ‘transition’ clinics especially for patients who are attending their first appointment in the adult service. Everything will be explained during your visit to the hospital. No one expects you to know everything! You will be given a lot of support as you begin to manage your own heart condition. No one will mind if you ask lots of questions
...no question is a silly question!!!



Tests at the clinic

Similarly to when you were seen in paediatric cardiology, before seeing your doctor you will have your height, weight and blood pressure recorded. You will have an ‘ECG’ (electrocardiogram) where they put sticky tabs on your chest to get a trace of your heart rate and rhythm. You may also have an ‘echo’ scan where they will put a type of jelly on your chest and an ultrasound probe will take pictures of your heart.

To make you feel more comfortable, if you would like a female or male member of staff to perform any of these procedures please let us know on arrival and we will try to arrange this for you.

Meeting the Doctor and Specialist Nurses



You may well know your paediatric nurse, Ann Jermyn, who has been working with you during your transition period. You will be given the opportunity to meet with Ann; alongside your new adult nurse specialists Sarah and Bethan; who will talk to you about your heart and discuss keeping your heart healthy.

You will then meet a paediatric (children’s) doctor alongside your new adult doctor. Together they will talk to you about how you are feeling and review your test results from the clinic. The doctors will discuss a treatment plan with you. The paediatric doctor will then hand over your information to your new doctor who will then see you for future appointments.



Ann Jermyn (Transition Nurse)



Sarah and Bethan (Adult nurses)



Dr Wilson (Paediatric Consultant)



Dr Szanthy (one of our Adult Consultants)