

A Guide to Adult Cardiac Care

Somerville
Heart
Foundation

Adult Congenital
Heart Disease

ACHD



For young people and adults
born with a heart condition



The Adult Congenital Heart Disease (ACHD) Clinic

Adult care begins between the ages of 16-18. This leaflet provides information to help inform and support ACHD patients of all ages.

Seeing the Doctor

It is a personal choice if you wish to take someone with you or attend alone. Having someone with you can be useful to help share the information and ensure understanding.

Be prepared

Your clinic appointment is an opportunity to talk to the Doctor about your health concerns. It may be helpful to prepare a list of questions to help you to remember everything you need to know. Don't be afraid to ask questions about your lifestyle e.g. tattoos, piercing, recreational drugs, alcohol, exercise, family planning etc. It is important to understand the effects these may have on your heart.



Individualised care from a Specialist ACHD Hospital

Everyone with Congenital Heart Disease (CHD) should be seen in clinic by an expert from a Specialist Hospital for a full assessment at least once.

In this clinic you will have your blood pressure and oxygen levels checked, an Electrocardiograph (ECG), and a heart scan called an Echocardiogram (ECHO).

The Doctor will perform a physical examination and discuss any symptoms you may have. You will be involved in discussions about your future care and any plans for additional tests.

Following this you should then receive a personalised written care plan. This can be in the form of a clinic letter for you to keep. This contains your diagnosis, current health status, medications, monitoring and future follow up plans specific to you.

In the adult care service, you will be encouraged to work in partnership with the medical team and take responsibility for your own health. You will make your own informed choices about your lifestyle and any procedures offered.

Read our 'Lifestyle Issues' leaflet for more information. Other leaflets including Pregnancy and Contraception are also available at:

www.sfhearts.org.uk

You can find a list of Consultants and Specialist Centres at www.sfhearts.org.uk

If your Cardiologist is not on the list, please call our helpline on 0300 015 1998 for advice



Your Rights

In the event that you are not happy with your hospital visit, you can discuss this with your Specialist Nurse or contact the Patient Advice and Liaison (PALs) Officer. Details will be available through your hospital switchboard or website.

This should not affect your relationship with your Consultant, as they are a professional, interested in treating you to the best of their ability.

You can apply to see your health records and are entitled to see them. This applies even if you are under 16, providing the record holder considers you will be able to understand what they say and mean.



Additional support after clinic

At each ACHD Specialist Hospital there is at least one trained Specialist Nurse available to offer advice and support to patients and their families. Most centres also have a Psychologist who can work with patients to help manage the more complex emotional issues of living with ACHD.

Somerville Heart Foundation also offers free access to Mental Health & Wellbeing Counselling Services to our members.





Between appointments

If you are concerned about any aspect of your health:

- You should see your GP (your local doctor)
- You can phone the ACHD Specialist Hospital and speak to your Specialist Nurse, who will be able to assess your concern and ensure you are seen by the correct person in a timely manner

The Specialist Nurse may decide to discuss your clinical issues with the Hospital Consultant

Contact details for the Specialist Hospitals can be found at www.sfhearts.org.uk



*** If it is a medical emergency call an ambulance or go directly to A&E ***



Keeping Your Appointments

It is very important that you attend appointments. These could be from every 3 months to every 5 years or somewhere in between, depending on the complexity of your condition.

If for some reason you cannot make an appointment, please let the hospital know so they can reschedule your appointment.



Personal Health Passport

You or the Consultant/Doctor/Nurse can record the details of your condition & medication, as well as the details of those looking after you, in a Personal Health Passport (PHP).

You could keep clinic letters or ECGs with this passport, or as photos on your phone. Some hospitals have online portals where you can access your personal medical records, including appointments and test results.

The Personal Health Passport is a free booklet and is very useful in an emergency. It helps you explain your condition to others including friends, tutors & dentists. You will either be given one at your ACHD clinic or just email info@sfhearts.org.uk to get a copy from our office.



#DidYouKnow

Somerville Heart Foundation has been supporting the ACHD community since 1993

In 1968 Professor Jane Somerville was the cardiologist for the first UK heart transplant

Around 90% of babies born with CHD now survive to adulthood as opposed to 15% during the 1950s and 1960s





Further Information & Support

This leaflet was produced by Somerville Heart Foundation.

We are a charity for young people & adults born with a heart condition. We are reliant on donations, fundraising and legacies. It's free to join but not free to run - your donations ensure the future of ACHD support for years to come.

Membership

You never know when you may need some extra help or advice - it's **free** to join as a Friend at www.sfhearts.org.uk. Access our leaflets, newsletters, travel & life insurance, mental health & wellbeing services and much more...

Once you're signed up you can meet others with CHD by joining our closed Facebook group: www.facebook.com/groups/achdpatient.org.uk



Somerville *Heart* Foundation

Contact us...



www.sfhearts.org.uk



01473 252007



info@sfhearts.org.uk

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This leaflet was reviewed by
Fiona Kennedy and Lynda Tellett
Somerville Heart Foundation,
Youth@Heart and Lloyd Lampard
Member of Somerville Heart Foundation

Many thanks to all involved

