

The
Somerville
Foundation

Supporting young people and adults
born with a heart condition



Personal
Health Passport



> Personal Health Passport

This Personal Health Passport is designed to hold important information about your heart condition and to help improve communication about your health and treatment.

Please take it each time you are seen as an outpatient or if you are admitted to hospital.

It would be sensible to keep it with you as often as possible.

> Advice and concerns

If you need advice about your health or have any concerns, you should contact the hospital which you visit and speak with the clinical nurse specialist, doctor or your consultant.

The Somerville Foundation helpline may also be able to advise you. See the back page for our contact details.

> The Somerville Foundation

We are a national charity providing much needed support for patients, their families, friends, colleagues and carers. We have a helpline staffed by trained volunteers, produce a quarterly magazine, GUCH News, and information guides on a number of important topics, including:

- Travelling
- Pregnancy
- Lifestyle
- and others

We thank the clinical nursing staff at The Heart, Royal Brompton and St Thomas' Hospitals for their help in producing this booklet as well as others who made very useful suggestions.

> Personal Details

Name: _____

Hospital Number: _____

Address: _____

Home tel: _____

Mobile: _____

Work tel: _____

Hospital details

Hospital Name: _____

Address: _____

Nurse/Specialist: _____

Contact tel: _____

Consultant: _____

Contact tel: _____

Shared care

Address: _____

Contact tel: _____

General Practitioner

Name: _____

Address: _____

Tel no: _____

In case of emergency notify

Name: _____

Relationship: _____

Address: _____

Tel no: _____

> Keeping a healthy lifestyle

Just like everyone else, people with congenital heart disease are also at risk of developing coronary heart disease (angina and heart attacks). The major risk factors for coronary heart disease are:

- smoking
- high blood cholesterol
- high blood pressure
- physical inactivity
- diabetes

(A 'risk factor' is something that increases your risk of getting coronary heart disease.)

You can reduce your risk of coronary heart disease by:

- stopping smoking if you are a smoker;
- controlling high blood pressure;
- eating a healthy diet and controlling your blood cholesterol level by:
 - eating at least five portions of fruit and vegetables a day;
 - eating fish, especially oily fish, two or three times a week, and
 - cutting down on fats in general, especially saturated fats;
 - taking at least 30 minutes of moderate physical activity a day, such as brisk walking, cycling or swimming (check with your cardiologist first);
 - controlling your weight;
 - if you are diabetic, controlling your diabetes.

> Looking after your heart

It is important that you understand your diagnosis. If you are unsure about anything please ask one of the medical team.

If you are admitted to another hospital please let them know which hospital you normally attend and show this passport to help them.

It would be a good idea to wear a medic alert bracelet or necklace, or carry a card or this passport with you always.

> Preventing endocarditis

Endocarditis is an infection caused by bacteria that enter the bloodstream and settle in the lining of the heart, a heart valve or a blood vessel. It is serious and needs prompt treatment. It is not a common infection but people with a heart defect, whether operated on or not, are at greater risk of developing it than those with a normal heart.

Fortunately, there are things you can do to prevent infection. The most important of these is to make sure your teeth and gums are clean and healthy. Make sure you go to your dentist for regular check ups. The guidance for taking antibiotics prior to going to the dentist was changed to not being generally recommended. Advice on this should be sought from your consultant if you are in any doubt. You may need to take antibiotics before other surgical procedures too. You should discuss this with your consultant.

You should have antibiotic cover before having any sort of body piercing – for example, ear-piercing. If in doubt, check with your doctor or cardiologist beforehand.

Avoid unnecessary courses of antibiotics. If you develop a fever for which there is no obvious cause, make sure the doctor takes a blood sample to identify the infection before you start on antibiotics.

In many cases the infection may develop quite slowly. Symptoms can develop gradually, over weeks or months, and can be vague at first. You

may feel generally unwell and have general aches and pains, tiredness, and be off your food. A fever (a high temperature) develops at some stage in most cases.

> Exercise & Sport

Regular exercise has been shown to have beneficial effects on physical and psychological health. Most people with congenital heart disease do not need to restrict their physical activity. There is no reason why you should not enjoy activities like swimming, cycling, tennis, dancing, Tai-Chi and yoga, if you feel you can do them.

For people with severe heart abnormalities it is important that the exercise programme is graded according to the person's level of fitness and heart problems. You are the best judge of what you can do and your doctor is the best judge of any risks.

For example, weight lifting can increase the pressure within the heart and should be avoided in many instances. People who take anticoagulants should not participate in contact sports. However, at least 30 minutes of walking or other such physical activity a day is recommended in nearly all cases.

It is important to request individualised advice from your cardiologist about what is safe.

> Travelling

You can travel but must take care during long bus, train and air journeys. Move about every 1-2 hours. Do not sit with your legs bent for long periods. Ask your doctor about taking aspirin or stronger anticoagulants for long journeys i.e. over 3 hours.

The worst part of air travel can be the airport. If walking long distances is a problem ask for assistance. This is better arranged well in advance. If you are blue, you may be helped by oxygen. The pressure of oxygen at high altitude is reduced and this can have bad effects on you. Again, the

provision of this should be arranged in advance.

Try to travel as comfortably as possible. Drink plenty of water and move about.

Do not be afraid to ask for help.

Be sensible about where you go and if you have any doubts, ask your consultant before you book.

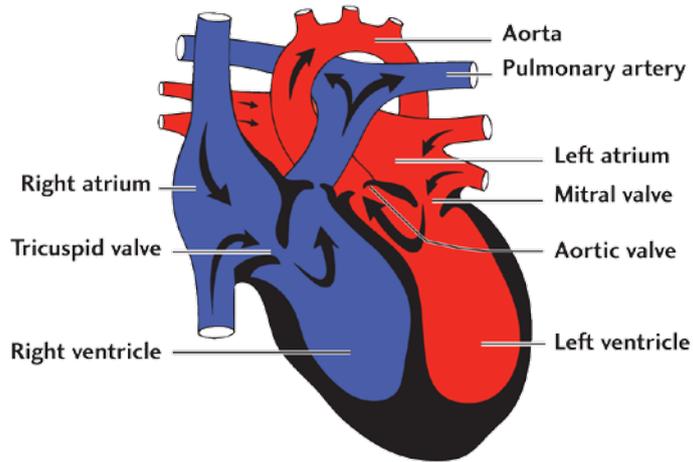
> Your heart

Diagnosis:

Operation(s) / Interventions:

Doctor to detail abnormality

For Doctor to draw further diagrams



(Normal Heart)

Drawing from Little Hearts Matter





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