

FACTSHEET



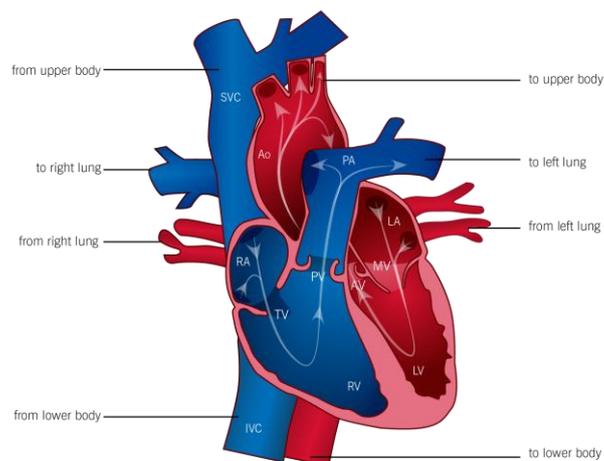
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Transitioning to the Adult Health Service with a Fontan circulation

This information is designed for use by young people with a Fontan circulation and their families.

It is important that you are able to describe your medical conditions to new people you meet when you transition to the adult health service. Although you will be transitioned to a cardiologist with skill in managing adults with congenital heart disease, you may meet other health professionals who are less familiar with your medical condition.

Normal Heart



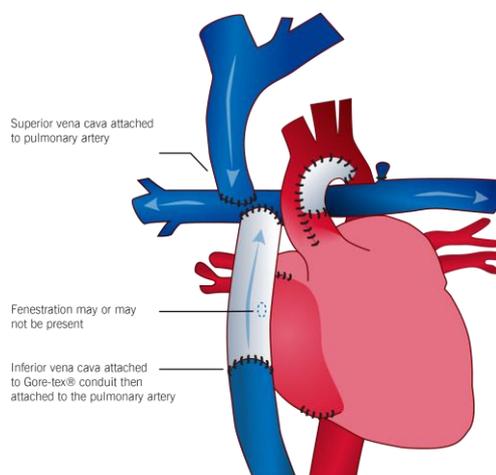
Legend

Ao = Aorta	LA = Left Atrium	IVC = Inferior Vena Cava	TV = Tricuspid Valve
SVC = Superior Vena Cava	RV = Right Ventricle	PA = Pulmonary Arteries	MV = Mitral Valve
RA = Right Atrium	LV = Left Ventricle	PV = Pulmonary Veins	AV = Aortic Valve
			PV = Pulmonary Valve

What is a Fontan circulation?

The Fontan operation is the final stage of a series of operations for people born with a single ventricle (pumping chamber). After a Fontan operation, the deoxygenated blood (blue blood) returns to the lungs directly without going through the heart. The single ventricle is then responsible for pumping the oxygenated (red) blood to the body. People with a Fontan circulation need specific medical care throughout their lives.

Fontan Circulation



Why is transition important? What are the goals of transition?

Transition is the process of moving from paediatric or child health to adult health services. The way the health system works in adult health care is different from child health care. You will be responsible for a lot more. To make transition easier you should start being an active participant in your own health care from about the age of 14. Then when you transition, you will have had practice in talking about your health and will feel confident.

It can be scary to think about moving your healthcare to a new place and this can be a time when you feel reluctant to come to medical appointments. This is also a time when you feel caught up with the other pressures of life, such as study or relationships. However, taking control of your own health and staying positive about transitioning to adult health care has been shown to lead to better health in the future. Slowly you will gain confidence as you take responsibility for your own health care.

Why are your medications important?

Most patients with a Fontan circulation will be on a blood thinner to prevent blood clots. Other medications can include; those that help keep the pumping chamber of the heart strong; and those that help keep the heart in the correct rhythm. These medications need to be taken as directed, every day to make sure they are working.

It is important that you understand why you are taking your medications, how much you should take and when to take them. Also you should know how to get your medications from the pharmacy.

Why are appointments important?

Appointments are important to make sure that you stay healthy. Patients with a Fontan circulation can have an excellent quality of life. Follow up appointments are important so that problems can be detected and sorted out early before complications occur. You should understand how to make your own follow up appointments and keep your own records.

Where will my care transfer to?

Not all cardiologists who look after adults have experience looking after patients with congenital heart disease. It is important that you have contact with a

specialised unit that looks after adults with congenital heart disease. Most young people with a Fontan circulation who live in metropolitan Sydney are referred to either Royal Prince Alfred Hospital or Westmead Hospital. Some cardiologists may visit rural locations. You should speak to your paediatric cardiologist about where your care should be transferred to.

"I honestly tried to stay at Children's Hospital for as long as I could and see my usual paediatric cardiologist. I felt very comfortable with him and he knew my other health problems I've had as a child and was always open to discussing them with me as well. Moving to an adult hospital was actually great, to my surprise. I received great support from the team there and I felt more comfortable asking more adult orientated questions about my health condition. They also gave me more of an insight into the future and procedures that I could undertake in the future." – Katarina, Fontan patient.

Cardiologists who care for adults with congenital heart disease

Royal Prince Alfred Hospital

Prof. David Celermajer
Dr. Rachael Cordina
Phone: (02) 9515 7110

Westmead Private Cardiology

Dr. David Tanous
Phone: (02) 9687 0054
Dr. Preeti Choudhary
Phone: (02) 9687 0866

St George Private Hospital

Dr. Peter Robinson
Phone: (02) 9588 6611

When will I transition?

The process of transition begins several years before it happens. However, the care of young people with a Fontan circulation is moved from the children's hospital

to an adult congenital heart disease unit after you turn 18, or around the time you finish high school. You may transition earlier if you and your paediatric cardiologist feel that you are ready. It is important that you are referred to and have an appointment with your adult cardiologist 6 - 12 months after your final childhood cardiology appointment.

How does transition work?

Your paediatric cardiologist will make a referral to the specialist in adult congenital heart disease. In some cases you may have already met this adult cardiologist before the transition. Before transitioning your paediatric cardiologist may arrange for some extra routine tests. These are used to provide up to date information to your adult cardiologist. These routine tests may include blood tests, ECG's, Echo's, Holter monitors, stress tests and MRI's. All of your medical information will be sent to your adult congenital heart disease specialist. It is important that you understand and have copies of your important medical information as well. You should ask your paediatric cardiologist for this.

What if I have a problem before I see the adult congenital heart disease specialist?

If you have concerns about your heart prior to your first appointment in the adult congenital heart disease unit, you should make contact again with your paediatric cardiologist. If there is a problem that needs to be dealt with soon your paediatric cardiologist will be able to advise you about the best options. If it is an emergency you should attend the nearest hospital emergency department. Remember to take copies of your medical information/test results with you!

Where can I get more information about transition?

If you want more information you can ask your paediatric cardiologist. If you have more than one health condition or you are having trouble managing your transition you can ask about Trapeze. This is a service run by the hospital to help support you transition. They have a website with lots of helpful information.

A final note...

Congratulations on reaching such an important milestone!

For more information contact:

Trapeze

Email: trapeze.schn@health.nsw.gov.au

Website: <http://www.trapeze.org.au/>

Phone: 02 8303 3600

Fax: 02 8303 3650

Address: Level 1, Suite 2, 524-536 Botany Road, Alexandria, NSW, 2015

"While I was sad to leave my childhood cardiologist behind I didn't have any nerves about transitioning to an adult cardiologist. I never saw it as this massive transition, but rather another step of growing up. Going into appointments alone finally like the appointments belonged to me and I was able to ask all the things I had been too embarrassed to say in front of my mum, so I found it be a positive thing." - Courtney, Fontan patient, 22 yrs.

