

Tetralogy of Fallot Child / Young Person

Facility:

(Affix identification label here)

URN:

Family name:

Given name(s):

Address:

Date of birth:

Sex: M F I

A. Interpreter / cultural needs

- An Interpreter Service is required? Yes No
 If Yes, is a qualified Interpreter present? Yes No
 A Cultural Support Person is required? Yes No
 If Yes, is a Cultural Support Person present? Yes No

B. Condition and treatment

The doctor has explained that you and/or my child has the following condition: *(Doctor to document in patient's own words)*

There are four major defects in Tetralogy of Fallot.

1. Ventricular Septal Defect or a "hole in the heart". This is a hole in the muscle between the left and right pumping chambers (ventricles).
2. Pulmonary Stenosis. Narrowing of the artery from the right pumping chamber in the heart, to the lungs (pulmonary artery).
3. Right Ventricular Hypertrophy. The right ventricle (pumping chamber) muscle increases in amount, from working at high pressure.
4. Overriding Aorta. The large artery (aorta) lies over the top of the "hole in the heart". Some of the blue blood from the right side of the heart flows through the hole to the aorta. It does not go to the lungs for oxygen. This blood with little oxygen is pumped into the aorta and around the body.

Your child's condition requires the repair of the Tetralogy of Fallot.

This condition requires the following procedure *(Doctor to document - include site and/or side where relevant to the procedure)*

The following will be performed:

Your child's chest is opened to reach the heart. The doctor will operate on the heart and large blood vessels.

C. Risks of this procedure

There are risks and complications with this procedure. They include but are not limited to the following.

General risks:

- Infection can occur which may require treatment including antibiotics.
- Bleeding could occur and may require a blood transfusion return to the operating room. Bleeding is more common if you have been taking blood thinning drugs such as Warfarin or Aspirin.

- Small areas of the lung can collapse, increasing the risk of chest infection. This may need antibiotics and physiotherapy.
- Impaired circulation may occur to a limb or to an organ which may require further treatment
- Death or brain damage as a result of this procedure is possible.

Specific risks:

- Obstruction of blood flowing out from the right ventricle.
- Leaking of one of the heart valves (pulmonary valve).
- Fluid collecting in the sac around the heart.
- Fluid collecting in the chest between the lungs and the ribs. This may need to be drained with a tube in the chest.
- Damage to the nerve (Phrenic nerve) that controls the diaphragm (breathing muscle).
- Stroke causing paralysis and long term disability.
- Blood transfusion. There is a risk of getting an infectious disease such as Hepatitis and HIV/AIDS.
- Abnormal heart beat. This may need medication to fix or a pacemaker.

D. Significant risks and procedure options

(Doctor to document in space provided. Continue in Medical Record if necessary.)

- Medical Treatment (no surgery)
Use of medication (beta blockers). The risks of medical treatment is:
 - Infection of the lining of the heart (Endocarditis)
 - Blood infection, which may cause an infection in the brain. (Cerebral Abscess)
 - Clots in the brain.
 - Decreased life span.
- Medical Treatment (no surgery)
The risks are noted above on this form.

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E. Risks of not having this procedure

(Doctor to document in space provided. Continue in Medical Record if necessary.)

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F. Anaesthetic

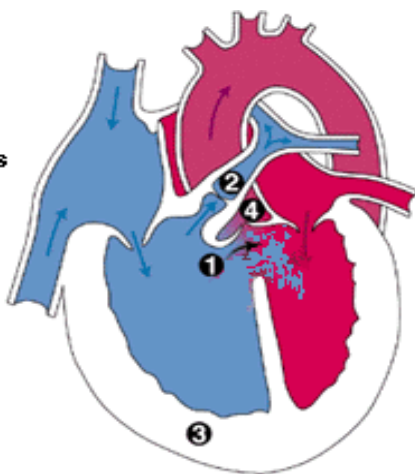
This procedure may require an anaesthetic. (Doctor to document type of anaesthetic discussed)

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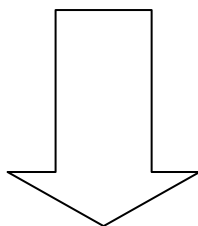
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Here is a picture showing the defect.

1. Ventricular Septal Defect
2. Pulmonary Stenosis
3. Hypertrophy Right Ventricle
4. Overriding Aorta



- This consent document continues on page 3 -



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G. Patient/ Parent / Substitute Decision Maker consent

I acknowledge that the doctor has explained to me and/or my child:

- the medical condition and the proposed procedure, including additional treatment if the doctor finds something unexpected. I understand the risks, including the risks that are specific to me.
- the anaesthetic required for this procedure. I understand the risks, including the risks that are specific to me/my child.
- other relevant procedure / treatment options and their associated risks.
- my / my child's prognosis and the risks of not having the procedure.
- that no guarantee has been made that the procedure will improve the condition even though it has been carried out with due professional care.
- the procedure may include a blood transfusion.
- tissues and blood may be removed and could be used for diagnosis or management of my / my child's condition, stored and disposed of sensitively by the hospital.
- if immediate life-threatening events happen during the procedure, health care will be provided in accordance with good clinical practice and in the best interests of the patient.
- a doctor other than the Consultant may conduct the procedure. I understand this could be a doctor undergoing further training.

I have been given the following Information Sheet/s:

- About your Child's Anaesthetic**
- Tetralogy of Fallot - Child / Young Person**
- Blood & Blood Products Transfusion**
- My child and/or I were able to ask questions and raise concerns with the doctor about the condition, the proposed procedure and its risks, and my treatment options. Any questions and concerns have been discussed and answered to my/our satisfaction.
- I understand that I have the right to change my/our mind at any time, including after I have signed this form but, preferably following a discussion with my doctor.
- I understand that image/s or video footage may be recorded as part of and during the procedure and that these image/s or video/s will assist the doctor to provide appropriate treatment.

On the basis of the above statements,

I request that my child has the procedure

Name of parent /

Substitute Decision Maker/s:

Signature:

Relationship to patient:

Date: PH No:

If applicable: source of decision making authority (tick one):

- | | | |
|---|--------|---|
| <input type="checkbox"/> Court order | —————> | <input type="checkbox"/> Court order verified |
| <input type="checkbox"/> Legal guardian | —————> | <input type="checkbox"/> Documentation verified |
| <input type="checkbox"/> Other: | —————> | <input type="checkbox"/> Documentation verified |

AND / OR for the young person

Based on *Gillick vs West Norfolk Area Health Authority* [1986] 1AC 112 a minor (i.e a patient under 18 years of age) is capable of giving informed consent when he or she achieves a sufficient understanding and intelligence to enable him or her to fully understand the nature, consequences and risks of the proposed procedure/treatment and the consequences of non-treatment.

I request to have this procedure

Name of patient:

Signature:

Date:

H. Doctor/delegate Statement

I have explained to the patient all the above points under the Patient Consent section (G) and I am of the opinion that the patient/substitute decision-maker has understood the information.

Name of Doctor/delegate:

Designation:

Signature:

Date:

I. Interpreter's statement

I have given a sight translation in

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(state the patient's language here) of the consent form and assisted in the provision of any verbal and written information given to the patient/parent or guardian/substitute decision-maker by the doctor.

Name of Interpreter:

Signature:

Date:

1. How does a normal heart work?

The heart works as a pump that keeps the blood flowing. The heart is divided into 4 chambers, two filling chambers and two pumping chambers. The veins drain the blood into the heart. The arteries carry blood away from the heart.

The chambers and vessels are separated by valves that control the blood flow. A wall of muscle separates the left and right side of the heart.

The pink blood carries oxygen around the body. The blue blood is returned to the right side of the heart, and into the lungs for more oxygen. The blood then flows into the left side of the heart and is pumped around the body again.

2. How does a child's heart work?

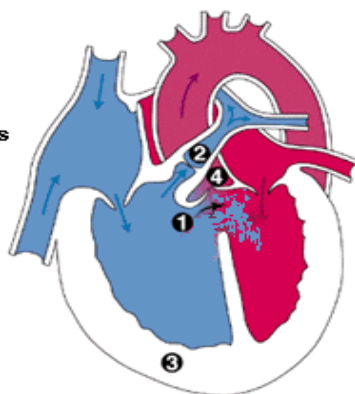
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- Right Ventricular Hypertrophy. The right ventricle (pumping chamber) muscle increases in amount, from working at high pressure.
- Overriding Aorta. The large artery (aorta) lies over the top of the "hole in the heart". Some of the blue blood from the right side of the heart flows through the hole to the aorta. It does not go to the lungs for oxygen. This blood with little oxygen is pumped into the aorta and around the body.

Here is a picture showing the defects.

3. Treatment Options

1. Ventricular Septal Defect
2. Pulmonary Stenosis
3. Hypertrophy Right Ventricle
4. Overriding Aorta



- Medical Treatment (no surgery)

Use of medication. (beta blockers). The risks of medical treatment is:

- Infection of the lining of the heart. (Endocarditis)
- Blood infection, which causes an infection in the brain. (Cerebral Abscess).
- Clots in the brain.
- Decreased life span.

- Surgical Treatment

The risks are noted below.

4. What is going to be done?

Your child's chest is opened to reach the heart. The doctor will operate on the heart and large blood vessels.

5. My anaesthetic

This procedure will require an anaesthetic.

See **About Your Child's Anaesthetic** for information about the anaesthetic and the risks involved. If you have any concerns, discuss these with your doctor.

If you have not been given an information sheet, please ask for one.

6. What are the risks of this specific procedure?

There are risks and complications with this procedure. They include but are not limited to the following.

General risks:

- Infection can occur which may require treatment including antibiotics.
- Bleeding could occur and may require a blood transfusion return to the operating room. Bleeding is more common if you have been taking blood thinning drugs such as Warfarin or Aspirin.
- Small areas of the lung can collapse, increasing the risk of chest infection. This may need antibiotics and physiotherapy.
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Specific risks:

- Obstruction of blood flowing out from the right ventricle.
- Leaking of one of the heart valves (pulmonary valve).
- Fluid collecting in the sac around the heart.
- Fluid collecting in the chest between the lungs and the ribs. This may need to be drained with a tube in the chest.
- Damage to the nerve (Phrenic nerve) that controls the diaphragm (breathing muscle).
- Stroke causing paralysis and long term disability.
- Blood transfusion. There is a risk of getting an infectious disease such as Hepatitis and HIV/AIDS.
- Abnormal heart beat. This may need medication to fix or a pacemaker.

7. What are the benefits of this procedure?

- Improved skin colour.
- Improved level of activity.
- Increased life span.
- Normal growth and development.

8. What happens after the procedure?

After the procedure, your child will spend time in the intensive care unit. The nurses and doctors will watch their condition and care for them.

When they are well enough, they will go to the children's ward.

9. Further questions to think about

Please ask your doctor if you have any further questions such as:

- How urgent and necessary is this procedure?
- Can I donate blood for my child?
- Will my child need a heart lung machine?
- How long will my child be in hospital?
- When can my child get back to normal play or exercise?
- When can my child go back to school or childcare?

Notes to talk to my doctor about: