

Information for Parents of Children at Risk of Infective Endocarditis

You have been given this leaflet because your child with congenital heart disease has been highlighted to have a higher risk of getting infective endocarditis. Please carefully read the information below and if you have any questions please contact a member of your child's healthcare team.

What is infective endocarditis?

Infective endocarditis is a serious and potentially life-threatening infection that affects the lining of the heart and its valves.

Children who develop infective endocarditis will require an extended admission to hospital with a prolonged period of intravenous antibiotics. If it is not identified early complications can develop which can include valve destruction and the need for cardiac surgery.

How does it happen?

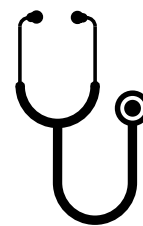
It is most commonly caused by germs entering the blood stream and settling on the heart lining or its valves. The bacteria are more likely to settle on abnormal, damaged or prosthetic heart valves as well as other damaged heart tissue. This causes further damage and can even destroy heart valves.

Common ways in which bacteria enter the blood stream are via the mouth, infections elsewhere in the blood stream and via medical or dental equipment.

How do I know if my child has infective endocarditis?

Infective endocarditis can be difficult to identify as it can present similar to a flu-like illness. We would advise you to seek medical advice if your child is experiencing any of the below symptoms for more than 5 days:

1. Fevers or chills.
2. Sweating at night.
3. Feeling generally unwell, tired or lethargic.
4. Unexplained muscle aches, weakness or weight loss.



How do I reduce the risk of my child getting infective endocarditis?

Unfortunately, it is not possible to stop all bacteria entering the bloodstream but there are two main areas which can significantly reduce your child getting infective endocarditis:

Oral and Dental Hygiene

Poor mouth and dental hygiene can be a source of bacteria entering the blood stream. We strongly encourage that your child should brush their teeth twice a day for two minutes with fluoride toothpaste.

Your child should have regular dental check-ups, at least once a year.

Please ensure that you inform your dentist that your child is at increased risk of infective endocarditis.

If you require help in finding a dentist then please visit the NHS website below:

<https://www.nhs.uk/nhs-services/dentists/how-to-find-an-nhs-dentist/>

Tattoos and piercings

Children at risk of endocarditis should avoid **ALL** body-piercings and tattoos as they carry a high risk of infection and easy passage for bacteria to enter the blood stream.

Although simple piercing of the ear lobe may be less risky, there are still cases of children getting infective endocarditis following a simple ear lobe piercing.

If, despite consideration of this advice, you decide to proceed with ear piercing please limit the piercing to the ear lobe, have it performed with appropriate health and safety regulations including the use of aseptic conditions and single-use disposable piercing cassettes.

If your piercing site becomes infected at any stage, it is important to remove the piercing and get prompt treatment with antibiotics from your GP.

Other useful information to help prevent your child getting infective endocarditis:

- Maintain good skin hygiene.
- Minimise the risk of skin lesions and be vigilant for any signs of infection.
- Be mindful of infections, particularly a fever for no obvious reason.
- Inform your child's doctor before any invasive treatments or procedures.

Does my child need prophylactic antibiotics?

Previously all patients at risk of infective endocarditis were offered antibiotics prior to certain medical or dental procedures. There is new guidance that recommends only patients at

high risk of infective endocarditis need antibiotics prior to certain medical or dental procedures.

Those at high-risk include:

1. Previous infective endocarditis
2. Patients with surgically implanted prosthetic valves, with any material used for cardiac valve repair.
3. Untreated cyanotic congenital heart disease, and those whose surgery includes prosthetic material, including shunts.
4. Patients with ventricular assist devices.

The new guidance highlights at risk dental procedures to include:

- Dental extractions
- Oral surgery procedures (including implant surgery)
- Dental procedures involving manipulation of the teeth (including root canal procedures)

Useful websites for further information:

South Wales and South West Congenital Heart Disease Network:

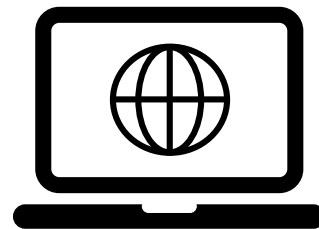
<https://www.swswhd.co.uk/>

National Institute of Clinical Excellence Guidance:

<https://www.nice.org.uk/guidance/CG64>

Children's Heart Federation:

<https://chfed.org.uk/how-we-help/information-service/heart-conditions/infective-endocarditis/>



The Trust cannot accept any responsibility for the accuracy of the information given if the leaflet is not used by Royal Devon staff undertaking procedures at the Royal Devon hospitals.

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