



*Better
Together*

Patient information

Preventing Infective Endocarditis

Trust wide Information

This booklet is about the care and treatment of people at risk of infective endocarditis who are undergoing procedures in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence), which recommends a change in current practice. It is written for people who are at risk of infective endocarditis but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe infective endocarditis or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you.

There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on page 7.

The advice in the NICE guideline covers:

Patients who are at risk of infective endocarditis, specifically:

- Adults and children with certain problems affecting the structure of the heart (such as a replacement heart valve or hypertrophic cardiomyopathy)
- Adults and children who have previously had infective endocarditis (whether or not they have an underlying cardiac problem).

People having any of these procedures:

- Any dental procedure
- Any obstetric or gynaecological procedure, or childbirth
- Any procedure on the bladder or urine system
- Any procedure on the gullet, stomach or intestines
- Any procedure on the airways, including ear, nose and throat procedures and bronchoscopy (a test used to diagnose some lung problems).

It does not specifically look at:

- People at risk of infective endocarditis who do not have heart problems (such as intravenous drug users).
- People having procedures that aren't in the list above.

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team (this could include your GP, practice nurse or cardiologist).

To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain infective endocarditis and the treatments for it simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments.

You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change.

Your own preference for a particular treatment is important and your healthcare team should support your choice of treatment wherever possible, but if you are a child or young person this does depend on your age. If you are over 16, or under 16 and fully understand the treatment, you may be able to give your own agreement. If you are too young, your parents or carers may need to agree to your treatment.

In an emergency, if the person with parental responsibility for the child can't be contacted, healthcare professionals may decide to provide treatment that is immediately necessary in the best interests of the child.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree, your family and carers should have the chance to be involved in decisions about your care. Family members and carers also have the right to the information and support they need in their roles as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

Infective endocarditis

Infective endocarditis is an infection in which the lining of the heart, particularly the heart valves, becomes inflamed. It affects people who have certain heart problems such as a replacement valve or a condition called hypertrophic cardiomyopathy (see 'Am I at risk of infective endocarditis?' on page 4). It is caused mainly by bacteria which get into the blood from outside the body. It is a very rare condition, but is serious.

New recommendations

In the past, people at risk of infective endocarditis have been offered antibiotics when they have certain medical or dental procedures. NICE is recommending a change in practice, so now you should only be offered antibiotics if the procedure is at a site where there is a suspected infection. This is because medical and dental procedures are no longer thought to be the main cause of endocarditis, and taking antibiotics carries its own risk.

Am I at risk of infective endocarditis?

Only some heart conditions put you at risk of developing infective endocarditis.

These include:

- Some types of disease affecting the heart valves.
- Having a replacement heart valve.
- Some types of heart problem present from birth that affect the structure of the heart, even if you have had an operation to correct the problem (but if you have a condition called an isolated atrial septal defect, a repaired ventricular septal defect or a repaired patent ductus arteriosus, you are not at risk of infective endocarditis).
- A condition called hypertrophic cardiomyopathy.
- Having had infective endocarditis before.

Should I be offered antibiotics?

You should **not** be offered antibiotics to prevent infective endocarditis for any of these procedures:

- A dental procedure.
- An obstetric or gynaecological procedure, or childbirth.
- A procedure on the bladder or urine system.
- A procedure on the gullet, stomach or intestines.
- A procedure on the airways, including ear, nose and throat procedures and bronchoscopy.

But you will be offered antibiotics if you are having a medical procedure at a site where there is a suspected infection in the gullet, stomach or intestines, or in the reproductive or urine system. Everyone with a suspected infection is given antibiotics if they have these types of procedure. The only difference for people at risk of infective endocarditis is that their antibiotics will be chosen so that they kill the bacteria that can cause infective endocarditis as well as other types of bacteria.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team, or to your local Patient Advice and Liaison Service (PALS). If they are unable to help, they should refer you to your local Independent Complaints Advocacy Service.

What do I need to know about reducing my risk?

You should ask your healthcare professional about:

- The benefits and risks of antibiotics and why antibiotic prophylaxis is no longer routinely recommended
- The importance of always looking after your teeth and gums, including toothbrushing, flossing and using mouthwash
- Symptoms to look out for that may indicate infective endocarditis and when to seek expert advice
- The risks of undergoing any kind of procedure that involves piercing the skin, including body piercing or tattooing.

Questions you might like to ask your healthcare team

- In the past I have been given antibiotics to prevent infective endocarditis for the same procedure but have not been offered them now. Why has this changed?
- Is there some written material (like a leaflet) about infective endocarditis that I can have?
- What can I do to improve my oral health?
- What symptoms should I look out for?
- Who do I contact if I think I have symptoms of infective endocarditis?
- What do I do if I think I have an infection?
- I've used a chlorhexidine mouthwash when I have had dental treatment in the past. Is this helpful?

More information

The organisations below can provide more information and support for people at risk of infective endocarditis. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

British Dental Health Foundation

Telephone: 0845 063 1188

www.dentalhealth.org.uk

British Heart Foundation

Telephone: 0845 070 8070

www.bhf.org.uk

Children's Heart Federation

Telephone: 0808 808 5000

www.chfed.org.uk

**Faculty of General Dental Practice (UK) The
Lay Advisory Group**

020 7869 6754

[www.fgdp.org.uk/patient info](http://www.fgdp.org.uk/patient%20info)

**Grown up Congenital Heart Patients
Association**

Telephone 0800 854 759

www.guch.org.uk

**NHS Direct online (www.nhsdirect.nhs.uk)
may also be a good starting point for finding
out more. Your local Patient Advice Liaison
service (PALS) may also be able to give you
further information and support.**

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

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