Coping after Endocarditis

A leaflet for people living with the effects of endocarditis

This leaflet is for people who have been diagnosed with endocarditis, who are receiving or have received medical treatment. As well as the physical effects of endocarditis, some people also find that the experience of illness, diagnosis and treatment can have an emotional impact. This leaflet provides some information about the ways people can be affected emotionally and what support is available.
You may already know quite a lot about endocarditis or this may be your first chance to read about it in your own time. It may help to read the information below. For more information, visit the British Heart Foundation website (www.bhf.org.uk).

**What is Endocarditis?**
Endocarditis is a rare condition in which the inner lining of the heart, usually the heart valves, becomes infected. It is quite rare and often happens to people who have an existing heart problem or abnormality. It is a serious condition, which can be life-threatening if not treated quickly. Most people recover well with antibiotic treatment if the infection is identified and treated quickly. However, some people experience damage to the heart valves as a result of the infection, which may need to surgery to correct. Coping with physical health problems can be challenging and heart problems in particular can be frightening. It is common for people who have been diagnosed with endocarditis to be affected in many different ways and find themselves, at times, struggling to cope.

**Who is most at risk of developing endocarditis?**
The people who are most at risk of developing endocarditis are more likely to have;
- a stiff or leaking heart valve
- a heart valve replacement operation previously
- an inherited disease of the heart muscle, where the muscle wall of your heart becomes thickened, called hypertrophic cardiomyopathy
- most types of heart disease that you are born with (i.e. congenital heart disease)
- intravenous drug users
- people who have a history of endocarditis

**Impact on mood**
It is likely you have been through quite a lot since becoming unwell. Diagnosis, treatment and recovery can each be challenging in their own ways and it is normal to be affected by these experiences. These effects are not only physical. The way you think, the way you see yourself, the world and the future, the things you do and how you feel emotionally can all be affected.

There are a number of points along the journey with endocarditis where people report finding things difficult. Perhaps some of the examples below will be familiar to you;
- **Becoming unwell unexpectedly** - you may have felt very physically unwell and not understood what was happening, which can be scary.
- **Being admitted to hospital** - your admission and urgent treatment could have been shocking and, for some, traumatic. If you were very unwell and things were happening very quickly, it may have been hard to understand what was going on.
- **Getting the news that endocarditis is serious** - you may not have even heard of endocarditis before and been understandably upset by this news. You may have been worried, uncertain and fearful for the future.
- **Coping with treatment** - being in hospital, sometimes for a long time, for treatment can be difficult. The early hours and days may have involved lots of uncomfortable tests and procedures and later, being stuck in hospital having treatment for many weeks in some cases, can be boring and stressful. You may also be worried about not being able to fulfil your roles and responsibilities at work or at home while you are recovering.
- **Turning your mind to the future** - After treatment for endocarditis you may be feeling physically better but continue to be bothered by worries about your recovery and the future. You may have lots of “What if?” questions running through your mind.
All of these feelings are very normal, and most people recover well from the emotional stresses of endocarditis. In fact, some people say that the experience of being unwell helps them to make some positive changes in their lives and to feel more hopeful about the future. If you’re struggling at the moment with feeling low or anxious, there is support available to help you get through this:

- **Read our longer leaflet:** *A leaflet for people living with the effects of endocarditis: Taking care of your emotional health*
- If after trying out some of the ideas in this leaflet, you continue to struggle emotionally or have great difficulty making the changes you want to make in the interests of your health, ask your healthcare professional about other support that may be available to you.

**INFORMATION FOR YOUR DENTIST OR DOCTOR**

**Do I need antibiotics before I receive dental treatment?**

**YES**, King’s Cardiologists, Cardiothoracic Surgeons and Medical Microbiologists have considered all the evidence and guidelines and agree that, although there is no proven link between dental treatment and endocarditis, antibiotics should still be offered to those with endocarditis or are at high risk (see below).

**We recommend antibiotics before dental treatment if you:**

**Have prosthetic (artificial) heart valves**
- Have had endocarditis in the past, regardless of whether you needed valve surgery or replacement as a result
- Have certain types of congenital heart defects, (present from birth) as advised by your cardiologist
- Have had a heart transplant and develop a problem in a heart valve

Antibiotics are only advised for patients with endocarditis or are at highest risk of endocarditis undergoing dental treatment involving bleeding gums (including scaling and root canal procedures).

**We do not recommend you take antibiotics if you:-**
- Have other heart or valve diseases

**Antibiotics should be taken by orally (by mouth) as a single dose 30-60 minutes before procedure. Options are:**

Amoxicillin (3g sachet, dissolved in water as per instructions)

Amoxicillin is a type of penicillin. If you are allergic to or intolerant of penicillin, the alternative is:

Clindamycin 600 mg

**NB** If your procedure has to be carried out under a general anaesthetic, you will not be able to take the antibiotics orally. Please ask your dentist to discuss your case in advance with a Medical Microbiologist.

**How is endocarditis prevented?**

Antibiotics before dental treatment will not completely protect you from getting endocarditis. If your doctor has told you that you are at risk, it is much more important that you look after your teeth and gums and have regular check-ups. If your dentist or doctor wants more information about antibiotic treatment, please contact your named consultant who will be happy to discuss it further.
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If you would like to read more about Endocarditis and Emotional Health, ask your nursing team for the longer booklet: A booklet for people living with the effects of endocarditis: Taking care of your emotional health.

King’s Patient Advice and Liaison Service (PALS)
This is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer - staff will be happy to direct you.

Tel: 020 3299 3601
Email: kch-tr.pals@nhs.net

The full range of IMPARTS booklets can be found at:
www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx