

Summary of ECD Online chat session held on 7th March 2009

6 Present

1. Much of the session was spent in discussing the wording that should be placed on the website regarding antibiotics and ECD. It is clear that some patients experience an increased susceptibility to infection, whether from the drugs taken to treat ECD or possibly from the disease itself. Some patients are recommended to take antibiotics, either prophylactically (to prevent the infection) or as soon as they have an infection.
2. One patient mentioned that the use of antibiotics prophylactically in the longer term may result in immunity being built up to that particular drug.
Editor's note: Bacteria can become resistant to the antibiotic. This means that the antibiotic may not be effective at killing that bacteria at a later time. Also, patients may develop allergies to antibiotics. These allergies range from minor skin irritations to very severe reactions.
3. The wording to be used on the website regarding antibiotics is still under discussion and will be agreed shortly.
4. One patient who had just started taking calcium had visited a cardiologist who recommended consultation with a nephrologist as calcium supplements may increase the likelihood of deposits forming on the inside of the arteries. Other patients are also taking calcium. It has been suggested that calcium may be useful as an aid to healing injuries affecting the bones.
Editor's note: A documented risk factor for anyone with excessive calcium is kidney/bladder stones.
5. Other supplements taken include vitamin D and magnesium. It may be worthwhile to consult some of the 'ECD doctors' to ask them whether there are any standard vitamins and supplements they would recommend.