



### **Advice for those with Cystic Fibrosis in relation to CF Trust outdoor events**

Cross-infection is an issue of considerable concern for the CF community. Those with CF attract different bacteria or 'bugs' that grow in their lungs. These 'bugs' are rarely harmful to those who do not have CF but may be harmful to others who have CF but who do not have the same 'bugs'.

This became a real problem in the 1990s in relation to *Burkholderia cepacia*, some strains of which can cause a very serious health problem in those with CF. It was agreed that those with *B. cepacia* should be segregated from other people with CF. It subsequently emerged that there are several strains of *B. cepacia* and some are more serious than others so people with *B. cepacia* were then further segregated according to the strain they had.

*Pseudomonas aeruginosa* is another 'bug' people with CF regularly acquire, mostly from the environment. This can usually be eradicated or kept at bay with early antibiotic treatment. It is expected that CF patients will pick up *Pseudomonas* from time to time. There are thousands of different strains of *Pseudomonas*. If this 'bug' gets well established and starts to become resistant to antibiotics, it can cause problems. There is some concern that CF patients are more likely to pick up strains of *Pseudomonas* that are difficult to treat from each other than from the environment. For this reason, CF Centres and Clinics are now encouraged to offer separate clinics for CF patients according to whether or not they have *Pseudomonas* and if so, whether the particular strain is known to be 'transmissible' that is, has been shown to have the ability under some circumstances to pass from patient to patient.

'Bugs' such as *B. cepacia* and *P. aeruginosa* can be transmitted from person to person by close personal contact, such as sharing rooms, sharing medical equipment, sharing cutlery or crockery and by kissing or coughing.

There is little risk of person to person transmission in an outdoor environment, but prolonged close contact such as travelling with other people with CF in a car or a coach

or joining them for a drink in the pub after the event, may introduce a higher level of risk.

For those reasons, the CF Trust has developed the following guidelines for outdoor events.

1. Those with *Burkholderia cepacia* should not attend any event where others with CF may be present.
2. Others with CF may attend at their own discretion but should observe the following rules:
  - a) Do not travel to and from the event with others with CF unless you usually share a room or house with another person with CF e.g. your brother, sister, parent or child who also has CF.
  - b) Observe good basic hygiene, such as hand washing. Wash your hands before and after eating, before and after attending any event, and always after shaking hands with another individual, whether or not they have CF, and after using the toilet. Cover your mouth and nose whenever you cough, and preferably cough into a tissue, which can be kept in a sealed container for later disposal. Do not spit your sputum onto the ground. Do not share drinking or eating utensils, or any food or drink, or any medical inhalers or equipment. Do not get involved in preparation or serving food for the event if people with CF are going to be present.
  - c) Do not shake hands with, or kiss on the cheek, others with CF. A friendly pat on the shoulder is a good substitute.
  - d) Do not go into the pub or the restaurant after the event if there may be others with CF. If you find you have accidentally arrived at the same venue, then try to sit well apart (more than 3 feet) and try to choose an outdoor seat.
  - e) Whilst participating in or attending the outdoor event, do not get in close proximity with others unless you are sure they do not have CF. Sometimes this is unavoidable, but try to ensure you maintain at least a separation of 3-feet at all times. This should still permit you to participate in an event. If you are having a bout of coughing, try to move further away from others with CF – if you are not sure, then move away from all other people while you are having a coughing bout, and wash and disinfect your hands afterwards (using alcohol rub). Think carefully before attending if you have a cold, your chest is worse than

normal, or if you are likely to have to cough so much during the event that maintaining good hand hygiene would be very difficult. Please also think very carefully before bringing very young children with CF to an event – can you be sure that they will maintain the same standard of hygiene?

We are sorry for any inconvenience or upset that this may cause. However the safety and well being of those with CF is our main concern, and we do not wish to expose anyone to unnecessary risk.

People attending an outdoor / challenge event should be aware that there may be other people with CF present at the event.

Thank you for your co-operation.

Reviewed by the Medical Advisory Committee on 2 July 2009