Cystic Fibrosis why we're here

Cross-infection Policy

Guidance for people with cystic fibrosis at events and meetings

This guide gives practical advice for people with cystic fibrosis (CF) on how to minimise their exposure to harmful bacteria and protect their health when taking part in outdoor events or attending indoor meetings and conferences etc. These guidelines are to be strictly followed at all events organised by the Cystic Fibrosis Trust and its volunteer branches, groups and committees.

1. Background to cross-infection concerns

Cross-infection is an issue of considerable concern for the CF community. Those with cystic fibrosis 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 cystic fibrosis 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 cystic fibrosis. It was agreed by CF Clinicians that those with *B. cepacia* should be segregated from other people with cystic fibrosis. 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 cystic fibrosis 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 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.

More recently, there is an increasing number of people with cystic fibrosis who are post transplant and are still at risk due to their immunosuppressed status. It is recommended that they should also follow the cross-infection avoidance protocols described below.

2. Guidelines for people with CF at outdoor events

For the reasons already explained, we have developed the following guidelines for outdoor events.

Those with *Burkholderia cepacia* should not attend any event where anyone with cystic fibrosis may be present.

For the reasons already explained, we have developed the following guidelines for outdoor events. Those with *Burkholderia cepacia* should not attend any event where anyone with cystic fibrosis may be present. For those without *Burkholderia cepacia*, there is little risk of person to person transmission for participants and spectators with CF 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. Therefore, to reduce the likelihood of cross infection, people with cystic fibrosis 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 eg your brother, sister, parent or child who also has cystic fibrosis.

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 cystic fibrosis.

d) Do not go into the pub or the restaurant after the event if there may be others with cystic fibrosis. If you find you have accidentally arrived at the same venue, then try to sit well apart (more than three 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 cystic fibrosis. Sometimes this is unavoidable, but try to ensure you maintain at least a separation of three-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?

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

3. Guidelines for people with cystic fibrosis at indoor events

Since close contact between people with cystic fibrosis is much more likely to occur at indoor events, which significantly increases the risk of cross infection, it is our policy for only one person with CF to be present or allocated a place at an indoor event organised by Trust staff or its volunteer branches, groups and Committees. This place is often reserved for a CF speaker or guest with cystic fibrosis and no other attendees with CF are invited to ensure there is no contact with another person with cystic fibrosis which could compromise their health status. Alternatively, the single place for a person with CF is allocated on a “first come” basis. This policy applies to all events and meetings organised by the Trust’s staff, branches, groups and committees.

This may mean that if a second person with cystic fibrosis arrives without prior arrangement, to protect their health and maintain the highest standard of care, it may not be possible for them to take part, or be present, on that occasion. We are sorry for any inconvenience or upset that this may cause, however the safety and well being of those with cystic fibrosis is our main concern, and we do not wish to expose anyone to unnecessary risk.

Thank you for your co-operation.