

The best questions attract the best answers – a word from the CF Trust



Seeing CF portrayed on TV and in the media can bring up questions, worries or concerns that people affected by CF might not have thought about before. If you are a parent, you might find your child asking questions that you find hard to answer or becoming aware of aspects of CF that you haven't discussed with them before. Every individual and family are different in the way they talk about difficult or sensitive issues, but being able to share worries or ask questions with people you love and trust can be really helpful. We have prepared this guide to support you in these conversations. Your CF team will also be able to support you and your family with any concerns.

It can help to ask open questions to start a conversation...

- "How does what you've seen or read compare to your experience of life with cystic fibrosis?"
- "What questions do you have about what you've seen? What parts of the film stuck with you? What questions did it bring up for you?"
- "Did you find out anything new about CF? How do you feel about that?"
- "Have you spoken to your friends about the film? What did they think about it? What questions do you think your friends might have about cystic fibrosis if they saw this?"
- "Is there anything you want to talk to your CF team about at your next appointment? How can I help you raise that with them?"
- "How CF specialists deal with cross-infection is very different in the United States – how do you think life for people with CF in the United States might be different from your own?"

Sometimes it can help to talk about ways you might feel, to encourage someone else to share their thoughts.

- "Some people might find that a bit worrying... How do you feel about it?"
- "That made me feel a bit uncomfortable – how are you feeling about it?"
- "I felt that [...] was portrayed really well – which bits did you enjoy?"
- "I found how they dealt with [...] really surprising – did anything catch you off-guard?"

Different topics and themes affect everyone in different ways, and it can be surprising what strikes a particular chord with different people, so you may find that what upsets you might not affect someone else, and that's OK – the important thing for everyone is to have the space and support to talk about it.

Everyone with CF is different, in terms of their health itself but also how they handle the challenges it can bring and how they feel about the condition. TV, books and in some cases, what we see online, is usually dramatised and 'creative licence' is used to make facts fit the story. Sometimes we need to talk it through to work out what is reality and what is drama, and how that makes us feel. We may see different views and perspectives of CF within just one film, book, video etc. It can be useful to talk about which of these someone does/doesn't identify with, and the fact that each one is a specific character created for the purpose of a story – in real life we are all a mixture of different views, and these can change over time as we grow, age and have different life experiences.

Research update



Here is a short summary of current and upcoming trials running at Exeter:

Adult trials that are open to new patients:

Living with CF: A Quality of Life measurement for people aged > 16 years with CF, in the UK CF Registry. Taking part involves completing an online questionnaire at annual review. Is your annual review coming up? If so, please get in contact if you would like to hear more about this study.

Hope-1 Study: This study is looking at the effect of a new nebulised treatment vs placebo (a dummy treatment) on lung function in people 18–50 years old with an FEV1 between 50–80%. Trial involvement lasts around 2 months.

Paediatric trials that are open to new patients:

Gilead Alpine 2: This study is looking at whether 14 days or 28 days Aztreonam Lysine (Cayston) is effective and safe for treating new-onset Pseudomonas infection in children who haven't grown Pseudomonas in the last two years (or ever).

CF Start: This study is looking to compare two strategies for giving antibiotics to new babies with CF. "Prevent and Treat" flucloxacillin prophylaxis (standard care in the UK) vs "Detect and Treat" antibiotics, prescribed depending on microbiology results.

Upcoming trials:

Vertex NextGen: This study is looking at the effect of a new triple therapy treatment in those aged 12 years+. This trial is planned to start in the Autumn.

Proteostasis: This study is looking at the effect of a new triple therapy treatment in adults 18+. This trial is planned to start in the Autumn.

OligoG: This study is looking at a new inhaled treatment for treating chronic pseudomonas in those aged 12 years+. Date of recruitment starting in Exeter not yet confirmed, but you can find further information about the study here: <https://oligogpivotalcf.eu>