

Young people and Kaftrio A peer research project

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The Cystic Fibrosis Trust's Youth Advisory Group (YAG) is a team of young people with CF and their siblings. In 2020 the group felt that the licensing of Kaftrio in the UK had resulted in tension in the CF community. YAG wanted to provide a platform for young people to share their thoughts on Kaftrio and show people that everyone's feelings and experiences are valid.

YAG created a survey for young people with CF, where they asked questions about feelings towards the Kaftrio news.

58 young people with CF responded, of whom 47 could take Kaftrio and 11 could not. Of the 47 who could take Kaftrio, 41 people had started taking it.



The survey found that almost everyone who responded felt more hopeful about the future after Kaftrio was licensed. However, this came with a mix of other emotions, such as happiness, guilt, stress and abandonment. People expressed anxiety about side effects (particularly weight gain), alongside less tangible concerns such as changes of identity and career prospects. There was a clear sense of hopelessness and abandonment from those who are unable to take Kaftrio.



Snapshot:

"Something that would make the situation with Kaftrio better or easier is..."

- "More hospital contact"
- "More communication about side effects"
- "Communication and clarity of advances (for those who cannot take Kaftrio)"
- "Good news about other treatments"
- "Support groups"
- "Stop talking about it"
- "Updates no matter how small"
- "Information about the long-term effects"
- "Less social media"

Almost every respondent said that the licensing of Kaftrio had changed their daily routine. However, this manifested differently for everyone, with some people reporting that they had increased motivation for exercise and treatments, and others reporting less. This was mirrored in those who do not benefit from Kaftrio, some of whom said that they felt more motivated to stay healthy, while others told us that treatments felt increasingly pointless.

There was a desire for more information and people had a lot of questions, particularly around side effects.

The advent of Kaftrio has resulted in a mix of emotions within the CF community. Regardless of whether or not someone can benefit from Kaftrio, the news is affecting not only how people view their futures, but also their actions in the short-term. There is a need for information and support, both for those who can benefit from the treatment and those who cannot.



Snapshot:

"The news about Kaftrio has led me to feel..."

Unfairness Conflicting
Gratitude
Relief Lucky Anger
Nervous Depressed
Frustration Shameful
Hopeful
Scared Surprised
Positive Apprehensive Curiosity
Exhausted Guilty Fear
Puzzled Epic Worried
Responsibility Uplifted
Concerned Overwhelming
Abandoned

(words appear larger depending on the frequency they were mentioned).

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