

# **Cystic** **Fibrosis** *our focus*

## **Emotional and social impact of Kaftrio**

Factsheet – November 2020

# Emotional and social impact of Kaftrio

Following the very welcome news that the CFTR modulator therapy Kaftrio can now be prescribed to a large number of people with cystic fibrosis (CF) aged 12 and over in the UK, the following information has been put together by some of the specialist CF clinical psychologists and social workers from CF centres across the UK. This information has also had input from a CF medical consultant. The possible medical benefits of Kaftrio are well publicised so will not be covered in this factsheet, but further information can be found on [the Cystic Fibrosis Trust's website](#).

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## **I'm not eligible for Kaftrio**

Kaftrio is available in the UK for those with CF who are aged 12 and over, and who have specific gene mutations. This means that while many people with CF will be offered this treatment, there are some people who won't be offered it because of their genotype. About 10% of the CF population are not eligible for Kaftrio because of their genotype.

There will be some people who do have the right genotype but are unable to take Kaftrio for other reasons. These can include medical issues or because drugs they are already taking would react poorly with Kaftrio, eg those with severe liver disease and pregnant women.

Over time more people may be eligible for Kaftrio but there will remain a number of people with CF who aren't. Some people with CF who have received organ transplants may not be prescribed Kaftrio in the UK for a number of reasons, which you can read about [here](#). However, this decision will always be made on a case by case basis.

While excitement and happiness about the availability of Kaftrio is very understandable, the CF community is very aware that major treatment breakthroughs are needed for all people with cystic fibrosis. Vigorous research is already taking place to find new treatments for those who will not be eligible for Kaftrio and you can find more information about this [here](#).

However, those who are still waiting for a new effective treatment may experience a mixture of emotions at this time, including frustration, sadness, anger and worry. It may also be difficult to explain to well-meaning friends and family that you or your loved one are not in fact eligible for Kaftrio, if they have heard about this in the news or on social media. You might feel some resentment on hearing about the benefits of Kaftrio from others with CF, or in your CF service, and then may experience guilt for having these feelings. For those with CF who have already had an organ transplant there may be other complex feelings about Kaftrio becoming available now.

Whatever emotions you find yourself experiencing, you might find it useful to share these feelings to someone if you think it will help. Your CF team will be well aware of those who won't be receiving Kaftrio in their service and will want to support them. Do not hesitate to raise any concerns with your team if you wish.

## **I am eligible for Kaftrio**

This factsheet has been produced to highlight some of the less obvious, but possible emotional and social impacts of taking Kaftrio. A lot of the information here is based on feedback from people with CF in the UK who have already started taking Kaftrio (whether through clinical trials or on compassionate grounds due to poor health). Kaftrio has not been available for very long, however, and as time goes on we will learn more about how it impacts people's lives.

We have also used the feedback of people who have experienced a sudden improvement in their health for reasons other than Kaftrio. Remember, you might experience some, all or none of the feelings on the following pages – there is no right or wrong here!

## Dealing with mixed emotions

People with CF and their families have waited for a highly effective new treatment for a long time. The main emotions you experience when you or your child are able to access such a treatment may be positive. For example, relief, joy, gratitude, impatience for the expected benefits and hope for the future. Alongside these welcome feelings, some with CF have also described other, perhaps less expected feelings. These may or may not happen to you, and even if they do, they are not necessarily a problem, but it is important for you to be aware of them.

- **Your relationship with CF** – As you start to feel the benefits of Kaftrio, how you see yourself and your CF may also start to change. Any change, however positive, can take a bit of getting used to. Some people have described feeling so much better that they realise CF may not have such a big place in their life in the future. While you might have wished for this, some have said that letting go of what you were used to can also be surprisingly hard or can take time. Most people with CF have grown up knowing that they have it, and see CF as part of their identity. Questions about the future or feelings of ‘who am I now?’ can be unsettling and you might need to give yourself time to adjust.
- **‘Survivor guilt’** – This can be a common emotion when someone feels they have an opportunity others don’t. It can range from mild to stronger feelings that can be difficult to explain to others. If feelings like this last a long time, or are interfering with your life, or with taking your treatments, do speak to your CF team. They will be able to support you in managing these feelings.
- **Thinking about the past** – Feeling much better and having more hope for the future can sometimes get you thinking about the past more. You might have been very sick with CF in the past and reflect on this now you are feeling better. Or you may think about decisions you have made and how things might have been different if Kaftrio had come along earlier for you. Time to process these emotions will be important.
- **Wondering about the future** – If your health improves a lot, or you feel that CF is going to have less of an impact on your life, you may have new thoughts and feelings about the future. This can be exciting, but can also feel quite scary or unsettling, especially if your confidence has been knocked by health issues or other life stresses. You may need time to adjust to a changed view of the future. Those around you may not realise that the possibility of new opportunities can actually feel quite complicated!
- **Parents of children with CF** – For parents of young people with CF, their role in their child’s life, ideas of the future and their identity as a ‘CF parent’ may also change. Your child’s CF care may change, and your views and expectations about being a parent of someone with CF may change too. Other family members, as well as partners and children of those with CF, might experience these feelings too. While improvements in the health of a loved one will be very welcome, again it is worth remembering that any big life change can take time to adapt to, even when it has been wished for for a long time.

## Managing physical changes

- **Changing symptoms** – Kaftrio is likely to change your CF symptoms in ways that are very welcome, but you may need time to adjust. It might take time to understand unfamiliar changes in your physical health, know how to respond to them, and identify your ‘new normal’. CF teams are also adjusting to treating people with CF who are taking Kaftrio, and you will need to work together to monitor your health and what changes may be needed in the future.
- **Managing disappointment** – Kaftrio affects people differently, and if you don’t experience the benefits you hoped for or expected, it’s natural to feel disappointment, worry, anger or other emotions. Other people have mentioned experiencing relief at getting Kaftrio, followed by worry about how long the benefits of the treatment will last for them. As Kaftrio is a new treatment, we do not yet have studies that tell us the long-term benefits of Kaftrio, so your CF team may not be able to answer this question yet.
- **Weight gain** – You are likely to gain weight if you start taking Kaftrio, and this change will be welcomed by many. However, if being a certain weight has been important to you and this changes, this can feel very difficult, even if you know there are medical benefits to being a healthier weight. For some people, changes in diet and other lifestyle factors will be needed to prevent them gaining too much weight. Making such changes after years of managing CF in a certain way can be hard and may take time, trial and error, and patience. Do talk openly to your team if you are struggling with any aspect of weight gain or body image concerns. Visit [cysticfibrosis.org.uk/bodyimage](https://www.cysticfibrosis.org.uk/bodyimage) for the Cystic Fibrosis Trust’s resource on body image and cystic fibrosis.

## Dealing with reactions of family and friends

- **Improving health** – If your health improves significantly, other people’s expectations of you may also change. This might be very welcome, or it might create extra pressures. If your health is noticeably better, people may start to see you differently, and this can cause your relationships to change. Like anything else, some time may be needed to adjust to changes in roles, expectations and dynamics of your relationships with family and friends.
- **Remaining challenges** – Kaftrio might improve your physical health significantly, but other life problems might remain, and feeling physically better does not necessarily mean that life will be easy. Normal life challenges, such as going through adolescence, difficult life events, stresses and worries will still happen, and you may even have more time to focus on these if you are not worrying as much about your physical health. You might need time and support to make changes in other areas of your life if this is something you are struggling with.
- **Improving understanding** – Family and friends who don’t have CF may find it hard to understand the emotional impact of taking Kaftrio or of your health getting better. Sharing this factsheet with them might help them to understand that it can sometimes be a little more complicated than it seems on the surface.

## Changes to your CF care

- **New procedures** – If you start taking Kaftrio, your health may need more monitoring for the first year. This can include procedures like blood tests to check the impact of the drug on things like your liver. For some this won't be a problem, but for others this can be hard, especially for children or those who have difficulty tolerating these procedures. Being monitored for side effects that you aren't able to notice yourself may also be stressful, but your CF team will let you know if they have any concerns at all about results from their monitoring. Do tell your team if you are struggling with any aspect of increased monitoring of your CF, as they will be happy to support you.
- **Fewer hospital admissions** – If you start taking Kaftrio and benefit from the drug, you will probably have fewer hospital admissions over time. For some people this won't be a huge change, while others will be glad to spend less time in hospital! However, though hospital admissions come with their own stresses, they can also help you to rest and give you a chance to recharge. For some, the absence of this will be challenging. CF clinic appointments may also become less frequent over time, and while this will seem like a very good thing for some, others may be surprised to miss their CF teams when they see them less!
- **Adherence** – How well people take treatments (aka 'adherence') varies hugely from person to person. Compared to other CF treatments, Kaftrio is relatively quick and easy, but this does not mean that some people won't struggle with adherence. Talk to your CF team if you are struggling to take Kaftrio – they will work with you, not judge you.
- **Remaining treatment burden** – Some people report that the 'burden' of other CF treatments can seem even greater if you start taking Kaftrio and feel better. You may even feel that some of your old treatments are not needed now. If this is the case, please speak to your CF team instead of stopping your treatments. Remember, your CF team are also learning about the best way to treat people who are taking Kaftrio and will try to make sure your treatments are as manageable as possible.

## Accessing support

You might find that you experience some of these feelings now that Kaftrio has become available to many. Whether you or your child are receiving Kaftrio and are having an unexpected emotional reaction, or you are not eligible for any modulator treatment and this is affecting your emotional wellbeing, the Trust and your CF team are here to help.

Often difficult emotions will be temporary, and are a part of healthy adjustment to change or stress. Sometimes support from family and friends, good self-care and time are what is needed to help you cope with stressful events or life changes.

The Cystic Fibrosis Trust is here to support you, and you can contact the Trust's Helpline at [cysticfibrosis.org.uk/helpline](https://cysticfibrosis.org.uk/helpline) if you would like to speak to someone. The following links also give some good general advice and tips about emotional health and looking after yourself well:

- Information on mental health and wellbeing, NHS: [www.nhs.uk/conditions/stress-anxiety-depression](https://www.nhs.uk/conditions/stress-anxiety-depression)
- Tips to improve your mental health and wellbeing, NHS: [www.nhs.uk/oneyou/every-mind-matters/top-tips-to-improve-your-mental-wellbeing](https://www.nhs.uk/oneyou/every-mind-matters/top-tips-to-improve-your-mental-wellbeing)

If you do need more help with any of the issues raised, do not hesitate to speak to your CF team. Rest assured you will not be the only one, and the specialist CF clinical psychologists and CF social workers in your centres are also ready to help as needed.

## Impacts on education, work, finances and family

When someone has a lifelong progressive condition like CF, it's assumed that this will continue. So when something comes along that makes a huge change to your health, it can make you think about practical concerns, like work and income, benefits, education and plans for the future.

Just as emotional reactions to Kaftrio vary from person to person, our family, work, housing and financial situations are unique. Some people might find that taking Kaftrio allows them to return to work or education, but they aren't aware of the options available. Other people might not feel ready or able to return to work, but want to know what support is available to them.

Getting your head around these changes, however positive they may be in terms of your physical health, is a huge task and can feel overwhelming.

It might help to think about what changes might take place realistically in the short and long term. This will help you to create a plan and feel prepared and reassured moving forward. Whether you are someone with CF, or a family member of someone with the condition, support is available from CF social workers and psychologists, as well as the Cystic Fibrosis Trust, to find the best possible way forward for you. This support might include:

- **Benefits** – Helping you to understand the different benefits that you may be entitled to when there are changes in your physical or mental healthcare needs.
- **Financial support** – Considering the financial implications that changes in your health might have on your lifestyle and family. Exploring alternative avenues of short and longer term financial support according to your needs.
- **Education and employment** – Thinking about education, training or a change of employment if your physical health has changed. Your social worker can provide you with information on local and national support services and help you to decide what works best for you and your family. They will support you to make these decisions in your own time.
- **Getting work-ready** – Ensuring that you are aware of local and national support available to you in searching for work and getting work-ready if you have not worked in a long time or at all.
- **Decision-making** – Remember that you don't have to make all of your decisions alone and immediately, especially in the light of the emotional challenges and adjustments you may be experiencing.

If you are worried about any of these issues, contact your CF social worker, or the Cystic Fibrosis Trust's Helpline at [cysticfibrosis.org.uk/helpline](https://cysticfibrosis.org.uk/helpline). Both will be able to provide you with advice on your individual situation.

**Factsheet produced by the Cystic Fibrosis Trust and written by members of the UK Psychosocial Professionals in CF group (UKPPCF) November 2020.**

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You can also find more information at our website [cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)

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The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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