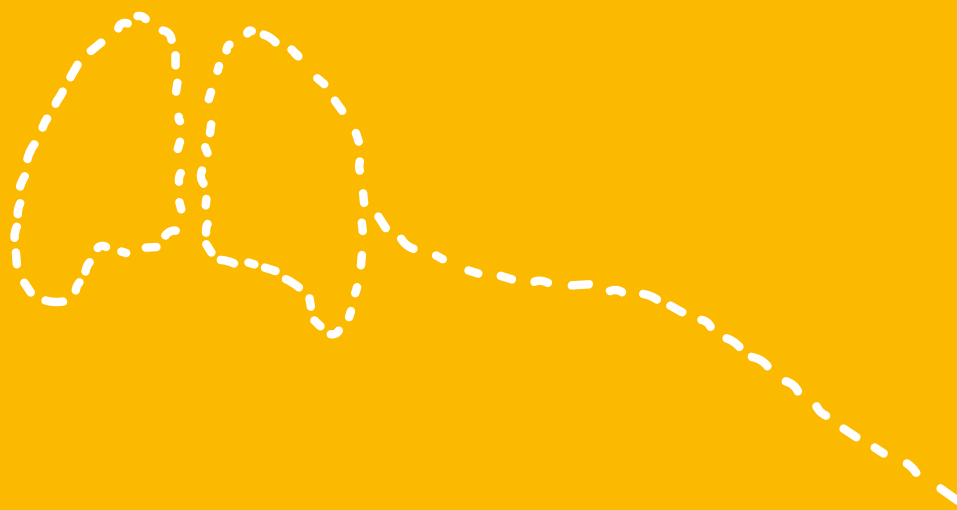


# Cystic Fibrosis talking about transplant




**Cystic fibrosis and transplant:**  
an information booklet for  
partners and families

Fighting for a *Life Unlimited*



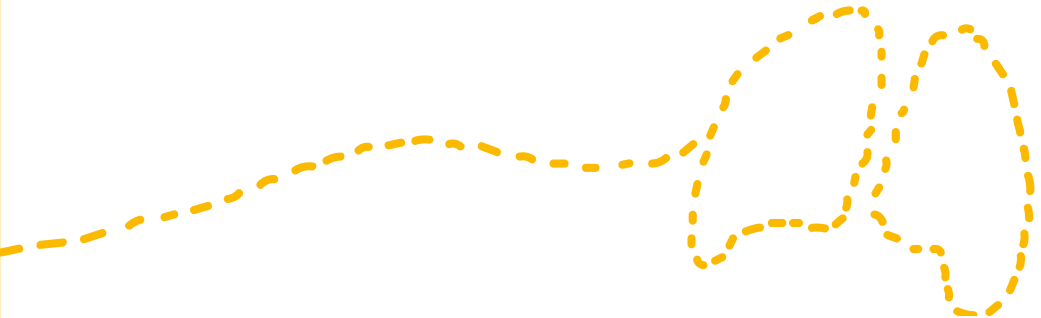
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# Cystic fibrosis and transplant



**As you will know, cystic fibrosis (CF) is a condition for which there is currently no cure. However, for people with CF who are no longer responding to the usual array of treatments, organ transplant is a potential option.**

It's a common assumption that an organ transplant for people with CF means lung transplant. This is usually the case, but CF can also cause damage to the liver or other parts of the digestive system to the extent that a transplant may be needed.

Transplant is not a cure for cystic fibrosis. The transplanted organ, whether it is the lungs, liver or another organ, will not have CF and will never develop the condition. However, cystic fibrosis is a genetic condition and this means your partner or family member will still have CF in the rest of their body, and they are likely to still need some CF treatment, even after a successful organ transplant.

The Cystic Fibrosis Trust works hard to encourage organ donation, but sadly there are still not enough organs for everyone who is listed for a transplant. For this reason, people who are listed do not know when, or if, they will get a transplant. The average wait for a lung transplant is 18 months but it can be shorter, longer, or might not happen at all.

# Transplant assessment

## Why is my loved one being assessed?

Some people are really surprised when they hear that their loved one is being assessed for a transplant. Even when someone is very poorly with CF, they may not always look sick, or any sicker than usual.

Also, when you see someone regularly you might not notice the gradual decline in their health and ability, in a similar way to how we don't notice children's growth when we're with them every day.

"I'm not well. I may look well but I'm not. I need people to realise that now and to start to take it into account."

(James, currently listed for lung transplant)

The multidisciplinary teams looking after people with CF have to decide when they feel someone is poorly enough to warrant a transplant, but well enough to be able to respond well to this difficult procedure. There is a window of opportunity for transplant and that window can close very quickly if someone with CF has a serious infection or decline in health.

CF teams and transplant teams work in partnership, drawing on all of their expertise and knowledge, to make sure that the transplant assessment is timed correctly, so that if an organ does become available the person with CF is prepared, in good enough health and ready to have the procedure. As already mentioned, donor organs are not readily available, so teams will also have to consider the timing of the assessment in the knowledge that there could be a long wait before suitable organs become available.

"I think transplant was always at the back of our minds and as Tara's health gradually declined the conversations naturally started. Tara was very poorly when she was assessed for transplant but I don't think I quite realised it until she was actually listed and that was a real 'gulp' moment for me."

(Graham, husband to Tara, four years post-lung transplant)



## What does assessment involve?

An assessment for transplant may take place at a transplant centre or, less often, at your loved one's CF centre. It can involve several days of clinical tests, education and psychological preparation, and can be quite overwhelming for the person with CF and anyone who goes with them. If you are attending, you can help by listening carefully to the information being provided and encouraging your partner or family member to ask questions.

"I stayed at the hospital for the four days of Vicky's assessment and was with her for everything that I was allowed to be involved in. We saw the psychologist as a couple but also individually."

(Erik, husband to Vicky, 18 years post-lung transplant).

The assessment process can be emotionally gruelling and is designed to really get people thinking about the pros and cons of transplant. Sometimes people with CF decide that transplant is not for them and, as hard as it can be for partners and family, it's important to remember that this is their decision.

"My fiancée and I had to travel to Newcastle from Belfast for my assessment. We were there for five days and I would phone my family each evening to let them know what was happening. I knew that my family and friends would support the decision I made about whether or not to be listed."

(Libby, five years post-lung transplant)





## What if my loved one isn't suitable for a transplant?

The assessment may indicate that a person isn't currently suitable for a transplant, sometimes because of a resolvable health issue or because they're not felt to be ill enough.

“At his first assessment, we were told that Doug's quality of life was still too good, so he wasn't recommended for listing. That was hard of course. As his mum, I'd seen the extent of the decline over the years and could see that his life was becoming more and more of a struggle. However, I just had to steel myself to trust the team and not to panic.”

(Elise, mum to Doug,  
four years post-lung transplant)

“At one of Doug's assessments they found a cardiac issue and we were told that he wouldn't be transplanted unless the cardiac problem resolved itself. We were asked to come back in six months for reassessment. Knowing his lungs were bad enough for transplant, but having the option taken away from us, was scary. Fortunately, there was sufficient improvement and six months later he was listed. We were delighted that transplant was now at least a possibility.”

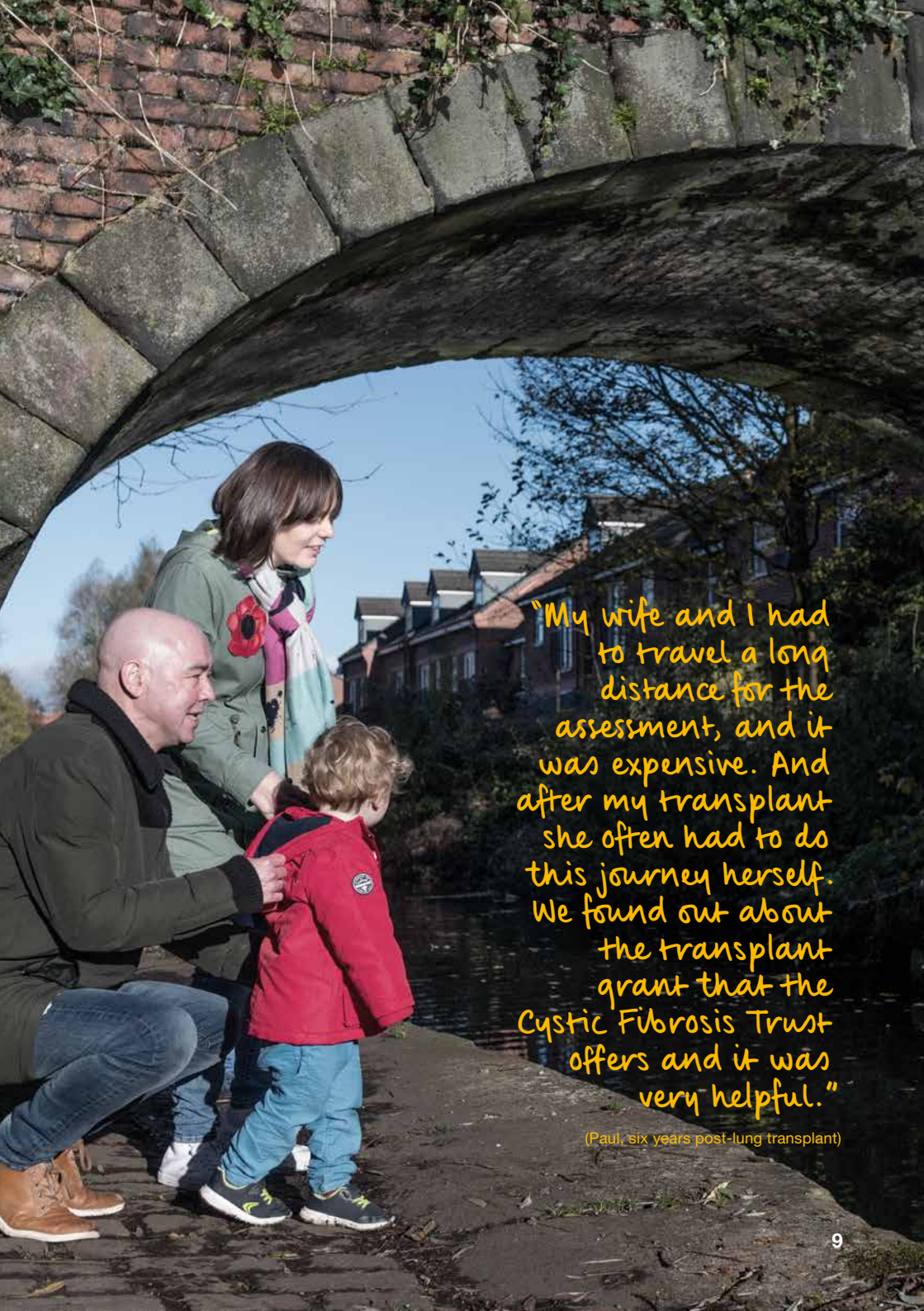
(Mary, wife to Doug,  
four years post-lung transplant)



Sometimes people are found to be unsuitable for a transplant without the prospect of reassessment – growing certain bugs, low weight and poor health are the main reasons for unsuitability. This can, of course, be incredibly difficult for the person with CF, and for their partner or family. The CF team will be there to provide more information and discuss plans for future care, and support from the palliative care team can be invaluable. The Cystic Fibrosis Trust helpline provides a listening ear and can be contacted on **0300 373 1000** (Monday-Friday, 9am-5pm).







"My wife and I had to travel a long distance for the assessment, and it was expensive. And after my transplant she often had to do this journey herself. We found out about the transplant grant that the Cystic Fibrosis Trust offers and it was very helpful."

(Paul, six years post-lung transplant)

# On the waiting list

## What does it mean to be listed?

If a person is found to be suitable for transplant and they wish to pursue this option, they will be listed for transplant. The list doesn't exist as a simple queue, so you don't have a 'position' on the list, such as first or second. Donor organs need to be biologically matched – lungs, for example, could become available, but might not be suitable for your partner or family member, regardless of how long they have been waiting.

Being on a transplant waiting list can be psychologically challenging - trying to live life normally, while waiting for a call that could be life-changing, and at the same time worrying that the call will never come. There are also certain practicalities that need to be addressed: childcare, work absence, pet care, transport for visiting, financial considerations and so on.

“For the first few weeks of Tara being listed I jumped every time the phone went, but after a while you just get back into normal life, although it's always hanging over you. I work away from home quite a bit so we had to make sure that we had plans in place should she get the call while I was out of immediate reach.”

(Graham, husband to Tara, four years post-lung transplant)

Depending on your relationship with the person going through transplant, you may be able to offer support during this wait, but it can be intense and worrying, so you may find that you could also benefit from support.

“I found it really helpful to confide in a friend who wasn't connected to Doug or our shared friends or family. I could talk to her about what really worried me, which was that Doug could die. I didn't feel I could share these feelings with friends and family who were close to Doug because we were all trying to be upbeat and positive.”

(Mary, wife to Doug, four years post-lung transplant)



## False alarms

Often people do get 'the call' only to find that the donor organ is not suitable for them after all. This is because transplant doctors need to visually inspect the donor lungs (or other organ) before a transplant can go ahead, and they may see signs of bleeding or infection, which would mean that proceeding with the transplant would not be recommended. These false alarms are common, but can be very difficult for everyone involved.

"Doug had one false alarm and it was hard, but we both felt that his life wasn't in immediate danger and just tried to forget and not to dwell. I think it's important to trust the system, understand what's happening and why, and to have confidence in the team."

(Mary, wife to Doug,  
four years post-lung transplant)

"False alarms were very hard. I remember my daughter Tor and I crying in the back of the car heading back home after a false alarm. But I would always focus on the family of the person who'd died and think that someone out there tried to help us tonight and it wasn't to be, but they are suffering more than us this evening."

(Christine, mum to Tor,  
six years post-lung transplant)







## Hoping for the best, planning for the worst

“We recommend to patients going through transplant assessment that they consider making a will prior to the surgery. There are risks associated with this procedure, so making a will is a sensible precaution.”

(Transplant Nurse Consultant)

People on the transplant waiting list will be aware that not everyone on the list will get the new organ they need. They may, therefore, wish to make plans in the event of them dying while waiting for a transplant. This can, of course, also be very hard for partners and families to come to terms with.

“I was advised at assessment to ‘arrange my affairs’. I didn’t think this was negative, I was so poorly then that it was a realistic possibility that I could die. My mum found it really hard, she thought I had a negative mindset, but I didn’t, I just felt strongly that I wanted plans in place should the worst case scenario happen.”

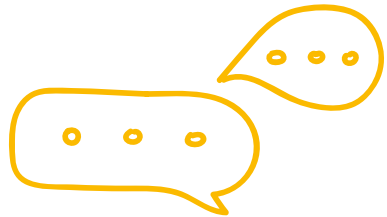
(Veronica, two years post-lung transplant)

“I struggled with the idea that my daughter, Tor, was being referred to palliative care. Hospice care meant only one thing to me: that she was going to die and, of course, I baulked against it. But the hospice team were lovely and supported us as a family at a very challenging time.”

(Christine, mum to Tor,  
six years post-lung transplant)



Support for end-of-life planning is available from the CF team or the palliative care team, and your loved one’s transplant team may be able to offer you support with end-of-life care planning once your loved one is on the waiting list. The Cystic Fibrosis Trust also has a booklet to help with the practical considerations around end-of-life planning. Visit [cysticfibrosis.org.uk/endoflifeplanning](https://www.cysticfibrosis.org.uk/endoflifeplanning).



We understand that these can be incredibly difficult conversations. If you want to talk, the Cystic Fibrosis Trust helpline can provide a listening ear. You can call our friendly team on **0300 373 1000** (Monday-Friday, 9am-5pm).

# Transplant

## What does transplant involve?

Organ transplant operations are usually lengthy procedures. A lung transplant, for example, can take between six and 12 hours.

*"We had been told that the operation would take six hours. I was quite relaxed until we got past the six hours and there was still no news. I started to think something had gone wrong. Thankfully, Tara's operation was a success, it had just taken longer than the six hours."*

(Graham, husband to Tara, four years post-lung transplant)



*"I think the operation in some ways was harder for my wife and family. I was out of it during the procedure and for some time afterwards, but she had to sit there waiting and wondering."*

(Paul, six years post-lung transplant)

*"Tor was in surgery for 10 hours. We drank a lot of tea, paced the floors and shared messages with our family."*

(Christine, mum to Tor, six years post-lung transplant)

Recovery will involve a stay in an intensive care unit (ICU), followed by a longer time on a ward. The ICU can be a frightening place to those unaccustomed to these environments – patients are often hooked up to several machines and, for some of the time, they won't be able to communicate. The mixture of pain relief medications, anaesthesia and disturbed sleep patterns can cause hallucinations for some people in the ICU, and this can be surprising and worrying for visitors. This is normal following this type of operation and the ICU team are very used to dealing with hallucinations.

“The ICU is difficult and overwhelming. It’s super noisy and there’s no sense of day or night. It’s not nice to see your loved one hooked up to lots of machines. I focused on Doug’s fingernails! They had been grey/blue for so long that to see his pink fingernails felt like the first sign of good news, of something healthy in an otherwise scary environment.”

(Mary, wife to Doug,  
four years post-lung transplant)

“I had asked to visit the ICU when Tara was assessed for transplant. I’m really glad that I did because when I saw her there after her transplant it wasn’t so shocking. In fact, she was hooked up to less machines than I’d thought.”

(Graham, husband to Tara,  
four years post-lung transplant)

Many ICUs will have strict visiting rules in place, particularly regarding the number of visitors allowed at one time, so if you are visiting do check with the hospital for local policies. Sometimes people going through transplant will have strong feelings about who they want to visit and when they might feel ready for visitors, so it’s useful to talk about that and be clear about their wishes prior to the surgery.

As you can imagine, taking lots of calls regarding the health of one patient can be time-consuming for ICU staff, so where possible it’s a good idea to elect one person who will relay updates to family and friends.

## Recovery

There isn’t a set recovery time following transplant. It’s a major operation, and complications and setbacks do occur. People going through transplant would usually expect to be in hospital for around four to six weeks, but it can, of course, vary significantly.

“Doug really had a tough time post-transplant and remained in hospital for about four months. Even once he was discharged, his recovery was complicated. It was challenging for me too. I was worried about him and didn’t have the same direct access to the medical team as we did in hospital, so it wasn’t so easy to ask questions and make sure everything was ok.”

(Mary, wife to Doug,  
four years post-lung transplant)

The emotional and practical support of partners and family through recovery can be invaluable.





"I was a bit of a sergeant major during Tara's recovery. I knew how important exercise and diet were post-transplant so I really encouraged her to get up, get moving and to eat, even when she wasn't feeling very hungry. We built exercise into our daily routine. I was lucky that my work is really flexible so I could be there with her and really participate in her recovery. I think it helped her recovery that we were on this journey together."

(Graham, husband to Tara,  
four years post-lung transplant)

"I knew CF but I didn't know transplant at all. It's given me a new lease on life, but it's not a cure and there are lots of issues that come with it. I look like a different person – steroids cause swelling and increased appetite, so I've gained a lot of weight and my old clothes don't fit. I have scars from the operation and transplant means that I won't be able to have a family. I did struggle with depression, anxiety and adjusting to this new life, plus a feeling of guilt about the donor and their family. But I was dying and now I'm not – I've had more highs than lows and I do have a new lease on life."

(Veronica, two years post lung transplant)

"I was surprised at Doug's mood as he came round from the transplant. The mix of drugs made him frustrated and irritable. I'd expected him to be happy with this miracle, but of course there's so much more to it."

(Elise, mum to Doug,  
four years post-lung transplant)



People with CF who've been through transplant have told us that the psychological recovery from the procedure can be very difficult, and that the challenges can persist for many months or even years following the operation. Psychological challenges can present themselves at different times throughout the transplant journey, often in response to the fluctuating state of a person's health and life events.

It's important to remember that transplant isn't a cure for cystic fibrosis – many people say that it's like swapping one condition for another. So it's understandable that some people can struggle to come to terms with their new reality post-transplant and this can be hard for partners and families too.



*"Transplant wasn't a taboo subject for us, but we both still found it really hard that we were actually at that stage."*

*(Erik, husband to Vicky, 18 years post-lung transplant)*





## Impact on partners and family

The impact that the transplant process has on you will obviously depend on the relationship you have with the person going through the process. For family and partners it can be very stressful, and it's important, in these circumstances, that you seek support when you need it, whether it's from your own personal support network or, for partners and close family, from the transplant team.

*"Just because you didn't have the incision doesn't mean that you don't need support."*

*(Mary, wife to Doug,  
four years post-lung transplant)*

In addition to possible emotional stress, there are practical considerations associated with the transplant process. Life continues – you may have a job, children or other responsibilities, and it can be challenging to keep this all going as normally as possible while supporting your partner or family member through transplant.

*"As well as the emotional stresses, there are lots of practical issues to deal with. The transplant process is massively time-consuming and that can be hard for people who are trying to do jobs and childcare while supporting someone who's going through transplant. After Tara had her transplant I was pretty much with her for six weeks – I was fortunate that I could work from the hospital. I developed a tooth abscess during this time, which I think was stress-related."*

*(Graham, husband to Tara,  
four years post-lung transplant)*

*"Doug was in hospital for four months. I'd taken unpaid leave from work so I could be with him. The drive from home was just too much, so initially I used the hospital accommodation, but over time that was becoming expensive and I switched to short-term lets, staying with families who were renting rooms. This saved a lot of money, plus I liked being out of the hospital environment and meeting new people."*

*(Mary, wife to Doug,  
four years post-transplant)*



“When I was in hospital recovering from my transplant, my dad camped in our campervan close by to the hospital and he cycled in every day to see me. It was January, so pretty tough for him. It was so hard for my mum too, being far away and having to take care of things at home.”

(Laura, five years post-liver, pancreas and small bowel transplant)

“My husband was working full-time, caring for our young son, caring for me and coping with the stresses of the transplant process. So in many ways, it was equally hard on him.”

(Vicky, 18 years post lung transplant)



Some family members may feel excluded from the process because their jobs and caring responsibilities mean that they can't be available as often as they'd like. This can cause feelings of guilt and frustration. All families are different and how you cope depends on your relationships. Staying in touch regularly, sharing information and helping each other to be involved with the transplant process may help everyone concerned with supporting your partner or family member.

Sometimes partners and family members find that their roles change during the transplant process. They may take on more of a caring role as the person with CF becomes poorly and more dependent prior to transplant. Naturally, this can be challenging for partners, families and the person with cystic fibrosis.

The roles can also change in the other direction when, following successful transplant, the carer's role can diminish as their loved one's abilities and ambitions change. This is a positive development, but it can disrupt relationship dynamics for some families and couples. It is helpful to talk together about the changing roles and responsibilities, and explore how you can all adjust to the changes.

# What can I do?

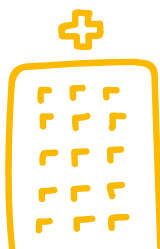
Ask your partner or family member what you can do to support them. Depending on your relationship, there may be lots of areas where your support would be appreciated, from being available to talk over worries or concerns, to practical support helping with childcare or domestic tasks. Some people ask their close family to be a second set of ears during the assessment, when the information can feel overwhelming, or to support them in hospital, for example by keeping an ICU diary that might help them to fill in any blanks or mixed up memories during this early period of recovery.

During recovery, supporting your loved one to follow their rehab schedule can be very helpful.

“During Doug’s difficult recovery, I saw my role as maintaining positivity and encouraging him with his rehab. When he was a child I brought him up to live as full a life as possible, despite having cystic fibrosis, and I applied that same approach in his recovery, encouraging him to keep perspective and put his trust in the new team.”

(Elise, mum to Doug,  
four years post-lung transplant)

Everyone going through the transplant process will have their own experience – there’s no set journey. We hope this booklet gives you an overview of the transplant process and a sense of the challenges that may come up for some people with cystic fibrosis, their partners and families.



"If people could just ask, "what can I do for you" or "I want to be there for you", that'd be supportive. Being flexible to accommodate the needs of someone waiting for or recovering from transplant would also be appreciated."

(Tor, six years post-lung transplant)





# Further information and support

The trained and friendly staff on the Cystic Fibrosis Trust helpline are available to support you with further information or to provide a listening ear. You can contact the helpline on **0300 373 1000** or at **helpline@cysticfibrosis.org.uk** (Monday-Friday, 9am-5pm).

The Cystic Fibrosis Trust understands that there are financial costs associated with the transplant process. A grant of up to £250 is available to help meet some of the costs incurred. Please contact our helpline for further information.



## Find us online

[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)

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