Cystic Fibrosis Trust

Post-lung transplant nutrition for people with cystic fibrosis

Cystic Fibrosis Trust is grateful to the dietitians from the British Dietetic Association Cystic Fibrosis Specialist Group who prepared the information in this leaflet.

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Trusted Information Creator
Patient Information Forum

BDA The Association of UK Dietitians
Cystic Fibrosis Specialist Group

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Introduction

People with cystic fibrosis (CF) may find that their nutritional needs change following a lung transplant procedure. This leaflet gives you information about what aspects of your nutritional treatment may change in the short and long term after a lung transplant, and how you can expect these to be managed by your transplant and CF teams.

Issues to consider in the first few months following a lung transplant

Recovery in hospital

Your nutritional needs in the first few weeks following a lung transplant will depend on the speed of your recovery and your nutritional status before your transplant. You will be guided by your transplant team as to when you can start eating and whether you should continue any nutritional supplements or tube feeding that you used before your transplant.

You may find that you regain your appetite easily or that it takes a lot longer, this is perfectly normal following major surgery.

Going home

Once you are ready to be discharged home you will be given nutritional advice to follow at home.

You will be taking immunosuppressive medications that stop your body rejecting your new transplanted lungs, but that reduce your body's ability to fight infection. This can also mean there is a higher risk of food poisoning.

Your transplant team will give you advice about which foods are safe to eat and how to cook and store foods safely. Ask your transplant team for further information if you are unsure what advice to follow. Make sure you share this information with family and friends who might be helping you to prepare food at home.

You may be given advice about avoiding some foods that may interact with your new medication. An example of this is grapefruit (including juice and products containing any grapefruit juice) which can interact with your immunosuppressive medication.

Managing your nutrition following a lung transplant

After your lung transplant you will attend regular clinic appointments. Initially these will be at your transplant centre, but eventually you may be seen at your CF centre as well. Your nutritional management may be split between your transplant centre and your CF centre. Depending on where you live, you may be referred to a local community dietitian if you are unable to visit your CF centre regularly. It is important that all areas of your nutritional treatment are regularly reviewed, this should include bone health, gastrointestinal issues, vitamin supplementation and CF diabetes.

Make sure you check with both your CF and transplant teams who will be responsible for reviewing the above areas. This will ensure you get good care for all aspects of your CF.

1. Weight management

Many people find that they gain weight following a lung transplant. This can be for many different reasons, and depending on your BMI before transplant could be either positive or negative. Weight gain can often be rapid, so it is important that you weigh yourself as regularly as your transplant centre recommends.

Weight gain can occur for the following reasons:

- Increased appetite due to steroid treatment, or just enjoying food more when you are feeling better
- Improved breathing allowing you to eat more easily
- Your body may not be burning as much energy now that your lungs are functioning better
- Not being able to be as physically active as you would like in the initial recovery period

Your dietitian will help you to set a realistic weight target; you should aim to keep your BMI in the healthy range of 20–25 kg/m2.

Some people may also lose weight following a lung transplant, especially if they stop their nutritional supplementation too early before they are able to meet their energy requirements with food alone.

Healthy eating is very important following a lung transplant, even if you have a BMI in the healthy range. You should try to follow a balanced diet including fruits and vegetables, starchy carbohydrates including whole grains, dairy products or dairy alternatives and sources of protein such as meat, poultry, fish, pulses, nuts and seeds, tofu and eggs. Limit the amount of high fat and sugary foods that you consume.

If you want to follow a vegetarian or vegan diet, please discuss this with your dietitian to make sure you are getting all of the nutrients you require. You can find further advice in our leaflet called **Healthy eating and cystic fibrosis**.

2. Bone health

Your bone health can be affected following a transplant, especially if you are taking a steroid medication such as prednisolone. It is very important that you receive regular review of your bone health following a lung transplant, as it may be more or less stable than before your transplant.

This may include having regular bone scans (DEXA scans) and blood tests to measure markers associated with your bone health, such as parathyroid hormone (PTH) and Vitamin D.

It is important that you have a good dietary intake of calcium-rich foods to ensure you meet your calcium requirements. Dairy products are a good source of calcium, so if you don’t like milk, cheese and yogurt then look for non-dairy alternatives. Make sure you buy the versions that are fortified with calcium. Ask you dietitian to assess your diet to see if you are getting enough calcium.

If you are prescribed Vitamin D supplements, try to remember to take them and get your Vitamin D levels checked regularly by your transplant or CF team.

You may need to start or stop medications (such as bisphosphonates) that improve your bone density. Make sure you check with your transplant and CF team.

3. Cystic fibrosis diabetes

Many people with CF also have a diagnosis of cystic fibrosis diabetes (CFD). Blood glucose levels can be affected by the immunosuppressive medication that is required after a lung transplant and will require careful monitoring.

If you had a diagnosis of CFD before your lung transplant

- Check your blood glucose regularly as directed by your transplant and CF teams and review these results with your teams.
- Keep a record of your insulin doses and be aware that these are likely to change during the recovery from your transplant.
- Always discuss your CFD control at each transplant and CF clinic appointment.
- If you are finding it hard to keep your blood glucose levels in your target range, ask for help.
- If you are under the care of a specialist diabetes team, keep them up to date with changes in your transplant care.

If you didn't have a diagnosis of CFD before your transplant

- You will still require regular screening tests to see if you are developing CFD. Check with both teams to find out who will be responsible for these.
- If you do develop CFD you may need to start insulin treatment.

For more information on this talk to your CF and transplant teams. They may refer you to a specialist diabetes team for additional treatment.

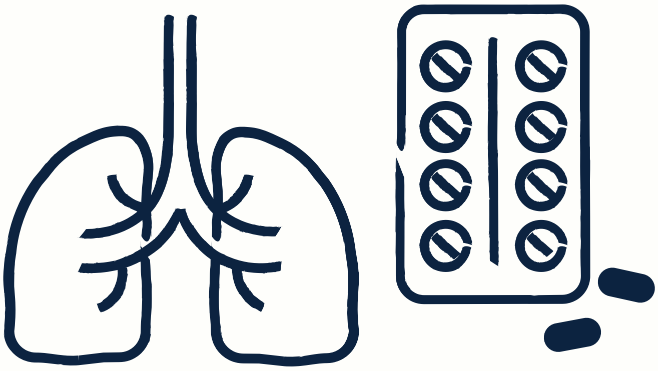
4. Vitamin supplementation

If you required vitamin supplementation before your lung transplant you will need to have this reviewed regularly.

It is important that you still have a blood tests at least once a year to monitor your vitamin levels. These will be to assess Vitamins A, D and E.

Some people find that they need to change or even stop some of their vitamin supplements following a lung transplant. Discuss your current supplementation with your CF and transplant teams.

If you are taking or thinking of starting any herbal or non-prescription vitamin and mineral supplements you must discuss this with your transplant and CF teams to make sure they will not interact with any of your medications.



5. Gastrointestinal issues

Although your new lungs are free from some of the effects of CF, your bowels and pancreas are still affected by the CF gene. If you were pancreatic insufficient and needed enzyme supplements prior to your lung transplant you will still require these.

You may be at higher risk of bowel problems such as Distal Intestinal Obstruction Syndrome (DIOS) or constipation during your initial recovery from lung transplant as your pain medication may cause your bowel transit to slow down and you may not be able to take as much fibre or fluid as you require.

In the longer term you may find that your dosage of enzymes changes slightly, especially if your diet is different and you are eating less high-fat foods. Make sure you drink adequate fluid and take your enzymes regularly.

Monitor your bowel movements carefully and if you notice any changes in colour, consistency and size, or if you experience any abdominal pain or blood in your stools, report these to your CF and transplant teams.

If you are thinking about starting any over-the-counter supplements such as probiotics, you should check with your transplant team as it may not be safe for you to do so when you are immunosuppressed.

6. Raised cholesterol levels

Increased cholesterol levels can develop following a lung transplant, caused by some immunosuppression medications.

If you are told that you have raised cholesterol levels, you may need to make dietary changes and take a cholesterol-lowering medication. Your CF and transplant teams will discuss this with you.

7. Kidney problems

Some immunosuppression medications can lead to kidney damage and you may need to make changes to your diet if your kidneys are not working properly. Your dietitian and medical teams will advise you on this.

8. Chronic rejection

If you experience episodes of rejection and your lung transplant is not functioning well, you may find that you start to have problems maintaining good nutritional status. If you are struggling with a poor appetite and finding it hard to maintain your weight, discuss it with your transplant team or your CF team who will be able to recommend ideas to help you improve your energy intake.

Ongoing nutritional care

Managing your nutrition following a lung transplant can be complex and there may be new medical issues to consider that you didn't experience before your transplant. Try to follow a healthy, balanced diet, maintain a healthy weight and make sure you have all the monitoring tests and reviews that your CF and transplant teams suggest. Your nutritional needs can then be well managed and will contribute to you having a better quality of life following your lung transplant.

Further information

Find more information resources about living with cystic fibrosis at **cysticfibrosis.org.uk/information**.

Our Helpline is open 10am – 4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

How to reach us:
- Call **0300 373 1000** or **020 3795 2184**
- Email **helpline@cysticfibrosis.org.uk**
- Chat with us on **Facebook**, **Twitter** or **Instagram**
- Message us on WhatsApp on **07361 582053**

Visit **cysticfibrosis.org.uk/helpline** for more information.

We welcome your feedback on our resources.

You can also ask for this resource in large print or as a text file. Email **infoteam@cysticfibrosis.org.uk**.

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This leaflet has been designed to be given out by a CF dietitian, along with their advice. If you downloaded or requested it directly from Cystic Fibrosis Trust we would advise you to discuss this information with your CF dietitian.

The information in this leaflet is based on clinical best practice and a consensus of opinion by dietitians within the British Dietetic Association Cystic Fibrosis Specialist Group. For detailed guidance on CF nutrition, please see the **Consensus document on nutritional management of cystic fibrosis**. Our consensus documents as well as other publications about cystic fibrosis can be found at **cysticfibrosis.org.uk/publications** or they can be ordered through our Helpline.

The information in this leaflet is general, please discuss it with your dietitian for a more personalised look at the topic.

Next review due: September 2027

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

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