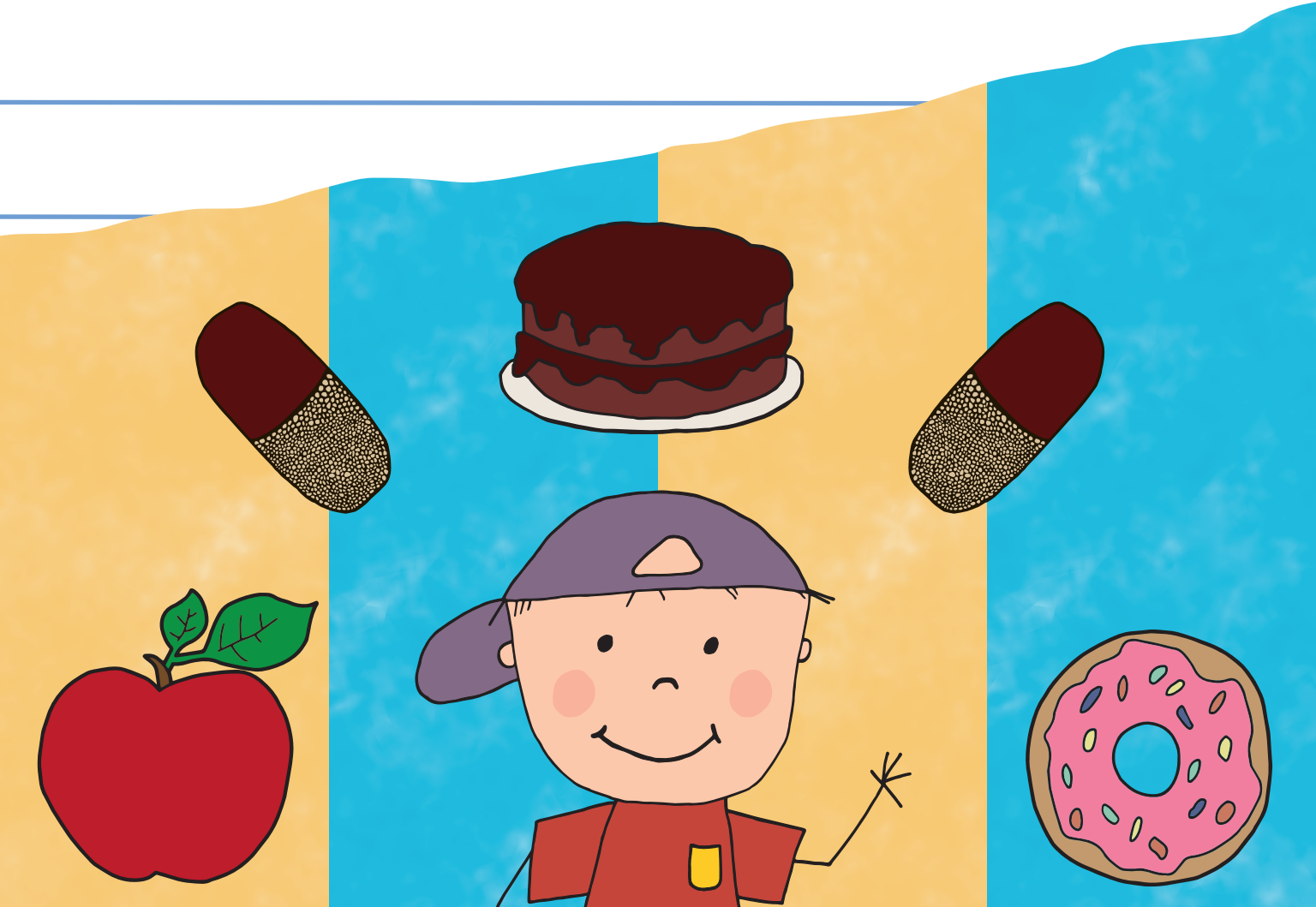
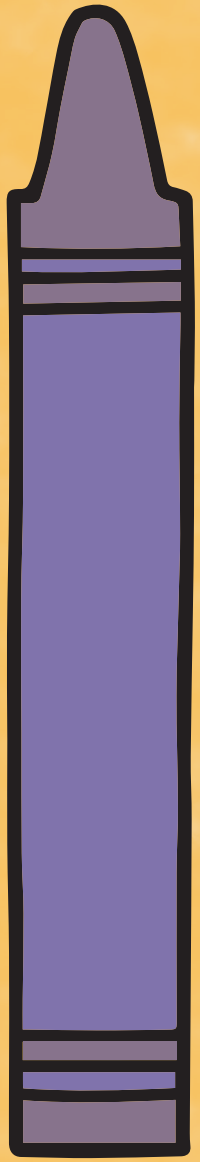
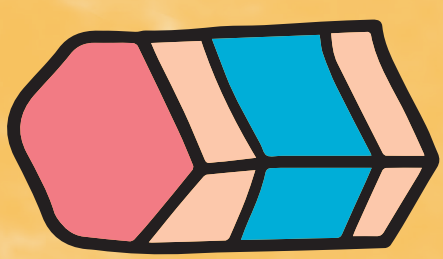
BENJI'S CYSTIC FIBROSIS FOOD FRIEND

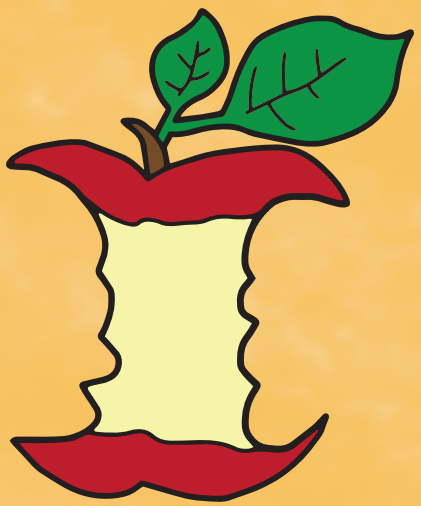


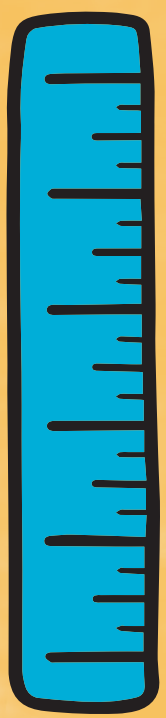
Benji's Cystic Fibrosis Food Friend
Book design by Nicola Louise Torch
Content written by Nicola Louise Torch
Illustrations by Nicola Louise Torch and Antonia Torch

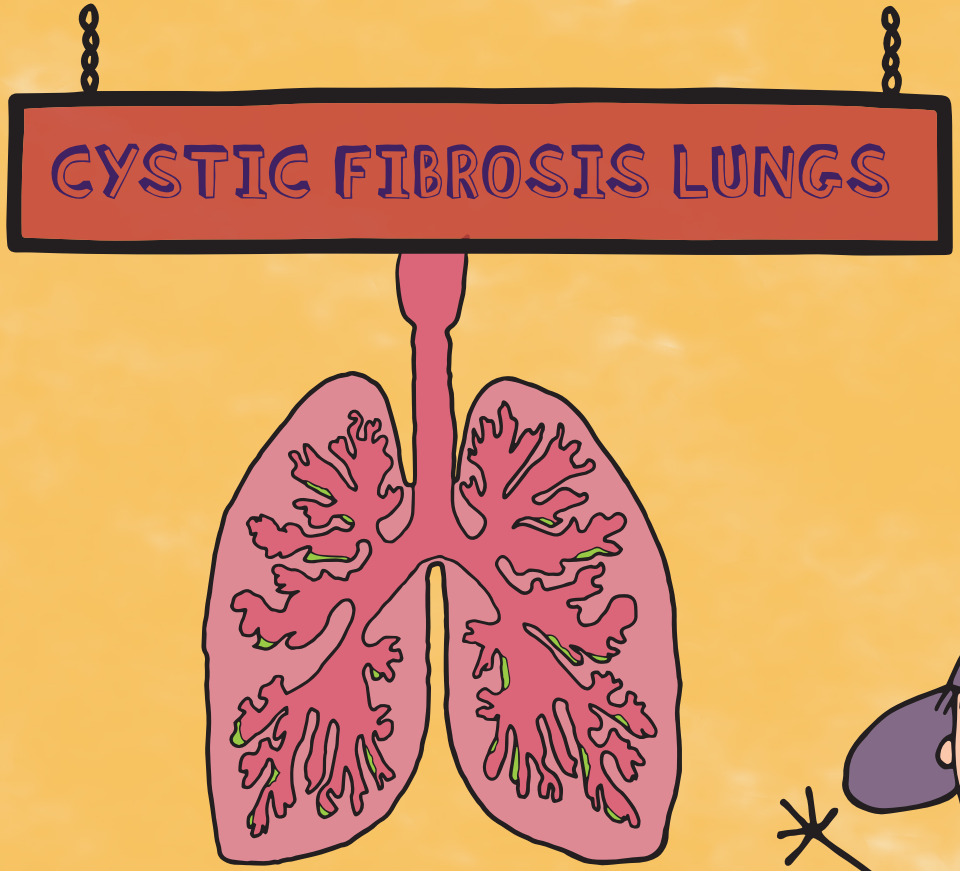
BENJI'S CYSTIC FIBROSIS FOOD FRIEND

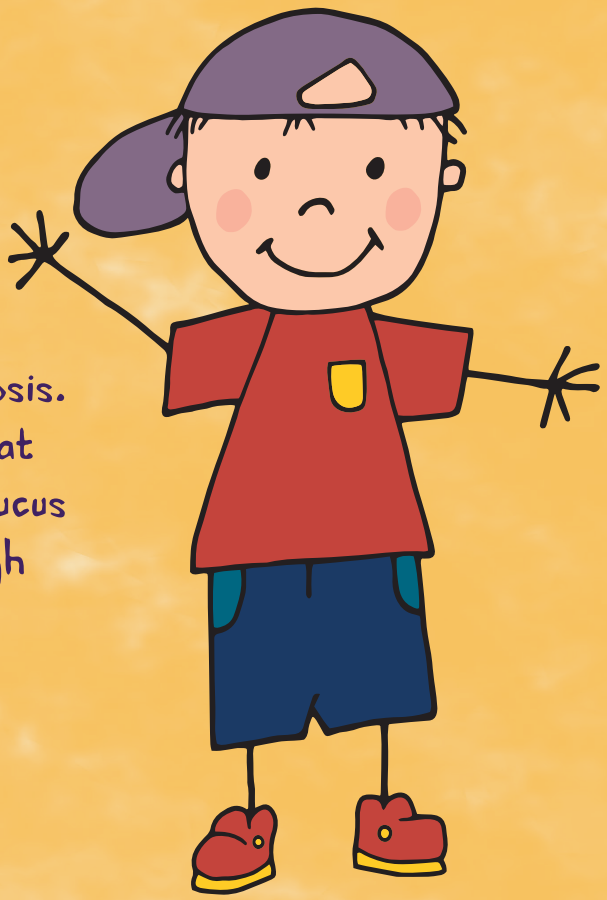












Hi, my name is Benji and I have Cystic Fibrosis. I call it CF for short! CF is a disease that makes my body create sticky mucus. This mucus gets stuck in my lungs and makes me cough

L O A D S !

I have CF because my mummy and daddy each had one faulty gene. Genes provide all the scientific information that makes us who we are.

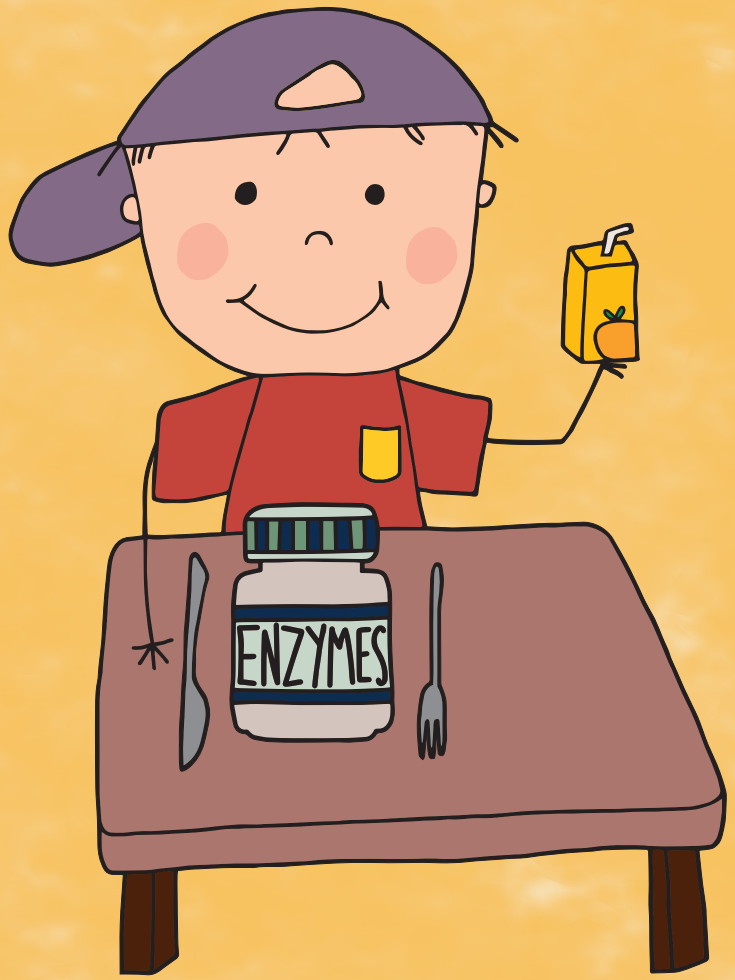
MUMMY'S FAULTY GENE

DADDY'S FAULTY GENE

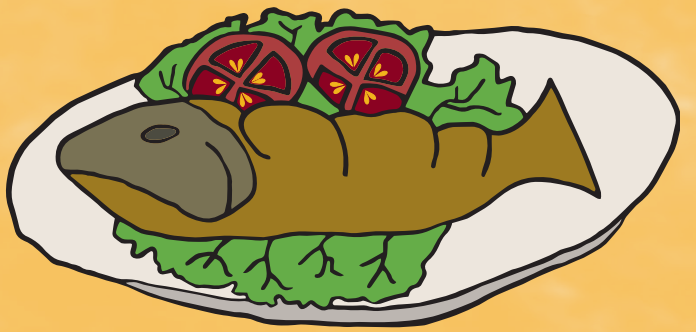
MY CF GENE

I got both faulty genes from my parents which means I was born with CF. Because I was born with it, you can't catch it.

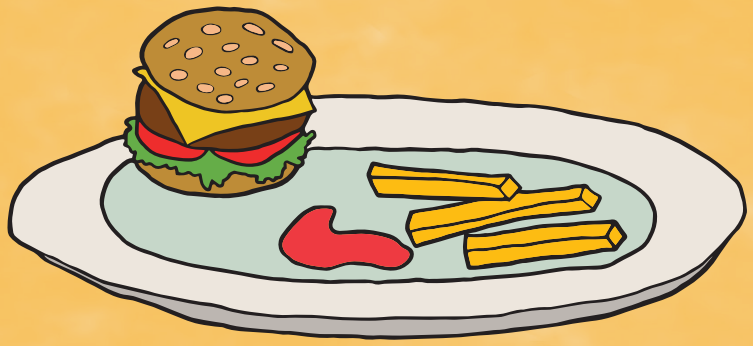
While CF mainly affects my lungs, it also can cause issues with my tummy. Because of the mucus in my body, I can't digest food properly.



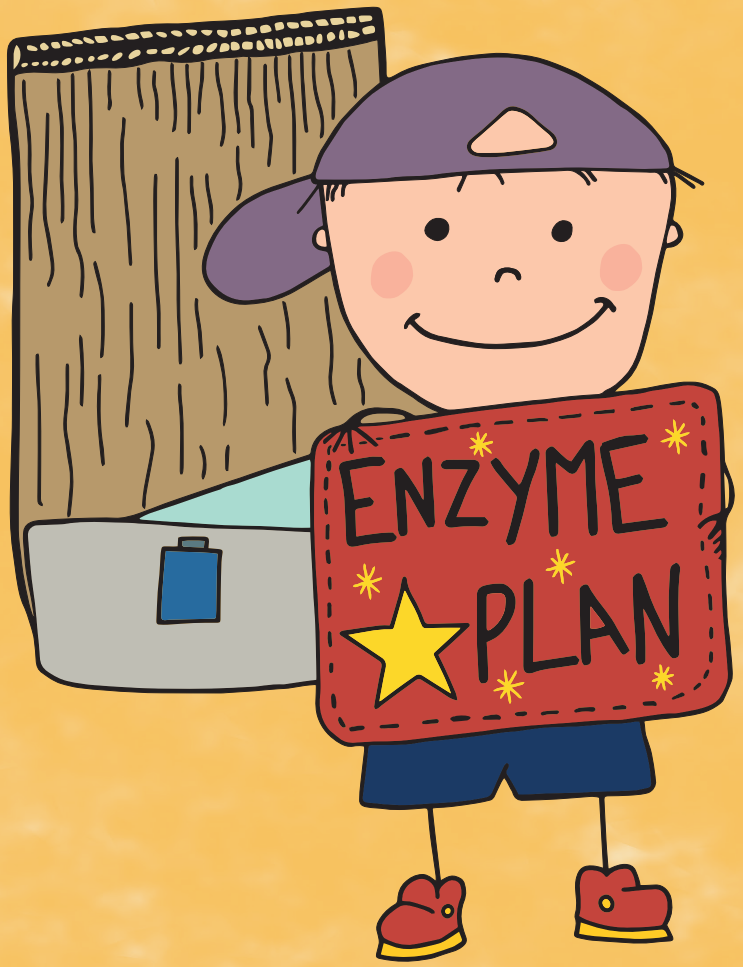
I have to take special tablets whenever I eat so that I get all the good nutrients from my food. These special tablets are called enzymes!



The amount of tablets I take depends on how much fat is in my meal.
If I eat food with a lot of fat then I have to take more tablets.



My dietitian helps me and my parents decide how many tablets to take as it can be a little tricky to begin with.



I will have to take more enzymes as I get older because my meal sizes and the amount of fat I eat will increase. I'm not worried though as my dietitian is great and will help me figure it all out.

I take my enzymes before I eat but I can also take them halfway through my meal if I like!

Even if I forget, I can still take them up to 10 minutes after I have finished eating.

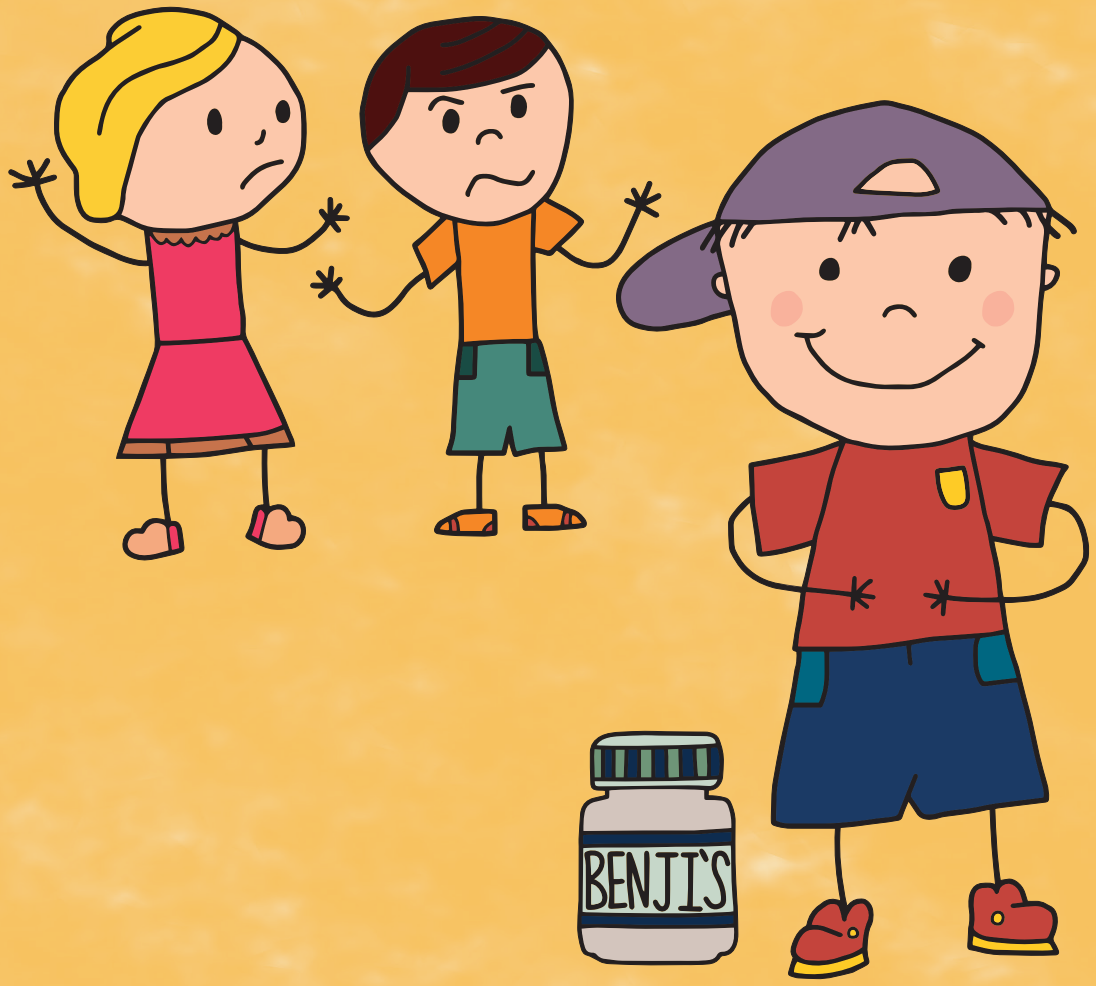
My parents remind me when I forget my enzymes but I try to be grown up and do it myself. I just take them with some juice one by one.

It's really easy and no problem at all!

My mum always puts my tablets in my lunch box for school. She will work out how many I need and put them in the corner of my lunch box.

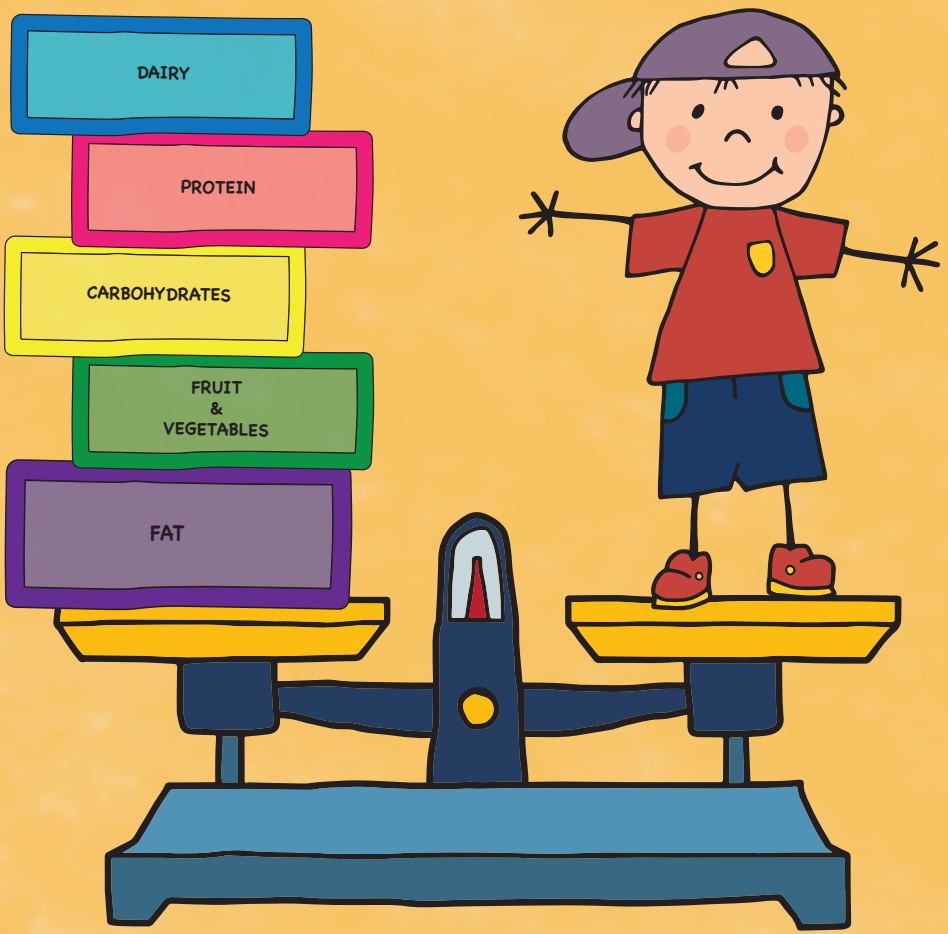
When I get a little older, I will be able to figure out how many enzymes I need and do it all by myself!

I don't mind taking them in front of people but sometimes my friends ask me what they do. I just say they help my tummy.

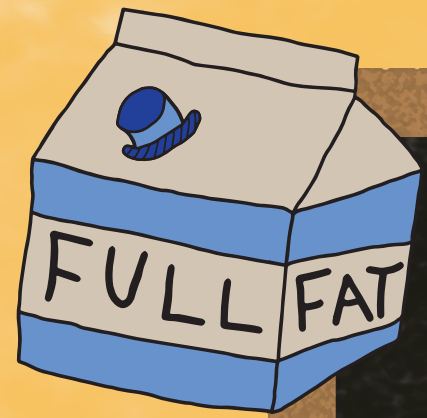


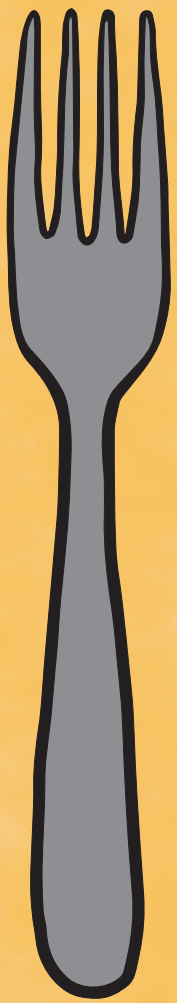
My friends aren't allowed to take my enzymes though. They are my special tablets and I'm not allowed to share them!

I struggle to put on weight so I also have to eat more food than my friends, especially more fatty foods.



I still eat a varied diet but just need to get some extra calories.





Benji's Top Tips

BREAKFAST:

- I add honey, marmalade or chocolate spread to toast
- I have full-fat milk on my cereal
- I have A LOT of butter on my toast

LUNCH:

- I add dressings or mayonnaise to salad
- I drink full-fat milkshakes
- I eat jacket potatoes with a lot of filling

For Extra Calories

DINNER:

- My parents try to fry my food rather than grill it
- I add extra butter to my vegetables
- My parents don't remove the fat from the meat I eat

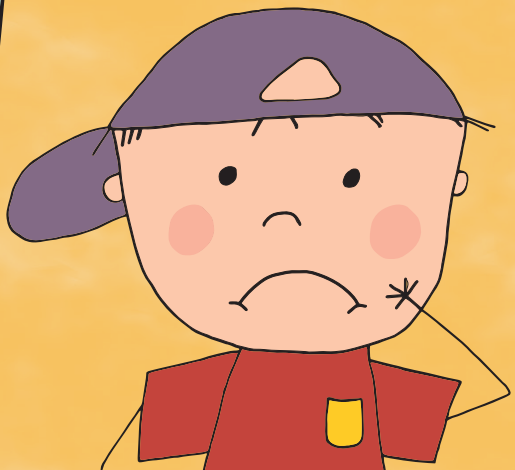
SNACKS:

- I eat a lot of chocolate, crisps and cakes
- I snack on packets of nuts
- I eat fruit crumble and full-fat yogurts for pudding

Sometimes my friends don't understand why I'm allowed more snacks than them, but getting all the nutrients I need is really important.

This is even more important when I'm sick because it can help my body and lungs fight off infections.

If I don't take my enzymes, I won't put on weight properly and I'll be more likely to get sick. I also get bad tummy aches when I forget them. I will be on the toilet for ages and my poo will be really liquidy and smelly!



As you can see, my special tablets and high calorie diet are very important.

As long as I take my enzymes and get all the nutrients I need then my CF tummy problems are all looked after and I can do everything my friends can do!

If you have Cystic Fibrosis, the next page could be really helpful in keeping track of how many enzymes YOU take with common snacks.

You can get your parents or dietitian to help you if you want. Just work out how many tablets you take with the foods listed and then put the number in the blue box.

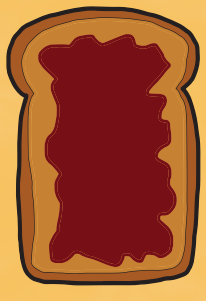
ENZYME CHART

ICE CREAM

CRISPS

CHOCOLATE

TOAST



CHEESE CUBES

COOKIE

YOGURT

HAM SANDWICH

CUPCAKE

Thank you for reading about my Cystic Fibrosis.

I hope it helped you understand why taking enzymes and eating the right foods are so important for someone with Cystic Fibrosis.

More Information About Cystic Fibrosis

Cystic Fibrosis is a genetic condition currently affecting around 10,500 people across the UK. CF mainly affects the lungs but it can also cause problems to the digestive system, bones, liver, nose, kidneys and the reproductive system.

Although there is currently no cure, strides are being taken daily to increase the duration and quality of life for people with the condition. Treatments are constantly being developed to help improve lung function and it is hoped that with continued research and funding, a cure will be found one day.

The treatment for CF is multifaceted with patients having to undertake daily medicines, physiotherapy, exercise as well as taking into account their nutritional needs. It is very important for people with CF to keep on top of their treatment regime as they are prone to repeated lung infections which slowly destroy their lungs.

A common misconception with Cystic Fibrosis is that the disease only affects the lungs, but it is hoped that this publication will help shed light on the fact that Cystic Fibrosis has a complex mix of symptoms and requires a host of different treatments.

For more information on Cystic Fibrosis please visit:

Website: cysticfibrosis.org.uk
Cystic Fibrosis Trust Helpline: 0300 373 1000
Email: helpline@cysticfibrosis.org.uk

Acknowledgements

A special thank you to Andrea Harvey for supplying her dietetics knowledge, Antonia Torch for helping in illustration, and finally to Scott Wilson for trying to keep me as sane as possible throughout the entire process.

I would also like to thank the Cystic Fibrosis Trust for their tireless dedication in the support of Cystic Fibrosis patients across the UK. Their nutrition booklets in particular guided some of the dietary recommendations within this publication.

Thank you to Holly-Rae Smith from the Trust especially, who helped in the very early stages of this publication and pointed me in the right directions. Working on the CF Youth Advisory Group particularly inspired me to create this resource as it constantly illuminates the various problems still affecting children and young people with Cystic Fibrosis today.

I would finally like to thank everyone at the Manchester Adult Cystic Fibrosis Centre for continually going above and beyond for all their patients and for providing constant support which definitely does not go unnoticed.


Benji is 8 years old and has Cystic Fibrosis.
His Cystic Fibrosis Food Friend details how the genetic condition not only affects his lungs but can also cause digestive problems. Join Benji as he explains his treatment, his diet and why taking his enzymes is so important.
Benji's story is designed to help children with Cystic Fibrosis understand a major part of their treatment in a fun and illustrative way. Benji hopes that his story will also inform friends, teachers and other people about Cystic Fibrosis and how it can affect his life.