

Hidden Disabilities

Cystic Fibrosis



#PauseChangeShare

What is Cystic Fibrosis?

Cystic Fibrosis is a life limiting inherited genetic condition caused by a faulty gene. The faulty gene controls the movement of salt and water in and out of cells. This causes a thick mucus to gather in the lungs and restricts the secretion of digestive enzymes into the gut creating a range of challenging symptoms.

Symptoms of Cystic Fibrosis

These include:

- Recurrent chest infections
- Airway inflammation,
- Coughing,
- Wheezing
- Shortness of breath
- Deterioration in lung function.
- Pancreatic insufficiency which means diarrhea, difficulty putting on weight and physical growth.
- Cystic Fibrosis related diabetes.
- Osteoporosis and Arthritis.
- Sinusitis and nasal polyps.
- Fertility issues.

Resources

www.CysticFibrosis.org.uk

Email: mp.read@cwgsy.net

Call: 07911747747

www.facebook.com/CysticFibrosisChannellIslands

**Cystic
Fibrosis...**

Our **Hidden Disabilities campaign** aims to promote positive attitudes towards people living with a disability which isn't immediately obvious. To find out more visit:



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We all Matter, Eh! in partnership with the Guernsey Disability Alliance (GDA).

Being a carer of someone with Cystic Fibrosis

Cystic Fibrosis is normally diagnosed within the first few weeks of birth with treatment beginning immediately. The treatment includes inhaled medication to break up the mucus, physiotherapy and breathing exercises to assist in clearing the mucus from the lungs, oral and inhaled antibiotics to keep lung infection to a minimum, digestive enzymes taken with food to allow absorption of nutrients and additional vitamins and high calorie supplements.

The specialist advice and care required for Cystic Fibrosis is not available in the Channel Islands so regular off island travel becomes a challenging feature of family life. Some hospitals on the mainland will have a Cystic Fibrosis team which includes respiratory consultants, specialist nurses, physiotherapists, dietitians and psychologists to assist with the care and support.

Top Tips

Top tips for the community interacting with someone with Cystic Fibrosis

- Advances in treatments and medication mean that children with Cystic Fibrosis can and need to be treated in the same way as their peers.
- There are few things that a person with Cystic Fibrosis is unable to do but it is a deeply personal life long challenge so they are often reluctant to talk about it. The best support someone can give is to be considerate and patient.
- Cystic Fibrosis isn't contagious.
- The condition is a part of their life but doesn't define them or limit their potential.
- Persistent and frequent coughing is normal. It's the only way to clear mucus from the lungs and has nothing to do with infection or smoking.
- Sufferers rarely look ill but will always be dealing with a range of challenging symptoms.

Watch the video

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