



## A DAY IN THE LIFE OF..... LILY- MAE COX

Cystic Fibrosis (CF) is the UK's most common life-threatening inherited disease. Cystic Fibrosis is caused by a single defective gene. As a result, the internal organs, especially the lungs and digestive system, become clogged with thick sticky mucus resulting in chronic infections and inflammation in the lungs and difficulty digesting food.

There is currently no cure for Cystic Fibrosis, and those with CF have to adhere to a daily treatment regime of medication and physiotherapy.

Lily-Mae is 11 months old and was diagnosed with Cystic Fibrosis following the heel-prick blood test she had at three weeks old.

Here is a day in Lily-Mae's life....

7.30	Wakes up
7.45	<b>Oral Medication -</b> 5ml Flucloxacillin (antibiotics) 0.6ml Abidec (Dalivit) (vitamins) 0.5ml Vitamin E
8.15	Breakfast Weetabix or baby porridge with SMA high energy milk <b>Oral Medication -</b> 3 scoops of Creon (digestive enzymes)
10.00	Nap
11.0	Playtime. 10-15 minutes exercise <b>Physiotherapy - shakes and pats (10 mins)</b>

12.00      **Oral Medication -**      5ml Flucloxacillin (antibiotics)

13.0        Lunch  
**Oral Medication -**      5/6 scoops of Creon (digestive enzymes)

14.30        Playtime. 10-15 minutes exercise  
**Physiotherapy - shakes and pats (10 mins)**

15.00        **Oral Medication -**      5ml Flucloxacillin (antibiotics)

16.00        Tea  
**Oral Medication -**      5/6 scoops of Creon (digestive enzymes)

17.00        Nap

18.30        Bathtime

19.00        Supper porridge with SMA high energy milk  
**Oral Medication -**      5/6 scoops of Creon (digestive enzymes)

20.00        Bedtime

Total amount of time spent on treatment: approx 45 minutes

## **ENDS**

### **For all media enquiries, please contact:**

Gemma Foy on 0208 290 7912 or email [gfoy@cftrust.org.uk](mailto:gfoy@cftrust.org.uk)

### **Notes to Editors**

- The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). It funds research to treat and cure CF and aims to ensure appropriate clinical care and support for people with Cystic Fibrosis.

- Cystic Fibrosis (CF) is the UK's most common life-threatening inherited disease. Cystic Fibrosis is caused by a single defective gene. As a result, the internal organs, especially the lungs and digestive system, become clogged with thick sticky mucus resulting in chronic infections and inflammation in the lungs and difficulty digesting food.
- Each week five babies are born with Cystic Fibrosis and three young people die – 90% from lung damage. Around half of the CF population can expect to live over 35 years, although improvements in treatments mean a baby born today is expected to live even longer.
- Further information can be found on our website [www.cftrust.org.uk](http://www.cftrust.org.uk). Help and advice for those affected by Cystic Fibrosis is available through our Helpline on 0845 859 1000. For further information, media should contact Gemma Foy on 0208 290 7912 or email [gfoy@cftrust.org.uk](mailto:gfoy@cftrust.org.uk)

**see off cf**

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*Patron: HRH Princess Alexandra, the Hon. Lady Ogilvy, KG, GCVO President: Duncan Bluck CBE*

*Cystic Fibrosis Trust registered as a charity in England and Wales (1079049) and in Scotland (SC40196)*

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