Cystic Fibrosis & New Health Technologies

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What is Cystic Fibrosis?

- The disease primarily affects the lungs and digestive system.
- This is caused by a build up of mucus lining the lungs and pancreas.
- It is a genetic disease which is inherited from both parent carriers.

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What is Cystic Fibrosis?

- CF patients require a daily routine of treatment and drugs.
- Life expectancy is currently 31 years.
- There are over 7,500 people across the UK diagnosed with Cystic Fibrosis at present.
- There is no cure.

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How does it affect me?

- I was diagnosed at birth
- I take oral medication daily and with food
- Physiotherapy and nebuliser twice a day
- I am sometimes limited to do things that people my age take for granted
- I have regular monthly checkups and IV treatment once a year.

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Cystic Fibrosis Patient Technology

- Oral medication
- Nebulisers
- Intravenous (IV) antibiotics
- Portacaths
- ‘Peg’ feeding
- Oxygen

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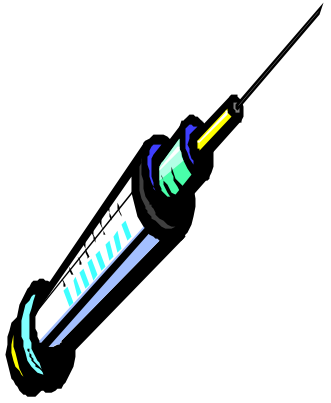
Portacaths

- Under the skin
- Provides instant vein access
- Convenient and reliable
- Permanent
- Are slightly visible



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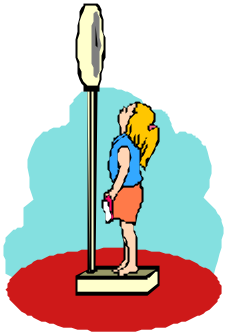
‘Peg’ feeding

(Percutaneous Endoscopic Gastrostomy)



- Instant liquid feed
- Help patients stabilise or re-gain weight
- Nutritional support over a long period
- Via feeding tube fitted directly into the stomach

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Oxygen

Cylinder

- Heavy
- Restrictive

Portable

- Lightweight
- Independence
- Relies on breathing patterns

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Summary of CF technologies

New technologies used by CF patients need to be:

- Portable
- Modern and funky
- Fit in with lifestyle
- Quick and easy to use

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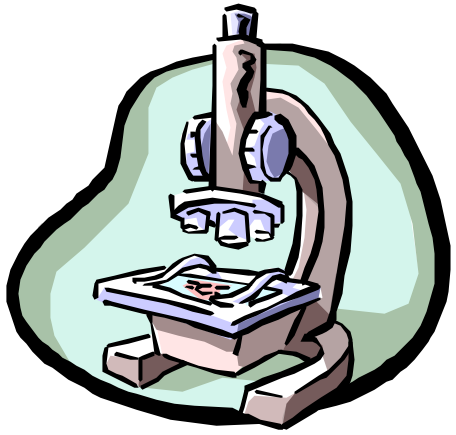
New developments

- Pro dose nebuliser
- Baby pro nebuliser (handheld)
  - Less time consuming
  - Compact and discreet
  - Gadgets are appealing
  - Better patient compliance



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Gene therapy – a new hope

- Gene therapy- replacing faulty genes with new ones
- Protein therapy- repairing faulty genes
- Therapy is planned to be administered through nebulisers
- Possibility of physical stimulation via magnetism or electroporation

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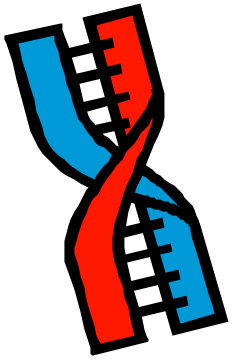
Problems

- Identifying the right dosage
- Non invasive treatment
- Correcting the CFTR gene



- How to measure the benefits of gene therapy
- Expensive to fund

Taken from Eric Alton's Gene Therapy presentation, American CF conference, October 2004.

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CF Trust Research agenda

- Correcting the cause
- Improving symptom control
- Lungs
- Infections
- Weight
- Improving clinical care
- Quality control

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Correcting the cause

- 70% of funds towards gene therapy
- Provides hope of finding a cure
- Funding taken away from other resources
- Disagreements on where money should go in CF community.

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Improving symptom control

- Maintenance of lungs, liver and digestive system.
- Cf patients will live longer if healthy
- Controlling symptoms for normal life
- Average life expectancy improving
- However, many CF patients still die very young

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Lungs

- 90% of deaths in CF due to lung failure
- Research into causes of lung infections
- Prevention
- Cross infection problematic for patients who may feel isolated.

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Infections

- Why are some bacteria more dangerous than others
- New drugs
- Identifying different growths and strains of bacteria
- Some newer drugs expensive and are harder to prescribe.

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Weight

- Use of hormones vitamins and supplements to improve weight gain
- Maintenance of weight
- Many CF patients are still under weight
- Problems with children eating food

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Improving clinical care

- Funding CF specialist care across the country
- Fund 80 medical staff in CF clinics
- Produce consensus documents
- These guidelines cannot always be met in smaller clinics
- Lack of funds and support from government

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Questions?

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