Starting Of Group: Breathtakers – Action for Bronchiectasis

Welcome to this the first edition of our newsletter. This is the brainchild of “Breathtakers – Action for Bronchiectasis” which was formed about 18 months ago partly at the instigation of Dr Adam Hill and Chest Heart and Stroke Scotland (CHSS).

As the name suggests, bronchiectasis is the focus of the Group and our aims are to aid rehabilitation, improve and maintain quality of life and to promote awareness of the condition. As bronchiectasis is becoming increasingly recognised as a condition in its own right – sometimes having gone undiagnosed in people for years and sometimes being mistaken for other respiratory conditions such as COPD – the feeling was that a specific support group was essential. I have the privilege of chairing the group although I must quickly say that I am ably supported by a small committee of interested volunteers.

Nothing secret about this – the Group is open to all with an interest in bronchiectasis, whether from the point of view of a patient or carer. And all will have a say in agreeing office holders for the future and indeed future programmes. We meet monthly and our current programme of meetings covers a wide variety of topics including latest developments in research, diet, physiotherapy, support for patients and carers etc.

newsletter

This newsletter is an attempt to cast our net more widely – both to convey important information as well as anecdotes and trivia. We plan that it be no more than a single sheet – so not a difficult read. We also see it as a means of publicising what we are doing in the Group. I do hope that you enjoy reading it and that it might attract you to come to Group meetings and become involved in helping to address the problems that many with bronchiectasis face in their daily lives.

James Wildgoose – Chairman

It is a great delight to write a few words for the first news article of the “Breathtakers”. The first article is to highlight how bronchiectasis is diagnosed and the Bronchiectasis Services which we provide.

Bronchiectasis as you are aware is a chronic condition in which the tubes in the lungs are permanently damaged. This leads to you having often daily cough with phlegm (sputum) production and recurrent chest infections. Most of you, I am certain will have been accused of cigarette smoking, despite never touching a cigarette!

We diagnose bronchiectasis on the basis of these symptoms but in addition we look for confirmation of these damaged airways with a CT scan of the chest (this will give detailed images of your chest). This has replaced the dye test into the airways called a bronchogram.

The Bronchiectasis Service is based at the Royal Infirmary of Edinburgh but offers specialist advice to the whole of NHS Lothian. The team for this service is listed at the end of this article. We offer the following:

1] Outpatient clinic
We run a specialist weekly multidisciplinary clinic where patients see a doctor (myself or my Registrar) or specialist nurse (Kim) and the specialist physiotherapist (currently Lorna Stevenson). We advise on optimum treatment for your bronchiectasis and give your GP clear guidance on what to do if you develop a chest infection.

2] Guidelines for GPs
We have set up via the Managed Clinical Network guidelines for GPs and others in primary care on how to manage bronchiectasis.

3] Intravenous antibiotics therapy
For severe exacerbations, we have facilities to treat patients with intravenous antibiotics (antibiotics via a cannula in your arm). This conventionally is given in hospital but our team of expert nurses led by Kim assess whether this treatment can be delivered at home by yourself or your carers. This offers an excellent alternative to hospital admission and allows you to be in better control of the bronchiectasis.

4] Research
We have an active research program and would like to thank all of those who have participated previously or are involved in ongoing trials. Continued over ..
National and internal guidance

We have been actively involved in the writing of the national British Thoracic Society Guidelines on bronchiectasis [Thorax. 2010 Jul;65 Suppl 1:i1-58]. We have written summary articles for Primary Care via the Primary Care Respiratory Journal [Prim Care Respir J. 2011 Jun;20(2):135-40]. These articles can be found in a PUBMED internet search.

In future articles, we will discuss in more detail our research programme to date. If there are particular issues you wish the Bronchiectasis Team to address, please let us know.

Adam Hill

Bronchiectasis Service-
Royal Infirmary of Edinburgh
Clinical Lead
Dr Adam Hill
Clinical Nurse Specialist Lead
Kim Turnbull
Physiotherapists
Jo Pentland and Lorna Stevenson
Researchers
Dr Maeve Smith, Dr James Chalmers, Dr Pallavi Mandal
Secretary
Solange Belleville

Patient Profile
G. B, Edinburgh says; I've had Asthma all my life and growing up suffered bouts of Bronchitis, Pneumonia and Pleurisy. In 2009 I had numerous bouts of Bronchitis and was referred to hospital.

But by March 2010, with the Bronchitis still evident I was asked to stay in Ward 204 for tests. It was then that I was diagnosed with Bronchiectasis and Aspergillus.

Hospitalised 5 times between March and July I felt I was making no progress. I was making no sense to my wife and it turned out that I was having a bad reaction to all the pills I was on. I was then taken off some of them.

I was transferred to Dr. Hill's clinic last year and have continued to gain in strength. I have continued to do lots of exercises at home and feel the benefit.

Inverclyde Globetrotters, one of Chest Heart Stroke Scotland’s smallest affiliated groups has a unique take on exercise, virtual walks. They set themselves a target distance (say Edinburgh to Glasgow) and try to walk it in a given time. Their latest challenge though is to ‘walk’ to the moon. For this they need the help of other CHSS groups, including ‘Breathtakers’.

So we (CHSS) are providing the groups taking part with pedometers, information of suggested routes, etc. and during September the miles walked by each group will be added up, hopefully reaching the target of the distance to the moon.

People go about their usually daily routine – and wear a pedometer to see how far they walk/cycle/or dance each week. Participants ‘check in’ regularly with the number of steps they have taken so that CHSS can count them. It's as easy as that.

The main aims are:

to have some fun whilst being active.
to raise the profile of Chest Heart & Stroke Scotland’s affiliated groups (yours is one!).
to increase referrals to our affiliated groups.
to help people stay fit…and…
to help get Inverclyde Globetrotters to the moon (virtually!).

Nicola Cotter – Voices Scotland Lead
Tel: 0131 225 6963

Diet

As with any other medical condition it is important for Bronchiectasis patients to make sure that we get the proper nutrients and vitamins in our diet.

This usually means eating enough fruit and veg – the 'five a day' that is often talked about. However many people find this difficult to do. One very simple way is to make soup. And it is so easy to do.

The following is one method; take 1 Sweet Potato, 3 Carrots, 1 Potato, part of a Swede, a slice of Onion, Cabbage, any other veg such as Peppers, Brussels Sprouts, Kale, etc.

Chop up all veg finely, place in a suitably large pot, add one or two jugs of gravy water. Then add salt, pepper and any herbs to taste. Bring to the boil and simmer for 30-40 minutes.

Future meetings of Breathtakers - Action for Bronchiectasis support group

September 27th - physiotherapy, breathing techniques & exercise.
October 25th - support for carers.
November 29th AGM & Fundraising (discussion of)

All held in RIE, Seminar Room 1640 (opposite ward 203), 3-4pm