

Catnap



Narcolepsy UK

Newsletter of Narcolepsy UK
April 2012

Picture courtesy of Edinburgh Inspiring Capital –
www.edinburgh-inspiringcapital.com



Heading to Scotland

It's been far too long since we had a meeting in Scotland but that is all set to change on Saturday, May 12, when Narcolepsy UK will be in Edinburgh.

This is not a Scottish conference but a conference held in Scotland and we do invite all those interested from the north of England who found getting down to Cambridge both difficult and expensive to join us for what will be a very special day.

In fact all members, wherever you live, are more than welcome to join us in Scotland.

The date is set and the location decided for the first Narcolepsy UK Conference of 2012. We are holding a spring meeting in Edinburgh at the prestigious Surgeon's Hall - right in the heart of the Scottish city.

We will be at the King Khalid centre - a wonderful converted church perfect for our needs, with lots of natural light in the main auditorium which has 158 seats and state-of-the-art AV equipment.

The reception area provides a great place for serving refreshments and just meeting and talking to other delegates. We will also have a relaxing room available for those who need to take a break. The meeting starts at 10.45am and will finish at approximately 3.45pm, with breaks for refreshments and lunch.

For this meeting not only will we have the latest news from medical professionals but also information on what is happening in the benefits system for people with narcolepsy and how you are now protected in law by the

2010 Equality Act.

We will also be providing updates on the important topics for people with narcolepsy. Top local and national speakers are guaranteed to make the day one of the highlights of the year.

Regular updates and a full programme will be available on our website later this month, so do keep checking for information. A booking form has been included with this edition of Catnap.

We are keeping the ticket price for 2012 the same as 2011 - that is £15 per ticket for members and that includes lunch and two refreshment breaks as well as access to the conference.

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If you have any stories you
would like to see in Catnap or
any suggestions for future edi-
tions, please contact the editor
using the details at the bottom
of this page.

We're heading for Edinburgh

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Remember membership is free to all those with narcolepsy or who work with or support people with narcolepsy. For non members the price will be £35 per ticket so now might be a good time to join us!

You can book your tickets by contacting Margaret on the Narcolepsy UK phone line on 0845 450 0394 or e-mail her at info@narcolepsy.org.uk Or simply fill out the booking form included with this copy of Catnap.

In addition, you can now buy your ticket securely online via our website using a credit card. Just go to www.narcolepsy.org.uk and follow the links.

Surgeons Hall is situated at the Royal College of Surgeons of Edinburgh, approximately 10 minutes walk from Princes Street or Edinburgh Castle.

Below you will find a map and directions to the venue along with some links to external travel websites that you may find useful.

Edinburgh conference travel guide

BY CAR

The nearest exit from the City Bypass (A702) is the Straiton junction. From here follow the signs for the city centre. The route is fairly straight, through Liberton. At the foot of Liberton Brae go straight on to Liberton Road and continue straight on at the traffic lights. Carry straight on for approximately 2km. This continues into Clerk Street, which then continues into Nicolson Street. There are metered parking spaces in Hill Place (very limited), and Chambers Street. A public car park is close by at the Pleasance.

BY RAIL

Edinburgh Waverley Station is 10 minutes walk from the complex. To check train times and fares call National Rail Enquiries

on 08457 484950 or visit www.nationalrail.co.uk

BY AIR

There is a regular bus and taxi service from Edinburgh Airport, which is situated to the west of the city. The airport bus terminates next to Waverley Train Station. Contact Edinburgh Airport on 0870 0400 007 or visit: www.edinburghairport.com/

BY BUS

Inter-city bus services terminate at the St Andrew's Square bus station, situated next to the St James Centre shopping centre. Buses from Princes Street (stops on the side of the street lined by shops are very frequent. Services passing the complex include numbers 3, 5, 7, 8, 14, 31 and 33.

Marathon efforts will be so vital for charity funding

AS YOU will read in other parts of Catnap we do rely on donations from members and this issue we would like to say thank you to the following for their support of Narcolepsy UK.

We hope what they have done inspires you and gives you some ideas!

Thank you Debbie Fryer for your donation which was sent in via our Virgin Giving website; this is by far the easiest way to donate to the charity and also lets us get the gift aid that much quicker – Debbie thank you for your support.

Julia Burnell isn't even a member of the charity but her sister in law is. We have to thank Julia and her employers who match funded the donations that were raised for a massive £5,000 for the charity.

Two things to learn from this impressive amount apart from how kind Julia and Helen are – if you know someone who might be able to help don't be afraid to ask them and of equal importance tell your employer!

It is quite possible, especially in the larg-

er firms, that they will support you with time and advice and if you are very lucky they might, like Julia's company, match the funds you have raised.

Finally we are indebted to two members who are running marathons for us this spring.

Jayne Collins is running in the Greater Manchester Marathon this month in aid of Narcolepsy UK and Iona Murray is running the Edinburgh Marathon in May.

Both have websites available where you can donate (and please do) and we will put links on our website to them.

For all those who donate - however large or small, thank you for your help. We couldn't do what we do without you.

If this has inspired you to help please go to the website and click on fundraising for 50 ideas to raise £50, sponsorship forms and a direct link to our Virgin Giving page.

We need your support to continue the good work of the charity.

Visit our website now for more details at: www.narcolepsy.org.uk

Donations are the key to sustaining our work

As you know we no longer charge for membership of Narcolepsy UK and that has led many people to ask how do we do keep the charity going financially?

Well we rely on you, the members, to support us through donations, fundraising or even leaving us a little something in your will.

This is so important to the charity that we have a whole new section on the website on fundraising with ideas on how to raise funds, material you can download and sponsorship forms. Anything you can do to help is really most welcome as we are always in need of funds.

Here are a couple of examples. The newsletter you are reading is produced and mailed out to you, on average four times a year. We now have over 800 members who request a copy of Catnap and we assume that most of them don't have access to the website where you can download a copy – so for them Catnap is the charity.

Costs have increased over

the last few years and printing is no different. However, through working with our suppliers we have probably got away with no increase in the last two years.

That has all been swallowed up by the increase in postage. While the cost of producing Catnap is no more than it was in 2010 it now costs almost 70p per issue to post out, which when added to the cost of production means that to send out Catnap in 2012 will cost just over £2,800.

To maintain that free of charge eats into our reserves but we feel it's important that we continue providing this lifeline. However, if you enjoy Catnap and can afford to donate something towards the cost of sending it to you we would be very grateful.

We have maintained the price of members attending conferences to £15 while non members must pay £35 per ticket.

Why the huge price difference? We don't make a profit from our conferences - the £35 is the actual charge to the charity of the day, which includes room

hire, refreshment breaks, lunch and all the other costs associated with holding a meeting.

The charity decides to pay out of its own reserves the difference between the actual cost and the membership price for several reasons. People with narcolepsy tend to earn less than most people but we want as many people as possible to attend the meetings and by keeping the price low we hope we can achieve that.

We do think it important to charge something but if you would like to come and can't afford £15 do let us know as we have bursaries available - these are donations from very kind members who can't attend but are willing to pay for someone else to attend in their place.

If you would be willing to provide a bursary to this or any narcolepsy meeting, please contact us via e-mail or telephone (details can be found at the bottom of the page).

Yes we could reduce the costs of the meeting. We could hold them in locations away from

city centres but that would make it more difficult for those who don't drive to attend.

Yes we could make it just a meeting and provide no refreshments but half the fun of a meeting is to talk to people over lunch and coffee, swapping stories, coping mechanisms and just meeting someone who knows what you are going through.

So, all in all we think we have the balance just about right but as you will see if we get 100 members attending the meeting in Edinburgh it will cost the charity £2,000. Times that by three meetings and you can see how expensive these become.

Which is why, if you can pay more to attend please do so. If you can't attend but would like to sponsor an individual (or two or three) let us know. Also it's important to raise funds for the charity and do try to remember us in your will if you can.

Your help now can help us maintain the lifeline of conferences and newsletters for people with narcolepsy.

Taking meetings closer to members is what you have asked us to do over travel worries

THREE conference meetings will take place during 2012 – and that's down to giving the members of Narcolepsy UK what they asked for.

We have now held two very successful conferences in Cambridge, where we welcomed over 500 delegates in 2010 and 2011.

However, one of the problems that lots of members mentioned in the feedback forms they filled in at these meetings was the difficulty of attending meetings in terms of travel.

We particularly noted last September how many people said the cost of travel had been a major factor in deciding to come to one or the other of our meetings in 2011 (a conference meeting

was also held in Sheffield) and couldn't we have more local meetings so it is not only cheaper to get to but also you don't have to stay overnight.

Well the committee have been listening and for 2012 we are arranging three meetings around the UK to satisfy those requirements.

We will still have leading professional speakers talking at each of the meetings and these meetings will still be held in locations that are easy to get to.

We will continue the breakout sessions and opportunities to ask experts one-to-one questions – but, and here is the difference, we are going to do it closer to where you live.

We are announcing in this issue of Catnap the date and time of our Edinburgh meeting. In June we will be in Leicester with our guest speaker Dr Andrew Hall - who as well as being a leading sleep specialist is also the treasurer of the British Sleep Society and a noted supporter of people with narcolepsy.

In September we will be holding a meeting in the south west of England which we hope our members in Wales will be able to get to easily. Professor Adam Zeman will be our guest speaker.

September's meeting is likely to feature the latest research on narcolepsy and the Pandemrix vaccine. We are aware of several interesting papers that are going

to be published in the months ahead that will have an impact on this story.

Further information will be available on the website and in the next issue of Catnap. The price for tickets will be the same at all three venues – just £15 for members and that includes lunch and two refreshment breaks as well as access to the conference.

Remember membership is free to all those with narcolepsy or who work with or support people with narcolepsy. For non members the price will be £35 per ticket.

Keep checking the website for more information on dates, times and venues for future conferences.

Equality Act puts a stop to disability questions

IS NARCOLEPSY recognised as a disability in the UK? The first question to be asked has to be, by whom?

People in the street would probably not think you had a disability and employers might also not realise the condition was so serious it could be classified as such.

However, since the introduction of the Equality Act in October 2010 there is no longer any doubt – narcolepsy is a disability.

The Equality Act 2010 is designed to protect disabled people and prevent disability discrimination. It provides legal rights for disabled people in the areas of employment, education, access to goods, services and facilities, buying and renting land or property and functions of public bodies.

In previous legislation, support was ‘prescriptive’ – by that we mean the Government would create a list of diseases it considered to be serious enough to warrant disability status.

The 2010 act has done away with all of that and has created definitions for ‘disability’ and if you fall within these definitions then you can be classified as disabled. In the act, a person has a disability if:

1. They have a physical or mental impair-

ment

2. The impairment has a substantial and adverse effect on their lives

3. The effects are long term

4. They effect their ability to perform normal day-to-day activities

For people with narcolepsy the important words in the definitions are substantial, long term and normal day to day activities.

The Equality Act also provides rights for people not to be directly discriminated against or harassed because they have an association with a disabled person. This can apply to a carer or parent of a disabled person. In addition, people must not be directly discriminated against or harassed because they are wrongly perceived to be disabled.

There can be no doubt that narcolepsy is a disability and that people with the condition can use the act to get the help they need.

In terms of employment this means you can’t be harassed, dismissed or made redundant because of your condition. It also means that your employer is required to make reasonable adjustments in the workplace so you are not disadvantaged.

In terms of education, an education

provider can’t discriminate against a student because of something that is due to their disability. They must make reasonable adjustments to ensure that disabled students aren’t discriminated against. This could include changes to practices or procedures, changes to physical features, changes to how learners are assessed and providing extra support and aids (such as specialist teachers or equipment).

The Education Act 1996 provided for the publication of a Special Educational Needs (SEN) Code of Practice and all publicly-funded pre-schools and nurseries, state schools and local authorities must take account of this code. Ask to see a school’s policy on SEN or you can also request a ‘statutory assessment’ of your child’s needs.

Finally you can’t be discriminated against in goods or services either. Your car or house insurance can’t be higher because of your narcolepsy. Providers should be thinking ahead and looking at the way they provide services and how they can make improvements for disabled people.

More information about the Equality Act, and how you can obtain copies of it, can be found at: www.homeoffice.gov.uk/equalities/

Narcolepsy does not shorten your lifespan

MANY members have raised the concern that taking medication long term might reduce their life span. Some of the medication used by people with narcolepsy can be quite toxic so these concerns are understandable.

Today we are able to report on new research due to be published later this year that provides conclusive proof that having narcolepsy does not reduce your life.

The research was carried out in Denmark using over almost 40 years of data by Dr P Jennum of the Danish Sleep Centre.

He took a group of over 800 patients diagnosed with narcolepsy and then matched them on a 1:4 ratio with a control group of people without narcolepsy (one person with narcolepsy against four without) but who matched the same characteristics in terms of age, height, sex and even the area where they lived.

While looking at mortality in Denmark he did also check other areas such as school success, work patterns and for the first time he also looked at how living with someone with narcolepsy affects the partner.

First the good news; there is absolutely no difference between life expectancy of a person with narcolepsy compared to someone

without the disease.

In fact the news gets better for people with narcolepsy who were concerned they might get “hooked” on their medication as again the results of this study found that this just does not happen.

So, if you are worried about how your medication is possibly destroying your body – don’t be because it probably isn’t.

But, and it is a big but, that is where the good news ends for people with narcolepsy.

Take whatever social condition you want, from child pregnancy through to school results, employment, income and remaining in a relationship, people with narcolepsy under perform the control group by between 15 per cent and 25 per cent worse.

A couple of examples that stood out; people with narcolepsy in Denmark are 20 per cent more likely to be unemployed than the control group.

If they are working they are likely to earn up to 16 per cent less than people doing comparable work, 23 per cent less likely to get promotion and 29 per cent more likely to retire early.

The other sad fact documented was how narcolepsy affects the entire family of a person with narcolepsy. First they are more likely to stay single longer (29 per cent against a norm of 23 per cent) and then relationships do tend to last shorter periods until the late 30s and then narcoleptics in relationships actually outperform the control.

H1N1 and Pandemrix plea for help

DID YOU have narcolepsy before you took the H1N1 vaccine in 2009 or 2010? Has your narcolepsy got worse since that date?

Are you over 21 and had the H1N1 jab in 2009 or 2010 and developed narcolepsy since then?

Were you given Pandemrix instead of the winter flu vaccine between December 2010

and February 2011 and have you developed narcolepsy or seen your narcolepsy get worse?

If you answered yes to any of these questions we would like to talk to you - please e-mail info@narcolepsy.org.uk or leave your name and contact details with Margaret on 0845 450 0394 – discretion is assured as ever.