

AMNET NEWS

AMNET IS AN EASTERN COUNTIES, SELF-HELP GROUP OF FORMER AND NEW ACOUSTIC NEUROMA AND MENINGIOMA PATIENTS AND CARERS, BASED IN ADDENBROOKE'S HOSPITAL, CAMBRIDGE UK

Summer 2001
Issue 19

Facial Rehabilitation – a must for all patients with Cranial Nerve 7 Damage

A talk by Diana Farragher MSc, Grad Dip Phys, DipTP, FCSP

Reported by Chris Richards



We were very pleased to welcome Diana Farragher to our 5th anniversary meeting to talk about her work with patients suffering facial palsy. The last time she spoke to us was 4 years ago.

Diana opened her talk by asking how many people in the audience were receiving facial physio and noted that the number was still a small proportion of the total.

Diana is a physiotherapist who studied a physiology degree and did some research on nerve recovery in 1986. Since that time she has worked with patients with facial nerve problems. She maintained that it seems down to a whim whether people get help with facial problems – the philosophy is often wait and see. She maintains that no muscle will get better unless it is worked.

The nerves affected following surgery for acoustic neuroma are the 5th, 7th and 8th cranial nerves. The 7th nerve controls facial expression and the 5th cranial nerve sensation to the face. The nerve normally supplies the muscles in the forehead, cheek, neck and scalp. If it is damaged it comes back a little at a time. If it is not helped new nerve pathways cannot be brought to full potential.

When she first sees a patient Diana will test for signals from the facial nerve with an EMG (Electromyograph) machine – this can help in determining where a problem lies and the degree of injury. It also allows stimulation to be more accurately targeted whilst repeated testing on follow up visits monitors the treatment outcome. This machine has developed over the years from a large machine which had to be moved on a trolley to the present hand held machine which produces videotape film and has a microchip which will design specific signals to stimulate nerves. When there is facial nerve damage the face will lose balance if one side doesn't work the other side may pull. The EMG pinpoints areas of weakness and where the muscle needs stimulating. This

stimulation is carried out using a Trophic Electrical Stimulation machine which copies the underlying signals which nerves in normally functioning systems feed to the muscle to keep it in good health. The repeated signal is the impetus for the muscle to rebuild itself, but this takes time.

Diana maintains that age or length of time the paralysis has been present, is no bar to recovery of facial nerve function but the earlier a pattern of activity is instituted the easier it is for the brain to recover normal activity.

A major problem with recovery is that the middle of the face may recover first and this can lead to synkinesis. Synkinesis is a condition in which muscles which should not be connected move together eg if the eye is closed the mouth moves up. This is due to immature nerves which show mass activity. These nerves need to be trained and to mature so they act on only the muscles they should. Treatment using a trophic stimulator can produce signals which will inhibit the mass activity so that the nerves can mature. As EMG machines get better so stimulation can get better. Exercises are very important in training the brain to recover normal activity.

Following surgery patients need to know that synkinesis will occur and be prepared to work on it to recover normal movement.

If the facial nerve is cut and resutured or nerve grafts are applied the nerve will still need rehabilitation and need to learn how to work the graft. If surgery is necessary you need to be clear about what you want the result to be and ask specific questions of the surgeon.

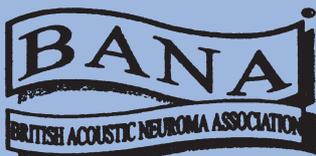
Exercises

Diana outlined some exercises which can be helpful in synkinesis. She suggested that initially it is better to lie down with a mirror and to move the eyebrow using your finger and then try to maintain the position when the other eyebrow is raised. This will encourage forehead movement without mass movement of the cheek. With the mouth raise the corner of the mouth, using a cotton bud doing all the work with the cotton bud so the muscles under the eye remain relaxed. Think about the small muscles in your cheek and remove the bud and try

Next meeting

September Meeting

The meeting in September will be held on Saturday **22nd September** at 13.00hrs at Addenbrooke's Hospital and the speaker will be **Mr Robert MacFarlane MD FRCS** Consultant Neurosurgeon



to hold the smile. Eventually this will give you a nice smile without eye movement whilst lying down. Eventually you can try the exercises sitting up. The combination of exercises and trophic stimulation can, over time, train the nerves to act more normally.

Makeup

Diana discussed the importance of using clothes and makeup to direct attention to our best features and away from the asymmetry. Colour is important and wearing black and dark colours will make you look insignificant. If you don't have symmetry no-one looks for it so tilting your head when having a photo taken can distract people from lack of balance in the face. Strategies which can help with makeup are based on creating an illusion of balance. This can be done by plucking eyebrows so they match and by using wider eye makeup around a small eye. Diana's message was to look for signs of recovery and look for the maximum potential so you can then move on and live your life.

Questions

When asked how long nerves continue to grow Diana responded that it can be ad infinitum. Most recovery is between year 2 and 3. The nerve starts to grow as you begin to feel better.

When asked about the concept of misdirected nerves, Diana said that this is a fallacy and that the problem is that immature nerves do not have insulation so the message spreads to other nerves as well. These nerves need training. Using the nerve helps it to develop insulation and therefore proper movement.

To finish, Diana described her plans, working with Dr Bob Targan, chairman of the National Centre for Facial Paralysis in America, to set up a number of private clinics around the UK. They also plan to open 3 major centres for facial rehabilitation within the UK over the next 2 years so that help will be available to many more people.

We would like to thank Diana for her interesting and encouraging talk. If you would like to know more about the treatment you can contact Diana at:

The Lindens Clinic
214 Washway Road
Sale
Cheshire
M33 4RA
Tel 0161 718862
Fax 0161 718684
email dfarragher@ic24net

Membership of BANA

In clarification of a point raised at the last meeting the committee have been in touch with BANA about the status of our membership. We hold associate membership of BANA and we receive information and some newsletters, but the agreement does not include automatic membership of BANA for AMNET members.

Editorial

Dear All

Welcome to the Autumn edition of AMNET NEWS. I hope you all enjoy what we have for you. There are lots of pictures this time and I hope to make pictures a more prominent feature of future newsletters.

The pictures this time are of our AGM and I think all those who came will agree it was a very successful and enjoyable day, and for those of you who could not be there I hope you will find the reports interesting.

We also have a couple of personal experiences for you this time. I'm sure all of us can identify with Carl Whiffen's feelings on having to come to terms with his newly acquired deafness.

Rachel Pearson, who I'm sure you have noticed as a regular contributor has her own column this time and has kicked it off with a very amusing account of problems associated with a trip to the supermarket. I'm sure we all share similar experiences so please write to Rachel with your stories and solutions if you have any. With your participation this could be a very lively and interesting feature of the newsletter.

Also don't forget any other contributions. As I say every time – this is your newsletter help me make it relevant to all of you!

Best Wishes

THANK YOU!

The members of the committee would like to express their thanks and appreciation of the gifts presented at the AGM.

We would also like to express on behalf of all the members a **special thank you** to Alison who has worked so hard and enthusiastically and dedicated so much time to make AMNET the successful organisation it is now.

Report from the AGM 2nd June 2001

Alison reported that AMNET is now five years old and recalled her experience of finding out she had a tumour. 'On a personal note this is the establishment and continuation of an idea begun in November 1992. Mr Moffat had told me about the tumour in my head and the need for its removal. I couldn't talk to anyone that day because of the shock I felt. Fortunately my husband had come with me and retained a lot of the information we had been told. The fleeting thought was – I'd like to talk to someone who has been through this. Nothing was offered so I submerged the thought and concentrated on getting through the then three months wait, operation and recovery. It was not until nearly two years later that the series of meetings began which culminated in our inaugural meeting on June 1st 1996, kindly paid for by Mr Moffat. To get AMNET established I have had support from committee, lots of medical staff and numerous other professionals as well as members of other charities. Their continued input strengthens and maintains the network so it can spread and grow. People contact us with a single question or needing complex long term support. Snippets of information from television, radio, papers and the internet also help.

Our committee has remained more or less the same over the 5 years and I thank them for their hard work. Some people have joined us for short times in our committee meetings. This helps us not to become stale. If this appeals to anyone contact a committee member for the date of the next meeting.

Communications with the hospital have improved slightly

this year with three New Patients Meetings being held and some new members recently. In February Emma Stanton, the nurse practitioner left the neurosurgery department to move to oncology. We thank her for her input to AMNET. The new person in this post is Jean Hatchell who was a senior staff nurse on A5. We welcome continued liaison with her.

Our speakers this year have included Mr Sarkies in April, postponed from September because of the fuel crisis, and a return visit from David Baguley, the Senior Audiologist, in December.

For this meeting 55 specific invitations were sent out to professionals who have helped us over the past 5 years. Mr Moffat was unable to come but sent his apologies and best wishes for the future of AMNET.

My thanks to everyone who has helped AMNET in any way. And for the future – will we be here in 5 years time – if there is still the need – a resounding YES!

Treasurer's Report

Joanne reported that the income for the year was £2828.82 and the expenditure was £2573.74 giving a surplus for the year of £255.08. At the end of the financial year there was £1278.38 in our current account and £3004.95 in the Business Investor account making a total of £4283.33. She thanked Michael Bartlett for auditing the accounts.

She noted that donations were down from last year but we still had a small surplus and there had been 10 new members in the last 2 months.

Election of Officers

		Proposed	Seconded
Chairman	Alison Frank	B Lummis	D Munn
Vice Chair	Chris Richards	M Allcock	J See
Secretary	Tony Monk	C Richards	J See
Treasurer	Joanne See	T Pye	P Mayhew

Other officers

New Patients	Neil Bray	Trophic Stimulator distribution	Margaret Allcock
Librarian and Information	Ray Maw	Recording meetings	Graham Allcock
Internet	Roy Edgar	Fundraising	Tony and Eleanor Monk
Newsletter Editor	Chris Richards	Newsletter Distribution	Thelma and Bill Pye
Chief Tea Lady	Jill Smith		

At the end of the meeting the committee members were presented with champagne, flowers and gift tokens as a thank you from the members.



Some longstanding members of the committee (from left to right) Ray Maw, Joanne See, Chris Richards, Neil Bray and Alison Frank

Five Ye

Complementary Therapies

The afternoon session of our AGM was lead by Collette Hay and Jenny Cox, holistic therapists who teach beauty therapy students at Cambridge Regional College. They are trained in aromatherapy, reflexology, Indian Head Massage and other complementary and alternative therapies.

Aromatherapy

Jenny described aromatherapy to the groups outlining some of the oils used and the conditions they may be used for. Essential oils can be used in compresses, for massage, in baths, inhalations, diffusers or sprays and are usually mixed with carrier oils, such as almond oil, (2 drops to 5 mls) before use, as they can be very powerful if they are not diluted. Mixtures of oils can be relaxing or stimulating and can be designed for individuals with individual problems. Jenny then went on to demonstrate and encourage the groups to try hand and arm massage. This can be done with blended oils and can be a relaxing and pleasurable experience. Those who tried it found it very enjoyable.

Indian Head Massage

Collette introduced us to Indian Head massage, the history of which can be traced back nearly 4000 years to the Ayurvedic view of health described in ancient Indian texts. This view of health concentrated on physical, emotional and physical well-being. Traditional Indian head massage was practised by women in India for their families to relieve tension and was later developed as a stimulating head massage by barbers.

Head massage as it is practised now includes the back, upper arms shoulders, neck head and face and in general is done dry through light clothing.

Stress and tension in the head and neck are very common today and this leads to restricted blood flow to the head and shoulders. Massaging these muscles improves blood flow and releases tension and tightness in the fibres providing a valuable treatment for stress linked problems like headache and eye strain as well as other more serious conditions.

As you can see from the photographs members of the group also had a go at this which many found relaxing.



ears On



Hear Today, Gone Tomorrow

A personal reflection on hearing impairment.

Carl Whiffen wrote this article for a nursing journal while he was waiting for surgery to remove an acoustic neuroma. He has since had his operation and is recovering after a couple of setbacks.

I am a registered nurse working in a nursing home. In July of last year I developed a viral infection which was treated by my GP with antibiotics. As with any infection, cold etc, it generally affects the senses in some way ie taste, smell or our hearing is affected. In my case both ears became blocked. I became concerned after 2-3 weeks when the hearing in my left ear was not returning to normal. I was then referred by my GP to see an ENT consultant at the hospital and for an assessment by an audiologist. The doctors at the time thought that my hearing loss was due to a viral infection which had affected the auditory nerve. About 6 weeks later I was referred to the scanning department for an MRI scan, as there had been no change in my hearing. Within a week the consultant phoned me and told me that the scan results showed that I had an acoustic neuroma.

On hearing the news that I was going to be totally deaf in my left ear, I was devastated. At 36 years old I was unprepared for deafness. I had no experience of its effect. I was completely unaware of its profound and far-reaching consequences on my life and family. It was shattering beyond belief, I was painfully, inwardly aware of what I had lost. 'Blindness cuts you off from things; deafness cuts you off from people'. This at times I find quite problematic, especially when I am in noisy environments eg supermarkets, as the lost hearing creates anxiety, confusion and at times, loss of decisiveness.

It has had a profound effect on my life. Man is a social animal, and it is fundamental to our well being that we interact with our environment and those within it. With my hearing loss my ability to interact becomes impaired. As a result my quality of life is sometimes, I feel, affected, and my hearing loss then becomes a disability.

I have been a nurse for 17 years looking after people with varied disabilities, and it's not until something like hearing loss makes you appreciate life, and good health. It also highlighted my awareness of people with disabilities, and the problems people face physically, socially and most importantly it's psychological effects. With my hearing loss I find it hard to understand spoken language when there is a lot of background noise. The hardest thing I find to cope with my hearing loss is asking people to repeat themselves because I couldn't understand or pick up certain aspects of the person's speech. Some people, when you tell them you are hard of hearing, are helpful, others I feel slap a label on you like a jam jar.

The attitude of some people around the hearing impaired person is also significant. It is important for people to realise that the underlying personality has not changed, although their communication difficulties may mean that their

behaviour is modified. Sometimes I prefer not to go out in noisy environments, because I often misunderstand the conversation and make an inappropriate response. By nature some people are better able to cope with a hearing loss, but no matter how resilient they are, you still experience increased stress levels because of the difficulties you experience in communication.

Since the diagnosis of my condition I have had a lot of support from the audiology team. The hearing therapist I see at the hospital has been very helpful in helping me come to terms with my disability. They provide aural rehabilitation and counselling to people with a hearing loss and their families. Their aim is to help people to come to terms with their acquired hearing loss and any other associated disorders such as tinnitus. They work as part of a multi-disciplinary team. I have also had a visit to my workplace by an employment protection officer, whose role is to see that the nursing home is accommodating my needs, and to assess if I need any special equipment. As a result of the visit, the home will be getting 2 digital cordless phones, so I can never miss any incoming calls, and also an electronic stethoscope which amplifies sounds needed when listening for blood pressures etc.

The main thing I have learnt is to look at my disability, not as an end, but as a process of changes and adjustments in my life. I have now adjusted, to some degree, to my hearing loss, but I am still experiencing new situations and trying to come to terms with my new disability with a more positive and forward thinking approach.

Carl Whiffen

Travel to AMNET meetings

Would any members who plan to attend the meetings at Addenbrooke's Hospital and are willing to offer lifts to others who have no transport of their own please contact Philip Mayhew on 01206 501054 giving me your telephone number and towns/villages on your route. Similarly, should any member require a lift please do not hesitate to contact me on the above number and I will try to put you in touch with a person who is travelling in the same direction. We hope this will make it possible for members who have problems with transport to attend meetings more easily.

Rachel's Corner

I'm sure you have all enjoyed Rachel's previous contributions to the newsletter. She is now hoping you will join her in sharing accounts of life after an acoustic neuroma.

Picture the scene. We are in a supermarket on Saturday morning and have rashly paused at the delicatessen counter. All around shoppers are excitedly discussing the football, shrieking at little Jason, who is ramming the trolley against his brother, and fighting noisily over the reduced baked beans.

To your horror, you realise that the delicatessen girl is looking at you impatiently.

"Are you number 74?" she asks, obviously not for the first time.

"Er yes" you mumble. "Two slices of ham please"

"Globbdob or glishy?"

"I beg your pardon"

(At this point the assistant, spotting the contorted features and general idiocy, changes tack completely.)

"I said.....would.....you....like....smoked.....orLeicestershire?.....This oneor that one?" (said with a VERY kind smile, as to the half-witted)

At this point you ditch all thought of buying coleslaw as well, gratefully accept the nearest ham and rush for the tills, scattering children en route because your balance leaves something to be desired. You hope desperately that no-one actually recognises you!

As they say, It's the little things Have you got a particular bugbear about being one-eared? Tell me about it! What is embarrassing? What is really difficult? The most common and/ or interesting ones will be published and readers invited to offer tips and solutions. Write or e-mail

(Mrs) Rachel Pearson

4, The Oaks

Horringer

Bury St Edmunds

Suffolk IP29 5SH

e-mail rachel.pearson1@btinternet.com

Honour for Diana Farragher

I'm sure members will be very pleased to hear that Diana received an MBE in the Birthday Honours list. We have sent her a congratulations card and I'm sure everyone will be very pleased that her work is being recognised.

postbag



No letters from members this time – where are you all? However I do have a couple of other letters I thought you might like to see.

The first is a response to the Committees decision to sponsor a member of the CAMTAD team who have been very helpful to us, in the London Marathon

Dear AMNET

Thank you very much for sponsoring Amanda for £20 in the marathon. She got round in under 4 hours which was tremendous, considering this was her first marathon. As this building has now been privatised, we will probably have to move shortly and will be very glad of the money that this sponsorship has raised. Thank you for your contribution.

Yours sincerely

Sue Hempstead, Organiser CAMTAD.

The second letter was from Collette and Jenny who led such enjoyable sessions at our last meeting.

Dear All

Thank you so much for the lovely card, Jenny and myself were delighted to hear that everybody enjoyed the talks and demonstrations. We too, thoroughly enjoyed ourselves, not only giving the talks but for having the opportunity to meet such lovely people. The interest shown at the end was overwhelming. Now that I have finished lecturing for the summer, I am in the process of trying to locate centres in certain areas where training can be given, particularly in Indian Head Massage for those who requested it.

Jenny and I would be delighted to attend the Christmas function in December, and look forward to seeing you then if not before.

Yours truly
Collette M Hay.

Surfing the Net?



RNID Tinnitus Helpline
(Registered Charity 207720)
Castle Cavendish Works, Norton Street,
Nottingham NG7 5PN
Tel/Textphone 0115 942 1520
For further information:
Email: tinnitushelpline@binternet.com
Website: <http://www.rnid.org.uk>

The British Tinnitus Association (BTA)
(Registered Charity 1011145)
Web site: <http://www.tinnitus.org.uk/>
Email: bta@tinnitus.org.uk

The BTA is a charitable organisation which supports a network of self-help groups and contacts. The association provides information and advice to help people to come to terms with tinnitus and supplies helpful retraining audio cassette tapes and details of relaxation cassettes. For an annual subscription members receive "Quiet", the association's quarterly journal.
Contact: BTA 4th floor, White Building, Fitzalan Square, Sheffield S1 2AZ

Please think about writing something for your newsletter. It can be anything you feel will be of interest to members.

Anything from a few lines to a couple of pages

It all helps to make the newsletter more interesting.

Contributions on paper and/or disc (Microsoft Word) to:-

Chris Richards
12 Sudeley Grove
Hardwick
CAMBRIDGE
CB3 7XS
by



14th October 2001

AMNET Advisory Panel at Addenbrooke's Hospital

Mr David Baguley MSc MBA
Principal Audiological Scientist

Mr Robert Macfarlane MD FRCS
Consultant Neurosurgeon

Mr David Moffat BSc MA FRCS
Consultant in Otoneurological and Skull Base Surgery

Mr N J C Sarkies MRCP FRCS
FRCOphth Consultant Ophthalmic Surgeon

Sue Woodford RN
Staff Nurse Clinic 10

BANA has produced some new booklets which may be of interest:-

A Basic Overview of Diagnosis and Treatment of Acoustic Neuroma

The Facial Nerve and Acoustic Neuroma
Headache after Acoustic Neuroma Surgery
Eye care after Acoustic Neuroma Surgery
Balance

All these booklets are available from Alison or direct from BANA. There is a charge of £2.00 for some of them.

Next time you go surfing don't forget our AMNET web-page on <http://ii-group.com/amnet>

If you want to suggest any contents please let us know.

Also which-doctor.co.uk

The new web-site search directory to help you find a doctor with a particular skill, service specialist or research interest, anywhere in the UK.
<http://www.which-doctor.co.uk>
email info@which-doctor.co.uk

Addresses and Web sites

Addenbrooke's new website
www.addenbrooke's.org.uk

Changing Faces
(Registered Charity 1011222)
1-2 Junction Mews, London W2 1PN
Tel 0202 7706 4232

Email: info@faces.demon.co.uk
Website <http://www.changingfaces.co.uk>

Changing Faces acts as a resource for the empowerment of people with facial distinctions. Free information packs and booklets are available.

A Necessary Note

AMNET News is very appreciative of the opportunity to publish items relevant to the interests of acoustic neuroma and meningioma patients. This includes instances where members of AMNET have experienced relief, improvement, difficulties or otherwise and write to us of their experiences in order to pass on information for the interest and possible benefit of other members. However, AMNET cannot endorse proprietary products or be held responsible for any errors, omissions or consequences resulting from the contents of this Newsletter.

BANA

British Acoustic Neuroma Association
Oak House, Ransomwood Park
Southwell Road West
Mansfield, Notts NG21 0HJ

Tel 01623 632143 Fax 01623 635313
Email bana@btclick.com

Library

Book Amnesty Alison is missing a number of books she has sent out over the years. If you have borrowed books from AMNET we would be grateful if you could check your bookshelves and return any books you may find. This can be done anonymously if you wish. We would just like to keep a good supply for new people who request information.

FORTHCOMING MEETINGS

September Meeting

The meeting in September will be held on **Saturday 22nd September** at 13.00hrs at Addenbrooke's Hospital and the speaker will be **Mr Robert MacFarlane MD FRCS Consultant Neurosurgeon.**

Christmas Meeting will be on **Saturday 8th December** from 12.00hrs. It will be our usual social meeting and we hope everyone will contribute some food. We hope to have some visitors from Addenbrookes as well as allowing members the opportunity to discuss issues of particular interest to them.

Facial Stimulators

AMNET has some Facial Trophic Stimulators which are available to members for short term loan. There is a charge of £20 at present which includes maintenance and postage. If you would like to know more please contact: **Margaret Allcock on 01493 700256**

Chairman	Secretary	Treasurer	Newsletter Editor	New Patients Officer	AMNET Librarian
Alison Frank	Tony Monk	Joanne See	Christine Richards	Neil Bray	Ray Maw
01953 860692	01353 778423	01487 814380	01954 211300	01223 561234	01787 248036