IN FORMATION

THE IN GROUP ISSUE No.3 JUNE 1993

THE NEWSLETTER OF THE INFLAMMATORY NEUROPATHY SUPPORT GROUP OF VICTORIA INC.
Supporting sufferers from acute Guillain-Barre Syndrome (GBS) and
Chronic Inflammatory Demyeiinating Polyneuropathy (CIBP).

PAIN IN INFLAMMATORY NEUROPATHIES

by Dr BRUCE DAY.

Clinical Neurophysiology Dept, Alfred Hospital
Consultant Neurologist to The IN Group

Pain is considered an unusual feature of inflammatory neuropathies."There are some specific pain syndromes that do occur but these are rare.

We do see acute pain in the more acute version of GBS, particularly back pain as an initial feature of the illness. This pain can go on to become quite severe. This pain seems to respond fairly well to a single injection of steroids. This is a well recognised but poorly understood phenomenon in GBS.

In the more chronic inflammatory neuropathies pain is an unusual occurrence. Patients often do complain of "positive sensory symptoms" - pins and needles, shooting pains, electric shock-like pains - and this helps to distinguish them from the inherited neuropathies. "Negative sensory symptoms" are due to lost sensation, such as the inability to know how hot the bath is. "Negative sensory symptoms" are more a feature of the inherited de-myelinating neuropathies than of the acquired ones.

A nerve is composed of two major structures. One is the cell body with its axon which is the long tube of neu-ro filaments along which various chemicals and nutrients, travel up and down and maintain the integrity of the nerve from its source in the spinal cord to the muscle in the limb. The other is the membrane around the nerve that is responsible for the electrical conduction. This conduction either brings "information" from the periphery or sends out "information" from the brain via the spinal cord to make the muscle contract.

Electrical activity is maintained by a layer of insulating material - the myelin - that covers the nerve. It is wrapped around the axon like a roll of paper, in layers. There are separate cells that provide this myelin called Schwann cells.

In demyelinating neuropathies the myelin is what is primarily under attack. In most of inflammatory neuropathies there is some some sort of immune process that is recognising components of the insulating material as if it is a foreign intruder. It is the immune system that is responsible for fighting off bacterial and viral infections. We don't know for sure for chronic inflammatory neuropathies but for acute inflammatory neuropathies like GBS there is a high incidence of people suffering flu-like illnesses before developing the neuropathy. This may be because the virus or some other type of pathogen such as gastro-intestinal bacteria somehow incites the immune system to attack the virus or bacteria. The immune system then goes on to recognise the proteins in the myelin layer as being part of the virus or bacteria and attacks it. As a consequence it strips off the insulating material which covers the nerve. This in itself does not kill the nerve but it does very rapidly lead to the inability of the nerve to conduct a current. If it is a nerve coming from sensory receptors in the periphery - the skin, the joints - the patient will lose sensation or awareness of where their limbs are in space.

Although we tend to think of sensation as what we feel on the skin we are getting sensation as well from internal parts of the musculo skeletal system.

So why do we get pain? The majority

of pain fibres don't have myelin. When you hit your thumb with a hammer you know there is a perception of time, a definite delay, before you feel anything. This is because the pain fibres conduct very slowly as they have no myelin. (One of the effects of myelin on nerves is to speed up the rate of conduction. It allows the electrical activity jump from junction to junction between the myelin cells rather than having to travel in a continuous way along the nerve.)

So if pain fibres don't have any myelin why do you suffer pain? If you have a neuropathy why do you get pins and needles? Why don't you get just loss of sensation? There are many theories as to why this occurs. Pain is'a very complex mechanism. Its basic ^pathology is not well understood. We know it travels largely by small, slowly conducting, unmyelinated fibres. We know there are two types of pain. One type is the sharp stabbing pain such as first experienced from a hit on the thumb. Then there is the dull aching pain that follows. These two qualities to pain we know travel in different pathways, one much quicker than the other.

When these pain messages get to the spinal cord we know that there is a great deal of influence on whether the message is transmitted up the spinal cord to the brain and into consciousness. We know for example that footballers can break arms and go on playing the match as if completely free of pain. Soldiers in battle zones can suffer major injuries that will be incredibly painful but will go on without feeling any pain.

There are many mechanisms as to why this is. We have our own opiate secreting mechanisms in the brain - the end-orphins - which are chemicals that are like narcotic analgesics. They can be released in the brain under various stress situations. There are descending pathways coming out of the brain that can damp down the message coming to the spinal cord from a pain receptor.

We also know that large myelinated fibres which carry the message of where your joints are in space, how much your muscles are contracting, come to the spinal cord and send branches that ter-minate on the incoming pain fibres. These in themselves can block out the message from pain fibres. This mechanism is called Wall's Gate Control Theory. It was described by Patrick Wall who has written the major textbook on pain. This theory has major ramifications. Some argue that this the reason acupuncture works. The needle stimulates the large fibres and that sends a message up the large fibres to damp down the incoming message from the pain fibre. This sounds plausible but we still don't know why, if you have acupuncture for pain relief, after you stop the stimulation you still get pain relief for several hours afterwards.

We know also that there is a very common reaction after you hit your thumb with a hammer is to rub it. This activates the large tactile pathways in the skin which sends messages up these fibres to influence the incoming pain fibres to reduce the sensation of pain. The Wall's Gate Control Theory of pain has become reasonably well established as a core theory. Does it have any bearing on why a person, with a neuropathy that affects the large mye-linating fibres and not the small pain fibres, experiences pain? The best explanation is that these large myelinat-ing fibres do more than just transmit tactile sensation but also give an input into the spinal cord pathways that are bringing in pain and they modify them, damp them down. If these myelina-ting fibres lose their power to conduct then the pain fibres get a "free ride" into the nervous system with the full force of their message. So you get pain from relatively innocous stimuli, a well recognised phenomena known as all-odynia in. which a patient perceives a light touch as painful.

'When the nerve is under attack and has lost its myelin it may not just lose its ability to conduct current but it may get little foci along its length where it will fire spontaneously. The reason the nerve conducts current is because it keeps a gradient of electrolytes which are charged particles on one side of a membrane versus the other. It does this by pumping various electrolytes across the membrane.

An illustration of electrolytes is when you put salt into water and get a solution. Salt is made up of a toxic gas - chlorine - and a corrosive metal - sodium - which when combined become common salt. If you put a current ac-

ross the salt solution you can "drive" the chloride atoms in one direction and the sodium atoms in the other because they have different charges. The body does this across membranes in order to sustain electrical messages along the nerve. To do this requires energy. This is the whole purpose of the metabolic function of the cell.

When there is a demyelinating process going on these channels spread along the nerve. The membrane is not fluid but is quite viscous. The channels can move and in so doing change the conduction characteristic. Normally if you touch a nerve such as the radial that runs down your arm you don't feel anything other than the touch but if you have some problem with the nerve,, the touch can create a shooting pain up and down the nerve. If you bang ' the funny bone and get a tingling sensation up and down your hand then that is the sort of sensation that you can get from a touch if the lining of a nerve is damaged. The nerve becomes more susceptible to mechanical distortion and that can produce pain. Sometimes even the slightest mechanical irritation of the nerve can produce pain as it sets up a lot of aberrant discharges along the nerve, firing off repetitively.

So there are many complex issues that surround the genesis of pain in peripheral neuropathies especially in the neuropathies that don't characteristically attack the pain fibres.

This brings up the whole issue of what to do about it. We have already addressed some of the potential therapies, 'ale talked initially about the acute pain of GBS that responds to star-" oids.

The other types of chronic pain that you get in inflammatory neuropathies may respond to the treatments that sta-blise membranes, that stop these abnormal currents being generated. The medications that do that are not the traditional painkillers. There are two main types - the anti-convulsant medication as used for treatment of epilepsy and the anti-depressants used for depressed patients. Both these medications have been noted to be very effective in controlling what is called neuropathic pain as distinguished from joint pain such as arthritis.

I don't have much experience of these medications for inflammatory neuropathies but we know that the neuropathy from diabetes which is often very painful responds fairly well to these medications, independent of whether the patient is depressed or has a seizure disorder.

Some other medications seem to be effective. There are the non-steroidal anti-inflammatory medications traditionally used to treat joint pains from arthritis. They also have been found to have quite a significant effect on pain fibres in the spinal cord.

We have a substance called capsaicin derived from the capsicum species of plant especially in hot chilis. If you put in on the skin it will gradually be absorbed into the nerve fibres and be transported up into the spinal cord where it will gradually deplete the spinal cord of a substance called Substance P which is the major neuro transmitter for pain in the spinal cord. This substance is now available under the name Capsig. You rub it on the skin. I have used the ointment with success on patients with painful feet from a painful neuropathy but not an inflammatory neuropathy. It is mainly used for easing the pain of shingles.

The medications that are singularly ineffective in controlling neuropathic pain are the narcotic analgesics. They are the most potent painkillers. They have certain problems in their chronic use - they lose their efficacy so you have to use more to get the same benefit and if you stop using them you experience withdrawal, ie they are addictive. Their pain relief in people with neuropathic pain is only related to their degree of sedation. In a way it is like giving a person a sleeping tablet so they sleep through their pain. This is widely held to be true although every doctor has had one patient that seems to get good pain relief from narcotic analgesics who can't seem to get pain relief in any other way and yet they are not clearly being sedated by the medication.

So while there are situations where you would use these medications we tend to use them as *a* last resort especially for chronic inflammatory neuropathies where the pain may be long lasting. Narcotic analgesics are an effective means of pain control for people with terminal illness because you are not worried about the addiction issue

and the increasing doses as they are inexpensive (except on the black market).

Pain is a very frustrating thing to treat. You can go through the various medications including combinations and not get adequate control of pain. You are left with alternative methods. I have not had much experience with using acupuncture in inflammatory neuropathies in controlling pain. It would not surprise me that it was effective in certain cases. I have seen it work well in other sorts of pain. I remember a patient who used to get severe pain when getting his chemotherapy for acute leukaemia. After trying all sorts of agents to control his pain we consulted the hospital pain clinic acupuncturist who put studs in the patient's ears. For several days before the chemotherapy the studs would be massaged. This completely relieved the pain during the period of the therapy. There are probably patients with severe painful neuropathy that will respond to acupuncture. The difficulty is knowing who is a good acupuncturist. These therapies have not been subjected to rigorous study so we don't know how to use them properly.

We have another mechanism - the Tens Unit - which probably works in a similar way to acupuncture. 'ale know that if a patient has a focal pain problem and we put the Tens Unit on it for 20 minutes or so, when you stop it the pain doesn't immediately come back. It may take several hours and this is similar to an acupuncture treatment.

These types of therapy tend to be only useful if you have focal pain, say confined to one lag or a small part of the body. For severe cases of chronic pain surgically placing the electrical stimulators along the spinal cord may be helpful. I have seen cases where this has proved very successful. I have even had patients where one of the wires for the stimulating electrode has broken and they have known within a short period of time that their pain has come back quite abruptly. With a repeat operation to restore the circuit the pain was once more very much controlled.

I^any of these techniques tend only to be available in major pain centres where there are a number of specialists interested in pain. One of the difficulties is that if the pain doesn't seem to respond to medications the only person experiencing it is the patient. It may become then difficult to convince the doctor of the authenticity or severity of the pain, particularly if compensation or other secondary gain is involved, it can be difficult to convince the doctor. It may then be difficult to get a referral to a pain centre. In such a situation it is worth striving to be seen at a pain centre where they have a lot of experience in dealing with intractable pain.

I have never had to refer a patient with inflammatory neuropathy to a pain centre. One reason is that such pain is a rare complication of inflammatory neuropathy. Another reason is that satisfactory treatment of the neuropathy -steroids, plasma exchange, etc. - results in resolution of the pain.

Sometimes even in these pain centres they have major difficulty in controlling pain. It is then necessary to help the patient adjust to *a* life with ongoing pain. This involves psychotherapy and encouraging continued social and physical activity. Sometimes this substantially benefits the patient.

ANNUAL GENERAL MEETING

The Annual General Meeting of The IN Group is to be held on Tuesday 10th August at 7.30pm at 4 Alandale Ave Balwyn, the home of our Deputy Director, Ray Dahlitz. The Director's and Treasurer's Reports are published in this issue. Details of the agenda, etc, are set out in the enclosed leaflet.

Following this business, hopefully by 8pm, we will be addressed by Barbara Burzak-Stefanowski, Chief Physiotherapist of the Fairfield Hospital. Details again are on an enclosed leaflet.

ANNUAL SUBSCRIPTION NOW DUE.

The annual subscription to The IN Group is due from 1st July 1993. A form is enclosed. A prompt renewal (and a donation - which is tax deductible - if you think our efforts deserve more support) saves a lot of secretarial work.

DIRECTOR'S REPORT YEAR 1992/3.

Encouraging progress has been made in our commencement year thanks to the support of many people, starting off with our Patrons, Consultants and Committee, followed by family and friends and then most importantly by the many present and past sufferers of GBS and CIDP and their families who were enthusiastic about the establishment of a support group. Membership

As of 22/6/93 we have 87 members of whom 62 are present or past sufferers. An initial group came through a notice kindly accepted by "The Age" in their "Help Needed" column and then a more substantial number came through the help of the Fairfield Hospital management in contacting many patients treated for GBS since 1985.

As the IN Contact Network gets established in the other major hospitals we can expect to have further membership increases. Incorporation

One of the earliest actions taken was to have The IN Group incorporated under the Associations Incorporation Act 1981. Incorporation was a necessary step to obtaining tax exempt status for The IN Group from the Australian Taxation Office. We adopted a constitution based on the Model Rules for An Incorporated Association. Copies are available from the Secretary. Tax Exempt

The IN Group was successful in being accepted by the Australian Taxation Office as a public benefit institution. This means that donations of more than $2 are allowable income tax deductions. Receipts for this purpose will be made out by the Secretary on request. Also goods for use by The IN Group are exempt from sales tax. Vic. Inflammatory Neuropathy Registry

Encouraged by Professor James McLeod and Associate Professor John Pollard and with guidance by Dr Bernard Gilli-gan we initiated a project to establish the Victorian Inflammatory Neuropathy Registry As a means of assessing the prevalence and incidence of acquired demyelinating neuropathies in Victoria. To date 68 people have given permission for entry of their medical details into the Registry through signing the Permission form.

The IN CONTACT Network

Following the initiative of membe such as Greg Gillespie of Peterboroug Vilma Clarke of Wangaratta and Do Mills of Wakool (NSW), The IN Grou CONTACT Network has been established provide a ready personal support t those who have become afflicted with t GBS or CIDP disorders and to the families.

The objective is to establish for ea major Victorian Hospital or country regi an IN CONTACT Person from our membersh who will be known to the relevant medica authorities as the person available f personal support.

To date we have it well established a the Fairfield Hospital where Dr Bri Speed has agreed to contact me as The CONTACT Person as and when person support is needed.

The Monash Medical Centre has com enced posting to past patients or givi to present patients an envelo containing our brochure, the Regist Permission form, stamped-addressed--envelope plus covering advice from the hospital. Mr E Kearley has agreed to be the IN CONTA Person for this hospital.

The Alfred Hospital is about to beg similar arrangements with Mr Roy Pott being The IN CONTACT Person.

Other hospitals that have been ap roached, with our nominated IN CONTA Persons, are:

Austin Hospital - Mr Greg Vipond. Box Hi Hospital - Mr Graham Blanck. Repatriati Hospital - Mr Greg Vipond. St Vincent Hospital - Or David Ashton.

Geelong Hospital - Mr Murray Richardso

We still have to approach the Roy Melbourne, Children's and Western Ho pitals and perhaps some others.

The building up of the Network ha proven to be a slow process what wi overcoming problems of patient confi entiality and the fact that GBS and CI are rare disorders amongst a plethora other medical complaints. But I belie that its establishment is a basic fact for a continuing and effective suppo group.

Quarterly Meetings

The three meetings of The IN Group held quarterly have proven most successful. We have been fortunate in having excellent speakers - Dr Bruce Day on "Inflammatory Neuropathies" (Dec'92) and "Managing Pain of the IN Patient" (May'93) and Sister Kate Fielding on "Care of the IN Patient" (May'93) - to inform us and a pleasing locale to make the attendees, averaging 25, feel at home. Thanks Ray Dahlitz, our Deputy--Director. Newsletter "IIMformation"

This is the third issue of "INfor-mation", the newsletter of The IN Group. Such a means of communication to and between members is vital to an organisation such as ours and it is pleasing to hear from many members how.well it is has been so far received. The Newsletter is yours so make the most of it. Funding

Whilst subscriptions and donations are adequate to keep us going (see our Treasurer's Report), extra funding would be helpful in such areas as advertising of our existence in the press to further discover past sufferers of GBS and CIDP and also to obtain some extra equipment that would be helpful such as a fax machine.

Approaches have been made for funding to The Australian Brain Foundation, The Victorian Health Promotion Foundation and The William Buckland Foundation. We have received knock backs from the latter two but still have hopes from the first. Publicity

We received good publicity when the Executive Director of the Australian Brain Foundation, Maxine Miller, published an article about our organisation in their journal "Brainwaves". Maxine tells me its circulation is some 13,000. The Year Ahead

Ibelieve we shall continue to grow and develop support in the forthcoming year, such has been the congratulations expressed by many at the birth of The IN Group. I hope at the AGM we find some more members able and willing to play a further part, such as becoming an office bearer or a committee member, in our organisation.

JAMES GERRAND,
Director.

TREASURER'S REPORT FOR THE YEAR ENDING 30/6/93

INCOME and EXPENDITURE

IMCOME:	Membership, fees and donations	$1602.00
	Bank interest	20.21
	Total income	$1622.21
EXPENDITURE:	Postage	$334.45
	Stationery	
	Copying, wordprocessing, facsimiles	114.00
	Telephone	
	Secretarial	
	Incorporationcharges	91.00
	Total expenditure	
Total income over expenditure		$945.62

30/6/93

N. A.Blyth,
Treasurer.

LETTERS

Dean. }ame-6,

7 hank you £01 the. "IN" JLe.ce.-wed this week. - o-f. tremendous interest to me.. Afteji 50 yeans at last I am. receiving Aome. education, on. the. AU&--ject o£ QBS,

*In natch 1939 - I was 17 ye.au> old. -I contracted what was diagnosed 45 ye.ans IOJJ&JL aA * ? my elitis" . (See. my siepoxt. Helow). AHout 1990 I /Lead -in a da-Liy pape./i ojL a Dav-i* Cap playeA. who had contracted QBS and the. description o£ his symptoms proved to He identical with mine., nence the. ji.g-t>aw puzzle. has gradually fallen -into place. - Hut thejte OJie. Atill a -few pi&ceA to -/Lit in,*

I would veJiy much love to attend you/L meetings Hut they Hewing held at n-ight make. -it impoAA-iHle. £0/1 me:. I dfL-ive extensively in dayl-ight Hut veJiy little. at n-ight and certainly not too . fiiom home..*

wish you 7 he. IN Q/LOup euesiy AUCC-and look JLosiwajid with eagex. antici.-pation to £utuJLe. newsletters,

J.OHNSON

(Extract from article.)

I had no feeling of being ill, no numbness or pain, nor any previous or pras-ent illness at all. Firstly I noticed my inability to stand on my tip-toes, next weakness in the knees, and after a couple of days unable to stand. A couple more days and hands and arms and eventually back were all affected. I tuas unable to sit up or even hold a teaspoon (hence for three months u/as spoon-fed ujhilst quite horizontal). About a week after first symptoms I was hospitalised in IMhill and a couple of days later transferred to Western 3ase Hospital in Horsham where an "Iron Luna" was at the ready but thankfully was not required. My doctor was constantly in touch with with Melbourne doctors but (in retrospect) they apparently had no answers or enlightenment. For the three months I was unable to sit up, sand bags were used to position my legs in the bed and removable plaster casts were used to hold my feet and ankles. At about 4 months, when my hands and arms and back had improved considerably, I graduated to a wheelchair and gradually began to learn to walk with the aid of a stick (no walking frames then). The treatment for the 10-12 months consisted of daily injections of Vitamin 3 and exercises (no physio in 1939).

Improvements continued for the next couple of years and the end result is no muscle control in toes and ankles -both left and right - (foot-fall I suppose you'd call it). Eventually I discarded the stick and led a very active life in business, travel, marriage (with 2 children both Caesarian births), My major handicap was that I could not run, or walk very fast.

Now I would be most interested to hear how your older members - those af flicted in the 1940s - have fared in their 60s and 70s. I find my mobility decreasing with age - my balance at times poor and find I fall over virtu ally nothing sometimes and as a result have suffered fractures on numerous oc casions (IM.O.F. both sides, wrists, clavicle and knee-caps - all in the last 6 years. Actually I trip myself on the least uneven surface by not lifting my feet - I have to lift from the knee to counteract the non-use of ankles. Ninety percent of time I use a walking stick for balance and confidence.

I guess that 54 years was quite a long time to wait for the enlightenment of the past few days. Maybe the foregoing will add a little to the history of UDu.

(Thanks, Gwenda, for your enlightening account. We hope to arrange transport for you to attend our August meeting. JHG)

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BLANCK.

HELP NEEDED

A number of members are already helping in the activities of The IN Group, notably being IN CONTACT Persons.

Another activity is contributing to this INformation Newsletter. It is your Newsletter. This can include writing articles, letters, poems, sending news or other items including cartoons that you think will interest readers and members.

Then there is the more mundane work of helping with the preparation, publishing and mailing of the Newsletter.

Finally there is the important area of suggesting ways we can better achieve our aims.

THE NERVE RESEARCH FOUNDATION

The following is of interest from the President's Report in the Annual Report, 1992 of this Foundation, which has its Director, Associate Professor John Pollard, and one of its two Deputy Directors, Professor James McLeod. These Professors are two of the patrons of The IN Group.

In addition to this assistance for research work, the Foundation has been pleased to encourage the development of patient support groups such as the Guillain-Barre support group of NSW and the IN (inflammatory neuropathy) group of Victoria. These important new groups have been created through the energy and enthusiasm of patients who have seen the need for continuing care and fellowship among sufferers of inflammatory neuropathies and a greater public awareness of these conditions. In particular, these groups have set up a network of former patients to visit in hospital, patients newly diagnosed with Guillain-Barre syndrome in its more acute or chronic forms.

E Barnum

NEUROLOGICAL RESOURCE CENTRE OF SA INC

I was pleased to receive a visit in May from Heather Trenorden, Ca-ordinat-or plus two other members of this Centre. The centre incorporates a number of organisations including the GBS Support Group Inc.

Heather advised that now The In Group has been formed in Victoria they would consider it appropriate for our Group to look after the 27 Victorian members of their Group. I advised that at least two of their members, i%rgot Browning and Lucy Shakespeare, have already joined our Group. Heather is to send me the names and addresses of the other 25 members and we will ask them if they wish to join The IN Group.

JAMES GERRAND,
Director.